DOCUMENT RESUME

ED 129 764 SP 010 479

TITLE	Getting Ready for National Health Insurance: Shortchanging Children; Hearings Before the Subcommittee on Oversight and Investigations of the Committee on Interstate and Foreign Commerce, House of Representatives, Ninety-Fourth Congress, First Session on the Role of Government in Preventive Health Programs That Primarily Affect Children.
INSTITUTION	Congress of the U. S., Washington, D. C. House Committee on Interstate and Foreign Commerce.
PUB DATE	Oct 75
NOTE	159p.; Not available in hard copy due to print quality of original
AVAILABLE FROM	United States Government Printing Office, Washington, D.C.
EDRS PRICE	MF-$0.83 Plus Postage. HC Not Available from EDRS.
DESCRIPTORS	*Clinical Diagnosis; Federal Programs; Health Insurance; *Health Services; *Medical Care Evaluation; *Preschool Children; Primary Health Care; *Public Health Legislation
IDENTIFIERS	Department of Health Education and Welfare; DHEW

ABSTRACT

This hearing inquired into questions on the quality of care and the utilization of services in the child health area. Questions covered included: How does the government assist in preventive medicine programs? What are the gaps in current health care and delivery systems? How can current legislation in this field be better implemented? The early periodic screening, diagnosis, and treatment program (EDSDT) is essential to good health care for children. Low-income children need this service, and good community health centers are needed to implement this preventive health program. The Department of Health, Education and Welfare (HEW) is responsible for overseeing state operations and enforcement of this program. Testimony indicates the job is not being done well. There is inadequate funding through medicaid; there is a lack of rapport and communication between HEW and state officials; and eligibility of children for the program is hard to determine. There are wide gaps in execution of the program as intended by congress, and there is a lack of proper administration by HEW. The Committee requests a report from HEW on steps they will take to bring the program into conformity with the statutes of the U.S. Government. (JD)

GETTING READY FOR NATIONAL HEALTH INSURANCE: SHORTCHANGING CHILDREN

HEARINGS

BEFORE THE

SUBCOMMITTEE ON
OVERSIGHT AND INVESTIGATIONS

OF THE

COMMITTEE ON
INTERSTATE AND FOREIGN COMMERCE,
HOUSE OF REPRESENTATIVES,

NINETY-FOURTH CONGRESS,

FIRST SESSION

ON

THE ROLE OF GOVERNMENT IN PREVENTIVE HEALTH PROGRAMS THAT PRIMARILY AFFECT CHILDREN

OCTOBER 7 AND 8, 1975

Serial No. 94–43

Printed for the use of the
Committee on Interstate and Foreign Commerce

U.S. GOVERNMENT PRINTING OFFICE
60-800 O WASHINGTON : 1975

COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

HARLEY O. STAGGERS, West Virginia, *Chairman*

TORBERT H. MACDONALD, Massachusetts
JOHN E. MOSS, California
JOHN D. DINGELL, Michigan
PAUL G. ROGERS, Florida
LIONEL VAN DEERLIN, California
FRED B. ROONEY, Pennsylvania
JOHN M. MURPHY, New York
DAVID E. SATTERFIELD III, Virginia
BROCK ADAMS, Washington
W. S. (BILL) STUCKEY, JR., Georgia
BOB ECKHARDT, Texas
RICHARDSON PREYER, North Carolina
JAMES W. SYMINGTON, Missouri
CHARLES J. CARNEY, Ohio
RALPH H. METCALFE, Illinois
GOODLOE E. BYRON, Maryland
JAMES H. SCHEUER, New York
RICHARD L. OTTINGER, New York
HENRY A. WAXMAN, California
ROBERT (BOB) KRUEGER, Texas
TIMOTHY E. WIRTH, Colorado
PHILIP R. SHARP, Indiana
WILLIAM M. BRODHEAD, Michigan
W. G. (BILL) HEFNER, North Carolina
JAMES J. FLORIO, New Jersey
ANTHONY TOBY MOFFETT, Connecticut
JIM SANTINI, Nevada
ANDREW MAGUIRE, New Jersey

SAMUEL L. DEVINE, Ohio
JAMES T. BROYHILL, North Carolina
TIM LEE CARTER, Kentucky
CLARENCE J. BROWN, Ohio
JOE SKUBITZ, Kansas
JAMES F. HASTINGS, New York
JAMES M. COLLINS, Texas
LOUIS FREY, JR., Florida
JOHN Y. McCOLLISTER, Nebraska
NORMAN F. LENT, New York
H. JOHN HEINZ III, Pennsylvania
EDWARD R. MADIGAN, Illinois
CARLOS J. MOORHEAD, California
MATTHEW J. RINALDO, New Jersey

W. E. WILLIAMSON, *Clerk*
KENNETH J. PAINTER, *Assistant Clerk*

SUBCOMMITTEE ON OVERSIGHT AND INVESTIGATIONS

JOHN E. MOSS, California, *Chairman*

RICHARD L. OTTINGER, New York
ROBERT (BOB) KRUEGER, Texas
ANTHONY TOBY MOFFETT, Connecticut
JIM SANTINI, Nevada
W. S. (BILL) STUCKEY, JR., Georgia
JAMES H. SCHEUER, New York
HENRY A. WAXMAN, California
PHILIP R. SHARP, Indiana
ANDREW MAGUIRE, New Jersey
HARLEY O. STAGGERS, West Virginia
(Ex Officio)

JAMES M. COLLINS, Texas
NORMAN F. LENT, New York
EDWARD R. MADIGAN, Illinois
MATTHEW J. RINALDO, New Jersey
SAMUEL L. DEVINE, Ohio (Ex Officio)

MICHAEL R. LEMOV, *Chief Counsel*
ELLIOT A. SEGAL, *Special Assistant*
LESTER O. BROWN, *Research Assistant*
PATRICK M. MCLAIN, *Counsel*
SHIRLEY A. FULP, *Staff Assistant*

CONTENTS

GETTING READY FOR NATIONAL HEALTH INSURANCE: SHORTCHANGING CHILDREN

TUESDAY, OCTOBER 7, 1975

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON OVERSIGHT AND INVESTIGATIONS,
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met at 10 a.m., pursuant to notice, in room 2123, Rayburn House Office Building, Hon. Richard L. Ottinger, presiding [Hon. John E. Moss, chairman].

Mr. OTTINGER. The Subcommittee on Oversight and Investigations of the Committee on Interstate and Foreign Commerce is resuming hearings today on the subject of "Getting Ready for National Health Insurance: Shortchanging Children" by indicating that it is a most auspicious time to hold a hearing concerning child health, since October is "Immunization Action Month" and yesterday was "Child Health Day for 1975."

I note in the Proclamation of Declaration for Child Health Day the President indicates that, thanks to vaccines, poliomyelitis is no longer the widespread crippler that it once was. Children can now be protected against measles and the risk of death or brain damage resulting from this disease.

Immunization against rubella not only protects young children, but also protects pregnant women from contracting the disease and risking the mental health of their unborn children. There is no better example of effective cost control and human benefits than to uncover and treat a preventable disease early.

For example, the National Communicable Disease Center, for a 5-year period, estimated that immunization efforts averted 10 million cases of measles and 3,200 cases of mental retardation. It also estimated that immunization saved 973 lives, 555,000 hospital days, 291,000 years of life, 1.6 million work days, 32 million school days, and $423 million.

I, therefore, find it very appropriate for us to convene this hearing today to look at how the Government assists in preventive medicine programs. Now that we do have certain new technologies, such as vaccines, are they being utilized to the extent necessary to protect our people and reduce long-run health costs?

During these hearings, we wil look at aspects of preventive health and communicable diseases. We hope to find out why approximately 5 million of the Nation's 1- to 4-year-old children are insufficiently immunized. Why is that of 14 million preschool children in this country, one out of every three is insufficiently immunized?

I find it inexcusable that in 1973 50 children died and more than

40,000 youngsters developed complications, including brain damage, due to measles.

As the President's proclamation points out, one of the greatest success stories in American medicine has been the determination of the causes and the development of immunization by vaccine for polio.

Surveys now indicate, however, that in 1964, 88 percent of American preschoolers were protected against polio. In 1973, that figure dropped to 63 percent. The figure is even lower—approximately 51 percent—for nonwhite preschool children living in the central cities of major metropolitan areas.

This set of hearings on "Shortchanging Children" is geared to acquire information and to explore the gaps in our current health care delivery system. The purpose is to assist in developing the bases for new legislation and better implementation of current legislation.

We intend, as part of an over-all study of "Getting Ready for National Health Insurance," to be able to gather information that may help this subcommittee, and particularly the Health and the Environment Subcommittee chaired by my able colleague, Paul Rogers, as they begin to consider the need for new national health insurance legislation.

These hearings will focus upon the quality of care and the utilization of services in the child health area.

We will hear from citizens who have had firsthand experiences as well as experts from Government and the field of medicine.

It is in the spirit of gathering information and developing recommendations to help insure consumers of health care better quality in a cost-effective manner that I open these hearings.

We have scheduled for this morning five witnesses: Dr. Frederick Green of Washington, D.C.; Mr. and Mrs. John Maguire, Yeadon, Pa.; Dr. Gerald Haas of Boston; and Congressman Ralph Metcalfe of this committee, a Member of Congress; and Dr. Wilbur Cohen, former Secretary of Health, Education, and Welfare.

In order to be able to have the committee hear from all of these witnesses, I am going to try to set pretty firm limits for each witness, about 20 minutes total per witness, to make sure we get everybody in. I hope the witnesses will do what they can to accommodate us in that regard.

Our first witness is Dr. Frederick Green. I understand that he is accompanied by three parents. If they would like to, they may accompany you to the witness table.

I would appreciate it if you would identify them.

STATEMENT OF FREDERICK C. GREEN, M.D., ASSOCIATE DIRECTOR, CHILDREN'S HOSPITAL NATIONAL MEDICAL CENTER; DIRECTOR, OFFICE OF CHILD HEALTH ADVOCACY; AND PROFESSOR OF CHILD HEALTH AND DEVELOPMENT, GEORGE WASHINGTON UNIVERSITY SCHOOL OF MEDICINE, ACCOMPANIED BY MRS. PAMELA SPEAKS, MRS. PATRICIA YOUNG, AND MRS. IRENE DRIVER, AND THEIR CHILDREN

Dr. GREEN. Thank you very much, Mr. Chairman, and members of the subcommittee. I am pleased to have the opportunity to appear here this morning—the day after Child Health Day, which was declared

by Presidential proclamation—to discuss a situation which is, in my opinion, a national disgrace. I am referring to the failure of Federal, State, and local governments to implement a program which would assure better health care for all children in this country—particularly those at gravest risk. Perhaps the content of this testimony will make some of you uncomfortable, but it is our hope and intention to speak in the best interest of our children and to give voice to the critical concerns of those we serve. Accompanying me today to aid me in this presentation are three families—families that are currently forced to cope with the devastating consequences of our societal neglect. Later in this testimony, you will have an opportunity to meet and talk with them.

My name is Frederick C. Green. I am a pediatrician, currently serving as associate director, Children's Hospital National Medical Center; director of the hospital's office of child health advocacy; and professor of child health and development, George Washington University School of Medicine, Washington, D.C.

I have had the unique opportunity of serving not only the individual needs of children as a pediatrician in private and institutional practice in New York City, but also of serving the collective needs of our Nation's children as the Associate Chief, Children's Bureau, OCD, HEW from August 1971 until my resignation in June 1973.

Throughout my career, I have become intimately familiar and increasingly distressed with the physical, social, intellectual, and emotional wastage resulting from the unconscionable high incidence of uncorrected correctable deficits among children in this country.

The early periodic screening, diagnosis, and treatment program (EPSDT) is potentially the most comprehensive program of preventive health care for children ever undertaken by the Federal Government. The program was mandated by Congress in response to the need for eliminating health-related causes of disability and dependence among the Nation's poorest children. EPSDT provides for the identification and prevention of correctable physical deficits through the provision of early detection, diagnosis, and treatment services.

In the EPSDT guidelines issued by the Department of Health, Education, and Welfare, the following screening services were recommended: Taking a medical history and performing a physical examination; assessing immunization status; screening for dental, hearing, and vision problems; screening for anemia, lead poisoning, sickle cell disease, and trait, bacteriuria, and tuberculosis.

These general services provide a superficial method for detecting the presence or absence of pathology which then must be further explored through the diagnostic and treatment phases of the program. The guidelines also recommend a developmental assessment; however, the nature of this component is currently the subject of fervent national debate. I will expand on this issue later in my testimony.

In spite of the clear intent of Congress to insure basic health protection for the Nation's needy children, the EPSDT program has encountered formidable obstacles. Although the program was enacted into law January 2, 1968, HEW did not release regulations and requirements until late in 1971; these became effective in February 1972. Shortly thereafter, Congress levied a financial penalty—1 percent of State AFDC funds—in an effort to speed implementation and make

States more accountable for the program. Yet, one year later, in March of 1973, 28 States still had either no program at all or programs rated as having major problems.[1]

It is apparent that there is a need for a penalty provision to assure State compliance. It is unfortunate that enabling a generation of children to reach their full potential as productive members of society has not proven to be an adequate incentive for State governments. However, although the carrot has proven insufficient, I question Congress choice of a stick. When we penalize States by withholding welfare payments, we are actually penalizing the very people whom we have agreed are most in need of help.

In effect, we are saying that if States fail to deliver one type of human service, we will reduce their capability for providing another. Surely, it would be more rational to penalize States by withholding funds allocated for purposes other than direct human services, such as moneys for highway construction or capital improvements.

Further evidence of the ineffectiveness of both the State programs and the congressional penalty can be found in the available data on the number of children served by EPSDT.

Considering only those who quality for medicaid, there are approximately 13 million children eligible for EPSDT services. Of those, only 15 percent (1.9 million) had been screened by the end of 1974. Of the small percentage of children who were screened, nearly one-half were found to need additional diagnostic and treatement services. Due to inadequate case reporting procedures in the States, there are no reliable data concerning the number of children who actually receive adequate followup.[2]

Many States have argued that the figures reported for EPSDT services do not reflect the actual number of children receiving such services from other public or private providers. However, these claims are refuted by a recent evaluation report on four EPSDT research and demonstration projects funded by the Social and Rehabilitation Service. These projects provided EPSDT services to all children regardless of medicaid eligibility status. They found that over 90 percent of the problems identified were either new or previously known but not under care.[3]

The large proportion of problems in the latter category previously known but not under care underscores the lack of adequate referral and followup procedures and need for formalized accountable case monitoring mechanisms.

Findings from those projects also clearly indicate that medicaid eligibility alone is not a clear predictor of the number of disabilities that will be found in a given population of children. It is estimated 20 to 40 percent of all children in low-income families suffer from one or more chronic conditions and that only 4 out of every 10 of these children are under treatment. Further, although 97 percent of all children require some dental care before the age of 6, 40 percent of all

[1] Early and Periodic Screening, Diagnosis, and Treatment: Conference Proceedings. The Human Services Institute for Children and Families, Inc., Arlington, Va., June 18, 1974.
[2] Medicaid's Early and Periodic Screening, Diagnosis, and Treatment Program. DHEW. Mimeographed. Washington, D.C., Aug. 1, 1974.
[3] First Quarterly Evaluation Report of the EPSDT Demonstration Projects. Dickson, H.D., et al., University of Texas Health Science Center at San Antonio, San Antonio, Tex., Nov. 20, 1974.

children in low-income families reach the age of 17 without any professional dental care.[4]

In spite of this evidence of need, only about half of the Nation's 25 million low-income—that is, poor and working poor—children are eligible for medicaid and EPSDT services. The remainder are ineligible; yet many are too poor to pay for preventive care. Indeed, in this time of rampant inflation and high unemployment, the working poor often cannot even afford occasional episodic care.

On this point I find it necessary to express a personal bias. It is my belief that certain basic child health services are a right and should be universally available. Yet our history of legislative protection for families in need has been characterized by exclusivity rather than inclusivity. We have excluded children by income, by race, by geography, by age—by just about every characteristic that would enable us to distinguish one child from another.

It is sadly ironic that we penalize those who are actively trying to progress from welfare dependence to gainful employment by effectively denying them a means of assuring good health. I recognize that national health insurance in some form is likely to become a reality in the not too distant future. However, while the bureaucratic wrangling over costs, methods, and feasibility continues, the 12 million children from low-income families who are not eligible for medicaid wait in a vacuum. They wait at risk of permanent disability due to conditions which the medical profession has long been able to prevent or ameliorate.

One out of every ten children in the United States suffers from some form of communication disorder. Of these, over half have some type of speech pathology; a third have severe hearing impairment; and the remainder are totally deaf.[5] Untreated communication disorders literally isolate a child from his environment and render him unable to carry out the myriad learning tasks of childhood.

The prevalence of vision deficits is relatively low among preschool-age children, affecting approximately 5 percent of this population. However, 1 out of every 4 school-age children has some kind of visual handicapping condition.[6]

The incidence of anemia also varies with the age of the child with the highest prevalence rates occurring during the first 4 years of life. As reported to the 1970 White House Conference on Children, the incidence of anemia is highest among children from low-income families. For example, almost half of all 2-year-olds in the lowest income quartile and over a third of those in the lower middle quartile were found to be anemic. For children between the ages of 2 and 6, the reported prevalance rates were somewhat lower; however, it remains that nearly 1 out of every 5 of these children was diagnosed as anemic.[7]

---

[4] Medicaid's Early and Periodic Screening, Diagnosis, and Treatment Program, DHEW, Mimeographed, Washington, D.C., Aug. 1, 1974.
[5] Learning to talk: Speech, hearing, and language problems in the preschool child, DHEW National Institutes of Health Public Health Service, Washington, D.C. 1970.
[6] A Guide to Screening: EPSDT Medicaid, Frankenburg, W. K. and North, F. A., DHEW, Social and Rehabilitation Service, Washington, D.C., 1974.
[7] Profiles of Children: The 1970 White House Conference on Children and Youth, U.S. Government Printing Office, Washington, D.C., 1970.

Though the prevalence rates for a symptomatic urinary tract infection due to bacterial is substantially lower than that for anemia, such infections place children at risk for developing permanent kidney damage. At least 5 percent of all girls will acquire bacteriuria during their elementary and secondary school years.[8] Moreover, this condition is frequently recurrent. Two of the parents here today have agreed to share with us some insights into the lives of children who have experienced kidney failure.

The alarming increase in the numbers of children who are inadequately immunized against childhood infectious diseases has prompted a nationwide campaign to reverse the trend. October has been designated "Immunization Month" by the National Center for Disease Control. It is known that 2 out of every 5 children 1 to 4 years of age have no protection or inadequate protection against poliomyelitis and measles. In central city areas containing poverty pockets, the situation is even more alarming—scarcely half of the children are completely immunized.[9]

The high incidence and drastic consequences of lead poisoning have prompted many urban areas to initiate locally funded lead screening programs. Such an effort has been spearheaded in the District of Columbia by the Committee for L.E.A.D., which operates under the auspices of the Office of Child Health Advocacy, Children's Hospital National Medical Center. Since the beginning of the committee's efforts, the incidence of elevated blood lead levels has decreased slightly each year. Nevertheless, in fiscal year 1974, 16 percent of the more than 14,000 children screened had elevated lead levels. Nationally, 600,000 children still carry undue body loads of lead absorbed from a polluted environment. Each year 300 to 400 children die of lead poisoning, and an additional 6,000 suffer irreversible mental retardation and damage to the central nervous system.[10] The mother of one of these children is with us today.

While child abuse and neglect is not directly addressed in the EPDST guidelines, the early and continued health assessments offered by this program provide a critical opportunity for reaching and helping children who are victims of this tragedy. The provisions of the Child Abuse Prevention and Treatment Act, signed into law on January 31, 1974, reflect the growing national concern over the frightening increase in the numbers of brutalized and abused children.

Although there is substantial evidence of underreporting of child abuse, estimates range from 60,000 [11] to between 250,000 and 400,000 [12] cases each year. Of these between 200 and 400 children are killed.[13]

While it is obvious that the EPSDT program offers an unprecedented opportunity for impacting on the physical health status of children, the program guidelines also address the need for screening

[8] "A 10-Year Study of Bacteriuria in Schoolgirls: Final Report of Bacteriologic, Urologic, and Epidemiologic Findings." Kunin, C. M., the Journal of Infectious Diseases, 122:382–393, 1970.

[9] Immunization Against Disease: 1972. DHEW, Center for Disease Control, Atlanta, Ga., 1972.

[10] Statistics and Epidemiology of Lead Poisoning. DHEW, Office of Child Development, Washington, D.C., February 1972.

[11] Helping the Battered Child and His Family. Kempe, C. H. and Helfer, R. E., J. B. Lippincott Co., Philadelphia, Pa., 1972.

[12] "The Myth of the Battered-Child Syndrome." Newberger, E., Current Medical Dialog, 40:327, 1973.

[13] "Child Abuse and Neglect: A Priority Problem for the Private Physician." Green, F. C., Pediatric Clinics of North America, 22:329–339, 1975.

to identify possible development difficulties. In developing a rationale for this component, HEW has stated that 14 percent of all schoolchildren suffer some form of emotional dysfunction, ranging from severely psychotic—0.6 percent—to mildly disturbed—10 percent. An additional 3 percent are said to be suffering from mental disabilities such as mental retardation, seizure disorders, neuromotor disabilities, and school-learning problems. Though these data reflect serious need for various types of therapeutic and special education services, the issues surrounding the inclusion of a developmental screening component in EPSDT are extraordinarily complex and currently the subject of intense debate.

We recognize the need for a replicable screening instrument for measuring developmental differences that is sensitive to the widely varying child-rearing practices and cultural backgrounds of children in this country. Some developmental landmarks—largely physical abilities, such as the attainment of gross and fine motor skills—can be considered culture-free. However, at present we do not have a reliable screening instrument for assessing such qualities as "intelligence and learning ability" or "emotional stability and social coping" among all children in our multifaceted society.

Further, there is an inherent danger in any screening process which is particularly relevant to developmental screening: People tend to think of screening as a form of diagnosis. It is not. Screening is simply a convenient way of sorting out individuals who have some likelihood of pathology in a given area. Commonly, screening is done by nonprofessionals, and there is a danger that children who fail a given procedure will be labeled as suffering from the suspected condition. Let me emphasize that screening is not a labeling process. Diagnosis is required before a condition is identified and labeled. Moreover, diagnosis should always be prescriptive—that is, diagnosis for treatment of the condition identified, rather than for attaching a label to the condition.

It is necessary, then, to proceed with extreme caution. It is imperative that we do not attempt to mandate program efforts that are in advance of our knowledge. We must avoid the truly tragic consequences of inappropriately labeling large numbers of children being developmentally retarded or having learning disabilities.

Should developmental screening be undertaken, it is critical that the labeling phenomenon be avoided, that diagnosis be in the hands of professionals, and that treatment be made readily available. Further, such an effort should only be undertaken in the context of identifying the strengths as well as the weaknesses of a child, with prescribed treatment that capitalizes on the first while offering remediation for the second. Having said that, I do not mean to imply that we should discontinue those efforts at diagnosing and treating children with psychosocial or learning deficits that are within our present capabilities to correct.

The foregoing has outlined the extent of the problems to be confronted—both in terms of the health status of children and in terms of the administrative difficulties encountered in program development. If the EPSDT program is to realize is potential, the first step is to assure that the program becomes a viable and effective resource for medic-

aid-eligible children. When this is accomplished, there will be a corresponding improvement in the quality of care accorded all children through a ripple effect. We must, then, examine some of the specific major difficulties which have impeded implementation of EPSDT.

In the wake of Federal efforts to decentralize control of spending programs in favor of State management and accountability, we find woeful chaos in many human service programs. Formula grants requiring proof of implementation of specified services are often apportioned without adequate assistance or guidelines to enable States to follow through with acceptable delivery mechanisms. The EPSDT program is a particular case in point. It requires the delivery of services—typically under sponsorship of the State public health agency. The services are to be directed toward a specified population— usually identified through the State welfare agency. Finally, the services are to be reimbursed with Federal moneys and matching funds which are generally funneled through the State fiscal offices. That such an arrangement should prove dysfunctional is not surprising. That the regional HEW offices should be forced to engage in costly house to house surveys to determine whether or not services are being delivered rather than conducting administrative audits is also not surprising.

In January 1975 the Comptroller General issued a report to the Congress concerning improvements needed to speed implementation of EPSDT.[14] Among the general problems identified in the report were:

Inadequate outreach techniques;
Lack of utilization of allied health professionals;
Inadequate procedures for periodic updating of screens; and
Inadequate follow-up mechanisms.

The Federal policy of giving the States a free hand in administering EPSDT has produced not one program but 50 different programs. Unfortunately, most of these programs share at least two regrettable characteristics. First, many States, in an effort to reduce costs, have subscribed to the philosophy that requiring frequent recertification for eligibility will reduce utilization of services. Thus, costs are controlled by reducing services—a philosophy of questionable propriety. The negative consequences in terms of availability, accessibility, and continuity of care within the EPSDT program for each participating child are obvious. I submit that, at a minimum, each child should be guaranteed continuity of care through a single screening, diagnosis, and treatment sequence. Failure to diagnose a condition after screening and failure to treat after diagnosis because of shifting eligibility status is medically and ethically intolerable.

The second area of similarity among the programs is the general failure on the part of State agencies to utilize competent area resources to implement the program. Instead, there is a trend toward the development of separate freestanding clinics to carry out EPSDT functions which could easily be incorporated by existing facilities. In pursuit of the pork barrel, some State agencies have gone to truly incredible lengths to avoid contracting for services from existing resources. Examples include requiring that all screening be conducted at designated

[14] Improvements Needed To Speed Implementation of Medicaid's Early and Periodic Screening, Diagnosis, and Treatment Program. Comptroller General of the United States. DHEW, Social and Rehabilitation Service, Washington, D.C., January 9, 1975.

State-operated clinics, failure to utilize other federally sponsored services such as children and youth projects, and failure to establish formal fee-for-service protocols that would enable the private sector to render needed diagnostic and treatment services.

The net effect of these policies has been longer waiting lists for diagnostic and treatment services from "approved" providers. With luck—the reasoning goes—eligibilty will run out before the child reaches the top of the list. It is essential that these problems be addressed and remedial action taken. It is essential that States be made accountable for children in need of care.

I therefore submit to the subcommittee the following observations:

It is imperative that States be required to assign responsibility for conducting the EPSDT program to a single State agency or department, and stringent penalties which do not impinge on human services should be enforced for those States which fail to comply.

The State agency or department should be in direct receipt of Federal funding for the program, subject to regional administrative review, and have access to adequate technical assistance from the Federal Government throughout implementation of the program.

Accountability for service delivery is not incompatible with the concept of stage-managed programs. In addition, States should be required to provide adequate assurances that those indeed are actually being served and that continuity is maintained throughout the screening, diagnosis, and treatment process.

Federal guidelines should require that States make adequate use of existing health care resources.

Adequate Federal regional staff should be assigned to provide proper monitoring of State programs.

We at Children's Hospital National Medical Center, in recognition of both the potential and shortcomings of the EPSDT program, are currently in active pursuit of private funding to establish a collaborative service integration project (CSIP). This project will seek to develop ways of coping with the identified problems associated with the delivery of EPSDT services and to maximize the utilization of existing community resources.

Planning for the CSIP has been a cooperative effort between the hospital, the District of Columbia Department of Human Resources, and other public and private purveyors of care. This effort is evidence of the concern we at the local level and in the private sector feel for children such as these before you today.

In summary, we have briefly reviewed some of the pressing social, economic, and administrative aspects of child health care, in general, and the EPSDT program, in particular. It is essential, however, that we do not allow the individual child to become obscured in a maze of percentages, conditions, categories, and criteria.

In order that we might, for the moment, consider the individual and personal consequences of inadequate health protection, I have brought with me today three children whose lives have been drastically altered and whose potential for contributing to the growth of society has been incalculably impaired. Each of these children could have been spared his or her handicapping condition through early detection and rapid and full treatment. As we consider each child in turn, let us remember

that we possess the technology to have avoided these devastating consequences.

I would like to introduce Irene Driver. On my right, Mrs. Driver and her daughter, Judy, who has a very serious chronic renal disability that requires renal dialysis and a kidney transplant.

Unfortunately, the child's condition has deteriorated to the point that she was unable to accompany us today. Her condition is the direct result of an undetected prolonged urinary tract infection.

Mrs. Patricia Young on my left, and her son, Eddie, who has a serious hearing impairment that was suspected by the mother at 6 months of age but was not professionally corroborated and treated until much later thus leading to serious developmental impairments.

Third, Mrs. Pamela Speaks and her two children, Yvette and Ella, were found to be suffering from lead poisoning, and it was only detected through a routine health assessment.

Mr. Chairman, these are the parents.

Thank you very much for your attention.

Mr. OTTINGER. Thank you very much, Dr. Green.

That is a very poignant and informational statement you have given to the committee.

Because of the time shortage, we only have about 10 minutes for questioning.

Mr. Scheuer, do you have any questions?

Mr. SCHEUER. No, Mr. Chairman.

I appreciate the witness' statement very much. It was very thoughtful.

Mr. OTTINGER. Congressman Sharp?

Mr. SHARP. Mr. Chairman, I will withhold questions.

Mr. OTTINGER. Congressman Santini.

Mr. SANTINI. Dr. Green, do you have an specific recommendations within the broad scope of your excellently considered and evaluative testimony?

Dr. GREEN. Sir, the major recommendation that I make is, first of all, that there be adequate funds authorized and allocated to the various States and stiffer penalties apply to States that fail to comply with the EPSDT component of the medicaid program.

I do feel that there is a critical need from what I understand of further monitoring staff in HEW regional offices to make sure that this program is functioning effectively.

Mr. SANTINI. In your judgment, right now we have the legal machinery and authorization to do the job if we provide the funding and oversight to implement it?

Dr. GREEN. I believe so, sir. As long as there is a real commitment to do the job.

Mr. SANTINI. Thank you very much, Dr. Green.

You have done a superb job.

Mr. OTTINGER. Mr. Segal has a question.

Mr. SEGAL. Dr. Green, in your statement you say that 1 out of every 10 children is suffering from communication disorders, particularly hearing. Could you describe the kind of consequences that sometimes come from undetected hearing disorders and the difference it makes from an early screening to one later on?

Dr. GREEN. Yes, sir; I will be glad to.

An undetected hearing problem may delay normal language development as well as eventually lead to a perceptual disorder that will reflect itself in the child's capacity to work in school. Once they are labeled "dull" or "EMR" (educably mentally retarded) on the basis of a perceptual deficit, which is all too common, 90 percent of children so labeled and put in so-called slow learning classes are doomed to stay in such classes.

I think that when perceptual deficits are not recognized early on, not only the hearing but the visually impaired as well as those suffering moderate or mild brain damage, it impacts negatively on their capacity to take full advantage of the educational system to prepare them for a productive role as an adult.

Mr. SEGAL. In following through on that point, you noted that there were about 11 million children last year out of an eligible population of 13 million eligibles under EPSDT who had not been screened.

Would it be a fair statement to say approximately 1 out of every 10 of those would suffer some kind of auditory hearing deficiency when screened?

Dr. GREEN. They will perhaps suffer some form of perceptual deficit, whether it is auditory, visual, or central nervous system.

To say exactly auditory would not be, I am sure, quite accurate.

Mr. SEGAL. It would be a fair conclusion to draw that it may very well be 1 million children who would have one of these deficits that could be treated earlier if screened appropriately under this program?

Dr. GREEN. Absolutely.

Finally, in response to Mr. Santini's question regarding further legislative initiatives, there must be strengthening also of the outreach programs of EPSDT to make sure all the children who are eligible to participate are really brought into the system.

Mr. OTTINGER. Mr. Wunder, do you have any questions?

Mr. WUNDER. I have one question.

Dr. Green, what, in your opinion, would constitute an effective outreach program?

You indicated the need for one in your statement.

Dr. GREEN. I feel an effective outreach program is one in which individuals from the neighborhood in which the health facility is located are trained to go into the community to identify children at risk and bring them into the health system. Such community visiting may also be carried out by community health workers, physicians' assistants, nurse practitioners, visiting nurses, social workers, and other allied health professionals.

In essence, a structured method of going out, identifying and bringing children into the health system.

Mr. WUNDER. Thank you, Mr. Chairman.

Mr. SANTINI. Mr. Chairman, I would like to have these children presented.

Mr. OTTINGER. I was going to do that, myself.

Were the problems of the families before you picked up in the screening process under this program or were they picked up or identified in some other way?

Dr. GREEN. Could I ask my parents to respond to that?

Mrs. Speaks, would you respond to the question of how your children were identified as having lead poisoning?

Mrs. SPEAKS. They were identified when I took them to the clinic for lead poisoning, because they always took sick and they could hardly hear anything I said.

Mr. OTTINGER. How did you find out that it was lead poisoning that was their problem?

Mrs. SPEAKS. At the Children's Hospital clinic.

Mr. OTTINGER. What about the other parents who are here?

Mrs. YOUNG. My son was more or less screened through me at home.

Due to the fact that I had had one normal child, I could tell that this child was not normal in that he did not respond to me as children do, babies do. It was through my watching and looking and seeing that he did not develop normally as far as his response to me.

It was then that I decided to point this out to his pediatrician who then thought that perhaps there was a hearing loss. This is how it all came about.

Mr. OTTINGER. Were you aware that there was a screening program?

Mrs. YOUNG. No.

First of all, neither deafness nor any of these problems ever entered my mind at all except for the fact that I knew that there was something wrong.

I was not aware of any screening that could have been done on him sooner.

Mr. OTTINGER. Mrs. Driver.

Mrs. DRIVER. My daughter has a renal problem. When her problem occurred, she was about 5 years old, and I carried her to the clinic regularly. They said too much protein. This private doctor told me it cleared up.

Two years ago, I carried her to the hospital. They told me her kidneys were almost completely gone. We tried to put her on the machine. It didn't work. Then they said they had to flush her kidneys. She was almost on the critical list.

Then, finally, about a couple months after that they put her on medicine and a diet, a real expensive diet, and medicine. They brought her back into the hospital. They put a shot in her arm, removed her kidneys.

She has had a renal problem since the day she was 5 years old. If she had stayed in the clinic, probably she wouldn't have the problem now.

Mr. OTTINGER. The doctor said that if this had been identified earlier you wouldn't have had to have the transplant?

Mrs. DRIVER. I don't know whether she would have had to have the transplant but she could have been treated with the diet.

Now, if she had been in the clinic, where she could go to the clinic regularly with her problem, when she first started having the problem, then they would have known; I really believe they would have known, that she had a kidney disease.

Nobody can tell me that kidney disease happens overnight and you go to the doctor and they tell you don't have any kidneys; they are already gone. I will never believe that.

Mr. OTTINGER. I want to thank you all very much for being with us. I wish we could spend more time at it.

Thank you very much for being with us.

Mr. SANTINI. Could I ask one quick question?

How simple a screening process would it have been to have detected the particular ailment of these children beforehand and what are the cost-factors involved?

Dr. GREEN. The cost factor for checking urine would be roughly 35 to 40 cents a visit. The problem is continuity.

I think what we have here is the need for continuity, ongoing evaluation, rather than this haphazard episodic kind of care, and this is what EPSDT is to do.

The screening for hearing test can be done by audiometry for a very small amount of money once there is an audiometer available.

Screening for lead poisoning costs roughly in a private laboratory about $8 per screen. It can be done now in the Department of Human Resources here in the District, free of charge, to any parent, regardless of socioeconomic status.

So, the cost of screening is minimal. It is the after effects.

Mr. OTTINGER. Thank you.

Next we will hear from Mr. and Mrs. John Maguire of Yeadon,

STATEMENT OF MR. AND MRS. JOHN MAGUIRE, YEADON, PA., ACCOMPANIED BY MICHAEL T. McDONNELL, JR., AND DENNIS HAGERTY, COUNSEL

Mr. MCDONNELL. My name is Michael McDonnell. I am attorney for the Maguires in a civil matter out of which this arose.

I would like to introduce to you my clients.

This is Ann Maguire, sitting to my immediate right; John Maguire, her husband, and the father of Christine and Christine is sitting to the right with the blond hair.

This is Dennis Hagerty, who is also an attorney, who will introduce himself.

Mr. HAGERTY. Mr. Chairman and members of the subcommittee, I am Dennis Hagerty, also for the Maguires, a lawyer in Philadelphia, member of the National Advisory Council and consultant to the President's Council on Mental Retardation.

Mr. OTTINGER. We are very pleased to have you here.

We also would appreciate it if you could submit your statement for the record [see p. 16] and just describe to us informally the information that you have for us if you would like.

Go ahead.

Mrs. MAGUIRE. Right Honorable Representatives of the Congress of the United States, members and staff of the Subcommittee on Oversight and Investigations of the Committee on Interstate and Foreign Commerce, distinguished guests:

My name is Ann Maguire (nee DiDonato). I was born February 24, 1938. I am 37 years old. I graduated from high school in 1955 from the West Catholic Girls High School in Philadelphia, Pa.

Throughout my school years, I was an above-average student. I have a superior IQ. I have passed civil service tests for secretarial positions and worked in that position with the Inspector of Naval Material in the city of Philadelphia.

60-800 O—75—2

My parents are both living, and my father's name is William DiDonato and my mother's is Anna DiDonato (nee Pollitt). Both my parents were born in the United States and are citizens of the United States, attended school and were raised in the city of Philadelphia.

My father retired from Gulf Oil in Philadelphia in 1973. My mother had been and continues to be a housewife. They are both in good health and fully functional.

I am one of two children, with a sister named Joan Ference, 41, born February 3, 1934. She is similarly in good health.

My husband, John Maguire, is employed as a steamfitter with Philadelphia Electric Co. and has been so employed for 16 years. He is in excellent health, is present with me this morning, and has no physical disabilities known to me. He is the son of Mary and John A. Maguire, now deceased, both citizens of the United States and of the city of Philadelphia, Pa.

He knows of no living relative of his father, other than his aunt who is in good health and alive. His mother's family, of whom there are one sister and five brothers, are all well.

On December 29, 1956, I married my husband in St. Lawrence's Church, Upper Darby, Pa. We took up residence together with my parents at my home in Upper Darby, Pa.

My first son was due 10 months after my marriage and was delivered at the community hospital for the Upper Darby area, that is, Delaware County Memorial Hospital. I was a fee-paying patient of a doctor whose specialty was limited to obstetrics, one Dr. E. Earl Trout, with offices in Springfield, Delaware County, Pa.

I had all the approved prenatal care and prescriptions which were then used. I followed my doctor's recommendation in regard to diet. I do not know of any failure on my part to follow a good prenatal regime and believe that I did all that was suggested by the physician for my own well-being and that of my baby.

John was full term and in obvious good health at the time of delivery. He was attractive and 8 pounds, 8 ounces. John is a victim of PKU. John is now 18 years old and a full and complete life is totally denied to him because of the retardation as a direct result of the PKU disease.

John's care was undertaken by Dr. Charles McCutchen, a general practitioner, and I followed all recommendations made by him to the letter with regard to every aspect of infant care.

At the time of John's birth, we lived at my parents' home, my husband then being in the service. I thus had present my mother, who had cared for both myself and my sister and was familiar with the care of a healthy child, having cared for both myself and my sister.

It was apparent to her and to myself that John was not making progress physically but was, in fact, having what appeared to be considerable physical difficulty for a newborn.

Just to recite a few observable problems and not so as to exclude others, I was, at all times, aware and made aware by my mother that there was a peculiar odor on John's diaper at changing.

This observation was, to my knowledge, a common one by anyone who, during that period, came to change this child, which included my husband, my father, and my sister, who lived in the neighborhood and was frequently there.

I also observed a rash which I had little success in controlling, no matter what was used.

John, being the first born, was watched by the many adults in our home and strongly encouraged to do such things as walking, standing, and any other behavior that would indicate his reaching developmental milestones.

However, he would pass the time period for reaching such milestones and invariably be much, much later in reaching them than was expected of him because of his size and general appearance, which continued to be and is to this date, physically attractive.

Mr. SANTINI. What is PKU?

Mrs. MAGUIRE. Phenylketonuria.

Mr. SANTINI. For the ordinary lawyer, what does that mean?

What happens physically?

Mr. MAGUIRE. Phenylketonuria is an inherited digestive disorder in which the body lacks a chemical necessary to convert one animo acid—chemical—phenylalanine; to another amino acid; tyrosine. Due to the inability to change the phenylalanine into the next chemical, tyrosine, the body accumulates an excessive amount of phenylalanine. This acid builds up in the blood and leads to destruction of certain brain tissue.

PKU is the abbreviation for phenylketonuria. This is the disease, itself.

Mr. SHARP. Could that be discovered by a simple test after the birth?

Mr. MCDONNELL. Yes; a Heal test.

Mrs. MAGUIRE. John's developmental milestones were all very, very late. He walked, sat, talked, and ate long after what should have been the time for him to do these things.

