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ABSTRACT

Statements and papers presented to the U.S. Senate during 3 days of hearings on the Child Abuse Prevention and Treatment and Adoption Reform Act Amendments of 1983 are included in this document. Witnesses include physicians, psychologists, human services administrators, parents, heads of social service agencies, and organizations advocating adoption. Witnesses are questioned by members of the Subcommittee on Family and Human Services of the Committee on Labor and Human Resources. In addition, articles and publications on abuse and adoption and copies of letters on abuse and adoption are included. Among aspects addressed are ethical issues involved in the "Baby Doe" case, experiences of adopting children with special needs, status of child abuse demonstration projects, and the prevention of birth defects. (CL)

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CHILD ABUSE PREVENTION AND TREATMENT AND ADOPTION REFORM ACT AMENDMENTS OF 1983

HEARINGS

BEFORE THE

SUBCOMMITTEE ON
FAMILY AND HUMAN SERVICES

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

NINETY-EIGHTH CONGRESS

FIRST SESSION

APRIL 6, 11, AND 14, 1983

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WEDNESDAY, APRIL 6, 1983

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
SUBCOMMITTEE ON FAMILY AND HUMAN SERVICES,
Washington, D.C.

The subcommittee met, pursuant to notice, at 2 p.m., in room 430, Dirksen Senate Office Building, Senator Jeremiah Denton (chairman of the subcommittee) presiding.

Present: Senators Denton, Nickles, Weicker, and Grassley.

OPENING STATEMENT OF SENATOR DENTON

Senator DENTON. This hearing will please come to order.

Good afternoon, and welcome. I'll ask you to indulge some hoarseness on my part today.

I want to welcome my colleague and respected friend, the distinguished Senator from Oklahoma, Senator Nickles. We also expect the Senator from Iowa, Senator Grassley. I understand Senator Weicker, my distinguished colleague from Connecticut will be introducing one of our principal witnesses later on.

This afternoon the Subcommittee on Family and Human Services begins its third hearing of the 98th Congress and its first hearing in a series of three on the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act, the Federal program that assists States in combating child abuse and neglect, and that helps facilitate adoption of children with special needs.

We couldn't have a more authoritative witness than the Surgeon General, and I want to welcome him; Ms. Dotson, who is with him; and the others who will soon be called up, as well as all of the interested members of the public and the media who have come today.

The hearing this afternoon will focus on a particular type of neglect—the withholding of nourishment and medical treatment from infants born with mental or physical impairments.

This issue burst into public view last April with the so-called "Infant Doe" incident in Bloomington, Ind. The public was shocked when an infant born with Down's syndrome and an incomplete esophagus was starved to death after his parents decided against an operation that could have saved his life.

Although the State intervened, a judge upheld the right of the physicians to withhold treatment upon the parents' request. The judge also refused to stay his ruling to allow time for appeals.

An appeal to the U.S. Supreme Court was in progress when "Infant Doe" succumbed. The parents, the doctors and the ruling judge were all aware that several couples had expressed an interest in adopting "Infant Doe" and permitting the life-saving surgery.

This incident presented rather starkly some of the troubling questions about our Nation's attitude about the value of protecting and nurturing one of the most defenseless forms of human life—handicapped infants.

In the *Bloomington* case, the infant was clearly not dying, but, rather, needed an operation that our Surgeon General, and witness today, Dr. C. Everett Koop, and many other doctors, say is nearly always successful.

Furthermore, the decision to treat the infant was not made on the basis of the feasibility of medical treatment but, rather, on various predictions about the quality of life the infant would attain.

Finally, in a modern, 20-century American hospital, an infant was denied nutrition and fluids, until he starved to death.

The entire incident suggested that the pediatricians attending the infant were acting more in accord with the expressed interests of the parents rather than with those of the silent infant that they were purportedly serving.

Incidents such as that—and there have been several documented—raise the question of whether the failure to protect our most defenseless citizens does not undermine one of the most fundamental premises of our Constitution; namely, the equal protection under the law of all human life. Such incidents also raise the question of whether or not State and Federal child abuse statutes are adequately addressing a particularly egregious form of child abuse—starvation.

For that reason I have included as part of the reauthorization bill for the Federal child abuse program, language that specifically addresses the treatment of handicapped infants issue.

Most of you in this room must be aware of the administration's recent regulation requiring the posting of signs in health care facilities stating it is a violation of Federal law discriminatorily to deny handicapped infants nutrition and medical treatment solely because of their handicaps.

That regulation has been challenged in court. Arguments on the case will be heard April 8, 2 days from now.

Many groups representing handicapped individuals have applauded the regulation and on March 29, six of these groups announced that they were asking to sign on as codefendants in the suit.

The groups that, in contrast, have brought suit against the administration have raised serious objections to statutory and regulatory intervention. They have claimed that isolated examples like "Infant Doe" do not warrant Federal intervention, and that there is no evidence that "the care of handicapped infants represents a critical national problem."

The contention that the practice of denying treatment is relatively rare is refuted by a recent documentary aired by WNEV-TV in

Boston. The reporters involved in compiling the documentary—including a Pulitzer Prize winner—accumulated evidence on about 100 cases where treatment was withheld or withdrawn.

We will see an excerpt from that documentary today, and I commend the reporters and the station for courageously exposing this issue.

Furthermore, a paper published by two Yale pediatricians in 1973 stated that fully 14 percent of the deaths in their nursery were a result of withholding treatment.

I hope that the witnesses today will give further estimates about the withholding of care to handicapped infants, or the incidents of withholding of care.

My personal belief is that this problem is of paramount importance. Allowing the less than perfect among us to die raises the terrifying possibility that more and more groups will he labeled as somehow defective and allow to perish. As Dr. Koop and others have often written or orally pointed out, Nazi Germany's final solution was the last phase of a purification program which began in the 1930's with the killing of handicapped infants. These statistics and their implications demand a response.

The language on the treating of handicapped infants that is included in the reauthorization bill I intend to introduce today, with Senator Hatch, is identical to that included in the House bill. It will require States to have in place procedures that insure that infants at risk with life-threatening congenital impairments will be provided with nourishment, medically indicated treatment, and appropriate social services.

The language is not intended to apply to those infants who, to quote Dr. Paul Ramsey, are "born dying," or those infants who have diseases for which there is no known therapy.

However, in the vast majority of cases the indicated treatment is clear, and most handicapped infants can be treated. The language of the bill merely requires equality of treatment, and that all infants will be fed.

I am sure that Dr. Koop will further clarify the intent of the administration's regulation for us today.

There is rampant criticism that this policy might permit continued life for some extremely mentally or physically handicapped children. But there appears to have been rapidly increasing error in the opposite direction—error that has resulted in needless killings or needless allowings to die; error that places too high a value on imperfect estimates of the quality of life a child might enjoy; error which ignores unanticipated favorable changes from "natural causes" as well as ignores improvements achievable by the not widely known but notable recent breakthroughs in both pediatric surgery and therapies applied after the infant has left the nursery.

We will hear some fascinating testimony about some of these breakthroughs today from our panels of witnesses.

We will also address one final aspect of the withholding treatment question that is often tragically ignored in discussions about whether to treat handicapped infants. There are many people in this country who are willing—even anxious—to adopt severely handicapped infants and to permit life-saving surgery.

The *"Infant Doe"* case has already been cited and, in fact, there is currently a waiting list of parents who want to adopt children afflicted with Down's syndrome.

The reauthorization bill contains provisions that make the adoption of infants with congenital impairments a priority of the Federal adoption opportunities program.

We will meet this afternoon a family from Connecticut that has adopted 11 severely handicapped children. They will share with us some of their experiences in raising these children, and explain what advice they give to prospective adoptive parents.

Before we show our film excerpt, I would invite Senator Nickles for any opening remarks he cares to make.

Senator NICKLES. Thank you, Mr. Chairman.

I would like to commend you for holding this hearing, especially for including in the hearings on the reauthorization of the Child Abuse Act today's hearing on the very sensitive and critical issue of the treatment and care of handicapped infants.

I appreciate your leadership in this field, and also your interest. I'm not that familiar with the legislation which you are introducing, but I commend you for your personal attention that you've given to this very critical, sensitive, and difficult issue that many of us have wrestled with. I've had a personal interest in this area for some time and have been working on it; and I hope that we can make progress in seeing some positive improvement made throughout—not just in Federal policy—but throughout the hospitals and pediatric wards in this country.

It wasn't until the Nation became familiar with the plight of "Baby Doe" about a year ago in Bloomington, Ind., that the general public really became aware that a problem existed. I believe that most people find that it is unconscionable that physicians and parents would consider it an option to allow a newborn baby to die by starvation or by lack of common medical treatment.

Today surveys of doctors and medical journals, both of which are cited by Dr. Koop's, indicate that there are physicians advocating nontreatment of handicapped infants. The majority of physicians would support parents' wishes not to feed children with Down's syndrome.

Unfortunately, we don't know how often it happens today but with the attention this issue has received in recent weeks, there are indications that nontreatment and starvation of handicapped infants occurs more often than we might care to believe.

The television documentary produced by the CBS affiliate in Boston which aired last month took a detailed look at the problem. Their findings reveal that even the most routine care to handicapped infants is not usual. During the confirmation hearing of Secretary Heckler, I asked for and later received histories on cases of alleged instances of infanticide.

I still have some questions concerning the enforcement of section 504 in these cases. I will address those later in this hearing.

Up until recently this was an issue that was primarily debated in the medical circles. Perhaps one of the greatest values of today's hearing might be to raise the consciousness of society at large, and not just a few select organizations or communities.

The issue of appropriate medical treatment for handicapped infants is very complex, both medically and ethically. However, we, as a society, should not allow this complexity to serve as a barrier to seeking solutions which are now confined to only a few.

It is precisely because of the complex and interdisciplinary nature of the choices being made that we need broad participation in determining public policy. No single group should take sole responsibility for creating and establishing standards for a multifaceted issue with national implications.

This issue, as I mentioned before, Mr. Chairman, is sensitive; it's a civil rights issue; a moral issue; a national issue; and also a personal issue that affects many people. It cuts across every political affiliation and it begs, I think, a responsible action.

I again wish to commend you for holding this hearing and also for Dr. Koop's participation, as well as Ms. Dotson, and our other panelists. You have assembled quite a cadre of experts to give their thoughts and opinions on the entire issue of infanticide and I congratulate you for that. I hope that we'll be able to move expeditiously toward making some improvements in this area.

Senator DENTON. Thank you, Senator Nickles. And, again, my admiration for your longstanding interest and activity in this field. It's a pleasure to sit with you today on what should be a portentious occasion for progress in the field.

At this point, before showing the film clip and beginning the hearing therewith, I would like to ask unanimous consent that a statement by Senator Dodd, ranking minority member of the subcommittee, be inserted in the record.

[No response.]

Without objection, it is so ordered.

[The prepared statement of Senator Dodd follows:]

PREPARED STATEMENT OF SENATOR DODD

Mr. Chairman, I am certain that we have a great deal to learn from the distinguished witnesses you have called before us this afternoon. I would like to direct special attention, however, to the last group of witnesses who will testify today: namely, the Rossow family.

My connection with Rachel and Carl Rossow goes back to 1975 when I first visited the 3-bedroom ranch house they shared with their eight children. Since that time, they've moved to a larger house to accommodate the new additions to their family: six more children.

The Rossow family literally makes the expression "disabled does not mean unable" come alive. The accomplishments at home and at school of all 14 children deserve our highest praise. The efforts of Rachel and Carl Rossow in promoting their children's accomplishments merit our undivided attention.

Through the Rossows' experience in raising their children we can learn more about the kinds of supports, financial, educational, and otherwise, which must be provided to other parents of handicapped youngsters. Today, the Rossows will present the subcommittee with a brochure carrying a message of support for new parents of handicapped children. This brochure should be just the first step in providing families like the Rossows with the specific assistance they need to insure that their children lead full and productive lives.

Senator DENTON. We will begin this hearing by watching a short portion of the WNEV television documentary to which both Senator Nickles and I referred, entitled "Death in the Nursery," which aired last month on four consecutive nights in Boston.

This is an excerpt of that program, a series of excerpts.

[Film excerpt projected.]

Senator DENTON. Our first panel of witnesses consists of Dr. C. Everett Koop, U.S. Surgeon General, and a practicing pediatrician for some 35 years.

Joining him is Ms. Betty Lou Dotson, Director of the Office of Civil Rights, Department of Health and Human Services.

I would like to welcome both of you and to acknowledge that Dr. Koop is not only, by virtue of his position the ranking doctor in the United States, but he is also by his experience and his pediatric practice an extremely authoritative witness on this subject.

So, if you care to, please proceed.

STATEMENT OF C. EVERETT KOOP, M.D., SURGEON GENERAL OF THE UNITED STATES, AND MS. BETTY LOU DOTSON, DIRECTOR, OFFICE OF CIVIL RIGHTS, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. KOOP. Thank you, Mr. Chairman.

I have a prepared statement for the record, which I will summarize in the time allotted to me.

I am C. Everett Koop. I am a medical doctor. I am Surgeon General of the U.S. Public Health Service.

But, for the subject of today's hearing, I will call upon my 35 years' experience as a pediatric surgeon.

When I began my career, sir, there were only half a dozen people in the United States who specialized in surgery for infants and children. When I came to Washington I had been practicing my specialty longer than anyone in North America.

As you know, regulations protecting the handicapped newborn were issued by the Department of HHS last month. These regulations are now the subject of litigation; and while I can discuss the issues of health care for handicapped infants and the Department's policies concerning it, I must decline to offer an opinion regarding matters presently in litigation.

Accompanying me today is Ms. Betty Lou Dotson, Director of the Department's Office for Civil Rights, and we look forward to discussing some of the many issues regarding care of the newborn child with handicaps or operable defects.

I'm sure that you agree, sir, that our government is concerned with the provision of health care and not about withholding it. The withholding of care and treatment from an infant born a year ago this month—as you have already indicated, known as "Baby Doe"—was the chief factor in focusing national attention on this matter.

As a result of the "Baby Doe" case, the President instructed the Attorney General and the Secretary of HHS to exercise their powers to enforce Federal laws that prohibit discrimination against the handicapped.

I will not repeat what you have already said about "Baby Doe," sir, but will say that the basic principle of this case is that the child was allowed to die because someone else made the judgment that the child's life was not worth living.

Mr. Chairman, I can assure you that there is no way to predict the I.Q. or the potential of the Down's syndrome child at the time of birth. I believe that the presence of Down's syndrome is never an indication to withhold the correction of an accompanying defect, like esophageal atresia.

You should know that the surgery in question is nearly always successful. My colleagues and I have performed some 475 such procedures with almost 100-percent survival and good-swallowing function in full-term babies; and 88 percent is our record in prematures.

The moral issue here is that no one may judge the quality of life of another, and we must not tolerate the attempts of those who take it upon themselves to do so.

Whether a handicapped person's life is worth living or not is not a medical question. The Government's position ought to be seen in the context of its support for the provision of—not the withholding of—treatment for disabled infants.

Thus, an enlightened Government becomes the natural ally of enlightened medicine.

While I have said and believe that medical science constantly provides new ways to save life and to improve it, medicine may never have the answers to all the problems that occur at birth. Let me stress here that some problems simply are not correctable. Some handicapped infants, unfortunately, face imminent death. For such infants it is very important to note that we do not seek to fruitlessly prolong the process of dying; rather, we seek to guarantee that infants who would live, given ordinary care, will not be denied the opportunity for life by those who would decide that their lives are not worth living.

I presume that the unfortunate exceptions I have noted here are not the subject of this subcommittee's interest. The vast majority of disabled youngsters are within the realm of treatment.

Even so, the bottom line in all these cases is that you must nourish the patient. When an infant in hospital is denied food and care, or whether an infant at home is denied food and care, the result is the same; it is child abuse.

The willful withholding of therapy, including nutrition, which leads to the death of a child is infanticide. This practice naturally is unlikely to be widely discussed outside a small, tight, circle of those involved in a particular case.

Nevertheless, we believe that "Baby Doe" was not just a singular instance, but rather, representative of a disturbing pattern about which we are becoming increasingly aware.

Obviously, the number of such patients is difficult to estimate. It is not rare, and it is certainly not an isolated instance.

In 1976, when I was presented with the Ladd Gold Medal for excellence in surgery by the American Academy of Pediatrics, I took that occasion to draw the attention of the academy to the growing practice of infanticide, and pointed out its moral and its ethical implications.

I was aware then of what I said because at that time I had been practicing pediatric surgery for 30 years, and traveled enough as a speaker to know most of the pediatric surgeons in this country on a familiar basis, and to be aware of what some were doing.

In my role as editor-in-chief of the Journal of Pediatric Surgery for 15 years, I had my finger on the pulse of pediatric surgery and its practices. Let me offer some additional evidence which has been accumulated:

You've already referred to the Duff and Campbell report in the New England Journal of Medicine in 1973 from Yale University, where the authors acknowledged that over a 2-year period, 14 percent of the deaths in the newborns of their unit had been decided upon and engineered in some way.

In 1977 the journal Pediatrics published a survey of the surgical section of the academy by Shaw and Randolph. A questionnaire had been sent to all pediatric surgeons in the academy and selected pediatricians. A great number of those answering the questionnaire felt that what might be a poor quality of life, in their estimation, was sufficient reason not to treat the child for a defect which may have been incompatible with life but nevertheless was amenable to surgical correction.

Several months ago the CBS television program "Sixty Minutes" called attention to several families who had made different decisions on the preservation of the lives of their newborn children. And, more recently, there was the Boston documentary which we have just seen a portion of.

A just-released report of the President's Commission on Biomedical Ethics refers to several surveys among pediatricians. A survey of California pediatricians showed that most would honor parents' wishes not to treat Down's syndrome newborns who had life-threatening intestinal obstructions, and another survey showed that many pediatricians would do the same with Down's syndrome in children born with congenital heart disease. Finally, a survey of Massachusetts pediatricians showed that 51 percent would not recommend surgery to correct intestinal blockages in newborns with Down's syndrome.

In the past several years, sir, I have personally received about 20 calls from nurses who objected to carrying out orders from doctors to deny food to handicapped newborns. Some of these nurses have been faced with disciplinary actions or the threat of such actions because they opposed the decision to withhold nourishment.

Handicaps and unhappiness do not always go hand-in-hand. Some of the unhappiest children I have known were perfectly normal, physically. Many handicapped youngsters have cheerfully accepted difficulties that I would find hard to bear.

In other words, the quality of life is not measured by material and physical terms alone.

I don't believe food should ever be withheld from a disabled infant. If the motivation is to hasten death, deliberate starvation is inhuman.

If treatment is withheld, as it is sometimes indicated, there are several principles: First, the physician must be fully aware of and knowledgeable about the infant's disease process or disabling condition.

Second, the physician has to know as much as possible about his patient.

Third, the physician has to draw important conclusions about how that process or condition affects his patient.

And, finally, physicians must be extremely cautious in making any guesses or offering any speculations as to what quality of life the patient may ultimately enjoy.

We usually have no way of predicting accurately how smart or active or productive a person may be at some future time.

The job of the physician is to do all that he can to enhance the patient's enjoyment of whatever he or she ultimately determines is quality.

I don't minimize, sir, the difficulty of sheepherding a family through tough times, of providing access to all available support mechanisms, and of espousing the cause of patient and family until they are figuratively on their feet. I spent my career doing that, and not without some satisfaction.

I think it significant that no patient or parent has ever told me later that he or she wished that we had not tried so hard to save the life of their child. I think that is particularly important when one considers that when I came to Washington, I probably had operated upon more newborns than anyone in this country.

If the decisions we face in this area today seem complex, let me point out that the future holds out even more complexity, and for one important reason: it holds out more hope.

What is extraordinary in medicine today will be commonplace tomorrow. And this is no more true in any medical field than in neonatology.

Advances in medicine enable us to restore and repair limbs and organs whose malfunctions and malformations previously meant death, deformity, or permanent disability.

As a society, we should help both families and the health care professionals who care for the less-than-perfect newborn to continue their remarkable work.

The most compelling opportunity is for our Government and our Nation's leaders to reaffirm our national commitment to providing compassionate, high-quality medical care for all of our Nation's children.

I thank you, Mr. Chairman. And following Ms. Dotson's remarks at this time, she and I would be most happy to consider whatever questions you may have.

[The prepared statement of Dr. Koop follows:]

PREPARED STATEMENT OF C. EVERETT KOOP, M.D., SURGEON GENERAL, PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. Chairman, I am C. Everett Koop. I am a medical doctor and the Surgeon General of the United States Public Health Service. For the subject that is before the Committee this morning, I will draw upon my personal experiences of 35 years as a pediatric surgeon. When I began that career there were only a half-dozen people in the U.S. who specialized in surgical procedures for infants and young children. Pediatric surgery has since become an important life-saving specialty in medicine and I am very proud to have been part of that history and development. When I came to Washington in 1981, I had been practicing the specialty of pediatric surgery longer than anyone in North America.

Before I continue, Mr. Chairman, may I introduce to the Committee my colleague, Ms. Betty Lou Dotson, who is Director of the Office for Civil Rights of the Department of Health and Human Services. The two of us look forward to discussing with you and this Committee some of the many concerns surrounding the issue of care for the newborn child with handicaps or operable defects.

I am sure you will agree that our government -- regardless of the branch or which political party may be dominant at the time -- is primarily concerned with the provision of health and medical care, not about withholding it. Indeed, that point of view was emphasized last Spring in an April 30 memorandum in which the President instructed both the Attorney General and the Secretary of Health and Human Services to exercise their authorities to enforce Federal laws that prohibit discrimination against the handicapped. President Reagan took special note of Section 504 of the Rehabilitation Act of 1973, which (and I quote from the President's memorandum) "forbids recipients of Federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to persons without handicaps." The President noted that the law specifically applies to "hospitals and other providers of health services receiving Federal assistance."

As a follow-up to the President's instruction, then-Secretary Richard S. Schweiker asked Ms. Dotson to issue a notice to health care providers which are reimbursed under Medicaid and Medicare. The Secretary said; "In providing this notice, we are reaffirming the strong commitment of the American people and their laws to the protection of human life."

Last month, as you know, the Department promulgated regulations which require that reminders of the applicability of Federal law to the protection of handicapped newborns be conspicuously posted in hospitals. The regulations also offer a means for any person with reason to believe that the law is being violated to bring the facts to the attention of proper authorities.

As you know, these regulations are now the subject of litigation. While I can discuss the issue of health care for handicapped infants and the Department's policy concerning it, I must decline to offer any personal opinions regarding the matters presently in litigation.

The recent regulations were not just the result of the Infant Doe case, but also of our growing awareness that this case was not an isolated incident, but part of a larger pattern.

Infant Doe was born with Down Syndrome, a form of mental retardation that is genetically transmitted. We know that Infant Doe also suffered an esophageal atresia, a malformation of the esophagus which prevents the taking of nourishment but which may be corrected by surgery. Surgery was not performed to correct the atresia; Infant Doe was not fed, either orally or by the intravenous method and seven days after birth, the child died.

The basic principle in this case is that the child was allowed to die because someone else made the judgment that the child's life was not worth living. Mr. Chairman, I can assure you that there is no way to assess or to estimate the I.Q. or the potential of a Down Syndrome child at the time of that child's birth. Whatever the degree of retardation may be, this handicap is never a justification for withholding treatment. The moral issue here is that no one may judge the quality of life of another, and we must not tolerate the attempts of those who would take it upon themselves to do so. The President's Commission on Bioethics in Medicine is in substantial agreement with these points.

In all cases of esophageal atresia, corrective surgery is indicated and is nearly always successful. I do not mean to minimize the difficulty for the surgeon, the anxiety for the parents, or the discomfort of the patient. These are all familiar to me, as I was among the first to perform such an operation 37 years ago and since then my colleagues and I have done some 475 procedures Each case was special. But after recovery, these babies were all able to take nourishment by mouth. In my own experience, I did not lose a full-term baby in the last eight years when I was a surgeon and my survival rate for premature babies was 88%.

Mr. Chairman, just as an aside, let me say that one of the benefits of being a 66-year-old pediatric surgeon is that now and then I meet a person, full of life and health, whom I had first met as a newborn lying on my operating table, struggling with an esophageal atresia or another condition, which was successfully corrected.

Such procedures are no longer unusual. Often it seems as though every day medicine adds another new life-saving procedure to an already impressive list of victories. More and more therapeutic options are opening up, giving physicians greater opportunities, in the words of the Hippocratic Oath, "to help the sick according to my ability and judgment, but never with a view to injury and wrongdoing."

Whether a handicapped person's life is worth living is not a professional medical question. A decision not to treat, for instance, a Down's Syndrome infant because of a child's potential mental retardation is not a medical judgment. The President's memorandum, our Department's notice to providers and our new regulations ought to be seen in this context, as indicating the government's support for the provision of --not the withholding of --treatment for disabled infants. In this respect, an enlightened government becomes the natural ally of enlightened medical practice.

In my experience, this type of event has two important aspects. First, there is the nature of the medical problem presented by the infant itself. Second, there is the role of the family of the infant, the people who are responsible for the infant appearing in the first place.

I indicated that medical and scientific advances constantly provide new ways to save lives and improve the quality of life for the newborn. But medicine may never have all the solutions to all the problems that occur at birth.

Some medical problems are not correctible, and some handicapped infants, unfortunately, face imminent death; for such infants, we do not intend to fruitlessly prolong the process of dying. Rather, we seek to guarantee that infants who would live, given ordinary care, will not be denied the usual opportunity for life by someone who judges that their lives are not worth living. I would presume that these unfortunate exceptions are not the center of this Subcommittee's interest.

In most instances, however, the course of treatment is quite clear. The vast majority of disabled infants are within the realm of treatment. Moreover, Mr. Chairman, I believe there is one "bottom line" in all these cases and it is that you nourish the patient -- that is, at least give it ordinary care.

Indeed, in the case of Infant Doe, the fact that nourishment was completely withheld throughout his seven-day life probably did more than any other single act to shock the medical profession and the general public. Mr. Chairman, we should not let anyone's emphasis on the most difficult cases distract our attention from the basic principle that we must not discriminate against handicapped infants.

This point was made last May 18 by Assistant Secretary Dr. Robert Rubin in the course of his appearance on the evening television program, "The MacNeil-Lehrer Report." Speaking for the Administration, Dr. Rubin said:

> "We're not talking about prolonging a life that inevitably is going to die. What we're talking about here is discriminating against children who, if it weren't for the fact that they were handicapped, would be given appropriate medical treatment."

There are those who contend that child abuse only means battering or other forms of physical attack. I wish to stress that it also entails lack of protection and lack of basic sustenance. For example, whether an infant in a hospital is denied care and treatment, or whether an infant at home is denied care and treatment, the result is the same.

It is very difficult to acquire statistics on the denial of ordinary care to handicapped infants because doctors tend not to report that the cause of death was starvation or other denial of ordinary care. There is evidence showing that withholding of care does occur, and that it is a significant problem. Even one case is one too many.

The willful withholding of therapy, including nutrition, which leads to the death of a child is infanticide. People who practice this means of case management of disabled youngsters are unlikely to discuss it outside a very tight circle of those involved in a particular case. This accounts for the difficulty in securing firm data, but enough evidence has emerged to indicate that infanticide is not rare in this country.

In 1976, when I was presented the Ladd Gold Medal for excellence in surgery by the American Academy of Pediatrics, I took that occasion to draw the attention of the Academy to the growing practice of infanticide and pointed out its moral and ethical implications. I was aware then of what I said because I had been practicing pediatric surgery at that time for 30 years and traveled enough as a speaker to know most of the pediatric surgeons in this country on a familiar basis and to be aware of what they were doing. In my role as editor-in-chief of the Journal of Pediatric Surgery for 15 years, I had my finger on the pulse of pediatric surgery and its practices. Let me offer some additional evidence which has accumulated:

- In 1973, Duff and Campbell of Yale University published in the New England Journal of Medicine a report concerning dilemmas facing pediatricians in the newborn nursery. They acknowledged that over a two-year period, 14 percent of the deaths in the newborn nursery were deaths that had been decided upon and engineered in some way.
- In 1977, the journal Pediatrics published a survey of the surgical section of the Academy by Shaw and Randolph. A questionnaire had been sent to all pediatric surgeons and to selected pediatricians in the Academy of Pediatrics which asked about their behavior in the presence of certain treatable conditions, such as duodenal atresias, in newborns with Down's Syndrome. A great number of those answering the questionnaire felt that what might be a poor quality of life, in their estimation, was

sufficient reason not to treat the child for a defect which may have been incompatible with life but nevertheless was amenable to surgical treatment.

- Several months ago the CBS television program "Sixty Minutes" called attention to several families who had made different decisions on the preservation of the lives of their newborn children. More recently, a television station in Boston had four consecutive nights of documentary film on the use of infanticide as a treatment option in this country.
- A just-released report of the President's Commission on Biomedical Ethics refers to several surveys among pediatricians. A survey of California pediatricians showed that most would honor parents' wishes not to treat Down's Syndrome newborns who had life-threatening intestinal obstructions, and another survey showed that many pediatricians would do the same with Down Syndrome newborns who had congenital heart disease. A survey of Massachusetts pediatricians showed that 51% would not recommend surgery to correct intestinal blockages in newborns with Down Syndrome.
- In my own experience, let me say that I have received over 20 contacts in recent months from nurses who objected to carrying out orders from doctors to deny food to handicapped newborns. These nurses have been faced with disciplinary actions, or the threat of such actions, for their stands.

Mr. Chairman, I want to focus now on another question and draw from my personal experience as a physician. Once a handicapped child is being cared for within the realm of medicine, what ought we reasonably to expect from physicians? Let me suggest several principles that some physicians have found useful when they confront the kinds of situations we are discussing:

First, handicaps and unhappiness do not necessarily go hand in hand. Some of the unhappiest children I have known have been perfectly normal physically. and many handicapped youngsters have cheerfully accepted difficulties I think I would find hard to bear.

Second, the physician must know a great deal about the infant's disease process or disabling condition. As science and medicine continue to evolve, this is an ever-growing responsibility and requires that physicians must have great knowledge about and experience with the lesion in question.

Third, the physician has to know as much as possible about the patient.

Fourth, based on the first two, the physician has to draw some very important conclusions about how that process or condition affects the particular patient.

Fifth, physicians should be extremely cautious in making any guesses as to the "quality of life" the patient or his family will ultimately enjoy. We frequently have absolutely no way of predicting how happy or smart or active a person may be at some point in his or her life. The task for the physician is to do whatever possible so that the patient can enjoy to the fullest whatever he or she ultimately determines is "quality."

Mr. Chairman, I said that there are two aspects of these cases that bear close study. The first aspect I have just discussed and its focus is directly upon the infant and the infant's medical condition. The other aspect concerns the type of support the infant's family is given by the physician, the hospital and the community.

I would like to suggest certain principles which, if followed, will enable those who care for handicapped child to work better with the family to achieve the greatest possible benefits for the child. Having followed these principles, I can also tell you that I have never had a patient or a parent tell me that they wished I had not saved their life or that of their child.

First, the physician must sit down with the family and thoroughly go through the nature of the infant's condition, what the medical experience with such a condition has been so far, what kinds of things can be done immediately, and what the options may be later on.

Second, the physician must be familiar with and understand the natural responses of parents to the disabled newborn: their feelings of sadness, guilt, anger, even of shame. The parents will be concerned about the judgments of their neighbors and friends. Therefore, the physician represents not only medical care -- but the outside world as well.

Third, the physician must demonstrate that the parents are needed as partners in the processes of medical care and that, for a disabled infant just as for a "normal" child, there is just no substitute for loving, caring parents. Gradually, as the network of support grows. the parents will become more centrally involved and more competent to care for their child and for themselves, too.

Fourth, a physician should try to get the child into the hands of the family just as soon as possible. Staring through a pane of thick plastic at a little baby in a covered isolette over in the corner is just not my idea of how to bring parents and any new child together. In my own experience, I suggest that the parents visit the child as soon as possible. Even though the baby may be bandaged, intubated, monitored, and fed with a hyperalimentation line, the parents can and should touch the child -- if possible, hold it and cuddle it.

Fifth, physicians and hospitals must take a positive, active role in getting the parents and the child linked up with available social and medical support groups in the community. Continuity of care and total care is important for all patients -- it is critical for infants with a disability. And above all the responsible physician must have the determination and commitment to assure the family that he or she will be an advocate for their child and for the parents.

Finally, we all must work to eliminate the stigma of being handicapped in our society. Communities must be willing to offer support and aid to those coping with a handicapped family member. Positive attitudes toward those physically less fortunate than most of us need to be encouraged. Enlightened community acceptance of the handicapped will be invaluable to them in terms of education, services, employment, recreation, and so on.

Certainly, parents faced with the prospect of caring for a disabled child will worry about the impact on their financial resources. Increasing awareness of this issue can result in better response from the many voluntary social service agencies and private foundations which exist to help families in need.

In conclusion, Mr. Chairman, permit me to return to science and medicine for a moment. If the decisions in this area that we face today seem complex, then the future holds even more complexity, and for one important reason -- it also holds more hope. What is extraordinary in medicine today will be ordinary tomorrow, just as what was extraordinary in medicine yesterday is ordinary today. And this is perhaps true in no field more than it is in neonatology.

During the past decade we have made progress in neonatology, in intensive care for newborns and in pediatric surgery that enables us to treat successfully many conditions not treatable only a few years ago. It enables us to provide the precision care required by very premature and very sick babies. Advances in pediatric surgery allow us to restore and repair organs and limbs whose malfunctions and malformations previously caused death, deformity or permanent disability.

As a society, we should help both the families and the health care professionals who care for the less-than-perfect newborn to continue their remarkable work. The most compelling opportunity is for our government and our nation's leaders -- in all fields and at all levels -- to reaffirm our national commitment to providing compassionate, high quality medical care for all our nation's children.

Thank you, Mr. Chairman. Ms. Dotson now has a short statement describing the activities of the Office of Civil Rights and then she and I will be happy to answer questions.

Senator DENTON. Thank you very much, Dr. Koop.

Ms. Dotson?

Ms. DOTSON. Mr. Chairman, I appreciate the opportunity to appear before you and the subcommittee on a matter of such vital concern, namely, the discriminatory failure to properly care for newborn infants who are handicapped and who are entitled to the protection of the Federal civil rights laws.

I have presented a more detailed statement for the record, and in the time allotted for me, I will attempt to summarize that statement, placing particular emphasis on our regulation which was issued March 7.

Our office is responsible for enforcing various civil rights statutes which prohibit discrimination on the basis of race, color, national origin, handicap, and age in health care and human services programs.

One of the laws, we enforce, section 504 of the Rehabilitation Act of 1973, prohibits discrimination on the basis of mental or physical handicap in federally assisted programs.

Under section 504, no qualified handicapped individual "may be excluded from, denied the benefits of, or be subjected to discrimination" in any federally assisted activity or program solely because of his or her handicap.

The medicaid and medicare programs provide Federal financial assistance to most hospitals in the United States.

The regulation which the Department first issued in 1977 to implement section 504 makes it very clear that Down's syndrome and other serious birth defects are handicaps within the meaning of the statute.

Following the death last year of a handicapped newborn known as "Baby Doe," in Bloomington, Ind., the President directed the Department to notify health care providers that section 504 did in fact apply to handicapped infants. The President was concerned about reports that potentially life-saving treatment was being withheld from handicapped infants which would have been given as a matter of course to those without handicaps.

In furtherance of the President's directive, on May 18, 1982, I issued a notice to health care providers. In that notice, hospitals were reminded that section 504 prohibits withholding from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if:

First, the withholding is based on the fact that the infant is handicapped; and,

Second, the handicap does not render the treatment or nutritional sustenance medically contraindicated.

Subsequent to the issuance of the notice in May 1982, our office developed and put into operation a specific program for expeditious investigation of complaints of discrimination which related to this notice.

Generally, the complaints that we received after the issuance of this notice alleged that handicapped infants were not being treated for potentially life-threatening conditions, or that handicapped infants were being denied life-sustaining nourishment. In other cases, it was reported that a handicapped infant had been placed in a life-threatening situation, and we were asked to investigate.

In each complaint case involving a baby in a life-threatening situation, OCR initiated a prompt and thorough investigation. Our basic approach has been to dispatch an investigator or investigative team to the facility immediately in emergency cases to assess the facts and make a compliance determination.

Simultaneously with the dispatch of one of our investigators to the site, we have alerted our medical consultants to be available on an as-needed basis.

We interview all of the affected parties, including the complainant, attending physicians, and hospital staff.

We also attempt to coordinate the investigation with State and local authorities, such as child abuse agencies. These agencies are contacted to exchange information and, in several instances, we have been able to arrange it so that State officials accompanied us during our investigation.

We examine pertinent medical records which relate to the case.

In addition, we've made arrangements to insure that Public Health Service physicians and independent neonatal specialists could be called upon immediately to provide medical advice and analysis during the course of an investigation.

In 1982, subsequent to the issuance of the notice, we have initiated several on-site compliance reviews at four major teaching hospitals: Yale, New Haven; Stanford University; University of South Alabama Hospital and Clinic; and University of New Mexico Hospital.

The purpose of these reviews is to determine whether hospital practices and procedures for handling newborn infants conform to the requirements of section 504.

Our basic objective in investigating complaints and in conducting compliance reviews is to prevent the discriminatory failure to treat and feed handicapped infants; and to save their lives.

We expect that our actions will have a wider deterrant effect beyond the individual cases which come to our attention. To achieve that objective, we will continue our investigative activity combined with more intensive efforts to inform all affected parties of their rights and obligations as established under the law.

Our experience indicated to us that we needed a better means of making sure that people had a means to instantly communicate to us to report or supply to us information about possible violations of section 504.

Subsequently, on March 7, 1983, our interim final regulation was issued. The purpose of this regulation is to insure that medical practitioners, State and local authorities, parents, and the general public are made aware of the section 504 nondiscrimination requirements. The regulation was effective on March 22.

Now, this regulation requires that hospitals post notices in a conspicuous place in each delivery ward, maternity ward, pediatric ward, and nursery.

The notice informs the public that the discriminatory failure to feed and care for handicapped infants violates Federal law. Persons having any knowledge of any violation are encouraged to contact the Department immediately by utilizing a special hotline number, or to contact the local child protective agency.

In addition, to expedite investigations and necessary enforcement action where immediate action is necessary to protect the life or health of a handicapped infant, the regulation permits us to refer cases to the Justice Department for prompt court action without having to wait the previously required 10 days.

Also, it enables the Department to obtain immediate access to medical and other relevant records at a hospital inasmuch as it requires that the hospital records be available on a 24-hour basis.

We have taken the following measures to implement our regulation of March 7:

A memorandum was sent to 6,738 hospitals across the country on March 16, informing them of the hotline number and enclosing a copy of the regulation and a replica of the required notice.

On March 17 we mailed to each of the 6,738 hospitals 10 posters, 5 in English, 5 in Spanish.

Also, a list of the addresses and telephone numbers of State child protection agencies was forwarded to all hospitals so that the appropriate telephone number of the State agency could be added to the posters. Many State agencies also maintain a 24-hour toll-free hotline service.

Our hotline is activated. It's staffed between 8 a.m. and 8 p.m. by professional employees at our headquarters in Washington. During the night all incoming calls will be received by an answering service. When the answering service receives a call, the information will be relayed immediately to a designated employee of the Office of Civil Rights.

The hotline number is 800-368-1019. In Washington, it is 863-0100.

These procedures are designed to insure that the Department receives timely information about violations. The telephone complaint procedures will facilitate the reporting of these kinds of violations to us.

In conclusion, Mr. Chairman, I wish to reiterate our commitment to protection of the rights of handicapped infants by enforcing the laws and regulations in an effective expeditious manner. This has been our record throughout.

Thank you, Mr. Chairman.

[The prepared statement of Ms. Dotson and responses to questions asked by Senator Nickles follow:]

PREPARED STATEMENT OF BETTY LOU DOTSON, DIRECTOR, OFFICE FOR CIVIL RIGHTS, DEPARTMENT OF HEALTH AND HUMAN SERVICES

I appreciate the opportunity to appear before the Subcommittee on a matter of vital concern: the discriminatory failure to properly care for newborn infants who are handicapped and are entitled to the protection of the Federal civil rights laws.

The Subcommittee asked me, as Director of the Office for Civil Rights, to discuss the Department's recent regulation on this subject, and to explain the procedures we are following to ensure compliance with the requirements of the regulation.

The Office for Civil Rights gives priority attention to protecting the rights of handicapped infants. In the main, cases may arise that, by their very nature, are emergency cases that require immediate action. And it seems to me that in any situation where life-and-death issues are or may be at stake, we must endeavor to bring to bear all the resources and sensitivity that we can to help prevent and resolve compliance problems.

To put the regulation in proper perspective, I think it would be helpful at first to review the background and sequence of events — the compliance standards that apply, the investigative activities and other steps that have been taken and are underway to enforce the law.

Section 504

The Office for Civil Rights (OCR) is responsible for enforcing various civil rights statutes which prohibit discrimination on the basis of race, color, national origin, handicap, and age in health care and human services programs. This is a far-reaching and important mandate — and we are determined to carry it out effectively.

One of the laws OCR enforces, Section 504 of the Rehabilitation Act, prohibits discrimination on the basis of mental or physical handicap in federally assisted programs. Under Section 504, no qualified handicapped individual "may be excluded from, denied the benefits of, or be subjected to discrimination" in any federally assisted activity or program solely because of his or her handicap. The Medicaid and Medicare programs provide Federal financial assistance to most hospitals in the United States. The regulation which the Department issued in 1977 to implement Section 504 makes it clear that Down's syndrome and other serious birth defects are handicaps within the meaning of the statute.

Following the death of a handicapped newborn, known as "Baby Doe," in Bloomington, Indiana, the President directed the Department to notify health care providers that Section 504 applies to handicapped infants. The President was concerned about reports that potentially life-saving treatment was being withheld from handicapped infants that would have been provided as a matter of course to those without handicaps. He stated at that time:

> "Our nation's commitment to equal protection of the law will have little meaning if we deny such protection to those who have not been blessed with the same physical or mental gifts that we too often take for granted."

To carry out the President's directive, I issued a notice to all health care providers on May 18, 1982. In that notice, hospitals were reminded that Section 504 prohibits withholding from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if:

(1) the withholding is based on the fact that the infant is handicapped; and

(2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.

For example, under this standard it would be unlawful for a hospital to decline to treat an operable life-threatening condition in an infant, or refrain from feeding the infant, simply because the infant is believed to be mentally retarded.

The notice also reiterated the fact that noncompliance with Section 504 requirements could lead to the termination of Federal funds.

Investigative Activity

In May, 1982, OCR developed and put into operation a specific enforcement program to investigate complaints of discrimination and to review the practices of a number of health care providers on-site.

In general, the complaints that OCR received after the notice was issued alleged that handicapped infants were not being treated for potentially life-threatening conditions; or that handicapped infants were being denied life-sustaining nourishment. In other cases, it was reported that a handicapped infant had been placed in a life-threatening situation and OCR was asked to investigate.

In each complaint case involving a baby in a life-threatening situation, OCR initiated a prompt and thorough investigation. Our basic approach was to:

o Dispatch an investigator or investigative team to the facility, immediately in emergency cases to assess the facts and make a compliance determination.

o Interview all affected parties, including the complainant, attending physicians, and hospital staff.

o Coordinate the investigation with State and local authorities, such as child protection agencies. Agencies were contacted to exchange information and, in several instances, agency personnel worked closely with OCR during the investigation.

o Examine all pertinent medical records and legal documents related to the case.

In addition, OCR made arrangements to ensure that Public Health Service physicians and independent neo-natal specialists could be called on immediately to provide medical advice and analysis during the course of an investigation.

If I may illustrate how the procedure worked — on December 7, 1982 OCR received a complaint alleging that a baby in an Oklahoma hospital was not receiving life-sustaining nourishment and was being deliberately dehydrated.

On December 7 — the same day the complaint was received — an OCR investigator arrived at the hospital and began the on-site investigation. Hospital staff were interviewed and a Public Health Service physician reviewed the pertinent medical records. The investigation disclosed that:

o The infant was born on November 10, 1982 with initial diagnosis of primaturity hydrocephalus.

o The infant's condition was later diagnosed as hydranencephaly (complete or almost complete absence of cerebral hemispheres) and transposition of the great vessels (reversal of main vessels into heart). Life expectancy of infants with congenital anomalies such at this is very short.

o Appropriate tests and procedures were conducted. Appropriate supportive services and nursing care were provided.

o The hospital followed its policy as it applies to critically ill infants. The infant was transferred to a perinatal unit and immediately placed on the critical list. Nursing services and medication were immediately initiated.

o Records show that from the start the infant was incapable of feeding due to the lack of sucking reflexes. Feeding was conducted by nurses at the perinatal unit by gavage feedings, that is, insertion of a tube down the esophagus. The amount of formula given was in accordance with guidelines prescribed by the American Academy of Pediatrics.

o Medical records also show that the infant grew and gained weight. As the infant grew, there was a corresponding increase in the formula. All medications, ancilliary services, and care were fully documented.

Fortunately, in this case OCR did not find evidence of a discriminatory withholding of care or nourishment. The case does, however, demonstrate our commitment to take prompt and effective action as soon as complaints or reports of possible discrimination are received.

As I indicated earlier, OCR's compliance program goes beyond reacting to complaints and reports of alleged violations. Starting in 1982, OCR initiated on-site compliance reviews of four major teaching hospitals: Yale-New Haven Hospital, Stanford University Hospital, University of South Alabama Hospital and clinic, and University of New Mexico Hospital/ Bernalillo County Medical Center. The purpose of these reviews is to determine whether hospital practices and procedures for handling newborn infants with congenital anomalies conform to Section 504 requirements. To make a determination, OCR investigative teams review the medical records of newborns born with one or more congenital anomalies and interview hospital personnel. OCR has available medical specialists serving as consultants who are assisting in the analysis of medical records.

Our central objective in investigating complaints and in conducting compliance reviews is to prevent the discriminatory failure to treat and feed handicapped infants and to save their lives. We expect that our actions will have a wider deterrent effect beyond the individual cases that come to OCR's attention. To achieve that objective, the Department will continue its investigative activity, combined with more intensive efforts to inform all affected parties of their rights and obligations established under the law.

March 7, 1983 Interim Final Rule

Information available to us suggested a lack of knowledge on the part of individuals concerning how to report possible violations of Section 504 to the Department. Consequently, the Department issued a regulation on March 7, 1983 to ensure that medical practitioners, State and local authorities, parents, and the general public were made aware of the Section 504 nondiscrimination requirements and complaint procedures. The regulation became effective on March 22.

Although a suit was filed on March 18 (American Academy of Pediatrics, et al v. Heckler), the U.S. District Court for the District of Columbia denied plaintiffs' motion for a temporary restraining order. The court has scheduled a hearing on plaintiffs' motion for a preliminary injunction on April 8.

The Department's regulation requires that hospitals post notices in a conspicuous place in each delivery ward, maternity ward, pediatric ward, and nursery. These notices inform the public that the discriminatory failure to feed and care for handicapped infants violates Federal law.

Persons having knowledge of any violation are encouraged to contact the Department immediately by using a special hotline number or to contact the local child protective agency.

In addition, to expedite investigations and necessary enforcement action in cases where immediate action is necessary to protect the life or health of a handicapped infant, the regulation: (1) permits the Department to refer cases to the Justice Department for prompt court action without having to wait 10 days to notify the hospital or other provider, as was previously required; and (2) enables the Department to obtain immediate access to medical and other relevant records at a hospital to investigate an alleged violation.

The Department is developing a cooperative working relationship with State child protection agencies. OCR Regional Directors are meeting with State agency personnel to discuss investigative procedures. In several of the Infant Doe cases that OCR has investigated so far, the State agency also received a report of suspected child neglect and took steps to investigate the report. The Department will contact child protection agencies whenever a complaint is received that indicates a possible failure by parents to consent to necessary medical care.

OCR has taken the following measures to implement the regulation:

o A memorandum was sent to 6,738 hospitals across the country on March 16, informing them of the hotline number and enclosing a copy of the regulation and a replica of the required notice.

o On March 17, OCR mailed to each of the 6,738 hospitals ten 17 1/2 x 14 inch posters — five written in English, five written in Spanish.

o A list of the addresses and telephone numbers of State child protection agencies also was forwarded to all hospitals so that the appropriate telephone number of the State agency could be added to the posters. Many State agencies also maintain a 24-hour, toll-free hotline service.

o OCR has activated the 24-hour hotline, which is staffed between 8 a.m. and 8 p.m. by professional employees at OCR headquarters in Washington. During the night, all incoming calls will be received by an answering service. When the answering service receives a call, the information will be relayed immediately to a designated OCR employee. The hotline number is 800-368-1019 (863-0100 in Washington, D.C.).

When a call is received, OCR staff completes a "hotline report," recording as much information as it is possible to obtain from the caller, including the name of the infant, the name and location of the facility, the diagnosis and treatment being provided, the baby's condition, and other pertinent information. The report is then telephoned to one of OCR's 10 regional offices, which contacts the facility and makes arrangements to initiate an investigation.

These procedures are designed to ensure that the Department receives timely information about violations. The telephone complaint procedure will enable those having knowledge of violations to promptly notify the Department.

In conclusion, Mr. Chairman, I want to reiterate our commitment to protect the rights of handicapped infants by enforcing the laws and regulations in an effective, expeditious manner. This has been our objective throughout and I believe the record demonstrates that we have approached the task with the urgency, sensitivity, and thoroughness that is required.

ADDITIONAL QUESTIONS SUBSEQUENTLY SUBMITTED TO MS. DOTSON

Senator NICKLES. I thought enforcement of 504 had not been very strong in the past. Has there been any investigations (of infant doe cases) under prior Administrations under that section of the law?

ANSWER. The Department's Office for Civil Rights received a complaint in 1979 concerning a baby born with Down's Syndrome and an intestinal obstruction at Kapiolani Children's Hospital, Hawaii. The parents refused consent to surgery to remove the obstruction. The child was sent home, where it died. OCR found that the hospital administration denied any knowledge of the situation. However, upon being notified of the complaint, the hospital agreed to take voluntary corrective action to address the issue and resolve the complaint. The hospital issued a memorandum to all staff reminding them that, in the future, they should immediately report to the hospital administration any cases where parents refused to consent to needed medical procedures. An immediate referral would then be made to Children's Protective Services. In addition, staff were reminded that, pursuant to Section 504, no child would be discriminated against on the basis of handicap. The hospital made no admission of guilt or responsibility in the specific case. The case was closed based on corrective action.

Senator NICKLES. Could you give us the number, and whether there actually has been any enforcement of this section (504) involved previous to this administration and the numbers again for the last couple of years?

ANSWER. According to our records there were no Section 504 cases relating to "Infant Doe" referred to the Department of Justice prior to this administration. Since May 1980, the Department of Health and Human Services has made six Section 504 referrals to the Justice Department, and only one involved an "Infant Doe" situation. (Crawford Memorial Hospital, IL, denial of access; rather than specifically requesting enforcement action, in this case we asked DOJ to "review the circumstances of the case and determine what action might be appropriate and legally supportable, including the possibility of seeking immediate injunctive relief . . .")

Senator DENTON. Thank you, Ms. Dotson.

I note the arrival of our friend and colleague from Iowa, Senator Grassley. Do you care to make an opening statement?

Senator GRASSLEY. I want to thank you, Mr. Chairman, for holding this hearing and being concerned about the civil rights of all people. I recognize that this is a very difficult issue to deal with from the standpoint of people's honest feelings on both sides. that result in different views.

My feeling is that we have to be concerned about withholding nourishment and medical treatment from handicapped infants, because if we start weighing the life of one individual with a smaller figure than we do other individuals, it isn't long before all of us are affected.

So from that standpoint I appreciate your bringing to our attention this issue, and look forward to helping you resolve it so that there's an understanding that life at any stage of development is treated equally.

Senator DENTON. Thank you, Senator Grassley.

We will begin asking questions.

Dr. Koop, how do you account for this problem of allowing to die by not supplying nutrition or by not providing operative care which is available—how do you account for that being so widespread in the case of infants?

Dr. KOOP. I think the probable answer to that, Mr. Chairman, is that infants are small and they are weak; they cannot speak for themselves.

I would submit to you if it were possible for these youngsters who are being discriminated against to be large and active, they would have just as important a lobby in this city as many other handicapped groups do.

Senator DENTON. Thank you, sir.

With the regulatory and statutory proposals now being advanced, do you foresee that pediatricians will have difficulty in assessing what the medically indicated treatment is for some handicapped infants, or, indeed, whether to be closer to the nitty-gritty, when there is indication that medical treatment should be applied?

There are various ways of phrasing that, but that seems to be the nut of the issue.

I believe that you said on a television program, however, that regulatory and statutory proposals being advanced would not have made a bit of difference in the way you treated even one patient during your 35-year career as a pediatrician.

If that's correct, would you discuss that issue of gray area versus black and white, and so forth?

Dr. KOOP. Well, I think any two physicians can look at this whole spectrum very honestly in two different ways. There will be those who see issues as black and white, others will see a narrow black stripe and a white stripe and a very broad gray area.

I think the very presence of these regulations will help physicians to sharpen their spectrum and to see things more clearly as black and white rather than as gray.

In reference to the comment you referred to that I made on television, that is correct, sir; if I were out there in the medical establishment where I spent so much time, I confess that these regulations would probably annoy me. They would make life perhaps a little bit more difficult for me.

But they would not in any way hamper my ability to deal with patients the way I always have.

Senator DENTON. Again, Dr. Koop, there have been a number of stories broadcast and printed by the media alleging that the administration's proposals would require physicians to take steps which would merely prolong the lives of infants who are irreversibly dying.

There was one like that in one of the local newspapers.

Would you please explain what effect the regulation would have on these situations when the child, the infant, is irreversibly dying in the conscientious mind of the physician?

Dr. KOOP. Well, as you already have referred to Professor Ramsey's comments, some children are born dying; and others face death a little bit further down the road. It is absolutely not this Department's intention to formulate any regulations which would interfere with a physician's understanding of the difference between giving a patient a life to which he was entitled, as opposed to prolonging his act of dying.

We are particularly concerned, as I said in my statement, about having ordinary commonplace care such as clothing, sustenance of both food and nutrition, and so forth, given to children, no matter what.

Senator DENTON. Perhaps you saw, Dr. Koop, the Washington Post article this past Sunday dealing with one particular case of an allegedly dying infant being kept alive in Jackson Memorial Hospital in Miami. Physicians and others in that hospital claim that the infant is being kept alive—I understand the infant died in the last few hours—was being kept alive at the expense of other infants who could more successfully be treated, were they provided access to the same medical care and equipment; it was alleged that sufficient equipment simply is not available.

Could you comment on the medical ethics of that particular situation?

Dr. KOOP. Well, I read that article, sir, and it is true that the child died, I think, early in the hours of Monday morning.

It was a difficult article to assess because there were many quotations from various people working in the institution and, very often, as you well know, it's difficult to read such a report and know what the person actually meant in the context in which it was said.

But the way that article reads, it sounds as though that hospital had absolutely finite ability to care for children, and that if they had one more patient added to the system it somehow or other became disruptive and they couldn't care for that patient.

I can honestly say that many times in my experience let's say we had 10 children on respirators and had 10 respirators. And the 11th child arrived and we needed a respirator. That didn't mean we chose the life of one as opposed to the other. We went out and borrowed a respirator from a neighboring hospital and expanded our facility to take care of one more child.

In a day or two that would go the other way.

So that I think it's almost a cop-out, sir, to say that in order to take care of one handicapped child in a large institution you're jeopardizing the lives of others.

Senator DENTON. Well, to pursue that just a little further, I, myself, though not expert in the field could conceive of a situation, say, in an advanced echelon emergency hospital under wartime conditions in which the doctor would be confronted with the ultimate question: which one of these soldiers do I attend first? Knowing that the sequence he chooses will result in the death of some and the saving of others; and the decision he makes, the manner of it would be complex.

Granting that, if you will, such circumstances can arise—are you of the mind that this business of denying nutrition or normally available operative procedures to a child because of handicaps, is simply not the proper way of analogizing it?

Although that situation can arise theoretically, it is not the governing limitation on this particular subject we are addressing here today, is that correct?

Dr. KOOP. Oh, I think we're discussing oranges and apples.

In a military situation there's no doubt about the fact that triage is a well-defined science of deciding what you can do on the spot with the blood available, with the equipment available, with the personnel available.

But in the situation we are talking about, sir, withholding treatment or nutrition from handicapped children, there is never that kind of urgency or ever that type of circumstance.

Senator DENTON. I only have one more question, and then I'll turn it over to my colleagues.

As you know, Dr. Koop, I introduced a bill to reauthorize the Child Abuse Prevention and Treatment and Adoption Reform Act.

As part of that bill I included language identical to that found in the House bill that addresses the withholding of treatment question. Would you as the Surgeon General, speaking for the administration, support that language?

Dr. KOOP. Speaking for the administration, we do support the intent of the language in reference to handicapped youngsters that appeared in the House bill, sir.

Senator DENTON. Thank you, sir.

Senator Nickles?

Senator NICKLES. Thank you, Mr. Chairman.

Is the questioning for both members of the panel?

Senator DENTON. Yes. I'm going to stand pat on Ms. Dotson's statement, myself, as I understand you might have a few questions on that which I think preempt what I would have asked.

Senator NICKLES. Thank you, Mr. Chairman.

A couple of questions—one, I again appreciate your testimony and also some of the statements that you've made over the last year which I think are very commendable.

You've been in the field of pediatric surgery, I think you said, what, for 35 years? And you've mentioned your experience with problems has been greater than that of any other pediatric surgeon in North America. I think that's certainly noteworthy.

Are you convinced that there are instances where treatment would be routinely provided to nonhandicapped infants but has been discriminately denied to handicapped infants?

Dr. KOOP. I have no question about that at all.

Senator NICKLES. Have you any idea about how often this occurs?

Dr. KOOP. It is very difficult to get numbers because people don't like to talk about what they are doing. And I think the best information we've ever had about how widespread geographically this is, is what turned up in the film that we saw at the beginning of this hearing.

And my own feeling is it exists in out of the way hospitals, in rural areas; it exists in the most prestigious teaching hospitals, and you've seen testimony from outstanding pediatric surgeons and even apologists who admit that this is the manner in which they treat such patients.

Senator NICKLES. How is the choice, say, to treat or to not treat a Down's syndrome child for a routine medical condition regarded in the medical profession.

Dr. KOOP. Well, 10 years ago it would have been scandalous. But in the past 10 years there has been a gradual drift, as indicated in the various surveys that I mention in my testimony and as you saw on television. I would say in the select circle of people who make these decisions, probably more than half feel that a Down's syndrome child has the quality of life not worth living and, therefore, would not do anything to protect it by doing, say, surgery on an accompanying anomaly.

Senator NICKLES. So this trend has increased substantially over the last 10 or 15 years?

Dr. KOOP. Well, in my lifetime it's increased from nothing to what it is today, and I would say that in the last decade, most particularly.

Senator NICKLES. Why do you think this trend to withhold treatment from only handicapped infants exists today? Why is it so much more commonplace?

Dr. KOOP. I think it all started with the beginning discussion of "what is quality of life?" And as I tried to make clear in my testimony, sir, I don't think you and I can assess the quality of another person's life.

And what we're talking about here is not a quality of life issue, we're talking about an ethical, moral, medical, legal, and a civil rights issue.

And I think these children deserve the protection of the law.

Senator NICKLES. Historically, I guess, the only real monitoring of physician recommendations and activities in this area have been internal, primarily among pediatric professionals, peer pressure. How effective do you think this has been in protecting handicapped infants from being discriminated against?

Dr. KOOP. Well, theoretically, you would believe that if a hospital had an ethics committee, and a decision were made, that that would be an ethical decision. I'm not always in agreement with that.

The excerpt of the film that you saw on television moments ago, Johns Hopkins Hospital, indicates, in parts that you did not see, that they had a battery of professed experts they could get—as I recall, a professor of pediatrics, professor of pediatric surgery, psychiatry, chief nurse, social worker, and chaplain—and the decision was made that that child had a quality of life not worth living, and the child was given nothing by mouth until it starved a few days later.

Senator NICKLES. Well, if the peer pressure, the ethics review, or whatever is not adequate, what would be your recommendation for protecting these infants from being starved or not treated?

Dr. KOOP. Well, I think it was the consideration of the President and his concern, of the Department of Justice and Department of Health and Human Services, that the present system was not adequate. Therefore, the regulations which were instituted—imperfect though they may be—were at least a stopgap measure.

Senator NICKLES. You think the regulations the Department issues will be adequate to address these problems?

Dr. KOOP. I would predict that what would happen, sir, is what I said a moment ago, that a lot of people who have been thinking gray will now begin to think black and white.

And I would think the best thing that could come from these regulations is not the fact that Ms. Dotson has to investigate and that somebody has to prosecute, but rather, that there would be a deterrent effect just because of the existence of those regulations.

And because hearings like this have brought this to the minds of the public, and people now can bring their own moral and ethical feelings to bear upon this important issue.

Senator NICKLES. Many organizations, including American Academy of Pediatricians, and the President's Commission on Bioethics, are suggesting that the answer to assuring adequate protection in complex cases is to establish an ethics panel in local hospitals to review the controversial, difficult cases.

What do you think of these suggestions?

Dr. KOOP. I have an opinion about it, sir, but I just wonder whether, in view of the litigation that is now taking place about this regulation, that it would be better not to answer that one and jeopardize our case.

Senator NICKLES. OK.

I have wondered whether or not—I shouldn't dwell on that—I have an opinion on that, too; but I won't ask you to concur with my opinion.

Some people fear that there would be an unspoken pressure to support the doctor among hospital personnel so that an ethics panel and outside participants might not feel confident to question the physician's judgment; so that a decision not to feed an infant would go unchallenged.

From your experience in hospital structure or ethics panels, do you think these concerns are valid?

Dr. KOOP. I think it depends a little bit on the hospital. You can find some hospitals where almost everyone has the same opinion about the manner in which the quality of life should be the deciding factor.

In others you find that even as in the case of the Bloomington baby, somebody on the staff stands up and says, "I'll be an advocate for that child." And that then leads to a discussion with at least two different points of view.

Senator NICKLES. It might vary from institution to institution?

Dr. KOOP. Without question.

Senator NICKLES. Some believe the best way to protect infants whose lives are in jeopardy is to create a third-party right of action; and this will enable any person who has sufficient reason to believe that an infant is being denied treatment the standing to enter a court on their behalf.

Do you have any opinion on that thought?

Dr. KOOP. Well, I think that that is the current practice, that if there is a difference of opinion and the hospital committee or the hospital administration or just peer pressure says, we haven't come to a consensus, then it frequently turns to the court and asks that the court accept custody of the child, and the decision is made outside of the emotional aspects of the parents's decision.

Senator NICKLES. Thank you.

Ms. Dotson, a couple of questions:

What is your general enforcement investigative procedure?

You might turn the microphone to you.

Ms. DOTSON. OK.

When we receive a complaint we determine the jurisdiction, we assign it to an investigator who makes—goes out and makes a finding.

With respect to the "Baby Doe" cases, we've identified medical consultants who are to be on call to us whenever these cases arise, since we have no control over the time that we might have to go out on a case.

In the "Baby Doe" cases where we have an allegation of an infant being at risk, several things happen. We simultaneously determine the jurisdiction, that is, our jurisdiction to get involved; we notify the State agencies; we contact the administrator of the hospital; we dispatch one of our people immediately to the premises for the purpose of looking at the records, oftentimes accompanied by the medical consultants.

Senator NICKLES. It was announced that since the installation of the hotline in your office, you've received a lot of phone calls.

Can you tell us how many you've received?

Ms. DOTSON. As of this morning it was, I believe 420 phone calls.

Now, there were great variations as to what these calls were about. Some of them were just checking our number, and hung up—that kind of thing.

Senator NICKLES. I'm not too interested in the number of crank calls you had or any wrong numbers; but how many calls have you had that said: We feel like there's a problem and some action should probably be taken before too long, because an infant's life may be in danger?

Ms. DOTSON. We've had seven such calls.

Senator NICKLES. Seven such calls since the installation of the hotline number?

Ms. DOTSON. Yes.

Senator NICKLES. That's been in existence for how long?

Ms. DOTSON. Well, we began getting calls on March 17 as we already had the number in, but the regulation was effective March 22.

So we've received calls since March 17.

Senator NICKLES. And you've had seven?

Ms. DOTSON. In which there was an allegation that there was an at risk infant.

Senator NICKLES. An "at risk infant?"

Have you narrowly defined that? Have there been a lot of other allegations that, hey, here's a child that—I don't know how you would determine "at risk," but a child that's being denied treatment because they're handicapped in one way or another? Is that greater than seven?

Ms. DOTSON. No.

When I say "at risk," basically I am talking about an allegation that there has been in fact a violation of 504, that the baby is in fact alive at the time we receive the call, that nutrition is being withheld, or that they're not getting adequate customary medical treatment.

Senator NICKLES. How many—have you investigated those seven?

Ms. DOTSON. We have.

Senator NICKLES. Previously when I asked Secretary Heckler, she mentioned that you had some cases under investigation. Do you remember how many? Previously to that?

Ms. DOTSON. Prior to that—at that time I think there were about five or six.

Senator NICKLES. She told me seven, and I think we found out nine.

Ms. DOTSON. Well, that's—whatever we submitted, that's accurate But that does not—that is not reflected in the numbers that I have given you.

Senator NICKLES. So you've had——

Ms. DOTSON. Yes.

Senator NICKLES. Have you saved lives in that event? What's happening in some of those cases? You've submitted to my office details of those nine cases, I think; and I'm not familiar with the additional cases you just mentioned?

Have lives been saved?

Ms. DOTSON. We have not made a finding of a violation. I'm not able to say that lives have been saved.

Senator NICKLES. We did look into a couple of the cases. Are you familiar with the case in Illinois?

Ms. DOTSON. Yes.

Senator NICKLES. I didn't know if I should mention that or not. I'm not trying to put a black eye on anybody or any hospital or any group of doctors or anyone else; but in the investigation that we reviewed, and also in the brief summary report that was supplied by HHS, there was a lot of discrepancy between the information from what my staff was able to find, and the findings of the HHS report.

Before I get into that specific case, maybe I'll ask you a couple of other questions:

Have any of these cases we are now discussing actually been turned over to Justice for follow up on it?

Ms. DOTSON. No, they have not.

Senator NICKLES. In cases, should they have been?

I look at the law and I'm not familiar with Senator Denton's legislation, or the legislation that's been introduced in the House; but as I read section 504, the law looks pretty adequate if it's enforced.

But I don't know that 504's been enforced. Or I don't think we would have seen instances like those that were alluded to on the TV screen and others that are surfacing around. When we start hearing these things, it seems to me that 504 hasn't been enforced in the last several years.

Ms. DOTSON. Well, 504 provides that a recipient of Federal financial assistance, which would be the hospital, cannot discriminate on the basis of handicap. Now, with the cases which have been investigated to date we have not determined that the hospital in fact did discriminatorily refuse indicated medical treatment or sustenance.

I might add that our process is such that under 504, if in fact we did make a finding that a hospital or health care provider has discriminated against an infant, then after we issue a letter of findings, we still are required under our regulations, under our laws, to seek to bring that institution into compliance.

But to date in the cases, the factual situations, the investigations which we have followed through, we have not seen the kind of evidence which would sustain us in making a finding that the health care provider was in violation.

Senator NICKLES. Are you satisfied with the quality of the investigations that have been made?.

Ms. DOTSON. Yes, I am.

Senator NICKLES. Here again I can't claim any expertise. We've glanced at a couple of these cases and seemingly found some discrepancies. Instead of reviewing or going over the case, can I assure that you are familiar with the one in Illinois?

Ms. DOTSON. Yes, sir.

Senator NICKLES. Looking at the report that was issued it appears if there hadn't been some intervention—well, let me ask a question: Did your office bring in the Justice Department in this case?

Ms. DOTSON. Yes; as I recall in the case, on May 18, the date the notice was issued, simultaneously I believe the case was referred to Justice.

Senator NICKLES. Excuse me, would you mind repeating the last part of it?

Ms. DOTSON. The day that the notice was issued, the day that our investigator came onsite, I believe there was a referral to Justice from the Department and——

Senator NICKLES. This was May 18?

Ms. DOTSON. Yes.

Senator NICKLES. Well, my information was showing that the baby was born—and here again, we show some difference on that: Your report shows the baby was born April 30; I have some information it was April 25. This particular infant was born with spina bifida, I believe.

Perhaps Dr. Koop could elaborate a little bit. But it was our understanding that it was important that children with spina bifida receive medical attention immediately, certainly sooner than it was administered; and—correct me if I'm wrong—that the hospital, the original hospital, was encouraging surgery but the parents were originally saying no.

Ms. DOTSON. My understanding of the case is as follows: I will look again in my report.

The baby was born, in fact, according to every record that I have seen, was born on April 30. Our status report was in error in that we—I believe the status report indicated that the baby was born in another hospital. The baby was not born at that hospital, but was transported within hours of his birth. The baby was transmitted, transferred, rather, from there to a third hospital on May 1.

Now the middle hospital, which would have been the health care provider, did in fact as best we can determine from our examination of the records, recommend a medical correction of that condition. They recommended surgery. And the baby in fact was discharged or transferred from that hospital against medical advice to the third hospital.

Now, when we get to the third hospital, when we examined the facts, we find that the third hospital with great dispatch did in fact notify the appropriate State agency, so the State agency was also involved in this case.

Now, it's my understanding that the baby subsequently did receive surgery, I think about 3 or 4 weeks after he was transferred from the third hospital to a hospital in Chicago.

It's my understanding, also, that the consultant on the case indicated that the care which the child had received at the third hospital was entirely appropriate for the condition.

I believe that the consultant indicated that had he been, as I would say, in charge, and had he had the opportunity he would have preferred to operate at the time the baby was born.

Senator NICKLES. I wasn't wanting to mention the hospitals' name. Here, again, I am not looking to put any black eyes on any individuals or anything else; but the summary of this case is the child whose parents had initially said we do not want treatment or the necessary operation for spina bifida, did relent, I guess, or changed their mind, or the Justice Department's intervention did. The operation was at a later date and the child has now been adopted, and is healthy.

Is that correct?

Ms. DOTSON. Yes; it is my understanding that the parents, after they consulted with the consultant who was called in on the case, and given the pros and cons of what was involved, elected to give up custody of the baby to State agencies. Then almost simultaneously that baby was transferred to the hospital where he eventually received surgery.

I believe that the baby was adopted some time in July.

Senator NICKLES. Just a final comment: Looking at the statutory language that now exists, it seems to me like section 504 is adequate but possibly could be improved upon by the legislation Senator Denton is proposing.

Originally, when I first began looking at this and found out that it was happening on a fairly frequent basis, thought we might need to legislate this away. But in looking at the legislation which already exists, it seems to me that it's adequate on the books, as long as it's enforced.

And so let me again say I think it's very, very important, I think you have a large responsibility to enforce the law. I compliment the administration for trying to alert institutions that this is on the books and that they do plan on enforcing it.

And I would hope that your office would certainly cooperate with the administration in enforcing it. If we're going to reverse current trends, as I called it, I think it's going to take some enforcement efforts on behalf of your office and also on Department of Justice's, to reverse the trend and to see that it doesn't happen in the future.

Ms. DOTSON. Well, my office is entirely committed to enforcement of this policy and certainly I, as part of this administration, am personally committed to it.

Senator NICKLES. Thank you very much.

Thank you, Mr. Chairman.

Senator DENTON. Senator Nickles, before I ask Senator Grassley for his question, I would inform you that a copy of my bill is in front of you; and your staff has had an advance copy; and I'll be very interested in the comments you have to make.

It is a step to buttress the situation, to eliminate such questions as the national incidence of child abuse and neglect, we have a requirement that there be a study and that they investigate, the National Institute of Child Abuse and Neglect, including a determination as to the extent to which incidence of child abuse and neglect are increasing in number and severity; and a determination of those instances of child abuse and neglect which involve the denial of nutrition, medically indicated treatment, and so forth, which is one of the questions that you had asked of Dr. Koop.

So that question would be answered by this law as a requirement. It also requires that a hospital and so on have in place throughout the State within 2 years after the effective date of the Child Abuse Act, procedures to be followed by child protective service agencies, health care facilities, health and allied medical professionals, and other agencies, et cetera, to insure that nutrition and medically indicated treatment, and general care, and appropriate social services are provided for infants at risk with life-threatening congenital impairments.

In other words, the focus is in more narrowly on the area which seems to be giving the most problem in terms of growth of what could be considered unfortunate practices as mentioned by Dr. Koop, none when he started and quite a lot of them now; and this is the majority of kinds of cases being addressed in this bill.

It is my duty, since I have this under my jurisdiction, to reauthorize the act. I've tried to tighten it up a little, and would welcome either your criticism or your coming aboard to cosponsor.

Senator Grassley.

Senator GRASSLEY. Ms. Dotson, following up where Senator Nickles left off, are there any written guidelines or standard procedures that are issued as followup regulations?

In other words, once a legitimate phone call has been made, for an investigation, is there a written policy on how to proceed?

Ms. DOTSON. There are internal administrative guidelines that were issued to cover the expedited process that must be used to deal with the "Baby Doe" situations.

It is an expedited process of what we ordinarily do to investigate any complaints of discrimination.

Senator GRASSLEY. Then we do have a procedure so that in each case there could be a precedent set, one investigation to another?

Ms. DOTSON. Yes.

Senator GRASSLEY. In regard to the hotline, and you've had some seven supposedly legitimate calls that would require followup; have you had any indication that the hotline is used—or I should say abused—by irate employees, getting even with somebody else; or even with the doctor, or that sort of thing?

Ms. DOTSON. We've had a couple of calls which we are still trying to establish the authenticity of. But 2 out of 400, I would be reluctant to say it was being utilized for that purpose.

I believe that some of the health care providers and some of the involved State agencies have taken advantage of the 800 number to call us and ask us other information about posters and the regulations.

Senator GRASSLEY. I assume that the purpose of a hotline is that nobody has to give their identity, the person calling in; right?

Ms. DOTSON. Yes; we try, however, to get their identity; but we are bound to protect their confidentiality.

Senator GRASSLEY. In seven cases that have called for investigation, in each one of those seven cases do you have the names of the persons calling—I realize you cannot release them—but do you have the names of the seven people, of the seven different people who called in to tell you about seven instances they thought should be investigated?

Ms. DOTSON. I honestly don't recollect whether—because I've taken some calls myself. I believe there were probably about, at least three were not, or proved to be false.

Senator GRASSLEY. All right.

Dr. Koop, I was going to ask you if there is any court challenge to this. You indicated in a further colloquy here that there is already a court challenge?

Dr. KOOP. Yes, sir.

Senator GRASSLEY. Was that immediately instituted?

Dr. KOOP. It was rather immediately instituted, and the hearing is 2 days hence.

Senator GRASSLEY. That's district court, Federal district court?

Dr. KOOP. Yes, sir.

Senator GRASSLEY. Have there been, Dr. Koop, any public statements by any institution—I should say by the administrators of any institutions, or by any medical personnel who have simply outright said that they weren't going to abide by these regulations?

Dr. KOOP. I——

Senator GRASSLEY. I suppose one might assume since there is a case in court that such defiance had to take place; but have there been any overt attempts to discredit it, even in a passive manner ignore it?

Dr. KOOP. There have been many statements about how this is an intrusion into the practice of medicine, which I've already covered; not to my knowledge has anybody said: I don't care what the law says, I'm not going to abide by it. And that includes not just what I've read in the paper, but I've been on the road an awful lot, and I encounter the hostility of the people to regulations. But I haven't had anybody say: "We're not going to do it."

Senator GRASSLEY. From your standpoint as a spokesman for the administration do you anticipate there will be a very, very high degree of cooperation with the regulation? Is that your anticipation?

Dr. KOOP. My prophecy, sir, would be that we would have black and white instead of gray, and that just the presence of this regulation will do an awful lot to sharpen up the things we are concerned about.

I can tell you that at one institution I visited recently, I was told sub rosa that just because regulations are in place, a lot of attitudes had sharpened; people knew where they stood, they were not uncertain any more.

Senator GRASSLEY. I assume that we have a small percentage of hospitals in the United States that don't receive any Federal funds, and, hence, are not covered by the regulations. Do you have any indication from those, that even though they are not covered by regulations, bound by it, that they might adhere to it anyway?

Dr. KOOP. I have no such hard information, but I would suspect that peer pressure would come to bear on that.

Senator GRASSLEY. Would this be less than 5 percent of the hospitals which receive no Federal funds and hence are not covered by the regulations?

Ms. DOTSON. I just really don't know. The distribution of posters and the regulations was to health care providers who were receiving some type of Federal financial assistance as of December 1982. And I just don't have any idea of the other numbers.

Senator GRASSLEY. Mr. Chairman, I have no more questions.

I assume the record will be left open so we may submit questions later in writing to Dr. Koop?

Senator DENTON. The record will be held open, Senator Grassley, as customarily, for that purpose; and before thanking you and before you depart, I would place you both on notice that you may receive further written questions; and ask that you try to return them to us answered within 10 days.

I, myself, would base those questions, if any, upon testimony that we will receive from the other witnesses which raise those questions in my mind.

I want to thank you very much, Dr. Koop.

Senator NICKLES. Mr. Chairman.

Senator DENTON. You have a question? Go ahead.

Senator NICKLES. I thought enforcement of 504 had not been very strong in the past; has there been any investigations into alleged withholding of treatment for handicapped infants under prior administrations under that section of the law?

Ms. DOTSON. I don't know.

Senator NICKLES. Would you find that out for us?

Ms. DOTSON. You want to know whether——

Senator NICKLES. Whether there have been any investigations by your office or by the Justice Department into infanticide cases under section 504 previous to this administration?

Ms. DOTSON. Investigations? I'm sorry. I am sure there have been investigations.

Senator NICKLES. Could you give us the number and whether there actually has been any enforcement of this section involved; and what that enforcement in numbers has been previous to this administration?,

Thank you very much.

Senator DENTON. Again, Dr. Koop and Ms. Dotson, thank you very much for your informative testimony and your responses which will be of great value to the file on this matter.

We will ask the next panel to step forward.

Senator DENTON. There will be two physicians and two experts on medical ethics on our second panel. The physicians are Dr. George Little, a neonatologist representing the American Academy of Pediatrics; and Dr. David McLone, chief of pediatric neurosurgery at Chicago's Children's Memorial Hospital, and an expert on spina bifida.

The two ethicists are Father John J. Paris, S.J., and Dr. Paul Ramsey. Father Paris is an associate professor of social ethics at Holy Cross College in Worcester, Mass., and was a consultant to the President's Commission on Biomedical Ethics. Dr. Paul Ramsey is Harrington Spear Paine professor of religion, emeritus, Princeton University, and the author of several books on medical ethics.

I might add that with the exception of Dr. Little, the panel is representing their own views and not those of any university or organization.

I would ask the panel to try to restrict your oral testimony in terms of formal statement to 10 minutes each; your entire written statements will be entered in the record.

The previous two witnesses did observe the time limitation.

I want to welcome all four of you gentlemen. Thank you very much.

STATEMENTS OF GEORGE A. LITTLE, M.D., AMERICAN ACADEMY OF PEDIATRICS; DR. DAVID McLONE, PEDIATRIC NEUROSURGEON, CHILDREN'S MEMORIAL HOSPITAL, CHICAGO, ILL.; FATHER JOHN J. PARIS, S.J., ASSOCIATE PROFESSOR OF SOCIAL ETHICS, HOLY CROSS COLLEGE; AND DR. PAUL RAMSEY, PROFESSOR OF RELIGION, PRINCETON UNIVERSITY, A PANEL

Dr. LITTLE. Thank you.

What I would like to do is to paraphrase the written remarks which are in the body of material passed out. My understanding is that that—it's permissible? I'm a little bit unfamiliar with those procedures here today. But I welcome the opportunity to be here.

I represent the Academy of Pediatrics. I am chairman of the department of internal and child health at Dartmouth Medical School, which has obstetrics, pediatrics, genetic services, and so forth in it. I'm a practicing pediatrician and neonatologist.

Let me go through the statement just by the points that are enumerated in the written statement in your material and make a few comments on those, and move on to some other statements.

No. 1, the rule in the Federal Register violates physician's and hospitals' ability to exercise professional medical judgment in the best interests of their patients.

The process outlined in the new Federal rule is poorly defined and, more importantly, without precedent. In no other area of medical practice has this type of intrusive procedure been employed or proposed.

It really creates an adversarial process between physicians, health-care providers, and their patients.

Point 2, the rule is excessively vague and simplistic.

HHS insists in its rulings that infants receive customary medical care, this phrase does not have a clear meaning, not only to those of us who are physicians, neonatologists, nurses, and other health-care providers, but it's apparent that it really doesn't have a clear meaning within the Department, itself, which has failed to define it or to establish guidelines.

The simplistic ruling does not recognize the complexity and delicacy of serious illness in newborns. The ruling implies that decisions regarding dealing in customary medical care should be handled independently of the actual handicap; and as a physician I just want to point out you've got to deal with and treat the whole human being.

The rule is equally vague about the definition of a handicap:

Is an infant weighing less than 750 grams, or 1½ pounds, a handicapped infant? Some people would argue yes; and other people would argue no. There really has got to be additional thought given to this concept of just what is the newborn handicapped, without hurried application of rules.

The rule attempts to make a specific point about nutrition, but, unfortunately, the term does not have a simple meaning to the health care professional. To those familiar with care of the newborn, there are many ways to provide nutrition: through oral feedings, tube feedings into the stomach or intestine, or tube feedings into the vascular space.

It is possible, for example, to keep a child with no intestine alive and growing over the short term. Eventually, however, most develop chronic and very, very severe complications. The medical profession and society is grappling with this issue of total parenteral feeding, that is, feeding through intervenous channels or the vascular fed. The answers are simply not yet available.

Point 3, the rule is disruptive to hospital-patient relationships.

Putting up these signs, conspicuous signs, throughout the hospital concerning failure to feed handicapped infants or provide customary medical care implies distrust of the hospital in the decisions of all health care professionals.

This mechanism imposes Government intervention and will trigger confusion in the minds of parents already in a highly stressful situation.

Point 4, the rule violates basic confidentiality guarantees.

Confidentiality is an essential component or relationship among health care teams, parents and other interested parties involved in the caring of infants.

Let me simply add in here something I wasn't going to say—but I think the testimony that you heard a few minutes ago is good evidence of what many of our concerns are:

If I heard correctly, a hospital name and a patient name was mentioned.

And I spend a tremendous amount of time in my teaching of medical students and nursing students, nurses, and so forth, to try to guarantee confidentiality. And yet, today, in a body of very experienced people and so forth, we heard this problem with confidentiality come right to the fore.

Point 5, inappropriateness of the role of child protection agencies in this issue. Contrary to the suggestion of the rule, child abuse and neglect is not a parallel issue to concerns about handicapped children.

Child abuse and neglect situations involve health care providers who willingly recognize their obligation under existing law to report situations. They support institutional processes through which the health care establishment detects abuse and neglect, and attempts to deal with it.

Point 6. the rulemaking process and mechanisms of the rule really have serious problems both in the way in which the rule was promulgated and the mechanics.

The process was hurried, didn't allow for the 60 days of public comment through May 6, et cetera.

The Academy of Pediatrics objects strongly to the hotline mandated by the rule. Visitors to the intensive care unit who may not in any way be involved in the care of a particular child may report situations.

One example of a misinterpretation which might occur involved the sign on a basinette reading "NPO"—meaning "nothing by mouth."

And I'll diverge again here because I saw the clip from that film. "NPO" is an important designation with some children. There may be medical or surgical contraindications to do something by mouth.

Now, if a situation arises and the hotline is employed it's possible to try to diffuse an initial situation; but how do you take care of the inconvenience, stress, and bad public relations which emanates upon investigation which may have originated from an unreliable or unreputable source?

The rule is untimely, it's cumbersome; it's untried.

Point 7. Health and Human Services has not identified or investigated the problem to be addressed.

It's not produced any direct evidence of epidemic, inappropriate treatment of severely ill newborns. Indeed, retrospective compliance reviews have apparently found all facilities to be in compliance with section 504.

Now, this isn't to minimize the fact that one inappropriate death is wrong; but the fact is, that there has not been an objective data base for the application of a hurried rule.

And I think we've heard today that there seems to be a lack of production of an objective data base.

I think that other authorities besides myself would at least like to get in the situation of combing the literature and discussing with Dr. Koop openly his concerns about trend of data.

Data is available: Reviews of vital statistics and so forth can be made which have causes of death on them, and so forth and so on. And I think we need to at least question whether Dr. Koop's perfectly legitimate and authoritative observation is in fact correct.

Now, having made these points, let me move on to the concern that is most central and profound of the issues being addressed:

That really is the issue of how do we provide newborn care to all sick newborns, or all newborns including the severely ill?

There has been a report from the President's Commission on Bioethics, after lengthy study and investigation; they came up with some principles and problems and enumerated those.

Two problems do occur: One, parents occasionally receive outdated and/or incomplete information, and this limits their capacity to act as a surrogate decisionmaker; and,

Two, in what appears to be a limited number of cases, inappropriate decisions are being made without triggering a careful reevaluation.

Now, the Commission has made some specific recommendations for review boards, multidisciplinary review boards—clergy, physicians, parents, laymen, et cetera—and there's a process, one they recommended:

Verify the best information is being used; confirm the propriety of the decision and the range of discretion that the parents employed is appropriate; resolve disputes among those involved in the decision; and refer appropriate cases to public agencies.

There are review mechanisms which already exist in hospitals.

Now, the Commission has reported that difficult decisions usually involve two categories of infants, the very low birth rate premature, and those babies similar to the "Baby Doe" situation.

The Commission has found that hospitals, most hospitals, follow the following approaches:

Treatment is rarely withheld when there is a medical consensus it would benefit the child.

Two, predictably few endeavors are considered not to be legally or ethically justified—and that's important.

And there are a small number of infants who don't fall into a category. And it's this last group that really demands attention.

But the problem with the HHS rule is that all it does is it shifts responsibility to the Federal Government.

Now, we're here today to discuss the issue of reauthorization of child abuse programs. The Academy of Pediatrics is extremely supportive of that, and will submit testimony for that record.

However, lumping that issue of treatment of severely ill newborns, in our estimation, and my own personal estimation, is really a problem. It's a separate issue.

In addition, the Academy is concerned about the potential drain on existing child abuse and neglect programs and resources if they are diverted to another area.

Since the rule has gone into effect we've begun to receive anecdotal information; we don't have in a short time frame—but there are cases that apparently have occurred where the care of a baby or the welfare of a family has been disrupted. These occurred on the West Coast. They occurred in New England—concerns and problems about morale and infants and so forth.

Let me just finish up—I see the red light is on, but if I could just make a quick summary here?

I'm going to diverge from what's in the prepared comments and try to put a though in here:

There is a problem. The medical profession has known about it for some time. In fact it's written about. And it's been written about in the Academy of Pediatrics official Journal of Pediatrics.

It's great that this problem is finally coming out into broader consensus and is receiving broader attention. Members of the medical profession have been trying to do that for some time.

The difficulty is it's very hard to get a handle on this problem; it has different meanings to different people.

The Academy of Pediatrics is extremely supportive of handicapped individuals' rights, including the adoption of handicapped individuals. There's a committee on adoption and so forth.

The problem is that first of all we get involved in the issue, you're not supposed to do harm. That's what health care provision is all about.

I personally feel, and the Academy of Pediatrics feels, that this rushed-up process of rulemaking can and will be and has been harmful to babies; it can and will be harmful to families; it's going to be harmful to health care professionals; and it's going to be harmful to community-responsive institutions such as hospitals, most of whom have public boards of trust and boards of trustees who vouch for hospitals in most communities.

Now, there is a parallel issue. Ten or so years ago whenever it was the issue came up about biomedical research. That involved medical processes. That involved ethical problems. That involved surrogate decisionmaking. That involved civil rights.

At that time a responsible, aggressive, academic, private, professional and Government initiative came underway and local institutional review boards are now present in all academic-medical centers and so forth in this country to permeate the medical establishment.

To the best of my knowledge as an academic chairman I would like to state that I think that issue was handled, and handled well.

The Academy of Pediatrics is disappointed and I'm personally disappointed that higher expectations of a past good track record between Government agencies, Health and Human Services, to get together and discuss issues and come up with game plans were not followed in this specific instance.

We need to stop being defensive, emotional, nonconstructive about this, and get together along the lines of a cooperative effort, and deal with a very real problem in American medicine.

[The prepared statement of Dr. Little follows:]

PREPARED STATEMENT OF GEORGE A. LITTLE, M.D., F.A.A.P., ON REAUTHORIZATION OF THE CHILD ABUSE PREVENTION AND TREATMENT AND ADOPTION REFORM ACT, TREATING SEVERELY ILL NEWFORMS

The American Academy of Pediatrics, an organization of more than 25,000 pediatricians dedicated to improving the health and welfare of our nation's infants, children and adolescents, welcomes the opportunity to appear here today to discuss with you this most sensitive and complex issue. Severely ill newborns deserve every possible protection, and to that end physicians continue close consultations with families involved as well as with hospital and community representatives. Always the presumption is in favor of life -- and that presumption is tempered only by health care providers' personal and professional dedication, within legal and ethical guidelines, to reduce pain and suffering.

The Academy strongly supports and defends Section 504 of the Rehabilitation Act. It similarly supports the stated intent of the so-called "Baby Doe" rule recently promulgated by the Department of Health and Human Services (HHS): that no infant is to be discriminated against on the basis of a handicap. But, to be sure, the issue before us now is not discrimination against handicapped infants -- it is rather the definition of appropriate care for severely ill newborns, an issue with profoundly far-reaching medical, ethical, social and legal implications.

The interim final rule proposed by HHS, although well-meaning, is a simplistic, arbitrary and imprudent mechanism which, for the following reasons, will impact dangerously on the care of severely ill newborns.

I The rule violates physicians' and hospitals' abilities to exercise professional medical judgment in the best interests of their patients.

The procedures required by the rule are contrary to most medical and ethical opinions on how to address problems involving handicapped newborn children in the United States. All health care providers are increasingly aware of the fact that childbirth is an important physical and emotional process, but more particularly that the presence of a problem in pregnancy -- whether a stillbirth, a newborn death, or a deformed or otherwise sick infant -- is an extremely stressful event. The standard procedure in our country is to respect parental and child confidences and to work with parents in arriving at difficult decisions regarding care alternatives. This process may take days or weeks and usually involves other parties, such as members of the nursing profession or clergy, social workers, trusted friends and others, working in a collaborative relationship. Sensitive consideration is required; the process can be disrupted easily by inappropriate prejudicial interventions, with directly resulting harm to the infant, and indirectly so to parents and family.

The process as outlined in the new federal rule is poorly defined and without precedent. In no other areas of medical practice has this type of intrusive procedure been employed or proposed. There is nothing voluntary about it. This rule would create an adversarial process between physicians or health care providers and parents, while federal authorities make medical decisions on the treatment of handicapped infants. A physician literally may be forced to provide medical care or change a course of treatment for an infant out of fear of an enforcement action by the federal government.

The complexity of and continuing controversy surrounding issues such as parenteral nutrition or the use of life-support mechanisms mean physicians today still must make judgments on the best available facts and bases of knowledge. As a consequence, individual physicians inevitably may differ on what is the best course of action for an individual child. This is true in the practice of any age group in medicine, but it is especially true in the evolving subspeciality of neonatology.

II The rule is excessively vague and simplistic.

HHS insists under its new rule that infants receive "customary medical care," a phrase whose meaning is considered murky not only by physicians, but by the department itself, which has failed to define it further or establish guidelines. In fact, each case involving a severely ill newborn is unique, and must be assessed on its merits. This is not to suggest that the specific procedures or approaches used to determine such care are different from those employed to determine care for a "normal" infant, but that other considerations which necessarily emerge regarding care alternatives are more complicated and delicate.

HHS, lamentably, fails to recognize that reality. Its rule implies that decisions regarding the feeding of and customary medical care for infants with handicaps should be made independently of the actual handicap. This separation of problems creates the potential for inappropriate medical care. For many infants, the nature of their handicap is part of their medical condition, and must be considered in formulating an optimal treatment program. For example, an infant with severe congenital heart disease, resulting in congestive heart failure and might also have a bowel obstruction. The best medical plan might necessitate postponement of surgical intervention for the bowel obstruction and limitation of fluid administration because of the cardiac handicap. To do otherwise could result in death. An individual without complete medical information and understanding of this information could be misled into considering this treatment plan as an example of discrimination based on the handicap of severe congenital heart disease.

The rule chooses to allow government investigators (rather than the medical team, parents and potentially the courts) to decide "customary medical care." If the interpretation is limited to support of the comfort and well-being of the infants, we would not quarrel with the ruling. But if the government interpretation includes the use of all medical, surgical and life-support mechanisms that are technically possible, regardless of the likelihood of ultimate success, then we disagree. It is doubtful, to say the least, that even the best-intentioned federal bureaucracy could serve these stricken infants better than the local, experienced professionals who deliver intensive care to newborns.

The rule is equally vague regarding the definition of a handicap. Is an infant weighing less than 750 grams (1½ pounds) a handicapped infant? Some would argue yes; some no. Is an infant with an intracranial hemorrhage, bowel perforation and respiratory failure (all acute conditions occurring after birth) a handicapped infant?

If a handicap is construed to include extreme conditions such as a massive cerebral hemorrhage, or an anencephaly, it will strip discretion from doctors and families with respect to continuing or discontinuing life-support systems.

Potential exists in the rule for indefinite prolongation of futile life support with attendant pain and suffering of the patient and the family, misuse of scarce and vital medical resources and enormous expense to the community. Indeed, after an exhaustive three-year study, the President's Commission on Bioethics submits it is legally and ethically justifiable not to provide clearly futile therapies to an infant.

The rule attempts to make a specific point about nutrition, but unfortunately that term does not have a simple meaning to health professionals. For those familiar with the care of the newborn there are many ways to provide nutrition. It can be done through oral feedings, through tube feedings into the intestine, or through feedings into the vascular space. In fact, today it is possible to have a child with little or no intestine survive and grow for a period of weeks or months using parenteral feedings. However, many such infants eventually develop severe chronic complications. The medical professionals and society is grappling with this issue of total parenteral nutrition but the answers are not available.

Medical care in a neonatal intensive care unit is continually evolving. As new medical findings are reported, technology is developed and experience is gained, standards of care are modified rapidly and often. There are also legitimately differing views of the appropriate treatment for the same conditions. For example, an infant with frequent and prolonged apneic episodes would be attached to a mechanical respirator by some neonatologists. Other equally competent neonatologists, concerned with the long-term problems associated with respirator therapy, and having sufficient personnel, would recommend that someone stay with the infant continuously, and stimulate the baby by touch or movement every time, he/she ceases to breathe. Depending on the orientation and knowledge of a physician, either approach could be considered as non-optimal and discriminatory toward an infant who is handicapped.

How would non-medical HHS investigators, sent to a hospital on the basis of an anonymous telephone tip, understand what treatments are appropriate and what treatments are not? How, for example, could they be expected to know about the controversy as to whether closure of a spinal defect in an infant with associated hydrocephalus should be appropriately delayed until the problem of the hydrocephalus has been corrected? Placing non-medical investigators into a busy neonatal intensive care unit to study such cases presumes that they have been trained in and received guidance in highly technical areas of medicine, surgery and bioethics, and we are not aware that any such guidelines now exist. Medical investigators might legitimately differ but necessarily be right. Also who will assume that medical investigators will be non biased? Who will recruit them?

A non-professional concept of appropriate care might be that maximal treatment is optimal care. This regulation itself could give that impression, and thus do a disservice to some handicapped infants.

III The rule is disruptive to hospital-patient relationships.

The very presence of conspicuous signs throughout a hospital concerning failure to feed handicapped infants or provide customary medical care will necessarily give rise to the inference that physicians practicing there engage in the described activities.

The mandatory posting of notice regarding the HHS regulation and putting up a "Baby Doe Hotline" number imply a distrust of physicians and of the decisions of all health professionals. It imposes governmental intervention in an area where the unique expertise of the health professional combined with the considered sentiment of the family and local advisors is the only appropriate input in these highly sensitive, painful and difficult decisions.

Posters placed in the nursery, the emergency rooms, and other areas of hospitals will trigger confusion in the minds of parents who are already in a highly stressful situation. Parents of the critically ill newborn often will go through the classical stages of depression, denial, hostility and anger. A poster suggesting to them that the hospital is not doing everything possible to treat their baby can only foster further feelings of guilt and hostility toward the staff. Such an unfair suggestion that the hospital care given is not in the best interest of these children is totally unacceptable, untenable and unjustified.

IV The rule violates basic confidentiality guarantees.

This rule will place undue and disruptive pressure upon the relationship among members of the health care team, parents, and other interested parties involved with a specific case concerning a handicapped infant. That relationship must remain fiduciary and have guarantees of confidentiality. A reporting and investigation process entailing the intervention of ill-defined, poorly-structured procedures could be deleterious to all parties, including the infant.

The issue of confidentiality of medical records is completely unaddressed in the rule. Hospital records and the discussions between the health care professional, i.e., the pediatrician, and the parents about the well-being of a child are considered to be privileged and highly confidential. Such trusts might be violated by responding to telephone inquiries from federal investigators. A great deal of effort currently is devoted by individual providers, hospitals and academic institutions to guaranteeing confidentiality of hospital records. There is no provision in the new federal rule to guarantee this confidentiality, and we are concerned that inevitable disclosure, formal or informal, might occur, with great harm in the physician/patient relationship.

V Inappropriateness of Child Protection Agencies.

Contrary to the suggestion in the rule, child abuse and neglect is not a parallel issue. In these instances health care providers are child advocates and are obligated under existing law to report any situation involving such abuse or neglect. These important institutional processes, which we support, deal with a different clinical situation from that with newborns. The health care establishment detects abuse or neglect in children generally beyond the infancy stage, and attempts to deal with it. The existing local and state mechanisms, which are used in child abuse or neglect situations, have little or no similarity with hospital procedures on newborns. These agencies often have an excessive caseload, are underfunded, and have varying staff capabilities.

The local and state mechanisms which already exist for reporting of child abuse and neglect include requirements that health care providers report instances of abuse and neglect, and that these reports may be anonymous. However, because of current fiscal reductions, child protection agencies, which provide essential and life-saving services for abused and neglected children, are increasingly understaffed and underfunded. Not only would this rule, by encouraging reports from a wide variety of informers, decrease the agencies' effectiveness in providing the services for which they were designed, but it fails to recognize that their personnel have no procedures for, experience with or training in problems involving newborns with handicaps. Their experience has been with parental neglect, not to date medical neglect.

VI Rulemaking process and mechanics of the rule.

The Academy has serious problems with both the manner in which the rule was promulgated and the mechanics of the rule.

Entirely apart from the substance of the regulatory step, we take strong exception to the process by which HHS has pursued its implementation. Only 15 days were allowed between the March 7 announcement of the new guideline and its March 22 date of effect -- yet the prescribed period for public comment on the matter runs 60 days, through May 6. Such an accelerated time frame effectively precludes collection and consideration of necessary additional data as well as further study of the complex issues involved.

While recognizing and concurring with the need to assure all infants adequate nutritional support and appropriate medical care, the mechanism proposed in this rule also has major logistical difficulties. With more than 6000 obstetrical and nursery units and approximately 3000 counties with their own child abuse and neglect protection agencies, the ability of a single central office to assure appropriate investigation and intervention is questionable. The danger of inappropriate investigation and/or intervention is the possibility of harming or causing the death of the infant. The requirement that such investigation and intervention must take place immediately in medical situations that are highly complex increases the potential for a negative impact.

The Academy also strongly objects to the "Hot Line" mandated by the rule which will trigger calls from efficatious intermediaries and spiteful persons. Visitors to the intensive care unit who may not be in any way involved in the care of a particular child may report situations where that person has absolutely no knowledge. Just one example of a misinterpretation might be when a sign is posted on a bassinette reading NPO, meaning Nothing By Mouth, which may be interpreted by a well-intentioned visitor to indicate a child is not being fed. NPO is a necessary medical precaution in preparation for many procedures, including surgery, or because of any number of feeding problems in a child. However, a child may be receiving parenteral nourishment.

Having a baby is an important but anxiety laden time for many families. Those families with sick or handicapped babies are under enormous strain. Reactions to this stress, as with any other life stress, vary. Some parents blame themselves, other are guilty, others are angry or vindictive. These families present the most difficult of situations for hospital staff because of their psychological problems. The consequences of patient care if a staff were diverted by a "hotline" investigation emanating from an angry or alienated spouse can be considered as nothing but deleterious and harmful. Intensive care nurseries are already "pressure cooker" environments.

The remedy proposed in the rule is not only untimely, it is cumbersome and untried, and there is no way of knowing if it will make the present situation better or worse. It well may lead to overtreatment of many infants with every technology available to hospital intensivists, against the best interests of the infants, simply prolonging the process of dying. To propose such a radical change in the way health care is delivered in this country, without adequate data, without awaiting public discussion or review, and in the face of alternatives proposed by thoughtful official bodies, is surely imprudent.

VII HHS has not investigated and identified the problem to be addressed.

The Department of Health and Human Services has not produced any direct evidence of inappropriate treatment of severely ill newborns. Indeed several retrospective compliance reviews conducted by the department since May 1982 have apparently found all of the facilities to be in compliance with Section 504. Further, it is our understanding that although seven cases were reported during that period, none was found to be a violation. This is not to minimize the importance of even one inappropriate death, but to emphasize that the department has issued a completely untried procedure to remedy a situation which it cannot define. There is no evidence to justify the assumption that hospitals routinely are treating babies inappropriately.

The illogic of HHS's procedure is amplified by the fact that after a three-year study of hospital procedures, including interviews with physicians and ethicists, the President's Commission on Bioethics does not recommend the new federal approach. Instead, it identifies key problem areas and suggests solutions. We strongly question the promulgation of such a revolutionary rule with total disregard for the evidence and recommendations of a commission which has deleberated this issue for several years.

What concerns us is that the more central and profound issue of relevance here is not being adequately addressed, namely, how to insure that appropriate care is offered to all newborns -- including the severely ill. For this I turn to the report of the President's Commission on Bioethics, which after lengthy study and investigation, concluded that even though decision making usually adheres to the precepts outlined by the commission, two problems do occur: 1) parents receive outdated or incomplete information from their physicians. and this limits their capacity to act as surrogate decision makers; and 2) in what appears to be a limited number of cases, inappropriate decisions are made without triggering a careful reevaluation.

To this end the Commission recommends that hospitals establish local review processes which would:

1) "Verify that the best information available is being used.

2) Confirm the propriety of a decision that providers and parents have reached, or confirm that the range of discretion accorded to the parents is appropriate.

3) Resolve disputes among those involved in a decision, by improving communication and understanding among them.

4) Refer cases to public agencies (child protection services, probate courts) when appropriate."*

"Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone. Other cases, such as when the physician and parents disagree, might well also be reviewed. The policy should allow for different types of review and be flexible enough to deal appropriately with the range of cases that could arise."*

The Commission further states that "such a review mechanism has the potential both to guarantee a discussion of the issues with a concerned and disinterested representative of the public and to insulate these agonizing tragic decisions from the glare of publicity and the distortions of public posturing that commonly attend court proceedings."*

It is important to recognize that such review mechanisms do already exist in many hospitals, but we need to establish guidelines for their use, to determine their advantages and disadvantages, and to promote and establish universally such effective mechanisms.

To fully understand the Commission's recommendations, we must also understand the population we are dealing with. The Commission reports that difficult issues regarding newborns usually involve two categories of infants: "the low-birth weight infants and those infants with life-threatening congenital abnormalities. Within the second category two types of conditions have been especially prominent in discussions of the ethics of neonatal care: neural tube defects and permanent handicaps combined with surgically correctable life-threatening lesions."*

The Commission outlined the following structure to facilitate appropriate decision for care of these infants, an approach which the Commission found most hospitals do follow:

1) Treatment is rarely withheld where there is medical consensus that it would provide a net benefit to the child. The Commission concluded "that a very restrictive standard is appropriate: such permanent handicaps justify a decision not to provide life sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant."* This a standard is strictly defined and is irrespective of perceived negative effects that an impaired child's life might have on other persons, including parents, siblings and society. These children should be treated no less vigorously than their peers.

2) It is legally and ethically justifiable not to try predictably futile endeavors. "Such therapies do not help the child, are sometimes painful for the infant (and probably distressing to the parents), and offer no reasonable probability of saving life for a substantial period. Obligations to comfort and respect a dying person remain, and infants whose lives are destined to be brief are owed whatever enhancement and relief from suffering that can be provided, including medication for pain and sedation, as appropriate."*

3) "Although most infants fall into the previous two categories, difficult questions are raised by the small number for whom it is difficult to know whether treatment offers prospects of benefit. "Much of the difficulty in these cases arises from factual uncertainty. For the many infants born prematurely, and sometimes those with serious congenital defects, the only certainty is that without intensive care, they are unlikely to survive; very little is known about how each infant will fare with treatment."*

It is this troublesome group to which we must address our attention, notably perhaps toward the Commission's recommendation for local ethics' committees, which can best insure that accurate information is imparted and appropriate decisions are rendered. The HHS rule will not only fail regarding this third group, but it promises to compound the current situation by inappropriately assuming a decision regarding the previous two categories. Our point is a simple one: that the HHS rule does not assist or support medical and health care professionals, parents, nurses and others who must make difficult decisions. The rule merely shifts the responsibility for such decisions from the above group to the federal government, and in doing so mandates procedures which may be harmful to the care and treatment of infants.

The Academy strongly supports the recommendation of the President's Commission on Bioethics and is preparing a research study to determine how medical and legal systems are currently dealing with this issue. It will assess the advantages and disadvantages of systems, recognizing varying resources and populations, and suggest guidelines that can be used by appropriate bodies.

It also should not be forgotten that we are here today to consider the issue of reauthorizing child abuse programs. The Academy is extremely supportive of child abuse programs and will submit testimony for the record on our specific recommendations. In light of the focus of today's hearings, however, we would emphasize that we do not favor including provisions regarding the medical treatment of severely ill newborns into child abuse legislation. The President's

Commission has studied this issue for several years, identified key problem areas and suggested an approach to address those problems, i.e., hospital ethics and review committees. The Academy would support any efforts to implement this recommendation. Further, the Academy is seriously concerned about the minimal resources and problems which current child abuse programs already face; we are concerned about the potential drain on these programs.

As you know, the HHS rule has already gone into effect -- and while we sit here deliberating logically its ramifications, hospitals are grappling with life-and-death decisions. We are already beginning to receive distressing case reports information on the effects of this rule.

Everyone appreciates the government's good intentions, but we must in closing convey our sense of outrage that federal officials would choose to operate in such an irresponsible and dangerous fashion, oblivious to the impact this rule will have on human life. It is easy to raise the banner that such intervention will save babies' lives, but we, and the medical and health community at large, are here to tell you that it will not. Crucial issues surrounding the controversy of severely ill newborns persist still -- and this HHS interim rule does nothing but worsen prospects for progress.

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* Deciding to Forego Life-Sustaining Treatment -- A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions, March 1983. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.

Senator DENTON. Thank you, Dr. Little.

Dr. McLone?

Dr. McLONE. Yes, you have my prepared text, and I thought what I would do is to talk about specifically spina bifida. Spina bidifa and Down's syndrome seem to be two of the most common cases in which there lies difficulty with decisionmaking.

I am a pediatric neurosurgeon at a large metropolitan children's hospital, and because I operate only on children and as a neurosurgeon I see a large number of children born with congenital anomalies of the central nervous system; and, in fact, have treated some 2,000 children with handicaps involving the central nervous system.

In the review of spina bifida if you look at the literature and go back prior to the 1950's and you talk about the problem of spina bifida, there really wasn't a problem prior to that; because the vast majority—some 85 to 90 percent of these children—died from their illness, because we had as a profession little to offer these children.

In the 1950s and through the 1960's the availability of the shunt system were developed. We now treat the child's hydrocephalus or the child's water-on-the-brain and essentially cure it or render it nonprogressive.

And so larger and larger numbers of children began to survive.

Led by a group of physicians in England it then became the common treatment that all children born with spina bifida should be aggressively treated, their back closed in the first 24 hours, and their hydrocephalus, should it develop, treated with the shunt system.

In reviewing the outcome of that vigorous program in England, the results were in their opinion so appalling that they then began to advocate a criteria:

They said that this criteria was valid, predictive of outcome, and that certainly you could examine a newborn child and say something about that child's quality of life.

I think the evidence overwhelmingly now indicates that all of those criteria, taken individually or collectively, are inappropriate and really of little value.

Certainly the outcome of aggressive treatment is quite contrary to to the results of aggressive treatment in this country.

In the late 1970s the CT Scanner became available and we've—in almost all institutions—and we now had another thing in our armamentaria to monitor the child's hydrocephalus and to treat it.

And then recently the introduction of clean intermittent catheterization has given these children the ability to have control over their bladder and bowel systems and that these children now can remain dry and can be in a regular classroom system.

Unfortunately the vast majority of literature that exists for us through pediatrics comes from the British literature. And a lot of decisions are made to deny treatment to these children, in my opinion inappropriately, based on British literature which is outdated and contrary to the experience in this country.

The mortality rate at our institution where we treat all children born with spina bifida—we attempt to treat them all within the first 24 hours of life and close their back; if hydrocephalus develops and is progressive, they then receive a shunt—the mortality rates in the 1950's was 85 to 90 percent in our institution and in the last 8 years is now only 15 percent.

So only 15 percent of these children are dying in the first years of life.

That's fine, the fact that we've reduced the mortality. But what about this question of "quality of life?" What do you tell a family who is confronted with this horrendous event of having anticipated a normal newborn, suddenly have a child who has probably the most severe congenital malformation consistent with productive survival or survival at all?

Remember that what I'm going to tell you are statistics, and these statistics no more than the criteria advocated by the British can be used to judge how any one single child is going to do. There is no valid way to determine what the outcome would be of the treatment of the newborn child, in my opinion.

And that's having personally operated on 200 children in the last few years.

The child born with spina bifida—and spina bifida is a disease without known cause; we have a variety of possibilities, but there is no single cause. In the laboratory we can produce it with a variety of mechanisms both in fetal mice and chickens and other animals.

But the child is born not dying; the child is born alive and healthy in the vast majority of cases. In a few cases there are obvious progressive hydrocephalus evident at birth which requires that that be dealt with immediately.

The reason that these children die, and in the British system, they, as you heard, elect to let three out of four of these children die—and the way that you can guarantee that they die is deny them food and water; I think that rarely if ever occurs in this country.

It may, it has been documented in a few cases in the literature; but, in my opinion, denying food and water to these children is rare.

But what is not uncommon is denying the children immediate progressive treatment. If the child's back is not closed quickly within the first 24 hours, infection will ensue. If the infection is severe and ascends into the rest of the central nervous system, the mortality rate of the untreated group, even if they are fed and watered, is 60 percent.

The 40 percent who survive, a high percentage of those individuals will have sustained additional damage, more paralysis in their lower extremities; and, I think most significantly, if they have a central nervous system infection, the most common cause of mental retardation in spina bifida is not the spina bifida itself or the syndrome, but is inflicted on them by infections of the central nervous system, either through lack of treatment or through the complication of the shunt infection.

The data is now well established at our institution, at an institution in Cleveland, and at Yale University, that mental retardation by and large is inflicted on these children either through infection that occurs as newborn or through a complication of the shunt system in treating the hydrocephalus.

If you took 100 consecutive newborns who were over the age of 4, now—and from our institution and no child was denied treatment, and this is a consecutive series—52 percent of those children ambulate in the community. That is, they don't use a wheelchair; they are able to get up, walk; they have significant bracing, some of these children; but they are considered community ambulators, that they will walk in the community.

Now, 85 percent of these children are continent in bladder or bowel. It used to be the single most difficult thing to deal with in these children—getting them mainstreamed into regular schools—is the fact that they were wet or they had a diversionary device on their abdominal wall. We have not diverted the urinary system to the abdominal wall in about 7 years; in fact, we have undiverted 60 children now; and they are now on intermittent catheterization and continent.

Seventy-three percent of our children have an IQ within the normal range. That's quite contrary to anything else that I think is in the literature, and it is a tremendous tribute I think to my colleagues.

And the results that I'm telling you here are not specific to our institution, but is common in all of the institutions that I know of in the United States where a pediatric neurosurgeon is involved in the aggressive treatment of newborns with this disease.

In fact, 37 percent of the children I consider essentially normal. They have normal intelligence, they are continent of bladder and bowel—that can be through intermittent catheterization, but they are continent of bladder and bowel; and they are community ambulators.

Again, just to make sure that we understand, that this outcome of treatment does not apply to all children; but you cannot identify the child who is going to have a poor outcome, at birth.

Fifteen percent of the children have died, and these children have sorted themselves out in spite of all that was done for them; it soon became impossible to sustain their life; and these children have died.

There's probably an additional 10 percent of the children of the 100 newborns who are going to require some kind of custodial care.

But if you look at the group, and their "quality of survival"—that word plagues us and it is difficult to define—but if you look at this group of individuals, taken as a whole, the number of survivors and the quality of the survivors exceeds what the British experience and tells us what will happen with treatment of not only that group they call the very best, or the one out of four children that they select for treatment.

Senator DENTON. Excuse me, Dr. McLone, I may be wrong, and I wish to be corrected if I am—the statistics you have just given regarding the proportion of children who are ambulatory and have normal IQ's and can control their bowels—I don't find that in your prepared statement.

Dr. MCLONE. No. This is outside of my prepared statement.

Senator DENTON. Well, may I ask that you include that as part of your written testimony to us? Because I find it interesting and relevant.

Dr. McLone. Yes, this—the statistics that I'm quoting is an indication, and in fact will be part of the next volume of Clinical Neurosurgery which will be coming out; in fact, the galleys have gone back.

But I will send you a copy of that article.

Senator Denton. You can give us something that is roughly identical to what you have been saying?

Dr. McLone. Yes. Those are the same, and they are from that article.

One final point I would like to make, this was brought to my attention by a colleague who had supplied in work through the development of the spina bifida program in Australia—and their experience is similar to that which occurred in Great Britain—and he's a retired physician, and has had great experience with this group of children.

He pointed out that, I take some responsibility for every child's back which I close. And I think my nightmare is that I have preserved a life or assisted a child in survival only to have normal intelligence and to be ambulatory in the community, but then to be denied by the community and by the lack of programs the ability to become independent and competitive.

My nightmare is a group of children which number almost 1,000 I care for now, with normal intelligence, sitting in nursing homes because they have not been habilitated or given the opportunity to participate in our society, pay taxes, and compete for jobs.

Thank you.

[The prepared statement of Dr. McLone and additional information supplied follows:]

PREPARED STATEMENT OF DAVID G. MCLONE, M.D., PH. D., ASSOCIATE PROFESSOR OF SURGERY (NEUROSURGERY), NORTHWESTERN UNIVERSITY MEDICAL SCHOOL, AND CHAIRMAN, DIVISION OF PEDIATRIC NEUROSURGERY, CHILDREN'S MEMORIAL HOSPITAL

My purpose in this presentation is to address some of the problems, paradoxes, and ambiguities surrounding the care of the child born with a serious handicap.

There is documentation that handicapped children have been denied life saving medical care and occasionally even basic nutrition: food and water. The extent of this problem is unknown. In the small, local sample provided by review of the last 200 patients with spina bifida referred for treatment, 10 children were found to have been denied prompt surgical therapy prior to transfer to our hospital. None of these had been denied food or water. If this sample be representative, then the incidence of delayed care may be on the order of some 5% of newborns with spina bifida.

Federal regulations now require that all handicapped children receive food, water, and customary medical care. Very few disagree with this in principle. Controversy arises from the interpretation of "customary medical care" in specific clinical contexts.

Most physicians would agree that newborns with life-threatening but completely remediable diseases should be treated as aggressively as necessary to ensure their survival and future health. Most physicians would also agree that newborns with irremediable, lethal malformations should be given nutrition and simple care. They should be made as comfortable as possible, and allowed to die in peace.

Opinion diverges sharply on proper care for the newborn with life-threatening disease when all possible treatment will ensure survival with serious handicap. In this context, the parents, the physician, and the public weigh the patient's long-term survival, quality of life and possible eventual self-support. In this weighing, well-intentioned individuals of like morality may yet derive different conclusions.

I personally have had experience with well over 2000 handicapped children, principally those with spina bifida, hydrocephalus, prematurity, birth injury, and other birth anomalies. The overwhelming majority of these children have received prompt, often life-saving care. A small but significant number received less than that prior to transfer to our hospital; a form of euthanasia based upon withholding of available therapy and supportive care.

Some parents and physicians hope to find a medical and moral middle ground by inaction--"allowing nature to take its course". In the case of newborns with spina bifida, for example, they might provide food and water but deny prompt surgical repair of the open nervous system in the hope that the inevitable infection, meningoencephalitis, will prove rapidly fatal. This dereliction of responsibility fails for two reasons, among others. First, one half of the children will survive the infection and will still require additional, often more extensive, surgical care. Second, the more severe hydrocephalus and brain destruction caused by the infection markedly reduce the functional capacity of the 50% of patients who do survive. A policy of so-called "benign neglect" then is both offensive and ineffective.

Other parents and physicians seek to provide or deny therapy "rationally" by applying a set of medical "selection criteria" for identifying the newborns with spina bifida who are likely to have good clinical and functional outcome. Historically, these criteria were elaborated in Britain where many of the spina bifida patients are denied sustenance, are sedated, and are allowed to die. The British experience is entirely contrary to the recent experience in this country. However, because the majority of the medical literature dealing with management of spina bifida is from Great Britain and because many of the U.S. physicians who see only 1 or 2 such patients depend upon the literature for guidance, the "selection criteria" advocated by British physicians continue to be used, inappropriately, by some physicians in this country. In fact, medical advances have been so rapid that the functional outcome in unselected U.S. patients is now better than that predicted for the few "best" patients selected by the British criteria.

In my experience, decisions to passively euthanize severely handicapped children are almost never made because of callousness or amorality. Rather, those parents and physicians appear to have felt deep compassion for the child, deep concern for the suffering it would face, and overwhelming despair at its future prospects. The single most common reason for the denial of care was lack of recent information on available treatment and the outcome of that treatment. When confronted with recent developments in medical care and documented advances in patient outcome by physicians with substantial experience in the care of these children, most of these parents and physicians were able to resolve their doubts and decide in favor of treating the child. In most cases then, continuing education of the public and professionals provided the solution to the dilemma.

Since information availability and public/professional education are so important in salvaging the handicapped child, a number of steps have been taken. Progress is being made to keep the medical literature current by documenting the recent advances in care of these patients. State and national parent support groups like The Spina Bifida Association of America are forming to provide parents and physicians first confronting this problem with informational, emotional, and financial support at the time the critical choices must be made. Government and media awareness programs have all contributed to a reduction in the number of neonates with spina bifida who are denied treatment. The developing pediatric tertiary care centers and available expert opinion should further decrease the level of ignorance. Obviously, we as a group with a vested interest in the welfare of the children feel much more can be done.

We have become increasingly concerned about the paradox presented by our government. On the one hand, we are told by the executive branch through HHS and the Justice Department that no handicapped child can be denied food, water, or customary medical care. Mechansims are put in place to monitor, through signs and hot lines, how the medical profession deals with this problem. At the same time, the funds needed to deal with the cause of these handicaps and to habilitate these handicapped individuals dwindle.. The physician must now struggle not only with the intangible "quality of life" but also with the rather frightening concept that "cost-benefit analyses" and "cost effectiveness" enter into life and death decisions. Shrinking social programs will undoubtedly adversely affect the "Quality of Life" of handicapped individuals.

Evidence now exists that a significant portion of children born with spina bifida are the result of poor preconceptual or prenatal nutrition of the mother. The decline of social programs aimed at improved prenatal care is likely to result in the birth of additional handicapped children at the precise time that loss of support to treatment and habilitation programs erodes the quality of life these families can anticipate for their handicapped child.

Finally, some handicapped infants may be denied care despite expert opinion and in obvious violation of federal regulations. As a physician and advocate for handicapped children, I feel we must, on these occasions, step between the child and the child's parents. The interjection of the courts into the patient-physician relationship is distasteful, but we are morally and ethically obliged to care for our patient--the child.

RESULTS OF TREATMENT OF CHILDREN BORN WITH A MYELOMENINGOCELE

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INTRODUCTION

As new operative procedures, medications, and ancillary care develop, the natural history of a disease can be progressively altered. The impact of the cerebrospinal fluid shunting on hydrocephalus and the even more recent utilization of computed tomography (CT) to diagnose and assess treatment of hydrocephalus are good examples of this type of progress. Periodically the effect of progress on the outcome of treatment of children born with a myelomeningocele needs to be determined.

We would argue that it is moral and ethically correct to treat all children born with a myelomeningocele and that no valid criteria exists for the selection of infants for nontreatment. Certainly as the "quality of survival" improves through medical progress, the poor outcome which the selection criteria[3] purport to accurately predict becomes less distasteful. An added scientific benefit of treating all children is that it affords the opportunity to measure the effectiveness of treatment without the bias of selection.

The initial decision to operate upon a newborn child with a myelomeningocele rests on the premise that: (1) the physician informing the parents is familiar with the disease, (2) the information available concerning outcome is current, and (3) the outcome is predictable based on the clinical condition of the newborn. The first is often lacking, the third is not true, and the second is the subject of this paper.

CLINICAL MATERIAL

Beginning in 1975 and extending through 1978, 100 consecutive, unselected newborn children with a myelomeningocele were transferred to Children's Memorial Hospital of Chicago. Extensive data were collected in a prospective study to evaluate outcome of treatment by a multiple disciplinary team. All children had their myelomeningocele repaired following evaluation by the team. Orthopedic and urological treatment was begun during the initial hospitalization. Nursing, occupational and physical therapy, dietary, psychology, and social work were involved as part of the team from the outset. After discharge the children were followed closely by the same team in the outpatient clinic. Education of the child, of the parents and assistance to the family in habilitation of the child in order to attain the most independent competitive adult life possible is the ultimate goal of the team.

RESULTS

The period of follow-up is from 3.5 years to 7 years. Two of the children have been lost to follow-up, 14 have moved, but a recent evaluation is known to us, and the remaining living children are followed in our clinic.

Eighty-nine percent of the children had their back closed in the first 24 hours of life. The other 11 children were transferred later than 48 hours of life and were assumed to be infected. Following antibiotics and cleansing of the back the repair was undertaken when cultures of the back were negative.

Preoperative motor function is summarized in Figure 1. Following surgery, at 10 days of life a repeat motor examination showed a significant improvement in motor function. Motor improvement was considered significant if the functional improvement added function across the next joint. Functional improvement persisted beyond the 1 year follow-up examination. Deterioration in function is considered an indication for diagnostic study. Hydromyelia, tethered cord and inclusion dermoids have explained deterioration in children followed in our clinic, but not part of this series and deterioration has been reveresed by appropriate treatment.

Hydrocephalus requiring a shunt developed in 80% of the children. The ventricular volume was abnormally large in an additional 15% but no shunt was inserted if the ventricles were stable on sequential CT scans and the child's development was on time.

Almost half, 48%, of the children with a shunt have not required a shunt revision. One revision was required in 16%, 2 in 16%, 3 in 8%, 4 in 8%, and 5, 7, 9 each in 1%. A shunt infection occurred in 10.3% of the procedures. The majority of gram negative infections occurred in the first month of life and were significantly higher in children with delayed back repair.

Yearly developmental assessments including intelligence are obtained on most of the children. Development is normal in 73% of the surviving children.

One half, 54%, of the children are community ambulators and only 8% are confined to a wheelchair at the present time.

Twenty-four percent are exercise ambulators and 14% use a wheelchair in the community but not in their home.

Urinary continence has been achieved in 87% of the children who are over 4 1/2 years of age. We do not feel incontinence prior to 4 1/2 years predicts continence at school age. Urinary diversions to the abdominal wall were performed in 5 of the earlier cases and 3 of these subsequently were undiverted. Clean intermittent catheterization in combination with pharmacotherapy has led to the high continency rate and made urinary diversion rarely necessary.

The surgical mortality is 2%. One child died immediately after surgery of respiratory distress and another died of sepsis following breakdown of the back repair.

The overall mortality is 14% at 3.5 to 7 years of follow-up. Twelve children died subsequent to discharge, 7 of these deaths were associated with hindbrain problems of the Chiari II malformation. Three children died because of respiratory problems caused by compromise of the thoracic cavity by hemivertebra and fused ribs limiting the development of the hemithorax. Attempts at surgical correction on children not part of this series has not been successful and it was therefore elected not to operate on these children.

Apnea, strider, and reflux with aspiration - one of these or in some combination - was significant in 32% of the children. Chiari II symptoms are more severe in our series in those children with low lumbosacral lesions and function in their legs. Posterior fossa decompression was performed on 4 of these children. Subsequent to decompression, 2 died, 1 still requires a tracheostomy and 1 has become asymptomatic. Of the remaining 28, 9 have died, 1 continues to require a tracheostomy and the problem has resolved in the other 18 children. Thus 11 of 32 have died for an overall mortality of 34%. It should be pointed out that 2 of these are the children considered operative deaths and 3 are the children with compromise of their hemithorax.

Of the 86 survivors who are over 4 1/2 years, 47% are intellectually normal, continent of urine and community ambulators. An additional 28% over 4 1/2 years are intellectually normal and continent but do not ambulate in the community. Total percentage of children who could be independent and competitive is approaching 70-80%.

DISCUSSION

This study represents an unselected consecutive series of patients. The extent of prior selection by the physicians who refer to Children's Memorial Hospital is unknown. All children were aggressively treated initially. In about 10% of the cases it ultimately became clear that continuation of aggressive therapy was inappropriate. The operative mortality should be near zero in this group of children. Renal failure as a primary cause of death has almost been eliminated. Symptomatic Chiari II problems continues to be the major cause of death in these children.

Close scrutiny of these children reveals that almost all of the children have some symptoms of hindbrain problems. Mothers relate that they "spit up" more, choke easily, tolerate changes in food texture poorly, and have occasional respiratory paus [illegible] the children with symptoms will present a significant problem. About 5% (5/100) will progress toward [illegible] and we have performed posterior fossa decompression in that group. In 1/3 of this symptomatic group, about 1% of the total 100, death will be directly or indirectly attributed to these problems. In almost 2/3 of the children the condition resolves with time. Resolution would appear to be the natural history of the hindbrain problem. [illegible] value of posterior fossa decompression is still debatable. [illegible] of our children who were decompressed (decompression carried into the posterior fossa), an immediate improvement was noted. Two subsequently died and [illegible] continued to have significant problems. To advocate [illegible] decompression on all symptomatic children, a [illegible] rate greater than 2/3 must be demonstrated.