I was, of course, conscious of these because I had girl friends of my age having babies of their own who would bring their babies around and they could do more than my John could do even though they were younger.

I continued regular visitations to Dr. McCutcheon and explained to him throughout this time my observations which are not limited to those mentioned above.

I, of course, could recite numerous other observations which were equally and timely reported to the physician.

John, in addition to being "cared for" by Dr. McCutcheon, was only 1 month old when he was returned to Delaware County Memorial Hospital because of difficulty with his bowel movements. At that time, all the manifestations of PKU disease were plainly visible, together with the bowel complication, which is also a symptom of the disease.

Despite all these careful efforts throughout his childhood into his pubertal period and through and into adolescence, the disease went undetected by his treating physicians, who, at age 2, became a general practitioner by the name of Dr. James Dunn.

At age 4, he was hospitalized for a hernia at Delaware County Memorial Hospital. At age 5, he was hospitalized for tonsils at the same hospital. At all times, both by history and by appearance, being blond, fair and blue eyed, he was a victim of the disease known as PKU.

His care continued in the professional responsibility of Dr. Dunn through and into 1967 when, at the birth of his sister, the care was transferred to a gentleman who held himself out as a pediatrician. This gentleman's name is John Bomberger.

He, too, was a member of the staff of Delaware County Memorial Hospital.

John was never diagnosed at all on the basis of his own symptoms. In fact, he would have gone undiagnosed perhaps forever, were it not for the diagnosis made by a Dr. Eleanor Gordon at Kencrest of his brother, William.

From infancy through childhood through adolescence and into young manhood, this disease was undiagnosed.

Mr. OTTINGER. Mrs. Maguire, because of our time limitations, I think we would use the time better if we could have your statement in the record.

If you could summarize the problems you had and use the little time for exchange, I think it would be better than going through the statement. Otherwise, all the time will be used in reading the statement. We do have that and it will be made a part of the record.

I wondered if you could tell us in just a few words about the problems that your other children did experience. Then we would have an opportunity to have some questions from the committee.

Mrs. MAGUIRE. William is now 16 years old. He is severely retarded. He is in Spring City, in the Pennhurst State School and Hospital for the Mentally Retarded.

Mr. OTTINGER. He has the same problem with PKU?

Mrs. MAGUIRE. Christine has the same problem. She was born in 1967. She was tested for PKU at the Delaware County Hospital but it was not picked up. She is now in the special education classes and does have brain damage.

[Testimony resumes on p. 20.]

[Mrs. Maguire's prepared statement follows:]

STATEMENT OF MRS. JOHN MAGUIRE, YEADON, PA.

My name is Ann Maguire (nee DiDonato). I was born February 24, 1938. I am 37 years old. I graduated High School in 1955 from the West Catholic Girls High School in Philadelphia, Pa. Throughout my school years I was an above-average student. I have a superior IQ. I have passed civil service tests for secretarial positions and worked in that position with the Inspector of Naval Material in the City of Philadelphia.

My parents are both living and my father's name is William DiDonato and my mother's is Anna DiDonato (nee Pollitt). Both my parents were born in the United States and are citizens of the United States, attended school and were raised in the City of Philadelphia. My father retired from Gulf Oil in Philadelphia in 1973. My mother had been and continues to be a housewife. They are both in good health and fully functional.

I am one of two children, with a sister named Joan Ference, 41, born February 3, 1934. She is similarly in good health.

My husband John Maguire is employed as a steam fitter with Philadalphia Electric Company and has been so employed for 16 years. He is in excellent health, is present with me this morning and has no physical disabilities known to me. He is the son of Mary and John A. Maguire, now deceased, both citizens of the United States and of the City of Philadelphia, Pa.

He knows of no living relative of his father, other than his Aunt who is in good health and alive. His mother's family, of whom there are one sister and four brothers, are all well.

On December 29, 1956, I married my husband in St. Lawrence's Church, Upper Darby, Pa. We took up residence together with my parents at my home in Upper Darby, Pa. My first son was due ten months after my marriage and was delivered at the community hospital for the Upper Darby area, i.e. Delaware County Memorial Hospital. I was a fee paying patient of a doctor's whose specialty was limited to obstetrics, one Dr. E. Earl Trout, with offices in Springfield, Delaware County, Pa. I had all the approved prenatal care and prescriptions which were then used. I followed my doctor's recommendation in regard to diet. I do not know of any failure on my part to follow a good prenatal regime and believe that I did all that was suggested by the physician for my own wellbeing and that of my baby.

John was full term and in obvious good health at the time of delivery. He was attractive and 8 lbs., 8 oz. John is a victim of PKU. John is now 18 years old and a full and complete life is totally denied to him because of the retardation as a direct result of the PKU disease. John's care was undertaken by Dr. Charles McCutchen, a general practitioner and I followed all recommendations made by him to the letter with regard to every aspect of infant care.

At the time of John's birth, we lived at my parents' home, my husband then being in the service. I thus had present my mother, who cared for both myself and my sister and was familiar with the care of a healthy child, having cared for both myself and my sister. It was apparent to her and to myself that John was not making progress physically, but was, in fact, having what appeared to be considerable physical difficulty for a newborn. Just to recite a few observable problems and not so as to exclude others, I was, at all times, aware and made aware by my mother that there was a peculiar odor on John's diaper at changing.

This observation was, to my knowledge, a common one by anyone who, during that period, came to change this child, which included my husband, my father, and my sister, who lived in the neighborhood and was frequently there.

I also observed a rash which I had little success in controlling, no matter what was used.

John, being the firstborn, was watched by the many adults in our home and strongly encouraged to do such things as walking, standing and any other behavior that would indicate his reaching developmental milestones. However, he would pass the time period for reaching such milestones and invariably by much, much later in reaching them than was expected of him because of his size and general appearance, which continued to be and is to this date, physically attractive. John's developmental milestone were all very, very late. He walked, sat, talked, and ate long after what should have been the time for him to do these things. I was, of course, conscious of these because I had girlfriends of my age having babies of their own who would bring their babies around and they could do more than my John could do even though they were younger.

I continued regular visitation to Dr. McCutheon and explained to him throughout this time my observations which are not limited to those mentioned above. I, of course, could recite numerous other observations which were equally and timely reported to the physician.

John, in addition to being "cared for" by Dr. McCutheon, was only one month old when he was returned to Delaware County Memorial Hospital because of difficulty with his bowel movements. At that time, all the manifestations of PKU disease were plainly visible, together with the bowel complication, which is also a sympton of the disease.

Despite all these careful efforts throughout his childhood into his pubertal period and through and into adolescence, the disease went undetected by his treating physicians who, at age 2, became a general practitioner by the name of Dr. James Dunn. At age 4, he was hospitalized for a hernia at Delaware County Memorial Hospital. At age 5, he was hospitalized for tonsils at the same hospital. At all times, both by history and by appearance, being blond, fair and blue-eyed, he was a victim of the disease known as PKU.

His care continued in the professional responsibility of Dr. Dunn through and into 1967 when, at the birth of his sister, the care was transferred to a gentleman who held himself out as a pediatrician. This gentleman's name is John Bomberger.

He, too, was a member of the staff of Delaware County Memorial Hospital.

John was never diagnosed at all on the basis of his own symptoms. In fact, he would have gone undignosed perhaps forever if it were not for the result of a diagnosis made by a Dr. Eleanor Gordon at Kencrest of his brother, William.

From infancy through childhood through adolescence and into young manhood, this disease was undiagnosed.

This disease, which is the most common inherited disease causing retardation, was missed by the hospital, the authorities in the schools, who were allegedly in charge of running special classes, the county who was aware of his siblings' profound retardation requiring commitment and the entire family background, including John's slowness and placement in retarded programs.

The effect of the degree of retardation in John has destroyed not just his prospect for a normal life, but also for the opportunity to engage in life, liberty and the pursuit of happiness.

Perhaps the greatest burden John has had to carry throughout the years is his normal appearance. This appears to be contradictory. However, it must be recalled that there is no notice to anyone dealing with John as of his slowness. In fact, he is inordinantly attractive. Thus, the expectation level of the persons dealing with him is set at the level of his appearance to them which signifies to them normal, at least average, behavior. Thus, John, throughout his school years, has had the crushing burden of dealing with his peers who expect him to be able to do the things that they do, adults and teachers with the same expectations, and a future of similar expectations from employers.

There is no doubt that the almost continuous failure of John to reach the expectation that people put into his appearance has been, perhaps, the most invidious injury of all. He is slow academically, athletically, socially and economically. His horizons for social completion, i.e. dating and family, are not only diminished, but virtually eliminated in an upper-middle income, predominantly above-average intelligence people in which he has continually had to compete.

His economic horizons are equally dimmed since he is not only mentally retarded, but, together with that, suffers from diminished reflexes and frequent inappropriate emotional behavior.

It is not unfair to suggest that the responsible persons have destroyed not just John's social and economic horizons, but also perhaps the most important horizon, i.e. his emotional adjustment and place in society. He will be constantly, as he has in the past, presumed normal and an expectation level developed that in no way John can meet and the failure of which will be met with, as it has in the past, desperate injury to him and his family and obviously to society as well.

The second born child of our marriage was William, born June 26, 1959. William was, at birth, 7 lbs. 5 oz. and was born at Delaware County Memorial Hospital. William is now 16 years old. William is profoundly retarded and a resident of Pennhurst State School, Spring City, Pennsylvania. William has been institutionalized from age 5 and has spent time at the following locations: Pry Home in West Sunbury, Pa.; Kenerest, Phoenixville, Pa. and Pennhurst School, Spring City, Pa. William was also seen for purposes of treatment and/or evaluation and/or both at the following Pennsylvania and New Jersey Hospitals: Delaware County Memorial Hospital; Children's Hospital of Philadelphia; Butler Memorial Hospital, Butler, Pa.; Children's Seashore Hospital, Atlantic City, New Jersey.

The doctors, as in John's case, included my obstetrician, Dr. Trout; thereafter, the below named doctors, inter alia, at different times: Drs. Dunn, Scott, Baker, Turnblacer, Bookbinder, Embrie, Ashbaugh, and other staff physicians of the various before-referred to hospitals.

Billy was, is and always has been a classic PKU victim in both clinical and laboratory terms. Shortly after birth, he manifested an extremely, distinct decline of all his physical and mental capacities, manifesting itself particularly in an inability to turn over or sit up until months beyond the milestones. His body was covered with a rash which was totally uncontrollable. His hair was blonde, his diaper smelled. It was apparent, especially to me, as well as to my wife and my mother in law that the baby was not making progress and, in fact, was maturing very little in the way of good responses.

We went to the doctor to complain. We took the baby to the hospital for indicated surgery. We did everything told to us by the medical people to attempt to contain the obvious decline of this child without avail. We were criticized for our spoiling the child and thereby causing some of the symptoms which we noted and described above and which must have been noticeable to the attending physician because they would occur in his presence as well.

I was so concerned with the progress that I demanded that a referral be made to a physician associated with Children's Hospital of Philadelphia so that I could get some confirmation of what was happening to my boy. This was done and still no one mentioned either the word retardation or the cause of it.

I was at all times encouraged to continue doing what I had done previously.

I did not hear the word retarded from any of the physicians until Dr. Dunn finally told me, by inadvertence, that one of the reasons why I was having difficulty controlling Billy was that he was, in fact, retarded. Again, no effort had been, theretofore, made to my knowledge to ascertain the reason for such retardation.

Billy's retardation was of such level that it was impossible for me to continue to care for Billy at home in any way. Thus, the County of Delaware, in Pennsylvania, was contacted for assistance in finding a suitable residence for Billy at a private care center where his condition could be looked after.

In fact, what occurred was that he was warehoused in custodial care in Western Pennsylvania at a home which had no physicians on its staff, whose proprietor had no training whatsoever in mental retardation on a professional and, indeed, on any level. Despite this, the warehousing continued for a period of 7 years when it was terminated only because Billy got a critical illness which necessitated his immediate hospitalization.

Billy's situation is different than John in every aspect in that he has never, at any time, been able to do even the more basic things, such as clothe, feed or see to his own elimination. Indeed, the entire time he was at the Pry Home he was not trained in any way and was and has continued to wear a diaper.

The single effect of the governmental agency, who together with the health care facility's removing Billy from both the Home and the neighborhood was to assure that diagnosis would not be made of his condition and thereby immediately advising us as to the presence of the disease in our family. This, of course, prevented any possibility of detection of the disease and the institution of treatment and care of my after-born children, of which there were four in number.

Billy was the genesis, however, of the discovery of the disease upon immediate observation by Dr. Gordon at Kencrest in Montgomery County, Pa. What was not done theretofore, was done by Dr. Gordon, viz. the detection of PKU. The instant I was informed by Dr. Gordon of the possibility of a disease which, had it been treated, could have been cured, as the source of the problem in my three children. I was, of course, determined that if it was within my capacity, this would never happen to any parent again anywhere in the world.

I had three unaffected children between Billy and Christine who sits with me here today. Christine, at the time of her birth, as had John and Billy, was a perfectly normal child. They were not only normal, but they were physically attractive and obviously in good health being of full term and weight.

The same symptomology which had been observed by me in the two earlier children, i.e. John and Billy, was immediately observed by me in Christine.

Christine was born May 7, 1967, at Delaware County Memorial Hospital. She was delivered by Dr. Trout who had delivered my prior children. She was, from birth, placed in the care of a pediatric specialist by the name of Dr. John Bomberger. Dr. Bomberger and the hospital were charged with compliance with the then-existant testing system for the disease known as PKU in Pennsylvania which provided alternate testing methods. Christine's original test was not done as required by the statute prior to her discharge from the hospital at birth, but was done as a result of a callback made by the hospital to my wife and a request that she be returned to the hospital for this specific purpose. As requested, we delivered Christine to the hospital for the test. It was done and I was of the impression that the test had exonerated Christine from the disease.

However, with the continuing decline of Christine, as had her brother John particularly, together with all the symptomology, I was continuously concerned and continuously reminding the physician that I had other children who had retardation problems and that the appearance of this child indicated to me that she was much like her brothers who were retarded.

However, I was not ever, at any time, made aware of the nature of PKU or the symptomology and/or the hereditary nature of the disease.

Indeed, up until the time of the discovery by Dr. Gordon, there was a total lack of communication with me at all as to the possible causes, if any, of retardation in two siblings.

I assure this panel that had any information been given to me as to even a scintilla of possibility of heredity in the disease pattern, I would have investigated it fully and would certainly have discovered within the family that a maternal cousin's children were victims of PKU but had been detected and timely treated for the disease.

This gap in investigatory procedures was at every level, physician, hospital, public service agency, and social service agency. No one, at any time, broached

with me the possibility that there could be a familiar connection with the problem my children were having and, indeed, ever even suggested that there was a cure for the affliction which we, my children and I, have now suffered. If any pattern is more apparent, it is that Christine will suffer at least as much as John has on the social and economic ladder.

I have tried to avoid this continuing failure to meet challenges by continuing to confine her to schools for retarded children, but because of her normal brothers and sisters, she is constantly confronted with and has to deal with problems which are beyond her capacity to solve.

It is my opinion that all of my children were and are and always have been normal in every aspect of their lives, with the exception of this disease.

There is not any reason for me to believe that the appropriate treatment at the appropriate time would not have left my children normal children in every respect.

The children's parents were and are totally commited to their personal well-being and would have followed a diet to absolute letter. Indeed, the first opportunity that I was ever given to observe the dietary program was not given to me locally, but in Dr. Guthrie's clinic in Buffalo, N.Y., where I was tremendously impressed with the total effort to both discover and cure this most pernicious disease.

In conclusion, if my testimony before this Committee has any purpose at all, it is my honest hope that its purpose will be to set up a continuing screening and follow-up effort of all retarded children everywhere to discover the basis for their retardation and to exclude as a possible basis PKU.

Indeed, there should be a national commitment to the similar prevention of this horrifying illness by a mandatory detection and program of follow through on diet which could and should be modeled after the program I had pleasure to witness in Buffalo.

I am prepared now to answer any questions relating to the statement I have just read.

However, I am certain this Committee understands the purpose of my preface and the limitations contained therein. I will consult with my attorney in regard to answering questions placed by the Committee.

APPENDIX A

Gentlemen: I regret that both my statement and my answers to questions will be limited, to some extent, in my testimony before you this morning due to the existence of litigation.

I cannot and will not speak to any of the issues involved in the litigation. I will be required to consult with counsel on any question prior to answering it and will reserve my right to do so.

This is done not simply in my own interest, but primarily in the interest of the three affected children in my household who have a significant part of their economic future dependent upon the outcome of the civil litigation and whose rights I cannot and will not waive.

With those limitations, I will attempt to fully and completely answer your questions and trust that I will answer fully completely any questions asked by you.

Mr. OTTINGER. We thank you very much for this testimony.

Mr. Scheuer, do you have any questions?

Mr. SCHEUER. No questions.

Mr OTTINGER. Mr. Sharp?

Mr. SHARP. Did you say Christine was tested for PKU?

Mrs. MAGUIRE. Yes, she was.

Mr. SHARP. Was it discovered in the first test?

Mrs. MAGUIRE. No, it wasn't.

Mr. SHARP. Would this suggest if you had done this test again within a reasonable period of time you might have discovered it then?

Mrs. MAGUIRE. The test came back negative. They said there was no reason to test her again.

Mr. SHARP. Is the test for PKU now standard in that hospital? Was it not for the first child?

Mrs. MAGUIRE. It was not for the first child. It was for Christine.

Mr. MAGUIRE. Mr. Sharp, when Christine was born, she was released from the hospital. The hospital had found out that the test had not been done. So, they had her come back.

Now, this test is usually done around the third or fourth day. If it is done on the first day, results can be negative. She was out 2 days. So, the sixth or seventh day it would be more natural for it to show up and the test was negative.

Mr. SHARP. Thank you very much.

Mr. OTTINGER. Mr. Santini.

Mr. SANTINI. I appreciate your sharing your experience with us. It helps us to form a better educated judgment on the practical problems we are facing here as well as the legislative problem.

Mr. OTTINGER. Mr. Segal.

Mr. SEGAL. I would like to ask, with your permission, that there be inserted in the record articles, one describing mass screening for genetic disease and another article describing neonatal screening for phenylketonuria, indicating that more than 10 percent of the infants with PKU today are not screened and not being detected properly by screening; and related articles on inborn genetic screening.

Mr. OTTINGER. Without objection, it is so ordered.

[Testimony resumes on p. 38.]

[The articles referred to follow:]

Mass Screening for Genetic Disease

ROBERT GUTHRIE *State University of New York, Buffalo*

Automation has already brought our screening capability to the point where the same specimen can be used to detect a number of hereditary aminoaciduria in addition to PKU. Yet application falls far behind: only six laboratories in the U. S. now do such automated multiple testing. Regionalizing the effort could close this gap – and involve practically no increase in cost over that of screening for PKU alone

It is now some five years since mass screening of neonates for phenylketonuria became routine throughout the United States. The tests have been made legally mandatory in 43 states and are carried out voluntarily in the other seven, thereby covering an estimated 90% of the 3.5 million infants born annually in this country; similar measures are under way in at least 15 other nations. All told, these screening programs add up to perhaps the most extensive exercise in preventive medicine since the development of polio vaccine.

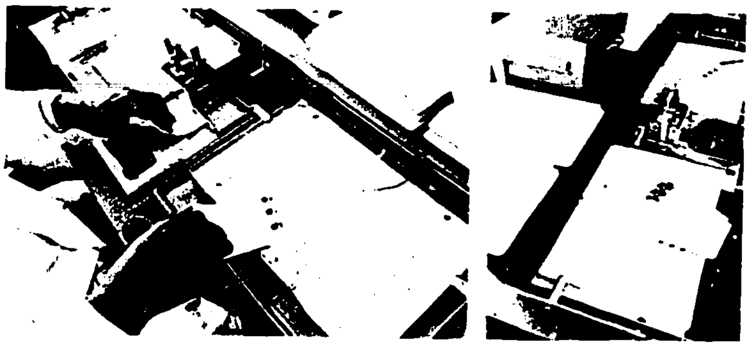
Given a public health effort of this magnitude, a review of the results would be appropriate in any case. But such a review seems especially desirable now, in the light of some current efforts to discontinue screening programs under the guise of a misconceived "economy." In fact, as I shall demonstrate, PKU screening has proved itself not merely a medical but also an economic success, figured in the most hard-nosed budgetary terms: the ounce of prevention that saves an expensive pound of amelioration. It is also, as we are learning, a prototype of other mass screening programs that can pay more modest, but no less real, medical and economic dividends in the prevention of genetic disease.

The first test for PKU was, of course, the well-known "blue diaper" test, which depends on the reaction between ferric chloride and the phenylpyruvic acid in the urine of an affected infant. With the aid of this procedure, a number of cases of PKU were detected. These were treated by means of a low-phenylalanine diet, with results that were somewhat equivocal but encouraging. However, this test was unsuitable in many ways. First, it usually gave positive results at best no earlier than about a month after birth, owing to the delay in rise of serum levels of phenylalanine to the point where its metabolic product would show up in the urine; thus there was reason to suspect that by the time treatment could be initiated the infant might already have suffered some degree of irreversible brain damage. Then, its success as a mass screening device depended heavily on the cooperation of untrained or inexperienced individuals – parents, public health nurses, etc. – who would have only the most general notion of what to look for, since their chances of having seen another case of this rare condition were remote.

In the late 1950's, my associates and I were asked to run tests on serum phenylalanine levels to monitor the dietary treatment of two PKU patients. Dissatisfied with existing procedures, which were cumbersome and costly, we devised the bacterial inhibition test, which is neither.

This procedure employs cultures of *Bacillus subtilis* in an agar medium. Normally, this organism is capable of

Automated screening for PKU and other unborn metabolic disorders begins with the arrival by mail of blood samples like those shown above, on a recent Thursday a total of 137 arrived at the New York State health department's laboratory in Buffalo



Filter papers containing the blood sample are placed in machine for punching (left) ... dried blood spot ... shown at far right, each of which is [illegible] ... in a separate dimpled tray ... for testing. Another ... is punched for trays containing agar medium; trays of this type can be seen at the technician's right. [illegible]

synthesizing phenylalanine (which it requires for growth), but if the medium contains the compound β-2-thienylalanine, an analogue of phenylalanine, some essential metabolic process is blocked, so that the bacterium cannot reproduce. When a filter paper disc impregnated with serum or blood from an affected individual is placed on the medium, however, the exogenous phenylalanine diffuses into the medium, producing a zone of growth surrounding the disc. By appropriately adjusting the concentration of the inhibitor, the test can be made sensitive over virtually the entire range of expected phenylalanine concentrations, the width of the zone of growth being proportional to the amount of phenylalanine present.

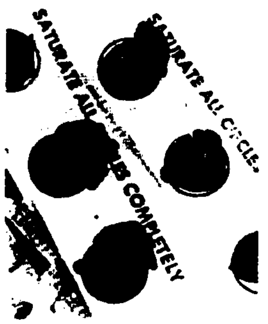
Since it was soon determined that the serum or blood did not need to be fresh, the test could be applied on a mass basis, with samples processed in batches at central locations. There was a consequent gain in both reliability and economy, an advantage already suggested by trials with urine-impregnated filter papers. Further modifications involved using standard-sized discs, mechanically punched from the impregnated paper, and spores of *B. subtilis*, rather than the organism itself, for "seeding" the medium. This "instant" culture technique obviated the sterile procedures previously needed to maintain the culture and perform the test.

It is this test that has become the standard method used in nearly all PKU screening programs. It has proved itself accurate, quantitative and reliable, as any test designed to screen for a rare disease must be. As might be expected, its widespread use has taught us a good deal about PKU itself. In most European and American populations, PKU incidence turns out to be about one case per 10,000 births, implying a gene frequency (allowing for consanguinity) of something less than one per hundred of population. Though this incidence is low, it is significantly, I think, a great deal higher than previous estimates based on urine testing. One might note, incidentally, that both Ashkenazic Jews and (especially) Afro-Americans appear to have an unusually low incidence of PKU.

The fact that the test is carried out in the immediate postnatal period (3 to 5 days in normal infants, 5 to 8 days in prematures), in addition to making possible more timely treatment, has sharpened our awareness of the potential significance of particular phenylalanine levels. Originally, a level of 20 mg% or more was considered diagnostic, but the diagnostic level has steadily been lowered to the point where now the test is so adjusted as to pick out all infants with levels exceeding 4 mg%. A test this sensitive can be expected to turn up many "positives," and in fact we find that we can expect to retest [illegible] to 50 suspicious cases to turn up one actual case of PKU. Nonetheless, the extra sensitivity is justified, since it has become apparent that there is no sharp correlation between inherited lack of the enzyme phenylalanine hydroxylase (the fundamental biochemical defect in PKU) and actual serum levels of the amino acid. Of all infants with the enzyme defect, as determined by phenylalanine loading tests, some 25% maintain phenylalanine serum levels of between 8 mg% and 15 mg% on a normal diet—levels that would once have been considered benign.

Of course we cannot be certain that these infants would grow up retarded, since the only conservative (and ethical) course is to limit their phenylalanine intake as if they were "typical" PKU cases. But it is significant that

Dr. Guthrie is Research Professor of Pediatrics and Microbiology, State University of New York at Buffalo, and Buffalo Children's Hospital.



[illegible] In the three samples [illegible] phenylalanine [illegible]

studies in Germany, Austria, Denmark, Scotland, and the U.S. of mentally retarded populations have turned up a significant number [illegible] of persons with elevated phenylalanine levels [illegible] of individuals with serum levels in the low range [illegible] phenylketone does [illegible] suggesting [illegible] term for the [illegible]

[illegible] levels of [illegible] for two weeks after [illegible] phenylalanine [illegible] patients [illegible] diet. This [illegible] in the general [illegible] that [illegible] what we know about the nature of [illegible] growth retardation. Because of its [illegible]

growth limitation. It follows, then, that any delay in treatment beyond the minimum period necessary for a confirmed diagnosis risks brain damage; it is during the first few months of life that the brain grows most rapidly.

It is possible that in some of these marginal cases the patients may not be true PKU sufferers but may be manifesting a transient, idiosyncratic phenylalaninemia, which appears not to be uncommon among young infants. These cases, however, can be eliminated by periodic monitoring of blood phenylalanine levels, which on a low-phenylalanine diet could be expected to drop below normal (roughly 2 mg%) as the transient disturbance subsides. And monitoring is of great importance in any event, to check on the effects of the dietary regimen. Here, as elsewhere, we are learning that overtreatment, resulting in hypophenylalaninemia, may be quite as damaging as undertreatment. Moreover, clinical experience has demonstrated that individual requirements for phenylalanine among PKU patients vary greatly; one child may require three times as much dietary phenylalanine as another to maintain the same blood level. The difference, apparently, is in the rate at which the amino acid is metabolized and excreted by alternative metabolic routes.

Monitoring is now [illegible] the [illegible] screening. Indeed, it does not even require the infant's being brought to a clinic or physician's office, since the mother can quickly be taught how to take a blood specimen on [illegible] filter paper blank that can be mailed to the testing center.

Given prompt, [illegible] and carefully [illegible] treatment along these lines, there is every reason to hope for a favorable outcome, in the sense of producing a normal, healthy [illegible] [illegible]

Whether early treatment, adjusted to the individual's metabolic needs, will prove successful in *all* cases remains to be proved; these sophisticated modalities have been employed for only a few years, so that long-term studies of such patients do not yet exist. It can be said, however, that several such studies have now passed the five-year mark, and that in all cases the IQ of the children falls into a normal distribution. Moreover, the incidence of behavioral disturbances such as hyperactivity, which are a conspicuous feature in some (though not all) cases of untreated PKU, seems no greater than normal.

The prospect that most or all PKU patients will grow up into essentially normal individuals, however, raises another health problem that will require attention: prenatal or "maternal" phenylalaninemia. Physicians have already accumulated a limited amount of experience with this condition, owing to the fact that a small but significant fraction of untreated PKU patients are of normal or low-normal intelligence, i.e., not so retarded as to require institutionalization and therefore (if female) not unlikely to become pregnant.

The majority of infants born to such mothers show severe retardation even though their (postnatal) serum phenylalanine levels are normal. Not infrequently we find evidence of more serious growth disturbance, such as microcephaly, which is seldom found in "ordinary" PKU. The obvious presumption is that they have been damaged by high phenylalanine levels in the mother's blood. The amino acid crosses the placenta, and studies of a pregnant [illegible] in which phenylalanine [illegible] reduced by means of a special diet have shown that levels of the [illegible] were even higher in the fetus. The equally [illegible] conclusion is that during pregnancy the mother should be put on a low-phenylalanine diet, and this has been done in several cases (see illustration on page 00[?]).

Evaluation is complicated by the fact that a minor fraction of infants born to PKU mothers show no intellectual impairment. One source of this apparent anomaly may well be the previously noted "marginal" cases in which the mother's serum phenylalanine approaches normal levels, certainly [illegible] case where all the

Newborn Screening Tests[1] for Inherited Abnormalities

Disease	Test Substance	Test	Automated	Treatable
Phenylketonuria	Phenylalanine	BIA[2]	✓	✓
Maple Syrup Urine Disease	Leucine	BIA	✓	✓
Tyrosinemia (transient and permanent)	Tyrosine	BIA	✓	✓
Homocystinuria	Methionine	BIA	✓	✓
Histidinemia	Histidine	BIA	✓	✓
Valinemia	Valine	MBIA[3]	✓	✓
Galactosemia: Transferase or Kinase Deficiency	Galactose	MBIA or Coliphage	✓	✓
Transferase Deficiency only	Galactose Uridyltransferase	Beutler	Partly	✓
Argininosuccinic Aciduria	Argininosuccinic Acid Lyase	EA[4]	✓	✓
Orotic Aciduria	Orotidine 5'-phosphate Decarboxylase	EA	✓	✓
Hereditary Angioneurotic Edema	C1 Esterase Inhibitor	FST[5]	Partly	No
Emphysema (adult) Liver Disease (infant)	α-Trypsin Inhibitor	FST	Partly	No
Sickle Cell Anemia	Hemoglobin	Electrophoresis	Partly	Palliative only

1 Using dried blood spot filter paper specimens 2 Bacterial Inhibition Assay
3 Microbiologic Bacterial Inhibition Assay 4 Enzyme Autotroph Bacterial Assay
5 Fluorescent Spot Test

children were of above normal intelligence, the mother's serum phenylalanine was found to be only 10 mg%. It is also not unlikely that variations in fetal enzymes are involved here. We now know, contrary to earlier beliefs, that the enzyme phenylalanine hydroxylase is manufactured prenatally in the fetal liver, but there is doubtless appreciable variation in the time when that enzyme becomes manifest. Accordingly, there must be variation in the degree to which it can protect the fetus by metabolizing the exogenous (maternal) phenylalanine.

Be all that as it may, it is clear that with some hundreds of PKU cases being detected and treated annually, the population at risk of prenatal phenylalaninemia can be expected to rise rapidly as the "first generation" of screened and treated girls reaches childbearing age. The low phenylalanine diet will probably be discontinued at puberty or (usually) earlier, both for practical reasons and because it may be found that phenylalanine has only minimal effects, in most cases, after brain development is completed.

In principle, prophylactic dietary treatment of pregnant PKU patients should not be particularly difficult or expensive [illegible] gestation. This points up the importance of long-term follow-up of these individuals, many of whom may be totally unaware that they suffer from what would have been, if untreated, an incapacitating metabolic defect. What we have here is a problem in the logistics of medical information: how does the physician, knowing that his patient is at risk of producing an abnormal child 10 or 20 years from now (by which time she may well have moved a thousand miles away), ensure that she and/or her then physician have the information needed to avert the risk? The answer is certainly not a simple one. But it is relevant not merely to PKU but also to other genetic diseases, to the extent that they too are correctible and liable to affect the patient's offspring.

Considering only the United States, with [illegible] now being screened for PKU annually; this, at a generous estimate, represents an outlay of something like $1.5 million a year. Compared to the tens of billions of dollars spent annually by the Defense Department or even the billions expended on space programs and supersonic jets, this is pretty small potatoes, but it is still big enough to draw the eyes of state legislators and budgeteers seeking "fat" which they can cut to reduce the admittedly serious current deficits in their funds. The first attempt to discontinue PKU screening occurred in Illinois two years ago, and though it was beaten back by the efforts of parents and physicians, similar attempts can be expected as the budgetary pinch on state governments grows tighter, which it seems likely to do over the next few years at least.

It is therefore necessary to say flatly that (and I choose my words carefully) discontinuance of PKU screening would represent not merely medical but also fiscal irresponsibility of the grossest sort. The detection and treatment of one case of PKU represents an outlay (assuming it is the outcome of 10,000 screening tests, each costing 50¢ to $1.00 in the U.S.) of up to $50,000. But failure to detect that case means a child that must almost certainly be institutionalized for the rest of its life, representing an outlay of at least $250,000 (this assumes an average life span of 50 years and an annual expenditure for custodial care, conservatively estimated at $5,000). The $250,000 figure includes no allowance for the future earnings of the treated case, or of the tax income from such earnings. It does not allow for the suffering experienced by the parents of a permanently retarded child, which is not, in any case, quantifiable in terms that are likely to make sense to a budgeteer. We are not talking here about human values but purely economic ones: whether it is better to spend $50,000 now or five times that sum later.

There is, for that matter, good reason to expect that the $50,000 figure can itself be somewhat reduced. One approach to this is through the use of automated test equipment, of which I shall have more to say in a moment. However, to get full value from this

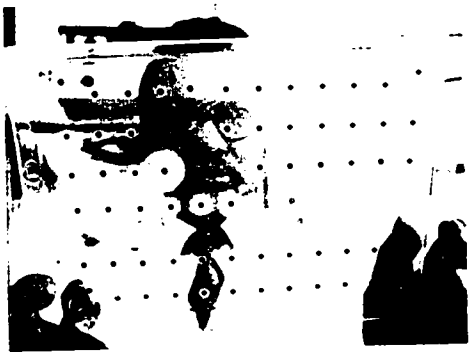
apparatus, testing must be done on a large scale: a minimum of 25,000 births a year. This constitutes a powerful argument for regionalization of screening programs; given the validity of tests based on dried blood spots, which can be mailed in to the testing center, there is no good reason why any hospital should find it necessary to carry on its own, small-scale, screening program. The centralized, consolidated programs also possess advantages from the standpoint of staff morale. A program covering only a few thousand births per year can easily run for several years without turning up a single true case of PKU, so that the personnel involved may acquire the feeling they are engaged in a pointless exercise. When the screening load reaches the level of 30,000 or 100,000 per year, however, the expectable number of cases will provide tangible evidence that the program is performing a valuable prophylactic function.

It would be misleading, however, to suggest that the cost of screening is likely to be markedly lowered by even the most rational organization of these programs. The main cost factor is, and will remain, the actual gathering of specimens and the necessary follow-up on positive tests; the actual processing is a relatively minor item. Authorities in New Zealand, for example, find that with automated equipment the entire testing load—some 50,000 New Zealand births per year, plus several thousand others mailed in from various Pacific islands—can be easily handled by one person, whose work includes preparing and "seeding" the culture trays, placing the test discs on them, and reading the results. The economics of mass screening will continue to rest, as they do now, on the demonstrated fact that prevention is cheaper than nonprevention.

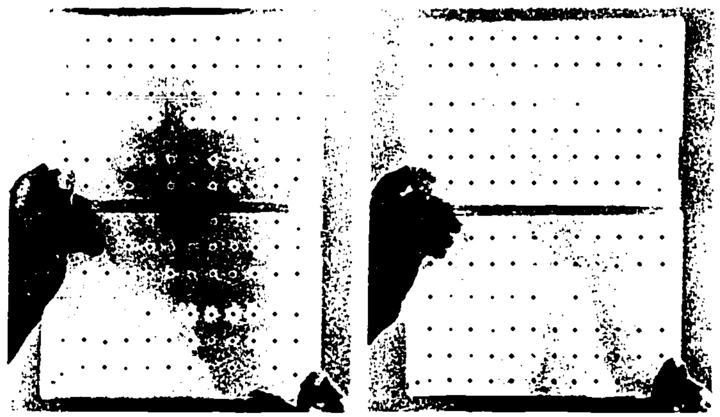
The automated equipment grew out of the finding that the inhibition assay procedure can be adapted to the detection of several other hereditary aminoacidemias simply by varying the inhibitor dissolved in the culture medium. These conditions include galactosemia, tyrosinemia, histidinemia, homocystinuria (in which we test for methioninemia), and maple syrup urine disease (leucinemia). With automation, all these tests plus the phenylalanine test can be carried out at no more cost than the latter alone, unautomated.

The machine, called a punch indexer, handles test specimens in batches of 56. It automatically punches out four 1/4-inch discs from each specimen blood spot and transfers them to predetermined locations on four different culture trays, each containing a different inhibitor—in each case, of course, the same spatial location for a given specimen. The testing array is completed with four control discs, one in each corner, as a check on uniformity of the medium, and a row of up to 12 control discs across the center of the tray, which contain blood (taken from the "expired" bottles of a blood bank) loaded with several standard concentrations of the amino acid in question. In PKU testing, for example, we use discs with normal, 2, 4, 6, 8, 10, 12, and 20 mg% since each of these produces a growth zone in the culture of differing width, any positives in the test specimens can be approximately quantified immediately by visual comparison with the range of control discs.

Much the same mechanized procedure can be used for large-scale testing to unearth other metabolic defects, though the biologic and chemical rationales differ somewhat. Galactosemia, for instance, can be detected by the metabolite inhibition assay test, here employing a mutant strain of *E. coli*. (The principle for this test was suggested by Dr. Kenneth Paigen, Roswell Park Memorial Institute, Buffalo, N.Y.) This organism has the same metabolic defect as human galactosemics, so that galactose (or galactose-6-phosphate, in another form of the disease) accumulates in the cells, inhibiting growth. The diameter of the "zone of inhibition" (as opposed to the "zone of growth" in the tests described earlier) is proportional to the amount of galactose in the specimen disc. The same test can detect valinemia, since *E. coli* growth is inhibited by valine also. Galactosemia of one type can also be diagnosed by the Beutler test, which is chemical rather than biologic and measures enzyme activity directly rather than the accumulation of an unmetabolized substrate. The Beutler test involves a reaction between the enzyme galactose uridyltransferase, present in normal erythrocytes, and a synthetic substrate, the product of which is fluorescent. For the test,



Chief technician Emerson Barr examines agar tray that, after incubation overnight, shows one positive PKU result requiring follow-up of the infant. This can be seen in row 3 from top; halo surrounding disc indicates that phenylalanine in blood sample prevented the usual inhibition of growth of B. subtilis by the 3-2-thienylalanine present in medium. Row 4 contains control discs with known concentrations of phenylalanine.



Shown above are results of additional bacterial inhibition assays. Trays at left were tested with phenylalanine (top) and tyrosine (below); positive can be seen in row 3 below. Control discs each tray corner also has control disc. Trays at right show top tests of leucine for maple syrup urine disease, with no positives and below, methionine homocystinuria, one positive in row 4.

blood-specimen discs are placed, by the same machine, in "dimples" in a plastic tray, each of which serves in effect as a miniature test tube for the reaction. A solution of the substrate is added and, after incubation, a failure to fluoresce points to enzyme-deficient cells.

Direct assays of enzyme activity are generally considered superior to assays of the enzyme substrate, since they measure the metabolic defect itself rather than its consequences. Unfortunately, however, enzyme assays cannot be performed in PKU, since the enzyme in question is found only in the liver. Several other inborn errors, however, resemble galactosemia in that the "missing" enzyme is a normal constituent of erythrocytes, and is not destroyed by drying, so that its presence or absence can be detected in blood spot samples.

Two of these tests, developed by Dr. William Murphey in our laboratories, are of the Enzyme Auxotroph Assay type, employing mutant strains of *B. subtilis*. One strain, for example, requires exogenous arginine for growth; it cannot produce the amino acid from a medium containing the substrate argininosuccinic acid. Normal erythrocytes, however, contain the enzyme argininosuccinic acid lyase, which liberates arginine from that substrate, permitting the organisms to grow. If the organisms fail to grow, the enzyme is absent from the specimen, which is to say that the individual suffers from argininosuccinic aciduria. A similar test with a different bacterial strain can detect absence of orotidine-5-phosphate decarboxylase, which is the underlying defect in orotic aciduria. Altogether, some 20 different enzyme activities can be detected in dried blood from normal neonates by one or another means. For most of these there are as yet no known instances of congenital absence or inactivity of the enzymes involved, so there has been no attempt to adapt the tests to mass screening.

In addition to clinical conditions produced by enzyme deficiencies, there are also conditions resulting from a deficiency in an enzyme inhibitor. Recently, Dr. Murphey has developed two simple and accurate fluorescent spot tests, applicable to the dried spots of blood, for inherited deficiencies of enzyme inhibitors. One of these, inherited as a Mendelian autosomal dominant trait, is hereditary angioneurotic edema, associated with a deficiency in C1 esterase inhibitor. Although several hundred cases have been listed in the literature, mass newborn screening reveals it to be a very rare condition. The second condition, α-antitrypsin deficiency, inherited as a Mendelian recessive trait, appears to be more frequent, since it has been claimed to be associated with at least 1% or 2% of all cases of emphysema. It can also be associated with infantile liver disease. Its true frequency remains to be determined, since routine screening of newborns for this condition has only just begun.

It is likely that other enzyme deficiencies exist but are sufficiently uncommon to have thus far escaped detection. Alternatively, such defects could be not uncommon but associated with little or no impairment of physiologic function. This appears to be the case, for example, in many or most types of glycinuria, several cases of

which have been discovered accidentally in the course of other, unrelated investigations. Because clinical and research attention has, for obvious reasons, been focused on pathologic errors of metabolism, we have doubtless overlooked many anomalies whose functional effects are obscure or benign. Yet I believe that with increasing knowledge it will become clear, as Garrod suspected more than 60 years ago, that pathologic inborn errors are in fact only exaggerations of the innate chemical differences present in all of us.

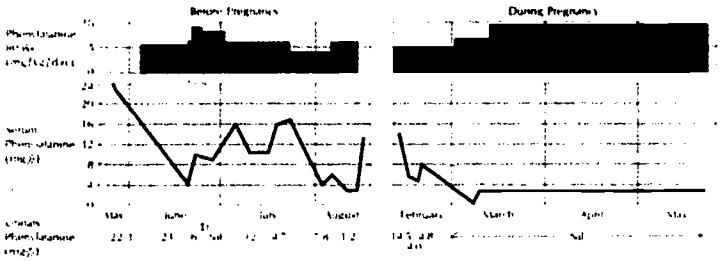
Recently, a practical method of using the newborn dried blood spot (or specimen) in mass screening for sickle cell hemoglobin and other hemoglobin variants has been developed by Dr. Michael Garrick in our laboratory. This method uses discs punched and placed by the punch-index machine in the dimples in the plastic dimple-tray. These discs are then eluted in the dimples, after which the eluates are used for electrophoretic separation of hemoglobin bands in cellulose acetate strips. A follow-up procedure, using agar electrophoresis, can differentiate the ss heterozygote from the ss homozygote. Using this procedure, filter paper specimens for the PKU test can be screened by a laboratory already performing multiple tests on the specimens at a material cost of $0.03 per specimen. The capital investment for equipment is less than $1,000 to acquire the capability for screening up to 100,000 specimens per year.

This screening procedure is the first one to be developed by our laboratory that permits detection of the "carrier" heterozygote by mass screening. It is also the first procedure developed anywhere, to our knowledge, that permits detection of S hemoglobin in the newborn infant by mass screening, in spite of the presence in such specimens of more than 90% fetal hemoglobin. Because of the recent increased interest in prevention and treatment of sickle cell disease within the United States, it is hoped that this test will receive a large scale trial in the near future.

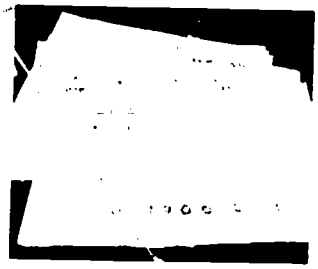
During the past five years the screening laboratories collaborating with me have demonstrated that, with automation, six to eight of the tests described above can be carried out at little increase in cost over the single PKU test, providing a sufficient volume of specimens are available. The minimum is approximately 25,000 per year; increasing volume further reduces the cost and produces other advantages. For these reasons, we have recently been proposing development of model, or demonstration, "regional" centers for inborn errors of metabolism.

By "regional" program, I mean, first of all, one in which a sufficient number of newborn specimens are screened daily to permit application of those methods of automation already routine in a number of laboratories for the purpose of carrying out at least 8 of the 13 tests available.

Even more important for such a program is close and continuous liaison between the screening center and the medical follow-up and management of the cases detected in screening. Several programs with these features have been developed in the past few years in Europe and in New Zealand. In fact, although approximately 24 multiple-test laboratories, using four or more of my tests on the dried spots of blood collected for PKU screening, have come into existence since 1964, almost all of these are located in other countries except for the original four in the U.S., which have been working with me as part of a joint collaborative effort. However, the health departments of Ohio and Maryland recently purchased punch-index machines and have now begun multiple testing. This occurred as a result of a conference we held in February 1971.



That control of phenylalanine levels in the pregnant PKU woman can ward off mental retardation in her offspring is indicated in records above of patient reported from Dublin by Allan and Brown. This patient had borne three children observed in school to be mentally retarded; her urine was strongly positive for phenylketones, that of the children negative. Detailed investigation found no explanation other than high intrauterine phenylalanine for the mental deficiency in the children. In the first phase of the study graphed above, efforts were made to determine what diet a low phenylalanine diet could effectively reduce the mother's serum levels; this was accomplished during three months of hospitalization. Spikes in graph at left reflect breaches in the diet when a night attendant "took pity" on the patient and gave her a glass of milk. When she subsequently became pregnant, she reentered the hospital for dietary maintenance during the last five months. At birth the fourth child had a cord blood level of 7.6 mg% phenylalanine, at 6 hours the serum level was 5.2 and at 48 hours a normal 1.4. Tests later showed normal intelligence.



Beutler test for one type of transferase deficiency assays enzyme activity on a synthetic fluorescing substrate added to discs, spots that do not fluoresce under UV light after incubation are positive

The three principal problems in our own country that have impeded expansion of PKU test programs to include tests for other conditions are

1) Lack of liaison between screening centers and medical centers;

2) Restrictions of screening areas by state boundaries, as states often contain too small a population of newborn infants per year for efficient PKU screening, let alone screening for more rare conditions;

3) Fragmentation of screening, even within large states, when private facilities are used. An outstanding example is California, where, I am told by a health department official, newborn tests for PKU are carried out by more than 200 different private laboratories at a charge that varies from $1 to $15 per test! With the same funds, one or two regional centers could test all infants for a dozen conditions and have more than half of the money left over to assist with medical follow-up and management.

If a continued search for these and other rare or obscure biochemical anomalies has (as yet) no "practical" value in the sense that they involve either diseases for which no treatment exists or a disease that need not be treated, it nonetheless seems to me to possess great scientific importance. I would say it has enough scientific value to encourage mass screening for as many biochemical anomalies as possible, always assuming that this can be done without dipping into funds needed for more urgent aspects of health care.

An obvious approach to this is to expand the "six-for-the-price-of-one" achievement that automation has already brought to screening into a "20- or 50-for the price-of-one" arrangement. Already our laboratory is working on several approaches to this goal, all of them involve not simultaneously testing several specimens from the same individual for different anomalies, as is done with the punch-index machine, but testing a single specimen simultaneously for several anomalies.

One possibility is a "multiple inhibition assay," involving the addition of two (or more) antimetabolic analogues to the culture medium in such concentrations that the culture would respond to *either* of the abnormal constituents if present in any specimen. Thus, if one added 4-azaleucine plus β-2 thienylalanine at appropriately low concentrations, the culture should, in theory, respond to either leucine or phenylalanine. Thus far, however, we have been unable to devise such tests in a form suitable for routine use.

Another, and currently more promising, approach involves two or more strains of *B. subtilis*, each one resistant to all but one of the inhibitors used. Again a response is predicted to any of several abnormal serum constituents. Yet another approach, which we call the "multiple auxotroph" test, again employs mutant strains, but this time each of the mutants requires a different amino acid for growth. A mixture of strains requiring, respectively, phenylalanine, leucine, and histidine, for instance, would respond to PKU, maple syrup urine disease, and histidinemia. A cardinal difficulty here is that the mutants can interact when mixed, for reasons still obscure, producing either inhibition or stimulation of growth. However, two such multiple tests appear promising.

In all these instances, of course, a positive response could mean any of the several conditions the test was designed to respond to, with differential diagnosis requiring further tests. These, however, would involve only a few score or at the most a few hundred specimens, as against the tens of thousands eliminated by the initial multiple screen.

Given the further development and perfection of multiple screening tests, mass screening can become not merely a way of rapidly detecting PKU and other treatable genetic diseases but also a source of invaluable information on biochemical differences in large populations. Given the fact that screening for PKU alone has proved itself not merely medically but also economically sound – which seems to me unarguable – we can (one hopes!) safely assume that specimens will continue to be collected by the hundred thousand and screened by one or another technique. And if that is the situation, it is surely only common sense to seek screening procedures that, for the same outlay, will yield steadily increasing "fringe benefits" of data on both pathologic and benign innate metabolic differences. □

Selected Reading

Allan JD, Brown IK: Maternal phenylketonuria and foetal brain damage: An attempt at prevention by dietary control. Some Recent Advances in Inborn Errors of Metabolism. Holt KS, Coffey VP, Eds. E & S Livingstone Ltd., Edinburgh and London, p 14, 1968

Guthrie R: Screening for "inborn errors of metabolism" in the newborn infant – a multiple test program. Birth Defects Original Article Series IV: p 92, 1968

Guthrie R: Screening for phenylketonuria. Triangle 9:101, 1969

Murphey WB, Patchen L, Guthrie R: Screening tests for argininosuccinic aciduria, orotic aciduria, and other inherited enzyme deficiencies using dried blood specimens. Biochem Genet 6:81, 1972

Proceedings of the International Symposium on Phenylketonuria and Allied Disorders, Tel Aviv, June 15-22, 1969. Cohen BE, Raicu MI, Sternberg A, Eds. Translators' Pool, Israel, 1971

MacCready RA, Levy HL: The problem of maternal phenylketonuria. Am J Obstet Gynecol 113:121, 1972

60-800 O - 75 - 3

Neonatal Screening for Phenylketonuria

I. Effectiveness

(Neil A. Holtzman, MD; Allen G. Meek; E. David Mellits, ScD)

Programs for the detection of phenylketonuria (PKU) were evaluated by surveys of health departments and PKU clinics. Effectiveness was measured by determining (1) the proportion of live births screened, (2) the occurrence of PKU infants missed by screening (false-negatives), (3) the proportion of presumptive positives in whom a diagnosis of PKU was confirmed by follow-up studies, and (4) the interval between screening test and follow-up.

More than 10% of infants with PKU are either not being screened or are not being detected by screening. Infants with PKU who are screened on the first 3 days of life are more likely to be missed than those screened later. The infants in whom a diagnosis of PKU was confirmed constituted only 5.1% of all infants with presumptive positive screening tests. Programs differ greatly in the incidence of presumptive positive tests and in the time necessary to follow up positive tests.—(JAMA 229:667–670, 1974)

The prevention of retardation due to phenylketonuria (PKU) requires initiation of a low-phenylalanine diet early in infancy before symptoms are manifest.[1] To accomplish this, most states in this country have laws that require screening of all newborns for elevations of blood phenylalanine values.

This study was undertaken to evaluate the effectiveness of newborn screening programs. An ideal program would detect all infants with PKU and a minimal number of false-positives. In addition, it would permit the initiation of treatment in time to prevent retardation. The attainment of perfection is beyond the scope of any program dealing with biological processes and their inherent variation. The findings, however, indicate imperfections in the programs that are amenable to change.

Source of Data and Methods

Questionnaires were sent to each state health department in the United States during 1970, as well as to departments in the provinces of Ontario and Quebec.

Information requested included:

1. Total number of infants screened.
2. Number of infants screened on each day of life during a one-year period.
3. Number of infants in whom results of routine screening were normal but in whom a diagnosis of PKU was subsequently made (false-negatives). This information was also requested in a separate questionnaire sent to PKU clinic directors.
4. Method of screening and upper limit of normal.
5. Number of infants with elevated levels of phenylalanine screening-test results. For each infant in which the test result showed an elevated phenylalanine level, the following was requested: sex, age at time of screening test and result, follow-up blood phenylalanine test result, and age at which result was obtained.
6. Number of infants being treated for PKU and having diagnosis as a result of screening.

Only four states were able to provide the information requested in items 2 and 5. One additional state provided an estimate of the number of infants screened on each day that was based on a sample of 1,000 infants from ten hospitals. Seven other states and two subdivisions of New York indicated that the individual results were available but could not be analyzed by local personnel. In order to obtain information in items 2 and 5, one of us (A.G.M.) visited these health departments and their screening laboratories. The number of infants screened on each day was determined from a random sample of 3,000 to 4,000 test results from among all newborn tests performed during a one-year period. The sample size was selected such that on any day of life the relative error of calculation would be no greater than 10%. (The formula was

$$RE = SD/p$$
$$SD^2 = \frac{N-n}{N-1} \times \frac{p(1-p)}{n}$$

[1] Holtzman NA: Dietary treatment of inborn errors of metabolism. *Ann Rev Med* 21:335–356, 1970.

where RE indicates relative error; SD, standard deviation; n, sample size; N, universe size; p, proportion of infants screened on a given day. When p is small, the equation can be simplified, SD=p/n. In order to limit the standard deviation to 0.0025, for a relative error of 10%, a sample size of 4,000 is needed when the smallest proportion of infants screened on any day of life is 0.025 of infants screened on all days [0.0025=0.025/4,000]). Birthweight and tyrosine level, if available, were also collected for all infants whose test results had elevated PKU levels during the same year.

Live births per year were obtained from the National Center for Health Statistics.[2]

Completeness of Screening.—In a one-year period between 1968 and 1970, 1,107,000 infants were screened in the 16 states providing information (California, Delaware, Georgia, Hawaii, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Montana, Nevada, New Hampshire, Ohio, Oregon, South Carolina, and Virginia). Each of these states has legislation requiring PKU screening. The infants screened comprise 88.8% of the live births. For individual states, the percentage screened ranges from 62.3% to 103%. The estimates are probably high because of the inclusion of some repeat tests. The southern states had the least comprehensive coverage.

Sensitivity of Screening.—The survey showed 23 infants from eight states whose initial test results were negative but who were subsequently proved to have PKU with maximum blood phenylalanine levels in excess of 20 mg/100 ml. Eighteen were screened by the Guthrie bacterial inhibition assay, three by fluorometric assay, and one by enzymatic assay. In one infant, the method was unknown. The states or clinics reporting these false-negatives reported, over the same time, 253 patients in whom the diagnosis of PKU was made as a result of screening. Therefore, in these states aproximately 92% of infants, with PKU were discovered by screening. This is a maximum estimate, as reporting of false-negatives is almost certainly incomplete.

Fifteen of the 23 false-negatives, or 65.2% were screened on or before the third day of age (11 on the third day and 4 on the second) although only 44% of all infants were screened by that age. This is a significance difference (chi square, $P<.05$). (Data on the distribution of infants screened on each day of life was supplied by four of the states reporting false-negatives and eight others.) Thus the probability of missing a case of PKU is greater if screening is performed early in the neonatal period. Further evidence is presented in Table 1. The incidence of PKU among infants screened after the fourth day of life is 1.6 times higher than among infants screened earlier.

Female infants predominate among the false-negatives (14:9). In view of the excess of male infants with PKU discovered by screening,[3,4] the finding supports the hypothesis that the discovery of PKU in female infants is more likely to be missed than in male infants.

Of 15 infants with false-negative tests in whom the type of feeding at the time of the first test was known, six were breast-fed (40%). Of 185 infants with PKU whose first test showed elevated levels of phenylalanine and in whom the early feeding history was available, 41 (22%) were breast-fed. This difference is not statistically significant.

TABLE 1.—DEPENDENCE OF PKU INCIDENCE ON AGE AT TIME OF SCREENING[1]

Group tested	Age at time of screening	
	0 to 4 days	More than 4 days
Infants with PKU	32	23
All infants screened	611,889	275,384
Incidence per 100,000 screened	5.2	8.4

[1] Data provided by health departments of Delaware, Georgia, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Nevada, New Hampshire, New York (Buffalo, New York City regions only), Oregon, South Carolina, and Virginia. The data is for 1 year between 1968 to 1970 except for Virginia which provided data for 1968 and 1970.

[2] *Vital Statistics of the United States: Summaries for 1969, 1970.* US National Center for Health Statistics, US Government Printing Office, 1970, 1971.

[3] Holtzman NA, et al: Neonatal screening for phenylketonuria: III. Altered six ratio: extent and possible causes. *J Pediatr*, to be published.

[4] Dobson J, Williamson M: Provocative observations in the PKU collaborative study. *N Engl J Med* 282:1104, 1970.

Presumptive Positive Screening Tests.—The vast majority of infants with elevated levels of phenylalanine on screening tests have normal blood phenylalanine concentrations by the time of follow-up. Among the 6,062 infants whose phenylalanine levels were elevated on the first test, 5,062 (85.0%) had a phenylalanine level of less than 6 mg/100 ml on the follow-up; 662 (9.9%), greater than 6 but less than 20 mg/100 ml; and 338 (5.1%), greater than or equal to 20 mg/100 ml. (This data was provided by the health departments in Alabama, California, Colorado, Connecticut, Hawaii, Maryland, Missouri, Nevada, New Jersey, New York [Buffalo and New York City only], Ohio, Ontario, Quebec, Rhode Island, South Carolina, Tennessee, Texas, Virginia, and Washington.)

The infants with phenylalanine concentrations between 6 and 20 mg/100 ml on the first follow-up fall into two categories based on additional determinations. The first category consists of those in whom moderate increases of phenylalanine will persist while on a normal diet but without risk of retardation.[5-7] (From other surveys,[8] one third of the infants fall into this category.) The second includes those in whom the phenylalanine concentration will fall within a few months. This group can be further subdivided into infants with and without associated tyrosinemia. Tyrosine concentrations were reported in 85 of the infants whose phenylalnnine level was between 4 and 20 mg/100 ml on the first follow-up examination. In 43.5%, elevated tyrosine levels (greater than 4 mg/100 ml) were reported. No tyrosine level elevations were found in infants whose follow-up phenylalanine value was greater than or equal to 20 mg/100ml.

Only 5.1% of infants with phenylalanine increases on screening had blood phenylalanine levels of greater than or equal to 20 mg/100 ml on follow-up and can be considered to have classical PKU. As 27.5% of these had phenylalanine levels on screening of 10 mg/100 ml or less,[9] any effort to improve specificity by raising the cutoff level above 4 or 6 mg/100 ml would result in greater failure to detect PKU, if all other factors were kept constant.

Time Before Follow-Up.—The length of time between screening test and follow-up may have some bearing on the prognosis. Kang et al[10] report that infants treated within the first 3 weeks of life have a better outcome than those treated between 3 and 6 weeks of age.

The mean interval between screening test and follow-up for 1,283 infants whose initial phenylalanine concentration was elevated was 24.9 days. In 22.6%, the interval was more than 30 days. The interval differed significantly in the 11 different programs providing data (Chi-square equals 196.431; degrees of freedom, 20; $P<.001$).

Variation in Incidence.—In the 31 states (and Ontario and Quebec) providing data, the mean ± standard deviation of all incidences of PKU was 6.7 ± 3.9/100,000 (n=495 phenylketonurics; range, 0 to 19.8/100,000). The mean incidence is close to that predicted from the frequency of the condition among institutionnlized mental defectives,[11] but the range is surprising. A number of factors contribute to this variation:

1. *Chance.*—For a disorder as rare as PKU, more infants will have to be screened in some states before the incidence is considered statistically reliable.

2. *Differences in Diagnostic Criteria.*—The incidence of PKU in infants known to have a blood phenylalanine level of 20 mg/100 ml or more prior to treatment was 5.3/100,000. The incidence of infants being treated for PKU at the time of the survey was somewhat higher, 6.4/100,000. Some treated infants might not have had blood phenylalanine levels of 20 mg/100 ml or more prior to treatment.

3. *Ethnic Variation.*—States with a large proportion of births in families of Irish[12] or Mediterranean descent[13] might be expected to have a higher incidence

---

[5] Berman JL, et al: Causes for high phenylalanine with normal tyrosine. *Am J Dis Child*, 117:54–66, 1969.

[6] Berman JL, Ford R: Intelligence quotients and intelligence loss in patients with phenylketonuria and some variant states. *J Pediatr* 77:764–770, 1970.

[7] Levy HL, et al: Persistent mild hyperphenylalaninemia in the untreated state. *N Engl J Med* 285:424–429, 1971.

[8] Cunningham GC: Phenylketonuria testing—its role in pediatrics and public health. *CRC Crit Rev Clin Lab Sci* 2:45–101, 1971.

[9] Holtzman NA, Mellits ED, Kallman C: Neonatal screening for phenylketonuria: II. Age dependence of initial phenylalanine in infants with PKU. *Pediatrics*, 53:353–357, 1974.

[10] Kang ES, Sollee ND, Gerald PS: Results of treatment and termination of the diet in phenylketonuria. *Pediatrics* 46:881–890, 1970.

[11] Jervis G: Phenylpyruvic oligophrenia. *Res Publ Assoc Res Nerv Ment Dis* 33:259–282, 1953.

[12] Cahalane SF: Phenylketonuria: Mass screening of newborns in Ireland. *Arch Dis Child* 43:141–144, 1968.

of PKU. Three states with relatively high incidences of PKU (Connecticut, Massachusetts, and Rhode Island) also had relatively high proportions of first and second generation Irish and Italians in their populations in 1970,[14] but for the other states, there was no correlation between the incidence and the proportion of first and second generation Irish or Italians in their populations.

4. *Variation in Laboratory Performance.*—Table 2 indicates the incidence of presumptive positive Guthrie tests among all infants screened at 3 days of age in those regions in which 3 days of age was the modal day of screening (with the exception of Massachusetts in which day 4 was modal and day 3 next). The high incidence in Massachusetts is partly explained by its use of a lower cut-off value (2 mg/100 ml) than the other states, which employ 4 mg/100 ml with the exception of Maryland, which uses 6 mg/100 ml. Despite this high cut-off, Maryland has the second highest incidence.

TABLE 2.—INCIDENCE OF ELEVATED PHENYLALANINE LEVEL ON GUTHRIE TESTS PERFORMED ON THE 3d DAY OF LIFE

State and year	Number of infants with elevated levels	Total screened	Incidence per 100,000
Kentucky, 1970	24	21,120	114
Maryland, 1968	38	25,180	151
Massachusetts, 1970	81	29,470	275
Michigan, 1968	9	80,140	11
New York-Buffalo, 1970	1	19,465	5
New York City, 1970	18	52,467	34
Oregon, 1968	4	15,893	25
South Carolina, 1970	4	12,615	32

This survey indicates four problems in screening effectiveness:

1. Infants Not Screened.—While virtually all newborns are screened in some states, fewer than 70% are screened in others. In the states providing data, there were 147,534 newborns who were not screened in the year covered by the survey. As the incidence of PKU, discovered as a result of screening, in these same states, in the same year, was 5.4/100,000, approximately eight infants with PKU were not screened. (Sixty-three were discovered by screening.)

2. Early Age at Screening.—There is a greater probability of detecting PKU if screening is performed after four days of age (Table 1 and Holtzman et al[9]). Unless it is acceptable to miss approximately 5% to 10% of PKU infants,

the time-dependence of the blood phenylalanine concentration of newborn phenylketonurics requires either that infants not be discharged from nurseries before 4 days of age or that those discharged early be screened after nursery discharge. Infants with PKU screened on the first four days of life whose screening test was positive had lower values on the screening test than those screened later.[9]

3. Delay in Follow-Up.—In some states, more than 60% of infants with elevated levels of phenylalanine on screening-test results were followed up within two weeks, whereas in others, fewer than 20% were followed up in that time. Irreversible brain damage might occur before diagnosis could be confirmed in the phenylketonurics and low-phenylalanine diets instituted. This problem is even more severe for disorders such as galactosemia and maple syrup urine disease in which death in the neonatal period is not unusual. Screening for these disorders will not prove beneficial unless rapid follow-up is assured.

4. Laboratory Performance.—The variation in the incidence of elevated levels of phenylalanine on screening tests (Table 2) suggests that noticeable differences in the performance and interpretation of the Guthrie bacterial inhibition assay test exists.

The problem of laboratory error is compounded by the fact that in some states more than one laboratory performs the test. In California in 1967, at least 194 laboratories performed screening tests.[15] Variability due to differences in labora-

[13] Efron ML: Classical and Mediterranean phenylketonuria, In Nyhan W (ed): *Amino Acid Metabolism and Genetic Variation*. New York, McGraw-Hill Book Co, Inc, 1967, 115–117.

[14] *1970 Census of Population: General Social and Economic Characteristics (PC[1]-C)*. US Bureau of the Census. US Government Printing Office, 1972. Table 49.

[15] Cunningham GC: PKU screening. *Calif Med* 10:11–16, 1969.

tory methods could be reduced if fewer laboratories performed the test and strict quality control was imposed. Several of the states reporting false-negatives did not have centralized screening or quality control.

In order to facilitate evaluation in future programs, states should agree on the information required and standardize the forms used.

[From Pediatric News, March 1975]

IMMUNOASSAY USED TO SCREEN NEWBORNS FOR HYPOTHYROIDISM

(*World Medical Reports*)

ST. LOUIS.—Every newborn in the Province of Quebec is now being screened for hypothyroidism by means of a recently developed immunoassay that can measure thyroxine rapidly and accurately on the fifth day of life. Dr. Jean H. Dussault reported at the American Thyroid Association meeting.

From the 49,000 measurements made so far, the frequency of neonatal hypothydroidism appears to be about 1 : 7,000, warranting such a mass screening program, said Dr. Dussault, of Le Centre Hospitalier de l'Université Laval, Quebec City.

Thyroid hormones are essential for normal brain development and growth. It would therefore be expected that early treatment of hypothyroidism could prevent the neurologic and mental deficits secondary to thyroid deficiency early in life, he pointed out.

However, because of the clinical difficulties involved in making the diagnosis of neonatal hypothyroidism, the disease is seldom detected before the third month of life, after irreversible central nervous system damage has occurred, he said.

USES THYROXINE ANTIBODY

The test Dr. Dussault described uses a specific thyroxine (T_4) antibody that can detect the hormone in eluate of dried blood spotted on filter paper.

In Quebec, almost every newborn is screened for multiple inborn errors of metabolism, and the blood is taken at the time of discharge from the neonatal unit. The spotted filter paper is sent to the Central Laboratory of the Quebec Network for Genetic Medicine, Dr. Dussault said.

The mean T_4 concentration obtained from the 49,000 measurements has been 1.60 ng/40 µl dried blood.

Whenever the T_4 value has been found below 0.4 ng, the subject has been immediately recalled for a new blood sample. If the concentration is between 0.4 and 0.8 ng, the measurement is repeated from the original filter paper and only then, if the value is still below 0.8 ng, is a new sample required, Dr. Dussault explained.

A total of 0.9% of the subjects screened have been recalled, he noted.

OBTAIN SERUM

Serum had to be obtained from 10% of this new population because of confirmed low T_4 values, and then the free thyroxine, triodothyronine, and thyroxine-binding globulin (TBG) were measured in the serum.

In this way, seven hypothyroid infants and three with abnormally low TBG have been detected, Dr. Dussault reported.

In all instances, the T_4 concentration in the eluate was below 0.3 ng, he said.

False positives have occurred in 0.9% of the measurements, and this is considered an acceptable number, equivalent to about 15 samples per week out of 1,800. It is almost impossible to obtain valid data on false negatives, but none is known to have occurred, Dr. Dussault said.

In sum, the immunoassay seems to be a method of choice for mass screening of neonatal hypothyroidism, at a cost of about 30 cents a sample, he said.

Dr. Dussault's associates in the study were Dr. Claude Laberge and Pierre Coulombe.

[From Medical World News, October 11, 1974]

Zeroing in on Hypothyroidism Much Earlier

For most hypothyroid infants irreversible brain damage begins at birth, and life is downhill from then on. But a new neonatal screening test, now being used in Quebec, pinpoints the disorder months—even years—before clinical symptoms normally appear, allowing for prompt treatment.

Endemic goiter is nonexistent in developed nations. But neonatal hypothyroidism—cretinism—strikes about one in 12,000 Quebec babies, Dr. Jean Dussault, the test's developer, told the American Thyroid Association meeting in St. Louis last month. Its primary causes are congenital underdevelopment of the thyroid gland and dyshormonogenesis—though many other confirmed cases remain unexplained. Its incidence is about the same as that of phenylketonuria, screening for which is mandatory in Quebec and in most of the U.S.

"On the basis of our present knowledge, hypothyroidism would be an excellent disease to test for in newborn babies," commented Dr. Harvey Levy, principal investigator at the Massachusetts Metabolic Disorders Detection Program. "It appears—and we don't know for sure—that the babies are born normal and then develop brain damage and other organic problems. Unfortunately, by the time a child is exhibiting enough clinical symptoms to be diagnosed by a physician, it's often too late for treatment. On the other hand, hormone therapy is simple and readily available. To minimize brain damage one would want to begin treatment as soon as possible after birth."

The new test, done a few days after birth, involves radioimmunoassay for the thyroid hormone, thyroxine, in a pinprick blood spot obtained from a newborn's heel. It costs only about 25¢ per test, since the spot can be made on the same filter paper used to test for phenylketonuria, galactosemia, and tyrosinemia at clinics like Laval University's central laboratory of the Quebec Network for Genetic Medicine, where Dr. Dussault works.

A normal infant's thyroxine concentration is about 1.6 ng/40 μl of dried blood. When the Quebec laboratory detects a reading less than half that, the original sample is retested. If the first reading is less than 0.4 ng, the infant is immediately recalled for a new blood sample. In either case, if the second reading is again below 0.8 ng, the infant returns to the Laval University clinic for four further thyroid function tests. At the present level of efficiency, Dr. Dussault says, a hypothyroid infant can be discovered and began on hormone treatments within the first month of life.

Since last April the Laval University clinic (one of three using the test in Quebec) has screened about 55,000 neonatal blood samples, discovering seven infants with neonatal hypothyroidism. The assay has the desirable fault of oversensitivity. Of the first ten positive results only six turned out to be true abnormalities on further testing, and to Dr. Dussault's knowledge there have been no false-negatives.

The procedure has also been used on an experimental basis by physicians in Toronto. After screening about 1,300 infants at the University of Toronto's Mt. Sinai Hospital, the Toronto team has confirmed the test's accuracy. In their study, four of the 38 infants who had positive results were abnormal on retesting, and one of these was truly hypothyroid, reports Dr. John O'Donnell, one of the Toronto investigators.

"As soon as we can get the financial support, we hope to set up a testing program in Toronto and eventually on a provincewide basis," adds Dr. Paul Walfish, director of Mt. Sinai's endocrine division.

American neonatologists are also eager to try the new test—but there are complications. Not used before in the U.S., the screening program is still considered experimental by most hospitals, even though the same pinprick provides blood for mandated PKU tests in some states. Dr. P. R. Larsen and a team at the University of Pittsburgh began using the test last month on about 500 newborn babies. "One problem we have is getting a consent form signed for every sample we obtain," he told MWN. "It's quite time-consuming."

Developing and implementing neonatal screening tests will be easier in Canada than in the U.S., Dr. Levy feels, until this country develops a more centralized screening system. "We need fewer state labs and more regional labs," he comments. "The system we have now is wasteful and inefficient."

"Lots of times it's difficult to convince the government on a purely humanitarian basis," adds Dr. Larsen. "What we have to do now is show on an economic

basis that the cost of screening, say, 10,000 infants to find one with hypothyroidism is so low that it's much better than the alternative—hospitalization in a state mental institution."

[From Pediatric News, March 1975]

WOULD SCREEN INFANTS FOR HYPOTHYROIDISM

World Medical Reports

WINNIPEG, MAN.—All neonates should be screened for hypothyroidism because early diagnosis can lead to prevention of mental retardation in affected children, Dr. Paul G. Walfish said at the annual scientific meeting of the Canadian Society of Endocrinology and Metabolism.

Neonatal hypothyroidism appears to be the most common endocrine-metabolic cause of mental retardation: its incidence is about twice that of phenylketonuria (PKU), said Dr. Walfish, of the University of Toronto, Mount Sinai Hospital.

A mandatory screening program in the province of Quebec employs the determination of thyroxine activity in dried capillary blood obtained from a heel prick, Dr. Walfish reported at the meeting.

"In my view, newborn thyroid screening in this country is inevitable, and it is only a question of how it will be organized," Dr. Delbert Fisher said in an interview with this newspaper.

Dr. Fisher is chairman of an ad hoc committee of the American Thyroid Association on newborn thyroid screening, and professor of pediatrics and medicine at the University of California School of Medicine, Los Angeles.

The committee has currently adopted a policy of observation and study of the pilot programs that are now in existence, he said.

There are pilot studies in Pittsburgh and Boston to evaluate the dried capillary blood method that was originally described by Drs. Jean Dussault and Claude Laberge, of the University of Laval, Quebec.

This technique, currently in use in the mandatory program in Quebec, can detect neonatal hypothyroidism and other causes of low serum thyroxine, but there are methodologic limitations that contribute to a high rate of false positive results, Dr. Walfish reported at the scientific session.

Another method, which appears to be more accurate, measures the level of thyroid stimulating hormone (TSH in cord blood obtained at the time of placental separation. This approach was first reported in 1974 by Drs. Klein, Agustin, and Foley, of the University of Pittsburgh, Dr. Walfish said at a press conference after his presentation.

The dried capillary blood method was used to screen 3,000 infants in Mount Sinai Hospital. Of the children screened, 93 were selected for follow-up on the basis of low thyroxine levels, a follow-up rate of 3%.

Of these 93 children, 88 were found on further testing to be normal, having had false positive results. Only five children had confirmed low serum thyroxine levels.

Causes of low thyroxine levels included three patients with congenital thyroxine binding globulin deficiency, one with neonatal hypothyroidism, and one with drug-induced hypothyroidism in an infant whose mother was taking propylthiouracil.

The false positives are the result of sampling and collection errors, errors induced by high hematocrit, and other methodologic factors. Maternal drug ingestion and thyroiditis also contribute to false positives.

Fetal prematurity and twinning can contribute to initial low thyroxine levels, but there is usually spontaneous recovery.

"For adequate sensitivity and prevention of false negatives, we feel that the dried capillary blood method requires a 2–3% high follow-up program," Dr. Walfish said.

Preliminary results show that the determination of TSH in cord blood is a more definitive screening test for neonatal hypothyroidism, Dr. Walfish said.

There is a clear elevation in cord blood TSH levels that is unequivocal in infants with hypothyroidism.

Of 600 babies screened, only 1 had to be recalled for a possible underactive thyroid gland, and that baby did have the disorder. There were no false positives, he noted.

The problem that remains with the TSH test is one of logistics. The serum samples must be obtained under proper conditions and transported to the central laboratory for testing. Lowering the rate of recall of infants may be a factor in matching the additional cost of transporting the serum samples.

LIFELONG THERAPY

Special learning programs or institutionalization of these children should also be taken into account in a cost/benefit ratio of the screening test, Dr. Walfish commented.

The disease usually is not inherited and occurs sporadically, so it is not possible to identify a high-risk population and screen only those children.

If treatment is begun before the infant is 3 months old, there is a 70–0% chance that the baby will reach a normal IQ. If treatment is delayed beyond 6 months, the baby will have a 90% chance of being mentally retarded, he said.

The children will require lifelong therapy with thyroid hormone but this is simpler than the special diets required after identification of children with PKU. There is currently no major PKU screening program on a national basis in the United States, Dr. Walfish said.

CENTRAL QUALITY CONTROL

The screening programs for PKU in the United States are mostly state-based and require each individual physician to ensure that testing is done. There is therefore no central quality control of the laboratories doing the testing, and no guarantee of follow-up and treatment, Dr. Fisher said in an interview with this newspaper.

This is the wrong way to approach the problem, he said.

The province of Quebec has set up a central laboratory in which there is quality control and feedback to physicians. A screening program in the United States should be efficiently and appropriately managed so that maximum use of samples for multiple testing, quality control, and follow-up are built into the system.

Regional, governmentally supported screening laboratories (state or federal) would meet these requirements and provide a structure for incorporating future screening methods, Dr. Fisher said.

Dr. Walfish's associates in this study were Dr. J. O'Donnell, and A. Frankl and G. Shachter.

[From the Lancet, Aug. 23, 1975, p. 356]

MASS SCREENING FOR CRETINISM

Neonatal feeding difficulties confront the paediatrician daily. Common causes include birth shock, infection, and jaundice; but, along with constipation and respiratory troubles, feeding difficulties may be the presenting clinical feature of hypothyroidism. The classic cretinous facies is seen in only a quarter of cases diagnosed before three months, the proportion increasing with increasing delay in replacement therapy.[1]

Cretinism is a rare cause of mental retardation but a treatable one. It can be easily missed until later in the first year of life, and early replacement therapy is unfortunately essential. In a Great Ormond Street series,[1] 14 out of 19 children diagnosed and treated before three months of age had I.Q.'s over 90, whereas only about a third of those treated later reached this level. These findings are borne out by Klein and his co-workers.[2] Eayrs [3] has shown that thyroxine is essential for brain maturation in prenatal and early postnatal life and only small amounts of thyroxine cross the human placental barrier.

In the neonate there is acute release of thyroid-stimulating hormone (T.S.H.) during the first hours of life, causing an increase in all indices of thyroid function.[4] Serum protein-bound iodine, butanol-extractable thyroxine, ^{125}I-triiodothyronine uptake in erythrocytes or resin (T3 tests), dialysable thyroxine, and ^{125}I uptake in the thyroid gland should all be raised—i.e., the normal infant is hyperthyroid. Rogowski and co-workers [5] report that the rise in dialysable

[1] Raiti, S., Newns, G. H. *Archs Dis. Childh.* 1971, 46, 692.
[2] Klein, A. H., Meltzer, S., Kenny, F. M. *F. Pediat.* 1972, 81, 912.
[3] Eayrs, J. T. *Br. med. Bull.* 1960, 16, 122.
[4] Utiger, R. D., Wilber, J. F., Cornbathy, M., Harm, J. P., Mack R. E. *F. clin. Invest.* 1968, 47, 97.
[5] Rogowski, P., Riersboek-Nielsen, K., Hansen, J. M. *Acta paediat. scand.* 1974, 63 201.

thyroxine parallels the rise in total thyroxine; therefore the increase in plasma-thyroxine is not caused by an increase in thyroxine-binding proteins, as has been suggested.[6]

Until lately only small series of infants have been studied, because of the quantity of blood needed for macromethod testing of thyroid function. But now micromethods permit testing of large numbers. The series of Dussault et al.,[7] in Canada, is the largest so far. 47,000 newborns have been studied by a cheap, reliable micromethod using the T4 test, which has revealed an incidence of hypothyroidism of 1 in 7000. In a smaller series from the U.S.A., Klein and others[8] used a T.S.H. screening procedure and found an incidence of 1 in 500, which they compare with the incidence of phenylketonuria in the United States—1 in 14,300. These figures present a serious case for routine screening.

Mr. SEGAL. I have one question for Mr. and Mrs. Maguire.

Could you describe very briefly the kinds of trauma and difficulties in having children with problems of this sort in terms of normal everyday activities that you encounter?

Mrs. MAGUIRE. The biggest problem is they all could have been well because of the diet. It is really not easy to have to visit your child at a State institution, either. I really don't know what else you can say.

Mr. MAGUIRE. What I think my wife would like to say is that if this is found out at birth they have a diet. Lofenalac, which is low in protein but has just enough protein to supply the daily requirement.

In our son William's case, he was on a high-protein diet and he was on a regular normal diet which was high in protein. So, this accelerated the disease. If this diet had been followed and adhered to, as we would have done for the first 5 years of life, after that you could drop it and they would be normal.

Mr. OTTINGER. Mr. Wunder.

Mr. WUNDER. No questions, Mr. Chairman.

Mr. OTTINGER. Thank you very much, Mr. and Mrs. Maguire, for being with us.

Mr. HAGERTY. Mr. Chairman, you will hear some success stories during your hearings about early screening and the effect of it in prevention. Here we don't have that because of lack of early screening.

One more important thing here was the lack of uniform testing; the quality of testing is at issue here, of course.

We have the parents of three retarded children who economically will be disastrous over the lives of these people. The institutionalized child represents an annual cost of $20,000 and going up annually for institutional care for that one child.

The cost of this child in special education is four times what it would be for a child in normal education.

Those kinds of costs can be projected for these three children for this family, either tax dollars of the individual family, itself.

Mr. OTTINGER. What kind of facilities were available for the Maguires in their community?

The children were born in the hospital.

Mr. HAGERTY. Mr. Chairman, you would think the facilities were adequate to meet the problem and diagnose it early enough and treat it. In fact, one child was born after the passage of the mandatory PKU statute in Pennsylvania. That is why it is so difficult to under-

[6] Chadd, M. A., Gray, O. P., Davies, D. F. *Archs Dis. Childh.* 1970, 45, 374.
[7] Dussault J. H., Coulombe, P., Laberge, C., Letatle, J., Guyda, M., Khoury, K. *Pediatrics*, 1975, 86, 670.
[8] Klein, A. H., Agustin, A. V., Foley, T. P. *Lancet*, 1974, ii, 77.

stand why these failures occurred. But it occurred because of a lack of uniformity in testing and a lack of, as the doctor testified to earlier, the outreach programs being monitored properly at the national level.