The majority of children with [illegible] criteria [illegible] because of [illegible] at birth, low level of the lesion, [illegible] extremities.

We may be [illegible] an emphasis on intellectual [illegible], it would seem that if our primary goal is the most [illegible] independent adult possible in a technologically [illegible], normal intelligence is a requisite. Obviously [illegible] less than normal intelligence have [illegible] and everything must be done to make their lives [illegible] meaningful. Many of the children with less than [illegible] care, should [illegible] our society.

In a previous publication we demonstrated that retardation is acquired in most of these children as a result of shunt complications.[4] Unfortunately, our shunt infection rate in this series was still too high. Children closed late were at greatest risk for gram negative ventriculitis. Every effort should be made to keep the shunt infection rate at a minimum.

Management of the hydrocephalus in reviewing the data was much less of a problem than the author thought. We tend to remember the child with 9 revisions and forget that 20% were not shunted, 50% of the shunted children have not required a revision and only 10% have required between 4 to 9 revisions.

Motor deterioration in a child with a myelomeningocele dictates further diagnostic studies. Tethered cord, hydromyelia, and dermoid tumors have explained motor deterioration in children followed by our team but not included in this series. Recovery followed appropriate surgical intervention. Postoperative improvement after myelomeningocele repair noted at 10 days of life, has persisted through the period of this study. Improvement followed by deterioration to the previous level, as a natural history of the disease described in the literature was not borne out by this study.[1]

The final ambulatory status of many of these children will be determined during their teenage years. The projected rate of community ambulation may be to high but with improved orthosis and habilitation techniques this level may be reached.

The mortality rate, now at 14%, should stabilize within a few percentage points of 14%. Most of the children with severe problems have died. The children most at risk are those with hydrocephalus. All of the children who have died in this study had hydrocephalus. A shunt malfunction or a complication of a revision may cause the death of children in the future.

The survival and functional status of this group of children is superior to most studies in the literature including those evaluating only patients selected for treatment.[2,5,6] Aggressive management by a knowledgeable team and close follow-up ensures both survival and improved function.

CONCLUSION

Although we are far from a cure, the future becomes progressively optimistic for these children. Only time will confirm what is in store for these 86 surviving children. The mortality rate is low in this series and the quality of survival for the majority of the children appears good. Habilitation, accessible housing, and job opportunities remain as societal problems to be solved.

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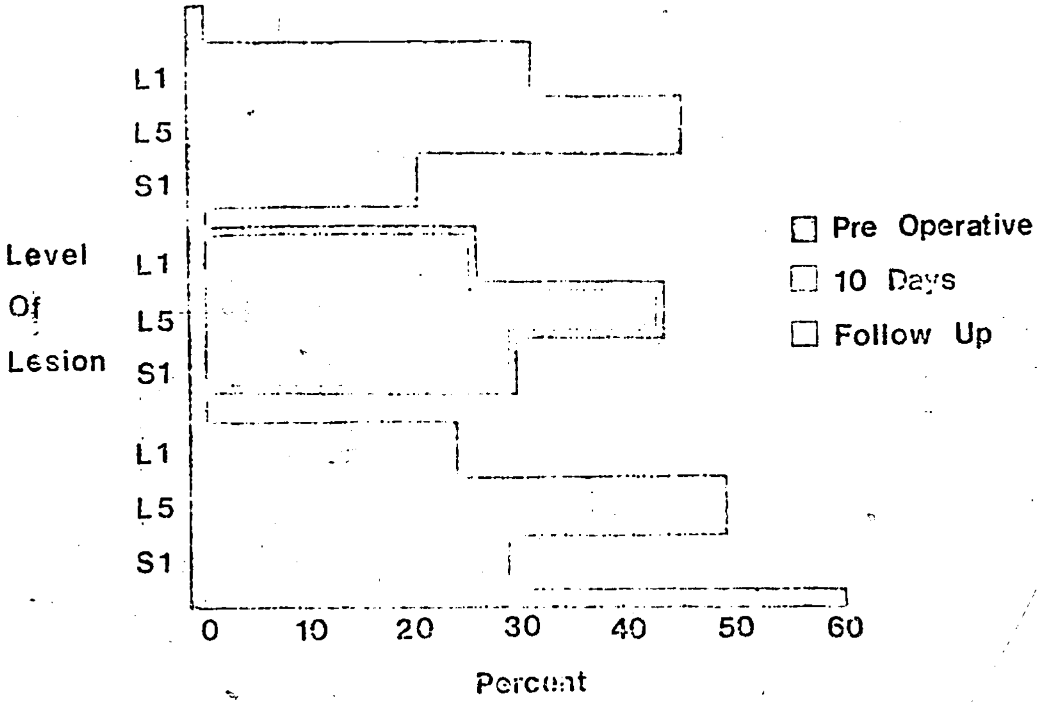

Figure 1: Graph illustrates the preoperative, 10 days postoperative, and follow up motor evaluation.

Senator DENTON. Thank you, Dr. McLone.

Father Paris?

Father PARIS. Yes, sir. You have my statement—there's one correction. Page 9 of the text, at least as it was distributed, is from Dr. Ra[illegible]'s article, and not from mine. My page 9 is missing. [Laughter]

I think that the first anniversary of the death of "Infant Doe" is an appropriate occasion for reflection on some of the moral implications of that act. It certainly has stirred a raging national debate on infanticide: "letting nature take its course;" some even seeing it as an occasion for mercy killing.

Perhaps the most well known exponent of that view is Dr. Raymond Duff of Yale New Haven Hospital, a physician with whom I've been in communication on issues over the past 2 years; and with whom I disagree completely, totally, and unreservedly on the nontreatment of Down's syndrome children. I've told him so.

I think his position is unconscionable; I think it's utterly unacceptable; I think it ought to be denounced by the profession of medicine; I think it's somewhat appalling that the established practice of medicine has let him get away with it—the sort of articles he printed in Pediatrics—in an unresponded way in the past few years.

For instance, in 1976 in Pediatrics, he wrote: "achieving death and in fact killing may be a sorrowful and painful obligation."

Similarly, I think there's no ability on the part of any serious person with ethics to accept the sort of statements we saw of Dr. Alex Haller, that film the Kennedy Institute did several years ago, in which he argues that "since it is morally licit to terminate the life of a Down's syndrome fetus, so likewise we ought to be able to terminate the life of a newborn Down's syndrome child."

Such action is murder; it ought to be treated as such.

Such action I also believe is directly contrary to the whole Judaeo-Christian tradition and our understanding of life.

Life is in fact not something that we ourselves design, but it is a gift of God. It's a gift and it's a task and it's also a journey.

But death is likewise part of that journey. Death, at least in the Christian tradition, is not the final victor, not the final state; it is a stage along life's way.

In fact the past week we celebrated Holy Week, the story of life, suffering, the passion, the death, and then the resurrection of Jesus.

And it's against that story that at least the Christian determines how we ought to act with regard to life.

Unfortunately I think that in this particular age, if God is not dead, he is at least irrelevant to the practice of medicine. It's an age of unbelief in which we substitute other value. There are two really rampant in the land, one of which is Dr. Duff's self-centered hedonism in which personal pleasure and personal predeliction becomes the only value. Suffering at all costs is to be avoided.

But there's a second kind of response which is a substitute equally as dangerous and fully, I believe, as threatening to the Christian tradition, one I call vitalism. One which elevates life from the sacred into the absolute, makes life into an ultimate; and it demands and requires all known measures to prolong it be used, regardless of the quality, regardless of the cost, regardless of the consequences, regardless of the suffering.

Its position, I believe, is as idolatrous as the first; the new golden calf before which many bow down to worship.

It is a value which I think would transform us from persons having worth and dignity as God's gift to being cogs in a machine, being something plugged in, the world turned into a hell.

Death in that scheme of things is always an unmitigated evil, always a disaster, always a failure. This is the view you saw in "Whose Life Is It Anyway?"—what Dr. Emerson decries the newly deceased person as a failure of medicine, incompatible with its practice.

If you take these kinds of modern idolatries and apply them over to the practice of medicine, what do we have? The vitalists would insist that we must always do everything possible to preserve life; the pessimists would end it whenever the burden or difficulty is tedious.

If you see life in the Christian tradition as something sacred but not absolute, you'll understand that there are limits on what we can do and there are limits on what we ought to do.

We do not end life then because it presents emotional or financial strains on the family, or because of the philosophical disposition of the physician, or because it's considered a private matter; because we understand that even loving parents can and have made mistakes.

We also see that the decision to act is not simply a technical one.

We also realize as the editors of Lancet spoke in 1980, that the simple-minded solution of simply doing everything is to cause potential ruin and pain on the family and on the patient is not necessarily the only way to proceed.

I think to proceed with the vitalist stance and proceed with the argument we must always do everything possible is a tragic mistake, and one which violates good ethics.

So I believe the Health and Human Services regulation is a misguided misapplication of good ethical principles. It's too broad, it's too blunt for the kind of delicate, nuanced complex decisions to be made in neonatal units. I think it violates the principle of subsidiarity that says that we ought to use the local as opposed to a higher level decisionmaking if at all possible.

I think that the phrasing is altogether too vague and too open-ended, subject to misunderstanding, to misinterpretation, to mistaken application.

Even such things as customary and ordinary care, such things as food, are subject to widespread misinterpretation. The celebrated case in Los Angeles at Kaiser Permanente Hospital in which I testified for 2 days, had to do with the question of the withholding of treatment from a comatose patient, a patient that reports subsequently indicated, never stood a chance to attain anything but a chronic vegetable condition.

The nurse protested, you cannot withdraw the treatment, because "food is an ordinary means everyone has a right to ordinary means."

The judge in that case, ruled that the physician's action was the appropriate medical response for a hopeless condition.

I think that Dr. Gordon Avery, who is the chief of Neonatology at Children's Hospital here in Washington, put it best in an op-ed column he wrote in the Washington Post about a week ago, in whiih he said, the particular regulation we have now would simply reduce physicians into being technicians.

What then can we have as guidelines, as norm?

Certainly the Roman Catholic Church has been an institution very concerned with the sanctity of life. In 1980 it issued a declaration on euthanasia in which it attempted to recapitulate again its 400-year-old tradition on this topic.

And it said that what we have to do is to assess the proportionate benefit and burdens that accrue to the patient from the treatment being proposed. It says that life-sustaining interventions are not always morally obligatory, not morally obligatory for handicapped children, nor morally obligatory to any other patient.

And we don't distinguish children from others. We look at all as God's gift, we look at them all as humans with dignity and worth to be protected.

But there may be a time in which interventions which are available and can be used may produce a disproportionate burden on that individual and merely prolong the suffering and the dying.

The assessment of these are necessarily going to be value judgments, not mathematical, computer-based decisions.

What we need are guidelines.

Father Richard McCormick, a colleague of mine at Georgetown, I think provided the finest statement of this in an article he wrote in The Journal of the American Medical Association in 1974, "To Save or Let Die"—in which he said that we have to make quality of life decisions. They are inevitably going to occur. There's no escaping that, because any determination not to treat must be made on a decision that the quality of suffering and prolonged agony is not in the patient's best interest.

And we have just authored an article which will come out in the next week or so in which we tried to extend those guidelines.

The President's Commission report, which I think is a magnificent statement, and I think it's the model that this committee ought to use in its own formulation of policy, tells us that we have to have very strict standards; and the defect that we would have to find would be such that it would be so severe that a competent individual would decline treatment under such circumstances.

Certainly, the Commission says, and I agree, Down's syndrome is not of that magnitude. It is not and never has justified nontreatment.

One of the things we must realize is that concrete rules, concrete regulations, do not make decisions. They do not replace professional judgments; they do not replace prudence. They cannot illuminate doubt, uncertainty, anxiety and ambiguity.

The President's Commission tell us, and I think they are correct, that judges and bureaucrats are not the best way to go, precisely because they are too remote from the clinical situation. What they propose is, and I support the idea, that we should have in-house treatment issue committees or ethics committees to make the assessment.

In that way we guarantee that there will be guidelines, there will be familiarity with the medical setting, there will be community standards, there will be an insulation from the glare of publicity, from the autonomous phone call in the night.

There will be protection from fostering of political forces that might serve their own purposes. It's a way I think of distinguishing infanticide from acceptable medical options; and I think it's the approach to go.

[The prepared statement of Father Paris follows:]

Reflections on the Care of Handicapped Children: A Catholic Perspective

John J. Paris, S.J.

The first anniversary of the death of Infant Doe, (April 16, 1982), a Down Syndrome baby with a trachaeo-esophageal fistula, who was left unfed and untreated in a Bloomington, Indiana hospital for eight days until it expired "of natural causes," presents the occasion to reflect on the moral implications of that case. Two Monroe County Courts and the Indiana Supreme Court heard arguments on the issue and each determined not to intervene against the parents' determination to let the child die. Some called the parents actions "infanticide;" others labeled it "an acceptable moral option."

The full facts in the case will never be known because the courts have sealed the records to protect the family. Whatever the facts, and they were twice debated by some six physicians before the lower courts, Chief Justice Richard Givan of the Indiana Supreme Court maintained the parents were loving, caring people who "wanted only to do what was best for the child."

Infant Doe's death stirred a raging national debate over the policies of doctors and hospitals on the treatment of severely handicapped newborns, a debate which revealed a wide diversity of views and expectations. Some saw the action as homicide, others as "letting nature take its course," still others as an occasion for "mercy killing." Today I would like to reflect with you on some of those responses. Perhaps the most well-known--and in my view unconscionable and utterly unacceptable--position is that of Dr. Raymond Duff of the Yale-New Haven Hospital. In his famous <u>New England Journal of Medicine</u> article in 1973 on "Moral and Ethical Dilemmas in the Special Care Nursery" Duff argues, as does the family attorney in Infant Doe, that these are "private decisions" which should be left up to the families and their professional advisors. In an article which I wrote in Law, Medicine and Health Care in June, 1982 I criticized Duff's position as "normless." There are no guidelines, no principles, in Duff's proposal for the physician's recommendation or the parents' decision. They are simply *ad hoc* decisions and, as such, they can be made quite poorly as easily as quite well.

As the famous Johns Hopkins case makes abundantly clear, parents or physicians may determine not to treat on such slender grounds as "A Down Syndrome child with duodenal atresia would be a financial and emotional burden on the rest of the family."

In subsequent articles Duff has gone even further. In Pediatrics for April 1976 he writes, "There are occasions when death may be a more prudent choice and achieving death (in fact, killing) a sorrowful and painful obligation." He then proceeds to argue that James Rachel is correct that there is "No moral difference between active and passive euthanasia." As recently as March 1981 in another article in Pediatrics Duff argues, "The role of the family must be acknowledged and supported even though the resulting decisions occasionally risk violating one or another of numerous, perhaps conflicting, moral, religious, or legal doctrines."

Duff is joined in his views by such physicians as Dr. Alex Haller of Johns Hopkins who argues that since it is morally licit to terminate the life of a Down Syndrome fetus it ought likewise to be morally licit to terminate the life of a newborn Down Syndrome child. This is simply murder. It should be treated as such.

The issue is, how are we as a society best to respond to such threats to the sacredness of life? First, we must place life and our obligations and duties to preserve it in perspective. What in the Judaeo-Christian tradition would equip us for, help us to resolve, some of the terribly difficult ethical dilemmas that confront parents, physicians and society at the birth of a severely handicapped newborn? Before examining the specific question, let us examine some of the general theological themes of the Christian tradition that provide understanding and wisdom of what it means to be human. The tradition begins with the belief that God is the creator of life and its preserver, that life is a gift, and that life has value because God is its end and goal. As Gustav Mahler put it so eloquently in his Second Symphony: "We have come from God, and to Him we must return." Life is not only a gift and a task, it is also a journey. We are on a journey from God and back to God, and death is a part of that journey. Death is not a victor but a stage along life's way: not a final state. The ultimate goal of life is the restoration of the fullness of the kingdom. Thus, it is eternal life, not life itself, which is ultimate. For the Christian, and those who believe in the life, death and resurrection of Jesus, death has been overcome. It is not the final victor, and all those who believe and accept that we can likewise have overcome its defeat. They, in the words of John's Gospel, "will be raised up on the last day."

For the believer, this story provides the meaning, the purpose and the value of personhood. It also tells us the meaning, the purpose and the value of life's journey. When decision making is separated from this story, it loses its perspective.

A serious problem facing our present age is that it is an age of unbelief. With the demise of religious values, we have one of two very diverse substitute values. One, a self-centered hedonism which tells us that our own personal pleasure is the only value in life; that suffering is an evil to be avoided at all costs. Two, the elevation of life from something sacred to an absolute. Life then becomes the ultimate value and all procedures to maintain it become a moral requirement. This second response is as idolatrous as the first. It makes of life not a gift but an end and a goal in itself, a new golden calf before which we may worship. This is the view, one which I call a vitalist position, which is a threatening to the sanctity of life as the positions of Drs. Duff and Haller. It would [illegible], ultimately, into being nothing other than cogs in some machine. And it would make of death what Dr. Emerson calls it in that film, "Whose Life Is It Anyway" —the enemy, a failure, a disaster, an unmitigated evil.

Death, in the Christian context, is not an absolute unmitigated, total, awful evil. It is a part of the human condition, a part of the process of what it means to be human, a part of the journey which is the totality of life. For the believer, life is good, but it is not the ultimate good; as such the duty to preserve it is a limited one.

At this point we might ask, how do we apply these insights from our religious tradition to the care of severely handicapped newborns? First we would reject the vitalist position that life is the ultimate value and that we must use all means to preserve it regardless of cost, regardless of [illegible], regardless of suffering to the newborn. Second, we would understand that life as a gift from God is not ours to end whenever it becomes burdensome or produces pain or suffering or trial. Third, the issue of the care of sick children ought not be framed in terms of emotional or financial burden to the family or the philosophical predisposition of the physician but should focus on the best interests of God's gift, the child.

That interest may or may not demand treatment. As my colleague, Fr. Richard McCormick of Georgetown and I have written, "There are cases of dying patients, or those so submerged in suffering in the struggle to survive that the best treatment may be no treatment."

These, though, are not "private matters" to be left to the family and the physician. For despite the obvious love and concern of parents, such as those in Infant Doe, loving parents can and do make mistakes. To think otherwise is to confuse the goodness of the decision maker with the rightness of the decision.

And that is [illegible] be very [illegible] ethics in principle and sound public policy.

A further caution to be observed from these cases is the danger of leaving the formation of social policies exclusively in the hands of practitioners. As one who teaches medical ethics in two medical schools, I can attest that the medical profession is little trained in and not particularly adept at setting social values. You need only refer to famous studies of Drs. Shaw and Todres as evidence of physicians' attitudes that this society would find unacceptable -- and rightly so -- in the care of Down Syndrome infants.

* * *

Where then does this leave us? The editors of Lancet correctly [illegible] that [illegible] is not necessarily the right course for [illegible] -- [illegible] pain and burden to the patient and [illegible] [illegible] themselves. November 14, 1981). [illegible] mistake, one which would [illegible] practice and [illegible] public policy. Consequently, I believe that the [illegible] Department of Health and Human Services' is a misguided and mistaken policy. It is far too [illegible] an instrument for the delicate, nuanced and complex decisions [illegible] in the neonatal nursery. The principle of subsidiarity would [illegible] that these decisions ought to be made at the local level with guidelines and norms established by the society. Secondly, the directive, as written, is [illegible] open to misunderstanding, misinterpretation and mistaken application. [illegible] the recent dramatic case in Los Angeles, California in which two physicians were charged by the District Attorney for murder for withholding life-prolonging treatment from a comatose patient [illegible], such terms as "customary medical care" are [illegible] to be useful in regulatory directives. Dr. Gordon Avery, the Director of Neonatolgy at Children's Hospital Center in Washington, D.C. put it best in his op-ed editorial in the Washington Post (March 21, 1983, p. A-[illegible])

"The potential exists in this rule for indefinite prolongation of futile life supports with attendant pain and suffering, misuse of scarce and vital medical resources and enormous expense to the community." As he concludes, "If this term includes all medical, surgical and life support maneuvers that are technically possible regardless of prognosis and likelihood of success, then those of us who give intensive care to newborns have been rendered blind technicians, robbed of our facilities of judgment."

If the HHS regulation is an inadequate standard, what would be the proper positive criteria to be applied? In 1980 the Vatican issued its "Declaration on Euthanasia" in which it discussed the means to be used to preserve life: "It will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources."

Here the Vatican has identified two elements that ought to anchor our judgment in life-sustaining decisions: burden and benefit. This means that life-sustaining interventions are not morally obligatory--for handicapped infants or for anyone else--if they are either gravely burdensome or useless. These are, of course, value judgments not mathematical assessments. The evaluation of burden-benefit is not always easy. Indeed, it can be very borderline and controversial..

An earlier guideline Fr. McCormick and I developed for dealing with handicapped newborns focused on the potential for human relationships associated with the infant's condition. ("To Save or Let Die: The Dilemma of Modern Medicine," Journal of the American Medical Association, July 8, 1974.) If that potential was simply non-existent or be utterly submerged and undeveloped in the mere struggle to survive, that young life had achieved its potential and no longer made life-sustaining claims on our care.

That standard was admittedly general. It could clearly be misued and stretched beyond recognition. But, we are convinced that it is fundamentally sound and that if further specified and concretized, can be helpful to families, physicians and society in making decisions in future <u>Infant Doe</u> situations. We suggest the capacity for human relationships--as a summary of the burden-benefit evaluation--can be further specified as follows:

1. Life-saving interventions ought not to be omitted for institutional or managerial reasons. Included in this specification is the ability of <u>this particular family</u> to cope with a badly disabled baby. This is likely to be a controversial guideline because there are many who believe that the child is the ultimate victim when parents unsuited to the challenge of a disadvantaged baby [illegible] undertake the task. Still, it remains an unacceptable erosion of our respect for life to make the gift of life once given depend on the personalities and emotional or financial capacities of the parents alone. No one ought to be allowed to die simply because these parents are not up to the task. At this point society has some responsibilities. To face these agonizing situations by allowing the child to die will merely blunt society's sensitivities to its unfulfilled social responsibilities.

2. Life-saving interventions may not be omitted simply because the baby is retarded. There may be further complications associated with retardation that justify withholding life-sustaining treatment. But retardation alone, as ~~both~~ Chief Justive Givan of the Indiana Supreme Court made clear, is not an indication for non-treatment. To claim otherwise is a slur on the condition of the retarded, one that would mandate fundamentally unequal treatment of equals.

3. Life-sustaining interventions may be omitted or withdrawn when there is excessive hardship on the patient, especially when this combines with poor

treatments (e.g., repeated cardiac surgery, low prognosis transplants, increasingly iatrogenic oxygenization for low birthweight babies).

4. Life-sustaining interventions may be omitted or withdrawn at a point when it becomes clear that expected life can be had only for a relatively brief time and only with the continued use of artificial life-sustaining systems (e.g., Baby Stinson).

These norms, we believe, provide some guidance for the types of cases under discussion. Here the term "some guidance" must be emphasized. Concrete rules such as these do not make decisions. They do not replace prudence and eliminate conflicts and doubts. They are simply attempts to provide outlines of the areas in which prudence should operate. They do not replace parental-physician responsibility, but attempt to enlighten it. If even good and loving parents can make mistakes--and they can and have--then there ought to be some criteria (even if general) by which we can judge the decision to be right or wrong. For ethical persons ought to be reason-giving persons.

But doubts and agonizing problems will remain. Hence a certain range of choices must be allowed to parents, a certain margin of error, a certain space. Guidelines can be developed which aid us to judge when parents have exceeded the limits of human discretion. They cannot cover every instance where huamn discretion must intervene to decide. The margin of error tolerable should reflect not only the utter finality of the decision (which tends to narrow it), but also the unavoidable uncertainty and doubt (which tends to broaden it).

Responsibility for the Decision

It is clear that the judgments of burden and benefit are value judgments, moral choices. They are judgments in which, all things considered, the continuance of life, is either called for or not worthwhile to the patient. Such judgments are, as is clear from remarks made above, the onerous prerogative of those primarily responsible for the welfare of the family--the parents. When parents exercise this prerogative in a way that is questionably no longer in the best interests of the infant--especially by allowing the infant to remain untreated--society has the duty to intervene. That intervention can take many forms: legislation, crim prosecution, child neglect hearing, etc. The purpose of such proceedings is to guarantee that the primary decision-maker acts in a responsible way, one that sh be able to sustain public scrutiny. We believe that public accountability and review, a review that guarantees that the values of the society are respected and adhered to, can be invoked short of judicial intervention.

One approach to achieving that goal is found in the "Decisions to Forego Treatment" Report of the President's Commission for the Study of Ethical Problems in Medicine. There we read: "The judicial responsibility to protect incompetent patients is not necessarily best fulfilled by judges taking upon themselves the role of principal decision maker." Remoteness from the clinical situation and inability to keep pace with the on-going fluctuations in the patient's condition, particularly in a neonatal intensive care setting, are strong arguments in support of that thesis. The <u>Report</u> favors having the parents' decision in difficult cases reviewed by an in-place, broadly based multi-disciplinary hospital ethics committee which would be familiar both with the medical setting and with community standards. That consultative body, which would have an on-going charge of establishing standards of treatment and issuing guidelines for the institution, would provide a framework for impartial but sensitive review of hard choices. It would guarantee that the interests of the patient were being considered without the formality and intensely adversarial character of a court proceeding.

If after all this, irreconcilable disagreement still persists, the <u>Report</u> recommends referral to the court for the appointment of a legal guardian who would be empowered to evaluate the options and make a decision "in the best interest of the infant." The decision, of course, would be subject as a last resort to judicial scrutiny.

We agree that this approach, one which guarantees a discussion of the issues with a concerned and disinterested "representative of the public" while at the same time insulating the agonizing and tragic decision from the glare of publicity and the distortions of political posturing, is a sensible and desirable way to proceed. It is also a way of insuring that as a society we distinguish between acceptable medical options and infanticide.

Senator DENTON. Thank you, Father Paris.

Dr. Ramsey?

Dr. RAMSEY. Our Nation is in a deep moral crisis, a crisis of which road to take, the road of faithfulness to a fundamental principle of Western morality—the equality of life—or the road of discretionary judgments concerning the quality of a life, permitting private persons to weigh that life's inherent capability or its worthiness to be treated equally, protected equally.

Whether we, Mr. Chairman, are explicitly religious or genuinely humanistic, a fundamental agreement in our society has been the equality of life, and our common verdicts have been against anyone's privately accomplished discrimination against any other human being based on that life's alleged or actual worth to others, or its seeming or actual inherent comparative disability.

Equal protection of life can be violated by negligence, as we all know, on the part of persons morally bonded to care. Not everyone is an innocent bystander.

Physicians and nurses are bonded to care. And medical ethics, like any other professional ethic, is only a special case of our common morality; and can claim no exemption from its overriding norms.

Equality of life means, in a medical context, equal medical care and treatment. Equal treatment does not mean relentless treatment, abandoning a patient to modern medical technologies when they can no longer help, but whose only effect is to prolong a patient's dying that is inexorably on course.

Instead, by equal treatment we mean the same care relevant to the same treatable medical condition for anyone who suffers it.

Similar treatment of similar cases is, indeed, simply a restatement of the principle of equality.

A bowel obstruction or a heart lesion in an infant calls for the appropriate operation to save its life. If a normal infant would be so treated, likewise should be the care extended to an infant who is a person who has Down's syndrome or Mongoloidism.

I do not say an infant who is a Down's or is a Mongoloid.

Of course, infants born defective, physically or mentally, and those born without those defects are not observably similar; they are not actually equal; and in important respects, indeed, they are not equal.

But in medically relevant respects they are equal, and as rights-bearers they are equal.

To give any weight to an untreatable abnormality and withhold life-saving operations on a bowel obstruction, or to withhold heart surgery because of that, is not a medical judgment.

Physicians and families who wish privately, claiming immunity from our common morality, to make such determinations and to execute them negligently, are making comparative judgments of inherent capability or of social worthiness for which they have no competence.

Indeed, no one has such competence, morally.

As I understand it, cystic fibrosis is treatable; spina bifida we've just heard is treatable. Persons suffering these defects should be treated. To help them requires a series of procedures over a long time.

If we hesitate to do this by measuring the quality of life that all along or in the end can be delivered to them, to test that for discrimination and unequal treatment—ask yourself: What would we do to rehabilitate a person, a normal child, who because of some body-crushing accident requires a comparable series of incursive operations and lengthy physical therapy, one who may, like many spina bifida patients, still wind up in a wheelchair?

All the way from no treatment equally to hazardous trials, physician judgment has free rein. But it should not wander from the line between those extremes by factoring in untreatable disabilities as reasons for choosing to help one and not another patient.

If in some way Down's syndrome someday can be relieved, then and then only will that important difference between some people and others become a relevant clinical, medical matter, favoring, however, the alleviation of that condition also and not only removing the associated life-threatening physical conditions now within our power.

The Bloomington baby case demonstrates once again that to insure a small human being's equal title to life, more is needed than standards to be laid down by the medical profession and more than national guidelines issued by the President's Commission.

Some source of law is usually needed to brace ourselves to be our best amidst life's great dilemmas and the pressures and heat of daily circumstances.

When I first heard, Mr. Chairman, that the main response to this case might be President Reagan's directive to the Secretary of the Department of Health and Human Services to refuse Federal funds to medical centers that in future permit such negligence to take place within their walls, I was dismayed.

Is money the only resource we have, I asked myself, to guarantee the equal protection of life?

However, I have since learned better. And we all have heard here today about the various administrative regulations, the public laws that are on the books, regulative of Health and Human Services which are only implemented by the interim rules the Secretary has promulgated.

With the Office of Civil Rights within HHS, given provision for prompt notice in such a case, no new regulatory powers, no new law, no new legislation—no more than clarifying revision—seem to me to be necessary to make it very clear that neglect is something that can take place within a medical setting.

The Department proposes only prompt oversight and full use of State and local enforcement agencies. My comments then need be only two:

If this is not our national medical consensus, if it is not the medical moral behavior to be expected of professionals and parents and of our medical institutions, this should be a decision consciously and expressly made—not one brought about by incremental decisions made by private parties more or less in secret until we come to a time when we are told that the laggard equal protections of the law have to be changed or be simply ignored in the light of accepted practice.

That would be to say that what becomes accepted defines the acceptable; that the way to tell what is desirable is to ask what is desired.

I know no one competent in moral reasoning who would fail to say that that is anything other than an absurdity.

What I mean here, Mr. Chairman, is that it would be more honest and forthright to adopt a deliberated national medical policy of delayed birth certificates, with standards by which we decide who is to be admitted to the human race than for incremental decisions made by private parties in medical settings to become accepted practice in our society.

And second, if medical centers are going to take the low road of private discretionary quality of life decisions concerning defective infants, there is to me no argument that can sustain taking 1 cent in taxes of citizens at the Federal, State and local level in support of such a policy.

If we are to privatize such life-and-death decisions they should be truly and fully private in funding no less than in exercise; let those who say such decisions are right, medically and morally, stand up and say so and put their money where their mouths are.

I personally regret very much the apparent necessity to monitor physician-family decisions in this way. Still this will hedge and bother an ethical physician in no way. To ask physicians to step back from the foreign territory of quality of life decisions is no limit upon medical discretion in the treating of treatable ills of humankind.

It seems, therefore, to me that the complaint of the American Academy of Pediatrics is baseless.

Of course, if you keep what an infant may need vague enough to be stretched to count an untreatable defect against saving its life, then there might be confusion and disagreement over proper treatment. But not if the regulations do not require prolonging an infant's act of dying, but only the protection of that infant's act of living, though it may live still with untreatable abnormalities through appropriate nourishment and care.

It is my hope that this apparently intrusive notice and reporting procedures will be an instrument never to be used because it need not be. Until that ideal day dawns there is no more reason for abandoning persons to private discriminatory decisions because they are small, because of their physical or mental condition, when they are voiceless and come into the human world in a hospital, than there is to deprive persons at large in our society who have voices and may be discriminated against because of race or gender or age, of the equal protection of the law that to date also requires appropriate sorts of monitoring and reporting.

So I suggest to this committee that we ought not to enshrine in medical practice or in law a new right, namely, the right to judge in one's own case what is or is not medical neglect of infants.

And if that is allowed, Mr. Chairman, I would like to conclude by suggesting that when you get your breath I want you to consider getting the Federal Government off of us life-tenured professors in the universities because we make as many subtle, diverse, complicated decisions that only experts who know how to weigh carefully the scholarship of one candidate against another could ever possibly make. The public should know that; and you also should know that we would never, never, never—we have committees on top of committees—bring in an incorrect or biased decision. Yet it is widely believed that we experts may count gender and race in our deliberations. So we are not to be trusted in every respect. There are bureaucrats in the Labor Department ready to be telephoned; there's access to the courts, by which the privacy of these complex decisions which are on all fours with medical decisions, may be insured against discriminatory practice.

[The prepared statement of Dr. Ramsey follows].

Submitted to the United States Senate
Subcommittee on Family and Human Services
by

Paul Ramsey**

April 6, 1983

Our nation is in a deep moral crisis, a crisis of which road to take, the high road of faithfulness to a fundamental principle of Western morality -- the equality of life -- or the low road of discretionary judgments concerning the quality of a life, permitting private persons to assess that life's inherent capability or its worthiness to be treated equally, protected equally, as any other life would be treated and protected.

In our moral heritage, equality of life stems from the traditions of the religions of Western culture, whose teaching is that each of us has his title to life from God, from not only nature but nature's God, and certainly not from any State's or societal or private judgment that that life may or may not be entitled to equal care and protection. In my view, the equality of life can be sustained as a fundamental principle by acceptable notions of the equal dignity, equal claims, of any life in a valid, truly humanistic morality. So whether we are explicitly religious or not, a fundamental

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agreement of our society has been the equality of life, and our common verdicts have been against anyone's privately accomplished discrimination against any other human being based on that life's alleged or actual worth to others or its seeming or actual inherent comparative disability.

Equal protection of life can be violated by negligence, as we all know, on the part of persons morally bonded to care. Not everyone is an innocent bystander.

There is no such thing as an ethics of the medical and helping professions simply because they have expertise that ordinary citizens do not possess. Any professional ethics is only a special case of our common morality, and can claim no exemption from its overriding norms. I state this connection as follows: if private persons, including physicians, are to make discretionary quality of life judgments, that will be our common morality as a nation. If, on the other hand, ours is to remain a civic righteousness based on the equality of life, no such capability or social worthiness judgments can be allowed. So we stand before a fundamental choice: between life equal and death by discriminatory judgments for our whole society and for all futures.

The first battlefield between the "moral" forces is described, in law, as homicide by some kind or degree of negligence. The struggle is first joined over the youngest claimants to equal protection among us. (Why this should be so I comment on later.)

Equality of life means, in a medical context, equal medical care and treatment. By equal treatment we do not mean relentless treatment, abandoning a patient to modern medical technologies when they can no longer help, but whose only effect is to prolong a patient's dying that is inexorably on course. Instead, by equal treatment we mean the same care relevant to the same treatable medical condition for anyone who suffers it. "Similar treatment of similar cases" is, indeed, simply a restatement of the principle of equality. To favor and acknowledge equal claims to life requires practical wisdom in distinguishing between morally relevant and morally important similarities and irrelevant or unimportant ones. We do this when we say, "Never tell a lie except to save someone's life from the Gestapo," and know it is silly to say, "Never tell a lie, except on Tuesday to an Irishman with a wart on his nose." The former details make an important and morally relevant difference in what is right to do; the latter do not; but both point to similar situations that are possibly repeatable. Yet we rightly say that anyone similarly situated should do the same in speech to save life, if we say that we should. Still we know well enough not to say that the latter excuses lying in our case or anyone's.

Now, some illustrations in a medical context. A bowel obstruction or a heart lesion in an infant calls for the appropriate operation to save its life. If a "normal" infant would be so treated, likewise should be the care extended to an infant who is a person that has Downs syndrome (or Mongoloidism) -- I do not say an infant who is a Downs or is a Mongoloid. Of course, infants born defective, physically or mentally, and those born without those defects are *not* observably similar -- not *actually* equal -- and this in *important* respects, but *not* in *medically relevant* respects. To give any weight to an *untreatable* abnormality and withhold a life-saving operation on bowel obstruction, or to withhold heart surgery because of that, is not a *medical* judgment. Physicians and families who wish privately, claiming immunity from our common morality, to make such discriminations and to execute them negligently, are making comparative judgments of inherent capability or of social worthiness for which they have no competence.

If but only if Downs syndrome someday becomes treatable in some way will that important difference among infants become a medically relevant consideration. Or for that matter, being born with low grade I.Q. Would it not be unconscionable if ever anyone seriously said that an indicated treatment should be withheld from *this* particular patient because if saved he would still have only the same old moronic existence? Or if someone said of a patient so incompetent as to be unable to consent or to dissent that if he were intelligent and lucid for a moment, and took into account his incompetence, he would decline to live under those unacceptable conditions; and so *impute* to that patient a refusal of treatment, and act accordingly? I.Q. is not a relevant consideration in a hospital setting; but I suppose it may be in preventive community medicine, broadly understood, and in public policy that may have effect upon poverty, the proper nourishment of pregnant women to prevent premature births, child care, or the training of defectives.

As I understand it, cystic fibrosis is treatable. Spina bifida is treatable. Persons born suffering these defects should be treated. To help them requires a series of procedures over a long time. If we hesitate to do this by measuring the quality of life that all along and in the end can be delivered to them, to test that for discrimination and unequal treatment ask yourself, What we would do to rehabilitate a perfectly normal child who because of some body-crushing accident requires a comparable series of incursive operations and lengthy physical therapy -- one who may, like many spina bifida babies, still wind up in a wheel chair?

But some spina bifida babies are born dying. To start treatment would have no other effect but to prolong their dying. They should be let die. Tay Sachs babies are, after six or so months, on an irreversable course of dying, which may take several years. To betube them and deliver high caloric nourishment does nothing to cure or care, and cannot -- for they are irreversibly dying (which is quite different from having a "terminal" illness).

I do not see how any of the above can be said to limit a physician's medical discretion. What is excluded is only non-medical judgments of comparative worthiness. That is a corruption by overextension of the ambit of proper discretion to treat the medically treatable, similarly and equally.

Nor is physician discretion excluded -- or required to be infallible -- in deciding not to start or to intervene to stop relentless machines that have no other effect than to prolong the dying of the dying. Again *the same* treatment is the test, in similar cases. A baby too premature to be saved calls for no attempts to do so to be instituted, although born a month later that baby would have been a normal and highly intelligent child. *The same* condition of prematurity in the case of a baby having a serious genetic abnormality likewise warrants no vain attempts to be instituted. Here *the same* -- equality of care -- means *no treatment* to be extended to *either* dying infant. No morality requires anyone to do the useless, and what at the same time can only prolong the dying process. But our common morality does require the same for both the normal and the abnormal who are equally in need of equal treatment of all their treatable (i.e. medical) problems.

Two celebrated cases in my experience demonstrate the rapid decline from equality-of-life practice to quality-of-life practice during only about ten year's passing time in this country. While the outcome was the same in each case -- a baby was let starve to death in a medical setting -- there are significant differences that tell us a great deal about what was the day that was in medical morality, and in the legal enforcement of a small human being's equal title to life.

"The day that was" was when the unquestioned ethics of the medical profession and the practice of all our great medical centers was clearly that of equal protection. If parents of a child needing medical care refused the necessary consent, hospital administrators took the case before a judge, obtained temporary custody of that child, and gave the life-saving medical care. This was proper acknowledgment of the fact that when an infant is born there devolves upon every person surrounding it (parents -- unless they relinquished custody -- nurses, physicians, administrators) an absolute obligation to care for and protect that life, regardless of what might be their variable sentiments or wishes.

Ten years or so ago a film was made simulating a decision made at the Johns Hopkins University Medical Center that was shown at a conference here in Washington, sponsored by the Joseph P. Kennedy, Jr., Foundation. The case was that of an infant with Downs syndrome, who had a bowel obstruction requiring a simple enough operation to remove, an operation that certainly would have been given to any normal infant. Without the mother's consent, the operation was not performed. The doctors did not even provide the child with IV nourishment (requiring no consent) to give the mother time after the trauma of such a birth to consider later whether to consent to the operation. Instead, the infant was allowed to starve to death over 15 days.

I said to a doctor-friend of mine at Johns Hopkins, not involved in the case and whom I admire very much, that if the hospital was not going to seek temporary custody from the courts those parents should have been faced with the necessity of taking the child home to die. That, he said, would have been "cruel" to them. But who was cruel to the infant, I asked; to the nurses who were forced to watch the baby slowly starve to death, the father calling every day or so to inquire as to its condition.

My point was simply this. The hospital and its personnel should not have been accomplices in medical negligence. If they were not going to place the case in the public forum by an appeal for temporary custody, the parents should have had to take that infant out into the public forum where their child abuse or negligent homicide might have been noticed and prosecuted -- instead of hidden behind hospital walls, that death brought on by their entangled co-conspirators (who were professionals) and not by them.

Now only a brief time later we have the case of the Bloomington Baby. "Baby Doe" he or she was called, thus protecting from direct public scrutiny the parents and the physicians of the Indiana University Medical Center. This case got into the public forum, but I know not whose agency in calling the matter to the attention of a prosecuting attorney. An injunction was sought in time to save the baby. Several families asked to be given custody of the child. The judge denied the injunction, and then also refused to stay his ruling to allow time for appeals to be made through the courts above. While the attorney was on his way to Washington to try to get a Justice of our Supreme Court to stay the death-dealing negligence until the case could be heard and concluded, Baby Doe died.

Since starvation (like pregnancy) won't wait, is it not standard and expected legal practice, in a life or death matter such as this, for a judge to stay his ruling until that ruling can be appealed and reviewed? Concerning the parents' preference to retain their natural custody, and exercise it to death, the question to be asked is: Does a woman's right to control her reproductive life extend to the right to see that no child bearing her genes (or those parents' genes) shall remain alive. Is a defective infant only a "product of conception"?

The Bloomington Baby case demonstrates that more is needed than the President's Commission's Report -- however influential that may be. Some source of law is usually needed to brace us to be our best amid life's great dilemmas and the pressures and heat of daily circumstance. As Martin Luther King used to say, the law can't make you love your fellowman, but it can make you treat them justly. The law can't teach you to be what he believed was a truly virtuous person, but it can teach you to act as if you are, in many respects important to others. The law can, at least, help to insure that the moral history of this nation is not outrun and overrun by its medical and scientific history.

When I first heard that the main response to this case might be President's Reagan's directive to the Secretary of the Department of Health and Human Services to refuse Federal funds to medical centers that in future permit such negligence to take place within their walls, I was dismayed. Is money the only recourse we have, I asked myself, to guarantee the equal protection of life? Should not the chief legal officer of our nation -- the

Attorney General of the United States -- or the Department of Justice have been the first voice heard? Or the Chief Justice of the Supreme Court? Or -- since in our Federal system the States have police power -- should not some Association of States' Attorneys General have spoken, to brace all officers below them to the enforcement of equal protection?

These were my questions, and they still are the fundamental ones, since at stake is whether equal protection enshrined in our laws shall be eroded by discriminatory quality-of-life decisions by private parties -- this time with the complicity of courts and lawyers who acknowledge not the law they are sworn to uphold.

However, I have since learned better the administrative regulations in place in Health and Human Services that are only implemented by the interim rules the Secretary has promulgated; and also more about the Congress' responsibility to promptly and appropriately revise the "Child Abuse and Treatment and Reform Act."

There is an Office of Civil Rights within the Department of HHS, and in cases of other sorts of discrimination prompt notice and complaint procedures have well served the cause of equality. I need not quote Section 504 of the Rehabilitation Act of 1973 which expressly protected handicapped individuals from discriminatory neglect with Federal Funds. No new regulatory powers need be brought into play, nor are any proposed in the interim rules. Moreover, the Department proposes only prompt oversight, with full use of State and local enforcement agencies.[1]

My comments, then, need be only two. (1) If this is not our national moral consensus, if it is not the medical-moral behavior to be expected of professionals and parents, and our medical institutions, this should be a decision consciously and expressly made, not one brought to pass by incremental decisions, made by private parties, more or less in secret, until we come to a time when we are told that the laggard equal protections of the law have to be changed, or be simply ignored, in the light of accepted practice. That would be to say that what is accepted defines the acceptable; that the way to tell what is desirable is to ask what is desired. I know no one competent in moral reasoning who would fail to say that that is an absurdity.

If we mean to allow comparative quality-of-life judgments in a medical context, instead of proceeding that way as if we do not know what we are doing, or only letting happen, it would be at least more honest and forthright to adopt the policy of "delayed birth certificates" so as to have time to choose those of our progeny that are to be admitted to the human race. That would be at least some sort of equality, and similar treatment of similar cases. No infant would have a right to complain that he or she was discriminated against arbitrarily.

(2) If medical centers are going to take the low road to private discretionary quality-of-life-decisions concerning defective

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[1] Nondiscrimination on the Basis of Handicap, Federal Register, Vol. 42, No. 45, Monday, March 7, 1983.

infants, there is no argument that could sustain taking one cent of the taxes of citizens, at the Federal or State or local level, in support of such a policy. If we are to privatize such life and death decision, they should be truly and fully private, in funding no less than in exercise. Let those who say such decisions are right, medically and morally, stand up and say so; and put their money where their mouths are.

I personally regret very much the apparent necessity to monitor physician-family decisions in this way. Still this will hedge and bother an ethical physician in no way. And it is the profession and hospital administrators who have so rapidly abandoned the practice of seeking court awarded custody of an infant in order to give it medically indicated care and treatment. In this they have stepped on foreign territory. To ask them to step back is no limitation upon medical discretion in treating the treatable ills of humankind.

The complaint of the American Academy of Pediatrics is clearly baseless. Of course, if you keep what an infant may need vague enough to be stretched to count an untreatable defect against saving its life, then here might be confusion and disagreement over proper treatment. But not if the regulations do not "require prolonging the act of dying [in normals or in defectives], but rather protecting the act of living [despite untreatable abnormalities] through appropriate nourishment and care."[1] In the

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[1] Surgeon General C. Everett Koop, as reported in The New York Times, March 23, 1963, p. A15, with my own bracketted inserts.

cases of deliberate starvation, I have not heard that while withdrawing caloric feeding the physicians arranged a drip that can prevent dehydration while slowly wasting away from lack of nourishment. So first, these babies were caused to die, and then they were not comforted and cared for in the process of dying.

Moreover, perhaps ethical physicians will be braced -- and the consciences of others awakened -- by the President's Commission's guidelines. Perhaps systemic or institutional reform will be brought about. In that case, the apparently intrusive notice, reporting and monitoring procedures -- and anybody's telephonic connection with the Office of Civil Rights of Health and Human Services -- will be an instrument never to be used, because it need not be. Until that ideal day dawns, however, there is no reason that I can see for abandoning persons to private discriminatory decisions because they are small, because of their physical or mental condition, when they are voiceless and come into the human world in a hospital, than there is to deprive persons at large in our society, who have voices, and may be discriminated against because of race or gender or age, of the equal protection of the law that, to date, also requires appropriate sorts of monitoring and reporting.

Senator DENTON. Thank you, Dr. Ramsey.

Before we begin the questioning of this panel I would like to announce to the four in this panel that following in one more panel we do have a family from Connecticut who have adopted 11 severely handicapped children; and I announce that for what it's worth in case you care to stay around and meet them.

Dr. Little, I would be the last to pretend expertise in this field. I'm not a doctor. My brother is. He has informed me many times about the evils of governmental intervention in medical decision and so on. And I am also aware of the complexity of this issue. I don't think I have all the answers.

I do believe that we'd like as human beings to sort of choose up sides and argue about things and turn them into more diverse a nature than they really are.

I believe that this particular sign that we're talking about in this particular regulation is really aimed at a relatively narrow and relatively newly discovered area in which we can become more specific and more informed and that the sign and regulation are nothing more than focal points around which that might become possible.

That's my own particular view of this matter. I don't mean to present myself as a "social medicine type" as I am not.

But I would address your remarks. I think you have propounded very well what you must propound given your position and most assuredly your convictions.

But you say the rule violates physicians' and hospitals' abilities to exercise their professional medical judgment in the best interest of their patients.

What bothers me about that is the knowledge imparted by the TV script and by other anecdotes to the effect that parents once advised by physicians against their own wishes have expressed gratitude that they didn't follow those instructions; and that in particular the doctors in one of the anecdotes in the film were advising what seemed to be in the best interests of what they perceived the parents' well being to be, rather than that of their patient, the child.

And I find that contradictory in your opening statement. Would you care to comment on that, sir?

Dr. LITTLE. Well, I think you—the way in which you've introduced the question, asked the question, made it very clear that we're really not talking about black and white. We're talking about large spreads of gray.

Senator DENTON. If you would yield on that?

I believe that there are large fields of gray in many areas of medicine. I think what we have come upon is an area in which we may be able to delineate more clearly that which is right and wrong in a specific area, or areas, of medicine. I think that's what the Surgeon General believes, and what I am persuaded to believe.

Dr. LITTLE. Well, Senator, if I interpret your question properly—let me say I agree with you about the issue that something needs to be done with this particular group of patients.

And I will maintain that the medical establishment has not been keeping this issue under a bushel basket. It's been out in the open. The Kennedy Foundation put a film out on it, et cetera.

The problem really is, and I speak as a practicing neonatologist and a very concerned individual, that the sign, the process, that has been invoked here really can and does have deleterious effects.

We don't try to do anything up until now about our hospitals and health professionals except to support them in a fiduciary way, in a trustful way. And to have a family that comes in to have a baby, which, even having a normal baby is a bit of an anxious—you know, it gets the juices up; it's an anxiety-producing time—but to have an abnormal baby is an extremely disruptive time.

And these signs, the way they're phrased, really imply, you know, look over your shoulder—somebody might not be doing the right thing. I don't believe the Academy of Pediatrics or I, personally, or the consensus of people in all the health professions would deny that there's an issue that needs attention.

But to give it attention and try to solve it in this hurried and contrived way is inappropriate.

I hope that answers your question, I'm not sure.

Senator DENTON. Well, I certainly acknowledge your good will and the honesty with which you addressed it.

I think Dr. Koop acknowledged that this is not a perfect regulation.

But I still believe, and I wish to be persuaded otherwise, that the regulation here might be better made than not made. It's needed not because doctors as a group are bad. I rather think they are among the more altruistic and better intended professionals of the world.

But doctors can fall into the sort of lassitude Dr. Ramsey was talking about; and I am referring to the overall societal trends in the United States as being less attentive toward the pursuit of liberty and pursuit of happiness—of other individuals. The pursuit of happiness and liberty is something that one must keep in mind as being not reserved for one's own instant self-gratification or even 5 years of enjoyment, but for everyone.

And that child's quality of life—how would you judge it on a scale of 10?

I must say that the most joyous moments of my life I have spent without being able to move a muscle, and in considerable pain for long periods of time. I couldn't have achieved that quality of life. I have been on a zero on a scale of 1-to-10 quality of life in terms of my happiness when I was bathing myself in luxury.

So I can feel for an individual who's handicapped. I found myself unable to communicate with normal, none physically-handicapped people, when I came home from prison. Only the handicapped could understand what it was I was 18 inches off the ground about.

And, therefore, I have problems, too, with this quality of life idea. Quality relative to what?

To them life is infinitely important, and to them it is infinitely endowed by their Creator. And I believe they are entitled to it. And I think we should be less hasty—should the word "hasty" be used—in rendering yes or no to that person's right to life.

And that comes in with Father Paris' bit about life and death are part of a journey—I go along with that. But I get pretty reticent about who's going to decide when it is I take this latter part of this journey.

So I believe that we're all speaking here from good will. I believe that some of us are speaking from more expertise than others relative to the relatively narrow spectrum of medicine which is truly involved here. That's my honest-to-goodness belief about this discussion.

I'll turn it over to you now and then come back; OK?

Senator NICKLES. Thank you very much, Mr. Chairman.

I appreciate the comments, the very thoughtful comments, by our panelists, and also the expertise which you have in this area.

Dr. McLone, a couple of questions:

You mentioned there's still a significant number of children that are born with spina bifida that are not treated? Is that correct?

Dr. McLONE. Well, I don't really have a good incidence number. I can give you what I think is going on.

If you look at the population that I treated in the last 200 children, there are about, out of 100 children, there are about 15 children who come to our facility late. They have been in some other hospital, in my opinion, being denied proper early treatment.

They ultimately get transferred to us. The reasons for those are varied:

Somewhere between 5 and 15 percent of children were denied early prompt treatment both because of lack of available information to the physician and to the parent. The physician was using criteria which, I think, has been shown to be completely unreliable. They were instructing a family using that criteria, and they together made in my opinion a decision not to treat a child based on lack of information.

And that number of children I think is somewhere between 5 and 15 percent. But that may be the tip of the iceberg.

My reason for coming here is to point out that there is in fact a problem, that there are children being denied not food and water, in my experience—because I don't see those cases I know are reported—but in my experience they're being denied prompt appropriate treatment.

Senator NICKLES. You mentioned in most cases infants are not denied food and water?

Dr. McLONE. I can't think of a case in the group that I'm familiar with, the spina bifida children, in which the child was denied nutrition, food and water.

Senator NICKLES. There's possibly a significant number that are denied any operation?

Dr. McLONE. Right. And as Dr. Koop mentioned I get phone calls from nurses who have over the years trained with me at Children's Hospital and from physicians, and there are children at hospitals in the Midwest where spina bifida children are not treated, and die; because of a lack of treatment.

Infection ensues and they, in my opinion, are born living and acquire a fatal illness due to inactivity.

Senator NICKLES. You were brought into the case which I mentioned earlier, I believe; isn't that correct?

Dr. McLONE. Yes.

As the managing physician, and as the physician who cared for that child, I think it would be inappropriate for me to comment. And I think Dr. Little's point is well taken.

Let me just again point out that the problem in almost all of the case—not speaking specifically to this case—but in all of the cases that I have been involved in, in which the child is ultimately given what I consider proper care, has been the fact that the physician was operating under information that was not valid at the time, and for a variety of reasons had not sought consultation from somebody who was conversant with the disease he was dealing with.

I think if we can find a mechanism to make an appropriate consultation available to families and physicians who are confronted with the disease in which they may have seen only one or two of these children in their entire practice, if they can get expert consultation and expert diagnosis of what is appropriate treatment and so forth, themn all of the 20 cases or so that I can come up with in our clinic, those cases were all turned around simply by making families aware of what's available and what's the likely outcome to be.

Senator NICKLES. Can that information be dispensed through Dr. Little's publication or other publications?

Dr. McLONE. I think the American Academy has spoken to that in their committee, and I think that's perfectly appropriate; and that is probably the best way, is to get education through the committee to the pediatricians, if not to make them totally conversant with these few diseases that they may only rarely see, at least make them aware of lines of communication to get to expert consultation, so that appropriate decision can be made for the newborn.

Senator NICKLES. Dr. Little, here's a question in a similar vein. I'm trying again to get some kind of feel for the problem. You mentioned that there is a problem and there has to be some change.

You didn't particularly agree with the administration's proposal. I don't know that it's perfect, either.

I think you called for an ethics committee or something along that line.

In your opinion, is this a significant problem? Is it an increasing problem? Is the legislation, section 504 sufficient if it was enforced, or if it was better known in the medical community?

Dr. LITTLE. There are several questions, I'll try to get to them as quickly as I can.

The law, 504, as far as I know personally has academy support, fully.

The issue of changing technology, changing medical knowledge, and getting that out into society as a whole, is a generic problem. It's not different than changing knowledge about the body of law. It's a generic problem.

That means that the medical infrastructure, assisted by the Government and so forth, is going to do its doggonedest to get a system of postgraduate education and so forth out there.

I agree with Dr. McLone that that's a basic problem in spina bifida, for example.

That's the qeneric problem of which we're seeking a solution—to try to get systems and things underway and strengthen existing ways to deal with the problem, which are onscene and do work. And I'll be perfectly happy to support with additional testimony, for example, information about regional perenteral care systems which have been supported by the Federal Government and instituted by the Federal Government and which have kind of consultative channels that Dr. McLone talks about; the Academy of Pediatrics and Obstretrics and Gynocologists is soon to come out with a manual in an attempt to deal with this generic problem of diffusion of information and changes in approaches out into the medical establishment and society as a whole.

Senator NICKLES. You mentioned also that there was relevant data available through your academy or through some other medical professional.

Could you supply that to the committee?

Dr. LITTLE. What I tried to mention I believe, and correct me if I'm wrong on this, is that the statement was made by Dr. Koop that this is a known and increasing problem.

And I think there is an equal amount of authoritative opinion and so forth that the problem is known and decreasing.

Senator NICKLES. Could you supply that?

Dr. LITTLE. And we will try to get some of that information to you.

I would also state that part of the solution to any problem is an adequate, obective data base; and I suggest that we wouldn't be here talking this way today if there was an adequate, objective data base.

Senator NICKLES. If you had knowledge of a physician treating a child born with spina bifida and the physician recommended to the parents, or maybe the parents recommended that no treatment would be made, would you concur with that? Should the Government get involved in any way?

I was going through a lot of your comments, statements, which I would generally concur with that we must not have greater Federal Government involvement; but conversely, should there be Government involvement in those cases where we have a physician, as the one who testified on the film clip, that it was his opinion that discrimination should actually take place if the child was going to be severely retarded, et cetera?

Dr. LITTLE. Yes, it is the function of Government in my opinion, and I think the academy's opinion, to have enlightened and helpful involvement by Government.

I tried to use the example of the institutional review board in biomedical research to try to point out how the Government, working in conjunction with professional groups in the medical profession and so forth, has really been helpful in solving problems which have real difficulties.

Our position at this time to what came out on March 7 is not the principle of law, or the fact that kids need help or handicapped children, and so forth. It is the fact that this process has not received adequate testing in light of day, and in our opinion, it really is going to be harmful in many situations.

Senator NICKLES. Thank you, Mr. Chairman.

Senator DENTON. Thank you, Senator Nickles.

Dr. Little, you have raised the issue of Federal intervention and you mentioned haste here; and it's certainly a valid position to take.

Your own task force on pediatric education report, the AAP's Task force on Pediatric Education Report, states that: "The care provided to children with chronic handicapping conditions continues to be grossly inadequate"—and I'll just underline the word "grossly"—"although pediatricians are uniquely qualified to provide this care, too many resident programs underemphasize this aspect of pediatrics."

And then in a survey 40 percent of the pediatricians responding to it say that their residency experience was "insufficient in preparing them to care for patients with various manifestations of chronic cerebral disfunction." Another survey reports that practicing pediatricians were significantly more pessimistic about the ultimate abilities of mentally retarded adults than psychologists and educators who worked closely with retarded after they leave the nursery.

I believe that proves what you were saying, that this is being aired in the medical profession, and to its credit; because it is open and honest.

I believe on the other hand it does indicate that there may have been a stage reached at which there should be some sort of manifestation which might be useful—governmental manifestation—which might be useful in accelerating the knowledge which physicians say they lack, in disseminating it and in resulting in changing attitudes on the part of doctors who might be unaware of recent breakthroughs.

So I again acknowledge that socialized medicine is not good, Government intervention is not good; but when it reaches this stage as described in your own manuals and discussion, I don't think it's too hasty to put in something as mild as has been proposed.

But I would ask your comment on that?

Dr. LITTLE. Well, I think that's a very good example and I welcome the comment.

That document which you refer to was not put out only by the Academy of Pediatrics, the Task Force on Pediatric Education was put out by multigroups, pediatric department chairman and a number of psychiatrists and so forth. It identified deficiencies in pediatric training.

Changes have come about in pediatric training because of that. And I can vouch for that in my own department where we have a primary pediatric care residency grant.

Those changes came about because, Senator, the Government got involved; the Office of Health Manpower got involved, and has helped bring about those changes.

And so the issue of additional training and handicapped in orthopedics, developmental problems, and so forth, has been addressed in an objective and logical fashion.

Now, the underlying problem—and Dr. McLone has talked about this—is just what are the resources that are being allocated to handicapped kids and pediatricians so they can further understand what's going on?

We really need to look very carefully at the issue of human services for children who often turn out to be disenfranchised.

But your example I think supports my contention that an objective, aggressive, coordinated effort by the Feds and by the private sector and the professional groups and so forth, works; and it's occurring in the eighties.

Senator DENTON. Well, I'm all for the coordination. And I just hope that the regulation isn't considered an omen of over-intervention to be developed in the future; because I personally still support it.

Father Paris, I have before me your statement by Rev. Edward M. Bryce on behalf of the Committee for Pro-Life Activities of the National Conference of Catholic Bishops. This document pertains to the interim final rule, nondiscrimination on the basis of handicap, published in the Federal Register March 7, 1983.

Speaking for the National Conference of Catholic Bishops, Father Bryce says in reference to this issue we are discussing, the sign in the hospitals and so forth, "The new interim final rule adds nothing substantive to these principles. It simply provides for reporting of violations and facilitates corrective actions so that lifesaving treatment can be provided in emergencies. The notice is to be posted in federally funded hospitals therefore refer only to cases in which a handicapped infant is being discriminatorily denied food or customary"—underlined—"medical care"—that's the end of the quotes.

"Several remarks can be made," and I am continuing to quote his article—"several remarks can be made at the outset concerning this legal development. One, the regulation is perfectly consistent with Roman Catholic declarations on the dignity and rights of the handicapped infant. For example, the Pastoral Statement on Handicapped People issued by the Bishops of the U.S. in 1978 condemned the denial of 'ordinary and useful medical procedures' on the basis of a child's handicap."

It goes on and develops that, and point two, "there is no contradiction between these regulations and Catholic moral teaching on the withdrawal of medical treatment. This teaching emphasizes that the deliberate omission of necessary sustenance in order to cause death can be equivalent to murder," and he goes on about that.

And his third point here is, "the regulation also is consistent with American legal traditions regarding the State's duty to protect children from neglect of parents and physicians."

From your statement I gather that that's not entirely in consonance with your views. The Vatican also stated that "the deliberate failure to provide assistance or any act which leads to the suppression of the newborn disabled person represents a breach not only of medical ethics but also the fundamental and inalienable right to life."

That was from the statement on International Year of Disabled Persons, 1981.

It appears that there is an inconsistency between some of the positions you took and those of the Vatican, in particular regarding the regulation.

Father PARIS. Well, I think there was no inconsistency, Senator.

There's nothing inconsistent with Catholic teaching in saying that clearly we should provide customary care. That's clear.

I surely, certainly, agree and believe that the Government ought to insist that ordinary and customary care be provided and that no one be denied it discriminatorily because they are handicapped.

The question that arose here is: Is a Federal regulation of the type that was issued by Department of Health and Human Services, the best way to achieve the goal which Dr. Little and this committee and I all agree is a good goal: The protection and assurance that no one is discriminated against because of a handicap.

I think it is overly blunt and yesterday I had occasion to attend a meeting of the—all of the pediatric neonatologists of Metropolitan Washington, a meeting at Children's Hospital, and it was clear that already there have been very adverse impacts upon the practice of medicine because of this regulation.

Children's Hospital, itself, has received children whom outlying hospitals have clearly convinced are dying, and there's nothing they can do; and they send them in to Children's Hospital, lest they be accused of not giving all the possible care that could be delivered.

And so Children's Hospital in Washington now is being burdened by children for whom there's really no care that they can provide different from the community hospitals, but which the community hospitals have now in light of this regulation are afraid to treat.

Senator DENTON. Well, I think we're being very reasonable now about the way we're discussing this thing, not that we ever had diverted from that.

But Father Bryce does go on to say in the National Catholic Bishop's statement, after having approved the regulation, that:

> Although the Catholic health care system has willingly implemented this new regulation, some medical organizations have voiced objection. They claim the regulation interferes with sound medical judgment and imposes new legal burdens on physicians and hospitals. This charge seems premature at the very least. The regulation makes the proper distinctions in this area and there's no evidence that it will be enforced arbitrarily or unreasonably.

That's at least what this paper maintains. So I think we're talking about degrees of reasonableness of intervention; and I hope that we can at least achieve an agreement that nothing dire is intended and it's a matter of whether or not there is too much or too little governmental intervention.

I must say that as a Senator I tend to agree with Dr. Ramsey and Dr. McLone; but I have no less respect for what Dr. Little and Father Paris have had to offer. That's the only reason I'm not asking Dr. McLone and Dr. Ramsey any questions.

Senator Nickles?

Senator NICKLES. Father Paris, to follow up—I listened attentively to your statements and find myself agreeing with most of the things that you had to say.

I might reiterate and I'm assuming that you were here when Dr. Koop made his statement?

Father PARIS. Yes.

Senator NICKLES. I heard probably three times, I think, during the course of his statement that this rule was not to be interpreted to not prolong dying.

And I heard that strong throughout your statement, and you've repeated it again. I think it's worth mentioning. I don't think that by this regulation—I've read the regulation—I don't read that into it.

Maybe that's an overreaction by some hospitals or what, I don't know; and maybe some clarifications might be made by HHS to make sure that that is communicated.

Father PARIS. The regulator may say, "we do not intend this," but surely the recipient of that becomes quite nervous at the thought that all of their Federal funds are going to be taken away.

I had occasion last night to attend a dinner with some six physicians, I believe, one of whom is medical director of a very large hospital, who reports that within their institution they have treated a child born with anencephaly totally beyond any possibility in anyone's judgment of being viable; and yet the infant was treated because of the fear of this regulation.

And I said, "Doctor, that's unconscionable for you to do that."

He said, "but you don't understand what it is to have some bureaucrat ready to take away your funds."

Now, I think it's——

Senator NICKLES. Is he aware that 504 has been on the law books almost 10 years?

Father PARIS. Yes, but now there's a phone call; and the thought that somebody's going to call up——

Senator NICKLES. The law hasn't changed.

Father PARIS. That's correct.

Senator NICKLES. I would appreciate hearing your ideas if you think that the signs will have an adverse impact, I don't know—but if there are some inequities, some injustices to handicapped children that are losing their lives this notification and the signs and the toll-free number may not be the right step.

If you have some other ideas to help correct this problem, Dr. Little—you indicated an interest in communication; I think you'll find persons receptive.

But it's obvious when you see this type of comments being made, it certainly is increasing public awareness.

Dr. McLone, do you have a feeling that this type of discrimination is increasing or decreasing?

Dr. MCLONE. I think I agree with Dr. Little. I think it has been there for a very long time. In spina bifida particularly, as I said, before 1950 it wasn't a problem because we had nothing to offer.

And I think that it's important that we understand, and I think Father Paris said that—we're talking about children who are born, who are going to survive handicap, and they have a handicap and we can make them survive by doing something about children dying; and that there isn't anything that can be done.

How do I feel about the regulation? I think it's probably something I ought to speak to:

I am concerned about Government intervention into the doctor-patient relationship. I find it distasteful when the courts step between me and my little patient. But it is a major problem.

However, I think maybe—if Government is being accused of being too premature in implementing this rule, maybe those who were advocating that it is premature, I think may be also acting prematurely.

I think we ought to look at this thing and see what the effect of it is. There's no doubt that there are children denied prompt treatment in this country. If this regulation and the posting this regulation which we should all know about anyway is the law, if posting this regulation causes more harm and no good, then I think we ought to step back from it.

However, if it causes some difficulties or interferes with some of our practices, yet benefits a few, even, newborn children, gets them appropriate treatment or they get the water and food that they need; and that those cases don't recur, then I think maybe it's a good rule.

I'm not—it's outside of my area of expertise. I don't know what the effects of signs are on people. And I'm not a sociologist and can't give testimony in that area.

There is a problem, there are children being denied care; if this gets some of those children appropriate care, then—fine.

But if it doesn't, if this does not do that, and it causes harm, then I think we ought to step back.

Senator NICKLES. Thanks very much.

Senator DENTON. Dr. Ramsey, before we—well, actually, I want to hear a last word from you regarding the President's Commission, and any comments you have to make; because you haven't been asked any questions.

And then, if I may, if the third panel would defer until we allow the family to come in, because they've been waiting out there for quite some time?

Dr. Ramsey?

Dr. RAMSEY. Two or three small points before I make a comment that I would very much like to make about the President's Commission, that have arisen in our discussion.

Senator DENTON. Would you put the mike a little closer?

Dr. RAMSEY. Yes.

I think, Mr. Chairman, you will find that the death certificate for "Baby Doe" does not show it died of starvation; and not because there was any coverup. If you were withheld nourishment you, too, would die of something else; anyone would:

Second, I've never heard, in this matter of slowly starving patients, of physicians who having chosen that form of child neglect have then chosen a form of drip that will not deliver calories but will prevent dehydration. That can be done, I understand. If it is not done, that means they first decide to neglect patients to death, and then decide not to comfort and care for them as against the unknowable possible pain of dehydration.

My third point is addressed to some of my fellow panelist. Perhaps customary is a vague term. So let me note as a matter of record that the two houses of the Indiana legislature have in conference now just about removed any discrepancy between the two bills, and that State will soon pass a law that states that the treatment shall be given in the case of a defect that would be given to a normal.

Now that was the substance of my testimony. And it is not at all unclear.

It is indeed a golden rule of argument, which braces the mind, like being shot at sunrise. If the medical profession is not willing in its practice in the State of Indiana after that law is on the books—which requires in the case of a defective child needing some surgery that the test be, would I give that to a normal child in like need?—then I don't think the question is vagueness or lack of exactitude in knowing what would be right to do, or what the law requires by way of equal treatment without weighing in the noncorrectible abnormalities.

Do I have time for a brief comment or not on the President's Commission?

Senator DENTON. Yes, sir, very brief because we do have the Rossow family waiting.

Dr. RAMSEY. Well, I hope I can make it because it—I think one has to be very, very good at reading committee reports. It sounds like it's very strict, about young patients, a strict standard is to be imposed. They not to be denied anything clearly beneficial to the patient.

I saw on the TV the other night on the nightly news the picture of the smallest baby yet born to survive, a little over a pound; its heart was shown, the size of your thumbprint.

It had already had a heart operation. The nagging question—it's not even clearly beneficial to that baby—is would it have been as clearly beneficial had the physician also known that that little baby about the size of a quarter-pound of butter, was also afflicted with an uncorrectible genetic anomaly?

The statement of the President's Commission nevertheless permits the withholding of treatment for defective newborns on the basis of defect if continued the existence would or would not be beneficial to the patient.

Now, a flag went down for me on the field at that expression.

The Commission's phrase crept into medical ethical literature first as the wrong of continued existence. To withhold treatment if continued existence would not be of net benefit to the child is a euphemism for that so-called wrong.

And I would suggest that the Congress, which may have an overrepresentation of lawyers, consider that twisting of tort law if the wrong is continued existence, rephrased as a judgment that continued existence would not be of benefit, is to be a privately practiced guideline.

It is twisting utterly the notion of harm, of tort, of wrong that is behind the phrase, first the phrase the wrong of continued existence and then the phrase opening the possibility of nonmedical judgment that continued existence is not of net benefit to a patient because of medically untreatable handicap.

I thank you very much.

Senator DENTON. Thank you, Dr. Ramsey, Father Paris, Dr. McLone and Dr. Little. Your testimony was superb. We thank you.

The next group is about to come in. We will move forward to them.

Next is the Rossow family from Ellington, Conn. The Rossows have adopted 11 handicapped children. They will share with us today some of their experiences in nurturing these 11 youngsters.

Please move the chairs so the wheelchairs can get in.

The Rossows happen to be personal friends of the ranking minority member of this subcommittee, Senator Dodd, who is unfortunately unable to be with us today.

Welcome, Mr. Rossow, Mrs. Rossow and all the little Rossows.

The senior Senator from their home State of Connecticut, Senator Weicker, will be in presently to say a few words of introduction.

I want to remind the guests that we have a further panel who have kindly delayed so that the Rossows won't have to wait out in the hall; Senator Weicker, who is well known for his interest in the handicapped, is their Senator, and he will introduce them.

STATEMENT OF CARL AND RACHEL ROSSOW, ACCOMPANIED BY THEIR THREE NATURAL CHILDREN AND 11 ADOPTED MEDICALLY FRAGILE CHILDREN; AS INTRODUCED BY HON. LOWELL S. WEICKER, A U.S. SENATOR FROM THE STATE OF CONNECTICUT

Senator DENTON. Welcome.

Senator WEICKER. Mr. Chairman.

Senator DENTON. Senator Weicker.

Senator WEICKER. Senator Nickles, it's with great pride that I introduce to you Rachel and Carl Rossow and their family, from Ellington, Conn.

They are some of the best Connecticut has to offer.

A few weeks ago when they were featured on a program produced by WNEV-TV channel 7 in Boston, President Reagan was among the viewers. And so inspired was he by their story that he put a call through to them that very day.

I know that you'll find their example equally inspiring.

To call Rachel and Carl a remarkable pair of parents would be to understate the case. In addition to raising three children of their own, who are now in their teens, they have since 1971 adopted 12 severely-handicapped children. One of them, Christopher, a 4-year old with cerebral palsy, died last year.

Today the adopted Rossows range in age from 2 to 15 years old. Their disabilities are equally wide ranging, but all of them severe.

The Rossows also take into their home severely handicapped children on an emergency placement basis while these children await adoption.

The reason the Rossows do this is very simple: they believe that multiple handicapped children can best achieve their whole potential in a setting that combines family love and support and professional care.

And that's why in 1973 Carl quit his job to devote himself full-time to children.

He and Rachel formed Alpha-Omega, a nonprofit organization which acts as an advocate for handicapped children. Five years later Alpha-Omega received a grant from the State of Connecticut to build a house especially designed for these children.

Today the home's annual budget of $105,000 depends on donations, and the State Department of Children and Youth Services which reimburses them for each child.

Rachel has been a valuable and eloquent witness before the Subcommittee on the Handicapped in time past. I am sure she and indeed all the Rossows have much to tell and teach us all today.

It's a great honor to have you with us in the U.S. Senate, and indeed, you are a living example to all.

And I hope that you will be able to so state the case, that there will be a great deal of additional funding for what you do and others like you do for the children that you have with you and the children who are not here today.

Thank you very much.

Senator DENTON. Thank you very much, Senator Weicker.

Mr. Rossow. Thank you, Senator Weicker, Senator Denton, Senator Nickles; and thank you, Senator Dodd, who could not be here today, but who has been a very dear friend and a very good supporter of us, too.

I was going to take rollcall because we have a number of our children from all over the United States represented—Missouri, where I'm from, and Rachel's from California—Kentucky and Florida, and a Texan, some Connecticut kids, and a child even from New York.

We are very happy to be here, I assure you, it's a privilege.

If I would be very honest, I would say I am nervous, because it's very weighty. We are not sophisticated in our testimony, but it comes from our heart; as we introduce our children later on in our testimony, I think you will understand why.

We have 14 children. Sometimes the numbers get mixed up a little bit, natural children, adopted children and permanently placed foster children. All the children are with us; our commitment is on a permanent basis.

Likewise, as Senator Weicker mentioned, our little Christopher who came with us at a very early age and died last year. Our philosophy basically has been that only in a family environment together with trust and stability and love and so forth, can a child reach his fullest potential.

The things which we are going to address today basically center around support services, to parents such as ourselves, but mainly, natural parents who give birth to a disabled child—what do they need.

Rachel will address briefly the "Baby Doe" situation and some suggestions that she hopes you will take into mind.

And then we're going to talk about the value of every person; and we're going to talk a little bit about our family because they're here and we're just very proud of them. And they can oftentimes speak much better just by their presence than we can, especially little Benjamin, who's here with us today [indicating].

I think we'll begin then just by delineating a few things that we see a need for in support services and how they have related over the past years to our experience.

Rachel, how about you addressing just the basic issues about the families being out there and so forth?

Mrs. Rossow. Sometimes people will make comments to us that we're special. And it bothers us because we're really not; and I want to make just a few references there—there's an agency in Washington, D.C., that's receiving 200 letters per month from families requesting children with disabilities or otherwise known as "hard to place children."

Within Connecticut there have been many families that have been placed—I'm mostly familiar with the New England area—last year in Massachusetts there were two children with known terminal illnesses that were placed in adoptive families; one of the children has since passed away. A little girl from Illinois, 6, with a multiplicity of anomalies was placed in an adopted family in Florida and she has since left this Earth.

I just mention these few little situations so that there are families that are all over that are realizing the value, the joy, and the excitement of sharing their family with a youngster who needs a home, and just happens to have some form or another of disabilities.

I would also like to say that within Connecticut, again that's where I am the most familiar with, over the last 10 years the entire adoption picture has changed. Right now there are not any babies that are free for adoption that are not already placed in permanent families.

That's very, very exciting, because one of the situations we hear in reference to the "Baby Doe" is that, all right, if the babies were saved the families might be straddled with a situation that they would not care to have the rest of their life; and I truly ache for that family—and we'll get into that later.

But I just want to make this point so firm and so clear: that there are families out there.

There also is a role that the Federal Government can play in this:

Families have contacted us from various States that have had difficulties, particularly if they move. In one State there may be a subsidized adoption law; in another State there might not be.

They might be disagreeing in policies within adoption agencies in different States.

So there certainly are areas that the Federal Government can give 100-percent subsidy for families. In other words, when a child goes from foster care system to the adoptive system, some States maintain the same financial support of that family; some States don't.

So again, I see a definite role the Federal Government could play in this area.

An exciting thing in Connecticut in the last 10 years in this area is that the adoption of children with special needs has mirrored the adoption of children without special needs, which I think is very exciting. The children that they are having more difficulty placing right now are older children and sibling groups. No matter how involved the anomalies, even to the point of known terminal illness, the families are there.

And I think what that bespeaks is not only that children need a family, but the families need the children. And it's very much a two-way street.

Mr. Rossow. Another important aspect which really has been prominent over the last number of years, too, as our children have entered the public school system and all has been 94-142.

And I mention it here today because it has really been a necessary piece of legislation that has allowed us to participate and to educate our youngsters.

There are numerous examples of this particular thing and I serve on the local board of education in Ellington, too, and sometimes I'm familiar with both sides of the fence.

But for example, well, Rachel, why don't you just tell them?

Mrs. Rossow. Until September of 1980 when the 94-142 actually came into effect, our children were not able to go to the bathroom during the school day. There really was not a law on our side if we pushed it, which meant that various children had to have collecting devices underneath their wheelchairs.

The moment September of 1980 came and that law was on the Federal books, everyone was marvelous, all of a sudden. Within our school system, it was under $500 to make the school completely accessible; and then they could use the facilities.

This is our young one [indicating child].

Mr. Rossow. Another aspect, very briefly, too, is that aspect of 504, the accessibility requirements. I think many of us who walk cannot really understand until we sit in a chair, what it means to try and get some place.

I know you've heard this before. But I can give examples of hotels. We've been in one that was supposed to be accessible, but when a child can't even get into a shower, you know, and bathe himself or herself—it's very much of a necessary thing.

Around Washington, it's really a neat thing because we can get around. A lot of cities aren't like that, however. And a lot of churches haven't even been until these past number of years when the accessible process has begun.

But we see that aspect of barrier redesign and accessibility especially to public places as being a very important thing.

And I would just like to make one other comment about that, too.

As Rachel and I have approached a lot of these things we have sensed the practical aspects of what that means. And a lot of times a very commonsensical approach can do the job, but you have to address that particular need. Just as an example when we moved into our new house, the mirrors were placed by the builders at a 6-foot level, where the architect—he was sincere, but he just didn't sit in a chair and realize the child who would be trying to get to the mirror could not look at himself or herself. So the mirror was up here [indicating].

Obviously, when we told him, he changed the mirrors and brought the mirrors down where the child could see in them.

Anyway, these are some examples which we consider very important.

Another one which really relates to the disabled community, especially children—and I would speak for the natural born parent and family; and that's the help required when a child is born.

And Rachel is going to address that issue more later. But for example, catastrophic medical care or health type of coverage. For the parent who just carries some type of insurance from where the parent works or whatnot, this is one of the areas that can really be a disaster.

They have enough things to go through. We above all people in my own opinion, should be able to help that family and that child.

That is one contributing factor where that child can stay within the family and not be turned away.

Would you like to speak to that, Rachel?

Mrs. Rossow. I would like to share with you some thoughts, and I've been speaking on the staff level, I believe to both of your staffs, and also Senator Dodd's staff, about a suggestion on the "Baby Doe" situation.

I've been concerned that some of the reaction that I'm hearing right now is very negative to new parents that have just given birth to a child with a disability. I see a tremendous need for a positive outreach to those parents immediately when that child is born.

What I would like to do is explain some of the goals, and ask the continuing help of your staff and Senator Dodd's staff to work on the implementation of the specifics of it.

Some of the goals are the following:

First, if the parents could be moved in this immediate crisis situation, at least 2 weeks, perhaps a month, down the road. In our country all of our laws are based on not allowing people to make tough decisions during a crisis time. If you want a divorce, you must wait by law; if you want to adopt a child, a minimum of 6 months. In making every major lifelong decision, you must wait—except in the case of these parents who are being asked within the first 24, 48 hours to make life and death decisions for their child.

So one tremendous goal is to help bring those parents at least 2 to 4 weeks out of the immediate crisis situation.

During that time if it would be possible to extend what's already in our country and known to be good, to extend a little bit further—NIH continues their data bank, and if hospitals the moment a child, with a severe disability/medically fragile condition would be born, if the hospital could be required to contact NIH.

NIH could just give them all the experts that would be known in dealing with the disability of their child in their area—who could the parents turn to? What kind of parent-to-parent support groups are right within that locale, their names, addresses, phone numbers?

And from a national adoption pool that there are two families in the Midwest, say, interested in adopting a child, or have expressed an interest in adopting a child with such and such a disability. If that information could just be presented to the family, I would think that would help them very, very much.

A second aspect of this is, if it would be possible—every child who is born in a hospital, some one makes a decision immediately as to whether or not that child is medically fragile. Either they go into special care nursery, or into a regular nursery.

In Connecticut we use the APCAR score. Some places use different types of immediate evaluations, sometimes the nurse, sometimes a doctor.

If somehow that could be added with a yes-or-no question: Is this a medically fragile child, is this a child where these decisions of withholding food might be considered? And if a yes-answer to that could set the child up into a due process—that could either be 504, it could be 94-142. I understand even 10 States now go down to zero-birth exclusions—in Madison, it's been very exciting to the University of Wisconsin how, if the parents desire, they can sign their child literally in the delivery room into their local school system.

They can start learning about care, learning about the support services there, early intervention programs that are available for the child.

The biggest thing we're trying to do is help those parents realize they're not alone; because I think one of the things that some of the negative aspects and some of the antagonistic aspects that have come out of the "Baby Doe" situation, one of the negative spinoffs of this is that the parents and the doctor have become more isolated and people that are out there and trying to help, there is resistance to getting them in.

It seems as though there's more of an adversarial atmosphere and this concerns me.

A third aspect, and this is a critical one I could turn it over to the lawyers, that if there could be a hinged kind of a legal mechanism whereby if the moment the parents would decide to withhold food—and by that I would define tube-feeding, intravenous feeding, cut-downs—these are not involved procedures; one of the youngsters that had a gastrostomy feeding, and when I asked the doctor how long he would be in the hospital for the tube to be implanted, he said if he were an adult he'd do it as an outpatient in his office.

So we're not talking about severely involved medical procedures.

To insure that while the parents in the decisionmaking process have 2 weeks or a month, that that child could receive nourishment and have the chance for life; then if, as I say, the hinged kind of a decision that if the parents were to decide to terminate food on that youngster, automatically, they would be terminating their own parental rights.

I am stressing this because then, there would be the protection that the rest of us in society would have for that youngster, that we could go in, possibly to the parents—they could be encouraged, they could be given information; but knowing that if that decision's made to withhold nourishment, then automatically the parental rights would be terminated.

One of the aspects of that I would like to point out is that then immediately the positive adoption process could occur.

And again, through HHS, through NIH, through their working together as part of a national data system—I know they have the technical capability for doing this now, and I know the families are there. I don't think that would be too hard to pull this together.

And again we are talking, the best estimate I've heard is perhaps one child per State per year is going to be in this kind of a very critical situation where it might be a recommendation to withhold food. So we're not talking about thousands of youngsters.

If that were the case then first off, the negative, involuntary termination of parental rights that might be imposed would not have to be gone through. Immediately, once the parents would go along with or would make the decision and terminate food, all we're doing really is pushing up what's going to happen in another 5 or 7 days—their own parental rights would terminate when the child dies.

If the termination of parental rights were pushed up, the local State could come in with the adoptive process—the adopted parents could be on board within 24 hours; again, making the decisions for that child.

I would like to continue working with this idea and trying to find out how, as I say, the mechanics, the implementation could come about.

And I would just perhaps like to say one more comment regarding the whole "Baby Doe" issue:

I do not believe that at any other point in history has one small baby lived for such a short period of time and had the impact on the American consciousness that that one child did.

When people ask: "What is the value, or what is the influence of a child's life?" The influence that that child has had, as I say, on the American conscience—only lived for 5 days, has been totally remarkable.

Mr. Rossow. Just in summing up these resources, I want to emphasize again the first step from Rachel's and my viewpoint, too, is one the life is here then that life must be supported; and life must be supported from the very beginning, from the natural parent, and the schooling, and work, and so on.

That's a very important aspect. And without that support and where we're coming from, we could not have given to our youngsters, they could not have given to us. And there's been a lot of people involved in this support, too, that have encouraged us in a very real way.

So I just want to end that aspect of it saying that it's a very important part of this. We are alone a lot, but you all have to be out there helping us.

Rachel, go on.

Mrs. Rossow. Yes.

I'm afraid I'm nervous.

I prepared this [indicating booklet] for what I was just talking about and I forgot it. [Laughter].

May I—this is an open letter to parents of children with disabilities. It was written to provide answers to the questions that we are asked most often.

Parents at that point in time are given tremendous medical data, and they must hear the words, like paralysis, hydrocephalic; they must hear these words—potential severe retardation; they have to hear those words.

But they also must hear that the majority of children with severe disabilities now with education and training are joining regular competitive society, that some children as our Charlie, Mary, and Ellen, can learn and can do productive, meaningful tasks and enjoy work and smile—she likes her new haircut and is proud of the pin that the President gave her.

In other words—they are children with the same hopes, and dreams, and fears as every other child.

And perhaps a last bit——

Mr. Rossow. This leads in—I think we'll talk a little bit about our children. We are proud of them but they do relate a story.

Our three normal born, Robert, Susan, and Rachel-Marie, and our family has grown over the past 11 years—well, longer than that, Rachel-Marie was born in 1966; but over the last 11 years.

And then Eddy joined our family. And Eddy's on the far right. I'm going to embarrass you a bit, Eddy, today, but it's OK. Eddy was severely handicapped; very aptly Eddy could be put into a box of not being able to do things. But Eddy has done a whole bunch of neat things. He's presently a sophmore at Ellington High School, with his brothers and sisters; he conquered O-3 this year on skis. You see on his hands he doesn't have fingers and he's missing one leg, and so forth and so on.

Those are the things Eddy doesn't have but the things he does have is he is just a wonderful person.

Eddy was the one who kind of brought this whole thing to our attention, and Rachel and I didn't really have an idea of handicapped children; we had just wanted a child and that was Eddy who came into our life at one time.

And our three natural-born supported this whole effort and they have continually done so too, to become one family.

Basically I guess in a way we—our children are of three different types: those that will be able to go out into society, and we can prepare them with education and so forth, and they will be able to contribute totally.

Simone, even Simone, please raise your hand? [Child waving.]

There is Simone.

Simone's in junior high, she's a cheerleader.

Mrs. Rossow. If I could?

She comes out on the basketball court first. In her uniform with black and white saddle oxfords, size 4, toddler—just the same, exactly as the rest of the team; the uniform is the same—except I made it and it wasn't made quite as well as the others—she comes out first with her little pompoms, and the other girls jog behind her.

And you can hear her voice and her school spirit and enthusiasm going to the bleachers. And, frankly, it's very disarming for the opposing teams. [Laughter.]

But, you know, she's a regular eighth grade student.

We're really going to get raspberries, because we're going to embarrass all our children today, they'll give us a fit tomorrow for having done this.

But we're so proud of each one.

And we're proud of our community. It's the regular public school that's accepted them—I mean, when they don't do their homework they get a zero or reprimanded; and they do very well and receive a star just like any other student; and they are given the same chances and opportunities. And it's just evolved, it's just grown.

Mr. Rossow. And Simone's a normal teenager, 13 years old—I get the whole business. But Simone, and Dina, for example, who is the young lady over here; and David, who's in high school now; and Eddy, are children that will go out to society. And we're doing many, many things with each one. They're getting their education under their belt. The President told her she's got to do better on her homework, and I hear she's going to take that advice. [Laughter.]

But it's these sort of very normal things. The fact that they're in a wheelchair is just—you have to do things a little different; but you have to address the same problems as every other child.

There are other children who will need some more support and services that are homebound educationwise and maybe do not have as much intellectual capability; but, they, too, have charm, they have charisma, and they can be positive contributors to society.

Our third little class are people such as Benjamin and so forth; I won't mention, that are very difficult situations; they are not economically productive; they'll never go out and earn a dollar; but they have great, great value; and they have great human value. It's not things that, you know, you can tell society, hey, this child is worth so much or he's going to be a senator, or something else—but they give to each one of us in what we believe is just a very special way.

And their life sometimes is very precarious. Benjamin, he, himself, is—he just has a brain stem; he does not have a brain at all; he's been on borrowed time for the last 3 years.

But this little boy—and you've got to believe it—has already done more today than you and I and everybody else put together.

That's kind of what we are about. We are about the hope of the human spirit, the hope in our children. He's sleeping right now, but—just the beautifulness of the human person and many times I have learned this lesson and Rachel has told me; we probably have reached a plateau on one, and said, oh, that's it. And she really has led me to this, and all of a sudden there's been another breakthrough.

Mrs. Rossow. I would like to just make two final comments, that, our little Patrick over there—Patrick—who just adores his papa and adores Mr. Staubach; he's the family's big football fan; and we'd like to mention the decision on Patrick before we met him was to withdraw treatment. And he had quite a large meningocele that was draining—and the point that I'm making with this is that it is impossible at the time of birth to determine the capabilities of anybody.

The second point I would like to make is—we have heard it said that some children are just not lovable, are just not; that their life could not be worse—that death would be better.

And I would just like to answer that by looking at little Benjamin who as Carl said, he truly—there are many things: He doesn't have any memory, he doesn't have any balance; that's what he doesn't have.

But he's a beautiful little fellow with gorgeous blue eyes; he's kind of worn out from all of the excitement of everything we've been doing today.

He does have the ability to chuckle and to laugh, and when he does, he makes people feel good.

And I'd just share one of many experiences that has happened within our community:

A young girl down the street from us lost a very dear friend in a traffic accident. She was a senior in high school at the time.

And she stopped by and she asked if she could hold Benjamin.

And she held him for several hours, just rocking in a rocking chair. And as she went to leave she came over and she just said, "Thank you, I feel better."

What Benjamin did for her at that moment I really don't think a psychiatrist or perhaps even priest or minister could have done at that time. He allowed her to touch the core of her own humanness, and helped her set her own priorities straight: She was alive and she was breathing and what was she going to do from then on with her life?

And he has the ability to do that, a sort of charisma that helps to stop and take all of the cultural baggage; biases, prejudices, everything, and just put them aside—because he can't have any of those.

What he has is a beauty and a charisma, and he shares it with us by allowing us to feel very grateful that we are alive, too.

And we thank you very, very much for your sensitivity and listening and for allowing us to come. This is a tremendous honor.

Mr. Rossow. I just want to close by thanking my children for being with us today. It's been a long haul, and I really appreciate each one of them and what they have done that would help us today, too. Thanks, kids. [Applause.]

Senator DENTON. Thank you.

Mr. Rossow. Do you have any questions, or do you wish to just proceed on?

Senator DENTON. No politician would pollute the light that came into this room—but the world needs you, now, perhaps more than ever!

There's a song we sing at church, "Let There Be Peace on Earth, and Let It Begin With Me"—you exemplify that. We wouldn't have any wars, we wouldn't have any neglected children; we wouldn't have any crime; we would feel very little transition from here to Heaven. Example is not just the best teacher, it's the only teacher. And you've shown us that! Thank you.

Mr. Rossow. Thank you, sir.

Senator NICKLES. Mr. Rossow, I had the pleasure of visiting with Rachel, and I appreciated that. And I say—you've got quite a fan club, including, I think, the President of the United States, and a lot of other people. And you are certainly to be congratulated. And also I'd say your kids are to be congratulated.

You exemplify a lot of things that many of us would hope that we would see in ourselves, and many of us don't; and for that I think you can be proud, and certainly the kids can be proud, and the team can be proud—and we're certainly proud of you, too. God bless you!

Senator DENTON. You may be sure we will stay in touch with you. We have tried to incorporate such things as you have communicated to us prior to this day; we will stay in close touch with you regarding all the other things you said today and whatever you think of in the future.

Thank you very much.

Our final panel consists of two experts who treat mentally and physically handicapped infants after they leave the nursery.

Dr. John McGee is a psychologist at the University of Nebraska Medical Center and treats children with mental handicaps. Welcome to you, Dr. McGee.

Karen Green-McGowan, a registered nurse, treats children with severe cerebral palsy and other physical disabilities; she's been a consultant to 22 States and the Canadian Government.

Welcome to you, Mrs. Green-McGowan. And would you begin, Dr. McGee?

STATEMENT OF DR. JOHN McGEE, PSYCHOLOGIST, UNIVERSITY OF NEBRASKA; AND MRS. KAREN GREEN-McGOWAN, R.N., GLENWOOD, IOWA

Dr. McGEE. First, I would like to thank you very much, Senator Denton and Senator Nickles, for being here, as well as having your committee focus on this very vital issue.

In the 10 minutes that I will spend here, I want to emphasize basically just one point: That all life has meaning; that all people have developmental potential; that all children—the children you've seen, those who are in back wards of institutions, those who are forgotten, those who don't have the love that the Rossows showed to us—that all those people have the capability of learning and integration in the mainstream of family and community life, given our posture toward these children or adults with special needs, and adequate support across their lifespan.

To begin, I would first like to show a little TV excerpt of a middle-aged woman whom I will call Maria. She is 38-years old. She is not cute like the children we just saw. She nevertheless has the same developmental potential as all other persons.

She spent more than 30 years in the backward of a really dreary State institution. They told us that she was incapable of learning; that her life was meaningless; that she really didn't deserve to live.

The behaviors that you will see Maria showing us can be termed repugnant, repulsive; they move here away from us; she hurts herself; she bites; she kicks; she scratches; she screams.

I put before you, though, the postulate that even Maria is a developmental being and that if it weren't for our Government's intervention that many Marias would die at birth or soon after birth, or God only knows in the future, even in their middle age.

If the videotape is ready?

[Film excerpt shown.]

She had done this for over 30 years in the backward of the State institution.

Many professionals, I would suppose, said that she belonged apart from the community.

Her body was a scab from head-to-toe from selfmutilation. She would bang her head.

This is the first day I ever met Maria.

In spite of what we see, we hold that Maria is a developmental being.

I'm not a priest nor a preacher, like some of today's witnesses, and I don't know how long the road of life should be for her, but I think our posture has to be that it should be as long as possible; it should be in the mainstream of family and community life; and that if she is to change like the little children you just saw, it depends more on our posture, on the love that we show to her, more than anything else.

You can stop it.

[Film viewing ended.]

The developmental assumption is built on our posture toward the Marias of our Nation. More fundamental than technology, the law, or money or posters or hotlines, is our acceptance of the Marias as full, developmental, beings, as full people; in spite of what we see or hear or smell.

Our posture toward her primarily determines whether she will live, whether she will have a decent life, and it also determines our interdependence with her, where it brings us to the point where we recognize her as our sister.

I teach at the University of Nebraska Medical Center, the College of Medicine. We're proud to work with the little Marias and the big Marias and integrate them into our community.

I'd like to show you Maria three weeks later—3 weeks later—not because of technology or good teaching or rules or laws or anything—but primarily because of a posture which is combined with the supports she needs.

Three weeks later by people just being close to Maria and working with her, she is bonded. She has developed a relationship of interdependence with others. She has moved, as you'll see on the videotape, from a state of disconnectedness to meaningful human engagement.

I don't think some of the previous testifiers here could really determine by seeing her that she could do this, that she could bond with others.

Over 30 years of developmental despair was transformed into developmental hopefulness.

Can we see her. It's about 440.

[Film excerpt shown.]

This is the same person, 3 weeks later!

I don't know if she'll ever become a self-sustaining citizen; but she's moving toward it.

I don't know that she'll be able to live on her own; but she can live in a group home or an adoptive or foster family in a regular neighborhood.

She may not be able to learn academics; she may not be able to learn to read and write; but she can learn to care for herself, dress herself, feed herself. She may not be able to learn to speak, but as you just saw, she can kiss and show love and bond with us as her equals.

I feel that it's almost ridiculous that we have to testify to this point. But redundant as it may seem, it's necessary apparently to affirm and reaffirm that the little children you saw, that Maria, and all the other Marias of our country are capable of human development.

And those who grow slowly or almost not at all are still full human beings. The little excerpt of Maria showed us this.

Yet, the Marias of our Nation apparently need to be protected from those who hold that life is meaningless and that starvation and death is indicated.

This despair-laden posture led to two sad trends in our country. The first has been the sending into back wards the Maria's of our Nation, in institutions with the subsequent developmental despair embodied in what you initially saw in the video tape—a very spiritual death, moving away from people.

The more recent trend is the medical-legal approach which determines who is meaningful and who isn't as embodied in the "Infant Doe" case.

Institutionalization has been the posture of the past century and a half when society has been confronted with "Infant Doe's," a posture most recently enunciated in some court cases in Alabama—nine leading mental retardation professionals sadly stated that the Marias of our nations are decerebrates, brainless people, not capable of living among us.

In another recent case in Pennsylvania, 21 State attorneys general said that people like Maria are a threat to society. They couldn't learn. They said the Marias should be separated from family-community life.

Physical death, the death of the "Infant Doe" can only be a breath away from this recommended developmental wasteland of some of our leading professionals.

Modern research shows that all children and adults are full developmental beings. Ironically, children with Down's syndrome are among the easiest to teach, and among the easiest to integrate into family and community life.

Given early intervention they progress at remarkable developmental rates. In recent studies their self-care skills have been shown to be between 85 and 100 percent of normal peers—almost the same as their normal peers.

I work in other countries and in one community in particular in Portugal, a town called Agkeda, where every single severely handicapped child is in regular classrooms. You can't recognize the children. They are the same as the normal children in terms of their socialization skills.

Those "Infant Doe's" who survive and are placed into the back wards of our institutions are full developmental beings, even though, as in the case of Maria, at first glance we might think not.

I recently saw another young woman in a State institution near Washington. She was described as "dangerous" as an "animal". They kept her for years laying on a mat in an ICFMR funded sunporch, where nobody would go near her. She spent most of her time in restraints.

I think as a nation we can do better.

These two interlinked trends, actual death or spiritual death, are based on a posture that the Maria's lives, that the "Infant Doe's" lives are meaningless, hopeless, nondevelopmental.

The alternative to this death seeking is to integrate as you saw with the Rossow children; place the children into the mainstream of family and community life.

In my community of Omaha we have over 1,000 severely profoundly retarded multiply handicapped children and adults integrated into our neighborhoods, into our schools, into our work-training centers and classes; 221 of these people in Omaha can't toilet themselves; yet, they live in neighborhoods; 150 are very medically fragile, yet they live with foster families, adoptive families or in small group homes. They are like Maria, screaming initially, biting, kicking, scratching; yet, they live in our community.

These same people, if they had been the "Infant Doe's," would be dead.

The Maria you just saw would be dead.

I'll finish in about 2 minutes.

Senator DENTON. If you can.

Dr. McGEE. The irony is that community care costs less, what you saw costs less. I think in Connecticut that same care for these 11 children would be $40,000 a year, with no benefit in any institution you could name.

In our Omaha program where we have over 1,000 people, the cost is on average about 40 percent less than institutional care.

We just took a young man like Maria out of the State institution who had been hogtied most of his life; and for that hogtying it was costing us $72,000 a year—to warehouse him.

He lives in a group home now and goes to a workshop at the cost of about $27,000 a year.

But that's almost beside the point. It's the posture that counts, the value of the Marias in the mainstream of community life.

The Marias warehoused make a mockery of our Nation. The "Infant Doe's" make a mockery. Our Nation I think, and I think you've said, Senator, is built on justice and brotherly love; our nation is justice, it is brotherly love. It is much better served through the promotion of life and community integration rather than death and starvation.

I urge your protection of newborn babies, and of the older Marias.

I urge your promotion of the value of all "Infant Doe's" and of all the Marias; and I urge your presence, not just at birth, but across their life spans. They need the presence of our Government; they need our support.

And I ask that the Marias and the children you just saw and the voiceless "Infant Does" not be subjected to early death, but of ongoing life.

Thank you.

Senator DENTON. Thank you, Dr. McGee.

Mrs. Green-McGowan?

Mrs. GREEN-MCGOWAN. Thank you, Senator, for the opportunity to speak to you today.

I would like to spend a few moments addressing some of the technological explosion that we've had in the last few years, and also in part some of the reasons I believe that physicians are currently making some of their not-to-live decisions concerning some of the severely handicapped children such as may have been represented by the Rossows.

I need to turn my slide projector on and ask the lights be lowered.

[Slide.]

This is an ordinary infant, and one of the difficult things about making decisions about newborn infants in my 20 years in the nursing field now, 18 years of working with very severely handicapped individuals—and more and more that is adults who have spent the majority of their lives in institutions, because I consider severely handicapped infants too easy to manage, frankly.

The occurrence of the syndrome called Down's is about 1 in 600 to 700 live births, and, frankly, gentlemen, I have a very difficult time understanding how anyone would question the right of a child like this to live, when, by and large, all these youngsters are making it in regular preschools, are showing increasingly that they can make it in competition with regular children, through kindergarten and the first and second grades; and many parents out there without children would simply go crazy to have a chance to adopt one of these children.

Primarily what these youngsters need is the same thing that other children need, and occasionally we have youngsters born with esophogeal atresia and other children with congenital heart defects; and yet I continue to see children who have treatment withdrawn simply on the basis of the fact that they have different facial features, and their hands have an extra crease, and they may have some other minor problems of short stature, but, sure enough, these children are fully capable of when given the appropriate environment of being productive, self-supporting individuals, and in larger and larger numbers in our society.

[Slide.]

This is a very dark picture and—it represents one of the reasons—it's hard to tell with the lights on, but this is a youngster with hydrocephalus whom I found in a pediatric care facility deep in the heart of the South. And this facility was funded by Federal funds.

This child was a failure of the withdrawal of treatment and decided to live anyway. And so he was sent into a facility where the manager of the facility told me that whenever she had the chance she and the physician who consulted there tried to help these children try whenever they could get the opportunity.

The problem that many physicians face I think is in believing that this is the only type of existence for these youngsters, and it is true that it represents too often an option that is chosen when many, many more adaptive models are available.

There are precious few places in the United States where communities are given the financial support that's necessary to provide more adaptive types of care, because Federal funding at this point in time continues to support congregate care models or State institutional setups with these precious few dollars and little left to be given to community care.

So that children like this are sent still in large numbers to congregate care facilities when family management would be far better for them.

[Slide.]

This is a child not unlike many of the children that you saw here today with the Rossows, who was allowed to lay on his back for increasingly long periods of time without any stimulation whatsoever; and as could be well expected, this child was surely in a few years not only more physically handicapped than when he began; but now developmentally deprived as well.

So the thing I want you to take a look at is: who really has the problem?

Very often the child has the problem because at birth they may look different, and a physician who has unfortunately maybe not to his or her wishes been placed at the right hand of God, and expected to behave that way, and doesn't know what to do—and because they are expected to come up with an answer, they tell the family that nothing can happen.

So children like this are simply either sent home and the family is asked to take care of them until they have to put them away; and sure enough, the child becomes what we call an iatrogenic retardation.

Dr. R. B. Kearsley at Tufts University in Boston has described the syndrome that he calls the iatrogenic or physician-made retardation, a syndrome of learned incompetence because the failure of adaptation of these individuals grows worse in the light of low expectation.

The family becomes depressed and has no support, even though there is more and more types of adaptive support for families today.

The community has precious little experience with children like this and if you've never had the opportunity to learn to work with or have the opportunity to interact with a severely handicapped person, I hope you will not let too much more of your life escape you without taking that chance; because it's simply one of the best things that has happened in my life.

In 18 years—I don't do it because I am a do-gooder, I do it because it does so much for me.

So that the consumers' problem in many cases is the severely handicapped individual doesn't have enough behavior—they do have physical obstacles to development; but the problem is that when we deny opportunities, and we send these children on a deviancy career; and the physician says, "I cannot as a responsible professional participate in a decision that will allow a child to lead a life like that."

If I were in a position of having to send children, I suppose, off to congregate care facilities where their only life entails a 3-by-5 feet square mattress on a bed along a concrete wall, I'm not sure I wouldn't make that same decision.

My criticism of the medical community is they take little opportunity to make themselves aware of the technological explosion that we have gotten into in the last 10 years or so with regard to the treatment of these type individuals.

This is a little boy who was born with severe retardation.

[Slide.]

He had seizures almost continuously. He was snuck away to a State institution in Nebraska. Dr. McGee and I sort of are from the same State. And we snatched him back when he was about a month old.

We kept him long enough to get his seizures under control and then released him directly into a family situation, because we fully believe that the only place for children is in a family construct.

It's not only cheaper, it's better and everybody benefits.

And if the natural family is not up to the challenge there are many, many families out there waiting in line.

[Slide.]

This is another child was born in the State of Utah, to very young parents who were told that this child would be dead at the age of 18 months.

The family was sent home with the infant. When we got him, sure enough, at the age of 18 months he had ulcers all over his head; he had no surgery; he had no shunt in place because the medical practitioners were so convinced that he was not going to live.

We have a child who was speaking at the age of 18 months, feeding himself his own bottle, moving all of his limbs; and it's too late to fix the head—which could have easily taken place if the decision had been made early on. This would have been a perfectly normal child.

Even yet, however, this child today, some 5 or 6 years later, lives in the community, lives in a family home, and goes to a public school. He is very handicapped yet, but my specialty I guess is coming in after years and years of neglect and providing youngsters with a kind of adaptive service they need; because it's my firm belief that it is never too late.

[Slide.]

This is a lady named Ruth Synkiewitz, and she sent me these slides. Ruth, for the first 28 years of her life, was living in an institution in the State of Massachusetts, flat on her back, so that the majority of disabilities that you see are a result not of the initial insult at birth, but of 28 years of neglect.

So I want to speak briefly about the family's problem, and I'll come back to Ruth in just a moment.

Families, as Mrs. Rossow said, need special support in the early times. They need models of adaptive resolution. They need someone who's walked the same road to come in and tell them what to do.

The physician often comes in wanting to rescue the family, saying, if I were in your place, gee, I wouldn't want a child like that.

And it's easier to say to the family, well, if I were in your shoes I would probably not choose to do therapy or choose to withhold food, and—what is the family to do under those circumstances?

So it's a personal value crisis followed by a reality crisis because there are precious few professional who are medical professionals in particular who have any information and who impart that in a way that reflects what's really going on today.

I would like to see the services available to individuals expanded from beyond our current congregate care system into more cost-beneficial community and service delivery systems.

You see, the family model is not only better, it costs about a third as much. And so we're spending billions of dollars in the United States to support institutional facilities when families are waiting in line to adopt children they can't have, because they're being sent to institutions in this country.

Physicians in Omaha about 10 years ago, there was a survey, and at that point at least only one-third of the physicians in the city of Omaha were willing to provide services at all to any person with a physical handicap at any point in their life!

The interesting thing that's happened after 10 years of having 1,000 or 1,600 people in their midst in the community is I think if you did another survey I think you'd find physicians in Omaha who've changed their minds; because there's so much there.

The service problem still however is when you place a diagnosis on a child you have a tendency to blame the system. You have a tendency to make the child the killer of the family, the ruiner of the siblings, the person who does everyone harm. And so pretty soon the child, of course, does not wish to disappoint you; and the youngster indeed fails to try and we place that child out; and that child indeed fails to thrive; so the dogma goes on.

And people are making decisions now on the basis of inadequate treatment.

This is the child I showed you earlier.

[Slide.]

And he lives in a foster family in Omaha. He still is very handicapped. This is a preventable, totally preventable handicap. This child should not look like this.

However, in spite of the severe disability which was created for him because of lack of appropriate intervention, he now lives in a home and he attends public schools in the city of Omaha.

[Slide.]

This is the second little boy I showed you, he also lives in a family who have been trained by enlightened medical professionals, such as physio and occupational therapists, to provide that very special type of thing that some of these children do need, but in a home context 24 hours a day--a loving family context.

And many of the things that people need on the basis of technology is not all that difficult to provide. It simply means teaching parents how to prevent deformities, teaching them how to provide handling to children in a way that doesn't make the problem worse; and just carrying on with the ordinary business of living.

I would like to sort of, because we're running out of time——

[Slide.]

This is a young lady who lives in south Georgia. I do work all over the United States and Canada, and our Canadian friends share many of our idealogical dilemmas I think around the treatment of individuals.

This is a 14-year-old young lady with severe physical disabilities, and this is her teacher in publicly funded public school program. She is doing a series of physiotherapy maneuvers which have been incorporated into the regular school day, and she's a regular teacher's aid.

I'm simply training, teaching her how to incorporate those special handling procedures as part of the regular school program without interferring with any of the regular activities.

These youngsters don't need any special type of therapy. We don't cure this by immersing them in hydrotherapy tanks. We take a look at the ordinary routine of day and how we can help manage persons that don't disrupt the ordinary routine, and don't make people look any more different.

[Slide.]

This is my friend Ruth, who spent 28 years on her back. She now lives in Springfield, Mass., in an apartment with her husband. She has an IQ of 150. She's just written a book called "I've Got Feelings," describing her 28 years on her back; and she is an incredible individual who would have a lot to tell you, I suspect, about what it is that really physicially handicapped people feel. She was labeled until she was 28 years old as profoundly retarded.

That basically is the text of my presentation. I'd welcome any questions you may have.

Senator DENTON. Thank you very much.

I would like both of you to react to a Washington Post article on April 3 on the treatment question; they quote the hospital staffers as saying in the context of this subject you've been dealing with, "And what kind of life will they have if we do save them? They'll probably be retarded."

How would you respond to that?

Mrs. GREEN-McGOWAN. That's for me really a pervasive question that I get asked a lot, and I am forced to say that many of the people I've worked with over the last 20 years have been labeled severely or profoundly retarded, are among the most human-reinforcing, incredibly productive persons I know. And I'm given to say, so what if a person is retarded?

That person can still have enormous value.

Dr. McGEE. I agree and I think that's why there's so much backlash to your protecting these newborn infants, many do hold or have the posture that the lives of these children is a meaningless existence.

And it's a posture. It's not technology. It's not law.

It's a way of perceiving others. And there's really not much you can say except to show that the Marias can live in the community:

Senator DENTON. Are either one of you familiar with the case which I think perhaps more than any other draws all this together. I happened to see it when I was down on a business trip in Palm Beach 4 or 5 years ago. It originated in the United States but I think it's about an English person who was abandoned by his parents and was thrown into a garbage can, in a plastic bag.

He was a boy, he had very little of one stump of an arm, and practically—and some fingers sticking from the other arm. He never got bigger than that [indicating] in his entire life. He was placed in an institution where he used to bite himself and others and scream and spit at everybody.

And they gave him I imagine the kind of care they proportionally give considering the load they have there.

And then a man and a woman who had been individually losers their entire lives up until then, the guy was a drunk and she was a man-to-man type woman. They were married and kind of put their lives together. And they decided to adopt this child, I think at about age 13, who at that point was just as antagonistic toward them as he was to the others.

But after they loved that child for some years, they got that child into high school. He became a great musician, composer, writer, and student at Oxford.

Now, I saw that on television and read about it perhaps a year ago again and I can't for the life of me track it down. Are you familiar with that case?

Mrs. GREEN-McGOWAN. I haven't heard of that case.

Dr. McGEE. I saw a newspaper account of it.

What it points up to me, Senator, is, first, not all the children we're talking about are capable of doing that.

Senator DENTON. No.

Dr. McGEE. They're not all cute as all the children we saw here.

Senator DENTON. An extreme case of your Maria?

Dr. McGEE. Yes.

And the potential is there.

I think the most important thing is—and the law can't do it—but it's our posture; and then the only thing that law can do are those like the Rossows who are willing to do it, is to give them the kinds of support they need, so that more and more people can support these children.

Senator DENTON. I agree with you, Doctor, when you say it's sad we have to be testifying about having hearings about this subject. What bugs me about it is that it says right there—all created free and equal—and it doesn't mean equal in that we all have two arms, two legs, two eyes—it means equal in human nature, endowed by their Creator with certain inalienable rights—and the first one they mention is the right to life.

And we are treating that as if it's been repealed. And that's the basic tenet of this Government, as I understand it.

Excuse me.

Mrs. GREEN-McGOWAN. Senator, I attended a conference in Pennsylvania about 7 years ago with many of the physicians who have been—Dr. Duff, for one, and several others—and I had the opportunity to have a chat with the English folks who make those kinds of decisions.

And I talked with Dr. Duff. And I asked him, I said, "Under what conditions would you change your mind and not advise families to allow children to die?"

And he said to me, "If I didn't have to send those children off to institutions." He said, "If I could have the kind of a service system that you describe in your—in my presentation—I would have no problem allowing children to have adaptive help, or to allow families the same."

And I think very often the decision that is seemingly given to the family is in fact not the family's at all. It's made by the physician.

But I have sympathy for them because I feel in many cases they do it because they think they are saving children from a greater life of abuse.

Senator DENTON. I've only been here a little over 2 years. But one thing I think I have noticed and that is that the Federal Government, even in the present administration, sees an entire bureaucratic structure going from a Secretary of something or other down to the person being helped.

Or they see an entirely private enterprise, such as that directed in the President's Task Force on the Private Sector.

I recognize that there are United Ways and that sort of thing which help private enterprises, volunteer enterprises. But I don't think we have conceived of that approach, which I am having difficulty labeling in my own mind, philosophically, but I guess it would be help people, with Government money, who are already helping other people; and do it in a way that is synergistic.

In other words, under this approach the benefit of a dollar of Federal expenditure will do a great deal more than if we pay that entire bureaucracy to perform the same service. Dr. Thomas Sowell, that great black economist out at Stanford says, that if we took one-third of the money that we try and appropriate for the poor, if we took one-third of that and gave it directly to the poor, there would be no poor.

That's what's wrong with that system. That's the real trickle down.

The system I envision is one where we help organizations that have a large voluntary component. It seems to me that when those people are already doing what they want to do, what they can do, and showing they can do it well, that's the place I think we could help.

Now, I don't know how to even label what I'm talking about. Most of you are in the same kind of operation and I've seen so many of you who are.

We had a black priest in here from Chicago who had a theory about adoption—one church, one child. I use him as an example all the time. The first time he preached the sermon to his congregation, he got 17 children adopted.

If each black church would adopt one child we'd have no black children running around the street. And just to disseminate that word and his example with Government money would help get it done.

And I don't know how to articulate that.

Mrs. GREEN-MCGOWAN. Many handicapped children are now having to leave their families because there's no support available through the governmental means or any means they can get their hands on to give families what they truly need.

Sometimes what a family needs is somebody 4 hours a week.

Senator DENTON. Yes, the family is the unit we ought to try to get it done in; there's no question of that.

Mrs. GREEN-MCGOWAN. And many States yank the child out and put them in a $60,000 a year option.

Senator DENTON. Right. All of them buying the most expensive beds on the market and all that; a lot of money goes there.

Mrs. McGowan has a 6:45 plane; did you know that?

Mrs. GREEN-MCGOWAN. Yes, I think I already missed it. [Laughter].

Senator DENTON. Well, good luck. And thank you very much.

We hope you'll answer any questions we submit to you afterwards.

Dr. MCGEE. Certainly.

[Additional questions, responses, and statement submitted for the record follow:]

Questions for Dr. John McGee submitted for the written record by Senator Jeremiah Denton.

1.) Dr. McGee, is it true that it is impossible to predict the severity of the mental impairments at birth? What early intervention techniques have been developed that improve substantially the mentally handicapped infant's I.Q.? Why are these techniques not immediately provided to some infants recognized as mentally impaired?

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Merrill T. Eaton, M.D., Director

August 18, 1983

Senator Jeremiah Denton
United States Senate
Committee on Labor and Human Resources
Washington, D.C. 20510

Dear Senator Denton:

In response to your inquiry about the predicatability of the severity of mental impairments at birth, what early intervention techniques might help children with these needs, and why are these techniques not immediately available, I have written the enclosed paper which reviews the circumstances surrounding the lives of nine children with very severe disabilities. The paper deals with each of your questions in depth.

In summary, I would give the following replies to your questions:

1. The possibility of the predictability of the severity of mental impairments at birth...

   While it is possible to assess physical and sensorial impairments at birth, it is virtually impossible to state the intelligence of a any child at birth. We can predict, based on past expeirences, that particular children will likely function in the retarded range of cognitive performance. For example, it would be fair to say that a child with Down's Syndrome would likely function in the moderate to mild range of mental retardation. But even this does not really say anything about the person's ability to function in the community, to develop relationships, to contribute to community life.

2. Useful early intervention techniques that improve I.Q...

   There is a range of common techniques which improve the infant's ability to function in the mainstream of family and community life. These techniques likely improve cognitive functioning, but more importantly, prevent secondary disabilities and increase the child's ability to participate more fulle in the mainstream of family and community life: physical therapy, adaptive equipment such as positioning chairs, speech therapy, alternate communication systems such as language boards. Perhaps the most important intervention is to teach the parents how to integrate the child into family life and to teach the parents basic techniques such as those listed above.

   An added dimension to this particular question is the issue of extending P.L. 94-142 to cover these types of cost-beenficial services. Many states have done this already.

3. Availabilty of early intervention...

We could say that early intervention often comes too late! The primary reason is that P.L. 94-142 does not cover these services unless State law permits the extension of the federal law to the 0-5 age group. In Nebraska, for example, our State law extends P.L. 94-142 to the date that the child is identified as handicapped. Thus, a child with Down's Syndrome would be immediately referred to the local school district for infant development services. In States where such a law does not exist early intervention is done on a catch as catch can basis.

I hope these summary replies give the guidance which you sought. As you read my in depth paper, you will clearly see the answers to your questions.

Senator Denton, I wish to thank you for your courageous advocacy on behalf on infants with special needs. If I can be of further assistance, please call on me at any time.

Sincerely,

John J. McGee, Ph.D.
Associate Professor of Medical Psychology

Senator Jeremiah Denton submitted the following question to Dr. David McLone to be included in the written record.

1.) Dr. McLone, an article in the Chicago Tribune on October 17, 1982 quoted a parent as saying, "They (the doctors) told us our daughter had a hole in her back, that she would never walk, and that maybe it would be better for her and us if something happened to her." After surgery at your hospital, she was not paralyzed, she was able to walk and she was not retarded. Is this lack of information regarding the newest surgical techniques widespread? Besides trying to improve communication through medical journals, what can be done to spread the word about these recent advances?

Senator Christopher Dodd submitted the following questions to Dr. David McLone to be included in the written record.

1.) You specifically mention the importance of proper prenatal nutrition in preventing spina bifida. What do you anticipate the effects of budget cuts in the WIC program will be?

2.) What other budget cuts in social programs will adversely affect the quality of life of handicapped children?

3.) What role should the federal government be playing in structuring programs to prevent birth defects?

4.) What role should the federal government be playing in providing financial, educational, and other forms of assistance to families with handicapped children?

the
division of
pediatric
neurological
surgery

David G. McLone, M.D., Ph.D.
Chairman, Pediatric Neurosurgery
312 880-4372

Regina Lenz
Coordinator, Pediatric Neurosurgery
312 880-4373

May 2, 1983

Jeremiah Denton
United States Senator
United States Senate
Washington, D.C. 20510

Dear Senator Denton:

In response to your letter of April 15, and your question concerning information dissemination. Medical journals and medical meeting are, in my opinoin, only moderately effective in rapid to current information dissemination. The time from preparation of a manuscript to presentation or publication is often long. Journals tend to be read by a select group, e.g., Journal of Neurosurgery is read by neurosurgeons, and not read by physicians in other specialties and certainly not by the lay public. The American Academy of Pediatrics has recognized the problem and is developing programs to speed up this process. One of the most effective means of reaching large numbers of people of diverse backgrounds is the lay press. Although not well accepted by many medical groups we have found it very effective. Recently there has been a rapid narrowing of the information gap because of public interest in spina bifida.

Concerning Senator Dodd's questions -

In the State of Illinois 0-3 programs have been eliminated, which will obviously slow the habilitation of these children. Special areas like occupational therapy and speech therapy have been drastically cut, again critical to early care of these children. The incidence of spina bifida has been decreasing since the late 1940's. Evidence now is available that substantial numbers of congenital anomalies, spina bifida, and low birth weight babies are caused by poor maternal nutrition. If the number of poorly nourished women becoming pregnant increases, a significant increase in spina bifida should result. This would be compounded by the lack of programs to care for these children. By not habilitating these individuals we allow them to become a financial burden on society in addition to their loss of dignity as independent competitive people (tax payers).

the children's memorial hospital
2300 children's plaza
chicago, illinois 60614

A Member of the McGaw Medical Center
of Northwestern University

The prevention of birth defects can be accomplished in 2 ways: 1) prevent the birth of children with birth anomalies, i.e., terminate the pregnancy; 2) determine the cause and prevention of anomalies or develop techniques and methods to correct the anomaly. The latter requires research and a commitment by society.

The generation of children to take our place is obviously vital to America. The quality of these generations depend on our commitment to them and will be reflected in the quality of our country. Therefore, the birth of a child is very special to the family but also it is an event that we all share. If we accept the future contributions of children destined to be competitive we must also share the risk and therefore the cost of habilitating and caring for the child less able to compete. Maybe it is time for an insurance which demonstrates that we all accept and share the risk. The catastrophe does not occur to an isolated American family but to all of us. It would seem even more obvious that an investment in the handicapped, which removes them from welfare roles and makes tax payers of them, is in our best interests.

I have included some articles that may be of interest. With best regards, I remain,

Sincerely yours,

David G. McLone M.D.

David G. McLone, M.D., Ph.D.
Chairman,
Pediatric Neurosurgery

DGM:rl

Enclosures

Senator Christopher Dodd submitted the following questions to the Rossow Family to be included in the written record.

1.) You referred to several federal programs you feel are essential to assist families with handicapped children, including a.) P. L. 94-142, b.) Section 504 of the Rehabilitation Act, and c.) catastrophic health insurance. What other programs must be strengthened to ensure that handicapped youngsters lead full and productive lives?

2.) What new programs might further assist families like yours?

NATIONAL CATASTROPHIC HEALTH INSURANCE

We would like to discuss some thoughts about health insurance, viz., complete medical coverage for the disabled child. In our state, for example, complete medical coverage is provided for foster children thru Title 19 and Connecticut has extended this concept to cover the medical costs of an adopted handicapped child via the state's subsidized adoption law. But it is still a fact that the family who gives birth to a disabled child is often left with inadequate or no coverage at all for the medical costs for their child. In fact we believe that is a major factor which makes it more attractive for a family to give their child up.

If we are to encourage families to consider keeping their child, promoting life and encouraging the disabled child to live within the family and community, then we must provide a means for them to obtain the medical services they need to sustain their child's life.

At the moment various states have some programs, many none at all. This problem must be addressed at the federal level to bring about a standard of consistency. If we are to be truthful we all know that medical costs are simply astronomical. This is not a fault of the child or the family who must care for the child; nevertheless thechild and family must in reality deal with these costs--- and they need help.

We would suggest that from the moment of birth (or even from the moment that a permanent disability occurs, such as an accident) that some sort of program be available to cover the medical costs. Standard major medical packages can provide limited protection, but for the most part addtional coverage must be avaiable for on-going care.

NATIONAL SUBSIDIZED ADOPTION

This program which we would like to see modeled after the Connecticut subsidized law has been our lifeline. It should be instituted on a national scale to permit the process of adoption of hard-to-place children, handicapped children, etc. to be standardized. Basically the law provides for full medical coverage on an as-needed basis, especially for severely disabled youngsters. In addition, there are provisions for a subsidy to meet the extra costs associated with caring for a handicapped child. We cannot emphasize enough what this means for prospective adoptive parents. Case in point - Our son Eddy was refused commercial medical coverage on my major medical. We simply could not have met his needs had it not been for the medical coverage provided by the subidized adoption law in our state. VERY IMPORTANT PROGRAM!!!!!

COMMENTS REGARDING P. L. 94-142

During our testimony we referred to P.L. 94-142, the Education for All Handicapped Children Act. There are several aspects of these regulations which we deem very important based on our extensive experience over the past years. In general, without such a provision, the resources would not have been available which allowed many of our children to progress successfully through the public school system. Because of the varying and diverse needs of our children, we have explored many avenues of the educational system. For example, several of the youngsters have required a full or part time aide to help with their physical or educational needs or both. Some have been mainstreamed; others have not. But in every case the needs of the child are being met.

We are happy to see that the proposed regulation changes of 94-142 have been withdrawn. Some of those changes would have had disastrous effects on parents and the parent-child-teacher relationship. For example, it had been proposed that all the procedures local agencies follow when notifying parents of meetings and involving them in discussions and curricula development would have been deleted from the regulations. It is our opinion that without direct parent involvement in developing individualized education programs, the overall needs of the child could not possibly have been addressed. With due respect to education professionals (I am currently the secretary of our local Board of Education), the <u>parent</u> is probably the <u>most important resource</u> to help develop a good educational program. Without exception, it has been our experience that administrators, teachers, special education personnel and parents <u>must</u> work together very closely if the program is to succeed.