That brings us to grips with what our national priorities are and how can we effectively see the dollars put forward so that these agents in Washington can be used to the best advantage. I don't propose we should go the route of taking moneys from another department and penalizing the State at all.

I do propose fast coming to grips with the States versus a Federal system problem of priorities and how to deal with them.

Mr. SHARP. Could I ask counsel further: It disturbs me, although I understand prior to having the testing there was no way to discover about the first child, but the same problem with the second and third child bothers me more because obviously actions had been taken in the interim. Is there any system in that hospital or in the State of Pennsylvania whereby records are kept so that one would be more attentive to this problem if it ran in the family or something of that sort?

Maybe I don't understand the disease.

Mr. HAGERTY. I assure you, Mr. Sharp, that after this case went to suit that they are keeping records now that they did not keep before and they are much more attentive to the problem.

But, because of the lack of monitoring, the delivery of the testing, and because of the ongoing review of the cases as the prior witness testified, the doctor from Washington here, this is a child who fell between the gaps even after we had mandatory legislation for PKU screening.

When a small county like Delaware County decides it wants to do its own lab testing and does not have the facilities or the number of testings per week or per day that Children's Hospital in Philadelphia would have, it tends to let the testing device lie until they have enough to send to the lab. That kind of slipshod method lets this thing occur.

Mr. SHARP. Is your impression that the testing apparatus did not work properly or just that even if it worked properly the child would have to be reexamined at some other date?

Mr. HAGERTY. Mr. Sharp, I defer to trial counsel.

Mr. MCDONNELL. I am going to have to object to that. That may well be one of the issues in the civil litigation in which we are involved. I would prefer that it not be answered by myself or opposing counsel with your indulgence.

The economic well-being and entire future of these people are involved and significant ongoing civil litigation obviously is the reason for our appearance today.

Mr. OTTINGER. We certainly would not want to interfere with that litigation.

Mr. SANTINI. Thank you, Mr. Chairman.

The disturbing implication of this kind of testimony is, to my mind, as a father of a child who was born with a birth defect, how many children do we have in State institutions throughout this land who, with proper screening, as Dr. Green suggested, would not be there at all?

Have there been any investigations by the Department of Health, Education, and Welfare to answer that kind of question?

Mr. HAGERTY. Mr. Santini, the population of State institutions, the facilities for retarded, epileptic or cerebral, is approximately 210,000 throughout this country. The doctor testified approximately 10 percent of those could have been caught in early screenings, as you are aware.

The majority come from socioeconomic, deprived areas such as the lead poisoning that you heard about, when the child eats lead paint, and that can result in brain damage, and poor diet control in socioeconomic areas.

You have 210,000. Ten percent of those would probably not have occurred and would not be permanent if early screening were used.

Mr. SANTINI. What is the cost factor for maintaining, if there is a national average, one child in a State institution for 1 year?

Mr. HAGERTY. Mr. Santini, I can't talk of the national average. Pennsylvania is $20,000 per child.

When the mandatory regulations go into effect, which are presently before HEW, it is my opinion the costs will increase by five to $100,000 per child per year.

Mr. OTTINGER. We will have representatives from the Department of Health, Education, and Welfare before us tomorrow.

Of course, we have with us today, who is more knowledgeable in this area than anybody else I know, Dr. Cohen, whom we will hear from later today.

Mr. MCDONNELL. Mr. Chairman, to give you a key to the seriousness of the incidence of this particular disease, this is the most single inherited retardation disease which is curable in the Unted States.

In other words, this is a totally curable disease. There is no reason why any of these three children should have had mental retardation.

Mr. OTTINGER. I want to thank you very much. I know it must have been difficult for you to come here, Mr. Hagerty and Mrs. Magnire. But I think you will be of help to us in trying to prevent this kind of problem for other families in the future.

We do appreciate your being here.

Mr. MCDONNELL. Thank you.

Mr. OTTINGER. Our next witness is Dr. Gerald Hass, Boston, Mass.

He also had with him a family that has experience in this case vision problems attributable to lack of screening.

Dr. Hass, we appreciate your being with us. If you could also submit a statement for us we would be glad to receive it. You proceed as you feel best.

Introduce the family that is with you. Thank you for being with us.

STATEMENT OF GERALD HASS, M.D., PHYSICIAN IN CHIEF, SOUTH END COMMUNITY HEALTH CENTER, BOSTON, MASS., ACCOMPANIED BY MRS. JOVITA FONTANEZ AND MELINA FONTANEZ

Dr. HASS. Thank you, Mr. Chairman.

I should like to introduce Melina Fontanez on my left and her mother, Jovita Fontanez.

Mr. Chairman, members of the Subcommittee on Oversight and Investigation, thank you for the opportunity for appearing before you.

My name is Gerald Hass and I am a practicing pediatrician and physician-in-chief of the South End Community Health Center in

Boston, Mass. With my colleagues, I take care of 9,000 children in the inner city of Boston. Most of these children are recipients of medicaid.

I have been practicing medicine for 17 years, am on the teaching faculty of Boston University and Harvard Medical School and I am a fellow of the American Academy of Pediatrics.

In 1969, together with a group of people in search of better health care for their children my colleague Mel Scovell and I designed and founded a neighborhood health center. The South End Community Health Center has for the past 6 years delivered care to a mixed ethnic inner-city community including 70 percent Spanish-Americans. In 1975 it was voted the most outstanding health center in Massachusetts.

Our source of funds are principally medicaid earned by seeing patients.

We are proud of the fact that we are fiscally solvent and this we owe to the skill and management expertise of our cofounder Mel Scovell, who is now the head of the Massachusetts medicaid program and is a recognized national authority on the management aspects of the delivery of health care.

Your invitation to me specifically requested that I would bring with me today a patient who would illustrate a medical problem that would show you a real life situation and how it was handled in our health center.

Melina, who is with me now, is 12 years old next week, and she was one of our first patients. She had a condition called lazy eye blindness, the medical name for which is amblyopia and I am happy to tell you that she now has excellent corrected vision in both eyes.

Melina's problem was first noted by a school vision screening program and she was referred into a hospital eye department. She unfortunately did not follow through at the hospital but the condition was again picked up because by this time she was in regular pediatric care in our health center and vision testing was a part of our care. We made sure that she followed through by having her seen by an eye specialist and we emphasized the importance of wearing her glasses which would correct her condition.

Because we found many similar gaps between diagnosis and treatment of eye conditions we developed our own eye care service within our health center. We brought together optometrists and ophthalmologists working closely with other health professionals so that children and adults could receive the whole range of vision services. We performed screening, diagnosis, and treatment.

Melina was in a system of care that was able to treat her condition as well as making sure that she followed through, because she attended for all her health needs. This is called comprehensive care.

Melina's mother became very much involved with the health center eventually becoming the president of our governing board. Through her concerns for her child's health care she developed a real understanding of the meaning of comprehensive care and the importance of a continuous relationship between a family and their source of health care.

Dr. James Hughes, a pediatrician in Norwich, Vt., in his recent letter to the chairman of the Oversight and Investigations Subcommittee, referred to the concept of every child's having a medical home.

This concept is vividly exemplified by Melina, who untreated would have lost vision in one eye. Fortunately, Melina had a medical home in our health center which took responsibility for her total health care.

We have seen many examples of this concept. A boy of 10 with a cleft palate untreated because of his parents' fear of hospitals, several girls untreated with known urinary tract infections, dozens of infants with anemia and children with mental retardation.

These examples are not unique to our health center. They are common problems in children everywhere, and they need to be treated.

The responses of many Federal planners to these problems have been to develop programs that fragment rather than consolidate care. Federal legislation for early and periodic screening, diagnosis and treatment (EPSDT) was intended to address the health problems of medicaid children.

EPSDT forces States to separate screening from diagnosis and treatment by its reporting and tracking requirements.

The establishment of screening programs with referral for detected diseases may be the easiest way to develop statistics but is not the kind of health care we would want for our own children.

In those States where EPSDT represents a new and higher standard of care, one would support the imposition of EPSDT. In Massachusetts, however, a literal interpretation of EPSDT would result in fragmented and lower standard of care.

I believe that a State that has the resources to provide a medical home for every child should not be forced to set up a separate and less than equal health care system for its medicaid children.

Melina was fortunate because her condition was diagnosed and treated. On a nationwide scale there are very many children who have not been treated for their known health problems.

The American Academy of Pediatrics is currently focusing on the status of maternal and child health programs in the United States. Their findings bear out what I have expressed to you. I would recommend their report to your subcommittee with other material which documents my opinions in more detail.

Thank you for your interest and consideration.

Mr. OTTINGER. Thank you very much, Dr. Hass.

I am very interested in what you say.

The administration of this EPSDT program is not done in conjunction with neighborhood health centers in which diagnosis is available immediately to the people whose problems are detected through screening; there is a separate screening process that is initiated; is that correct?

Dr. HASS. In many States this has been the way that EPSDT has been delivered with its accept on screening and then referral elsewhere.

This sets up a fragmented health care program. In Massachusetts, we have been very fortunate to try to include the screening diagnosis treatment all at one stop where the patient is under routine regular care and where all the components are together. This we call health care.

Now, the problem has been that the Federal regulations for EPSDT demand screening statistics. If you don't screen; that is, if you look after children properly by giving them proper health care, you can't deliver screening statistics.

Your own committee sent out a questionnaire asking for screening statistics. That was a very tough questionnaire to answer if you look after children instead of screening them.

You see, this is a paradox. As a consequence, we in Massachusetts are potentially in danger of being penalized because instead of screening we provide comprehensive health care.

But we recognize that EPSDT is an attempt to involve States in providing care and we think that in concept it is a good idea; it is the way that it is carried out that gives us great concern.

Mr. OTTINGER. Mr. Scheuer.

Mr. SCHEUER. No questions, Mr. Chairman.

Mr. OTTINGER. Mr. Sharp.

Mr. SHARP. No questions, Mr. Chairman.

Mr. OTTINGER. Mr. Santini.

Mr. SANTINI. No questions.

Mr. OTTINGER. Counsel?

Mr. SEGAL. I would like to ask, Dr. Hass, what would have been the consequences if the lazy-eye problem of Melina was not treated?

Dr. HASS. Melina would have suppressed the vision in one eye.

After a period of time, probably 10 to 15 years, she would have been essentially blind in one eye.

You may think that is not necessarily a problem because you always have one good eye. The problem arises if something should happen to that good eye in which case she would have been completely blind. Yet this is a completely reversible and curable condition if detected early. That would be under the age of 10 and preferably under the age of six. It is like PKU. It is something that is a sure-fire disease to pick up early with a superb o[illegible]

Mr. SEGAL. How preva[illegible]this? Out of approximately 11½ million children who were not s[illegible]reened last year, how many might you expect to be children with lazy eye?

Dr. HASS. The figures that are given are at least 6 percent of childhood population.

Our figure in our health center is somewhat higher than that. It is probably around 8 to 10 percent.

It is a familiar condition, by the way, and can be detected in families.

Mr. SEGAL. So you are talking about approximately, if extrapolated, 600,000 or 700,000 children out of the unscreened population who might be expected under normal epidemiological factors to have this disease?

Dr. HASS. The figure would be of that order.

Mr. SEGAL. Thank you.

Mr. OTTINGER. Mr. Wunder.

Mr. WUNDER. Dr. Hass, you mentioned in your statement a boy with a cleft palate whose parents were afraid of doctors. Is that a big part of the problem in light of the fact that we have volunteer programs now that there is reluctance on the part of parents to bring in their children and how do you get at a problem like that?

Dr. HASS. I am happy to tell you that we worked very hard with this family and were able after something over 6 months of intensive friendly persuasion, to be able to get this child operated on.

I saw him recently at 16. His palate is superbly closed, his speech is good. I think it is a relatively minor problem compared with nonaccessibility of health care.

The reason I raised this example was that education, understanding, and trust are essential parts of comprehensive health care. You get to know your patient.

If a child is being screened in ESPDT, being screened by perhaps a paraprofessional and different person every time, they may never build up the rapport and trust that is necessary.

My answer to your question is that I don't think they had the opportunity of ever having good health care so they never learned to trust anybody.

We found this particularly in a migrant population who have never had the opportunity of good care.

I think you have to deliver the good care to make sure that the things that are screened are taken care of. I agree, you have to screen, but that should be part of the care; otherwise, you are doomed to failure.

Mr. SEGAL. Thank you, Dr. Hass.

Thank you, Mr. Chairman.

Mr. OTTINGER. I wonder if Mrs. Fontanez or Melina have anything they would like to add, having taken the trouble to come.

Mrs. Fontanez, could you give us a statement in terms of how the health care system is available to you and what you feel as a parent ought to be done to improve the situation?

Mrs. FONTANEZ. I think a migrant family, a poor family, and probably working poor because we are not just speaking in terms of medicaid patients, we are speaking of working poor who might not be able to afford health insurance. This screening and health care that goes on at a health center level in a community setting is very important. There are many folks who, because of language problems, do not trust the university hospitals or city hospitals because of the care they have gotten during the past; they are very distrustful.

The health community setting has community people working there and in our particular health center we have bilingual people.

You form a friendly atmosphere so that you do not feel harassed if you come there or if you come late or if you may not come on your appointment date.

We try to make sure that the people come on their appointment date. Many times people have other priorities come up, working, going to school, whatever. I believe that health centers are the only way to provide good health care.

Mr. OTTINGER. Is Dr. Hass' health center available in your community?

Mrs. FONTANEZ. Yes; just down the street from me.

Dr. HASS. I think Melina wants to say something.

Ms. FONTANEZ. I want to thank the health center because if it was not for them, I would be blind right now in one eye.

Dr. HASS. Thank you, Melina.

Mr. OTTINGER. We are very glad too, Melina.

Thank you all for being with us today.

Dr. HASS. Thank you.

Mr. OTTINGER. Our next witness will be a member of the full committee, our distinguished colleague, Congressman Ralph Metcalfe.

We welcome you before the subcommittee. We will be pleased to have your testimony.

STATEMENT OF HON. RALPH E. METCALFE, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ILLINOIS

Mr. METCALFE. Mr. Chairman, I would first like to congratulate you and the members of the subcommittee for holding these hearings today. Preventive child health care, and particularly the EPSDT program, is among the most necessary, and sadly, most ignored, of all health programs.

The importance of preventive health care for children, and especially for poor children, cannot be overestimated. We have today literally millions of young people who are suffering from a desperate lack of medical attention.

A recent study in New York State, for example, reports that as many as 40 percent of the children in school there have not received necessary polio and rubella vaccinations.

Hundreds of thousands of children suffer hearing and eyesight problems which affect their achievements in school, yet are untreated because they have been undiagnosed.

Many children suffer serious dental problems which will cause them great suffering in later life but which are untreated because they too are undiagnosed.

The apparatus for dealing with these and other child health care problems exists, Mr. Chairman. We are not confronted with the laborious and time consuming process of writing new legislation.

The Congress, in 1967, saw the need for preventive health care and, as amendments to the Social Security Act, enacted the early and periodic screening diagnosis and treatment program. The program called for the Federal Department of Health, Education, and Welfare to establish this program of health screening and treatment for between 10 and 13 million eligible children.

The legislation, Mr. Chairman, required that this program be implemented by July 1, 1969. It was not implemented by July 1, 1969 or July 1, 1970 or 1971 or 1972. In fact, the program has still not been fully implemented.

HEW did not only not implement the program by July 1, 1969 as required by law, they never even issued regulations for the program until February, 1972—more than 2½ years after the deadline required by Congress for full implementation.

This needless and irresponsible delay on the part of HEW dealt a blow to this program from which it has not yet fully recovered.

The States, in their concern for the cost of the program, made little or no effort to implement EPSDT as long as HEW in Washington practiced its policy of benign neglect toward the program and toward the health needs of more than 10 million children.

In 1972, I requested that the U.S. General Accounting Office investigate the EPSDT program to determine the extent of its implementation in my home state of Illinois and throughout the Nation.

In January 1975, the GAO issued their report. Their findings and conclusions made clear that, despite the law and despite the obvious human need that the program could serve, HEW all but ignored the existence of EPSDT for more than 5 years.

The GAO reported that, by the end of fiscal year 1973, of the more than 1.8 million eligible children living in eight sample States, less

60-800 O - 75 - 4

than 58,000 had received even the minimum screening as required by the law. This was a screening rate of about 3 percent or, to put it another way, more than 97 percent of the eligible children in these eight States did not receive the preventive care mandated by act of Congress more than 6 years before.

I should note here that the GAO statistics referred to 58,000 different children who had been screened, for the most part, only one time in the 4 year period since the program was to have been implemented.

A screening manual developed by the American Academy of Pediatrics under a grant by HEW specifically for EPSDT recommends that, for preventive health care to be truly effective, seven complete physical examination are necessary in the first 25 months alone of a child's life. This same manual recommends additional complete examinations be provided approximately once every 2 years thereafter.

In other words, where the GAO indicates that 3 percent of the eligible children had been screened once in the first 4 years of the program, HEW's own manual recommends to the States that as many as eight separate examinations be provided children in that same period.

To my knowledge, no one, not one single child, has been screened that many times in the EPSDT program.

It should be noted that the GAO reported on screenings, or preliminary physical examinations, only. The States and HEW were unable to provide the GAO with any figures on how many of those children had actually been treated for illnesses diagnosed during those screenings.

In sum, then, the GAO reported that 3 percent of the eligible children in this country had received the minimum, limited care under this program.

Statistics which HEW has recently made available show that, in fiscal year 1975, EPSDT has shown some improvement. If these figures are accurate, and I must seriously question whether or not they are, the EPSDT screening rate has improved to around 12 percent this year. In other words, of the 13 million eligible children around the country, there were about 11½ million who still received no care at all under the EPSDT program in fiscal 1975.

The question we must ask is how?

How could a program this important fall victim to insensitivity, disinterest, and bureaucratic ineptness?

HEW, for the first years of the program's existence, acted as if the program wasn't even there. Whether this was a deliberate flaunting of the law or simple incompetence, I do not know.

I do know that during the previous administration the deliberate sabotage of social welfare programs was a common and often stated policy. I would not be at all surprised if some of those at HEW attempted to do to this program what was done to OEO during those same years.

Deliberate sabotage or not, HEW clearly did not provide the States the necessary guidance for implementing EPSDT. It was not until 1975 that HEW provided the States with screening manuals to assist them with the technical aspects of the program.

Many States have had serious problems in providing effective outreach to inform parents of the need and availability of preventive health care. HEW has not provided incentives to the States for improving this all important service.

States have also made poor use of available health care personnel. Many States have insisted on using physicians for all aspects of the EPSDT program although it has been shown that public health nurses and other allied health professionals can perform many screening functions at less cost and to many more children. Here, too, HEW has not provided the all important technical assistance necessary to train and properly use allied health professionals.

HEW has, in fact, been unable to even effectively monitor the progress of the program.

HEW is obliged by Federal law to penalize those States which have not provided effective outreach and screening programs. The law states that this penalty is to be 1 percent of the Federal share of Aid to Families With Dependent Children (AFDC) funds.

This summer, in fact, HEW did penalize eight States a total of more than $3 million. These penalties were assessed in the same inept manner as the rest of the program had been administered, however. No recipients were even interviewed by the HEW regional office staffs charged with monitoring the program. No accurate statistics were ever compiled. In fact, there seems to be no rhyme or reason for the assessment of many of these penalties.

My home State of Illinois is a case in point.

Although the HEW region V office in Chicago recommended Illinois be penalized for noncompliance, its investigation was so shoddy and poorly documented that HEW General Counsel's office in Washington had to recommend that the penalty not be assessed until the regional office could get its information straight.

These are but a few examples of the kind of incompetence that has marked HEW's administration of the EPSDT program.

It has shown by its own example that preventive child health care is low on the list of priorities and the States, sadly, have followed that example.

In the past year, former Secretary Weinberger began to call the program one of his top priorities. Unfortunately, this change in rhetoric was not accompanied by a change in actions.

We must make clear exactly who at HEW has been responsible for the failure of EPSDT. It has not been those persons directly responsible for the program who have wrecked it over these past 6 years, rather it seems to have been higher level officials of the Social and Rehabilitation Service and the Medical Services Administration and those officials of the HEW regional office around the country who have so badly damaged this program.

I do not know if this attitude will carry over to the administration of Secretary Matthews. I hope not. If it does, I hope that the Congress will make it abundantly clear to the administration that we will not stand for such flaunting of law and the will of Congress.

It is time that the executive branch understand that they, too, have an obligation to obey the law.

I would like to conclude by briefly talking about the cost of this program—both in human terms and in purely financial ones.

Unfortunately, the GAO was unable to provide me with a comparative cost analysis of the EPSDT program.

HEW, itself, however, has recognized that the program will in the end provide a net saving to the Government in its efforts to provide health care to low-income children.

Keep in mind that the 13 million children eligible under this program are eligible for other medicaid services as well. If the Government does not provide them preventive health care now, it will sooner or later be responsible for providing them with treatment for illnesses which did not even have to develop. Dr. Eli Newberger of Childrens Hospital in Boston and one of the Nation's most distinguished experts in the field of child health care, has estimated that a complete preventive child health care, from the time a mother is 6 months pregnant to the time the child is 16 years old would cost about $1,000 per child. Compare that with the current rate of hospital care and the current cost of drugs. That $1,000, which could go a long way toward keeping a child healthy for his entire life, would not even pay for 2 weeks confinement at a hospital at today's prices.

In terms of pure economics, which we hear is of primary concern in these days of talk of Federal deficits and inflation, this program can represent a substantial savings to the cost of child health care.

On human terms, and we must not forget that we are talking about the health and well being of 13 million children, the cost of this program's failure is incalculable.

The cost to our society in children who cannot complete school simply because they cannot see the blackboard or clearly hear their teacher is enormous. There are hundreds of thousands of children in this country who will have no chance of making it in society only because they suffer from easily treated, but undetected, physical impairments.

Two sets of statistics provide a valuable insight into just how badly preventive child health care programs like EPSDT are needed.

The first, provided by the National Center for Social Statistics, indicates that, of those children screened through EPSDT, fully 47 percent of them required a referral to a physician for treatment.

The second, provided by the GAO in its report on Alabama's EPSDT program, which, incidentally, was the most successful that the GAO studied, reports that in that State, among 39,000 children screened there were diagnosed more than 40,000 incidences of illness of impairment. That is, an average of more than one physical problem identified for each and every child tested.

Mr. Chairman, it is clear that these children desperately need proper health care. For low-income children, many of whom suffer from improper diet and poor living conditions, the importance of preventive health care and regular physical examinations cannot be stressed enough.

These children need this health care. They deserve it. It is their right.

The law, economics, and our conscience demand that this program be fully implemented.

I can only ask how could we have allowed a program of this importance to fail for so long.

I hope that these hearings will provide the answer to that question and also provide some insight into how we can move ahead to make it work in the future.

Thank you, Mr. Chairman.

Mr. OTTINGER. Thank you very much, Congressman Metcalfe.

The subcommittee is very grateful indeed to you.

The report that you requested from GAO to a large extent raised the questions that are the foundation of this program.

We are grateful to you for the information you have provided to the committee.

Mr. METCALFE. Thank you, Mr. Chairman.

Mr. OTTINGER. Are there any questions?

If not, we appreciate your taking the time to be with us.

Mr. METCALFE. Thank you very much, Mr. Chairman.

Thank you, gentlemen.

Mr. OTTINGER. Our next witness is Dr. Wilbur J. Cohen, former Secretary of Health, Education, and Welfare.

Dr. Cohen, it is a pleasure indeed to have you here. We look for ward to any light you can shed on this important problem.

Without objection we will be glad to include your statement in the record at this point.

Mr. COHEN. Mr. Chairman, I would prefer if you would put my entire statement in the record [see p. 51] and within the time limit I prefer to just touch on two or three points and have you ask me any questions on the general tenor of my testimony.

Mr. OTTINGER. We will do that and you may proceed.

STATEMENT OF WILBUR J. COHEN, DEAN, SCHOOL OF EDUCATION, AND PROFESSOR OF PUBLIC WELFARE ADMINISTRATION, SCHOOL OF SOCIAL WORK, UNIVERSITY OF MICHIGAN

Mr. COHEN. I presume, Mr. Chairman, that one of the reasons you asked me to come here is because it is alleged that I am the Godfather of this program that you have been discussing today and I accept the paternity.

Mr. SCHEUER. I trust the witness' use of the word Godfather was a slip of the tongue.

I originally designed this particular screening program as an idea to try to take a step in the direction of my ultimate hope and that was a national health insurance program covering all children in the United States.

I believe the experience that we have had in this program does indicate, first, the social and economic value of the general approach and, secondly, it has identified some of the problems which I think now would lead us into the direction of strengthening that program and ultimately absorbing it into a national health insurance program for children.

In my testimony I suggest that one way, although I don't think the only way, would be to take the screening program now, apply it to all families throughout the Nation whose incomes are below the poverty threshold, providing that the Federal Government pay 100 percent of the cost of the program above whatever amounts the States now put in, that is, to hold the States to the amount of financial aid that they are

now giving, and then over the course of time hopefully institute a national health insurance program for all children under the age of 6 to begin with, ultimately stepping up to age 12 and then to age 16 or 21 in which ultimately then the screening program would be absorbed into the national insurance program.

Of course, if we were starting from a clear slate, I would not suggest that is the only way to arrive at this conclusion. But I believe when you recognize all the problems we have in the implementation of health programs, the cost side, the personnel side, the impact upon inflation, the lack of resources and facilities and so on, it is important for us to take what I call an incremental point of view in the development of national health policy. Therefore, I believe that perhaps one of the best ways to make a step in this whole national health insurance is not to think of the whole ball of wax at one time for 220 million people covering all medical care in 50 States and 3,000 counties with all the administrative problems, but to take a step toward a counterpart to medicare by a program for children under the age of 6 to begin with, and put our incremental or marginal economic resources into this new program at the present time.

Therefore, I might say that the same recommendation I made in my recent testimony to the Committee on Ways and Means is that if you are thinking of a national health insurance program, why not start with children first?

We have had a lot of experience now in the screening and diagnosis and treatment program. We have identified a lot of problems. We need to train more personnel. But it is within our administrative ability over a period of, I think, 4 to 6 years to implement this proposal. That is the basic tenor of my recommendation.

I also in my testimony feel that this program has indicated the importance of our continuing on a vigorous, dramatic and comprehensive research program.

I am also very proud of the fact I had a good deal to do as Chairman of President Kennedy's Task Force on Health and Social Security in 1960 with what became eventually the National Institute of Child Health and Human Development.

However, that institute, after about 10 or 12 years, still only gets about $126 million in the existing budget. I think there has been a signal failure on the part of the Federal Government to undertake the kind of fundamental basic research in the problems of child health that would save millions. I would say potentially, billions of dollars, in preventing the kinds of problems that you heard about today.

I have in my testimony identified a number of them, taken primarily from the Department of Health, Education, and Welfare's report, the Forward Plan for Health, which was just issued. I have included in my statement about 5 to 6 pages from that report on the research areas of child health which if I were still Secretary of HEW, I would plow a great deal more money into the National Institute of Child Health and Human Development for that fundamental research coupled simultaneously then with a health and medical care program for children on the preventive, diagnosis, curative, treatment, side, which I think then would make a real step forward.

I believe your subcommittee hopefully ought to look at the interrelationship of the screening program and the medicaid portion thereof

in relation to proposals for national health insurance and in relation to the program of the National Institute of Child Health and Human Development. That is the basic thrust of my testimony.

I present the figures there which you know very well, that there are some 10 million children in the United States in poverty; that our infant mortality rates are still high; that they vary by States, and that, if we are going to have an effective comprehensive program for dealing with the health of children, we must not merely correct the defects that we found in the screening program, and I might say I wholeheartedly concur in the recommendation of the General Accounting Office with regard to this program, and I would hope that Secretary Mathews would eliminate the disadvantages—that is the best word I can think of—that have infiltrated into the failure to implement this program. And I feel that they are largely administrative.

Now, you asked some questions about that and I only want to finish with one suggestion. The key reason why this program failed in my opinion was the failure to take the States into a cooperative relationship in the implementation of the program.

This program is a Federal-State partnership. There might be other ways and better ways to do it, through national health insurance in my opinion, but the fact of the matter is that Congress, in 1965, and in 1967, determined that this aspect was going to be a Federal-State partnership.

But under the leadership of the Department prior to Dr. Mathews' coming on as Secretary, there was not only an unwillingness to work with the States to accomplish the objectives in the law, but a failure to communicate with the States, to cooperate with the States in an effective cooperative program.

In my opinion, that was the central reason why the program didn't make as much headway as I originally thought it would when I handled the legislative implementation of this program in Congress in 1967.

[Testimony resumes on p. 61.]

[Mr. Cohen's prepared statement and attachment follows:]

STATEMENT OF WILBUR J. COHEN, DEAN, SCHOOL OF EDUCATION, AND PROFESSOR OF PUBLIC WELFARE ADMINISTRATION, SCHOOL OF SOCIAL WORK, THE UNIVERSITY OF MICHIGAN, ANN ARBOR, MICHIGAN

THE FIVE GIANTS IN OUR LAND

In his famous report issued in 1942, Sir (later Lord) William Beveridge summarized many years of research and study on the problems of poverty and family disintegration by saying:

". . . Want is one only of five giants on the road of reconstruction and in some ways the easiest to attack. The others are Disease, Ignorance, Squalor and Idleness." [1]

Despite the tremendous economic and social progress made in the United States in recent decades, these five giants still stalk in far too many American homes. And it is particularly unfortunate that at the present time we seem to be quite willing to accept a policy of détente with these giants which are bent on the objective of family disorganization and dependency.

If we were to adopt and implement a national policy which had as a national goal the banning of these giants from our land, destroying the weapons they use,

[1] *Social Insurance and Allied Services*, The MacMillan Co., New York, 1942, page 6, paragraph 8.

and placing control of them under national surveillance with impartial inspection teams, we could substantially improve family life within the next decade.

That is the goal I suggest we work toward: The eradication of want, ignorance, squalor, and idleness, and the prevention of disease among every child and youth in the nation.

POVERTY AMONG CHILDREN

The most recent estimates of poverty in the United States by the Census Bureau show that for 1974 of the 24.3 million persons with incomes below the poverty line, some 10.2 million were children under age 18. (For poverty thresholds see Table 1.)

In 1973, there were 9.5 million children in families with incomes below the poverty level. Between 1973 and 1974 this figure increased by 8 percent to 10.2 million, even though the number of children in the total population decreased. The poverty rate for children, therefore, increased from 14.2 percent in 1973 to 15.5 percent in 1974.

Most distressing is the fact that there has been no continuous decrease in the number or proportion of children in poverty in the past five years (1970–74) as there was in the previous ten years (1959–69). There were 17.2 million children in poverty in 1959, or 26.9 percent of all children. These figures declined to 9.5 million children in 1969 (and also in 1973) and to 13.8 percent.

In addition, there is a very high incidence of poverty among children in families when the head of a family is a woman (51.5 percent) and an even higher percent when the head of the family is a black woman (65.7 percent).

The poverty rates for black children were about 4 times those of white children. (See Table 2.)

POVERTY AMONG CHILDREN BY STATES

Poverty among children varies widely by states and by counties within states. Table 3 displays the data from the 1970 Census for children age 5 through 17 which shows the lowest poverty rates ranging from 7.2 percent to 7.7 percent in Connecticut and New Hampshire to a high of 41.5 percent in Mississippi.

There were seven states in which there were counties with a poverty rate above 70 percent. These were Alabama (71.4 percent), Alaska (93.1 percent), Georgia (74.6 percent), Kentucky (71 percent), Mississippi (75.9 percent), Tennessee (70.7 percent), and Texas (70.4 percent).

INFANT MORTALITY RATES BY STATES

The infant mortality rate under one year has been declining for a number of years. In 1974 there were approximately 52,400 infant deaths resulting in an infant mortality rate of 16.5 per 1,000 live births. This was the lowest annual rate ever recorded in the United States and represented a 7 percent decrease from the 17.7 rate for 1973.

The variation by states in 1973 was from 13.7 in Hawaii to 25.2 in Mississippi. There were seven states with rates below 15 and 8 jurisdictions with rates above 20 as follows:[2]

Rates below 15:		Rates above 20:	
Hawaii	13.7	Mississippi	25.2
New Hampshire	14.2	District of Columbia	23.1
Wisconsin	14.4	South Carolina	23.0
California	14.6	Alabama	22.2
Connecticut	14.7	Tennessee	21.8
Kansas	14.8	North Carolina	21.5
Oregon	14.9	New Mexico	20.5
		Louisiana	20.2

AID TO FAMILIES WITH DEPENDENT CHILDREN

About eight million children currently are receiving welfare payments under the Aid to Families with Dependent Children (AFDC) program, as compared with the ten million children whose families have incomes below the poverty line. The AFDC program does not generally provide aid to families with children where there are two parents except in cases of disability or unemployment of one of the parents.

[2] *Monthly Vital Statistics Report*, "Annual Summary for the United States, 1974," Vol. 23, No. 13, May 30, 1975, Department of H.E.W., National Center for Health Statistics, p. 15.

AFDC payments vary widely. The average per child payment was $66.08 for the nation in March 1975 varying from $109.07 in Massachusetts to $14.35 in Mississippi.[3]

Standards of assistance vary widely. In May 1971, the standard for basic needs for a family of four without any income varied from $4,356 in Indiana to $2,400 in North Carolina.[4]

IMPLICATIONS OF STATE VARIATIONS

There are other significant variations among the states such as in educational expenditures per child and physicians in relation to population. These variations when considered in relation to the wide variations in per capita incomes among the states indicate that an effective program to improve the health, education and welfare of the children of our nation cannot be achieved in the near future without the substantial financial assistance and leadership of the federal government and the cooperation of the states.

Ultimately we must have a welfare reform plan which will provide some simplified and equitable minimum payment to all families with children whose income is below a minimum level. In the interim it would be a step in the direction of broadening AFDC protection to children by amending section 406(a) of the Social Security Act by striking out the existing language which restricts the program to a needy child "who has been deprived of parental support or care by reason of the death, continued absence from the home, or physical or mental incapacity of a parent," and coupling this with a minimum standard which would be federally financed.

SCREENING, DIAGNOSIS AND TREATMENT OF CHILDREN FOR HEALTH NEEDS (EPSDT)

In 1966–67, I recommended to President Johnson the proposal eventually incorporated in the Social Security Amendments of 1967 as EPSDT—the Early Periodic Screening, Diagnosis and Treatment Program. This program is in the Medicaid provisions of the law—title XIX, section 1905(a)(4)(B) of the Social Security Act as follows:

"effective July 1, 1969, such early and periodic screening and diagnosis of individuals who are eligible under the plan and are under the age of 21 to ascertain their physical or mental defects, and such health care, treatment, and other measures to correct or ameliorate defects and chronic conditions discovered thereby, as may be provided in regulations of the Secretary;"

With the experience gained in implementing this program in the past six years, we should now take steps to strengthen, improve, and expand it.

One way to do this would be to amend the existing provisions so that effective July 1, 1977 it would be made to apply to all families throughout the nation whose incomes are below the poverty threshhold and provide that the federal government pay 100 percent of the cost of the program above whatever amounts the states were contributing to this program in the fiscal year 1975.

A NATIONAL HEALTH INSURANCE PROGRAM FOR MOTHERS AND CHILDREN

I do not believe, however, that it is desirable for the long run to have an income conditioned program for health care. I, therefore, view any such program as a transitional step toward a universal eligibility program based solely on residence. I, therefore, favor enactment of a national plan covering initially all children under the age of six and prenatal, postnatal and all other medical services associated with childbirth. I would extend this program to children up to age 12 about two years later, and to children up to age 18 or 21, two years thereafter.

In this way, there would be time to make the necessary plans with all parties concerned. As this plan expanded, the EPSDT program would contract and eventually be terminated.

I would not have any co-insurance or deductibles under the national health insurance program for mothers and children. This would greatly simplify the bookkeeping under the plan. Payments to primary care physicians could be on a per capita basis thus encouraging preventive care and discouraging unnecessary services.

---

[3] *Social Security Bulletin*, Sept. 1975, p. 54.

[4] *Welfare Programs for Families*, Senate Committee on Finance, July 21, 1971, pp. 44–45.

HEALTH CARE EXPENDITURES FOR CHILDREN

Children under the age of 19 represented 34.1 of the population in 1974 but accounted for only 14.9 percent of all personal health expenditures. As might be expected, persons age 65 and over were only 10.2 percent of the population but accounted for 29.5 percent of all health expenditures.[5]

Per capita expenditures for all personal health expenditures varied widely with age. For children under age 19, per capita expenditures in 1974 were $183, compared to $420 for persons 19–64 and $1,218 for person age 65 and over.[6]

From these figures we can draw a preliminary observation that we could develop a comprehensive health care program for all children in the immediate years ahead at probably around $300 a year per child or about $1.8 billion for all children up to the age of six plus the cost of prenatal and postnatal care for approximately 3.2 million births per year, probably at a cost of around $2 billion a year.

To the extent we could take some or all of the financial burden for health care costs of children off of the young and lower-income families in the nation, we would be making an important contribution to family life in an inflationary period.

CURRENT HEALTH AND WELFARE COSTS

Total personal health expenditures in 1974 for children and youth up to age 19 were $13.4 billion of which $9.8 billion was from private and $3.6 billion from public sources. Federal sources accounted for $2.2 billion and state and local governments the other $1.4 billion.

In the same year, about $8 billion was expended under the AFDC program for children on welfare and their parents, of which more than half came from federal funds.

RESEARCH ON PREVENTIVE HEALTH CARE FOR CHILDREN

There is an imperative need to continue and extend the research program of health care for children being conducted by the National Institute of Child Health and Human Development (NICHD). This Institute created as a result of the recommendations of the task force of which I was chairman in 1960 is responsible for developing new knowledge that will improve the quality of life for the nation's children and encourage the quantity of children appropriate to the nation's resources.

The mission of the NICHD is to contribute to the good health of all citizens through efforts to understand the many factors related to the adaptation of populations to available resources and the expansion of knowledge on family planning, maternal and child health, and human development. The primary emphasis of Institute efforts is prevention of disease and disability.

I have included as a supplement to my statement the pertinent portions relating to Child Health which apepar in the *Forward Plan for Health, FY 1977–81* published in June 1975 by the Department of Health, Education, and Welfare (pp. 85–86 and 227–231).

I would like to draw attention to several critical pending areas of research in child health which I believe merit your strong support.

1. Low-birth-weight infants.—About 240,000 low-birth weight infants are born every year in the United States. A fifth of these children will not survive the first five months of life, and those that do often sustain permanent development impairments. In addition to immeasurable personal suffering, the cost to society for medical care in the first year of life alone will total about one billion dollars. Research has resulted in the development of early prenatal intervention programs, improved diagnostic techniques, methods to delay the onset of labor and special attention to groups such as teenage mothers at high risk for having a low-birth-weight infant.

2. SIDS.—Among the chief priorities of the NICHD is the eradication of the tragedy of sudden infant death syndrome (SIDS). It is the leading cause of deaths among infants between the ages of one month and one year. Between 7 and 10 thousand healthy infants die each year and no apparent cause of death can be discovered by the attending physician. Since 1971, the NICHD has sponsored research-planning workshops to identify specific areas of the SIDS prob-

[5] Marjorie Smith Mueller and Robert M. Gibson, "Age Differences in Health Care Spending, Fiscal Year 1974," *Social Security Bulletin*, June 1975, p. 3.
[6] Previous source, p. 10.

lem requiring indepth studies. These workshops have suggested special emphasis on abnormal breathing patterns during sleep, and anatomical abnormalities among other suggestive leads for research. In addition to research connected with the cause of SIDS, considerable activity has been devoted to research involved in counseling and support of families of SIDS victims.

3. Antecedents of developmental impairment.—There are currently 15 million Americans who have a birth defect serious enough to drastically affect their lives. Genetic defects account for developmental disabilities in up to five percent of all live births. Investigation sponsored by the NICHD has made significant progress in the diagnosis of phenylketonuria, and other diseases. Recent work in hearing, speech, and language disorders using audiometry has improved the assessment of very young children who may have an organic basis for future learning problems. The Institute intends, in the near future, to initiate new research efforts in dyslexia to assist the 15 percent of children who experience difficulty in learning to read.

4. Teenage pregnancy.—While unplanned and unwanted pregnancies have declined in the population above 20, they have increased in the teenage group. During the period from 1965–70, over two and one-half million "unwanted" babies were born, a significant proportion of which were to teenage mothers. The proportion of all births that are illegitimate doubled between 1963 and 1973 rising from 6.3 to 13.0 percent. Among teenage girls, the proportion of illegitimate births rose from 18 to 35 percent in the same period. Births among adolescents contribute heavily to infant mortality and morbidity and to the welfare rolls. One in four low-birth-weight infants has a teenage mother. The NICHD supports studies to examine the sexual and contraceptive patterns of young people and will continue to increase knowledge in this area. During the coming year the Institute will hold a conference to assess current knowledge and to identify the gaps in understanding of the behavioral and biomedical aspects of teenage pregnancy.

In order for the NICHD to mount new efforts to solve these important problems which bear so heavily on the prevention of adult disease, sufficient funds must be provided. The 1976 President's Budget for the NICHD, far from providing an increase to start new programs, proposes a $20 million decrease. In the light of the research opportunities that abound in the area of responsibility of the NICHD, the proposed reduction is unwise and unsound.

I am an enthusiastic and vigorous supporter of the research program of the NICHD. I strongly recommend that the Institute budget be restored to the 1975 level and that an additional $6 million be provided to begin the "Major Research Programs for Mothers and Infants" which the Institute has developed. From a cost-benefit standpoint, this is a sound proposal. We stand to save millions in health care costs for children by the investment of $6 million.

A COMPREHENSIVE PROGRAM FOR CHILDREN, YOUTH AND THE FAMILY

As Secretary of Health, Education, and Welfare, I developed a comprehensive program for children, youth and the family. While several of the recommendations are beyond the jurisdiction of this Committee, the total program may be of interest to the members of this Subcommittee and I attach my current revision for your review.

A Comprehensive Program for Children, Youth and the Family

By Wilbur J. Cohen, Formerly Secretary of Health, Education, and Welfare

1. Extend comprehensive prenatal and postnatal care for all women as part of a national health insurance program so that insofar as possible every child will be born well.

2. Extend comprehensive medical care to all children with correction of any disabilities as part of a national health insurance program so that insofar as possible every child will have had the opportunity to have any disabilities corrected or alleviated before the child goes to school.

3. Extend family planning services to all persons who want them so every child is born a wanted child and so that children are spaced to enable parents to give them the affection, understanding and support they need.

4. Provide for a health education program which brings medical, nutritional and scientific knowledge to every person so that disabilities will be minimized and the health and nutrition of individuals will be improved.

5. Provide for the establishment of special pediatric high-risk birth mobile units to assist in handling births of children with high risks.

6. Develop and extend special maternal and child health demonstration units to assist in reduction in infant and maternal mortality.

7. Provide for maternity leave for women with full pay for three weeks prior to childbirth and seven weeks after childbirth. Provide for one week paternity leave for men during period of birth of the child.

8. Extend preschool programs through the Head Start program, day care of children of welfare families, and Title I of ESEA so that by 1980 every parent who wishes his or her child to have preschool experience will be able to do so.

9. Revitalize and strengthen the work of the President's Commission on Mental Retardation so as to extend preventive, rehabilitation and employment services for the mentally retarded.

10. Increase the number of Neighborhood Health Centers so that families may have prompt and convenient access to primary health care of high quality.

11. Extend and expand the Child Welfare Services provisions in Title V of the Social Security Act so that states can improve, strengthen, and extend services to protect neglected and abused children, license and inspect child care institutions, provide adoption and foster care services, etc., so that every child will have available the services needed.

12. Provide additional funds for research, information, and dissemination of information on Sudden Infant Death Syndrome.

13. Expand the research program of the National Institute of Child Health and Human Development with a view to preventing disabilities, and assuring constructive child and parental development.

14. Increase a child's benefit under the social security system from 75% of the parent's benefit to 80%. Omit from consideration of the provision limiting a child's social security benefit up to age 22, if prior period spent in the Teacher Corps, Peace Corps, military service, or any other approved community service program. Thus, a person who had spent two years in the Peace Corps could have the period of benefits extended to age 24. Increase the minimum payment to a child to $150 a month.

15. Provide in the federal law-making grants to states for dependent children that the minimum standard of need for each child with no other income shall be $100 a month.

16. Extend and improve the vocational education program so that every boy and girl who wishes to learn a relevant skill and develop a career can do so.

17. Develop adequate and diversified summer programs for employment, training, recreation, and useful experiences for children and youth.

18. Provide appropriate means to assist young persons age 14–18 to obtain paid employment which will assist in developing skills, responsibility and independence and under circumstances which will not discourage their continued education.

19. Provide additional federal aid for able students to become physicians, nurses, dentists and other professional members of the health and medical care system.

20. Encourage bilingual education and the preservation of cultural traditions among children and families from non-American backgrounds.

21. Encourage all children to learn a non-English language so that they may be able to work with people of other nations, in the furtherance of world peace, prosperity and cultural inter-change.

22. Intensify efforts to eliminate and reduce the availability of hard drugs; expand educational programs to discourage the use of drugs, tobacco, alcohol among children and youth.

23. Provide for a method of expunging federal and state arrest and conviction records of individuals for acts performed before age 21 which were not felonies.

24. Increase and diversify federal and state financial aid for students to enter community colleges and universities so that every youth with ability will have an equal chance to enter and continue in post-secondary education.

25. Strengthen the research and services of the National Institute of Mental Health so as to assist parents, children and youth achieve a state of constructive mental health and well-being.

26. Encourage government agencies to work with non-governmental agencies to play an important role in research, demonstration projects, services, and leadership in working with children, youth, and families.

27. Establish by federal and state laws a Child, Youth and Family Policy Act which sets out the importance and priority of strengthening, defending, and preserving family life with rights and responsibilities for children, parents, and the family.

TABLE 1.—SELECTED POVERTY LEVEL THRESHOLDS IN 1974 BY SIZE OF FAMILY AND SEX OF HEAD, BY FARM-NONFARM RESIDENCE

Family unit	Total	Nonfarm, male head	Farm, female head
Aged person	$2,352	$2,387	$2,002
Aged couple	2,958	2,984	2,533
4 persons	5,008	5,040	4,262
6 persons	6,651	6,706	5,702

Source: "Money Income and Poverty Status of Families and Persons in the United States:" 1974 (advance report); current population reports, consumer income, series P-60, No. 99, July 1975, table 14, p. 16.

TABLE 2.—POVERTY RATES FOR CHILDREN, 1974

	Total	White	Black
Total, all ages	11.6	8.9	31.5
Under 3 yr	17.4	13.4	39.9
3 to 5 yr	16.5	12.4	39.4
6 to 13 yr	16.1	11.6	42.8
14 and 15 yr	14.1	9.9	39.6
16 to 21 yr	12.3	8.9	34.7
5 to 17 yr	15.3	10.9	41.7

Source: See Table 1—Table 19 p. 20.

TABLE 3.—CHILDREN AGED 5 THROUGH 17 IN POVERTY FAMILIES BY STATE, 1970 CENSUS

State	State average (percent)	Low and high county percents: Low	High
50 States and District of Columbia	14.8	1.6	93.1
Alabama	29.5	15.7	71.4
Alaska	14.6	1.8	93.1
Arizona	17.5	10.7	57.2
Arkansas	31.6	12.6	59.2
California	12.1	5.7	26.0
Colorado	12.3	3.8	44.0
Connecticut	7.2	4.9	10.5
Delaware	12.0	9.7	17.9
Florida	18.9	10.4	48.3
Georgia	24.4	6.7	74.6
Hawaii	9.7	8.8	12.2
Idaho	12.0	4.0	27.2
Illinois	10.7	2.3	53.6
Indiana	9.0	4.0	19.5
Iowa	9.8	5.4	24.6
Kansas	11.5	2.2	26.2
Kentucky	25.1	9.2	71.0
Louisiana	30.1	10.7	68.2
Maine	14.2	9.3	23.7
Maryland	11.5	3.9	29.4
Massachusetts	8.4	4.0	18.5
Michigan	9.1	4.2	31.1
Minnesota	9.5	3.8	30.9
Mississippi	41.5	14.9	75.9
Missouri	14.8	4.5	52.2
Montana	12.9	5.6	35.6
Nebraska	12.0	2.2	44.6
Nevada	8.8	5.8	17.9
New Hampshire	7.7	6.3	11.4
New Jersey	8.7	3.1	16.7
New Mexico	26.3	1.6	65.0
New York	12.2	3.9	27.9
North Carolina	24.0	9.0	57.1
North Dakota	15.7	9.4	45.8
Ohio	9.8	4.1	33.0
Oklahoma	19.5	8.9	53.1
Oregon	10.3	4.8	21.7
Pennsylvania	10.6	3.8	22.3
Rhode Island	11.0	6.1	14.8
South Carolina	29.1	39.1	59.9
South Dakota	18.3	7.4	50.5
Tennessee	24.8	14.3	70.7
Texas	21.5	3.0	70.4
Utah	10.0	2.6	43.4
Vermont	11.4	7.5	21.0
Virginia	18.2	3.3	51.4
Washington	9.3	6.4	24.6
West Virginia	24.3	6.7	48.4
Wisconsin	8.7	3.2	43.6
Wyoming	11.2	4.5	18.4
District of Columbia	23.2		

Source: U.S. Department of Commerce, Bureau of the Census, "1970 Census of Population" (from a special tabulation). Counts of children in poverty families were divided by the total number of children 5 through 17 by county and by State.

CHILD HEALTH INITIATIVE

In the area of child health, the knowledge development requirements go beyond the purview of any one Institute or any one Health Agency. Thus, efforts to coordinate research activities which pertain to the health of mothers and children have been intiated that involve several of the Institutes of Health, ADAMHA, HD, SRS and SSA. Several intradepartmental, intra-Public Health Service, and intra-NIH committees serve as mechanisms for infirmation exchange and policy recommendation in the area of maternal and child health. Efforts to improve the effectiveness of coordination and collaboration mechanisms will continue. If we trace child health research needs from the inception of the fetus through the development of the child, the following efforts require special attention:

(*a*) Fertility Regulation: New and improved methods of fertility regulation will be explored. This exploration will involve assessment of existing contraceptive approaches with respect to undesirable side effects and acceptability, and will look into possible means of overcoming infertility. Continued support of basic research in reproductive biology is essential in order to provide the knowledge base for development of safer, more effective, and universally acceptable family planning techniques.

(*b*) Pregnancy, Labor and Delivery: Research in this area should focus on high risk obstetrical conditions that contribute to infant morbidity and mortality, such as diabetes, hypertension and toxemia. It is also essential to determine the maternal and intra-uterine conditions that are optimal for fetal growth and maturation. To prevent the premature onset of labor, research is necessary to determine why labor begins. Further exploration is needed of the contribution of various analgesic and anesthetic agents administered during labor to the development of depression of the fetal nervous system, and which can result in central nervous system damage.

(*c*) Surveillance of Fetal Well-Being: Improved methods are needed to detect fetal pathophysiology, including increasing the number of diseases which can be diagnosed prenatally with special attention to sickle cell disease, cystic fibrosis and thalassemia. Emphasis should be placed on ensuring that the latest developments in prenatal diagnoses are disseminated and made available to practitioners.

(*d*) Infants at Risk: Since low birthweight infants (5½ pounds or less) account for 60 percent of all infant deaths, it is imperative that research focus on the causes of infants being born too soon or too small. Particular emphasis needs to be given to preventing illnesses in infants weighing less than 2½ pounds, such as hyaline membrane disease and neonatal jaundice, which contribute to infant mortality and morbidity. The sudden infant death syndrome, which is the major cause of death after the first month of life, continues to require research emphasis.

(*e*) Nutritional Assessment: Attention needs to be given to the development of more accurate clinical tehniques to assess the nutritional status of the pregnant woman, her fetus and of children from one month of age through adolescence. Research is also needed to determine the relationship of the nutritional status of children to obesity, hormonal and metabolic disorders, dental caries, musculoskeletal defects and susceptibility to infectious disease. Survey instruments need to be improved which can be incorporated into ongoing nutrition assessments.

(*f*) Accident Prevention: Additional research is needed in the areas of toy safety, safe packaging of drugs, and home and automobile accident prevention, since accidents are the leading cause of death in children after the first year of life.

(*g*) Mental Health: The complex questions of the mental health of children need to be addressed by research which looks at the 1) biological, behavioral and socio-cultural aspects of mental illness and behavior and learning disorders, 2) biological, psychological and social correlates of development, and 3) psychological and emotional preparation for assuming adult roles. ADAMHA has identified child mental health as one of its major cross-cutting research priorities.

B. Child Health

Attitudes toward personal health care are developed at very young ages and tend to reflect the attitudes of parents and guardians. Early preventive health care can play an important part in formulating a consumer's life-long attitudes toward health and in improving later health status. A preventive health care strategy for children should include the following areas: genetic factors, infant mortality and low birth weight, immunization, nutrition, dental health, and mental health.

1. Genetic Diseases

Genetic conditions are individually rare and even in the aggregate occur in only 3 to 4% of live births, but they account for approximately one fourth of all hospital admissions, a major portion of infant and childhood mortality, and an enormous financial burden in terms of medical care, provision of special social services, and institutionalization.

Recent medical advances have begun to make inroads on this array of diseases. Amniocentesis and genetic counseling permit families to engage in informed decisions about genetic factors. Screening at birth for PKU and galactosemia, and appropriate diet therapy for those afflicted, has virtually eliminated these conditions as causes of mental retardation. Further research to identify causes, methods of treatment, and prevention of genetic factors should be undertaken. Efforts should also be made to extend to the general public currently available diagnostic, preventive, and therapeutic measures.

2. Infant Mortality and Low Birth Weight Infants

Although the infant mortality has been reduced considerably to a 1974 rate of 17.3 per 1,000 live births, 10% of the more than 3,000 U.S. counties reported infant mortality rates above 33.4. The non-white population had almost double the rate (28.8) of the white (15.2). The prematurity rate, like the infant mortality rate, varies among different population groups. In 1973, for example, 26% of all low birth weight infants were born to teenage mothers.

There is strong evidence of a positive correlation between the receipt of maternal health care services and the reduction of infant mortality. There is further indication that health services play a particularly important role in infant mortality reduction in the neonatal period (0–28 days) when ¾ of all infant deaths occur. The non-medical factors appear to have an effect more on post-neonatal period (29 days to one year).

A proposed project would target resources for the prevention of infant mortality to those areas of greatest need. Areas would be selected based on a number of indices including rates of infant mortality and low birth weight infants. Seed money would be awarded to sites to facilitate the process of targeting resources on the problem of infant mortality.

The contribution of family planning to improving the health of children is important, particularly as it relates to reducing the incidence of genetic disease, infant mortality, and mental illness.

PHS will continue its family planning services with emphasis on: optimal family size based on health, economic resources, and family considerations; birth intervals which promote maternal and child health; and child bearing during those years which pose the least risk for the mothers and the best chances for a healthy baby.

3. Immunization

In spite of the success in recent years in the control and prevention of measles, poliomyelitis, and rubella, there is one area of concern which will require special attention: the immunization of preschoolers from low income families. CDC immunization programs will focus on Head Start, EPSDT, Day Care and Neighborhood Health Center populations.

4. Nutrition

Nutritional care, including dietary counseling, should be integrated into the preventive, diagnostic, and restorative health services of all the PHS programs for all family members. However, it is especially important that nutrition services for the subsets of the population with high vulnerability to malnutrition and with special nutritional requirements, i.e., pregnant and lactating women, infants, young children, and adolescents, have priority in efforts to reduce morbidity and mortality rates. Nutrition plays a vital role in the treatment of conditions such as phenylketonuria, maple syrup urine disease, and cardiovascular disease. Untreated, these conditions seriously endanger health and increase stress for individuals and families as well as increase costs for long term care.

The health service programs and USDA's Supplemental Food Program (WIC) and other food assistance programs should coordinate efforts to insure that women, infants, and children in needy families are authorized to receive supplemental foods or other types of assistance.

5. Dental Health

Although a number of oral disease entities impact on children, the most significant in terms of the number affected are dental caries and incipient

periodontal disease. The caries process, once initiated, is irreversible and requires therapeutic intervention to prevent further tissue destruction and ultimate tooth loss, and to restore normal function and appearance. The course of periodontal disease during childhood, while more subtle and less immediately visible, sets the stage for even greater damage to the future oral health status of the adult patient, i.e., potentially total edentulousness even in the absence of caries. More importantly, however, the periodontal disease process is preventable and can be reserved during its early stages in the childhood years. Therefore, a special focus on preventing dental disease in children is appropriate. Options include:

Promoting the maintenance of optimal fluoride levels by supporting the installation and initial operating costs of fluoridation of community and school water supplies; identifying those water systems that are either deficient or excessive in fluoride content; and by mounting a program of continual monitoring of all public water systems so that problems can be quickly identified.

Promoting public visibility for and increased professional awareness of recently developed health education and preventive care practices by sponsoring a National Conference on Dental Health Education and Prevention.

Encouraging the expansion of the dental component under the EPSDT program by sponsoring two-day workshops designed to bring together HEW regional EPSDT coordinators and dental personnel.

6. Mental Health

Eight to twelve percent of the U.S. population under 18 years is believed in need of mental health services for psychotic disorders (including schizophrenia), behavioral disorders, depression, organic disorders, neurotic and personality disorders, adjustment reactions and mental deficiency.

In calendar year 1975 it is estimated that 90 percent of these mental health needs will be unmet. Thus there is a continuing need to focus on child mental health.

The NIMH will continue to promote public education, a primary prevention device on the psychosocial dimensions of severe mental illness, chronic physical illness, learning disorders, child abuse, attitudes about nutrition and food choice, and infant development. Cooperative activities with OMCH and NICHD, directed toward the mental health problems associated with Sudden Infant Death Syndrome, will continue. NIMH will develop further the capabilities of the CMHC in support of these efforts. NIMH will focus on developmental assessment in an effort to assist MSA in developing policy on this matter.

7. HSA Programs

Mothers and children are among the major beneficiaries of the Health Services Administration's Bureau of Community Health Services programs designed to provide high quality health services primarily to underserved areas. In addition to specific activities described above, these programs may provide a range of preventive, therapeutic, and rehabilitative ambulatory services—as in Community Health Centers—or address health needs of special populations—such as migrant and seasonal farmworkers.

A special Rural Health Initiative to develop health care systems in selected medically underserved areas with critical health manpower shortages has been undertaken in 1975, utilizing resources of the National Health Service Corps, Community Health Centers, Appalachian Regional Commission, and the Migrant Health program. Proposed continuation and expansion to integrate additional resources in 1976 will increase health services delivery capacity to these areas.

8. Exploration of School Based Delivery of Health Care

Current changes in traditional school health programs offer a timely opportunity for the Public Health Service to explore the possibilities of combining primary care delivery with a focus on preventive medicine for school age children. Potentially, school-based programs would incorporate preventive medicine as a fundamental component of primary care early in the life cycle of the child. Such services as preventive dentistry and accident prevention could have a major impact. (Ultimately, many school-based programs may be more amenable to cost controls and offer significant advantages in terms of the delivery of selected forms of care.)

Alternatives open to the PHS include:

Encouraging communities to combine existing EPSDT programs with their own school health efforts, utilizing the experiences of existing model school health programs.

Examining the relationship between National Health Insurance proposals and a variety of school-based health care delivery systems.

Evaluating the possibility of creating a National School Health Service to be operated by the PHS at school sites being Federally funded.

Developing a model Child Growth Center that combines medical care, social services, and educational activities.

9. Early Periodic Screening, Diagnosis and Treatment

To assure that poor, high-risk children receive important health services the PHS will work closely with MSA on the conduct of the EPSDT program.

Because the PHS can only provide direct health services to a very limited portion of the EPSDT-eligible population, the major contributions of the PHS are in other areas. For example, the PHS is undertaking evaluations of screening procedures to determine their effectiveness, reliability, and overall usefulness; relevant research from the activities of the NIH are being culled and channeled to the MSA; ADAMHA, under an agreement with MSA, is reviewing the best current knowledge on developmental assessment, and acting as the principal advisor to MSA in this area; inter-agency committees have been established with PHS participation in each of the Regional Offices to monitor the progress of EPSDT implementation.

Where PHS-supported health activities are performing the screening or providing treatment for children screened through other programs, efforts are underway to eliminate the barriers to more effective program utilization. PHS staff members are developing management and policy tools for the resolution of financial problems (particularly Medicaid reimbursement questions) where these have arisen.

Source: *Forward Plan for Health.* FY 1977–81, U.S. Department of Health, Education, and Welfare, Public Health Service, June 1975, pp. 85–86, and 277–231.

Mr. OTTINGER. We have a lot of indications that the States and the localities just weren't able, or didn't assign sufficiently high priority to allocate funds to this program, that the States in fact had been cutting corners in the implementation of the program because of an unwillingness or inability to come up with those funds.

That gets more and more severe as we have an economic downturn in the country. The States are having a lot of problems in meeting their budgets.

New York State, as you know, is in a desperate situation the city even worse.

Is it your recommendation that you think this plays a major factor and that the Federal Government until such time as we have national health insurance, should come up with 100 percent of the funding or a larger percentage of the funding than they do at the present time?

Mr. COHEN. I will say this: If you are going to have the Federal Government pay 100 percent of the cost, you will have to put more kinds of controls in the program.

Let me first discuss the basic point you mentioned.

Yes; as long as this program is financed on a roughly 50 to 80 percent Federal matching with the large State only getting about 50 percent of the total cost, under present circumstances with medical care costs rising so rapidly, they have been under a very, very difficult handicap in improving or extending the medicaid program.

Now, let me tell you one thing, though, that happened. In that original medicaid law in 1965 Congress adopted a provision that the States had to show a continued increase in the program as part of the condition of getting their Federal funds. a constant improvement.

The Ways and Means Committee and the Senate Finance Committee both accepted that amendment and it was in the law until about either 1969 or 1970, after I left. It was then repealed on the recom-

60-800—75——5

mendation of Governor Rockefeller on the grounds that New York could not possibly continue to implement progressive implementation of the medicaid program within its financial budget and Congress repealed the requirement.

Well, that gives you some indication of the financial problem. I would therefore say either the 50 percent must be raised to 75 percent, as it is in other programs or you would have to design the program in such a way that the Federal Government would pay more of the cost. That is the only way I can see within its orbit of improving the coverage along the lines of what Congressman Metcalfe would like to achieve.

Mr. OTTINGER. Let me ask one other question, and then I will turn to the rest of the subcommittee members.

Does it make any sense at all to penalize the state in either its medicaid fund or its overall human services fund for failure to adequately implement a statute such as this which was suggested by one of the witnesses, that perhaps we should penalize some other kind of funds.

Somehow, or other, it is hurting the very children that your program is intending to benefit. We see this in a number of programs.

I know that you have been the author of many of these programs where remedy for failure of the State to take proper action is to cut programs for poor people.

The Federal Government is very reluctant to cut those programs because it is the poor people who are going to be hurt and it does not seem to be very effective.

I should like to put in the record at this point the record of that, the actual assessments of penalties have been made but they have not been enforced in many instances because of his reluctance.

I understand counsel has two documents to show that without objection I will put those in the record at this point.

[The documents referred to follow:]

EXHIBIT 4

STATEMENT BY CASPAR W. WEINBERGER, SECRETARY OF HEALTH, EDUCATION, AND WELFARE, JUNE 2, 1975

As some of you are aware, the program of Early and Periodic Screening, Diagnosis, and Treatment of low-income children is one of the highest priorities of this Department. The law prescribing the screening and treatment was enacted in 1967. When I joined the Department in early 1973, I found that few children had been screened and treated any many States were moving slowly, if at all, to implement the law. I quickly made the program a top priority of the Department and undertook a personal commitment to get these disadvantaged children the medical attention they need.

The Congress also put some new teeth into the law, and prescribed that, beginning this fiscal year, States which failed to implement the program adequately for welfare children would be assessed a penalty of one percent of their Federal share of costs under the Aid to Families with Dependent Children program for each quarter of the year in which they failed. After careful review, I am now applying the first penalties under that law against seven States that have failed to carry out one or more of three key actions—informing, screening, and treating—necessary to bring medical care to eligible poor children during the July through September quarter of this fiscal year.

Hawaii, which failed its obligation to inform AFDC families, a penalty of $75,847.

Indiana, which failed its obligations to inform AFDC families and to screen children, a penalty of $143,516.

Minnesota, which failed its obligations to inform AFDC families and screen AFDC children, a penalty of $280,997.
Montana, which failed its obligation to inform AFDC families, a penalty of $27,889.
New Mexico, which failed its obligation to screen AFDC children, a penalty of $70,646.
North Dakota, which failed its obligation to inform AFDC families, a penalty of $26,206.
Pennsylvania, which failed its obligation to inform AFDC families, a penalty of $1,048,441.

These States are not necessarily the only ones that failed to conduct the three basic steps of informing families, screening, and treating medical defects in AFDC children during the first quarter. Some other State programs are still under review and penalties against them may be applied soon.

I hope that the seven States cited today have or will act promptly to correct their deficiencies. Our purpose is not to penalize but to bring medical attention to these children early so as to prevent long-term incapacity and dependency as well as to avert suffering.

Most States are now moving ahead on the EPSDT program. Altogether, the States screened and treated fewer than two million children in the preceding years. This fiscal year our goal is to screen and treat three million but there are a total of about 13 million eligible children in the country, and we have a formidable task ahead of us. I'm confident it can be done, with incalculable long-term benefits to the nation.

HEW News Release

California has been assessed a penalty in the tentative amount of $1,926,439 for failure to take action required by law under the Federal-State medical program for low-income children during July to September 1974, HEW Secretary Caspar W. Weinberger announced today. California thus becomes the eighth State to be penalized for not carrying out requirements of the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program.

John A. Svahn, Acting Administrator of Social and Rehabilitation Service, said that California did not fully carry out activities with respect to the informing, screening and treatment of its eligible poor children—all of which are necessary to the delivery of both preventive and remedial health care services. That assessment was based on the State's EPSDT program compliance in the first quarter of FY 1975.

Under the law, States which fail to implement the EPSDT program adequately are penalized one percent of their Federal share of costs under the Aid to Families with Dependent Children (AFDC) program for each quarter of inadequate performance. California will have an opportunity to apply for reconsideration of the ruling.

Other EPSDT penalties were announced June 2 by Secretary Weinberger against seven States: Hawaii ($72,904); Indiana ($143,516); Minnesota ($280,997); Montana ($27,889*); New Mexico ($70,646); North Dakota ($26,206); Pennsylvania ($1,048,411).

However, Secretary Weinberger stressed that the purpose of the program is not to penalize States, but to provide needy children with medical attention at an early stage to prevent long-term ill effects.

Mr. Svahn emphasized that he considers the EPSDT program one of the highest priorities of HEW.

California was cited in part for the following reasons:

Informing.—The State failed to inform all eligible recipients of the availability of EPSDT services. Although it mailed out a "check stuffer" notice at the close of the first quarter which met at least minimal regulatory requirements, it failed to include in that notice those AFDC eligibles who were members of Prepaid Health Plans (PHPs). Notification to his group of recipients (which constitutes about 14 percent of the State's eligible AFDC population) did not occur until November 13, 1974. The State admits that PHP members were not included in the first quarter mass mailing, but argues that notification was accomplished, nevertheless, through alternative means. With few exceptions, however, the State has failed to substantiate its rebuttal on this issue.

Screening.—California generally failed to make screening services available to eligible recipients and in many cases did not undertake even the most rudimentary steps to assure that where screening was provided that it was done so on a timely basis.

Treating.—California could not assure that treatment services were being provided on a timely basis after screening results were complete, or that there were complete lists of treatment providers made available to those recipients in need of treatment.

Mr. OTTINGER. It does seem to me that we have to have some better method of enforcement. I wonder if you have any ideas on that?

Mr. COHEN. First, I am not in sympathy with the idea of the penalty provision in the form in which it is in present law.

I can understand Secretary Mathews' point of view which I suppose distresses other members of the committee about enforcing a kind of penalty which may adversely affects the program and the people it serves.

Now, if you were going to have it, I would apply, in my opinion the penalty to Federal revenue sharing. That would be a much more effective way to get state cooperation.

If you want the Governor and the legislature to cooperate in doing this, which is what you need, the budget director, the Governor, the legislature, reduce Federal revenue sharing to the States about 10 percent and you will get them to cooperate in this program. They probably might not care if you reduce the aid to the families for dependent children 1, 5, or 10 percent. They might be happy in some States if you cut it 50 percent.

I think therefore the penalty that is in the law is the wrong approach. It has not produced the kind of result that the Congress wants or any of us wants in connection with the program. It puts the penalty in the wrong place at the wrong time under the wrong circumstances.

I believe it goes back to the point I mentioned that if you want to get cooperation from the States to effectuate the program, then you have to have a good rapport between the people who are administering the program.

I just have to say this because I spent 25 years of my life trying to make the Federal-State program work. During the last 5 years it has collapsed in HEW. There has been a virtual disintegration of the cooperative approach between the Federal Government and the States under an administration which was committed to try to help the States.

I don't understand it. I think it has been tragic. The best I can say is that if Secretary Mathews can turn that around in health and in education, he will be making a tremendous contribution in his tenure. That is where we ought to work on it—on the administrative side of the State people in charge. They want to do a good job.

The State people are not against the program. They have financial problems, administrative problems, staff problems.

If you work with them, the program would be a lot better than it is today.

Mr. OTTINGER. Thank you very much, Mr. Secretary.

I have a conflicting obligation. I will turn over the Chair to my colleague from New York, Mr. Scheuer.

We appreciate your being with us.

Mr. COHEN. Thank you.

Mr. SCHEUER [presiding]. I have a few questions for you, Mr. Secretary, but before I ask them, I am going to recognize my colleagues on the Democratic side.

As an old friend, let me say that it is a great pleasure to see you and to have the benefit of your counsel and wisdom.

Congressman Sharp.

Mr. SHARP. Thank you very much, Mr. Chairman.

I am very much concerned with what you have said about the distintegration of the Federal-State cooperation.

I recently met with hospital administrators in my district, several of whom said for years they have worked and actually looked rather favorably on what the Federal Government was doing.

In fact, several of them said: Now they are the enemy of the Federal Government and that from here on out, they intend not to cooperate; they intend to frustrate, a couple of them indicate, the efforts of the Federal Government because they said what they have seen in recent years is on again, off again regulation, increased paper work with little apparent result from their point of view of improvement in basic health care delivery.

Essentially, all they have gotten is more penalties, more regulation.

I guess I am speaking of frustrations and asking you if you see a way in which we can restore that cooperation.

I assume one problem is in personalties involved. Obviously, you have to have that commitment, and that spirit but perhaps we have seen too much Federal arrogance in process of defending these programs and not enough understanding that somebody on the local scene might have some ideas and might be trying to do a good job.

Mr. COHEN. I have lots of suggestions; some of which I have already passed on to Secretary Mathews at his request.

Let me say, your point is absolutely well taken. It is not only the hospital program, the Hill-Burton program; it is not only the medicaid program. It is the AFDC program; the whole social service implementation of title XX that is now going on.

There is a kind of attitude of confrontation with the States and the kind of adversary relationship that has permeated the situation in the last 5 years, which I must say I never knew in the previous 20 years that I was there.

I think it is very unfortunate. I will just give you two illustrations:

Mr. Weinberger would issue regulations before any State person ever was consulted in their formulation.

Now, there is no Federal law that says he has to do it but I think any good administrator before he asks for more paper work and more responsibility, will get a better response from people if he consults them beforehand and irons out the bugs.

The last two regulations Mr. Weinberger issued on the day he left the States had never been seen by State agencies before.

I might add that this is a very nonpartisan thing because States with Republican Governors feel exactly the same way about this as Democratic Governors. It is not a partisan thing that I am discussing at all. It is a failure of participation.

I think that overemphasis on paperwork, failure of consultation, thinking of the States as if they were an adversary rather than a partner, requires a tremendous change in the whole way in which things are operating there.

Mr. SHARP. Thank you very much, Mr. Cohen.

I will give my colleague a chance to ask some questions.

Mr. SCHEUER. Congressman Santini, of Nevada.

Mr. SANTINI. In summary, might we say, Dr. Cohen, that there has been a deliberate sabotage on the part of at least some level of administrative direction within HEW in the past in terms of the health services programs that we are examining today?

Mr. COHEN. I don't want to use the word "sabotage," because I think it was a different conception of their role. The major responsibility, in my opinion for this failure is due to Mr. Dwight, who was the SRS administrator during that period of time.

He had a completely different conception of what the Federal Government's role and responsibility was. As, for instance, take a specific problem, in the outreach, searching out these children who are eligible. He said, no, that is not the Federal Government's responsibility to try to go out and beat the bushes to see who is eligible. Allow the States to do what they want.

My best source for that, by the way, is a very excellent article by John K. Iglehart, National Journal Reports, back in 1974, which quotes various people.

I am not making this up out of my mind or experience. But in there you will find that various things that were suggested by Mr. Newman——

Mr. SANTINI. Mr. Chairman, I ask unanimous consent that the document be identified for the record initially and then admitted as part of our evidence in this hearing.

Mr. SCHEUER. Without objection, it is so ordered [see p. 67].

Mr. COHEN. I think you will find this document more revealing than the GAO report because it cites people and quotations.

Mr. SANTINI. Would you identify the document again?

Mr. COHEN. This is an article by John K. Iglehart from the National Journal Reports of June 29, 1974, entitled "Health Report/HEW States Child Care Record May Affect Agency's Insurance Role."

If you will just give me a second to answer your question, I will try to give you a quotation.

For instance, here is a quotation in here:

> Mr. Dwight says, "SRS has a primary interest and obligation under the law to assure the availability of EPSDT service," but he maintained that the statute does not require the kind of aggressive outreach program that Newman and Rosoff envisioned.

Parenthetically, Mr. Newman was at that time an administrator of the medicaid program. Mr. Rosoff was the Acting Director of the Office of Child Development. He is the current Deputy Director.

> The Federal Government will not directly engage in outreach and will not require any State to engage in outreach to secure additional eligibility for the title 20 medicaid program, Dwight said in his memorandum dated February 14, this is a prerogative and choice which should be strictly limited to the States. The States are the operator of title 19 and their choice determines the scope of service and eligibility for title 19.

Now, I think it was that difference in philosophy about how you work with the States to effectuate a Federal Government responsibility that was largely the cause of a kind of laissez-faire doctrine here which resulted in exactly what Mr. Metcalfe said was true and what the GAO reported in its report.

Mr. SEGAL. Mr. Chairman, might I ask if the additional updated article from the National Journal, the date I believe is January 11, 1975 [see p. 74], also be put in the record at this time.

Dr. COHEN. I think that would be good to put the both together. You would have a very good story.

Mr. Iglehart, I might say, was a very conscientious investigator of this. He did a very good job, I think.

Mr. SCHEUER. Without objection, it is so ordered.

[Testimony resumes on p. 78.]

[The National Journal Reports articles referred to follow:]

[From the National Journal Reports, June 29, 1974]

HEALTH REPORT/HEW, STATES' CHILD CARE RECORD MAY AFFECT AGENCY'S INSURANCE ROLE

(By John K. Iglehart)

Nearly seven years ago, Congress directed the Health, Education and Welfare Department to design a plan for finding poor children with medical problems and providing treatment for them.

Two years ago, HEW still had not come up with a workable program and Congress imposed a July 1, 1974, deadline on the department, hoping to force faster action.

But despite the personal interest and involvement of HEW Secretary Caspar W. Weinberger, the department has no hope of meeting the deadline.

And its inability to cope with a relatively small slice of the total national health problem is raising doubts on Capitol Hill that it would deal effectively with a national health insurance program.

The program in question is Early and Periodic Screening, Diagnosis and Treatment (EPSDT), a small element in HEW's vast array of health missions.

It is difficult to pinpoint any single reason for the department's failure to meet the deadline.

Part of the delay has been caused by internal HEW bickering over the best approach. States partly are responsible because of their concern that they cannot afford a fully implemented program, which eventually could cover as many as 13 million children.

Either way, the delay has hurt HEW on Capitol Hill.

The department's unwillingness to persuade states to comply with the law raises questions about the department's ability to launch a national health insurance plan, a medical task of far greater magnitude.

The unwillingness of some states to implement EPSDT largely because of potential costs works against the Administration's argument that states should play a major role in administering and monitoring national health insurance.

"The performance of HEW and the states on EPSDT doesn't leave much to your imagination on how they might perform under health insurance," said an aide to Sen. Abraham Ribicoff, D-Conn., who was a leading sponsor of the child health plan in 1967.

"For all intents and purposes, Congress has given up on HEW's implementation of EPSDT within the context of the present medicaid program," said a House Ways and Means Committee official. "Congress now is prepared to federalize medicaid."

In its health insurance legislation (HR 12084, S 2970), the Administration has called for establishing two financing programs, one for the working population and another for nonworking and low-income groups.

The states would play a key role in financing the second program, a task that would give them more incentive to control costs, according to the Administration analysis.

Sen. Russell B. Long, D-La., chairman of the Senate Finance Committee, and Rep. Wilbur D. Mills, D-Ark., chairman of the House Ways and Means Committee, are advocating health insurance bills that call for federal administration of the program. States would have only a secondary role.

Mills told Weinberger at a health insurance hearing April 24:

"You are going to have a hard time convincing me that any state has administered medicaid as well as the Social Security Administration has administered medicare," Mills said. The EPSDT program is a part of medicaid.

Standing.—On paper at least, the EPSDT program enjoys priority standing with Weinberger. He has emphasized his interest in it at staff meetings and voiced concern in private conversations with ranking department officials that HEW's programs may be overemphasizing the older population at the expense of the young.

Moreover, implementation of EPSDT is one of the Secretary's program objectives for fiscal 1974.

In reality, though, the department never has committed the resources necessary to aid or prod states to implement the program. A telling statistic is the number of staff members which HEW has assigned to the task.

Seven professional staffers work on EPDST in Washington, but four have decided to leave or have left HEW. In the department's 10 regional offices, one staffer, on the average, is responsible for working with the states in each region.

HEW never has been able accurately to estimate how much states spend for EPSDT because the funds flow from a general pot of medicaid money that will total in excess of $10 billion in fiscal 1975. The department does estimate that 30 per cent of these monies are spent for children's health services of all kinds.

Under the program, which was first authorized by the Social Security Amendments of 1967 (81 Stat. 821), states must inform all recipients of Aid to Families With Dependent Children (AFDC) of "the availability of child health screening services." The eligible child population is estimated to number 13 million.

States also must "provide or arrange for the provision of such screening services" and "arrange for . . . corrective treatment." The services are financed under a medicaid formula which obligates the federal government to pay from 50 to 83 per cent of the cost; the states pay the rest.

Pressures.—Pressures are mounting on HEW to account for its efforts to implement EPSDT six and a half years after Congress authorized creation of the program.

Sen. Ribicoff asked Weinberger in a letter dated June 11 to describe in detail what the department has done to implement the program.

Further, court suits have been brought against 10 states, claiming they have failed to implement the program fully. The states are California, Colorado, Connecticut, Illinois, Indiana, Michigan, New York, Ohio, Pennsylvania and Vermont.

Thus, with hope of meeting the statutory deadline of July 1 gone, with Ribicoff's expressed interest, and with the pending court suits, the department is going to have to develop a strategy for enforcing the stiff penalty which Congress mandated as a part of the Social Security Amendments of 1972 (86 Stat 1329).

Under the provision, HEW "shall" reduce by 1 per cent the federal payment to the Aid to Families with Dependent Children (AFDC) program of any state which fails to implement the EPSDT program.

With federal expenditures of $4.1 billion provided for the AFDC program in the President's fiscal 1975 budget, the financial pain of a 1 per cent reduction in a state's payment could be substantial.

Problems.—Full implementation of EPSDT has been stymied by a number of factors, the most important being concern at HEW and in the states over the potential cost of screening some 13 million eligible children for medical ailments and then providing corrective services.

States.—The federal-state medicaid program itself has been a significant impediment to the full implementation of EPSDT. Although financed primarily with federal dollars, medicaid really is a state program, or, more accurately, 50 state programs.

Within general federal guidelines, states select the kind and amount of services they wish to provide, determine the groups eligible for assistance, dictate the standards health-care providers must follows, set the levels of reimbursement and administer the program.

The commitment that states have made to the medicaid program varies widely. California and New York offer a broad range of benefits to medicaid recipients. In New York, the medicaid budget now exceeds that of the budget for aid to needy children (AFDC).

A number of states offer only the minimum range of benefits required by law: inpatient and outpatient hospital care, skilled nursing home care, physician care, home health services, laboratory and X-ray services, family planning services and screening and treatment of individuals under the age of 21.

Although EPSDT is one of medicaid's mandatory services, states have implemented it with the same varying degrees of enthusiasm that they have shown for the total medicaid program.

SRS.—The child health care program is only one of several that has been hindered by bureaucratic warfare between the director of the Social and Rehabilitation Service (SRS) and his career staff.

SRS Administrator James S. Dwight Jr. has established priorities which feature efforts to improve management of the welfare system and to purge the public assistance rolls of ineligible recipients of welfare funds. Dwight's prescription includes relentless budget cutting, both within SRS and in the programs it administers.

The SRS career staff has a totally different set of priorities, which favor liberalizing the agency's programs so that more, rather than fewer, low-income families receive federal help.