It might be helpful at this point to briefly delineate a case history of one of our youngsters. Our son Eddy, institutionalized for 4½ years before joining our family, was the first of our youngsters to require special education services. Eddy is a multiple handicapped child, having been born with serious birth defects such as aglossia adactylia (absence of tongue and extremities - fingers, leg, etc.), moebius syndrome (facial paralysis and the absence of two cranial nerves), severe lung problems, and eye and ear irregularities. But despite the physical problems which obviously would be a challenge, it was evident that Eddy had much potential. Eddy began regular kindergarten in the early seventies and participated to the greatest extent possible with the help of a full time aide. Eddy experienced some successes and some failures. It became evident that indeed Eddy could and did learn, but the process in helping him to learn was difficult requiring a full time aide, large print books, and an auditory trainer . Progress came slowly, but it came. Today Eddy is a sophomore at

Ellington High School. He is transported to school on a van with other disabled children. He has various special education classes in English and Biology, but participates with all the students in other classroom subjects such as mathematics and retail merchandizing. This year he requires one hour per day of special education aide time. For his last two years of high school he will be totally independent as a necessary step in preparing him to become an economically productive and contributing member of society, as well as a really wonderful person. Eddy would not be where he is today had it not been for the provisions provided by P. L. 94-142.

There is another important aspect of our experience which should be mentioned. We sensed several years ago that the community in which we live might be more accepting of our children if they knew that they would not have to fund the extra special education costs. We approached our state representative in 1975 and together introduced and passed a law which would provide full (100%) state reimbursement for special education costs for handicapped children in certain situations. The act removed a "roadblock" and was instrumental to the success of our educational objectives.

This particular act related to foster care children only. It is evident now that the same type of legislation must be applied nationally to allow the disabled, adopted or natural born child to be more readily accepted in the community. A case in point - just recently a couple came to us asking what they should do about the situation in their town. They were hurt and in total despair. Apparently, the community (at least some members of it) was lashing out at them when they heard that the couple was about to bring a newly adopted Downs Syndrome child into their town. The town did not want to assume the responsibility for the extra costs involved in special education. We would like to see this type of problem addressed from the viewpoint of 100% reimbursement to the community for educational costs of a disabled child. As one can readily see from this approach the extra costs are then distributed evenly throughout the tax base of the country.

COMMENTS REGARDING SECTION 504 OF THE REHABILITATION ACT

Our family was in Washington in May, 1977, at which time Section 504 was signed into law. We were elated that such a regulation could give the disabled community access to and participation in the most important aspects of life in our country. When the Department of Justice began its redraft of the regulation it was obvious that the disabled community might lose many of the important aspects of the regulation which would in effect undermine the basic civil rights of disabled persons. We, as parents of children with multiple handicaps, were devastated by such news. We, like many others wrote to our representative and senator asking them to help us keep 504 unchanged. We were glad to hear that very recently Vice President George Bush corresponded with Senator Lowell Weicker and advised him that the Department of Justice and the Presidential Task Force on Regulatory Relief have concluded their review and decided not to issue a revised set of coordination guidelines. Obviously this news comes as a great relief to all in the disabled community since Section 504 of the Rehabilitation Act is a cornerstone and foundation of equal rights for the disabled.

SUMMARY

In summary, a few thoughts about where do we go from here. We hope that our testimony has made a difference, that there is an awareness now that possibly wasn't there before, that acceptance may become the norm, that there may be commitment both on the part of individuals and the government, that there may be an appreciation for life and the inherent value of being human despite our frailties and limitations. We would like to think that federal help and programs would not be necessary, but the fact is that they are not only necessary, but vital. As we have previously mentioned such laws and regulations as P.L. 94-142 and section 504 are very important to us and the children who are in our care. We hope the government will be open to other suggestions such as national health insurance for children with disabilities.

It has been an honor for us to be able to come before you to express our thoughts and feelings and to make suggestions. Thank you for taking the time to listen. Your caring and sensitivity have given us great hope.

April 15, 1983

Dr. George Little
American Academy of Pediatrics
1300 Nothr 17th Street
Suite 350
Arlington, Virginia 22209

Dear Dr. Little:

Thank you for taking the time to testify before the Subcommittee on Family and Human Services on April 6.

I believe the hearing contributed substantially to the debate currently surrounding the issue of treating handicapped infants. Your testimony was valuable, and I appreciate your answers to questions asked by members of the Subcommittee.

Because of time constraints, I was unable to ask all the questions I had prepared. I would appreciate it if you could respond within two weeks.

1. Dr. Little, the AAP apparently takes umbrage at inferences that denial of treatment to handicapped infants occurs often in American hospitals. We saw in the videotape prominent neonatologists acknowledging that it takes place. A 1977 survey reported that two-thirds of those pediatricians surveyed would accede to parental requests to withhold treatment for an intestinal blockage in a Down's Syndrome baby. Testimony before a Congressional committee in 1974 suggested that three-fourths of American physicians admit to regular practice of "passive euthanasia," presumably both adult and pediatric. Dr. Koop cited other surveys about the extent of the problem. Finally, a Birmingham News article in 1980 quotes a Birmingham Children's Hospital staff surgeon as acknowledging that treatment is denied to infants with Down's Syndrome. In fact, the doctor is quoted as saying that in one instance a doctor in Los Angeles sent a Down's baby to Children's Hospital because of that hospital's policy and because his hospital in Los Angeles would not allow him to leave the baby untreated. What is the AAP's response to these facts?

Dr. George Little
April [illegible], 1983
Page Two

2. Dr. Little, instead of regulatory and statutory intervention, the AAP has come out in favor of hospitals forming internal review panels to review cases where a decision has been made to withhold treatment. However, hospitals have personnel hierarchies as do all businesses, with those at the top exercising considerably more influence than those at the bottom. At the top of the hospital hierarchies, of course, are the physicians. Given the statistics we have heard about the predilections of some physicians, I am skeptical that these review panels would change current practice enough. What is your response? I agree that panels might be helpful, but are they enough? Would you say there is no need for legal standards on this issue?

3. Dr. Little, hasn't the federal government become involved in this area because of a lack of "self-policing" on the part of the medical community?

I will be happy to send you a copy of the hearing record when it is printed. This process usually takes several weeks.

Again, thank you for your time and assistance.

Sincerely,

JEREMIAH DENTON
United States Senator

JAD:dh

American
Academy of
Pediatrics

Office of Government Liaison
American Academy of Pediatrics
1300 N. 17th Street,
Suite 350
Arlington, Virginia 22209
(703) 525-9560

Elizabeth J. Noyes
Director

May 6, 1983

Honorable Jeremiah A. Denton
United States Senate
516 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Denton:

Your personal interest in the issue of treating handicapped infants is much appreciated. Testifying in front of the committee was my first such experience, and I must say I found your questions to be well structured. Moreover, our discussion at the hearing seemed marked by a reasonable degree of interpersonal communication. Thus I regret being a bit tardy in responding to your letter of April 15, which had to be forwarded to me at my office in New Hampshire. I will do my best to answer your questions completely.

Your first question relates to facts said to be based on numerous sources, including a video tape of neonatologists, a 1977 survey, testimony before a congressional committee in 1974, Dr. Koop's comments and a 1980 Birmingham News article. To go right to the issue, let me clearly state that the American Academy of Pediatrics and I personally have said in many forums that there is in fact need for additional study of current attitudes and practices regarding care of the seriously ill newborn, and especially those infants with constitutional abnormalities who have associated problems which might be life-threatening. The problem is that the objective data base is very poor. Much of the reference material you cite is anecdotal, including the video tape and the newspaper articles. The surveys are outdated being more than 5 years old. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research has pointed out and we agree that the link between attitudinal surveys and actual practice is unclear. Indeed the President's Commission found that decision-making usually follows the precepts outlined by the Commission. Nor has the Department of Health and Human Services produced any direct evidence of inappropriate treatment of severely ill newborns -- a fact noted by Judge Gesell in his recent decision involving litigation on the interim final rule. Several retrospective compliance reviews conducted by the Department since May 1982 have apparently found all of the facilities to be in compliance with Section 504 of the Rehabilitation Act. We are not saying this matter does not need further study; it does. The present data base is inadequate and study needs to be thorough and sophisticated.

Thus, as a final comment to your first question, let me say that a cooperative multi-disciplinary study actually to delineate attitudes and practices of the mid-1980s is a venture which should be undertaken.

Your second question has several parts; I will attempt to address them straightforwardly. With respect to hospital hierarchies and whether physicians are at the top of those hierarchies, I simply have to state that in the administrative and legal sense they are not. Most hospitals function with public boards of trust, and there is a difference of opinion as to whether physicians even should be on those boards of trust. Physician privileges emanate from the trustees. One of the healthy changes that is occurring in the American health care delivery system is the increasing awareness of responsibility by trustees and by professional hospital administrators of matters of professional conduct. I realize that physicians are frequently perceived as independent self-anointed rulers of the roost. That type of behavior is very unusual, and always has been difficult to establish and maintain in the hospital environment, and has been and will be more and more difficult to maintain for many reasons not the least of which are those mentioned above and the increasing medical-legal activity. Furthermore, as I believe I stated in my testimony, complex newborn problems are not in this day and age usually handled on a simple one-to-one fashion by a single physician and a parent or parents. Nurses, social workers, members of the clergy and many others are involved with a team concept of management. Thus many parties are involved and the relationship is not one on one.

You state that the panels would be helpful and ask whether they are enough. I feel that in the vast majority of cases the review panels would find little with which to quibble, and that if they were properly constituted utilizing professionals and non-professionals, including members of the community, they would rarely if ever have to resort to alternatives such as the judicial system. Some form of double check regarding panel decisions would be appropriate but a great deal of thought needs to be given to this subject. In response to your question about legal standards, I suspect that you and I agree that there is practically always a need for legal standards on most issues, including this one. Unfortunately, legal standards are not able to anticipate each and every complex human bioethical problem. Furthermore, certain legal standards may in fact be wrong. Some governments legally condone racial prejudice.

Your third question relates to whether federal government involvement is due to a lack of "self policing" on the part of the medical community? I would state that the medical community has been self-policing. As a matter of fact the surveys which you quote appeared in previously referenced medical journals, including one published by the American Academy of Pediatrics. This indicates to me that the profession has been, is and will be acting responsibly in its attempts openly to direct attention to and address difficult issues.

In the past, problem solving in difficult areas usually has emanated from cooperative private- and public-sector efforts. We have drawn to your attention the institutional review process for biomedical research. Cooperative efforts between the AAP, other professional organizations and the federal government have been and will be very productive. There is no reason why such mutual problem solving cannot be employed now for the care of seriously ill newborns in spite of the difficulties which have arisen because of the interim final ruling of March 7 and the subsequent court proceedings.

I look forward to meeting with you again sometime in the future.

Sincerely yours,

George A. Little, M.D.
Chairman, Department of Maternal and Child Health
Darmouth Medical School
Hanover, New Hampshire
Chairman, Committee on Fetus and Newborn
American Academy of Pediatrics

GAL:km

April 15, 1983

John J. Paris, S. J.
Department of Religious Studies
Holy Cross College
Worchester, Massachusetts 01610

Dear Father Paris:

Thank you for taking the time to testify before the Subcommittee on Family and Human Services on April 6.

I believe the hearing contributed substantially to the debate currently surrounding the issue of treating handicapped infants. Your testimony was valuable, and I appreciate your answers to questions asked by members of the Subcommittee.

Because of time constraints, I was unable to ask all the questions I had prepared. I would appreciate it if you could respond within two weeks.

1. You say on page 5 of your statement that "the principle of subsidiarity would argue that these decisions ought to be made at the local level with guidelines and norms established by the society." Isn't that exactly the situation we have right now? Yet we still have multiple examples across the country of Down's Syndrome babies being allowed to starve based on a "norm" established at the local level.
2. You imply several times (page 9) in your statement that it is "the values of society" or "community standards" that should be the determining factor in a decision to treat or not to treat. Just how should we define those values? Are there not some absolutes that we/should apply here? After all, in Nazi Germany the physicians involved in the extermination of handicapped individuals could have asserted that they were abiding by "the values of their society."

John J. Paris, S.
[illegible] 15, 1983
Page Two

I will be happy to send you a copy of the hearing record when it is printed. This process usually takes several weeks.

Again, thank you for your time and assistance.

Sincerely,

JEREMIAH DENTON
United States Senator

JAD:dh

Enclosure

P. S. Thank you for sending my staff information on your expenses. Could you also fill out the enclosed white form and sign the blue one so that we might begin processing your reimbursement request? I apologize for the delay in getting these forms to you.

COPY

COLLEGE OF THE HOLY CROSS
WORCESTER, MASSACHUSETTS 01610

DEPARTMENT OF RELIGIOUS STUDIES

May 2, 1983

The Honorable Jeremiah Denton
United States Senate
Committee on Labor and Human Resources
Washington, DC 20510

Dear Senator Denton:

In response to your letter of April 15, 1983 on my testimony before the Subcommittee on Family and Human Services on April 6, 1983, I would make the following observations.

(1) I argued that the decision should be made at the local level with guidelines and norms established by the society. That is not exactly the situation which we have had up until now. And there is no doubt that there have been some instances of Down Syndrome children allowed to die by non-feeding or starvation. The guideline I proposed would not be a local but a national norm. Such a standard has been established in the President's Commission Report on "Deciding to Forego Life-Sustaining Treatment." On pages 218 and 219 of that Report we read: "A very restrictive standard is appropriate: such permanent handicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant." The Commission goes on to say, "Though, inevitably, somewhat subjective and imprecise national application, the concept of 'benefit' excludes honoring idiosyncratic views that might be allowed if a person were deciding about his or her own treatment. Rather, net benefit is absent only if the burdens imposed on the patient by the disability or its treatment would lead a competent decision maker to choose to forego the treatment. As in all surrogate decision making, the surrogate is obliged to try to evaluate benefits and burdens from the infant's own perspective." The Commission then goes on to state very explicitly: "The Commission believes that the handicaps of Down Syndrome, for example, are not in themselves of this magnitude and do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract."

The Commission goes even further when it states, "This is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings and society." And the Commission concludes, "We treat handicapped children no less vigorously than their healthy peers or than older children with similar handicaps would be treated."

Here, I believe, for the first time we have clearly articulated and forcefully stated norms on the appropriate treatment of handicapped children. Now that they have been promulgated, I believe that the enforcement mechanisms already in place in the local community are the more appropriate way of dealing with this issue.

Senator Jeremiah Denton
Page 2
May 2, 1983

Your second question follows from the first. These "values of society" or "community standards" must, in fact, be defined from within our society. When coming to the determination of those values, we will reflect upon our religious, philosophical, and historical tradition. From this reflection--which in our society will involve some absolutes on the sanctity of life--we can and we have devised norms and guidelines for appropriate moral behavior.

There is always the tendency to believe that we can completely eliminate abuses or evil or sin from our society if only we had rigid laws and absolute norms. History to date gives us very little confidence in the success of such an undertaking. It is also helpful to recall that the Nazi experience was brought to us by directives from the "federal government."

I am certain you have seen the editorial response to Judge Gesell's ruling in the Boston Globe, the New York Times and the Wall Street Journal. My own views are most aptly summed up by the Wall Street Journal: "Conservatives ought to be the first to recognize that some problems, in particular moral ones, really can best be solved not by trying to reduce them to rigid rules, but by private decisions of private individuals in the nation's communities and families. Conservatives ought also to understand that the fear that somewhere in this broad land someone may some time make a mistake is not a reason to have platoons of bureaucrats and lawyers second-guessing some of the most sensitive and most private decisions imaginable."

The nation is indeed indebted to those who have called attention to the abuses and serious abuses which have occurred in treatment decisions for handicapped infants. It was the clarion call of such groups which brought about the national study of the President's Commission. It also produced the HHS regulation. That regulation, though, as I testified, has already produced serious adverse consequences for the practice of good medicine. The enclosed clipping on the Oregon case is proof positive of the detrimental effect of attempting to regulate neonatal care by federal directives.

I believe it is now the task of those genuinely committed to the conservative traditions of our society to realize that, given the option of federal intrusion into the nursery or very strict guidelines drawn up and enforced by local communities, the latter option is the preferred route to take.

If I can be of any further assistance to you or your committee in this difficult and trying area of law, medicine and ethics, I shall be happy to assist.

Sincerely,

(Rev.) John J. Paris, S.J.
Chairman

[illegible] THE WASHINGTON POST

Brain-Damaged Baby Dies Amid Court Fight Over Treatment

By Philip J. Hilts
Washington Post Staff Writer

A 10-day-old Oregon infant with severe brain damage died Thursday in the midst of a court fight over her parents' right to refuse to allow the baby to be fed intravenously.

The case was the first public test of the issues involved in the federal government's "Baby Doe" rule, which went into effect two months ago. The rule was intended to protect handicapped infants from being starved or negligently treated because of their deformity.

The rule has since been struck down by a federal court, but the Department of Health and Human Services is appealing the decision.

All sides in the case, including the Oregon Right to Life group which took the parents to court, agreed that the infant would die soon regardless of what treatment was given. Doctors familiar with the case said she had no sucking or swallowing reflex and could not eat without special intravenous or force-feeding. The infant's brain was only partly intact. She was apparently unable to see or hear.

Rita Radich of the Oregon Right to Life group said yesterday that though she knew the baby could not live, "We wanted to show that the child should not be starved to death. We heard there was a doctor's recommendation to the parents not to feed the child because the child would die sooner. We felt it was no more appropriate to starve the child than to inject it with something that would kill her outright, which everyone agrees is not proper."

Radich said, "We were successful in our major objective here" in that the court ordered the infant fed intravenously and kept on life-sustaining equipment until the case could be decided on the merits.

"This child could not live very long anyway," Radich said, but she hoped to establish the principle about feeding, "because this same recommendation is given even in cases where much less handicapped children are involved."

William Bernstein, president of the Coos County Medical Society and one of the doctors called to consult on the case, said, "The decision about what to do with this kind of case is very personal and very difficult . . . and the doctors and families resent the outside influence from the government or others."

Karen Green, a state assistant attorney general for the Children's Services Department, said the reaction to the interventinn of Oregon Right to Life was "outrage . . . that a family which had the trauma of having a deformed child in the first place should then be dragged into court and have it suggested that they are not being proper parents . . . . The people I have spoken to are unhappy," she said.

The infant was born about dawn on April 11 in Coquille Hospital in Coos County, Ore. The girl's skull had not grown together properly, and a membrane sac containing fluids and some primitive brain parts hung from the back of her head.

Her massive brain damage curtailed a number of the infant's bodily functions. She died Thursday afternoon when her breathing stopped because her damaged brain could not maintain it.

But a week before she died, Radich received a telephone tip that an infant at Coquille was not being fed because of her deformity. Radich said she called the Children's Service Division of the state health department and the Health and Human Services Department Washington hotline established to deal with cases of alleged discrimination against handicapped infants.

According to a hospital spokesman, there was never an attempt to starve the baby. Bernstein, who was consulted on the case but did not examine the infant, said there were attempts to feed the infant by mouth but the she could not eat.

Judge Richard Barron of the circuit court in Coquille heard the case, and based on the testimony of the attending doctor, Peter Wolfe, determined that there was not enough evidence to establish any negligence in the case. But he ordered intravenous feeding to be attempted while the case was appealed.

State Court of Appeals Judge William Richardson then also ordered the feeding continued while the case was argued.

Meanwhile, the infant was taken from the 30-bed Coquille hospital to the Doernbecher hospital of the Oregon Health Science University in Portland, 229 miles away.

David Lillig, North Bend public defender and attorney for the parents, said the right to life group had no right to represent the infant in court, and that the infant's parents were upset by this.

He said the decision to withhold intravenous feeding and other treatments was taken after getting "the best medical advice in the state."

The federal government flew investigators to Oregon to question witnesses, and will carry on the investigation even though the infant has died.

DEPARTMENT OF HEALTH & HUMAN SERVICES
Office of the Secretary
Washington, D.C. 20201

MAY 6 1983

The Honorable Jeremiah Denton, Chairman
Subcommittee on Family and Human Services,
Committee on Labor and Human Resources
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

I am pleased to transmit for the record the responses of the Surgeon General to questions by Senator Dodd about resources available to handicapped infants and their families through the government and the private sector. As you known, these questions were submitted in conjunction with the Surgeon General's appearance on April 6 before your Subcommittee to discuss Federal Policy on the treatment of handicapped infants in America.

A copy of these responses will also be sent to Senator Dodd.

Sincerely yours,

Thomas R. Donnelly, Jr.
Assistant Secretary
for Legislation

Senator Dodd

Q. What role do you see the Federal government playing in both (1) providing assistance and (2) encouraging private aid?

A. The Federal government, together with state and local governments, has an important responsibility to handicapped persons in society. Through several assistance programs, it offers services which in some cases may not be readily available through private channels and which in others augments the efforts being made by the private sector.

Through the Department of Health and Human Services, help is given to the handicapped under the Social Services Block Grant, the Developmental Disabilities program, the University-Affiliated Facilities research and rehabilitation network, for certain handicapped persons under Medicare, and for the medically needy under Medicaid. Our Maternal and Child Health Block Grant enables states to target aid to families at risk. Food and nutrition assistance is provided through the Department of Agriculture's Women, Infants and Children (WIC) commodities program, and the Department of Education administers programs which benefit the handicapped through education and training for self-sufficiency.

As you know, a few weeks ago the President announced the formation of a Cabinet-level task force charged with examining the gamut of problems faced by the handicapped in this country, and the services available to them. This body is headed by Secretary Heckler. Among its duties will be to report on the programs serving the handicapped which are funded by the Federal government and specifically, to deal with the special problems of parents and families of handicapped infants.

In addition, Secretary Heckler has reauthorized the Federal intradepartmental board which was empowered to waive rules for Medicaid patients so that they could be cared for at home without loss of Medicaid eligibility. This board had been established in the wake of the situation faced by Katie Beckett of Cedar Rapids, Iowa, who could be cared for more appropriately and less expensively at home, but who would have lost Medicaid eligibility as a result. The Secretary has asked each State Governor to appoint a representative to work with the Department in developing alternatives to institutionalization under Medicaid. This effort has been and will continue to be of great importance to the severely handicapped, giving them options on a case-by-case basis to institutionalization when appropriate without jeopardizing Medicaid coverage if they need it.

The government as a provider of services or a conduit for the transfer of money will not solve the problems of families with handicapped infants. It can act as a catalyst for greater commitment by the private sector, including voluntary service agencies, foundations, and private industry. Its role can include acting to increase public awareness of the physically less fortunate, and to spearhead a "team effort" by government and the private sector.

One important step in that direction, which goes to the heart of both parts of your question, can be found in the 1982 Surgeon General's Workshop on Children With Handicaps and Their Families. This unique undertaking brought together experts from government, the medical community, education, and the handicapped population to consider what is already being done as well as what needs to be done. I am providing you with a copy of the Workshop report so that you may review its proceedings and conclusions.

The Administration's policy regarding handicapped infants underscores an important point. One hallmark of a compassionate, civilized society is the degree to which it defends the interests of its weakest members. In this respect, we have heightened society's awareness of the vulnerability of handicapped infants and the need to safeguard their rights as citizens. At the same time, it has stimulated discussion and action in government and the private sector toward the goal of assuring that handicapped citizens will not be discriminated against on the basis of handicap and that their special needs will be addressed.

Senator Dodd

Q. What assistance is now available for families of handicapped infants from the private sector?

A. There are, and have been for some time, a variety of voluntary service agencies and private foundations which serve the handicapped with rehabilitation, educational opportunities, and assistance for medical care and treatment. These include such familiar organizations as the Easter Seal Society, the March of Dimes, Spina Bifida Association of America, the Down's Syndrome Congress, the National Association for Retarded Citizens, the United Cerebral Palsy Association of America, and others.

It must be pointed out that while these agencies and foundations fulfill an important role and are indispensible to the handicapped population, their services are not always uniformly available in all parts of the country. The American people have consistently demonstrated their compassion, generosity and support through their voluntary financial backing of groups dedicated to helping the handicapped. As my testimony points out, with wider awareness of the problems facing the handicapped and their families, I believe the private sector's response can be enhanced in helping to deal with those problems.

The private sector continues to build on its long-standing record of generous support for the handicapped. For example, the Allstate Insurance Company, through its "Helping Hand" project, serves as a clearinghouse to the handicapped for community agency services. Its volunteers work with deaf children and at residential care facilities for the mentally handicapped. American Telephone & Telegraph (AT&T) maintains the "Telephone Pioneers" program, which provides communications equipment, training and services to the deaf, the blind, those with ambulatory disabilities, and other handicapped persons. It publishes "Helping the Handicapped," a resource guide to communications assistance available to the handicapped.

Other projects include:

- The Corporate Angels network, based in Greenwich, CT, which utilizes private corporate aircraft to transport the seriously ill at no charge to receive needed medical care.
- Civic organizations such as the Benevolent and Protective Order of Elks, which alone, between January and October 1982, had contributed $22 million to various projects benefitting the handicapped plus a comparable amount in donated time and labor.
- The Woodward & Lothrop Company of Washington, D.C., which is a leader in employment of the handicapped and spearheads efforts in the National Capital Region to encourage other businesses to hire the handicapped.
- The Miller Brewing Company, which helps sponsor recreational opportunities for the handicapped. It supports the Southeastern Lite Professional Invitational Tennis Tournament, whose proceeds are used to employ and rehabilitate the handicapped.

Of course, there is a wide array of other projects and programs underwritten by private industry, often in partnership with state and local governments and voluntary service agencies. These examples merely serve to indicate that a significant amount of help is available through the private sector.

In December 1982, the Department sponsored the Surgeon General's Workshop on Children With Handicaps and Their Families. The results of that workshop include reviews of the kinds of private-sector initiatives now in place to help the handicapped, highlights some of the difficulties which need to be overcome in rendering better service to the handicapped, and offers specific recommendations for improvements. We look forward to a cooperative partnership between the private sector and government in addressing the issues covered therein.

April 15, 1983

Dr. Paul Ramsey
Department of Religion
Princeton University
613 Seventy-Nine Hall
Princeton, New Jersey 08544

Dear Dr. Ramsey:

Thank you for taking the time to testify before the Subcommittee on Family and Human Services on April 6.

I believe the hearing contributed substantially to the debate currently surrounding the issue of treating handicapped infants. Your testimony was valuable, and I appreciate your answers to questions asked by members of the Subcommittee.

I will be happy to send you a copy of the hearing record when it is printed. This process usually takes several weeks.

Again, thank you for your time and assistance.

Sincerely,

JEREMIAH DENTON
United States Senator

JAD:dh

COPY

AMERICAN LIFE LOBBY INC.

[illegible]

April 5, 1983

Honorable Margaret Heckler
Secretary
Department of Health & Human Services
200 Independence Ave., S. W.
Washington, D C. 20201

Dear Mrs. He[illegible]

Due to an [illegible]ely sloppy and inaccurate intitial investigation we hereby requ[illegible] you re-open the DHHS investigation of the denial of surgery to a handicapped newborn, then at Crawford Memorial Hospital, Robinson, Illinois, that was suffering from Spina Bifida that resulted from our telegram complaint to U. S. DHHS and the U.S. Department of Justice on May 14, 1983.

Although this handicapped newborn was ultimately moved from Crawford Memorial Hospital and received the necessary surgery and is alive and well living with adoptive parents, it is clear from the status report on this case that I received in a letter, dated March 7, 1983, from Nathan Dick, Deputy Director, Office of Program Operations, Office for Civil Rights, that your Department is missing many essential facts and has others such as the date and place of this baby's birth wrong.

I enclose two sworn documents entitled "Answer to Report of the Office of Civil Rights, U. S. Department of Health and Human Services, Investigation of Infanticide at Crawford Memorial Hospital, Robinson, Illinois" and "Date by Date Account of Effort to Save The Robinson Baby" executed by Laura Jean Canning.

Based on these two documents we believe that there is a sufficient amount of information concerning this case to re-open the investigation to determine if the actions of Crawford Memorial Hospital should loose it's eligibility for federal funds under Section 504 of the Rehabilitation Act of 1973.

I specifically call to your attention the statement that the Administrator of Crawford Memorial Hospital replied to the statement someone had to help the baby "Well, its not going to be me." and that information on Spina Bifida surgery was sent to the hospital administrator. Combined with the fact that when transferred from Crawford Memorial Hospital, the baby's wound had developed an infection from lack of surgical closure (previously scheduled and cancelled against medical advice).

A.L.L. ". . . for God, for Life, for the Family, for the Nation"

After reading these two sworn documents it is impossible to sustain the routine finding of your Office for Civil Rights that "There is insufficient evidence for OCR to conclude that there was a violation of Section 504.". The facts as outlined in these two sworn documents indicate that the DHHS investigation was exceedingly sloppy. A re-opening of this case and a thorough and vigorous investigation into <u>all</u> the facts is merited.

Sincerely,

Gary J Curran

Gary J. Curran
Legislative Consultant

STATE OF OKLAHOMA)
) SS:
COUNTY OF OKLAHOMA)

ACKNOWLEGEMENT

BE IT KNOWN BY THESE PRESENTS, that on the 29th day of March, 1983, before me a Notary Public of this State, personally appeared, Laura Jean Canning, to me known to be the identical person described in and who executed the within and foregoing, "Answer to Report of the Office of Civil Rights, U.S. Department of Health and Human Services, Investigation of Infanticide at CRAWFORD MEMORIAL HOSPITAL, Robinson, Illinois" and acknowledged to me that she executed the same as her free and voluntary act and deed for the uses and purposes therein set forth.

In Witness Whereof, I have hereunto set my official signature and affixed my notarial seal the day and year first above written.

Nancy J. Robinett
Notary Public

My Commission Expires: January 13, 1987

An Answer to Report of the Office of Civil Rights, U.S. Department of Health and Human Services' Investigation of Infanticide at CRAWFORD MEMORIAL HOSPITAL, ROBINSON, ILL., (See copy of Report Attached)

A LINE-BY-LINE REPLY BY LAURA CANNING, WHO FILED THE ORIGINAL COMPLAINT

Under "Allegation"

The allegation states that the complaint was received May 14. This may have been the date the written complaint was received. but the actual complaint was transmitted by me, Laura Canning, to Susan Shalhoub of the Office of Civil Rights (OCR) in Washington, between May 7 and May 10. Susan said she would have Tom Janzer of the Regional Office covering Robinson, Ill. call me. (That region is covered by the Chicago Office). Tom said he needed a written report before he could act. I noticed that when I reported the incident in Tulsa, Oklahoma, the Regional Director in Dallas sent out an investigator immediately and did not require a written report. There was time wasted in the Robinson incident that could have been saved had OCR responded as it did in Dallas.

1. The Office for Civil Rights (OCR) reports that the original allegation was that Crawford Memorial Hospital "failed to perform necessary surgery." That was not the charge. Crawford Memorial Hospital could not possibly have performed the surgery. They are ill-equipped to do so. They have no facility for this type of sensitive surgery. Crawford Memorial is a 107-bed hospital which, at the most has "two pediatric patients at a time" in residence, according to a report I had from a minister in Robinson, Illinois who frequents the hospital. So, the actual allegation was that Crawford was ill-equipped to help the child so it should see that the baby was moved.

Under "Investigative Findings"

1. Baby's birthday was April 25, 1982. The baby was not born at St. John's Hospital, but at small town Lawrenceville, Ill. hospital, in Lawrence County, neighbor to Crawford County (where the baby ended up after his trip to St. John's Hospital in Springfield, Illinois), which has an excellent perinatal department. Lawrenceville is about a 10 or 20 minute car ride from Robinson, Ill. The hospital, I believe, is on a par with Crawford Memorial in Robinson, as far as number of beds and medical capabilities. Apparently, the Lawrenceville hospital saw its duty clearly, since they had the baby transferred to an excellent hospital, St. John's in Springfield, immediately after birth when his condition was recognized.

Under "Investigative Findings", Continued

3. The OCR states that there was "no evidence to support that the recommendation for surgery, during the infant's hospitalization at Crawford Memorial Hospital required emergency procedures". The fact: then why was the baby transferred from St. John's where he was scheduled for surgery to a hospital ill-equipped to do so. Also, I sent the administrator an article on Dr. David McLone, of Children's Memorial Hospital, head of the National Center for Spina Bifida. The article states clearly that he operates on "every child with myelomeningocele (spina bifida)" right away. Crawford had an obligation to find out about dangers in not immediately closing the baby's back. I, as a lay person learned that time is important. The spinal fluid could leak, the longer treatment is postponed, causing meningitis, infection of the brain, hydrocephalus, infection of the back (making closing more difficult) and possibly mental retardation. It would seem a simple duty of a hospital to make it their business to do some investigating about this illness. Surely, I gave administrator, Carlton King, enough information to make him act when I phoned him.

   Dr. McLone told me that if non-treated surgically,"60% of these kids die; the other 40% live anyway and are a real mess as a result."

4. It was not the "parents", as the OCR report states, but the baby's father who made the decision to move the baby from St. John's against medical advice. As I later learned, the mother was quite emotional and did not want the baby moved. Divisions in the family were occurring.

6. The OCR states that the parents were "counselled regarding the pros and cons of surgery to enable them to make an informed decision," and that there was some indication that the risk of surgery was greater during the earlier hospitalization at St. John's".

   My response: Even if the baby needed to wait a few days before surgery to gain strength, why was he moved, and why, when it was clear that he had gained strength, did it take more than 3 weeks for IDCFS to act in getting him the necessary surgery. As McLone states in the enclosed *Chicago Tribune* article (May 2, 1982)

   > "Spina bifida is a disease of the spinal cord which causes paralysis, urinary and bowel problems, and often hydrocephalus, an accumulation of fluid in the cerebral ventricles that causes enlargement of the skull and compression of the brain. If there is mental retardation, it is a result of infection of the brain" (if the fluid leaks because back not closed). "But if the hydrocephalus is treated early, you would predict normal intelligence or the intelligence of the family that the baby was born into".

Under "Investigative Findings", Continued

7. The OCP report states that "medical records and medical authorities agree that the baby's condition improved during the stay at Crawford Memorial Hospital" but that the recommendation for "non-emergent" surgery remained in effect.

   My answer: Then why was the baby's back infected when Dr. McLone received him at Children's Memorial Hospital in Chicago. It took 10 days to constantly wash the back when the baby arrived at Children's before surgery could be done. Also, the baby did later develop hydrocephalus, and Dr. McLone had to put a shunt in to drain the spinal fluid through his stomach. Although the cause for the hydrocephalus would be hard to prove, one question does come to my mind and that is, whether the delay in surgery caused the complication of hydrocephalus.

   The OCR states that the treatment was within the bounds of "reasonable medical judgment" and does not reflect the withholding of life-sustaining treatment based on handicap.

   My answer: When I called Crawford Memorial Hospital on May 6, and spoke with Administrator, Carlton King, I told him that someone had to help the baby; he replied, "Well, it's not going to be me."

   After federal intervention, Dr. David McLone was called into the case. He flew to Robinson, Ill. and saw the baby, and spoke with the parents. He phoned me and said, "Laura, this is not for the press, but they (the parents) wanted him dead. They did not want to raise a handicapped baby."

   My reply: If 60% of these children die as a result of non-treatment, then how is this not a clear violation of the handicapped child's right to 504's guarantee of life-sustaining treatment. You can feed and diaper and hold a baby, but if he needs surgery, and you deny it you are killing him. Ostensibly, everything looked like it was in order -- nursing care and a clean baby, gaining weight - but the hospital and IDCFS did not take custody nor enter a petition for neglect with the state's attorney's office for surgery. The baby was not given proper care, "medically necessary care", <u>until</u> the parents relinquished custody. The parents were politically powerful and I later learned had contracts with the State of Illinois for asphalting the state highways. Not in the way of rumor-mongering, but in hopes of giving a rational explanation for state delay, I offer this fact, besides the fact that there was a real lack of knowledge about spina bifida on the state and hospital's part, a culpable ignorance I might add, since information is so readily available and since DCFS had dealt with other spina bifida cases and should have had information they needed. One advocacy group receiving state funds, IDDAA (Illinois Developmental Disability Advocacy Authority) I later learned battled for a spina bifida child's care. The family was ordered to get him the care he needed, were so

Under "Investigative Findings", Continued

8., Continued

angry about it that they wrote to every state legislator. IODAA was dissolved and lost all its funds.

The Handicapped Advocacy Commission for the state, now Guardianship and Advocacy Commission, which receives federal and state funds, had been fighting for the Robinson baby. That is, until the Governor's office ordered them out of it. This could have been plain old executive fiat that proved to be politically advantageous since he wanted to protect IDCFS from any neglect that might be uncovered.

I have since learned from the State of Illinois Office of the Budget that the Guardianship Advocacy Commission will be dissolved as of July 1983.

9. Under 9, of the OCR investigation, I also question the "promptness" of the State's action. My information shows that IDCFS was alerted by St. John's hospital. It was not until May 7, according to my information at my prompting that an investigator from ICDFS went to Crawford Memorial Hospital.

"Reasonable medical judgment" is not the point. Rather, the facts are what are important: The infant needed surgery, was shipped to a place ill-equipped to do it, the hospital co-operated with the parents, as if the child was their property, contrary to provisions under 504, and contrary to medical evidence. Neither the hospital nor the state entered a petition for neglect with the State's Attorney's Office despite the fact that time was important in his treatment.

10. "Crawford County State's Attorney discussed the situation with the ICDFS investigator" and, says the OCR report, determined not to take further action against the parents or hospital "until the situation changed".

My response: I learned that a private party could enter a petition for neglect. I drove to Crawford to do that. Crawford County State's Attorney, Jon Anderson was not at the office. Judge Hanby Jones contacted him about my filing a petition by proxy. He said no, since his information was from ICDFS and they found "no cause of neglect."

I found out that Lawrence County State's Attorney (William Strange) also had jurisdiction to take in a petition since the baby was born in Lawrenceville. Despite my acquainting him with Dr. McLone's work and with what Dr. C. Everett Koop, Surgeon General, had found in treating

Under "Investigative Findings", Continued

10. Continued

these spina bifida children, he refused. He stated: "Well, Dr. Bob says the fluid is already leaking." This is a very telling statement.

"Dr. Bob" is Dr. Robert Salesman, who was the baby's doctor while he was at Crawford Memorial. If Salesman thought that, it was all the clearer that the baby should have been moved immediately. Crawford Memorial Hospital, recipient of federal funds, did not do that. William Strange used words like "vegetable" regarding the baby and it was clear that he was in touch with Dr. Salesman.

They did not want the family to have to keep that "vegetable" and that was evident.

When the State of Illinois publicly exonerated itself in a press release, both Dr. Salesman and William Strange wanted me to retract all statements. Dr. Salesman wanted a public apology.

William Strange wanted me to "put in writing" that "you are formally dropping your petition for neglect."

Strange, is right, especially since he would not take the petition in -- there was no petition to drop, and stranger still since the baby still was not in the safe hands of Dr. David McLone.

I refused to comply.

DEPARTMENT OF HEALTH & HUMAN SERVICES
Office of the Secretary
Washington D.C. 20201

MAR 7 1983

Mr. Gary L. Curran
Legislative Consultant
American Life Lobby Inc.
6 B Library Court, S.E.
Washington, D.C. 20003

Dear Mr. Curran:

On March 2, 1983, we notified you that our regional offices had been informed of your request for a copy of all complaints of possible infanticide received by our office.

Enclosed is a status report on all investigations of alleged violations of Section 504 of the Rehabilitation Act of 1973, relating to health care for handicapped infants, conducted by the Office for Civil Rights.

Please be assured of our strong commitment to vigorous enforcement of Section 504 as it relates to health care for handicapped infants.

Thank you for contacting us concerning this matter.

Sincerely,

Nathan D. Dick

Nathan D. Dick
Deputy Director
Office of Program Operations
Office for Civil Rights

Enclosure

CRAWFORD MEMORIAL HOSPITAL

Robinson, Illinois

Allegation

On May 14, 1982, the Office for Civil Rights (OCR) received a complaint from an advocacy group official who, responding to an anonymous call, alleged that:

1. Crawford Memorial Hospital (at the parents' request) failed to perform necessary surgery on an infant born with myelomeningocele (spina bifida);
2. The parents did not want the child to live; and
3. The hospital was permitting death to occur.

Investigative Response

On May 15, 1982 (through May 20, 1982), an OCR investigator conducted an onsite investigation. The investigator interviewed all pertinent hospital officials and personnel at the Illinois Department of Children and Family Services (IDCFS) who had conducted an investigation into this case.

Investigative Findings

The investigation revealed that:

1. Baby Doe was born on April 30, 1982, at St. John's Hospital in Springfield, Illinois. The baby was transferred to Crawford Memorial Hospital on May 1, 1982.
2. Baby Doe was initially diagnosed as having mild myelomeningocele (spina bifida).
3. There is no evidence which would support that the recommendation for surgery, during the infant's hospitalization at Crawford Memorial Hospital, required emergency procedures.
4. The parents, independently, made the decision to remove the baby from St. John's Hospital against medical advice, and had the baby transferred to Crawford Memorial Hospital. St. John's Hospital recommended and was prepared to perform surgery on the baby.

5. St. John's Hospital discharged the baby against medical advice. IDCFS' May 11, 1982, "Unusual Incident Report" reflects statements that two St. John's physicians concurred that it was the parents' choice to decline surgery and that they did not feel the parents were medically neglecting the child.

6. Medical records and allied documents clearly state that the parents were counselled regarding the pros and cons of surgery to enable them to make an informed decision. There was some indication that the risk of surgery was greater during the earlier hospitalization at St. John's Hospital.

7. Medical records and medical authorities agree that the baby's condition improved during the stay at Crawford Memorial Hospital though the recommendation for surgery (nonemergent) remained in effect.

8. The treatment provided was within the bounds of reasonable medical judgment and does not reflect a discriminatory withholding of life sustaining treatment on the basis of handicap.

9. IDCFS conducted a prompt investigation of this infant's situation and determined there were no grounds for filing a petition of neglect and abuse with the Crawford County State's Attorney. On this basis, IDCFS did not take custody of the baby until the parents voluntarily relinquished their parental rights to IDCFS.

10. The Crawford County State's Attorney discussed the situation with the IDCFS investigator and determined that he had no basis for taking any further action against the parents or the Crawford Memorial Hospital unless the situation changed.

Conclusion

Based on the investigative findings, there is insufficient evidence for OCR to conclude that there was a violation of Section 504.

STATE OF OKLAHOMA)
) ss:
COUNTY OF OKLAHOMA)

ACKNOWLEGEMENT

BE IT KNOWN BY THESE PRESENTS, that on the 29th day of March, 1983, before me a Notary Public of this State, personally appeared, Laura Jean Canning, to me known to be the identical person described in and who executed the within and foregoing, "Date by Date Account of Effort to Save the Robinson Baby", and acknowledged to me that she executed the same as her free and voluntary act and deed for the uses and purposes therein set forth.

In Witness Whereof, I have hereunto set my official signature and affixed my notarial seal the day and year first above written.

Nancy L. Kolinett
Notary Public

My Commission Expires: January 13, 1987

DATE BY DATE ACCOUNT OF THE EFFORT TO SAVE THE "ROBINSON BABY"

April 25 - Baby born in Lawrenceville, Illinois.

May 3 - While in Springfield, I learn about baby from pro-lifer, Pat Rudolph from Decatur. I ask her to find out what she can.

May 5 - Pat Rudolph tells me story:

Anonymous call from nurse at St. John's Hospital in Springfield, Ill. reports there is a baby with milomydomeningocele (spina bifida) who was scheduled for surgery to have his back closed. Father calls off surgery, has baby moved to Crawford Memorial Hospital in Crawford County (101 beds, no pediatric facility or provision for this type of surgery). Nurse describes family as "politically powerful."

May 5 - I call Dr. Greg White of River Forest, Illinois. He says baby needs immediate medical treatment - tells me about dangers if surgery not given - infection of the brain, paralysis, hydrocephalus - baby is already 10 days old - he says meningitis is "almost inevitable "

May 6 - I call Crawford Memorial Hospital Administrator, Carlton King. He says he cannot "affirm or deny" whether baby is there. He keeps saying he cannot "violate the confidentiality" of the parents. I say, "Well, someone has to defend this baby." His reply: "Well, it's not going to be me." I later sent him an article on Dr. David McLone (May 2, 1982) Chgo. Tribune, a surgeon working to save spina bifida children. Article discusses miracles done with spina bifida children.

I call DCFS in Olney (area for Crawford County). A Mrs. King says when I report the baby, "We know all about it." When pressed further she tells me to call a child abuse hotline in Carbondale, Illinois.

I call. They act like they know nothing about the case.

I call Dennis Horan. He says contact Tom Marzen at Americans United for Life Legal Defense Fund and ask him to check into the Rehabilitation Act of 1973, Section 504. He says to call spina bifida association, Mr. Kent Smith, Chicago.

Tom Marzen says they tried to save Bloomington baby with 504, but court system moves so slowly baby was dead! Tom and I agree to make it public - to hold more harm from being done until we can help baby. He says contact downstate papers and press.

I call Terra Haute Star, Decatur Daily Review, Springfield State Journal Register, Ch. 2 Terra Haute

May 6. Continued

I call Hyde's office, Helms' office, Mr. Schweiker's office, Alan Dixon's office.

Ann Belanger and I call state politicians in the Robinson, Illinois area.

I alert spina bifida, Mr. Kent Smith.

May 7 - Hilna Hawkins at 800 number child abuse hotline number and I talk. I report possible abuse/neglect of Robinson baby. She said she would fill out report and send out investigator same day. Says she hadn't heard about it before.

Ann Belanger contacts Crawford State Attorney's office (Jon Anderson) Marcia [illegible]ters is the secretary.

A reporter from Terra Haute Star, Randy Schaeffer calls. Tells me a pro-life group (Ill. Fed. for Right to Life) told him baby will be taken care of, just in a "weakened condition". They're getting him ready for surgery - I don't believe him.

May 8 Trip to Robinson, Ill. Crawford Memorial Hospital [illegible] walk through the halls - can't find where baby would [illegible] not in the Maternity Unit.

I see 2 Special Care Units - Baby possibly in one of them.

Pr[illegible]rs are acting scared. Per phone conversation with [illegible] who [illegible] the hospital. "How would you like to be a "vegetable?" [illegible] lifer [illegible]et will take in a petition for neglect to the State's [illegible]s office. Lawyers had advised me it had to be local people. Everyone [illegible] saying it would be "extraordinary means" to treat this baby - I still don't know with certitude the baby's condition.

May 9 - Mothers' Day - I see an article in CHGO TRIBUNE on Dr. David McLone (Children's Memorial Hospital in Chicago), and miracles he has done with spina bifida children. I learn they are operated on a day or two after birth'. Time is ticking by.

May 10 - I call Dr. McLone. He says, "I need to see the child, and I will if they call me. I cannot call them" He says he operates on every child with myelomeningocele. Usually the child needs surgery and does well if he receives surgery. He said he would have to "move fast" when I tell him how old the baby is because "the back is probably already infected" and "we'd have to clean up the back before we could do the surgery."

I begin getting Dr. McLone's name out to everyone concerned with baby. I cannot get in touch with baby's parents. I still don't know their names.

May 10 ? - Susan Shalhoub from Mr. Schweiker's office calls back. She tells me that per my phone call to her she is having Tom Janzer of the Regional Office of Health and Human Services in Chicago call me for a report of my complaint on a violation of the baby's civil rights. Mr. Janzer says he will send me a complaint form which he does. I charge the hospital in Robinson, Ill., (Crawford Memorial Hospital) with neglect.

May 11 - Someone calls with family's name! I learn it doesn't have to be a local person. In order to enter my own petition for neglect, I decide to go to Robinson tomorrow.

Jeff Plesko (via call from SPINA BIFIDA is in the fight now). He is with a state agency called, the Guardianship Advocacy Commission. He is an attorney and he is fighting like this is his own baby's life. His agency is supposed to enforce and protect handicapped laws for the State of Illinois. Jeff tells me he has never defended a baby yet, only adults thus far.

May 13 and May 14 - I go to Robinson, Illinois with Greg Morrow. First of all I want to try to talk with family of baby. If they will listen there is no need for my petition. They can take their baby to Dr. David McLone and have his back fixed. I have parents' names, and grandparents' name and address.

Post Script for May 11: Nurse who saw baby when he was born in Lawrenceville said, "Golly, have you seen that baby. They ought to let him die."

Grandmother opens the door slightly - is not hostile. Greg and I begin to tell her about the baby's need for surgery, about Dr. McLone, about Chicago's being the national center for the treatment of spina bifida. I asked her if she would take an article about a program at Loyola Hospital in Chicago, which was begun to help spina bifida parents. She said no, but that she would take the phone number. I tore that off the bottom of the article. A younger woman then came to the door and said, "We don't have to talk to you; we've said everything we want to say." And that was the end of the communication.

There was no other recourse: A petition for neglect had to be filed. Jon Anderson of Crawford County seemed to be the likely state's attorney since the baby was residing in a hospital in his county. He couldn't be reached, so I called the Judge - Hanby Jones, to ask if he would appoint a proxy state's attorney in Anderson's absence to take in the petition. But then he reached Anderson who said he would not take it since he got his information from DCFS. We also tried Lawrence County, Bill Strange. He would not take in a petition either. He slipped at one point and said, "Well, Dr. Bob said the fluid was already leaking." We had told him about the article from Dr. McLone, what doctors had said, played part of a tape on Infanticide by Dr. Koop. Nothing would convince him. We left for Chicago not knowing what the next move would be. I called Jeff Plesko. He started to talk like the rest of them. "Well you know, we have to think of optimal life".

May 14, P.M. - When I walked in the door, I had message to call the Deputy Assistant Attorney General for the federal government's Justice Department. American Life Lobby had heard about our baby and contacted the Justice Department and HHS.

The gentleman from Justice said that they were preparing a federal lawsuit against Crawford Memorial and against DCFS. Needless to say I was thrilled. They expected to go to federal court in Illinois on Monday.

May 15 - Tim Cooke, attorney from Justice, calls. I learn case can't be brought in yet - all Illinois federal judges are at a meeting.

I tell him I'm going to continue with my own strategy (petition). If the feds move, great. If they don't, we will not have lost any time.

Tom Marzen says any Illinois attorney can take in a petition for neglect. I called five attorneys in Robinson. They all said "no". One said, "You're not going to find a lawyer in this town who will take in a petition for you." I began calling Chicago attorneys. They said they didn't have the time to do it because it would probably involve several trips to Robinson.

P.S. - Throughout the whole battle, the downstate media was calling almost constantly. I do believe that confining the use of the media to the immediate area was effective. If national media had gotten in too soon I believe it would have worked against the baby. They might offer sympathy, thus giving the parents support. Whereas, the confinement to area and local media enabled the question to be a "family" one. The controversy would keep him safe. It did.

May 20 - I got a call from the Justice Department. "Dr. David McLone is the baby's doctor. There's just a little bit of paralysis below the ankles. The fluid hasn't leaked. Dr. McLone called the baby 'one tough baby.'" McLone was going to be flown in on a state plane, but at the last minute the parents didn't like the way that looked, so they had the doctor flown in themselves.

May 21 - I am told, though I never saw it - DCFS sends out a press release quoting McLone saying that the hospital did all it could. Reporters begin to call, asking why I made such a noise about the issue "since the baby's all right."

William Strange, state's attorney for Lawrence County, calls and tells me he wants me to "put in writing" that I am dropping my petition for neglect. Here's a man who wouldn't even consider it - Now, he wants it in writing that I'm dropping it to exonerate himself. My answer is no.

May 21 - Continued

Dr. Charles Salesman, doctor from Robinson, Ill. calls. "I want an apology from you to me, to the hospital, to the staff, etc., etc."
"Why should I apologize. You knew that baby needed surgery. You were unequipped to do it, but you endangered him anyway at the request of the parents."

May 25 - Dr. McLone calls me. "This isn't for the press, Laura, but you don't apologize to anyone. The parents wanted the baby dead. They were receiving advice from medical people in the family. They didn't want to raise a handicapped infant. 60% of these kids die from lack of treatment. The other 40% live anyway and are a mess because they weren't treated."

May 27 - Complete surprise. Natural parents release baby to Ill. DCFS for adoption.

* * * * * * *

Surgery must wait. Back is infected and has to be cleaned before surgery can be done.

* * * * * * *

I call Jeff Plesko, (Guardianship Advocacy Commission). He tells me (now I know why he was reticent when I called him from Robinson, Illinois) that the Governor's Office called him and told him to back off the fight. I earlier learned from Betty Anthony of IDDAA, another advocacy group for the state, that when she once went to bat for a spina bifida baby, the parents became so angry that they wrote to every state legislator about IDDAA. Funds were almost completely cut off for that group.

June 18 - Article CHICAGO TRIBUNE - Baby has been adopted!

I talk to Dr. McLone. Surgery was successful, back almost healed. Baby has normal intelligence. He should be walking in two years. Has no brain damage. Did get hydrocephalus. Has to have a shunt put in his head, but his head is normal size.

Tom Janzer, HHS, Civil Rights Division Regional Office, called me before baby's surgery to ask if I would drop the complaint. "Now that everything is being taken care of." He said he had a lot to do in Madison, Wisconsin, and reports took a long time to work up. I said that I wanted the report. As we currently stand, I am waiting for a copy of the report as it will go to Mr. Schweiker's Office.

3/23/83, P.S. - The only report I have is a letter from Nathan Dick of HHS's Civil Rights Division (dated September 29, 1982) and a "Status Report" on all investigations of complaints on violations of Section 504 directed to Gary Curran of American Life Lobby (March 7, 1983) from Nathan D. Dick, Deputy Director, Office of Program Operations, Office for Civil Rights.

WRITTEN TESTIMONY

SUBMITTED TO THE SUBCOMMITTEE ON
FAMILY AND HUMAN SERVICES
COMMITTEE ON LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ON

REAUTHORIZATION OF THE CHILD ABUSE PREVENTION AND TREATMENT AND ADOPTION REFORM ACT: WITHHOLDING OF CARE FROM HANDICAPPED INFANTS IN HOSPITALS

By: H. Richard Nesson, M.D.
President
Brigham and Women's Hospital
75 Francis Street
Boston, Massachusetts 02115

I am the President of the Brigham and Women's Hospital, which is a 720-bed hospital in the City of Boston. It is affiliated with Harvard Medical School, and participates in the regional perinatal center known as the Joint Program in Neonatology with Children's Hospital Medical Center and the Beth Israel Hospital. Brigham and Women's operates a 40-bed three-level neonatal intensive care unit, the largest in the Commonwealth of Massachusetts.

I am writing to urge that the reauthorization language for the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 not include language that would establish a reporting procedure for any interested person to report to appropriate authorities any known or suspected instance of the denial of nutrition, medically indicated treatment, general care, or appropriate social services to infants at risk with life-threatening congenital impairments. Such language is similar in intent to the recently promulgated interim final rule issued by the Office for Civil Rights of the Department of Health and Human Services.

The interim final rule, and the proposed changes in the Child Abuse Act, give the impression that the current system is resulting in the wrongful death of many children. This is simply not the case. As Michael F. Epstein, M.D., Associate Chairman of our hospital's Department of Newborn Medicine and Director of our Neonatal Intensive Care Unit, wrote me in a letter of March 7 which I have transmitted to Secretary Heckler, "(c)are is provided to newborns in neonatal intensive care units such as the one at Brigham and Women's Hospital by a team of health professionals who work long and hard to preserve life. Surely the phenomenal gains made n reducing neonatal mortality in the last decade support the concept hat life is held primary in such settings. Decisions to withdraw or ithhold support from critically ill infants are rarely necessary and hen made, these decisions nearly always affect the timing of an nevitable death, not its occurence."

This practice is entirely consistent with the recommendations in the recent report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which we support. Further, Dr. C. Everett Koop, Surgeon General, in a recent appearance before the Senate Subcommittee on Family and Human Services, testified that "(s)ome medical problems are not correctible, and some handicapped infants, unfortunately, face imminent death; for such infants, we do not intend to fruitlessly prolong the process of dying."

In contrast to the decision a year ago in Bloomington, Indiana, I am confident there is general agreement that a hospital should not deny nutrition or simple corrective surgery to otherwise healthy infants with Down's syndrome. As the President's Commission states, both ethics and the law require that such a child receive such care because he or she would clearly benefit from it.

The interim final rule, and the proposed changes in the Child Abuse Act, also err in assuming that federal or state intervention will improve the decisions made on whether to give or withhold treatment to seriously ill newborns. The President's Commission, the courts, and medical experts are in agreement that such a decision should be made by a child's parents, as advised by their physician and other health care professionals, unless they are clearly acting against the child's best interests. In fact, the kind of collaborative decision-making that takes place in the neonatal intensive care units of the country's teaching hospitals serves to protect infants from arbitrary decisions--by parents or professionals. As Dr. Epstein said in his letter, "(t)he need to explain, defend, and seek wide-based support for a plan of action, whether to vigorously utilize or to compassionately withdraw heroic means of life support, is the best guarantee of proper and ethical conduct." In those rare cases when parents refuse to authorize life-saving treatment for their infants, and hospital staff think it is warranted, the hospital has the duty to seek an order in Juvenile Court to insure that treatment is given, and does not hesitate to do so.

Investigators from DHHS, the Justice Department or state child protective agencies who are not trained in medicine or ethics cannot be expected to come to decisions on the treatment of a newborn that are wiser than those of the child's parents in conjunction with NICU staff who devote their professional lives to such matters. It is counterproductive to imply, as the interim final rule does, that they can. As A.G.M. Campbell wrote recently "(a)dmittedly, as with many medical decisions, much depends on trust in the knowledge, judgment, and integrity of the doctors and parents in putting the infant's interests above their own. With rare exceptions this trust appears to be justified." ("Which infants should not receive intensive care?" <u>Archives of Disease in Childhood</u>, 1982, 57,569-571.)

The interim final rule and the proposed changes in the Child Abuse Act are regrettable in the damage they do to DHHS' relationship with hospitals. Hospital staff, including physicians and nurses, cannot help but resent the atmosphere of suspicion engendered by the encouragement of anonymous tips to the hotline, midnight visits, instant Justice Department suits, and threats of the cut-off of all DHHS funds, particularly when federal intervention appears of no benefit.

Finally, the impact of the interim final rule and the proposed changes in the Child Abuse Act on the new parents of critically ill babies cannot be a constructive one. At this time of great stress, they need support and compassion and access to the best medical advice, not blatant suggestions on well-displayed signs that their babies may not be receiving proper medical and nutritional care.

In summary, I believe that the system that is in place works as well as is humanly possible. Many decisions affecting the treatment of sick newborns are not easy and never will be, and are made more difficult by the enormous strides made in recent years by the new science of neonatology. But the decision makers are now the appropriate ones: parents and the health care team, and when warranted, the state courts. To tamper with the system will not produce better medical care, or more living infants.

Senator DENTON. This hearing stands adjourned.

[Whereupon, at 6:20 p.m., the hearing was adjourned.].

CHILD ABUSE PREVENTION AND TREATMENT AND ADOPTION REFORM ACT AMENDMENTS OF 1983

MONDAY, APRIL 11, 1983

U.S. Senate,
Subcommittee on Family and Human Services,
Committee on Labor and Human Resources,
Washington, D.C.

The subcommittee met, pursuant to notice, at 2:35 p.m., in room SD-430, Dirksen Senate Office Building, Senator Jeremiah Denton (chairman of the subcommittee) presiding.

Present: Senators Denton and Grassley.

Opening Statement of Senator Denton

Senator Denton. Good afternoon, this hearing will come to order.

Unfortunately, we find many times in our careers here in the Senate that we are to be in three places at one time. I just left a hotel, a very large meeting, and I should have been able to get out of there at 1:30. There was no way to get through the crowd. I deeply apologize to all of you who have been detained.

I am also still bouting with the flu, so if my voice runs out, I have a capable fill in, Senator Grassley, who will be taking over as chairman.

This is the second in a series of hearings on the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act, which is the Federal program assisting States in combating child abuse and neglect, and it facilitates the adoption of hard-to-place youngsters. We will focus on the child abuse portions of the bill this afternoon with the adoption portion on Thursday.

As you may know, last Thursday, Senator Hatch and I introduced S. 1003, the reauthorization bill for the Federal child abuse program. Our first hearing on the bill concerned itself with the issue of insuring that infants born with treatable defects would be provided with nutrition, medically indicated treatment, and appropriate general care.

The hearing today will focus on several other different problems addressed by the Federal child abuse program.

There is no doubt that child abuse is a national tragedy and that the effects of child abuse linger long after the bruises heal. The statistics are sobering. The vast majority of felons now behind bars in American jails are said to have been abused as children. Children who have been abused are more likely to grow up into child abusers themselves. There are even indications that girls who come from child abusing families are more likely to give birth as teenagers. Equally distressing are the statistics indicating that only about half of those perpetrators to child abuse respond to remedies. The other half continue to abuse their children. This strongly suggests that emphasis should be placed on preventing that first abusive act and on breaking the child abuse cycle.

Today we will hear a number of witnesses discuss child abuse, its forms, possible causes, remedies, and solutions. Naturally, they will treat child abuse as a separate and distinct issue, and to some degree, I suppose it is. But after serving as subcommittee chairman for over 2 years and addressing a myriad of issues involving family and human services, I would say that I find our policies to date are overly addressing symptoms while not at all addressing the cause of all or most of these symptoms. That basic cause is a fundamental crisis in the values traditional to our society, particularly the values of love and of respect for the dignity of other human beings, and of the institution of marriage.

Tragically, the brunt of this crisis is being borne disproportionately by those most innocent and vulnerable members of our society, our children.

The hearing this subcommittee is holding today is but one part of a larger series of hearings on the problems created by the disintegration of the family unit. I am afraid that resolving this problem of child abuse or the overall problem will require far more than the reauthorization of the Federal Child Abuse Prevention Act. But I am pleased that the administration has in fiscal year 1983 made prevention activities a top priority of the discretionary portion of the program. I know, too, that some States, including my own State of Alabama, have used money from their State grants for prevention activities.

Some individuals have voiced concern that the program with its emphasis on reporting suspected incidences of child abuse has on occasion necessarily intruded into situations that were properly family matters. The broad definition of mental abuse seems to be a particular concern, and we will ask several of our witnesses to address themselves to that issue.

We will also hear today from a number of witnesses who are involved in the identification, prevention, and treatment of sexual abuse. I know that the National Center for Child Abuse and Neglect has made sexual abuse another focus of the program's discretionary component.

Finally, we will hear today from witnesses who will describe what activities are being undertaken in the private sector to combat child abuse. Some of these efforts focus on providing parenting information to new parents and apparently have met with some success.

Other programs, like those undertaken by Parents Anonymous, concentrate on giving parents an outlet when their frustrations and tensions are mounting. Other efforts emphasize information dissemination to those in the community who are directly involved in this field.

We will hear about what more can be done to spur private sector involvement in a problem that affects entire communities. I look forward to hearing from the distinguished panels who have graciously accepted our invitation to testify this afternoon.

Before I welcome our first witnesses, I want to note that Senator Hatch and Senator Dodd have statements they would like to enter into the record. I have the two statements, and without objection, they shall be entered in the record.

[The prepared statements of Senator Hatch and Dodd follow:]

PREPARED STATEMENT OF SENATOR HATCH

We in Congress continue our efforts in striving toward making the United States a better country for all to live. Yet we must not ignore the shattering effects of the devastating social problem of child abuse. The causes are multiple; the results diverse. Yet, yearly over one million children are estimated to be abuse victims. Therefore, Federal efforts must continue to assist States in conquering child abuse to assure the welfare and well-being of all children.

I am pleased to join Chairman Denton today in the family and human services subcommittee hearings focusing on child abuse. Furthermore, I am pleased to join Senator Denton in sponsoring legislation to continue Federal efforts aimed at assisting States to preserve children's welfare.

I look forward to hearing and reviewing all the testimony received today. The witnesses assembled here provide us with expert evidence on the problems as well as possible solutions. In addition, I would like to thank Dr. Marty Palmer for traveling across the country to discuss child abuse prevention and treatment programs in Utah. It is rewarding to have Dr. Palmer with us today speaking not only from his work as director of the ambulatory care program at Primary Children's Hospital, but also from his work in developing community support resources. These programs work throughout Utah combining family and community efforts in prevention and treatment. This intertwining of volunteers and professionals demonstrates and effective method to curb child and sexual abuse. Through his work on these child protection teams, Dr. Palmer brings added insight.

Children are our most important national and natural resource. We must do all that we can to protect them. They have a right to live in healthy, happy homes surrounded with love and security. Since the future of our country is in the hands of our children, their welfare should be our first priority. Following this hearing, I urge expeditious consideration of this legislation.

PREPARED STATEMENT OF SENATOR DODD

Mr. Chairman, I am certain that all the witnesses testifying before us today will agree that child abuse is one of our greatest national tragedies. Battered children often have emotional and physical scars which may take years to heal, if at all. And, children who are mistreated today may grow to mistreat their own sons and daughters tomorrow.

Social service agencies from my State of Connecticut across to California have reported an alarming upsurge in cases of child abuse and neglect. Even more frightening is the news that in many States, the death rate from such acts of violence over the past year has soared by more than 40 percent.

The connection between the skyrocketing rate of child abuse and the current economic pressures being placed on families is clear. A 2 year study conducted in Wisconsin showed that in counties with the highest unemployment rate, instances of child abuse jumped by close to 70 percent. In those counties with the lowest rates of unemployment, on the other hand, reports of child abuse rose only 12 percent. In the same manner, a recent study in North Carolina revealed that children whose parents are unemployed are three times more likely to be abused than those whose parents have jobs.

At the same time that the rate of child abuse is climbing, Federal and State funds both for treatment and prevention programs are being cut back. Due to such budget cuts, many States have been forced to re-define abuse and neglect, handling only the severest cases. Some States are said to be considering helping only those abused children who are under age 12, simply because there is no longer the staff to investigate all reports of abuse.

In light of this dramatic increase in child abuse tied to our nation's economic troubles, the 1981 budget cuts in the child abuse prevention and treatment act were shortsighted indeed. S. 572, a bill I recently introduced to provide emergency assistance for children, would restore funding for child abuse prevention and treatment of sexually abused children. The sexual abuse treatment program was not reauthorized under the Omnibus Reconciliation Act of 1981 and must be reinstated now if we are to help the ever-rising number of children who are victims of such exploitation.

These Federal dollars can in no way solve the problem alone. Rather, such funds serve as seed money to be more than matched later by private contributions. In my State of Connecticut, for example, over a 1 year period $260,000 worth of professional services were volunteered by child protection teams.

As some will testify today, the data we have on reported instances of child abuse may only be the tip of the iceberg. It is estimated that for every abused child that comes into contact with appropriate agencies, there are ten abused children who escape notice.

Mr. Chairman, it is clear that child abuse has reached crisis proportions in this country. I urge my colleagues to join with me in helping national, State and local agencies meet this emergency by authorizing increased funding for the Child Abuse Treatment and Prevention and Adoption Reform Act.

Senator DENTON. Our first witness this afternoon is Mr. Clarence Hodges, the Commissioner of the Administration for Children, Youth and Families, which administers the Federal child abuse program.

Mr. Hodges will present the Administration's views on the reauthorization.

Welcome, Mr. Hodges, and again my apologies for my tardiness. It was entirely unavoidable.

STATEMENT OF CLARENCE E. HODGES, COMMISSIONER, ADMINISTRATION FOR CHILDREN, YOUTH AND FAMILIES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY JAMES A. HARRELL, DIRECTOR, NATIONAL CENTER ON CHILD ABUSE AND NEGLECT, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. HODGES. Thank you very much, Mr. Chairman. It is a privilege to be hear today, and I wish to express deep appreciation for having been invited to participate in these very important hearings.

I personally am most impressed with the strong stand that you have taken, Senator, not only within your great State of Alabama, but nationally as you have addressed this issue of child abuse and neglect. We are certain that with the kind of leadership you are providing and others who understand the magnitude of this problem that we are going to begin to see some positive improvements in this area.

Today I would like to just discuss briefly the situation of child abuse and neglect, the Administration of Children, Youth and Families, the National Center for Child Abuse and Neglect, some of the things that we are doing to help to resolve and have an impact on this problem.

We estimate that over 1,100,000 children are victims of abuse and neglect each year. Unfortunately, despite the large number of cases currently reported, we cannot assume that most abused and neglected children are now being identified and helped because our data indicate that a large number of maltreated children recognized by educational, medical, and mental health professionals are not now known to the local child protective services.

No area raises more troubling issues than child abuse and neglect. Nothing challenges us more for the future strength of our Nation's families than prevention of these problems.

The issues raised cut across social, geographic, ethnic, and economic boundaries. I am pleased to be here today to provide the subcommittee with an update on the activities of the National Center for Child Abuse and Neglect, and to tell you that the administration endorses continuation of a Federal role in this area.

Congress enacted the Child Abuse Prevention and Treatment Act, Public Law 93-247, in 1974. The legislation was subsequently amended in 1978 and 1981. It currently extends through September 30, 1983.

The law mandates four major functions to the National Center on Child Abuse and Neglect: generating knowledge and improving programs; collecting, analyzing, and disseminating information; assisting States and communities in implementing child abuse programs; and fourth, coordinating Federal efforts.

Today I will sort of highlight my testimony with a request that the total be inserted in the record.

My testimony today will describe briefly the accomplishments of the Department of Health and Human Services in implementing its responsibilities under this legislation. In partnership with the States, we aim to continue to provide national leadership in developing effective methods of addressing the human service needs of these most vulnerable citizens and supporting the development of State and local capacity to deliver appropriately targeted services.

In the area of research and demonstration, 65 projects across the country current receive funding from the National Center on Child Abuse and Neglect. These projects encompass a broad breadth of activities. The major areas involve prevention of child abuse and neglect; clinical treatment; public child protective services; and legal juvenile court services; prevention and treatment of sexual abuse; prevention and treatment of adolescent maltreatment, including sexual exploitation; protection of children in special institutions; special issues, including developmental disabilities, mental health, public health, and military families and their problems.

Our information function, and the second major area, the National Center has supported activities related both to research and information dissemination. Our most significant efforts in this area relate to incidence and reporting data.

Ten regional resource centers are disseminating information on a variety of family-related topics, including child maltreatment, and are fostering local support networks. States efforts to prevent child abuse represent another significant aspect of the authorizing legislation. The State grants portion of the act provides eligible States with funds to develop, strengthen, and carry out prevention and treatment programs.

The major vehicle for accomplishing the fourth function of coordination responsibilities of the National Center on Child Abuse and Neglect is the Advisory Board on Child Abuse and Neglect. Twenty agencies participate on the advisory board.

I want to mention that a strength of that group lies with the public representatives who are required by a 1978 amendment to the act. These individuals in particular ask difficult questions and challenge and prod not just the Department staff, but other Federal agencies as well to different perspectives on problems relating to child abuse and neglect.

For our planned activities, as part of the human development services, fiscal year 1983 coordinated discretionary funds program, the National Center on Child Abuse and Neglect will build on the results of past experience to launch key initiatives in several areas.

Finally, we plan to strengthen our emphasis on private sector coordination of nongovernmental groups, such as business, service clubs, and volunteer groups to prevent child abuse and neglect.

Mr. Chairman, we support reauthorization of the Child Abuse Prevention and Treatment Act and the Adoption Reform Act, and we have submitted to Congress a proposal for reauthorization of these programs.

Again, I state it is a pleasure on my part to be here, and I welcome the opportunity to answer questions that you may have.

[The prepared statement of Mr. Hodges follows:]

STATEMENT OF

CLARENCE E. HODGES

COMMISSIONER FOR CHILDREN, YOUTH AND FAMILIES

BEFORE THE

SUBCOMMITTEE ON FAMILY AND HUMAN SERVICES

LABOR AND HUMAN RESOURCES COMMITTEE

OF THE

UNITED STATES SENATE

MONDAY, APRIL 11, 1983

Mr. Chairman, I appreciate the opportunity to appear before this distinguished subcommittee to discuss the reauthorization of the Child Abuse Prevention and Treatment Act and Adoption Reform Act.

We estimate that over 1,100,000 children are victims of abuse and neglect each year. Unfortunately, despite the large number of cases currently reported, we cannot assume that most abused and neglected children are now being identified and helped, because our data indicate that a large number of maltreated children recognized by educational, medical and mental health professionals are not known to the local child protective services.

No area raises more troubling issues than child abuse and neglect. Nothing challenges us more for the future strength of our nation's families than prevention of these problems. The issues raised cut across social, geographic, ethnic and economic boundaries. I am pleased to be here today to provide the subcommittee with an update on the activities of the National Center on Child Abuse and Neglect and to tell you that the Administration endorses continuation of a federal role in this area.

Congress enacted the Child Abuse Prevention and Treatment Act (P.L. 93-247) in 1974. The legislation was subsequently amended in 1978 and 1981. It currently extends through September 30, 1983.

The law mandates four major functions to the National Center on Child Abuse and Neglect:

- Generating knowledge and improving programs;
- Collecting, analyzing and disseminating information;
- Assisting States and communities in implementing child abuse programs; and
- Coordinating federal efforts.

My testimony today will describe briefly the accomplishments of the Department of Health and Human Services in implementing its responsibilities under this legislation.

At the outset, I want to emphasize that these tasks are interrelated and involve multi-disciplinary, multi-service delivery systems. The Administration believes that in this fact lies the greatest strength and, simultaneously, the greatest challenge for the program.

In partnership with the States we aim to continue to provide national leadership in developing effective methods of addressing the human service needs of these most vulnerable citizens and supporting the development of State and local capacity to deliver appropriately targeted services. We are attempting to improve integration with other social services of activities addressing child maltreatment and this concern is reflected in our coordinated discretionary funds program. Let me begin by discussing the National Center's program development and improvement function.

RESEARCH AND DEMONSTRATION

Sixty-five projects across the country currently receive funding from the National Center on Child Abuse and Neglect. These projects encompass a breadth of activities. The major areas involve:

- prevention of child abuse and neglect
- clinical treatment
- public child protective services
- legal juvenile court services

- prevention and treatment of sexual abuse
- prevention and treatment of adolescent maltreatment (including sexual exploitation)
- protection of children in special institutions
- special issues (including developmental disabilities, mental health, public health and the military)

I would like to spend just a minute highlighting a few areas which I believe are of special interest to the subcommittee. These include:

- Primary prevention of child maltreatment. Among an array of ongoing projects are several which are actively working to improve hospital practices and community education to support young parents facing particular difficulties with their parental responsibilities.
- Prevention of child sexual abuse. Six projects have developed materials (curricula and a film) to be used with school students from preschool through high school, to make children aware of sexual abuse, to provide them with help in preventing the problem and to let them know how to go about seeking assistance if abuse is happening to them, a sibling, or a friend.
- Projects which stress the multidisciplinary nature of the response to child maltreatment. Providers of mental health and health services have received grants to coordinate their work with public child protective service agencies in order to better identify developmental disabilities and to improve treatment for victims of abuse and neglect.
- The adolescent maltreatment victim and the juvenile justice system. The adolescent has been found to be at considerable risk

of child maltreatment, though service systems are not readily available. Often these children enter the juvenile justice system and as a result increase costs to society. Efforts at developing diversion strategies have been undertaken in various cities.

- Parental and victim self help. Parents Anonymous now has over 1300 chapters across the country and in some overseas cities with large American military populations. Parents and victims are afforded the opportunity to help each other prevent child abuse and neglect and improve family life for all members. Parents United, a self help organization for families that have sexual abuse problems, has also received funding and chapters are now being established across the country without federal funds.

INFORMATION FUNCTION

In the second major area, the National Center has supported activities related both to research and information dissemination.

Our most significant efforts in this area relate to incidence and reporting data. Through the National Center, the Department gives funds to the American Humane Association to conduct an ongoing national study on child neglect and abuse reporting. This project collects and analyzes statistical information about suspected child abuse and neglect that all 50 States receive from child protective service agencies.

A major achievement was the completion of the first National Incidence Study which provides us with baseline reporting data.

One of the basic strengths of the National Center's activities lies in its capability to disseminate information through clearinghouse activities and annual program and research analyses.

Ten regional resource centers are disseminating information on a variety of family related topics, including child maltreatment and are fostering local support networks. Another dissemination activity which I know is of major interest to the Congress is the Military Family Resource Center, a joint venture with the Department of Defense and the Department of Transportation (Coast Guard). DHHS is receiving approximately $500,000 in 1983 from these agencies to provide information and technical assistance to enhance military support systems on behalf of vulnerable military families worldwide.

Equally important is the effective fashion in which the program has helped to identify and define pressing issues in the field. In 1982-83, this is being accomplished through a series of symposia on specific issues as well as through the Sixth National Conference on Child Abuse and Neglect, which will be held September 25-28 in Baltimore, Maryland. Hosted by the Junior League of Baltimore and the State of Maryland, sixteen organizations are co-sponsoring the conference, which represents a major national outreach effort for the field.

IMPLEMENTATION FUNCTION

States' efforts to prevent child abuse represent another significant aspect of the authorizing legislation. The State grants portion of the Act provides eligible States with funds to develop, strengthen and carry out prevention and treatment programs. Awards amounting to $6.7 million will be made in FY 1983. The number of States eligible for this funding has jumped from four in 1975 to forty-eight in 1982. The States currently ineligible for a child abuse and neglect State grant either fail to include in their State statutes a definition of child abuse and neglect substantively consistent with the definition of child abuse and neglect in the Act or fail to meet the Act's requirement to provide a guardian ad litem for the child in every case involving an abused or neglected child which results in a judicial proceeding.

A major purpose of the State grant program is to support start-up activities which, if proven successful, will be continued by the State with other funds. Approximately 30 percent of projects conducted with State grant funds have been continued after the start-up phase using State appropriated funds. Most of the others involved one-time-only activities such as development of protocols, procedural manuals and central register systems for compiling information or reports. Most exciting to us is the exchange of information among the States about successful projects and effective approaches. Through the leadership of the National Center, an informal yet very effective peer support system of State child protective services agencies has developed over these past years. We believe that when social services are needed, they are best defined and administered through the public and private institutions at the level closest to the problem--State and local governments and private community agencies.

One other item of note under this function is that, as mandated by the Act, the National Center on Child Abuse and Neglect, in cooperation with the National Advisory Board, has developed and published standards for child abuse and neglect prevention and treatment programs and projects. The publication, entitled Child Protection: Guidelines for Policy and

Program, provides a useful summary of standards for the field. Another document which will be available this year as a result of State requests is Child Protection: A Guide for State Legislation.

COORDINATION FUNCTION

The major vehicle for accomplishing the fourth function of coordination responsibilities of the National Center on Child Abuse and Neglect is the Advisory Board on Child Abuse and Neglect. Twenty agencies participate on the Advisory Board. I want to mention that a strength of that group lies with the public representatives who are required by a 1978 amendment to the Act. These individuals in particular ask difficult questions and challenge and prod not just the Department's staff, but other federal agencies as well, to different perspectives on problems relating to child abuse and neglect.

PLANNED ACTIVITIES

As part of the HDS FY 1983 Coordinated Discretionary Funds program, the National Center on Child Abuse and Neglect will build on the results of past experience to launch key initiatives in several areas. These projects, most of which will have increased private sector and voluntary support, include:

- Demonstration of parent support in the work place to prevent child abuse and neglect.
- Measuring the effectiveness of prevention strategies.
- Demonstration of the use of therapeutic family day care homes to prevent foster care placements.
- Demonstration of mechanisms for training middle and senior State Child Protective Services management.

- Validation of existing theories on factors contributing to the sexual victimization of children.
- Demonstration of effective procedures for management of State intake and investigations of child abuse and neglect.
- Demonstration of alternatives to litigating child abuse and neglect cases.
- Demonstration of the use of committees of inquiry in case of child fatalities.

Let me assure you that, while child abuse and neglect research is planned and funded through the OHDS coordinated research process, the importance of child abuse and neglect efforts is in no way diminished. In fact, we found in the FY 1982 coordinated process that research for one program was enhanced as a result of linkages with other human service programs.

Under the reauthorized Act, we propose to support efforts to enhance the educational system's involvement in early intervention in cases of child maltreatment; analyzing and packaging the wealth of material generated by recently completed grants; continuing the emphasis of the information collection and dissemination clearinghouse on child abuse and neglect; and following up on experience gained in dealing with the maltreatment of children in residential treatment facilities.

In the implementation area we see a need to continue strengthening of interstate sharing, focusing on the use of State grants to get maximum effects. In the private sector and voluntary efforts, we will support Parents Anonymous' priority of organizing children and adolescent service groups to address their prevention and treatment needs. Finally, we plan to strengthen our emphasis on private sector coordination of nongovernmental groups, such as businesses, service clubs and volunteer groups to prevent child abuse and neglect.

Coordination issues pose new challenges to the Department with respect to the increased public attention and concern generated by the Infant Doe case and the medical and judicial systems' response to the issue. We support the intent of the suggested legislative language to focus special attention on protecting potential Infant Does and ensuring that professionals are aware of the potential for placing them in adoptive homes. We are committed to increase the efforts of the Department of Health and Human Services to work with the States to ensure that child protective service agencies and medical facilities and professionals carry out their legal and moral responsibilities to protect endangered handicapped infants.

1983.

REAUTHORIZATION

Mr. Chairman, we support reauthorization of the the Child Abuse Prevention and Treatment Act and the Adoption Reform Act, and we have submitted to Congress a proposal for reauthorization of these programs. While we believe that financial support to the States for purposes of this Act should be continued at its current level of $6,720,000, we are asking for an appropriation in FY 1984 which consolidates and reduces the research, demonstration and information funding for social services discretionary activities. This reflects the Departmental policy of targeting limited Federal resources to direct service activities. In keeping with these efforts to restrain Federal spending, we will refine and target discretionary activities to achieve maximum effects and link with State agencies to ensure dissemination and implementation of these activities on a nationwide basis. We strongly affirm that this legislative authority embodies a fair, viable and responsible approach to a vexing national problem and we support its continuation.

On a related topic, Mr. Chairman, as stated in Dr. Koop's testimony before this subcommittee on April 6, the Administration supports the aims of the Infant Doe provisions of your reauthorization bill. Secretary Heckler, in testimony before the Senate Labor and Human Resources Committee addressed a most urgent situation. She said:

> "Last year, millions of Americans were stunned, shocked and angered when the death of a handicapped newborn infant in Bloomington, Indiana, brought to public attention the tragedy of that and other cases where nutrition or medical care is deliberately denied to handicapped infants.
>
> The President responded swiftly to the tragic tidings from Bloomington. He directed the Health and Human Services Department to make clear to every health care facility in the United States of America that Section 504 of the Rehabilitation Act of 1973 protects <u>all</u> handicapped persons, <u>including</u> infants. The HHS Office for Civil Rights did as the President directed on May 18, 1982, in a written notice which was sent to hospitals nationwide."

In addition, Mr. Chairman, the Department of Health and Human Services has taken a further step to implement the President's direction on handicapped infants by publishing in the Federal Register on March 7, 1983, interim final regulations requiring that each and every recipient of Federal funds who provides covered health care services post and keep posted in a conspicuous place a notice stating that "discriminatory failure to feed and care for handicapped infants in this facility is prohibited by Federal law."

The notice will put the public and medical profession on notice that anyone who has knowledge that a handicapped infant is being discriminatorily denied nutrition or medical care can and should immediately contact a toll-free, 24-hour Health and Human Services hotline, or, in the alternative, the State child protective agency to report the alleged violation.

The Department's action is prompted by the accumulation of additional evidence that handicapped children's lives are in jeopardy -- that some have indeed been lost by decisions to withhold food or services.

Mr. Chairman, we trust that these actions by the Department will be effective. The Administration supports your effort to address this important problem.

Thank you, Mr. Chairman. I will be happy to answer any questions.

Senator DENTON. Thank you very much, Mr. Hodges. And, as requested, the full written statement which you submitted will be included as part of the record. I thank you for summarizing orally.

I will ask you several questions, sir. As I mentioned in my opening remarks, concerns have been raised about including mental abuse within the definition of child abuse. Does the administration have a view on this matter, and what can be done to clarify and narrow the definition to give Sates more guidance on the definition?

Mr. HODGES. Presently, Mr. Chairman, we do address the issue of, what we term, emotional maltreatment. And there is—where there is observable harm, where there is a lasting effect, and where there is the possibility of a handicapping condition. That very definitely is an issue we address, and we look at it within the family setting. We work with the States on this issue, and we are helping each State to recognize their responsibilities as they relate to what we term emotional maltreatment or mental maltreatment to make sure the children who suffer this kind of treatment, this kind of maltreatment, are protected also.

Senator DENTON. I just want to clarify what we are talking about here. This is mental abuse without any physical abuse, for example oral intimidation or insult?

Mr. HODGES. That is correct.

Senator DENTON. That is an entirely separate area from any physical abuse whatever?

Mr. HODGES. That is correct, Mr. Chairman. There are times when a person is physically abused and there is mental abuse that goes with it.

Senator DENTON. Yes.

Mr. HODGES. And there are also times when there is emotional abuse without physical abuse, but verbal abuse, psychological abuse, the kind of activity that one can suffer without being bruised or physically touched.

Senator DENTON. Could you describe some of the National Center's activity in the sexual abuse area?

Mr. HODGES. We are looking at that presently with a number of agencies and organizations around the country, particularly with our discretionary funding projects, some that were granted last year, fiscal year 1982. We have been looking at the prospects in fiscal year 1983 of awarding additional grants to get a better handle on that problem, to get a better understanding, as well as to determine ways that we might be able to improve our reporting.

It is difficult to get information on this issue because persons will not voluntarily and willingly share with us this kind of maltreatment of children. We do see an increased incidence in some areas, and we are getting, utilizing, and providing for States and counties methods of determining when this kind of abuse should be suspected.

We are working very closely with medical institutions, with our social workers and our county welfare agencies, and we are making sure that they are getting proper kinds of training; we have disseminated manuals to help persons to understand how to detect this kind of maltreatment, how to assure proper investigation, and proper action on the part of counties and State governments.

Senator **Denton**. From your position, do you have any perception as to even generally classifiable causes of individuals becoming prone to sexually abuse a child?

Mr. **Hodges**. I consider very often the ugliness of abuse of children, and I have had opportunities to visit some of our major hospitals where children are treated and seen some of those who are victims.

And I have sought to discuss with persons who have responsibilities in this area to determine what kind of person would perpetrate this kind of crime on a child. We do find a different kind of person who would sexually abuse from the person who would normally physically abuse.

The sexually abusing person often has severe problems with how he perceives and sees himself; an inability often to relate on a proper relationship basis with other adults; the inability to establish meaningful relationships, many times, with persons of the opposite sex.

These persons have great problems with personal identity and with finding any satisfaction with themselves. We are concerned. They do require treatment, extended treatment, and it is important that where there are such cases suspected, that there is proper investigation to make sure that such a person is treated so that there will not be a continuation of such suffering by innocent children.

Senator **Denton**. Will sexual abuse continue to be one of the primary focuses of the National Center for Child Abuse and Neglect's discretionary program in the coming years?

Mr. **Hodges**. That is correct, Mr. Chairman. We recognize that as a continuing problem. And we wish to continue to direct resources toward that problem.

Senator **Denton**. I am aware that the administration is devoting a significant portion of the limited available Federal funds in the area of prevention. What are some of the activities now taking place in this area, and will you continue to emphasize prevention?

Mr. **Hodges**. Prevention is an area that we must continue to emphasize. Not only must we treat and seek to help those persons who are victims, but we must seek to prevent others being added to those large numbers. The funds that we grant to the States, for the most part, are used to expand upon their preventive capabilities and their service programs, as well.

The programs where we use discretionary funds include a number of volunteer agencies and nonprofit agencies. They work with those persons who might very well be suspected, of child abuse.

We look at children with birth defects, where there are families with tremendous pressures and a great need for respite. There is a great need to support those families and to work with those parents who have themselves been in the foster care system or have been victims of abuse as children. We look to those agencies to help them before there is a crying out need for relief. We can provide preventive services, support services, so that there families can be strong, and can know how to express themselves verbally as opposed to with physical abuse in relating to children.

Senator DENTON. Do you have any statistics on the incidence of child abuse perpetrated against children of unmarried or divorced women by boyfriends or live-in mates?

Mr. HODGES. We do not have exact figures on this kind of problem, but there have been reports indicating serious problems with step parents; with boyfriends, and there are those problems particularly where you have young people who are not prepared to be parents, teenage parents.

Those persons often—not only have one child, but usually they will have a second child very close to the first while they are still teenagers. With 1 million teenage pregnancies a year and the sizable number of persons who are under 15 years of age that give birth each year, we can reasonably expect large numbers of children to be problem parents.

These children often expect that which is impossible of their babies. They expect babies to walk at 4 or 5 months. They expect them to talk and to do other things. They expect them to be potty trained. When they do not see their expectations fulfilled with their children, they turn against them very often with abuse.

There is a great need to help these persons develop family strengths so that grandparents or others can offer support to those children who are children of children. Further, there is a serious problem of boyfriends possibly becoming abusive, along with mothers when these parents themselves are very young and do not have resources to provide for themselves and their children to the extent they would desire.

Senator DENTON. Well, thank you very much, Mr. Hodges. Your testimony was informative and will be very useful to this subcommittee. Your responses were most articulate, and we greatly appreciate your taking the time to come down this afternoon.

Mr. HODGES. The pleasure was mine. Thank you, Senator.

Senator DENTON. I do have three questions from Senator Hatch. I can submit them to you in writing or I can ask them on his behalf right now.

Mr. HODGES. At your pleasure, Senator. I would be pleased to answer them now or——

Senator DENTON. All right. Just to save the writing, I will ask you the questions.

First, in your estimation, are State child protection agencies adequately prepared to respond to complaints of denial of treatment?

Mr. HODGES. I think they are adequately prepared, and they are preparing themselves more. We are providing some technical assistance, and it is an area in which States have given increased recent attention to this issue. States have looked at it prior to the recent publicity. Many States have taken very strong action already in some cases.

We are confident that we will be able to provide some technical assistance. We have done that to help States respond adequately to the problem where there is denial of services to a child.

Senator DENTON. Are their staffs adequate, both in numbers and in professional skill, considering medical and nursing skills, to deal with cases in the highly technical atmosphere of the neonatal intensive care unit?

Mr. HODGES. For the most part, there are staff persons involved that have that kind of expertise, and States have availability to resources within the offices of the Administration for Children, Youth and Families, the National Center for Child Abuse and Neglect, and our 10 regional resource centers. We provide extensive technical assistance to the States, and we also have relationships with a number of hospitals and universities that have expertise that is not always available in every State or to every agency. But it is available in general, and we are happy to make such expertise available to the States.

Senator DENTON. With the increase in incidence of child abuse and neglect and the added burden that this new category of abuse, denial of nutrition, would add to the already heavy caseload, is the proposed budget in the reauthorization of the act adequate to provide for the increase in staff needs?

Mr. HODGES. I would think so, Senator. There is always a situation where more money could be used by any governmental agency. But at the same time, as we look at our limited resources, we are confident that this is an area that is serious enough that there should not be a budget cut with our grants to our States.

But with what the States are doing, what has already been done, and what is being built upon because of services that were provided by our agency in fiscal year 1982; they will not need recurring expenses to the same extent due to our extensive manuals and training that has already been provided. We are confident that the funds that are available in 1984 will be able to build upon what is there and to expand, as the act suggests, so that there will be sufficient resources for the needs of each State.

Senator DENTON. And Senator Hatch's last question is: the legislation that Senator Denton and I have introduced expands the Advisory Board on Child Abuse and Neglect to include issues on adoption opportunities.

Do you know if the administration or you representing the administration supports this coalition of efforts?

Mr. HODGES. We are very much concerned, and we do see some linkage of concern with adoption needs. We have not thoroughly thought out and determined a specific position. On Thursday of this week, I believe, Assistant Secretary Hardy will be testifying before this committee, and perhaps by that time we will have a more specific response.

Senator DENTON. All right. Thank you very much, Mr. Hodges. There will be some written questions submitted to you at least on the part of Senator Dodd. And we will hold the record open for 10 days for other Senators of the subcommittee to submit questions to which we solicit your early answers in writing.

Mr. HODGES. We will respond as rapidly as possible. Thank you very much, Mr. Chairman.

Senator DENTON. Thank you, sir.

Our second panel of witnesses consists of Mr. Wayne Holder, director of the Children's Division, American Humane Association; and I will ask these persons to please come forward; Mr. Wayne Holder, welcome to you sir; Dr. Eli Newberger, a pediatrician from Children's Hospital in Boston.

Welcome to you, Doctor. Mr. Gregory Loken, senior staff attorney at Covenant House in New York City; welcome to you.

Mr. Holder, would you care to begin with your opening statement.

STATEMENT OF WAYNE M. HOLDER, DIRECTOR, CHILDREN'S DIVISION, AMERICAN HUMANE SOCIETY; ELI NEWBERGER, PEDIATRICIAN, CHILDREN'S HOSPITAL, BOSTON, MASS.; AND GREGORY LOKEN, SENIOR COUNSEL, COVENANT HOUSE, NEW YORK, N.Y.

Mr. HOLDER. Yes, Mr. Chairman.

I am pleased to be here and thank you for this opportunity. Within my written statement, which I would like to have entered in officially, I took three perspectives.

I would like to speak to those perspectives briefly. Before I do, I would like to mention something about the American Humane Association. We are the oldest national organization devoted to addressing the problem of child maltreatment. We are a private, nonprofit organization based in Denver.

We provide a wide range of services to States and local agencies, including consultation, education, research, and evaluation. Through our professional staff and 40 faculty located around the country we maintain a keen awareness of the state of the art on child protection and fluctuations in the problem of child abuse.

The three perspectives that I took in my statement look at the problems of child abuse and protection before the national center was set up, during that time, and now. You certainly in your opening remarks adequately stated the nature of the problem, the size of it, and probably in every statement people mention the size of it, as has just been stated in the previous remarks.

So I will move to the during. During the last 8 years or so, the national center has been the major primary force behind activity in this area and has been very effective in raising, elevating the awareness of child abuse among professionals within the community.

I would like to characterize that activity as having a primary impact in knowledge gaining. We are much better prepared to do the job now. We are much more aware because the national center was established and did its work.

But we have moved from that time and transitioned into a new time. The national center does need to be reauthorized, but the emphasis needs to be changed. We have moved away from a period of discovery into a period of application, the need for application.

It would be good if we could gather together and talk about how well we are doing in combating the problem, but the truth of the matter is we are not. The problem is increasing much faster than we are able to deal with it. We have been effective in identifying the size of the problem and have a better understanding of the characteristics and nature of the problem.

But we are not applying the information and knowledge we have about what to do about the problem. And I am speaking specifically with regard to treatment and rehabilitation in the area of child protection. It is time to begin to move in that area, for in so doing we not only address those families and children that are in need, but we begin to address the question of prevention as well by treating those children that are in need now.

As I identified within my paper, the change in the economic status within our country, the change in the nature of what is going on in States, the reduction in staff, the problems with regard to increasing caseloads, and so forth, have left our systems of care in the situation where they are less able to adequately meet the needs of the families that they see.

Furthermore, the system is being challenged by litigation and cries of outrage by community, press, and otherwise with regard to the quality of care being given. I do not think necessarily this is an indictment against the people who are doing it, who are all good intentioned and well committed people.

The problem is that there is such a lack of resource and a lack of requirement within our society, within our community to do something about the problem that we have a second rate, inadequate system delivering care. Training is not enough. Qualifications for workers are not high enough, and the resources with which they work are not adequate enough.

I am of course recommending reauthorization, but in doing that I am asking for an emphasis shift, and I am suggesting that NCAN be given a standard setting function with due regard to State autonomy. I realize that these are not the days when it is popular to talk about the Federal Government doing any regulatory kind of activity, but I believe we are at a point where we have moved past getting knowledge to the point that we need to set standards and require that those standards be met. We need to consider uniformity in practice throughout the country and an elevation of the quality of practice.

I think NCAN's purposes should be related to quality of practice and application of the knowledge that has been gained through its efforts in the last several years. Part of that can be done by emphasizing dissemination of information and sending out that knowledge in assertive ways and in association with the standards setting that NCAN has accomplished.

I believe State grants should be continued, and perhaps consideration being given to elaborating that effort. There should continue to be a study of the problem of child maltreatment in terms of nature, size, and change, so that we are always monitoring and staying in touch with fluctuations.

Specialized studies, some of which you alluded to in your questions about sexual abuse, and so forth, should be continued, and some efforts should be given to activities for preventing child abuse in a primary prevention sense.

Further, I would like to suggest that if funding is not at least set at the $30 million level, then what we are doing is making a clear comment with regard to how we feel about our children and how we feel about the families that are taking care of those children.

With regard to the question of mental injury, I would recommend that that be placed and defined within the child abuse statute. I think it is critical because of the fact that it is such a difficult thing to deal with. Clearly, mental injury always coexists with other forms of maltreatment, but it also stands alone as a problem that needs to be dealt with.

It is the most difficult form of abuse to substantiate, and unless it is articulated in statutes, whereby it can be revised over time, related to practice, it will continue to be the most difficult to work with.

States are likely to follow to deal with this in their statutes, those States that do not have it.

This concludes the comments I would like to make. And I would be pleased to respond to questions.

[The prepared statement of Mr. Holder follows:]

The American Humane Association
Preventing cruelty to children and animals since 1877

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AMERICAN HUMANE

STATEMENT OF

WAYNE M. HOLDER, ACSW
DIRECTOR
CHILDREN'S DIVISION
THE AMERICAN HUMANE ASSOCIATION

BEFORE THE

SENATE SUBCOMMITTEE ON

FAMILY AND HUMAN SERVICES

Monday, April 11, 1983

Mr. Chairman, I appreciate the opportunity to appear before this distinguished subcommittee to discuss the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act.

As an introduction, I am currently the Director of the Children's Division of The American Humane Association. I have been involved in state and national efforts to combat child abuse for the last fifteen years. I have authored books on the subject, designed national training programs, taught and consulted internationally and designed and evaluated programs at the state and local level. My experience includes work within the field of child protection in all capacities: as a direct service practitioner, administrator and planner and now as a consultant and executive. Professionally I am a social worker.

The American Humane Association is the oldest national organization devoted to addressing the problem of child maltreatment. We are a private non-profit organization based in Denver. We provide a wide range of services to state and local agencies including consultation, education, research and evaluation. Through our professional staff and forty faculty located around the country we maintain a keen awareness of the state of the art on child protection and fluctuations in the problem of child abuse. We are a membership organization led by a national board of directors.

I consider the question of the reauthorization of the Child Abuse Prevention and Treatment Act from the perspective of what preceded the Act, what has the Act done and what is the status of child abuse and child protection efforts today. By doing this, recommendations clearly come into focus. So I will briefly share with the subcommitte my perception of the past fifteen year history.

The 1967 amendments to the Social Security Act included provisions for restructuring child welfare services nationally and for separating social services from economic services. There was a specific requirement that child welfare services must be accessible and available in all jurisdictions of each state. States responded by reassigning staff and redesigning programs. The result was a dilution of child welfare practice expertise. In 1967 American Humane conducted and published a nationwide survey of the state of child protection practice. The survey identified the following:

. No state and no community had developed a child protective service program adequate in size to meet the service needs of all reported cases of child neglect, abuse and exploitation.

. Much of what was reported as child protective services was in reality non-specific child welfare services, or non-specific family services in the context of a financial assistance setting. While the spirit and intent to serve neglected and abused children was present in many of the reported programs, when evaluated in terms of identifiable and specific child protective services, it was often no more than a token program.

. Almost two-thirds of the 47 states which reported a protective service program were found to lack total geographic coverage within the state.

. Responsibility in the department of welfare at the state or local level for services to abused children under the state reporting law varied considerably.

. Date submitted by state departments of welfare quite consistently described child welfare staff as <u>not fully trained</u>.

. Fifty percent of the states reported a need for change in the state law to more clearly define protective services and emotional neglect.

- Two-thirds of the states expressed a need for more adequate ncing to support a better child protective service program.

- Ninety-two percent of the states listed a need for more staff for better qualified staff to improve their child protective service ram.

- Somewhat more than one-third of the states cited a need for cooperation from community resources, especially from courts and ols.

- For a variety of reasons almost all states statutes governing ld abuse and neglect matters were less than adequate.

In summary, our country entered the 1970's with limited knowledge ut the problem of child abuse and neglect, compounded by an unfocused vice system, poor programs and unqualified personnel. The resulting ponse to this social problem could be descirbed as fragmented and rofessional.

Part of the motivation behind the Child Abuse Prevention and atment Act was to improve the condition of child protective services. 1975 the field was bolstered by the federal legislation and the National ter on Child Abuse and Neglect (NCCAN). The issues were clear. Child ltreatment was a problem that the country needed to address through velopment of knowledge, public awareness and programs. There is no estion that NCCAN has had a profound impact on the enhancement of efforts sociated with child protective services. Much has occurred since 1975 d as a result of NCCAN's influence:

- Throughout the last eight years NCCAN has funded a vast number of research and demonstration projects in all parts of the country. From that activity there has been a tremendous broadening of the knowledge base about child maltreatment. More is known about the nature of the problem, the people who are caught in the grip of the problem and the most appropriate and effective methods for addressing the problem.

. Public and professional awareness has increased considerably in terms of recognizing the seriousness of the problem and the responsibility to identify cases.

. A major emphasis has been given to identifying and reporting abusive or neglectful situations. States redesigned intake systems, redefined eligibility criteria and have experienced huge increases in referrals.

. All states revised and improved their child abuse statutes; generally speaking, there is now a soundness and consistency in laws among states.

. All states have improved their data collection capability so that better information exists about cases reported, characteristics of families and the response of the social service system. This has also resulted in national data about the problem of child maltreatment.

. Training efforts have increased along with higher quality of training, more systematic approaches to educating staff and vastly improved education resources in the form of literature, films, etc.

. Much was accomplished in the area of multidisciplinary involvement. Prior to the NCCAN's efforts, the public social service worker worked primarily alone. Now a wider range of professionals participate in child protective services. Multidisciplinary teams participated in over one-third of the counties in 1978. Many states have established multidisciplinary advisory committees.

. On the basis of other NCCAN work practice standards have been developed which define the parameters of acceptable child protection practice.

. The general activity in the states has been great as influenced by the NCCAN state grants. States have used the grants creatively to strengthen the child protection programs. In summary, states have used the grants in these ways:

To establish or refine information collection systems;

To establish and operate hotline telephone systems;

To establish or strengthen the child protection program by setting up positions or work units and through program design and development;

To establish volunteers and parent aide programs;

To establish comprehensive emergency services;

To provide access and obtain specialized training, consultation and technical assistance;

To establish or increase treatment services such as counseling, evaluation or homemaker services;

To conduct public awareness campaigns.

In almost all circumstances states sought other funding to continue initiatives; <u>in over 50% of the states activities begun with the NCCAN state grants have continued with state or private money</u>.

In summary, NCCAN has been the single most important influence in the child protection field since 1975. It has been successful in three ways: (1) elevating the awareness of child abuse as a significant problem; (2) providing the impetus for program improvements; and (3) increasing the knowledge base about child abuse.

Where are we now? What are the conditions of the child maltreatment problem now? Are we effectively managing the problem now? Actually, the facts are sad. The problem of child abuse is growing. The latest national data (1981) shows 850,980 cases reported. Furthermore, other data indicate that for every child known to CPS, there are two others known by professionals. This represents only what is known, not incidence. Some estimate that for every known case there are ten children abused who are not known to agencies. These facts suggest that from two to three million children are at risk. No other childhood problem is as great. This is a most serious social problem.

American Humane has just completed a survey questioning the current status of child protection effort. The results are alarming. During the past year:

. Referrals for CPS services have increased

. The severity of client ~~problems~~ have increased

. The percent of clients in crisis precipitated by economic problems has increased

. Most services and multidisciplinary consultation are at the same level or less

. Out-of-home placement is probably on the increase

. Legal intervention is increasing

. One-third of the agencies are narrowing eligibility standards at intake

. Funding for CPS has decreased

Through our contact with the field we are finding that many states are decreasing staff and reducing administrative support services such as consultation and training.

Malpractice litigation against agencies and workers is flourishing. Grave concern is being raised over child fatalities, particularly where agencies have been involved with families. From New York to California media is inquiring into the quality of practice in child protective services.

American Humane has conducted a number of field evaluations and find that the quality of work is generally suspect in most places. Most effort goes into investigating reports; little is done with regard to treatment. Recidivism is 50% in most places. Practice is unsystematic, impulsive and superficial. Decisions are usually based on inadequate information, lack of input and not necessarily related to client circumstances. We are currently conducting a study in which counties show wide variation in decision making; however, we cannot determine differences in the counties to explain the variation. It appears that decision making is random or idiosyncratic. A previous study on foster care placements indicated that decision making was random. In most states supervision of workers is insufficient and inadequate.

In summary, the current state of the art in child protective services is marginal to poor. This is not an indictment of those who deliver the services, most of whom are well intentioned and committed people. The problem with service quality is not ignorance. Sufficient knowledge exists to do quality practice. It is easy to understand that poor quality issue in view of the increase in child abuse, rising caseloads, reduction in effort and the apparent lack of priority that we as a society place on protecting children who are at risk.

The situation is bad but better than in the early 1970;s. This is true because of the work of the NCCAN and particularly because we are better equipped with knowledge to combat the problem. The field has moved forward due to NCCAN, but cannot respond adequately because of such things as overload, worker incompetence, inadequate supervision, inadequate leadership, lack of resources and inadequate community support.

NCCAN is needed now as much as ever but for different reasons. Nationally we must become concerned with quality of practice. Therein lies NCCAN's role. There is and always has been a clear need for a federal role in regulating the quality of practice in child protective services. In the same sense that an apendectomy is performed in the same way in Miami as in Seattle, so should child protective services be performed uniformly and in accordance with accepted standards. This is critical because child protective services involves such sensitive areas: civil rights, family maintenance, government intervention.

I am, therefore, recommending reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act and the National Center on Child Abuse and Neglect. Furthermore, I recommend that:

. NCCAN be given a standard setting function with due regard to state autonomy. This function could be strengthened through federal funding requirements and stipulation. This role should be designed and implemented through positive, helpful means.

. NCCAN's purposes be related to quality of practice and application of knowledge.

. NCCAN emphasize dissemination of information and knowledge gained in assertive ways and in association with its standard setting function.

. State grants be continued.

. NCCAN continue to study child maltreatment in terms of the nature, size, change in the problem and that efforts in specialized study continue.

. Some effort be given to activities for preventing child maltreatment.

. Funding be increased to no less than the FY 1981 level of $30 million as a reflection of the need for this country to show its concern for its children.

Finally, I recommend that "mental injury" be included in the definition section of the child abuse statute for these reasons:

. Mental injury or emotional abuse co-exists with other forms of abuse, but is also manifested as a discreet form of abuse.

. Mental injury is the most difficult of abuses to substantiate, in part because it has not been defined.

. In order to evolve to more effective intervention in mental injury cases, it must first be officially recognized in statute.

. By including mental injury in the federal statute, there is greater likelihood that states who have not done so will follow.

Thank you Mr. Chairman for this opportunity.

Senator DENTON. All right, Mr. Holder. We will withhold the questions until all three have offered their opening statements.

Dr. Newberger.

Mr. NEWBERGER. Thank you, Senator. I have chosen as the title for my remarks to your subcommittee, "The Helping Hand Strikes Again." This is with a view to focusing on the serious and unintended consequences of our national child abuse program. The effort focuses, it seems to me, entirely too much on case reporting, case reporting which sometimes leads to inappropriate, heavyhanded and sometimes harmful intrusions into family life.

It is well to note that it is now 20 years since the publication of the seminal medical article by Prof. C. Henry Kempe and his colleagues in Denver, entitled "The Battered Child Syndrome."

When this paper came out in 1962 it stimulated an outpouring of editorial concern in virtually all professional and lay media, and it was directly associated with the drafting by the lead agency for children in the Federal Government, the Children's Bureau, of a model Child Abuse Reporting Statute.

By the end of the 1960's, every state had a law mandating the reporting of child abuse to authorities who, at least in theory, had some ability to provide some rescue for these children.

In retrospect I think it is of interest that it was the heyday of the civil rights movement that made possible the fertile ground in which this seed was planted. The national child protection movement that flourished in the 1960's could only have done so at a time when there was a different view of what Government could and should do with respect to protecting children and to supporting families.

But the halcyon years of generous and humane expansion of social programs during Lyndon Johnson's day appear now to have passed. Now we need seriously to rethink the strategy implicit in this legislation.

In the early 1970's a substantial literature on child abuse developed, and it became clear to those working in the field that people who abused their offspring were not cruel, sadistic murderers. They were people who were burdened by psychological problems and by family stresses. They were people whom the case reports suggested were poorer than other people in the population.

A humane philosophy of intervention developed. It was believed that with the infusion of professional resources, and with love, and good will, that the problems like child neglect and child abuse, child sexual abuse, deprivation of medical, educational, and moral supports for children's growth increasingly would be acknowledged and would be addressed.

This subcommittee, Senator, was formed in 1971, partly in response to the recommendations of the 1970 White House Conference on Children. In 1974 Public Law 93-247 was passed, there was debate much as now about whether resources should be allocated preferentially to treatment or to services, as Mr. Holder has just stated, or whether resources ought more to be committed to research, to coordination, to prevention.

There was debate as to whether or not physical abuse as opposed, say, to psychological or mental injury, should be the focus of attention. And there were countervailing arguments in the literature and among distinguished committees.

The Federal personnel in the Children's Bureau took the view which I have characterized as the view of the service idealists, that the thing to do was to define child abuse as broadly as possible in order the children's cases might come to light, and that hopefully some humane and appropriate response would follow.

The countervailing view, expressed mainly by the civil libertarian branch of the American law community, was concerned about the possibility of dangerous intrusions into family life.

In retrospect, it appears that the service idealists won the argument. At this time no one could have foreseen the prevalence of child abuse as it has now been established by a variety of surveys, and no one could have predicted that case reports would rise from the 7,000 to 8,000 range in 1968 to over 700,000 case reports in the last year. In the household survey reports, the estimates far exceed the case reports.

With respect to sexual abuse, it appears that 1 in 10 boys and 1 in 5 girls will have had one or another sexually victimizing experience by the time they reach the end of adolescence.

With respect to physical abuse, it is clear from the surveys that there are between 1 million and 4 million serious incidents each year, and that 3 in 100 American children will at one or another time face their parents with a knife or a gun.

Senator DENTON. Excuse me. Could you repeat that last sentence, please?

Mr. NEWBERGER. At one or another time, 3 in 100 American children will face their parents with a knife or a gun.

This is from the survey by Murray Straus, Richard Gelles, and Suzanne Steinmetz, published in the book, "Behind Closed Doors," 2 years ago.

Now, in every State we face a vexing and cruel dilemma. In many cases the only way that social services such as homemaker services, daycare services, or social work counseling services can be gotten to families is by the making of a child abuse or neglect case report. What used to be child welfare services in this country have increasingly become child protection services.

And the question now needs to be raised: Are they indeed protecting children? Well, without question in my view in many cases they are. But in many cases, they are not.

Sometimes the only resources which are available are hurtful. In many localities, children are placed in foster home care at the first rather than as the last resort. There, they can languish unattended for many years. Often the physical and psychological handicaps which may have led to problems with their parents in the first place go unattended.

More frequently, the reports themselves are incompetently addressed, and the situation, with respect to the provision of child protection services in this country at this time in my view is nothing less than scandalous. This has resulted in several class action suits around the country and in several court orders to ameliorate these services.

There is a rich irony in this. The promise implicit in the child abuse reporting laws has become an empty promise for many children. This is all the more regrettable in light of present knowledge about what we can do effectively to treat and to prevent child abuse.

Unfortunately, however, the issues go beyond the acts of reporting. I would like to report briefly on a study that my colleague, Robert Hampton, a sociologist at my hospital and at Connecticut College, are completing, which suggests that it is class and race, not severity of injury, that may drive hospital reporting of child abuse.

We have done an analysis of the national incidence study, which the National Child Abuse Center in response to this legislation submitted to the Congress. We looked at patterns of reporting from hospitals around the country and attempted to dissect from the estimated 77,000-odd cases that were seen between 1979 and 1980 which factors identified who would be identified and reported for what.

Hospitals, as you would expect, identify many more cases of physical abuse than other agencies. This is a study that was unique in its ability to measure which cases were selected for reporting, the first such systematic undertaking of its kind.

The ethnic and social class distributions of the report suggest a significant underreporting of white and more affluent families. Serious injuries were often unreported. Fewer than half the cases which should have been reported were not reported. The findings suggested that class and race, not severity, defines who does and who does not get reported by hospital personnel.

And it suggests that the reporting process contributes to a widespread myth in this country that the families who abuse their children are poor people, members of ethnic minorities, and members of socially margin populations. The problem we face, it seems to me, is that when we identify problems as poor people's problems, we often mandate poor services for them.

To make matters worse, we have unfortunately a trend across the country increasingly to criminalize child neglect and child abuse, to make reports to police and to district attorneys where the social work agencies are failing.

At issue, I will say in closing, is not whether to narrow the child abuse reporting laws. I think this must be done. The question is whether or not we are going to provide help or punishment to these families.

I very much favor a redirection of our resources in the direction of prevention and with respect to those uncharted areas of knowledge that will enable us to use what we have in a more parsimonious and efficient way.

Thank you very much.

[The prepared statement of Mr. Newberger follows:]

THE HELPING HAND STRIKES AGAIN

Unintended Consequences of Child Abuse Reporting

Testimony given before the Subcommittee on Family and Human Services,
Committee on Labor and Human Resources,
United States Senate

April 11, 1983

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Twenty years after the publication of the influential medical report, "The Battered Child Syndrome,"[1] it is well to reflect on the significance and the effectiveness of the modern child protection movement. This paper stimulated an outpouring of editorial concern in professional and lay media. The U.S. Children's Bureau promulgated a model child abuse reporting law. By the late 1960's, all states had laws mandating the identification and reporting of abused children. Although the problem had been documented for as long as we have had records of mankind, and notwithstanding a century-old activism against cruelty to children in the United States, it is notable that it took a medical article, and a recasting of child abuse as a medical syndrome, to stimulate a broad national concern.[2]

In retrospect, it is notable that this concern coincided with the civil rights movement of the 1960's, a time of concern for the rights of disadvantaged people, including children, a time when it was widely believed that state and national governments had not only the ability, but the responsibility, to provide, protect, and shelter where families could not.

By the early 1970's, a substantial clinical literature and experience had accrued. It came to be generally understood in professional circles that people who abused children only rarely were cruel, sadistic murderers. They were troubled, burdened by psychological and family problems; and they could, and should be helped, through treatment, more adequately to protect and to nurture their offspring.[3] Case report statistics suggested that far the majority of the victims lived in poor families.[4]

A humane philosophy of intervention evolved in the first decade after the publication of "The Battered Child Syndrome" article. Physical child abuse, and its intervention, was increasingly perceived to be associated with other human problems which could respond to an infusion of professional attention and personal good will and affection: child neglect, child sexual abuse, and deprivation of medical, educational, and moral supports for a child's growth.

In February, 1971, a U.S. Senate Subcommittee on Children and Youth was created. With no authority over existing programs, it became a forum for advancing proposals made at the 1970 White House Conference on Children. The need for a coherent federal role in the identification, prevention, and treatment of abused and neglected children stimulated the drafting of legislation. The discussions, and politics, which culminated in the signing of Public Law 93-247 in 1974 have been described clearly by Ellen Hoffman, who served as Staff Director of this Subcommittee. Among the points of conflict at the time were the extent to which resources should be committed to research or services, and the appropriate role of the federal government. In Ellen Hoffman's words:

> "Another priority question revolved around whether the limited resources under the Act should be directed primarily at the children who are abused, children who are neglected, or both. The original Senate bill did not even define "abuse" and "neglect." It was felt to be unnecessary because the law was to be a program of services, research and the like, not a punitive or regulatory measure. Moreover, an attempt at a federal definition might work unnecessary hardship on states and localities, which already had widely varying definitions in their own laws. The House, however, did insert a definition that included not only physical but also mental injury.
>
> "The authors of the bill had no illusions that it would service all of the families implicated by reports of abuse or

neglect so widely defined. This was a political judgement based on the recognition that funds available for the new program would not be adequate to provide services even to those children and families already defined as needing them.

> "Thus, although there is not statutory statement, the legislative history (testimony, committee reports, and floor statements) reflects the clear intent of Congress that priority be given to helping children who are the victims of physical abuse."[5] (pp. 168-69)

This may have been the intention, but many physicians and social workers in this field of practice, and officials in the Children's Bureau, appear to have construed the mandate for the National Center on Child Abuse and Neglect differently. When the time came to stipulate a definition of child abuse in state statutes as a condition for eligibility for the states' shares of federal funds, officials in the Department of Health, Education, and Welfare defined child abuse broadly, and they elaborated a long list of professionals to be mandated to report. This action was taken notwithstanding a growing concern among a different professional community that unless the flow of case reports into the child welfare service system were controlled, the system could be overwhelmed. This view was expressed, in fact, in the report of an expert commission to study child abuse reporting.[6] The debate between the service idealists, who would open wider the portals of entry in the service system, and the civil libertarians, who were concerned with the prospect of more incompetent and damaging intrusions into family life, appears to have been resolved in favor of the idealists.[7]

At this time, no one could have foreseen that the prevalence of child abuse, however narrowly defined, was far greater than was believed at the time of the publication of the "Battered Child Syndrome" paper or the signing of Public Law 93-247. Where 7000 to 8000 reports were received nationally in 1967 and 1968, over 700,000 were received in 1978.[8] Estimates of severe inflicted injuries to children deriving not from case reports, but from household surveys, range from one to four million incidents per year.[9,10]

Nor was it possible to predict that the humane and generous expansion of social programs during the administration of Lyndon Johnson would contract in the years since the national child abuse program was passed. I have no doubt that had professionals like me known then what we know now, we would never have urged on Congress, federal officials, and state legislators broadened concepts of child abuse as the basis for reporting legislation.

For we now see in every state a vexing and cruel dilemma. In many if not most jurisdictions, the only way to get social services such as day care, homemakers, and counseling to children and parents is to make a child abuse or neglect case report. Child welfare services have to a great degree become "protective services." Are they protecting children? Without question, in many cases they are. A higher level of awareness of child abuse and neglect among professionals, parents, and children, has led to the timely identification, and certainly the rescue, of many families in jeopardy.

But in order to help a family, a physician like me must, in effect, condemn the parents with a diagnosis that means, implicitly, that they are bad parents. Sometimes, the only resources available are hurtful. In many localities, children reported as victims of neglect or abuse are placed in foster home care as the first, rather than the last resort. There, ironically and tragically, they may languish for years, often shuttled around from foster home to foster home, and their health and emotional needs are often cruelly neglected by the very system designated to serve them.

Or, perhaps more frequently, the reports are unattended, or are given the most superficial screening and review. Then, children may suffer more grievous harms until their injuries may come to light in the criminal courts, where their parents may be prosecuted, or in the ever more frequent news exposés of failures in child protection programs.

This scandalous situation has resulted in several class-action law suits, in which those initiated in Massachusetts by the Massachusetts Committee for Children and Youth and by Greater Boston Legal Services have recently led to court orders assuring a child's right to a timely investigation when she or he is the subject of a child abuse or neglect case report and specifying the maximum caseloads which protective service social workers can carry.

Ironically, the promise implicit in the child abuse reporting laws has become an empty promise for many children. This is all the more regrettable in light of present knowledge about what we can do effectively to treat child abuse.[11]

The issues we face in this area of practice go beyond the acts and the consequences of reporting, however. They have to do also with some fundamental realities of the provision of medical care and social services which are uncomfortable to mention aloud in the halls of the Senate.

My colleague Robert Hampton and I are completing a study of hospital recognition and reporting of child abuse which documents, to the extent that we can determine for the first time, the pervasive significance of class and race in defining who gets identified and reported for what.[12] The findings are disturbing.

The study is a secondary analysis of the National Study of the Incidence and Severity of Child Abuse and Neglect of the National Center on Child Abuse and Neglect, the data for which were collected between May 1, 1979 and

April 30, 1980. A careful effort was made to collect data on a sufficient number of subjects to permit an extrapolation to the national experience. Eight hundred and five cases of child abuse and neglect came to the attention of the hospitals in the study during the year of examination. A projected estimate of 77,380 cases of abuse and neglect suspected by hospital professionals was derived from this number by weighting and multiplying these reports, employing standard sampling methods. Strict criteria for inclusion in the national incidence measurement had been articulated, and 35,088 cases fell within the scope of these definitions. Compared to other agencies in the sample, hospitals identified children who were younger, who had younger parents, and who contained relatively higher proportions of families in urban areas (65.8% vs. 42.1%) and who were black (25% vs. 16%). There were no major differences between the hospital and other agencies with respect to income, mode of medical payment (public or private), proportion of single parent families, sex of the child, and other demographic factors.

Nationally, approximately 652,000 children met the operational definitions of abuse and neglect during the study year, of whom 212,400 would have been known to the local child protective service agencies.

Hospitals identified many more cases of physical abuse than did other agencies. (The proportion of cases in this category alone exceeded the proportion of physical, sexual, and emotional abuse cases recognized by all the other agencies; over half the hospital cases were in one or another category of abuse.)

The study was unique in its ability to measure which cases were selected for reporting. Never before had a systematic effort been made to identify cases before reports were made and to ascertain the differences between the cases which were reported and those which were not.

The ethnic and social class distributions for all children reported to child protection agencies as alleged victims of abuse or neglect were similar to the sample distribution, but there was significant underreporting of white and more affluent families.

Surprisingly, notwithstanding the fact that hospitals identify more serious cases of child abuse and neglect than other agencies, serious injuries were often unreported.

Although hospitals reported cases of abuse and neglect within the scope of the study definitions more frequently than did other agencies, they failed to report almost half of the cases which should have been reported.

A more penetrating analysis studied in detail the differences between reported and unreported cases. The following factors appeared most powerfully to affect case reporting: income, the role of the mother in maltreatment, emotional abuse, race, the employment of the mother, sexual abuse, emotional neglect, the number of vitims, and the education of the mother. Disproportionate numbers of unreported cases were victims of emotional abuse, in families of higher income, whose mothers were alleged to be responsible for the injuries, and who were white.

These findings suggest that class and race, but not severity, define who does and who does not get reported by hospital personnel to child protection agencies.

They suggest that the reporting process contributes to the widespread mytrology that these problems are confined to people who are poor or who are members of ethnic minorities. This myth, that families who abuse their children are different from the rest of us, has led this country to identify child abuse and neglect as "poor people's problems," for which we have created traditionally programs of poor quality, programs, which like the current national child protection program, may mete out punishment in the guise of help.

As if this were not enough, we now find across the country a movement to remedy the problems in the overburdened child protection agencies by making it required for professionals to report cases to police departments and to district attorneys. The failures in our ability to provide help to troubled individuals and families are, it would appear, being addressed by criminalizing family problems and, unfortunately, demeaning those professional groups, especially social workers, who are best able to provide help to abused and neglected children and their parents.

The data from our study suggest that were reports to be mandated to more intrusive, and punitive agencies, even fewer white and more affluent families would be reported. Child abuse and neglect will appear even more to be the poor people's problems than we may want them to appear to be.

To make matters worse, the Department of Health and Human Services has now promulgated a regulation which requires that incidents where severely handicapped infants are denied medical services to assure their survival must be reported on a toll-free number to a national clearing house or to local child protection agencies. Signs are to be posted in all nurseries to announce this policy. Hospitals which do not comply risk losing federal reimbursements for services, training, and research.

This policy imposes an inappropriate burden on agencies which are inadequately equipped to do what they are supposed to do, and which are manifestly unprepared to investigate medical practices, parental suffering and grief, and hospital professional procedures. It represents a further extension of the notion that through the provision of child protective services, we police, and control, family life.

The child protection movement in this country is now at an important crossroads. We must decide whether our objective is, truly, as the laws state, to protect children and to strengthen families by offering help to them.

By its very nature, child abuse and neglect case reporting leads to intrusions into the family. This is necessary to assure the protection of thousands of children each year.

My concern is that reporting as a way of getting services to families may no longer be an effective national policy to treat child abuse. Rather, we should consider the needs of all the children who might be vulnerable to maltreatment. Through a national program focused on prevention, addressed to every family, we should be able effectively to put to use our existing knowledge.[13]

The essential question with regard to child abuse reporting is not whether to narrow the definitions; it is whether reporting is to be the method we chose to treat the problem. Reporting has not been a wholesale failure; but it has not been an unqualified success. Reporting of child abuse must now be supplanted by a marshaling of resources toward prevention, along with an effort to train, among others, physicians and medical workers, more appropriately and wisely to make use of preventive and therapeutic resources.

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Prevention of Child Abuse: Theory, Myth, Practice

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ABSTRACT

The focus of professional and public concern with child abuse has been on identification and reporting of the victims: Prevention is largely ignored. This is in part due to an intellectual failure to come to terms with theoretical issues of causality. The frailty of the theory base may be more responsible for the failure of programs to treat child abuse than the lack of intervention resources.

The explanatory theories of child abuse are classified into unitary and interactive theories. The former predominate. Although each theory contains important insights and action implications, the narrowness of each explanatory framework also contributes to prevailing myths about cause, prevention and, cure. Unitary psychodynamic theory defines and limits much current protective service work. The focus on individuals and the belief in the curative value of love and talk obscures familial and social dimensions and confines intervention. In ecologic theory, child abuse is seen as a symptom of disturbance in a complex ecosystem with many interacting variables. It provides a more holistic conception of cause and effect, with more useful implications for prevention.

Politically plausible preventive actions are suggested, derived from theories of etiology. Prevention must be broadly conceived at levels of individual, community, and society, to be effective.

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PROFESSIONAL AND public concern with the increasingly visible problem of child abuse has focused primarily on identification and reporting of the victims. Where in 1967 there were fewer than 7,000 case reports, there were more than 700,000 in 1978.(1,2) Virtually every professional in contact with children is obliged by law to report suspected cases. In the absence of sufficient personnel and in an inadequately developed and managed national child welfare program, much harm is done to children and families in the guise of helping them.(3) This has led to recommendations from groups such as the Carnegie Council on Children and the Juvenile Justice Standards Project of the American Bar Association to recommend greatly limiting the reach and authority of child welfare and protective services and family and juvenile courts.(4,5)

The president of the City Council of New York City announced on October 9, 1979 that her office would investigate the city's system of providing foster home care. She cited a death rate among the city's foster children that is nearly twice the national average and noted that 18 foster children in the city's program had died since the beginning of the year, with at least five of the deaths attributed to maltreatment by foster parents.(6) Other inquiries suggest a bleak picture of services for victims of abuse and neglect even though they are reported as law requires to child welfare agencies.(7,8) A recent court initiative by the Massachusetts Committee for Children and Youth attempts to redress the disparity between the promise of help implicit in the reporting laws and the failure of the protective service effort by asserting a legal (as well as moral) right for children to be protected by the state from abuse and neglect in their homes.(9) It is well to note that this concern and activism is necessary despite public pronouncements of support for children. 1980 was the International Year of the Child and the 20th anniversary year of the United Nations Declaration of the Rights of the Child that codified a child's right to protection from harm: "The child shall be protected from all forms of neglect, cruelty, and exploitation."(10)

What accounts for the failure adequately to provide services that protect children from harm, despite clear public statements of concern and well-developed mechanisms for reporting children who are at risk? This discrepancy may be explained in part as a consequence of limitations in the ways in which we think about the causes of child abuse, which give rise to myths about its prevention and treatment, reflected in turn by policies that do not work.

THE IMPORTANCE OF THEORY CONSTRUCTION

In the child abuse literature, insufficient attention has been given to the nature of the processes whereby etiologic formulations are made and tested, and thus to the validity of the theories used to explain, and to generate strategies to prevent and to treat child abuse. The frailty of the theory base may be more responsible for the failure of programs to treat child abuse than the lack of intervention resources.(11) To target adequately efforts at prevention will require first a reckoning with the etiology of child abuse. This, in turn, cannot be understood without a formal coming to terms with the assumptions and limitations implicit in various theoretical approaches.

The process of theory construction in regard to child abuse began in 1962, when Henry Kempe and his colleagues at the University of Colorado Medical Center surveyed the landscape and called to public attention something that physicians hadn't noted before, that children were being injured nonaccidentally. He called this "The Battered Child Snydrome."(11) The process began with the discrimination of a phenomenon and giving it a name.

Even though child abuse was known to exist for centuries, it was not identified as a discrete entity apart from a swirl of childhood misfortunes associated with tumult in family and society. The next task in the development of the field was the generation of hypotheses about why this phenomenon occurred. At this early point in the development of theory simple cause and effect relationships were identified. In other words, the implicit assumption in the search for etiology was that a single powerful factor could be found that would universally explain why children are abused. As several factors were identified, one by one, each gave rise to unitary theory, i.e., a single factor formulation of the origins of child abuse, and each theory carried with it implications for action.

For example, child abuse has been explained as the direct product of parental psychopathology.(12) With a unitary psychodynamic theory, parental psychological characteristics are considered the primary determinants of child abuse, and must be understood in order for a treatment to take place. This theoretical orientation in fact, guides most modern child welfare work. As with all theories, its action consequences derive from how the problem is understood. And to a great extent the limits of current protective service work derive from a relentless focus on individuals and a collective belief in the curative value of love and talk.

As the field has developed, there has been an increasing appreciation for the variety and complexity of etiology, which has produced an approach to theory that can be described as interactive. In other words, etiology is understood not as the product of a single powerful factor, but as the consequence of interactions among several factors. For example, child abuse might be explained as the consequence of effects of stress on vulnerable personality types. The action consequences would include attention both to situations or conditions that produce stress, as well as counseling around es of personal adaptation.

Much of the thinking in the field, however, still rests on unitary hypotheses, and these have given rise to myths of cause, prevention and cure that have hampered efforts to effect meaningful change.

In Table I are outlined major theories that have been applied to explain the etiology of child abuse; myths of cause, prevention, and cure that have arisen from too narrow a focus on one or another of these explanatory formulations, and practice implications contained within these approaches.

Each of these unitary theories has provided a focus and generated research that has expanded our understanding of the origins of child abuse, but they are each limited to one explanatory lens focused on one part of a complex picture. As a field develops in its search for an adequate theory base, the limitations of the unitary theories become clear to some thinkers. For example, with regard to psychoanalytic theories, the few controlled studies suggest that only a few of the abusing parents show severe neurotic or psychotic characteristics and that child abuse may be associated with several parental personality types.(14)

TABLE I UNITARY THEORIES OF ETIOLOGY IN CHILD ABUSE: THEORY, MYTH, PRACTICE

Theory	*Myth*	*Practice*
Psychoanalytic: Child abuse is a product of parental psychopathology.[illegible]	Parents who abuse children are "ill" and require professional intervention for prevention and cure.	Psychotherapy and/or counseling
Learning: Child abuse is a behavior learned from the experience of having been abused as a child. Parents model abusive parenting for their children.[illegible]	Children who are abused grow up to abuse their own children.	Parent education, and reeducation to learn nonabusing techniques
Attachment: Child abuse is a consequence of early separations between mother and child that interfere with the process of forming a protective bond of closeness and love.[illegible]	Parents who abuse their children are not "attached" to or do not love their children. There is a critical period during which attachment must occur.	Preventive attention to the provision of contact between mother and newborn, i.e., encouraging rooming-in and handling of prematures.
Stress: Child abuse is a product of poverty and other factors that stress families, including sexual and economic inequality.[illegible]	Short of a social revolution, preventing child abuse is impossible.	Advocacy to reduce or eliminate sources of stress in individual families. Political action directed toward social change. Community services to support persons in times of stress.
Labeling: A child abuser is a person to whom the label has been successfully applied. By labeling some (usually socially marginal) parents as deviant (i.e., abusive), others do not have to acknowledge their own abusiveness toward children, and their own personal and professional interests are served as it creates a need for the "helping" professions.	Paying attention to persons identified as abusive is a cover-up of the wider violence in our society.	Social action directed toward a change in values about violence and inequality in our society.

Even for those individuals in whom individual pathology is found, the unitary psychoanalytic theory does not necessarily explain the presence of a history of child abuse. A particular psychiatric diagnosis does not predict abuse. The theory does not in itself enable a differentiation between parents with a given diagnosis who do and who do not abuse a child.

The stress theory is also unsufficiently comprehensive. Obviously, not all poor or stressed families abuse their children. A history of poverty is disproportionately representated because of the large number of lower class families who receive services from institutions that report the large majority of cases, and from which research samples are drawn. And although poorer families are more likely to be given the child abuse label, it would be a grave disservice to dismiss their very real problems as socially defined, or to interpret those who seek to help them as acting only to maintain their own social dominance.

While socioeconomic factors might sometimes place added stresses on basic personality weakness, these stresses are, of themselves, neither sufficient nor necessary causes of abuse. This model neglects *internal* sources of family strength and stress that render individual families more or less sensitive to external circumstances and events. It does not address qualities of the interaction between and among family members and their importance to a family's capacity to nurture its young, nor does it adequately account for parental dysfunction in seemingly privileged homes.

We are now at a point in the development of the field where we are moving from unitary to interactive theories of child abuse. We can recognize that a theory of psychopathology is inadequate without the integration of the factors in the individual and in his or her history and environment that render him or her vulnerable to psychopathology and to its particular expression of child abuse. An environmental theory is inadequate without the integration of those personal and social qualities, experiences, and characteristics that render the individual vulnerable as a parent to the eroding effects of poverty and stress.

An integrative approach seeks to define how one aspect of experience mediates the effects of another, in order better to understand what renders some families vulnerable and other families strong.

With the development of a field from a set of unitary theories to a set of integrative hypotheses, investigations shift in focus from trying to find *the cause* to enabling the identification of individual differences in etiology. We will need basic research into the identification of the many variables that are implicated in child abuse, but the focus is on elaboration rather than closure.

It is in what has come to be called ecologic theory that major strides have been made in understanding and dealing with the interrelationships among attributes of child, parent, family, and social setting. Child abuse is seen in this theoretical context as a symptom of disturbances in a complex ecosystem with many interacting variables. We and our colleagues on the Family Development Study have reported elsewhere on findings of a large epidemiologic study at the Children's Hospital in Boston,(20) and Garbarino and Starr have reported on large data sets in New York and Michigan.(21,22) These studies lead to what David Gil called a more holistic notion of child abuse and its prevention, with a conceptualization of cause and effect that operates at different levels (individual, family, society) and with different modes of etiology for different children and families.(23) A decade ago, Julius Richmond coined the notion of a family's ecology of health. This seems now to be an especially relevant concept for the understanding and study of child abuse.(24)

CHILD ABUSE PREVENTION

Because child abuse is a complex problem with multiple causes, prevention strategies must be comprehensive and operate at the different levels of individual, community, and society. Each of the theoretical approaches discussed above contains important implications for prevention. The following measures are among the politically plausible prevention initiatives that show promise of an effective impact.

From Psychoanalytic Theory

1. Acknowledge the importance of mental health to the functioning and well-being of children and families by formalizing a conception of health that includes emotional as well as biological health. This can be achieved through the training of physicians and others to recognize and attend to emotional as well as physiological issues in practice, and by providing third party reimbursement for performing "as the patient's advisor, counselor, and health advocate."(25)

From Learning Theory

2. Give parents access to information and understanding of child development, including nonviolent methods of socializing their children.(26)

From Attachment Theory

3. Elevate the parent-child relationship to an appropriate position of respect and importance in clinical practice, through facilitating the formation of bonds of attachment at birth, by preventing prematurity through prenatal care, humanizing the delivery experience, bringing fathers into the delivery room and emphasizing their supportive role toward mothers and their participation in child care, and by encouragement of paternity as well as maternity leaves from employment.(27)

From Stress Theory

4. Provide quick telephone access to parents at times of distress with their children through hotlines.(28)

5. Make available to all children health and mental health well child care, diagnosis, and treatment. Children who are sick or handicapped may be more vulnerable to abuse.(29)

6. Make available emergency homemaker and/or child care services to families in crisis.(30)

7. Reduce social isolation by making universally available such avenues of access to other people as telephones and public transportation.(31)

8. Support existing community institutions such as churches and women's organizations that offer support and a sense of community and of personal value to their membership.(32)

9. Empower women. Acknowledge the extent to which sexual dominance and subservience ramifies both in the abuse of women and children and in professional settings where male-dominated, symptom-oriented professions (medicine, surgery, law) hold sway over professions composed mainly of women (social work, nursing, child care).(33)

From Labeling Theory

10. Remove the stigma from getting help with family problems by detaching protective service programs from public welfare agencies. Abandon the heavily value-laden nomenclature of "the battered child syndrome," "child abuse," and "child neglect" in favor of a broader and more humane conception of childhood social illness. Increase the sensitivity, timeliness, and competency of medical and social work practice.(34)

11. Expand public awareness of the great prevalance of child abuse and domestic violence, and disassemble the conventional wisdoms attaching child abuse to deviant and minority individuals and groups, placing emphasis on the reality that the potential for violence is in all of us, and priority on individual and social action to interevene when violence occurs.(35)

CONCLUSION

Systematic attention to the prevention of child abuse will force a needed communication among clinicians, social scientists, and architects of social policy. The National Center on Child Abuse and Neglect in Washington can guide this effort through the implementation of its comprehensive plan for the prevention and treatment of child abuse which was mandated by Congress in the continuation of Public Law 93-247 in 1977.(36)

The development of a theory base that enables a competent analysis of the many kinds of family problems that culminate in the physical symptoms of child abuse and neglect will guide an intelligent prevention program. Not only is better knowledge needed, in terms of understanding the nature and distribution of different families' problems, but a much more adequate understanding of the factors that enable parents to cope and the social-demographic and familial ramifications of parent and child competency and strength. These, in turn, will permit the development of a more appropriate and rational practice and a useful intellectual foundation for prevention.

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Child Abuse: The Current Theory Base and Future Research Needs

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Contained in each causal explanation for child abuse is a theory of etiology. The nature and quality of our knowledge is approached in this paper from a review of studies of the impact of abuse on children, for which a critique of methodology is given. The relation between theory construction, study, and clinical action is addressed. Recommendations with respect to the focus and content of future research are made.

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Definition and Prevalence

Child abuse has been noted to have many causes: as a childhood symptom of mental illness in parents, as the culmination of a lifelong experience of violence toward the caregiver, of environmental and social stresses on the family, and of society's acceptance and promotion of physical violence. Contained in each causal explanation is a theory of etiology. And within each theory, researchers extract from the complexity of families' lives those particular factors that are believed to be causal agents for violence against children. Clinicians are frequently frustrated by the limited focus and use of the diverse theories on child abuse. In order to select which factors to study, researchers must exclude other factors. Clinicians, facing a variety of distinctive life events, personal characteristics, and unique circumstances of the families and children they serve, are not always content with the explanations for the origin of child abuse found in the research literature.

Child abuse and child neglect are catch-all euphemisms for a variety of childhood injuries that are believed to be derived from parental acts of omission or commission. The diagnostic tags focus attention on symptoms and propose entirely too simple formulations of etiology. In this paper, child abuse refers to the many problems suggested by child abuse and child neglect. This is to focus more on the causes than on the manifestations of child maltreatment.

By the middle 1960s, after a model Child Abuse Reporting Law was promulgated by the U.S. Children's Bureau, every state adopted one or another form of child abuse reporting statute. In 1979, according to The National Center on Child Abuse and Neglect in the U.S. Department of Health and Human Services, over 711,000 reports were received. This represented a 10-fold increase in the course of a decade.

Although the true prevalence of child abuse is unknown, the concern regarding the consequences of abuse is, for individuals and for our society, universal. We address at the outset of this paper what we know of the impact of child maltreatment on the child. From this discussion will emerge a general impression of the nature and quality of our knowledge, with focus on theory and methodology of study.

Impact of Abuse on Children

The clinical literature on child abuse contains many assumptions about the consequences of child abuse for the victim, his or her family, and society. For example, Schmitt and Kempe (1975) assert that the dangers of child abuse extend beyond harm to the victim: "If the child who has been physically abused is returned to his parents without intervention, 5% are killed and 35% are seriously reinjured. Moreover, the untreated families tend to produce children who grow up to be juvenile delinquents and murders, as well as the batterers of the next generation" (p. 111).

Such concerns on the part of clinicians derive in part from the frequently noted multigenerational nature of identified clinical cases of child abuse: the parents of abused children are often themselves perceived to have been abused and neglected in childhood (Steele and Pollock, 1974). In adulthood, the parents may have more frequent drug and alcohol abuse, criminal behavior, and psychiatric disturbance (Smith et al., 1975), leading to worry about what will be the fate of their offspring. Concerns about the developmental sequelae of child abuse are also supported by the

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observations of psychiatric workers on the behavior of small numbers of abused children in clinical and laboratory settings (Galdston 1971; Martin et al., 1974; Silver et al., 1969).

Corroboration for these small studies is found in reports from the Select Committee on Child Abuse of the Legislature of the State of New York (Alfaro, 1973, 1977). In a study of 4,465 children and siblings who were reported as victims of maltreatment in the early 1950s in 8 New York counties, between 10 and 30% were identified in subsequent agency contacts for several categories of juvenile misconduct. In 3 counties, [illegible] of the girls and 35% of the boys reported to a court as delinquent or ungovernable and had been previously reported as abused or neglected. The strength and stability of the association between reported maltreatment and juvenile misconduct was subsequently examined in reference to the sex, religion, ethnic status, and family composition of the subjects; the disproportionate representation of nonwhites and the prevalence of absent fathers (41%) and mothers (15%) was discussed in relation to existing knowledge about the etiology of child abuse and neglect and the dynamics of case reporting and intervention (Carr, 1977). Left open in the discussion, and unfortunately not susceptible to definitive analysis in this sample, is the extent to which the preferential selection of poor children both for reporting for maltreatment and for delinquency may have affected the perceived association and the extent to which poverty per se may have determined both problems. Such an analysis would best be conducted on a sample generalizable to all maltreated children in New York and controlled for certain potentially confounding attributes (Newberger and Daniel, 1976).

In the single controlled study referenced above (Smith et al., 1975), a failure to match cases and controls on social class led to a serious confounding by social class in the analysis. Abusive parents were found to have a number of social and psychiatric problems in relation to the comparison group, but the contribution of a critical third factor, poverty, could not be extricated from the case-control differences because the cases were significantly poorer than the controls. The New York State study, though impressive in numbers and worrisome in conclusions, is further difficult to interpret because it is both biased to favor poor children for selection, and uncontrolled.

The contribution of Elmer (1977a, 1977b) brings into focus the limited state of our understanding of the long-term effects of child maltreatment. Her findings suggest that we must attend to the social and familial circumstances which equally affected the outcomes of cases and controls. The study concludes "that the effects on child development of lower-class membership may be as powerful as abuse" (Elmer, 1977b, p. 80).

Elmer's "follow-up study" (her characterization) was composed of 17 abused children and 17 children who were victims of accidents, matched in age, sex, race, and socioeconomic status of their families. Each of these "traumatized" groups was matched with a group of children who had not suffered early trauma on these variables, in addition to the attribute of early hospital admission. Nine still intact "abusive families" were identified from the original case pool and were studied intensively in regard to the stability of demographic characteristics, indices of personal and social support for parents and children, mother's behavior in relation to the child, and the following attributes of the children: health; language and hearing; perceptual-motor coordination; school ability and achievement; and behavior, focusing especially on impulsivity, aggression, and empathy.

The startling paucity of case-control differences in this study is described with candor and humor: "When the follow-up study was completed, we were at a loss to explain the lack of significant results differentiating between the abused, accident, and comparison groups or any of the subgroups. Across the board, there were very few differences between the groups, and these were relatively minor. The follow-up staff was astonished and disbelieving. It then turned out that several of the examiners had kept a private tally, showing their opinions of the classifications of each child. In no case had these tallies been correct any more often than would be true of selections made purely by chance. In addition, the clinicians' opinions had differed for individual children, showing that their combined judgments could not effectively differentiate the groups" (Elmer, 1977; p. 275)

The implications of Elmer's study have been discussed elsewhere in detail in a discussion for pediatricians and others concerned with child health (Cupoli and Newberger, 1977). We noted that the findings suggest that health or social intervention alone will allay the developmental impact neither of abuse nor of poverty, for both the case and the control groups suffered impressive developmental losses, despite the provision of medical and social services.

This is not to say, however, that abuse—or poverty—dooms a child to failure. If a child and [illegible] family have available and can participate in several well-conceived and administered intervention opportunities, a child's prospect for healthy psychological growth is enhanced. Martin (1976) points out in the summary of his book on the abused child: "We have especially focused on treatment for developmental delays and deficits, crisis care, psychotherapy and preschool or day care. . . . These various treatment modalities for the child have worked. They have made possible considerable growth and development in the abused child. They should be considered as treatment options for all abused children" (p. 93). Martin's study has serious limitations, as will be addressed subsequently, but his descriptions of intervention and conclusions about their relationship to the children's development are useful and persuasive.

Such comprehensive programs for disadvantaged families as the Maternal and Infant Health programs of the Department of H.H.S. have yielded important and encouraging results in child health and development, and analyses of the data and issues in the heredity-environment controversy suggest that a nurturant and supportive environment can permit the natural unfolding of a child's best qualities and capabilities (Martin, 1976). Many materially poor families are able to provide sufficient love, stimulation, and discipline to enable their offspring to grow and develop well. But, to paraphrase a contribution to this discussion by Wolff (1976), so long as poverty persists, we will have the technical wherewithal neither to anticipate nor to prevent its damaging consequences on parents and children.

In assessing the meaning of the Elmer (1977b) study, it is well also to attend to the apparent developmental resiliency of the abused children, in comparison to those in the control group. The strengths of these children lead inevitably to critical questions about the pathologic orientation toward both children and parents implicit in current practice and in other research.

A critical review of the conceptual bases, design, methodology, and instrumentation of currently available work on the developmental impact of child maltreatment suggests that many investigators begin with an ominous portent of doom and select small uncontrolled samples, generally from severely impoverished populations, and examine them with psychologically focused, loosely quantified tools.

These reports on the physical, social, emotional, and cognitive developmental consequences of child abuse yield inescapably to an impression of serious and profound pathology in the victims, but analysis of these studies demonstrates the following major methodologic flaws which limit their generalizability, scientific validity, and utility for building theory and for guiding practice:

1. Bias of selection favoring poor children (de Castro et al., 1978; Galdston, 1965, 1971; Morse et al., 1970; Silver et al., 1969; Starr, 1978);

2. Sample size inadequate to form claimed associations (Galdston, 1965; Koel, 1969; Lynch, 1976; Sandgrund et al., 1975; Silver et al., 1969);

3. Lack of a comparison group (Galdston, 1971; Koel, 1969; Martin et al., 1974; Silver et al., 1969);

4. Inadequate matching of cases and members of the comparison group on socioeconomic status and other variables, leading to consequent confounding by poverty or other spurious attributes (Lynch, 1976; Morse et al., 1970);

5. Imprecise definitions of child abuse or neglect (Galdston, 1965, Koel, 1969; Lynch, 1976; Martin et al., 1974; Morse et al., 1970; Sandgrund et al., 1975; Silver et al., 1969); and

6. Conceptual framework restricted to psychodynamic dimensions (Galdston, 1965; Glaser et al., 1968; Martin et al., 1974).

If the knowledge base on the impact of maltreatment on children appears to be insubstantial, there is no paucity of recommendations for intervention and treatment based on current presumptions and fears. These have been reviewed by us elsewhere in relation to the state of our understanding of child abuse epidemiology (Newberger and Daniel, 1976), the principles and implications of current practice (Newberger and Hyde, 1975), proposals to screen children for risk of maltreatment (Daniel et al., 1978), the functional implications of present classification systems for childhood illness of familial and social origin (Newberger et al., 1977), the approach to maltreatment in child health and legal policy (Bourne and Newberger, 1977; Newberger et al., 1976), the implications for social policy of child maltreatment research which focuses on samples which are disproportionately representative of families which are poor, socially marginal, or of ethnic minorities (Daniel et al., 1978; Newberger and Daniel, 1976), and the extent to which family crisis and childhood injury has become overly professionalized (Newberger and Bourne, 1978). In brief summary, despite the speculative nature of the prevalent conclusions about the developmental sequelae of child abuse, professional warnings support a practice of separating children from their natural homes in the interest of their and society's protection. They focus professional concern and public wrath on "the untreated families" (Schmitt and Kempe, 1975) and may justify punitive action to save us from their children. The lack of knowledge, or, perhaps more accurately, the inadequate understanding of the state of knowledge promoted by the anxiety which child abuse stimulates in all of us, is translated to recommendations for intervention, many of which are heavy-handed, unspecific, and insensitive; and some of which can be downright harmful.

When populations representative of all children and adults are studied in longitudinal perspective, a picture of development emerges which contrasts sharply with the dismal portraits of maltreatment and its effects. Quite different and more optimistic perspectives on children's growth, development, and adaptation to hardship are offered in the reports of the Fels Research Institute's longitudinal study (Kagan and Moss, 1962), in the more recent publications from the Kauai and Newcastle longitudinal studies of child development (Werner and Smith, 1977), and the Levinson (1978) and Vaillant (1978) studies of adult development. Although the theoretical orientations, cultural contexts, ascertainment and follow-up intervals, and scientific instrumentation in these reports differ from one another (and the Levinson and Vaillant reports are of the development of selected, successful adult men), it is well to note briefly their principal points of convergence with our findings about health, social and psychological competence, and vulnerability. These and our studies argue for a broadened conception of the etiology of developmental attrition, embracing social, familial, and environmental, as well as psychological dimensions.

Several large-scale studies, employing broadly conceived, developmental conceptions of child abuse and its impact, have been granted support recently by The National Center on Child Abuse and Neglect. Their designs and some rigorous thought about the etiology and consequences of maltreatment are reported in the recent issue of *New Directions for Child Development* under the title, "Developmental Perspectives on Child Maltreatment" (Rizley and Cicchetti, 1981).

Importance of Theory to Knowledge, Prevention, and Treatment of Child Abuse

Insufficient attention has been given in the child abuse literature to the theoretical construction of knowledge of the problem. Although this has in part to do with the fascination by clinicians with the bewildering variety of physical and psychological manifestations of the many problems which are characterized as child abuse or neglect, the nature of the process whereby etiologic formulations are made and tested has received scant attention. An insufficient theory base may contribute more to the failure of programs to treat child abuse than the lack of intervention resources (Gelles, 1973, Newberger, 1977). An adequate understanding of etiology is necessary in order to focus intervention efforts where they will be most effective. For example, in a program where child abuse is understood as a product of parental psychopathology, individual counseling is the logical and customary intervention response. The failure of counseling to effectively treat many families in such programs is not parental failure, nor even necessarily a failure of psychotherapeutic skill and compassion. Rather, it is a failure deriving from a theory of etiology which is too narrowly defined to be broadly effective. It is necessary, therefore, to come to terms with the theories which guide work with families in which abuse has occurred and with the assumptions implicit in those theories.

Before turning to the major theoretical approaches of child abuse and their operational consequences for treatment and prevention, it is well to reflect briefly on the uses and construction of theories. All human beings construct theories. Theories are necessary to explain and to contain the complexities of our lives. Some of our theories are better than others. Some have been firmly tested by experience over time. Some are tentative beginnings. Some may be overextensions of theories that fit past experience, but which misfit present realities. Some theories are borrowed from others without examining whether they accurately fit what we perceive, or whether we accurately perceive what we think they fit. Indeed, every theory distorts. In order to select, we must exclude; and our theories of what to look for limit what we see. Yet without theories, we would be helpless to select what is important from what is, and to act purposefully in the world.

The construction of scientific theories is also a process of searching for pathways through experience in order to explain cause and effect. In contrast with personal theories, scientific theories have formal rules for testing the accuracy of their fit with experience. Yet the characteristics of a good theory are not dissimilar for individuals and for fields of inquiry. A good theory must, first of all, make sense. It must account reasonably for a good part of the data or experience, and it must account for that data better than rival theories. It must be plausible to other people searching for pathways through the same terrain. And it must be useful. It must enable one to operate more effectively in the world.

The explanatory theories for child abuse can be classified into two groups: unitary and interactive. The unitary theories are these: psychoanalytic, social learning, environmental, cognitive developmental, and labeling.

The psychoanalytic approach posits that unconscious parental drives and conflicts determine abusive behavior (Galdston, 1973; Steele and Pollock, 1974). In a review of the abundant literature which views child abuse from a psychoanalytic perspective, the primary causes were seen to be in the parents' psychological troubles. Kempe et al. (1962), for example, described the abuser as the "psychopathological member of the family."

Another of the consistent explanations proffered for child maltreatment is that individuals who have experienced violent and abusive childhoods are more likely to grow up to become child and spouse abusers than individuals who experienced little or no violence in their childhood years (Parke and Collmer, 1975). Social learning theory suggests that child abuse is learned behavior. Violence in one's family of orientation is seen as predictive of violence in one's family of procreation.

Environmental theory posits that child abuse results from social and environmental stress. Stressful life events and conditions, such as poverty, unemployment, inadequate housing, and a violent social milieu are prominent factors considered within this theoretical orientation. The perspective emphasizes factors in the environmental context of a family which, by being felt as overwhelmingly stressful, interfere with a parent's ability to care for its children. Child abuse can be viewed as a symptom of distress in a family that compromises its ability to protect and nurture its children.

A somewhat newer approach to understanding child abuse has been offered by research on parental awareness (C. Newberger, 1980). This theory states that child abuse reflects an underlying egocentricity of the parent's understanding of the child and of the parental role. This cognitive-developmental approach identifies four levels of parental thinking about children and the parental role. The developmental level at which parents understand the child and the parental role, is viewed as related to child abuse and neglect (C. Newberger and Cook, 1983).

The labeling theory proposes social inequality as a basis for its approach to child abuse. This theory posits that the interests of dominant power groups are served by defining as deviant a class of socially marginal individuals (the "child abusers"), whose individual problems become the proper concern of the helping professionals (Pfohl, 1977). This perspective, supported by some empirical work using officially reported cases of child abuse, argues that even though domestic violence occurs at all income levels, low socioeconomic status families are more likely to be labeled as abusive.

Each of the above theories could be described as "unitary theories." In other words, each offers an explanation of child abuse from a single point of view. Each theory has power and adherents because each theory explains some part of the data. Historically, psychoanalytic explanations have guided much of the work in this field. Approximately one parent in ten has been found to have a defineable psychiatric condition, but that figure is comparable to the rest of the population (Smith et al, 1975). Further, child abuse has been found to be associated with several personality types (Green, 1976), and no particular diagnosis can predict child abuse.

Other unitary theories share comparable limitations in their ability to explain enough of the data to effectively guide intervention. For example, environmental theories do not take into account intra-individual and inter-individual sources of strength and weakness which render families more or less vulnerable to environmental experiences and conditions. Nor do they account for child abuse in seemingly affluent homes. And labeling theory, although helpful in pointing out pervasive biases with respect to who gets identified and reported as abusive, is of scant help in the emergency room when addressing the needs of a family whose child may have cigarette burns on its body.

Increasingly, sensitive professionals and researchers are critically evaluating the utility of unitary theories of etiology and are integrating the more helpful parts of these theories into interactive, multicausal theories. These theories seek to understand how different aspects of experience may exacerbate or weaken other aspects of experience. Are particular personality types more vulnerable to certain kinds of environmental experiences? Are there features of the social environment, or ways of understanding the child, that enable families to cope with stress without resorting to violence? Child abuse may be understood in this theoretical context as a symptom of dysfunction in a complex ecosystem with many interacting variables. Furthermore, the task of understanding is not in fitting the family into a narrow theoretical box, but rather in finding the explanation that explains *this* family.

Several studies have conceptualized child abuse as a phenomenon to be approached from the multiple levels of individual, family, and society, leading the field to a more comprehensive theory base from which to guide intervention (Garbarino, 1975; Newberger et al, 1977; Starr, 1978).

A clinical model for understanding child abuse, which draws from ecologic theory was recently developed to enable pediatricians to organize the complex data with which they contend in clinical practice (Bittner and Newberger, 1981).

Future Research Needs

Two recent surveys suggest substantial defects in the knowledge base on child abuse. Gelles' (1980) review of family violence research in the 1970s suggests an urgent need for theory testing and building for longitudinal study designs, for samples drawn from nonclinical populations, and for increased diversity of measurement instruments and data-collection techniques. Gelles subsumes child abuse in his concept of family violence, an approach which appears to be increasing in favor among researchers in the field. He summarizes aptly the progress in the last decade: "Whereas research in the '60's tended to view domestic violence as rare and confined to mentally disturbed and/or poor people, research in the '70's revealed family violence as an extensive phenomenon which could not be explained solely as a consequence of psychological factors or income" (p. 873).

Garbarino (1981) surveyed 14 nationally recognized experts and concluded that "we are making some progress, but that major questions remain unanswered." The following principal research issues emerged in the Garbarino survey:

1. *Incidence estimates continue to be confused* by a lack of precision in the definitions used in research, policy, law, and practice. Studies of maltreated adolescents suggest different causes and consequences from cases involving younger children.

2. *Identification of risk for maltreatment remains statistically unreliable*, thus frustrating attempts at early intervention and prevention.

3. *Treatment of child abuse is inadequate*, and successful treatment is imperfectly understood. Conventional social-work approaches are associated with high rates of re-injury, but low recidivism is reported with innovative and resourceful programs with selected clinical populations.

4. *Nearly all treatment efforts focus on parents.* Not only are the developmental and health needs of children ignored, but the children may be harmed by interventions which place them in foster-home or institutional-care settings. Focus on the childhood antecedents, precipitants, and concomitants in research and practice is limited. Poorly differentiated clinical approaches neglect the unique needs of adolescents.

5. *Preventive initiatives are largely unexplored*, notwithstanding, for example, the suggested potency and cost-effectiveness of facilitating the formation of bonds of parent-child attachment at birth.

6. *The medium and long term consequences of physical and sexual abuse are poorly understood*, although experts concur on the increased vulnerability for severe problems in school, in behavior in the community, and in later family life. Few longitudinal studies have begun, and these are likely soon to end, because of severe constraints on research funding.

Conclusions

Clinical approaches to child abuse remain constrained by an inadequate foundation of theory and knowledge. Clinicians working with violent families typically work on a case-by-case basis. Hence, they must practice what they know and accumulate new knowledge through experience with the type of families they see (Light, 1979). Although eager to improve the success of their work and to improve the quality of data available to others in the field, they typically have little time to piece together the results of their work and of studies in the field. Nonetheless, clinicians have made important contributions to our knowledge base on child abuse.

Because academic research and clinicians have different work roles and work in different organizations, they frequently approach the same topic in different ways (Gelles, 1982; Snyder et al., 1982). Shared concerns by both researchers and clinicians working in the family violence field have not led to a high level of interchange regarding concepts, theory, or data. Research results frequently are not in a form to guide clinical decisions. The concerns most central to clinicians frequently are not phrased in a way that provides focus to research.

Well-conceived, controlled, longitudinal studies hold great promise for prevention and treatment of child abuse. This research must be conceived, operationalized, and disseminated in such a way as to provide useful guideposts for practice and policy.

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Senator DENTON. Thank you, Dr. Newberger.

Mr. Loken.

Mr. LOKEN. Thank you, Mr. Chairman. I am here today as a representative of Covenant House and also of the Covenant House Institute for Youth Advocacy, organizations which exist to provide for the care and protection of street kids, and advocacy for their most serious needs.

Because we are convinced that a Federal role in the protection of children from abuse, and in particular, sexual abuse, is absolutely crucial to the care of our Nation's children, we are delighted to be here today, and in particular wish to address you regarding the question of sexual abuse of American children.

I think, first of all, it is appropriate to tell you a little bit about Covenant House. It was founded very informally by a Franciscan priest, Father Bruce Ritter, in 1968. He entered into the crisis care of kids really quite by accident. Forced off campus by students who told him he ought to practice what he preaches from the pulpit, he found himself on the Lower East Side, and the first children that he gave shelter to were six children from a self-formed family who had been used in making a pornographic movie in exchange for food and shelter

Since that time he has built a major organization that now cares for approximately 12,000 kids a year, 8,000 of them in New York, the rest in other crisis shelters in Toronto, Guatemala, and soon in Houston and Boston.

The program operates on a 24-hour, open-intake policy with a wide range of services: a fully staffed medical clinic, a legal staff, staff psychologists, professional social workers, and vocational counselors. Covenant House, of course, sees the whole range of problems related to child abuse, but with regard to sexual abuse, we perhaps have a very special interest because so many of the children who come to us have been caught up in the sex industry which is centered in Times Square.

Our Under 21 crisis center in New York is located right in the heart of the Minnesota Strip sex area. Of Covenant House's children, our medical staff estimates that up to 35 percent have been sexually abused prior to their entrance into street life. Once they are on the street, some 60 percent or more become a part of formal or informal prostitution; that is, trading sex for survival.

The best scholarly estimates for the rate of sexual abuse nationally put the figure at approximately 1 in 10 boys prior to age 18; 1 in 4 girls prior to that age. Of course, these estimates are subject to some dispute, particularly with regard to the definition that is appropriate for sexual abuse.

But the difference between the extremely high Covenant House rate and the national rate of sexual abuse, I think, points to at least two factors which are related to the results of sexual abuse in children.

First of all, there is a tremendous increase in the chance that a sexually abused child will run away from home and end up on the street.

Second, there is an extremely increased chance that such a child will eventually enter into some form of prostitution. Of course, the other effects of sexual abuse of children are well documented and extremely severe. They range from severe emotional trauma to serious sexual dysfunction. They include numerous physical problems for children. We, in many ways, think of a badly sexually abused child, particularly one who has then entered into the sex industry in New York City, as having suffered a form of psychological death that is the equivalent of an extreme case of physical abuse.

There is no real limit on the age range of sexual abuse. We have seen babies of 3 months who have been sexually abused. We have also seen girls in later adolescence who have been raped or sexually abused. The average age, however, is around 10 to 11 years for the first reported instance of sexual abuse in a child.

Our response to the problem of sexual abuse in the kids we see basically parallels the response that we use with regard to all the kids who come to Covenant House. That response is a multidisciplinary one for all the children we serve, but particularly for kids who are involved in sexual exploitation or in past sexual abuse, we adopt a multifaceted approach. We have a crisis team for handling these kids, which is composed of representatives of the various professionals disciplines within Covenant House.

That approach corresponds, incidentally, with some other successful intervention programs against sexual abuse, one of which—the Institute for Community as Extended Family—is located in San Jose, Calif., and another—the child sexual abuse victim assistance project—here in Washington, D.C. These programs may not have the answer to the problem of sexual abuse, but they attempt to look at it from every possible angle and work the problem if possible.

Our principles at Covenant House are "humanistic" in a Christian sense. We use five basic rules: No. 1, immediacy, urgent response to the child's needs.

Second, sanctuary, protection of confidentiality, and safety.

Third, value communication; we have values at Covenant House. We are not afraid to state those values to the children, but we do not expect them instantly to adopt our own moral vision.

Fourth, structure; where rules are necessary, they must be enforced, and we do enforce our rules at Covenant House and try to bring the child back into a frame of self-discipline and forward movement.

Finally, the principle of choice; no child has to participate in the Covenant House program, but we believe that by leaving that choice open for them, there is a chance they will turn their lives around.

In order to give you an idea of what a sexual abuse case at Covenant House might look like, I have chosen one case history to review with you. It is the case of Marian, who was age 19 when we began working with her. She was abused sexually by her maternal uncle; her mother and grandmother denied the situation, refused to recognize it. This went on while Marian was aged 9 to 13.

At 13 she found herself out on the street, soon was beaten up by a young man who was furious over his own impotence. She then fell into the hands of a pimp named Raymond who fathered a child born to her at age 14. She worked on the street for 4 years.

She attempted suicide a number of times. She got a number of breaks from the street because she was, after all, the mother of the pimp's child. And so he did give her some time off. She finally came to Covenant House. With luck and God's grace she managed to turn her life around slowly. She is now, we understand, successfully coping in a program for former prostitutes located in the West.

Her case illustrates, I think, some of the key problems in dealing with sexual abuse under the current system.

No. 1, noncustodial sexual abuse is technically not a part of the national effort against child abuse, protection, and treatment. Unless that noncustodial abuse is incorporated in the statutory definition of abuse and neglect, the Federal law is going to remain impotent in dealing with over half of the cases of sexual abuse.

Second, children who wish to pursue cases of sexual abuse find themselves blocked by outmoded rules of evidence and problems in presenting testimony. It is extremely traumatic for a child to present testimony in a court of law regarding an abusive incident, particularly a sexual abuse incident. But the rules of hearsay prevent the introduction in many States—in fact, nearly all States—of statements by a child made to a child protective worker soon after the event. The child must come into court and present testimony for the record to be established.

Second, no system of videotape testimony has been introduced in the various States to allow a child to testify in a somewhat less threatening, nonpublic atmosphere while still preserving the confrontation rights of the defendant.

But we believe that even beyond emphasizing these legal difficulties, it is important to reach out to the children of this country, because they are the only ones who know whether, in fact, they have been sexually abused. We think an appropriate response for the Federal Government, in addition to changing its statutory definition of abuse and encouraging changes in evidentiary rules, would be to adopt a national media campaign to educate children on the limits on sexual activity.

Many children in this country are not educated as to what is sexually right or wrong. They have no concept of how far an adult should be allowed to go with them. A media campaign would reach many of them, because after all the average age of a sexual abuse victim is 10 or 11, which is a prime TV age. Ads directed to children might let them know that there are limits of touching and that they have a place to go if there is a case of sexual abuse in their house.

Finally, we would emphasize that there are few long-term treatment options for children who have been cast off from the family by sexual abuse, particularly for children who have become involved in prostitution. Estimates go as high as 900,000 juvenile prostitutes in this country. There are perhaps 500 beds at most in existing programs to handle juvenile prostitutes. And, in fact, most of the programs that handle child abuse are not fully appropriate for handling sexual abuse problems.

We think the Government's capability of intervening successfully in the area of sexual abuse is limited by the mystery and the intricacy of the entity that is the American family.

But we urge you to go as far as you can go—reauthorize this act, tinker as far as you can with the definitions of sexual abuse, and extend Federal intervention to bring as much help to children as is possible.

I would ask finally, Mr. Chairman, that my written statement be entered into the record.

[The prepared statement and additional material of Mr. Loken follow:]

PREPARED STATEMENT OF GREGORY A LOKEN
SR. STAFF ATTORNEY, COVENANT HOUSE

Mr. Chairman, Members of the Subcommittee, I am Gregory Loken, Sr. Staff Attorney at Covenant House, New York, New York. I was delighted to receive your invitation to discuss the problem of sexual abuse of children in the context of your consideration of reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act.

Covenant House, founded by Father Bruce Ritter in 1968, is a not-for-profit organization dedicated to the crisis care of runaway and homeless youth. Its main facility, the Under 21 crisis shelter located in Times Square, right off the "Minnesota Strip", annually provides shelter, food, and clothing along with medical, legal, vocational and educational counselling to about 8,000 kids under the age of 21. By the end of this year similar facilities - actually called "multi-service centers" - will be open in Houston and Boston; a similar center in Toronto has just passed its first anniversary. In sum, we expect to provide crisis shelter to about 12,000 children during 1983. About six percent of Covenant House's funding comes from governmental sources; the rest, including some seventy-five percent from small and moderate donors, from private sources.

The first six children to whom Father Bruce provided shelter were homeless - all from one self-constituted family - and prior to knocking on his door, had been coerced into making a pornographic movie for food and shelter. Since that time the work of Covenant House has been inextricably bound up with the problem of sexual exploitation and abuse of the young. As our perspective is from the darkest edge of the lives of sexually abused children, however, we think it is important first to provide something of an objective account of the nationwide blight of sexual victimization of the young. Against that backdrop the Covenant House experience is more understandable, less charged with emotion. So, too, the suggestions of Covenant House for your future action on behalf of sexually abused children are more easily scrutinized when framed by national - as opposed to our particular program's - needs.

I. Sexual Abuse of Children - The National Problem

The tendency of "professionals" and "experts" to discuss children in narrowly categorical terms - without any real effort to keep an overall human perspective on children's problems - once drew this icy criticism from the great children's advocate Lillian Wald:

> Perhaps Solomon the Wise had specialists in mind when he tested the love for a child by the unwillingness to have it dismembered. Certainly the studies of the specialists themselves constantly are showing that to understand fully the kinds of trouble into which people fall - sickness, poverty, difficulties in home or job - we need to know all the factors that affect their lives. This understanding is especially imperative in the case of children who necessarily are governed to a far greater degree than adults by conditions about them over which they have no control. [1]

It is therefore always dangerous to isolate one aspect of childhood experience for special scrutiny; the limits of "scientific" study of complex human events are all too obvious and severe. Yet sexual abuse is one blotch on American childhood so widespread, so severe, and so destructive as to warrant the most exacting and specific attention.

A. Extent of Sexual Abuse. That term has been given various, often legalistic, definitions, but the problem stated generally is simply that of overt sexual contact between adults and children. More than a problem, actually, sexual abuse of children is a national epidemic. Now the top professionals in the field estimate that some 500,000 children per year experience some form of sexual abuse. By the end of their adolescence one fourth to one third of all girls, and about 10% of all boys, will have been sexually victimized to some degree.[3] As one leading expert put it: "Child protection workers all over the country report that they are overwhelmed by the influx of new cases of sexual abuse. Whereas ten years ago there was hardly a case anywhere, today the reporting rate is increasing exponentially and shows little sign of abating."[4] Our national confidence in American progress can only be shaken by the knowledge that studies indicate the rate of incest in this country increased from one case per million population per year during the period 1910-1930 to 5,000 cases per million population per year from 1945-1965.[5]

In part, of course, these extraordinary figures are a sign that reporting of sexual abuse has improved.[6] The recognition by Congress and state legislatures that sexual abuse exists and is severely harmful to the children abused has evidently borne great fruit. A recent survey of adults in Boston found that those interviewed had a surprisingly accurate understanding of the scope of sexual abuse and a strong resolve to report such abuse when it occurs.[7] That same survey, however, produced a frightening statistic: 47% of those interviewed stated that they had personal knowledge of sexual abuse either through personal experience or through some person in their social network.[8] That degree of direct public knowledge of sexual victimization does not seem likely to have resulted simply from increased sophistication in reporting or detecting sexual abuse; rather, such increased awareness by parents plus the skyrocketing figures of reported sexual abuse support a view that actual sexual abuse is rising significantly.[9] As Dr. A Nicholas Groth, director of the sex offender program at the Connecticut Correctional Institute, recently declared, "The dimensions of the abuse are staggering. If we saw these same numbers of children suddenly developing some kind of illness, we'd think we had a major epidemic on our hands."[10]

B. Effects. An epidemic it is, and one with the most damaging of consequences for its victims. While measurement of the extent of sexual abuse is extremely difficult and open to professional disagreement, there is little doubt about the effects that abuse can create in its victims. Those effects have been found to include: (1) problems in sexual adjustment; (2)interpersonal problems; (3) education problems; (4) suicidal ideation; (5) obesity; (6) sleep problems; (7) delinquency; (8) running away from home; (9) prostitution; and, worst, (10) becoming a child molester.[11] Vincent De Francis, author of the seminal study of sexual abuse, concluded that at least two-thirds of sexually victimized children suffer emotional disturbances; for fully 14% those disturbances are severe.[12] Above all, perhaps, there results from such abuse "a lack of basic trust" and "a tendency for social isolation and difficulty in establishing close human relationships."[13]

C. The Abusers. Experts on sexual abuse have spent so long telling the public something it already knows - that "child molesters" are more often members of the child's family than the "dirty old men" of legend - that one scholar finally was provoked to say: "The literary device of debunking the myths has worn thin, and could use some rest."[14] Although some older studies indicated that a majority of sexual abusers were strangers to their victims,[15] the recent weight of professional opinion has swung completely to the opposite view. Now strangers are believed to be the perpetrators in only about one quarter of all sexual abuse cases.[16]

It is important to note, however, that strangers remain a quite substantial minority of sexual abusers. If anything, sexual abuse by a stranger is less likely to be reported than abuse by someone known to the victim.[17] Further, parents probably constitute no more than a fifth of sexual abusers; parents and other relatives together make up only about 40% of such offenders.[18] About a third of the sexual abuse perpetrated is the work of "friends" of the victim - persons who while known to the victim do not normally stand in a custodial relationship with him or her.[19]

Overall, then, about half or more of all sexual abuse is perpetrated by persons with no custodial responsibility for the abused child. If patronage of juvenile prostitutes - of whom there may be as many as 900,000 nationwide at any given time[20] - is included in the concept of "sexual abuse," that proportion would be higher still. Any strategy against sexual abuse which does not encompass this non-custodial group is at best sadly incomplete.

II. Covenant House - Incidence and Treatment Of Sexually Abused Residents

Covenant House, with its Under 21 crisis shelter located in the heart of Times Square and its billion-dollar sex industry, is confronted in all its work with the exploited sexuality of the children who seek shelter there. According to our Health Services, ninety-nine percent (99%) of the residents at Under 21 have been sexually active; approximately sixty percent (60%), perhaps more, have engaged either in formal prostitution or in trading sexual favors informally for food and shelter. Many are irretrievably tied to street life, and about half of the residents leave Under 21 within three days - unable to accept even the nomimal structure which a crisis program must demand. The other half of the residents stay usually between two weeks and two months.

A. Incidence and Nature of Sexual Abuse. The first sexual victimization of children, whether by family, familiar adults, or strangers tends to fall at a tender age - on the average, at about age 10 or 11.[21] As the vast majority of Under 21 residents are 15 and over, it is a comparatively rare event for the program to include a child fresh from his or her first sexual encounter or series of encounters with an adult. Rather, the program instead deals extensively with children who have a history of sexual abuse in earlier youth, many of whom now are being sexually exploited for the commercial profit of the sex industry.

In providing crisis shelter, of course, it would be extremely damaging to children just off the street to ask intimate questions about sexual abuse that may have occurred years before. Often a child volunteers that information after a relationship with the program staff has been developed. In determining the incidence of sexual abuse in residents' histories, then, we must rely largely on behavorial symptoms of previous sexual abuse. Those symptoms are well defined in professional literature;[22] they often are not, unfortunately, exclusive of other possible sources of trauma.

Still, based on observation of behavioral symptoms, on frank conversations with many residents, and on familiarity with the environments from which the children come to the program. Under 21 Health Services staff members estimate that perhaps half of the girls and possibly as many as 35% of all residents seen by Health Services have been the victims of "sexual abuse" - that is, sexual victimization by an adult prior to the child's entrance into street life. At present, Covenant House is preparing a carefully controlled research project to test these estimates in a rigorous manner. In comparison with the best estimates of the incidence of sexual abuse nationwide, the Under 21 figures are, quite naturally, extremely high. Because running away and entrance into prostitution are two widely recognized consequences of sexual abuse, however, that is hardly surprising. Over half of all juvenile prostitutes have been sexually abused;[23] entrance into street life is a logical consequence of the self-loathing sexual abuse creates in its victims.[24]

Numerical estimates and clinical theory have their place in analysis of the problem of sexual abuse, but ultimately only attention to the stories of individual children can provide real insight into what sexual abuse finally means. Following this statement are five case histories of current or recent residents of Under 21 with histories of sexual abuse. Not all the cases involve sexual abuse by a parent, but all evidence betrayal of the child by those he or she should have been able to trust. Nor do all show a successful resolution of the case by our program: the damage inflicted by sexual abuse is not necessarily reversible, and certainly is often completely outside the rehabilitation capacity of a short-term crisis program. What all the cases do evidence is the pathetic need of victims for the most basic components of survival - food, shelter and medical care. And all of the cases illustrate, too, [illegible] for exclusion of these children from any sort of [illegible] familial relationships.

B. The Covenant House [illegible] Children who arrive at the door of Under 21 are all in crisis, fleeing the street and all that it represents. For all those who arrive the [illegible] responds on the basis of five basic principles:

1. Immediacy. The urgent needs of the children who arrive must be met without delay - particularly such basic needs as food, medical attention, or a shower - before planning for them can begin. That means even the most perfunctory intake procedure must wait if there are immediate needs to be met.

2. Sanctuary. The identities of all residents are confidential under Under 21 policy, as well as under federal and state law. Children residing at Under 21 are not judged on their past, which is to be investigated only when necessary for effective case planning.

3. Value Communication. Just as Under 21 offers unconditional acceptence - 24-hour open intake - of any new child who presents himself, so it is important that the residents understand the basic values that give rise to that acceptance. "Rules" are minimal except where absolutely necessary; residents are to be confronted with the values of respect and affection for which rules too often substitute.

4. Structure. Rules, when necessary for the program to function, must be enforced, and residents

> must be encouraged to see the value of structure and self-discipline. At the same time, the structure must not be inexorable; human variations must be anticipated, and, as far as possible, tolerated.
>
> 5. *Choice*. Children who arrive at Under 21 in crisis cannot be shaped into well-adjusted, secure people unless they are willing participants. Residents are free to leave the program at any time; they must, indeed, feel their staying at Under 21 is a conscious choice. Their ability to make any progress away from the street depends on their developing a sense of independence and personal responsibility.

These five principles, developed in the midst of many heartaches and early failures, govern the approach of Covenant House to *all* its clients, not simply those with a history of sexual abuse.

Because sexual abuse involves special medical, psychological and legal problems, of course, in practise those principles result in a form of special treatment. The suspicion of sexual abuse of any child is immediately reported to child protection authorities. A thorough medical examination, particularly for any signs of physical trauma or venereal disease, is also conducted without delay. Analysis of the legal options available to the children is undertaken with a view to advising the child - after consultation with medical and psychological staff - whether he ought to go forward with criminal proceedings. Child care staff and a social worker, finally, investigate all possibilities for long-term shelter care of the child, including the possibility of a return home if the situation warrants. Meetings with family members are arranged wherever possible to facilitate reconciliation with the concerned resident if appropriate.

The approach of Under 21 is emphatically not mechanistic; it is aimed at a human relationship with children in care. That approach is fundamentally different from nearly all established child-care systems - particularly the foster-care system - which strongly discourage the development of relationships between staff and children in care. Under 21 tries - and sometimes fails - to avoid the "institutionalism" that afflicts so many well-intentioned social service systems with the passage of time. Its model of a covenant relationship - limited by the crisis-care character of the program - is, interestingly, remarkably close in approach to that used successfully by the Child Sexual Abuse Treatment Program in Santa Clara County, California.[25] Its success, however, depends largely on the availability of suitable long-term programs to which the children can turn after their period of crisis is over.

III. Proposals for Consideration

Covenant House applauds and fully supports the efforts of the federal government to improve protections against sexual abuse through the Child Abuse Prevention and Treatment and Adoption Reform Act (the "Act"). Unquestionably that initiative prompted significant reforms in state laws across the country, and has provided desperately needed funds for prevention and treatment of sexual abuse. We would be remiss, however, is we failed to urge consideration, as the Subcommittee deems appropriate, of the following areas of needed reform:

A. Definition of Sexual Abuse. The Act of course encompasses "sexual abuse or exploitation" within its general definition of "child abuse or neglect". Unhappily, however, only abuse "by a person who is responsible for the child's welfare" falls within that definition as currently worded. With respect to physical or emotional abuse, which seldom is inflicted with serious consequences by an adult outside the family, the limitation to a custodially responsible person makes sense. Sexual abuse, by contrast, is more often than not - as discussed above - inflicted by someone *not* in a position of legal responsibility for the child. Children are targets for sexual abuse by adults outside the family in a way that they are clearly not with respect to other types of abuse. Further, numerous parents seem generally far more willing to tolerate sexual advances on their children than other sorts of abuse.[26]

A broader definition of "child abuse or neglect" within the specific context of sexual abuse would serve at least two purposes. It would, first, remove all doubt about the ability of a state to intervene where a passive parent allowed - *e. g.*, through "good faith" disbelief of a child's story or simple inability to put the pieces of a story together - sexual abuse by a non-relative.[27] Second, it would open up funding of research and demonstration projects to groups interested in the whole spectrum of child sexual abuse, not merely those concentrating on incestuous relationships.

B. *Revision of Evidentiary Barriers to Protection of Children.* Many a child is legally protected, in theory, from sexual abuse but on a practical level has almost no chance of securing effective court intervention if he needs it. That divergence between practice and theory results from the enormous pressure placed on abused children to repudiate earlier accusations of sexual abuse. Although children almost never invent stories of sexual abuse,[28] they are extremely vulnerable to familial pressure to keep silent.[29] Unless their first -virtually always accurate - statement of accusation is available to a court, the proceeding is unlikely to produce conclusive results.

1. Problem of Hearsay Rule. Most tellingly the hearsay rule will preclude admission of out-of-court allegations of sexual abuse by children unless the victim's statement is considered an "excited utterance". See, State v. Kriener, 415 Mich. 372 (1982). As many children wait for some time before disclosing an incident of sexual abuse,[30] the "excited utterance" exception is often of little value.[31] Simple relaxation of the hearsay rule to allow out-of-court statements by an allegedly sexually abused child - if only in civil custody proceedings - would make the whole process more humane.

2. Out of Court Videotape Testimony by Child. As one study concluded: "Most children resist going to trial because of the embarrassment of having to relate in front of strangers the details of the sexual assault."[32] Defendants, of course, are entitled to the opportunity for cross-examination;[33] they have the right, too, to a public trial.[34] One student of the problem, however, proposed an ingenious solution some

time ago: conduct the testimony and cross-examination of the child in a non-public setting before videotape cameras.[35] The videotape, replayed before a courtroom and jury, would seem adequately to protect the rights of the accused while deferring to the extreme vulnerability of the child. In a custody proceeding, the videotaping of a child's testimony soon after the report of sexual abuse could substantially diminish the likelihood of family pressure and vacillation on the part of the child. Nothing would prevent a child from appearing in person to give testimony at the time of the trial (or abuse/neglect hearing), but the videotape would be an extremely valuable truth-finding tool even in those cases.

Under the Act Congress could provide financial incentives for states to remove hearsay obstacles to admission of children's out-of-court statements and to allow for videotaped testimony of sexually abused child witnesses. Each of those concepts deserves a chance to demonstrate whether it can soften the agony of legal proceedings for already traumatized children while preserving intact fundamental procedural fairness.

C. Prevention of Sexual Abuse. The causes of sexual abuse are so extraordinarily complex, so rooted in particular family relationships that no government program, however skillfully conceived, can wholly define or resolve them. What the government can do is throw its prestige and financial power behind an effort to educate the children of this country as to the appropriate limits of adults' sexual advances. In a period when children are used as sexual lures by advertisers, and when no young T.V. viewer can fail to acquire extraordinary precocity in the games of sexual attraction, children cannot be expected to sort out on their own the permissible scope of sexual contact with their elders. We have watched largely successful media attacks on cigarette smoking and obesity; isn't it time the federal government, or the states, entered the arena on behalf of the sexual integrity and health of our country's children? The Act does make some provision for "treatment" of sexual abuse, but at least as important is conveying the message to children that such abuse should be prevented and condemned.

It is our view, then, that the Act should be modified to encourage widespread advertising of the dangers of sexual abuse - advertising designed to reach children and let them know how to handle an abusive situation. If such advertising reaches only a few of the thousands trapped in sexual abuse because of their own ignorance, it will have many times over repaid its cost.

D. Long-Term Treatment Needs. Covenant House in its work encounters youths far beyond any help that "preventive" or even standard treatment measures could provide. A child who has run away at age 11 or 12 because of sexual abuse, who has lived on the street for years by selling her -to her mind, "cheapened" - body, without an education, proper medical care or nourishment: this is the young lady we are likely to meet at intake on any given day at Under 21. At our program, she has a chance to begin to turn her life around, to begin, at least, making relationships based on trust and to find some reason to believe in herself. But in a crisis shelter - even one, like Under 21, with its multiple services - there is not time fully to repair the damage of four years without hope. Covenant House is not going to give up on her, but she needs, for once, to be out of a crisis environment, in a stable setting where full human relationships are encouraged. She needs a secure and nurturing setting where she can somehow transfigure her anger.

Yet there are seldom such places available for young people like her. "Treatment" of the sexually abused or exploited all too often means only the rendering of limited, categorized professional services - not a long-term commitment to helping them overcome their pain and enforced social handicaps. Confronted both by overwhelming needs for more crisis care services and the long-term needs of current residents, Covenant House is unable to do either to full satisfaction.

We do not presume to present facile answers to this wrenching problem of sexually exploited, now ash-canned children. Yet the cost of losing those children to the street is not one that conscience or prudence could bear. Admittedly they make up only a small portion of the children who have been sexually abused, but their fate is an extremely cruel one. A recent study of sexually exploited street kids called them bluntly the "homeless adults of the future".[36]

In considering reauthorization of the Act, then, we urge the members of the Subcommittee to consider seriously the addition of funds targeted specifically for long-term (i. e., six months to a year) programs for sexually exploited homeless children. Those programs should provide security, rehabilitation and above all a sense of relationship. Design of such programs should be a challenge worthy of the best humanitarians and most exacting organizers.

IV. CONCLUSION

Sexual abuse, however clinically it is analyzed, is in essence a symptom of crumbling respect for the value of children. No government can force its citizens to love their children; its ability even to protect children from parents is limited by the difficulty of dissecting the extremely complex entity of the family. But it can offer some protection and more important, it can by its actions demonstrate that children do have value and are entitled to respect. A campaign to prevent sexual abuse must be public and make use of the media. Important as efforts at prevention are, however, they cannot obscure our need to care for the victims of past abuse. It is a need, not merely a duty: only by showing the public that abused children are not worthless children can the government's voice in this area achieve real power.

In the face of an ugly tide of children sexually betrayed and abandoned, we cannot but support the work of the Subcommittee

as it attempts to refine the national strategy against sexual abuse. Covenant House, whose population carries the worst scars of such abuse, can ultimately ask not only for attention to the central problems of sexual victimization but to the fringe as well: the children now grown slightly older, with no place but the street to hide from their past. Including the broken, sexually exploited and hardened children of the street in a vision of the reality of American sexual abuse may make the picture almost too fiendish for rational response. Yet in this subject we find ourselves prying into the darkest, most incomprehensible crevices of the human heart and the American family. If what we find confounds our specialized logics, our only choice is to confront it as perplexed, but passionately caring human beings.

NOTES

1. Lillian Wald, Shall We Dismember the Child, 18 Survey 458 (1929-30), reprinted in Bremner, Children and Youth in America, Vol. II (1971), 786-87.

2. "Abused Child's Legacy As Fear," Denver Post, 3/12/83, p. 1-B (estimate of Dr. C. Henry Kempe, director emeritus of the Kempe National Center for Child Abuse and Neglect); Gagnon, "Female Child Victims of Sex Offenses" in Studies in Human Sexual Behavior: The American Scene, Ailon Shiloh, ed. (1970).

3. "Abused Child's Legacy As Fear", supra note 2; Gagnon, supra note 2; Russell, Preliminary Report on Some Findings Relating to the Trauma and Long-Term Effects of Intrafamilial Childhood Sexual Abuse, Paper presented to Conference on Child Prostitution and Pornography, Boston, 1981; Finkelhor, Sexually Victimized Children (1979).

4. Finkelhor, Sexually Victimized Children, (1979), 131.

5. Romney, Incest in Adolescence, 11 Pediatric Annals 8/13 (1982).

6. Finkelhor, Sexually Victimized Children, (1979), 131-32.

7. Finkelhor, Public Knowledge and Attitudes About Child Sexual Abuse: A Boston Survey, Family Violence Research Program, Univ. of New Hampshire, Durham, N.H. (1982).

8. Finkelhor, Child Sexual Abuse in a Sample of Boston Families, Family Violence Research Program, Univ. of New Hampshire, Durham, N. H. 91982).

9. See. e.g, "Child Sex Abuse Reports Up Sharply in Colorado," Denver Post, 3/12/83. But see, Finkelhor, Sexually Victimized Children, (1979), 131-32.

10. "Studies Find Sexual Abuse of Children Is Widespread," N.Y. Times, 5/13/82, p. C 1.

11. A thorough review of the literature on the effects of sexual abuse is contained in Mrazek & Mrazek, The Effects of Child Sexual Abuse: Methodological Considerations,

in Mrazek & Kempe, Sexually Abused Children and Their Families (1981), 235-245. See especially, Tilelli, Sexual Abuse of Children, 302 New Engl. J. Med. 319 (1980); Steele & Alexander, Long-Term Effects of Sexual Abuse in Childhood, in Mrazek & Kempe, Supra this note, 223-233; Pomney, Incest in Adolescence, supra note 5.

12. DeFrancis, Protecting the Child Victim of Sex Crimes Committed by Adults (1969), 169.

13. Steele & Alexander, supra note 11, p. 226; Geiser, Hidden Victims: The Sexual Abuse of Children (1969), 58-59.

14. Finkelhor, Public Knowledge and Attitudes About Child Sexual Abuse, supra note 7, 17.

15. Landis, Experiences of 500 Children with Adult Sexual Deviants, 30 Psychiatric Quarterly Supp. 91, 97 (1956); Gagnon Female Child Victims of Sex Offenses, 13 Social Problems 176 (1965).

16. DeFrancis, supra note 12 70; Finkelhor, Sexually Victimized Children (1979) 155; Luther & Price, Child Sexual Abuse: A Review, 50 J. School Health 161, 162 (1980).

17. Finkelhor, Sexually Victimized Children (1979), 139-40.

18. Id., 155, and studies cited therein.

19. Id., 155, and studies cited therein.

20. Deisher, et al, The Adolescent Female and Male Prostitute, 11:10 Pediatric Annals 819 (1982); Young, Juvenile Prostitution: A Federal Strategy for Combatting Its Causes and Consequences, Youth Development Bureau, Office of Human Development Services, U.S. Dept. of Health, Education, and Welfare (1978).

21. Finkelhor, Sexually Victimized Children (1979), 154.

22. See, e.g., Heindl et al., The Nurse's Role in the Prevention and Treatment of Child Abuse and Neglect, Nat'l Center on Child Abuse and Neglect, U.S. Dept. of Health, Education and Welfare (1979), 15-16.

23. James, Entrance into Juvenile Female Prostitution: Final Report, Grant # MH29960, Nat'l Institute of Mental Health (1980); James, Entrance into Juvenile Male Prostitution: Final Report, Grant #29968-05, Nat'l Institute of Mental Health (1982).

24. Deisher et al., The Adolescent Female and Male I 11:10 Pediatric Annals 819 (1982).

25. Giarretto, A Comprehensive Child Sexual Abuse T Program, in Mrazek & Kempe, supra note . The C.S.A.T.P. involves a "professional co a "volunteer component,: a "self-help compo and an overriding "humanistic attitude."

26. See, Sexual Exploitation of Children, Hearings Before the Subcommittee on Education and Labor, 95th Cong., 1st Sess. (1977), 42-43 (lease, then sale of 9-year-old boy by parents to older man for sexual exploitation) (testimony of Lloyd H. Martin, L.A. Police Dept.); Id., at 66-68 (identifying child pornography actors as (1) "throwaways"; (2) the "children of parents involved in the sexual industries" who are "as young as 6 years old"; and (3) the children of a "parent so [economically] desperate that he knowingly and willingly permits the child to be abused") (statement of John Freitas, Jr., San Francisco District Attorney).

27. Bulkley, Analysis of Civil Child Protection Statutes Dealing With Sexual Abuse, in Child Sexual Abuse and the Law, A.B.A. Nat'l Legal Resource Center for Child Advocacy and Protection (1981) (hereinafter "Child Sexual Abuse"), 81,85.

28. Orr, Evaluation and Management of the Sexually Abused Child, 14 Sexual Med. Today 12,13 (1980).

29. Finkelhor, Sexually Victimized Children (1979) 67.

30. DeFrancis, supra note ___, 63-65.

31. In her article,Evidentiary Theories for Admitting a Child's Out-of-Court Statement of Sexual Abuse at Trial, in Child Sexual Abuse, 153-165, supra note 27, Josephine Bulkley argues that the "excited utterance" exception may permit the introduction of many out-of-court allegations of sexual abuse. It is worth noting, however, that even in her account the exception is riddled with technical problems - most specifically, the long period which often elapses between the event of sexual abuse and the child's disclosure. The court in People v. Kreiner, supra, for instance, took pains to point out that "the child did not tell her mother [of the sexual assault] at "the first opportunity." (Slip opinion, p. 5.)

32. Weiss & Berg, Child Victims of Sexual Assault: Impact of Court Procedures, paper presented at the annual meeting of the American Academy of Child Psychiatry, Chicago, 1980, p. 12.

33. Pointer v. Texas, 380 U.S. 400 (1965).

34. Globe Newspaper Company v. Superior Court for the County of Norfolk, _____U.S.____, 50 U.S.L.W. 4759 (1982).

35. Libai, Protection of the Child Victim of a Sexual Offense in the Criminal Justice System, in Schultz, Rape Victimology (1975) 277, 314-27.

36. Dillingham & Melmed, Child Pornography: A Study of the Social-sexual Abuse of Children, Washington School of Psychiatry, Washington, D.C. (unpublished manuscript) (1982), p. 4.

RECENT CASE HISTORIES

Residents of Covenant House/Under 21

1. Mitchell, who is eighteen, was raped at age nine and had been involved in an incestuous relationship with his mother, sister, and two younger brothers for the previous two years. Crying profusely while discussing his history Mitchell told us that he had never discussed this experience with anyone and "the feelings are tearing me apart".

He had left home about five months before and found himself in desperate need of food and a place to live. This situation soon resulted in his recruitment into a pornographic movie operation in a plush suburban area of New Jersey. He had escaped this occupation prior to coming to Covenant House but was seeking assistance from us in dealing with the urges of returning to the sex industry in spite of the pain, rage and guilt his involvement in the industry provoked.

Mitchell also spoke to us of his feelings of intense rage against youths who are effeminate and his frightening desires to destroy them if he could not be helped. He is currently a resident in our Under 21 program in which he is struggling with independent living skills and receiving professional counseling.

2. When Lorraine was about thirteen years old she was escorted by her mother from her hometown in Virginia to Washington, D.C. There she was sold to a pimp from whom she escaped and returned to her 'home'.

She was soon readmitted to a psychiatric hospital in which she resided from age 9 to 12. Subsequent to her release she was raped by two men while her father threatened her with a gun. It was fired twice, injuring her in the arm. (In addition to the emotional trauma she has since experienced impaired hearing in the ear closest to the gunfire.)

After leaving her mother again she came to New York, wandered into a church, was referred to the police and then brought to Covenant House/Under 21. Lorraine left our shelter within two days and her whereabouts remain unknown to us.

3. Alex is a sixteen year old boy who had been missing for over six months when he was escorted to Covenant House by the police in February. His parents were divorced three years ago after numerous physical conflicts with each other. During one such incident, the mother stabbed the father in the back in the presence of Alex.

With his older brother, and several women, Alex frequentl participated in sex parties hosted by his father. Alex also became the sex partner and companion of a 40-year-old man (Bert) while simultaneously experimenting with various drugs.

At fourteen, Alex entered a residential school for emotionally disturbed children. After 18 months he asked to return to his home. His mother's refusal, for fear of his relationship with Bert, prompted another drug experience which resulted in his expulsion from school. He was soon registered, against his desires, in another school.

With the help of Bert, Alex ran away from the school after five weeks. Seven months passed before he was picked up by police in New York City and brought to us.

Alex absconded from Covenant House during the night of his arrival while his parents were discussing the case with our staff.

Alex later called our administrator who was handling the case and expressed a desire for assistance in pressing charges of abuse against his parents. He agreed to return the following day but was scared-off by a police raid on the apartment in which he was staying. Alex was not there, although several adults and young boys were taken into custody. The police were tipped off by Alex's father.

Alex phoned again the following day saying that because of the arrest of his friends no one will hear from him again. That was almost two months ago.

4. Marian was 19 when she arrived at Covenant House last July. She fled from New Jersey to New York City seeking shelter from her pimp - Raymond.

She claimed that she was sexually abused from age 9 through 13 by her maternal uncle while her mother and grandmother denied her allegations. At age 13 she was beaten by a 17 year old youth who was upset by unsuccessful attempts at intercourse. Raymond, who had been a companion of Marian's mother assaulted the boy and is the father of a child born to Marian while she was 14. Marian feels no attachment to this child.

For the following four years Marian worked the streets for Raymond who allowed her intermittent breaks because of her status as mother of his daughter. After several suicide attempts she finally found the courage to break from him.

Our attempts to assist Marian in her desire to leave the Metropolitan area, finish school and begin work have been very successful and rewarding. We were able to secure a place for her in a small midwest program which apparently has met her needs.

At our request the authorities in New Jersey followed up with the investigation of the welfare of Marian's daughter at Raymond's address. Marian refused any suggestion of prosecution of Raymond with the sad reply, "After all, he raised me."

5. Denise was 18 when she arrived at Covenant House. Her father abandoned the family when Denise was an infant leaving the mother to care for the five children.

When Denise was 13 her mother married a man who within a year, threw out the kids telling them to live with the oldest brother. Denise stayed with her brother for the school year and then returned to her mother for only a few days until told to leave again by the step-father. This demand overpowered the desire of the mother to care for Denise.

Denise began to fend for herself living with friends and surviving through prostitution. She attempted to seek help from her older brother but that possibility ended following a fight between Denise and her sister-in-law.

Again Denise returned to her mother. Soon thereafter, the step-father held Denise responsible for the loss of a gold chain and demanded that she "work a stroll" for him in repayment.

Denise fled and came to Covenant House with reports of sexual abuse incidents involving her step-father and half-sister. She also claimed that her step-father had a few girls working for him and was encouraging his son in a pimping career.

Fear of revenge against her mother or herself prevents Denise from pressing charges against her step-father. It is likely that this fear also prompted her decision to leave our program prematurely.

COVENANT HOUSE UNDER 21
460 WEST 41 STREET
NEW YORK, N.Y. 10036
(212) 613 0300

THE INSTITUTE FOR YOUTH ADVOCACY

June 9, 1983

Ronald E. Docksai, Staff Director
Committee on Labor and Human Resources
Room 4230, Attention: Mr. Powell
Washington, D. C. 20510

Dear Mr. Docksai;

As you requested I have made minor grammatical and clarifying revisions in my oral testimony before the Subcommittee on Family and Human Resources on April 11, 1983. I enclose the revised copy of that testimony for your use.

Because you requested as well any documents or information requested during my appearance before the Subcommittee, I have also taken the liberty of enclosing for your purpose copies of a letter from Senator Denton requesting more information about certain aspects of my testimony and of my response. While Senator Denton did not request that information on the day of the hearing, I believe he was prevented from doing so only by an unexpected illness that forced him to leave the latter stages of the hearing. I would ask, of course, that you inquire of his office whether it is appropriate to include either of the letters in the record of the proceedings.

Thank you for the opportunity to correct some of my more egregious departures from Ciceronian eloquence, and for your diligence in executing your important public trust.

Very truly yours,

Gregory A. Loken
Senior Staff Attorney

GAL:jh
encls

cc: Senator Jeremiah Denton

United States Senate
COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, D.C. 20510

April 19, 1983

Mr. Gregory Loken
Senior Staff Attorney
Covenant House
460 West 41st Street
New York, New York 10036

Dear Mr. Loken:

Thank you for taking the time to testify before the Subcommittee on Family and Human Services on April 11. I sincerely apologize for the inconvenience that my illness may have caused you.

I believe the hearing provided a helpful forum for debate on the many issues surrounding the federal child abuse program. Your testimony was valuable, and I appreciate your answers to questions asked by members of the Subcommittee.

Because of time constraints, I was unable to ask all the questions I had prepared. I would appreciate it if you could respond within two weeks.

1. Mr. Loken, you mention in your testimony that the media could play a significant role in helping to prevent sexual abuse. Has Covenant House had any success in involving the New York media in this campaign against sexual abuse? Other than improving the quality of programming, what specificially can television do to help in this area?

2. Mr. Loken, you mention in your statement the need for facilities offering long-term treatment for sexually abused children. Can you identify any successful such programs that are currently in operation?

I will be happy to send you a copy of the hearing record when it is printed. This process usually takes several weeks.

Again, thank you for your time and assistance.

Sincerely,

Jeremiah Denton

JEREMIAH DENTON
United States Senator

JAD:dh

COVENANT HOUSE UNDER 21
460 WEST 41 STREET
NEW YORK, N Y 10036
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THE INSTITUTE FOR YOUTH ADVOCACY

June 9, 1983

Honorable Jeremiah Denton, Chairman
Subcommittee on Family and Human Services
Committee on Labor and Human Resources
United States Senate
Washington, D. C. 20510

Dear Senator Denton:

My apologies for this delayed response to your questions concerning the sexual abuse of children, but I wanted to take the time necessary to respond to your very pertinent inquiries in as complete a fashion as possible. As earlier, I am delighted to be of assistance to you and the other members of the committee as you wrestle with this tragic problem.

I am happy to expand on the two questions you raise. Concerning the proposed use of the media in the prevention of sexual abuse, certainly an upgraded standard of television programming is desirable and would certainly have a positive impact in clarifying for young people the many ambiguous value messages current programming communicates. What would be of even greater and more direct value, however, is a media campaign - advertisements, special programs, commercials - which clearly admonish young people that their bodies belong to them, and that no one has a right to touch or approach them in ways that make them uncomfortable. An excellent model for this approach is a project now being explored by the Victim Services Agency of NYC in conjunction with ODN Productions. ODN has already produced an impressive set of prevention-oriented films on adolescent rape and incest, and the project now under consideration is a similarly designed prevention film on juvenile prostitution and its link to sexual abuse. An earlier film by ODN, "No Secrets", searchingly developed the issue of sexual abuse in a non-threatening way appropriate for children. By making films such as these available to all elementary schools and high schools, and by adapting this approach to the requirements of television, we hope significant strides toward prevention and early reporting of sexual abuse may be possible in our area.

During the hearing you expressed some legitimate concerns about the danger that in educating children about sexuality they may in fact be conditioned to believe that early sexual involvement is socially acceptable. Certainly we think that with regard to sexual abuse this peril is extremely unlikely - the thrust of any media campaign against sexual abuse must be to emphasize to them their fundamental right of privacy, which incidentally includes their right to be free from inappropriate sexual contact. State and federal agencies with responsibility for prevention of child abuse would seem to me the ideal sponsors and overseers of such an education campaign, particularly if they made use of the best advice and experience of private agencies and professionals.

You asked, in addition, whether we know of any successful long-term treatment facilities for sexually abused children. Two such organizations which have an exemplary record in providing nonresidential treatment are Parents United, in San Jose, California (phone number: (408)280-5055), and the Child Sexual Abuse Victim Assistance Project (at 111 Michigan Avenue N.W.) in Washington, D.C. We enclose, in addition, the 1982 annual report of the Minnesota Program for Victims of Sexual Assault of the Minnesota Department of Corrections. (That report recommends, it is worth noting, the development of sexual abuse education programs directed to children (p.6) and of means to meet victims' "life sustaining needs" such as temporary housing, pp.6,20.)

As for programs with a residential component which are aimed specifically at long-term treatment of sexual abuse, we have searched in vain for a perfect example. Perhaps the Children's Village operated with reportedly great success by Childhelp International in Beaumont, California, is the best example of a residential program for treatment of such children, although the program there is directed at treatment of all forms of child abuse. Because sexual abuse is so often attended by significant physical abuse or neglect, of course, any treatment program must, like Childhelp's, have the capacity to respond to all the injuries inflicted on the child. Clearly the absence of residential programs suitable for victims of sexual abuse is a gaping flaw in our response to the overall problem of abuse and neglect - a flaw we hope that Congress can help the nation address as soon as its resources permit.

Thank you again for your great courtesy in extending to us the invitation to testify before your distinguished

Subcommittee; you and your staff (especially David Yensen) made it a memorable and inspiring event. Please feel free to call on us in the future if we may be of further assistance on this or other matters related to the care or protection of children. We appreciate the depth of your demonstrated commitment to the protection of children from all forms of sexual exploitation; and we wish you God's blessings in your continued public service.

Very truly yours,

Gregory A. Loken

Gregory A. Loken
Senior Staff Attorney

GAL:jh

cc: Ronald E. Docksai, Staff Director
Committee on Labor and Human Resources

QUESTIONS SUBMITTED BY SENATOR DENTON TO MR. GREGORY LOKEN

1. Mr. Loken, you mention in your testimony that the media could play a significant role in helping to prevent sexual abuse. Has Covenant House had any success in involving the New York media in this campaign against sexual abuse? Other than improving the quality of programming, what specifically can television do to help in this area?

I am happy to expand on the two questions you raise. Concerning the proposed use of the media in the prevention of sexual abuse, certainly an upgraded standard of television programming is desirable and would certainly have a positive impact in clarifying for young people the many ambigious value messages current programming communicates. What would be of even greater and more direct value, however, is a media campaign - advertisements, special programs, commercials - which clearly admonish young people that their bodies belong to them, and that no one has a right to touch or approach them in ways that make them uncomfortable. An excellent model for this approach is a project now being explored by the Victim Services Agency of NYC in conjunction with ODN Productions. ODN has already produced an impressive set of prevention-oriented films on adolescent rape and incest, and the project now under consideration is a similarly designed prevention film on juvenile prostitution and its link to sexual abuse. An earlier film by ODN, "No Secrets", searchingly developed the issue of sexual abuse in a non-threatening way appropriate for children. By making films such as these available to all elementary schools and high schools, and by adapting this approach to the requirements of television, we hope significant strides toward prevention and early reporting of sexual abuse may be possible in our area.

During the hearing you expressed some legitimate concerns about the danger that in educating children about sexuality they may in fact be conditioned to believe that early sexual involvement is socially acceptable. Certainly we think that with regard to sexual abuse this peril is extremely unlikely - The thrust of any media campaign against sexual abuse must be to emphasize to them their fundamental right of privacy, which incidentally includes their right to be free from inappropriate sexual contact. State and federal agencies with responsibility for prevention of child abuse would seem to me the ideal sponsors and overseers of such an education campaign, particularly if they made use of the best advice and experience of private agencies and professionals.

2. Mr. Loken, you mention in your statement the need for facilities offering long-term treatment for sexually abused children. Can you identify any successful such programs that are currently in operation?

You asked, in addition, whether we know of any successful long-term treatment facilities for sexually abused children. Two such organizations which have an exemplary record in providing nonresidential treatment are Parents United, in San Hose, California (phone number: (408) 280-5055), and the Child Sexual Abuse Victim Assistance Project (at 111 Michigan Avenue, N. W.) in Washington, D. C. We enclose, in addition, the 1982 annual report of the Minnesota Program for Victims of Sexual Assualt of the Minnesota Department of Corrections. (That report recommends, it is worth noting, the development of sexual abuse education programs directed to children (p. 6) and of means to meet victims' "life sustaining needs" such as temporary housing, pp. 6, 20.)

As for programs with a residential component which are aimed specifically at long-term treatment of sexual abuse, we have searched in vain for a perfect example. Perhaps the Children's Village operated with reportedly great success by Childhelp International in Beaumont, California, is the best example of a residential program for treatment of such children, although the program there is directed at treatment of all forms of child abuse. Because sexual abuse is so often attended by significant physical abuse or neglect, of course, any treatment program must, like Childhelp's, have the capacity to respond to all the injuries inflicted on the child. Clearly the absence of residential programs suitable for victims of sexual abuse is a gaping flaw in our response to the overall problem of abuse and neglect - a flaw we hope that Congress can help the nation address as soon as its resources permit.

Senator DENTON. Thank you, Mr. Loken. I will not make a habit of going out of order, but you mentioned the billion-dollar sex industry in New York.

Mr. LOKEN. Yes. There is.

Senator DENTON. Is that just in New York City, or is that nationally?

Mr. LOKEN. Of course, estimates of the amount of money going through the New York sex industry are very difficult to substantiate because much of it is not reported. But the best estimates from law enforcement officials is that in total, the sex industry in New York brings in at least $1 billion a year. It may be substantially higher than that just in New York City.

Senator DENTON. You mentioned a program to inform the children what was right and wrong in sex. From my experience in the adolescent pregnancy program, I am not sure that those up to age 17 are being told that there is anything right or wrong about sex. It is called a "value free" program. My experience with it would not have given it that favorable a label. I would have labeled it propremarital sex. So I do not know under whose auspices you would solicit a program to educate youngsters about what is OK and what is not OK; it is a fascinating field.

Mr. NEWBERGER. Senator, if I may——

Senator DENTON. Anybody can comment on any of those, and I was going to get into formal questions——

Mr. NEWBERGER. As we contemplate what might be done to prevent the physical and sexual abuse of children, it might be worth mentioning here that there have been some excellent materials developed for the education of preschool, school-age, and older children about the prevention of sexual abuse. The National Committee for the Prevention of Child Abuse in Kansas has developed a play called "The Bubbleonian Encounter," which is somewhat fanciful, but it basically advances the point to kids that there are some touches that are not OK. And there are some parts of your body which you should not let other people touch.

This is very important to get across to kids. When the sociologist, David Finklehor of the University of New Hampshire, surveyed parents in the Boston area about what they told their kids about sex and sexual abuse, they found that parents for the most part did not want to talk with their kids about sexual abuse, and would not, it appeared, feel comfortable in talking with them.

So, it is going to have to be done, it seems to me, Senator, by someone else. There have been, in addition, excellent media materials. A firm called Family Information Systems, working with the Massachusetts Society for the Prevention of Cruelty to Children, the oldest statewide child protection agency, has developed some slide tape materials called "Some Secrets Should Be Told," in which puppets are used. I have seen this used with first graders, and it is marvelously effective. I think we do have to begin there to give kids the opportunity to say no.

Senator DENTON. I want to welcome and acknowledge the arrival of the Senator from Iowa, Senator Chuck Grassley, who has, among his many interests and influences here in the Senate, an interest in child pornography, and has a bill pending in that field.

Senator Grassley, for the time which you wish to do so, I would propose to invite you to chair this meeting. And if you do find yourself having to leave at 4 o'clock, I will either relieve you myself or have Senator Hatch do so. Is that OK by you?

Senator GRASSLEY. Yes, Senator.

Senator DENTON. And I have something I can be doing for 20 minutes.

Senator GRASSLEY [presiding]. Mr. Holder and Dr. Newberger, the National Center has published a guide for State legislation in which it defines mental injury as, "an injury to the intellectual or psychological capacity of a child as evidenced by an observable and substantial impairment in his ability to function within his normal range of performance in behavior, with due regard to his culture."

Does this definition give States better guidance as to what is meant by mental injury?

Mr. HOLDER. I believe that it does. Any statute, though, has to allow for interpretation with regard to individual cases, and so forth. I think that adequately outlines the nature of the problem to the extent that medical and psychological evaluation and social work evaluations can result in a more precise understanding of the individual circumstances in a case whereby it can be dealt with in court.

Senator GRASSLEY. Dr. Newberger.

Mr. NEWBERGER. With due respect, Senator, I believe emphatically that it does not. I believe that it creates enormous ambiguity and confusion, both for the administrators and for the social workers who are instructed by statute to respond to these reports.

Across the country we see that it is precisely these reports that are not addressed when children who are identified as victims of so-called mental injury have to compete, say, with infants who are victims of severe physical abuse or adolescents who might be victims of sexual abuse.

I think that the time has come for us to sharpen, to narrow our definitions in order to be able to use our resources more capably.

Senator GRASSLEY. Mr. Holder and Dr. Newberger, what specifically can the national center do to assist State child protective service agencies to improve the quality of the services they provide in the child abuse area?

Mr. HOLDER. I think one of the things that has to occur is regulation, what should be expected is a national effort toward adherence of standards and knowledge that has been developed. NCAN could be instrumental in promoting for stronger adherence to a higher quality of practice based on what has been learned during the last several years.

The role of the national center up until now has primarily been to gather information and then disseminate it. Now is the time to change the emphasis toward States to comply to standardization of practice. That has not occurred.

So I think that is a beginning point.

Mr. NEWBERGER. Senator, the National Child Abuse Center has already begun some excellent work in this direction. They published a monograph entitled "Working Together: A Plan to Enhance Coordination of Child Abuse and Neglect Activities," which offers some very useful guideposts for State action.

First, it seems to me, we have to get beyond the primitive, overly psychiatric counseling approach that is taken toward child abuse.

There is a widespread belief, which, I believe is mistaken, that parents who neglect or abuse their kids are mentally ill. And for the most part in State child protection agencies all that young social workers can do is talk. For many of these families, talk is not primarily the issue. There need to be bridges constructed between the social workers and other agencies in the community which can offer medical, homemaker, child care resources.

Clearly the resources available, that is to say, the money committed for such services, needs greatly to be expanded. Right now the national program is largely one of pretend. It is an empty promise that is made to kids who are reported when a social worker comes out, does not have the wherewithal to examine a child, and may ask a few questions about how things are going with their parents, often then to leave without any prospect of helping the child in a situation of potential danger.

This is the reason, it seems to me, why there are so many press exposés and lawsuits around the country around the provision of protective services. It is not simply a question of applying in practice the homilies and bromides which make up much of the child protection literature. We need to look sternly and rigorously at what we know and how better to apply it.

Senator GRASSLEY. I am going to submit a statement that I was going to give if I had been here earlier, in the record; it deals with my interest in child pornography and my effort to—which is culminated in my introduction of S. 29 to comply or to parallel the Federal Pornography Act with the *Ferber* case that was decided last July.

[The prepared statement of Senator Grassley follows:]

PREPARED STATEMENT OF SENATOR GRASSLEY

I will commence by commending Senator Denton for his unfaltering diligence in seeing that this and other problems related to the victimization of our youth are aired so that we might begin the difficult process of rehabilitation.

I am aware that the Senate Judiciary Committee has conducted hearings on the problem or runaway and homeless youth. One of my interests in attending this hearing has to do with a bill that I have introduced, S. 29, a bill that seeks to halt the profusion of child pornography.

Child pornography might be labeled a "fallout" from the runaway problem which in turn could be prompted by the abuse that the child encounters in the home, in that homeless youth, alone and without resources, often emotionally disturbed, risk being victimized by exploiters. They may become involved in prostitution and in forms of delinquency which involve major costs to the youths themselves and ultimately to society at large.

Current federal law prohibits the use of children in pornographic materials only if the materials meet the difficult and confusing standard of legal obscenity. Last July the Supreme Court decided that where our children are concerned, the regulation of pornography need not comport with the legal definition of obscenity. Hence my bill, S. 29, would remove the requirement of legal obscenity from child pornography statutes thus making it easier to prosecute offenders and protect our children.

In the *Ferber* decision the Court held that the obscenity standard developed in *Miller* v. *California* does not apply to a photographic or other depiction of children actually engaged in sexual conduct. Abandoning the *Miller* standard as a definition of child pornography was predicated upon the Court's recognition that a State has a compelling interest in protecting the physical and psychological well-being of minors. The Court held that child pornography constitutes a category of material-like obscenity—which is outside the protection of the first amendment.

No discussion of this bill would be complete without noting how harmful the use of children or pornographic materials is to the physiological, emotional, and mental health of the child. It should be noted that because the child's actions are reduced to a recording, there is a permanent record of the child's participation and the harm to the child is intensified by circulation.

According to one study by the Academy of Child Psychiatry, sexually exploited children are unable to develop healthy affectionate relationships in later life, have sexual dysfunctions, and tend to become sexual abusers as adults. Another report by the Illinois Legislative Investigatory Commission emphasizes that sexual molestation by adults is often involved in the production of child sexual performances. Justice Sandra O'Connor, in her concurring opinion, summed up the Supreme Court decision when she wrote that:

"A 12-year-old child photographed while masturbating surely suffers the same psychological-harm whether the community labels the photograph 'edifying' or 'tasteless'. The audience's appreciation of the depiction is simply irrelevant to New York's asserted interest in protecting children from psychological, emotional, and mental harm."

At stake is the emotional and physical health of minors. I conclude by noting that Congress designated 1981 as the Year of the Child. It is my hope that 1983 will become known in Congress as the year that we made that promise good both in fact and in form.

Senator GRASSLEY. In regard to that case I would like to ask you Mr. Loken, if you are familiar with the *Ferber* case and your views on extending that court decision to the Federal statute.

Mr. LOKEN. Thank you very much, Senator. Covenant House filed two briefs amicus curiae in the *Ferber* case. We were involved with it from the very beginning, supporting New York's petition for certiorari and then once again during its consideration on the merits. So we have weighed the issue very carefully.

Many of the children at Covenant House have in fact been involved in child pornography. We view the problem really as a question of child abuse. It is a question of violating a child's privacy. A child who is used in pornography is not only sexually abused at the time the pornography is made, his image then remains on movie screens around the country, perhaps for the rest of his life or her life. There is no escape from that.

It is a permanent record of the child's sexual abuse. So your bill, as I understand it, Senator, would extend to the area of distributing child pornography the stringent rules that currently apply in the area of producing child pornography, that is, you would remove the obscenity requirement from the distribution sections of the child pornography statutes.

That is what the U.S. Supreme Court said in the *Ferber* decision may be done. And I applaud you, Senator, for taking that initiative because it is vital to fighting child pornography that we attack it at its one visible moment, which is when it is distributed.

Every other part of the process is invisible. Law enforcement has been completely ineffective in stopping production. Only by attacking distribution do we have any chance to address this problem fully.

Senator GRASSLEY. We got the bill through the Senate last fall, but too late to get it through the House of Representatives, and I hope we can get enough steam behind it this year so we get it passed early on.

I want to tell the panel that Senator Dodd has four questions that he wants to submit. Two of the questions are for Mr. Holder and the other two questions are for Dr. Newberger. But these will be submitted to you in writing, and we would ask you to respond.

At this point I would like to thank each of the panelists for participating in the hearings very much for the testimony submitted.

I will call the next panel.

Is Congressman Wheat from Missouri still in the audience, because I know that Congressman Wheat wished to introduce Mr. Sherman? He is not here.

Our final panel is made up of Mrs. Thelma Bigger, president of Parents Anonymous in Alabama; Mr. Timothy McNally of Johnson & Johnson, Inc., from Skillman, N.J.; Mr. Arnie Sherman, president of Camp Fire, Inc.; Ms. Fran Becchiolla, project coordinator for Connecticut Children Protection Project; and I should ask Fran to correct me on the pronunciation of her last name, probably; and, Dr. Marty Palmer from Primary Children's Center, Salt Lake City, Utah.

We will proceed in the order in which I called each of you distinguished witnesses, and I would ask you to give your statements in 5 minutes, each of you, and your written statement will be printed in the record, as previously stated. That is our practice. So we would ask you to summarize.

Will your start off, Mrs. Bigger.

STATEMENTS OF THELMA BIGGER, PRESIDENT, PARENTS ANONYMOUS, ALABAMA CHAPTER; TIMOTHY McNALLY, GROUP ACCOUNTING MANAGER, JOHNSON & JOHNSON, SKILLMAN, N.J.; ARNIE SHERMAN, NATIONAL DIRECTOR, CAMP FIRE, INC.; FRAN VECCHIOLLA, PROJECT COORDINATOR, CONNECTICUT CHILDREN PROTECTION PROJECT; AND MARTY PALMER, MEDICAL DIRECTOR OF AMBULATORY CARE, PRIMARY CHILDREN'S CENTER, SALT LAKE CITY, UTAH

Ms. BIGGER. Thank you.

Mr. Chairman and members of the Family and Human Resources Committee, I thank you for asking me to come and talk to you today about funding for child abuse. I think that the size of the problem has already been established by other speakers, the latest figure being something like 1,800,000.

I will bring the problem down to Alabama and speak about the work of Parents Anonymous, both on the State and local level. That is what Senator Denton asked me to talk about.

For those of you who might not know, Parents Anonymous is a national, self-help, crisis-intervention group for parents who abuse, or who are afraid they may abuse their children.

The call we like to get on our care line is the one that says, "I haven't done anything to my child yet, but I am so tense and nervous and angry I'm afraid I'm going to do something terrible to my child".

This caller definitely can be helped.

Parents Anonymous is currently serving some 15,000 families in 1,500 chapters in the United States, Canada, and abroad, while another 20,000 families are involved by phone only.

These are the parents who call for counseling on the phone, which we are happy to provide if this is the only way we can get to them. These are the parents who never have the courage to come to a chapter meeting, but if they will not come we are happy to provide professional volunteer counselors on the phone for them.

Parents Anonymous chapters were developed as early as 1974 in Birmingham and Mobile, followed by groups in Huntsville, Tuscaloosa, and Talladega.

The first State board was organized in 1978 and reorganized in 1981 when it received a seed grant from National Parents Anonymous of $4,000. In October 1982 the State board applied for a grant from the Alabama State Department of Pensions and Security and in December received $32,500 to set up a State office in Anniston and hire an executive director.

Presently, the State office is sharing space with the Calhoun County Director in the United Way Building.

The new director's job is to develop new chapters of Parents Anonymous in Alabama and to encourage existing ones. There are now 13 existing chapters and 4 in the process of being developed.

As each new chapter is formed it becomes self-supporting, for example; in Calhoun County we are supported by United Way; the two groups in Tuscaloosa by the Junior League; in Dothan by the Service League and Exchange Club.

To come down to local activities I will describe the activities in Calhoun County because I am familiar with them, but similar activities are taking place in other areas of the State.

Parents Anonymous has several objectives: One of these is to work with families to keep the families together and the children in the home if at all possible; another main objective is acting as advocates for the children to make the public aware of child abuse and willing to report it if necessary.

We are getting more involved in prevention activites as time goes on, both on the State and local levels.

Back to local activities: We have four active chapters in Calhoun County. In these groups the parents come together for support and to talk out their fears, frustrations and anger, rather than taking these out on their children.

We have chapters meeting on Tuesday night, Thursday morning, and Thursday night. The Thursday morning group meets on the base at Fort McClellan.

We also sponsor a Monday evening discussion group for parents of teenagers.

Parents Anonymous works with abusing parents by providing them support and group therapy in chapter meetings; by providing programs presented by mental health professionals on stress management, anger, communication skills, et cetera; by providing parenting classes in the chapter sessions using the STEP program [Steps To Effective Parenting].

We also provide parenting classes outside chapter meetings for the general public. We do this in cooperation with the community education coordinator of the Anniston City Schools. We have classes now running in three of our elementary schools.

Parents Anonymous is also planning a week of classes in May, working with the schools, with mental health, the Department of Pensions and Security, Regional Alcoholism Council, and other groups to design a series of studies for parents and adolescents.

What we are trying to do here is to get the parents to talk to their teenage children. We have had so many pregnancies in our schools that the schools and agencies are becoming very concerned about the fact that parents do not talk to the children, and in turn, when they are in trouble, the children, the teenagers do not talk to the parents.

Someone mentioned the Bubbylonian Encounter. We have a puppet show that we use with elementary schoolchildren. It is entitled, "There Is Someone to Talk To". It is designed for grades 2 through 6. It deals with medical and situational neglect and touches lightly on sexual abuse. We are meeting with a great deal of success.

We have been invited to schools in other cities and they are not only asking for this puppet show that touches on sexual abuse for the grades 2 through 6, but they are asking for it for kindergarten and the first grade.

We feel we are breaking down barriers. In talking to Senator Denton I said I agreed with the young man who said earlier that we need a media campaign to educate the public about the prevalence of sexual abuse, to make them aware. It is here with us. We may as well bring it out of the closet. We need to talk to children about incest.

We need to say to them—there are places on your body that you have the right to say "no" if someone wants to touch you. We need instruction in schools to say to these small children, if someone touches you in your private places where you do not wish to be touched, you have the right, even though you respect adults, to say "no", you cannot do this to me.

There are some classes being held like this now in schools over the country, by parents request, and the children are being led in saying certain things like, "No, you may not touch me here". This is good, I hope we can get into this more.

[Material referred to follows:]

RECOMMENDATIONS

(1) That funding for NCCAN be continued and increased.

(2) That small stage agencies be given seed grants to develop innovative programs to prevent child abuse and neglect.

(3) That funds be made available specifically for sexual abuse and incest, both for prevention and treatment.

(4) That funds be provided for better training for social workers, especially in their field placements. Training should include special training in handling sexual abuse and incest cases.

(5) The federally funded media campaigns be instituted to make the public aware of sexual abuse and incest.

[The prepared statement of Parents Anonymous of Alabama follows:]

PARENTS ANONYMOUS OF ALABAMA, INC.

Post Office Box 2638 Anniston, Alabama 36202 (205) 236-4952

THE SENATE SUBCOMMITTEE ON FAMILY & HUMAN SERVICES,
SENATOR JEREMIAH DENTON, CHAIRMAN

Background Information on Parents Anonymous

Parents Anonymous is a national self-help program for parents who abuse their children. The organization is currently serving 15,000 families in 1,500 chapters in the U. S., Canada and Europe, while another 20,000 families are involved "by phone only." During the past year all of the national, state and local Parents Anonymous organizations and affiliates handled more than 100,000 calls from parents in stress and professionals seeking P.A. assistance for families in need of child abuse prevention and treatment services.

Funding to support all levels of Parents Anonymous has reached $1,000,000 annually, yet the cost to serve each family remains at about $50 to $75 annually.

This is because some 15,000 professionals and lay persons donate so many hours of their time to provide some ten million dollars in in-kind services. (For example, in Anniston, AL, there are six professionals donating at least five hours each week to help in four groups sponsored by P.A. and three professionals form an advisory board, meeting six times a year with sponsors and chairpersons. There are many other professionals available to P.A. as needed).

Volunteer assistance comes in many forms:

Sponsorship at Parents Anonymous meetings by human service professionals, educators, ministers, et al, who assist parents in their search for answers to child abuse problems;

Children's group volunteers, including college students, service clubs, church volunteers and other agency volunteers;

P.A. Board of Directors membership assistance from business leaders, professional and lay persons;

Cost free meeting rooms for P.A. parents and children;

Help to P.A. programs with publicity, transportation, education development, workshops, fund-raising, publications, etc., from hundreds of lay persons as individuals or members of groups including church auxiliaries, Junior Leagues, social sororities, Council of Jewish Women chapters, service clubs, Rotary, Kiwanis, Exchange, et al.

The National Parents Anonymous is now developing a children's treatment project so that communities everywhere will have information and guidance on how to establish low cost, high quality service for abused children and teens. This is again oriented to the self-help philosophy using a minimum of dollars for basic costs to underwrite a creative effort to break the cycle of child abuse in the next generation.

Parents Anonymous was founded in 1970 in Redondo Beach, CA., by a frustrated parent who was seeking help for her own abusive behavior.

Parents Anonymous In Alabama

Parents Anonymous chapters were developed as early as 1974 in Birmingham and Mobile. In the years following, chapters were formed in Huntsville, Tuscaloosa and Talladega. Some were relatively short-lived for lack of state coordination and support.

A state P.A. Board was organized in 1978 by three active chapter sponsors: Kinley Ettrein, Birmingham; Glenn Rowe, Mobile; Michael O'Bannon, Tuscaloosa.

The board was reorganized in October, 1981 and three new chapters were developed. Presently there are thirteen chapters in Alabama: four in Anniston; two in Tuscaloosa; one each in Birmingham, Dothan, Enterprise, Huntsville, Decatur, Montgomery and Randloph County.

During 1982 a statewide board was formed and funding sought by its members to spread P.A. chapters over the state. State legislators were contacted, private foundations in Alabama contacted and a grant application sent to National Parents Anonymous.

The state board received a grant of $4,000 from National Parents Anonymous and later in the year in November, being notified that they might apply for a grant from the Alabama State Department of Pensions and Security, did so, and in December of 1982 received a grant of $32,500 to set up a small state office and hire an executive director.

This has been done, the new director, Miss Mary Dryden was hired in February and is sharing an office in the United Way Building in Anniston, AL, with the Calhoun County Parents Anonymous director.

Groundwork has been laid for chapters in Piedmont, Jasper and Mobile. The director's first task was to visit these places and complete plans for the organization of support committees which precedes the forming of P.A. chapters for parents.

It has been found that P.A. chapters are more stable when support committees are first organized to provide services needed by P.A. parents, child care, transportation, phone line, etc. Once formed, chapters are self-supporting. For example: In Anniston, by United Way; in Tuscaloosa, by the Junior League; in Dothan, by the Service League and Exchange Club; in Randolph County, by the

Health Council.

Inquiries have come in from Ozark, Lee County, Washington County, and Gadsden.

Plans are being made for a workshop this summer and many good things are happening over the state of Alabama in Parents Anonymous.

Kappa Delta Sorority contacted the state president last month and offered to raise money for a state WATS line for the state P.A. Money has already been raised for installation and the first three months service. Members over the state are enthusiastic. Child abuse has been chosen as the national philanthropy for Kappa Delta.

Local Chapter Activities

P.A. local activities will be much the same over the state, but we will describe those in Anniston and Calhoun County because we are more familiar with them.

Parents Anonymous has two main objectives:

1. To work with the families in order to keep the family together and the children in the home if at all possible.
2. To act as advocates for the children and make the public aware of child abuse and willing to report it if necessary.

To implement the first objective we have organized three Parents Anonymous chapters and one discussion group for parents who are having problems with their teen agers. (We did have two chapters in our Mental Health Center, but when state money was prorated in October of 1982 the youth program was dropped there for lack of funding and the P.A. chapters folded).

These chapters meet weekly, the discussion group on Monday night, regular P.A. chapters on Tuesday night, Thursday morning and Thursday night.

The Thursday groups were placed near Fort McClellan and primarily are for the military personnel. Beginning April 21, 1983 the morning chapter will be moved to a meeting site on the base at Fort McClellan. Military professionals are most cooperative and will make referrals to this group and Army Community Services has said it would not go against the record of military personnel to come to P.A. but attendance at the group would be a plus for parents.

(Statistics show there is no relationship between socio-economic status and child abuse, but one thread crops up consistently, there is more abuse reported in the military than in any other group).

In working with parents, Parents Anonymous offers group discussion with other parents; group therapy with a professional counselor present; parenting classes like the S.T.E.P. program (Steps to Effective Parenting) which offers training in Parenting Techniques; films: "Nutrition and Behavior", "The Chain to be Broken"; professionals are brought in to speak on "Anger", "Stress Management", Communication Skills", "Care and Feeding of Infants", and related subjects designed to teach parents good patterns of loving and nurturing and discipline to replace destructive patterns and to ease their relationship with their children and ease the problem of child abuse.

Acting as advocates for the children in the community to make the public aware of child abuse, Parents Anonymous cooperates with the Anniston City Schools Community Education Coordinator in putting on parenting classes in the schools. Three classes are presently being carried on in three schools in different neighborhoods with the emphasis on helping the single parent. The topics being presented are: "Parent-Child Relationships; Techniques of Discipline" and

"Basics of a Good Home Environment".

P.A. sponsors, along with the medical groups in the county, an annual seminar at Northeast Alabama Regional Medical Center and Jacksonville State University.

The seminar at the hospital is designed for medical personnel, the one at Jacksonville State University for social workers, teachers, students and lay persons.

Speakers have been Dr. Robert ten Bensel, University of Minnesota and Mrs. Thelma Baily, American Humane Association.

Plans are being made now for the October, 1983 Seminar with Dr. Ray Helfer as speaker.

P.A. is cooperating with the Anniston City Schools in presenting a puppet show to elementary school children. It is entitled, "There Is Someone To Talk To" and deals with medical and situational neglect and touches lightly on sexual abuse. Designed especially for grades two through six, we are being asked to show it to kindergarten and first grades because of increasing reports of child molestation and incest.

Calhoun County P.A. was one of 25 sites over the U.S. to be awarded a grant to design a Children's Treatment Program. We are in the process, with professional help, of structuring a program to build the children's self-esteem, alter destructive patterns of behavior and help them understand what is happening in the family.

As a part of advocacy we are constantly giving programs for schools, churches, civic clubs and keep leaflets and brochures in doctors' offices, hospitals and many public areas.

Along with other agencies in the community we are planning workshops in the month of May on "Parent-Adolescent Communication", with a speaker from "Project H.E.L.P.", a state organization.

Plans are complete for publicity in the county for "National Child Abuse Prevention Month" in April and materials are being sent to other areas in the state.

Much work remains to be done in Alabama as we think about 24,000 children being abused in 1982. We know that many volunteers will continue to work, but we also know that there comes a time when only being able to fund a project will keep it going.

CHILD ABUSE FACT SHEET

Reported Cases - National - 1981
More than one million, reliable estimates range from one to two million.
Deaths - 1981 - 5,000 - 18 per day directly attributed to child abuse.

Reported Cases - Alabama - 1980 - 17,315
1981 - 18,654

[illegible] Cases first 6 months of 1982. [illegible]

Child Abuse - Extends through all socio-economic levels, is not confined to lower economic levels.

Types of Abuse - Physical
Physical Neglect
Verbal
Emotional Abuse and Neglect
Sexual

Approaches - (a) Traditional Protection Programs
Social Service, foster care, detention, incarceration.
Studies show that 80% of young people in detention centers are abused children.
From 90 to 100% of adult prison inmates have been abused as children. In Alcatraz at one point, each man there had been an abused child. The cost of prison care is already known.

(b) Self-help programs like Parents Anonymous, founded in 1970 by an abusive parent. The parent members are the best evidence of its success. Cost estimate to serve each family $50 to $75 annually.

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Senator GRASSLEY. Thank you, Mrs. Bigger.

Ms. BIGGER. Thank you.

Senator GRASSLEY. Mr. McNally.

Mr. McNally. Thank you, Mr. Chairman.

I am here today representing Johnson & Johnson, a health care company which is headquartered in New Brunswick, N.J. And I am also representing the National Committee for the Prevention of Child Abuse and its New Jersey chapter, of which I am a board member.

The national committee is a nonprofit organization of volunteers whose mission is the prevention of child abuse and neglect. I welcome this opportunity to address you.

I would like to talk to you a little bit about Johnson & Johnson's role and what they have done. In 1979 Johnson & Johnson funded the founding of the New Jersey chapter through a $35,000 grant. At the same time they placed the president of the baby products company on the board of directors of the national committee and the vice president of personnel on the New Jersey chapter.

We have and will continue to provide financial support and people support and time and organizational support to the national committee and the New Jersey chapter. We—the New Jersey chapter ran a corporate breakfast in order to promote corporate awareness to child abuse. It was hosted by Johnson & Johnson Baby Products Co., and it was paid for by the baby products company.

At that breakfast, some of the speakers were Mr. Cockman, president of Popsicle Industries; Mr. W. Clement Stone, founder and chairman of the Combined Insurance Co. of America; and Mr. Jim Itaski, president of Baby Products Co.

The Honorable Thomas Kean, Governor of the State of New Jersey, also attended and signed a proclamation declaring June as prevention of child abuse month. The New Jersey chapter and the national committee, Popsicle Industries and Baby Products Co. also sponsored a fund raising event in January of this year, a Peter, Paul, and Mary concert held in New Brunswick, N.J.

The idea again was community awareness and community involvement. The event was well received, and there were a number of corporate donations, and a number of community people that attended the event.

The New Jersey chapter has had a couple of projects, and one in particular—two in particular are of note. One is called—it is a parent linking project, and it is called the Chestnut Street School. The Chestnut Street School takes in pregnant teenagers or pregnant adolescents and teaches them how to be mothers.

This, we feel, is one of the prime ways to prevent child abuse. It also provides the adolescent the ability to continue and stay in school, which does not usually occur in this particular case.

Also we have a speakers bureau that is designated to speak at different functions, and their ideas and the way they tailor their talk is directed toward that particular group.

I am also representing today the national committee, and the following is in context as role of a member of the national committee. We feel that the funding should be increaed to the level of the 1970's in order to continue the good work that NCAN has started.

I am very pleased to have this opportunity to address you, Mr. Chairman.

[The prepared statement of Mr. McNally follows:]

Testimony to the
Senate Subcommittee on Family and Human Services
on the reauthorization of the
Child Abuse Prevention and Treatment and Adoption Reform Act

April 11, 1983

Presented By:

Timothy C. McNally

Group Financial Manager
Johnson & Johnson Baby Products Company
Skillman, NJ 08558

Member of the Executive Committee
New Jersey Chapter
National Committee for Prevention of Child Abuse
Newark, NJ 07102

Representative of the
National Committee for Prevention of Child Abuse
Chicago, IL 60604-4357

Mr. Chairman, my name is Timothy C. McNally, and I am here today representing Johnson & Johnson, a Health Care Company which is headquartered in New Brunswick, New Jersey. I am also representing the National Committee for Prevention of Child Abuse and its New Jersey Chapter, of which I am an Executive Board Member.

The National Committee is a nonprofit organization of volunteers whose mission is the prevention of child abuse and neglect.

I welcome this opportunity to address you today.

Johnson & Johnson Corporate, and in particular Johnson & Johnson Baby Products Company, has been and will continue to be extremely supportive of the National Committee for Prevention of Child Abuse and its New Jersey Chapter. With a grant of $35,000, Johnson & Johnson, through its Baby Products Company subsidiary, funded the formation of the New Jersey Chapter in 1979. At that time, Mr. Robert C. Stites, President of Johnson & Johnson Baby Products Company, became a member of the Board of Directors of the National Committee for Prevention of Child Abuse; and Mr. William F. O'Brien, Vice President of Personnel for Baby Products Company, was named to the Board of Directors of the newly formed New Jersey Chapter.

Johnson & Johnson, through its Baby Products Company subsidiary, has continued its support of the organizations by providing financial donations, volunteer personnel, and organizational advice.

In 1982 the New Jersey Chapter requested that the Baby Products Company supply them a Director with a financial background. I volunteered for the position in May of 1982 and am proud to be serving such a worthwhile group.

One of the New Jersey Chapter's main goals is to promote public awareness of this growing, terrible condition that exists in our communities across the nation. In order to promote awareness, the New Jersey Chapter sponsored a Corporate Breakfast hosted by Baby Products Company, Skillman, New Jersey. Corporate heads were invited from all over the state, and attendees were informed how their companies could participate in the prevention of child abuse cause. The event was paid for by Baby Products Company, and speakers included Mr. James Cockman, President of Popsicle Industries; Mr. W. Clement Stone, Founder and Chairman of Combined Insurance Company of America; and Mr. James R. Utaski, President of Baby Products Company. The Honorable Thomas Kean, Governor of the State of New Jersey, attended and signed a proclamation declaring June "Prevention of Child Abuse Month."

The National Committee, the New Jersey Chapter, Baby Products Company, and Popsicle Industries sponsored a Fund Raising/Community Awareness event in January 1983. The event, held in New Brunswick, New Jersey at the Hyatt Hotel, was a "Peter, Paul & Mary Dinner Concert." This very successful event raised the community awareness and some needed funds to continue our work. The Johnson & Johnson Family of Companies purchased 10 tables. The Baby Products Company donated many employee hours, and along with Popsicle Industries, was responsible for numerous Corporate donations.

These kinds of events are extremely successful in involving the Corporate Community to donate their efforts because Preventing Child Abuse Through Public Awareness is in their interest. Furthermore, all the people involved in the setting up of the events are community volunteers. (A list of major donors of the New Jersey Chapter is attached.)

The New Jersey Chapter has a number of programs. The two most effective are the Parent Linking Project (Chestnut Street School) and the Speaker's Bureau - A Family Focus.

The Chestnut Street School Project takes in pregnant adolescents which allows them to continue their education and affords them the benefit of professionals and trained staff to help them cope with being parents and still survive the rigors of maturing into adulthood. This is a very unique program, as pregnant adolescents normally have to drop out of school and do not get the professional help they need to cope with their new lives. This is real prevention of potential child abuse. (A one page synopsis of this program is attached.)

Mr. Chairman, as I am appearing today in several capacities, I want to make clear that the following statement is delivered in the context of my role as a representative of the National Committee for Prevention of Child Abuse.

The National Committee has three requests that they feel will make this Bill more effective on the National and State levels. They feel that the budget should be increased to the 1970's authorization level of $30 Million. This would enable NCCAN to continue their fine work in an era of increased incidents of child abuse. Last year, 1982, was a particularly poor year. On an average, the states reported an increase of 10% in child abuse and neglect cases. In New Jersey, deaths relating to child abuse and neglect have risen from 12 in 1981 to 22 in 1982--a staggering 83% increase.

Given just the two facts above, one should have something to think about when considering the level of funding.

Another item the National Committee is supporting is the request that a substantial amount of money be earmarked for prevention instead of treatment. It could be very cost-effective in the long run.

The third item is that the National Center be given much more visibility by having the Secretary of the Department serve as Chairperson on the Advisory Committee. This would enable the Secretary to have "hands on" access to the daily working of NCCAN and enable the Director to interface more directly with associated agencies.

One of the most disturbing new factors in child abuse is the recent connection with unemployment. There seems to be a correlation between higher unemployment rates and increased incidents of child abuse. A research article by Mr. Peter Coolsen, M.S.W. is attached. The stress of unemployment seems to affect the whole family environment and sometimes manifests itself in child abuse.

I am very pleased to have the opportunity to submit this testimony to you.

THE NATIONAL COMMITTEE FOR THE PREVENTION OF CHILD ABUSE (NCPCA)

The National Committee for the Prevention of Child Abuse is the only national, charitable organization dedicated solely to prevent child abuse. It is a volunteer-based organization of concerned citizens working with community, state, national and international groups to expand the knowledge of child abuse prevention; increase awareness and understanding of child abuse and its prevention; and stimulate action for the development of policies and programs which help to prevent child abuse.

Since its founding ten years ago by Donna Stone, NCPCA has become a recognized leader nationally and internationally in efforts of preventing child abuse. As a charitable organization it has existed and grown primarily through generous efforts and contributions from individuals, private foundations, corporations, membershipsand fundraising efforts. The National Committee today is composed of a national office in Chicago, Illinois and thirty-two chapters throughout the United States - and it is still growing. This national network provides resources, technical assistance, information, consultation and education to promote the creation and expansion of community support services to children and their families to prevent child abuse.

THE NEW JERSEY CHAPTER - NCPCA

The New Jersey Chapter, NCPCA - was created in 1979, as part of the National Committee's local and state system, with the purpose of involving concerned citizens in action to prevent child abuse and neglect. It is a charitable organization working at a statewide level to raise public awareness, develop prevention programs, provide education and consultation, and to speak out on behalf of children and their families.

In 1980, the New Jersey Chapter developed the PARENT LINKING PROJECT as a model parenting education and support project in Newark. The project provides information, education and counseling to new parents so that they can more positively influence the physical and emotional growth of their children. It has operated in three Newark sites (1 hospital, 2 schools), serving over 700 families, most of whom were inner-city black and Hispanic teenage parents. During the Fall of 1982 the PARENT LINKING PROJECT was selected for presentation as a model program at both the Fourth International Congress on Child Abuse and Neglect in Paris, France and the National Leadership Conference of the National Committee for Prevention of Child Abuse in Detroit, Michigan.

The New Jersey Chapter-NCPCA reinforces the highly effective public awareness campaign conducted by the National Committee by maintaining their FAMILY FOCUS Speaker's Bureau. It utilizes trained volunteers to make individualized educational presentations to lay or professional groups on a variety of topics related to preventing child abuse and strengthening families. Its purpose is to stimulate community understanding about the problem of child abuse and neglect and involvement in its prevention.

NATIONAL COMMITTEE
FOR PREVENTION
OF CHILD ABUSE

NEW JERSEY CHAPTER
17 Academy St., Suite 709
Newark, NJ 07102 (201)643-3710

MAJOR DONORS OF NEW JERSEY CHAPTER

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Victoria Foundation	5/30/80
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7/82

NATIONAL COMMITTEE
FOR PREVENTION
OF CHILD ABUSE

NEW JERSEY CHAPTER
17 Academy St., Suite 709
Newark, NJ 07102 (201)843-3710

NEW JERSEY CHAPTER - NCPCA
PROJECT DESCRIPTION:

THE SPEAKER'S BUREAU ON PREVENTION OF CHILD ABUSE - A FAMILY FOCUS

Our Speaker's Bureau was created in 1981 in order to stimulate a community response to an involvement in the problem of child abuse and neglect and related parenting issues. With financial backing from a foundation, a corporation and a Junior League, we utilized the diverse talents of about thirty-five (35) volunteers. They received an intensive two-day training in communication skills, an overview of child abuse and neglect from a humanistic perspective, information about New Jersey Chapter abuse statutes and statistics, and prevention strategies.

This public awareness project differs from most in two important ways - (1) it individualizes the educational presentation to the needs and interests of the audience, with carefully selected audiovisuals and written materials; and (2) it includes written information about available community prevention services and specific ways on can get involved in preventing child abuse. Topics have included the following:

-identification, prevention and handling of child abuse and neglect

-education for parenthood

-changing familial trends in society, relevance to abuse

-NCPCA Community Plan for Prevention - suggested community programs

-role of medical, legal, or educational professional in dealing with abuse

-responsible sexual decision making by adolescents for prevention of premature parenthood

-special problems/needs of teenage parents

-our role in prevention, individually and collectively

Because research has shown the importance of public awareness in getting people to reach out for help before a crisis erupts, we feel our Speaker's Bureau is a vital component of our prevention activities.

NATIONAL COMMITTEE
FOR PREVENTION
OF CHILD ABUSE

NEW JERSEY CHAPTER
17 Academy St., Suite 709
Newark, NJ 07102 (201)643-3710

NEW JERSEY CHAPTER - NCPCA
PROJECT DESCRIPTION:
PARENT LINKING PROJECT

The New Jersey Chapter-National Committee for Prevention of Child Abuse developed a demonstration parenting education project in 1980. The goal of the project is to enable the new parent to maximize his ability to positively influence the physical and emotional growth of the child. The supportive interventions are designed to help prevent child abuse and neglect. It is designed for an urban population primarily consisting of teenage minority single parents. It has been operational in three Newark sites: University Hospital, St. Ann's School, and Chestnut Street School.

The project includes personal contact by a professional health educator with each of the parents, dissemination of a monthly newsletter "Pierre the Pelican", and a trained volunteer to act as a supportive listener who is knowledgable about child development and community social services. The newsletter, which has the American Medical Association endorsement and has been used statewide in eight states for many years, provides anticipatory guidance to new parents. The trained volunteer continues contact for up to one year post partum. The volunteer approach is based on research findings which support the value of trained laymen acting as positive role models to break patterns of isolation and child abuse.

To date the project has served 760 new families in the three project sites. Our volunteers represent a diverse cross section of the greater Newark area. The volunteers include local parents, day care workers, nursing students, Essex County Community College students, foster parents, and La Leche League mothers. The New Jersey Chapter trains these volunteers in communication skills, child development patterns, and child abuse prevention strategies. Thirty volunteers have been involved to date and new volunteers are being recruited and trained on an ongoing basis. The benefits of this parent education project are evident for both the volunteers as well as the new parents.

Our Chestnut Street School project has been tentatively selected for presentation at the International Congress on Child Abuse and Neglect, September 7 - 10, 1982, in Paris, France. In addition to the basic project components 250 pregnant adolescents attending this school have the benefit of a professional who conducts staff development training and runs student rap groups.

The preliminary evaluations seem to indicate the benefits of projects like the Parent Linking Project in the promotion of good parenting skills and the prevention of child abuse and neglect.

PARENTING IS A TOUGH JOB.

COPING BECOMES MORE DIFFICULT AND FRUSTRATION ESCALATES WHEN A PARENT EXPERIENCES:

ADOLESCENCE
LOW SELF ESTEEM
INADEQUATE EDUCATION
ADVERSE FINANCIAL CONDITIONS
VIOLENT ENVIRONMENT
SINGLE PARENTHOOD
LIMITED EMPLOYMENT PROSPECTS
SOCIAL ISOLATION
UNREALISTIC ATTITUDES TOWARDS CHILD/PARENTHOOD

THE N.J. CHAPTER OF THE NATIONAL COMMITTEE FOR PREVENTION OF CHILD ABUSE Feels **THE PARENT LINKING PROJECT** Can Help

The *PARENT LINKING PROJECT* was developed by the New Jersey *CHAPTER OF THE NATIONAL COMMITTEE FOR PREVENTION OF CHILD ABUSE* as a model parenting education and support project. The goal of the project is *TO MAXIMIZE A TEENAGE PARENT'S ABILITY TO POSITIVELY INFLUENCE THE PHYSICAL AND EMOTIONAL GROWTH OF HER CHILD.*

–Since our organization concentrates its efforts on prevention of child abuse and neglect, we are concerned with parents who are at high risk of becoming abusive and neglectful.

–Almost 12,000 babies were born in 1980 to teenage mothers in New Jersey. Of these over 1,000 in Essex County were to mothers 17 and under.

–Developing childrearing skills and support systems is vital to successful parenting.

The *PARENT LINKING PROJECT* is designed for an urban population primarily consisting of teenage minority single parents. The project has operated in three such sites in Newark, New Jersey (1 hospital, 2 schools) and has served over 700 new families.

This project was selected to be presented as a model program at:

- –Fourth International Congress on Child Abuse and Neglect, Paris, France, 1982.
- –National Committee for the Prevention of Child Abuse Leadership Conference, Detroit, Michigan.

PARENT LINKING PROJECT offers:
*technical assistance, including staff training and multi-media resource information on such topics as child abuse and neglect, family dynamics, and sexual abuse.
*small group discussions on relevant topics such as life skills and values clarification.
*dissemination of a monthly newsletter offering month-to-month information on the childs growth and development
*linking each new parent with trained community volunteers

More About Volunteers

PARENT LINKING PROJECT has recruited 30 community people to work along with the new parents providing:

- supportive listening
- information about child development
- referral information about community services
- a role model

Phase II of the *PARENT LINKING PROJECT* provides an educational and social forum in which new parents can share feelings and concerns.

Phase II offers:

- parent discussion groups
- newsletter continuation
- volunteer follow-up, including involvement in discussion groups

For more information contact:

NEW JERSEY CHAPTER
NATIONAL COMMITTEE FOR
PREVENTION OF CHILD ABUSE
17 Academy Street, Suite 709
Newark, New Jersey 07102
Phone: (201) 643-3710.

Executive Director's Letter
By: Brenda Byrne

A Look At Current Trends in the Child Abuse Field

In response to increasing concern an interest in the changing child welfare system, the national office of NCPCA has recently conducted a survey to measure the Impact of Federal Cutbacks on State and Community Responses to Child Abuse. I would like to share some of the findings with those of you in New Jersey who have indicated concern in this problem.

A brief look at the past is important if we are to view changes in proper context. Since 1972 we have seen these contrasts:

THEN	NOW
-No federal child abuse and neglect program	-NCCAN (National Center on Child Abuse and Neglect) has provided National focus for information, program development and research
-States had reporting laws	-Strengthened laws
-Emerging child protection programs in all states	-Improved approaches including 24 hour reporting facilities, specialized units, multidisciplinary teams, etc.
Emergence of a few self help groups, some Parents Anonymous chapters, no Parents United programs	-Over 1500 Parents Anonymous Chapters, over 100 Parents United groups
-Few community-wide child abuse councils	-Frequent, common use of community child protection councils or coalitions (as in New Jersey)
-Little concern for or understanding of prevention	-Greater interest and knowledge of how to prevent it
-Lack of public awareness of problem	-L Harris survey indicates 90% of adults are aware of problem, increased understanding of correlation between abuse and unemployment/juvenile and adult crime; only 10% understand how to prevent it

The impact at the state level is significant. During a telephone survey in the Spring of 1982, state agency spokesmen indicated some of the following important indicators evident since economic stress and federal cutbacks became more prevalent:

-In Michigan, where unemployment hovers around 15%, child abuse cases have increased by 37% in four counties most affected by automobile plant layoffs. More than 50% of the child abuse and neglect cases referred to their state agency came from four counties. Other populous counties do not reflect these increases.

-Texas reports more serious forms of abuse.

-Wisconsin shows an average increase of 123% in child abuse reporting from the 10 counties with highest levels of employment.

-39 out of 50 states are reporting (during our telephone survey) an increase in reported cases, with most of these (33) indicating an increase in severity, as well.

-Sexual abuse was reported by 35 state spokesmen to have dramatically increased.

-32 states had already noticed cutbacks, with 17 saying child abuse was such a high priority that state funds were filling the gaps created by federal cuts. A decrease in community based public services was seen by many.

-Efforts to narrow the interpretation of the child abuse laws was noted in four states, while 26 indicated a loose interpretation was evident in their states.

At the local level the study was less gloomy, with the private sector responding to the problems in a creative way. Locally we see a proliferation of volunteer-based acitivities, private donors concerned with the problem; creation of prevention programs and networks (such as the 12 new chapters of NCPCA within the past 6 months) and the development of grass-roots supported legislation that creates a funding base for local prevention efforts, like the Children's Trust Fund in six states.

In essence, we should commend local initiative that can turn a potentially devastating situation into a motivating force. The New Jersey Chapter-NCPCA remains "at the ready" to assist with any such prevention approach. Let's work together!

March 15, 1983

The Honorable Austin J. Murphy, Chairman
Subcommittee on Select Education
U.S. House of Representatives
Washington, DC 20515

Dear Representative Murphy:

As a nation we are more aware of the child abuse problem and how to respond to it than a decade ago. This is in large measure due to the existance of the small but effective federal program, the National Center on Child Abuse and Neglect (NCCAN) created by the 1974 Child Abuse Prevention and Treatment Act. NCCAN has been a catalyst for the nation; triggering state and local community responses to the problem. This National program has accomplished a lot. But clearly, much more needs to be done. We are delighted with the leadership you have taken in seeking reauthorization of the Child Abuse Act; we ask that the following be included in your hearing record.