The conflict between Dwight and the SRS bureaucracy has generated turmoil within the agency. Staff morale is low and a number of recent resignations have resulted, including thosee of Howard N. Newman, medicaid commissioner; Karen F. Nelson, medicaid's chief of program, planning and evaluation; Joseph Manes, medicaid's long-term care specialist; and Barney F. Sellers, head of EPSDT.

Congressional discontent with Dwight's stewardship of SRS also is mounting. The best reflection of it was in the passage May 21 by the House of a bill (HR 14225) that would remove the Rehabilitation Services Administration, the most popular SRS program, from that agency and place it in Weinberger's office. The vote was 400–1.

Earlier in the year, Congress removed the Administration on Aging from SRS and placed it in the Secretary's office because, in the view of legislators, Dwight's support of the program was weak.

EVOLUTION

The history of the EPSDT program is a textbook example of what happens to a program which Congress authorizes—and then rarely tends to—and to which the executive branch never fully commits itself.

The problems of a lack of financial resources, an absence of available screening services and the inability of states effectively to link eligible children with services which are available all have stood in the way of fulfilling a commitment which President Johnson first articulated in a message to Congress on Feb. 8, 1967.

Mr. Johnson outlined a 12-point welfare program which included a commitment to "expand our programs for early diagnosis and treatment of children with handicaps."

The President noted that nearly 500,000 children were receiving treatment at that time under HEW's health program for crippled children, but he said "more than twice that number need help."

"The problem is to discover, as early as possible, the ills that handicap our children. There must be a continuing follow-up and treatment so that handicaps do not go neglected," Mr. Johnson said.

EPSDT was sold to the President by former HEW Secretary (1968–69) Wilbur J. Cohen, when he was the department's undersecretary.

Chairman Mills scheduled hearings before the Ways and Means Committee a week after the message. And by Aug. 17, the House had passed the Social Security Amendments of 1967, which included a provision that required states to screen, diagnose and treat the medical ailments of children of low income families starting July 1, 1969.

The Senate Finance Committee approved similar legislation and the program cleared Congress on Dec. 15 of that year. President Johnson signed the bill into law Jan. 2.

HEW dragged its feet in developing regulations to implement the program. But two and a half years later, the former SRS administrator, John D. Twiname, proposed "tentative" regulations for EPSDT which interpreted the law quite broadly.

The regulations stipulated that states were to provide screening services for all eligible children under 21. If ailments were found, the states were obligated to correct them regardless of whether the necessary treatment was a service normally provided under the medicaid program.

States strongly objected to the proposed regulations, arguing that the comprehensiveness of the services required would have a dramatic impact on state budgets.

As a result, HEW rewrote the regulations and watered them down. The new regulations instructed states to provide services to children that normally were a part of medicaid benefits which they offered.

HEW also said that states were obligated only to screen, diagnose and treat children under age six at the start, eventually expanding the program to serve all children under 21 years.

The Senate Finance Committee gave its blessing to the department's more restrictive interpretation of the law by including a provision in the Social Security Amendments of 1970 which conformed with the proposed regulations. These amendments, however, never became law.

Finally, almost four years after President Johnson signed into law the Social Security Amendments of 1967; former HEW Secretary (1971–1973) Elliot L. Richardson approved EPSDT regulations on Nov. 4, 1971, to become effective 90 days later.

Congress showed its concern over the lack of movement on the part of HEW and the states to implement EPSDT when it approved as part of the Social Security Amendments of 1972 a provision imposing a tough penalty on jurisdictions that did not meet the statutory requirements.

But, on the whole, Congress has paid little attention to the program. Besides Ribicoff's letter, the most recent expression of congressional interest in EPSDT was voiced by Rep. David R. Obey, D-Wis., a member of the House Appropriations Subcommittee on Labor-HEW.

At a hearing April 24, Obey pressed Dwight to explain why HEW's implementation of EPSDT never has gotten off the ground.

CONFLICT

HEW policy makers always have been at odds over the degree to which the department should commit itself to implementing the EPSDT program. There are essentially two schools of thought on the question.

One school advocates an aggressive approach to implementation, "beating the bushes to link the children with the services," said one HEW official who supports this approach.

The other school frowns on such tactics and maintains that HEW should adopt a passive role, not going out of its way to advertise the program and not forcing states to implement it fully.

The two schools clashed last year through internal department memoranda and the result has been a middling approach to the implementation of EPSDT.

Newman memo.—The seeds of conflict were planted by a memorandum dated Dec. 12, 1973, from medicaid commissioner Newman and Saul R. Rosoff, acting director of the Office of Child Development, to their program chiefs in HEW's 10 regional offices.

Newman and Rosoff announced that they had agreed to fund some 200 demonstration projects that would utilize private, nonprofit Head Start agencies "in making EPSDT services available to medicaid eligible children ages 0-6."

Newman and Rosoff noted that the medicaid and Head Start programs had "common bases" which could facilitate implementation of the EPSDT program. They continued:

"Both agencies serve low income families. Both are concerned with continuity of health care and have the similar objective of integrating services provided through all available state and local resources. These similarities set a common frame of reference that can generate a wide range of local collaborative activities. Therefore, medicaid and Head Start are initiating a collaborative effort."

Although the language was bureaucratic, Newman and Rosoff were saying that HEW would institute an aggressive program that would seek out low-income youngsters to undergo medical screening and receive corrective services, if necessary.

"Head Start will refer potentially eligible Head Start children to medicaid for enrollment and medicaid will pay for needed health services as required by EPSDT regulations," the memorandum said.

Dwight rebuff.—SRS Commissioner Dwight learned of the Newman-Rosoff memorandum some weeks after it had been sent to the department's regional offices. Several states, an HEW staffer said, including Connecticut and Texas, had expressed concern to Dwight that the new EPSDT-Head Start project would force these jurisdictions, against their will, to expand the screening program.

On Jan. 10, 1974, Dwight wired SRS's regional commissioners: "Disregard the 12-12-73 memorandum from Howard Newman and Saul Rosoff, 'collaboration between selected Head Start grantees and state local medicaid agencies for delivery of EPSDT services.' That memorandum has not received SRS clearance and should be considered only as a recommendation to me."

Dwight also asked regional commissioners to comment on the Newman-Rosoff proposal. One month later, he issued another memorandum to SRS regional commissioners which essentially outlined the passive approach toward implementation of the EPSDT program.

Dwight said that "SRS has a primary interest and obligation under the law to insure the availability of EPSDT services," but he maintained that the statute does not require the kind of aggressive outreach program that Newman and Rosoff envisioned.

"The federal government will not directly engage in outreach and will not require any state to engage in outreach to secure additional eligibility for the Title XIX (medicaid) program." Dwight said in his memorandum, dated Feb. 14. "This is a prerogative and a choice which should be strictly limited to the states. The states are the operator of Title XIX and their choice determines the scope of service and eligibility for Title XIX."

Dwight directed that the "primary emphasis" of the 200 Head Start demonstration projects be to make EPSDT services "available to medicaid eligible children who are also enrolled in Head Start" rather than encouraging these children to enlist in the program.

But recognizing, as Dwight put it, that "out reach is inevitable in such a project," he directed that state medicaid directors and Governors would have to approve individual demonstration projects "before this activity is initiated in any state."

Dwight oversees medicaid and SRS' other programs while adhering to a view that for HEW to prod states to take actions they essentially do not want to take is an unproductive exercise.

"I have an affinity for how to get states to do something—otherwise I have wasted five years of my life." Dwight said in an interview. "If we start dictating procedures to the states then we will get ourselves in trouble."

Dwight came to Washington in 1972 to work as an associate director of the Office of Management and Budget. Before that, he served in California as a deputy finance director in the administration of Gov. Ronald Reagan, R.

Dialogue.—Dwight's plan for limited implementation of the program, as outlined in his Feb. 14 memo and as evidenced in the number of people he has assigned to the task, is the subject of mounting debate within HEW.

The issue has been a topic of discussion at two of the Secretary's recent management meetings. Weinberger regularly holds such sessions to keep track of objectives which HEW's agencies establish through a system of management that the Administration has adopted in most executive departments.

The system is known as management by objective (MBO). Under MBO, the departments each year must set objectives and, once they are approved by the Office of Management and Budget, mold their operations to accomplish the stated goals. (*For a report on MBO, see Vol. 6, No. 17, p. 609.*)

Weinberger meetings.—At the Secretary's management meeting Jan. 15, Stanley B. Thomas Jr., assistant HEW secretary for human development, brought up the issue which had arisen over utilizing Head Start grantees to implement EPSDT.

Dwight explained that he had rescinded the Newman-Rosoff memo because of complaints from a number of states about the use of private Head Start grantees as an outreach vehicle for state-run EPSDT programs.

The ensuing discussion revealed that the key issue was the extent to which the availability of EPSDT services should be advertised by HEW, and thus generate additional demands on state medicaid programs without state consent.

Weinberger concluded the discussion by directing Newman, Rosoff and Dwight to reconcile their differences, or, failing that, submit a memo to the Secretary on the issues involved.

The concern expressed by Thomas about the implementation of the EPSDT program was echoed two and a half months later by Bernice L. Bernstein, director of HEW's New York regional office, at another management meeting March 28.

Dwight led off the discussion on EPSDT by reporting that his agency had been overly optimistic in setting a goal of screening two million children in fiscal 1974. A more realistic estimate, Dwight said, would be the screening of from 1.2 million to 1.4 million children.

At that point, Mrs. Bernstein, who was speaking for all of HEW's regional directors, said that a lack of commitment on the part of SRS to provide adequate field staff to implement EPSDT was a major problem. She also called for more active involvement in the task by the office of Dr. Charles C. Edwards, assistant HEW secretary for health.

Dwight replied that SRS was not able, unfortunately, to provide additional medicaid staff members to the regions because all employees were fully committed to higher priorities until July 1975. He said the situation could worsen for EPSDT implementation.

Weinberger concluded the meeting by emphasizing his strong commitment to implement EPSDT. The official m' es of the meeting read:

"The Secretary stressed that t . is an extremely important objective which should not fall short of achievement due to inaction or delay on the part of HEW. He expressed his strong desire that regional PHS (Public Health Service) personnel take an active role in assisting states to implement this program. . . ."

Young memo.—More recently, John D. Young, HEW's assistant secretary-comptroller, also has questioned whether the department's implementation of the EPSDT program complies with the law.

Young, according to several SRS staffers, sent a memorandum to John R. Ottina, assistant HEW secretary for administration and management, suggesting that, in light of the July 1 deadline, SRS's management objective for implementing the EPSDT program be strengthened.

Young said in the June 5 memo:

"The SRS proposal to make available EPSDT services to eligible children and to screen three million children should be reconciled with the legal mandate to provide screening for all children, in other words eight million plus.

"Now that push has come to shove, as far as the financial penalty is concerned, we suggest that SRS invest much more than $40,000, which in budget terms represents two man years, in the effort.

"Also, the OPS (Operational Planning System) objectives should detail how SRS will monitor EPSDT and apply financial sanctions where necessary. The plan should also include development of a tracking system to indicate whether health screenings are actually followed up with by diagnosis and treatment."

Young was making reference to the MBO management system. Ottina and Thomas S. McFee, his deputy for management planning and technology, are responsible for administering the internal management system.

The implementation of the EPSDT program was a management objective established by the SRS in fiscal 1974. McFee said in an interview that because of Weinberger's commitment to the goal it likely would be upgraded in fiscal 1975.

It was SRS' first crack at upgrading the objective which Young questioned. Dwight had suggested that the "resources required" to operate EPSDT in fiscal 1975 totaled $2.6 million, including $40,000 for the salaries and expenses of two staff members.

STATES

HEW's grudging commitment to the children's health program has been reinforced to a large degree by the states, which have feared from the beginning that EPSDT would only add to what was already an onerous financial burden—medicaid.

States have recognized the problems which exist, according to Howard Newman, but they have failed to correct most of them because of a concern over the potential cost.

In a speech March 12 to the National Health Forum, Newman said:

"There was universal acknowledgement of the need for comprehensive health services for poor children, and that such services were not readily available or accessible to the needy.

"Today, many of those problems still exist. In certain areas, a child in a poor family has only half the chance of those with higher incomes to live to his or her first birthday. Half of all poor children are not immunized against polio. About

two-thirds have never been to a dentist. And poor children have three times more heart diseases, seven times more visual impairment, six times more hearing defects, five times more mental illnesses than the more affluent," Newman said.

He said that EPSDT got caught in the squeeze between rising welfare expenditures and the states' concern over the potential cost of the screening program.

"States were reluctant to embark on this venture, and the federal government was reluctant to insist. The number of welfare program recipients had been increasing steadily and the bulk of this increase was in the addition of children whose families needed public assistance... Despite its obvious long run, and even short run, benefits, EPSDT posed a problem for public budgets," he said.

Links.—Beyond the problem of its potential costs, EPSDT posed a significant obstacle for medicaid programs that never had been called upon to develop services. To make the vital link between providers of care and the intended recipients was a new and foreign task for state medicaid programs.

Medicaid was established in 1965, primarily as a federal-state mechanism to finance the cost of the basic health needs of some 27 million poor Americans. Many state programs are not equipped to manage the development of new service programs within the context of medicaid, even if they had the money.

But pressed by court suits, a number of states now are committing new resources to develop the EPSDT program. The states which have most impressed HEW with their efforts to implement EPSDT are Alabama, Iowa, Michigan, Missouri, Mississippi and Virginia.

In California, the EPSDT program helped influence the state legislature to enact a law which directed the state government to make screening services available to all children.

Texas has made a special effort to extend dental services to children eligible for the EPSDT program. Dental services are generaly the most difficult to attain of those services provided under the program.

New York.—New York has decided to step up its implementation of EPSDT, in the face of a court suit which charges the state with not developing a program and, as the result of the recent appointment to a high state post of Beverlee A. Myers, a former HEW official committed to EPSDT.

In a project that will start in September, New York State's Department of Social Services and Department of Health will strive to link children eligible for EPSDT with a comprehensive range of health services.

"The program began in 1972 in New York, but to date it has not been effective in reaching the target population," according to a state document which outlined plans to upgrade EPSDT implementation.

Through a marriage of New York's medicaid program and the regional medical program (RMP), another HEW enterprise which seeks to improve the health delivery system in a variety of ways, the state agency hopes to make the vital link between eligible children and screening services.

The agency plans to focus its efforts initially on approximately 450,000 eligible children in upstate New York. Medicaid funds would finance the screening, diagnosis and treatment services. But RMP monies would be used to identify the children and educate their parents to the merits of EPSDT.

New York spends more than $2 billion a year to finance health services under medicaid. It spends an average of $300 a year on individuals who participate in medicaid.

Mrs. Myers, a deputy commissioner of the State's Department of Social Services, rejects the notion that the EPSDT will be a costly endeavor for states. "We may well be able to reduce that $300 figure, or at least control how it is spent better, through EPSDT because it will encourage the delivery of more primary care and less hospital care."

"The program should demonstrate that a relatively small amount of flexible RMP funds can be used as leverage to make the expenditure of relatively large amounts of medicaid funds more effective," Mrs. Myers said in an interview.

In New York City, the state agency plans to follow two approaches to implementation. One is to inform parents of preschool children through letters of the availability of screening services, which are provided by New York City's Health Department.

Second, New York plans to screen older children through a linkage with the schools they attend, an approach which has not been used widely in other jurisdictions. Before New York can move forward with this approach, though, HEW must grant its approval because it will require the department to waive a program regulation.

OUTLOOK

Come July 1, Dwight said, HEW would be prepared to assess the penalty provided by law on states that have failed to implement the EPSDT program. But he said that "assessment of the penalty is an admission of failure" to put EPSDT in place.

SRS's apparent strategy, as reflected in Dwight's comments and the agency's MBO statement, is to grant states the benefit of the doubt on the question of implementation.

SRS's proposed MBO statement on implementing EPSDT indicates that the agency does not plan to move precipitately to impose the penalty.

For one thing, a lot of money is involved and a quick cut-off would bring screams of indignation from the states and their representatives on Capitol Hill.

Second, a reduction in the funds would only hurt those individuals who can least afford it—the welfare recipients. And third, Dwight is prepared to give states every benefit in finding ways to comply with the law, such as phasing in programs over time.

SRS's proposed MBO statement on implementing EPSDT shows that the agency plans to use the first three months of fiscal 1975 to assess which states have not complied with the law.

On Capitol Hill, meanwhile, a spokesman for Sen. Ribicoff said that he is prepared to take HEW to task if it fails to require states to comply with the EPSDT law.

[From the National Journal Reports, Jan. 11, 1975]

Health Report/HEW Plans to Fine States for Not Implementing Program

(By John K. Iglehart)

The Department of Health, Education and Welfare, though it has made only a token commitment to implement a 1967 children's health program, is preparing to penalize a number of states for failing to develop fully the same program in their own jurisdictions.

HEW plans to impose the penalty, as required by the Social Security Act, on about a dozen states which it believes have failed to implement the department's beleaguered Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.

In a separate development, the General Accounting Office (GAO) underscored the problems of EPSDT implementation in a report released Jan. 8 which criticized the efforts of HEW and some states in carrying out the program.

Rep. Ralph H. Metcalfe, D-Ill., who ordered the GAO examination, said in a statement:

"(HEW) Secretary (Caspar W.) Weinberger owes the Congress an explanation of why he did not see fit to provide for the physical well being of these children. . . . I intend to see to it that these children, their parents and the Congress hear from the Secretary why this vitally important program was delayed for so long."

PROGRAM

Under the program, authorized by the Social Security Amendments of 1967 (81 Stat 821), states must inform all recipients of Aid to Families with Dependent Children (AFDC) of "the availability of child health screening services." An estimated 13 million children are believed eligible for the program aimed at detecting and correcting health problems.

The law says the states must "provide or arrange for the provision of such screening services" and "arrange for . . . corrective treatment." The services are financed under a medicaid formula that obligates the federal government to pay from 50 to 83 per cent of the cost; the states pay the rest.

Weinberger.—HEW's lack of progress in implementing EPSDT is contrary to a commitment Weinberger made five months ago when he promised to step up the department's efforts to develop the program. Weinberger told state officials at regional meetings on EPSDT implementation that HEW would assign additional manpower for the task.

Then HEW Undersecretary Frank C. Carlucci made similar promises Aug. 16 in a San Francisco speech to state health officials. "We have set aside 125 job slots specifically for the medicaid children's program (EPSDT)," Carlucci said.

"We are making this commitment at a time when agency job ceilings are in effect and positions are scarce, so this should give you an idea of our determination to move this program ahead."

Despite Weinberger's stated commitment, he declined on Dec. 24 to fulfill a request to increase the EPSDT staff by 35 people, or a little more than half the number he agreed to allocate three months earlier.

In early January, it looked as though the program would get 35 new positions anyway through the intervention of James S. Dwight Jr., administrator of HEW's Social and Rehabilitation Service (SRS).

Dwight allocated 90 new positions to medicaid, and its commissioner, M. Keith Weickel, said he would assign 35 of these slots to EPSDT. The positions were authorized under the fiscal 1975 Labor-HEW appropriations bill. Under the legislation, Weikel said, the positions must be assigned to HEW's Washington headquarters.

Weinberger's failure to approve the new positions himself reflects HEW budget constraints and the Secretary's apparent unwillingness to bolster EPSDT by shifting manpower from other programs.

States.—While progress at HEW has been negligible, a number of states that previously neglected EPSDT has committed new resources to the program, although HEW staff members who reported this could not immediately document it.

One pressure pushing the states to act is concern over the statutory penalty HEW plans to impose and court suits pending in 10 states which claim these jurisdictions have failed to implement the program fully.

A potential fallout from the failure to implement the program is the effect it has from the standpoint of influencing congressional attitudes on the role states should play in a national health insurance program. The Administration's proposal, which HEW developed, places states in a prominent role.

But Members of Congress who favor a program dominated by the federal government point to lack of EPSDT implementation to support their opposition to the Administration's plans to vest states with major powers under national health insurance.

GAO REPORT

The program to detect and treat illnesses in poor children has been neglected since its birth in 1967 as part of amendments to the Social Security Act. (*For details on EPSDT's early history and more recent problems, see Vol. 6, No. 26, p. 969.*)

The failure to implement EPSDT moved Metcalfe to ask the General Accounting Office, an investigative arm of Congress, to examine the program. Between June and December 1973, GAO investigators checked the EPSDT program in Alabama, Idaho, Illinois, Massachusetts, Oregon, Rhode Island, Washington and Wisconsin. GAO investigators also reviewed the status of the program at HEW headquarters and at regional offices in Boston, Chicago and Seattle.

In its report to Metcalfe, the agency said:

"States are required to provide EPSDT under their medicaid programs. This requirement is to get states to get more actively involved in preventive health care by identifying and treating medical problems early. In the long run, the EPSDT approach has great potential for reducing the incidence of long-term, costly medical care.

"HEW has been slow in developing regulations. Also, HEW has not aggressively tried to make states comply with the law and federal regulations. Both HEW and the states have been concerned also with the potential cost of providing EPSDT. As a result, only a small percentage of the eligible children have been screened.

"As of June 30, 1973, three of the eight states had not started EPSDT screening, and EPSDT screenings had been provided to only 58,000 of the 1.8 million eligible children in the eight states. EPSDT screenings that have been performed appear to effectively identify health problems."

Outreach.—Guidelines issued by HEW recommended that each state actively seek eligible children by:

informing parents that these services are available and when and where they can be obtained;

helping parents understand the nature and purpose of the screening program;

enlisting community agencies to locate children eligible for EPSDT services;

providing the necessary transportation to the services.

The GAO said it found "a wide variety of outreach methods" and reported that states with the most aggressive methods had higher screening rates.

"For example," it said, "most of the areas in Idaho and Alabama were using a variety of outreach methods and, statewide, had higher screening rates than Illinois and Washington which had done little more than mail EPSDT inserts to families with eligible children."

Texas.—The University of Texas Medical School's Regional Health Services Research Institute conducted an EPSDT "impact and evaluation study" in communities in eight states, other than those examined by the GAO.

"The (Texas) study showed that the average rate of children who appeared for screening was highest in those localities where families were personally contacted," the GAO report said.

Allied health.—EPSDT program guidelines promulgated by HEW provide that screening should be performed under the supervision of, or with consultation from, physicans, dentists, optometrists and other specialists. However, in some states a lack of available personnel is said to have inhibited the development of the program.

"Those shortage areas that extensively used allied health professionals to perform EPSDT screened more children than shortage areas that used only physicians," the report said. "For example, in one area in Washington, few children were being screened because only two doctors were providing EPSDT, and allied health professionals were not being used.

"In contrast, in many areas of Alabama, doctors were not available so public health nurses were doing the screening. The percentages of children screened in these areas were as high as 62 per cent."

"The number of children screened could be greatly increased nationwide if HEW would encourage the states to use more allied health professionals in the screening process," GAO concluded.

Treatment.—The Social Security Act requires states to arrange treatment of medical problems discovered through the screening procedure. But because most states lack adequate tracking systems, most jurisdictions "generally did not know whether these children were being treated," the GAO said.

"Several states had plans for computerized systems which could monitor the health care received by children, but at the time of our field work only Alabama had an automated follow-up system which could be used statewide," the report said.

"We recommend that the Secretary of HEW direct the administrator, SRS (Social and Rehabilitation Service), to require the states to establish procedures to follow up on children with problems identified during the screening process to insure that needed treatment is provided."

HEW performance.—The GAO criticized HEW for its lack of commitment to implementing EPSDT, the screening and treatment program. "As a result of this and the states' concern about the cost of providing EPSDT, the states have been slowly implementing EPSDT and only a small percentage of the eligible children have been screened," it said.

GAO also chided HEW for its slowness in promulgating EPSDT program guidelines, saying that only "growing congressional concern and a court suit against the Secretary encouraged HEW to issue final implementing regulations."

"In those cases where the states are not complying with the law or SRS regulations, we recommend that the Secretary require . . . more aggressive action, including formal compliance hearings, to bring these states into compliance," he said.

Program impact.—The deficiencies in HEW's performance have been recognized within the department for some time. Weikel, commissioner of HEW's medicaid program, said in an interview, "Most of the things in the GAO report we are trying to implement. Obviously the GAO made some valid points."

An HEW official said privately, "The document will have some real value because it will attract congressional attention. That will be helpful at this point."

State reaction.—Before the GAO released its study, the eight states examined by the agency were granted the opportunity to comment on the report. "Each of the states responded and generally agreed that our report was accurate as of the time of our fieldwork. However, they said that much had been done since that time to implement EPSDT."

Alabama.—Alabama's medicaid director "agreed that the cost of the EPSDT program concerns all the states but he said that the major problem in Alabama's program implementation is the incapacity of available providers to screen, diagnose and treat the large number of eligible persons on a timely basis. . . ."

Idaho—The Idaho administrator told GAO that the state's program "has been expanded since the time of GAO's fieldwork and many of the problems cited in the report have been solved."

Illinois—The director of the Illinois Department of Public Aid told GAO that many children there "were receiving adequate medical attention under the state's medicaid program and that there was no need to screen these children."

Oregon—The director of the Oregon Department of Human Resources conceded that the state had no program. "He pointed out that there was no statutory or regulatory requirement for outreach or followup until July 1, 1974, the effective date of the Social Security Amendments of 1972."

Rhode Island—The director of the Rhode Island Department of Social and Rehabilitation Service told GAO that many children there were examined by physicians working outside of EPSDT.

Washington—Since the GAO's fieldwork, the director of the Washington Department of Social and Health Services said the state "has 146 providers of EPSDT services and has achieved statewide coverage."

Wisconsin—The secretary of the Wisconsin Department of Health and Social Services said that GAO's report generally reflected the situation then, "but a great deal has been accomplished since then."

MANPOWER ISSUE

Within HEW, a battle has been underway for five months to bolster the EPSDT implementation effort through increasing the staff, as Weinberger pledged.

Since making his commitment, Weinberger held two management meetings to discuss progress toward the goal. In the latest meeting Dec. 24, he declined to approve the allocation of new positions to EPSDT.

Though he did not shut the door completely to the request for new positions, he apparently had found no way to squeeze additional manpower from other HEW programs, and the Office of Management and Budget refused to allocate new positions for the program.

But now EPSDT apparently will be upgraded as a the result of a new commitment of manpower that Jim Dwight has made to implementing the program.

Meetings.—HEW's responsibility for implementing EPSDT has been debated in a series of meetings Weinberger has held over the last year.

During early discussions, program chiefs said the department has a legal obligation to fully implement the program. This position was presed by Howard N. Newman, who headed medicaid for four years before leaving in July 1974, and, to a lesser extent, by Stanley B. Thomas Jr., assistant HEW secretary for human development.

Dwight, administrator of the Social and Rehabilitation Service, the bureaucratic umbrella under which medicaid operates, was considered the major stumbling block to aggressive implemetation of EPSDT. (*For details on the early meetings and Dwight's role, see Vol. 6, No. 26, p. 959.*)

When Weinberger learned last June of the impediments to EPSDT implementation—a personal goal of the Secretary's—he sought an explanation from Dwight. In the course of these discussions, Weinberger directed SRS to revise its fiscal 1975 program objective for EPSDT so that more children could be screened.

The revision in the objective, if carried out, would mean a dramatic shift in EPSDT implementation. The first EPSDT objective advanced by SRS simply said:

"By June 30, 1975 assist the states to make available EPSDT services to 13 million eligible children, and to screen during that fiscal year at least three million of those eligible."

After Weinberger intervened, SRS upgraded its EPSDT program objective to read:

"By June 30, 1975 assist the states to make available EPSDT services to 13 million eligible children, and to bring into the health care system for screening, diagnosis and treatment (where indicated) during the first year for the first time at least three million of those eligible. This will increase the total number under EPSDT or equivalent care from 10 percent of the eligible population (end of fiscal 1975) to more than 33 percent."

To finance the greater effort, SRS estimated that salaries and expenses for the necessary staff would cost $2 million, a sharp increase compared with the funds needed to undertake the initially stated program objective.

60-800—75——6

In line with Weinberger's commitment to increase EPSDT manpower to 125 people, SRS identifed the need in September for 102.5 "man-years" to undertake the task. But on Sept. 26, Undersecretary Carlucci told Dwight that "a total ceiling of 65 positions for EPSDT could not be increased."

Dwight wrote an appeal to Weinberger. Responding, Weinberger asked SRS to justify an increase in the EPSDT staff, even though two months earlier he publicly had committed the department to enlarging the staff.

In a management meeting with SRS No. 20. Weinberger expressed dissatisfaction with the explanation of Dwight and asked for more information, according to HEW staffers who attended the session.

In an internal department memorandum dated Dec. 20. 1974, John R. Ottina, assistant HEW secretary for administration and management, backed the request by SRS for more personnel. The memo, prepared as a briefing paper for a meeting Weinberger held Dec. 24 to discuss the EPSDT staffing issue, said:

"Throughout the entire EPSDT effort, both at the central and regional office level, inadequate manpower has caused implementation delays and, in some cases, certain functions have received less than adequate attention.

"The present on board staff (15 central office, 20 regional offices) cannot perform adequately all the tasks which were originally projected to require a staffing level of 100 positions. Inadequate staffing at headquarters has caused problems in policy development, interagency coordination and program planning but inadequate regional staffing is especially critical:

"no regional office has its full complement of EPSDT personnel;

"all but two regions have unfilled vacancies

"three regions (Boston, Atlanta, Seattle) have only one EPSDT person on board.

"In addition to the other tasks required of regional office personnel (technical assistance, monitoring, penalty assessment, and reporting), the most immediate need is personnel to assist those states which are not in compliance with the EPSDT penalty provision to develop a corrective action plan."

Penalty.—In the face of a statutory requirement that states which failed to implement EPSDT fully be penalized. HEW is determining which jurisdictions have failed to abide by the Social Security Act.

Under the Social Security Amendments of 1972 (86 Stat 1329), HEW "shall" reduce by 1 percent the federal payment to the AFDC program of any state which fails to implement the EPSDT program by July 1, 1974.

With federal expenditures of $4.1 billion provided for the AWDC program in the fiscal 1975 budget, thefinancial penalty of a 1 percent reduction in a state's payment would not be cheap.

In New York, for example, a 1 percent reduction would amount to $8.7 million. In California it would amount to $8.3 million, in Illinois $4.3 million. Michigan $3.8 million, Indiana $800,000 and Wyoming $32,000.

Weikel said that "using the penalty is a double edged sword. The people who get hurt under it are most times the program recipients. We would rather encourage the states through a positive incentive."

But meanwhile, staff members of the EPSDT program are determining which states SRS should recommend for penalties.

Mr. SANTINI. Prior witnesses indicated that as a consequence of at least in part the failure of HEW to give any substantive reenforcement of program and direction of the program that Congress instituted with your guidance in 1965 that there would not now be 21,000, which is 10 percent of the 210,000, in State facilities for either the physically or mentally handicapped, who would not be there had there been adequate screening at the time?

Mr. COHEN. I don't know what the exact figure is. I think it is much larger than 10 percent, myself.

I can't prove that by any immediate statistics I have.

I think, tomorrow, when the HEW people and particularly Dr. Kretchmer who, I think, will accompany them from the National Institue of Child Health and Human Development will be here, you will get a better estimate.

I have always assumed in my previous studies on this that there is something in the neighborhood of 5 to 7 percent of the children born with some kind of physical, mental, or learning handicap, which could be prevented or cause less trauma or difficulty for parents of the children if there were early screening and diagnosis and treatment before the age of 6.

I think there is a whole host of areas. Let me give you one which is touched on in my paper which I have received from studies of the National Institute of Child Health and Human Development. Just take low birth weight alone. If we could overcome by further research how to raise the birth weight of children, it is possible, according to the estimates, that we could save about $1 billion a year in cost to parents and society, from just that one problem alone.

I think the whole problem of further research on improving that one aspect in early births, the problem of teenage mothers in association with that whole problem is well worth a good deal of further research on prevention.

I think all the way along, that problem, the mental retardation problem, dyslexia, you know, on the question of being able to read, and learning disabilities, if you encompassed all of those in the totality of physical, mental, educational and learning disabilities, in my opinion the prospect of savings to the Nation runs into the billions of dollars, Mr. Santini.

Mr. SANTINI. Dr. Cohen, I would like to ask you if to your knowledge—and you have already referred to the Comptroller General's report to Congress dated January 9, 1975, and I am informed that HEW has concurred in many of the recommendations contained in this report—to your knowledge has HEW done anything to date to implement any of the recommendations contained in that report?

Mr. COHEN. I do not know of my own direct knowledge which they have and which they haven't. But I have not seen in the end product any large scale result from that.

I think one of the problems involves the increase in the number of personnel at the central and regional offices to make that work.

I have a question in my mind whether that has been done. In any case, I would wholeheartedly support all of these recommendations for as prompt implementation as possible.

Mr. SANTINI. To your knowledge, Dr. Cohen, has Health, Education, and Welfare done anything to implement widespread use of the screening procedures that were contemplated by both you in your inspiration and Congress in its enactment 10 years ago?

Mr. COHEN. I think that I would have to say that my original enthusiasm and optimism when I first recommended this to President Johnson, in 1966, was that this would be a starting program for just what you talked about today, about eliminating all the preventable diseases and disabilities that occur to these 10 to 15 million low-income children. That has just not happened to the extent that I thought it would be feasible 10 years later.

I recognize the difficulties but I must say that we are very substantially far behind where I thought we would be by now.

Mr. SANTINI. Would it be fair to say in summary, Dr. Cohen, that virtually nothing of substance has been done to implement the screening procedures that were contemplated?

Mr. COHEN. I wouldn't want to go that far. I think what has been done so far on the screening—after all, 11 million children, this last year, received some kind of medical benefit under medicaid—I don't want to diminish that—out of 26 million people that received some kind of medical benefit paid for under the program.

Recognizing the financial difficulties of the States and these other problems, I think that is appreciable step forward, but not significant enough in my opinion for the earliest diagnoses and substantial treatment.

Mr. SANTINI. Dr. Cohen, I particularly want to express my admiration and appreciation for the quality and substance of your testimony to this committee. It is helpful as a foundation for further inquiry with other representatives from the agency who may be appearing to testify before us.

Mr. COHEN. Thank you, sir.

Mr. SCHEUER. Dr. Cohen, I would like to take you up to the mountaintop for a moment and ask of you a sort of philosophical explanation for one of the anomalies we face in designing a national health program today.

In America we have something over 10 percent of our population that is poor—that is 20 million Americans.

Looking at the children of the poor, we find that 50 percent more kids in poor families than in other population groups are not immunized against polio. Nine percent are mentally retarded by age 13. 40 percent have never seen a dentist by age 17. There are three times more heart attacks among the kids of the poor, seven times more visual defects, six times more hearing defects and five times more mental illness.

Now, my question to you is to what extent does the available data indicate that the higher incidence of disease, and almost all of this is preventable, is due to the lack of availability of health care to the lower socioeconomic classes? To what extent is this due to the lack of effective use of the existing health care system and to what extent is this due to the personal behavior and life style or let us say, the differences in personal behavior and life style, of the parents of these kids?

I will remark parenthetically that there seem to be enormous differences in health and infant mortality in England and Scotland among various socioeconomic groups, even though public health services are available to all.

In our own country, for example, there was one study done on the use of dental services by the poor as compared to the middle-income groups, and the only dental service that was used more by the poor than by middle-income people was tooth extractions, which is evidence of the failure of the system.

All other services involving preventive health were used far more by the middle-income members of this local health services delivery system.

In designing a national health program we know that we have a limitation on our resources. We are already spending 8 percent of GNP on health, and there must be some upper limit. It may be 10 percent, or 12 percent, or it may be the 8 percent we are spending now, but it is certainly finite.

We can't do anything. Do we spend our finite resources primarily in providing more sophisticated health services? Or do we also try to help people use more effectively the health services that are already available? Or do we try to have more of an impact on individuals' life styles, on diet, on exercise—for example, the use of alcohol, tobacco, drugs, and, of course, diet of women during pregnancy?

What is the mix, in other words, in the end product; namely, health? What produces good health? What should our priorities be in providing more sophisticated health services, in trying to utilize the system we have more effectively, in trying to have an impact on people's personal behavior and life style?

Or is it a little of everything?

Mr. COHEN. I think I would have to say it is a little of everything, because I guess I am the kind of person who believes I should diversify my portfolio if I could put it in those terms.

We need a lot more health education, particularly for teenagers, for instance. There is no question in my mind that a great deal of the problems that we are presented in the child field come from birth by 14-, 15-, 16-year-olds and the low birth weight and the mental retardation and the other problems, lack of parental responsibility and so on, flow from there.

I think there is a great deal for parent education in that area. I would do a lot about that.

At the same time, as I pointed out, I would put some more money into more basic research certainly to find out how to resolve quite a number of the problems.

I would put a lot more money into family planning services. If we are talking about what we were talking about a few minutes ago, I think the failure of HEW to put more money and the administration to put more money into the implementation of the family planning program where the cost-benefit results are simply tremendous, is important.

We are not talking there about billions. I am talking there may be another $25, $50, $75 million a year which would be significant; $10 or $15 million a year more for NICHD. These are not the big-spending programs. They are putting money into the research, the health, education, and the family planning areas which I think are very consequential. But that is not to say in my opinion that there are quite a lot of poor people who are not getting the same volume of health services that people with higher incomes get.

When you study that situation, annual doctor visits per person in 1973, were 3.8 for poor people and 4.3 for nonpoor people. So that poor people were obviously getting about a half of one physician visit per year less for all children under the age of 17.

I think that that is related in part to lack of understanding and accessibility to the health system.

But it is also related to the lack of facilities where mothers and children live. Here is my point on that. The reason I have always been a very strong supporter for neighborhood health centers, which I know you have been, is because for many women who are poor with young children, taking the child to get health services is a big logistic thing, especially if you have two or three children and you don't have

an automobile, and you have to go to some place where you wait a long time.

I think for child health services you must do even more than you do for adults to bring the health services physically in proximity to the family. You can't ask the mother or child to go 10 miles. You have to have those services in the community and they should be invested with a high degree of health education, family planning, screening, diagnosis, and preventive work.

So I guess my answer to your question is that I think we could do somewhat better on all the aspects you mentioned, particularly where the Federal Government's role is in stimulating the access to those services.

Mr. SCHEUER. I am particularly sensitive to what you say about the poor performance of the administration in supporting the family planning program.

I was the House author of the 1970 Population Research and Family Planning Act which had the support of George Bush, who was chairman of the Republican House Task Force on Population and Family Planning, and, of course, Joe Tydings in the Senate.

Being the only survivor of that trio in the Congress, it has fallen to me to push Federal appropriations for family planning and, particularly to generate some enthusiasm for it in the administration.

I am as perplexed as you are as to why the administration has been so indifferent to it and why it has imposed its policy of benign neglect on the family planning program.

There is no program today which will so enormously impact on the quality [illegible] in our country 15 years from now as family planning—preventing unwanted births.

As you said, the cost-benefit factor of a dollar of Government investment in family planning is absolutely spectacular when you consider the direct expenditures.

And this cost-benefit factor becomes overwhelming when you consider the indirect cost of the unwanted child to the Government, and the probability that costs of mental retardation, physical disability, and emotional instability will be concentrated in the low income sector of the population.

When you extrapolate the cost to society of taking care of those kids and their special education, health, and housing needs, and the cost of the unwanted kids in broken families who bump their heads, rather predictably, against the criminal justice system, it seems almost a mindless abberation not to help women who don't want to have any further offspring to achieve that goal or to space children according to the preference of the women.

There are anywhere from 3 to 4 million women in our country who still cannot get family planning—either the information or the techniques—in their neighborhoods, even though the goal of the 1970 Population Research and Family Planning Act was to reach within 5 years the estimated 5 million women of childbearing years who we felt then did not have this information. We have now completed the 5-year period and there are still at least 2½ million to 3 million women in this country who desperately need family planning and don't have it.

I did not mean to make a long speech, but I did want to indicate my sensitivity.

Mr. Lemov, do you have anything to ask?

Mr. LEMOV. No, Mr. Chairman.

Mr. SCHEUER. Mr. Segal?

Mr. SEGAL. I would like to ask two questions, Mr. Secretary: You mentioned cost containment as one of the issues that you felt should be required as the Federal share increased.

As you are well aware, this subcommittee looked extensively into areas of unnecessary surgery and the need for good utilization review criteria.

Would you think that that is an example of the kind of cost containment possibility you were referring to in a very general sense?

Mr. COHEN. Yes; of course, I favor an effective program of utilization review and professional standards review organiaztion.

I recognize the difficulty one has in persuading many physicians to undertake that responsibility, but I believe the two provisions in the existing law ought to be implemented more cooperatively with the physicians.

I would hope now that the AMA case against HEW on the utilization review has been withdrawn, HEW and the physicians can get together and discuss what is an effective utilization review standard and make that work. That, I think, is one of the big responsibilities for this next year or two.

Mr. SEGAL. Would you think HEW and Congress ought to develop stronger incentive programs than currently exist, particularly in line with your point about this program which is not an incentive program but a penalty program, that States ought to be given incentives to do things rather than penalties.