The problem is one which is on the rise, as is clarified in the three attached articles. Last year 45 states reported an increase in the amount of child abuse; 33 reported an increased number of serious cases of abuse; and 14 reported an increase in the number of deaths. Unemployment appears to be one of the catalysts of these increases. During the same time period 33 states reported significant cutbacks in the size of the state's program which investigates and treats child abuse cases. Thus, we have more cases and a deteriorating response and treatment system.

The National Committee for Prevention of Child Abuse is deeply committed to seeing that Public Law 93-247, the Child Abuse Act, is reauthorized. Further, given the rapidly increasing magnitude of the problem, and the cost to society for waiting to respond after the fact, we want to see a dramatic increase in NCCAN's budget and thus a restoration of the authorization levels for Public Law 93-247 before the Reconciliation Act of 1981 at a minimum.

We want to see a substantial proportion of the discretionary dollars spent by NCCAN used specifically for primary prevention activities, e.g., activities directed at keeping the problem from ever occurring in the first place as distinct from rehabilitation after abuse has occurred. We would like to see the states encouraged to use portions of their state grants from NCCAN for prevention.

And, we would hope that NCCAN would continue minimally to provide states with grants at current funding levels per state. Thus, if additional states become eligible for state grants, additional funds ~~should be~~ made available under the state grant program. Finally, we would like to see NCCAN receive greater secretarial attention within the Department of Health and Human Services. Given the magnitude of the child abuse problem, the fact that child abuse appears to be the linchpin or common-denominator for so many of our other social problems, and the fact that child abuse is a health as well as human service and legal and educational problem, we believe that the D/HHS Secretary must become more involved with the activities of NCCAN to assure intra- and inter-agency and departmental cooperation in responding to the child abuse problem. We would like to see the Secretary serve as the Chair of the Child Abuse Advisory Committee established under the Act; and, we would like to have NCCAN update annually a plan for inter- and intra-agency and departmental activities for submission to the Secretary. We believe that these two actions will strengthen NCCAN's ability to accomplish its objectives as set forth by Congress.

We do hope the comments and the attached articles are of use. Thank you for your commitment in seeing the Child Abuse Act reauthorized.

Sincerely,

Anne H. Cohn
Executive Director

AHC/kck

Enclosures

Unemployment and Child Abuse

Peter Coolsen, M.S.W.

America is experiencing its highest level of unemployment in 40 years. The national unemployment rate reached 10.8 per cent by early December 1982, with more than 12 million people out of work. States like Ohio and Illinois are suffering from rates above 13 per cent; Michigan, the hardest hit, has one of every six workers looking for a job. Even states like Alabama and Texas in the boom areas of the South and Southwest are feeling the impact. And for the first time since the Depression, the jobless rate for men has topped that for women.

The media have devoted considerable coverage to the effects of high unemployment on families. Numerous articles have raised the possibility of a link between the rising unemployment rate and the increasing incidence of child abuse. While it is easy to assume a simple connection between the two, it may be valuable to explore this connection more deeply and to analyze the research available on the subject.

Unemployment obviously has a tremendous impact on families. In addition to the loss of income and the threat to the family's economic stability, there are numerous psychological assaults. An unemployed parent often experiences loss of self-esteem, reduction of economic power, and decreased social status. These experiences can lead to depression and to conflict among family members. (One of every seven workers in a Detroit survey reported increased conflicts with children after being laid off.[1]) It is not unusual for an unemployed breadwinner to spend hours a day in a depressed frame of mind, demoralized by the stress of unpaid bills and by rejections encountered in the job search. If the person out of work is a single parent, these pressures can be even more profound.

Children also need to make an adjustment during a time of unemployment. Often they must do without things that were available in more prosperous times. This deprivation may be particularly stressful for school-age children who interact daily with children of families not suffering from joblessness. Also, basic relationships between children and parents may change during this period. In a two-parent family an unemployed father may find himself spending more hours as caretaker of the younger children, and this comes at a time when his patience, self-esteem, and positive energy are at a minimum.

Consequently, the stress level is very high for both parents and children during a time of unemployment. Whether these stresses lead to violent or neglectful incidents or whether family members pull together and survive the crisis depends on a number of realities, some internal and some external to the family.

Research

Unemployment and economic stress have been cited throughout the child abuse literature as frequent correlates of maltreatment.[2-4] Few research efforts, however, have explored this relationship thoroughly. In a national survey conducted in the late 1960s, David Gil reported that 47.5 per cent of the fathers of abused children were unemployed during the year before the child was abused, and 11.8 per cent were unemployed at the time of the abusive act.[5] In a statistical analysis of Gil's data, Richard Light concluded that unemployment was the variable that could most frequently be related to child abuse, and that the data confirmed the theory that family stress from unemployment "ties in to incidence of abuse."[6] In 1975 a study with the United Auto Workers in Flint, Michigan, revealed that during the year in which the unemployment level reached 20 per cent in Flint, the incidence of verified child abuse doubled.[7]

Over the past year or so a number of statistical comparisons have been made between unemployment rates and child abuse reports[*] in states hardest hit by the recession. In Wayne County, Michigan (Detroit), the unemployment rate rose from 15.0 per cent in 1981 to 17.1 per cent in 1982. During the same time the number of substantiated abuse and neglect reports increased by 37 per cent.[8] In Wisconsin the Bureau for Children, Youth, and Families conducted a preliminary analysis of child abuse reports in counties with the highest levels of joblessness. It was found that while reported cases of abuse increased by 6 per cent in the state during 1981, they increased an average 123 per cent in the 10 counties with the greatest rise in unemployment.[9]

The state reporting statistics also give the impression of a growing severity of child abuse. In some of the states hardest hit by unemployment there has been an alarming increase in reports of seriously injured children and abuse-related deaths. In Texas, for example, where the unemployment level has recently begun to escalate, the total reported cases of child abuse increased 12 per cent over the past year. During the same period the number of "priority one"—or life-threatening—cases rose by 30 per cent.

Statistics like these seem to indicate a clear connection between unemployment and child abuse. It is imperative, however, to point out the limitations of such data. While cross-

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About the author
Peter Coolsen, M.S.W., is associate director of the National Committee for Prevention of Child Abuse. He is currently at work on a publication concerning child abuse prevention in the workplace, which is a product of the 1982 NCPCA conference on "Strengthening Families through the Workplace," held in Racine, Wisconsin.

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[*] Note that "reported" cases of child abuse are not always an accurate reflection of the actual numbers of cases; reporting rates may go up or down depending on what is used as the definition of an acceptable report.

Unemployment

(continued from page 7)

a recognition and awareness by the community that unemployment carries with it heavy economic and psychological stresses and that efforts geared to supporting jobless parents will pay off in the long run by producing healthier families and maintaining stronger communities. ◆

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The loss of self-esteem, economic power, and social status that comes with unemployment can lead to depression and family conflict.

sectional studies and statistical comparisons provide some evidence of association between the two phenomena, they do not provide evidence of causality. It is possible, for example, that some unexamined variable connected with both the incidence of abuse and the level of unemployment may account for the association.

These comparisons also present some inconsistencies that go unexplained. For instance, while the child abuse reports for Wayne County increased by more than one-third during 1981-82, the number of reported cases for the entire state of Michigan remained at its previous year's level. Since Michigan was suffering from the highest degree of unemployment in the country, child abuse reports might be expected to have increased. Also, while the 10 Wisconsin counties with the greatest unemployment showed an average increase of 123 per cent in child abuse reporting, one of these counties actually showed a 42 per cent decrease, and while 8 of the 10 Wisconsin counties with the greatest *decline* in unemployment also showed a decline in reports of child abuse, 2 of those counties showed a substantial increase in abuse cases.[10]

An investigation conducted in two southern California counties has offered an example of a more rigorous research design and has provided a more conclusive statement about the relationship between unemployment and child abuse.[11] The study tested the hypothesis that undesirable economic change "leads to" increased child maltreatment. Changes in work force size rather than unemployment rates were used as the indicator of economic stress; data were examined over a 30-month period; and adequate controls for other variables were included. Analysis of the data revealed that a decline in work force size was significantly related to reported child abuse in two metropolitan communities and that "increases in child abuse are preceded by periods of high job loss." The investigators cautioned that since this was the first study of its kind, the results may not offer adequate guidance for social policy.

A significant insight provided by some of the research studies is that a change in status from employment to unemployment may be as significant as the actual unemployment itself, if not more so. That is, stress related to recent job loss may be more closely linked to maltreatment than the enduring condition of unemployment. This finding could account for the constant level of reported abuse cases in Michigan, where unemployment has taken on a somewhat chronic character.

What, then, can be concluded about the relationship between child abuse and unemployment? As of now, although there is good evidence of a correlation between the two and some evidence of causality, it is not possible to be precise about the mechanisms at work. There is a need for further carefully designed investigations.

Assistance

Supportive and preventive efforts for unemployed parents and their families need not wait for more research data, however. The evidence is already strong enough that unemployed families are at high risk for child maltreatment (even though most jobless parents never actually resort to abuse and neglect). Communities need to gear up their assistance to such families, particularly in areas where there is a high incidence of recent job loss. In hard-hit communities concrete assistance such as unemployment benefits, food stamps, food pantries, and similar programs are essential.

Of primary importance, too, are efforts such as self-help and support networks aimed at reducing the isolation and psychological burden of unemployed parents. In one large metropolitan area, for example, a local church sponsors self-help groups for jobless members of its congregation. These groups assist members to find work and to deal with their emotional stress.[12] In the same community a coalition of churches sponsors an Unemployment Rally to aid local people who are out of work.

Union networks are another source of help for unemployed workers. Union social service committees, such as those of the Amalgamated Clothing and Textile Workers Union, furnish information and referral to members at the time of layoff and facilitate direct counseling to workers dealing with the trauma of unemployment. Union community service representatives and retraining programs are examples of other union resources that deal with unemployment.

What is most important, perhaps, is

(continued on page 10)

Senator GRASSLEY. Thank you very much.

Mr. Sherman.

Mr. SHERMAN. Thank you, Senator. On behalf of Camp Fire I am pleased to be with you today.

No other domestic issue is less understood and hidden than child and adolescent abuse and maltreatment. There exists a tremendous public misunderstanding of the nature and scope of the crisis, to the extent that insensitive attitudes and inadequate programs often result.

I cannot help but call to your attention one recent and unfortunate example of such callousness. Just last week, Senator, in the Senate Judiciary Committee, of which you are a member, it was noted and widely publicized that the nominee for one of our Nation's most important and influential youth positions advertised, "Have You Slugged Your Kid Today," on his automobile bumper.

When questioned, the nominee claimed it was a joke. I believe that millions of Americans—and I hope you also—would fail to see the humor in that. I am sure the over 1 million children who every year are physically, sexually, and emotionally abused would also find it no laughing matter.

If the public could just see these children as I have, if they could see the 4-year-old who has been beaten and sodomized by his mother's boyfriend, or a teenage girl at the door of my runaway shelter in a prom dress, blood pouring down her face after being attacked with a high heel shoe by her alcoholic mother just for coming home late; if the public could see, they would begin to realize how vulnerable and victimized our children really are.

There is little to laugh about in the following sobering statistics: In 1981, 851,000 reported cases involving 1.3 million children took place; over 7 percent involved sexual abuse. One woman in every five reports being sexually abused. The average age of abused or neglected children in this country is 7½. For the age group of zero to 5 years old, which makes up 28 percent of the population, they account for 74 percent of all abuse fatalities, which there is estimated to be as many as 4,000 a year.

There are over 200,000 children molested each year. Abuse cases reports double each year. And it happens to boys as well as girls, with the majority of adolescent abuse cases involving boys, in excess of 75 percent.

The effects of child abuse are profound and interwoven with a variety of society's ills. Seventy percent of all runaways are victims of sexual abuse. Fifty-five percent of all juvenile offenders have been sexually abused. And victims of abuse, as you well know, are more likely to become adult offenders and to abuse their own children.

Seventy-five percent of all prostitutes have been sexually abused as children. Abuse of children and adolescents is a complex problem related to other issues confronting the American family. Obviously, unemployment is one vivid example. Child abuse has risen 10 percent in the past year, and unemployment is clearly one of the major factors.

Certain other factors are considered as triggers, factors such as financial problems, being unable to find work, low self-esteem, confusion about role within the family. And with more than 30 million

Americans living below the poverty level, the highest in 16 years, there is every expectation that even more children will become victims of abuse.

Camp Fire has a long history of involvement in child abuse prevention and education. As you may be aware, Camp Fire is a national organization founded in 1910; its purpose then, as it is now, is to provide through a program of informal education opportunities for youth to realize their potential and to function effectively as caring, self-directed individuals, responsible to themselves and others, and as an organization, to seek to improve those conditions in the society which affect young people.

I would like briefly to share with the committee some of the current, important child abuse projects Camp Fire is engaging in, and then to give a short summary of our legislative recommendations to the committee.

Camp Fire is operating a variety of national programs designed to provide self-reliance to young children. One of them—I can do it—has helped 18,000 boys and girls every year feel more secure and less vulnerable when they are alone at home or away from home and their family.

Another national program that we have been operating is called caution without fear, resulting from the Atlanta murders. This program is designed to offer role-playing opportunities for children to learn to be alert and to be aware without being fearful. Over 160 Camp Fire Councils around the country are operating that program.

Camp Fire, as you also may be aware, serves over one-half a million boys and girls, with 120,000 volunteers in over 35,000 communities in this country. We also offer a program called I am safe and sure, which is a crime prevention program designed to help children in kindergarten and first grade recognize potentially dangerous situations and respond calmly and wisely.

Recently we have developed a resource packet called Community Education for Healthy Parenting. The packet includes materials and suggestions on how local communities can combat child abuse. Of our local councils, 125 have reported implementing programs to educate about child abuse; 55 percent or 160 of them have advocated reduced child abuse, and many local programs have resulted from this activity.

Just briefly, the legislative recommendations are: First, Camp Fire actively supports the reauthorization of the Child Abuse Prevention and Treatment Act.

We believe that the Federal Government must maintain its commitment to attacking this problem. As budgets get tighter at the local level as a result of economic conditions, State and local government look to the Federal Government for direction. Without a commitment at the highest level of government, State and local governments may retreat from their efforts at the local level.

Although Camp Fire child and sexual abuse programs are conducted usually without the aid of Federal funds, it is impossible to assume that private support can fill the gap left by the elimination of public support. And this statement comes from an organization whose backbone is built on volunteers.

Second, in terms of funding level, Camp Fire activities and programs are directed by a set of guiding principles. I would like to insert a copy of these in the record at this time.

In the context of these principles, we are proud to join numerous other child care organizations in support of S. 572, the child survival bill. Embodied within that bill is the recommendation that the child abuse and prevention program should receive $30 million in funding.

Although this figure may appear to be a substantial increase over previous years of funding, we believe that this amount is needed to adequately address the problem. As economic conditions have worsened, so have the incidents of child abuse and sexual abuse.

We simply cannot turn our heads from this fact, and we must respond to the situation. If we fail to respond, we will have millions of young people who have reached adulthood permanently scarred by those earlier incidents.

Third, in regard to the length of the reauthorization, we would recommend that the program be reauthorized for at least 4 years. This would provide stability for the program, and it would allow for the development of prevention techniques. Any shorter length of time would not allow for a systematic approach to the problem.

Fourth, in regard to the direction of the act, one of the guiding principles of Camp Fire is to insure that all children and youth have access to physical and mental health care services, which are responsive to individual needs and are of high quality and have a focus on prevention and health maintenance.

Therefore, we recommend that a substantial portion of the funding provided to the program be targeted to prevention and increasing the quality of care. If the Federal Government is not willing to risk developing techniques and expertise in the development of prevention programs, the local government will surely not.

We must do more in the area of prevention; otherwise, our efforts will be merely applying the bandages after the fact.

These are general recommendations for the reauthorization of the act. Camp Fire is thankful for the opportunity to be here today. And I would be happy to respond to any questions.

[The prepared statement of Mr. Sherman and the Camp Fire set of guiding principles referred to previously follow:]

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GROWING WITH YOUNG PEOPLE FOR 72 YEARS

Hearing Before the Senate Subcommittee
on Family and Human Services,
Labor and Human Resources Committee

Chairman: Jeremiah Denton

Testimony by:
Arnold E. Sherman
National Executive Director,
Camp Fire, Inc.

Mr. Chairman and members of the subcommittee, on behalf of Camp Fire I would like to thank you for the opportunity to testify before you on the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act. However, before I speak to this issue, I would like to briefly tell you a little about Camp Fire, Inc., our experience in child and sexual abuse, and the background for our recommendations.

Camp Fire is a not-for-profit national organization that was founded in 1910. Its purpose then, as it is now, is to provide, through a program of informal education, opportunities for youth to realize their potential to themselves and to others; and as an organization to seek to improve those conditions in society which affect youth.

Today, there are over 300 councils chartered by Camp Fire, serving a half-million young people in nearly 35,000 urban, rural, and suburban communities. The philosophies and values of Camp Fire are as timely today as they were nearly a century ago, but the programs and priorities within Camp Fire have changed over the years, reflecting the changing world we live in. As social conditions have altered, Camp Fire has responded with programs designed to meet those needs.

Child abuse, for instance, is not a new problem, and Camp Fire has a long history of involvement in child abuse programs. But recent economic downturns in our nation have magnified the problem of child abuse into a crisis.

The statistics on child abuse are shocking. In 1981, 851,000 cases involving an estimated 1.3 million children, were reported. And those are only the reported cases. Seven percent of those cases involved sexual abuse. Because we don't like to talk about sexual abuse, or even think about it, those statistics are even more shocking.

-- One woman in five reported being sexually abused as a child, according to a survey of college students.

-- 28 percent of college females said they had sexual relations with an adult prior to the age of 13, according to another survey of college females. Only 6 percent of those cases were reported to authorities.

-- 200,000 to 300,000 female children are molested every year in the United States, according to estimates by the American Humane Association.

-- Every year, the number of reported sexual abuse cases doubles, according to the New York Society for the Prevention of Cruelty to Children.

The figures are unacceptably high, and it's anybody's guess how many cases go unreported. It is unacceptable when even one twelve-year-old girl is afraid to go home, afraid of what might happen, wondering if tonight will be one of those nights when her father gets drunk and abuses her.

And girls are not the only victims of sexual exploitation. Boys are victimized, too, and one researcher goes so far as to say that boys and girls are equally at risk. One sex abuse hotline totalled up all its calls for a month and found they had twice as many boys as girls calling.

Sexual abuse can and does take the form of exhibitionism, fondling, hugging, and kissing in a sexual manner, masturbation and vaginal, oral and anal intercourse. Sexual abuse in also physical abuse and mental abuse of our children and adolescents. Physical effects may include cuts, bruises, injuries to the genital area and venereal disease in young children. Other effects may include thumb-sucking and even multiple personalities. If a child cannot bear the abuse, she will wipe it from her consciousness by becoming somebody else.

The effects of child abuse are profound and are interwoven with many other aspects of society's ills. The consequences of abuse and exploitation point out the complexity of the problem.

-- 70 percent of all runaways are victims of sexual abuse. They're running <u>away</u> from the problems at home and straight <u>into</u> the problems of the street -- malnutrition, drug abuse and other serious medical disorders. They rarely refer themselves for help. Some see suicide as the only way out.

-- 55 percent of all juvenile offenders have been sexually abused. Victims of abuse are more likely to become adult offenders, too, and to abuse their own children when they become parents.

-- 75 percent of all prostitutes have been sexually abused as children.

The abuse of children and adolescents is a complex problem -- one that is directly related to other pressing issues confronting the American family. Perhaps foremost among those issues is unemployment. Child abuse has risen ten percent in the past year, and unemployment is a major reason, according to the National Committee for the Prevention of Child Abuse. Certain factors are considered "triggers" for child abuse -- such factors as financial problems, being unable to find work, low self-esteem, confusion about the role a person plays in the family. Obviously, all those "triggers" are present in a family where the wage earners cannot find work, and, in fact, are giving up hope of ever finding work. With more than 30 million Americans living below the poverty level, the highest number in 16 years, there is every expectation that even more children will become the victims of abuse.

The physical and mental health of children, youth and families have been priorities for Camp Fire since its inception in 1910. Camp Fire's youth development and prevention programs have addressed the problems of children, including child abuse, in a variety of creative, responsive ways, without the aid of federal funds.

For example, Camp Fire has several self-reliance programs that help children to learn to respect themselves and do things for themselves.

-- The "I Can Do It" program has helped over 18,000 boys and girls across the country feel more secure and less vulnerable at home and away from home.

-- The "Caution Without Fear" program was developed in response to the murders of children in Atlanta. Using role playing, children learn to be alert and aware without being fearful of every new situation or person they encounter.

-- A new program called "I'm Safe and Sure" is scheduled for publication this summer. It's a crime prevention program designed to help children in kindergarten and first grade recognize potentially dangerous situations and respond calmly and wisely, whether by using the telephone to get help or by summoning the police or trusted family, friends, and neighbors.

In 1981 Camp Fire provided to all its member councils a child abuse resource packet called "Community Education for Healthy Parenting." The packet included informational materials and suggestions on how councils could help combat child abuse in their communities. Many local programs resulted from the priority placed on the issue by the national Camp Fire organization.

One local Camp Fire program which specifically addresses the issue of sexual child abuse is "Myself and My Family," developed by the Yakima Valley Council of Camp Fire in Yakima, Washington. The program, which won the outstanding program award from the national organization, was developed in cooperation with the Central Washington Comprehensive Mental Health Association, the Family Violence Resource Center in Yakima County, and the child abuse committee of the state Parent-Teacher Association (PTSA). Local college students were also involved as performers in skits that are part of the program.

Groups ranging from age 6 to adult participate in role playing and discussions. While the actual content of the program is adapted to the age level of the audience, all sessions explain that touching is part of life and that there is good touching, bad touching, and confusing touching. Children learn that their bodies are their own and that if they are touched in a way they don't like, they have a right to say "no," a right to talk about it, and a right to ask for help.

The concept of good touch/bad touch is also at the center of the Child Sexual Victimization Project of the Central Massachusetts Council of Camp Fire in Worcester. The project was developed in cooperation with the local Rape Crisis Program and the Worcester Area Community Mental Health Center, which received a $97,000 grant from the National Institute of Mental Health to fund the program from September, 1982, through August, 1985.

Clark University is also involved in the program and is testing children's knowledge before and after they participate in the Camp Fire project.

When two children died as a result of child abuse in Lewiston, Idaho, the Sacajawea Council of Camp Fire there began a program called "Dare to Care." The program helps children understand the difference between discipline and abuse and the importance of reporting abuse. It also reassures children that parents who are reported for abuse do not automatically go to jail, but can be helped by adults who have special training.

The program encourages Camp Fire girls and boys to learn about community agencies that deal with child abuse and to raise money to help combat child abuse. One fund raising drive was for money to buy a set of anatomically correct dolls which are used to help young victims of sexual abuse explain to professionals what happened to them. Children may be too shy, too embarrassed or lacking in the necessary vocabulary to tell what happened, but they can show what happened, using the dolls.

The Sacajawea Council also received a $400 grant from the Potlatch Corporation to establish a child abuse resource center with books, pamphlets, and audio-visual materials available for use by the entire community.

Several other councils have conducted forums in their communities, often in cooperation with other community agencies.

LEGISLATIVE RECOMMENDATIONS FOR REAUTHORIZATION OF THE CHILD ABUSE AND PREVENTION ACT

1. Support of Reauthorization

Camp Fire supports the reauthorization of the Child Abuse Prevention and Treatment Act. We believe that the federal government must maintain its commitment to attacking this serious problem. As budgets get tighter at the local level as a result of economic conditions, state and local governments look to the federal government for direction. Without a commitment at the highest level of government, state and local governments may retreat from their efforts at the local level.

Although Camp Fire child and sexual abuse programs are conducted usually without the aide of public funds, it is ridiculous to assume that private support can fill the gap left by an elimination of public support. And this statement comes from an organization whose backbone is built on volunteerism.

2. Recommended Funding Level

Camp Fire activities and programs are directed by a set of guiding principles. I would like to insert a copy of these in the record at this time. In the context of these principles, we were proud to join numerous other child care organizations in support of S. 572, the Children's Survival Bill. Embodied within that bill is the recommendation that the Child Abuse and Prevention Program should receive $30 million in funding. Although this figure may appear to be a drastic increase over previous years of funding, we believe that this amount is needed to adequately address the problem. As economic conditions have worsened, so have the incidents of child abuse and sexual abuse. We simply cannot turn our heads to this fact; we must respond to the situation. If we fail to respond, we'll have thousands and millions of young children who have reached adulthood permanently scarred by those earlier incidents.

3. Length of Reauthorization

Camp Fire would recommend that the program is authorized for at least four years. This would provide stability for the program and it would allow for the development of prevention techniques. Any shorter length of time would not allow for a systematic approach toward the problem.

4. Direction for the Act

One of the guiding principles for Camp Fire is "to ensure that all children and youth . . . have access to physical and mental health care services which are responsive to individual needs, are of high quality and have a focus on prevention and health maintenance." Therefore, we would recommend that a substantial portion of funding provided through the program is targeted to prevention and increasing the quality of care. If the federal government is not willing to risk developing techniques and expertise in the development of prevention programs, the local government surely will not. We must do more in the area of prevention, otherwise our efforts will be merely applying the bandages after the fact.

These are general recommendations for the reauthorization of the Act. Camp Fire is thankful for having the opportunity to present our views before the subcommittee. We stand ready to assist the subcommittee in its deliberations on this important issue.

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Camp Fire's Guiding Principles

In order to carry out its purpose Camp Fire will strive to ensure that all children and youth:

- are cared for and loved, and have the opportunity to learn, grow, play, make friends and find a meaningful life experience.
- have adequate food, shelter and the basic necessities essential to their survival and healthy development.
- live in an environment free of prejudice and stereotyping on the basis of race, sex, income level, disability, religious beliefs and country of origin.
- experience supportive relationships with adults who act as models, mentors and leaders during their lives and especially during critical periods of development.
- have educational opportunities which encourage full mental, physical and social development and which are responsive to individual needs, including those of children with mental, physical and social disabilities.
- have access to physical and mental health care services which are responsive to individual needs, are of high quality and have a focus on prevention and health maintenance.
- have opportunities to participate in deciding the present and future directions of their lives through involvement as partners with adults in meaningful roles in the family, school, religious community, social institutions, community and nation.
- have opportunities to learn values and skills which will make for life-long satisfaction in the workplace and opportunities to make a meaningful contribution to society.
- live in a society which nurtures positive social values and democratic ideals and which assures personal freedoms.
- experience a world where there is a balance between environmental concern and technological development and where there is ample opportunity for inspiration, recreation and education in the out-of-doors.
- have leadership from government at all levels which keeps their needs and interests at a high priority and addresses those needs and interests in a responsive, positive, developmental manner.

In Camp Fire's efforts in behalf of children, youth and their families, the organization will work with public and private organizations, institutions and individuals to ensure the full implementation of these guiding principles.

1983

Senator GRASSLEY. Thank you, Mr. Sherman. Let me say to Francine Vecchiolla that Senator Dodd could not be here to introduce you, but had this statement he wanted me to read for the record.

Mr. Chairman, it is with great pride that I introduce Francine Vecchiolla. She has helped make the child abuse, prevention, and treatment program in Connecticut a notable example for other states to follow.

Her work in attracting support from the private sector is especially commendable, having reached the attention of the House Subcommittee on Select Education two years ago. She has come to testify here today, even though she must thereby miss an important event in Connecticut to kick off Connecticut's observance of Child Abuse Prevention Month.

I thank her for coming to enlighten us.

And we thank you for that. But before you proceed, I want to also state to Dr. Palmer that I do not think Senator Hatch is going to be able to come here. He sends his apologies for not being here. And he wanted me to express to you, too the fact that he appreciates your participating in this.

Would you go ahead, Francine.

Ms. VECCHIOLLA. Yes. My thanks to Senator Dodd for that lovely introduction.

You know, each time I talk about child abuse I feel like I am on a racehorse because there never seems to be enough time to tell everyone all that we need to consider when we think about this important problem.

April is National Child Abuse Prevention Month, and the activity that I am missing today is Connecticut's kickoff for their observance of National Child Abuse Prevention Month.

It seems very important that we be considering this legislation in view of that fact. Between 1976 and 1981 there has been 106 percent increase in child abuse reports, nationwide. Last year child abuse related deaths increased. Many States fear that child abuse incidents will continue to rise as economic pressures faced by families, including unemployment, increases.

This year Michigan is seeing a 500-percent increase in the number of middle income families being reported. At least 35 States indicate that they are seeing more serious cases of abuse, and the amount of reported child sexual abuse is dramatically increasing.

Funding cuts have forced child protective services to lay off staff. Therefore, social workers are carrying even larger caseloads. With fewer staff to handle increasing reports of child abuse, attention to the children is now prioritized based on severity of abuse. One State said that only reports of children under age 12 are being accepted.

I urge you to reauthorize the Child Abuse Prevention and Treatment Act for 4 more years and to increase the support over the $17 million requested in Senate bill 1103. I would like to provide you with some evidence of the effectiveness of this act. Consider that only $6.7 million was appropriated to the States through this act last year. And consider the following examples of results achieved.

I know that Senator Grassley is knowledgeable about the many ways that these Federal child abuse dollars have been used in his State. Iowa's mobile parenting library for high school students and the home visitor program are two models that are also being used by many other States.

Missouri has developed an investigation handbook which described the step-by-step procedures which State socialworkers are to use when investigating child abuse reports. This handbook will make it possible for Missouri child protection staff to improve services provided to families and children.

I spoke with my colleagues throughout the country, specifically in Maine, Arkansas, Texas, Florida, California, and Massachusetts. Each time the story is the same. That is they wish you to know that the Child Abuse Prevention and Treatment Act has made it possible for them to at least begin to strengthen their child abuse prevention and treatment capabilities.

I think Mary Carswell from Alabama expressed our thoughts best when she said, "We definitely miss this money because it is the sole source for child abuse programing in our State."

Since Connecticut first qualified for these Federal child abuse dollars in 1974, a unique and effective system of community-based child protection resources has emerged. Connecticut's model system of child protective resources is based upon the collaboration of the public and private sectors.

The system is made up of a variety of programs, the core elements of which include a multidisciplinary team, parent aid services, and parental self-help groups. In 1976 Connecticut had only one team operating and serving 11 towns.

Currently, there are 25 teams serving 150 towns. During 1982, 456 families received services from these teams. Of the 25 teams, only 7 were seeded with Federal child abuse dollars, and each of these grants was small, approximately $10,000.

In 1981 an estimated $260,000 worth of professional services were donated to these child protection teams. In 1977 Connecticut had one parent aid program. Presently there are 18. During 1982, 517 families received services from these programs. Only two of these were seeded with Federal child abuse dollars.

Parent aid services are among the key methods for keeping children in their own homes after a crisis. The estimated cost of providing this service for one family for 1 year is $1,200. The cost of providing foster home care is estimated at $2,000; group home care, somewhere between $7,000 and $12,000 per child per year.

Although it is not possible to eliminate the need for out of home services, parent aids can significantly reduce the numbers of children needing more costly kinds of care.

And, finally, Connecticut has 37 of the 1,400 Parents Anonymous chapters which are located throughout the country. In Connecticut we serve about 925 families per year through this service at an annual cost equivalent to $59 per family. Parents Anonymous makes extensive use of volunteers. The 60 professionals who serve as resource people to Connecticut's 37 groups donated approximately 185,000 dollars worth of professional time last year.

Although Federal child abuse money acted as a catalyst, the $95,000 which Connecticut receives could never become the sole funding source for this type of resource system. In fact, State and local funding, inkind contributions, corporations, and foundations are each essential to make the ongoing operation of Connecticut's public-private resource system work.

Last year Connecticut received $100,000 in State general funds for child abuse programs. In Connecticut we are also grateful for the growing interest and support which corporations are providing to these programs. Throughout the State private sector funding has increased, both in the number of corporations providing fiscal resources and the amount of funds provided.

Of each program's funding, 25 percent is estimated to come from local sources. In order for these public and private partnerships to grow, there must continue to be nationwide focus on child abuse and neglect. Sometimes our attempts to identify the indicators or cost and program effectiveness have blurred our vision.

As we ponder the charts and graphs and contemplate the numbers served, we lose touch with the children. And as we distance ourselves from them, the decisions we make about policies become very far removed from the day to day reality of their powerlessness and suffering.

At a time when we each feel that our personal economy is threatened, we must continue to preserve our sense of human compassion and caring for these children. We can only do that if we reauthorize the Child Abuse Prevention and Treatment Act.

Thank you.

[The prepared statement and additional material of Ms. Vecchiolla follow:]

Regarding S 1003

The Reauthorization of the
Child Abuse Prevention and Treatment and
Adoption Reform Act, Public Law 93-247

Testimony before the
Subcommittee on Family and Human Services
Committee on Labor and Human Resources
of the United States Senate

April 11, 1983

Francine J. Vecchiolla, M.S.W.
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Division of Children & Protective
Services
Department of Children & Youth Services
Hartford, Connecticut 06105

Mr. Chairman, I appreciate the opportunity to appear before the members of this subcommittee concerning the reauthorization of the Child Abuse Prevention and Treatment Act.

April is National Child Abuse Prevention Month. And so today, it is particularly fitting that we consider the present status nationwide, of abused children and the capability of child protective services to respond to them.

.Between 1979 and 1981, there was a 106 per cent increase in child abuse reports nationwide.

.Last year, child abuse related deaths increased.

.Many states fear that child abuse incidents will continue to rise as economic pressures faced by families, including unemployment, increase. This year Michigan is seeing a 500 per cent increase in the number of middle income families being reported.

.At least 35 states indicate that they are seeing more serious cases of abuse and the amount of reported child sexual abuse is dramatically increasing.

.Funding cuts have forced child protective services to lay off staff; therefore, social workers are carrying even larger caseloads. With fewer staff to handle increasing reports of child abuse, attention to these children is now prioritized based on severity of abuse. Some states are responding to funding cuts and staff shortages by changing eligibility criteria. One state said that only reports of children under age 12 are being accepted.

Indeed, the magnitude and complexity of this problem is far greater than any of us imagined. Last year, 1.1 million children were abused, neglected or exploited.

Each year between 2,000 - 5,000 children are killed by their parents or caretakers.

A continued national focus on child abuse is the only way to be sure that these children's voices will continue to be heard wherever they are. In the past 9 years, this law has helped states and communities begin to reach these special children:

- .To be certain that they can be protected.
- .To reach families early and strengthen them so children can return home; and
- .Ultimately, perhaps most importantly, to begin to identify ways and means of prevention.

I ask you to listen to the voices of each of these children and to continue the effort that was begun in 1974 with the passage of the Child Abuse Prevention and Treatment Act. This ACT, Public Law 93-247, The Reauthorization of which you are considering now, has provided the only nationwide, federal government focus on the terrible plight of these children. I urge you to reauthorize the Child Abuse and Prevention Act for four more years and to increase the support over the $17 million requested in S 1103. I would like to provide you with evidence of the effectiveness of this ACT. Consider that only $6.7 million was ppropriated to the states through this ACT last year. Consider the following examples of results achieved.

- .Senator Denton, I think you will be pleased to know that Alabama has used the $119,000 that it received through the Child Abuse Prevention and Treatment Act for a wide variety of service improvement and staff training activities. For example, parenting education projects have been started which provide abusing parents with in-home assistance as well as parenting classes. In these programs, volunteers are used extensively.

- The Buckeye State has used some of their federal child abuse dollars to develop CHILD ABUSE REPORTING KITS. These kits are designed to teach professionals about child abuse and neglect. Over 160,000 kits have been distributed throughout Ohio - to schools, pediatricans, hospitals, libraries, sheriffs, day care centers, and universities. These kits are the type of tool, that will improve the identification of abused children and ensure that their families receive treatment.
- Senator Eagleton, Missouri, like other states, considers these funds "crucial" to improving their child protective services system. One highlight of their activities includes the development of an INVESTIGATIVE HANDBOOK which describes the step by step procedures which state social workers are to use when investigating child abuse reports. This handbook will make it possible for Missouri child protection staff to improve services provided to families and children.
- Senator Grassley, my colleagues from your state tell me you are knowledgeable about the many ways that these federal child abuse dollars have been used in your state. Iowa's mobile parenting library for high school students and the home visitor program are two program models that were seeded with federal funds and are now being replicated in other states
- I also spoke with my colleagues in Maine, Arkansas, Texas, Florida, California and Massachusetts. Each time the story is the same; that it is the Child Abuse Prevention and Treatment Act that has made it possible for states to at least begin to strengthen their child abuse prevention and treatment capabilities. I think Mary Carswell from Alabama expressed our thoughts best when she said, "We'd definitely miss these dollars because they are the sole source for child abuse and neglect programming in our state."

Since Connecticut first qualified for these federal child abuse dollars in 1974, a unique and effective system of community-based child protection resources has emerged. Connecticut's Model System of Child Protection Resources is based on the collaboration of the public and private sectors. The system is made up of a variety of programs, the core elements of which include a multidisciplinary team, parent aide services and parental self-help groups.

A child protection team is composed of a paid coordinator and several volunteer child welfare professionals from the fields of medicine, education, social work and the law. In 1976, Connecticut had a team operating that served 11 towns. Currently, there are 25 teams serving 150 towns. Of these 25 teams, 7 were seeded with federal child abuse dollars through grants of approximately $10,000 and were used as models for the development of 18 others supported by state and local agencies. During 1981, an estimated $260,000 was donated through in-kind services by professionals on these teams. During 1982, 456 families received services through the teams in Connecticut.

Parent aides are professionals who provide nurturance and instruction to parents in order to build parental competence. The service is provided in the home, several times per week over several months and includes 24-hour telephone availability. In 1977, Connecticut had one parent aide program. Presently, there are 18 programs. During 1982, 517 families received services from 66 aides, paid and volunteers. Two of these programs, both of which use volunteer parent aides were started with federal child abuse dollars. The others were developed in response to the needs of families in specific areas with support from state and local agencies.

Parent aide services are among the key methods for keeping children in their own homes after a crisis. The estimated cost of providing parent aide services for one family for one year is $1,200. The cost of providing foster home care is estimated at $2,000; group home care is $7,000 - $12,000. Although it is not possible to eliminate the need for out of home services, parent aide services can significantly reduce the numbers of children needing more costly kinds of care that require separation from their families.

Parents Anonymous of Connecticut is part of an international network of self-help groups for abusive parents. Of the 1,400 chapters of Parents Anonymous nationwide, 27 are located in Connecticut. Connecticut's Parents Anonymous groups serve approximately 925 families per year at an annual cost equivalent to $59.00 per family.

Parents Anonymous makes extensive use of volunteers. The 60 professionals who served as resource people to Connecticut's 37 groups donated approximately $185,000 worth of professional time last year.

Although federal child abuse dollars acted as a catalyst, the $94,000 Connecticut receives could never become the sole funding source for this type of resource system. In fact, state and local funding, in-kind contributions, corporations and foundations are each essential to and make possible the ongoing operation of Connecticut's public/private resource system.

Other states are also beginning to develop a wide variety of funding sources to continue programs seeded with federal funds. For example, the California legislature recently appropriated $10 million for child abuse prevention. Although California is unique in the large amount of state dollars it allocates, many states are beginning to move in this direction. Last year, Connecticut appropriated $100,000 in state general funds for child abuse programs. In Connecticut, we are also grateful for the growing interest and support which corporations are providing to these programs. Throughout the state, private sector funding has increased both in the number of corporations providing fiscal resources and the amount of funds provided. Approximately 25 percent of each program's funding comes from local sources.

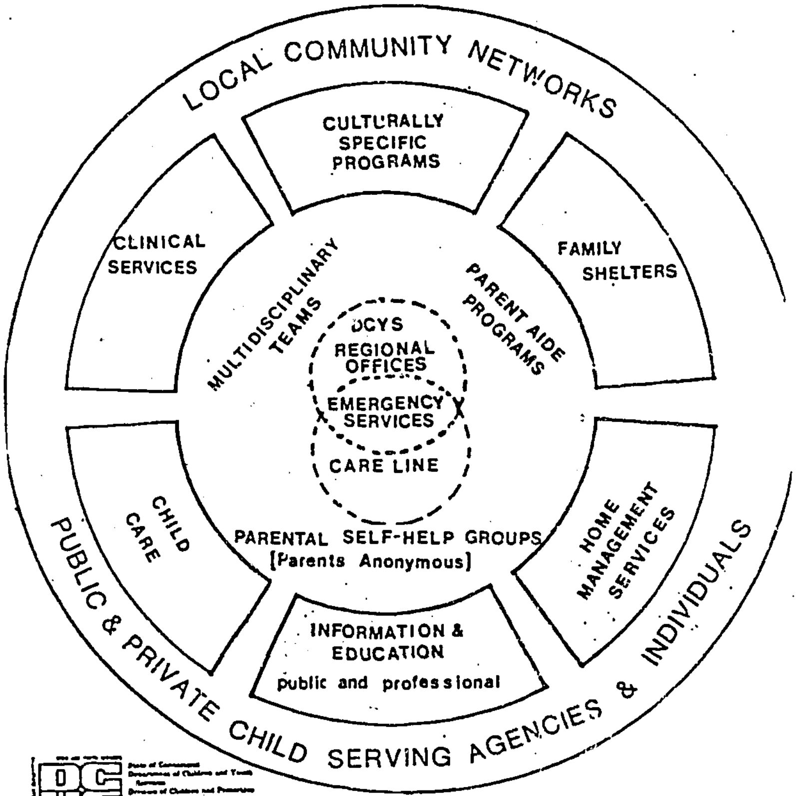
In order for these public/private partnerships to grow, there must continue to be a nationwide focus on child abuse and neglect.

Sometimes our attempts to identify the indicators of cost and program effectiveness have blurred our vision. As we ponder the charts and graphs and contemplate the numbers served, we lose touch with the children. And as we distance ourselves from them, the decisions we make about policies become far removed from the day to day realities of their powerlessness and suffering. At a time when we each feel that our personal economy is threatened, we must continue to preserve our sense of human compassion and caring for these children.

The Child Abuse Prevention and Treatment Act has been essential to improving our identification of and response to a serious and complex problem. But 9 years is not enough time; 1.1 million abused children are far too many and state and corporate support is still too small for us to stop our work now.

CONNECTICUT MODEL SYSTEM

OF COMMUNITY RESOURCES FOR CHILD ABUSE & NEGLECT PREVENTION & TREATMENT



Questions from Senator Christopher J. Dodo -

1. Is there a role that states can play in stressing preventive services under the state grant program?

Some states are already stressing prevention in public and professional information and education activities. Many states also use the state grant to seed prevention programs. For example, in Connecticut, state grant funds have been used to fund home visitor programs. Through these programs, high risk expectant mothers are supported before and after the birth of their babies. This program makes it possible for some of these families to be strengthened before they are referred to the state child protective services agency.

What can the Federal Government do to stress prevention of child abuse?

The Federal Government, through the National Center on Child Abuse and Neglect can continue to seed service improvement programs which are preventive. Federal child abuse dollars frequently function as a catalyst in that many of the programs which are started with federal funds are picked up and continued with state and local funding. They also become tho models for the development of similar services in other areas.

2. What are some of the issues that states will have to confront in order to comply with the language in S 1003 referring to the treatment of handicapped newborns?

At this time, states have the responsibility and capacity to investigate situations in which parents decide to withhold medical treatment against medical advice. It will be a challenge for states to develop the expertise and procedures to investigate situations in which parents and physician agree that withholding treatment is appropriate. Developing this capability is likely to require the hiring of additional staff and will definitely include specialized training for direct service staff.

3. What kinds of supports will have to be provided to the parents of these severely handicapped infants?

I worked with severely handicapped children and their parents for three years. Based upon my professional experiences with these families, it is clear that they require a full complement of medical, social and educational services resources. We must also recognize that even if such an array of supports exist and are affordable, some parents may choose to relinquish their parental rights. When adoption is the treatment of choice for a severely handicapped child, we must be prepared to have adoptive homes available.

4. I understand that the average state grant varies from $50,000 to $200,000.

Is there a need for increased funding under the state grant program?

Yes. Although it is impossible to eliminate a problem of the magnitude and complexity of child abuse with a single piece of legislation, it is apparent that many results have been achieved as a result of the Child Abuse Prevention and Treatment Act. In the testimony presented before the Senate Subcommittee on Family and Human Services, you were provided with examples of how the states have used federal child abuse dollars to seed community child protection programs. Much more could be done if the funds for the state grant programs were increased.

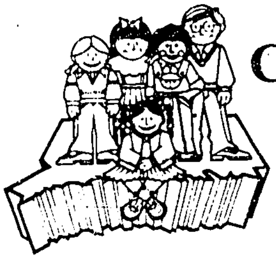
5. What can states do with increased funding?

States can continue to strengthen public/private partnerships so that children who are abused, neglected and exploited are identified and provided with the services they need. States can continue to improve the quality and comprehensiveness of the services they provide to these children and their families.

States can continue to educate the public and professional communities about child abuse and act as a catalyst in developing community-based services which help these families.

States can also begin to address problem areas which have not received much attention to date, such as the occurrence of child abuse and neglect in institutions.

Finally, states can collaborate in the sponsorship of prevention efforts.



Connecticut's Children

About Children and Protective Services in Connecticut

Volume III Number II

Spring, 1983

Events Set for Prevention Month Observance

Connecticut will observe National Child Abuse Prevention Month during the month of April with activities and events in each of the five DCYS Regions.

Organized by the Connecticut Children's Protection Project program affiliates in each region with leadership from team coordinators, and with resources from the New England Resource Center for Children and families, activities have been designed to mobilize community networks around child abuse prevention activities, and to strengthen public awareness and knowledge about child abuse and neglect

Some affiliates have produced or gathered educational materials which are being donated to local schools and libraries to ensure the impact of the prevention month continues beyond April.

Building on the theme of Reach Out to Prevent Child Abuse, events have been planned to touch the lives of many people: children, their families, community leaders and child serving professionals. Many are highlighted on

(continued on page 3)

Calendar of Special Events in April

4	5	6	7	8
11	12	13	14	15
18	19	20	21	22
25	26	27	28	29

April 1
"Reach Out to Prevent Child Abuse" billboards in Norwalk and Bridgeport
Pat Blumenthal, 846-0388

April 4
Month-long Resource-in-Residence program in Waterbury
Kathy LeBlanc, 575-7075

April 9
CAPTCAN *Hansel and Gretel* opera benefit, Hartford
Debbie Coubrough, 347-6971

Northwich Health Fair
Peggy Ayer, 442-0711

April 10
Bloomers, A Musical Revue, Woodstock at 7:30 p.m.
Tickets 774-7257

April 11
"It's Happening" conference and luncheon, Ramada Inn, East Hartford
Donna Davies, 643-2761

April 21
Learning Center booth at Middletown Health Fair
Donna Vanderheiden, 344-8816;
Debbie Coubrough, 347-6971

April 25
Appreciation Reception
Ethan Allen Inn, Danbury
Ann Natavaty, 748-4542

April 27
Resource Day at Newtown High School
Ann Natavaty 748-4542

April 29
Resource Fair, Danbury High School
Ann Natavaty, 748-4542

From My Desk

Children, Families in Distress: Too Little, Too Late?

By Albert J. Solnit, M.D.

We are living in an era which dramatizes how interdependent we all are in determining the kind of world our children enter and experience. It has always been true that the family and community are interactive, each providing the other with what they need and deserve. However, this interlocking relationship, positive and negative, is more painfully, more threateningly and more promisingly clear in a period of increasing unemployment and economic privation. The ways in which public and private agencies can help or hinder each other can determine whether the relationship between family and community is harmonious or dissonant, constructive or destructive, painful or inspiring. The same is true of the relationship between our volunteered and subsidized services.

Nowhere are these opportunities and risks more clear than in child neglect and abuse. In each instance of child abuse and severe neglect evaluated and treated at the Child Study Center or at any agency at which I have consulted, there has been tragic evidence of "too little, too late" in regard to useful services available to parents in distress. A view into the past of each of these children and their parent or parents has indicated that there was a direct or indirect "call for help" before the child was abused or severely neglected.[1]

We are in urgent need, each time a child is abused or severely neglected, of asking how did WE fail this family. WE refers to all of us, the state and private agencies, the volunteer and paid-for services in the neighborhood and the community in which they belong. The question, "Why don't THEY provide services more quickly, more effectively?" should be changed to "Why don't WE provide services more attractively, more quickly, more effectively, more graciously, more generously?" WE includes neighbors, churches, preventive and curative health services, private and public clinical services and all of the network of helping, humanizing services of which our communities are capable.

In cases of child abuse or neglect when we find that there were early distress signals from parents and that attractive, accessible services were not available, WE should put our heads together with those of our Regional Advisory Councils for Children and Youth Services, with those of our Social and Protective Service Teams, and with our appropriate groups to see if WE can't innovate, create and deliver such services out of the fabric of existing resources; or find new resources if necessary. In most instances, it is the redirecting and reorganization of existing services that are both more realistic and more effective. Our parent aide service programs represent such a redirection of existing energies from state and private resources, as well as the wedding of paraprofessional development and services to volunteer professionals' know-how.

Repeatedly, we can look backward and detect instances in which neglecting, abusing parents were asking for help long before their need reached the level of neglecting or abusing their children. Such instances include parents who feel isolated and unsupported in a new community, who are severely stressed when their family or others are unable to come to their rescue in connection with the care of a premature fussy child, a child with minor defects, a marriage that is breaking up, a new pregnancy before the parents felt ready, the beginning of a serious psychiatric disorder in one parent, a recent move that was disappointing, the overwhelming problems of a chronically ill child, the loss of a job and many more.

It is time for us to prevent the number of reporting crisis by developing a sensitivity to early signals of distress that can activate tactful offers of voluntary attractive support services. In most instances, by the time there is a mandatory report of neglect or abuse we have lost the best opportunity to be of help to that child and his parents and we are left sorting out what is least intrusive, least coercive and least harmful.

Tragically, the violent abuse and severe neglect of children by adults, often parents, is as old as recorded history. Sad as it may seem, most of us would not want to live in a society that could prevent every single instance of neglect and abuse because such a guarantee could only be approximated in a prison-like state. At the same time, each of us wants to prevent as much child abuse as it is possi-

(continued on page 4)

Connecticut's Children

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William A. O'Neill, Governor
State of Connecticut

Mark J. Marcus, Commissioner
Department of Children and Youth Services

Raymond Farrington, Director
Division of Children and Protective Services

Francine J. Vecchiolla, Project Director
Connecticut Children's Protection Project

Polly J. Macpherson, Editor

Scott Kaeser, Technical Consultant

Footnotes

[1] N. M. Rosenberg, S. Meyer & N. Shackleton (1982) Prediction of Child Abuse In An Ambulatory Setting. *Pediatrics*. 879-883

2. Goldstein, J., Freud, A., and Solnit, A. J. *Beyond the Best Interest of the Child*. New York: The Free Press, 1973. New Edition with Epilogue, 1979

Events Set for Prevention Month Observance

(continued from page 1)

the accompanying calendar. for more information about a specific activity, call the contact person or Polly Macpherson at DCYS at 566-8067

Region I

Billboards and local cable T.V. will be used to bring the child abuse prevention message to local residents and child welfare professionals as well. Five sites, three in Bridgeport and two in Norwalk will feature the CARE LINE number and the Reach Out to Prevent Child Abuse message. They are being donated by the Murphy Outdoor Advertising Company of Bridgeport. The billboard design will also be used on the video introduction for several cable T.V. programs being aired over Channel 12, and for a series of Cablevision Public Service Announcements.

Pat Blumenthal of the Greater Norwalk Coalition for Children & Youth, Inc. (846-0388) is coordinating these activities. Plans are underway to expand the billboards to the Stamford area as well.

For details on activities around Stamford, call Karla Pendexter, Stamford Hospital, 327-1234. Audio visual materials and pamphlets on child sexual abuse will be made available through the Sexual Abuse Resource Team, call Marty Kosstover at 324-6127 for details.

Region II

A specialized child abuse book collection is being added to several school libraries as a result of prevention month observances in Meriden and the Lower Naugatuck Valley.

Working with the child care programs and Home Economics Departments in five local high schools, Josephine Segatori (736-2606) of the Parent Child Resource Center in Shelton, will be presenting workshops on child abuse and neglect and donating the selected books. Books will include *Child Abuse and Neglect in The Community* by Ray E. Helfer, M.D. and C. Henry Kempe and *Tell Me Right Away* by Linda Sanford.

In addition, parent aide programs in the region will be reviewing newly published books and materials and will select a number of them to be added to their agency collection.

Region III

Six C.C.P.P. affiliates are sponsoring a booth with the theme "Healthy Parent/Child Relationships" at the Middletown Health Fair, on April 21 at City Hall on DeKoven Drive from 10 a.m. to 7 p.m. The booth is being organized by Donna Vanderheiden of the Middlesex County Child Protection Team (344-8816) and Debbie Conbrough of the Community Health Center Parent Aide Program (347-6971). The Junior Women's Club and a number of journalism students from Middlesex College will assist at the booth during the day. The booth will incorporate a "Learning Center" for the prevention of child abuse for parents, children and professionals and will feature continuous showings of a video tape of Sara Elston's puppet theater on Personal Safety. While children are viewing the puppet show, their parents can review books and materials on child care, child development, discipline and issues of child rearing.

In the New London area, a combination of T.V. cameras and community facilities will ensure that child abuse prevention month activities will last well beyond April. Two lectures, one entitled "The Effects of Media on Children" and one presented by Police Chief Larry Bangham on "Victimless Crime" have been taped and will be made available, free of charge, to community groups. Descriptive brochures and discussion leaders are also available to accompany these tapes. Peggy Ayer of the Southeastern Connecticut Child Protection Council, Inc. has coordinated these seminars and will arrange for bookings of the lectures. She can be reached at 442-0711, Ext. 2476.

In the 21 town Danielson area, the centerpiece of Child Abuse Prevention Month is the production of *Bloomers*. Judy Hyde of the Child Protection Council of Northeastern Connecticut (774-2020) and the Exchange Club of Danielson are sponsoring this musical revue April 10 at 7:30 p.m. for the benefit of the Child Abuse Resource Project and Parents Anonymous Chapters. The program is featuring local talent and even a group of musicians direct from the stages of . . . Hartford!

The Child Protection Council is also observing Child Abuse Prevention Month by donating books to elementary schools in each of the 21 towns they serve. Teachers and elementary librarians will be given a list of books from the Economy Company's series entitled "Trolley Books" from which they may choose up to 10 titles. The books, all for early elementary grades, include topics such as self-concept, liking yourself, community helpers, and feelings.

Region IV

The nine Connecticut Children's Protection Project program affiliates in the North Central Region have planned a major conference for Tuesday, April 11, at the Ramada Inn, East Hartford. "It's Happening" will include eight workshops in two sessions, a luncheon and service fair.

Drawing from a wide range of child serving professionals, conference planners have engaged lawyers, physicians, child development specialists, nurses, psychologists, child protective services experts and program specialists as workshop leaders.

The all day conference is $7.00; although the conference committee recommends full-day participation, half-day registration is possible for $3.50 (lunch not included). For more information, contact Donna Davies, Regional Child Advocacy Team, Child and Family Services, Manchester, 643-2761.

Region V

The Waterbury public schools, through the libraries in the Middle and High Schools, will feature a special display of books and materials on child abuse and neglect to help observe National Child Abuse Prevention Month. The books have been selected by Kathy LeBlanc and Sid Horowitz of the Waterbury Collaboration for the Prevention of Child Abuse and Neglect (575-5075) and a set of books will be donated to each of the six schools.

To compliment the book display, the Collaboration has organized the Resource-in-Residence Project, and is making it available to each school on an ongoing basis. The Resource-in-Residence program features a child welfare professional who will spend one afternoon a week in each school library assisting both students and faculty in learning about child abuse and neglect and in gathering information on this topic. The Resident Resource Person will be able to answer questions and direct students to sources of information and programs as well. In addition, the Collaboration

(continued on page 4)

Prevention Month Observance

continued from page 1

plans to purchase several audio visual educational materials for loan to libraries, schools and community groups.

The week of April 25-29 is the high point of activities which the Danbury Regional Commission on Child Care Rights & Abuse, Inc. has organized in Newtown, Danbury and Ridgefield to help Region V observe Child Abuse Prevention Month.

In Newtown, activities will culminate in a Resource Day at the high school on Wednesday, April 27 from 9 a.m. to 1 p.m. The high school Leadership Club and the Key Club have joined the Commission Staff in planning the displays and a balloon lift-off involving students and faculty. Several Newtown area agencies will be present during the Resource Fair to describe their program and services; these include the Youth Services Bureau and the Host Home Program.

In Danbury, the events of the week will begin Monday, April 25 with a proclamation by Mayor James E. Dyer, to be followed by an "Appreciation Reception" at the Ethan Allen Inn for volunteers, citizens and corporate and business supporters of the Commission over the past year. The Danbury High School gym will also be the site of a Resource Fair on Friday, April 29, from 11 a.m. to 4 p.m.

In addition, each public library in the ten surrounding towns has agreed to feature selected posters, books and materials on the child abuse prevention theme including parenting, child care and family support.

A special feature of the Danbury area's observance is the direct involvement of children. Working with elementary art teachers in each school, the Commission will sponsor a poster design and coloring contest. Children will design, draw and complete their own interpretation of "Things I Like To Do With My Family." Judging will be by Danbury resident and children's book illustrator, Steven Kellogg. Mr. Kellogg will also serve as honorary chairperson of the Danbury Child Abuse Prevention Week activities. Every child who submits a poster will receive a certificate commemorating their efforts. More information about these activities is available from Ann Natavaty at 748-4542.

Children, Families in Distress

continued from page 2

ble to prevent in a free society in which the democratic values of family privacy and the pluralism of differing lifestyles are protected and supported.

Only by combining all of our resources, by maintaining optimal communications and planning at the regional level and by developing attractive voluntary services that are responsive to early signals of distress can we minimize "too little, too late" (Goldstein, Freud & Solnit, 1979).² At the best of times and at the worst of times, we are in urgent need of supporting the autonomy of parents and the integrity of families, a sound, humane policy in the service of children who can represent the best of our past and our future.

Albert J. Solnit, M.D., is Director of the Child Study Center at Yale University and Chairman of the State Advisory Committee of the Connecticut Department of Children and Youth Services.

Children's Center Luncheon May 6

The Children's Center of Hamden will celebrate its 150th anniversary with a noon luncheon on May 6 at the New Haven Lawn Club. Guest speaker at the event will be child psychiatrist Bruno Bettelheim. He will discuss "Children's Services: Past, Present and Future." For more information, call 248-2116.

Ann Quinn Interviewed

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45-minute visit. What's going on here? Was it an accident? Do we have the facts? What kind of red flags do we have? Sometimes parents are very reluctant to really sit down and really talk about what's happened and what they've done. Once the intake worker has made the initial investigation, the case is (if our intervention is warranted) turned over to a treatment worker who works with the family until we are convinced that the risk to the children has been reduced sufficiently.

The stress of dealing on a daily basis in a system that deals with individuals who abuse, even kill their children, can take a toll. The ability to work with a family and help them to remain intact can be most rewarding. To find a balance between the stress and the rewards is most difficult, but not impossible.

Q. What more can be done to identify child abuse situations, stop it from continuing and prevent deaths from occurring?

A. Well, I don't know, as long as we have parents and we have people who have children and aren't prepared to have children, that we're ever going to completely wipe out child abuse. I do think that the more publicity, the more things that we can do, to talk in terms of the fact that it's out there, that it exists, that people need to believe that even their brother, sister, close friend or whatever, who may be a person who in all other spheres of their life is functioning well, that that person has potential — that we all have within ourselves potential — to be child abusers. The second thing is that as long as DCYS can be clear in terms of learning more and more about who really are the parents who tend to hurt their kids severely. And who are the parents who, really through ignorance or whatever, can do this and can be helped?

Q. How do you feel about the court system, in relation to child abuse?

(Goldstein Freud & Solnit 1979).² At

A. As I've already related to you, I'm a firm believer in a system that has at its heart "shared decision making." The court provides another piece of the checks and balances needed to bring about as often as possible the "right" decision. We can all get upset and blame the court when a decision doesn't go our way. I'm no different. But after the heat has subsided we have to look at whether we presented the best possible case or whether the legal system failed. Sometimes the court's decision looks good with hindsight; sometimes it doesn't. When it doesn't then the Court has to take the responsibility.

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Courant Interviews Ann Quinn, DCYS Norwich

By Rosemary Keogh,
Hartford Courant Staff Writer

Ann E. Quinn, program supervisor in the Norwich office of the state Department of Children and Youth Services, has dealt with cases of child abuse and neglect for almost 20 years, both as a social worker and a supervisor.

Q. What indications do you look for to identify a child abuser?

A. OK, there are a number of things that we must refer to as red flags in a situation. One of the high-risk parts of the investigation has to be the age of the child. Obviously infants and young children are at higher risk, both because they can't get away from parents or protect themselves in any way, but secondly because they have little visibility in the community.

When kids don't go to school (and) they're not out playing and that kind of thing, so that they can be seen by the neighbors and friends, then the risk is higher that they may be abused and someone isn't going to pick up on that right off the bat. We know that child abuse tends to continue, to repeat itself, so that in most situations when we get involved, we find that there have been earlier instances that may or may not have been seen by somebody and may or may not have been reported.

. . . classic child-abusers tend to be social isolates. They may have parents, relatives, people they call friends — but they really have no one that they are very close to . . .

We look at what is the family situation. Are they under a lot of stress? What's the age of the parents? One of the key things that we've learned most recently [illegible] and I think in all of the serious cases that I've seen [illegible] is that parents who tend to abuse their kids and are really classic child abusers tend to be social isolates. They may have parents right nearby, relatives, a whole host of people they may call friends — but they really have no one that they are very close to and very little in the way of any kind of support system.

That's really one of the red flags we key in on very quickly. Other things, like are they having marital problems? Is one child singled out? Are there four or five kids, but only one child who seems to be repeatedly abused? How are they dealing with that kid? How are they seeing that kid? How do they describe that child? Very often that's the child who gets described as bad, different, like somebody that they don't like, or maybe like themselves. So those are just a few of the red flags that we look at.

Q. In deciding whether a child should be removed from the home, what factors are considered?

A. Well obviously, the protection of the child is paramount. We ask, what kind of risk, what level of risk is that child under? How predictable is it that the abuse is going to happen again? What kind of support systems can be put in so we can feel more comfortable about the situation and that would begin to alleviate some of the stress the child or family may be under.

One of the things that we try to do is to recognize and be very sensitive to the fact that every time you remove children from their parents, you raise a great risk that because of the system, because of the parents themselves and their inability to get their act together, that child may never return home, or that it may be a long period of time before that child returns home.

So you have to really weigh in the risk of removing the child versus a lot less known risk, which is the risk of moving a kid too soon and maybe disrupting the family and never being able to put it back together again.

Q. What kind of emotional toll does that decision-making take on you?

A. Well, it's a really difficult decision for a worker, and certainly at a time when there's any publicity regarding a case in which something serious has happened to a child and any questioning about that; then that anxiety is so much more high.

We're always seeing a greater increase in workers saying, "Maybe we need to take this action." We talk in our office about shared decision-making. The decision to remove a child should never be the worker's alone. Nor should it be really the worker and the supervisor, but that all of us ought to help make the decision. The worker, supervisor, program supervisor and in some cases, even our Central Office staff.

The other thing (that) is just as difficult is to leave kids in the home, and to be concerned that there are risks involved in doing that. So we spend a lot of time looking at what really needs to be done in the situation. How comfortable can we be? What risks are we taking and how safe can we really feel that even though there are risks, that there's enough support system there to get to us before something serious happens? It's a difficult decision. We — the department — have put together guidelines to help workers in relation to removing kids. Basically they're very stringent and they really tend to underscore the fact that we need to be sure that the kids need to be removed before we take that kind of action.

. . . you have to weigh the risk of removing the child versus a lot less known risk, which is the risk of moving the kid too soon and maybe disturbing the family and never being able to put it back together again.

Q. What is the most difficult part of handling a child-abuse case?

A. I think the investigation. And the pulling together of the pieces of information to begin to decide, is this a (child abuse) situation? And this has to be done very quickly. Usually what happens is a call comes in from someone saying that child abuse is suspected and your intake worker is dispatched, and the worker knocks on the door and gains entrance to the home and immediately has to make some assessment in terms of a half-hour or

(continued on page 41)

State of Connecticut

By His Excellency WILLIAM A. O'NEILL, Governor: an

Official Statement

The talents and abilities of our young people are the most precious resources of our society. It is the efforts, initiatives and achievements of our young people which will shape our nation's history in the years to come.

Preparing our children to meet the challenges of the future is a vital task that merits the concern and imagination of all our people. Safeguarding their health, physical and emotional well being is also an essential part of this important endeavor.

Unfortunately, child abuse threatens the health of our children and the promise of a bright future. Child abuse is one of the most devastating tragedies of family life. It inflicts physical and psychological damage which may scar generations of the future. It also sets in motion a vicious cycle of helplessness, bitterness and pain.

It is the responsibility of all our citizens to protect these children and to assure them the health and happiness they deserve.

The people of Connecticut take great pride in the fact that our state is a leader in this vital area. The state Department of Children and Youth Services has long been committed to our state's children and to enhancing the cooperative network which exists among the public and private sectors toward the prevention of child abuse.

Therefore, in an effort to strengthen this vital network and in recognition of the dedication of citizens and organizations throughout our state to ending child abuse, I am pleased to designate the Month of April 1985 as Connecticut Child Abuse Prevention Month.

[illegible]

Mr PALMER. Thank you. It is my privilege to be here today to represent the child abuse and neglect program in the State of Utah, and by so doing, respond to three requests which were given to me by Senator Denton. Those were that I tell you a bit about the child protection team in the State of Utah; that I tell you how we have used community resources in our State; and finally, how we have been able to utilize and obtain non-Federal sources for funding.

In order to clarify those issues with you and to tell you a bit about child abuse in the State of Utah, I need to tell you that the child abuse and neglect team in our State is an outgrowth of a Governor's task force in 1974 and 1975. That task force was a broad representation of many groups, which included the then existing child protection team at the University of Utah Medical Center, and a variety of governmental and community agencies.

The various groups that were represented include some of the following: there were representatives from many of the school districts in the State of Utah; there were representatives from the colleges of education and special education; nursing; the school of medicine; colleges of social work, psychology, as well as a broad representation from the various mental health districts, hospitals throughout the State; community action programs and affairs offices; police agencies; the juvenile court; the detention centers; the Junior League; the LDS social services; Catholic Charities; Hill Air Force Base; the children's center, which is a special program, a private community supported program for the support of severely mentally ill children, at that time, at least, in the preschool age group; and as I mentioned, there was broad representation from the State of Utah's government through the division of family services.

In other words, our team began in the State—or I should say, was augmented from the then existing team with a broad representation and dialog from both the public, private, as well as the child protection team as it is now established.

The child protection team which was established in 1974–75 continues to exist with approximately the same representation. That is that there is—and this is one of the more important issues that I would like to share with you in terms of the effectiveness of the child protection team—the coordinator of our child protection team is a full-time employee of the State of Utah, division of family services.

She, herself, is a child protection worker, and that gives us amazing entrance into the system, if you will, within the State in terms of credibility for the child protection team within the child protection network.

The child protection team further includes 2 arms of the team; one of them is at the University of Utah Medical Center. One of them is at Primary Children's medical center. The composition of the team at both centers is essentially the same: a pediatrician, a psychiatrist, several social workers, and so on.

We additionally have representation with our team from the Salt Lake County prosecutor's office, juvenile court, district court, circuit court, Salt Lake County sheriff's office, et cetera.

We have neurosurgeons on our team and other people who rotate in and out of our team.

Now, our team is a working team. Last year between the 2 arms of the team we saw approximately 500 children for medical evaluation. In 1982 in that same period there were 6,350 reported incidences of child abuse and neglect in the State of Utah, of which 2,379 were in fact valid.

Now, there is a difference in how child abuse and neglect is reported, or I should say, from whom it is reported in the State of Utah, compared to the statistics which Dr. Newberger shared with you earlier. For example, in our State, 48.7 percent of the reports to the division of family services come from neighbors, relatives, and friends of the potential abused child.

Only 6.3 percent of those reported cases originated from the medical system; 9 percent came from the public schools, and there was 13.3 percent that came from the courts. In other words, child abuse and neglect in the State of Utah is reported to the system by those who are concerned about children. That is not necessarily saying that that is not true in other States also, but it is not from official reporting agencies.

In my own experience last year in 1982 and for the first 3 months of this year I saw 183 sexually abused children. My experience is different than that which you have heard about at Covenant House. The age of my victims, if you will, was from 6 months up through age 17, which is the oldest of the children that we see at our hospital.

The average age, however, of the children that I see is somewhere around 4½ to 5½ years of age.

In addition to that, I saw or supervised the seeing of 108 children at Primary Children's who were severely physically abused enough to be in the hospital, and we saw another 53 children who came through the aggravated sexual assault program, which is a program we have for the—with the Salt Lake County attorney's office.

The reason that we have been designated, if you will, as the facility where children who are sexually abused or allegedly sexually abused need to be evaluated is because of the strong feeling that the act of the evaluation should in no way endanger the child or be more harmful to the child than the event which we are evaluating.

We have heard about the touch program this afternoon in a variety of different settings; I feel strongly that a physician is under every bit as much obligation as is the parent not to violate the rights of the child during the physical examination.

Therefore, we strive very hard not to do that. Children should not be held down when they are examined. In no way should they have any kind of violation of their willingness to give consent for the examination.

Now, in terms of community interaction, our team really, be- use of the way it began, has had community dialog since its in- ption. I mentioned to you some of the agencies and programs nat participated with us on the Governor's task force in 1974. hose same agencies and same programs now continue to be in- lved with the team, and new programs have sprung from their ıvolvement.

For example, the Junior League in the State of Utah has been the genesis for the family support centers which are similar to crisis intervention agencies that may be present in other States. They were instrumental in getting three programs like that started.

The YWCA has a women in jeopardy program for spouse abuse. Along with the YWCA's women in jeopardy program, they have an art therapy and diagnostic program for children who have been sexually abused or allegedly sexually abused. In other words, those agencies that were involved from the beginning, so to speak—not that long ago—but, anyway, from the beginning in our State's activities were in fact involved and are still involved with child abuse and neglect issues in the State.

The importance of having the full-time employee, if you will, from the division of family services as a coordinator of the child protection team must be emphasized again. I am not sure how many States or how many other teams have that kind of coordination, but what it really does do is give us dialog within the system.

There is no pseudoterritorialism. There are no delusions of grandeur. There are no other activities on our child protection team except those that are in the best interest or at least intended to be in the best interest of the children.

It is not "doctor, this," "your honor, that." It is on a first name basis; both incoming and outcoming, it is on a first name basis.

It is very important for us to have dialog also on our team with the police agencies, with the prosecuting agencies so that they understand where we are coming from, but similarly so that we understand where they are coming from, because each of us in the child protection issue has a specific role in which to function. Once we understand one another's role and once we understand one another's activity, then we respect and can work much more closely and much more efficiently together in the well being of children.

As far as how we as a team—or how we as a State are able to garner, if you will, other funds, other than the $85,000 that we received in 1982 from the national center, I suppose it is a wise and miserly investment, if you will, by the division of family services, which has provided seed money for over 40 active current programs in the area of child abuse and neglect, very small, most of them, since we have $85,000 to use.

Our own team has basically $33,000; that is what we received for the team's support. That is on a fee for service basis. In other words, there is a tremendous amount of volunteerism in at least the State of Utah, as I am sure there is in other areas as well, on all aspects of child abuse and neglect.

It was interesting to hear what you have been doing in Connecticut in terms of volunteerism and money that that actually has saved.

Finally, I would like to just end with one comment. I am an active, heavily involved person in child abuse and neglect in all aspects. I spend a lot of time in court. I spend a lot of time providing consultation for other law enforcement and prosecuting jurisdictions. Since we have dialog with the family practice residents, the pediatric residents, nursing students, and so on, 80 percent of whom go into practice in the intermountain area, and we have an extension of a continued dialog with those that we have worked with in the training process.

As far as the funding of the new child abuse and neglect issues, my own personal feeling would be from one who is heavily involved in terms of time, that there are not enough resources in the States to deal with the issues that Baby Doe would create if it were part of the legislation. It would inundate the already inundated system. It would constipate an already waterlogged system, and I just cannot see how $30 million, or whatever it might end up being, could in fact allow—we have in the State of Utah five level 3 intensive care nurseries. We have eight level 2 nurseries. We have varyingly the highest birth rate in the Nation.

It would be very difficult to pull out death certificates, go over them, and extract babies who would fulfill Baby Doe criteria without a tremendous amount of time, effort, and so on.

I thank you very, very much for the opportunity to be here this afternoon.

[The prepared statement of Mr. Palmer follows:]

Testimony by

William M. Palmer, M.D., F.A.A.P.

Reauthorization of the Child Abuse Prevention and Treatment and Adoption Opportunities Act

before the

Subcommittee on Family and Human Services
Committee on Labor and Human Resources

April 11, 1983

Mr. Chairman and members of the Subcommittee for Family and Human Services. I appreciate the opportunity and privilege afforded me in appearing before you this afternoon. Senator Denton has asked that I provide you with information concerning the activities of our child abuse and neglect team in the state of Utah. I have also been specifically requested to tell you how our team or our child protection effort has involved community support resources and finally, how we have been able to find non-federal funding for our program. If time permits in my verbal comment, I would like to make a few remarks concerning proposed legislation to reauthorize "The Child Abuse Prevention and Treatment and Adoption Reform Act Amendment of 1983." However, if time does not permit, I will comment on the bill in the written testimony.

In order to understand the function of our team it is necessary to tell you a little of how we came to be. We, as well as other child protection interests in our state, are an outgrowth of a 1974 governors task force on child abuse and neglect in the state of Utah. That task force culminated in a governors committee on child abuse and neglect. The committe was composed of a broad representation from groups concerned with the welfare of children and families. The committee included representation from various school districts, colleges of education and special education, nursing, the school of medicine, psychology, and social work from the universities and colleges in the state. The committee also included representation from mental health districts, hospitals, consumer affairs offices, police agencies, the juvenile court, detention centers, the Junior League of Salt Lake and Ogden, the LBS social services, catholic charities, Hill Air Force Base, the children's center, (special treatment programs for preschool children who have significant emotional illness), and a broad representation from the division of family services in the state of Utah. In other words our team began with broad based community and state-wide dialogue. The communication which was established in 1974-75 has been the basis for our continued acceptance by the community. As I will note later, it is also at the basis of the "high incidence" of child abuse and neglect which is noted in the National Center for Child Abuse and Neglect in their yearly state statistics.

It might be of interest to comment on the Utah statistics in terms of child abuse and neglect. In 1982, there were 6,350 reported cases of suspected child abuse and neglect to the reporting agency in the state of Utah which is preferably the division of family services or as an alternate, the appropriate law enforcement jurisdiction. Of these 6,350 reports, 2,379 were felt to be valid issues of child abuse and neglect. In breaking those statistics partially down, it would be of interest to note that 6.3 percent of those patients originated from the medical system including 2.1 percent from physicians, 3 percent from hospitals, .6 percent medical clinics, and .6 percent from nurses, 9 percent originated from schools. 48.7 percent originated from neighbors, relatives and friends, (22 percent, 17 percent, and 9.7 percent respectively). Also, 13.3 percent originated from law enforcement and court jurisdiction. Those figures do not add up to 100 percent, but I have only keyed on some of those that would be of interest to the committee. In my own case from my experience, I saw 183 children at Primary Children's Hospital in the past 15 months who have been allegedly sexually abused. In addition, we saw 108 children over the 1982 year at Primary Children's where there was some concern regarding physical abuse. Similarly, the University Medical Center arm of our child protection team saw roughly the same number of patients, or between our two hospital based teams we saw approximately 500 children for medical evaluation in the system. In addition, in 1981 there were thirteen deaths related to child abuse and neglect, and there were 11 deaths in 1982. Approximately 75 percent of the children who died were also involved in live-in boy friend situations and approximately 40 percent of these or 3 to 4 children of those that died were also sexually abused. Because Primary Children's represents a trama referral center which includes many head injuries, we saw many of those children at Primary ourselves.

It would be of interest to describe now for you, what is the child abuse and neglect team that I represent. The child protection team which I am representing before you today is an outgrowth of the governors task force in 1974-75 and the then 1974 existing child protection team at the University of Utah Medical Center. We include as the director or coordinator of our child protection team a full time employee of the state of Utah the division of family services who is the coordinator. The two arms of our team, one at the University Medical Center includes a pediatrician, Dr. Thomas Metcalf, a child psychiatrist, Dr. Claudia Berenson, and an MSW social worker, Nancy Lang. The arm of our team at Primary Children's, of which I am a member, includes a pediatrician, myself, a child psychiatrist, Dr. Thomas Halverson, and a MSW child protection social worker who has expertise in sexual abuse, Mr. Thomas Harrison. In addition, our team is composed of regular participants from the Salt Lake County juvenile court in terms of the county prosecutors as well as the Salt Lake County adult court in terms of their prosecutor participants. In addition, we have members of the Salt Lake County Police Department and the Salt Lake City Police Department who are regular participants in our team activities. We have various other community social workers, law enforcement professionals as well as judicial and legal representation on a selected basis from time to time in our team activities. The responsibility that our child protection team was given as a result of the governors task force was as follows:

1. Since our team processes approximately 500 plus children yearly, or at least in 1982, we are a working team whose responsibilities include diagnosis, treatment, prevention, and consultation with other professionals.

2. We were established as a demonstration team and therefore we have traveled throughout the state of Utah as a team to provide teaching and organizational help to other professionals throughout the state to help them establish child abuse and neglect programs for the professionals in their area. In the past year, we have traveled to Price, Vernal, Cedar City, and will soon go to Moab for workshops on child abuse and neglect activites.

3. In addition, individuals on the team have taught extensively to various professional and lay groups throughout Utah, Idaho, Wyoming and into the four corners area of Utah, Arizona, New Mexico and Colorado. The discussions which we have given in those areas were to medical staff, state PTA activities as well as local PTA programs, paramedics, emergency medical technicians, the Junior League, the Literary Club, the League of Women Voters, the Catholic Womens Organization, and also have had the opportunity to speak at many high school class activities in child psychology and child development in the Salt Lake area as well as other areas in the state. We participate at the graduate level in the schools of psychology and social work in the child abuse and neglect program within the graduate schools of those colleges. We also provide yearly sessions to the Utah State Police Academy on issues of child abuse and neglect.

4. It is important to note that all of the members of our team, (including the county prosecutors, the social workers, the psychiatrists, and the pediatricians) have regular dialogue with the medical students, the family practice and pediatric residents, and the nursing and social work students in colleges of Utah state, University of Utah, and the Brigham Young University. In the case of the pediatricians and the psychiatric and social work component of the team, we provide daily dialogue with family practice, pediatrics, and medical student professionals. This is important to note because, approximately 70 percent of the pediatricians who leave the University of Utah/Primary Children's Hospital Medical Center pediatric residency program enter private practice in the innermountain area. Similarly, approximately 80 percent of the family practice residents enter private practice in the innermountain area as well. This gives us continued dialogue with the physician in practice and gives us access to them and them to us for consultation and case referal and management.

5. Our team has also been charged to help other areas in the state establish child protection teams, and there are now ongoing teams in Ogden, Provo, as well as others beginning here in the Salt Lake Valley. In terms of community and state-wide acceptance, it is important to note that all of the members of our team have remained the same as when we were established in 1975. It is also important to note that with the exception of our state division of family services coordinator all of us have other full time responsibilities in our various repective medical center responsibilities.

Some comments on the Utah statistics

The state of Utah has the sixth highest incidence of child abuse per 1000 children of any of the states; why?

1. Our team coordinator is a full time employee of the state of Utah and is herself a child protection worker. This gives us considerable credibility within the system as far as the field workers in child protective services; allows continued dialogue and communication; and allows acceptance by our team of other professionals and similarly allows the team to gain entrance into the system throughout the state. In other words there is ongoing bi-directional communication and interaction which fosters activity and child protection reporting.

2. There is no pseudo-territorialism or false delusions of grandeur. We are all hard working committed individuals to the welfare of children and are on a first-name-basis, again this gives us acceptance by other child protection workers and increases the likelihood of referral both within and without the system.

3. Finally, all of us are committed child and family advocates. We have been able to work together long enough that we still enjoy the respect of each other and have come to appreciate the particular strength that each of us possess and also the knowledge and understanding of the system within our state, both its strengths and its weaknesses.

4. By virtue of our teams interaction with law enforcement and the judicial component of our state child protection activity, we have developed credibility as expert witnesses in the court; and therefore, we spend a considerable amount of time in court testifying for and on behalf of children.

5. All of the above with the very broad reporting law which is present in our state, plus the state demographic and geographic population characteristics

state, plus the state demographic and geographic population characteristics added to the inherently high value of children in the state of Utah create the higher likelihood for child abuse and neglect to be reported to a responsive system. However, it is really immaterial whether Utah has the highest or the lowest incidence of child abuse and neglect; we have more than enough child abuse and neglect in our state to keep all of us more than overly busy.

I would next like to tell you of our involvement with the community support agencies and organization. Because of the initial task force approach in the tackling of child abuse and neglect in the state of Utah, there were many groups involved along with the original child abuse and neglect team in the creation of a child protection network in the state of Utah. These community agencies have been instrumental in creating new programs in addition to the original support and resource which they provided in the governors task force activity. For example, there are lay therapy groups, (Super Parents), which have been created through the division of family services in many areas. Also, the YWCA has created a women in jeopardy program (which deals with spouse abuse), along with their TEEN MOM Program. The family support centers are heavily used by our team as a referral source in the community. They offer parents who recognize the risk of potential abuse within their families to leave their children there or in fact stay there themselves for up to 72 hours without any charge. There are volunteer therapists and child care workers in the family support centers. The Children's Center, (which are privately funded programs for severely disturbed children) are support centers which have been instrumental in providing parenting experiences for potentially abusive or actually abusive parents. The parenting courses may be voluntarily taken or may be court ordered. We have way the community resources available to parent, schools, professionals, and other groups who are interested in the prevention of childhood sexual abuse. Included in the brochure is a description of the problem and its magnitude and a listing of some of the resources that are available in a private and volunteer funded basis:

1. The art therapy program for sexually abused children in association with the YWCA's Women in jeopardy program.

2. "Child Abuse," a slide presentation on the history, causes, and prevention of child abuse and neglect in the state of Utah is sponsored by the women's auxiliary of the Utah State Medical Association. This slide presentation is aimed at primary school age children and is hoped to be a preventative tool.

3. The children's centers whose resources that have already been mentioned.

4. The children service of Utah with particular emphasis on helping in placement of "special children" for adoption and also counseling adolescent girls regarding the decision of either keeping their child or placing the child for adoption and also counseling on the implications of each decision.

5. The community crisis center is a private non-profit United Way supported agency whose scope includes drug and alcohol abuse, school based drug and alcohol prevention programs, and also is the house or the residence, if you will, for the parents united program, a self help program for sexually abusive perpetrators, their families, and the victims within the families.

6. Family support centers as already described in Salt Lake City and Ogden and originated by the Junior League.

6. Family support centers as already described in Salt Lake City and Ogden and originated by the Junior League.

7. The guardian ad litem program of Salt Lake, Ogden, and in the process of being established in Price, Vernal, Logan, and throughout other DSS districts in the state of Utah. The child protection team has given workshops for these volunteers who will be the child's advocate during the court process.

8. The Legal Aid Society of Salt Lake City which stresses services free of charge to youths, their parents, and their families.

9. Mothers Against Drugs (MAD) which is affiliated with the Odyssey House and is aimed at lessening drug and alcohol abuse at home and, thereby lessening the risk of child abuse and neglect for the children.

10. "Parents Lets Talk" which is a program sponsored by again the Utah State Medical Association Women's Auxiliary and the March of Dimes which is aimed at helping parents provide sex education for their children in their home.

11. Finally the pamphlet described the Parents United and Daughters and Sons United self-help and referral program for incest victims. There are many other programs in the state particularly concentrated from Logan in the north to Provo in the South or along the Wasatch front. 80 percent of the population in the state of Utah is also concentrated in this area. Our current challenge in our state program is to extend the many resources which are available to parents, professionals, and children in this area to lesser populated areas in our state.

In the area of non-federal funding there has been considerable success in creating volunteerism as you might appreciate from the partial descriptions already mentioned of programs available. It is worth noting that the state of Utah received in 1982, 85,000 dollars from the National Center for Child Abuse and Neglect. The division of family services in our state has been successful in investing these funds wisely. In the past, and as well currently, there are some forty small contracts which have been awarded through the use of these funds including our own child abuse and neglect team. Many of the current privately funded and volunteer programs were originally seeded through the use of these funds. The success of the program has stimulated the Utah State Legislature to provide an additional 3 to 4 million dollars yearly to support child protection and child and family well being program in the state of Utah. In our own team, there is a heavy degree of volunteerism. We have a contract with the state of Utah for approximately 33,000 dollars a year to provide services for the many programs mentioned on a fee-for-service basis. As you might expect, it is necessary, in order to do what I have described for you, to have a considerable amount of volunteer activity in order to "live within our budget." This leads to some final remarks which I wish to leave with you concerning the current bill pending in both the House of Representatives and before this commitee. As I mentioned previously, I have seen approximately 130 allegedly sexually abused children in the past 15 months. My own activities are only an example of the kind of activity that many other professionals in the area of child abuse and neglect find themselves. They work very hard and always find themselves in short funding situations. It is necessary for our own team to "scrounge" from various funds in order to even continue with some of the programs which I have mentioned above. Were the child abuse and neglect effort to be diluted by considering the "Baby Doe" issue as part of the child abuse and neglect enabling legislation, it would be a tremendously difficult situation in which to work with the already existing programs and many, many children who need services with the limited funds available. Imagine if you will the number of newborn intensive care nurseries that exist throughout the United States, we have five or six in the state of Utah alone. Similarly, imagine the number of infants who would be born with characteristics that might fit the "Baby Doe" description in the legislation -- that is severely and congenitally involved infants. Also consider the magnitude of the task of non-professionals screening birth certificates (which would be the only way to accurately assess the problem) and coming up with many infants who might fit the broad criteria for "Baby Doe" but who in reality would have non-similar medical histories. It would take substantially more manpower, financial aid, and would involve non-professionals interacting with situations which are highly technical in terms of the medical problems and the indicated treatment described to even come close to making some kind of an assessment as to the number of these children who might be "abused or neglected." Not only would it burden the medical systems, the needed funding for the professional or non-professionals to interact and case find; but it would also burden the already over-burdened child protection program, (the average case load of the child protection worker in the State of Utah varies between 20 and 50 children), and of course finally, the courts both juvenile as well as district, would become even more water logged and constipated than they currently are. As you might suspect, I would not be an advocate for the enactment of that legislation. However, I recognize the rights of the "Baby Doe" children and would certainly feel strongly that the systems involved in the already active hospitals professional and ethical programs as well as the

President's Commission for the Study of Ethical Problems in Medicine an Biomedical and Behavioral Research have already, and do daily deal with issue. I would hate to see the already diluted and insufficient funds be even more diluted through enactment of legislation such as this.

In conclusion, I very much appreciate the opportunity to share with you the information and the activities of our child protection team in the state of Utah. Similarly, I also appreciate the opportunity of sharing with you the tremendous amount of volunteerism and successful community interaction which is present in the child protection arena in the state of Utah. I hope that my remarks may have been of some interest to you, and help to you as you consider the reappropriation of the child abuse funding. Hopefully, it might be even funded at larger amounts the currently anticipated.

Senator DENTON. Thank you, Mr. Palmer.

Mrs. Bigger, I want to welcome you publicly since you are from my home State. I am glad to see you here and congratulations on the work you are doing with Parents Anonymous in Alabama.

You mentioned to me privately when we met that you did need the seed money because you have the volunteers available, but you do need that money. And I favor Government programs which deliver services through ongoing programs by paying the expenses of that program. It is synergistic, whereas going through an entire bureaucracy, the managerial, clerical, people of that nature, present enormous expense.

I have seen some material in your testimony that $75 a year covers the cost of servicing one family.

Ms. BIGGER. I believe we say that one family can be serviced with between $50 and $75 a year. As far as volunteers are concerned, we man a 24-hour phone line. We have 100 people on our support committee. We have a 24-member board in Calhoun County. And when I talk about Calhoun County, it is because I know about it. But these same things are being duplicated in other counties in the State. Then we have the people involved in our parenting programs, in the teaching, in the setting up of the programs with the city and county schools.

We have the churches who do our transportation for us. We have 24 churches who take a month about, doing our transportation. I would say that we get $75,000 a year in volunteer services for the little amount of money that is put into one county in Alabama.

Senator DENTON. How much progress have you seen achieved in an area in which others seem not to be addressing; that is, helping children who have been abused?

Ms. BIGGER. I think we are making progress there, too. We held the children and baby sat with them for about 3 years. And then last year in May we made application to the National Parents Anonymous for $4,000 as seed money for a program. We have been running a whole year now on that $4,000.

But what we do, we pay consultant fees, and then these people recruit and train the volunteers in the nurseries. We do see progress. We had, for example, one family where the oldest little boy—there were three boys—had been sent to a home away from Alabama because no foster home could take care of him.

Now we have the two younger children and Brad and Montez both are really hyperactive children. And they do need supervision. But they are making progress, and the week before last, I believe it was, when Brad came in, there was a little confusion, and so not wanting to be a part of this, he asked to be put in the timeout chair. We felt then that he was making real progress. The child care volunteers are doing things with empathy, with behavior modification techniques and with the timeout chair, and these things I think are really helping the parents.

We are also talking to the parents about what we are doing for the children so that they will go home and carry through with some of these things.

Senator DENTON. How much of your funding comes from private sources?

Ms. BIGGER. We are funded by United Way.

Senator DENTON. You are funded by United Way?

Ms. BIGGER. We are funded by United Way and private donations in our county. And then our $32,500 grant on the State level came through the Alabama State Department of Pensions and Security. We received that in December, and that is the money that we used to hire our new State director and set up a small office in Alabama.

Senator DENTON. Mr. McNally, I want to join all of those who would commend Johnson & Johnson for their altruistic involvement in child abuse. The Levi Strauss Corp., and the Scholl Foundation have also been involved through Parents Anonymous organizations. How would you suggest that we successfully solicit further participation on the part of the private sector in this area?

Do you know whether, for example, there is anything in the President's report on the private sector task force initiatives?

Mr. MCNALLY. Personally, I do not know that there is anything in that report, but it seems in the couple of programs that we have run to promote corporate awareness that corporate members talking to other corporate members is one of the best ways to get other people to do things and to get other corporations to go along.

And it seems—that seems to be the most workable solution. It is almost a one on one.

Senator DENTON. Do you have other companies in your area with plans to participate?

Mr. MCNALLY. We have a number of companies that do donate to our chapter, and, for example, Merck, Prudential, Squibb, Allied Chemical, Knowle Pharmaceutical; there are a number of corporations in New Jersey that do donate time and money.

Senator DENTON. Your Chestnut Street project is certainly worthwhile. Do you plan for any more such primary prevention projects?

Mr. MCNALLY. We have applied for a grant from Gulf & Western that would extend the Chestnut Street project to a day care center also. So it would be a continuation. The Chestnut Street project, that parent linking project, has helped over 760 families in the State of New Jersey in the 2½ years that it has been running.

So we hope to expand it in that manner.

Senator DENTON. Thank you, sir.

Mr. Sherman, I was not here for your testimony; however, I read your testimony last night, and I would want to congratulate you for your comprehensive program and the effectiveness of the Camp Fire program.

I noticed you had references frequently to boys in there. I have heard of Camp Fire Girls; I have never heard of Camp Fire Boys. How does that work out?

Mr. SHERMAN. Well, Mr. Chairman, Camp Fire became a coed organization 7 years ago, and changed the name from Camp Fire Girls to Camp Fire, Inc.

I am the first male director since 1943 to head the organization. And of our 500,000 members at this particular time, roughly 15 percent are boys, and it is an ever increasing number of our membership. We offer the same range of programs, camping programs, our small group club programs, and innovative response programs to boys and girls separately and together at all different levels within the Camp Fire program.

As a matter of fact, in your home State in Birmingham, Ala., we have one of our fine Camp Fire programs in operation that serves both boys and girls, that is doing youth employment programs.

Senator DENTON. Have you been able to enlist community agencies into your efforts to educate people about sexual abuse?

Mr. SHERMAN. We have done a nationwide prevention education program in the area of abuse and sexual abuse, and many local projects emerged from that. And most of those local projects were collaborations in local communities between community youth serving organizations, child organizations, universities, the United Way, and other Camp Fire programs.

And so there has been a good deal of collaboration that has taken place as a result of the education and information program that we have established.

Senator DENTON. Ms. Vecchiolla, I apologize for not having been in here for your oral testimony, and you did not have a written statement.

Ms. VECCHIOLLA. I do have a written statement, Senator Denton. I am sorry it is late. My secretary was on vacation last week.

Senator DENTON. I know the problem.

Ms. VECCHIOLLA. I also have for the record two pieces of material that I would like to submit. One is a copy of issue of "Connecticut's Children," which I think you might find interesting, as well as an overview of the Connecticut model system, which is the program I spoke about in my testimony.

Senator DENTON. With your indulgence, then, I will read all of your material and then send you written questions.

Ms. VECCHIOLLA. Thank you.

Senator DENTON. Dr. Palmer, we hear a lot of complaints about the Baby Doe provisions, but not many constructive solutions. Do you have any ideas about what we can do to prevent such a horrible form of child abuse as denial of nutrition and treatment to handicapped infants?

Mr. PALMER. I believe that, first of all, I think—I guess the direct answer to that question would be that I think that many of the people who are working in newborn intensive care nurseries—in fact, before I came here to testify, I talked with the directors of our newborn intensive care nurseries, which are networked with the University of Utah program, and we really had a hard time thinking of any—perhaps maybe two—that we could think of collectively, infants that would fit the Baby Doe kinds of issues that are laid out in this concern.

I think—I guess I feel that many people who are in newborn intensive care nurseries, most neonatalogists that I know, most of the geneticists, at least that I am personally acquainted with in our program in Salt Lake, are advocates for Baby Doe children, and are not involved, at least in the things that Baby Doe legislation is attempting to prevent.

And my concern, of course, in that issue—and looking at it perhaps from our own State's issue—would be that it would be terribly difficult to clarify who is a Baby Doe under the circumstances where someone is being denied appropriate medical therapy; you know, what is appropriate medical therapy? And by whom should that be decided?

And, you know, I believe that promotion of the well being of children, truly being children's advocates is the best way to deal with the issue. I do not know that putting up signs and clogging the system by looking at—trying to find infants when there are so many other infants and children who need that money; I am not sure, at least in this funding time, is the appropriate use of funds.

Senator DENTON. I wish you had been at our hearing. We came pretty close to reaching a meeting of the minds with those among whom such a meeting would be unanticipated: The representation from the American Academy of Pediatrics took the position that the Government ought to stay out of that.

And I acknowledged to myself as I approached the hearing that the nub of the matter was the term—there are various ways of saying it, but what was your term, ordinary medical treatment?

Mr. PALMER. Acceptable medical therapy.

Senator DENTON. Yes. OK. There are several terms used for that. But it sort of begs the question to assume that that is always a definite and black and white definition. However, what came out of the hearing, I think, as a result of the Surgeon General's testimony and the other testimonies, is that what is really intended by our bill language is not a gross generalization about overall care of children, but a more specific approach to something which the American Academy of Pediatrics itself reports in its journals as having been grossly misunderstood. For example, there are now new treatments for spina bifida, which, if they are implemented early and properly, can change markedly the expectations which have been brewing in the minds of too many regarding the pessimistic outcomes for those children.

It seems that the actuality is that what the Department of Health and Human Services regulation does is not address the broad general area, but rather specifically spina bifida and other defects where therapies are known to exist. The intent is to insure that nourishment is not turned off for a child for these very limited defects which the government believed were not being treated in some cases, perhaps not from a motive of anti-Hippocratic principle, but from ignorance because it is a new and fast developing expertise.

And information about treatments was not getting around in the profession. It is not a perfect regulation. But I was persuaded, and I think most at the table were—in fact, I would hazard to say all were—that unless it proves to be troublesome in these sense that you mentioned, namely, that in many cases it is impossible to make a determination it is better to go ahead with it, with the understanding that it applies to that which would previously be outlined as the area of application.

That is the one missing link in that law, I believe, for what it is worth.

Mr. PALMER. Senator, my concern is in one sense that we take a setting where a decision has to be made as an emergency, which is what must be done in terms of spina bifida or myelomeningocele; that is, if the child has an open spine, that must be closed in the first 48 hours of life or the child will get meningitis 60 to 70 perent of the time. So it is difficult to make a decision knowing that that will in fact last with the child for the rest of his or her life. And yet——

Senator DENTON. What is going to last? There was much testimony about people ignoring the advice of doctors who said their child was going to be a vegetable. They went ahead, had the therapy applied and the child was not a vegetable at all. We had examples of kids being stars on television shows and things like that.

Mr. PALMER. I agree. I think if you make that first step, then you must make the other steps that are inherent with that decision.

Senator DENTON. Why not make the first step if it is scientifically ascertainable by statistics now that if the step is taken, the odds are extremely good.

Mr. PALMER. I believe you should take the step. I am coming from a treating program. I am not talking about not taking that first step.

Senator DENTON. Well, as I said the representative of the American Academy of Pediatrics admitted that in some instances the step was not being taken. The suggestion was made that the parents who may be in trauma for the first couple of weeks or so by not consenting to feed the infant would automatically lose parental rights. And then parents who would adopt would be permitted to adopt and they would go ahead and give the permission.

That was the sense of much of the testimony. It was rather interesting to me because I am not a doctor; my brother is. And I am not entirely ignorant of it, and I have learned a lot from laymen and reading about it.

But I think you would not have been discouraged by the way it was all aired out.

Mr. PALMER. I appreciate that. And I was really making my remarks only in terms of lessening funds for the child abuse issues that we all are talking about this afternoon.

Senator DENTON. Right.

You feature a multidisciplinary approach to the child abuse program. Do you see a definite benefit from that type of approach?

Mr. PALMER. Oh, the benefit is just immeasurable because what that does is it gives you interaction with each of the disciplines that the multidisciplinary approach represents in the community, and in order for any child protection effort to be successful, you must be thought of as somebody who has a helpful program in the community. And a dialog that is possible through the multidiscipline approach is not only for the child's well-being in terms of being better managed and better treated, but also for the rehabilitation aspects of getting the child and family together in a successful way.

[Additional material supplied for the record follows:]

CHILDREN'S HOSPITAL AND HEALTH CENTER OF SAN DIEGO, CALIFORNIA

Submitted by

David Chadwick, M.D.
Medical Director
Children's Hospital and Health Center
of San Diego, California

before the

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES
SUBCOMMITTEE ON AGING,
FAMILY AND HUMAN SERVICES
Jeremiah A. Denton, Chairman

Re: FY 1984 Budget Request for the
CHILD ABUSE PREVENTION AND TREATMENT ACT,
as amended

April 7, 1983

Introduction

The Children's Hospital and Health Center (CHHC) in San Diego, California, is a 158-bed tertiary care pediatric center serving two million people in San Diego and Imperial Counties. The Center offers the community several specialized services, including a hospital-based child abuse prevention and treatment program. As Medical Director of CHHC and as a physician who has devoted a major portion of my professional career to combating child abuse, I submit these comments on the reauthorization of the Child Abuse Prevention and Treatment Act (Public Law 93-247), as amended (the Act).

My testimony arises from two perspectives. First, as head of the child protection program and as an active member of the physical abuse review committee at CHHC, I treat scores of abused children every year. Second, as one of two consultants to the American Academy of Pediatrics on child abuse problems and as a frequent witness in civil and criminal proceedings, I can attest to the profound impact which child abuse plays in shaping the formative years of vast numbers of this nation's young people.

Since enactment of the Act in 1974, we have made significant progress in both knowledge and treatment of child abuse. The National Center on Child Abuse and Neglect (NCCAN) is to be commended for its major role in heightening our awareness of this problem through its research on the issue and its guidance to state and local agencies in combating the problem. NCCAN currently funds 65 vital research and demonstration projects nationwide which encompass a variety of activities. The major areas involve: prevention; clinical treatment; public child protection services; legal juvenile court services; sexual abuse prevention; adolescent maltreatment (including sexual exploitation) and prevention; protection of children in special institutions; mental health programs for abused children; and programs aimed at children with developmental and other disabilities. However, budget reductions, in the face of increased instances of child abuse nationwide, threaten NCCAN's progress in these areas.

Budget Overview

In 1981, the Administration proposed that the programs authorized by Public Law 93-247, as amended, should be enfolded into the Social Services Block Grant in FY 1982. While Congress rejected the Administration's proposal, funding for the programs was cut from the FY 1981 level of $22.9 million to $16.2 million. Specifically, $9,479,000 was appropriated for the discretionary funds program and $6,720,000 was appropriated for the state grant program.

In 1982. the Administration again proposed a substantial reorganization of the child abuse prevention and treatment programs for FY 1983. Funds for the state grant program were to be reduced by $2 million and the discretionary funds for research and demonstration activities were to be grouped with other Office of Human Development Services (OHDS) projects under a single level of funding at $31 million. This latter proposal provided for no increase in funds over the FY 1982 level. Congress again rejected the Administration's proposal and agreed to fund these programs at the FY 1982 appropriation level.

This year the Administration is proposing to continue funding for the state grant program at $6,720,000 for FY 1984. However, for the discretionary funds program, the Administration is proposing to block grant funding allocated for child welfare research, child abuse prevention and treatment projects, social services research and adoption opportunities at $9 million. Compared with the FY 1983 levels of funding ($22 million) for all of these programs, this figure represents a catastrophic budget reduction.

Consequences of Budget Reductions

Since implementation of these budget reductions, states across the country have reported increased instances of child abuse. A survey of child abuse specialists in all fifty states and the District of Columbia, conducted in the fall of 1982 by the National Committee for the Prevention of Child Abuse, revealed that 39 states witnessed an increase in reported cases of abuse in the past year. Moreover, 14 states recorded an increase in the number of deaths due to abuse and 33 states reported more serious cases of abuse.

For the State of California, a fifty percent increase in physical abuse cases and a 95 percent increase in sexual abuse cases were seen from 1979 through 1981. During this same time period, San Diego County witnessed astronomical increases in the reported cases of physical abuse (271.82%) and sexual abuse (467.08%). In Imperial County, substantial increases also were recorded during this time frame for physical abuse (16.06%) and sexual abuse (92.86%).

At the San Diego Children's Hospital, the numbers of child abuse deaths have risen since 1979. In 1979, CHHC was credited with no child abuse deaths. However, in 1980, four deaths were recorded; in 1981, six deaths; and in 1982, another six deaths were reported.

Indications from local authorities reveal that these soaring rates of increase have continued unabated throughout the past year. To a degree, these increased reports of child abuse reflect our heightened awareness and recognition of the problem itself. In the State of California, more stringent reporting requirements as well as severe economic pressures on families also have been cited by officials as contributing to the marked rise in child abuse cases.

Yet, at a time when child abuse appears to have reached epidemic proportions, the State of California has been forced to reduce by approximately twenty percent the number of budgeted social work positions to administer child protection services. This reduction has occurred as a result of federal cutbacks in funds for child abuse prevention programs since 1981. In turn, this reduction in the work force has raised the case load per social worker.

Because of these circumstances, every county in the State has been forced to limit the type of cases handled by their child protection agencies. For example, several counties have implemented policies not to treat children above the age of twelve years except in rare circumstances. Other counties are considering more stringent limitations such that children above the age of six years will not be treated. As a result of these restrictions, a child above a certain age limit with superficial injuries -- *e.g.*, slight bruising, welts or scars -- will not be admitted for treatment. Only children with more severe injuries -- *e.g.*, black eyes or burns -- will be handled by the child protection agencies. Clearly, as a result of budgetary constraints at a time of record increases in reported child abuse cases, the State of California has been forced to provide primarily crisis intervention rather than preventive and supportive services.

Conclusion

Despite the increase in public awareness of this national problem, more work clearly needs to be done in the areas of child abuse prevention. The very success of NCCAN's programs has led us to realize that abuse and neglect of children is a serious, and unfortunately growing, problem in America today. Recent studies have confirmed that each year over one million children are needless victims of abuse and neglect. Over 44,000 children are the victims of sexual abuse. At least 1,000 children die annually as a result of severe physical abuse and neglect. These estimates are based only on cases which actually have been reported. Most experts agree that the real incidence of abuse is two to three times higher.

The National Center on Child Abuse and Neglect stands as a model federal initiative: it was created to address an acute national problem; it has served as a resource for state child abuse programs; and it has joined successfully with the private sector to address the many problems associated with child abuse and neglect.

If we are going to continue to have an impact on the problem of child abuse in the United States, it is critical that the federal presence be maintained and that the activities of NCCAN and the programs it administers be given sufficient financial support. Any cutback in federal funds, particularly at this time, will have a devastating effect on our ability to combat this serious national problem. In fact, if additional funds are not authorized under the Act, an already severe national problem will continue to deteriorate without any hope of improvement in the near future.

For these reasons, we urge this Subcommittee to reject the President's FY 1984 Budget Request and to reinstate the FY 1981 authorization level of $30 million for the child abuse prevention programs in the FY 1984 Budget Request. Moreover, we request this Subcommittee to target at least $15 million of the discretionary funds within OHDS specifically for child abuse prevention and treatment projects to enable continuation of the vital work in these areas.

STATEMENT OF THE
NATIONAL CHILD ABUSE COALITION

SUBCOMMITTEE ON FAMILY AND HUMAN SERVICES
COMMITTEE ON LABOR AND HUMAN RESOURCES
U.S. SENATE
APRIL 11, 1983

Prepared by Thomas L. Birch
Advisor, National Child Abuse Coalition

A tragic consequence of our nation's prolonged recession and high unemployment has been the sharp increase in child abuse incidents and in the numbers of deaths of children caused by abuse.

The rise in reports of child abuse comes at a time when federal support for children and families has declined. In 1982, federal child abuse money was reduced from $22.9 million to $16.2 million. Funds for Title XX — the major federal program of support to states for social services — were cut by 23 percent. Assistance under Title XX goes to the core services needed to help families under pressure: protection for abused children, and daycare and homemaker services that can prevent child abuse.

Significant reductions were also made in other federal support programs for families: maternal and child health, care for women and infants, foster care and adoption.

The combination of funding cuts and the pressures of unemployment and the depressed economy, touching many of the nation's families, raises the question of how changes in support for social and health services are affecting our response to child abuse.

Unemployment and Child Abuse

A survey of twelve states conducted in the spring of 1982 by the National Child Abuse Coalition offered a preveiw of the seriousness of the problem.

In Oregon, where lost jobs in the timber industry pushed unemployment well above the national rate, the reports of child abuse rose in 1981 by 46 percent over 1980. The Protective Services Unit of the Oregon

Children's Services Division had this to say about the increase:

> We believe the marked increase of 865 child abuse reports in 1981 can be partially attributed to the distressed economy which resulted in an increase in unemployment and related individual stress problems.

In the first four months of last year almost 200 more children were abused in Oregon than during the same time in 1981.

In South Carolina, where mill closings contributed to an unemployment rate of 11.3 percent in early 1982, five children had died as a result of abuse in the first five months of that year, the same number of child abuse related deaths as in all of 1981.

In a state with unemployment at 15 percent, over half the cases of abused and neglected children referred to the Michigan Protective Services Division came from the four counties where major automobile plants supply the jobs. Other highly populous counties not as heavily dependent upon the automobile industry did not show as large a share of the state's cases of abused children.

A study conducted in Wisconsin from 1979 to 1981 reported that in the ten counties with the highest unemployment increases cases of child abuse went up by 69 percent, compared with a 12 percent rise in the ten counties with the lowest increases in unemployment.

Increased Reports of Child Abuse

In January 1983 the National Committee for Prevention of Child Abuse (NCPCA) conducted a telephone survey of all 50 states to obtain statistics on the number of reports of child abuse and related deaths in 1980, 1981, and 1982. Of the 29 states that had official data, 21 states showed an increase in the number of reports in 1982 over 1981. Among those there was an average increase of 12 percent. Some states were much higher: in North Dakota reports increased by 15 percent; the number of child abuse cases in Oklahoma rose by 25 percent in one year; cases in New Mexico were up by 29 percent.

In Alabama, where figures are not yet out on the last six months of the year, over 12,000 cases of child abuse were reported in the first half of 1982. If the trend continues it is estimated that some 24,000 child abuse cases in Alabama will be recorded for the year, above 1981 figures of 18,654.

More than one in four states reported an increase in child abuse deaths, and among those states the number of deaths rose by 44 percent. Some states recorded even higher increases. In Kentucky, the number of children dead from abuse tripled between 1980 and 1982. Deaths in Utah quadrupled over the three years. In Maryland, six children were reported dead from abuse in 1980; 10 deaths occurred in 1981 and last year abuse accounted for the deaths of 22 children in Maryland.

Cuts in Services to Abused Children

At the same time that states are experiencing increases in reports of child abuse, in reports of children being abused more severely and in numbers of deaths caused by child abuse — as well as an increase in the amount of reported sexual abuse — federal and state funding cuts to child protective services agencies have resulted in layoffs of staff and cutbacks in services for abused children. Half the states have had to reduce both staff and service dollars.

Cuts in funds have been felt first at the administrative level, meaning layoffs in staff in order to keep service programs. But state and local governments have been forced to go further, prioritizing programs in order to continue funding protective services for children. As a result, child abuse preventive services have often taken the largest cuts.

In many states that face reduced staff and increased reporting of abuse, attention to children is decided based on the severity of the abuse reported. Small numbers of staff cannot handle the increased reports of child abuse if all cases were seen as before. In some states neglected children are given little or not attention. Others are considering redefining, in response to reduced budgets, the types of reported child abuse that would be investigated. For example, children of school age or children over age 12 would not generally be considered endangered.

In West Virginia for example reports of child abuse have increased while staff in child protective services has declined because of funding cuts. Caseloads have become unwieldly and priority of attention is given to children who are more severely abused. Services to prevent child abuse have been almost eliminated.

Minnesota reports reductions in staff, resulting in prioritizing of cases based on severity, early closing of cases and limited response to reports of child neglect.

On the positive side, seventeen of the states surveyed by NCPCA asserted that no cuts had been made, explaining that child abuse is a priority in their states and a certain level of support is maintained for child abuse programs.

Federal Response to Child Abuse

It is against this background that we must consider the role of the federal government in dealing with child abuse and neglect.

In 1974, Congress enacted the Child Abuse Prevention and Treatment Act (P.L. 93-247) establishing the National Center on Child Abuse and Neglect (NCCAN) as the focal point for federal efforts to address this problem.

Professional capacities and resources to handle the problem of child abuse are still in their infancy. We have only begun to find effective ways to protect children and strengthen families. We still need to find a way to prevent child abuse on the large scale which it is occurring. In 1980 the Government Accounting Office (GAO) identified child abuse as "a serious nationwide problem" that needs more attention from the federal government. Continued national focus on child abuse from the federal government is essential.

Consider what NCCAN has accomplished.

Public Awareness: Through its support of programs to educate the public about child abuse and neglect, NCCAN has helped to increase public awareness of the problem and develop a better understanding of what can be done to combat child abuse. In a Harris poll conducted in 1981 for the National Committee for Prevention of Child Abuse, more than three of every four Americans rated child abuse as a serious problem, and one in which the government should take a major responsibility.

The Harris poll had this to say:

> The American public is no longer unaware of child abuse and its consequences. Far from it. The feeling that child abuse constitutes a major and growing problem is widespread, as is the mandate for government and individual action.

> Americans want something done to prevent child abuse, they may be ready to identify what they can do; it is timely to provide such education.

By supporting public awareness efforts, NCCAN has opened the door to families in trouble. People now know that help is available.

State Grants: Through its program of grants to states NCCAN has helped the states improve their own child abuse laws and programs to prevent and treat child abuse.

The federal involvement in child abuse through NCCAN highlights child abuse as a critical concern for state governments.

NCCAN's state grant program shares information among states about successful efforts in states, approaches and models that can be duplicated elsewhere. States have used their money for a variety of innovative programs -- hotlines, public information campaigns, establishing special clinics.

All fifty states now have statutes requiring the reporting of child abuse and neglect. NCCAN has helped states establish effective protective services with better trained staff. Federal grants have supplemented state funds for child abuse services with seed money to support special treatment programs for abused children and their families.

Leveraging Funds: Assistance from NCCAN to states and local organizations has worked to leverage funds in support of child abuse services.

Professional services have been volunteered worth dozens of times over the initial federal investment.

Money has been used as a catalyst to form local programs of volunteers working with parents and abused children.

Funds to state agencies have been successful in interesting other public and private agencies to sponsor programs for treating and preventing child abuse.

State funds have been appropriated to carry forward support for programs that were seeded with federal funds from NCCAN.

Support has gone to Parents Anonymous, the self-help organization with programs in every state that has proven to be one of the most effective approaches to the treatment of child abuse.

Federal Leadership: NCCAN provides leadership in demonstrating improved ways of preventing and treating child abuse and in addressing problems of national concern.

To encourage support from business and industry, NCCAN plans to assist projects at the work place such as parent self-help groups and education on parent-child problems.

In response to increased reports of child abuse and the reaction of some child protective agencies to order priorities for making investigations, NCCAN will assist demonstration projects in more effective management of child abuse investigations.

To prevent family separations and the need for foster care placements, NCCAN will support projects in family day care homes that care for abused children while allowing contact with their parents who are also being treated.

What Is Needed

At the current funding level of $15.2 million NCCAN is restrained from exercising its full responsibility to give leadership in preventing and treating child abuse. There is much more that needs to be done.

Emphasize Prevention: Increased emphasis should be placed on prevention. The alternative is too costly. Given what we know about the consequences of child abuse — that children who run away from home, who may be pulled into prostitution and pornography, who may suffer drug and alcohol abuse, have often been abused at home; — that 80 to 90 percent of the nation's male prison population were abused as children; — that many times parents who abuse were themselves abused as children; — that violence is learned as an acceptable way to handle problems; — given the disturbing increases in recent years in the numbers of America's children who are abused we cannot afford to ignore the importance of preventing child abuse.

GAO has reported that NCCAN has devoted little to prevention. It suggested that NCCAN "identify and disseminate information about practical and effective programs or approaches for preventing child abuse and neglect and help states and localities implement such approaches."

The area of child abuse prevention is still in an embryonic stage. Professionals and volunteers are casting about in many directions to find effective and efficient ways to promote healthier families and reduce the risk of abuse to children. NCCAN could provide leadership by supporting programs that demonstrate ways to prevent child abuse in different kinds of communities. Emphasizing volunteers and paraprofessionals who can be effective in prevention programs, makes this a cost-saving approach in its own right.

The National Child Abuse Coalition recommends that P.L. 93-247 be amended to direct that NCCAN spend a substantial share of its funds on efforts to prevent child abuse. The coalition believes that 30 percent of NCCAN funds directed at prevention efforts would be an appropriate beginning. States should be encouraged to use a portion of their NCCAN grants for prevention activities.

Enhance NCCAN Leadership: Child abuse and neglect are not problems existing in isolation from other issues of children's health, well-being and growth. The National Center on Child Abuse and Neglect should be brought into closer coordination with other related federal programs. With the focus on child abuse and neglect in NCCAN, greater attention to the prevention and treatment of the problem will result from a more broadly established federal effort.

The 1980 GAO report advised more attention to coordinating federal child abuse programs to prevent duplication and to realize a more efficient use of federal resources.

Toward this goal, the National Child Abuse Coalition makes two recommendations. First, the Secretary of Health and Human Services should be designated to chair the Advisory Board on Child Abuse and Neglect. Other federal agencies should be similarly represented on the board. Communication on child abuse and neglect at this level would make easier compatible, cooperative planning among agencies.

Second, the Advisory Board should annually report to Congress a comprehensive plan to coordinate best the goals and activities of all federal agencies responsible for programs related to child abuse and neglect. P.L. 93-247 required such a report as a one-time measure. An annual report would encourage more coordinated planning throughout the federal government and reduce the occasion of duplicative efforts.

Increase Authorizations: Finally, the National Child Abuse Coalition recommends the authorization level for NCCAN research and demonstration programs and state grants in child abuse and neglect be raised to $30 million for fiscal 1984.

Given the tremendous increase in reports of abuse and neglect of children, and the rising incidence of deaths related to abuse, and given the damaging effect of unemployment on families, contributing to child abuse, national leadership is important to help states and communities protect children and build strong families. Yet, because of restricted budgets, this is the very time when services are being cut. Abused children cannot wait for the economy to improve. They need help now.

Beyond the current magnitude of the problem there are other reasons for raising the level of support to NCCAN.

The legislation under consideration expands the responsibility of the National Center to study and investigate the national incidence of harm to infants born at risk with life-threatening congenital impairments. NCCAN is further required to extend technical assistance to states in handling these cases. This additional mandate needs to be considered in setting the authorization level in the bill.

In order to continue current levels of funding to states, a higher authorization is needed. Seven states and two territories are now ineligible for assistance. When, as expected, more states become eligible the amount each state receives would be reduced. Just to maintain current funding levels a higher authorization is necessary.

The size of state grants from NCCAN is already small, averaging $140,000. At the low end, Vermont receives $36,700. An increased authorization would also accomodate a boost in state grants when states need the help the most.

An authorization of $30 million — the same level authorized in P.L. 93-247 for FY 81 — would also enable NCCAN to address several priorities now underemphasized.

More attention could be paid to demonstrating ways of preventing child abuse and neglect. States could be encouraged to use a portion of their NCCAN grants for prevention activities.

NCCAN could direct support to developing better services for the abused children of battered women. Specialized services and referrals for children are needed in shelters, including coordination with other community agencies that help children.

Improving existing services to abused children demands high priority among NCCAN 's activities, especially now that protective agencies are suffering reduction in staff, forcing curtailment of services. Raising the level of support to NCCAN would enable more timely grants to go for improving services — assistance which pays off. In one year NCCAN awarded a total of $3 million to 67 sites around the country in service improvement grants, funding which was picked up by other resources after the NCCAN grants were completed. An increased authorization could help reverse the negative consequences of insufficient treatment services in states throughout the nation.

A National Priority

The National Center can target a limited amount of federal money on child abuse that means extra spending at the state and local levels. This program offers seed money needed to develop services that can stand on their own feet. Support for NCCAN will continue to emphasize child abuse as a national priority demanding the attention of everyone

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The National Child Abuse Coalition was formed in 1981 to coordinate advocacy on behalf of abused and neglected children. A list is attached of the national voluntary and professional organizations belonging to the coalition.

THE ASSOCIATION OF JUNIOR LEAGUES, INC.

TESTIMONY
SUBMITTED BY
THE ASSOCIATION OF JUNIOR LEAGUES, INC.
ON
S. 1003, THE REAUTHORIZATION OF THE
CHILD ABUSE PREVENTION AND TREATMENT
AND ADOPTION REFORM ACT OF 1978
TO THE
SUBCOMMITTEE ON FAMILY AND HUMAN SERVICES
OF THE
SENATE LABOR AND HUMAN RESOURCES COMMITTEE
ON
APRIL 21, 1983

825 THIRD AVENUE, NEW YORK, N.Y. 10022 • (212) 355-4380

The Association of Junior Leagues appreciates this opportunity to present written testimony in support of the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978. The Association of Junior Leagues, an international women's voluntary organization with approximately 142,000 individual members and 242 member Leagues in the United States, promotes the solution of community problems through voluntary citizen involvement--including direct service provision and fundraising as well as advocacy.

The Association and the individual Junior Leagues have a long-standing interest in children's issues in general and child abuse legislation in particular. The Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 is a high priority for the Association this year. This testimony provides background information about the involvement of Junior Leagues in children's issues, particularly child abuse and neglect projects, summarizes League support for child abuse programs through public policy activities and identifies the Association's position regarding S. 1003.

Junior League Projects Including Children

A recent survey in which Junior Leagues were asked to identify program areas of interest showed that more than half of the 211 responding Leagues were interested in children's programs; their interests were concentrated on child abuse and neglect, child care, and advocacy in support of improved services to children. Other topics identified, which involve children's interests, include domestic violence, parenting, teenage pregnancy, substance abuse, and youth programs.

In 1981-82, Junior Leagues reported involvement in 1,740 projects and expenditures of $7,125,260 on community activities. Many of the projects focused on children's issues. The following table provides an overview of project areas involving children's issues.

1981-82 Junior League Projects -
By Project Areas, Which Include Children's Issues

Project Areas	Number of Projects	Junior League Money Spent
Child Health and Welfare	338	$1,093,072
Criminal Justice	72	292,518
Education	217	538,007
Health & Well-Being	457	1,040,878
Total	1,084	$2,964,475

Junior League Public Affairs Activities

A recent compilation of all public affairs activities of the Junior Leagues identified more than 300 public affairs activities involving children's issues (nearly 50% of all public affairs activities in which Leagues participated). Leagues were involved in child welfare issues such as adoption, foster care, and child abuse and neglect; child care; juvenile justice; public schools; and teenage pregnancy, among others.

Child Abuse and Neglect

During 1981-82, 65 Junior Leagues reported involvement in 76 projects directed toward the prevention and/or treatment of child abuse and neglect. During this same period, Junior Leagues contributed approximately $320,000.00 to these programs. In addition, almost 700 Junior League members were working with other community volunteers and professionals in many local agencies administering and implementing services in this area. These projects cover a wide range of programs, including emergency child care, parent counseling, self-help groups, hotlines and research activities. At least 12 Junior Leagues were involved in guardian ad litem and court appointed special advocate projects.

Collaboration

Many child abuse and neglect projects were implemented through collaborative efforts between Junior Leagues and other organizations. Leagues worked in cooperation with local agencies including hospitals, schools, youth groups, libraries, and other community groups. Junior Leagues also collaborated with local, state and federal government agencies, police departments and courts.

Since its enactment in 1974, the Child Abuse Prevention and Treatment and Adoption Reform Act has served as a catalyst for Junior League activities. For instance, a Florida initiative in support of state legislation to establish a guardian ad litem program was launched to bring the state into compliance with the federal law. Many Junior Leagues also have assisted in the development of Parents Anonymous chapters and worked for the passage of child abuse reporting laws in their states.

The Association also collaborates with organizations at the national level in support of programs to prevent child abuse. It is a member of the National Child Abuse Coalition, a group of 20 organizations formed to support the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act, and will co-sponsor the Sixth National Conference on Child Abuse and Neglect in Baltimore, September 26-28, 1983.

Projects Related to Adoption

Junior Leagues and State Public Affairs Committees (SPAC's) also have played an active role in supporting the expansion of adoption opportunities for hard-to-place children. Junior Leagues in several states played a key role in obtaining passage of subsidized adoption programs, and Junior Leagues across the country joined the Association in advocating for the passage of the Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272). Junior Leagues and SPAC's also have supported specific adoption projects in five states, providing volunteers and more than $30,000 in program funds. In addition, Junior Leagues have been involved in public affairs activities specifically concerning adoption and numerous related public issues such as permanency planning, foster care review boards, court appointed special advocates, and guardian *ad litem* projects.

Support for Reauthorization of Child Abuse Prevention

We have attended the hearings of this subcommittee and listened to the testimony of various organizations. We have read the reports--countless reports of nationwide increases in child abuse and neglect. We wish to add our voice to the many which this subcommittee has heard. We believe that the progress made in the last decade was the result of good legislation, national leadership, and the commitment of resources to the long-standing problems of child abuse and neglect. The passage of the Child Abuse Prevention and Treatment Act in 1974 and the establishment of the National Center on Child Abuse and Neglect (NCCAN) were key elements in establishing federal government leadership.

Since 1980, the reduction in federal support for child abuse programs, combined with the reduction of other social welfare commitments and a nationwide recession, has resulted in a simultaneous increase in incidents of child abuse and neglect and a decrease in resources to combat the problems. Reports of increases in child abuse and neglect have come from many groups, including the National Committee for the Prevention of Child Abuse, as well as Junior Leagues involved in Child Watch, a citizen monitoring project developed by the Children's Defense Fund in collaboration with the Association of Junior Leagues. A 50 state survey conducted by the National Committee for the Prevention of Child Abuse revealed increases in child abuse in 45 states. Many of the Child Watch projects coordinated by individual Junior Leagues also have found increased incidences of child abuse over the last year. For instance, the Wilmington, Delaware Child Watch Project found a 30 percent increase in reports of child abuse and neglect.

The Des Moines Child Watch Project discovered that child abuse and neglect reports are the highest ever and, as the result of a statewide reorganization of welfare department staff, there has been a marked reduction in the number of case investigators available to follow-up neglect and abuse reports. Albuquerque's Child Watch Project reported an increase in reports of rape and other forms of sexual abuse of children. The Hartford Child Watch Project reported increased reports of children being denied basic needs such as food, and stated: "The number and severity of child abuse cases are increasing resulting in the placement of more children in foster care."

The Child Watch Project in Baltimore reported that, while the increase in child abuse and neglect reports was only eight and one-half percent from 1981 to 1982, the degree of abuse in reported cases was significantly more severe, including an increase in fatalities. Social service workers reported changes in the families in which abuse is reported: there were more multi-problem families whose problems are more intractable, and more families who have not traditionally sought help (i.e., middle-class families) are seeking help.

The Birmingham, Alabama Child Watch Project reported an increased need for child protective services. The Salt Lake City Child Watch Project reported: "More children are being abused and the abuse is far more serious (more frequent and more violent)." These are just samples of reports which corroborate a nationwide trend.

Need for Federal Leadership

We need a renewed commitment to the prevention and treatment of child abuse and neglect. Further cutbacks in funding, together with a decrease in federal leadership, would be devastating. Congressional leadership is crucial both in the area of child abuse and neglect and adoption programs designed to assist special needs children.

The Administration's proposed cutbacks in child abuse prevention and treatment funding to a level of $6.7 million would result in a federal expenditure of approximately $6 for each of the more than one million children reported as abused each year. Considered another way, the funds requested by the Administration are equivalent to less than one-thousandth of a percent of the federal budget for Fiscal Year 1984. Obviously, this nation can do more and can afford to do more to support the prevention and treatment of child abuse.

Recommendations for Changes in S. 1003

While we strongly support reauthorization of the child abuse legislation, we have some specific concerns about S. 1003 as introduced in the Senate on April 7. First, we believe that the authorization is too low. The proposed authorization of $17 million for NCCAN research and demonstration programs and state grants in child abuse and neglect would merely maintain the current funding level for these programs. If the seven states and two territories currently not eligible to receive funds from the legislation were to become eligible, current state grants--already low--would need to be reduced. Moreover, additional funds would be needed to help states implement the "Baby Doe" provisions of S. 1003. While the Association has not taken a stand regarding these provisions, we believe that no additional requirements should be placed on states without providing additional funds to implement them.

We urge an authorization of $30 million for child abuse programs. Such a funding level would allow NCCAN to expand the state grant program and increase its support for prevention programs, something recommended by the Government Accounting Office and strongly supported by the Association and the National Child Abuse Coalition. In fact, we recommend that the language of the legislation be amended to direct NCCAN to spend a substantial share of its funds on prevention programs. We suggest that states also be encouraged to use a portion of their grants for programs designed to prevent child abuse and neglect. In addition, we regret that the separate authorization for programs designed to prevent, identify and treat sexual abuse was dropped from S. 1003 and urge that it be reinstated.

We also recommend that the reauthorization be for a minimum of four years and that the Department of Health and Human Services be required to develop a comprehensive plan annually to provide for coordination of activities of all federal agencies responsible for programs in child abuse and neglect.

Concerns About Adoption Provisions in S. 1003

We also have serious concerns about the language relating to adoption in S. 1003, particularly the proposed changes in Title II, Adoption Opportunities, Section 201 of the Act which state: "...infants born to teenaged individuals, unmarried parents and thousands of children in institutions or foster homes may be in serious jeopardy and...such infants and children are in need (emphasis added) of placement in permanent adoptive homes..." The language appears to infer that all children born to single parents and/or teenage parents are in serious jeopardy. The proposed changes could be interpreted to justify government intrusion in the personal affairs of many families fully capable of caring for their children. Further, adoption should not be considered the only alternative in cases where children are in serious jeopardy since, in many cases, natural parents lack resources rather than motivation and the desire to care for their children.

Assistance is needed in helping adoption agencies to develop creative programs that will find adoptive homes for the approximately 100,000 special needs children identified as needing adoptive homes. We urge the subcommittee to retain the original language of Section 201 which focuses attention on special needs children, those children most in need of adoptive homes. There are thousands of homes waiting for healthy infants. The need is to continue the leadership at the federal level to develop creative approaches to strengthening interstate collaboration in the development of programs to successfully place this country's neediest children in adoptive homes.

The Association appreciates this opportunity to submit this testimony in support of the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act, and urges you to maintain this subcommittee's leadership on behalf of children.

Virginia Thomas Austin
Public Policy Chairman
The Association of Junior Leagues, Inc.

STATEMENT

of the

AMERICAN MEDICAL ASSOCIATION

to the

Family and Human Services Subcommittee
Labor and Human Resources Committee

U.S. Senate

RE: S. 1003 - Reauthorization of the National
Center on Child Abuse and Neglect

April 27, 1983

The American Medical Association takes this opportunity to submit its comments on S. 1003. The AMA supports reauthorization of the National Center on Child Abuse and Neglect (Center), but opposes provisions of S. 1003 that relate to handicapped infants.

This bill would reauthorize the Center for three years. The funding authorization would be $17,000,000 for each of the three years. Included in the $17,000,000 is $7,000,000 for state child abuse prevention and treatment grants and $2,000,000 for activities.

Several statutory changes would be made by this bill apparently to address situations where severely handicapped infants might be denied medical treatment or nutritional sustenance.

This bill would require the Center to conduct a study on the national incidence of child abuse including a "determination of those incidents of child abuse and neglect which involve the denial of nutrition, medically indicated treatment, general care, or appropriate social services to infants at risk with life-threatening congenital impairments." The Center would report to Congress the findings and recommendations for legislative and administrative changes as are appropriate.

In addition to current activities, the bill would require the Center to provide technical assistance and training that will encourage and assist the states in developing, implementing or improving procedures to ensure "that nutrition, medically indicated treatment, general care and appropriate social services (including services assured under the provisions of section 504 of the Rehabilitation Act of 1973) are provided to infants at risk with life-threatening congenital impairments."

To qualify for grants for prevention and treatment programs in child abuse and neglect, this bill would require states to have procedures to "be followed by child protective service agencies, health care facilities, health and allied medical professionals, such other agencies or individuals as a State may deem appropriate, social service providers, and courts of competent jurisdiction, to ensure that nutrition, medically indicated treatment, general care, and appropriate social services are provided to infants at risk with life-threatening congenital impairments." Further, the current requirement that a state provide for the reporting of suspected child abuse and neglect would be expanded to require a procedure for "any interested person to report to appropriate authorities any known or suspected instance of the denial of nutrition, medically indicated treatment, general care, or appropriate social services to infants at risk with life-threatening congenital impairments."

The adoption provisions would also be amended to require the Secretary to review model adoption legislation and make changes to facilitate "adoption opportunities for infants at risk with life-threatening congenital impairments."

COMMENTS

National Center on Child Abuse and Neglect

Child abuse is an important health problem. In 1981 the Center reported there were 652,000 known cases of child abuse per year. These included 207,000 cases of physical assault, 138,400 cases of emotional abuse, 108,000 cases of physical neglect, and 44,700 cases of sexual abuse. These statistics do not, however, provide a true measure of the full extent of the problem. The National Center's study does not include the incidence of child abuse and neglect known to non-professionals, but not reported. Expert observers believe that the actual incidence is at least 1,000,000 cases per year. It is also estimated that 2,000 - 5,000 children die each year as a result of physical abuse or neglect and many more are severely injured or impaired as a result of abuse or neglect.

The magnitude of the problem and its tragic consequences for children and society make it imperative that all elements of society, governmental and non-governmental undertake programs to minimize and if possible eliminate the abuse of children. The AMA and physicians recognize the essential role that medicine plays in controlling child abuse. The AMA

House of Delegates, in December 1982, approved a report entitled "AMA Involvement in Prevention and Treatment of Child Abuse and Neglect." A copy of this report is enclosed. This report discusses the problem of child abuse, the physician's role in addressing the problem, and plans for increased AMA involvement in this area.

At the same meeting in December 1982, the House of Delegates approved a report of the Judicial Council which states, in part, "The physician who fails to comply with the laws requiring reporting of suspected cases of abuse of children and elderly persons and others at risk can expect that the victims could receive more severe abuse that may result in permanent bodily or brain injury or even death . . . The obligation to comply with statutory requirements is clearly stated in the Principles of Medical Ethics. As stated in 1.02, the ethical obligation of the physician may exceed the statutory legal requirement." A copy of this report is also attached.

The most useful and beneficial role of physicians is the prevention of abuse and neglect. They can provide or arrange for prenatal and postnatal family counseling, identify problems in child rearing and parenting, and advise about family planning and birth control. Physicians should understand and be sensitive to the factors such as the quality of marital relationships, disciplinary styles, economic stresses, emotional problems and substance abuse that result in the abuse of children. Physicians who are caring for patients have an excellent opportunity to identify families with special problems at an early stage and to refer them to appropriate professionals so the family may receive treatment before a child suffers serious injury.

In these situations where a physician observes that a child has been abused, the report states it is "the physician's responsibility to protect the child from further harm." This may require promptly informing the appropriate agency that handles child protection matters and, in some cases, admitting the child to a hospital. According to the report, it is necessary for the physician to conduct a prompt evaluation of the child's physical, emotional and developmental problems when the child is hospitalized. Consultations with other physicians should be conducted as necessary to evaluate and document the physical and psychological results of the abuse or neglect. During the evaluation process it is essential that the physician record the findings in the medical chart, since the medical record may provide the means of preventing further abuse including pivotal evidence in juvenile or family court.

The report provides for increased AMA activities in the area of child abuse, including:

1. Working with state medical societies to facilitate existing programs that focus on prevention and treatment of child abuse and neglect, particularly those capable of stimulating greater physician involvement and illustrating the value of multidisciplinary teamwork.

2. Encouraging state medical societies to establish committees on child abuse.

3. Urging state and county medical societies to establish liaison with specialty societies, the educational community, the legal and dental professions and other civic, community and professional groups involved in this area.

4. Preparing and distributing printed and audio-visual materials to inform physicians of the nature and extent of the problem of child abuse and neglect and the role they can play in identification, treatment and prevention.

5. Delineating treatment approaches at various levels of physician participation, so that specific guidelines can be prepared to help physicians carry out their reporting and case management responsibilities.

6. Encouraging the AMA Auxiliary to take a leading part in disseminating information, promoting parent education programs, creating coalitions with other volunteer organizations, and conducting preventive programs utilizing volunteers.

7. Sponsoring a national conference to highlight model programs of prevention and treatment, especially those in which state medical societies play an important part, and to help the profession keep abreast of new developments in the field.

8. Recognizing, through awards, outstanding child abuse programs and other achievements in detection, prevention, treatment and public and professional education regarding child abuse problems, for the purpose of encouraging continuing support for such programs.

This report was only recently adopted. The AMA is now planning the programs to accomplish these recommendations. An advisory panel is assisting us in the implementation phase of this project.

While the AMA and other non-governmental organizations are essential to efforts aimed at reducing the incidence of child abuse, the governmental sector is a necessary partner. The Center has served an important role in the prevention and treatment of child abuse since its establishment in 1974. The major functions of the Center are: 1) generating knowledge on prevention, treatment and improving programs; 2) collecting, analyzing and disseminating information on child abuse and neglect and programs to reduce the incidence; 3) assisting states and local communities in implementing child abuse programs; and 4) coordinating federal efforts on child abuse prevention and treatment. The AMA believes that if these activities were to be discontinued, current programs to prevent and treat child abuse would suffer significantly and progress in the area would be slowed. Therefore, we support reauthorization of the Center.

Handicapped Infants

Recently, the tragic circumstances of infants born with severe handicaps and medical complications have received public attention. Regulatory and legislative initiatives have been proposed to address these situations which are tragic for families and agonizing for physicians, other professionals such as nurses, and institutions called on to assist parents and child. We must urge against adoption of any provisions that would result in direct governmental intervention in the family and the functions of physicians in such situations.

Throughout its history the medical profession has wrestled with the issues of what is appropriate treatment for a given individual and who should make that determination. These are issues of the greatest difficulty and significance that have to be made in the best interest of the infant by all who have responsibilities for the infant. At the same time, societal interests are involved. Nevertheless, in the absence of overriding circumstances, we believe there cannot be any substitute for the informed decisions of the parents based on the advice of physicians personally involved in a particular situation.

The medical profession is dedicated to healing and to the preservation of life. This dedication - strong as it is - is surpassed by the depth and intensity of feeling and the bond which exists between parents and their children. The natural instincts of the parents are for survival of the newborn. These instincts are strong. We recognize that child abuse occurs and is a serious problem for the children, parents and the community, but we should not lose sight of the fact that for the vast majority of parents survival and the best interests of their children are paramount. The natural ties of parents to their children and their love and concern for the total welfare of the infant in the context of the immediate circumstances cannot be fully understood nor is it truly addressed by those who debate the issues in an atmosphere quite separate from the reality of the event. The physician - and all others involved - must offer compassion, information and understanding and reach out to the parents who, in the throes of tragedy and grief, are searching for answers and advice.

The physician in such cases is in a difficult circumstance and is also in need of guidance. The experience gained by the profession over the years is expressed in AMA Judicial Council Opinion 2.10 adopted to provide guidance to physicians in these difficult situations. The text of the Judicial Council Opinion reads as follows:

> QUALITY OF LIFE. In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness or advanced age, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued. In desperate situations involving newborns, the advice and judgment of the physician should be readily

> available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.

In our view, decisions as to the treatment of a newborn should be determined by the parents following consultation with their physician in the manner described above. The intent of this bill, however, is to encourage governmental intervention into medical treatment decisions involving handicapped infants. We believe such government intervention intrudes on the rights and responsibilities of parents, families, physicians and institutions. There is no evidence that the provisions of this bill will benefit the child, the parents, the physicians or the institutions involved; therefore we oppose these provisions.

This bill would define certain decisions regarding appropriate medical treatment for handicapped infants as "child abuse." We oppose this approach. We believe such situations are unique and are fundamentally different from the generally accepted concept of "child abuse." We believe that the causes or the situational factors are totally different. It is therefore inappropriate to address the issue of handicapped infants within the context of child abuse legislation. Furthermore, the development and implementation of these procedures will divert public attention and resources from essential efforts to prevent and protect children from abuse by their parents.

The AMA is gravely concerned that such activities will increase stress in a situation where the family is already experiencing extreme stress. This is not beneficial to the parents, the infant or other children in the family.

CONCLUSION

The AMA recognizes that child abuse is a serious health and societal problem and therefore is involved in activities to enhance physicians' knowledge and skills in areas of prevention and treatment. We believe the Center makes significant contributions to efforts directed at reducing child abuse and neglect, and we support reauthorization of the Center.

However, we oppose provisions of the bill that will result in governmental interference in the decisions concerned with the medical treatment of handicapped infants. We believe that unless there is convincing evidence that the parents are not acting in the interest of the child, the parents should decide what medical treatment their child will receive. We cannot support efforts that will result in governmental interference with and second-guessing these parental decisions made in consultation with their physician. S. 1003 should be amended to delete the provisions relating to handicapped infants.

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REPORT OF THE COUNCIL ON SCIENTIFIC AFFAIRS

Report: J
(I-82)

Subject: AMA Involvement in Prevention and Treatment of Child Abuse and Neglect (Substitute Resolution 75, A-81)

Presented by: William D. Dolan, M.D., Chairman

Referred to: Reference Committee E
(Edward Sattenspiel, M.D., Chairman)

Report T of the Board of Trustees (I-81), which was adopted by the House of Delegates, called for a study to determine the feasibility of AMA activity in the area of child abuse and neglect. This report was in response to Resolution 75 (A-81), which had been referred to the Board and which urged the Association to develop an educational program focusing on the prevention of child molestation, incest and exploitation.

Subsequently, the Council on Scientific Affairs appointed an advisory panel for the purpose of assessing the major considerations and making specific recommendations for AMA participation in this area.

After a comprehensive review, the advisory panel recommended to the Council that the AMA assume an active leadership role in a renewed attack on the widespread problem of child abuse, including sexual abuse.

The Council believes that the AMA, in cooperation with state medical and specialty societies and the AMA Auxiliary should (a) increase awareness of the problem among physicians and the public; (b) improve training and education in the use of existing modalities for diagnosing, treating and preventing abuse; (c) promote the development of innovative programs that will advance medical knowledge and competence in this important field of child and family health; and (d) encourage physicians to work with child protective teams drawn from many fields, including law, social work, psychology and the lay volunteer community.

Extent of the Problem

Child abuse is known to exist in all racial and ethnic groups and in all levels of society. Based on the National Study of the Incidence and Severity of Child Abuse and Neglect published in 1981, the National Center estimates the annual incidence of child abuse and neglect at 652,000 cases per year. Of this total, about half are attributed to physical, sexual and emotional abuse, and the rest to various forms of neglect, including physical, educational and emotional.

Past House Action: I-81:49-50; A-81:232

Physical assault was the most frequent form of abuse identified in the study (207,600). Among the major categories of neglect, educational neglect was the most frequently cited (181,500). Incidence rates for sexual abuse were 44,700, emotional abuse, 138,400, physical neglect, 108,000, and emotional neglect, 59,400 cases per year. A significant number of children die or are severely injured or impaired as a result of abuse or neglect.

The number of missing children in this country has been estimated as high as 1.8 million annually, according to the Department of Health and Human Services. These children, whether runaways or victims of abduction or child snatching, are exceedingly vulnerable to physical, sexual and emotional abuse and exploitation. Such exploitation can take the form of pornography, drug trafficking and other illicit activities in which adults can profit.

Widespread public concern about the problems of child abuse and neglect is largely a phenomenon of the past two decades. Mandatory reporting laws for suspected cases of child abuse and neglect now in place in all states, offer those persons who report in good faith protection from retaliatory litigation. Early reporting statutes were directed primarily to physicians. However, most states have expanded the list of those required to report to include other health professionals, as well as teachers, law enforcement personnel and child care workers. Many states have broadened the concept of reportable circumstances to include not only physical injury but also sexual abuse, neglect and, in some cases, exploitation.

Definitions

States and communities define child abuse and neglect in a variety of ways. These definitions can be found in state statutes, case law and agency regulations. For the purposes of this report, child abuse and neglect are defined as physical, emotional and sexual abuse as well as negligent treatment or maltreatment of a child under the age of 18 by a parent or caretaker who is responsible for the child's welfare.

"Child abuse," which includes physical, sexual and emotional abuse, occurs through an act by a parent or caretaker which is not accidental and which is detrimental, or threatens to be detrimental, to a child's physical or mental health or welfare.

"Child neglect" is an omission, specifically the failure of a parent or other person legally responsible for a child's welfare to provide for the child's basic needs and an adequate level of care. Child neglect tends to be chronic and involves inattention to the child's basic needs for food, clothing, shelter, medical care, supervision, affection and intellectual and social stimulation. "Educational neglect" refers to a parent or caretaker who knowingly permits chronic truancy or fails to enroll the child in school. "Physical neglect" involves abandonment of a child, disregard for the child's safety or inattention to the child's medical needs. "Emotional neglect" refers to inadequate nurturance of or affection for the child.

As the term implies, "physical abuse" is non-accidental trauma such as fractures, burns, bruises, welts, cuts and/or internal injuries. Frequently, physical abuse is used as a disciplinary or punitive measure, and can range from a slap or a kick to the use of such objects as straps, belts, kitchen utensils, pipes, etc.

"Sexual abuse" involves any contacts or interactions between a child and an adult or caretaker in which the child is being abused or exploited for the purpose of sexually stimulating the perpetrator or some other person. The most common forms of sexual abuse are incest and molestation. Child pornography would also be considered an act of sexual abuse since the child is being exploited to meet the sexual needs of others, often for profit.

"Emotional abuse" frequently manifests itself in the form of verbal abuse or excessive demands on a child's performance and often results in impaired psychological growth and development.

"Child snatching" is the abduction of a child by a non-custodial parent or other relative. This may occur when parents separate and one or the other illegally kidnaps the child (or children) and moves to a distant location. As a result, the child's emotional supports found in the family, home, friends and community are abruptly eliminated.

Legislative and Administrative Responses

The 1974 Child Abuse Prevention and Treatment Act created a National Center on Child Abuse and Neglect (NCCAN) whose major functions have been to support a variety of research and intervention efforts at the state and local level, and to maintain a national clearinghouse of information.

The agency designated by law to receive child abuse reports varies considerably from state to state. Most reporting laws require that reports be submitted directly to a local or state social services department; some statutes mandate that reports be filed with law enforcement agencies or one of several social service agencies. In recent years, several communities and states have established centralized reporting hotlines and remote access computer terminals to receive and transmit reports.

The Child Protection Services (CPS) agency is responsible for the coordination and often the provision of treatment or rehabilitation services. Statutory provisions require CPS agencies to accept referrals of suspected abuse or neglect, initiate investigations and determine the validity of submitted reports. Insufficient staffing and funding have produced serious difficulties for many of these agencies in handling the large caseload of investigations as well as the delivery of services. These agencies are manned by social workers who frequently are overworked, inadequately supervised and have little access to medical or psychiatric support, not to mention other social services.

Implications of the Research

In recent years, researchers and clinicians have regarded child abuse as a complex phenomenon that occurs in a setting where emotional and social deprivation and environmental stressors interact in such a way as to inhibit normal loving relationships between parents and children. Although knowledge about child abuse is incomplete, investigators have identified some characteristics of abusive adults and abused children.

A considerable amount of research has focused on the psychodynamic and sociocultural characteristics of abusing parents. Child abusers have been characterized as socially isolated with negative self-images, often abused or neglected in their own childhood, and exhibiting such traits as unrealistic expectations of their children and an inability to cope with stress. Their emotional disabilities often prevent them from obtaining appropriate support and assistance from healthy adults or professionals in learning to care for their children.

Stress, frequently cited as a contributing factor in abuse, may derive from unemployment, inadequate housing, lack of food and clothing, financial problems, marital conflicts, chronic illness in the family, or any other domestic crisis that produces fear or anxiety; such factors may provoke a parent to abuse a child or to overlook a child's needs, thereby leading to neglect. Alcoholism and drug abuse are also associated frequently with child abuse.

Investigators have identified several physical and emotional characteristics of children that are linked to abuse. There is no question that abused and neglected children are at considerable risk of acquiring emotional disorders and character traits which resemble the personalities of their abusive parents.

Mistreated children are also at an increased risk of developmental delays and deviations, including retarded intelligence, learning disability, language delay, perceptual-motor dysfunction and failure to thrive.

In the case of children with developmental disabilities, abusive parents may not be knowledgeable about their child's special needs and limited abilities during various stages of development, and unrealistic expectations may lead to abuse. An allied consideration is that because a handicapped child is often a disappointment to parents, such disappointment may manifest itself in anger and frustration during the child's development. In fact, any child can be a disappointment to parents and may be more susceptible to abuse if he or she fails to meet the parents' expectations (being a good student or an excellent athlete). It is also recognized that children with attention deficits are more likely to become victims of child abuse.

The abused child is frequently characterized as being unusual or unwanted, and therefore viewed as "different" by the parents. This "difference" may be real as in the case of the mentally retarded child or invalid as in the case of the scapegoated child punished for a parent's lack of self-esteem or sense of inadequacy, or as in the case of a child who is the product of an unwanted pregnancy.

Premature and low-birth weight infants are often the victims of abuse. Research indicates that the post partum period is influential in forming and strengthening the attachment between the mother and child. Necessarily, premature infants are separated from their mothers immediately after birth and for some time thereafter, thus delaying the bonding process. In addition, premature babies frequently develop more slowly and with varying degrees of difficulty. This may place extra demands on the parents.

Of special interest to some investigators and clinicians is the early identification of high-risk mothers during the perinatal period. This period affords a special opportunity to assess the mother and her baby for potential problems. Recent work on maternal-infant bonding suggests that child abuse may, in some cases, have its origins when mother and infant fail to bond during the earliest days of infancy. Studies on prediction and prevention of child abuse and neglect show that a high-risk population can be identified and that even modest intervention efforts with these parents can prevent serious injuries requiring hospitalization.

Special Challenges

Because there are various forms of child abuse and neglect, the family assessments, treatment programs and evolving prevention models should encompass a multi-disciplinary approach. No one individual or professional discipline has the expertise to deal effectively with this complex problem. The model of the multi-disciplinary approach can be found in a variety of settings, including hospital and community child-protection teams.

To develop appropriate intervention strategies, more emphasis should be placed on separate epidemiological assessments of various forms of child abuse. Child abuse and neglect cases should not be addressed as if they were a homogeneous group.

Reducing the incidence and lessening the impact of child abuse and neglect will require various approaches, depending not only on the needs of the family but also on available community resources. The scope of prevention should be placed in the context of primary, secondary and tertiary prevention.

Medicine's Responsibility

Since the etiology of abuse and neglect is complex, more than one type of treatment or service is needed to help abused children and to support families in which abuse occurs. Physicians are in a special position to play a key role because they have the techniques and knowledge needed to determine the nature and extent of physical abuse, and because they are obliged by law to report suspected cases of abuse. Finally, some forms of abuse and vulnerability to abuse can be detected only by physicians, such as hidden injuries detectable only through x-rays.

How involved the physician becomes in case management will depend largely on his or her personal attitudes, level of interest, previous training, time constraints and the availability of local specialists. Some physicians may choose to refer all cases to a local pediatrician or team. Others may prefer to manage the case with the use of consultants. Finally, some physicians may opt for extensive involvement through affiliations with child-protection teams and other community agencies.

Primary care physicians, emergency medicine specialists, surgeons, psychiatrists and other specialists who treat children should acquire knowledge and skills in the physical assessment of child abuse and neglect; the assessment of child development and parenting skills; the utilization of community resources; and the physician's legal responsibilities. In the primary care setting, the physician has an excellent opportunity to identify families with special problems at an early stage and to refer them to appropriate professionals. Physicians should be able to determine the nature and level of family functioning as it relates to child protection. They should understand and be sensitive to how the quality of marital relationships, disciplinary styles, economic stresses, emotional problems and substance abuse relate to child abuse.

The first step for the physician in becoming involved in suspected child maltreatment cases is to acknowledge that the problem exists. If a child manifests some of the classic features of abuse or neglect, the recognition process is easier. However, many times the physical evidence is not obvious, and a careful interview with the child and parents may reveal inconsistencies between historical and objective data.

If child abuse is suspected, the physician should consider discussing with the parents the fact that child maltreatment is in the differential diagnosis of their child's problem. During such a session, the physician should maintain objectivity and avoid accusatory or judgmental statements in interactions with the parents.

It is the physician's responsibility to protect the child from further harm. This may require promptly contacting the appropriate agency that handles child protection matters and, in some cases, admitting the child to a hospital. If the child is hospitalized, a prompt evaluation of the child's physical, emotional and developmental problems is necessary. If the physician who initially recognized the child abuse problem is not able to conduct the evaluation, he or she should seek consultations. It may be necessary to consult with surgeons, ophthalmologists, orthopedists, psychiatrists, and radiologists in order to evaluate and document physical and psychological manifestations of the maltreatment. During the evaluation process, it is essential that the physician record the findings in the medical chart, since the medical record may provide pivotal evidence in juvenile or family court.

One of the most useful and beneficial roles a physician can assume is to be instrumental in preventing abuse and neglect. He or she can provide prenatal and postnatal family counseling, identify problems in child rearing and parenting, and advise about family planning and birth control.

Physicians can also serve as the primary educators in the field of child abuse and neglect, since research has repeatedly shown that maltreated children have many more physical, emotional and developmental problems than non-abused children and, therefore, require more extensive medical evaluation and treatment. Physicians can participate in educating medical students, residents, other health and non-health professionals and laymen about the causes and means of preventing child abuse.

Members of the medical profession can contribute significantly at all levels of prevention through involvement in parenting education and perinatal care programs. Twenty-four hour hotlines, crisis care centers, and home visitor programs can be additional efforts the physician can promote at the community level.

However, since child abuse is a multi-disciplinary problem, physicians should be aware that their role in reporting and managing a case of child abuse is limited. Attorneys, judges, social workers and an array of other workers in the child protection field assume other roles, and the physician should be aware of their individual areas of expertise and responsibility.

Survey of State Medical Societies

In recent months, the AMA surveyed state medical societies to determine the ways in which child abuse issues are currently being, or should be, addressed at both the national and state medical society levels.

The majority of medical societies surveyed indicated that their child abuse programs should focus on legislative issues, professional education and public information.

Of the 37 respondents, 23 medical societies indicated they were currently engaged in legislative activities, 14 in physician education programs and 4 in public information activities. Regarding the AMA's role, 17 medical societies recommended distribution of printed educational materials on a regular basis; 19 suggested sponsorship of national or regional conferences; 16 called for the development of audio-visual materials; and 9 supported the concept of a consultation service or 24-hour hotline.

A number of medical societies urged the AMA to support efforts to identify children and families at high risk of child abuse, and to initiate appropriate parent education and family counseling programs involving primary care physicians. Several medical societies recommended that the AMA coordinate with specialty societies and other groups already involved in child abuse activities.

One medical society pointed out that the prevention, detection and treatment of child abuse and neglect are extremely complex issues; to understand these issues, physicians should be aware of cultural mores, economic trends, legal structures, as well as philosophical and ethical issues related to quality of life and rights of children.

A concern expressed by another medical society was that all physicians should be educated to recognize signs and symptoms of child abuse, neglect or failure to thrive.

AMA Initiatives

To enhance physician involvement in the area of child abuse prevention and treatment, the Council on Scientific Affairs recommends that the AMA undertake a program involving the following activities over the next three years:

1. Work with state medical societies to facilitate existing programs that focus on prevention and treatment of child abuse and neglect, particularly those capable of stimulating greater physician involvement and illustrating the value of multidisciplinary teamwork. State medical societies should be encouraged to establish committees on child abuse. To support this effort, the AMA would provide appropriate consultation services and resource materials.

2. Strengthen linkages and urge state and county medical societies to establish liaison with specialty societies, the educational community, the legal and dental professions and other involved civic, community and professional groups.

3. Utilize printed and audio-visual materials such as those available from the American Academy of Pediatrics to inform physicians of the nature and extent of the problem and the role they can play in identification, treatment and prevention.

4. Delineate treatment approaches at various levels of physician participation, so that specific guidelines can be prepared to help physicians carry out their reporting and case management responsibilities.

5. Work with the American Academy of Pediatrics and other involved organizations to identify consultants and technical experts who can advise the AMA and the Federation about implementing various aspects of the child abuse program, including the communications, consultation and training components.

6. Encourage the AMA Auxiliary to take a leading part in disseminating information, promoting parent education programs, creating coalitions with other volunteer organizations, and conducting volunteer-based preventive programs.

7. Sponsor a national conference to highlight model programs of prevention and treatment, especially those in which state medical societies play an important part, and to help the profession keep abreast of new developments in the field.

8. Ensure that national visibility of the AMA's involvement in child abuse is achieved through appropriate efforts in AMA publications and through the AMA Public Relations' distribution mechanism.

9. Recognize, through awards, outstanding child abuse programs and other achievements in detection, prevention, treatment and public and professional education regarding child abuse problems, for the purpose of encouraging continuing support for such programs.

The Council on Scientific Affairs, through its Panel on Child Abuse, is prepared to advise and assist in implementing these recommendations.

The Council on Scientific Affairs recommends the adoption of this report in lieu of Substitute Resolution 75 (A-81).

(Members of the Panel on Child Abuse are: Douglas A. Sargent, M.D., J.D., Chairman, Grosse Pointe Farms, MI; Marvin Blumberg, M.D., New York; Daniel D. Broughton, M.D., Rochester, MN; Calvin C. Clark, M.D., Vancouver, WA; Eugene Eldredge, M.D., Salinas, CA; Richard Krugman, M.D., Denver, CO; and Eli Newberger, M.D., Boston, MA. The Council is also indebted to W. Dean Belnap, M.D., Kaysville, UT; Anne Cohn, D.P.H., Chicago, IL; James W. Lauer, M.D., Denver, CO; Nancy Roeske, M.D., Indianapolis, IN; Rogers J. Smith, M.D., Portland, OR; Janice Hutchinson, M.D., AMA Health Education Program; and Hazel Lewis, AMA Auxiliary.)

FISCAL NOTE: Total cost estimates over the next three years will depend on the extent of medical society involvement and the response from the entire medical community. In the Fiscal 1983 budget, approximately $108,000 has been incorporated for child abuse prevention activities.

REPORT OF THE JUDICIAL COUNCIL

Report: A
(I-82)

Subject: Judicial Council Opinion on Abuse of Children, Elderly Persons, and Others at Risk

Presented by: John H. Burkhart, M.D., Chairman

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Matthew Marshall, M.D., Chairman)

Report J of the Council on Scientific Affairs (I-82) presents recommendations for AMA involvement in the prevention and treatment of child abuse and neglect. All states have child abuse reporting statutes, although these statutes vary. The Judicial Council is concerned about the specific problem of child abuse as well as abuse of other persons, such as the elderly. The Judicial Council presents to the House, for its information, the Judicial Council's opinion on the ethical responsibilities of physicians regarding abuse of children, elderly persons, and others at risk.

ABUSE OF CHILDREN, ELDERLY PERSONS, AND OTHERS AT RISK. Laws that require the reporting of cases of suspected abuse of children and elderly persons often create a difficult dilemma for the physician. The parties involved, both the suspected offenders and the victims, will often plead with the physician that the matter be kept confidential and not be disclosed or reported for investigation by public authorities.

Children who have been seriously injured, apparently by their parents, may nevertheless try to protect their parents by saying that the injuries were caused by an accident, such as a fall. The reason may stem from the natural parent-child relationship or fear of further punishment. Even institutionalized elderly patients who have been physically maltreated may be concerned that disclosure of what has occurred might lead to further and more drastic maltreatment by those responsible.

The physician who fails to comply with the laws requiring reporting of suspected cases of abuse of children and elderly persons and others at risk can expect that the victims could receive more severe abuse that may result in permanent bodily or brain injury or even death.

Public officials concerned with the welfare of children and elderly persons have expressed the opinion that the incidence of physicial violence to these persons is rapidly increasing and that a very substantial percentage of such cases is unreported by hospital personnel and physicians. An important element that is sometimes overlooked is that a child or elderly person brought to a physician with a suspicious injury is the patient whose interests require the protection of law in the particular situation, even though the physician may also provide services from time to time to parents or other members of the family.

The obligation to comply with statutory requirements is clearly stated in the Principles of Medical Ethics. As stated at 1.02, the ethical obligation of the physician may exceed the stautory legal requirement.

NATIONAL COUNCIL OF STATE
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OF THE AMERICAN PUBLIC WELFARE ASSOCIATION
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April 28, 1983

Senator Jeremiah Denton, Chair
Subcommittee on Family and Human
Services
Committee on Labor & Human Resources
A-624 I & N Building
119 D Street, N.E.
Washington, D.C. 20510

Dear Mr. Chairman:

On behalf of the National Council of State Public Welfare Administrators of the American Public Welfare Association, I want to congratulate you for your national leadership on behalf of abused, neglected and special needs children. Your proposal to extend the Child Abuse Prevention and Treatment and Adoption Reform Act (S. 1003, co-sponsored by Senator Orrin Hatch), and your decision to hold three days of hearings on this important legislation, reflect the kind of national direction needed if we, at the state and local levels, are to meet the ever-growing needs of children and families at risk.

The National Council of State Public Welfare Administrators is composed of those public officials in each state, the District of Columbia, and the territories charged with the responsibility for administering publicly funded human services programs, including services to abuse, neglected and special needs children and youth. Since its beginnings at the time of the Great Depression, the Council has been an active force in promoting the development of sound and progressive national social policies and working with the Congress and the Executive branch in assuring that these policies are responsibly and effectively administered. We actively worked to secure passage of P.L. 96-272, the Adoption Assistance and Child Welfare Act of 1980. Since its enactment, we have continued to strive, individually and collectively, to implement the child welfare and foster care reform in this law to achieve stability and permanency in the lives of all children.

I appreciate the opportunity to submit, on behalf of the National Council of State Public Welfare Administrators, comments on both the child abuse and the adoption sections of S. 1003. These comments are respectively submitted for your consideration and for inclusion in the hearing record.

Title I Child Abuse Prevention and Treatment

We strongly support the extension of the authorization for the National Center on Child Abuse and Neglect (NCCAN). In these times of social and economic stress, as many parts of the country are experiencing increases in the incidence of abuse and neglect, NCCAN serves as a focal point for child abuse prevention and treatment activities across the country.

We would, however, like to register concern about the expansion of the definition of child abuse to cover "the denial of nutrition, medically indicated treatment, general care, . . . to infants with life-threatening congenital impairments." Our concern stems from the fact that the proposed legislation would appear to require child protective service agencies to play the lead role in policing hospitals and second-guessing decisions made by trained medical personnel. We agree there is a need to establish additional protections for infants born with handicaps. We also agree that in some situations child protective service agencies might have a role to play. However, state agency administrators do not believe that child protective services agencies have the technical expertise to play the lead role in either establishing standards for medical treatment or in policing the delivery of medical treatment to infants with life-threatening congenital impairments. We would instead recommend that Congress urge the Department of Health and Human Services to immediately begin a dialogue on this problem with the medical community and others who have a clear interest in this area, including state and local public health and social service agencies. If we are to prevent further "Baby Doe" cases from occurring, the medical community must be at the core of any prevention activities.

Title II Adoption Opportunities

The passage of P.L. 95-266 established as national policy that those children unable to remain in their own homes should have to the greatest extent possible the opportunity to be adopted into loving, secure families. The passage of P.L. 96-272 created for the first time a federal subsidy program to assist individuals and families who adopt these special needs children. While progress has been made as a result of these two laws, we all agree that there is much more that can and should be done for those special needs children who are awaiting new, permanent homes.

In your hearing on April 14, you asked witness to address the issue of barriers to adoption. On behalf of those state officials responsible for implementing the Title IV-E adoption assistance program, I would like to briefly respond to your question. The American Public Welfare Association recently sponsored a meeting of state and local public child welfare administrators to address the topic of special needs adoptions. During the course of this meeting the administrators voiced their views on some of the difficulties encountered in the implementation of the Title IV-E adoption subsidy program. Among the issues raised as barriers were:

- Uncertainty of continued federal support for the Title IV-E Adoption Assistance Program--The Title IV-E adoption assistance program was not on the books even six months, when the Reagan administration sent a proposal to Congress to repeal the program and include it in a block grant to states. This proposal was reintroduced in a slightly different version in FY 82. Although Congress has consistently supported the continuation of Title IV-E, some states have been reluctant to enter into subsidy arrangements with adoptive parents when it seems likely that the federal contribution to the subsidy may be withdrawn.

- Inadequate federal guidance--Despite the fact that states meeting the requirements of P.L. 96-272 could begin participating in the Title IV-E adoption assistance program as of October 1, 1980, there are still to date no federal regulations to guide us. Among the unanswered questions are: how are state agencies expected to document Title IV-E expenditures (i.e. develop audit trails) to meet future federal audit requirements? how are states expected to maintain the confidentiality of adoption records, specifically mandated by many state laws, under the federal adoption program? how should the new federal adoption subsidy program relate to existing state adoption subsidy programs (over 40 states had adoption subsidy programs at the time P.L. 96-272 was enacted)? what are the requirements governing interstate adoption subsidy agreements, specifically with reference to obtaining necessary medical care? Many of these are strictly administrative issues that the National Council of State Public Welfare Administrators, through the American Public Welfare Association is working with the Department of Health and Human Services to resolve. The publication of federal regulations should serve to clear up these and other issues, thereby removing some of the administrative barriers to adoption.

There are other obstacles which we believe should be the focus of activities supported by the Title II funds in your bill. In this era of shrinking resources, limited federal money should focus on those activities which can be identified as most critical to the adoption of special needs children. Among the types of activities that should be supported are: a national adoption exchange; development of innovative approaches to recruitment of adoptive families; improved communication and linkages between all of the agencies involved in adopting and placing special needs children (this might include developing greater interjurisdictional cooperation in conducting home studies); and development of methods (training materials, workshops, incentives) to overcome local worker reluctance to either release a child for placement in another jurisdiction or place a child with a subsidy in a home that does not appear to "need" a subsidy. (This has been identified as a major barrier, especially in those states that previously had a state adoption subsidy program with a means test; P.L. 96-272 specifically prohibits using income in determining eligibility for an adoption subsidy).

This list is not intended to be exhaustive but is illustrative of the types of activities we think could best assist public agencies in increasing the number of special needs children removed from the foster care rolls and placed in permanent homes.

Thank you for the opportunity to submit these comments on S. 1002. Once again, we applaud you for your leadership and stand ready to assist you in any way possible as we move forward toward our mutual goal to improve the life of children and families at risk.

Sincerely,

Merle E Springer

Merle E. Springer
Executive Deputy Commissioner
Texas Department of Human Resources
and
Chair, NCSPWA Social Services Committee

MES:dr

The American Humane Association
[illegible]

P.O. Box 1266
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[illegible]

AMERICAN HUMANE

May 10, 1983

Senator Jeremiah Denton, Chairman
Subcommittee on Family and Human Services
Committee on Labor and Human Resources
Washington, D.C. 20510

Dear Senator Denton:

Thank you for the opportunity to prepare responses to Senator Dodd's question. I respectfully request that you make these statements available to him. Furthermore, I am enclosing a monograph, Understanding Child Neglect and Abuse, for your perusal and for Senator Dodd.

If I may be of further service to you as you proceed with this critical work, please call on me.

Cordially,

Wayne Holder

Wayne Holder, ACSW
Director
Children's Division
The American Humane Association

WH:jd

Encl.

cc: Diane DePanfilis
Washington Office

Level of Authorization

At the current funding level of $16.2 million, NCCAN is restrained from exercising its full responsibility in providing leadership in the prevention and treatment of child abuse and neglect. Although financial resources by themselves will not solve the complex problems associated with child maltreatment, increasing the funding to no less than the FY 1981 authorization level of $30 million is essential to more realistically address a problem of this magnitude.

To highlight several points from my written testimony, states are seeing tremendous increases both in numbers and severity of child abuse and neglect referrals nationwide. At the same time, federal financial support has declined. In 1982, federal child abuse money was reduced from $22.9 million to $16.2 million. Funds for Title XX were cut by 23 percent. The combination of these events has had major implications for children and families as well as reducing the numbers of program innovations which would serve to improve the overall quality of child protective services.

Another factor needs to be considered. Over the years, the number of states and territories elibible for funds under the state grant program of the Act has increased resulting in fewer actual dollars available for each state to creatively strengthen their child protection programs.

As a national organization concerned with the protection of children for over one hundred years, The American Humane Association strongly urges that an funding level be authorized which is more consonant with the need.

Prevention

In its recent publication, *Child Protection: Guidelines for Policy and Program, the National Center on Child Abuse and Neglect has emphasized the following:

> In order to reduce the incidence of child maltreatment, efforts must be undertaken on three levels: (1) primary prevention to strengthen all families; (2) secondary prevention, or early intervention, through provision of support and treatment services in at-risk situations; and (3) tertiary prevention through intervention in situations where child abuse and neglect are known to have occured. These efforts require a commitment on the part of a variety of professional groups and organizations, together with public and private institutions or "service sytems" which assist families or intervene in family life.

From an historical perspective, most of the efforts have been on elevating the awareness of child abuse and neglect through the encouragement of identification and reporting of "actual" cases . It has been estimated that slightly more than 20% of federal child abuse research and demonstration funds have been directed toward primary and secondary prevention . Findings of serveral surveys of the states indicate that cuts in overall funding to social services programs has resulted in the need for state and local governments to prioritize programs. In many cases, child abuse preventive services have experienced the greatest impact.

Given what we know about the long term effects of failing to effectively prevent child maltreatment, this "after the fact" approach may be short sighted. More efforts need to be made in all three types or prevention. The overall "cost" to society of waiting is too great.

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*National Center on Child Abuse and Neglect. Child Protection: Guidelines for Policy and Program. Washington, D. C.: U. S. Department of Health and Human Services, June 1982, p. 6.

Mental Injury Included in the Act

As outlined in my written testimony, The American Humane Association strongly supports the inclusion of mental injury in the definition section of the federal law. Much of the debate on this issue stems from a lack of understanding and confusion over definitions. The National Center on Child Abuse and Neglect suggests that states define mental injury as follows: "Mental injury is an injury to the intellectual or psychological capacity of a child as evidenced by an observable and substantial impairment in his ability to function within a normal range of performance and behavior, with due regard to his culture." [1]

In the context of the Act, "child abuse and neglect means the physical or mental injury, ...or maltreatment of a child. . . by a person who is responsible for the child's welfare. . ." [2] The federal regulations further clarify that harm or threatened harm can result from the "acts" and "omissions" on the part of a person responsible for the child's welfare. [3]

Given these parameters, we are not talking about taking away a parent's right to appropriately set limits for a child or about intervening in instances if a parent occasionally raises his/her voice in the process of administering discipline. We are talking about an equal standard of intervention for suspected cases whether the effect to the child is physical or emotional.

In many cases, the long term effects of emotional abuse may be more devastating to the child than other forms of child maltreatment.

For these reasons, there needs to be a mandated system for intervention in all types of child maltreatment.

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[1] National Center on Child Abuse and Neglect. Child Protection: Guildelines for Policy and Program. Washington, D. C.: U. S. Department of Health and Human Services, June 1982, p. 13.

[2] Child Abuse Prevention and Treatment and Adoption Reform Act. Public Law 93-247 as amended.

[3] Federal Register. Child Abuse and Neglect Prevention and Treatment Program; Final Rule. (Part 1340 of 45 CFR). 48(18), January 25, 1983, p. 3702.

Emotional injury - example

Vincent De Francis defines emotional neglect as follows: "Children are emotionally neglected when their mental health is affected by failure to provide for a child the nurturing qualities which are so necessary for the development of a sound personality."[1] The critical question in assessing emotional maltreatment relies on the pervasive quality of the parent-child relationship. In general, is the relationship characterized by fear, distance and anger; or is it love, nurturance and concern?[2] Max Wald has described emotional neglect:

> Many of the parents of emotionally neglected children are caught up in a vicious circle of neglect and deprivation which seems to perpetuate itself from generation to generation. These parents raise families in settings very similar to the ones in which they themselves were raised, and they tend to produce in their children the same physical and emotional problems which they have. Many of these parents have been so hurt, so deprived, so rejected in their own childhood that their personality development has been stunted. They are suspicious of people in general and fearful of being hurt and rejected again. They often act impulsively and have little sense of responsibility and tend to lie. They project or distort in order to avoid responsibility for their failures. Some are passive, others adopt a blustering, aggressive, hostile manner, but underneath they often feel worthless and accept the low opinion which the community has of them as inadequate parents, poor providers and useless citizens. Some are so depressed and overwhelmed by their problems of long standing that they are immobilized, seeing little hope of things getting better.[3]

This description characterized what might be considered the "classic" type of emotional maltreatment. The effects of living in this type of environment with a lack of a positive, developing relationship with a parent can be devastating and have a multitude of specific impacts to the child. According to Ackerman, a child attempting to cope with a depriving and threatening environment many react in one of several ways:

1. The child can attack the family and attempt thereby to coerce gratification of basic needs. In this category fall the aggressive conduct disorders and the psychotic forms of behavior.

2. The child can narrow or withdraw from contact with his family. In this category fall recessive personality developments and trends toward excessive preoccupation with self and body.

3. Finally, the child may react to conflict with his family with excessive anxiety, internalization of conflict and with production of one and another structural form of psychopathology.[4]

Emotional Injury-Example, continued.

[1] DeFrancis, Vincent. "Protecting the Abused Child - A Coordinated Approach", A National Symposium on Child Abuse. Denver: The American Humane Association, 1972.

[2] Holder, Wayne M. and Schene, Patricia. Understanding Child Neglect and Abuse. Denver: The American Humane Association, 1981.

[3] Wald, Max. Protective Services and Emotional Neglect. Denver: The American Humane Association, n.d.

[4] Ibid., pages 6 and 7.

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April 5, 1983

Mr. David Yensen
S.H. 347
Senator Denton's Office
Washington, D.C. 20510

Re: Senate Sub-Committe
Hearings on Families and
Children.

Dear Mr. Yensen:

As per your request, I am submitting testimony to be submitted at the Senate Sub-Committee Hearings on Child Abuse and Neglect Prevention.

I have spent over 20 years as a child welfare practitioner. During this period I have functioned in various capacities including, caseworker, reasearcher, social work supervisor, board member of various grass roots organizations concerned with children, private consultant, clinical instructor and adjunct professor at various graduate schools of social work in the New York City area. I have conceived, designed and operationalized programs to keep children in their homes while treatment is provided to the entire family. I have developed a successful group treatment program for parents and children. This program has a strong community outreach component and is presently operating in New York City. I have traveled throughout the United States helping many localities develop their own adoption and child maltreatment programs. Frankly, I am appalled at the present state of the art.

The machinery for reporting, documenting and referring cases of Child Maltreatment is an effective operation in most states. While Federal, State and local child welfare agencies investigate, document and refer cases of child maltreatment, American Children continue their plight as victims of murder, rape, starvation, burnings and all other heinous crimes. At this very moment, somewhere in the United States children are being killed by parents and adult caretakers. As you read this testimony multitudes of children are being inappropriately separated from their families because successful community family orientated programs are not available to their crisis ridden families. They are unable to get help because it is not accessible to them. Millions of our children are deprived of the necessary growth producing childhoods that are so important if children are to develop into the responsible adults that our country so desparately needs. The destiny of the United States is directly tied to the plight of its children. Most experts on child welfare matters agree that the plight of our children is a national disgrace. Valid studies have shown that many of our youth who join the ranks of criminals were abused, neglected and maltreated as children. No doubt, many of these wayward youth would be responsible tax paying citizens if only accessible comprehensive community based programs had touched their lives and the lives of their caretakers.

Until primary, secondary and tertiary child maltreatment programs are evolved from those community based institutions that work directly with children and families, child maltreatment will continue to rise. These programs must be sufficiently comprehensive and varied in scope. Programmatically they must be designed with equal impact from local community institutions. These institutions include churches, synagogues, mosques, day care centers, head start programs, P.T.A.'s, community boards, civic associations, fraternal orders, secondary schools and all other social, educational, and cultural organizations that are local and community involved. A system of monitoring these programs could be located under the auspices of the National Center for Child Abuse and Neglect with appropriate Federal and State oversight.

Since the United States is a patchwork of vast and varying ethnic, racial and cultural communities, and since child abuse and neglect is a national phenemenon that involves all communities; programs must be actualized that are sufficently heterogeneous to respond to the nation's racial, cultural and class salad bowl. To the extent that folkways and mores vary from community to community, Child Maltreatment Prevention Programs should also vary. In other words programs should be structured in such a way that they match the patterns of behaviors that make up the structure of each community they are expected to serve. In addition to being culturally orientated, programs must be destigmatizing and sensitizing. Families should be made to realize that parenting children requires appropriate skills in interpersonal communications. If they lack these skills they must not be made to feel like criminals. Inadequate parents can be trained appropriate parenting skills in non-stigmatizing community learning clusters.

It has been my experience that these parenting classes are more effective if trainers are themselves parents. Parent Leadership Institutes conducted by New York City's Special Services for Children has trained more than 200 parents. Many of these parents, after realizing some insight into their own lack of parenting skills, have established peer counselling groups in their own churches and day care centers. Presently churches, day care centers and schools in the Queens area are requesting that Special Services for Children facilitate parenting classes for their parishioners and parents.

I agree with the experts on Child Abuse and Neglect that 90% of parents who abuse their children suffer from no serious psychiatric malady. Therefore, program designers of child maltreatment prevention programs must take this often overlooked fact under primary considerations when developing programs to stem the tide of child maltreatment. Despite the fact that child abuse and neglect crosses all community boundries and prevails throughout american society it is mainly the poor and minority children that end up in the child welfare sys[illegible]. Support programs must be institionalized from the public system. For it is the public child welfare that our minority and poor citi[illegible] must depend on in times of crisis. Public child welfare system m[illegible] p a partnership with the minority and poor community. Visi[illegible] dictate that this must happen if the minority and the poor are adequately served within the present structure. Progress must be made in the area of permanency and child maltreatment prevention for minority children. Presently, most public child welfare agencies do not have adequate outreach components. Concepts of community outreach vary from locality to locality. My experience has taught me that very few agencies ever make any serious efforts to involve the minority and poor communities when planning child maltreatment prevention. Presently, planning takes place with no impact from the very people who must use child welfare services. Very few public agencies on the Federal, State, Municipal or County level make funds available to local community organizations. In other words, agencies continue to talk to agencies while never talking to the community. This lack of minority community involvement on the part of the child welfare system has hurt its image in the minority communities throughout the United States. This lack of minority community involvement on the part of the child welfare system has caused many minority community leaders to view their local child welfare centers as "child snatchers". This image must be changed if a partnership is to be developed. This non involvement is one reason why minority children are inappropriately represented in the child welfare systems. Until adequate heterogeneous programs are actualized and made accessible to every community, the plight of our children will continue to be a national disgrace. For your information I have included copies of articles on successful child maltreatment programs that I have been involved with.

I thank you.

Respectfully yours,

Theartice Gentry, PH.D.

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Office for the Study of the Psychological Rights of the Child

April 15, 1983

David Jensen
Professional Staff Member
Sub-Committee on Family and Human Services
of Committee on Labor and Human Resources
Senator Dirksen Office Building
Rm. 428
Washington, DC 20510

Dear Mr. Jensen:

Thank you for the invitation to provide written testimony regarding the "mental injury" category of the Child Abuse and Prevention Act (42 U.S.C. 5101) which is presently under review. As Director of the Office for the Study of the Psychological Rights of the Child, I consider this to be a matter of substantial importance.

Mental injury, which I understand to subsume psychological or emotional abuse and neglect, is a problem of major proportions which we are just beginning to understand. Experts in the field of child abuse and neglect readily acknowledge that mental injury, which almost always accompanies physical abuse and neglect, is more prevalent than physical abuse and neglect and often more destructive in its impact on the lives of young people. Even though our knowledge lacks depth and consensus, research has identified a long list of negative conditions as possible consequences of mental injury. These conditions range from poor appetite, lying, cheating, and drug abuse; through low self-esteem, underachievement, and incompetence; on to severe anxiety, failure-to-thrive syndrome, serious emotional disturbance, and acts of violence directed at self and/or others. The major antecedents of suicide among the young, the third to second ranked killer of adolescents, are all forms of mental injury.

Neither psychology nor the law have adequately defined mental injury (i.e. psychological and emotional abuse and neglect), determined its forms, causes long term effects, or effective preventive and corrective procedures. The lack of understanding of these issues is the reason mental injury receives so little attention in comparison to physical abuse with its more visible and tangible forms. The states of this nation are finding it very difficult to identify, let alone correct, instances of mental injury. A review of state laws in regard to mental injury finds specificity within meaningful comprehensiveness to be generally lacking. The majority of states provide only mention of mental injury or a very general, ambiguous definition of the term. The present laws which go beyond this level tend to fall within one of three categories by dealing with incapacities of the parents for parenting, destructive parenting practices, or evidence of substantially diminished psychological (including intellectual) functioning on the part of the child as a result of abuse or neglect. While some of these laws may be considered superior to others, none adequately deals with the issues. In addition, cases successfully prosecuted appear to have been few in number and generally focused on the parents' inability to care for a child's physical and emotional needs due to mental illness or chronic alcoholism. While more subtle forms of psychological neglect and active forms of psychological abuse may have equally devastating effects on the developing child, such cases may go unnoticed due to the vagueness of reporting laws, or, if adjudicated, they are left to the discretionary wisdom of the court to interpret a non-specific statute.

The lack of clarity and action regarding mental injury certainly justifies focusing on this topic during the present review process. Much needs to be done. Progress will be made, in my opinion, by maintaining the category in the law; by expanding efforts to share information regarding the most constructive practices now in effect; and by developing and supporting efforts to further clarify the meanings, causes, and effects of mental injury. While the present law provides insufficient clarity and direction, its very existence acknowledges the seriousness of the issue; reinforces the more progressive legislative and service achievements; and contributes to a sense of work undone, hopefully an uneasiness that will stimulate further effort in this area. It would probably be wisest to leave the statement of national law in its present form at this time and to provide encouragement for the identification and application of best practices and the pursuit of further clarification which would eventually support constructive substantive improvements in the law. The National Center on Child Abuse and Neglect is certainly a logical vehicle for channeling such support. You may also be interested in knowing that the International Conference on Psychological Abuse of Children and Youth, to be held at Indiana University-Purdue University at Indianapolis, August 8-11, is intended to clarify, consolidate and expand the state of knowledge base in this area. This conference will bring together representatives of all the major helping profession and advocacy groups concerned with mental injury. It will produce recommendations for legislation, research, prevention and correction. As Project Director for the conference, I can assure you that its products will be made readily available to you and other interested parties.

However, if changes are to be made at this time to the present law in regard to the mental injury category, the following suggestions are made for consideration. First, "mental injury" should be changed to "psychological abuse and neglect," a phrase which more accurately labels the area of concern (presently incorporated in Hawaii's statute). Second, it would be helpful to recognize in the law and guidelines for its application that sufficient differences exist in levels of seriousness of mental injury, or psychological abuse and neglect, to require that different strategies be applied to dealing with them. This might mean that a first level of greater seriousness would be reserved for legal action to protect and prosecute; while a second level of lesser seriousness would be dealt with through counseling and consultation services to be provided to those specifically involved by a community resource team (omsbudsman included) to clarify, educate, and train for improvement. The level of seriousness might be judged by the degree of immediacy to which the child's healthy development is in jeopardy (for protection considerations) and the degree to which cause and effect relationships are known to exist (for prosecution purposes).

With the expectation that some types of mental injury would fall in more than one category, it is probable that some agreement could be reached by informed and reasonable people regarding the "level of seriousness" category for assignment. For example, category one (greater seriousness) might include instances of refusal by caretakers to provide needed psychological treatment for an emotionally handicapped child, denial of essential affection and stimulation in infancy, or parental encouragement and permission to engage in illegal or sexual offenses. Category two (lesser seriousness) might include instances of repeated public humiliation, severe marital discord creating a strongly negative emotional climate in the home, or demands for perfectionism.

If such a two-level approach to conceptualizing and dealing with mental injury were pursued, it would also be worthwhile to give consideration to a third category, supported by expert consensus, dealing with requirements for healthy psychological development. These prescriptions for psychological health could be incorporated in awareness, educating and training processes through community agencies (e.g. schools, churches, welfare agencies, daycare centers) and public media to decrease the likelihood of mental injury while supporting healthy psychological development. Psychological needs focusing on love and affection, development of competency, self-esteem and responsible group membership would be examples for inclusion here.

While constructive results might accrue from applying these recommendations now, it would, again, seem prudent to await the results of projects such as the conference cited previously so that the resources devoted to this area might have greater efficiency in application and greater impact. A good deal of work remains to be done to ensure that responsible handling of mental injury [illegible] occurs. Consideration must be given to the basic psychological needs or rights of human beings which, when denied, result in abuse. Experts and organizations tend to agree that children need affection, love, understanding, freedom from degradation, education, encouragement to develop abilities and talents, and responsible group membership. Consideration must also be given to the present level of research evidence regarding psychological abuse and neglect. For example, the failure-to-thrive syndrome has been strongly documented as resulting from affectional and stimulation deprivation, while the relationships between particular psychological conditions and marital disorder are just now being meaningfully explored.

In addition, it is essential that two very sensitive issues be clarified: the mental injury category's implications for family integrity and punitive versus ameliorative strategies. Concern about mental injury must not be communicated as a general condemnation of family living and parents, or as a threat to the integrity of families. Adults, as parents and non-parents, abuse and neglect young people, as do siblings and peers. Abuse and neglect occur in homes, schools, institutions and a wide variety of community settings. All forms of mental injury occuring in all settings and under all relationships deserve consideration. Experts in psychology, psychiatry, and social work recognize that the family is the central support base for stimulating and influencing psychological development in our culture. It is the only structure generally capable of meeting the fundamental psychological needs for safety, love and belonging, and being valued by others early in life. We must do all we can to enhance the integrity of family living. We have no proven substitute for it. Finally, it is important that it be recognized that punitive legal action, while it may be necessary in some cases, will be far less effective in dealing with the existing breadth and depth of mental injury than corrective and preventive procedures that train, educate and encourage people to apply practices promoting healthy psychological development.

The Office for the Study of the Psychological Rights of the Child and the planning committee for the International Conference on Psychological Abuse of Children and Youth will be pleased to provide further information and assistance in your efforts to protect and improve the psychological health of young people.

Sincerely,

Stuart N. Hart

Stuart N. Hart, Ph.D.
Project Director

SNH/ba

Camp Fire, Inc.
Washington Office
1725 K Street, N W , Suite 1211, Washington, D C 20006 / (202) 659-0565
GROWING WITH YOUNG PEOPLE FOR 72 YEARS

April 26, 1983

The Honorable Jeremiah Denton
Chairman
Family and Human Services Subcommittee
A 624 Immigration Building
Washington, DC 20510

Dear Senator Denton:

Thank you for giving Camp Fire the opportunity to testify before your subcommittee on child abuse.

The following is the response you requested to Senator Dodd's questions:

1) How many do you estimate may be in danger of sexual assault?

According to the latest figures from the American Humane Association, 7 percent of reported child abuse cases involve sexual maltreatment. If the number of children at risk of child abuse today is three million, at least 210,000 of those children are potential victims of sexual abuse.

For female children in particular age groups, the risk of sexual abuse is much higher. Among female children 9 to 11 years old, 20 percent of reported child abuse cases involve sexual mistreatment. For female children 12 to 17 years old, more than 15 percent of reported cases involve sexual abuse.

2) How important is it to authorize separate funds for the treatment and prevention of sexual abuse?

Camp Fire believes that sexual abuse is a complex and troubling problem for society. The mere public discussion of the problem causes people to feel uncomfortable. As I stated in testimony, we are engaged in sexual abuse education problems, basically without Federal assistance. If a set aside of funds for sexual abuse and prevention were provided in the authorization, it would accomplish several things.

First, it would target resources in a way that we could see an impact from scarce Federal funds.

Second, it would allow the National Resource Center to develop the adequate expertise to respond to requests for local assistance.

AN EQUAL OPPORTUNITY EMPLOYER

And third, a federal set-aside would raise public consciousness and sanction public discussion of the problem.

I hope this answers the questions completely. If Camp Fire can be of assistance to the subcommittee on anything else, please do not hesitate to ask.

Sincerely,

Arnold E. Sherman
Arnold E. Sherman
National Executive Director

AES:nh
cc: Senator Christopher Dodd

The Children's Hospital Medical Center

300 Longwood Avenue, Boston, Massachusetts 02115, Telephone (617) 735-6000

May 4, 1983

The Honorable Jeremiah Denton
United States Senator
Committee on Labor and Human Resources
Washington, D.C. 20510

Dear Senator Denton:

Many thanks for your letter of April 19. I very much enjoyed my testimony before your committee, and I am sorry that you were ill that day. You carried forth manfully while you were there, and I was pleased indeed to see the interest in the problem of child abuse which you so obviously demonstrated.

In this letter, I respond to the questions given to me in writing subsequent to the testimony. The questions, and my responses, follow:

1) Dr. Newberger, the question always arises about the proportion of money devoted to research and that devoted to services. Do we have enough research data and should more be spent on services?

RESPONSE: There is not nearly enough research data on child abuse. My colleagues Carolyn Moore Newberger, Ed.D., and Robert Hampton, Ph.D. have recently reviewed our knowledge and research needs in an article scheduled to appear in the Journal of the American Academy of Child Psychiatry, entitled, "Child Abuse: Current Theory and Future Research Needs." A copy of the corrected galley proof is enclosed. We conclude that much, if not most, of the research on child abuse is methodologically flawed, and that more research is needed specifically in the following areas:

a) Incidence estimates continue to be confused by a lack of precision in the definitions used in research, policy, law, and practice. Studies of maltreated adolescents suggest different causes and consequences from cases involving younger children.

b) Identification of risk for maltreatment remains statistically unreliable, thus frustrating attempts at early intervention.

c) Treatment of child abuse is inadequate, and successful treatment is imperfectly understood. Conventional social work approaches are associated with high rates of re-injury, but low recidivism is reported with innovative and resourceful programs with selected clinical populations.

d) Nearly all treatment efforts focus on parents. Not only are the developmental and health needs of children ignored, but the children may be harmed by interventions which place them in foster home or institutional care settings. Focus on the childhood antecedents, precipitants, and concomitants in research and practice is limited. Poorly differentiated clinical approaches neglect the unique needs of adolescents.

e) Preventive initiatives are largely unexplored, notwithstanding, for example, the suggested potency and cost-effectiveness of facilitating the formation of bonds of parent-child attachment at birth.

f) The medium-and long-term consequences of physical and sexual abuse are poorly understood, although experts concur on the increased vulnerability for severe problems in school, in behavior in the community, and in later family life. Few longitudinal studies have begun, and these are likely soon to end, because of severe constraints on research funding.

2) Dr. Newberger, do you have statistics on the incidence of child abuse perpetrated against children of unmarried or divorced women by boyfriends or live-in mates?

RESPONSE: It appears that we are seeing increasing numbers of cases of this nature, involving both physical and sexual abuse. In the past year, for example, a young teenage girl was raped by her mother's friend after he was asked by her mother to leave their home. In another case, a man suffering both from alcoholism and the Vietnam post-traumatic stress syndrome repeatedly beat a three year old child with whom he felt in competition for his mother's attention and affection. Under my supervision, medical students reviewed, the case data over a hospital year. Briefly to summarize our findings, there appeared to be a sharp increase from our and others' previous experience in the number of cases in which boyfriends were involved. There appeared to be the greater number of more severe incidents where they had been in the home less long, and presumably they did not have a deep and abiding emotional tie to the child; this was not always the case, however. Most of the physical abuse cases were quite young; by contrast, the sexual abuse cases were principally of teenagers. I should add, however, that in many of the cases, the boyfriends appeared to be an important source of support to the mothers, and our clinical concern was focused on sustaining the support of emotional ties while preventing future violence. Obviously this cannot be done in most cases of sexual abuse, and it is very difficult in many cases of child abuse where the mother is asked, to quote the boyfriend in the case involving the three year old child above, to "choose him or me."

I am pleased also to respond to the questions from Senator Dodd:

1) What can be done to prevent child abuse as opposed to treating it? What more should we be doing?

RESPONSE: My colleague, Carolyn Moore Newberger, Ed.D., and I have recently completed a review of what can be done to prevent child abuse. As I indicated in my testimony, we must rely ever less on reporting and more on prevention if we are going to use available resources efficiently to deal with child abuse. A copy of a reprint of this paper, "Prevention of Child Abuse: Theory, Myth, Practice," which has just appeared in the Journal of Preventive Psychiatry, is enclosed. Briefly summarized, our recommendations are these:

From Psychoanalytic Theory

a) Acknowledge the importance of mental health to the functioning and well-being of children and families by formalizing a conception of health that includes emotional as well as biological health. This can be achieved through the training of physicians and others to recognize and attend to emotional as well as physiological issues in practice, and by providing third party reimbursement for performing as the patient's advisor, counselor, and health advocate.

From Learning Theory

b) Give parents access to information and understanding of child development, including nonviolent methods of socializing their children.

From Attachment Theory

c) Elevate the parent-child relationship to an appropriate position of respect and importance in clinical practice, through facilitating the formation of bonds of attachment at birth, by preventing prematurity through prenatal care, humanizing the delivery experience, bringing fathers into the delivery room and emphasizing their supportive role toward mothers and their participation in child care, and by encouragement of paternity as well as maternity leaves from employment.

From Stress Theory

d) Provide quick telephone access to parents at times of distress with their children through hotlines.

e) Make available to all children health and mental health well child care, diagnosis, and treatment. Children who are sick or handicapped may be more vulnerable to abuse.

f) Make available emergency homemaker and/or child care services to families in crisis.

g) Reduce social isolation by making universally available such avenues of access to other people as telephones and public transportation.

h) Support existing community institutions such as churches and women's organizations that offer support and a sense of community and of personal value to their membership.

i) Empower women. Acknowledge the extent to which sexual dominance and subservience ramifies both in the abuse of women and children and in professional settings where male-dominated, symptom-oriented professions (medicine, surgery, law) hold sway over professions composed mainly of women (social work, nursing, child care).

From Labeling Theory

7) Remove the stigma from getting help with family problems by detaching protective service programs from public welfare agencies. Abandon the heavily value-laden nomenclature of "the battered child syndrome," "child abuse," and "child neglect" in favor of a broader and more humane conception of childhood social illness. Increase the sensitivity, timeliness, and competency of medical and social work practice.

8) Expand public awareness of the great prevalence of child abuse and domestic violence, and disassemble the conventional wisdoms attaching child abuse to deviant and minority individuals and groups, placing emphasis on the reality that the potential for violence is in all of us, and priority on individual and social action to intervene when violence occurs.

2) How has the "Coordinated Discretionary Research Fund" affected research on the prevention and treatment of child abuse? What would your research recommendation be?

RESPONSE: I believe that there must be a separately allocated and administered research and demonstration program, as mandated in the statute. By including the child abuse prevention and treatment research monies in the general pool in office of the Assistant Secretary for Human Development Services, the Department of Health and Human Services has successfully vitiated the research program of the National Center on Child Abuse and Neglect. There is sharply less money available for child abuse research, and no longer are full and complete proposals in areas of highest concern being solicited from researchers in the field. This, in my view, is a tragedy in light of the great needs for knowledge and the huge amounts of money which are committed for services, most of which are not evaluated, and many of which could be improved by knowledge gained from a coherent research and demonstration program. Additionally, a whole new research priority needs to be articulated and, in my view, to be guided by useful clinical research.

My recommendation would be to define with clarity a separate research mandate for the National Center on Child Abuse and Neglect and, further, to stipulate in the revised statute a coordination of these research activities with those of the National Institute of Mental Health and the National Institute for Child Health and Human Development. Unfortunately, these three important agencies have not successfully been able to collaborate in support of the research agenda for child abuse.

This, in my view, is not for any want of doing so by the staff of the National Center on Child Abuse and Neglect. It has rather to do with the extent to which they have been submerged in the DHHS bureaucracy and lack of priority given to an effective research program on child abuse by the past and present administrations. It can easily be changed, as I know that there are excellent points of expertise in both NICHD (Dr. Peter Vietze, Director of the Center for Research on Mothers and Children) and at NIMH (Dr. Saleem Shah, Director, Center for Studies of Crime and Delinquency).

With kind regards,

Sincerely,

Eli H. Newberger, M.D.
Director, Family Development Study

EHN:das

United States Senate

COMMITTEE ON LABOR AND
HUMAN RESOURCES

WASHINGTON, D.C. 20510

April 14, 1983

Dr. Harriette McAdoo
Professor of Social Research
School of Social Work
Howard University
Washington, D. C. - 20059

Dear Dr. McAdoo:

Thank you very much for your informative testimony before the Subcommittee on Family and Human Services on March 24 on the topic of "The Broken Family: Effects on Women and Men." Your statement will be most useful to the Subcommittee as it continues its study of the causes, effects, and possible remedies to the family breakdown crisis.

I would appreciate it if you could provide answers to the following questions for inclusion in the written record. The record will be held open for ten days so that you may prepare your answers.

1. On the last page of your statement your recommend that government adopt policies that reinforce rather than disrupt existing supportive networks of the families and community institutions that have been helpful to women. Can you give me some specific recommendations as to what you have in mind?

2. During the March 22 hearing on the effects of family breakdown on children, we heard some sobering testimony of the effects of divorce or father absence on children, particularly psychological effects. Testimony indicated that the effects range from rage over desertion to low motivation and low self-esteem, apathy, and an inability to defer immediate gratification. In addition, boys without fathers at home experience a greater liklihood of sexual identity problems in later life. Girls who lose their fathers by divorce are more likely to become sexually involved in adolescence than are other girls. Yet you say on page five of your written statement that "economic security is more important for effective parenting than the actual presence or absence of any one parent," suggesting that financial status is more important to the character and psychological development of a child than a relationship with two parents. Could you elaborate on that?

3. Let me ask you to comment on a quotation from Sexual Suicide by George Gilder:

> Doubly corrosive is money that goes to women under conditions that deter marriage. Our welfare program -- particularly Aid to Families with Dependent Children (AFDC) is tragic because as currently designed, it promotes social disintegration.

Do you have any suggestions on how we might better distribute our welfare benefits to those who need them most, while not making receipt of benefits contingent upon the father being absent?

My colleagues and I appreciate your time and effort to give the Subcommittee the benefit of your views on this vital issue.

With kindest regards,

JEREMIAH DENTON
United States Senator

JAD:na

Enclosures

COPY

(NOTE: The Committee had not received any response to the questions referred to by the time the hearing record went to press.)

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United States Senate
COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, D.C. 20510

April 14, 1983

Ms. Connie Mallett
President
Parents Without Partners
International Office
7910 Woodmont Avenue
Bethesda, Maryland 20814

Dear Ms. Mallett:

Thank you very much for your informative testimony before the Subcommittee on Family and Human Services on March 24 on the topic of "The Broken Family: Effects on Women and Men." Your statement will be most useful to the Subcommittee as it continues its study of the causes, effects, and possible remedies to the family breakdown crisis.

I would appreciate it if you could provide answers to the following questions for inclusion in the written record. The record will be held open for ten days so that you may prepare your answers.

1. Among those members of Parents Without Partners who chose to be divorced, do you find many feelings of regret, many feeling that they perhaps did not realize before divorce how serious the consequences for them would be?

2. Do you have any suggestions for how we might improve the collection of child support payments?

3. What would you identify as the leading cause of the extraordinary divorce rate that our society is experiencing today? What has happened in our society in the past decades to make this problem so serious, with women bearing the brunt of the effects of family disintegration?

My colleagues and I appreciate your time and effort to give the Subcommittee the benefit of your views on this vital issue.

With kindest regards,

JEREMIAH DENTON
United States Senator

COPY

JAD:na

Enclosures

(NOTE: The Committee had not received any response to the questions above by the time the hearing record went to press.)

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April 20, 1983

Honorable Jeremiah Denton
Chairman, Subcommittee on Family
and Human Services
Committee on Labor and Human Resources
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

Thank you for the opportunity to submit our comments to you in connection with the April 11, 1983 hearings before your Subcommittee concerning reauthorization of the "Child Abuse Prevention and Treatment Act." We submit this letter for the record of those hearings.

The American Bar Association supports the reauthorization of the Act and believes in the need for the federal government's continued involvement in the prevention and treatment of child abuse and neglect.

In 1980 the Association adopted a policy urging "the Congress of the United States to support extension" of the Act. Since that time, the Association's concern for the maintenance of a highly visible and productive federal role in this field has become greater than ever. The recent tragic increases in serious physical abuse and related child fatalities, the widespread cutbacks in state and county child protective service agency staffs, the growing awareness of previously understated forms of child abuse, such as sexual exploitation, and a host of other factors have convinced the Association that research and demonstration programs must continue at an accelerated pace to address these problem areas. Because these problems are nationwide in scope, it is incumbent upon the federal government to provide leadership in seeking solutions. While individual states must continue to respond to the problem, federal direction and oversight is necessary to help minimize duplicative research and demonstration projects and assure that child abuse funds are appropriately targeted and prudently invested.

The ABA is aware that legislation reauthorizing the Child Abuse Prevention and Treatment Act is likely to contain provisions placing new technical assistance responsibilities on the National Center on Child Abuse and Neglect and new investigative responsibilities on state and county child protective agencies regarding cases of newborn handicapped children denied medical or nutritional care. Based on four years of work with child protective service agencies, we believe these agencies will need considerable technical assistance and financial support to effectively implement such new responsibilities. We therefore urge you to increase the authorization level of the Act to assure that these significant new duties do not interfere with the child protective system's already overwhelming obligations to help maltreated children.

As additional evidence of the need for increased funding for the Act, we hope that you will consider the fact that, at present, seven states do not qualify for state funding under the Act. If in the next year they do become eligible, as the Administration hopes, this will reduce the already meager share of funding each participating state is allocated. We therefore also urge you to substantially raise the Act's funding level so that the states will be better able to deal with these problems through their child abuse block grant funds.

Should your Subcommittee desire additional information about the Association's position and work in the area of child abuse and neglect, please feel free to call upon Howard Davidson, Director of the Association's National Legal Resource Center for Child Advocacy and Protection, a program of our Young Lawyers Division, at 331-2250. We thank you and the members of the Subcommittee for your leadership in this area

Sincerely,

Robert D Evans

Robert D. Evans

RDE:tam
cc: Members of the Committee on
Labor and Human Resources

RESPONSES OF MR. CLARENCE E. HODGES, COMMISSIONER FOR CHILDREN, YOUTH AND FAMILIES, TO QUESTIONS SUBMITTED BY SENATOR DODD

1. Question: A 50-State phone survey conducted this past January by the National Committee for Prevention of Child Abuse revealed a big jump in reported instances of child abuse, specifically of severe and fatal cases. The number of deaths from 1981 to 1982, for example, rose by some 44%.

(a) In your testimony, you assert that "nothing challeges us more for the future strength of our nation's families" than the prevention of child abuse and neglect.

(b) Given the skyrocketing of child abuse deaths and your stated commitment to preventing such deaths, how can you request only level funding for this program?

Answer: The Child Abuse and Neglect State grant program, for which we are asking level funding in fiscal year 1984, is not the only program directed toward strengthening States' capacities to deal with child abuse and neglect. The principal sources of support for direct services from the Federal government are in the Social Services Block Grant program and Title IV-B of the Social Security Act, which support direct child protective services. In addition, programs such as Head Start and the Runaway Youth program can provide services which serve a preventive function. In keeping with the President's policy of fiscal restraint in Federal programs, we will use the current level of funding for the Child Abuse and Neglect State grant program as leverage in focusing resources from other Federal, State and private sources on meeting the problems of child maltreatment.

In addition, we would note that the great increase in reporting is one indicator of the success of Federal, State and local efforts to increase attention to this national problem.

2. Question: Given recent disturbing evidence of a correlation between child abuse and parental unemployment, what is the Office for Human Development Services doing to look into this problem?

(a) Have you formulated any specific initiatives to prevent and treat child abuse arising from unemployment?

(b) Have you awarded any grants to examine this problem and possible remedies.

Answer: The National Center on Child Abuse and Neglect is engaged in an in-house analysis of correlations between levels of unemployment and child abuse reports. On a national basis, correlations are not clear between these two sets of statistics; on a county-by-county basis, correlations are inconsistent. We believe that other indices of economic stress, such as levels of employment and instances of large-scale lay-offs within communities, may in fact be more closely linked to child maltreatment than unemployment statistics. We are continuing to monitor information pertinent to this relationship.

Meanwhile, many of the prevention programs formulated, supported and disseminated for replication by the National Center on Child Abuse and Neglect are relevant to helping families manage increased stress whatever the cause. These include information and referral to community-based family services, telephone stress counseling services, Parents Anonymous chapters and other forms of parent peer support groups and parent aide programs. The fact that the sources of stress may be economic does not change the techniques provided by such programs for coping with it in families at risk of child abuse and neglect.

We have a continuing grant relationship with the American Human Association to provide assistance to the States in collecting, analyzing and using statistical data on reports of child abuse and neglect. This grant project has taken on a related task of analyzing these data in light of changing economic conditions in the States.

3. Question: You mentioned that you support the language of S. 1003 focusing special attention on protecting severely handicapped infants. You further state that you can increase the efforts of Health and Human Services to work with the States on this specific problem without any additional funding.

(a) How do you plan to do so without cutting back other HHS projects designed to prevent or treat child abuse?

Answer: An analysis of State child abuse and neglect reporting laws leads us to the conclusion that the necessary legislative frameworks are in place within all States to deal with protection for severely handicapped infants within currently existing child protective service systems. We believe that we can, for very little expenditure of program funds, develop appropriate suggested procedures for consideration and adoption by the States, which will clarify roles and responsibilities specifically related to protection of severely handicapped infants. Such a process should involve input from medical, child protection and legal experts, resulting in a set of recommended procedures which can be supported by State child protective service agencies, the medical field and the judiciary. This process will not require expenditure of funds for research or demonstration activities. Thus, it will not result in reductions in our other efforts.

4. Question: How will recent proposals to reclassify and/or reorganize certain employees in the Office of Human Development Services affect the administration of the Child Abuse Prevention and Treatment and Adoption Opportunities Act?

Answer: We do not expect that either reclassification actions nor any of the reorganization proposals under consideration will adversely affect our ability to administer these two important programs effectively.

5. Question: How has the coordinated discretionary funds program improved the integration of targeted child abuse treatment and prevention services with other social services? Will you provide me with a listing of all grants made for FY 1981, FY 1982 and FY 1983 for work on child abuse?

Answer: Discretionary funds appropriated through the authority of the Child Abuse Prevention and Treatment Act, as amended, have continued to be managed as a separate priority within the coordinated discretionary funds program, in keeping with the Act's provision that all such discretionary activities shall be carried out through the National Center on Child Abuse and Neglect. In fiscal year 1983, NCCAN funding availability was included in the coordinated joint program announcement published in the Federal Register on December 7, 1982. Because NCCAN funds have not been made available for extensive joint funding activities, however, we only have a few examples of actual integration of targeted child abuse treatment and prevention services with other social services through this process, and those examples are programs managed by the National Center. They relate specifically to protection for developmentally disabled children residing in residential institutions. While findings from these projects are not yet available, having been funded only in September 1982, we can state that the pooling of program funds and program expertise to address issues of common importance to more than one of the populations served by the Office for Human Development Services holds promise of providing useful program models for the field of human services.

We are attaching a listing of grants awarded in fiscal years 1981 and 1982. With the exception of the 1983 award to Parents Anonymous, executed in February, other awards for continuation and new projects are currently under review and are scheduled to occur in June, July and September.

6. Question: You refer to data showing that many neglected and abused children are not known to local child protective services but are known to educational, medical and mental health professionals.

(a) What is the source of your data?

(b) How do you plan to help make such children known to local child protective agencies?

Answer: The source of this information is the Findings of the National Study of the Incidence and Severity of Child Abuse and Neglect, conducted by the National Center in 1979 and 1980. Concurrent with that study and subsequently, we have broadly disseminated profession-specific publications, training materials and other information aimed at helping such professionals to recognize child maltreatment and to know their mandated duties to report known and suspected cases to child protective service agencies. In addition, we have awarded grants to health and medical agencies, mental health agencies and law enforcement agencies for different services related to child protection and child abuse and neglect prevention and treatment. As a part of each such grant, we have required certification of coordination between the grantee and the local protective services agency. In Fiscal Year 1983, we intend to use discretionary funds to address linkages between child protective services and public schools to ensure better reporting and mutual support between these two community agencies.

7. Question: What efforts have been made to update the first national incidence study in light of the recent skyrocketing of reports of abuse?

Answer: While we have not undertaken an update of the national incidence study, we are working out ways of using reporting statistics, which we do collect annually, as a basis for projecting trends in actual incidence and severity. The development of such plans will form the basis for an ongoing study of incidence and severity.

8. Question: What specific new private initiatives are you planning with respect to prevention of child abuse?

Answer: An initiative which will begin in fiscal year 1983 is demonstration of programs to support families in and through the workplace. We expect to award several demonstration grants to human service agencies which can provide matching funds from private corporate sources to use already tested prevention approaches, such as parent aide, parent education and parent peer support programs, in the context of parents' places of employment. A second 1983 initiative is the Sixth National Conference on Child Abuse and Neglect, scheduled for September 25-28, 1983, in Baltimore, Maryland. Rather than sponsoring this conference as a unilateral Federally organized event, the National Center has enlisted the cosponsorship of 16 national professional and voluntary organizations. These private organizations have discrete program planning responsibilities for the conference and will be a part of its platform leadership. We believe that the opportunity that this conference affords for increased professional awareness and the exchange of program ideas enhances the field of prevention of child abuse in general. Finally, we are now engaged in a process begun in December 1982, to enlist private professional and voluntary organizations to work with the National Center in dissemination of prevention program models focused on support to parents of newborns, especially those suffering illness or congenital impairments. This effort is a follow-up to a demonstration program involving eight projects focusing on prevention support at the perinated stage funded by the National Center in fiscal year 1981.

PARENTS ANONYMOUS OF ALABAMA, INC.

Post Office Box 2638 Anniston, Alabama 36202 (205) ~~[illegible]~~ 237-6097

April 26,1983

Senator Christopher J.Dodd
U.S.Senate
Washington, D.C. 20510

Dear Senator Dodd.

Thank you for sending me the questions about the importance of federal seed money for child abuse programs and funding for specific projects for sexual abuse. These areas are of great concern to me, representing as I do not only the state of Alabama, but also th more local area of Calhoun County.

In answer to your question on how important federal seed money is, let me say it is very important indeed. It is probably a matter of life or death for some of the smaller agencies.

I have found after working in Parents Anonymous for four and one-half years that even though you do get private contributions, and almost everything is done by Volunteers, there comes a time when only stable funding will help with some project or problem.

In our local work in Calhoun County we have over 200 volunteers. I counted over 20,000 volunteer hours from our support group in 1982.

This includes volunteers on our 24-hour phone line, eight to ten people each week in child care; seven professional people serving as counselors; 24 board members; then the people who provide transportation; the teams of puppeteers; the 15 member publicity group; the people who teach our parenting classes; the office volunteers; the list is endless.

All of the people are working, but we still cannot manage without paying for the phone, publicity materials and printing, postage, all of the supplies that keep an organization going.

On the state level we have been laying the groundwork for new Parents Anonymous chapters since October of 1981, and last year we were able to start three new chapters with our volunteers. But it is only since we received a grant from the Alabama State Department of Pensions and Security in December of 1982 (which came through N C C A N) that we are really getting off the ground.

With this money, $32,500, we were able to hire a state director and set up a small state office. Now we are getting calls from all over the state for help in starting chapters.

Our new director has already been to Mobile, Jasper, Montgomery, Piedmont, Birmingham and this week will be in Dothan, Ozark and Enterprise.

We have calls in now from five other counties which she will visit soon.

You'll be interested to know that Kappa Delta Soroity has raised money for a WATS line for our office and has had it installed and will fund it for a year. (The seed money has sprouted here!)

Again, let me say, federal seed money is <u>very important</u>.

To your second question as to whether more federal seed money should be directed to fund projects specifically focused on sexual abuse: I feel very strongly that you should direct more seed money towards sexual abuse projects.

One of our top priorities should be a National Public Awareness and Education campaign about sexual abuse.

The National Committee for the Prevention of Child Abuse said: " People won't do anything about a problem until they know it exists. With more education and treatment programs, more individuals would seek help for themselves.

"The greatest obstacle to preventing and treating sexual abuse is (Society)."

As you know, I live in the "Conservative" South, but even here we are bringing sexual abuse out of the closet.

Last fall our child abuse seminar at Jacksonville State University, which we sponsor with the Medical Agencies in the community, dealt altogether with the various aspects of sexual abuse and incest. Then with our parenting classes and the puppet show "There's Someone TO Talk To," we feel we are making progress.

People here are beginning to recognize and talk about the problem.

Senator Dodd, I would urge your committee to vote funds for specific projects focused on sexual abuse and incest, and especially in the area of treatment.

Again, thank you for your questions, your interest, and your work in this field.

Sincerely yours,
Thelma Bigger
Thelma Bigger

Senator DENTON. Well, I want to thank you all for your testimony here today. It will be useful as we pursue our consideration of child abuse, the causes and prevention. And I do not think I have ever seen such a kind looking audience, the people attracted to such a hearing. You must be very compassionate, and it shows in your faces. I am sorry I was not more my usual, vital self today, but I have fever of 102 and the flu.

Thank you again. This hearing stands adjourned.

[Whereupon, at 4:55 p.m., the subcommittee was adjourned.]

CHILD ABUSE PREVENTION AND TREATMENT AND ADOPTION REFORM ACT AMENDMENTS OF 1983

THURSDAY, APRIL 14, 1983

U.S. SENATE,
SUBCOMMITTEE ON FAMILY AND HUMAN SERVICES,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10:15 a.m., in room SD-628, Dirksen Senate Office Building, Senator Jeremiah Denton (chairman of the subcommittee) presiding.

Present: Senator Denton.

OPENING STATEMENT OF SENATOR DENTON

Senator DENTON. Good morning. This hearing will come to order.

This is the third and final hearing on the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act. At previous hearings, we examined the child abuse sections of the act. Today, we will focus on the Federal programs that facilitate the permanent, adoptive placement of hard-to-place youngsters.

One week ago, Senator Hatch and I introduced S. 1003, a bill to reauthorize the Child Abuse Prevention and Treatment and Adoption Reform Act for 3 years. In our first hearing of this series, we examined the controversial treatment of some children born with life-threatening congenital impairments. S. 1003 contains several amendments that include such children in the programs that promote and enhance the adoption opportunities of special needs children. The bill also contains in the findings section a statement that the welfare of such children may be in jeopardy and that some such children may be in need of adoptive homes. The bill states that these children should not become the victims of denial of treatment or nutrition. Although the child abuse amendments address this issue more directly, these amendments to the Adoption Opportunities Act are a small step toward insuring that the infamous *Baby Doe* case will not be repeated. As you may know, several persons wanted to adopt *Baby Doe* before he was allowed to perish in a hospital. S. 1003 will encourage adoption opportunities for both the children and the potential adoptive parents. In addition, the bill requires the Secretary of Health and Human Services to review the model State adoption legislation developed under this act, and to make any appropriate changes to facilitate the adoption of children born with life-threatening congenital impairments.

In an effort to enhance private initiatives in the adoption field, the bill encourages private businesses to establish adoption benefit programs for their employees. We have received written testimony on this subject and will include it in the record. It is worth noting at this point, however, that although there are many couples and single parents who would like to adopt a child, the costs are often prohibitive. It seems that there are ways to contain the costs of adoption and the alternatives need to be explored. This is a serious responsibility to be borne by everyone involved in the adoption industry, including the placement agencies.

Finally, the bill would require the Secretary to continue to study unlicensed adoption, including the legal status of surrogate parenting. Surrogate parent contracts are often sought by persons who have experienced insurmountable obstacles to adoption. The unsuccessful search for a child sometimes causes potential adoptive parents to turn to this unconventional and controversial arrangement, which is in itself a type of unlicensed adoption by the nonnatural parents who contract for the child. Very little is known about the operation or enforceability of these contracts, and there is surrogate parent legislation pending before several State legislatures.

We have a distinguished panel of witnesses who will offer their perspective on the language of the bill and on particular aspects of the adoption process. We will focus on the continuing obstacles to the permanent adoptive placement of hard-to-place children. It is my understanding that there are more than enough families willing to adopt such children and that there should be no longer any need for a child to be cared for in an institution or in foster care. I will be interested to learn about the barriers that cause children to remain outside a loving adoptive family, and about the ways that we can remove those barriers for the best interest of the special children and families who wish to accept them.

I should mention that the subcommittee received written testimony from several witnesses who were unable to appear at the hearing today. Ms. Toni Oliver from the National Adoption Exchange addresses the issue of black adoption. Ms. Christel DeHaan, vice president of Resort Condominiums International, discusses corporate initiatives in the adoption field. Ms. Hope Marindin represents the perspective of single adoptive parents. Mr. Bruce Mueller, a private consultant, explains the development of employee adoption benefit plans. These are important contributions and, without objection, their written testimony will be included in the record at the appropriate point.

We also have a statement from Senator Dodd which we will include in the record at this point.

[The prepared statement of Senator Dodd follows:]

STATEMENT OF SENATOR DODD

Mr. Chairman, today we hear testimony on a serious problem: obstacles to adoption.

The Adoption Opportunities Act was passed to help place thousands upon thousands of children who have no permanent homes with adoptive families. Three years later, the same number of children eligible for adoption remain in foster care. That fact should truly alarm us.

Those who wait for adoption are children with so-called special needs. Some belong to minority ethnic groups. Others are members of sibling sets. Still others have emotional, mental, or physical handicaps.

Mr Chairman, as the Rossows testified so eloquently last week, there are families who wish to adopt these children but they run into roadblocks. Such families often face insurmountable redtape or fail to receive necessary supports, financial or otherwise. We must listen carefully to the panels today to learn now we can best remove such roadblocks against the adoption of special needs children.

We must also insure that this important adoption initiative receives essential Federal funding. S. 572, a bill I recently introduced, authorizes $5 million for this program Such an authorization merely restores funding to the level established prior to the budget cuts in the 1981 Reconciliation Act.

Without a strong Federal commitment to this program, Mr. Chairman, hundreds of thousands of special needs children will continue to languish in temporary placements. We must do all we can to prevent such a tragic scenario.

Senator DENTON. I want to welcome everyone here this morning and mention that we may have Senator Grassley in this morning to join us. I want to remind all our witnesses that their written statements, their prepared statements, will be included in full in the record.

But in the interest of time, I must ask that you limit your oral comments to 10 minutes. Our first witness today is the Assistant Secretary of Health and Human Services, Dorcas Hardy.

STATEMENT OF DORCAS R. HARDY, ASSISTANT SECRETARY FOR HUMAN DEVELOPMENT SERVICES, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Ms. HARDY. Thank you, Mr. Chairman. It is my pleasure to be here and to tell you a little bit about what the Department of Health and Human Services has done in the area of adoption and adoption opportunities.

As you know, Adoption Opportunities, title II of Public Law 95-266, was the first Federal legislation that specifically dealt with adoption. As you have stated, we are trying very hard to eliminate barriers to the adoption of special needs children—those children who are older; emotionally, physically or mentally handicapped; and sibling groups or minority children.

The activities that were developed under title II prepared the way for, and now very much undergird, the Adoption Assistance and Child Welfare Act of 1980, which is Public Law 96-272.

The focus is on permanent homes for children and, very clearly, children should either remain with or be returned to their birth parents if this is possible. If it is not, they should be placed in lifetime adoptive homes.

Public Law 96-272 also provides, for the first time, Federal reimbursement to States for adoption subsidies for special needs children who are eligible for AFDC or SSI, and a funding policy which does encourage States to place children in new adoptive homes rather than keeping them in foster care.

So, we see good news and the very positive news that foster care in this country and the foster care population have declined as much as 14 percent in the last 2 years, and that the number of special needs adoptions are increasing.

But despite significant progress in the States, we estimate that there are at least 50,000 special needs children in foster care who are legally free for adoption, and there are thousands more for parental rights have not been terminated but for whom on would be the plan of choice.

anency is very important to all of our children, and it is ortant to those of us who care about the family as the key n of our society. So, I would like to discuss just briefly are doing in the Department this year in terms of promoting loption of these waiting children.

We e a national adoption initiative which has been very positive will continue to be very positive in this area. Secretary Schweiker wrote to all of the State Governors, and I have communicated with the social service or child welfare directors. Thirty-three States have responded to our encouragement that they fully participate in this national adoption initiative with us.

Additionally, with this national initiative, we are placing emphasis several areas. One is a special emphasis on recruiting minority parents for minority children. Second, we are working on the training of adoption workers, trying to encourage increased State participation in the Federal adoption assistance program that I mentioned earlier, to address national issues such as adoptions across State lines.

We are also building on the reservoir of what you have called the commitment and energy represented by many of the individuals in this room today—voluntary groups, parents' groups, corporations, the media—so that we can get very exciting efforts going around this country in promoting adoption.

Two examples that might be of interest: in Atlanta, a volunteer parents' group publishes the photo listing book, called "My Turn Now," and that book is used by States and private agencies to help match prospective parents and the waiting children.

Also, in San Francisco and in Springfield, Mass., two private agencies, one of which is represented here today—Aid to Adoption of Special Kids, and Downey Side in Massachusetts—are working together to sponsor a national conference on special needs adoptions with private sector backing and participation.

We also believe that the media has played a key role and will continue to play a key role in focusing on recruiting parents and focusing on the important cause of adoption. We have nearly 60 television stations throughout the country that have put together "Wednesday's Child," "Tuesday's Child," and "Sunday's Child" programs, featuring a special needs child.

The placement rate of those children who are featured on those shows is more than 80 percent. For example, at KRON-TV in San Francisco, they had 600 calls for the first 16 children who were featured.

We have tried to make these stations feel even more important and have tried to say that we appreciate their efforts greatly by setting up an awards program for them.

We also have several additional organizations that are supporting the adoption initiative. The American Bar Association will designate special needs adoption at their presidential showcase program at their convention this summer. Also, the National Committee on Adoption and the North American Council on Adoptable Children, and other organizations have been very important in moving this initiative along.

In terms of Human Development Services, my specific area of HHS, we have committed almost $2 million in terms of adoption demonstrations over the country during the last year, and we anticipate doing that again this year.

Some of the highlights of that are the Illinois Department of Children and Family Services working with Father George Clements, a black priest in Chicago and an adoptive father, on the one church-one child program, where each church will recruit at least one family to adopt at least one child.

The American Indian Law Center is working to get Indian children adopted. Spaulding-Southwest in Houston, Family Builders of Colorado—all of them are very much working in the area of adoption and are being very successful.

Another key component of our strategy is the National Adoption Information Exchange, whom you will hear from, and they have been very successful, and I believe will continue to be successful, in registering children and families on the exchange nationwide, so that by the end of September we believe we can facilitate as many as 500 matches.

We have numerous other projects and efforts. The Model State Adoption Act has been developed and disseminated. We feel that we have made some strides in this area, but we do have more to do.

We believe that, working through the agencies, the minority organizations, adoptive parents and other kinds of groups, considerable progress can continue to be made. As you stated, most people who are involved in adoption have found that all of our children are adoptable and that there is a family somewhere for every waiting child, no matter how complex his or her needs.

We have shown again and again that black and Hispanic and Indian families are eager to adopt minority children if the placement agencies make the special efforts necessary to reach out to them and to help them through what we all refer to as the system.

We have learned that increasing the number of adoptions of children with special needs is very much a multifaceted effort and one that requires several simultaneous approaches and many resources.

We know that there is a commitment and a marshaling of resources out there, as well as within the Federal Government, to do the job. The number of children who are in foster care has declined; the number of adoptions has increased. We believe that that trend will continue.

I would cite again the State of Illinois. By overhauling their adoption practices and embarking on an intensive media campaign, they increased special needs adoptions by 70 percent in just 15 months.

Mr. Chairman, we are committed, through my Office of Human Development Services and the Department of Health and Human Services, to continue our efforts in this area. We believe we do have a significant responsibility and, in partnership with the States, with private agencies, parent organizations and others, we do support reauthorization of this act.

In that regard, I would like to make a preliminary comment on S. 1003. We do support the intent of the bill which would extend these important programs and add language creating a focus on the needs of infants at risk with life-threatening congenital impairments.

We are actively reviewing the details of the bill and will present a written bill report shortly with our views and any concerns that we may have. We are most interested in working with you and continuing to work on these very important programs.

I thank you for the opportunity to be here and I am available not only to answer questions, but also to continue to share with you and your staff some of the strides that we think we have made.

Thank you.

[The prepared statement of Ms. Hardy follows:]

Prepared Statement of Dorcas R. Hardy, Assistant Secretary for Human Development Services, Department of Health and Human Services

Mr. Chairman, thank you for the opportunity to appear before this subcommittee to discuss Adoption Opportunities as part of your reauthorization hearings on the Child Abuse Prevention and Treatment and Adoption Reform Act.

As you know, Title II, Adoption Opportunities (P. L. 95-266), passed in 1978, was the first federal legislation specifically dealing with adoption. Title II mandates a number of activities to eliminate barriers to the adoption of special needs children. Special needs children are older, emotionally, physically or mentally handicapped, in sibling groups, or minority children.

The activities developed under Title II prepared the way for and now undergird the Adoption Assistance and Child Welfare Act of 1980 (Public Law 96-272). The thrust of this act is assuring permanent homes for children. Children should either remain with or be returned to their birth parents if this is possible, and, if it is not, they should be placed in lifetime adoptive homes. P.L. 96-272 provides, for the first time, Federal reimbursement to states for adoption subsidies to special needs children eligible for Aid to Families with Dependent Children on Supplemental Security Income, a funding policy which encourages states to place children in adoptive homes rather than keep them in foster care.

I am pleased to report an encouraging trend since the passage of these two important acts: the foster care population appears to be declining and the number of special needs adoptions increasing.

Even so, we estimate that at least 50,000 special needs children in foster care are legally free for adoption and there are thousands more for whom parental rights have not been terminated but for whom adoption would be the plan of choice.

Permanency is important for children, of course, but it is also important to those of us who care about the family as the foundation of our society.

Today I want to share with you what the Federal Government and the states have accomplished under Title II—and I am especially eager to tell you about the initiative which our Department launched just this year to promote the adoption of waiting children.

In January, former Secretary Schweiker wrote the Governors of the states to announce the special needs adoption initiative and to encourage their full participation. In addition, I wrote to child welfare officials in every State. Thirty-three states have responded—sharing their progress, telling us about continuing obstacles and pledging to be a part of the initiative. Through this initiative we hope to increase public awareness and to open additional resources to help place special needs children into loving, lifetime homes.

Over the past several months I have had the opportunity to meet adoptive parents and special needs children—and the people who bring them together—in cities all over the country. I am convinced that there are as many potential parents as there are waiting children—we just have to find them and then make sure that the system responds quickly to match each parent and child. This is one of the major goals of our initiative and we are putting special emphasis on recruiting minority parents for minority children.

In addition, we are working to improve the training of adoption workers, encourage increased state participation in the Federal Adoption Assistance Program and address national issues such as adoptions across state lines.

We are also building on the reservoir of energy and commitment already being used—or waiting to be tapped—in national and local organizations, parent groups, voluntary agencies, corporations and the media. Here are some of the exciting efforts which I have discovered in my visits over the country:

In Houston, a young patent attorney, through the Young Lawyers Association, recruited 60 corporate attorneys to handle special needs adoptions, saving 70 families almost $30,000 in legal fees in less than a year;

In Atlanta, a volunteer parent group publishes the state's photo listing book, "My Turn Now" This book is used by State and private agencies to help match prospective parents and waiting children.

In Denver, the Piton Foundation has provided planning funds to help the regional adoption exchange begin a full service operation; and

In San Francisco, California, and in Springfield, Massachusetts, two private agencies, Aid to Adoption of Special Kids and Downey Side, are working together to sponsor a national conference on special needs adoptions with private sector backing and participation.

In addition, Mr. Chairman, the media are playing an important role in recruiting families for waiting children—and with outstanding results. Many newspapers and corporate newsletters throughout the country are printing weekly feature stories on a waiting child. Furthermore, nearly 60 television stations are doing weekly features on specific children who are waiting to be adopted. These segments are usually called Wednesday's Child or Thursday's Child, depending on the night the features are aired. Many of these stations fly their crews all over the state—or in some cases into several states—to film waiting children. Agencies working with these stations report a placement rate of more than 80 percent. KRON-TV in San Francisco had 600 calls for the first 16 children featured. I have been pleased to make a number of awards to stations for Wednesday's Child or Thursday's Child programs. I am also happy to report that, within a few weeks, NBC's Today Show will begin the first nationwide Thursday's Child and will feature children for five weeks.

Many organizations have undertaken activities to support our adoption initiative. For example, the American Bar Association has designated special needs adoptions as a Presidential Showcase program at its annual convention in Atlanta this summer. ABA is also launching a drive to raise $75,000 from corporations and foundations to support a project to assist lawyers, judges and other legal professionals in improving state laws and adoption practices. The Yound Lawyers Division of ABA is implementing a number of activities, including several mini-grants to local bar associations for child advocacy projects, with preference to projects relating to special needs adoptions.

Mr. Chairman, within the Office of Human Development Services, my program administrations are working together to coordinate our efforts and our resources to help get special needs children placed. This includes the Administration for Children, Youth and Families, which implements the adoption legislation, as well as the Administration on Developmental Disabilities, the Administration for Native Americans, and the President's Committee on Mental Ratardation, all of which serve segments of our special needs population.

We allocated $1.9 million of our fiscal year 1982 Coordinated Discretionary Funds program for innovative adoption demonstrations and we expect to allocate a comparable amount this year. Let me give you some examples of projects which are currently underway:

The Illinois Department of Family and Children Services is expanding the One Church/One Child project begun by Father George Clements, a black priest and adoptive father in Chicago. Father Clements' idea is that each church will recruit at least one family to adopt a child. Illinois is working with more than 70 black churches to recruit families for at least 75 black children.

The American Indian Law Center, Inc., in Albuquerque is working to strengthen tribal-state relationships and improve permanency planning for American Indian and Alaska Native Children. The Center will train 300 child welfare providers from 89 tribes and 18 states on joint permanency planning and how to develop tribal-state child welfare agreements.

Spaulding-Southwest in Houston is working in a neighborhood center to recruit and prepare Mexican-American families to adopt 15 Mexican-American children.

Family Builders of Colorado is providing training on permanency planning to 250 health professionals, social workers, teachers and others who work with developmentally disabled children. Sixty of the 250 trainees will work directly with 16 children to secure adoptive placements.

One of the most far reaching programs mandated by Title II is a National Adoption Information Exchange, a project which has been very successful. From 1980–1982, the Exchange, operated by the Child Welfare League of America, facilitated the adoptive placement of nearly 300 children, including large sibling groups, older adolescents and children with severe handicaps. In September of 1982, the Adoption Center of Delaware Valley began to establish and operate a computerized National

Adoption Exchange system. By the end of March, more than 100 children and 150 families had been registered. We expect the Exchange to register 1,000 children and 2,500 families by the end of September and to facilitate 500 matches.

The National Adoption Exchange is a major partner in our adoption initiative and is working enthusiastically with agencies all over the nation. The Exchange is also working to secure corporate sector involvement and will hold its first corporate advisory board meeting in Washington in May.

Mr. Chairman, to carry out the many aspects of our initiative, we are building on the activities—like the exchange—which we have carried out since the Adoption Opportunities Act was passed. Here are some of the activities the states, organizations and the federal government have accomplished together:

We have expanded the number of local, state and regional adoption exchanges. Prior to our efforts, there were 36 state exchanges and only a few local and regional exchanges. Today there are 39 local exchanges, 46 state exchanges (10 of which provide listing services) and 11 regional exchanges.

We have developed a National Child Welfare Reporting System, using data on substitute care and adoption services gathered and reported by the states through a "Voluntary Cooperative Information System" developed by the American Public Welfare Association. Analysis should be completed by May 15.

We have developed and disseminated a Model State Adoption Act for use by the states.

We have developed information, training and education materials on adoption of special needs children. The includes a 50-hour curriculum which has been used to train 300 trainers selected by the states. The curriculum is being translated into Spanish. We have also developed and disseminated a recruitment manual, 16 radio and television public service announcements to recruit foster and adoptive families, and six new publications to enhance workers' skills in placing children with special needs.

We have also developed a special adoptive parent effort to help agencies and adoptive parents develop a TEAM (Training and Education Adoption Method) approach to prepare potential families. Two hundred teams were trained. Through the North American Council on Adoptable Children we are continuing this effort to train 125 additional agency and parent teams, with a special emphasis on developing minority leadership.

Finally, we established 10 regional adoption resource centers which trained 30,000 social workers and supervisors and assisted in the formation of more than 200 new adoptive parent groups, including 67 minority parent groups. In FY 1982 we supported the funding of 10 children and youth resource centers which consolidated the 30 Regional Centers for Adoption, Child Welfare Training and Child Abuse and Neglect. We are working to see that the new consolidated centers help get children with special needs adopted.

Mr. Chairman, as a result of HDS funded projects and efforts of thousands of concerned people across the country—working through agencies, minority organizations, adoptive parent and other groups—considerable progress has been made over the past several years in helping more children with special needs to find loving families. Most people involved in adoptions have found that all children are adoptable and that there is a family somewhere for each waiting child, no matter how complex his or her needs. Similarly, the adoption of children by single parents, handicapped parents, foster parents, older parents and families with birth children has also become a more commonly accepted practice.

We have shown, again and again, that black, Hispanic and Indian families are eager to adopt minority children, if placement agencies make the special efforts necessary to reach out to them and to help them through the system. The recruitment of families, training of workers and supervisors, use of adoption exchanges and involvement of adoptive parent groups are now all recognized as essential ingredients for successful adoption programs.

We have learned that increasing the number of adoptions of children with special needs is a multifaceted effort, one that requires several simultaneous approaches and many resources. We know there is no one answer, but a variety of answers to increasing the number of children adopted. We also know that progress is not uniform over the nation and that many obstacles remain.

Nevertheless, we also know that where there is commitment and the marshalling of resources to do the job, the number of children in foster care declines and adoptions increase. The State of Illinois, for example, by overhauling its adoption practices and embarking on an intensive media campaign, increased special needs adoptions by 70 percent in 15 months!

Mr. Chairman, in the future, my office of Human Development Services plans to demonstrate ways to share adoptive home studies across jurisdictions, to develop manuals for agencies to assist them in preparing parents, to develop ways to streamline the adoption process and thereby reduce costs; to demonstrate ways that the corporate and business sector can promote the adoption of children with special needs, to provide seed money to adoptive parents groups to work with social service agencies to identify and use supporting resources, to fund new approaches to increase in adoption of minority children and to continue support for the National Adoption Exchange, at least through September 30, 1984, with Fiscal Year 1983 funds.

We will continue—in partnership with states, private agencies, parent organizations and others—our commitment to the adoption of children with special needs. We support reauthorization of the Child Abuse Prevention and Treatment Act and the Adoption Reform Act. In fact, as you know, Mr. Chairman, the Administration has sent a proposal to the Congress asking that these programs be extended for three years.

In that regard, I would also like to make a preliminary comment on S. 103, the bill which you introduced late last week. We support the intent of the bill, which would extend these important programs and add language creating a focus on the needs of infants at risk with life-threatening congenital impairments. We believe in the need to continue our efforts to encourage the adoption of special needs children, including especially those infants at risk at birth. We are actively reviewing the details of S. 1003 and will present a written bill report with our views and any concerns shortly. I would like to assure you, Mr. Chairman, that we are most interested in working with you to continue these very important progams.

Thank you for allowing me to report on our initiative and on our progress, under Title II, in providing adoption opportunities for children with special needs. I will be happy to answer any questions which the subcommittee may have.

Senator Denton. Thank you, Ms. Hardy. The evidence of your work is quite manifest, and I commend you for the work you have done within the adoption initiative. I have not seen any branch of government show more progress in any of the hearings of this subcommittee than what your office has shown.

Ms. Hardy. Thank you.

Senator Denton. I hope we can find ways to enhance your activities.

You mentioned that there are at least 50,000 special needs children, or you estimate that number, in foster care legally free for adoption, and thousands more for whom parental rights have not been terminated but for whom adoption would be the plan of choice.

What does the latter mean? I am a little bit confused on that—parental rights have not been terminated, but for whom adoption would be the plan of choice. Do, you mean that they are runaways or separated?

Ms. Hardy. Well, let me clarify here. Of the 50,000 children that we know of in the foster care system who are legally available for adoption, not all of them are special needs, but 95 or 96 percent are special needs children.

Second, in terms of the plan of choice, when the adoption worker or when the child welfare worker works with the individuals who are in the foster care system, they first would hopefully try and reunite that child with his or her parents.

If it appears that that is not at all feasible, then they would want to institute the termination of parental rights and adoption would be the plan of choice. The first aspect and the undergirding of the whole concept of permanency planning is a permanent home, but obviously the first choice is with those parents if that is at all possible.

Senator DENTON. And the National Adoption Information Exchange facilitated the adoptive placement of nearly 300 children. How many would be registered in that? You expect the exchange to register 1,000 children and 2,500 families by the end of September.

Why so few as 1,000 children? I assume this is national, and you estimate 50,000 special needs children. Is it that you just cannot identify more than 1,000 of them, in that you are expecting only 1,000 to be registered?

Ms. HARDY. Well, the Adoption Center of Delaware Valley did start this past September with putting together the computerized National Adoption Exchange. We anticipate that the startup of that whole computerization is not something that they can do overnight; they are doing a very good job now, partially into this project.

I would defer to the exchange on some of these answers, but it is also a question of letting the exchange know who those children are. They need to get that support from the other states and from local agencies who are aware of children in Colorado or in another State.

Senator DENTON. Recognizing that it is not easy to find them and that we really cannot count the number of special needs kids out there, it does seem as if 1 in 50 is not a very high number to be aiming toward, you know.

Ms. HARDY. I should also add, Mr. Chairman, that there are regional exchanges throughout this country and there are other exchanges. The one I mentioned in Atlanta, the photo listing, has children from throughout the metropolitan area of Atlanta and throughout Georgia. So, there are other means by which these children are identified.

Senator DENTON. Does the administration have a position on the expansion of the responsibilities of the Advisory Board on Child Abuse and Neglect to include adoption opportunities?

Ms. HARDY. We are looking at that currently. I think that many of these issues do fall into the area of child abuse and neglect. There are some people who are serving on that panel who are certainly interested in adoption opportunities. We would be glad to work with the staff and look at that positively.

Senator DENTON. If you do not finally decide to do it that way, there is an evident need for coordination. The Office of Adolescent Pregnancy under Marjorie Mecklenburg operates some programs that bear on adoption. I would think we would want to tie this coordination up as cozily as we can.

Do you have any idea which way you will be going on that?

Ms. HARDY. Well, I think some of the issues you have just mentioned may be beyond the scope of the specific adoption opportunities program that we have talked about today, but they certainly are of great concern to us. They include the idea of trying to coordinate much better through the Secretary and at the secretarial level so that it crosses many of the operating divisions—as you know, Marjorie Mecklenburg is under the Assistant Secretary for Health, which is another branch of the huge HHS.

We try and work together closely. We are aware of many of the issues, but I think they could be coordinated through the Secretary, and putting that kind of language in the law would be very positive.

Senator DENTON. S. 1003 would require the Secretary to review the Model State Adoption Act and to make any changes necessary to facilitate the adoption opportunities of special needs children.

As you know, in the Bloomington, Ill., *Baby Doe* case the parents did not terminate their parental rights in order to allow the child to be adopted by parents standing by who would have allowed the necessary treatment to be performed.

Would it be possible to add language to the Model State Adoption Act that would provide that parents who refuse to allow medically indicated treatment, and that means undebatably medically indicated, to be performed on a child who will more than likely not, as a result, die in a short period of time—by that refusal to permit the treatment would terminate their parental rights.

Would you add language to that effect? That was something that was recommended by a number of previous witnesses and they all seemed to nod in agreement not only at the witness table but also around the room on that subject. They seemed to recognize that the child is going to die anyway.

The parent would automatically relinquish his or her parental rights at a time very early in the process. If there are adoptive parents available and ordinary medical treatment available which could permit the child to live, why not terminate the parental rights in time to save the life of the child to achieve the adoption, and to perform the operation?

Ms. HARDY. Well, I think that is in concert with what the Department has done and the Department's testimony to Congress in terms of the whole *Baby Doe* issue.

In terms of opening up the model State adoption code, we would be glad to look into that. I think there are some experts around that we would want to consult. I do not have specific language on that, but I think we could look at the model State adoption code.

Senator DENTON. We could put it in our language; we have not written it yet. If you do not have any objection, we will do so, and hope that you all change it in any way you see fit. That just seems to make a lot of sense.

Ms. HARDY. All right. Well, we will look forward to working with you on that.

Senator DENTON. I just thought of this last night when we were reviewing the questions, and so we do not have it in there right now.

What is the single biggest obstacle to adoption? I read in an article in Working Woman that abortion has not decreased the number of available children free for adoption. The article contended that adoption is difficult today because most single mothers choose to keep and raise their babies. It is commonly known that only 6 percent of teenage unwed mothers choose an adoption plan for their babies Is this the result of family planning counseling that presents adoption in a negative light?

My own experience would be that it is not necessarily that, but it has just become a more peer pressure or peer opinion type of thing.

Excuse me; go ahead.

Ms. HARDY. I was going to add to that that it has become more acceptable, I think, in terms of society for that teenage parent to keep that child. We are having less children in terms of newborns in the foster care and adoption system.

However, the children that we have in the system already here, which we have been trying to focus on so much through this national adoption initiative—I am really trying to worry about them first and see if we cannot move them out of foster care and into homes. There are not as many newborns, certainly, coming into the system.

Senator DENTON. It is my understanding that family planning counseling does too often emphasize the horrors of being an unmarried young mother, rendering the alternative of abortion apparently preferable, with inadequate counseling not presenting adoption as a compassionate choice. As you know, the adolescent family life bill tends to do something to correct that.

I would think from your position that you would be interested in getting correction to that kind of counseling. You know, these are not even special needs babies; these are babies that are not permitted to be born and we have people waiting to adopt them. Yet, they effectively are advised to abort.

Ms. HARDY. Yes.

Senator DENTON. I am interested in knowing the origins of the adoption process, which obviously starts with the natural parents. Statistics show that most single women are choosing either to rear their babies or abort them.

The number of sought-after healthy white infants available for adoption has decreased dramatically in recent years. It seems that most children who are free for adoption or who are in foster care are special needs children.

What causes the parents of these children to place them outside the natural home? What are the motivations? Are the financial or emotional burdens overwhelming? Is it an irresponsibility or insensitivity to the requirements of child rearing on the part of the natural parents?

Is the overall breakdown of the family and traditional values contributing to a lack of commitment by the natural parents? How would you view that motivational genesis?

Ms. HARDY. I think all of the possible reasons that you have listed are certainly part of that. I also believe that when we look at the whole foster care population, one of the concerns—and that is why I mentioned Public Law 96-272—is that many of the children in foster care have been there a long time, and they have therefore become special needs children in our broad definition.

They have been, maybe, in 6 homes in 10 years or 10 homes in 10 years. So they therefore have, you could say, an emotional handicap and often become difficult for very valid reasons.

They may not have started out as a special needs child. The reason that they went into foster care may have been abuse, a need to separate, problems in the family; it could be abandonment.

Because they have been in foster care so long, it also gets worse. I think with the reforms that we were able to put in, which Congress mandated in Public Law 96-272, we are seeing a decrease in this. We are seeing a decrease in foster care and we are seeing an increase in moving these children out.

Senator DENTON. Well, I certainly admire what you have been doing, and I admire the work of people in this field. I do get the feeling as I progress through these hearings, which are apparently, ostensibly nonrelated, such as adoption, child abuse, and adolescent pregnancy, that they are indeed related; that there is a proclivity for seeing only the symptoms of a more central problem which the Government is not addressing at all, which deals with perhaps those values I mentioned in the first place.

I do not say this as a moralist, but more or less as an historian. You cannot drop the idea of loving your neighbor as yourself or the nuclear family bonds, or drop the sense of responsibility toward your own child and the respect for human life.

That transcends any other kind of consideration, such as your own quality of life—me, self-fulfillment, how much fun am I having? I do not know what the Government can do about any of that, but I have heard about it so many times.

For example, in the juvenile delinquency field, I heard a boy from the Bronx talking about why the kids were so tough up there; he was a guardian angel. He said, "Well, because we have lousy role models, the television and the movies and the books all give us the wrong things to admire. We are having slowly drained out of us that which we were born with—a certain feeling of love and respect for authority, and order and family, and so forth."

We used to have Government codes about things like that in various fields—the FCC, and so forth. I would be a very unlikely candidate to bring that back up effectively, but I think somebody ought to, because it is not promoting the general welfare. One of the responsibilities of Government is not to permit that sort of national prostitution of essential values to go on as it is.

We are ignoring laws on the books right now with respect to, obscenity and pornography. There is a black market in adoption, I guess. I cannot say that we are ignoring it, but I do get the frustrated feeling that we are looking very carefully and conscientiously at the symptomatic problems and not at the central core.

Our newspapers and the very tone of our own dialog on the floor of the Senate not only ignore but also feed the fire of that problem. That is my own personal comment. Do you have any feelings on that subject?

Ms. HARDY. I would just comment that I do concur with you in terms of the philosophy and but the decrease, perhaps, in our thoughts about values and society. At the same time, I am not sure that I have the answer, given the role of any government, Federal, State, or local, versus the role of the individual, versus the role of society. That is a tough question.

Senator DENTON. We are having one heck of a time just getting prayer in schools, for example. That is where we got our love for one another, from some kind of moral code.

Ms. HARDY. I agree with that.

Senator DENTON. That is what every society does. So, I do think government is delinquent in some respects and that that is why these problems are going on. But I agree, too, that I do not know what the answers are. It is a democratic voting system out there on the floor, but I do not think our people would have us vote here the way we are.

Well, thank you very much, Ms. Hardy.

Ms. HARDY. Thank you.

Senator DENTON. Again, I admire what you are doing and I hope we can help by cooperating with you. Senator Dodd has submitted some questions to be entered in the record for you to answer in writing, Ms. Hardy. Without objection, the questions will be entered and I will ask you to respond to them in writing within 10 days, if you will. There are four questions.

As I call the names of the second panel of witnesses, I would ask them to move to the table: Marlene Piasecki, director of the National Adoption Exchange; Toni McHugh, National Committee for Adoption; and Kathy Sreedhar, adoption representative of Mother Teresa.

I will ask Ms. Piasecki to begin with her oral remarks.

STATEMENT OF MARLENE PIASECKI, DIRECTOR, NATIONAL ADOPTION EXCHANGE; TONI McHUGH, CHAIRMAN, BOARD OF DIRECTORS, NATIONAL COMMITTEE FOR ADOPTION, ACCOMPANIED BY CANDACE MUELLER, DIRECTOR FOR PUBLIC POLICY AND PROFESSIONAL PRACTICE, NATIONAL COMMITTEE FOR ADOPTION; AND KATHY SREEDHAR, ADOPTION REPRESENTATIVE, MISSIONARIES OF CHARITY, A PANEL

Ms. PIASECKI. Thank you. Mr. Chairman, I appreciate the opportunity to appear before this subcommittee to discuss the reauthorization of the Child Abuse Prevention and Treatment Act and Adoption Reform Act. I will address my comments to title II of the act, Adoption Opportunities.

Since its original passage in 1978, the provisions of title II have helped to eliminate barriers to adoption and to provide permanent and loving homes for waiting children, particularly children with special needs. As a result of the training, technical assistance, and demonstration projects, thousands of children with special needs have been adopted.

This has been accomplished through several methods, including the training of social workers and child welfare administrators who have responded by helping to find and prepare families for the challenges of adoption.

In addition, many new adoptive parent groups were formed through the efforts of the adoption resource centers. These voluntary parent groups now speak out for the children in their own communities, encourage responsible planning for waiting children, and donate their time to recruit and counsel new adoptive families.

Despite this impressive record of success, there are still over 50,000 children who are legally free for adoption. These children are legal orphans with only the States as parents. They are waiting for us to find the families they can call their own.

The National Adoption Exchange, with your assistance, has accepted this challenge. As an exchange, we offer these basic services: Adoption information, multimedia recruitment, registration of children and families, match referral, and technical consultation.

Each service has been developed to address barriers which stand in the way of permanence for children. Among the barriers is inadequate information. Many States have not yet identified the legally free children who are waiting for adoption.

Without an accounting of each of the 50,000 waiting children—children for whom the States draw Federal moneys—adequate permanency planning and adoption services cannot be developed or delivered. And without an accounting, adoptive families themselves have difficulty obtaining information about the children who are waiting to be adopted.

On April 4, 1983, the National Adoption Exchange received a letter from a prospective parent after he had contacted a local adoption agency in Michigan. He wrote, "I explained my situation and was told that there are no white, older, handicapped children in Michigan. What a negative answer they gave me; no wonder you have trouble adopting children."

At the National Exchange, we are working to improve the quality and availability of information about adoption through our registration procedures and through national recruitment and public relations campaigns.

No waiting children are restricted from our program. State and local agencies determine which children will require the services of the National Exchange. In each State, special needs are identified according to local standards. Whenever a child is at risk of continued, expensive out-of-home placement, we are ready to work to find a permanent home.

Once the National Exchange receives a registration for a waiting child, we put that information in the hands of waiting families. We do this by registering families who are studied for adoption, and then matching these families with waiting children.

By permitting direct self-registration of families, we enable them to take the first step in finding their own child. Self-registration also combats a major barrier to the adoption of minority children—the saving of families. We have found that many organizations which approve families for adoption will not share information about those families, particularly minority families. They are saving them until a child becomes available who is currently in their own custody.

While this seems harmless, it leaves many children without families while prospective parents wait. The registration procedures established by the National Adoption Exchange bridges the gap between the families and the children.

While communities must make plans to care for their own children, they must also be willing to seek and to share family resources beyond their own boundaries. Are we to continue to institutionalize our children because the family they need belongs to another agency 100 or 1,000 miles away?

I am not suggesting that we look too far afield to find good homes for children, but concentrated, innovative marketing strategies are needed to bring forth the families which have been overlooked by traditional recruitment practices.

Greater cooperation among agencies is essential to insuring that these families become a resource for any child, without regard to geography. Through the use of media resources, the National Exchange has improved access to information about adoption.

In February, we sent almost 2,000 press releases to daily and minority newspapers, telling the story of special needs adoption and how families can respond. Later this month, NBC's "Today Show" will begin a 4-week waiting child feature, bringing the children themselves to over 6 million viewers.

While we are excited about our success in bringing information about adoption to large numbers of prospective adoptive parents, we are also concerned about the services which are available when families respond.

Many exchanges around the country have reported that families have a difficult time getting homestudies, even those families who are willing to accept our most hard to place children.

All too often, agency requirements exclude from the adoption process whole groups of families, particularly minority families. The need to respond positively when minority families step forward is doubly important, since minority children are vastly overrepresented in the total number of children who wait. Until agencies improve their response to these families, the overrepresentation of minority children will remain.

The national black pulse study conducted by the Urban League showed that a very large number of black families are willing to adopt. Special recruitment projects currently funded by this act similarly have found that when information about the children who are waiting is presented to the minority community, families respond.

We have set as one of our own top priorities the recruitment of minority families and the delivery of assistance to these families as they seek homestudies.

In addition to these informational barriers, there are significant fiscal barriers to the adoption of special needs children. Although Federal support for adoption subsidy has greatly increased adoption opportunities, it is not without problems.

Of particular concern to the families who are adopting is the availability of medical assistance payments and medical insurance. In our very mobile society, many families move across State lines after they have adopted, or they choose a child from a State other than their own.

These families, while certain that monthly maintenance will follow the child, are less certain about medical assistance through medicaid. The problem rests not in a change of eligibility, but in the unwillingness of health and service providers to accept the medicaid card issued by a State other than the State in which they are located.

Thus, families who do not fear a child's handicap do fear their own ability to provide medical care for that child when they are not assured that medicaid will be a viable source of medical treatment. For our most handicapped children, we must insure adequate medical coverage.

Another fiscal problem is the lack of purchase of service agreements between public and private agencies for special needs adoption services. Counties and States which are quite willing to pay for foster and institutional care on an indefinite basis are often unwilling to pay a one-time fee for adoption services.

Another barrier to the adoption of special children is the lack of postadoption services. Although many agencies which make placements continue to provide supportive services after the adoption has been finalized, the national need for training in postadoption services will increase as we are successful in achieving higher rates of placement of more severely handicapped and troubled children.

Despite the very real, continuing impact of these barriers, we see clear and dramatic changes in adoption practices. Many children considered unadoptable a few years ago are living in permanent homes. Many disabilities, such as Downs syndrome, once seen as leading to institutionalization are now accepted by large numbers of adoptive families.

Since its inception, the National Exchange has found a tremendous need for its services, and we are building relationships with both the public and private sectors in order to meet that need.

For example, we have quickly become a central place for information about adoption. We have strong relationships with the media so that both families and agencies know about the exchange and feel comfortable in calling us for assistance.

Just last month, three full pages in the National Leader, a national black newspaper, were focused on the minority children who wait and how families can contact the National Exchange.

We are also working closely with our colleagues in the field of adoption. A child welfare advisory group, representing exchanges, adoption agencies and State governments, has helped us to develop procedures and policies which make the exchange a viable member of the broad network of adoption services.

We are working hard to develop special relationships with the corporate sector. We believe strongly that there is a place for American industry and business in promoting the adoption of special needs children and supporting the efforts of adoption programs.

The National Exchange has formed a corporate advisory group and members have already played a significant role in making the exchange a success. Christel DeHaan, president of Vacation Horizons International and executive vice president of Resort Condominiums International, has made a personal commitment to the cause of children who wait. She and her senior corporate staff have provided extensive assistance in the development of appropriate computer technology and the use of communications media.

Her experienced management staff has helped to plan for automation of the exchange. They have helped us analyze our telephone systems, and are helping to meet the challenge of providing high-quality services using the best of today's technologies.