Mr. COHEN. One of the things I would do is to give an incentive for the program, talking about children, for paying primary physicians and pediatricians on a per capita basis rather than on a fee for services basis.

I think one ought to be able to work out with the American Academy of Pediatricians and Pediatrics in this country a kind of continuous care program for children which is what Dr. Green was really talking about a couple of hours ago, and pay the physicians not on a fee for services basis. Let me give you an illustration.

The average cost now would be about $250 per year per child to the physician: For every 12-month period, let us say $240 that is $20 a month per child, for each month that you agree to be responsible for the total basic primary care of a child, we will pay you $20 a month, $240 or $250 a year, whatever is mutually agreed upon.

Mr. SCHEUER. What would his kid load be?

Mr. COHEN. I don't know. Every time I say that, I get complaints from doctors who tell me it is too high.

I think on that professional question you ought to ask a pediatrician.

Mr. SCHEUER. This question is too important to be left to doctors.

Mr. COHEN. I understand.

I would say that if you include, of course, well baby care as well as sickness and so on——

Mr. SCHEUER. Also preventive.

Mr. COHEN [continuing]. Both for the kid and the parents—it is entirely possible that 1 physician could care in the course of a year for 750 persons.

Mr. SCHEUER. He would do well financially.

Mr. COHEN. That means not everybody is in. I am using a different kind of concept over the years, depending on how frequently he calls in a mother and child.

Mr. SCHEUER. At $240 a month for 750 kids, he would do considerably better than a Member of Congress.

Mr. COHEN. I produce in my paper the relevant figures from the Social Security report which show that the health expenditures for children under age 19 in 1974 was $183 for the United States, for everybody under the age of 19.

Mr. SCHEUER. Would you repeat that?

Mr. COHEN. Per capita expenditures for all personal health expenditures varied widely with age.

For children under age 19, per capita expenditures in 1974 were $183 compared to $420 for persons aged 19 to 64, and $1,218 for persons aged 65 and over.

That is in my testimony, produced from the study, the Social Security study on age differences in health care spending which you might like to look at.

Mr. SCHEUER. Eli Cohen, dean of the Columbia School of Business, told me a few weeks back, in New York City, that we are spending $2,500 a year per family on welfare for their health services.

Now, that would include many sick and elderly people, as well as women with good sized families.

But the mix produces a cost of $2,500 a year for the health care of people on welfare in New York.

Mr. COHEN. Could I make this observation, too, considering the three families that you had testifying this morning. My general thought is if everybody were to pay into some kind of fund over a long period of time, you average out the highest cost risks and the low cost risks. No parent knows, and here is the significant point, no parent knows, not a single one of those mothers that was before you today nor the father, knows whether they are going to have a mentally retarded child or not when their child is born or a child with a disability.

Mr. SCHEUER. Couldn't much of that be ascertained by tests during pregnancy—testing of the amniotic fluid?

Mr. COHEN. There are a lot of things that could be done, but basically, what I am trying to say is the risk of this tremendous economic and social tragedy is such that none of us who are parents really can say, because we are rich or because we have enough income or because we are healthy, we don't know the impact of the genetic, environmental, and other factors.

Mr. SCHEUER. We must socialize that cost.

Mr. COHEN. If you redistribute the cost over the sick and the well, the poor and the rich, the middle income and so on, we'll all be better off in the long run than the system we have now, which says, finance part of the cost for the poor along the lines you have, let somebody else take care of their own, and if it is a really high cost we will institutionalize the child.

That is not a very sensible approach in dealing with this problem.

Mr. SEGAL. Could I just conclude from the point you made about the capitation for a fixed annual amount for pediatricians, the next evolutionary step you would purpose would be to cover a population such as zero to age 6. This would provide for the Federal Government to pick up the cost, at the same time alleviate the State budgets and in the process provide the total comprehensive package of care necessary for children?

Mr. COHEN. Absolutely, Mr. Segal.

I think it would have these advantages: It would take part of this burden of financial cost of the States off the medicaid program.

Second, it would put a preventive, as well as a curative, approach into the total package, comprehensive range of medical services.

Third, it would enable you to approach it on a per capita cost rather than on a fee for service cost which I think would bring the whole concept of the primary practice of medicine into focus, giving an individual practitioner a comprehensive responsibility in giving people a family physician; the reason I make this suggestion is roughly, 18 million children up to age 6. That is a problem for size and dimension that is possible for use to handle.

When I can think of, which is a desirable objective of doing everything for 220 million people, very desirable objective, but when I think how I would get from where I am now to that point, I can see a lot of obstacles.

But for 18 million children, considering all the factors we discussed, there is a reasonable chance that we could do a reasonable job within certain cost limitations, certain administrative limitations, that are within the competence of the medical and health profession.

I think it makes it a feasible incremental step in the objective that everybody wants.

Mr. SEGAL. Do you feel the cost would be minimal or possibly negligible because physicians would have incentive to cut down unnecessary procedures and at the same time provide a comprehensive package of care?

Mr. COHEN. For the children—let me say this: I can't quite agree with this formulation for this reason: I don't think there are very many unnecessary procedures for children under the age of 6 at the present time.

There are, as I understand, too many tonsils and adenoids taken out but one of the reasons why I favor a no deductible, no coinsurance for medical care for children under 6 is that I don't think the over use, over utilization issue which applies to terminal illness and cosmetic surgery and all the other things, I don't think that applies to parents and children under age 6.

I can't conceive of what you would normally call abuse in terms of overutilization. What is an abuse? Going to the doctor every week or every month?

Well, if the mother is willing to cart the child to the doctor and wait in the waiting room, there must be something in her mind that she would like to have satisfied, and, therefore, I think the overuse, overabuse factor is not so present in the early childhood thing as it might be elsewhere.

My argument would be that any such program would increase utilization.

Mr. SCHEUER. Would you also apply that to prenatal care?

Mr. COHEN. Absolutely. I was going to say my whole conception of the idea is prenatal, postnatal and delivery and to the extent that our scientific knowledge could do the testing prior to birth as you indicated, fine.

Mr. SCHEUER. I think there is a doctor at the Rockefeller Institute at New York, Rene du Bois, who has done experiments on rats and mice indicating when you extrapolate it to human beings, that if a mother has had an inadequate diet during the prenatal period, or if the child has an inadequate diet during the first year of infancy, there is considerable, identifiable damage done to the cortex of the brain.

When that child has an adequate diet, there is some recovery. But even when the child gets a fully adequate diet, after the age of 2 or 3, there is much damage that is irremedial.

There is also some evidence that mothers who have had children born substantially under normal weight, when their history is examined, the only single identifiable feature that joins all these women is that they were born in a year, perhaps 18 or 20 or 22 years before, when there was a depression in which these mothers had inadequate diets.

Inadequate diet during infancy not only has some irremediable defects on the brain development of that child, but, if it is a female child, on her offspring as well, even though she has a normal diet and adequate health care from infancy on. I don't know of any more stark, pathetic or dramatic justification for the total kind of prenatal and postnatal care that you are talking about.

Mr. COHEN. I might say, Mr. Scheuer, I read the same material that you must be quoting from and I was impressed by it. I came to two final conclusions which might be well within the purview of your subcommittee.

I think the HEW program on nutrition——

Mr. SCHEUER. Would you repeat that?

Mr. COHEN. HEW's responsibility in the field of nutrition which I tried to set up when I was there, and I wish I had done more——

Mr. SCHEUER. We all wish we had done more.

Mr. COHEN. Yes; but I think that the nutrition program ought to be examined to see where that can be strengthened because of the point you made.

Second, I have suggested and recommended, since the Secretary of Agriculture has suggested it, that the food stamp plan be transferred to HEW, which he recommended, and that you take the food stamp program, however Congress amends it, or does not amend it in the future, and the nutrition program that is in HEW and bring them together and really have an expanded and strengthened nutrition program that would try to rifle into deal with the problem.

There is an area where incidentally, there is a great deal of agreement on what you and I are talking about, but somehow nobody is doing what everybody agrees ought to be done.

I think if that is within your committee's purview, you ought to take a good look at that because I think a lot could be done to improve that.

Mr. SCHEUER. Dr. Cohen, we thank you for appearing before us. Your appearances here are always a pleasure and a privilege for us. We value your counsel and wisdom as well as your inexhaustible friendship.

[Whereupon, at 12:45 p.m., the meeting was adjourned, to reconvene at 10 a.m. on October 9, 1975.]

GETTING READY FOR NATIONAL HEALTH INSURANCE: SHORTCHANGING CHILDREN

WEDNESDAY, OCTOBER 8, 1975

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON OVERSIGHT AND INVESTIGATIONS,
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met at 10 a.m., pursuant to notice, in room 2123, Rayburn House Office Building, Hon. Richard L. Ottinger presiding (Hon. John E. Moss, ... continue and conclude the second of 2 days of hearings on "Shortchanging Children."

Mr. OTTINGER. On Tuesday, October 7, 1975, we heard from public and private witnesses who presented both interesting and distressing testimony and data that impressed upon us the seriousness of the issues revolving around health care for children.

Today we will continue these hearings and receive more information from witnesses who have been involved in providing care to children and analyzing the kinds of services that are provided to children.

In addition, we will hear from witnesses representing the Department of Health, Education, and Welfare (HEW) in order to receive from them a report on the implementation of maternal and child health programs, with emphasis on the early and periodic screening, diagnosis, and treatment (EPSDT) program of medicaid and the effect on the Government's maternal and child health programs on the need for national health insurance legislation.

We are again operating under serious time constraints.

We are going to hear first from Ms. Carolyn Kalk Snow, the Research Coordinator of the Institute of Medicine, National Academy of Sciences in Washington.

Then from a panel of three pediatricians, and, finally, from a panel of the Health, Education, and Welfare.

We would like, if we can, to keep the ... time so that we will have at least an hour for the HEW people. I will try to regulate the time accordingly.

I start off with Ms. Snow.

We welcome you to the committee. We will be pleased to hear from you.

STATEMENT OF CAROLYN KALK SNOW, RESEARCH COORDINATOR, INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES

Ms. SNOW. Thank you, Mr. Chairman.

I appreciate the opportunity to be here today to tell you about a study done by the Institute of Medicine of the National Academy of

Sciences in 1971 and 1972, assessing the quality of medical care for children.

The study, "Assessment of Medical Care for Children," was designed as a field trial of a new methodology to measure medical care quality. Quality assessment was at that time—and still is today—a very primitive science. All efforts are beset by a number of problems: What things to measure, how to measure them, and how far to extrapolate the findings. Nevertheless, progress is being made. Even while methodologies are being refined, we can gain an important understanding of problems in health care delivery from studies such as ours so long as we understand their limitations and are careful in the kinds of conclusions we draw.

Our study rests on the premise that one can get indications of particular shortcomings or deficiencies in medical care quality by looking at what we call tracers. Tracers are medical problems and the specific medical services pertaining to those problems selected in such a way as to highlight common aspects of the care process that are critical to its effectiveness. Our study used four tracers—iron deficiency anemia, middle ear disease, hearing loss, and uncorrected vision defects. Families with children between the ages of 6 months and 11 years were selected from three areas of Washington—the Congress Heights neighborhood in the southeast, the inner city neighborhood of Cardozo, and the Shepherd Park and Takoma neighborhoods in the northwest. The 1,700 families included had a wide range of incomes and a wide variety of sources of pediatric care; namely, solo practitioners, small fee-for-service groups, a prepaid group practice, a neighborhood health center, hospital clinics and emergency rooms, and city-run public health clinics.

The purposes of the study were to determine whether any significant differences existed between the quality of medical care and the type of organization providing that care and whether such differences were related to the ways in which the practices were managed. Our focus was the general pediatric care given to children in the study population.

Data were obtained from four sources: An interview with the child's mother, a clinical examination of the child in facilities provided by Children's Hospital, a questionnaire sent to the physician named by the mother as her child's primary source of medical care, and, for three of the organizational groups, an abstract of the child's medical record.

This research design limits the kinds of generalizations that can be made about medical care for children:

Our subjects came from selected neighborhoods of one U.S. city.

Both affluent and poor families were included but the population studied was predominantly black;

Data for comparisons among the provider groups did not include all providers in Washington. Those included are represented only by the portion of their patients who lived in study areas.

Because of logistical and cost considerations, medical record data on the adequacy of care was obtained from just three of the six provider groups; and

Only four tracers were used in making health status and adequacy of care determinations.

I understand that a major interest of this subcommittee in scheduling these hearings is the early detection and screening program for medicaid patients.

Because screening techniques exist for three of our four tracers, I think some of our findings might be particularly relevant to your considerations. Of special interest are the vision and hearing problems which are so critical to the educability of school-age children.

One of the more striking findings was the high prevalence of all four health problems:

Middle ear disease in varying degrees of severity was found in one-fifth of the children examined;

Hearing losses were detected in 19 percent of the 4- to 11-year-old children. Over one-third of these losses were in the sound frequencies relevant to understanding speech;

Twenty-six percent of the school-age children failed a comprehensive vision screening test; and

Among the preschool children, more than one-fourth were anemic.

Contrary to accepted views, disease prevalence was not uniformly related to social class. Except for hearing loss, we did not find lower disease rates in children from higher income families. A more significant determinant than income was the educational attainment of the child's mother. While the prevalence of both anemia and hearing loss decreased regularly with increasing educational levels, middle ear disease or vision defect rates did not.

An unexpected finding was that prevalences rates for each tracer were the same regardless of the kind of organization providing the child's routine pediatric care. Thus the proportions of children with anemia, uncorrected problems of vision, ear disease and hearing loss did not vary according to whether their source of care was public or private, a single physician or a group of physicians, prepaid or paid by a fee for each service.

The adequacy of medical care for each of these conditions was judged by comparing information from the medical record on the care provided against a predetermined set of criteria of adequacy. The criteria were developed by panels of primary care physicians and specialists and specified what they considered to be standards for minimally adequate care.

All three provider groups included in this phase of the study—a prepaid group practice, a neighborhood health center, and 12 hospitals—performed poorly in the areas of screening and detection of disease.

Although 72 percent of their preschool patients had been screened for anemia, only 18 percent of school-age children had been tested for visual problems. The number of children found by our examination to have evidence of ear disease was only slightly less than their medical history documented over the whole period of their care. Less than 3 percent of the children had received hearing testing even though the medical records showed one-third to have symptoms of a diagnosis of ear infections, and thus to have a risk of hearing loss.

Compounding the inadequacies in screening we found frequent failures to follow up abnormal screening test results with treatment. Of

the children screened for anemia, 36 percent had laboratory test results below normal limits; yet 2 in 3 of them were neither diagnosed as anemic nor given simple iron therapy. We did find considerably better followup in referring vision and hearing test failures for specialty care.

Among the children who actually did receive care for their problem, cases of inappropriate treatment were also found. One-fourth of the patients with diagnosed middle ear infections were not treated with appropriate antibiotics. Among children who wore glasses, 72 percent were not corrected appropriately or adequately. We found cases where glasses were worn which were not needed and some children even had poorer visual acuity with their glasses than without them.

The major findings of this study, which I've briefly summarized, have provoked considerable discussion and distress in the medical community, especially here in Washington. Some may not agree with our criteria for determining disease-nondisease cases in the clinical study and some may disagree with aspects of our standards for judging adequacy of medical care. However, many of the more striking results are not dependent on potentially debatable areas of medical judgment, but rest on an uncontroversial foundation of what constitutes good medical practice.

Without more efforts of this kind—which are expensive and require years to complete—we have no real way of knowing how widespread such high disease rates are or how frequently such deficiencies in the adequacy of care occur. Despite some methodological limitations of the study, which I have described, I am confident the findings are valid. Since there is no reason to assume there is anything particularly unique about the population studied, we must be concerned about the kinds of inadequacies in medical care for children that this research documents.

Mr. Chairman, this completes my prepared statement. I would be happy to answer any questions the committee might want to ask.

Mr. OTTINGER. These are startling results. They have frightening implications.

Do you have any suggestions as to what Congress might do to help out in this kind of situation?

What you are saying is, in effect, if we go ahead and insist that HEW implement the screening program to its fullest, if it is done in the manner it is done here in Washington it will not make any difference anyway, it may make things worse.

Ms. SNOW. I think we have a problem with the treatment and followup of children who might fail such a screening program. We must guarantee that adequate care will be provided for those children who are referred.

Mr. OTTINGER. Does this indicate that a major effort ought to be made on training people to do the screening process in conjunction with any screening effort?

Ms. SNOW. I think in conjunction with any screening effort we have to insure that the system to which these children are referred is going to handle the problems uncovered in screening.

Mr. OTTINGER. Was that where the failure was? It was not the failure of the screening to pick up the problems?

Ms. SNOW. It was both.

There were findings that a number of children simply were not screened at all, and of those who were screened, many with abnormalities were not treated.

Our criteria perhaps are controversial but those children labeled as anemic on the basis of hematocrit levels, often failed to receive appropriate attention. It appears that laboratory slips placed in the record were never utilized.

Mr. OTTINGER. Mr. Sharp?

Mr. SHARP. Yes.

You indicated that the education level of the mother was of critical importance.

One thing that keeps coming back to us is that at some point somebody is not taking responsibility, whether it is the professional service that is offered or the screening organization of the family parent.

I am wondering if you have some suggestions on how we can more effectively reach these parents.

It obviously makes a difference, whatever socioeconomic level, as to whether or not the parents are aggressive in their own health care or for their children, it seems to me, and making sure they are getting the best treatment.

Most of us in our own families have had experiences where we are unwilling to accept an answer we are given and we press for another answer or go somewhere else. Obviously that may not be an option open to someone of a lower economic starta.

It sounds to me like we can make organizational reforms. We can require certain things to happen, and at some point we have to do a lot of consumer education.

Ms. SNOW. I think we do; yes.

I understand Children's Hospital plans a program here in Washington to do just that, to get the mothers involved in the system and to educate them about the resources available and what to look for in their child, what should prompt them to seek care.

Mr. SHARP. In your study, were you dealing with the parents, hemselves?

Did the people in the study have direct experience with these people or is this a paper work kind of thing where you actually don't communicate very closely?

Ms. SNOW. We had home interviews with the mothers of all the children. Then we brought the children to a clinic at Children's Hospital to be examined. Then we had followup contact with the mothers to insure that all the children found to have screening abnormalities got care.

We offered free medical care to children whose families could not afford it if their child had some problem uncovered by us in our examination. Many times, even though the care was free and we offered to provide transportation, people just simply didn't take advantage of it.

Mr. SHARP. Did you try to assess why that was the case, whether it was negligence on their part, of whether they were intimidated?

Ms. SNOW. Or perhaps they didn't understand that an untreated ear infection could lead to serious consequences in terms of hearing loss.

Mr. SHARP. It is very clear that most of us have not been very aware of how diet might affect our own health and I don't profess to know much about it. We hear startling kinds of statements made which most

60-800—75——7

of us have ignored. Even though we consider ourselves reasonably well-educated, I am just wondering how we can get beyond this position that ultimately even where people have information they don't act.

What can you do?

I feel some sense of responsibility toward the children. To an adult who refuses to act on information and opportunity, it is very difficult to sense a great deal of responsibility toward that person.

I guess I am philosophizing.

What was disturbing to the medical community? You said it created quite a controversy? What did the controversy surround? Are they concerned that some medical professionals don't believe that these children are not getting service? What shook people up?

Ms. SNOW. I think it was a mixture of some defensive reaction and some real concern. A common reaction was "It was not me; it was not the children I took care of, but we have the problem in Washington."

I think the medical society is concerned. I don't think any action at that level has taken place.

Mr. SHARP. Was there a resistance to the finding that in the problem of glasses, the problem of lack of treatment, lack of followup that, there was resistance to the truth, and they wanted to ignore that?

Ms. SNOW. There was close inspection of the criteria and examination methods we used. I think they stood the test of that scrutiny; now there is acceptance that the findings are valid for the people included.

I am not sure there is acceptance that the findings might be valid for a wider population.

Mr. SHARP. I wondered if you came across any organizational recommendation.

It seems to me once the child is in school it would be fairly easy, assuming that there is a decent attendance at school, to keep track of a child's medical record to guarantee that they have certain kinds of testing, certain kinds of followup if you have responsible school officials.

Obviously the real problem we are trying to get at is before school.

I wonder if you are aware of any way in which this might happen that would supplement parental responsibility.

Ms. SNOW. One thing we suspect in the finding that the pediatricians screen so few of their children for vision is that perhaps they assume that the school is doing it and, therefore, it isn't their responsibility.

Mr. SHARP. You are suggesting that professional people like pediatricians may not take seriously the question of vision?

I mean, some of them. I assume it is not universal. In other words, the standards within the profession, itself, as to what they ought to be concerned with vary and that one pediatrician may take very seriously vision and another may not screen for that.

Ms. SNOW. Or perhaps the pediatrician assumes that since the patient has glasses he must be receiving vision care somewhere: it would never occur to him to think that maybe these glasses were passed on from the patient's older sister, or were several years old.

Mr. SHARP. So, nobody in the system outside of the parent——

Ms. SNOW. We have such a mobile society that we have to focus the responsibility in the family. Perhaps there are ways that we can help them manage that responsibility. It seems to me that is where it ought to be.

Mr. SHARP. Thank you very much.
Mr. OTTINGER. Mr. Santini.
Mr. SANTINI. No questions.
Mr. OTTINGER. Counsel?
Mr. SEGAL. No questions, Mr. Chairman.
Mr. OTTINGER. Thank you very much, Ms. Snow, for being with us.

You have given us a good deal to think about. We appreciate it.
Ms. SNOW. Thank you.
Mr. OTTINGER. Next we will have a panel of pediatricians: Dr. George Lamb, Boston, Mass.; Dr. Frederick North, Pittsburgh, Pa.; and Dr. Alfred Yankauer, Worcester, Mass.

We are going to put the time clock to you very severely. We would like each of you to make a short statement. We will have to do this within an absolute maximum of 10 minutes each so that we will have some opportunity for interchange.

We certainly appreciate your taking the time and trouble to be with us. I have seen your statements. I think that they definitely contribute to our efforts.

Whichever of you would like to proceed first may do so. If you want me to resolve it, I will resolve it.

STATEMENTS OF A. FREDERICK NORTH, M.D., PEDIATRICIAN, PITTSBURGH, PA.; GEORGE A. LAMB, M.D., ASSOCIATE PROFESSOR, DEPARTMENT OF PREVENTIVE AND SOCIAL MEDICINE, HARVARD MEDICAL SCHOOL, AND PEDIATRICIAN AT CHILDREN'S HOSPITAL MEDICAL CENTER, BOSTON, MASS.; AND ALFRED YANKAUER, M.D., PROFESSOR OF COMMUNITY AND FAMILY MEDICINE, UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL, WORCESTER, MASS.

Dr. NORTH. I am Frederick North. I am a pediatrician.

I have been concerned with the early and periodic screening program in Pittsburgh, in Pennsylvania as a State, and been a consultant at the national level. Because I have written about screening, I have also heard the stories of my colleagues all over the country.

While I have no formal national role in ESPDT at the present time, I do tend to hear what is going on around the country.

The committe has already heard from testimony yesterday that early and periodic screening when followed by diagnoses and treatment is one very important component of the health care of children.

You have also heard that when screening is not followed by diagnosis and treatment it is costly and meaningless and sometimes dangerous and demeaning.

The testimony also brought out that such screening, diagnoses, and treatment is most effective and economical when it is provided in the direct context of comprehensive health supervision—the "medical home" which was mentioned yesterday—which also includes preventive services, including immunization, counseling, and guidance—perhaps getting at the point of patient education that was mentioned in the immediately preceding testimony—the care of acute illness and

injury which is the most pressing need that most parents find for health care of children; the management of long-term illness and handicapping illness which is the main thrust that the screening is really designed to get at.

Any separation of screening from this direct context of comprehensive care multiplies the cost and difficulties of providing preventive services and of insuring appropriate diagnoses and treatment.

Every time there has to be a referral there is another opportunity for broken appointment, another demand for expensive supporting services, another opportunity for missed communication between screener, patient, and consultant physician.

So that, any time that screening is taken out of the context where direct medical care can be provided on the spot, the complexity is increased immensely.

ESPDT, the Federal program, as currently defined and administered, I believe, has been and will continue to be a costly and ineffective approach to getting these needed health services to the Nation's children.

In addition to the various difficulties of administration that you have heard so much about, I think there are some more basic fatal flaws in EPSDT.

First, it is linked to the welfare bureaucracy which is already overworked, undertrained in health matters, and is constantly under political pressure to reduce welfare rolls, not to serve all needy children.

You can't find every child who needs screening under EPSDT without finding a lot of people who are eligible for welfare.

At best, 60 percent of those eligible for direct welfare payments receive them; 40 percent of those who are eligible, do not receive welfare payments.

By defining an eligible child as one who is already receiving AFDC, we have specifically included 40 percent of the neediest. A child receiving AFDC probably has a medicaid card in his hand and can receive care. Others are untouched and remain untouched as long as screening is linked to the welfare system.

EPSDT is also linked to the special problems of medicaid with its complex eligibility requirements, on and off eligibility, its endless forms, and its late and inequitable payments.

This is probably the main reason for the difficulty in getting physicians to participate in EPSDT. We have had too much bad experience with medicaid.

In those States in which medicaid has been administered smoothly and in an acceptable way, ESPDT has had greater success.

The third difficulty with the present EPSDT program is that it is conceptualized and administered as a screening program, not as a program of comprehensive health care.

There are a few bows in the direction of comprehensive health care and prevention, but the statistics you have heard from GAO count the number of children screened.

If you are evaluating a program on the basis of children screened, what you will get is children screened and not children taken care of. So, even though there are some philosophic gestures toward prevention, actually what is being demanded and measured, what the States are being assessed on, is how many children are screened.

As I mentioned before, screening in itself is a worthless exercise. The only purpose is treatment.

With all these difficulties, what might be an alternative?

The best estimates I have heard about the cost of ESPDT range from $½ billion to $1 billion a year. I understand nobody has been able to put a closer hand on the number.

The money now spent on ESPDT could be reallocated to provide a basic minimum program of comprehensive health supervision for all children in the United States, all 75 million, 0 to 21. Such a program might take the following form:

A set of vouchers would be issued to all parents for 14 health supervision visits in the first 21 years of life of each child, redeemable by physicians or clinics who provide acceptable health supervision services. Vouchers would eliminate complex and costly billing and payment procedures. Universal eligibility would eliminate costly and demeaning enrollment procedures and would insure that services were monitored, not only by poor and uninformed parents but also by well-informed, articulate, and demanding parents who indeed insist that the children get the kind of services they need, who don't necessarily accept what is available without questioning.

Vouchers would establish full freedom of choice between the patient and parent and providers.

The cost of the redeemed vouchers would approximate $750 million a year, well within the order of magnitude of what is being spent now in attempting ineffectively to get such services for only a small proportion of only the poorest children in the country.

What about the problem of getting parents to seek out this care?

We have heard that an army of outreach workers, people providing transportation and so forth might be necessary.

I would suggest before we go into that we might attempt another system. To offset part of the cost of transportation, babysitting and so forth that is associated with getting children to regular health supervision, a second set of vouchers redeemable by parents after each completed visit might be provided, perhaps in the form of a food stamp that could be redeemed in any supermarket.

With such a positive incentive, a much larger proportion of parents would seek and obtain health supervision for their children.

The cost of outreach workers, transportation, and other facilities and services to be provided by the Welfare Department could be greatly reduced.

The annual cost for parent vouchers worth approximately $10 for each visit would approximate $500 million, again within the range of what is currently being spent.

The total administrative cost, which I think is at least 50 percent of the total expenditures under the current ESPDT program, could be reduced under such a program to something around 1 percent, the basic cost of distributing vouchers which would be redeemable through currently existing systems.

I am concerned that such programs for preventive health care should be financed through Federal general tax revenues, not through insurance and tax mechanisms which impose their greatest proportional burden on those least able to pay. Even greater equity could be achieved if vouchers were regarded as taxable income so that those who

have no taxable income get the full value, those who are well able to, pay tax on it. This might help avoid the criticism that has been so discussed in the school lunch program, of providing free services for people who can pay.

A program such as I have described would not address payment for maternity care, dental care, acute episotic care of illness, nor management of chronic illness. But, neither, in reality, does EPSDT. These important services could be covered by the various service and insurance programs that exist.

I think the program would provide a base of preventive care of all children and thus reduce the cost which insurance and service programs must cover.

Thank you.

Mr. OTTINGER. Thank you very much for a very thoughtful statement. That is a very interesting idea.

Dr. Lamb, would you care to proceed.

STATEMENT OF GEORGE LAMB, M.D.

Dr. LAMB. Mr. Chairman, it is a great pleasure for me to be able to be here to discuss such an important issue with all of you.

Mr. OTTINGER. Will you identify yourself?

Dr. LAMB. Yes.

I am Dr. George Lamb. My present position is in the department of preventive and social medicine at the Harvard Medical School, and pediatrician at Children's Hospital Medical Center in Boston.

My comments are as follows:

First, it seems appropriate that the intent of the legislation to be discussed, at least one major intent, is to provide the same kind of programs for the poor children as are now being accomplished for the more affluent children, an issue of equity. This is indeed a very desirable goal and one that should be vigorously pursued. The findings of Project Head Start, particularly the medical component, and other studies indicate that previously undetected health problems do exist in the target population and that at least many of these can be remediated. It is my belief, however, that the screening component has to become an integral part of some ongoing health service system, a comment that I have heard repeatedly here as well as in the testimony from yesterday.

Thus, I feel that separate systems such as that presently existing in EPSDT is inefficient and costly in terms of reaching children and incorporating them into comprehensive health care. The priority, therefore, should be to provide an organizational framework for comprehensive health services to all children.

Second, a screening by itself, as Dr. North mentioned, is of no benefit to children and their families. In this context, we must recognize that many of our suggestions for screening, diagnoses and treatment are presently based on relatively poor pieces of information scientifically. Rather, they are based on the state of the art and what, in fact, occurs primarily in the private practice of pediatrics and the general consensus of good medical practice.

Therefore, I would suggest that a high priority be given to evaluation and/or research programs to accurately determine the payoffs

of presently accepted and yet unproven and new screening and treatment approaches.

Third, a monitoring of the implementation of a comprehensive health care program for children should be accomplished in a manner that maintains confidentiality. It also must not impose undue amounts of paperwork or financial disincentives to the providers. Here I would comment parenthetically that it seems to me that much of what Dr. North suggested would accomplish this.

At this point, the volume of paperwork and relatively low reimbursement causes difficulty in follow-up, diagnosis and treatment in people who have consistently already experienced difficulty with access to the system. It also imposes considerable financial cost on the provider and in many local instances I am aware of providers are not going through the EPSDT reporting process, specifically to avoid the cost of that kind of mechanism.

Fourth, it must be recognized that many health care providers are not presently able to deliver all the screening programs desirable and, in fact, suggested under the regulations. Thus, there must be some allocation of resources to the education of the health professionals and some assistance in obtaining and using new screening procedures and instruments. This will be an ongoing process and needs to be coordinated through other agencies such as American Medical Societies, American Academy of Pediatrics, and so forth.

Fifth, in some instances, the prevalence of problems is so high that screening, itself, should be dispensed with completely and direct therapeutic services instituted. For example, in one group I was involved in we found 62 or 65 children in need of dental services, 31 of these children had urgent problems in regard to their teeth. Thus, any further screening for teeth problems would be ineffective and inappropriate.

Sixth, attention should be given to the education of consumers regarding the need for screening as part of ongoing medical care. Recent reports by Holtzman suggest, for instance, that the screening for PKU can be most productive if the consumer is involved and informed in the screening process, obtains assistance in making a decision relative to the screening and is actively involved as a participant in all phases of screening, diagnosis, and treatment.

Similarly, a program involved with early education for parents involving over 300 families in a local program starting at 2 weeks of age indicates that families are receptive to more information around health and education issues and can act on the information.

This particular program does involve low socioeconomic children, as well.

Seventh, each area, town, county or region, needs to provide for coordination of services to children.

The Foltz report of the Connecticut experience indicates that inconsistencies of Federal regulations, lack of cooperation between State agencies and the delegation of responsibility for health supervision to the Welfare Department was ineffective. Another example might be again in a local area I am involved with where EPSDT programs are being delivered by local practitioners and local community hospital ambulatory facilities.

In addition, the towns are responsible for screening and interven-

tion beginning at age 3 under the new Massachusetts Law 766. They are responsible for screening, periodic screening, from age 3 to 21 or graduation from high school.

It seems obvious that there is a lack of coordination between these programs, creating costly duplications, gaps, and inconsistencies between these programs.

It is unclear in this instance where the responsibility rests, the Welfare Department, local practitioner, local hospital, local health department, or local schools.

Thank you.

Mr. OTTINGER. Thank you very much, Dr. Lamb. We appreciate your testimony.

By the process of elimination, I assume we have next Dr. Yankauer.

STATEMENT OF ALFRED YANKAUER, M.D.

Dr. YANKAUER. Mr. Chairman, I am Alfred Yankauer. I am a pediatrician, currently teaching community and family medicine at the University of Massachusetts Medical School in Worcester, and editor of the American Journal of Public Health.

I would like first to express not only appreciation for this opportunity to appear before the committee but also satisfaction that the committee is gathering information about programs for children that may have bearing upon future health insurance planning and implementation. Children are not little adults. They have special needs stemming from their growth and development and their future human resource potential. In spite of these obvious points, the history of health insurance both abroad and in this country displays an appalling neglect of children, perhaps because they do not vote. I would like to return to the special needs of children later.

There are many aspects of EPSDT which seem strange to me, but the strangest of all is the fact that the legislation itself should have been necessary in the first place. Medicaid was intended to meet the health needs of the American poor. The American tradition of health care calls for the delivery of preventive and curative care from a single source, thus distinguishing it from the delivery systems of Western European countries and causing it to resemble those of Eastern Europe. Yet medicaid had to be supplemented by special legislation calling for a preventive program directed at children as if neither prevention nor children were considered in the original medicaid legislation. It will clearly be important to avoid this sort of paradox in the future health insurance legislation.

I would like to leave the technical aspects of screening programs to others except for the following broad generalizations:

1. Well prepared nurse practitioners, working with physician colleagues, are probably superior to physicians alone in executing those parts of child health supervision usually associated with physicians—the interview, history and routine physical examination. Future legislation should take care not to discriminate against nurses.

2. Studies are badly needed to improve the effectiveness and efficiency of child health supervision. EPSDT provided a magnificent but lost opportunity to plan and execute such studies. Research and development in health services administration should be considered part of program costs as they are in industry.

3. In spite of our lack of specific knowledge, inductive reasoning and consumer and provider consensus demand that preventive care be covered in future health insurance planning.

4. Standards for the various components of a program like EPSDT can be set by consensus. More than that, they can also be ranked by priority order of importance by consensus. The order may be different in different parts of the country and for different ethnic or cultural subgroups. Given the individual costs of the various components, and the level of expenditure set by economic constraints, decisions on implementing program standards can be made at a local level with more sensitivity than they have in the past.

I would like to devote the rest of this time to exploring what I see as the reasons for an almost universal dissatisfaction with the EPSDT program. Many of the expressed dissatisfaction are, I believe, merely symptoms of violations of fundamental and long-known principles, violations that were built into the EPSDT program:

1. Detection, counseling, follow-up and treatment were not under control of the same source. The successful model here is tuberculosis screening by the health departments who provided follow-up and treatment themselves—although other treatment sources were not prohibited. The failing models, known for many years, are in the field of school health.

2. The means test of medicaid acts as a barrier to care through its stigmatization of consumers, and providers as well.

3. Administration by a welfare agency focuses on financial controls but even these have been poorly handled, turning off many potentially interested providers.

4. Instead of building up a new program slowly on the basis of pilot trials—research and development—as would be done with automobiles or drugs or other products, we jump right into a major new effort—walking bravely but foolishly into the dark.

5. State and local government agencies were not strengthened to help them face these new responsibilities yet in the end they must be the responsible parties.

6. Grassroots, consumer feed-in, education and voice—that is, community involvement—were not built into the program.

7. Follow-up and outreach services, often more expensive than the screening itself, were not provided for.

Finally, I should like to point out that the special needs of children, with which any health insurance plan must try to cope, are not only the early widespread application of known preventive measures—immunizations are the best known—not only the early detection of handicaps such as a hearing loss, but also their follow-up and care. The major problems of children tend to be problems that are health related but which do not yield readily to the simplistic medical model around which EPSDT is built. These are the chronic continuing conditions, the physical and mental handicaps with which we are all familiar. These handicaps cannot be cured—cure is the hallmark of the medical model.

In spite of the fact that these conditions cannot be cured, there is now abundant evidence indicating that their early detection and the prompt application of rehabilitative educational, psychological and social services together with medical services will result in very sig-

nificant personal gains for the child and future cost savings for society.

Such services applied as soon as they are needed—the earlier the better—must somehow be incorporated into or integrated with any health insurance plans that hope to meet the needs of children. Often enough, as in the case of the child with a severe hearing loss, the non-medical services are more important to the child and society than the medical services.

Thank you, Mr. Chairman.

Mr. OTTINGER. Thank you very much, Dr. Yankauer, and the rest of the panel.

Mr. Sharp, do you have any questions?

Mr. SHARP. Yes. Thank you very much, Mr. Chairman.

Dr. North, I wanted to follow-up on your suggestion of the voucher system. Are you aware of anyplace where this has been tried? Are there any demonstration models of this?

Dr. NORTH. I have never seen the model of vouchers. Both Finland and France, each of which has superb infant mortality statistics, have provided incentives for parents.

In France, you don't get your baby bonus until you present your completed health certificate. Finland has the same kind of arrangement. They instituted this shortly after the war. And it has resulted in 95 to 98 percent immunization and child health supervision.

This incentive to the parents—though I am not definitely committed to this particular form—is similar to the coupon book that you get for your car, that says this is for your 4,000, 8,000-mile checkup. It is a statement of what you would expect to be included in the checkup. I have not seen this particular model tried and perhaps, as Dr. Yankauer suggested, it ought to be done "small" before it is done "big."

Mr. SHARP. I was thinking it might be wise to try it out somewhere for a trial run. One of the problems is that I still forget to take my car in for a 4,000-mile checkup.

Obviously, it takes a bureaucracy to make sure that everybody gets a coupon book and if you have a bonus incentive plan where they can get refunds, you can do that.

I am wondering if we are not still stuck with the problem that in order to make sure that people you really want to help receive it. We need to have an outreach program in which somebody takes the coupon book, gives instructions on how it works, and follows up to see that it is used. So we have not escaped some of the bureaucracy.

It sounds like with the voucher system, ultimately, we will have to come back with a system of financial controls. In other words, we will be faced with a charge or fee or service plan—it varies from place to place—some tend to use it and others not.

Dr. NORTH. I think the problem of reaching every person is simplified over time. First, you do have almost universal contact with the health system at the time of birth and a contact with a reasonable health-related system at the time of school entry. Using these two entry points within a few years the cost of distributing such vouchers becomes a very trivial one on an annual recurrent basis.

Mr. SHARP. Also, one of the universal complaints we are hearing is that of the lack of a connection between the screening and follow-up treatment, the kind of thing which suggests the need for clearly localized health care centers or something in which one step clearly follows the other.

Dr. NORTH. I think the solution lies mostly in avoiding setting up any special screening. As Dr. Yankauer mentioned, our traditional systems, including the newer models such as C&Y projects and neighborhood health centers, are comprehensive programs. The need is to avoid settings such as unsuccessful school health or nontreatment providing baby clinics which we know are so ineffective in getting treatment and which have been specifically encouraged the way EPSDT has evolved.

Federal regulations talk a little bit about comprehensive care and then talk about using automatic equipment and briefly trained personnel for large groups. So the States have been equivocal. It is mostly avoiding allowing the setting up of special screening clinics from which you have to go someplace else every time you want something done.

Mr. SHARP. Do the other two gentlemen want to comment?

Thank you, Mr. Chairman.

Mr. OTTINGER. Mr. Santini.

Mr. SANTINI. Yes, Mr. Chairman.

I am interested in your concept of redeemable vouchers despite my own neglect of maintenance on my automobile. Recognizing your "fatal flaw" comments with regard to EPSDT and its linkage which you characterized with the welfare bureaucracy, do you have any feeling as to who could best administer any new program including your voucher concept?

Dr. NORTH. No; I don't. It may indeed be that the Social Security Administration, accustomed to administering one large universal population program, could do it effectively for another. I can't see that Health Departments have had experience in administering universal programs. Maybe the schools are the best. They are another universal service agency.

Health Departments have never attempted to serve everybody. I haven't seen good experiences in either health or welfare bureaucracies of serving everybody. I suspect that any of them could do it a lot better if the fatal flaw of specific eligibility were removed.

Mr. OTTINGER. Would the gentleman yield?

Mr. SANTINI. Yes.

Mr. OTTINGER. Do you have any idea—perhaps the staff has some idea—what percentage of children are born in hospitals in the United States today?