GTE Corp. has also provided extensive support and assistance. C. Thomas Taylor, vice president and general manager of GTE Telenet, made Telemail, a national telecommunications network, available to the exchange for testing as a 24-hour communications and data bank system.

GTE staff have worked closely with our own professional and technical personnel to develop a system which reflects the information needs of adoptive families and adoption agencies.

Business is responding and corporate leadership has made a difference in the way we do business and in the range of services we can offer.

Even with these accomplishments, many important questions that affect our ability to provide services are unanswered. What makes adoption work, and why are so many children still waiting?

To help find answers, we have brought together, at their own expense, a group of research professionals who are advising us on the kinds of questions which need to be asked to improve exchange services. Under the leadership of Robert Hill, associate director of the Washington Bureau of Social Science Research, the research advisory group will also participate in the evaluation of the exchange.

In closing, I would like to say that the passage of the act before you has brought about significant changes in the practices of adoption. Congress has challenged each of us as parents, workers and administrators to make good use of new resources, and we have been challenged to find new sources of support and new and more efficient ways of doing business.

Adoption services today are more competitive, more focused on special needs children. We need competition and we need excellence. There is always a market for better programs, programs that are more suited to the demands of today's children and today's families.

In all of those programs, we require a sense of commitment and a striving for excellence. We believe that that means bringing together the best practice in our profession, the knowledge from the field of child welfare, the technical expertise and assistance that America's businesses can lend, and the hearts of the families who make these children their own. Reauthorization of Public Law 95-266 will make possible the continued efforts of these groups and the achievement of permanent homes for children.

Mr. Chairman, thank you for letting me speak today.

[The prepared statement of Ms. Piasecki follows:]

PREPARED STATEMENT OF MARLENE PIASECKI, DIRECTOR, NATIONAL ADOPTION EXCHANGE, PHILADELPHIA, PA.

Mr. Chairman. I appreciate the opportunity to appear before this distinguished subcommittee to discuss the reauthorization of the Child Abuse Prevention and Treatment Act and Adoption Reform Act. I will address my comments to Title II of the Act—Adoption Opportunities.

Since its original passage in 1978, the provision of Title II have helped to eliminate barriers to adoption and to provide permanent and loving homes for waiting children, particularly children with special needs.

As a result of training, technical assistance and demonstration projects, thousands of children with special needs have been adopted. This has been accomplished through several methods, including the training of social workers and child welfare administrators. They have responded by helping to find and prepare families for the challenges of adoption. Importantly, many new adoptive parent groups were formed through the efforts of the Adoption Resource Centers. These voluntary parent groups speak out for the children in their own communities, encourage responsible planning for waiting children and donate their time to recruit and counsel new adoptive families.

The impressive record of success of this Act has set the stage for significantly improving the opportunities for special needs children. Where we have formed 300 parent groups, hundreds more are needed. Where we have trained a few thousand workers, many more could be prepared to better serve these young clients.

Today, over 50,000 children are legally free for adoption in this country. These children are legal orphans with only the states as parents. Some have brothers and sisters, other are without any family. They are waiting for us to find the families they can call their own.

The National Adoption Exchange, with your assistance, has accepted this challenge. As an Exchange we offer six basic services, (1) adoption information (2) multimedia recruitment (3) registration of children and families (4) match/referral, and (5) technical consultation. Each service has been developed to address barriers which stand in the way of permanence for children.

BARRIERS TO ADOPTION

The first set of barriers are informational. Many states have not identified the legally free children who are waiting for adoption. Without an accounting of each of the 50,000 waiting children, children for whom the states draw federal monies, adequate permanency planning and adoption services cannot be developed or delivered.

Often, adoptive families have difficulty obtaining information about the children waiting to be adopted. On April 4, 1983 the National Adoption Exchange received a letter from a prospective parent after he contacted a local adoption agency in Michigan. He said: "I explained my situation and was told that there are no white, older, handicapped children in Michigan. What a negative answer they gave me. No wonder you have trouble adopting children."

At the National Adoption Exchange, we are working to improve the quality and availability of information about adoption through our registration procedures and through national recruitment and public relations campaigns.

No waiting children are restricted from our program. State and local agencies determine which children require the services of the National Exchange. For states like New York, with 1,600 waiting children, a national audience of prospective parents is critical. In each state, however, special needs are identified according to local standards. Thus children are not denied services because they do not meet some externally imposed criteria.

Whenever a child is at risk of continued, expensive out-of-home placement, we are ready to find a permanent home.

Once the National Adoption Exchange receives a registration for a waiting child, we must put that information in the hands of waiting families. We do this in two ways. The first is by registering families who are studied and approved for adoption and then matching these families with waiting children. The families are active partners in this process. By permitting direct self-registration of families we enable families to take the first step in finding their own child. Self registration of families also combats a major barrier to the adoption of minority children—the saving or hoarding of families. We have found that many organizations which approve families for adoption will not share information on those families, particularly minority families. They are "saving" the families until a child in their custody becomes available. While this seems like a harmless procedure it leaves many children without families while prospective parents wait, knowing that children are available. The registration procedures established by the National Adoption Exchange bridge the gap between the families and the children. While communities must make plans to care for their own children, they must also seek and share family resources beyond their own boundaries for those children who require special and often rare families. Are we to continue to institutionalize our children because the family they need "belongs" to another public or private agency 10 or 100 or 1,000 miles away?

I do not mean to suggest that we need look too far afield to find good homes for these children. One of the most important lessons we and our sister exchanges have learned is the richness of opportunities in our own backyards. But concentrated, innovative, marketing techniques are needed to bring forth the families which have been overlooked by traditional recruitment practices. And greater cooperation among agencies is essential to insuring that these families become a resource for any child without regard to geography.

Through the use of media resources the National Adoption Exchange has improved access to information about special needs adoption. In February, 1983 the National Adoption Exchange sent almost 2,000 press releases to daily and minority newspapers telling the story of special needs adoption and how families can respond. Many newspapers ran features with local tie-ins. The response over the past six weeks has been tremendous, with calls from Iowa, South Texas, Pennsylvania, North Florida, Oklahoma, California and many others.

Later this month NBC's "Today Show" will begin a four-week "waiting child" feature, bringing the children themselves to over six million viewers.

While we are excited about our success in bringing information about adoption to large numbers of prospective adoptive parents, we are also concerned about the services which are available when families respond.

Many child welfare organizations, especially adoption exchanges around the country, have reported that families have a very difficult time getting homestudies—including families who would be willing to accept our most hard to place children.

All too often meaningless agency requirements exclude from the adoption process whole groups of families—particularly minority families. The need to respond positively when minority families step forward is doubly important since minority children are vastly over represented in the total number of children who wait. Until agencies improve their response to these families, the over representation of minority children will remain.

The National Black Pulse study conducted by the Urban League showed that a very large number of black families are willing to adopt. Special recruitment projects currently funded by the Adoption Opportunities Act similarly have found that when information about the children who are waiting is presented to the minority community, families respond. The Black Homes for Black Children project has accomplished much by offering a real alternative to traditional agency practices which had failed to bring forth what have now proved to be important minority resources. We have set as one of our own top priorities the recruitment of minority families and the delivery of assistance to these families as they seek homestudies.

Yet we need to know about how families are being served once they begin the process of a homestudy. In collaboration with the North American Council on Adoptable Children, the National Exchange will be contacting families whom we have referred for homestudies, and we will identify those barriers which these families may have experienced. By compiling this information and sharing it with the states, we feel that the states themselves will be in a better position to examine how their policies facilities or prevent adoption of children.

In addition to these informational barriers there are significant fiscal barriers to the adoption of special needs children. Although Federal support for adoption subsidy of special needs children has greatly increased adoption opportunities, adoption subsidy is not without problems. Of particular concern to the families who are adopting is the availability of medical assistance payments and medical insurance. In our very mobile society, many families move across state lines after they have adopted. Other families choose a child from a state other than their own. These families can be quite certain that monthly maintenance will follow the child to any state. However, there is less certainty about medical assistance through Medicaid. The problem rests not in a change of eligibility but in the failure to accept Medicaid coverage by another state. Health and service providers are often unwilling to accept a Medicaid card issued by a state other than the state in which they are located. Thus families who do not fear a child's handicap rightly fear their own ability to provide medical care for that child when they cannot be assured that Medicaid will be a viable source of medical care. For our most handicapped children we must ensure adequate medical coverage.

Another fiscal problem is the lack of purchase of service agreements between states and private agencies for special needs adoption services. Counties and States which are quite willing to pay for foster and institutional care on an indefinite basis, with annual bills for each child of 10, 20 and over 30,000 dollars are unwilling to pay from one to five thousand dollars for one time adoption services. One of the important accomplishments of the Adoption Resource Centers was their training of both public and private agencies about purchase of service and how it could facilitate placements. And we request purchase of service information when children are registered, in part to stimulate an awareness of this mechanism as one which will facilitate placements.

Another barrier to the adoption of special children is the lack of post adoption services. Although many agencies which make placements continue to provide supportive services after the adoption has been finalized, the national need for training in post-adoption services will increase as we are successful in achieving higher rates of placements of more severely handicapped and troubled children. Again, parent groups and other volunteer organizations can play critical roles. They can provide much of the support that is needed by families, as they derive their expertise from their own experience as the parents of special needs children.

Despite the very real, continuing impact of these barriers, we see clear and dramatic changes in adoption practices. Many children considered unadoptable a few years ago are living in permanent homes. Many disabilities, such as Downs Syndrome, once seen as leading to institutionalization are now accepted by large numbers of adoptive families.

Since its inception, the NAE has found a tremendous need for its services. For example, the Exchange has quickly become a central place for information about adoption. We have emphasized strong relationships with the media so that both families and agencies know about Exchange services and feel comfortable in calling for assistance.

In part, changing attitudes about adoption is a function of our presentation of children. Just last month, three full pages in the National Leader, a national black newspaper, were focused on the minority children who wait and how families can contact the National Exchange. A full page of photos, including older children, sibling groups and handicapped children, presented a new set of images about adoption and encouraged readers to see waiting children as real, individual and adoptable.

We found that many newspapers which had never carried a story about special needs adoption were willing to carry our story. Many families who had never read about special needs adoption in their home town news called and wrote with great excitement saying, "Can I adopt? . . . Who can I adopt? . . . Where do I go for help?"

We are working closely with our colleagues in the field. A Child Welfare Advisory group representing exchanges, adoption agencies, and state governments have helped us to develop procedures and policies which make the Exchange a viable member of the broader network of adoption services.

We are working hard to develop special relationships with the corporate sector. We believe strongly that there is a place for American industry and business in promoting the adoption of special needs children and supporting the efforts of adoption programs. The National Exchange has formed a Corporate Advisory Group and members have already played a significant role in making the Exchange a success. Christel DeHaan, President of Vacation Horizons International and Executive Vice President of Resort Condominiums International has made a personal commitment to the cause of children who wait.

Mrs. DeHaan's companies match the vacation plans of over 200,000 families with available vacation time at over 600 resorts worldwide. She, and her senior corporate staff, have provided extensive assistance in the development of appropriate computer technology and the use of communications media. Her experienced management information staff has helped plan for automation of the Exchange, in the analysis of our telephone systems and in helping to meet the challenge of providing high quality services using the best of today's technologies.

GTE corporation has also provided extensive support and assistance. C. Thomas Taylor, Vice President and General Manager of GTE Telenet, made Telemail, a national telecommunications network, available to the Exchange for testing as a 24 hours a day communications and data bank system. To date, we have provided demonstrations of the system to more than 25 adoption agencies and exchanges. Each has expressed an interest in joining our growing national network. GTE staff have worked closely with our own professional and technical personnel to develop a system which reflects the information needs of adoptive families and adoption agencies. The system is menu-driven and presents easy-to-read questions and statements. It provides direct access to our information about specific children and families.

Other corporate executives have agreed to join the Exchange's Corporate Advisory Group. The agenda for this group includes features for corporate newspapers about special needs adoption, development of adoption benefit plans, technical and monetary contributions, and professional consultation. Business is responding and corporate leadership has made a difference in the way we do business and in the range of services we can offer.

Even with these accomplishments, many important questions that affect our ability to provide services are unanswered. What makes adoptions work? Why are so many children still waiting? To help find answers we've brought together, at their own expense, a group of research professionals who advise us on the kinds of questions which need to be asked to improve exchange services—both our own and the services of other exchanges. We need to know more about the outcomes of adoptions and the ways in which families help overcome the disabilities and insecurity of their new members. We also need to know more about why some adoptions fail, and how to make better decisions about placements.

Under the leadership of Robert Hill, Associate Director of the Washington Bureau of Social Science Research, the Research Advisory Group will also participate in the evaluation of the Exchange. With their help to develop performance indicators, we will begin an analysis of how well we respond to inquiries, how agencies use our services—and most importantly how well we facilitate the placement of waiting children.

CHILD ABUSE AND ADOPTION SERVICES

We would also like to draw attention to the connection between our nation's response to child abuse and the adoption of special needs children. It may appear that these are unrelated topics, grouped together under this pending legislation because each deals with children. However, there is a fundamental and growing interrelationship which links abuse and the need for adoption services. Increasingly, abused and severely neglected children are listed with the National Exchange and with our 87 sister exchanges across the nation. For these victims of abuse we are now finding many very special families. Fear is being replaced by love.

Adoption opportunities are also needed by the thousands of victims of institutional abuse, particularly passive institutional abuse. Assistant Secretary Hardy, in her remarks to this committee on March 9, 1983, noted the critical need for the completion of a national study of abuse "for providing assistance to the states to establish procedures to ensure safety from deliberate neglect." Certainly, no child should suffer at the hands of persons whom we have selected to provide for their care and we support this effort to safeguard against the abuse and exploitation of handicapped children. Yet institutional abuse, the almost routine and continuing consignment to institutions of handicapped children who could be placed in foster or adoptive homes must end. When given the opportunity to provide adoption services, we have seen that severely disabled children can be accepted into new permanent homes. In these homes, children who had been diagnosed as too damaged to live outside an institution are now experiencing their real potential for active and more complete lives. Yet in state after state, thousands of mentally retarded and physically handicapped children remain in institutions because almost no one within the institutional system even considers adoptive placement. And once institutionalized, we tend to forget their abilities, and make it all too easy for these children to become increasingly dependent and passive institutional victims for the rest of their lives. The human and economic costs of inappropriate institutionalization should not be tolerated.

CONCLUSION

In closing, the passage of the act before you has brought about significant change in the practice of adoption. Congress has challenged each of us as parents, workers and administrators to make good use of new resources. And we have been challenged to find new sources of support, new and more efficient ways of doing our business.

Adoption services today are more competitive—more focused on special needs children. We need competition and we need excellence. There is always a market for better programs, programs that are more suited to the demands of today's children and today's families. And in all of those programs, we require a sense of commitment and a striving for excellence. We believe that means bringing together the best practice in our professions, the most knowledge that we have in the field of child welfare, the technical expertise and assistance that America's business can lend, and the hearts of the families who make these children their own. Re-authorization of Public Law 95-266, will make possible the continued efforts of these groups and the achievement of permanent homes for children.

I have spoken a great deal about "thousands of waiting children" and "thousands of families" but we can more easily understand the importance of the Exchange by looking at one child and one family at a time.

Tina is a 13 year old girl who lived with her birth mother until she was 11. Since 1980 she lived with a number of different foster homes and while she has moved around a great deal she retains a very positive image of herself and a desire to do well in school, to grow up and to serve other children as a foster mother. Tina is in good physical health but she needs one thing—and that's a permanent home. On January 24, 1983, Tina's social worker registered her with the Exchange hoping to find a family. Just a few weeks before, a very fine family in Idaho had registered themselves with us. They have one son and live in a small community. The mother works outside the home and enjoys special homemaking activities like sewing, weaving and cooking. The father coaches his son's baseball team and is an avid home remodeler. They are a close knit, loving and supportive family—active in their local church. On January 26, 1983, two days after Tina was registered, the National Adoption Exchange recommended this family to Tina's social worker. She reviewed the case records, as well as those of two other families. Next week Tina is going home. She's going from Ohio to Idaho to become part of a permanent family.

On February 18, 1983, Gilbert, an eleven month old boy in Florida, was registered with the National Exchange. A cute, appealing child who is alert and responsive to others, Gilbert has been in foster care since he was born. He has been diagnosed as having "delayed motor development" and he now is in an early intervention program. The services of this program are already helping him to improve his ability to focus his eyes, move his hands and pull a string to reach a toy. Young Gilbert needs a home now.

On February 23, just five days after Gilbert was registered, a single adoptive mother from Pennsylvania sent her registration to the National Exchange. She said she was willing to become a parent to a child with physical disabilities or conditions that require long term medication or special treatment. Gilbert will be moving to his new home this week, less than two months after he was registered with the Exchange.

As you can see by these two examples, the children who are waiting represent a wide range of needs. The families who are responding also represent a great voluntary resource which we cannot afford to ignore. For the thousands of children who now wait, we would hope to be able to say to them as we can for Gilbert and Tina, they are going home.

Senator DENTON. Thank you very much, Ms. Piasecki.

Ms. McHugh.

Ms. McHUGH. My name is Toni McHugh and I am the chairman of the board of directors of the National Committee for Adoption. I am also an adoptive parent. I have served on the board for 2 years, and during that time I have also served as cochairman of the New Jersey Committee for Adoption, which is a State affiliate of the National Committee for Adoption.

Accompanying me here is Candace Mueller, who is director of public policy and professional practice for the national committee staff.

As an adoptive parent and on behalf of the committee's board, member agencies and adoptive families in the committee's membership, I want to thank you very much for letting me testify today.

We support the continuation and expansion of the adoption opportunities law, and have discussed several barriers to positive adoption services in our written statement, which I would like to ask, Chairman Denton, if you would accept for the record.

Senator DENTON. We shall, thank you.

Ms. McHUGH. Thank you.

For the time I have alloted to me, I would like to summarize some of the main barriers which the committee's members and myself, as an advocate of good adoption services, have observed. I will also briefly comment on the ways that these barriers can be overcome, both through legislation such as S. 1003 and through the work of people committed to promoting adoption as a loving, family-building option. Of course, I will be happy to answer any questions that you or anybody else might have.

The National Committee for Adoption believes that the delivery of adoption services is more effective and costs less when provided by the private voluntary sector. Many children who could be freed for adoption and placed in permanent homes are caught up in the web of the public agencies' bureaucracies.

If the public sector would assertively develop purchase of service arrangements with the voluntary adoption agencies for the sole purpose of increasing the number of children freed for adoption and successfully placed in adoptive homes, I think we would see an increase in the number of children adopted.

I testified last December in the New Jersey Legislature on this very issue, recommending that the New Jersey Department of Youth and Family Services rely upon the private, nonprofit agencies to provide home-finding and adoption placement services.

So many children in New Jersey's foster care system are becoming special needs children simply because the present system allows too much time to pass before parents who are assuming no responsibility for the care of their children are forced to relinquish their rights.

I urge this subcommittee to recommend to the Department of Health and Human Services that the issue of reprivatizing adoption services be discussed as a model for the State governments to consider.

We also believe there needs to be a review of the current operations in States of the Interstate Compact for the Placement of Children. In many instances experienced by our members, the Compact procedures have hindered rather than helped the speedy adoption of children across State lines. Long delays in processing the forms, loss of important, confidential documents, and improper handling of confidential information are all examples of the negative experiences by adoption agencies.

The State of New Jersey has not entered into the Interstate Compact, and based upon the problems that I have cited and that I have heard from other agencies, the New Jersey Committee for Adoption would not want the State to participate.

In order for the Interstate Compact to really help the adoption of children, it seems to us that the review process needs to be streamlined for networks of voluntary and public licensed agencies working with exchanges and other groups to see that a waiting child can be adopted by a family in another State.

On the other side of the coin, the Compact administrators need to focus more attention on seeing that the placements of children by unlicensed intermediaries follow the Compact's rules.

Another major obstacle to getting infants and children adopted is the legal resistance to the termination of parental rights. One of the major obstacles cited by a group of children's agencies and advocates in New Jersey was the judicial system.

Admittedly, the decision to sever parental ties is a very serious responsibility for the family court judges in our country. However, the delays for children in need of homes is just as serious for the positive development of that child.

The Department of Youth and Family Services in New Jersey did a task force study last year, and to give you an idea of what I am talking about, as of June 30, 1982, of the 276 children that were in the process of litigation, 94 had been held up in litigation for over 6 months.

At the time the study was done, they were not sure how much longer these children would be held up. They did not know when the court would finally make a decision. So, you can see that it is a severe problem.

Adoptive Family groups and others concerned about children's rights to an adoptive home need to work constructively with the courts to improve termination proceedings.

In the case of a young, unmarried woman's plan for adoption for her baby, she can be frustrated by the legal requirements for the termination of the father's rights. Too often, fathers who have shown no interest throughout the pregnancy decide to claim custody after the baby is born.

A woman planning adoption is faced with the decision to allow her baby to be raised by this man and his family or to decide to forget about her plan for adoption and try to become a successful single parent.

An example of this problem is before the Supreme Court right now in the case, *Kirkpatrick* v. *The Christian Homes of Abilene*, which will be heard later this month. Past Supreme Court decisions relating to fathers' rights have been overreaching in their impact on the plans of unwed mothers to choose adoption.

Furthermore, the States have differing laws regarding the rights to notice and claiming paternity regarding adoption planning, and this creates confusion for pregnant women considering adoption.

The adoption opportunities law could direct the Department of Health and Human Services to compare State laws and the various interpretations of the Supreme Court decisions regarding the termination of parental rights, especially the putative fathers.

This brings me to the point of commenting on the proposal of S. 1003 to expand the advisory board to include those adoption activities of the Federal Government, including services to pregnant teenage girls considering adoption as a plan for their infants, and services to infertile couples wanting to adopt.

We support the intent of this provision to establish a resource panel which has experts who can link the prevention aspects of adoption to the child abuse program. We believe that one important focus for the prevention of child abuse and neglect among teenage mothers is to be sure that they have a clear understanding of their social and legal opportunities to voluntarily choose adoption for their babies, rather than trying unsuccessfully to be a single, young parent or resorting to placing their children in foster care.

I think it is important in counseling adolescents to keep in mind that many of these adolescents are 13 and 14 years old; that they have to have another alternative. They have to be made aware that they have a choice between abortion and parenting their children; that there is adoption if that is what they want and feel that they can do.

I think if we do not make this clear to them, while their babies are newborns and not "special needs" children, then they will decide to parent. Many will discover they cannot parent the child for one reason or other, whether it be economic, social, or emotional. Whatever the reason is, that child is going to become a "special needs" child in need of adoption.

So I think it is very important to include education of the public and of adolescent teenagers as to the positive aspects of adoption.

On the other hand, agencies, the national and regional adoption exchanges and adoptive family groups know from the many years of aggressive recruitment of families to adopt children with special needs that the major resource for many of the waiting children are couples experiencing infertility.

Therefore, the inclusion of experts in services to infertile couples on the advisory board is a logical response to bringing to the forefront a group that needs services in order to be successful adoptive parents to troubled, handicapped or older children with special needs, as well as infants.

Parents who make the most successful adoptive parents have resolved their infertility. In a recent hearing that was held in New Jersey in March, one of the things that was felt to be very important was that prospective adoptive parents have to be properly trained and properly aware of the circumstances they were getting into, and also, going along with that, be assured that they were making the right decision in terms of their own emotional and personal being. Services and support are needed to prevent potentially abusive adoptive family situations.

I want to close by urging the subcommittee to actively support the development of positive, marketable educational materials about adoption for school-age children. Not only would an understanding of adoption as a neat way to build a family help peers relate to their friends who are adopted, but also would help them in their support of their peers who become pregnant and must consider adoption as an alternative for their unplanned pregnancy. These materials could be used by adoptive parents for presentations.

Groups of adoptive families, adopted children who are grown up, and adoptive grandparents and relatives are the people who are part of the adoption circle who know best the joys of adoption. The Federal Government should use adoptive families as much as possible to promote adoption as a positive and possible option for more American families. The media can help, too.

I would like to submit an article for the record which has just appeared in a popular magazine which describes the adoption option for families. As the author starts out, "Adoption is possible, and adoption works because good relationships between parents and children are based on love, not biology." We agree wholeheartedly.

Thank you very much, Senator Denton, for this opportunity and I would be happy to answer any questions that you might have.

[The prepared statement of Mr. McHugh follows:]

Prepared Statement of Toni McHugh, Chairman of the Board of Directors, the National Committee for Adoption, Inc.

My name is Toni McHugh. I am the Chairman of the Board of Directors of the National Committee For Adoption (NCFA). I have served on the Board for two years and during that time also served as Co-Chairman of the New Jersey Committee For Adoption, a state affiliate of NCFA. My husband and I have two daughters, one is adopted. On behalf of the NCFA Board of Directors, the member agencies and adoptive families of NCFA's membership, I want to thank you for inviting us to appear at this hearing to testify in support of the continuation—and expansion—of the adoption opportunities law. This written statement not only covers the issues to which you invited us to testify—identifying barriers in State laws that continue to prevent permanent adoptive placement for children—but also discusses the areas where the National Committee for Adoption would like to see the Adoption Opportunities law require Federal attention.

The National Committee For Adoption is a national, voluntary membership organization for agencies, adoptive families and individuals. Through our membership, the National Committee for Adoption is working to promote to the public adoption as a positive option that: (1) enables a young, single or pregnant woman to make a choice to continue the pregnancy and make an adoption plan for her baby; (2) enables children, whose lives have been threatened by disease, or congenital disabilities, to be treated and cared for by parents who choose to adopt them when their biological parents cannot cope; (3) rescues children from growing up in inappropriate foster care or institutional care and gives them a permanent, loving adoptive family; and (4) assists homeless children from other countries to become members of loving, American families.

Because we believe so strongly in adoption as a sound, family building option, the National Committee For Adoption supports the extension and revisions of the Adoption Opportunities law as outlined in S. 1003, legislation introduced by Senator Denton and Senator Hatch on April 7, 1983. We have also submitted written testimony to the Select Education Subcommittee of the House Education and Labor Committee supporting the Subcommittee's decision to recommend re-authorization of the Adoption Opportunities law for four more years in H.R. 1904. There are many areas of adoption law and the delivery of adoption services which need to be improved to ensure that more of America's youngest, handicapped and homeless children waiting for adoptive homes get adopted. Even with a modest appropriation of $2 million per fiscal year, much can be done to increase the number of children who are made legally free for adoption and made members of new adoptive families.

The National Committee was formed in the Spring of 1980 by a group of agencies and individuals who were very concerned with a proposal called the Model State Adoption Act which had been mandated by Section 202 of the Adoption Opportunities law. We are now happy to be able to support the final version of the Model Act for the Adoption of Children with Special Needs which was published by the Department of Health and Human Services on October 8, 1981. This final Model Act focuses its attention on the barriers in State adoption laws which keep children with special needs from being adopted and it is a good example of how the Federal government can assist States in a cooperative way.

There is another effort now underway at the Department of Health and Human Services which we believe will have a positive impact on promoting adoption. Dorcas R. Hardy, assistant secretary for Human Development Services has the lead responsibility for the "Adoption Initiative" which will promote activities that will move children with special needs out of foster care and into permanent adoptive homes. Assistant Secretary Hardy has already begun to work with State and local agencies, voluntary organizations, the media and corporate leaders to increase public awareness of the problems of children waiting for adoptive homes.

As the new Chairman of the Board of Directors, I saw an increasing need for the National Committee For Adoption to focus on the entire range of adoptions. Therefore, at the Third Annual Meeting, a new, special committee of our Board was created on Service Needs for Special Children. Chaired by Theodore Kim, executive director of A.S.I.A., an agency specializing in the adoption of Korean children, the committee members include adoptive parents, such as Robert and Dorothy DeBolt, who have adopted children with special needs, and agency executive directors who are working with their State Departments of Child Welfare to see that children with special needs get adoptive homes. I am excited by the expertise of the members of the special committee and I hope that this Subcommittee as well as Assistant Secretary Hardy will see NCFA and its Board as a resource in working to encourage the participation of parents, caring professionals, adoptive family organizations, advocates, corporations and philanthropists—along with the voluntary and public child and family services sectors—to achieve real progress on behalf of those children who are relying on us to make adoption work for all who need it.

The National Committee For Adoption has appreciated the work of this Subcommittee and its Chairman, Senator Denton, in support of adoption and the continuation of programs that serve children and families, such as the Adoption Opportunities law in 1981 and the adolescent pregnancy program incorporated into the Adolescent Family Life Demonstration and Projects Act. We were invited to participate in the Adoption in America Hearing held by this Subcommittee on July 23, 1981 and urge the Subcommittee to review the testimony presented at that time for additional issues which still need to be addressed by the Federal government, including improvements in the Federal tax code on behalf of adoption as presented by Senator Jepsen.

The National Committee For Adoption sees six areas where the Adoption Opportunities law could focus Federal attention. These include:

(1) Identifying barriers to the adoption of infants and children and seeking solutions to them; (2) Promoting adoption as a positive family building option through the combined efforts of adoptive families, the business sector, and the media; (3) Reviewing the Federal tax policies for ways to encourage the adoption of children by

American families, (4) Collecting national adoption and foster care data and analyzing it, (5) Promoting improved adoption legislation and quality standards for adoption services in the States; and (6) Maintaining a national adoption exchange.

All of these areas need to focus on the adoption of children, broadly defined to include the welfare of infants at risk with life-threatening congenital impairments, infants born to teenaged, unmarried parents, and children in foster homes or institutions in need of placement in permanent, adoptive homes. The rest of this statement will expand upon these six areas of adoption issues, many of which have been included in the legislation, S. 1003, to amend the Adoption Opportunities law. While not all of these issues can be thoroughly discussed in a one-day hearing, we urge the Subcommittee to consider using the Subcommittee's investigative and oversight activities concerning adoption laws and programs to elaborate further on these topics.

IDENTIFYING BARRIERS TO THE ADOPTION OF INFANTS AND CHILDREN AND SEEKING SOLUTIONS TO THEM

The National Committee For Adoption believes that the delivery of adoption services to children and their families may be more effective when provided by the private, voluntary sector. In December, 1982, I testified on behalf of the New Jersey Committee For Adoption before a legislative hearing on the ways to improve adoption and foster care services being provided through the New Jersey Department of Youth and Family Services (DYFS). So many children in New Jersey become "hard to place" because the present system has unnecessary delays in the adoption process and allows excessive time for parents to exercise their parental rights without fulfilling their parental responsibility. The child's needs don't seem to be addressed first. The New Jersey Committee For Adoption's recommendation for improving the delivery of services was that the function of providing adoption services should be assumed by those private, non-profit social services agencies with a good record of providing high quality services while being cost efficient. By "reprivatizing" adoption services, the apparent conflict between DYFS's role as a regulator and funding agency and its role as a direct services provider could be alleviated. The proposal should also save the State of New Jersey money.

I would also like to see the issue of re-privatization of adoption services be discussed at the Federal level as a model for State governments to consider. The National Committee would like the Adoption Opportunities law to provide the arena for discussion of the development of State plans to shift more of the responsibility for the placement plans for children back to the non-profit, voluntary and sectarian child and family services sector. By "re-privatizing" adoption services in the States, children will be served more effectively and at less cost. We would encourage the Subcommittee to carefully review the current work of the Regional Resource Centers for Children, Youth and Families and consider shifting attention from these regional information centers to nation-wide working groups to tackle issues such as re-privatization of adoption services.

In States' current programs for the adoption of children with special needs, children whose adoption plans are being made by the voluntary sector are often not eligible for adoption subsidy programs and medical coverage. There is also resistance on the part of many States to allow the adoption planning work of the voluntary agency to suffice for the legal adoption. There needs to be a concentrated effort at the Federal level to identify the ways that the voluntary sector's role in promoting adoption at the State and local level can be used by the public child welfare sector to enhance the opportunities for the adoption of children waiting in foster care.

There have been legal and societal barriers to the option of adoption for infants born to teenaged, unmarried parents for over the past decade. One major obstacle to a young, unmarried woman's plan for adoption for her baby has been the legal requirements for the termination of the father's rights. Many agencies experience, along with the young women they serve, the frustrations of making adoption plans which are thwarted by putative fathers' decisions to claim custody after the child is born. An example of this problem is before the Supreme Court right now in the case, Kirkpatrick v. the Christian Homes of Abilene which will be heard later this month. The National Committee For Adoption has filed an amicus brief to the Christian Homes' case on behalf of the adoption plan for a baby born out of wedlock to a fifteen-year-old girl. Kirkpatrick, the father of the baby, decided after the bay's birth to file for paternity as well as custody of the child, even though he had been involved with the young mother in planning for the adoption of the child prior to its birth. Past Supreme Court decisions relating to fathers' rights have been overreaching in their impact on the placement of infants for adoption, the National Committee For Adoption believes. Furthermore, the States have differing laws regarding the rights of putative fathers in relationship to adoption planning and this creates a barrier to adopting across State lines, when one state will not accept the binding law and practice of the placing agency in another State. The Adoption Opportunities law should include a recommendation that among the legal issues reviewed by the Federal government should be the comparison of State laws—and the various interpretations of Supreme Court decisions—regarding putative fathers' rights.

A federal law, the Indian Child Welfare Act, has presented a barrier to many young pregnant women who are of Indian heritage, because their privacy cannot be maintained if they choose to make an adoption plan. The law requires the Indian tribe to be notified of the plans for adoption. Often a young woman, estranged from her family and Indian tribe because of her pregnancy, decides to leave her home area and try to parent rather than have her unplanned pregnancy known by the entire tribal council. We recommend that these issues be explored by the Office of Human Development Services, in coordination with the Bureau of Indian Affairs, which administers the Indian Child Welfare Act, and the Office of Adolescent Pregnancy Programs which is working to ensure adequate adoption referral and counseling services for pregnant young women.

As the Subcommittee is aware through its work on behalf of the Adolescent Family Life law, providing opportunities for adoption counseling and referral services to pregnant, unmarried teenagers is important. The National Committee supports the broadened focus of S. 1003 which includes providing opportunities for presenting adoption infomation, education and training materials to public and private agencies and organizations. The examples of service providers in Section 203 (b)(2), which would receive such information and training about the adoption alternative, includes hospitals, health care and family planning clinics and social services agencies. These will be useful groups to have an impact on in order to remove the informational barriers to adoption.

We would like to comment briefly on the proposal of S. 1003 to expand the advisory board to include those adoption activities of the Federal government, including services to pregnant, teenaged girls considering adoption as a plan for their infants. The National Committee supports the efforts of this provision to establish a linkage between preventing child abuse and neglect and providing adoption opportunities. As Commissioner Hodges stated in his testimony on April 11, 1983, before the Subcommittee, there is evidence that there is a great need to prevent teenaged mothers from becoming abusive and neglectful to their small children. One importnat focus for the prevention of child abuse among teenaged mothers is to be süre that a clear understanding of the social and legal opportunities of choosing adoption for their babies rather than trying to parent is available to all pregnant teenagers.

With respect to the Intestate Compact for Placement of Children which is adhered to by the majority of the States, the possibility that the Compact procedures hinder rather than help the adoption of children across State lines needs to be examined by the Federal government. There needs to be review of the current operations by State governments of the Compact procedures, taking into account the experiences of the National Adoption Exchange, regional and State exchanges, and the voluntary, non-profit adoption agencies working to place waiting children from one State with a waiting family in another State. Member agencies of the National Committee For Adoption have experienced long delays, loss of important, confidential records, and the improper handling of confidential information in their efforts to comply with the requirements of the Compact administrators in some States. While the Adoption Opportunities law has already funded efforts to improve the Compact's effectiveness, it seems that a more thorough review as well as revisions may be necessary to eliminate barriers of adoption across State lines currently caused by the Interstate Compact for the Adoption of Children.

For example, the State of New Jersey has not entered into the interstate Compact, and based upon the problems experienced by agencies of the National Committee For Adoption, the New Jersey Committee For Adoption does not recommend that New Jersey accept the Compact. In order for the Interstate Compact to really help the adoption of children, it seems to us that the review process needs to be streamlined for networks of voluntary, licensed agencies working to place waiting children across the State lines. On the other side of the coin, the States' Compact administrators need to focus more attention on seeing that the placement of children by unlicensed intermediaries is monitored carefully under the Compact's rules.

The National Committee is pleased that S. 1003 retains the role of the Federal government in studing the effects of unlicensed adoption placement on families. Not only are non-agency adoption "practitioners" often deficient in the way they serve infertile couples desperately wanting to adopt a baby, but also they are often coercive to vulnerable young pregnant women. This area of "black-market" adoption is still with us, and following fast in its tracks are the legal problems with surrogate mother contracts. These surrogate arrangements currently rely on perversion of States' adoption laws for "legality". The National Committee For Adoption is currently reviewing the various State legislative proposals which are either trying to legalize or out-law surrogate contracting. We plan to issue a position paper on our concerns with this faddish way of getting a baby. We welcome the provision in S. 1003 which would allow the activities of the adoption opportunities law to provide an arena for further debate on these nation-wide adoption-for-profit ventures.

The National Committee is also hopeful that professional groups such as the American Bar Association, the American Fertility Society, The American Academy of Pediatrics, etc., as well as the Federal government, would come out strongly in saying that independent, unlicensed, non-agency adoptions are unwise, and that all States should join the six States that have already made independent adoptions illegal. Short of that, we believe that work is needed to ensure that laws protect children who are placed through non-agency channels by requiring all of the same procedures required of licensed adoption agencies, such as a pre-placement home study showing that the prospective adoptive parents are suitable for the specific child involved and that the biological parents get adequate counseling and that all legal requirements are followed.

The National Committee For Adoption urges this Subcommittee and the Federal government to carefully examine the best interests of the child who is being adopted by parents of a different race or culture. We strongly support the statement of Rev. George Clements during the 1981 Adoption in America hearing before this Subcommittee when he answered Senator Denton's question about transracial adoption this way: "... I accept for an Anglo couple, or whatever nationality, rather than having that Black child languish in an institution." The courts also seem to agree with Father Clements. The State of New York Court of Appeals recently upheld the adoption of three Black children by a White couple and the D.C. Court of Appeals allowed a young Black girl who has lived with White foster partents from infancy to remain in that family as their adopted daughter. Even as the number of Black children in foster care remains disproportionate while White couples increase their pursual of transcultural adoption of foreign children, there are still groups who call for the abolition of all transracial adoptions. We urge the Federal Government to work cooperatively with all racial and ethnic groups to encourage them to adopt, but at the same time not dismiss the positive alternative of placing children in homes across cultural or racial lines when compared to numerous foster care settings or institutional care.

Another barrier to the adoption of children is the growing acceptance by a small but vocal minority that adoptive families must accept "open adoption" procedures in order to be successful parents. By "open adoption" we mean the requirement that identifying information about the biological parents and adoptive parents be shared, and that agreements must be made allowing the biological parents or other close relatives "visitation rights" after the adoption is finalized. These experiments in adoption planning are not child-focused, but rather are to meet the demands of a few biological parents, adoptive parents, and adoption "practitioners" who believe that privacy in adoption planning and for adoptive families is "unhealthy". The National Committee For Adoption, based upon the decades of experience of our member agencies, believes otherwise. Adopted children deserve the security of one legal family. Parents who choose not to parent voluntarily, or who are found by the child welfare system not to be fit parents, should he granted privacy in order to make an adoption plan for their children. State laws must maintain the building of adoptive families as a professional and confidential service.

Finally, but not least of all important, is eliminating the barriers to adoption information and referral for parents of an infant at risk with life-threatening congenital impairments. The National Committee For Adoption supports the efforts of adoption agencies to make sure that health care facilities have information about adoption to furnish the parent of a handicapped infant. We believe that increased attention and activities under the Adoption Opportunities law is necessary to ensure that the opportunity for adoption can be considered as a positive alternative for those parents who cannot cope with a handicapped infant. The National Committee also supports the concrete suggestions offered by the Rossow Family at the Subcommittee hearing on April 6, 1983, for supporting parents of handicapped infants. Among the recommendations made by the Rossows was the recommendation that the decision-making process be slowed down, so that the baby is taken care of while the parents learn a sufficient amount about the handicapping condition and the supportive services and groups, including other parents, knowledgeable about the handicapping condition, which are available in the community. Another interesting proposal, which should be reviewed by the Department of Health and Human Services as to the legal ramifications is the automatic termination of the parental rights and the initiation of the adoption process upon the decision of the biological parents not to treat their infant. The National Committee's member agencies are knowledgeable about the positive possibilities of the adoption of handicapped infants and based upon these experiences we believe that making this option available to parents in distress should be an essential component of any health facility's services to handicapped infants and their parents.

PROMOTING ADOPTION AS A POSITIVE FAMILY-BUILDING OPTION THROUGH THE COMBINED EFFORTS OF ADOPTIVE FAMILY GROUPS, CORPORATIONS AND SMALL BUSINESSES, AND THE MEDIA

Those who know best the joys of adoption are the people who are part of the adoption circle . . . adoptive parents, adopted children, adoptive grandparents and relatives, as well as the biological parents who know they made the best decision in planning adoption for their child. Groups of adoptive families should be utilized as much as possible by the Federal government in promoting adoption as a positive and possible option for more American families.

One way to encourage people to adopt is by recognizing the expenses involved in adopting a child and treating those expenses in a fashion identical to the medical costs of a pregnancy. One group which can help here are corporations, small businesses, and all employers who offer fringe benefit programs. There is a growing group of major corporations which are providing adoption benefits to their employees who adopt. The National Committee For Adoption assists these companies by providing samples of adoption benefit programs, and we link up the employee benefit officers of a company considering the plan with those companies which already offer the plan. Mr. Bruce Mueller, who has been invited to testify before this Subcommittee, is a good example of a member of the corporate comumity who has been a "patron saint" for the promotion of adoption benefit programs across the country.

We are very supportive of the new section 203(b)(5) which encourages the involvement of corporations and small businesses in supporting adoption, including the establishment of adoption benefit programs for employees who adopt children.

REVIEWING THE FEDERAL TAX POLICIES FOR WAYS TO ENCOURAGE THE ADOPTION OF CHILDREN BY AMERICAN FAMILIES

The National Committee supports the use of the Federal (and State) tax codes to give special treatment to families who adopt. While we realize that amendments to the Internal Revenue Code are not within the jurisdiction of this Subcommittee, we wanted to take this opportunity to encourage members of the Subcommittee and others in the Senate who are supportive of the following proposals to discuss them with their colleagues who are members of the Senate Finance Committee and to encourage the Administration to take a positive look at improvements in the tax code which would positively reinforce adoption as a positive family-building option.

We owe a great deal of gratitude to Senator Jepsen for his determined advocacy on behalf of adoptive families during the debate and conference deliberations on the Economic Recovery Tax Act of 1981. It was his commitment, supported by Senators Bentsen, Cranston, Durenberger, Hatfield, Hawkins, Levin and Metzenbaum, which assured the enactment by Congress of the first, positive amendment to the tax code for adoptive families: a deduction up to $1,500 for the expenses of an adoption of a child with special needs. Sen. Jepsen also testified before this Subcommittee in July, 1981, in support of more comprehensive adoption tax-deduction legislation.

These are the provisions the National Committee For Adoption would suggest should be included in a comprehensive tax bill for adoption:

(1) Exemption of $1000 for each child adopted ($3,000 for each child with special needs) during the year the adoption took place; (2) Allowance of a tax deduction for the total costs of an adoption, in accordance with State law, including infant, special needs or foreign child and relative adoption and excluding surrogate mother arrangements; (3) Election for an adoptive family to take a tax credit in lieu of a tax deduction for adoption expenses; (4) Exclude from employee's income adoption expenses paid by an employer; and (5) Treat employer contributions to adoption expense plans as an ordinary and necessary business expense.

All of these provisions were in bills introduced in the 97th Congress, S. 1580, introduced by Sen. Jepsen, and S. 1479 introduced by Senators Metzenbaum and Hawkins. If such comprehensive tax legislation for adoption expenses were enacted it would result in cost-savings to the Federal government by decreasing foster case expenses. Several states have tax deductions for adoption expenses or are considering such legislation. We encourage the Federal government to set an example so that more States will consider tax legislation.

COLLECTING NATIONAL ADOPTION AND FOSTER CARE DATA AND ANALYZING IT

Since 1975, there has been no Federal report on the number and characteristics of children adopted each year in the United States. The last report, "Adoptions in 1975" was issued by the National Center for Social Statistics, Department of Health, Education and Welfare in 1977 and relied upon the voluntary reporting of only thirty one States. Recognizing the need for detailed national statistics on adoption, the Adoption Opportunities law of 1978 mandated the Department of Health, Education and Welfare to create a system for gathering national statistics. Unfortunately, this requirement of the law has yet to be carried out effectively. It will soon be a decade since the Federal government has collected, in a reliable way, data about the number of children adopted or the number of children free for adoption in all States, annually. No one at the national level can reliably say how many children have been adopted since the enactment of the Adoption Opportunities law in 1978. No one can reliably say how many adoptive families there are in the United States today. No one can reliably say how many children still wait for adoptive families in the United States today. No one can describe those children who have been adopted, or are waiting for adoptive homes, as to their ages, race, physical and emotional characteristics and health. No one can describe the characteristics or numbers of women who choose adoption as a plan for their "unplanned" babies. The National Committee For Adoption urges the Subcommittee to carefully review the efforts of the Department of Health and Human Services to collect this important data.

The National Committee For Adoption, in an effort to better present the adoption picture, has been discussing the important need for adoption "numbers" with several officers of the Federal government, including the Bureau of the Census, the National Center for Health Statistics, the Office of Adolescent Pregnancy Programs, and the Office of human Development Services. We believe that more accurate information about the number of children living in adoptive homes could be collected through nationwide Census efforts rather than through reliance on voluntary State government reporting. We were very encouraged by Bureau of the Census Director Chapman's final remarks in this written testimony before this Subcommittee on March 29, 1983, where he achnowledged the lack of data concerning adoption and his desire to do more extensive investigation on this topic through census data.

We also believe that statistically reliable sample data, such as is collected in the National Family Growth Survey can also provide useful information about the characteristics of adopted children after they have joined their adoptive families. For example, an article by National Center for Health Statistics official, Dr. Christine A. Bachrach, using National Survey data of 1976, reports that adopted children were better off economically than children living with never married biological mothers. ("Children in Families: Characteristics of Biological, Step-, and Adopted Children", Christine A. Bachrach, Journal of Marriage and the Family, Feb. 1983, pg. 171-179.)

Therefore, the National Committee strongly supports the amendments included in Section 201(2)(B) and Section 203(b)(1) of S. 1003 that require HHS to consult with other appropriate HHS agencies and Federal departments, including the Bureau of the Census, for the establishment of an on-going adoption and foster care data gathering and analysis system, thereby not relying solely on voluntary state reporting.

PROMOTING IMPROVED ADOPTION LEGISLATION IN THE STATES

Section 202 of the current Adoption Opportunities law required the Department of Health and Human Services to publish model adoption legislation. On October 8, 1981, the Department of Health and Human Services published in the Federal Register the "Model Act for the Adoption of Children with Special Needs". This model act includes useful model statutory language for providing financial assistance to families who adopt special needs children; expanding the grounds for adjudictions freeing children for adoption; and clarifying the role of voluntary adoption agencies and the State adoption administration in arranging and providing support services for adoption. This Act is important because most adoption law is developed, enacted and implemented at the State level. The Model Act recognizes the need for improved State laws to free children for adoption and to improve services to adoptive families. This Model Act, as recommended by S. 1003, could also be reviewed by the Department of Health and Human Services for suggested additions to facilitate adoption opportunities for those "special needs" infants at risk with life-threatening congenital impairments. We support S. 1003's amendment for Section 202 which calls for the Secretary of Health and Human Services "to encourage and facilitate the enactment in each State of comprehensive adoption assistance legislation . . ." This process will be accomplished best with the cooperation of national, state and local child and family services organizations, including those representatives of minorities and adoptive families.

Because the National Committee For Adoption strongly endorsed the final Model Act, we secured private foundation funds to publish the Model Act for the Adoption of Children with Special Needs accompanied by a Section-by-Section Comment and Analysis. The National Committee feels that the Model Act deserves promotion and careful study by the State legislatures and believes that the Adoption Opportunities law should encourage HHS to assist States in using the Model Act. A copy of the National Committee's publication is included for the Subcommittee's review.

PROMOTING QUALITY STATE STANDARDS FOR ADOPTION SERVICES

The adoption of children is a complex social and legal procedure. Well-trained professionals working within the structure of public and private, non-profit agencies need the support of high standards issued by the regulatory, governmental bodies, as well as those instituted by voluntary agencies' boards of directors to do their jobs well. The Federal government need not write standards, but should be well informed about the availability of written standards of national organizations, State governments, and professional groups which would improve adoption services in some areas for some States. Information about as well as assistance in improving State standards is essential at the Federal level. The Adoption Opportunities law should direct the Department of Health and Human Services to promote quality services in several areas of adoption services including pregnancy counseling which presents adoption as a positive alternative to young, single or troubled parents; pre-placement, post-placement and post-legal adoption counseling and support services to families; and adoption subsidy and medical assistance plans and corresponding services necessary to implement these plans.

The National Committee For Adoption is working to develop a set of standards for adoption, pregnancy counseling and maternity services. At a national conference held last October, a set of principles for adoption services was discussed. This February, a conference was held to discuss principles for pregnancy counseling. Copies of these principles, which will form the basis of further standard development work this year, are included for the Subcommittee's review.

Another example of the development of model standards is currently being completed by a group of State and non-profit, voluntary child-placing agencies concerned about the importance of post-legal adoption services. This group is working under the direction of the Children's Home Society of Minnesota towards the development of a comprehensive "Model Statement on Post-legal Adoption Servces." It is the plan of the group of agencies involved to disseminate the Model Statement to national organizations, such as the Child Welfare League of America, the Council on Accreditation of Services to Children and Families, the Naitonal Committee For Adoption, the National Council of Juvenile And Family Court Judges, and the North American Council on Adoptable Children. These national organizations can then give consideration and possible endorsement to the Statement. All of the work to date has been completed without Federal funds. The Federal government could do much, however, to study, discuss and disseminate the results of this Statement or others like it on the need for on-going services to adoptive families, especially those who adopt children with special needs.

MAINTAINING A NATIONAL ADOPTION EXCHANGE

The concept of a national adoption exchange has matured under the funding and guidance of the Adoption Opportunities law. Seeing to it that waiting children from all parts of the country can be matched with waiting, approved adoptive families from other parts of the country is an important area for Federal involvement. These are America's waiting children, and they should not be limited in their oppotunities to be adopted by having to wait for an appropriate family from the State in which they are currently being cared for. The national adoption exchange should be maintained under the Adoption Opportunities law. We urge the Subcommittee to carefully review the development of the Nationai Adoption Exchange, its services to waiting children and waiting families, and its coordination with regional and State exchanges across the country. The country should have a system using telecommunications and computerized matching procedures so children waiting for homes can find them regardless of where they live in the United States.

With foundation grants and private contributions, the National Committee For Adoption operates the National Adoption Hotline, (202) 463-7563. This information and referral, telephone service offers an opportunity for prospective adoptive parents to learn more about waiting children with special needs. The volunteers have participated in a training session with the director of the National Adoption Exchange, Marlene Piasecki, so that appropriate referrals to the National Adoption Exchange can be made by the National Adoption Hotline. We plan to coordinate our efforts with those other groups and projects, based on our experience and the improved results for children as the National Adoption Exchange is implemented, to assure that Federally-funded and privately-funded efforts reach as many as possible with accurate information about adoption.

Finally, the National Committee For Adoption urges the Subcommittee to consider giving recognition to adoption as a loving, family-building option by designating the month between Thanksgiving and Christmas as National Adoption Month. Over the past several years adoptive families have joined the Congress in celebrating National Family Week during Thanksgiving Week. For example, the New Jersey Committee For Adoption, in conjunction with the New Jersey Catholic Conference, Bethany Christian Services and OURS held an "Adoption Fair", the first of its kind in New Jersey on November 21, 1982. Marking the beginning of National Adoption Week, and National Family Week, the Fair provided information for those who had adopted and for those who wanted to adopt.

Information about the newly enacted Amerasian adoption law as well as other adoption opportunities were discussed by local and national resource people. We believe that by formally establishing through the Adoption Opportunities law the time between Thanksgiving and Christmas as a time for recognition of adoption as a wonderful way to have a Family, this will serve as an important factor in gaining media interest and support in promoting adoption during a happy, family-focused time for our Nation each year.

Thank you for the opportunity to present the National Committee For Adoption's views about the important role the Adoption Opportunities law does have—and can continue to have—in helping children get adopted. We support the reauthorization of the Adoption Opportunities law, and hope the suggested changes for the law included in S. 1003, will be enacted into law.

Senator DENTON. We will have some for you, Ms. McHugh; thank you very much.

Ms. Sreedhar.

Ms. SREEDHAR. Mr. Chairman, my name is Kathy Sreedhar and I am the adoption representative for Mother Teresa's organization in the United States. I appreciate the opportunity to discuss your commendable effort to strengthen the adoption opportunities program.

You have heard testimony on many occasions regarding the plight of the countless thousands of children in the United States who do not have permanent families. Therefore, I would like to use my time this morning to describe briefly how Mother Teresa's program works in the United States, and draw on our experience in effectively placing special needs children to suggest some approaches you may want to consider in improving the adoption opportunities program.

Mother Teresa's order, the Missionaries of Charity, is an international organization serving the poorest of the poor in 31 countries. The Missionaries of Charity is licensed by the Government of India to place homeless children for adoption both incountry and intercountry.

Since 1974, they have successfully placed approximately 100 special needs children per year in permanent adoptive homes in 36 States throughout the United States, at a cost of $800 per child, not including air fare.

I work as a volunteer, in addition to being a single, working mother of three children, two of whom I adopted from the Missionaries of Charity. The children we place for adoption all have special needs. They are dark-skinned, come from unknown, deprived backgrounds, and suffer from a variety of diseases. A majority have physical, emotional or mental handicaps, are of school age, part of a sibling group, or a combination of the above.

Every parent who adopts a child from the Missionaries of Charity has an approved home study from a licensed adoption agency, and has met the preadoption requirements not only of the State and the Immigration and Naturalization Service, but also of the Missionaries of Charity and of the Government of India.

Most of these qualified families actively sought a special needs American child either instate or interstate. They were unable to adopt one because of Government and agency regulations, policies and procedures which discouraged rather than facilitated their adoption. I will highlight just a few of these which have direct impact on the families who applied to us.

Local agencies have authority and control over the children in their care, but are still subject to little, if any, review or accountability. Many still have no accurate information on the number and status of children in their care, much less share this information with other agencies or register them on exchanges.

They do not always provide information or home studies to waiting parents, nor enable parents to have access to children across State lines.

The exchanges have no authority to place children, even though they provide necessary information and services. Some waiting children have been listed on the exchanges for years. While a national exchange system which permitted prospective adoptive parents as well as agencies to register would be helpful, it would not solve the problem of local agency authority over the children.

Many agencies impose rigid and restrictive criteria both in judging overall parenting ability and in selecting parents for specific available children. They do not use the families who seek to adopt the waiting children.

Consider just a few examples of families unable to adopt an American special needs child who successfully adopted the same kind of child from India. All of these families had approved home studies and met their States' preadoption requirements.

In Iowa, a Republican delegate and his wife could not adopt a hard to place child locally, nor have their home study referred to another State, because their agency would not consider families who already had biological children. They adopted from Mother Teresa a 4-year-old boy with no use of his legs.

In Maryland 5 years ago, a family sought to adopt any child, regardless of age, handicap, race or sex. The local agency claimed there were no children available. They adopted from the Missionaries of Charity an 8-year-old post-polio girl who was mentally retarded.

Last year, this family and many families in their adoptive parent group attempted to adopt a special needs child using the exchange books which this bill made possible. None succeeded because the local agencies with authority to place children would not move them across State lines.

This family, just a few weeks ago, adopted another girl from Mother Teresa, who was 11 years old, had never attended school, and is physically and mentally handicapped.

Another family had two biological children and adopted a third who was legally blind and multiply handicapped. They requested a fourth child with any handicap under the age of 6 and identified through the exchange books twin girls in another State with the same problem as the child they already adopted.

Their local agency approved their home study only for an older child, and refused to submit the home study to another State. They just adopted from India a 2-year-old, failure to thrive girl with multiple congenital impairments.

These families are among the 10,000 every year who contact me about adoption. I reply with a form letter, included in the hearing record, which describes the placement process. This letter emphasizes the condition and problems of the children and the requirements necessary to adopt them.

When informed of the children's needs, the risks involved in adopting them and the long and complicated requirements, approximately 200 initially select themselves as motivated and able to undertake the risks and challenges of adopting a special needs child.

These parents who decide to proceed must have an approved home study and meet all the United States and Indian requirements. The Missionaries of Charity asks only that families write a letter describing themselves and their reaction to my description of the children.

We do not have criteria regarding age, marital status, family size, handicaps, or education, as we do not believe parenting ability is determined by these factors. This flexibility enables us to place even the hardest to place children with loving parents.

Thus far, we have found no child to be unadoptable. This month, Krishna, a 7-year-old athetoid, quadreplegic boy, who neither walks nor talks, was adopted by a family in Washington.

The families maintain at least yearly contact with the Sisters and report that the children are flourishing and the adoptions successful. Less than 2 percent of the children, all of whom were of school age, have been replaced with other families, compared to a national disruption rate of 15 to 25 percent for these children.

The Missionaries of Charity has successfully placed thousands of special needs children in permanent adoptive homes in India, the United States, and throughout the world primarily because of commitment to the children. Mother Teresa believes that the biggest disease is the feeling of being unwanted, uncared for, and deserted by everybody.

The program works also because it focuses only on placing these most needy children, is flexible, relies heavily on the self-selection process, and makes use of volunteers, adoptive parents, and other community resources throughout the placement process. It also costs less than most U.S. adoptions.

As a context for my comments on this bill, I would like to say that I appreciate this committee's interest in the problems that cause the breakdown in families and result in the children being separated from them. Your support of child welfare legislation which strengthens families and offers services which prevent children from getting into the foster care system is essential. However, it is also critical to provide programs which enable the children to get out of the system.

If the purpose of this bill is to enable homeless children to have an opportunity to be adopted, surely it can be phrased so that proven approaches such as those I have outlined are encouraged and supported.

I am concerned that the bill, as amended, has been broadened to include a number of programs and services which as important as they may be, do not have a direct impact on the waiting, special needs children, and have already been funded by this and other legislation.

More important, I fear these programs will dominate the use of funds and take away from initiatives that benefit the children. Since this is the only major bill with specific funding for these most vulnerable and otherwise ignored children, I strongly urge you to urge the limited funds for programs that effectively facilitate their adoption.

Since others will testify on specific sections, I will comment on only one finding. The bill adds infants born to unmarried parents to those who may be in serious jeopardy and are in need of adoptive placement.

Children of unmarried parents are not necessarily either in jeopardy, nor available for adoption. In fact, 10 percent of the Missionaries of Charity's adoptive parents are single and have successfully parented the most hard to place children. In addition, we use single parents for children who have had to be replaced from two-parent families.

I urge you to change this language and focus instead on the children most in need of adoption who have been waiting for years. I have been informed that unmarried parents refer to teenagers. Nevertheless, it is a little unclear.

I strongly recommend that the bill continue its original intent to meet the still unmet needs of the homeless adoptable children waiting for homes. The previous bill led to the development of a number of programs which met these needs.

These volunteer, private, and other efforts which you have supported, as well as the Missionaries of Charity, have demonstrated that they can solve problems, eliminate barriers, and succeed in placing special needs children and families.

I hope you continue to invest in initiatives like these, whose sole purpose is to place a specific number of, and specific available, children. They need only small amounts of money to continue their work.

I urge that this bill make specific provisions for strong, creative programs that actually result in the placement of children, which is the only measure of success. If we truly cannot afford to increase spending for these children, then we cannot afford to spend the limited funds on anything but moving children from the foster care system to permanent homes.

I know you recognize that the adoption opportunities program addresses only a small part of the need for services for adoptable children, particularly those with special needs. The major barriers that impede permanence for children are addressed in the Adoption Assistance and Child Welfare Act. I urge you also to implement and enforce the act and support its existence separate from bloc grants.

In closing, I want to emphasize that if this society and this committee have the same commitment as Mother Teresa to the unwanted, uncared for, and deserted, it will use all available resources to relieve the daily burden of the poorest and homeless children.

I thank you for inviting me to testify this morning, and I fervently hope there will be no need to testify 5 years from now on the same number of children needing homes, some of them exactly the same children as are waiting today.

I appreciate and, more important, the waiting parents and children are grateful for your efforts to bring them together. I will be happy to answer any questions.

[The prepared statement of Ms. Sreedhar follows:]

PREPARED STATEMENT OF KATHY SREEDHAR, ADOPTION REPRESENTATIVE, MISSIONARIES OF CHARITY

Mr. Chairman, members of the subcommittee, my name is Kathy Sreedhar and I am the Adoption Representative for Mother Teresa's organization in the United States. I appreciate the opportunity to discuss your commendable effort to strengthen the Adoption Opportunities Program, authorized in 1978 as part of the Child Abuse Prevention and Treatment and Adoption Reform Act.

You have heard testimony on many occasions regarding the plight of the 100,000 children in the United States legally free for adoption and the thousands more in long term foster care, who are in need of permanent families. Many of these children have begun to recognize the benefits of the Adoption Opportunities Program and the Adoption Assistance and Child Welfare Act (Public Law 96-272). However, an estimated 100,000 adoptable children, many with special needs, are still waiting for homes, while qualified families continue to face insurmountable obstacles in seeking to adopt them. This bill is needed to address the barriers and to support the initiatives that actually place these children, particularly those with special needs, in adoptive homes.

I shall describe briefly how Mother Teresa's program works in the United States and draw on our experience in effectively placing special needs children to suggest some approaches you may want to consider in improving the Adoption Opportunities Program.

Mother Teresa's order, the Missionaries of Charity, is an international organization serving the poorest of the poor in 31 countries in many ways. The Missionaries of Charity is licensed by the Government of India to place homeless children for adoption, both in-country and inter-country. Since 1974, they have successfully placed approximately 100 special needs children per year in permanent adoptive homes in 36 states throughout the United States at a cost of $800 per child, not including air fare.

I work as a volunteer, in addition to being a single working mother of 3 children, 2 of whom I adopted from the Missionaries of Charity.

The children we place for adoption all have special needs. They are dark skinned, come from unknown, deprived backgrounds and suffer from a variety of diseases. A majority have physical, emotional or mental handicaps, are of school age, part of a sibling group, or a combination of the above.

Every parent who adopts a child from the Missionaries of Charity has an approved homestudy from a licensed adoption agency and has met the preadoption requirements, not only of the State and the Immigration and Naturalization Service, but also of the Missionaries of Charity and the Government of India. Most of these qualified families actively sought a special needs American child, either in state or interstate. They were unable to adopt one because of government and agency regulations, policies and procedures, which discouraged rather than facilitated adoption. For example:

Federal and State funding incentives and mechanisms for foster care and adoption still encourage agencies to maintain children in care rather than placing them in an adoptive home.

Local agencies have authority and control over the children in their care, but are still subject to little, if any, review or accountability. Since these agencies do not benefit from moving their children, they do not enable parents to have access to children across state lines.

The exchanges have no authority to place children, even though they provide necessary information and services. Since all agencies must cooperate in order for the exchange to work, some waiting children have been listed for years. While a national exchange system, which permitted prospective adoptive parents as well as agencies to register would be helpful, it would not solve the problem of local agency authority over the children.

Many agencies impose rigid and restrictive criteria, both in judging overall parenting ability and in selecting parents for specific available children. They do not use the families who seek to adopt the waiting children.

Though many agencies are overworked, understaffed, underpaid and under trained, they make little use of community resources, adoptive parent groups, volunteers or team approaches. Consider a few examples of families unable to adopt an American special needs child who successfully adopted the same kind of child from India. All these families had approved homestudies and met their State's preadoption requirements.

In Iowa, a Republican delegate and his wife could not adopt a "hard to place" child locally, nor have their homestudy referred to another State because their agency would not consider families who already had biological children. They adopted from Mother Teresa a 4 year old boy with no use of his legs.

In Maryland, 5 years ago, a family consisting of a doctor, teacher of the learning disabled, and 4 children, sought to adopt any child regardless of age, handicap, race or sex. Their local agency claimed no children were available. They adopted from the Missionaries of Charity an 8 year old post polio girl who is mentally handicapped. Last year, the L's and many families in their adoptive parent group attempted to locate and adopt a special needs child, using the exchange books which this bill made possible. Neither they nor anyone in their parent group succeeded because the local agencies with authority to place children would not move them across state lines. The L's recently adopted another girl from Mother Teresa, who is 11 years old, had never attended school and is also physically and mentally handicapped.

The X's had 2 biological children and adopted a third who was legally blind and multiply handicapped. They requested a fourth child with any handicap under the age of six and identified through the exchange books twin girls in another state with the same problems as the child they already adopted. Their local agency approved them only for an older child and refused to submit their homestudy to another state. They adopted from India a 2 year old, failure to thrive girl, with multiple congenital impairments. This family agreed to my telling their story, but not to my identifying them, because they feared their agency would not approve them for a fifth "hard to place" child.

In Massachusetts, Miss J, a teacher, found insurmountable barriers to adopting in the United States because she is single. Over the last 6 years she has adopted from India 4 school age girls: one has spina bifida, 2 are abused siblings and the 4th was replaced from another family.

These families are among the 10,000 per year who contact me about adoption. I reply with a form letter, included in the hearing record, which describes the application, selection, placement, post-placement, finalization and post-adoption follow-up process. This direct, reality based letter emphasizes the condition and problems of the children and the requirements necessary to adopt them. When informed of the children's needs, the risks involved in adopting them, and the long and complicated requirements, approximately 200 initially select themselves as motivated and able to undertake the risks and challenges of adopting a special needs child from India. These parents who decide to proceed must have an approved homestudy and meet all the requirements of the agency, State, Immigration and Naturalization Service and the Government of India. The Missionaries of Charity ask only that families write a letter describing themselves, their motivation for adopting a child with special needs and their reaction to my description of the available children and that they contact parents who have already adopted a child from India. We do not have criteria regarding age, marital status, family size, handicaps, education or finances as we do not believe parenting ability is determined by these factors. This flexibility enables us to place even the "hardest to place" children with loving parents. Thus far, we have found no child to be unadoptable. This month, Krishna, a 7 year old athetoid quadreplegic boy, who neither walks nor talks, was adopted by a family in Washington.

The families maintain at least yearly contact with the Sisters and they and their agencies and parent groups report that the children are flourishing and the adoptions are successful. Less than 2% of the children, all of school age, have been replaced with other families—compared to a national disruption rate of 15-25 percent for these children.

The Missionaries of Charity have successfully placed thousands of special needs children in permanent adoptive homes in India, the United States and throughout the world, primarily because of commitment to the children. Mother Teresa believes that "the biggest disease is . . . the feeling of being unwanted, uncared for and deserted by everybody."

The program works also because it focuses only on placing these most needy children, is flexible, relies heavily on a self selection process, makes use of volunteers, adoptive parents and other community resources throughout the placement process and costs less than most United States adoptions.

If the purpose of this bill is to enable homeless children to have an opportunity to be adopted, surely it can be phrased so that proven approaches such as those I have outlined are encouraged and supported. Five years ago, this bill did focus on these especially needy children and began to promote programs which actually resulted in the placement of these children in families.

However, I am concerned that the bill, as amended, has been broadened to include a number of programs and services which, important as they may be, do not have a direct impact on the waiting special needs children and have already been funded by this and other legislation. More important, I fear these programs will dominate the use of funds and take away from initiatives that would benefit these children. For example, the bill calls for additional Advisory Boards, mechanisms to promote standards, clearing houses and studies. Though I welcome a study of the Missionaries of Charity and efforts like ours, I ask you not to use federal funds for this purpose, but only for programs that directly serve the children. Since this is the only major bill with specific funding for these most vulnerable and otherwise ignored children, I strongly urge you to use the limited funds for programs that effectively facilitate their adoption.

Since others will testify on specific sections of the bill, I will comment on only one finding before making a few recommendations.

In Section 7(a)(1) the bills adds "infants born to teenaged individuals and unmarried parents" to those who may be in serious jeopardy and are in need of adoptive placement. Children of unmarried parents are not necessarily either in jeopardy nor available for adoption. In fact, 10 percent of the Missionaries of Charity's adoptive parents are single and have successfully parented the most "hard to place" children. In addition, we use single parents for children who have had to be replaced from two parent families. I urge that you exclude these infants and focus instead on the children most in need of adoption who have been waiting for years.

I strongly recommend that the bill continue its original intent—to meet the still unmet needs of the over 100,000 homeless, adoptable children waiting for permanent homes. The previous bill led to the development of a number of programs which met these needs. These volunteer, parent group agencies and other efforts which you have supported, as well as the Missionaries of Charity, have demonstrated that they can solve problems, eliminate barriers, and succeed in placing special needs children in families. I hope you continue to invest in initiatives like these whose sole purpose is to place a specific number of and specific available children and who need only small amounts of money to continue their work. I urge that this bill make specific provisions for strong, creative programs that actually result in the placement of children—the only measure of success. Funds could be made available for demonstration or service projects designed to get children adopted. Consider a few possibilities:

Programs which would overcome jurisdictional barriers and move children across state lines; programs which would encourage public and private and volunteer sector partnerships to facilitate adoption; and programs which would enable United States agencies who have already developed successful approaches to train others.

If we truly cannot afford to increase spending for these children, then we cannot afford to spend the limited funding on anything but moving children from the foster care system to permanent adoptive homes.

I know that you recognize the Adoption Opportunities Program addresses only a small part of the need for services for adoptable children—particularly those with special needs. The major barriers that impede adoption are addressed in the Adoption Assistance and Child Welfare Act (P.L. 96-272). I urge you also to implement and enforce the Act and support its existence separate from block grants. Your support of the Education for all Handicapped Children's Act (P.L. 94-142), the Crippled Children's Program included in Maternal and Child Health Block Grant and Medicaid are also essential for the children with special needs.

In closing, I want to emphasize that, if this Society and this committee, has the same commitment as Mother Teresa to the "unwanted, uncared for and deserted," it will use all available resources to relieve the daily burden of the poorest and homeless children.

I thank you for inviting me to testify this morning. However, I fervently hope that there will be no need to testify five years from now—on the same number of children needing homes, some of them—the same children—as are waiting today.

I appreciate, and more important, the waiting parents and children are grateful for your efforts to bring them together.

I will be happy to answer any questions.

Washington, D.C.

DEAR FRIEND: Thank you for your interest in the adoption of a child from India. I regret that I cannot answer INITIAL requests personally, since I receive thousands of inquiries for approximately 100 children available for adoption per year. I am not an adoption agency, but work as a volunteer from my home after my regular working hours, and am the only U.S. resource for information and assistance for this program. The Missionaries for whom I volunteer are a charitable organization registered in India who have homes for orphaned, abandoned, destitute and handicapped children. This organization is authorized and recognized by the Government of India to receive children and to identify and place children whose best interests are served by adoption, both in-country and inter-country. The inter-country adoption process in a long and complicated one. I provide information and assistance on working with agency, state, U.S. Immigration and India laws, regulations and procedures. I hope this information will answer your questions. I would be happy to talk to you after you have read this letter and are interested in the children who are available for adoption.

The children: The children's home identifies the children legally eligible for adoption. They are available because they have been abandoned or relinguished due to poverty, malnutrition, tuberculosis, handicaps or being born out of wedlock. The children range in age from infants to 13 years. The children available for adoption now and in the forseeable future will be a few high risk infants, children of all ages with severe handicaps, are of school age or part of a sibling group or a combination of the above.

Since there are so many requests for so few babies, infants without handicaps are placed mainly with families who are childless or who have only 1 or 2 other children.

Children who are handicapped or over 3 are available to families regardless of their marital status, number of other children in the family, age or religion. The children who are Catholic must be placed with Catholic families. There is no religious requirement for the children who are not Catholic (religion unknown).

The children all have dark skin. Since you and your child may have a different skin color and features, you must be prepared for attention, curiosity, questions and hostile attitudes and behavior from others. If you have any doubts about persons of a different color, culture or race, these children are not for you.

The children may suffer from a variety of diseases, come from unknown backgrounds and there is no guarantee as to how they will develop, adjust or behave. We know little, if anything, about the child's biological family, prenatal care, medical, developmental and social history, emotional adjustment, behavior or even exact birth date.

Many children are abandoned at an impressionable age and suffer severe traumas.

Foundlings without exact birth dates have their birthdays estimated by bone x-rays and physical examinations. Medical examinations and treatment are provided for the children and a psychologist evaluates children when needed. The children usually suffer from one or more of the following: malnourishment, vitamin and protein deficiency, diarrhea and intestinal parasites and worms, skin diseases (e.g. lice, scabies, boils), upper respiratory and ear infections, rickets, salmonella, poor teeth, enlarged liver, malaria and positive tuberculosis tests.

Your child will know only Hindi and one of the other 14 major Indian languages. Therefore, neither of you will be able to communicate verbally for months, which may be frustrating and taxing for all of you. Most of the children delayed in their emotional and intellectual development.

A few children have had undetected problems and handicaps (hearing loss, blood disease, severe learning and emotional disabilities) which have permanent effects.

The children live in an environment in which the sisters love and know them and care deeply about their welfare and development. They suffer from being shifted, separated and having to learn to adjust to new people, new ways of being treated and a new language. Your child may feel homesick, deserted, frightened, bewildered, depressed, angry and be wary of forming close relationships. She may behave in any one or more of the following ways: she may be passive, withdrawn, unresponsive, rejecting (I don't love you, you don't love me, I want to return to the sisters) or he may attach himself to one parent and reject the other; be unable to let you out of his sight without panic; test you to make sure he won't be sent back if he's "bad"; demand attention, have temper tantrums, disobey, be destructive, bedwet, refuse to eat or sleep or have terrifying nightmares. Toddlers sleep in small cribs and may be frightened of large beds. Many of the children over 6 lie and steal. A child who expresses none of these emotions may be more disturbed than one who can deal with them openly. In order to buy affection and security, your child may regress and hide her insecurities and anxieties until adolescence when she may have a worse identity crisis.

Many families have experienced negative attitudes and behavior from their families, neighbors, school and church. Children have been taunted and called "nigger" or labeled as retarded because they have not yet learned English. Families have been refused admission to public and private recreation and other facilities. Some clergy have refused to baptize the children.

To repeat, as in any adoption or birth, there is an element of risk and there is NO GUARANTEE as to the health, intelligence, appearance, development or behavior of the child.

The process: The time from date of application to date of assignment of a child depends on the availability of the age and sex of the child you want. The time from date of acceptance of a child to date of arrival is three to six months, depending on how fast you complete your papers, on the court situation in India and on the U.S. Immigration and Naturalization Service approval of the Relative Immigrant Visa Petition.

You must have patience and be prepared for frustration, delays and last minute changes in procedures, regulations, papers required and flights.

Costs: The cost of the adoption is $1,350.00 per child, INCLUDING transportation to the east coast. This includes:

All expenses for legal, court, administrative work, physical exams and medical care, immunizations and medicines.

Obtaining, preparing and processing social and medical history, birth certificate, legal documents, photographs, passport and visa for the child.

All fees for child's transportation and an escort from Delhi to the east coast (New York or Boston).

There is no application fee. The $1,350.00 is payable in full only when you accept the referral of the child.

Additional costs: 1. Ongoing transportation. A volunteer escort will bring your child from the east coast to the airport nearest your home. The cost depends on where you live.

2. Large telephone bills. You must be prepared for many long distance telephone calls regarding preparation of documents, changes in procedures, travel arrangements, etc. Since we are volunteers, we place calls collect.

3. Document fees for notarization, certification and authentication of documents.

4. THE $35 FEE required by U.S. Immigration and Naturalization Service for filing the I-600 form.

Documents needed: If you are interested in adopting one of these children, you must meet the preadoption requirements in your state, the U.S. and India. Your NEXT step is to submit the following documents: (Please DO NOT send them registered or certified mail.)

1. A notarized copy of an approved homestudy. If you do not have a completed homestudy, locate an adoption agency licensed in your state to do one for you. If you have difficulty, India will request one for you.

2. A letter about your family and your reasons for wanting to adopt a child, particularly one from India.

Families who adopt children from us have a wide variety of backgrounds, lifestyles and values. You are in the best position to know whether this adoption is right for you. We would like to know more about you and have you include your birth and marriage dates, health, employment, and such things as:

A description of yourself, your family, your life, values, interests, activities, friends, community and work. What makes you happy, angry, and how you express love, anger. How you make decisions and share responsibilities, for example; rules, money, chores, child care?

Why you want to adopt a child, particularly one from India? What kind of child you want (age, sex, handicap)? Whose idea was it? How long have you been considering it? What alternatives you have explored? How did you learn about us? If you are infertile, how have you dealt with this issue?

What kind of children you like and dislike? What you want your child to be like now and in the future? Do you expect your child to appreciate what you do for her? What if she doesn't? What you have to offer a child? What makes a good parent and good relationship with a child? What is the difference between a biological and adopted child and parenting a biological and adopted child? What concerns you have about adopting? What has caused or would cause you to break a commitment to a loved one or adopted child?

Since your marriage, what has been different from your expectations and what adjustments have you made? What changes would you make in yourself, spouse, life? What changes you foresee with a new child fitting into the family; for example, yourself, marriage, freedom, time, money, chores, pressures?

Your reaction to this letter and the description of the children. How you feel you will cope with the problems that arise from the child's having an unknown history and a different color and cultural background from you. How you feel about your family being "mixed". How your family and friends view this adoption. How you would handle hostility from family, neighbors, church and school. How will you provide your child with its ethnic identity. How you feel about getting a child professional help if needed on arrival or in her teens.

3. A notarized letter from your doctor stating you probably cannot have a child by birth (for childless couples only).

4. A notarized letter of recommendation from your priest (for Catholic couples only).

You may find it helpful to meet parents in your area who have adopted a child from us. If you do not already know such a family, let me know and I'll put you in touch with one.

If the children's home selects a child for you, they will send a photograph, a brief medical report stating height, weight, birth date (approximate) and diseases or handicaps, if any. You will also receive legal papers and a short description of your child. However, the child originally described as shy may turn out to be assertive and vice-versa. You are in the best position to judge if the adoption of this specific child is right for you. If you accept the child, you must complete, notarize, certify and authenticate the legal documents for India. These consist of two powers of attorney, one medical certificate on your health, a declaration that you want to be guardian of this child and a financial statement. You must also file an I-600 with the U.S. Immigration and Naturalization Service for permission to admit the child into the United States.

When you are appointed guardian by the court, you will receive a birth certificate, proof of the child's availability for adoption (two affidavits from the children's home that the child has been released and is legally free for adoption), a court order appointing you guardian of the child and permitting you to remove her/him to the United States, an adoption deed, an Indian passport bearing your last name, an alien registration card and a health card indicating innoculations.

We prefer that you keep an Indian name for a middle name when you readopt the child in the United States. Most important, the Indian Council of Child Welfare, the court and the Sisters are very concerned about each child. The court requires that a 10,000 Rupee Surety Bond be posted by the Sisters for each case. The condition of the bond is that the adopting parents must submit a quarterly post-placement report and two color photographs to the Indian Council about the child's welfare and development until the child is legally adopted in the United States. These reports must describe the physical and emotional adjustment and progress of your child and reflect the love you have for your child. When the adoption is finalized, you must send the certified court order stating the child is adopted in your state so that the lawyer may go back to court and discharge the bond. You can obtain additional copies for yourself of the adoption decree from the Clerk of the Circuit Court which handled your adoption.

The Missionaries of Charity retains joint custody of the child until he or she is legally adopted in the United States. They love and care for the children and ask that, after legal adoption, you maintain yearly contact with them or me. If you do not feel you can maintain the commitment to keeping in close contact with India, PLEASE do not proceed.

You may also choose to be involved in your local adoptive parent support group.

If you wish further information or assistance, let me know. Be sure to include telephone numbers where you may be reached. I wish you the best of luck and success.

Sincerely.

KATHY SREEDHAR.

Senator DENTON. Thank you, Ms. Sreedhar. For your information, the printing of our wording is in error, and it should have read—and this will be corrected "infants born to teenage individuals and unmarried parents" they were added to those who may be in serious jeopardy and are in need.

It should say, "and some such children are in need of adoptive placement," OK?

Ms. SREEDHAR. Thank you.

Senator DENTON. We will certainly take everything that you have said about changes into our deliberations. We are just trying to help and we do not mean to muddy the waters. I do see the point of much of what you are saying.

I want Ms. Candace Mueller to feel welcome to comment with respect to any of the questions we ask, and I ask all three of the others to do the same when I ask any one person a question.

I certainly admire all three of you for what you are doing, and particularly those who have adopted children. You are a refreshing and opposite change to those who casually have and then fail to care for children who, in fact, are as important as the parent. I would think, the parent should feel even more love for the child than they feel for themselves. That is the normal mother instinct, and even the normal father instinct.

I just do not know where it has all gone in the last 20 years or so. Unwed mothers, for example, used to put their kids up for adoption out of the feeling of realism that they would get better care than they were able to provide them.

I do not know which one of you to ask this, but I want to understand better the issue of the father of the unwed child coming along later and saying he wants to take custody of the child. You mention that the mother is placed in the position of either acceding to that or raising the child herself, because if she puts it up for adoption, I presume that he gets sort of first shot at it. Is that the idea?

Ms. MUELLER. Yes.

Senator DENTON. Well, not in every case, would that be the worst fate in the world. I mean, if the guy's parents were going to really help him raise the child and he is the natural father, is that to be considered an undesirable alternative in every case?

I did not quite get the exact nuance of whosever statement that was.

Ms. MCHUGH. It was mine.

Senator DENTON. Yes.

Ms. MCHUGH. I think you are very right; it would not be undesirable in every case. But I think the implication must be that the biological mother who has carried the child to term with the understanding in the case that we are talking about that she did want to place the child for adoption because she felt that neither she nor the biological father could take care of the child in a proper manner, was all of a sudden faced with the prospect that that was not what was going to happen and that the biological father would then have the rights to the child.

What is being said is that she does not feel that he can take care of the child either.

Senator DENTON. Would there be some lack of objectivity occasionally in that feeling on her part? I would rather imagine so.

Ms. MUELLER. There could be, Senator. That is the role of the court in working with the biological mother and the biological father. to determine what would be in the best interests of the child.

Another consideration with regard to making that adoption plan is privacy. In the case before the Supreme Court, the biological father is planning to bring the baby back to a very, very small town, and that was of concern to the young woman.

That was the reason she was served in a maternity residence.

Senator DENTON. Served what?

Ms. MUELLER. In a maternity home and was making an adoption plan, because she felt her child deserved a fresh start that did not begin with all of the stigma which would result from the fact that this was an out-of-wedlock birth. So, that is a concern to her and to her family.

Senator DENTON. You mean the issue of privacy, as you use it, refers to the confidentiality of the fact that the child was born out of wedlock?

Ms. MUELLER. Yes.

Senator DENTON. What is the present state of things in that matter?

Ms. MUELLER. Well, with regard to this case, if the father brought the child back to raise in that community, there would be no confidentiality.

Senator DENTON. But if that were desirable in every other respect, should the confidentiality override the——

Ms. MUELLER. It would not, and that is the work that the courts have been involved in. This occurred in the State of Texas and the case has gone all the way to the Supreme Court of Texas, where it was determined that the father was not fit.

Senator DENTON. Well, what do you think? In other words, each case would be different, really, would it not?

Ms. MUELLER. Certainly, certainly.

Senator DENTON. OK. The thing that I am in most need of education in, and I do not want to waste the time of the panel or the audience or my staff learning it, but it seems to me that one of the keys to what you all have been talking about is the system of financial transfers that go on. They seem to be somewhat extensive and involve Federal, State, and then some private agencies.

There must be a myriad of State differences out there which make it very difficult for me to get a real handle on it. But, Ms. Piasecki, you seemed to be dwelling on that as much as anyone. Would you, in just a paragraph or two, try to clarify the relevant aspects of the financial arrangements which pose not only barriers to adoption, but I think what might be called ethical violations as well?

I see repeated charges here that an agency will not permit across-the-State-line adoption, which I presume tends to help them financially. Because they are making some kind of—I hate to use the term—profit on the care with respect to that child, if they lose it, you all have indicated that the remuneration setup is flavored so that it favors their keeping the child, which is a mess, to say the least, when we are trying to do just the opposite of that.

How would you summarize that?

Ms. PIASECKI. Well, I think that there is a mix of problems. Certainly, some people have said that private agencies are keeping children in extended care because public agencies will pay for that care.

I do not think that we can simply make a statement that that is, in fact, true. There is also a problem in that public agencies will pay for an extensive period of time a foster care payment or an institutional care payment, which can range anywhere from $5,000 to $30,000 per year, but will not provide an agency which specializes in the placement of special needs children for adoption a one-time, $1,000 to $5,000 placement fee because they say they do not have that in their budget.

So, it is that kind of reorganization of how we spend money that is appropriate. There are also problems in the mix of Federal and State dollars that support adoption subsidies. Yes, when children move across State lines, their monthly maintenance—that subsidy which the family receives to take care of everyday needs—follows them.

But there is a great deal of confusion regarding the medical subsidy following a child. We recently helped in a situation where a child from New Jersey could not find a provider in Oklahoma which would accept the New Jersey medicaid card, not because the child was not eligible, but because of the problem of medicaid payments across State lines.

It is a problem. Because it is an interstate problem, it can only be solved by the States, in cooperation and with some Federal leadership, determining how we can solve that problem.

So, the fiscal problems relate to the monies that go to the families themselves and how the State and the county agencies allocate funds and what service they buy. They need to look at buying more adoption, and realizing that buying more adoption, they will need to purchase less institutional or foster care for the same children.

Senator DENTON. Go ahead, Ms. McHugh.

Ms. McHUGH. Could I comment on that, also?

Senator DENTON. Yes.

Ms. McHUGH. I agree with what Ms. Piasecki is saying, and also with what Ms. Sreedhar said about coming up with more creative solutions to releasing special needs children for adoption.

There is a project that was done last year in Texas with a voluntary private agency in Texas called the Edna Gladney Home. They were given funds, through a contract for services from the State to the private agency. The Edna Gladding House placed, within a year, 98 special needs children.

They tried to put a monetary amount on it so that it could be decided if it financially was acceptable. Not only did they place the

98 special needs children, but the project cost $400,000 to run for that year.

They totaled up how much it would have cost to keep these children in foster care, or how much it had cost them to keep these children in foster care over the years that they had been in foster care, and it was $1 million.

So, you can see that in just this one project of creative child-placing sorts of ideas, they were able to save quite a bit of money, and also get these children placed. But I agree with both people that that is the way we have got to go, to try to use some creative ideas, and also, try to utilize private agencies, not only giving money for foster care, but for adoption placement.

Senator DENTON. Well, what role could the Federal Government play, or should it play, in insuring that there is an expeditious and sort of fairly flowing adoption across State lines, for example, and that they not sort of hold on to the kids?

How could we improve that situation from the Federal point of view?

Ms. SREEDHAR. If the incentives now are to keep the children in care, then there has to be some incentive——

Senator DENTON. I am sorry; I cannot hear you, Ms. Sreedhar.

Ms. SREEDHAR. If the financial incentives now encourage the agencies to keep the children in care, then there either has to be a financial disincentive to keep them in care or an incentive to move them out of care.

So, as you were referring to before, the mechanism has to be restructured to reward placement rather than reward maintenance.

Senator DENTON. Not only that, but it would save money over the long term.

Ms. SREEDHAR. Well, of course it would save money. I have one concern here, though, because it certainly saves money to place children. I mean, you have heard testimony on that for many years.

I am sometimes concerned about the amounts of money that are given to agencies to place special needs children. This example that Mr. McHugh used is excellent, but I was just up in Massachusetts where a great deal of money was given to an agency, about the same amount as you referred to, and they placed only seven children.

So, there has to be some relationship between the number of placements and the cost.

Senator DENTON. Go ahead, Ms. Mueller.

Ms. MUELLER. Senator, there is Federal law, Public Law 96-272, which has been mentioned here, not within your jurisdiction, which shows the kinds of barriers and the problems which still exist for getting children placed.

The adoption assistance program has a $5 million amount of money to spend for subsidies for children who are hard to place who could be adopted. That money is not being spent, Senator. It is an entitlement program and the States have not drawn down the money, which means they have not freed children and made them eligible for that program.

That is one of the goals that Assistant Secretary Hardy has expressed. That program is under her jurisdiction and she wants to work with the States to see that that money is spent, money which goes directly to adoptive families for the adoption of children.

Senator DENTON. I just want to get the answer to this one in the record from Ms. Sreedhar. It appears that few upper middle class families adopt children even though they have the potential resources to provide a home for a waiting child.

You personally, on the other hand, are not particularly wealthy and you are a working, single adoptive parent with a full-time volunteer commitment. How do you explain the paradox that people with great resources tend not to adopt, while people with fewer resources tend to seek to adopt, and would you relate that to what we might perceive over the years as a dwindling appreciation for family and an increasing propensity to be materialistic?

Ms. SREEDHAR. I said in my written testimony that though I would welcome a study of our parents, I did not think Federal funds should be used for this. But I am interested myself in how parents decide to adopt a child.

If we get 10,000 letters a year and 200 families select themselves, they are in the best position to know that they want this child. We do not make agency-type judgments on them.

But I do not know what these parents have in common, except a commitment to the children. They come from rural towns, big cities; some of them have never been to high school, some of them have Ph. D.'s. Some of them make $10,000 a year; some of them make several hundred thousand. Some of them, like the DeBolts, have 20 other children, and some are single parents with nine children. Some are handicapped.

I really do not know how to make a generalization about who is adopting. I will say, though, that one of the best methods for finding the best parents is to let parents decide for themselves; that is, to give the parents as much information as possible about these children, and rely on individual judgment so the parents can decide for themselves whether they want to do this rather than superimposing somebody else's judgment on them.

Senator DENTON. Go ahead, Ms. Mueller.

Ms. MUELLER. Senator, we do not know anything about who adopts. We do not have any national data to describe adoptive families or adoptive children or children who are waiting for adoption.

That is an area in the adoption opportunities law which has not been well done to date, if done at all, and needs to be done. I was very encouraged when Director Chapman testified before you from the Bureau of the Census and said he would like to collect that data.

What better place than the census, which can talk to all families and find out who has adopted, and can use viably valid sample data to tell you, to tell HHS, and to tell us who are the adoptive families in the United States?

I hope that that can be accomplished within the next couple of years, and from my conversations with the Bureau of the Census, they sure would like to, and this law would be a place where direction could come.

Senator DENTON. They are required to do that right now. By the way we have written the bill, I am informed.

I saw indications of what you all have forecast about media participation, and I certainly applaud it. Within the last few days, channel 13—I believe a Baltimore channel—had a feature, and I believe they are doing this weekly now, in which they give an award.

I do not know whether it is a motherhood award or a love award, but this time it was a black lady over in Baltimore who had raised something like 14 children, 10 grandchildren, and 6 great grandchildren, and they were all in this great big room.

They never had had a lot of money, but obviously they were each quite well adjusted, happy and extremely grateful to her as the matriarch from whom had flowed all this love. And as unimportant as it may seem, I think that our hierarchy of values has changed by virtue of the bombardment of the role models. We are shown a swinging pair who find happiness as the sun sets over the horizon—it has nothing whatever to do with being a good mother or a good father or a good husband or a good wife. It used to; you all just have not lived that long.

That is the way the movies used to end; they do not end that way anymore. They end with something else, and what is at the beginning and the middle is something different. I cannot, in my own view, believe that a role model is not an important thing.

As the young man testified, and as Socrates said when he condemned a trend in Greek drama similar to that which has taken place in our entertainment media which he predicted would have a disastrous effect—and he was accurate—on Greek society, "they poison him for his pains."

We will have questions from Senator Dodd for this panel, also, and I will have some more in writing for you. I understand that Ms. Donaghey here on my right has been working with some of you. I solicit your assistance to us in continuing to improve the Federal statutes relating to this.

As you pointed out, Ms. Mueller, some of them are not in my jurisdiction, but I believe that I would find my colleagues reasonable, and I would be happy to take the initiative of trying to coordinate from one place the adjustment of these regulations and rules.

I do not know what we can do about the States and that sort of thing, but maybe something. Your testimony was materially valuable. and I think things look optimistic in the adoption field. Is that right?

Ms. MUELLER. Yes.

Senator DENTON. It is kind of anomalous that this particular Administration is considered uncompassionate about human beings, when there does seem to be a stress within it from a good number of us on this compassionate endeavor.

I believe that it is more than just compassion and altruism; it is also a factor affecting the general welfare and the health of our society—an extremely important factor.

So, thank you very much, and please answer any questions we submit within 10 days.

Our third panel, and I will ask them to step forward as I call their names: Mr. Robert DeBolt, founder of Aid to Adoption of Special Kids; and Ms. Clara Valiente-Barksdale. Mr. DeBolt is the father of 20 children, 14 of whom are adopted. I am looking forward to watching his award-winning film, "Who Are the DeBolts, and Where Did They Get 19 Kids?"

I understand that Mrs. DeBolt spoke in Birmingham last week and met with my State director, Danny Cooper. Mr. Cooper was deeply moved by your wife's presentation.

Ms. Barksdale is an authority on minorities, specifically Hispanic adoption.

We are glad to have both of you here this morning. Mr. DeBolt, would you care to begin your testimony?

STATEMENT OF ROBERT W. DeBOLT, FOUNDER, AID TO ADOPTION OF SPECIAL KIDS; AND CLARA VALIENTE-BARKSDALE, EXECUTIVE DIRECTOR, NEW YORK COUNCIL ON ADOPTABLE CHILDREN

Mr. DEBOLT. Thank you, Senator Denton. I appreciate the opportunity to be here today and to present the written testimony. Since that written testimony is a matter of record, I will not read that, but I will simply paraphrase part of the testimony. I would also like to enlarge on certain aspects of it, and also to comment on some of the testimony that has been given this morning before me.

As you mentioned, I am indeed a parent of adopted children. My wife and I have adopted 14 children. Nine of these children are physically handicapped; the other children had emotional problems. Two of our children came out of long-term foster care—an issue which we talked about earlier today and I hope to talk about a little bit more.

In addition to that, my wife and I are the founders of Aid to Adoption of Special Kids, which is an organization that has been in existence for about 9 years. The purpose of this organization was to try to bridge the regionalism that exists in the United States in the area of adoption.

The program was founded to be a national organization, and since its inception it has indeed worked with all 50 States. We do have what we consider to be sort of a national flavor and know where the national pulse might be in adoption today.

In addition to that, of course, I am on the National Committee for Adoption, and I serve as a member of the board of directors of an organization in Ohio called Hickory Farms Youth Home, where we operate foster care homes. So, I have that aspect, too.

In the area of obstructions to adoption, there are many and they are varied, and they change tremendously from one State to another State. My home State of California has one set of problems. The State of Ohio, where we have an office now being established, has an entirely different set of problems.

It is very hard to generalize across the United States as to where the impediments are in adoption and what the problem is with foster care. There are some universal ingredients that exist, but there are so many unique items, from attitudinal problems with social workers, to archaic and unresponsive laws that exist in many States, to the judiciary in many States, with their inability to terminate parental rights when children have been in long-term foster care.

Dorcas Hardy, the Assistant Secretary of HHS, today mentioned in her testimony that there were "about 50,000 special needs children already terminated for adoption." Well, that in itself is a terrible statement to have to make. We should know how many children there are who have been relinquished for adoption; we say "about."

We do not know how many children there are in foster care in this country. We say about 500,000; others say about 350,000. What a terrible, wide-ranging difference we have between those two figures.

Historically, in the area of adoptions in this country there has been a lack of national networking. Because there are so many unique elements in each State, most organizations work only within their own States. There has been very little networking from one agency to another to try to take on what is a problem over here in Arizona and see what was done to correct that condition in South Carolina.

There has been very little networking of information on parents who want to adopt, and even children who are adoptable. There are tremendous listings services that are out today—DARE, CARE. There are all sorts of books that are put out showing beautiful pictures of children who are available for adoption, and descriptions of these children.

But, you see, this is not spread universally throughout all agencies in this country. The National Adoption Exchange is an attempt to put together some type of a system where, if a child exists in Florida and there is a family who exists in California who feels that they have the resources, emotional, financial, or whatever, to adopt that child, those two elements can be brought together.

We have heard testimony this morning that if a family wants to adopt a child with special needs—we will say a child with cerebral palsy—and they go to their local agency and say, "I want to adopt such a child and I have the ability to parent that child," quite often they are told, "No, that child does not exist."

We ran into a situation in Ohio just weeks ago where there was a family who went to Mercer County, Ohio, making that request and they were told, "No, there are no children of that nature here." But, next door in Richmond County, there were five children who could have qualified for that. Nobody went looking for those children; nobody stepped outside the jurisdiction of that little county in Ohio to say, "Hey, let us find a family for that child."

Now, I admit that this National Adoption Exchange is not going to be such that every agency is mandated to put those names of families and children into that exchange. But, by gosh, it is a start in the right direction.

The reason I would imagine that their numbers are low now is because they are just starting, and we are working with the National Exchange to put all of the names of children into that exchange as soon as we can. We are meeting with people this coming week on computer equipment requirements.

Along that line, that is an expensive element for an agency. We would hope that the National Adoption Exchange would be funded at a level which would allow it to have the participating agencies list the names without charge.

For some years, there has been an inconsistent Federal approach to adoption. A change of administration normally causes such things to happen, but we have always felt that through the Federal Government, the question of adoption of special children and the question of foster care and its terrible entrepreneurial aspects, has been something that has not been paid attention to by the Federal Government.

We are absolutely delighted with Assistant Secretary Dorcas Hardy's adoption initiative. We are participating in that and we think that will go a long way to bringing together what needs to be done to make these changes, and that is a collaboration between the Federal Government, State governments, private agencies, State agencies, and certainly the private sector.

Adoption subsidies are a tremendous need. We could not have adopted three of our children if it had not been for the fact that Crippled Children Services in California paid for the medical expenses directly connected with those children's handicaps.

One child, a little girl 5 years old who was born blind, had a corneal transplant—an expensive and extensive medical procedure which allowed her to see for the first time in her life, because Crippled Children Services paid for all of those medical costs. We could not have done that, and most families could not.

We found in working throughout the 50 States that adoption subsidies and medical care are one of the biggest incentives for people to adopt a special child. There is a natural reluctance, particularly when you are in the lower income brackets, and most of the parents who have adopted through AASK America have been in the lower to lower middle income brackets.

Eighty-five percent of the 2,000 people who have adopted through AASK have incomes less than $20,000 per year; 65 percent of those people are rural families. We cannot answer all of the questions of why, but we think that the 65-percent rural families probably comes from the fact that there are less distractions to the family in the rural environment than there are in a metropolitan environment.

AGENCY BARRIERS TO ADOPTION

We have heard about home studies not being allowed to cross county lines or State lines. We have also heard of the rejection of the nontraditional family.

Our families in AASK are almost all nontraditional—large families such as the Rossow family that this committee was privileged to hear from earlier this month. Many agencies would turn them down for another adoption just because they have that many children.

Single-parent adoptions is our second greatest resource of the adoptive family, and we also use handicapped parents. We have a tremendous recruitment campaign going on right now with minority families. In the past, minority recruitment has generally asked for the minority family to look minority, but to sound majority. They want them to look black, to look brown, but to have all of the white middle class values. I see this changing. Los Angeles County has a tremendous program in that.

In closing, I would like to urge this Committee in its deliberations on the Adoption Opportunities Act, which I hope you will extend for the 3 years, not to spend money on such items as agency awareness of special kids and training for social workers.

If those social workers are not aware and trained by now, they will not be, so let us not kid ourselves and throw money after that. Put in programs that work, gentlemen; put in programs like the National Adoption Exchange and other national programs that work.

Thank you for allowing me to be here, and also thank you very much for the professionalism and efficiency of the committee staff. They have been very good to work with.

[The prepared statement of Mr. DeBolt follows:]

PREPARED STATEMENT OF ROGERT W. DEBOLT, OAKLAND, CALIF.

I am pleased to have this opportunity to give testimony to this Sub-committee in support of the re-authorization of the Adoption Opportunities Act for four more years. Building of families through adoption is a major focal point of my life—as a parent and as a volunteer leader.

My wife and I are the parents of 20 children, 14 of whom are adopted. Nine of these adopted children are physically handicapped and many of the 14 have suffered mild to severe emotional disturbances. Our family's involvement in adoption dates back to the Fifties, when my wife, Dorothy, and her late husband added two adopted Korean children to their family of five biological children. Then as a widow with seven children, Dorothy adopted two physically-handicapped, war-wounded, Vietnamese boys in 1969.

Combined with my one child from a previous marriage, we started with ten children when we were married in 1970. Since that time, we have adopted ten additional children. Several of our adopted children are what society would consider to be severely handicapped. For example, one of our adopted children is a Black girl who was born without arms or legs. Another boy is blind and paralyzed from the waist down. These children, as well as their brothers and sisters, attend public school, are relatively self-sufficient, and are establishing successful lives on their own.

Our interest and problems in adoptions coupled with others interest in our family and their attempts to adopt, was the impetus in our forming a non-profit organization to encourage and assist in the adoption of special needs children nationally.

In 1973 we founded Aid to Adoption of Special Kids . . . now known as AASK America. Headquartered in the San Francisco Bay Area of California, this organization works with families as well as public and private agencies in all 50 states to promote adoption of physically or mentally handicapped children, minority children, older children and sibling groups.

I serve in a voluntary capacity as President of AASK America, member of its Board of Directors, and serve on several committees of the Board. In addition to my service to AASK America I am a member of the Board of Directors of the National Commission for Adoption, Washington, DC; Hickory Farms Youth Homes in Ohio; and AASK Midwest, Toledo, Ohio.

I am also on Advisory Committees of several national and international organizations having to do with child and adoption, and was a member of the White House Conference on Children and Youth. My interest in adoption of special children became so strong that I resigned my position as President and CEO of a construction company so that I could devote more time as a volunteer to AASK America.

My wife and I now make our living through professional speaking appearances and have spoken to groups in 45 states and three foreign countries in the last three years. These appearances, coupled with AASK America's national program, perhaps give us a unique and accurate view of the status of special needs adoptions in the United States today.

AASK America was founded in response to inquiries Dorothy and I received as a result of press and medial coverage concerning some of our adoptions. The letters and telephone calls we received from all parts of the country were similar. These people wanted to adopt children with special needs but for various reasons had been discouraged by their local agency. These inquiries had increased to the point where AASK America was organized. Since that time, AASK has grown tremendously and has been extremely effective in its goal of finding homes for special kids. This national organization has been responsible for the placement of approximately 2000 special needs children in the last ten years.

AASK American has a total staff of eight people and is a licensed adoption agency in California. In terms of scope and numbers our most effective service is AASK's National Referral Program. This is, in reality, an adoption exchange wherein we act as a matchmaker between the children who wait for homes and families who want to adopt special needs children. This program works with over 400 agencies throughout the United States and has received inquiries from potential adoptive parents in all 50 states. This program was established as an attempt to overcome one of the greatest barriers in adoption then and today . . . that is the regionalism which exists throughout the United States, which discourages placement across state lines.

The adoption of special needs children is severely limited by the following conditions:

1. Lack of current adoption and foster care adoptions.—One of the great services which could be provided by the Adoptions Opportunities Law is the collection of national adoption and foster care data. It has been almost ten years since there has been a Federal report on children adopted annually in the United States. There is almost no agreement among agencies throughout the country as to how many children are currently in foster care and the numbers available for adoption. We know that in the State of California, the numbers of children in foster care has increased during the past five years and have reason to suspect that that same condition exists in most of the other populous states. However, the voluntary reporting of the numbers of children by states has not been successful and we would urge the Subcommittee to encourage the Department of Health and Human Services to collect this important data. We further recommend that the Adoption Opportunities Law be amended to require the Secretary of Health & Human Services to consult with other appropriate agencies and federal departments for the establishment of an ongoing annual adoption and foster care data gathering and analysis system thereby not relying solely on voluntary state reporting.

2. Lack of national network of agencies and collaboration among agencies.—We believe that it is important that the Adoptions Opportunities Law continue the concept of a National Adoption Exchange. We have worked closely with the Adoption Center of Delaware Valley and believe that it is on the right track to developing an effective national exchange. In this day of telecommunications and computer technology it is almost unbelievable that adoption agencies would not already be matching waiting children with families through this modern process.

The cost of the appropriate equipment, however, is approximately $10,000 to $15,000 and will be difficult for most agencies to afford. It is not practical to expect agencies to pay a service charge to the National Exchange for listing children or families. The level of funding for the National Adoption Exchange must be maintained so that public and private agencies are encouraged to participate in the Exchange. This program will be a major factor in overcoming the regionalism which permeates the national adoptions picture.

AASK America's National Referral Program continually battles the problem of attempting to have agencies study families for other agencies children. A national listing of families willing to adopt special needs children will also encourage social workers to look with more favor upon the possibility of children under their auspices being placed outside their jurisdiction.

I hope that the Adoption Opportunity Law will take positive steps to encourage a higher degree of coordination among agencies nationally. Any long term solution to the problem of adoption of special needs children requires greater federal government and private sector collaboration in the future. The federal government must recognize that its funding role to solve this problem should should be increased, and not diminished. In addition, the federal government must particularly by sensitive to encourage purchase of services to private agencies for placement services to children in public care at the state level, and provisions of adequate adoption subsidies to families.

The private agencies, to adequately participate in any federal government-private sector collaboration, must:

(a) Continue to make increased numbers of placements;

(b) Continue to use their flexibility to test new, creative, less expensive, and faster ways to place children; and

(c) Initiate contacts with business and corporations to help finance agency adoption costs, and to involve the media in bringing to the attention of the public the availability and adoptability of special needs children. We believe that this media involvement is one of the best methods to recruit families. Several major cities in the country have T.V. news segments wherein children are brought into the studio and interviewed. These programs have high appeal and have been successful in finding homes for the children who have been allowed to appear. I hope that the Adoption Opportunity Law will encourage the press and the media to continue these efforts to bring these children before the public.

In the late 1970s, there was a film made on our family, entitled "Who Are the DeBolts? And Where Did They Get 19 kids?" When this program was aired as a Special on ABC-TV, we received over 60,000 letters from across the country. The exciting aspect of this is that nearly 17,000 of those inquiries came from people who expressed desire to adopt a special needs child.

There was no National Adoption Exchange at that time, nor for that matter, adequate networking among agencies. AASK was not able to assure that all of these families were seen as viable adoptive parents when we referred them to their local agencies for home studies.

3. *Inconsistent Federal approach to adoption.*—Irregular Federal funding patterns and fluctuating administration attention in adoptions has added to the leadership problem in the national adoptions scene. I hope that the Adoptions Opportunities Law will demonstrate to adoption agencies, parents and potential adoptive parents, that the Federal government has a substantial and continuing role in providing permanent, loving homes for children with special needs.

We are encouraged by the effort underway at the Department of Health and Human Services. Dorcas Hardy, Assistant Secretary, and her staff have developed the "Adoption Initiative" which encourages private and public agencies to work with the private sector including the press and media to promote new activities to move special children from foster care into permanent homes. Secretary Hardy has visited AASK America and we are convinced that the "Adoption Initiative" will be successful in finding permanent homes for children, and in attracting private sector dollars to be added to increasing federal dollars in partnership fashion.

The greatest needs for funding are in providing placement dollars to public and private agencies providing reasonable subsidies for adoptive families, and the purchase of services at the state level. Over 80 percent of the families who have adopted through AASK America are low to middle income families.

The availability of a subsidy is often the deciding factor on whether or not such a family can adopt. It is a national disgrace to pour millions of dollars into temporary homes for children and ignore the financial need of families who take these children into their homes on a permanent basis, thus relieving the government of millions of dollars of ongoing costs.

Mandating that public adoption agencies reimburse other agencies who make placements of children in their care is a paramount need. The cost of the home study, placement and supervision of the placement should the financial responsibility of the agency who has jurisdiction over the child.

4. *Agency barriers to adoption.*—This committee has heard testimony that there are a number of barriers to special needs adoptions. In our work at AASK America, we have found many significant barriers. We recognize that other agencies deal with these and additional barriers as well:

1. Adoption agencies are reluctant to do home studies for families for other agencies' children. In other words, if a family in Ohio contacts AASK America wanting to adopt a special needs child with certain characteristics, AASK America would probably know of the existence of such a child somewhere in this country. We would then find that child and ask the inquiring parents' local agency to perform a home study. More often than not, this agency would hesitate to do the home study unless the agency who had the child would purchase the services of the first agency.

2. Too many adoption agencies throughout the county reject the non-traditional family. Most of AASK America's placements have involved families, such as, single parents, large family groups, first-time parents, parents with low income, and parents who don't respond well to local agencies. We believe that one of the reasons why our disruption rate was 10 percent of our placements last year is because AASK America's social workers are adept at working with the non-traditional family.

3. Too many adoption agencies lack the ability to recruit and to respond to minority families, and overlook this excellent source of adoptive families. Many agencies, such as Los Angeles County, have effective minority recruitment programs and we would hope that the Adoption Opportunities Law will encourage the establishment of similar programs nationally.

4. Too many adoption agencies have a limited knowledge of how to use adoption exchanges. The establishment of a national exchange will not in itself cause all agencies to utilize the services of the exchange. As we have stated before, there is a

tendency for adoption agencies to operate only within the confines of their state or county and to overlook the possibility of having one of their children adopted by a family in another part of the country.

In summary, I believe that the Adoptions Opportunities Law should give attention in the following areas:

1. Collecting, analyzing and making available to the public data on numbers of children in foster care, freed for adoption, and in current adoptive placement.
2. Encourage and support coordination and collaboration among public and private agencies through such innovations as the National Adoption Exchange.
3. Maintain a consistent pattern of Federal and State funding of adoption and foster care related programs.
4. Identifying barriers to adoption and seeking solutions to them.

In summary, I wish to thank each of you. You are in a powerful position to bring about change. Thank you for allowing me to present my testimony and to share with you not only the facts about the DeBolt kids, but particularly the need for a continuing role of the federal government to bring about substantial change so that one day there will be no special kids lonely for a permanent home.

Senator DENTON. Thank you, Mr. DeBolt.

Ms. Barksdale.

Ms. BARKSDALE. Thank you, Senator. My name is Clara Valiente-Barksdale. I am the executive director of the New York Council on Adoptable Children. I am also an adoptive parent, Hispanic, and a social worker with 23 years of experience with minority families and children at risk in New York City.

I will focus mostly on New York City, which is the area that I know well, although we have reached out to other States in this country and we get referrals and we get requests from everybody.

The New York Council on Adoptable Children was founded in 1972 by adoptive families, and acts on the firm belief that every child of whatever race or age and regardless of any handicapping condition has the right to a permanent family.

In order to make this a priority for the child welfare system, financial incentives must change so that agencies are rewarded for placing children in permanent homes rather than keeping them in the limbo of foster care.

Clearly, child care agencies are not encouraged to make adoption their priority. In New York State, only 1,670 were placed in adoptive homes in the year 1982, while over 5,000 who have been freed for adoption or are going to be freed for adoption are still waiting.

Minority children make up over 60 percent of our State's foster care population. In New York City where we have 20,000 children in foster care, 60 percent are black and 28 percent are of Hispanic background. Over 4,000 of these children are free for adoption, but only 1,034 were placed during the last fiscal year.

Despite loss in the foster care population due mostly to demographics and discharges, 53 percent of foster children were discharged to their own responsibility in 1982. And you know where these children are, or do you? They are in the streets. Some of these children are 15 years old, and what we hear constantly is these children do not want to be adopted.

We have a child 8 years old that we recruited families for—four families. Finally, we were told that this child did not want to be adopted. He is 8 years old, in an institution and Hispanic. These are the children that end up in the streets and in jail.

According to a report from the Office of the New York City Council President, Carol Bellamy:

The funding mechanism for foster care and adoption may itself encourage agencies to keep children in care. Adoption and foster care funding create a situation which is counterproductive to an agency's economic viability to have children adopted.

Last December, the New York State Council of Voluntary Family and Child Care Agencies, representing 120 private agencies in our State, in a proposed position on reimbursement stated that: "The per diem rates hurt agencies who move children out of care." This is to reaffirm what was said before and what you were picking up on, Senator, on the problems that have to do with funding and how funding is distributed.

For the last 10 years, COAC has expressed its frustration when speaking about the correlation between resistance to moving children back to their families or into adoption and the per diem allocations, which means that each child stays in care because they pay for every day that he is in care, and so much per child—$29 a day in New York City for some children.

We believe that the obstacles to adoption are rooted in a system that is more willing to separate children from their families than to give support to families at risk and prevent breakup.

This plays itself out at different levels. The delays in moving children into permanent homes are only a reflection of outmoded practices based on attitudes or administrative resistance based on fiscal realities. As the head of a child care agency told us: "Every administrator in this field knows how many foster children must remain in his agency in order to meet payroll."

Since its inception, COAC has recruited over 10,000 families interested in adoption; we have them on file. Our files today have people of all backgrounds, including hundreds of blacks and Hispanics, interested in adopting the children of their communities.

This enormous response has not been translated into adoptive placements. It takes an average of almost 3 years to match a waiting child with a prospective adoptive parent. Despite our efforts to assist parents in negotiating the child welfare bureaucracies, only about 100 placements per year are achieved by our constituency.

I am here today to focus specifically on the Hispanic children who remain in public care longer than any other group, are too often institutionalized or labeled retarded due to language barriers, and when placed in adoptive homes, are frequently denied the continuity of experience that a family of their same culture could provide.

These are the children of poverty and stress, of families at risk; the children of the unemployed, the uneducated and the homeless. They are the victims of a population living at the bottom of the socioeconomic ladder, suffering from the culture shock caused by migration from a rural environment to our postindustrial urbanized society where the traditional extended family is broken down and identities are lost.

Hispanics are defined by the Office of Personnel Management as persons of Mexican, Puerto Rican, Cuban, Central American, South American, or other Spanish culture or origin, regardless of race. Our common bond is history, language and culture.

In the metropolitan area of New York, we estimate the number of Hispanics to be over 3 million. It is this population that our federally funded program is reaching out to in order to find parents for Hispanic children needing adoption.

We believe that the Hispanic family unit can provide the nurture and security needed by Hispanic children. We believe that as long as there are Hispanic families, and there are thousands, willing to adopt the waiting Hispanic children, they should be given first choice. In this way, we are providing permanence for these children through continuity of experience and a connection to their roots and their past.

We have encountered, however, barriers in achieving our goals. A most frustrating obstacle is the invisibility of Hispanic children who are often classified by race or color rather than by culture or ethnicity.

When we find the right classification, we find inaccurate statistics. In addition, we have met with great resistance to the recognition of cultural identification in planning for a permanent home.

Child care agencies lack bilingual and bicultural staff to properly serve Hispanic families. Staff who do not have a real knowledge of the Hispanic culture cannot properly assess the strength of an Hispanic family. This, of course, affects the screening of prospective adoptive parents.

Agencies staffed by non-Hispanics prefer to work with the Anglo population with whom they feel more at ease. They tend to be judgmental of Hispanics. Their humility, which is valued, is considered passivity; their emotionality is labeled hysterical. These misinterpretations can lead to rejection of many potential parents who could be not only acceptable but desirable if one understands their cultural mores.

As a consequence of barriers imposed on the Hispanic population, children of Hispanic background are either placed in Anglo-American homes or remain in care longer. Light-skinned, young Hispanic children are given to preferential Caucasian couples, as they are the closest to the unavailable white infant. The older or dark-skinned Hispanic child suffers the same fate as his Afro-American brother and becomes the hard to place, special needs and, many times, unadoptable child.

For children of minority background, adoption by the dominant ethnic or racial group in our society becomes a double message of rejection—first by his or her birth parents, then by his or her community—so that growing up in alien territory is the affirmation of having been unloved and unwanted.

I would like to clarify my point of view in terms of placing children across racial and cultural lines. Many Hispanic families are waiting for Hispanic children, and they can offer these children a home and cultural identity. But because of ignorance or lack of understanding of Hispanics, these people have no access to agencies, so that there is double discrimination against the children and against the families who are seeking these children.

Some examples to illustrate the point of obstacles that we encounter specifically with Hispanics: The children that are called by race or different shades wait longer because social workers decide what color their skin is and look for a family to match it.

Sibling groups of various shades separated as foster children are placed in separate adoptive homes to spend half their lives looking for each other. In New York where we have a lot of Puerto Ricans who are a very mixed race, we have many, many sibling groups that are separated. They are placed, the light-skinned with whites and the dark-skinned blacks, and then they can never get back together because they are sent to different communities and different racial groups.

Light-skinned children of Afro-American background are placed in white foster homes, and Hispanic children are placed in white foster homes, and neither one wants to be black or Hispanic later.

There are agencies who recruit families but do not place children with them, and agencies who have adoptable children but do not recruit families nor do homestudies.

It is easier for our staff to place a child from Maine into Florida or from Connecticut into Missouri, which we did last month, than to place a child from New York City into New Jersey, across the Hudson River.

We have the worse of all systems in New York. Not only do we have more foster children available for adoption, but 120 agencies in the New York metropolitan area creates total confusion.

Class prejudices play an enormous part in adoptive placements and minorities are used as foster parents, but when they apply for adoption, they are usually shafted.

Each State, each county, and each agency has different regulations and procedures. Some consider single parents; some do not. I do not want to repeat what other people have said.

I just want to add that I received your amendment yesterday, so I had no time to respond. I would like to put in writing some of my reactions to some of the things that were said and some of the problems that worried me, like the wording for unmarried parents. Somebody else raised it.

I want to add only that I feel that adoption of special needs children is my thing. I feel that all the other considerations are important, but at this point when our limited resources are making it so difficult to place special needs children and we have so many, I really would feel that this administration should help focus on those children so that maybe 10 years from now, we will not have the backlog.

We have a very big backlog of children who need homes, and we have to focus on them. This is my final point. I thank you again for having me here and for representing the growing Hispanic population of children.

In December in California, they had 24 children of Hispanic background available for adoption. In Los Angeles alone, they have 17,000 children and about 50 percent are Hispanics. What happened to the other Hispanic children?

[The prepared statement of Ms. Valiente-Barksdale and additional material follow:]

PREPARED STATEMENT OF CLARA VALIENTE-BARKSDALE, NEW YORK COUNCIL ON ADOPTABLE CHILDREN (COAC)

Senator Denton, members of the subcommittee, ladies and gentlemen: My name is Clara Valiente Barksdale. I am the Executive Director of the New York Council on Adoptable Children. I am also an adoptive parent, a Hispanic and a social worker with 23 years of experience with minority families and children at risk in New York City.

I want to thank you and the Sub-committee on Family and Human Services for the opportunity to testify here today. I would like to bring to your attention my concerns about the thousands of minority children needing permanent families who linger in foster care.

The New York Council on Adoptable Children (COAC) a non-profit organization founded in 1972 by adoptive parents acts on the firm belief that every child of whatever race or age and regardless of any handicapping condition has the right to a permanent loving family. We believe that adoption is a viable resource for homeless children and that for those who cannot return to their birthparents it is definitely the best alternative. We advocate for preventive services so that children will not come into public care in the first place or will be returned quickly to their homes with services. When this is not possible we seek to have these children adopted. In order to make this a priority for the child welfare system, financial incentives must change so that agencies are rewarded for placing children in permanent homes, rather than keeping them in the limbo of foster care.

COAC is an active member of NACAC, the North American Council on Adoptable Children and has been part of the adoptive parent group movement which has been instrumental in bringing about many needed changes in the adoption field in our country.

Clearly, child care agencies are not encouraged to make adoption their priority. In New York State only 1670 children were placed in adoptive homes in year 1982, while over 5,000 who have been freed for adoption still wait. Minority children make up over 60 percent of our State's foster care population. In New York City where we have 20,000 children in foster care, 60 percent are Black and 28 percent are of Hispanic background. Over 4,000 of these children are free for adoption but only 1,034 were placed during the last fiscal year. Despite loss in foster care population due mostly to demographics and discharges (53 percent of foster children were discharged to their own responsibility in 1982) the numbers of children available for adoption and the numbers of adoptive placements remain constant.

According to a report from the Office of New York City Council President, Carol Bellamy in 1981: ". . . the funding mechanism for foster care and adoption may itself encourage agencies to keep children in care. . . . Adoption and foster care funding create a situation which is counterproductive to an agency's economic viability to have children adopted." Adoption Web—D. Tobis and A. Rosa—New York 1981. Last December, the New York State Council of Voluntary Family and Child Care Agencies, representing 120 private agencies, in a proposed position on reimbursement stated that: "The per-diem rates hurt agencies who move children out of care". For the last ten years COAC has expressed its frustration when speaking about the correlation between resistance to moving children back to their families or into adoption and the per-diem allocations. We believe that the obstacles to adoption are rooted in a system that is more willing to separate children from their families than to give support to families at risk and prevent break-ups. This plays itself out at different levels. The delays in moving children into permanent homes are only a reflection of outmoded practices based on attitudes or administrative resistance based on fiscal realities. As the head of a child care agency told us: "Every administrator in this field knows how many foster chldren must remain in his/her agency in order to meet payroll."

Since its inception. COAC has recruited over 10,000 familes interested in adoption. Our files today have people of all backgrounds including hundreds of Blacks and Hispanics interested in adopting the children of their communities. This enormous response has not been translated in to adoptive placements. It takes an average of almost three years to match a waiting child with a prospective adoptive parent. Despite our efforts to assist parents in negotiating the child welfare bureaucracies, only about 100 placements per year are achieved by our constitutency.

I am here today to focus specifically on the Hispanic children who remain in public care longer than any other group, are too often institutionalized or labeled retarded due to language barriers, and when placed in adoptive homes are frequently denied the continuity of experience that a family of their same culture could provide. These are the children of poverty and stress; of families at risk. The children of the unemployed, the uneducated and the homeless. They are the victims of a population living at the bottom of the socio-economic ladder, suffering from the culture shock caused by migration from a rural environment to our post-industrial urbanized society where the traditional extended family is broken down and indentities are lost.

Hispanics are defined by the Office of Personnel Management in Washington, DC as: "persons of Mexican, Puerto Rican, Cuban, Central American, South American or other Spanish culture or origin regardless of race". Our common bond is history, language and culture. We are fiercely proud of our ancestry, whether Spanish, Indo-Spanish or Afro-Spanish. In New York's metropolitan area the estimated number of Hispanics exceeds 3 million. It is this population that our federally funded (Children's Bureau. Administration for Children, Youth and Families. Office of Human Development Services. U.S. Dept. of Health and Human Services—H.H.S.). Hispanic Adoption Program reaches out to, in order to find parents for the Hispanic children needing adoption. We believe that the Hispanic family unit can provide the nurture and security needed by Hispanic children. We believe that as long as there are Hispanic families—and there are thousands—willing to adopt the waiting Hispanic children they should be given first choice. In this way we are providing permenence for these children, through continuity of experience and a connection to their roots and their past.

We have encountered, however, barriers in achieving our goals. Most frustrating obstacle is the invisibility of Hispanic children who are often classified by race or color rather than by culture and ethnicity. When we find the right classification we find inaccurate statistics. In addition we have met with great resistance to the recognition of cultural identification in planning for a permanent home. Child care agencies lack bilingual and bicultural staff to properly serve Hispanic families. Staff who does not have a real knowledge of the Hispanic culture cannot properly assess the strengths of a Hispanic family. This, of course, affects the screening of prospective adoptive parents. Agencies staffed by non-Hispanics prefer to work with the Anglo population with whom they feel more at ease. They tend to be judgmental of Hispanics. Their humility which is valued, is considered passivity. Their emotionality is labeled hysterical. These misinterpretations can lead to rejection of many potential parents who could be not only acceptable but desirable if one understands their cultural mores.

As a consequence of barriers imposed on the Hispanic population, children of Hispanic background are either placed in Anglo-American homes or remain in care longer. Light-skinned, young Hispanic children are given to preferential caucasian couples as they are the closest to the unavailable white infant. The older or dark-skinned Hispanic child suffers the same fate as his Afro-American brother and becomes the hard-to-place, special needs and many times unadoptable child.

For children of minority background, adoption by the dominant ethnic or racial group in our society becomes a double message of rejection: first by his/her birthparents, then by his/her community. So that growing up in alien territory is the affirmation of having been unloved and unwanted.

As one begins to understand the multiple obstacles encountered by families in their pursuit of the adopted child and the bureaucratic maze that regulates agencies procedures one questions the system that we have created "in the best interest of children".

Some examples to illustrate my point:

Infants coming into public care whose mothers have surrendered them, are placed in temporary foster homes while agencies go through cumbersome procedures. In New York City it can keep a child out of an adoptive placement for over a year.

Children so called bi-racial wait longer while social workers decide what color their skin is and look for a family to match it.

Sibling groups of various shades separated as foster children are placed in separate adoptive homes to spend half their lives looking for each other.

Light-skinned children of Afro-American background placed in white foster homes who later don't want to be adopted by Blacks.

Dark-skinned or light-skinned Hispanic children placed with Whites or Blacks who want to be Black or White but not Hispanic.

Agencies who recruit families but don't place children with them; agencies who have adoptable children but don't recruit families, nor do homestudies.

It is easier for our staff to place a child from Maine into Florida or from Connecticut into Missouri than to place a child from New York into New Jersey, across the Hudson River.

Class prejudices play an enormous part in adoptive placements. College educated candidates have a better chance. Blue collar workers although proven to have more successful placements have to wait longer and accept more difficult children.

Each state, each county, each agency has different regulations and procedures. Some consider single parents, some don't. Some cross racial or religious barriers, some don't. Each placement requires hours of exploration and negotiations.

I could go on and illustrate each one of my points with an example. But time is running out. Before ending however, I want to touch on private adoptions as requested by Senator Denton.

Private adoptions are increasing. It is the way to get around a system that does not yield. Most states legalized the process in order to have some control over it. If we create bureaucracies that don't work, people who need the service find the alternative that does. Private or independent adoption could be the alternative to matching an infant with an adoptive family. Unfortunately, unscrupulous lawyers and other individuals who profiteer from this service are actually selling infants for up to $30,000. It is the principle of supply and demand that has created this black market. When we legalize private adoptions we must expect irregularities that should and must be stopped.

Although the independent adoption route of matching children and families is not yet plagued with the delays and frustrations of agency adoptions it has loopholes and risks that have to be carefully monitored to avoid transforming a service for children and families into a racket for profit seeking individuals.

In sum, we believe that as a society we have the obligation to find the best alternatives for all children in need of parents, whether they are white infants or older children, victims of abuse, neglect and abandonment. We must untangle the net that keeps 120,000 children who are free for adoption in our country, trapped in foster care. Adoption is the civilized way of meeting the needs of children without parents. It is also the most cost-effective service in child welfare. Public Law 96-272 passed in 1980 provided solutions and incentives for adoption. But the law cannot be adequately implemented without appropriate allocations. We need Public Law 96-272 to be fully funded so that adoption obstacles can be minimized and adoption can really become a priority service in child welfare.

Addendum to the Testimony presented by Clara Valiente-Barksdale, Executive Director of the New York Council on Adoptable Children (COAC) on April 14, 1983 before the U.S. Senate, Subcommitee on Family and Human Services regarding the Child Abuse and Prevention and Treatment Act and Adoption Opportunities Act of 1978 (Public Law 95-266 Title II)

This is in response to Senator Denton's request for comments to the amendment to Public Law 95-266 introduced by him.

I would like to state here that we share the Senator's concern with "infants at risk with life-threatening congenital impairments" specifically as it relates to "Baby Doe" and the tragic outcome of that case. We are also concerned with any child at risk of abuse and would want to prevent as much as possible, the kinds of maltreatment many children suffer at the hands of parents, care takers and professionals.

As an adoptive parent and a member of a parent organization representing hundreds of adoptive parents and concerned citizens, I would like to emphasize two issues:

(1) We do believe that the Adoption Opportunities Act which was created to promote and facilitate the adoption of special needs children should keep its focus on this population. Funds allocated for that purpose should serve the 120,000 American children waiting for permanent adoptive families. Minority children represent 60 percent of the children needing adoption. Finding adoptive homes for these and other special needs children is our goal. We need all the help we can get to make this an attainable goal. The five million dollars originally allocated for this program demonstrated the feasibility of adoption as the best alternative for children who cannot return to their birthparents. It is the commitment of adoptive parents and much of their volunteer efforts which has brought adoption into the limelight and is making an impact on child welfare services. We cannot stop now. We urge you to continue to fund this program which showed the cost-effectiveness of adoption as a unique service to children in need of parents.

(2) Although we agree with some of your bill, we are concerned with the language which is unclear and unqualified specifically when focusing on: Pregnant teenagers; unmarried parents; and couples experiencing infertility.

We do not believe that all children born to teenagers or unmarried parents are at risk; neither do we believe that all these children are candidates for adoption. We have seen many excellent teenage mothers, single fathers and mothers that are quite capable to raise healthy and happy children. Services to pregnant teenagers are being currently provided with federal funding by the Department of Health and Human Services under a special program created for this purpose. Infertile couples often do need counseling to resolve their problem. There are currently many services to meet their needs in this area.

Our priorities are clear. We urge the Subcommittee to look at our concerns and suggestions so that the special needs abandoned children of today don't have to wait any longer to find the home where they can grow and bloom. They have waited too long and time is running out for them.

Senator DENTON. Well, thank you, Ms. Barksdale. I would like to ask you and Mr. DeBolt if you have any problem with the thrust of the idea in the adolescent family life bill and the proper wording of our amendment, as you called it, which would try to present adoption to an expectant mother or one who has just delivered a child out of wedlock as a positive alternative to, A, abortion and, B, continuing with the increasing trend of the percentage of young women—and many of them are 12, 13, or 14 years old—to keep that child, because very soon a high percentage of them become special needs children?

Is there anything wrong with that, if we do not, you know, push them ahead as special needs before they are special needs? Do you have a problem with that?

Ms. BARKSDALE. Can I respond?

Senator DENTON. Go ahead.

Ms. BARKSDALE. I have been receiving several calls in the last couple of months, I would say, from the Citizens Committee for Children in New York and from a network of projects that work with pregnant teenagers.

They were saying, "What are you doing about them?" And I said I think we have to include something about them in our public education and our reaching out to the community in terms of this being a third alternative. We want to do that and we will do that.

But I think that within our organizations, we can absorb that piece of public education. I think there is a special project within Health and Human Services that has a lot of money, and adoption does not have a lot of money. We are all fighting for the same funds, and it is sad to say that, but that is the way it is.

I think that we should educate those teenagers, but I do not see that we should divert funds at this point to that. That is my opinion.

Senator DENTON. There is a tremendous, growing population out there of AFDC recipients who have children born out of wedlock one after another, and they cost money, too. So, it is not that you are going to be intercepted financially simply because some of those children would be adopted, because the money is all in that one big pot anyway.

Ms. BARKSDALE. But I think the Secretary referred to a liaison, or you referred to working on a liaison with that project, so that adoption can be somehow connected with that so that people do not see it as a separate issue, which it is not.

They are the same children that are abused and who eventually come into foster care and then have to be adopted. But since we have to work with pies and pieces of pies, I do not want you to take the pie away from adoption, and I think it is a very small pie.

It is a growing population of children who need it, and it is a growing concern that we need certain services within adoption so that these children can survive within the adoption system, because if we do not give those services, those children are going to fail.

If every time a new problem starts that has to do with abused children and they take away from this little pie of adoption opportunities, which is a very small one—we have 150,000 children needing adoption out there. Where does $5 million go? Not very far, if you also throw in the pregnant teenagers, who already have a project.

I am fighting for what I work for now and I feel that adoption needs every penny it has because it has very few. Do you see what I am saying?

Senator DENTON. Not exactly. I do not understand how any money is taken out of that pot. Do you mean if you expand the number of special needs children, then there will be less money available per child?

That is the only way I can understand what you are saying, because all we are doing is informing the girl that there are advantages to adoption. She should consider that her own going out to work or going to some job training program, leaving the infant in some day care——

Ms. BARKSDALE. But it is being done now; there are a lot of projects in New York City. As a matter of fact, I was talking to this network and the list of projects is very long. It is a matter to reaching out to those so that they incorporate adoption as a possibility.

Senator DENTON. I think there is less cost to the Government and less cost to the child in many of those cases if that child were adopted.

Ms. BARKSDALE. But then I also saw other things that you want to throw into this bill.

Senator DENTON. I am not throwing anything in that I know of. If you want to point out——

Ms. BARKSDALE. Yes; I read it on the plane.

Senator DENTON. OK.

Ms. BARKSDALE. Couples experiencing infertility—section 6 of the act is amended by inserting at the end, "coordinating adoption-related activities of children considering adoption as a plan for their infants; services to couples."

I do not see why they need services. I mean, they need services, but there are many people giving them services. "Adoption referral services for infants at risk"—I understand that.

I really think that all the emphasis should be put into the special needs children who are waiting. Maybe I sound obsessed with it, but I am.

Senator DENTON. Does it help any to say that the expansion of the advisory board to include services to teenaged unwed mothers would be funded under the child abuse portion of S. 1003, not out of $2 million in adoption opportunities?

Ms. BARKSDALE. No; I do not think it should be funded from here. They have money in Health and Human Services for that; they do. They have a whole department there; they do. They have $20 million. This is not $20 million; it is not even $5 million, and we have to take care of 150,000 children with it.

Senator DENTON. I say again I am not sure you are hearing me. The $2 million is not coming out of the adoption money. It is coming out of the child abuse portion.

Ms. BARKSDALE. All right, but do you consider child abuse in teenage pregnancy?

Senator DENTON. If the child becomes abused, I do.

Ms. BARKSDALE. If she abuses, yes.

Senator DENTON. And a tremendous percentage of the cases are.

Ms. BARKSDALE. Many are and many are not.

Senator DENTON. Yes.

Ms. BARKSDALE. I just feel very strongly about not throwing all the money into the same pie.

Mr. DEBOLT. May I comment upon this, also?

Senator DENTON. Sure, Mr. DeBolt. I do not see the same pie thing there, but I am listening.

Yes, sir?

Mr. DEBOLT I think all of us who are sitting on this side of the table have a tendency to look in the area of the adoption of special needs children. The child who is born to the young teenaged mother out of wedlock, I guess we could probably call a prespecial needs child.

While I admire the committee's interest in trying to prevent more children going into the system, I think that that is probably just a tip of the iceberg and we are chipping away at a part that maybe does not bring that many children into the system.

Senator DENTON. Only 3 percent, right now, of the unwed mothers' children are being put up for adoption.

Mr. DEBOLT. There are really two elements to adoption today. There is the adoption of the infant and the baby. Those children who are born to the teenage mother are going to have the same chance of having some birth defect as the general population.

So, those children are babies and they are readily adoptable commodities. Most agencies who deal with babies, and we do not, have waiting lists of 2 to 7 years for people who want to adopt such a child.

But in the special needs area of adoption, we have a different ballgame. We do not have people lined up for 2 to 7 years ahead of time to be able to adopt. We do have more children here who are adoptable than we have parents out there who have said, "Hey, I will adopt." We know the parents are out there; we just have not brought them in from the cold yet.

Senator DENTON. Well, these children of the teenaged unwed mothers would not be special needs children and would not be in that category.

Ms. BARKSDALE. Some will, some will not. We do not know.

Senator DENTON. Some would, but the same percentage as any other children.

Mr. DEBOLT. That is right; a very small percentage would be.

Ms. BARKSDALE. I feel very strongly about not taking children away from mothers. I cannot stand the idea that we are going to go advertising, "Give us your children to give to other people."

Senator DENTON. Nobody is going to take children away from their mothers.

Ms. BARKSDALE. People interpret things differently, Senator.

Senator DENTON. Ninety-seven percent of them are keeping their children. In many, many cases—I do not know what percentage to say, but perhaps two-thirds—those children are not very well off, to put it mildly, and I cannot see any compassion in not informing them about the adoption process.

Ms. BARKSDALE. Informing, yes.

Senator DENTON. That is all it says in the bill.

Mr. DeBolt, we mentioned earlier that the number of sought-after, healthy white infants available for adoption has decreased dramatically in recent years. It seems that most children who are free for adoption or who are in foster homes are special needs children.

What causes the parents of these children to place them outside the natural home? Are the financial or emotional burdens overwhelming? Is it irresponsibility or insensitivity to the requirements of child-rearing on the part of natural parents, or is it also possibly an indication of dissipation and the breakdown of family and traditional values, including a lack of commitment on the part of parents or anyone else in any other endeavor?

Mr. DEBOLT. I think the answer to that question, Mr. Chairman, would have to be "all of the above." I cannot really weigh which of these factors are paramount.

As children come into the system, in theory they come into the system temporarily. They do so only until such time as that biological home can be strengthened and they can go back into a secure environment. That is the No. 1 goal for all social agencies dealing in children's protective services.

Failing that, the object is to terminate the parental rights and let the child have an option to be adopted into a permanent, loving home. The sin of it all comes about when the biological home never gets to that secure position and the termination of parental rights never happens, so here is this body of thousands of children who are in this limbo.

A couple of months ago, we ran into a little boy down in Santa Barbara County, Calif., who was 8 years old, who had been in eight foster homes in 1 year. Now, in each case, when he moved from foster home one to foster home two, to him he was rejected. It was not that; it was the system that caused some change to happen.

But to that little boy, he was rejected at each and every one of those moves, and when we found him, the kid was a basket case, emotionally. We have a lot of emotional basket cases out there because of that.

I do not know what the answer is. I can tell you a bit about families as we see it. My wife and I are volunteers with AASK. We make our living through public speaking appearances across the country and we have been in 45 States in the last 2 years, I guess.

In those 2 years, we found what, to us, is a strengthening of the family, not a deterioration of the family. I suppose the pendulum during the 1960's was swinging in that direction. We see a real swing back toward what we would call the traditional family; not traditional in the sense of the mother and the father and 1.2 children per family, but traditional in the sense of the bonds of the family unit, whether it is the single parent and one child or four children, a large family, or whatever, but a strengthening of family.

Senator DENTON. I do not want to lose any opportunity to praise the single parent who exercises the responsibility to take care of that child. I was raised by one. I am not a worshipper of the nuclear family. I am simply a believer that it is better to, if we can, increase the probability that a man and a woman are going to stay together and raise their children than to decrease that probability.

Mr. DEBOLT. I am sorry; I did not hear that last part of your comment.

Senator DENTON. I think it is a worthwhile goal to do what we can to increase the probability that a couple who gets married or have intercourse—and hopefully they do that in marriage—stay together and, upon contracting the marital agreement, feel a commitment to raise their children.

There is a devastating assault upon that type of mind set in this country right now.

Mr. DEBOLT. That is correct; there is. We can encourage that. Unfortunately, we cannot mandate it.

Senator DENTON. That is right. It is not entirely a dilemma because there are some things that we can do. There are things that we can do, like not permitting government programs to encourage the opposite.

Mr. DEBOLT. That is absolutely correct.

Senator DENTON. And there have been some; there are some. As I said, there may be some governmentally led programs to require self-regulation with respect to the kind of intellectual and moral message that is transmitted constantly by three corporations into the homes of all of our citizens.

What are the messages they are getting? If I were a kid today, I do not know where I would be. I agree with you about the comeback; I think we have a better crop of young kids out there today than when I was a kid.

I believe the Vietnam experience and all the things that went on in the 1960's and early 1970's were very, very bad. But I was not encouraged by the statistics I heard. We have had two hearings on the breakdown of the family, and from Gallup and the poll and the census-taker guy and all the rest, it was not that encouraging.

There are signs that some things are happening favorably. There are signs that other unfavorable things are overriding. For example, by one of their calculations—and this was a mathematical extrapolation based on the drop in contracting first marriages, and it is amazing to see over the past 20 years the consistent drop in the various age groups, and it is across all age groups that that thing has been dropping—the incidence of first contractuals of marriage.

It was like in the first 30 or 40 years of the 21st century, we would have zero families remaining with the original formers of the spouse group together. That, of course, would be absurd, but that is the way the curves point. And it is not necessarily good; I think it is bad.

I think that the attention that is being given to adoption right now is one of the most healthy influences going on. It gets to the liberal as well as to the conservative. It gets to compassion, and that is what we are lacking.

Hopefully, we can remember where we got our compassion in the first place and not discard that as we have been rather formally, and certainly increasingly informally. At least, that is my overview of that.

Mr. DEBOLT. I subscribe to that, Senator Denton. However, you know, the message that comes across through the media—and I suppose this is an admission against interest because we are all in these programs very dependent upon the media to get the message across about the adoptability of the children—these 60 stations across the country who are showing these children who are waiting, and our own program, "Who Are the DeBolts," and all of that.

But 8 years ago, we took the television set out at home and we have never regretted that.

Senator DENTON. One of my seven children does not have one in his home and his wife was the daughter of two Ph. D's. I do not look at mine. I wish I could say I do not have one, but for the "news"—I probably watch 4 percent of the news that comes on the air.

I do not blame the media. I do not think the media is leading us down a primrose path. I think they are probably just reflecting something that is happening to us in general, but by virtue of the nature of their enterprise, they do lead us, but without any more culpability than the average citizen, in my view. They just have a more expressive, pervasive, and influential medium which they are working with.

Well, thank you very much, and we will be submitting questions to you, too.

Ms. BARKSDALE. Thank you.

Senator DENTON. And I solicit again your continued input to us.

Mr. DEBOLT. I wanted to assure the committee of our willingness to give continuing input at any time. Thank you again for this opportunity.

Senator DENTON. Thank you, and thank you for your compliment to my staff. I am appreciative of that. Senator Dodd also has questions for this panel which will be included in the record, and I ask them to answer in writing his questions.

Senator DENTON. The final panel of witnesses, and I ask them to come forward, include Ms. Laurie Flynn, executive director of the North American Council on Adoptable Children. She is accompanied by Ms. Elaine Winslow, a fellow Alabamian. Would you all come on up to the table?

I want to extend an especially warm welcome to you, Ms. Winslow. Ms. Winslow is president of Alabama Friends of Adoption.

I should mention that Mr. Bruce Mueller, an employee benefit specialist, could not be with us this morning. His testimony will be entered in the record. Mr. Mueller is an advocate of corporate adoption benefit plans for employees.

[The prepared statement of Mr. Mueller follows:]

PREPARED STATEMENT OF BRUCE A. MUELLER, SENIOR VICE PRESIDENT, EMETT & CHANDLER ILLINOIS, INC.

ADOPTION BENEFITS: REAL OR IMAGINARY

Thank you for the opportunity to present comments on why the Senate Subcommittee on Family and Human Services should consider legislative action which would encourage the development of an Adoption Benefit Plan that will enable companies to provide tax effective remuneration to employees who adopt.

If you look at the gamut of employee benefit plans being offered today, virtually every type of plan is in existence. Plans cover medical, life, disability, vision, legal, auto/home, dental, and other needs of the employees.

Let us focus on the Group Medical Plan. With the passage of legislation under the Carter Administration, maternity expenses must now be covered at the same level of benefits as any other illness. The level of benefits for maternity coverage increased dramatically for many employees. This was timely legislation, but the question is why was this legislation needed?

The cost impact of this maternity legislation was significant both on the company and on the employee. From our underwriting viewpoint, the cost or the maternity benefit increase was shared by all employees, regardless if the employee was of child bearing years, or if the employee could have children through natural process.

In summary, the maternity legislation dramatically improved benefits, and increased the cost for medical coverage for virtually all employees.

But, what about employees who cannot have children through the natural process and/or must rely on adoption as the means of having a family? What can a company do for these employees?

Currently, if a company wants to have an Adoption Benefit Plan for its employees, the benefit provided is generally treated as ordinary income to the employee in order for the company to deduct the expense.

This raises a number of plan design questions.

What should be the level of benefits?

What expenses should be included?

When is the benefit paid?

How can the company deduct the expense?

Why should the company have this benefit plan?

How much will the plan cost the company?

Will the plan have a positive employee relations impact?

The biggest question is why should the company have an Adoption Benefit Plan. Some of the main reasons are:

The plan makes for good employee relations. Employees appreciate a company that is forward looking and helps the employee in a time of need.

Since adoptions cost as much and, in most cases, more than a natural birth, the financial impact on an employee is lessened when there is an adoption plan.

In a natural birth now, because of prior legislation, the out-of-pocket cost to an employee can range from $0 to a few hundred dollars.

In an adoption, the cost to the employee generally averages several thousand dollars.

Some companies have a strong social conscience. Companies realize that having an adoption benefit plan will not directly increase the number of adoptions. Rather, the companies set up adoption benefit plans to lessen the financial burden of an adoption; to put it on a benefit level that is more equal to the benefits received from the medical plan.

The cost of the plan is small, especially in comparison to other employee benefits. The frequency of use is small, so the total cost of the plan is small. But, companies want to pay the benefit in a manner that still allows them to deduct the expense.

What about from the employee's viewpoint?

Any amount of benefit would reduce the cost of adoption.

The employees do not adopt just because the company has a plan. The employee can receive a benefit that will help pay for the adoption which could accelerate the timeframe for the adoption.

In virtually all the plans, the employee receives the benefit as ordinary income, and is taxed accordingly. This reduces the amount of the usable benefit.

If companies could see that a meaningful tax effective benefit could be provided to employees, more companies would give stronger consideration to offering Adoption Benefit Plans.

The final question for the Subcommittee is why should we not give the same tax treatment to adoption benefits that we give to maternity benefits.

The ultimate end of both benefits is the same—the establishment of or addition to a family. Why should one be penalized from a tax standpoint and not the other? Why should one receive a taxable benefit and the other a tax favored benefit? Why should one benefit be treated as ordinary income and the other as a non-taxable benefit?

With the right legislation, companies could be encouraged to offer adoption plans. Who benefits? We all do. The companies can offer a meaningful tax effective benefit and generate employee good will. Employees can receive a non-taxable benefit that would help reduce the cost of adoption. The timeframe for adoptions could be accelerated so that children can find their way into a family faster. Society benefits from children being placed in the family.

Surely, the loss of a few tax dollars received from the current taxation of adoption benefits will be far outweighed by the social gain from the implementation of adoption plans. The tax treatment of benefits received for maternity and adoption benefits will now be equal, consistent and fair.

COMPANIES THAT PROVIDE ADOPTION BENEFITS TO EMPLOYEES

Abbott Laboratories, Abbott Park, North Chicago, IL. Donna Volkman, Health Care Supervisor.

American Can Co., Greenwich, CT. Robert B. Bogart, Managing Director, Corporate Human Resources.

Banker's Life Co., Garden City, NY, George A. Ghiel, Vice President.

Baxter Travenol Laboratories, Inc., Deerfield, IL, Charles Racansky, Manager of Benefits Administration.

Control Data Corp., Minneapolis, MN. Sharon S. Collins, Manager, Corporate Benefits Administration.

Digital Equipment Corp., Maynard, MA, Paul Cornelius, Benefits Administration Manager.

Resource—Bruce Mueller, Senior Vice President, Emett and Chandler, Chicago, IL.

Emery World Wide Corp., Wilton, CT, Elizabeth Shera, Personnel Benefits Manager.

Felt Products Manufacturing Co., Skokie, IL, Robert C. O'Keefe, Industrial Relations Manager.

Foote, Cone & Belding Communications, Inc., Chicago, IL, Amy Mysel, Vice President for Human Resources.

Gannett Co., Rochester, NY, Jacqueline Dienstag, Employee Benefits Manager.

Hallmark Cards, Inc., Kansas City, MO, Bill Hall, President, Hallmark Educational Foundation.

Hewitt Associates, Lincolnshire, IL, Christine Seltz, Director of Public Relations.

Honeywell, Inc., Minneapolis, MN, Ed Lund, Vice President of Administration.

Humana, Inc., Kansas City, KS, Mary Don Eaton, Director of Personnel.

IBM Corp. Armonk, NY, C.I. Hemstreet, Employee Benefits Planning.

International Minerals & Chemical Corp., Mundelein, IL, Robert L. Brigham, Director of Employee Benefits.

S.C. Johnson & Son, Inc., Racine, WI, James Russell, Employee Benefits Manager.

Eli Lilly & Co., Indianapolis, IN. Elizabeth Ott, Manager of Pay & Benefits Administration.

Mennonite Mutual Aid Association, Goshen, IN, James Kraft, Vice President, Administrative Services.

Syntex Corp. Humacao, Puerto Rico.

Minnesota Mining & Manufacturing Co., St. Paul, MN, Richard Burger, Benefits Director.

Pfizer Pharmaceuticals, New York, NY, Martha Bucuvalas, Benefits Specialist.

Pitney Bowes, Inc., Stamford, CT, Carole St. Mark, Human Resources Director.

Procter & Gamble Co., Cincinnati, OH, D.C. Jones, Personnel Administration Dept.

G.D. Searle & Co., Chicago, IL, Jeane Gockenbach, Supervisor, Employee Benefits.

SmithKline Corp., Philadelphia, PA, Robert S. Bursch, Manager, Employee Benefits Administration.

Time, Inc., New York, NY, Ann Fitzgerald, Operations Manager of Employee Benefits.

Xerox Corp., Stamford, CT, Sharon D. Diehl, Benefits Operations Manager.

[From The New York Times, Aug. 18, 1982]

MORE EMPLOYEES GET ADOPTION AID, MORE COMPANIES AID EMPLOYEES ON ADOPTIONS

(By Enid Nemy)

Employee benefits that help defray costs of adoption and provide other assistance to adoptive parents are becoming increasingly popular with leading business concerns across the country. At the same time New York State has taken steps to balance inequities in the treatment of parents who adopt, and Federal legislation has been prepared that would exempt from taxes some of the financial reimbursement offered as company benefits to the parents of adopted children. As a comparatively recent development, there are reimbursements of adoption expenses, up to $2,500 in some companies, and/or leave of absence for female and, in some cases, male employees who adopt—in most instances whether single or married. Such policies were scarcely heard of a decade ago, and it is only in the last three or four years that the subject has been addressed with any intensity.

The new direction is considered a logical progression that at once generates employee good will and is of minimal cost. Though the number of companies involved is still small, it has doubled in the past two years, and 50 percent of the increase has come about in the last seven months.

"Companies just hadn't thought about it before," said Christine Seltz of Hewitt Associates, a Lincolnshire, Ill., management-consultant firm. "But once it's brought to their attention there's a willingness to consider it because it makes for good employee relations and it doesn't cost much. Not many people use it."

Among the companies that have added adoption reimbursement to their benefits this year are Time Inc. and Pfizer Inc. of New York; Emery World Wide Corporation, the freight company with headquarters in Wilton, Conn.; the Procter & Gamble Company of Cincinnati, and Control Data Inc. of Minneapolis. Pfizer provides up to $2,500 per child to help meet adoption expenses; the maximums at other companies range from $1,000 at P. & G. to $2,100 at Time. Four of the companies also provide leave without pay ranging up to six months; Emery allows 30 days' leave with full pay.

Ann Fitzgerald, operations manager of employee benefits at Time, said that since the company announced its policy in April "we have received very nice notes from the staff, some of whom had been adopted themselves."

A study conducted by Hewitt in 1980 found that the 14 major companies surveyed that had added adoption benefits had done so on the basis of equity. However, while pregnancy benefits accounted for something like 3 percent of a company's medical benefits, adoption benefits amounted to less than 0.5 percent.

An interesting note in the study is that the impetus for the program seems to be coming from the companies rather than their employees. "Because of the low incidence of adoption, employee pressure is not really a factor," the study said. "More favorable tax treatment might provide a boost, but this issue does not seem to be overriding."

George Heino of Inwood, L.I., and his wife, Susan, adopted a girl at the end of last year. After taxes he ended up with $1,550 of his $2,000 reimbursement from Emery, where he is in management. "It came in mighty handy," he said. "It alleviated a large portion of the financial problem we had going through with the adoption."

"We were amazed that the company thought of it," said Jim Martin, a senior vice president at Foote, Cone & Belding, the Chicago-based advertising agency, who has adopted two children. "It didn't have anything to do with our decision to adopt but it was generous of them and it showed foresight. No matter what you make, it's terrific to get the benefit."

Foote, Cone & Belding added some adoption benefits 12 years ago but equalized them with those given biological parents only three years ago. To date the company has paid benefits to 2[illegible] employees, who have adopted 24 children.

"We treat the adoption process as we would the natural-born," said Bruce Mueller, vice president for human resources. "If a young child is adopted the mother is given up to six weeks' leave of absence at the same rate of pay as for natural parents." The company also reimburses employees up to $2,500 per adoption, considered equivalent to the cost of a normal delivery in a local hospital.

Digital Equipment Corporation of Maynard, Mass., a computer manufacturer, and the Minneapolis headquarters office of Honeywell, the international electronics company, are among the 28 concerns known to offer adoption reimbursement. They provide up to $1,000 for each adoption and offer leaves without pay for periods of two to three months.

Adoption benefits meet two of the three criteria most companies set when they are considering their programs, according to Miss Seltz of Hewitt Associates. "The money spent should be tax-deductible," she explained. "It should not be taxable to the employee and it should meet employee needs."

The one criterion not yet in effect is that the benefit be tax-deductible to the employee. As tax regulations stand, adoption benefits are included in taxable income and most companies withhold taxes when the benefit is paid, which can reduce the amount by 20 or 25 percent.

The 1981 tax-cut bill provided an exemption of up to $1,500 for the adoption of a "special needs" child, but no exemptions were included for normal children. Last year Senator Howard M. Metzenbaum, Democrat of Ohio, and Senator Paula Hawkins, Republican of Florida, introduced a bill that would offer deductions equal to the adoption expenses received as employee benefits. During hearings by the Senate Finance Committee, the Treasury Department opposed the bill, but a number of presentations were made supporting it, including briefs or appearances by American

Can, Hewitt Associates, the National Committee for Adoption and American Citizens Concerned for Life.

This year New York State equalized its policy so that male and female employees who adopt are entitled to leave without pay for up to seven months, the same as for biological parents.

"I wouldn't do this if I couldn't take time off," said Sharon Weglinski of Schenectady, N.Y., who is in the process of adopting. "I think it's essential to spend as much time as possible with a baby."

Mrs. Weglinski, a principal accounts clerk with the state Department of Parks and Recreation, has accrued 12 weeks' paid leave and plans to take a good part of the allowed unpaid leave. "I'm going to stay out as long as I can afford to," she said. "I've waited 10 years for this."

Candace Mueller, director for public policy of the National Committee for Adoption, said: "We feel very much that if more companies took a minute to think, they would appreciate that the same benefits should accrue to parents who biologically can't have children." The committee, an organization of individuals and nonprofit groups, is encouraged because 28 large companies have added adoption benefits, that still more have indicated interest and that the small bandwagon is growing.

ADOPTION BENEFITS FROM EMPLOYERS

Taken from National Adoption Reports Vol. III, No. 1, January 1982

A brand new benefit for employees is being considered by dozens of companies. This benefit is for families who have children through adoption, rather than at the hospital. "We pay maternity benefits for those who have children naturally. Surely those who adopt deserve the same support," said Bruce Mueller, employee benefits director for Foote, Cone and Belding, an international advertising and public relations firm based in Chicago. Mueller's remarks appeared in McCall's in December, 1980. Since then, he has become adoptive parents' patron saint in corporate employee benefits circles. In an interview with Business Week nearly a year later (Nov. 2, 1981) Mueller reports that many other companies are deciding to follow the lead of companies like Foote, Cone and Belding, Hallmark Cards and other corporate leaders.

Although adoption benefit programs are being treated by companies as a part of the "fringe benefit package" offered to employees, Internal Revenue Service regards these benefits as taxable income. Sen. Metzenbaum and Rep. Oberstar have introduced bills which would require IRS to consider these benefits as tax-free. John Chapoton, Assistant Secretary at the Treasury Department, testified before the Senate Finance Committee in October, 1981, and adamantly opposed the inclusion of adoption benefit programs as tax-free fringe benefit. Robert B. Bogart, with American Can Company, responded to the Treasury's testimony by saying, "It seems to us that to subject this (adoption) benefit to income tax unfairly penalizes people who are merely trying to create loving families, and we strongly urge that benefit payments made for adoptions be treated in exactly the same fashion as benefit payments on behalf of a natural birth which are covered by our various employee-choice medical plans.

Companies like to be responsive to the requests of their employees. Many companies have been responsive to the request of adoptive parents to establish adoption benefit programs.

Here is a list of 19 companies with adoption benefit programs. The list is not complete. If you know of others, please contact Candace Mueller at NCFA.

Abbott Laboratories; American Can Company; Baxter Travenol Laboratories, Inc.; Control Data Corporation; Felt Products Manufacturing Company; Foote, Cone, Belding Communications, Inc.; Hallmark Cards, Inc.; Hewitt Associates; Honeywell, Inc., International Business Machines Corporation; International Minerals and Chemical Corporation; S.C. Johnson & Son, Inc.; Eli Lilly and Company; Pitney Bowes, Inc.; G.D. Searls & Co.; Smith Kline Corporation; Smith Kline & French Laboratories; Syntex Corporation; and Xerox Corporation.

ADOPTIONS BENEFIT

Eligibility.—Full-time, permanent employees with nine months' service at the time an adoption takes place are eligible for reimbursement of certain adoption expenses

Coverage.—Reimbursement of legal, court, and social agency fees incurred up to the medical hospital insurance plan maternity payment for normal delivery.

Cost.—FCB pays all costs up to the specified coverage amount.

Procedure. Advise Payroll Department in writing of the date of the adoption and submit receipts for fees paid.

Senator DENTON. Ms. Flynn, we want to welcome you and ask you if you would begin with your testimony.

STATEMENTS OF LAURIE FLYNN, DIRECTOR, NORTH AMERICAN COUNCIL ON ADOPTABLE CHILDREN, INC., AND ELAINE P. WINSLOW, PRESIDENT, ALABAMA FRIENDS OF ADOPTION

Ms. FLYNN. I really do appreciate the opportunity to testify this morning on behalf of the North American Council on Adoptable Children. I also would like to thank the subcommittee staff for what I think may be setting a record. This is the first time that I know of that we have had an adoption-related hearing where five of the witnesses have been adoptive parents.

The subcommittee clearly knows who some of the experts are in this field, and we are very, very proud to have this much participation by the families who adopt the youngsters.

As my written testimony points out, and I will not go through all of it due to the lack of time, I am an adoptive parent, like many of the others you have heard today, and have shared many of the kinds of experiences in adoption that have already been presented to you.

I would like to point out that I know that families are often concerned that when we discuss adoption of children with special needs, so often we focus on those youngsters only as problems. They are more difficult to place; they present serious challenges.

But I think it is important to get the impression across clearly to members of the subcommittee and the public that these youngsters offer enormous rewards. That is the key to the families who do adopt the children. There is a tremendous amount of personal satisfaction in being able to provide something so basic as family love to a youngster who is lacking that.

I am very pleased to see your interest, Senator Denton, in reauthorizing title II of Public Law 95-266 because we find that so many children and so many families are still without adoption opportunities.

In reference to your comments a few moments ago, at a time when so many families are fragmented and we see so much stress and difficulty, it is very inspiring for me to work with people who are dedicating their entire lives to building families for homeless children, one by one. We really do appreciate your continued interest in this issue and your support for programs that serve these children.

The legislative intent of Public Law 95-266 was quite clear, and I do want to make, on behalf of my organization, a point that I think several others have tried to make here today.

While there are indeed other kinds of adoption needs and other kinds of adoption issues, our focus and the focus of most of us who have dealt for years with the barriers to adoption, are the youngsters referred to this morning by the Assistant Secretary and others—those children with special needs for whom opportunities are still so limited and for whom so many barriers to permanent families still exist.

We think there are about 100,000 of those youngsters and, again, I reference Mr. DeBolt's comments. It is a sad commentary that we do not even know who these children are.

Senator DENTON. I think you are the second to mention 100,000.

Ms. FLYNN. Somewhere, we have to be able to get some accurate numbers, because we cannot plan for children we cannot identify.

Regardless of that number, whether it be 50,000 or 100,000 or 150,000, or an increasing number as we may see through implementation of Public Law 96-272, we know at our organization that families are available who do want to adopt youngsters that are waiting.

We get up to as many as 800 or 1,000 calls and letters every month from families who identify themselves as resources for these children, and who so often also identify themselves as discouraged and defeated in their efforts to find a child for their families.

We have attached to the written statement a fact sheet which we mail out annually with our adoption week kit, which details the enormous cost in terms of lives and dollars of ignoring these adoption resources and ignoring the needs of the youngsters.

In light of those continued problems, I would like to request that the subcommittee, even at a time of budget cutback and the severe difficulties we are facing at the federal level, seriously consider restoration of the funding to $5 million

As adoptive parents, our members know firsthand the fear and the loneliness of abused, neglected and abandoned children who feel that they do not really belong anywhere. In light of the continued expression of need and the continued expression of support for these programs, I wonder that we are asking still for so little at the Federal level.

Because the funding has been so limited, NACAC is opposed to some of the proposed amendments which have been discussed quite thoroughly earlier, which seek to broaden the focus of the legislation and, in our view, may thereby serve to weaken efforts already too limited to serve the older, handicapped, and minority children in need of adoption.

Particularly in referencing the new focus which has been included on children who may be born to teenaged parents, unmarried parents, and services to infertile couples, I would like to point out again that these areas of concern do not relate to the adoption of children with special needs

Services to unmarried pregnant teenagers have been addressed in some other Federal legislation, and children born to those mothers are not hard to place. Those youngsters, when they are released for adoption—and I agree that many should be—

Senator DENTON. Excuse me.

Ms FLYNN. Yes.

Senator DENTON. That does come out of the child abuse part of the funding. It does not touch this money that you have referred to.

Ms. FLYNN. Well, at least in the draft that I did receive, the findings broaden the concern of the adoption opportunities legislation to include youngsters who may be born to teenaged mothers and unmarried parents as children who are in jeopardy and who need adoption planning.

Again, my concern is, indeed, they may be in some cases children for whom adoption is a good choice. But they are not at the same level of need as these children already identified.

Senator DENTON. The technical error made there was that it is supposed to say "some such children." In other words, by the way, some of those children become really special needs children.

Ms. FLYNN. Well, in looking at that as an amendment to the findings, I think that inevitably dilutes the focus of this very small amount of funding and this very directed and targeted effort on a population of youngsters already born and already identified as very much vulnerable to living a life without a sense of belonging.

So, we really would like to work further with your staff to see if we can work some of those concerns out. But we really were very, very upset at the thought that concern for infants who are easy to place would be seen as needing the same kind of targeting as concern for youngsters whom we know are very difficult to place.

Let me then move on, since we have dealt with that one, and discuss our concerns in some of the other specific areas. We are very pleased to see that the Federal initiative has continued to be in place for the National Adoption Exchange. Our organization has worked very closely with exchanges, both the national exchange and State and local exchanges.

As I have pointed out, a great many of these efforts have been at the initiative of adoptive parents and parent organizations themselves.

As others have mentioned to you this morning, there do remain a number of barriers to their effectiveness. Because the exchanges mainly serve a clearinghouse and referral function, they cannot directly affect placement, and jurisdictional barriers remain, as others have testified, a major problem.

We believe that local agencies must recognize that when they seek to utilize exchanges and photolisting services to recruit families for children, they must be open to shared decisionmaking in placement choices.

In so many cases that we are aware of, children are registered and recruitment by exchanges yields the families, yet no placement is made. Someone pointed out to me recently that the experience is not unlike going window shopping when the store is closed. You just cannot seem to get the children from the books to the actual families.

This problem is also related to another one which I do not think has been mentioned very extensively this morning, but which we see as a very large issue—the problem so many families face in getting an approved home study.

We surveyed over 400 parent groups around the country last year and asked them what was the single most important barrier that they saw in providing adoption to children with special needs. Overwhelmingly, their response was that the availability of home studies continues to be very limited.

It is nearly impossible in some places to obtain a home study, and without a home study, families cannot adopt the waiting children. Even with an approved home study, many families find their options limited by geographic barriers. Many agencies will not share or explore family resources outside their jurisdiction, nor will they permit adoption of their children by families residing in another State or county.

This is an issue essentially of agency control that undermines much recruitment and results in countless lost adoption opportunities for children.

On a minor point, in section 203 of the bill you have mentioned replacing the term "adoptive parent groups" with "adoptive family groups." We would like to request that you consider the use of both terms, primarily because "adoptive parent group" has taken on a certain meaning and is an identifiable term to persons working in the field of adoption.

We would like to continue to have this as a term that is well used because so many of our groups themselves identify that way.

Senator DENTON. We will take that under advisement.

Ms. FLYNN. Thank you.

We were pleased to see a recognition of the role that corporate benefits play in promoting adoption as a viable alternative for many children. We would point out that such programs do not place children.

Again, in terms of considerations about use of funding that may become available, we believe that many of these corporate adoption programs can be operated entirely on a volunteer or corporate pro bono basis.

Further, we would oppose any efforts to make use of limited funding for adoption services to continue to study, as the amendments indicate, "the nature, scope and effect of placement of children in adoptive homes by persons or agencies who are not licensed. including a study of the legal status of surrogate parenting."

As the committee is well aware, a respected researcher, William Meezan, has already published a study entitled "Adoption Without Agencies." Again, we would point out that such independent adoptive placement almost always involves the healthy Caucasian infant, not the hard to place children for whom adoption opportunities are so limited.

Surrogate parenting, which we certainly are concerned about, and is a well publicized and controversial new phenomenon, has to date involved a very limited number of families and an even more limited number of actual adoptions.

And, we would be very concerned if there were to be directed toward such a rare and unusual and, at this point, still legally undefined area, funding for a study when so much is needed on behalf of the children who continue to wait.

We really agree to some extent with Mr. DeBolt's earlier statements. We do not need a lot of new Federal programs, new Federal studies, new research efforts. We do not really need new adoption recruitment techniques or new service modalities.

We believe these children can be adopted and our goals can be accomplished by applying what we have already designed and what is already known.

We have a page of amendment to our testimony which I will briefly go over, which are specific recommendations we would like you to consider. All funding that is directed through the adoption opportunities program, we believe should go to one of the six major areas we think still need attention.

The first is to continue to promote the important role of volunteer adoptive parents and minority groups in providing advocacy and support for the adoption of children with special needs.

The adoption resource centers which were federally funded through the authorization of this title—when their center directors got together at their closing meeting, listed the use of volunteer adoptive parent groups through a minigrant program that Elaine Winslow will describe to you in a moment as the most effective and the most longlasting legacy that they were leaving the children they had served.

The second thing we believe——

Senator DENTON. Excuse me, Ms. Flynn.

Ms. FLYNN. Yes.

Senator DENTON. In our written invitation to you, we asked you and Ms. Winslow to testify, you know, sort of as one. We have this room only until 1 p.m. I have a security and terrorism meeting which will prevent me from remaining longer than that.

This thing about the teenagers again, and services to infertile couples—the motivation behind the services to the infertile couples was to help couples who were trying to achieve fertility. If they learn that that is impossible, they are more likely to become adoptive parents, and the services come out of the $17 million in the child abuse portion of the program.

I think you will end up getting more adoptive parents out of that at just about zero cost to your part of it.

Ms. FLYNN. We would certainly be pleased to see efforts made to inform infertile couples about the children with special needs who are waiting for adoption.

Senator DENTON. Well, they have to learn that they are infertile first.

Ms. FLYNN. Indeed, and many of them do come to our organization and others seeking information about adoption. It is important to remember that most of those couples, by far the largest percentage, are not interested in special needs children. Most of them are interested in adopting the infants, and end up having to wait many years on waiting lists for those infants.

Certainly, we would want them to know about the rewards of special needs adoption and to consider it.

[The prepared statement of Ms. Flynn follows:]

PREPARED STATEMENT OF LAURIE FLYNN, DIRECTOR, NORTH AMERICAN COUNCIL ON ADOPTABLE CHILDREN, INC.

I am Laurie Flynn, representing the North American Council on Adoptable Children, Inc. (NACAC). I am an adoptive parent. My husband and I have 12 children. Five are youngsters who were born to us, and seven have joined our family through adoption. Each of our seven adopted children was considered "hard to place" due to their special needs.

Two were born to mentally retarded institutionalized parents and had serious developmental delays. One also has moderate hearing and speech difficulties requiring a special educational program. We adopted three adolescents; a brother and sister came to us at ages 12 and 14, and our last adoption was a 15 year old girl who suffered an adoption disruption after three years. One child has gran-mal epilepsy which requires medication and careful monitoring.

Our adopted children brought a variety of racial and ethnic backgrounds, which has enriched our family life. Two are Vietnamese, three are Black and two are Native American Indian. Although each of our youngsters has presented some difficulties and each has had problems, my experiences with adoption have been very rewarding.

As executive director of NACAC, I have the opportunity to work directly with adoptive parents and people interested in adopting, all across the country. I urge reauthorization of Title II of Public Law 95-266 because so many children and families are still without the adoption opportunity NACAC has long sought to expand.

NACAC is truly a unique organization. We are made up almost entirely of volunteers—parents who have made the personal commitment to provide family life and care to one or more children with special needs. We represent nearly 500 local adoptive parent organizations. We have pioneered in adoption by proving in our own lives that no child is unadoptable.

NACAC has provided a crucial element of leadership and citizen advocacy in adoption. Our local parent and family groups in every state are supported by our volunteer network of State Representatives and Regional Coordinators. We have sponsored the only continent wide Conferences on adoption and have held eight such biennial gatherings of parents and professionals since 1968. In 1976 we inaugurated National Adoption Week, held each year at Thanksgiving. This celebration has been widely shared in local communities and through the media, as a recruitment and public awareness effort on behalf of waiting children with special needs. Adoptalk, our national newsletter, published continuously since 1975, is an important source of news and information about adoption, foster care and parenting. Our information and resources office provides the latest and best materials on adoption and adoptive family life. Each month we respond to over 500 requests for adoption information and provide referral to local programs, agencies and parent groups. NACAC Board, staff and volunteers have worked closely with legislators and administrators at the federal, state and local level to help remove barriers to adoption of children with special needs. Our advocacy training, and parenting workshops provide our members with needed skills.

From our founding in 1974, NACAC has focused priority attention on children too long neglected and unserved—over 100,000 legally free children with special needs who wait and have waited, for adoption. These children are school-aged, mentally, physically or emotionally handicapped, members of sibling groups and racial and ethnic minority heritage. It is to these vulnerable children that we have pledged our advocacy efforts, and it is for their right to a permanent loving family that NACAC members are dedicated.

Further, it was to these forgotten children that our efforts to help draft, encourage passage and secure appropriations of $5 million for the original Adoption Opportunities section of Public Law 95-266 were directed. We worked with former Senator Walter Mondale, Senators Alan Cranston and John Heinz and former Senator Warren Magnuson to fund and implement the first federal adoption initiative. It took over four years from 1974-1979, to gain this important victory for our nation's homeless children.

Local adoptive parent groups have sponsored a wide variety of creative and successful programs to help remove barriers to adoption. Pre-adoption peer counselling and parent preparation classes reduce agency staff work and offer a realistic and practical approach to providing skills needed to parent challenging children. Post adoption support was invented by adoptive parents and continues to be the first line of defense against painful adoption disruptions. Buddy systems, telephone networks and programs offering information, advice, and encouragement have helped many families make it through severe difficulties.

Many groups also mount impressive recruitment efforts, reaching out to their communities on behalf of voiceless waiting children. Over 350 groups regularly feature waiting children's photos in their local newsletters. Some groups post flyers in public places such as libraries, churches and community centers. In the past year NACAC groups placed bus placards in New York City, Columbia, S.C., Minneapolis and Philadelphia to reach potential parents for waiting children.

In over half a dozen states, adoptive parents operate the only state-wide adoption photo listing service: Arizona, Ohio, Georgia, Minnesota, Florida, South Carolina and Wisconsin. Parents funded and operate regional exchanges in the Southeast, (SEE US, Columbia, S.C., Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee), the Southwest (SWARE, Oklahoma City, OK—Arkansas, Louisiana, New Mexico, Oklahoma, Texas), the Rocky Mountain States, (Colorado Parents for All Children, Denver—South Dakota, North Dakota, Montana, Wyoming, Utah, Colorado) and the (Delaware Valley Adoption Resource Exchange, Philadelphia, PA Delaware, Pennsylvania, New Jersey).

The CAP Book of Rochester, New York is the only nationally curculated comprehensive photo-listing service. It was started by adoptive parents ten years ago and continues to be effectively and efficiently operated by adoptive parent staff and Board members. The success of the CAP Book has served as a model for New York state and many other state and regional recruitment programs.

Agency policy and practice has often been cited as a barrier to adoption of children with special needs. Some parents and parent groups have become licensed as voluntary agencies in order to meet children's needs for permanence. Aid to Adoption of Special Kids (AASK), Western Association of Concerned Adoptive Parents (WACAP), Crossroads, Growing Through Adoption, Adoption Horizons and several others are just a few examples of the kind of direct service parents can organize to fill a gap in service to children.

These parent led efforts are all based on a major premise, articulated by NACAC: adoptive parents are not the "clients" of adoptional services, in the traditional sense. They are resources for the waiting children who are the real clients of adoption services. Effective use of parent resources is the heart of NACAC's widely acclaimed TEAM Program. TEAM was based on a highly successful program developed by Barbara and Bill Tremitiere, adoptive parents and staff members of Tressler-Lutheran Service Associates of Pennsylvania.

TEAM is based on the belief that by joining energies, agencies and adoptive parent groups can work more effectively to place waiting children and support adoptive families after placement. TEAM has five elements: public education and recruitment, parent preparation, family support and child advocacy. Details of implementation are presented in two manuals—Guide to Local TEAM Programs, to help parents and workers assess local needs and plan joint efforts, and TEAM Parent Preparation Handbook which provides a comprehensive approach to preparing prospective parents in an atmosphere of self discovery, shared decison making and mutual support. This group parent preparation course is provided by a team of social worker and experienced adoptive parent and replaces the traditional homestudy. The homestudy is largely self-prepared and is a more accurate and personal presentation of the parents. The TEAM model offers an exciting alternative to traditional practices, and can be readily implemented in both public and private agencies, using volunteer parents as co-leaders and resource people. A social worker with many years of experience in the adoption field wrote NACAC: "When the TEAM approach is used strengths are maximized, time is used more efficiently, more children are moved into permanent homes which are realistically ready for them, and the families receive a higher quality of service all the way through the process."

The TEAM Program has been funded since 1979 by the U.S. Department of Health & Human Services, under the adoption opportunities and discretionary grants programs. NACAC has provided TEAM training to over 200 parent/worker TEAMS who now are implementing TEAM programs and services in more than 50 communities. NACAC is enormously proud of this tremendous success and the dedication of hundreds of local adoptive parents and parent groups.

NACAC publications serve the adoption field by providing accurate information from a parent's perspective. Adopting Children With Special Needs and the soon to be published Sequel provide first person accounts of adoptive family life written by the real experts—the parents themselves. NACAC has worked closely with PBS and 3M to produce two editions of the Adoption Help Directory. Federal funds assisted our development of the Directory of Parent Group Resources and the pamphlet Adopting the Child With Special Needs (by Joan McNamara).

We also revised and expanded our Citizen Action Manual to enable local parent groups and child advocates to participate effectively in their state and community. A recently developed series of leaflets has been designed to provide answers to the questions we receive more frequently from the general public. (Copies of all NACAC publications and periodicals are attached for the Committee record.)

The important role of NACAC members was publicly recognized in 1981 by the National Council of Juvenile & Family Court Judges which honored us with their "Meritorious Service to the Children of America Award". NACAC member parent groups recently were advised of our 1983 program goals through a special issue of Adoptalk (attached). Because so many barriers remain, we must continue our aggressive efforts to make adoption a priority service. Even in times of budget cutbacks, NACAC believes that the plight of homeless children must receive greater attention.

The legislative history and intent of Title II of P.L. 95-266 is clear. The Congress was convinced that our nation had too long neglected thousands of foster children who were denied the love and security that only a permanent family can provide. At least 500,000 children have been removed from or abandoned by their biological family and consigned to a series of temporary placements in foster homes and institutions. 100,000 of these children are legally free for adoption, yet they remain unplaced. A fact sheet prepared by NACAC is attached, which details the enormous cost in lives and dollars, of this failure to provide adoption opportunities for children with special needs. The $5 million originally appropriated to address adoption needs was a good beginning, although this small amount is a mere fraction of the federal and state expenditures for foster and institutional care, estimated at $2 billion annually. Of all the public spending on children in substitute homes, approximately 97 percent goes to foster care and only 3 percent to assist adoption services. Even if an annual adoption subsidy of $1,200 is provided to facilitate adoption for 10,000 children with special needs, the cumulative savings over a 10 year period would be $1.3 billion.

NACAC is distressed that the funding level for federal adoption programs has been reduced to less than $2 million dollars. We question the seriousness of the federal commitment to adoption opportunities in light of such meager funding, especially when states are experiencing severe budget shortfalls and a reduction in federal funding for social service programs. As adoptive parents, NACAC members know firsthand the fear and loneliness of the abused, neglected or abandoned child who feels he doesn't truly belong to anyone. On behalf of these waiting vulnerable children we strongly urge the subcommittee to recommend restoration of funding at the $5 million level.

Because funding for Title II has been so limited, NACAC strongly opposes the proposed amendments which seek to broaden the focus of the legislation and thereby weaken further the efforts to serve older, handicapped and minority children in need of adoption. We do not understand the need to expand the work of the Advisory Committee on Child Abuse and Neglect, Section 5(a) (1) and (2) to include "coordinating all adoption related activities of the federal government." The goal of child abuse prevention and treatment is to restore family life for endangered children. Adoption deals with children at the other end of the child welfare continium, and is a last resort when the birth family cannot or will not assume parental responsibility.

Even more disturbing to NACAC is the inclusion of language which relates to infants who may be born to teenagers, and services to infertile couples. None of these areas of concern relates to the adoption of children with special needs—those 100,000 youngsters already here who have waited in vain for a permanent family. Services to pregnant teenagers are well addressed in other federal legislation. Children born to such young mothers are rarely hard to place. The infertile couples referenced in the amendment eagerly seek to adopt healthy infants, sometimes waiting up to five years to become parents. Most infertile couples are not interested in adoption of waiting children with special needs.

Adoption may be a viable plan for infants born with a life-threatening congenital impairment, provided legal action has been taken to terminate parental rights. These children, brought to public attention through the tragic "Infant Doe" case in Indiana, are of great concern to NACAC. We know many families are available to adopt such children if the birth parents do not wish to provide nurture.

NACAC opposes the language amending the "Findings and Declaration of Purpose for Adoption Reform, Section 201, 7, (a)(1), as inaccurate and judgemental. Specifically, we cannot agree that "infants born to teenaged individuals, and unmarried parents" are by definition "in serious jeopardy and that such infants and children are in need of placement in permanent adoptive homes." No such categorical statement can be fairly made or proven. Not all teenaged or unmarried parents are unable to properly care for their children. Recent studies by the Child Welfare League of America show that with support most young mothers can and do become successful parents. Single status has little to do with capacity for parenthood. Many agencies now welcome singles as adoptive parents, especially for waiting children. Again, we must point out that the children of teenagers and unmarried parents are not children who generally require specialized adoption services. With as many as 30 couples waiting to adopt each healthy infant or toddler available, these children do not need special federal efforts to expand their adoption opportunities. We suspect the inclusion of this unnecessary language speaks more to the needs of agencies who have failed to find families for the hard to place youngsters and seek justification and funding to return to infant placements. This ill-advised language also seeks to provide a new supply of infants by declaring that all such children are "in need of placement in permanent adoptive homes."

What has happened to the federal focus on the children who truly need our help—the helpless, hurting, homeless thousands whom agencies have ignored? As child advocates we must strongly resist this effort to place their urgent need for a loving family on a par with infant placement programs. All such expansion of the findings and purposes of this title, with the exception of amendments to protect the adoption opportunities for infants at risk whose parents have abandoned them, must be rejected as a serious diversion from our nation's commitment to hard to place children in the foster care system.

We are not certain just what "mechanism for the Department of Health and Human Services to promote quality standards for adoption services." (Sec. 201. 2, (A) is envisioned. It is clear that adoption, as a state service, is regulated through application of strict licensing standards. The Child Welfare League and other organizations have long provided professional standards for adoption and thus such a role by HHS may well be both unnecessary and ineffective. We do, however, support inclusion of pregnancy counseling which presents adoption as a positive alternative as part of a comprehensive set of adoption standards. Should HHS continue to see a need for federal efforts to promote quality standards, NACAC strongly suggests that adoptive parents, relinquishing parents, and adoptable children themselves, where feasible be consulted. Current professional standards and practices are often insensitive to real needs and many so called professional services are demeaning and patronizing. We believe a lack of confidence in agency programs and services is a major factor in the increase in independent adoption.

NACAC is pleased to support continued emphasis on the need for a national adoption exchange, as stated in Sec. 201. 2, (C). We are proud to work closely with dozens of state and regional exchanges, in partnership with the staff of the Adoption Exchange in Philadelphia. Exchanges and photolisting services provide the best means available to bring waiting children and families together. There remain major barriers to their effectiveness however. Because exchanges serve mainly a clearinghouse and referral function, they cannot directly affect placement. Jurisdictional barriers remain a major problem and the advocacy role of exchanges and photolisting services must be strengthened and supported. Local agencies must recognize that when they utilize exchanges and photolisting services to recruit families, they must be open to shared decision making in placement choices. In too many cases, children are registered and recruitment yields interested families, yet no placement is made.

This problem is directly related to the continued difficulty prospective parents face in getting an approved homestudy. A recent NACAC survey of parent group volunteers revealed this as the major single barrier to the adoption of waiting children. It is nearly impossible in some places to obtain agency homestudy services. Families and adoptable children wait because this basic adoption service is unavailable. Even with an approved homestudy, many families find their options limited by geographic barriers. Many agencies will not share or explore family resources outside their jurisdiction, nor will they permit adoption of their children by families residing in another state or county. This is an issue of agency control that undermines much recruitment and results in lost adoption opportunities for waiting children. In Section 202(b)(1) the Secretary is required to "review all model adoption legislation . . . to propose such changes as are considered appropriate to facilitate adoption opportunities for infants at risk with life-threatening impairments." While we are sympathetic to concern for such infants, we hope the review will not require convening of another expensive expert panel. HHS regulations on this issue and upcoming court tests should provide sufficient guidance and protection to avoid further "Infant Doe tragedies."

We request that where reference is made to adoptive family groups, as in Section 202(b)(2) and Section 203(b) that the designation read adoptive parent or family groups. The term adoptive parent group is widely recognized and understood in the field. We believe that changing the designation will only serve to confuse. As the national adoptive parent organization, NACAC and our local parent groups (composed almost entirely of adoptive and prospective adoptive families), has played a key leadership role in promoting adoption. We prefer to continue to designate our movement with primary use of the term parent groups.

NACAC applauds corporate efforts in offering employees adoption benefits (Section 203(7)). We have worked closely with parent groups to educate businesses and corporations to this need and have shared model policies with several hundred employers during the past three years. While such programs do not place children, they do equalize adoption as an alternative and recognized method of family building.

We are opposed to the use of limited federal funding for adoption for any continuation of efforts to study "the nature, scope, and effect of placement of children in adoptive homes by persons or agencies which are not licensed by or subject to regulation by any governmental entity, including the legal status of surrogate parenting." Respected researcher William Meezan has already published, pursuant to this legislation, a major study titled, Adoption Without Agencies. Further, such independent placement almost always involves a healthy caucasian infant, not the hard to place children for whom adoption opportunities are needed. Surrogate parenting, a controversial new phenomenon, has to date involved less than 200 couples nationwide, with fewer than 50 reported adoptions. To focus on this very rare and legally undefined area, when funds for waiting children are so limited, is an extremely poor choice. NACAC cannot support such a use of scarce federal resources to the detriment of children with special needs.

To summarize our concerns, I repeat our belief that Congress and the American people want to find permanent families for over 100,000 waiting adoptable children. Such children will not be placed through advisory committees, legislat[illegible] adoption benefit programs, federal coordination or studies. They can only be [illegible] if funds are made available to find and support adoptive families.

NACAC recommends that funds be designated to:

1. Increase availability of adoption homestudies for parents seeking children with special needs. Use of innovative methods and volunteer resources should be encouraged.

2. Waiting children must receive greater visibility through support of the National Adoption Exchange. Workers must be trained in adoption skills.

3. Top priority must be placed on serving children most in need of adoption: Black and Hispanic youngsters, school-aged, mentally, physically and emotional handicapped children, and sibling groups.

4. Provide support for the volunteer efforts of adoptive parent organizations. The federal mini-grants sponsored by the Adoption Resource Centers, were unanimously voted by Center directors as their most effective effort.

5. Seek creative ways to overcome persistent jurisdictional and geographical barriers to interstate and intrastate placement of children with special needs.

6. Direct challenge grants to public and voluntary non-profit agencies and organizations with the sole objective being adoptive placement of a specific number of children with special needs, including preparation of adoptive parents and post-placement family support.

We do not need to develop new federal programs. We do not need additional recruitment techniques or service modalities. We can accomplish our goals by applying what has already been designed.

Limited funding means we must focus strongly on outcomes for children. We must be accountable for the only acceptable outcome—a permanent family for every waiting child. This has been NACAC's goal since our founding. This is the goal of Title II, P.L. 95-266. We sincerely hope this Committee will consider carefully our recommendations and concerns in light of the continued unmet needs of the 100,000 children who wait.

Thank you for the opportunity to testify. I am deeply grateful for this direct participation on behalf of the thousands of families across the country who share our concern for waiting children.

CHILDREN NEEDING PERMANENCY

Approximately 750,000 American children are presently in foster care. This figure is, at best, a raw estimate—the number of children actually in the system is not definitely known. Many state welfare agencies admit they are not able to keep an accurate count of the children in their care.

The number of foster children has more than doubled since 1960. The seeds of welfare dependency, medical and psychiatric illness, and even criminal behavior are being sown as children move from place to place, never knowing permanency.

Recent studies of foster care cases reveal that 40 percent of the children remained in placement from one to five years. Many stayed longer. Some children have changed foster homes up to 18 times.

One reason for the frequent transfer of foster children is the inadequate support payments to the foster family. Figures show that in many areas, kennels receive more money to board a dog than a foster family receives to board a child.

Yet foster care is the largest single item in the child welfare budget, costing American taxpayers over $2 billion annually. Of all the public spending on children in substitute homes, approximately 97 percent goes to foster care and 3 percent to assist adoption services

Adoption is cost effective. About one-third of the foster children could be adopted if barriers were removed.

Even if annual adoption subsidy of up to $1,200 was provided to facilitate the adoption of 10,000 hard-to-place children, the cumulative savings over a ten-year period would be $1.3 billion.

The current national adoption profile includes children available for palcement who are between the ages of 6 and 16. About 60 percent are non-white. Some have physical problems. Some have emotional problems. Some have been abused, neglected, or abandoned.

Foster care is administered by overburdened, poorly paid staffs that are often professionally unprepared and ill-equipped to legally free children for adoption and to find families for them.

The courts also bear a responsibility for the fact that children spend unnecessary years in foster care. Severing parental rights is a painful decision many judges hesitate to make. Thus, the case drags on, and young childhoods are wasted.

For many years federal aid was provided in a manner which encouraged keeping children in foster care rather than offering incentive to get them back into their own homes or placed in an adoptive home. A new law, PL 96-272, the Adoption Assistance and Child Welfare Act of 1980, promised real reform of foster care, and a new opportunity for waiting children.

Ms. Winslow. I am Elaine Winslow, president of the statewide organization of Alabama Friends of Adoption. I am an adoptive parent and the mother of five.

Alabama Friends of Adoption is a nonprofit group whose membership consists of adoptive parents, social workers, foster parents, and other child welfare advocates. With the focus of adoption across the country moving from white, healthy infants to the adoption of special needs children, parent groups across the country have sprung up to help families find waiting children and to help waiting children find permanency.

Presently, we are involved in a number of programs which are important to recognize specifically, because many of them were regionally funded by the Federal Government through the region IV adoption resource center.

These programs include providing continuing education on an annual basis for foster and adoptive parents, social workers, lawyers, judges, and community advocates. We operate an adoption hotline statewide. Families can call in and find out about adoption of all varieties of children, and we try to channel them into a direction.

We provide support and backup for a Wednesday's Child television program. This enables an ongoing recruitment program for the adoption of special needs children. We provide statewide coverage and support for exchange books. I have the Alabama book here if anyone is interested in looking at it. This is an excellent recruitment took for families to be able to view actual waiting children and proceed from that perspective.

We also provide team leaders and parent preparation classes by coleading with social workers the adoption preparation classes. This lends a little credibility to the reality of parenting some of these challenging special needs children.

We also actively advocate on child welfare issues, both on a State and national level. All of these programs were originally funded by the region IV resource center, for a total of just a little over $5,000 over a 3-year period. That is a mighty small amount of money to implement what have become rather large positives for special needs children in our State.

With the phaseout of the region IV resource center and the combining of services and funds to the Southeast Resource Center for Children and Youth Services, no funds are specifically earmarked for foster care and adoption. Consequently, services to these areas will be miniscule.

What would we like from the Adoption Opportunities Act? We, too, are deeply concerned about the newborn infant and its proper care. However, we also enlist your concern and recognition of the fact that there are presently over 100,000 special needs children in this country waiting right now, today, for a forever home.

The Adoption Opportunities Act was originally intended to help these waiting children. We need the support and fiscal vehicles to recruit families, make placements and provide the necessary support following placement that it takes for families to be successful with these children.

The $5 million originally intended to fund this program is certainly needed to implement such adoptions. The adoption of children with serious medical and emotional problems brings extensive financial costs to families who adopt them. These children deserve the best possible medical and psychological treatment to be able to recover from the trauma of being lost in the limbo of foster care.

The medicaid coverage which might be available for some children will not adequately always cover a child's medical expenses. The child is able to qualify for better medical coverage as a foster child than as an adopted child.

From a purely fiscal standpoint, it would appear to be cost effective to place children for adoption and continue adequate medical coverage for these children. Through formal adoption, the savings in administrative costs of foster care would be substantial.

The support and maintenance of such organizations like the North American Council on Adoptable Children is crucial. These are the very people who provide the tools and the training for folks like us, volunteers, who are out in the community implementing volunteer programs that are not costing anyone a cent, and we really need these folks.

Parent groups need funds to begin to implement some of their volunteer programs. We need to begin some sort of program which will facilitate the actual placement of special needs kids.

We have a lot of studies, a lot of counting; now we need to get some action. We need the actual money to place children, perhaps in the form of challenge grants which might be made available to provide staff time for providing postplacement services for children.

In Alabama alone, we have a number of counties where a family cannot adopt; there is no one to do a home study. So, they could call until doomsday to adopt a 15-year-old, a 12-year-old, handicapped, or whatever, and they are not going to get any service because there is no one out there to do it.

We can all acknowledge the monetary savings made in placing children in permanent, loving homes. But we also need to realize that 75 percent of the children who grow up in foster care in our welfare system are back on the public dole as adults.

Seventy-five percent of them end up in the penal system, the welfare system or the mental health system. So, we are not just paying for these kids now; we are paying for them forever.

So, we just urge you to focus your attention on the actual placement of special needs children who are waiting right now. I appreciate being invited to testify, and thank you.

[The prepared statement of Ms. Winslow follows:]

Prepared Statement of Elaine P. Winslow, President, Alabama Friends of Adoption, Birmingham, Ala.

I am Elaine Winslow, President of a statewide organization known as Alabama Friends of Adoption. I am an adoptive parent and mother of five. Alabama Friends of Adoption is a non-profit group whose membership consists of adoptive parents, prospective adoptive parents, foster parents, social workers and child welfare advocates. We are presently in our fifth year of operation and have a total of seven operative satellite groups throughout Alabama. Our volunteer services to children and families encompass a broad scope. Acceptance by the local community, welfare departments and private adoption agencies throughout Alabama has enhanced our abilities to serve.

The focus of adoption across the country has moved from white, healthy infants to the adoption of waiting special needs children. Special needs children are defined as minority race children of all ages, white children who have permanent physical disabilities and/or some degree of mental retardation, members of a brother/sister group of three or more, or are teenagers (especially boys). With the advent of families adopting challenging children, a critical need for adoptive parent groups has evolved. Families need the caring support of others who have experienced similar challenges. Hence, Alabama Friends of Adoption was formed to help families find children and to help families parent effectively.

Presently, we are involved in a number of programs which are important to recognize specifically because many of them were originally funded by the fedeal government through the Region IV Adoption Resource Center. These programs have included:

Providing continuing education for foster and adoptive parents, social workers, lawyers, judges and community advocates through annual conferences and seminars.

Operating an adoption Hot Line (manned by trained volunteers) who disseminate pertinent adoption information concerning all types of children available within our state and throughout the nation.

Providing the backup support for a "Wednesday's Child" television program which features waiting special needs children on a weekly basis. This provides an on-going recruitment program for families who might adopt special needs children. In Alabama over the past two years 135 children have been featured and 93 of those children have been placed in an adoptive home.

Providing statewide coverage and support for Exchange Books (books featuring waiting special needs children)—an excellent recruitment tool. Families may actually view books with pictures and descriptions of waiting children available for adoption throughout the U.S. They may then pursue a specific child for adoption through proper channels.

Participating as team leaders in the parent preparation classes offered to those families interested in adopting special needs children (an experienced adoptive parent as a co-leader of these classes lends credibility to the reality of parenting some of these challenging children).

All of these programs were funded originally by the Region IV Adoption Resource Center for a total of $5,000 over a three year period. It is obvious that a lot was accomplished for children families with relatively small monetary outlay.

However, these programs cannot continue on the nickels and dimes that adoptive parents raise at garage sales and craft sales. With the phase out of Region IV Adoption Resource Center and the combining of services and funds to the Southeast Resource Center of Children and Youth Services, no funds are specifically earmarked for foster care and adoption. Consequently, services to these areas will be miniscule. I have been told by an advisory committee member for the Resource Center not to bother to apply for the mini-grants this year because Alabama Friends of Adoption has already received monies in the past from the Adoption Resource Center and will not be considered. With this attitude, the potential of increasing parent and family group involvement in special needs adoption will be reduced substantially. Mini-grants such as AFOA received in the past, give assistance to volunteers so that they may have the opportunity to serve.

What do we ask from the federal government and, more specifically, from the Adoption Opportunities Act? We are deeply concerned about the newborn infant and its proper health care. However, we also enlist your concern and recognition of the fact that there are presently over 100,000 special needs children in this country waiting TODAY for their forever home. The Adoption Opportunities Act was originally intended to help these waiting children. We need the support and the fiscal vehicle to recruit families, make placements and provide the necessary support following placement that it takes for families to be successful with these children.

Many of the children we are placing in families offer stern challenges. Presently, in my role as an adoption consultant, I facilitate a post-placement support group for children and their families. The group is composed of children of varying racial backgrounds (black, caucasian, and oriental), children who have been sexually abused, children who have never developed a moral value system, a child who has been in a psychiatric hospital for four months, one child with cerebral palsy who is retarded and two brothers who are both retarded and have behavioral problems. How families take on children like these at the ages of 6, 8 or 13 is an amazement to many. These families make a success of their parenting with the help of post-placement support. This is the only group of its kind in Alabama. No funds are available to provide this critical service elsewhere. If we expect families to be successful with these difficult-to-parent children, we must seek more innovative methods of providing help for these children in their new families. Locally post-placement support groups need to be developed.

The adoption of children with serious medical and emotional problems brings extensive financial costs. These children deserve the best possible medical and psychological treatment available to recover from the trauma of their initial rejection and placement in our welfare system. Federal subsidy needs to act as a supplement to state subsidy to help meet a child's specific needs. A family may desperately want to adopt a child with severe medical problems who is presently in foster care. However, the medicaid coverage, which might be available for some children, will not adequately cover the child's medical expenses. The child is able to qualify for better medical coverage as a foster child than as an adopted child. From a purely fiscal standpoint, it would appear to be cost effective to place the child for adoption and continue adequate medical coverage for the child. Through formal adoption, the savings in administrative costs of foster care would be substantial.

The support and maintenance of organizations like the North American Council on Adoptable Children is crucial. These are the people who provide the tools and the training for volunteers, such as myself and AFOA, to do the work for waiting children that is so critically needed now across the country. Parent groups need funds to be able to implement their volunteer programs. Foremost, we need to begin some sort of program which will facilitate the actual placement of these special needs kids. We do not need any more clearing houses, studies, or countings of children; we are aware of how many and where these children are. We need actual monies appropriated in the form of challenge grants, which will enable agencies to expand staff time placing and providing the post-placement services for the adoption of special needs children. Our focus should encompass the actual funds to place America's waiting children in permanent homes.

It is critical to recognize that each child already in our welfare system needs a permanent home. Many children wait, through no fault of their own, until it is to late to make changes in their lives. Fortunately, others climb out of the system and begin to thrive. A little girl named Stephanie, age 7, was adopted by one of our families over a year ago. Stephanie is severely crippled by cerebral palsy. Her mental capabilities are unknown. When she was adopted by her new family she sat limply in a stroller, her eyes darting, not uttering a sound. One year later this child feeds herself, walks with the aid of a walker, is beginning to use language appropriately and, with a big bubbling smile, boards the school bus every morning. Stephanie is not lost in the limbo of foster care any more; she is also off the public welfare roles. More importantly, she is a real person, beloved as a family member.

We can all acknowledge the emotional rescue and monetary savings made in placing children in permanent loving homes. Not only does this plan for permanency reduce the fiscal drain of foster care, it also reduces the substantial amount of money spent supporting these children in adulthood. It is my understanding that some 75% of the children who grow up in our welfare systems across the land end up back on the public dole in either the welfare system, mental health system or penal system. Surely it is advantageous to rescue these children early enough in life so that they might have the opportunity to grow into productive adults in society.

Senator DENTON. Thank you, Ms. Winslow, and I certainly concur. Aside from our duty to take care of our children, and particularly our special needs ones, it just makes fiscal, monetary, and economic sense to get them into a real adoptive situation as soon as possible, and it is worth the investment there because, otherwise, it is going to cost you more.

I think as we go toward the federalistic approach and as we go toward this block grant thing, we are going to have to continue to make many adjustments in the direction of recognizing where the money is actually invested, not spent, and that the investment is bound to accrue dividends, such as in this field, and I will be a proponent for that.

At a hearing this subcommittee held [illegible] weeks ago, Mrs. Rossow, an adoptive parent of several handicapped children, discussed the potential impact of parent support groups for couples or single parents who give birth to an impaired child or who are in the process of making a decision on the future of the child.

I think the concept has potential and I would like to see a system of this kind developed. Do you feel that support groups of this kind can be of help to such parents, and what feasible system could we establish to insure prompt accessibility to such support groups? Could such support groups avail themselves of funding under the Adoption Opportunities Act?

Ms. WINSLOW. First of all, I think that adoptive parent groups can be helpful in that respect. We receive a number of calls weekly from unwed women who are thinking about giving up their babies for adoption, and older children who would just like to talk to somebody who is an adoptive parent.

How we implement the support process is going to take a little bit of funding from someplace. It would be nice if part of it came from the Adoption Opportunities Act. I think as adoptive parent groups get more public recognition by both the media and public and private agencies across the country, they can then serve in a broader scope.

Senator DENTON. I am not that familiar with the vernacular of all of this, but does "parent support group" mean people who have adopted children?

Ms. WINSLOW. Many of our members are adoptive parents or prospective adoptive parents. We also have social and welfare——

Senator DENTON. But what Mrs. Rossow meant was parents who have adopted handicapped or special needs children and their going to a couple who has just undergone the traumatic experience of giving birth to a child with a substantial handicap, deformity, or something like that, and by their early intervention and empathy, not only lessening their pessimism about having that experience and what it means in the future, but preventing them perhaps from, you know, giving permission for postoperative procedures that could be lifesaving or to just sort of abandon the child later, where they would become one of these special needs children out there that you have to place.

Is there a great deal of efficacy to getting support groups like that, parents who have adopted or raised handicapped children, to talk to these new parents very early on before they reach some decisions that they might regret later or might be unfortunate for society?

Ms. WINSLOW. I am unaware of any specific program, but I feel sure that there are a number of contacts throughout community services that are available to families who might want to seek particular, specific information on particular medical problems that their child might have and, in turn, make some very important decisions.

Senator DENTON. I was trying to find out if it would be—I am not asking whether or not such a system exists out there. I am asking how valuable it would be, and there were a lot of people nodding that it would be quite valuable.

Ms. FLYNN. I wonder if I might offer a thought, Senator Denton.

Senator DENTON. Sure.

Ms. FLYNN. I think it could be very valuable, and we have seen some of this kind of effort made in some communities. I can remember visiting in Kentucky a year or so ago, where through one of the local agencies which had a pregnancy counseling program, and also some kind of a special effort made with families who do, in an unexpected way, deliver a handicapped or retarded child. They brought in routinely to the unmarried parents, adoptive families for them to see and know and hear about adoption, which so often they do not hear enough about, and not only to hear about it in a general sense from a social worker or a nurse, but to see and hear about it from a parent who has done it.

Similarly, in at least one case I heard about, they did have an adoptive parent go in and speak with a woman who, with her husband, had just given birth 2 days before to a child with some very serious physical defects.

In this instance, they were considering lifetime institutionalization for the youngster, and the woman who was the adoptive mother of several very handicapped youngsters went in and encouraged them to consider adoption as a better choice for the child and as a choice that would give them a sense of having really done some good in the child's life.

So, I think that while we have seen a few of these examples, it is an area that could be explored. And the value of the personal connection between parents who have chosen to raise these more difficult youngsters—the kind of support that they can give to both unmarried parents as well as couples who may find themselves in that position of decision, I think could be very valuable.

Senator DENTON. Well, I say to the community of you out there, if we were to implement a regulation which disestablished parental rights at the point at which the parents decided to end the life of the child by denying such and such a postoperative procedure which was justified, then you would have on your hands a special needs baby.

Ms. FLYNN. That is right.

Senator DENTON. If you can get to those people early enough, you will not have on your hands another special needs baby for adoption.

Ms. FLYNN. That certainly may be the case.

Senator DENTON. So, if you will help us remember that and find a way to get it into the bill without being intrusive or, you know, big brother too much, we would appreciate it. Thank you very much.

We have questions from Senator Dodd for the record, and we will be asking you two to answer them when you receive them.

I have learned a great deal from this hearing and from this series. I have to admit that my own attitude toward the blessings to be gained by adopting a special needs child has certainly grown. It has been a remarkable experience for me, and each of you has contributed to that and I admire you very much.

At this point I order printed all statements of those who could not attend and other pertinent material submitted for the record.

[The material referred to follows:]

PREPARED STATEMENT OF HOPE MARINDIN, CHAIRMAN, COMMITTEE FOR SINGLE ADOPTIVE PARENTS

Thank you for the opportunity given us to submit a statement on possible amendments to the Adoption Reform Act of 1978.

This Committee is a national information service for unmarried individuals seeking to become families, by adoption. As both our records and independent surveys have shown, the great majority of such persons are in their thirties, with stable careers and middle-class incomes, in the "helping professions"—social work, teaching, therapy—able and eager to provide a loving home for a child. We join the other adoption-related groups in our belief that every child deserves a loving, permanent home and can get one.

Overwhelmingly, the children you, and we, are concerend with are in public care, almost always placed with foster families, rather than in public institutions. As between restoration of the natural family and placement with a new adoptive parent or parents, we say only that a loving permanent family of either kind is infinitely preferable, for the support of the child, to the long temporariness of foster care. As an adoptive parent group, we do feel that the child deserves a deadline after which a decision must be made between one type of permanent family and another.

Parents exist for these children, and the children need parents—couples or single people. Why can't they be combined? We believe that it is because of barriers in the system or deliberate, though benignly intended, failure to place them.

SYSTEMIC PROBLEMS

Many public child welfare systems do not know where their children are, or what their status is in terms of emotional or mental health. Although there is supposed to be a record and a permanent plan for each child, too often this requirement is honored in the breach. It is easier to place the child in foster care and then leave him or her there. Inertia takes over. The foster parents may be provided with the available public services—payment, Medicaid-funded medical care, clothing funds, etc.—by the separate and appropriate parts of the public agency, and the individual caseworker may have a file on the child, but no effort is made to pull information together with the goal of returning the child to a permanent family. And the longer the child remains in foster care the less likely it is that the public agency will see the child as adoptable.

Yet there are public agencies that are developang excellent tracking and reminder systems, automated, that are keyed to permanent placement of their foster care children. Texas has one, I understand; the D.C. Department of Human Services is setting one up. Our first suggestion is that such examples be shared with all public social service agencies, and that some financial and informational assistance be provided to other states and jurisdictions to encourage them to adopt one or another such system.

Secondly, there are excellent adoption information exchanges and—thanks to Congress—now a National Adoption Exchange, getting started out of Philadelphia. Congress intelligently provided that the prospective family could register itself with the Exchange, rather than relying on its agency to register and follow up. We have hopes for this new Exchange.

The ticket of admission, however, is the "home study," and it is intensely difficult and time-consuming for hopeful couples and individuals to obtain this assessment of their general potential to be loving and capable parents. Providing this service is low on the priority lists of public and private agencies, even though it is the absolutely indispensable first step in adoption of any child.

We believe the reason is not so much the overworked staff, as usually stated, but cynicism, based on the inherent impossibility of making such an assessment correctly—of infallibly predicting who is or isn't going to be a good stable parent. The proof of this is that no jurisdiction really trusts the home studies conducted by any other jurisdiction. We tell our members that if they find a child they really want, in any of the Exchange books, to go personally to the jurisdiction with custody of the child and "sell" themselves to the child's caseworker.

To expect otherwise is to place too much weight on what is actually a very subjective test. The utility of the home study is really just to weed out the crazies, and we suggest that it be looked at in this light. It takes only one bad assessment to make almost any agency pull in its head and all four feet and decide to be a turtle from then on. The outcome is that the gate shuts for hundreds of families because a wrong prediction was made for one.

Our second suggestion is that agencies be directed, and possibly aided by a little funding, to make the home-study gate easier to open, and that less formal reliance be placed on this tool, because agencies are encouraged to supplement it with other tests or methods. As examples, we have in mind the group approach, one worker to five applicant families; better still, a group guided jointly by a worker and an adoptive parent group, such as has been introduced by Families Adopting Children Everywhere (FACE) in suburban Maryland. The study can be supplemented with self-examining quizzes and professionally-written tests. Again, we urge that a mechanism be developed to tell other public agencies about such innovations and how they work.

DELIBERATE FAILURE

With no ill intent, many agencies and their caseworkers are certain in their hearts that most of their waiting children are not adoptable. They are minority children in an area where that minority is small. They are retarded. They are heavily handicapped, physically or emotionally. Or they are just too old—often because they have been in foster care for so many years.

But adoptive parent groups and adoption exchanges, and some magnificent networks like Aid to Adoption of Special Kids (AASK) and the Family-Building by Adoption group of agencies, have proven time and time again that this is not true. Some breathtaking placements have been made.

In this Committee's experience, for example, for the ten years that we have been in existence we have queried people as to whether they would accept hard-to-place children and if so, what kind of handicap they could work with. By a margin of two to one they have said that a handicap, usually physical or emotional, is acceptable. In the majority of cases these individuals will accept school-age children, and a solid proportion would prefer them. A racial difference almost always makes no emotional difference to the prospective parent, and at least one good study (that of Dr. Joyce Ladner of Howard University, author of Mixed Families), has shown that children in trans-racial placements do not suffer, despite earlier fears.

Our third suggestion is that agencies be encouraged to open their doors to untraditional types of families and untraditional means of reaching them—networks of church groups, a paid Child Advocate, recruitment by adoptive-parent groups. Exhortation, even by Congress, won't do it alone. Give a financial reward for innovation—a bounty or a bonus!

Our fourth suggestion runs throughout our statement—communicate! Agencies can't copy what they don't know about. Direct the Department of Health and Human Services to set up a regular channel of information to all public child welfare agencies in every state.

Lastly. Stop "studying," stop "reviewing," stop "analyzing," and start serving the children. Put most of your $2 million into rewarding innovation, and the rest into making sure the word gets out.

You are understandably concerned about conserving domestic spending. Please believe all the child advocates—children need families; they don't need more studies. Families are at once the most efficient and the most economical way to help children.

PREPARED STATEMENT OF VIRGINIA THOMAS AUSTIN, PUBLIC POLICY CHAIRMAN, THE ASSOCIATION OF JUNIOR LEAGUES, INC.

The Association of Junior Leagues appreciates this opportunity to present written testimony in support of the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978. The Association of Junior Leagues, an international women's voluntary organization with approximately 142,000 individual members and 242 member Leagues in the United States, promotes the solution of community problems through voluntary citizen involvement—including direct service provision and fundraising as well as advocacy.

The Association and the individual Junior Leagues have a longstanding interest in children's issues in general and child abuse legislation in particular. The Child Abuse Prevention and Treatment Act is a high priority for the Association this year. This testimony provides background information about the involvement of Junior Leagues in children's issues, particularly child abuse and neglect projects, summarizes League support for child abuse programs through public policy activities and identifies the Association position regarding S. 1003.

JUNIOR LEAGUE PROJECTS INCLUDING CHILDREN

A recent survey in which Junior Leagues were asked to identify program areas of interest showed that more than half of the 211 responding Leagues were interested in children's programs; their interests were concentrated on child abuse and neglect, child care, and advocacy in support of improved services to children. Other topics identified, which involve children's interests, include domestic violence, parenting, teenage pregnancy, substance abuse, and youth programs.

In 1981-82, Junior Leagues reported involvement in 1,740 projects and expenditures of $7,125,260 on community activities. Many of the projects focused on children's issues. The following table provides an overview of project areas involving children's issues.

JUNIOR LEAGUE PROJECTS, 1981-82—BY PROJECT AREAS, WHICH INCLUDE CHILDREN'S ISSUES

Project areas	Number of Projects	Junior League money spent
Child health and welfare	338	$1,093,072
Criminal justice	72	292,518
Education	217	538,007
Health and well being	457	1,040,878
Total	1,084	2,964,475

JUNIOR LEAGUE PUBLIC AFFAIRS ACTIVITIES

A recent compilation of all public affairs activities of the Junior Leagues identified more than 300 public affairs activities involving children's issues (nearly 50 percent of all public affairs activities in which League participated). Leagues were involved in child welfare issues such as adoption, foster care, and child abuse and neglect; child care; juvenile justice; public schools; and teenage pregnancy, among others.

CHILD ABUSE AND NEGLECT

During 1981-82, 65 Junior Leagues reported involvement in 76 projects directed toward the prevention and/or treatment of child abuse and neglect. During this same period, Junior Leagues contributed approximately $320,000.00 to these programs. In addition, almost 700 Junior League members were working with other community volunteers and professionals in many local agencies administering and implementing services in this area. These projects cover a wide range of programs, including emergency child care, parent counseling, self-help groups, hotlines and research activities. At least 12 Junior Leagues were involved in guardian ad litem and court appointed special advocate projects.

COLLABORATION

Many child abuse and neglect projects were implemented through collaborative efforts between Junior Leagues and other organizations. Leagues worked in cooperation with local agencies including hospitals, schools, youth groups, libraries, and other community groups. Junior Leagues also collaborated with local, state and federal government agencies, police departments and courts.

Since its enactment in 1974, the Child Abuse Prevention and Treatment and Adoption Reform Act has served as a catalyst for Junior League activities. For instance, a Florida initiative in support of state legislation to establish a guardian ad litem program was launched to bring the state into compliance with the federal law. Many Junior Leagues also have assisted in the development of Parents Anonymous chapters and worked for the passage of child abuse reporting laws in their states.

The Association also collaborates with organizations at the national level in support of programs to prevent child abuse. It is a member of the National Child Abuse Coalition, a group of 20 organizations formed to support the reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act, and will co-sponsor the Sixth National Conference on Child Abuse and Neglect in Baltimore, September 26-28, 1983.

PROJECTS RELATED TO ADOPTION

Junior Leagues and State Public Affairs Committees (SPAC's) also have played an active role in supporting the expansion of adoption opportunities for hard-to-place children. Junior Leagues in several states played a key role in obtaining passage of subsidized adoption programs, and Junior Leagues across the country joined the Association in advocating for the passage of the Adoption Assistance and Child Welfare Act of 1980. Junior Leagues and SPAC's also have supported specific adoption projects in five states, providing volunteers and more than $30,000 in program funds. In addition, Junior Leagues have been involved in public affairs activities specifically concerning adoption and numerous related public issues such as permanency planning, foster care review boards, court appointed special advocates, and guardian ad litem projects.

SUPPORT FOR REAUTHORIZATION OF CHILD ABUSE PREVENTION

We have attended the hearings of this subcommittee and listened to the testimony of various organizations. We have read the reports—countless reports of nationwide increases in child abuse and neglect. We wish to add our voice to the many which this subcommittee has heard. We believe that the progress made in the last decade was the result of good legislation, national leadership, and the commitment of resources to the long-standing problems of child abuse and neglect. The passage of the Child Abuse Prevention and Treatment and Adoption Reform Act in 1974 and the establishment of the National Center on Child Abuse and Neglect (NCCAN) were key elements in establishing federal government leadership.

Since 1980, the reduction in federal support for child abuse programs, combined with the reduction of other social welfare commitments and a nationwide recession, has resulted in a simultaneous increase in incidents of child abuse and neglect and a decrease in resources to combat the problems. Reports of increases in child abuse and neglect have come from many groups, including the National Committee for the Prevention of Child abuse, as well as Junior Leagues involved in Child Watch, a citizen monitoring project developed by the Children's Defense Fund in collaboration with the Association of Junior Leagues. A 50 state survey conducted by the National Committee for the Prevention of Child Abuse revealed increases in child abuse in 45 states. Many of the Child Watch projects coordinated by individual Junior Leagues also have found increased incidences of child abuse over the last year. For instance, the Wilmington, Delaware Child Watch Project found a 30 percent increase in reports of child abuse and neglect.

The Des Moines Child Watch Project discovered that child abuse and neglect reports are the highest ever and, as the result of a statewide reorganization of welfare department staff, there has been a marked reduction in the number of case investigators available to follow-up neglect and abuse reports. Albuquerque's Child Watch Project reported an increase in reports of rape and other forms of sexual abuse of children. The Hartford Child Watch Project reported increased reports of children being denied basic needs such as food, and stated: "The number and severity of child abuse cases are increasing resulting in the placement of more children in foster care."

The Child Watch Project in Baltimore reported that, while the increase in child abuse and neglect reports was only eight and one-half percent from 1981 to 1982, the degree of abuse in reported cases was significantly more severe, including an increase in fatalities. Social service workers reported changes in the families in which abuse is reported: there were more multi-problem families whose problems are more intractable, and more families who have not traditionally sought help (i.e., middle-class families) are seeking help.

The Birmingham, Alabama Child Watch Project reported an increased need for child protective services. The Salt Lake City Child Watch Project reported: "More children are being abused and the abuse is far more serious (more frequent and more violent)." These are just samples of reports which corroborate a nationwide trend.

NEED FOR FEDERAL LEADERSHIP

We need a renewed commitment to the prevention and treatment of child abuse and neglect. Further cutbacks in funding, together with a decrease in federal leadership, would be devastating. Congressional leadership is crucial both in the area of child abuse and neglect and adoption programs designed to assist special needs children.

The Administration's proposed cutbacks in child abuse prevention and treatment funding to a level of $6.7 million would result in a federal expenditure of approximately $6 for each of the more than one million children reported as abused each year. Considered another way, the funds requested by the Administration are equivalent to less than one-thousandth of a percent of the federal budget for Fiscal Year 1984. Obviously, this nation can do more and can afford to do more to support the prevention and treatment of child abuse.

RECOMMENDATIONS FOR CHANGES IN S. 1003

While we strongly support reauthorization of the child abuse legislation, we have some specific concerns about S. 1003 as introduced in the Senate on April 7. First, we believe that the authorization is too low. The proposed authorization of $17 million for NCCAN research and demonstration programs and state grants in child abuse and neglect would merely maintain the current funding level for these programs. If the seven states and two territories currently not eligible to receive funds from the legislation were to become eligible, current state grants—already low—would need to be reduced. Moreover, additional funds would be needed to help states implement the Baby Doe provisions of S. 1003. While the Association has not taken a stand regarding these provisions, we believe that no additional requirements should be placed on states without providing additional funds to implement them.

We urge an authorization of $30 million for child abuse programs. Such a funding level would allow NCCAN to expand the state grant program and increase its support for prevention programs, something recommended by the General Accounting Office and strongly supported by the Association and the National Child Abuse Coalition. In fact, we recommend that the language of the legislation be amended to direct NCCAN to spend a substantial share of its funds on prevention programs. We suggest that states also be encouraged to use a portion of their grants for programs designed to prevent child abuse and neglect.

We also recommend that the reauthorization be for a minimum of four years and that the Department of Health and Human Services be required to develop a comprehensive plan annually to provide for coordination of activities of all federal agencies responsible for programs in child abuse and neglect.

CONCERNS ABOUT ADOPTION PROVISIONS IN S. 1003

We also have serious concerns about the language relating to adoption in S. 1003, particularly the proposed changes in Title II, Adoption Opportunities, Sections 201 and 202 of the Act, which state: ". . . infants born ot teenaged individuals, unmarried parents and thousands of children in institutions or foster homes may be in serious jeopardy and . . . such infants and children are in need (emphasis added) of placement in permanent adoptive homes . . ." The Act calls for adoption counseling in all such cases. The language appears to infer that all children born to single parents and/or teenage parents are in serious jeopardy. The proposed changes could be interpreted to justify government intrusion in the personal affairs of many families fully capable of caring for their children. Further, adoption should not be considered the only alternative in cases where children are in serious jeopardy since, in many cases, natural parents lack resources rather than motivation and the desire to care for their children

Assistance is needed in helping adoption agencies to develop creative programs that will find adoptive homes for the approximately 100,000 special needs children identified as needing adoptive homes. We urge the subcommittee to retain the original language of Section 201 which focuses attention on special needs children, those children most in need of adoptive homes. There are thousands of homes waiting for healthy infants. The need is to continue the leadership at the federal level to develop creative approaches to strengthening interstate collaboration in the development of programs to successfully place this country's neediest children in adoptive homes.

The Association appreciates this opportunity to submit this testimony in support of the reauthorization of Child Abuse Prevention and Treatment and Adoption Reform Act of 1978, and urges you to maintain this subcommittee's leadership on behalf of children.

NATIONAL COMMITTEE FOR ADOPTION
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June 1, 1983

Senator Jeremiah Denton
Chairman
Subcommittee on Family and Human Services
Committee on Labor and Human Resources
U.S. Senate
Washington, D.C. 20510

Dear Senator Denton:

The National Committee For Adoption was very pleased to have the opportunity to testify before your Subcommittee on April 14 in support of S. 1003. We are happy to respond to your questions.

1) The National Committee For Adoption strongly supports the expansion of the findings section of the Adoption Opportunities Act to include "the welfare...of infants born to teenaged unmarried individuals." This amendment to the current law is an important improvement because too often children born to young, unmarried parents end up growing up in foster care. Because the adoption opportunities program's goal is to alleviate the problems of children in foster care by promoting adoption for such children, we believe it is necessary to include adoption counseling to teenaged parents. Then when these young parents are faced with the realities of unsuccessful parenthood, adoption will be seen as a loving viable option for their children's futures.

   An investigation of the foster care system in New York City in 1977 showed that 22.7% of all the children in foster care came into the foster care system as infants. The author of the report, Professor David Fanshel concluded that: "Aside from the potentially longer periods of vulnerability to be in care infants have by virtue of being very young, there is evidence that their mothers visit them less often and that they tend to remain in [foster] care in disproportionately large numbers." (Footnote 11, "Children Discharged from Foster Care" CHILD WELFARE, Vol. LVII, No. 8, Sept./Oct. 1978, page 483.) NCFA believes that such vulnerable infants, most of whom are not "hard-to-place" for adoption, do have a "special need" for permanent, adoptive homes. As is evident from Fanshel's study, many young parents use foster care as a way to gradually relinquish responsibility for their infants. This approach to "termination of parental rights" is often not in the best interest of the infant who should be in an adoptive home rather than in a foster care placement. Counseling for young, unmarried mothers and fathers about the legal and social implications of trying to parent or making an adoption plan for their baby is one important way to prevent unnecessary foster care services after

the baby is born. Therefore expanding the findings to include services to these young parents--on behalf of better futures for their babies--makes good sense and represents sound adoption policy.

2) The expansion of the findings will not significantly or adversely alter the operations of currently funded projects. For example, at the hearing Mrs. Elaine Winslow described how the Alabama Friends of Adoption group which has Federal adoption opportunities funds receives several telephone calls a week from young, pregnant women or teenaged mothers who were inquiring about choosing adoption for their babies and who wanted to talk to adoptive parents about their families and experiences with adoption. Laurie Flynn, executive director of NACAC, also cited examples of adoptive parents' groups which offer presentations to groups of pregnant, unmarried women and their families on how positive adoption can be for a child. Even now, many funded projects as well as the Regional Resource Centers for Children, Youth and Families have focused attention on the needs of teenaged, unmarried parents and their infants.

With regard to future program activities under this proposed amended legislation the National Committee For Adoption would see this area of adoption services as one which deserves attention equally along with the many other important activities outlined in the adoption opportunities legislation. Focusing on pregnant teenagers' services needs for adoption information and counseling will only help reduce the number of children who become part of the foster care system and who later are described as "special needs" children in need of adoption.

3) The National Committee For Adoption believes improved coordination of adoption-related programs and activities of the Federal government in the Adoption Opportunities Act is very necessary. Adoption is a service for children who cannot be raised by their biological parents or close relatives. The reasons for this are usually due to problems of the parents, including child abuse and neglect, lack of financial resources due to inability to work, alcohol or drug abuse, teenage pregnancy, divorce, death or imprisonment. All of these problems are being handled by separate programs in the Federal government and the role of adoption counseling and services should be seen as integral to serving adults who cannot take on the responsibility of caring for their children. There are also problems associated with the children including illness, physical or emotional disabilities which can be better handled by trained and supportive adoptive parents rather than

by foster care or institutional settings. For all of these examples, it is evident that the Secretary of HHS should encourage and facilitate better understanding of adoption-related services by the many different programs and offices of HHS and the Federal government.

4) The National Committee For Adoption believes that there must be funding provided specifically for ensuring that children are placed in adoptive homes rather than staying in foster care. There are many private, non-profit agencies licensed for child-placing who have waiting lists of approved adoptive families, but they cannot serve these families because the public child welfare sector does not work vigorously enough to see that children growing up in foster care are legally freed for adoption. At the same time, States have not aggressively used available funds for adoption assistance from P.L. 96-272. The Federal government should work to develop models for effective agreements between State governments and the private, non-profit child-placing agencies to move children from foster care to adoption more quickly and with less cost to the tax-supported child welfare and foster care systems. The National Committee suggests that this Subcommittee urge the Department of HHS to work with the States in returning adoption services to the private, non-profit child-placing sector.

1) In response to Senator Dodd's questions concerning the funding level for the adoption opportunities program, the National Committee For Adoption supports a higher authorization level because the legislation enhances the scope of activities related to emphasizing adoption opportunities for handicapped infants in life-threatening situations as well as to emphasizing the importance of adoption for the welfare of many infants born to adolescent parents. We recommend an authorization level of $5 million which is the level provided for in the original authorizing legislation for adoption opportunities in 1978.

We hope that these answers assist you in your work to see S. 1003 passed by the Senate, accepted by the House, and signed into law.

Sincerely,

Candace P. Mueller

Candace P. Mueller, MSW
Director, Public Policy
& Professional Practice

CPM/db

COAC
N.Y. COUNCIL ON ADOPTABLE CHILDREN
875 Avenue of the Americas, New York, New York 10001 • 212/279-4525

Clara Valiente Barksdale
Executive Director

Murray Roberts
President

June 2, 1983

Senator Jeremiah Denton
United States Senator
Committee on Labor and Human Resources
Washington, D.C. 20510

Dear Senator Denton:

Thank you for sending me the written congressional record of my testimony. I am attaching here my answers to your and Senator Dodd's questions. I hope it will help you and your committee when making decisions on the role of the Federal Government in adoption issues and services.

Let me just add that I believe that adoption should be strongly supported and financed by federal funding as it is not exclusively a state or local service. The matching of special needs children with prospective adoptive parents is very often done by crossing country and state boundaries. There is somewhere a parent for every homeless child. Jurisdictional barriers in adoption should be minimized to expand placement opportunities for children.

Again, thank you for inviting me to testify.

Sincerely,

Clara Valiente Barksdale

Clara Valiente Barksdale
Executive Director

CVB/mr

QUESTIONS SUBMITTED BY SENATOR DENTON

1.) Do you know of parents or groups of parents wh have either given birth to a handicapped child, o. who have adopted a handicapped child and who make themselves available at hospitals to counsel or support families who give birth to such children? If so, what is the arrangement? How can such volunteer efforts be expanded?

2.) Specifically, how do you suggest that financial incentives for foster care be eliminated and replaced with an adoption incentive?

QUESTIONS SUBMITTED BY SENATOR DODD

1.) How important is it to restore funding for the Adoption Opportunities program to $5 million, the level authorized prior to the 1981 Reconciliation budget action?

2.) What should the federal government do to ensure that Hispanic children are properly classified by culture and ethnicity so they can be matched with appropriate families, either for adoption or foster care?

3.) How important is it to keep this program focused on special needs children?

ANSWERS TO QUESTIONS SUBMITTED BY SENATOR DENTON

I I know of a parent in Westchester County; N.Y. who as a consequence of having adopted a Down's syndrome child became involved in helping biological mothers who give birth to children suffering from this genetic handicap. She visits mothers in hospitals or at their homes, counsels, support and helps them in making the decision about keeping the child or surrendering for adoption. She advertises her volunteer services in many hospitals in the New York City area and recruits prospective adoptive parents for these children, mostly through word of mouth. Once she identifies the child and the family, she helps with the adoption placement. Thanks to her effort she has been able to find homes for over 150 Down's syndrome children and has helped many mothers accept and keep their retarded child. The Adoption Resource Center in Region II gave a minigrant to this parent in order to help pay for travel and telephone expenses, so she could continue to provide these valuable service.

II 1) "Agencies should be rewarded with larger adoption fees for children adopted quickly.

2) Adoption fees would gradually decrease for children who are not adopted within the standard set as the maximum to complete an adoptinn.

3) There would be a higher fee paid to agencies who place special needs children.

4) A range of sanctions should be used for agencies that continue to perform below the standard set by law. These sanctions should include a) transferring to another agency planning responsibilities for children who have not been adopted, b) cessation of new placements with the agency for a specified period of time and c) termination of contract with the agency." (1)

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(1) Adoption Web; Impediments to placing Foster Children in Permanent Homes. A report from the office of City Council President, Carol Bellamy, May 1981 (page 49).

ANSWERS TO QUESTIONS SUBMITTED BY SENATOR DODD

I The $5 million funding for Adoption Opportunities helped promote, publicize and stimulate adoptions throughout the country. It created a climate where adoption became a priority resource for waiting children in need of permanent families. The Adoption Resource Centers created through these funds in every federal region were catalysts for services that did not exist before. They helped develop networks and exchanges to match children with parents. These centers have recently merged with Child Abuse and Neglect centers and Child Welfare Training at the same level of funding so that, adoption issues receive 1/3 of the previously allocated funds. This of course is a big set back as the focus on adoption issues becomes diluted.

II Hispanic children should be identified as Hispanic and classified as such in any inventory of foster children. The tracking system mandated by PL96-272 should also mandate classification by ethnicity/race/culture for the minority children who make up over 60% of the foster care population. By helping children keep their ronts and connect with their past we are protecting their psychological well-being and giving them the continuity of experience needed to overcome the trauma of a disrupted family life. A National Network for Hispanic children can help identify Hispanic children needing adoption and find Hispanic homes for them.

III Special needs children are the high risk children of our society. They are either born with special needs due of birth defects or become so because of abuse, neglect and abandonement. It is our obligation to provide the best possible opportunity for them, so that we can repair some of the damage caused to them by their tragic experiences. There are currently over 100,000 children with special needs who could and should be adopted in our country. If we do not give them a permanent family life now they will continue to drift to become the dependent population that makes up our welfare rolls or fills our mental hospitals, our prisons and our shelters for the homeless.

C. V. Barksdale

Clara Valiente Barksdale
Executive Director

N.Y. Council on Adoptable Children

June 3, 1983

AFOA
ALABAMA FRIENDS OF ADOPTION

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June 2, 1983

Senator Jeremiah Denton
United States Senate
Committee on Labor & Human Resources
Washington, D.C 20510

Dear Senator Denton:

Please excuse the delay in replying to your letter. It seems that your communication to me was delayed in the mail. Attached you will find the information you requested for the two specific questions for me. I hope this will be of some help to you and your staff.

Those of us who work diligently advocating for children appreciate your time, interest and efforts on their behalf. Thank you for supporting P.L. 95-266 for the full $5 million. This is really a minimal amount to place over 100,000 waiting special needs children.

I will look forward to hearing from you concerning the future of this bill.

Sincerely,

Elaine P. Winslow

Elaine P. Winslow, President
Alabama Friends of Adoption
701 Rockbridge Road
Birmingham, AL 35216

Questions submitted by Senator Denton to Elaine P. Winslow, President, Alabama Friends of Adoption. 701 Rockbridge Rd., Birmingham, AL 35216, on the Reauthorization of P.L. 95-266.

1. Would you please submit to the Subcommittee the latest data on adoption and foster care that is available for Alabama? Are Alabama statistics consistent with nationwide statistics?

   Attached you will find some basic statistical information. Please note the large number of children remaining in foster care for over 4 to 10 years. This is an alarming figure. The longer children stay in an unstable situation the more emotional damage that occurs. Many rural areas across this country keep children in the foster care system indefinitely. Social workers don't feel that these children are adoptable. This is simply not so. These children need to be legally freed for adoption and homes actively recruited for them. Agencies across this country need to be challenged in the development of programs to place these waiting special needs children. Post placement programs need to be developed to help families adopting these challenging children be able to continue their commitment.

   I think you will find that basically these statistics are probably fairly normal for states across this country. You will find states like New York will have a much higher percentage rate of minority children who need homes. The recruitment of minority families is crucial. However, there is no need to recruit any families if agencies do not or will not serve the families wanting to adopt these special needs waiting children.

   Please take note that last year Alabama placed 323 children for adoption. This year alone we expect to have 725 children available for adoption. How these children are going to be placed for adoption is the big question. We have dramatic staffing cut-backs already and our staff is presently running 6 to 8 months behind in placing children. Surely there is an answer to some of this. If we were able to place these waiting children we would certain ly in the long run cut back on state and federal expenses.

2. Specifically, how- do you suggest that financial incentives for foster care be eliminated and replaced with an adoption incentive?

   One simply wsy to eliminate one of the biggest barriers to the adoption of waiting special needs children would be to provide the same medicsl coverage for the child after he is adopted that he receives as a foster child. Under the adoption subsidy act many children are eligible for Medicare Benefits. However, for many of the waiting children this is very inadequate coverage. Families just cannot assume the heavy medical expenses of many of these children is they adopt them. Insurance companies will not cover such children. Hence these children stay in the foster care system costing the state and federal government huge amounts of money not for just their medical expenses but for the continuing of their foster care. It would certainly appear to be cost effective to offer the same medical coverage and move these children into adoptive homes. It would certainly be an emotional plus for the child.

STATE OF ALABAMA

FOSTER CARE INVENTORY

MARCH, 1983

		Alabama	Jeff. Co.
Total Children:		4,468	415
Ages:	0 to 3 yrs.	535	52
	3 to 6 yrs.	546	59
	6 to 13 yrs.	1,515	121
	13 to 21 yrs.	1,872	183
Goals:	Return Home	1,046	66
	Relatives	439	48
	Adoption	751	78
	Independent Living	334	21
	Long-Term	1,898	202
Current Placement:			
	Group Home	329	67
	N. Home	29	5
	Institutions	338	25
	Foster Family	3,283	287
	& Free Home	16	3
	Related	338	14
	Residential	99	14
	Maternity	5	-
	DVS	31	-
Time in Care:	0 to 6 Mo.	922	81
	6 mo. to 1 Yr.	622	38
	1 Yr. to 2 Yrs.	755	68
		2,299	187
	2 Yrs. to 4 Yrs.	804	89
	4 Yrs. to 10 Yrs.	1,004	62
	10 Yrs. or More	361	77

STATE OF ALABAMA -- ADOPTION

DPS INFORMATION FOR FISCAL '81 - '82

DPS Placements for October 1, 1981 through September 30, 1982

	BLACK	WHITE	TOTAL
Birth to 2 years	52	82	134
Two to Six years	27	60	87
Over Six years	15	87	102
Totals	94	229	323

It is interesting to note that during this time period a total of 73 children over the age of eight have been placed. As you view these statistics you can see our great need for recruiting black homes for children over the age of six. We are also including some other IMPORTANT statistical information. Waiting families please pay attention. Many times we receive calls from those of you who are waiting for children. This is always a difficult time for families. We hope that the statistics listed below will help you to understand why there might be a delay in getting children to your home. Of course, this is only part of the picture. Staff and $$$ shortages are crucial to the lack of moving children to permanency. Also our judicial system in many cases contributes to the slow down. We are trying to work on these areas and educate our legislators as to our needs and those of children in limbo. We hope that the statistics listed below are helpful in this process.

Approved Homes in Alabama with DPS as of October 1, 1982

	BLACK	WHITE	TOTAL
Birth to 2 years	42	54	96
Two to Six years	12	144	156
Over Six Years	9	82	91
Totals	63	280	343

ROBERT W. DEBOLT
411 WILDWOOD AVENUE
PIEDMONT, CALIFORNIA 94611

June 2, 1983

The Hon. Jeremiah Denton
United States Senator
UNITED STATES SENATE
Committee on Labor and
Human Resources
Washington, DC 20510

My wife and I returned from vacation yesterday to find your letter of May 23, 1983, which included copies of my testimony before your Subcommittee and questions asked by you and Senator Dodd.

I apologize for not being able to have these answers to you at an earlier date and I hope that the record has been kept open so that this information can be part of the testimony to the Subcommittee.

I have answered the questions on the enclosure in the same order in which they were asked.

Thank you again for the opportunity to appear before you and your Subcommittee.

Sincerely,

R. W. DeBolt

Robert W. DeBolt

RWDeB:ss

Enclosure

QUESTION SUBMITTED BY SENATOR DENTON

1.) Specifically, how do you suggest that financial incentives for foster care be eliminated and replaced with an adoption incentive?

Your question is one which most of the 50 state adoption agencies are asking themselves at this time. Currently, a portion of the foster care payments reimbursed to county and private agencies covers not only the direct cost of maintaining the child in the foster family but also pays a portion of the foster care agencies' termination costs. In most states, this has the effect of encouraging the agencies to maintain the largest number of children possible in foster care in order to finance that portion of the agencies' operation. In other words, the more children in foster care, the more monies for the administration of the agency. The first step towards eliminating this problem is to accurately determine the status of each child in foster care. For those children who can be adopted, the foster care payments to the parents should continue for a stipulated amount of time (in my opinion, not to exceed three years). County and private foster care agencies should be encouraged financially to find adoptive homes for foster children who have been relinquished for adoption. I don't really have a plan as to how this can be accomplished but agencies should not be financially penalized for finding permanent homes for children.

QUESTIONS SUBMITTED BY SENATOR DODD

1.) How important is it to restore the authorization for this program to $5 million, the level it was prior to 1981 Reconciliation budget action? How would the funds be spent?

I feel that it is very important to restore the authorization for this program to $5 million. These funds should be used to encourage placement of children in permanent homes.

These efforts would include programs which educate and encourage the judiciary to terminate parental rights when there is little or no hope of reconciliation with the biological parents, assist private and state programs which have proven records of innovative and successful adoptive placements of children with special needs, and to help the states establish uniform programs of adoption subsidies.

2.) How important is it to determine the exact number of children in foster care? What happens when we do not have that kind of data?

The problem with the lack of current and accurate data concerning the exact number of children in foster care has allowed many children to slip through the statistics. In every state in which AASK America has worked, we have discovered hundreds of children in foster care, many already relinquished for adoption, who are not reported by the states. If agencies are to find permanent homes for children, we must know of the existence of every one of these children. States currently reporting numbers of children in foster care do so on a somewhat casual basis. An example is the state of Ohio, wherein the laws of the state require each of the 88 counties to report the number of children in foster care, time spent in such care, number of children adopted, and statistics on the characteristics of these children. However, there is no penalty for those counties who refuse to report or simply overlook the requirements of that law. The lack of uniformity among the states for reporting requirements is of major concern to us. When accurate and current data are unavailable on foster children, many of these children will continue to remain in the temporary home limbo when permanent loving homes could be found by agencies such as AASK America.

3.) How correct do Assistant Secretary Hardy's estimates of 50,000 children in foster care awaiting adoption sound?

Assistant Secretary Hardy's estimate of the number of children in foster care awaiting adoption is probably as good a guess as any other number the Department could choose. We have heard estimates ranging from 35,000 to 150,000 children in foster care, who are currently relinquished for adoption. The Child Welfare League uses the number of approximately 150,000. NACAC is currently using the figure of approximately 100,000. I think Assistant Secretary Hardy's estimate is very conservative but noone really knows. AASK America's National Program Director, Mary Bohan, believes that the figure exceeds 100,000 children.

4.) What role should the federal government play in providing medical assistance for the special needs children adopted by families?

The role of the federal government in providing medical assistance for special needs children should be through the state Crippled Childrens Services programs. This federally-mandated program and state-funded operation works very well here in Northern California. When parents knowingly adopt a child with a physical disability, the program pays for all medical costs directly connected with this disability until the child reaches his or her majority. My wife and I would not have been able to adopt five of the children we have currently in our home if this program had not been so successful in our part of California. There are other states whose programs work just as effectively as ours but the sad part is that these effective programs of Crippled Childrens Services are very rare. We would hope that the federal government would set standards for these programs and assist the states in the funding.

Reauthorization of the Child Abuse Prevention and Treatment and Adoption Reform Act: Obstacles to Adoption

Response to Written Questions

Prepared By,
Marlene Piasecki,
Director, National Adoption Exchange
June, 1983

QUESTIONS SUBMITTED BY SENATOR DENTON

1.) Could you explain in greater detail "purchase of service" agreements, and the way in which they can facilitate adoption at a lower cost to government?

Purchase of service is a process through which public agencies, state or local, make payments to private agencies for specific client services. In adoption, purchase of service contracts are typically used to reimburse a private agency for the costs of recruiting and studying an adoptive family for a special needs child. Additionally, purchase of service contracts are sometimes used to reimburse private agencies for providing supervision and post-adoption services to the families who adopt special needs children.

Purchase of services is a cost effective way to deliver special needs adoption services because a public agency pays only for the amount of service needed. Agencies which use purchase of service experience considerable savings in staff, specialized training, and special recruitment campaigns which are necessary for funding and preparing families for special needs adoption. Instead they pay one time fees for the recruitment and preparation of specific families appropriate to the children in their care who are waiting.

Unfortunately, many public agencies will not pay the one time purchase of service fee to a private agency for adoption services for a child, while they will pay indefinitely for foster care or residential placement for that same child. The costs of this practice are enormous. Most purchase of service contracts for the placement of a special needs child are under $7,000. The yearly cost of foster care in institutionalization of the same child can exceed $40,000. Of course the Federal Government pays a large portion of the foster care and institutional costs.

Thus federal expenditures for foster care could be reduced substantially if public agencies which refuse to purchase adoption services and instead keep those children in foster care and institutions made use of the specialized resources that are available.

2.) Specifically, how do you suggest that financial incentives for foster care be eliminated and replaced with an adoption incentive?

There are currently ceilings on federal funds available to states for both foster care and adoption services. If federal participation in adoption services was available without a ceiling, like the adoption assistance program, states would take the opportunity to create innovative adoption services. This would be particularly true if ceilings on foster care expenditures remained in place. It would make financial sense to reduce the state's foster care population through adoption.

Additionally, improved purchase of adoption services programs would shift the financial incentive private agencies now experience for offering foster care programs to adoption programs. Private agencies can be paid for the foster care programs by states but are often expected to deliver adoption services without receiving any reimbursement from the public agency. Under this system there is no incentive for private agencies to develop innovative adoption services. If they received full cost reimbursement for adoption services, private agencies would develop and deliver those services.

QUESTIONS SUBMITTED BY SENATOR DODD

1.) You mention that adoptive families are particulary concerned about receiving medical assistance (either payments or insurance) for the special needs children they adopt. What role should the federal government play in providing such assistance?

Adequate medical assistance for special needs children who are adopted and assurances that medical assistance will be fully available if the child moves across state lines is very important. Many families who are willing to adopt a special child have been unable to adopt because they could not be assured of adequate medical coverage.

The federal government can help to solve this problem in two ways:
1) Offer 100% federal fiscal participation in medicaid payments for adopted children who are eligible for adoption assistance. This would permit a child to obtain full medical coverage in any state and would allay the concern of states which fear that they will be responsible for the care of children from across the country if they institute progressive home study and child placement policies.

Recommendations for improvements in medical assistance coverage for special needs children are being developed jointly by the American Public Welfare Association and a group of State Child Welfare Administrators. The recommendations will be published as part of a model interstate Compact on Adoption Assistance and are worthy of support from federal officials.

2) Make information available to the private insurance industry on insurance policies which provide immediate coverage for the pre-existing conditions of adopted children. Innovative approaches in private insurance aid families and will reduce the burden on the federal government for the medical care of adopted special needs children.

2.) How important is it to restore the authorization for this program to $5 million, the level it was prior to 1981 reconciliation?

It has been said that success in the field of special needs adoption makes the work that remains to be done more, not less, difficult. When this act was first passed it was estimated that 100,000 children were waiting to be adopted. Today, the estimate is 50,000. Certainly part of the reduction can be attributed to the efforts of the Adoption Resource Centers and other federally funded programs which promoted special needs adoption.

However, our successes mean that the children who still wait are the most difficult to place. Thus the activities which will lead to their placement and which will make those placements work well may be the most expensive. Among the critical program needs are national media campaigns, intensive post-adoption services and adequate subsidies. Thus, as we focus our attention on the children with the greatest needs the full $5 million in funding should be made available to support the development of innovative programs. This very difficult population of children includes adolescent boys; children with severe, often life threatening, disabilities; and institutionalized children. Institutionalized children are most often those who are labeled mentally retarded and whose opportunities for development are severely limited by the lack of a permanent family.

Overall, full funding for Adoption Opportunities is essential to the placement of the children who still wait. They need the services of programs funded through the act particularly the National Adoption Exchange. The Exchange is now reaching thousands of families with the message that children are waiting. Through the continued growth of this national outreach effort more children will be placed in permanent homes.

RESPONSES OF MISS DORCAS HARDY TO QUESTIONS
OF SENATORS DENTON AND DODD

QUESTIONS SUBMITTED BY SENATOR DENTON

1.) Several witnesses suggested that adoption of special needs children would be enhanced if the regional and national adoption exchanges were given the authority to place children. Does the Administration have a position on such broadening of authority for the exchanges?

2.) Can the Administration suggest a better alternative to language in S. 1003, as reported from Committee, for a coordinating mechanism in the federal government for programs that are adoption-related?

3.) Will the amendments to the funding section of P.L. 95-266 contained in S. 1003 in any way affect the operation of programs under the law?

QUESTIONS SUBMITTED BY SENATOR DODD

1.) How will your plans to reclassify and/or reorganize the office of Human Development Services (OHDS) affect the implementation of the Adoption Opportunities Program (P. L. 95-266) and the Adoption Assistance and Child Welfare Act of 1980 (P. L. 96-272)?

2.) What proportion of OHDS "consolidated research and development funds" are derived from the adoption opportunities projects?

3.) What is the source of the data you have cited in your testimony, specifically, your assertion that children in foster care have declined by 14 percent and the 50,000 children in foster care available for adoption.

   a.) From how many states is it derived? Please submit the data for the record.

   b.) What are you doing to gather information on the number and characteristics of special needs children being served? Please cite the recent surveys conducted from 1977 on.

4.) Given the concern that minority, handicapped, and developmentally disabled children have not received enough attention under this program to date, what future federal support will be available for programs to help such children?

5.) What specific successful demonstration programs will continue to receive funding? For example, what will happen to the "homes for black children" project in Detroit run by a Child Welfare League of America agency? Please submit a list for the record.

QUESTION: Several witnesses suggested that adoption of special needs children would be enhanced if the regional and national adoption exchanges were given the authority to place children. Does the Administration have a position on such broadening of authority for the exchanges?

ANSWER: The specific placement of children in adoptive homes and the adoption process in general is the primary responsibility of the States. Therefore, it is the position of the Department that national and regional exchanges should not place children in adoptive homes.

QUESTION: Can the Administration suggest a better alternative to language in S.1003, as reported from Committee, for a coordinating mechanism in the Federal government for programs that are adoption-related?

ANSWER: The approach we recommend is the expansion of Section 203(a) of the Child Abuse Prevention and Treatment Act which requires the Secretary to establish coordination across the Department with respect to adoption and foster care. This section could be expanded specifically to include coordination within the Department of programs which provide services to pregnant teenagers, unmarried parents, and couples experiencing infertility with the Adoption Opportunities program. References to these topics could then be deleted from other sections of the bill, and the same purpose accomplished without unduly burdening the adoption opportunities program itself.

QUESTION: Will the amendments to the funding section of P.L. 95-266 contained in S.1003 in any way affect the operation of programs under the law?

ANSWER: The amendments refer to several topic areas new to the scope of the Adoption Opportunities program, such as counseling of pregnant teenaged children considering adoption as a plan for their infants, services to couples with infertility problems, and services related to infants of unmarried parents. While we agree that these are extremely important topics, we are seriously concerned that broadening the scope of the Adoption Opportunities program beyond its current focus on adoption for children with special needs could overburden this small but very effective program. In addition, there are other offices in the Department of Health and Human Services, such as the Office of Adolescent Pregnancy Programs, that address these needs. We would therefore recommend the approach outlined in the previous question as a way of avoiding overburdening the program.

QUESTION: How will your plans to reclassify and/or reorganize the Office of Human Development Services (OHDS) affect the implementation of the Adoption Opportunities Program (P.L. 95-266) and the Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272)?

ANSWER: We do not expect any current or planned personnel actions, including reclassification, to affect the implementation of either the Adoption Opportunities or the Adoption Assistance programs.

QUESTION: What proportion of OHDS "consolidated research and development funds" are derived from the Adoption Opportunities projects?

ANSWER: In the FY 1984 budget request, we are asking for a total of $9,250,000 in a consolidated discretionary account, for carrying out the purposes of Sections 426 (Child Welfare Services Research and Demonstration) and 1110 (Social Services Research and Demonstration) of the Social Security Act; the Child Abuse Prevention and Treatment Act (other than Section 4(b), State Grants); and title II of P.L. 95-266 (the Adoption Opportunities program.) $21,999,000 was appropriated for these programs in FY 1983, of which $1,912,000 was for Adoption Opportunities. However, for FY 1984, no amounts have been earmarked by us within the $9,250,000 consolidated amount. We are not asking for changes in the authorizing statutes for these activities, and we plan to ensure that the funds are used to carry out the purposes of each activity. We believe that the consolidated amount will give us more flexibility to address common issues among these program areas.

In FY 1983, we have followed a <u>coordinated</u> discretionary <u>process</u>, through which grants for most of the discretionary activities under OHDS will be awarded. However, the amounts appropriated by the Congress for FY 1983 in each of the discretionary areas will be specifically observed. For the Adoption Opportunities program $860,000 of the $1,912,000 appropriated for FY 1983 will be awarded through this coordinated process. This represents about 4 percent of the $21,450,000 to be awarded by OHDS through the coordinated process in FY 1983.

The remaining $1,052,000 in the Adoption Opportunities Program will be awarded through separate grant procedures.

QUESTION: What is the source of the data you have cited in your testimony, specifically, your assertion that children in foster care have declined by 14 percent and the 50,000 children in foster case available for adoption?

a.) From how may states is it derived? Please submit the data for the record.

b.) What are you doing to gather information on the number and characteristics of special needs children being served? Please cite the recent surveys conducted from 1977 on.

ANSWER: The estimate of a 14 percent decline in the total number of children in substitute care is based on a study conducted by Maximus, Inc. under contract with OHDS of nine States with large foster care populations. A comparison was made between the data collected by the Office of Civil Rights in January 1980 and the data provided by the nine States for December 1982. The three-year decline was 13.6 percent, 4.5 percent per annum. The state-by-state data is presented in the attached table.

The estimate of 50,000 children available for adoption is based on the findings of the 1977 National Study of Social Services to Children and Their Families. The study indicated that approximately 52,000 children in foster care were legally free for adoption and awaiting placement in an adoptive home. Another 50,000 foster care children had already been placed in adoptive homes. There were no more recent statistics available to estimate the number of children whose parental rights had been terminated and were awaiting placement in an adoptive home.

The term "special needs children" has meaning under P.L. 96-272 in the context of adoption and adoption assistance. Thus, special needs children can be identified in two groups: children who are legally free for adoption and awaiting placement in or finalization of the adoptive placement; and children in finalized adoptive homes. Data on these two groups are currently being collected and analyzed and will provide a sounder basis for estimating the numbers of children involved and their current status. Recently, the American Public Welfare Association has implemented the Voluntary Cooperative

Information System and has received reports from 48 States, which are currently being analyzed. In addition, OHDS has contracted with Maximus, Inc. to conduct two studies: a study of nine States with large foster care populations; and a national survey of a probability sample of 206 county agencies with a total of 2,000 children in foster care to obtain national estimates of the children in foster care and their characteristics. This data will be available by July 30, 1983.

The child welfare survey since 1977 include:

1977 National Study of Social Services to Children and Their Families, Children Bureau.

Year: 1977
Scope: National

1980 Children and Youth Referral Survey: Public Welfare and Social Services Agencies, Office of Civil Rights, DHHS.

Year: 1980
Scope: National, State, County

Voluntary Cooperative Information System, American Public Welfare Association (in progress).

Year: 1982
Scope: State

U.S. Foster Care Population for 1980, Child Welfare League of America.

Year: 1983
Scope: National, State

Child Welfare Indicator Survey, Phase I, Child Welfare Indicator Survey, Phase II, Maximus, Inc. (in progress).

Year: 1983
Scope: National, State

Total Children in Foster Care in Nine Selected States
1980-1982 Comparisons

	OCR (1980)	Maximus (1982)	% Difference (1980-82) (1980 Base) OCR-Maximus
California	27,534	31,288	+13.6%
Florida	9,922	6,156	-38.0
Georgia	5,959	4,002	-32.8
Illinois	11,480	10,392	- 9.5
Massachusetts	9,634	7,198	-25.3
Michigan	10,858	9,743	-10.3
New York	40,762	32,454	-20.4
Texas	6,818	5,403	-20.8
Virginia	8,458	6,913	-18.2
Totals	131,425	113,554	-13.6%

QUESTION:	Given the concern that minority, handicapped, and developmentally disabled children have not received enough attention under this program to date, what future federal support will be available for programs to help such children?
ANSWER:	Because the adoption needs of minority, handicapped and developmentally disabled children need special attention from the child welfare system, these groups were specifically identified in the coordinated HDS discretionary funds announcement this year for special attention. Proposals have been received and are currently being reviewed. We therefore anticipate funding grants for the development and demonstration of approaches that will address the concerns you raised.

QUESTION: What specific successful demonstration programs will continue to receive funding? For example, what will happen to the "Homes for Black Children" project in Detroit run by a Child Welfare League of America agency? Please submit a list for the record.

ANSWER: The National Adoption Information Exchange System has been funded through September of 1984. No other currently funded demonstrations will carry over into FY 1984.

We believe in using discretionary funds in a partnership relationship with the public and private sector to provide seed funds which demonstrate and help utilize innovative approaches and solutions to problems. By definition, demonstration projects are not intended to receive funding on an indefinite basis. With successful demonstration programs we are eager to assist State public and private resources to institutionalize these programs on an ongoing basis.

The Homes for Black Children project is not run by the Child Welfare League of America. The "National Center for Homes For Black Children", a program development effort sponsored by Homes for Black Children of Detroit, is in its final year of 3 years of funding. Since 1980, seven projects have been created, each known as "Homes For Black Children" or a similar name. Each project was provided seed money for the purpose of program implementation; each sought local funds and the National Center sought funds on the national level to support the programs. These programs are in varying stages of development. Some have recently secured local funds, others have been fully funded for the past year and several have not yet received funds. Built into this program was the plan for each program to continue through support of the public and private sector.

We believe that four or five of these programs, the ones fully funded and those close to a full complement of staff, will continue to operate after Federal funds are discontinued.

Senator DENTON. Thank you. This hearing is adjourned.

[Whereupon, at 1:03 p.m., the subcommittee was adjourned.]

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