Dr. NORTH. I think 98 or 99 percent. All of them are legally identified through vital statistics records. So birth is essentially a universal tabulating time for children.

Mr. OTTINGER. Presumably if we were to go on this kind of program, which I find very interesting, the hospital could administer it since they have contact.

Dr. NORTH. Yes; on an ongoing basis. There would be a first-time cost of reaching everybody who has already been born. After that, it should be extremely simple, as simple and noncontroversial as the making out of a birth certificate.

Dr. YANKAUER. Mr. Chairman, birth certificates are a universal function through the country and the linkage probably would be best there.

Mr. OTTINGER. We don't have a huge administrative problem there. You have somebody already having to deal with it.

Dr. NORTH. That is an example in which health departments do their job for every single person in the population, so perhaps my previous comment should be partially retracted.

Mr. OTTINGER. Thank you, gentlemen.

Mr. SANTINI. I am concerned in the testimony so far that there does not appear that there is any available data or study on the question of follow-up, which you suggest as one of the fatal flaws. Have you seen on the basis of your own individual experiences the success or failure of the followup activity in your own environment?

Dr. NORTH. I have seen successful follow-up, not in EPSDT but in a variety of others: Here again, the key feature seems to be a personal linkage between the nurse practitioner or physician who is providing the care and the parents of children.

My colleague in Pittsburgh is running a study on tonsils and adenoids. The patients refuse but fare "because you are giving us good service. We are coming back."

Whenever you avoid the necessity for referral—whenever the diagnosis and treatment can be done at the same site and same time as the need for it is discovered, you have eliminated immense costs.

Every time you make a referral, there is a 30-percent loss. Any time another appointment is needed, 70 percent keep it, 30 percent are lost. To my mind, this is one of the most important aspects. Whenever screening is divorced from the follow-up and treatment, you are building in defeat.

Mr. SANTINI. Dr. Lamb, I am interested in your observation concerning education of the consumer about the availability of the screening process.

We were advised yesterday by a witness who appeared before this committee, Dr. Cohen, who was formerly Secretary of Health, Education, and Welfare, that it is Health, Education, and Welfare's responsibility to make the services available, but not to go out and entice them.

In the face of that administrative enlightenment, what direction or course of action would you suggest?

Dr. LAMB. Where the responsibility for this educational program rests I think would depend on how the program was set up. It seems to me that many of the particularly lower socioeconomic group, being lower educated, particularly related again to the maternal educational level, do not have the information or the resources to be able to reach out and effectively get any of the screening, diagnoses, and treatment programs that we have talked about, and this would have to be a re-

sponsibility of some kind of program. Thus there needs to be a further reaching out to these particular people, not just availability.

Again, perhaps, the incentive approach would be more effective. By doing this, showing your coupon that you have gotten your car checked and tires checked and fixed, that in fact you could get more food stamps, which is the kind of approach that Dr. North was suggesting, would make it more effective. To some extent, many of the people who are unable to do this have more pressing problems such as where is the supper for my child coming from, not where am I going to go next week to get my eyes checked or my child's eyes checked.

If the two were incorporated into a meaningful incentive for the particular kind of person we are discussing, then in fact the people might be more apt to get the services.

I might comment on the other question. This might be the kind of situation where multiple trials on a small basis would be very appropriate, to have the incentive system or this kind of system tried in one community or one area through the health department and another area through the school department, so that we could get some experiences in terms of what is effective in terms of the incentive and the followup that one could get.

Mr. SANTINI. One of the witnesses was critical of the attempted screening and medical assistance that was offered at the school level to date. Now that may be because of an infirmity within the administrative process of the school or within the existing program offered in the school. Which is it, Doctor?

Dr. YANKAUER. I think I made that critical statement. The major issue here is the separation of preventive and screening services from the treatment sources. School health services are the illustration of that problem.

Mr. SANTINI. So deficiency was not administrative in terms of the school, it was inadequate in terms of service offered?

Dr. YANKAUER. If the school were in a position to provide full comprehensive treatment services, which is a little questionable, then the problem presumably would not arise. That is the supposition. It is administrative because it is administratively not feasible.

Mr. OTTINGER. All of us would like to pursue this more because it is very interesting. I think it is very important that we get an opportunity to hear from people who can do something about some of these problems.

Therefore, I am going to have to cut this short. Thank you very much for taking the time and trouble to be with us and for your very interesting ideas. We will try to pursue them.

We next have representatives from the Department of Health, Education, and Welfare, Dr. James F. Dickson, Acting Deputy Assistant Secretary for Health, Department of Health, Education, and Welfare, and the colleagues that he has brought with him.

Because of what we are about to engage in is controversial as opposed to the previous witnesses, I will revert to the original practice and ask that you be sworn. If you will stand and raise your right hands.

[The panel of witnesses as set out below were sworn.]

Mr. OTTINGER. Dr. Dickson, will you first identify the panel.

TESTIMONY OF JAMES F. DICKSON, M.D., ACTING DEPUTY ASSISTANT SECRETARY FOR HEALTH, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, ACCOMPANIED BY ROBERT VAN HOEK, M.D., ACTING ADMINISTRATOR, HEALTH SERVICES ADMINISTRATION; M. KEITH WEIKEL, PH. D., COMMISSIONER, MEDICAL SERVICES ADMINISTRATION; NORMAN KRETSCHMER, M.D., DIRECTOR, NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT, NATIONAL INSTITUTES OF HEALTH; CHARLES U. LOWE, M.D., SPECIAL ASSISTANT FOR CHILD HEALTH AFFAIRS, OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH; DALE W. SOPPER, ACTING DEPUTY ASSISTANT SECRETARY FOR LEGISLATION (HEALTH): AND IRA LURIE, M.D., NATIONAL INSTITUTE OF MENTAL HEALTH

Dr. DICKSON. Yes, Mr. Chairman.

The other members of the Department who accompany me are on my far right. Dr. Norman Kretchmer, Director of the National Institute of Child Health and Human Development, National Institutes of Health. On my immediate right, Dale Sopper, Acting Deputy Assistant Secretary for Health Legislation. On my left, Dr. Robert Van Hoek, Acting Administrator of the Health Services Administration. To his left, Dr. Keith Weikel, Commissioner of the Medical Services Administration. To his left, Dr. Charles Lowe, Special Assistant for Child Health Affairs in the Office of the Assistant Secretary for Health.

There are some other members of the Department behind us who have come today to be certain that any questions you and the other members of the subcommittee may have are answered in detail.

Mr. OTTINGER. Dr. Dickson, we have heard over the past few days a litany of testimony that the screening program is inadequate, that it does not reach but a small percentage of the people for whom it is intended, that because it is not followed up with care it is inadequate. We have seen a number of examples of children who are mentally retarded who are handicapped for the rest of their lives, who cannot see adequately, who cannot hear adequately, with health problems that could have been avoided if these defects were detected in an adequate preventive medical program.

I am very much concerned indeed that you have presented us with a 41-page document here which I will put in the record if you insist that it be put in the record but which I find totally inadequate because it does not address itself to any of these problems. It looks to me like it was produced by the Department in order to describe in a general way the programs which exist in the Department.

If I were in your position I wouldn't want it in the record, but I will be served by your preferences in that regard. We certainly do not want to hear it. We would like you to address the problems that have been brought to the attention of the committee and with which the committee is concerned.

Dr. DICKSON. Mr. Chairman, I would like to say that I feel at this time personally that we do have in the Department a very positive pro-

. . gram and a positive outlook with respect to it. I recognize it is also a complex and difficult situation. I feel that one of the reasons that it is complex is because it is a combination of initial legislative problems with respect to the program, problems of economics, availability of resources, and I believe it is also administrative problems within the Department.

We are certainly not without fault. I don't mean to suggest that we are.

Mr. OTTINGER. Caspar Weinberger, the head of the Department immediately previous to the current Secretary, described this effort at preventive health for children as the top priority of the Department. Is that still the assessment of the Department?

Dr. DICKSON. Mr. Chairman, before going to that question, if I may, I would like to ask whether you choose that I read an abbreviated version of our statement?

Mr. OTTINGER. I prefer not. I will put whatever you like in the record, but I am very, very much concerned to see to it that the problems that we are very much concerned about do get addressed by the panel.

Dr. DICKSON. Mr. Chairman, we will proceed as you direct. We feel, however, that this is a positive statement we would like all members of the subcommittee to hear it.

Mr. OTTINGER. I will be glad to insert it for the record at this point. You can distribute it so that the members can read it.

[Testimony resumes on p. 117].

[Dr. Dickson's prepared statement follows:]

STATEMENT OF JAMES F. DICKSON III, M.D., ACTING DEPUTY ASSISTANT SECRETARY FOR HEALTH, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Mr. Chairman and members of the subcommittee, it is a pleasure to have this opportunity to appear before you today to discuss the Department's programs and accomplishments in the area of child health. It is particularly appropriate in view of the President's proclamation which designated this past Monday, October 6, as Child Health Day, and the U.S. Center for Disease Control's designation of October as Immunization Action Month.

The Department has a commitment to maintain and improve the health of all children in the country. In the areas of research, regulatory activities, quality assurance and public education benefits are not limited to any one category of children. In the health service delivery programs, however, benefits are made available to groups of children who, for a variety of reasons, would otherwise not receive much needed health services. The categorical nature of many of the programs I am about to describe results in overlaps in some cases and gaps in others, in addition to a distribution of many child health authorities in different offices throughout the Department. Recognizing that it is necessary to coordinate these activities, the Department has recently established an Office of Child Health Affairs within the Office of the Assistant Secretary for Health. This office will, as one of its functions, coordinate and maintain liaison with all child health activities within the Department.

This morning I will briefly discuss the background of the programs, their accomplishments and their present activities. First, however, I would like to take a moment to indicate the present activities and project goals and direction that the Department has selected for child health activities in the Forward Plan for Health, FY 1977–81.

The Department plans a coordinated health perspective on all agency activities that are closely interrelated. One of the major priorities of this theme is prevention with a focus on children. Thus, the agencies of the Public Health Service involved in such activities as child mental health, accident prevention, and nutrition will devote special attention to an ongoing interchange of ideas and data.

A number of important child health initiatives are being developed within the Department which deserve special mention. They are identified in the Forward Plan for Health. For example, the focus on reducing infant mortality continues not only in the Maternal and Child Health Programs but is beginning in other program areas. The availability shortly of up to date data pinpointing high risk areas will mean more informed planning in such efforts as the Rural Health Initiative. In addition, efforts to improve dental health will be increased with emphasis on preventing tooth decay through the promotion and maintenance of optimal fluoride levels of community and school water supplies.

In addition to the major coordinated activities and initiatives, the agencies serving substantial populations of children will of course focus on their individual efforts in child health. In some cases this will mean a strengthening of already initiated efforts, and in others it will mean undertaking new challenges or using new perspectives.

The Maternal and Child Health programs, which have been making sizeable contributions over the years, will continue a special emphasis on infant and preschool health.

The Alcohol, Drug Abuse and Mental Health Administration will emphasize new activities related to alcohol use among adolescents; it will develop new approaches in prevention-related efforts within the mental health area, and as a means of continuing the efforts to combat drug abuse, priority will be given to projects that nurture healthy family life, such as family counseling and child development.

The National Institute of Child Health and Human Development will emphasize activities in the reduction of infant mortality and of low birth-weights, as well as understanding the causes of congenital malformation.

The Center for Disease Control plans to assist in the effort to stimulate and support water fluoridation. In addition, the Center along with the other agencies involved in serving children will continue their combined efforts in immunization programs including cooperative activities with the Early and Periodic Screening, Diagnosis and Treatment program.

Now turning to the programs themselves, I will indicate within the context of this broad subject area how the many and varied child health activities of the Department have progressed and at the same time discuss the extent of our current activities.

HEALTH SERVICES ADMINISTRATION

The Health Services Administration largely through the Bureau of Community Health Services conducts various programs which provide services to and which impact on the health of children.

Maternal and child health and crippled childrens programs

The creation of the Children's Bureau in 1912 marked the major beginning for involvement of the Federal government in the field of child health. That Bureau's investigations into such problems as infant and maternal mortality was largely responsible for the enactment on November 23, 1921, of the Maternity and Infancy Act (Sheppard-Towner Act) providing grants-in-aid to States to demonstrate the value of providing local health services to mothers and children. Although the annual amount was small, $1,240,000, and the Act itself expired in 1929, it paved the way for inclusion of maternal and child health and medical care of crippled children in the Social Security Act of 1935. Since then, under the authorities of Title V of the Social Security Act, Congress has appropriated funds annually for the continuation and expansion of both programs and, from time to time, has authorized the addition of special project grant categories.

Title V of the Social Security Act authorizes annual formula grants to the State Maternal and Child Health and Crippled Children's agencies.

In order to receive Federal funds from an allotment for maternal and child health and crippled children's services authorized under Title V of the Social Security Act, a State must prepare and have available for review a State plan which contains information which meets the requirements specified in Title V of the Act and the related regulations. Federal regulations also require assurances of cooperation with the State agency which administers the medical assistance program established under Title XIX of the Social Security Act and with the State agency which administers the State laws providing for vocational rehabilitation of physically handicapped children. Additionally, there are statutory requirements under Title XIX of the Social Security Act which mandate

that the State Title XIX agency utilize and reimburse as may be appropriate the State Maternal and Child Health and Crippled Children's programs for those services which are normally reimbursed by State Medicaid programs and which are provided by Maternal and Children Health and Crippled Childrens Service programs under their State plans.

Crippled Children's programs and Children and Youth Projects provide, in some States, both the clinic screening site and the source of referral for followup and treatment of children found in need of care under the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.

Maternal and child health services

The Maternal and Child Health program is responsible for extending and improving health services for mothers and children, especially in rural areas. These programs are designed to reduce infant mortality and also to provide maternal and child health care, with an emphasis on preventive services in low income areas.

The provision of maternal and child health services begins prior to the birth of a child by providing a complete range of health care to women early in pregnancy in order to prevent adverse outcomes in pregnancy for the mother and her infant; and after birth, by providing preventive health care and services for women and children with the intent of early detection of disease and unfavorable health conditions and increasing their own capacity to maintain and improve their health. The majority of funding to the 50 States, the District of Columbia, and the Territories is used to support State directed programs which provide a broad range of maternal and child health services including prenatal care, postpartum care, maternity and infant care, intensive infant care and well-child care. The services offered include health screening, preventive, diagnostic and treatment services including general health, visual, dental, and hearing care, as well as immunization services.

Virtually all State maternal and child health agencies provide physician directed well-child conferences. These conferences are designed to conduct periodic assessments of the way children are developing, screen them for conditions that may require medical intervention, and to maintain an appropriate level of immunization against infectious diseases. Additional services include pediatric clinics that provide consultation, diagnosis, treatment, and follow-up care for sick children and specialty clinics that provide similar types of services for such conditions as rheumatic fever or hearing impairments.

As examples of the magnitude of care provided under these programs in fiscal year 1975, there were 568,000 children registered for comprehensive services and $1,805,000 children attending well-child conferences.

The most commonly provided direct services for women are the maternity medical clinic services, maternity nursing services, and family planning services. Nationwide, about 600,000 mothers receive prenatal and postpartum care in these maternity clinics. Maternity nursing services were provided to about 2,000,000 new mothers in FY 1975. It is estimated that over one million women in 1975 received family planning services through the State maternal and child health services program.

The program activities of both maternal and child health and crippled children have evolved and expanded as national awareness of problems grew and as the medical technologies developed to treat these problems. For example: in 1951 Regional Centers for the treatment of congenital heart disease were established; in 1963, in an attempt to reduce infant and maternal mortality and the incidence of mental retardation in high risk groups, maternity and infant care projects were initiated; in 1965 children and youth projects were begun; newborn intensive care projects were added in 1967; early detection, expanded outreach, and dental care, were added to the authorities under Title V in 1967; and in the early 70's Family Planning programs were included in the aggregate of service programs provided to mothers and children.

Congress, through Public Law 93-53, directed conversion of various special project grants to a formula grant program by July 1, 1975. This included the project grants for Maternity and Infant Care (MIC), Children and Youth (C and Y), Dental Care, Family Planning, and Intensive Infant Care.

The Maternal and Child Health program has taken on an increased emphasis in recent years. Maternal and Child Health programs were originally involved primarily in providing preventive health services. Currently the programs are focusing treatment services to assist States in the delivery of curative and

clinical services and have exanded their provision of health care services for high risk mothers and their children, much the same as the Crippled Children's program.

In addition, the Maternal and Child Health program is an active and crucial participant in the Department of Agriculture's Special Supplemental Food Program for Women, Infants, and Children (WIC) which provides cash grants to make food available to pregnant and lactating women and to infants and children up to four years of age.

Crippled children's services

Formula grants are awarded to State crippled children agencies for locating children who are crippled or who have conditions leading to crippling, and to provide them with medical, surgical, corrective, and other care and services that are necessary.

Every State has a crippled children's services program, and State law either defines the crippling conditions to be included or directs the crippled children's agency to define them. All States include children under 21 years of age who have some kind of handicap that needs orthopedic or surgical treatment.

As is the case with the State Maternal and Child Health Services program, each State Crippled Children's Services program must be under the direction of a physician and must comply with Federal regulations including several designed essentially to assure (1) a high standard of care, including high standards for those personnel and facilities which are to be used in the provision of services; (2) that health care services to be provided are comprehensive in nature and (3) that there will be development, strengthening and improvement of standards, techniques, and services.

Since care of a handicapped child may be a financial burden greater than the parents can bear, the agency will help parents with financial planning and may assume part or all of the cost of care, depending on the child's condition, the family's resources, and the funds available to the State agency.

Approximately 10 percent of the Maternal and Child Health budget is devoted to research and training efforts to improve delivery of services to mothers and children. Research grants are authorized under Section 512 of Title V and are made to public or other nonprofit institutions of higher learning and public or nonprofit private agencies. The aim of the research program is to improve the operation, functioning, general usefulness and effectiveness of maternal and child health and crippled children's services. The research program through its projects is focusing on improving health and medical services to mothers and children. For example, one ongoing project is in the area of the design and development of new prosthetic devices for child amputees. The project also incorporates a study of the needs and problems of child amputees, and is preparing a new manuscript for a textbook on the treatment of the limb-deficient child.

Training programs, authorized under Section 11 of Title V, are designed to improve health and medical services to mothers and children through training of personnel involved in providing health care and related services to mothers and children, particularly mentally retarded and multiple handicapped children. A major proportion of the funds support university-affiliated centers for the developmentally disabled and mentally retarded where primary effort has been given to interdisciplinary training of multidisciplinary service providers. Grants to these institutions of higher learning provide support for faculty, traineeships, services, clinical facilities and short-term institutes and workshops. These centers provide specialized clinical training in a multidisciplinary setting for physicians and other maternal and child health personnel who focus their activity on the multiple handicapped child. Emphasis in the centers is on the provision of excellent quality health care conducted in a training setting. Pediatric Pulmonary Centers have been added to the training in the past year.

Sudden infant death syndrome

In coordination with the National Institutes of Health research effort in Sudden Infant Death, the Maternal and Child Health program, under Title XI of the Public Health Service Act, carries out a program of counseling, information dissemination, education, and statistical reporting relating to SIDS.

Community health centers program

In the late 1960's, under authority of the Public Health Service Act, the Department began focusing support on ambulatory comprehensive health care

programs for medically underserved communities. The subsequent development of community health centers has had a substantial impact on improving the health of children within the program's target population. In 1975, it was estimated that 488,400 children received services out of the 1.7 million children estimated to reside in the 157 medically underserved areas where Community Health Centers have been established. These children had access to a full range of health services including medical, laboratory, mental health (including alcohol and drug addiction programs), dental, physical or speech therapy, social services, and hospitalization. Under the new legislation authorizing expansion of the CHCs program, P.L. 94–63, primary health services which a center must offer must include preventive health services, including children's eye and ear examinations to determine the need for vision and hearing correction and well-child services. In addition, physician, preventive dental, diagnostic laboratory and radiologic, emergency medical, and transportation services must be offered. Supplemental health services, which must be provided directly as necessary to support primary health services, or which may be offered by referral include mental health, dental, hospital, vision, health education, pharmaceutical and rehabilitative services.

Migrant health centers

In 1962, the Public Health Service Act (PHS) was amended to specifically authorize health services to domestic migrating farm workers and their families. Today, Migrant Health projects provide a wide range of health services such as those included in CHCs. Many of the projects are actively participating in the Department of Agriculture's Special Supplemental Food Program for Women, Infants, and Children (WIC).

Indian health service

The Indian Health Service provides direct health services to children of Indian and Alaska Natives through a network of 51 hospitals, 99 health centers, and 300 health stations in 25 States.

Comprehensive health service formula grants

A portion of the formula grants to States for comprehensive health services under section 314(d) of the PHS Act is used for the provision of maternal and child health services and dental services to children.

National Health Service Corps program

Over 270 National Health Service Corps sites provide increased access to physician services and other medical services for families who live in medically underserved areas.

Health maintenance organization program

Health Maintenance Organizations supported by the Department are required to offer as primary and supplemental services a wide range of screening, diagnosis and treatment services for children.

Family planning program

In fiscal year 1974 approximately 29% of the estimated 2.2 million served in all organized family planning programs were 19 years of age or under. Family planning services as provided through Title X of the Public Health Services Act and through Maternal and Child Health programs under Title V of the Social Security Act include a variety of health services in addition to family planning literature, counseling and contraceptive devices. Most of the users of family planning services receive complete medical examinations which include pap smear and other laboratory tests and pelvic and breast examinations. All elements of the family planning delivery system provide a high level of diagnostic health care to patients. Reported data suggest that family planning programs have become a major source of preventive health care for young, low-income and largely healthy women of childbearing age and represent a principal point of access to the health care delivery system for many young people.

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH ADMINISTRATION

Although the problems addressed by this Agency are generally found throughout the population, the lives of a significant number of children are touched, some tragically, by the contemporary pressures attendant to their daily survival. The three Institutes which comprise this Agency, the National Institute on

Alcohol Abuse and Alcoholism (NIAAA), the National Institute on Drug Abuse (NIDA), and the National Institute of Mental Health (NIMH), have made firm and major commitments to the health of our children. Through a number of creative means and viable mechanisms, the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) has committed substantial Federal funds for myriad juvenile programs in connection with intramural research, training grants, hospital improvement grants, fellowships, consultation and education, staffing grants to community mental health centers, and innumerable other activities. For example, in FY 1975 the budget level for ADAMHA programs identified as including activities affecting children approximates $148.5 million.

National Institute on Alcohol Abuse and Alcoholism

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) is currently supporting, directly or indirectly, nearly $4.5 million of activities and programs which benefit children. These activities include counseling and referral services at 19 youth education programs, some of which vary in content and approach. Certain projects seek to enhance the leadership potential of parents, children, and other community members, particularly regarding their decision-making behavior in the use and nonuse of alcohol. Other programs provide preventive and supportive services for elementary school children of alcoholic parents.

The use of alcohol by children and youth is recognized as a growing problem of major proportions. The Forward Plan highlights this problem with greater focus. NIAAA now identifies and treats approximately 2,300 youth alcohol abusers under seven grants approximating $1.7 million. These treatment projects are located in several States.

Eight research grants have been awarded by NIAAA at a FY 1975 cost which approximates $460,000. One of the most pertinent alcohol studies seeks to identify the effects on the fetus of pregnant women who drink.

National Institute on Drug Abuse

In FY 1975, the National Institute on Drug Abuse (NIDA) expended approximately $39 million on programs and activities supportive of youth. Nearly $21 million augmented programs which provided services, and $11 million was employed for public information activities and consumer education.

Certain activities of NIDA supported the development of a profile of adolescent multiple drug users, and listed the residential and nonresidential treatment facilities and youth outreach facilities in the Nation. In addition, this Institute has funded a number of innovative projects concerning prevention, treatment, and research. Some of these projects focus on pregnant addicts and addicted mothers; others consist of studies which compare the offspring of mothers receiving methadone treatment with a nonaddict control group. NIDA also provides prevention services for over 10,000 individuals ranging in age between 5 and 14 years.

National Institute of Mental Health

During FY 1975, the total amount of money spent on child mental health related activities approximated $105 million. Of this amount, $19,405,000 was spent on research grants and $2,045,000 on intramural research. Training grants and fellowships accounted for $20,285,000 (approximately $5 million of this for the training of child psychiatrists).

The bulk of FY 1975 NIMH funds, $56 million ($28 million through Part F, Community Mental Health Centers Act) went to fund Child and Youth Services in certain Community Mental Health Centers. These Centers provided basic services to over 132,000 children last year under the age of 18. Some of these activities are aimed at preventing institutionalization and enhancing community outreach programs.

NIMH has continued its support of program activities in basic research of the biological and genetic aspects of child mental illness, as well as the developmental behavior of infants and young children. Further, this Institute also supports the training of specialists in mental health of children and youth, has focuses on SIDS (Sudden Infant Death Syndrome), runaway youth, and has awarded four contracts which focus on collecting incidence data on abused adolescents and supporting a national conference on this relevant subject.

NATIONAL INSTITUTES OF HEALTH

National Institute of Child Health and Human Development

The National Institute of Child Health and Human Development (NICHD) serves as the focal point for DHEW biomedical and behavioral research relating to the health of mothers, children, and families.

The mission of the NICHD is to contribute to the good health of all citizens through research to expand the knowledge of family planning, child health, maternal health, and human development. The primary goal of Institute efforts is research in developmental processes so as to improve our ability to prevent disease and disability. It is our feeling that the etiology of adult diseases, particularly degenerative diseases, begin in children. The underlying rationale is that success achieved by the NICHD in assuring healthier children will result in the long range benefit of a healthier adult population for this Nation.

Among the recent NICHD research advances which are likely to help meet the health needs of children are:

NICHD scientists have developed a vaccine which has the potential to prevent a type of meningitis which is the leading cause of acquired mental retardation. *Hemophilus influenzae* meningitis may be fully preventable if findings of the Institute's scientists are borne out in a recently initiated clinical trial of this vaccine under the Institute's auspices;

In part through Institute research, a number of maternal diseases, complications and environmental factors that can increase infant morbidity and mortality have been identified. Infant morbidity and mortality can be increased by maternal disease and complications of pregnancy such as poor nutritional status, diabetes, high blood pressure, anemia, drug addiction, smoking, and the psychic stress of pregnancy. Prenatal care practices have improved significantly in recent years as a direct result of this research;

NICHD research has identified possible causes of the sudden infant death syndrome (SIDS). Until this decade, SIDS, or crib death, was a complete mystery. Recently, however, some of this obscurity has been eliminated as new leads have evolved that indicate that SIDS might be related to: apnea, infection, and heart rate changes; developmental maturational lag; oxygen deficiency; lack of sleep; abnormality in the brain stem; immaturity of the nervous mechanism controlling heart function; and inadequate lung responses. Until 1974, it was believed that SIDS victims had been basically healthy babies. From data obtained and evaluated in 1974 and 1975, it now appears that SIDS victims had not been completely healthy. All of these leads may eventually provide clinical opportunities to save up to 10,000 infants per year; and

Identification has been made of relationships of nutrition to human development. NICHD research has resulted in new knowledge regarding the adverse impact of malnutrition in pregnancy in terms of the development of the progeny, and data are now becoming available concerning the beneficial effects on child development of nutritional supplementation during pregnancy.

CENTER FOR DISEASE CONTROL

One of the most dramatic achievements in child health has been the reduction, and in some cases the near elimination of childhood diseases such as measles, rubella, polio, whooping cough and diphtheria through vaccination programs. Most of these diseases are at their lowest level ever, but they still occur. The status of these diseases is as follows: 22,094 measle cases in 1974, down 70.7 percent since 1971; 11,917 rubella cases, down 73.6 percent since 1971; 7 polio cases, down 66.7 percent since 1971; 2,402 cases of whooping cough, down 20.9 percent since 1971; and 272 cases of diphtheria, up 26.5 percent since 1971, with most cases occurring among adults.

Paradoxically, the success of these programs also poses a danger. With the sharply reduced incidence of these diseases, the population has become apathetic and high immunization levels are difficult to maintain. This creates a potential for the introduction of disease and epidemics. Because of this, the Department is continuing a strong campaign to reduce this threat.

The Department's campaign has three chief features: (1) the provision of complete immunization protection to children receiving care in HEW supported child health programs; (2) the support of State and community immunization programs; and (3) a public education campaign which promoted October as

Immunization Action Month. These efforts, as I have indicated, involve the cooperation of several agencies.

The Center for Disease Control has also made substantial progress in the following areas:

Assisting communities in developing programs aimed at the prevention of poisoning from ingesting lead based paint;

Monitoring the incidence of birth defects aimed at preventing epidemics caused by new environmental agents;

Analytical investigations seeking to discover the etiology of birth defects which are not now epidemic;

A population-based study seeking to demonstrate that technical assistance to State and local health departments can greatly increase the number of women who have laboratory testing to determine if a fetus has a chromosomal disorder like Down's Syndrome (mongolism); and

Increased surveillance activities to monitor the effectiveness of RH hemolytic disease prevention efforts.

CDC recently was given responsibility for the Public Health Service's application programs dealing with prevention and control of dental diseases. A key feature of this program is the revitalization and furtherance of the Department's efforts to extend the benefits of fluoridation to all children on community water supplies.

This is the most effective dental preventive measure yet developed, and it is the easiest to implement and the cheapest to maintain. At the present time, however, more than half of our children who could be drinking fluoridated water are not doing so. Thus, the Department views this endeavor as another of its ongoing priorities.

SOCIAL AND REHABILITATION SERVICE—EPSDT

The Early Periodic Screening, Diagnosis and Treatment (EPSDT) program represents a major effort to provide preventive and comprehensive quality health care to disadvantaged children. The purpose of the program is to identify and treat handicapping or potentially handicapping conditions early, before they become severe or irreversible problems, endangering the child's future health and well-being—and before they become more costly to treat.

The basic concept underlying the EPSDT program is one of preventive and comprehensive health care. Children served by the program have usually never had contact with an ongoing health care system. Thus, EPSDT generally provides their first introduction to preventive medicine and often their first experience with health care other than crisis care.

I would like to review briefly the background of the enactment of EPSDT and the steps the Department is taking to see that the program is implemented.

The amendment was added to conform with changes made in the Title V (Medicaid) of the Social Security Act.

The amendment was added to conform with changes made in the Title V crippled children program which required States to provide for early identification and treatment of children in need of health care and services. In discussing these amendments, the Committee on Ways and Means stressed their intent that States make more vigorous efforts to screen, diagnose, and treat children with disabling conditions, and carry out "organized and intensified casefinding procedures," including follow-up visits and related activities.

The law requires that States must make provision in their Medicaid plans for providing or arranging periodic health screening for all eligible children under 21 and for follow-up treatment of conditions discovered through screening. The screening process must assess a child's physical health and his or her growth and development. Treatment covered under the State plan for conditions found through screening is required by law, except that treatment for hearing, vision and dental defects must be provided whether or not otherwise covered in the State plan. States must also inform all families receiving payment under the Aid to Families with Dependent Children program of the availability of EPSDT services, tell them where and how these services can be obtained, and, upon request, provide transportation services.

EPSDT is administered by the States, and in the early stages of implementation there were few resources and little experience in the States to establish and administer a child health care program of the scale and scope contemplated by the legislation. Each State developed its own administrative and policy solutions to program implementation, resulting in a wide variety in the scope and emphasis given to the EPSDT program.

Further, there was no firm consensus among health care professionals regarding appropriate preventive services and techniques or the frequency with which services should be provided. Also, adjustments were necessary in the existing health care system to provide accessibility and availability to the program and avoid duplication of services while integrating EPSDT into ongoing systems.

The very scope and complexity of EPSDT and the issues raised by such a program in the areas of quality of care, organization of service delivery, and appropriate utilization of services raise obstacles to easy or timely implementation.

Final regulations, published in the Federal Register on November 9, 1971, and effective February 7, 1972, required States to provide, in addition to those services normally provided under States' Medicaid plans, eyeglasses, hearing aids, other visual and hearing treatment, and dental care. Final guidelines were published in June 1972.

Title II of the Social Security Amendments of 1972 required the Secretary of HEW to reduce Federal Aid to Families with Dependent Children (AFDC) by 1 percent if a State fails to inform eligible families of the availability of screening services or to provide or arrange for screening and treatment services. Regulations to implement this provision were published on August 2, 1974.

As you are aware, the Department has officially found eight States to be out of compliance with the mandatory penalty requirements for the first quarter of FY 1975—California, Hawaii, Indiana, Minnesota, Montana, New Mexico, North Dakota, and Pennsylvania. This was the first "penalty" assessment for noncompliance with a Medicaid program provision.

Significant new regulations were published in the Notice of Proposed Rule-Making on August 20, 1975 which would revise the current penalty regulations. Our intent is to clarify the Department's expectation with regard to State actions to implement EPSDT and to improve the Department's ability to assess State compliance fairly and objectively. The revisions are designed to do this. Further, we believe the proposed changes will strengthen basic structural support for an effective program by adding minimal case management and follow-up requirements, further specifying information dissemination requirements, and requiring a minimum screening package.

Other efforts which we have initiated in the areas of program improvement and development include:

the provision of 75 percent Federal matching funds as a financial incentive for health-related support services;
working with States to develop specific program improvement goals;
providing substantial technical assistance;
funding research and demonstration projects; and
increasing data acquisition required by management information needs.

Interdepartmental coordination exists between the Office of Education, the Office of Human Development and the Public Health Service in bringing together resources that will enable EPSDT programs to more adequately meet the needs of the eligible individuals.

As an indication of the potential size of the program, there are approximately 13,000,000 children eligible for EPSDT. The Federal share of EPSDT is approximately $500 million per year. The Federal Medicare expenditures for those under 21 in non-EPSDT programs requires approximately $1.5 billion. The combined Federal and State Medicaid expenditures for those under 21 is approximately $3½ billion.

We believe that the basic concept of EPSDT—assuring early and preventive health care services, follow-up treatment and establishing patterns of continual periodic contact with health care providers—is the major strength of the program. Although this concept of health care is not new to the medical profession, it is innovative as a part of a national program of financial assistance for the costs of medical care.

In a larger sense, we see EPSDT as an ongoing demonstration to determine how our governmental and health care system resources can best accommodate the special health needs of children and youth, particularly those in low income families. Many States now have good operational EPSDT programs. Administrative systems and provider resources are in place in many areas where previously none existed. Low income children are being screened and introduced into the health care system. Clearly, this has not been an easy task and much remains to be done. However, we know that comprehensive child health care programs can be established with continuing commitment on the part of Federal and State administrators and health care providers.

OFFICE OF HUMAN DEVELOPMENT

Head Start

Turning now to the health services component of the Head Start program I shall begin by indicating the program's general objectives:

to provide a comprehensive health services program which includes a broad range of medical, dental, mental health and nutrition services to preschool children, including handicapped children, to assist the child's physical, emotional, cognitive and social development toward the overall goal of social competence;

to promote preventive health services and early intervention; and

to provide the child's family with the necessary skills and insight and otherwise attempt to link the family to an ongoing health care system to ensure that the child continues to receive comprehensive health care even after leaving the Head Start program.

The health services component of Head Start (medical, dental, nutrition and mental health) provides that for each child enrolled in the Head Start program, a complete medical, dental, and developmental history will be obtained and recorded, a thorough health screening will be given, and medical and dental examinations will be performed. These services were provided to approximately 350,000 preschool children in Head Start in 1974.

OFFICE OF EDUCATION

Several programs of the Federal government in the field of education assist financially limited school districts in providing health services. For example, this year the Title I program of the Elementary and Secondary Education Act will provide $1.9 billion for services to the educationally disadvantaged youngsters across the country. Health and related services are eligible for support under this program. Because of the Title I formula, a major portion of the funds flow into school districts where there is a large concentration of economically disadvantaged students. Therefore, in general, the school districts which have the maximum need for financial assistance stand to benefit the most under the Title I program. Other federally funded programs under which school health services are eligible for receiving financial support are: Title III of the Elementary and Secondary Education Act (Supplementary Educational Centers and Services), Title VII (Bilingual Education); Title VIII of the same Act (Health and Nutrition, and Dropout Prevention Programs); the Follow Through Program (a program to continue the Head Start activities); and Education of the Handicapped Act.

I am herewith submitting a table showing the estimated number of students served and the federally appropriated dollars expended in the category of health services for FY 1973 under the education programs enumerated.

PROGRAM

	Total	Migrant	Low income	Title III	Title VII	Title VIII	Follow Through	Education of the handicapped	Emergency school aid
Federal expenditures	$27,891,000	$2,189,000	$22,764,000	$225,000	$25,000	$148,000	$2,400,000	$110,000	$30,000
Students served	2,064,900	162,000	1,686,000	16,000	1,800	10,900	178,000	8,000	2,200

Conclusion

Mr. Chairman, we in the Department who are concerned with programs affecting our Nation's children are dedicated in a special way—not only to the fulfillment of our direct responsibilities but to the role we play in helping them to achieve optimum health and well-being. I believe we have demonstrated today that we are using our resources to the best of our abilities. As we have shown in our discussion of the programs themselves, the Forward Plan and our new Office of Child Health Affairs, we are striving to improve our child health research and service efforts in every way that we can.

Mr. Chairman, this concludes my statement. My colleagues and I will be pleased to try to answer any questions which you or other members of the Subcommittee may have.

Mr. OTTINGER. Is this matter of highest priority in the Department?

Dr. DICKSON. I would like to turn to Dr. Weikel, if I may.

Mr. WEIKEL. Yes, I think it clearly is one of the highest priorities within the Department. I think the record over the past year clearly indicates there has been significant progress in the implementation of this program.

Mr. OTTINGER. If this is a matter of the highest priority, why isn't the Secretary here, or even the Assistant Secretary? It seems to me that this involves the health of the children of the country, involves the waste of billions of dollars in wasted treatment for diseases that could have been prevented. I personally, and I think the members of the committee, consider it the highest priority. It seems to me worthy of the Secretary's consideration.

Dr. DICKSON. The Assistant Secretary, Dr. Cooper, is in St. Louis, Mr. Chairman.

The program does have the highest priority. There are other priorities that the Secretary has to attend to beyond health per se. He adjusts his time according to the relative priorities across the Department.

Mr. OTTINGER. I consider it an indication of the priorities to have the Administrator of the programs before us. We are dealing with major policy questions here. If this is a high priority matter on behalf of the Secretary it would have been incumbent on the Secretary to be here. I hope you will transmit to the Secretary that we on this committee feel this is a matter of paramount importance.

A vast amount of Federal money is being wasted, and is not reaching the very important goals that it should be reaching, and we would like to see this matter corrected, and would like to see the Department address itself in action, not just in words to make this a high priority of the Government.

Mr. WEIKEL. Mr. Chairman, I think whether this is a high priority is illustrated in the actions. I think the actions that the Department has taken over the past year clearly illustrates it is a high priority. I think the actions that the Secretary is continuing to take to support the program indicate that it is a priority.

There are clearly a lot of problems associated with the implementation of this program. I think there has been clear progress made during the past year by the Department in the implementation of this program.

Mr. OTTINGER. Reaching only 15 percent of the children who are eligible. That is a relatively small percent.

Mr. WEIKEL. That is correct.

Mr. OTTINGER. With the screening program. And then needing treatment, less than half of those. It does not seem to me to spell out very great success.

Mr. WEIKEL. First of all I would hope that since the referral rate only indicated a need to treat 50 percent we not waste additional money by treating people who don't need referral for diagnoses or treatment.

Second, in terms of the record on screening. I want to emphasize we don't believe the value of this program is in screening, the value of this program is in seeing that children ultimately get treated for the conditions that are identified. I think if you will look at the record,

the record indicates through July 1, 1974, we screened 1.5 million children. I think all of us believe that record is inadequate. It is not an acceptable level of performance.

On the other hand, during the past year in a single year we have screened 1.5 million children, and those are very hard numbers. We have eliminated a lot of numbers that were reported by States that we didn't think were valid numbers. So we have screened last year 1.5 million children out of approximately 9 million children who are eligible for the services.

In addition, that 1.5 million does not include any of the data for the equivalence to screening. There are a lot of children under medicaid who are receiving services under the program through private practitioners. If they are being seen by a pediatrician on a regular basis we believe that counts as the equivalent of a screen, again emphasizing that the issue is not screening it is whether the children are treated. We think we have a major initiative that is needed in that area, and we are undertaking a number of activities to make sure that the children are followed up and treated.

Dr. DICKSON. Mr. Chairman——

Mr. OTTINGER. Is one of the important elements of preventing handicaps and illnesses in children, nutrition?

Mr. WEIKEL. Is it nutrition?

Mr. OTTINGER. Yes.

Mr. WEIKEL. Obviously I think it is nutrition. Housing is also another element.

Dr. DICKSON. I think Dr. Lowe might comment on that.

Dr. LOWE. Mr. Chairman, I think it would be only fair to say that there is evidence that there are nutritional problems in the United States. The Department, as you know, mounted a 10-State survey, and this certainly confirms the suspicion that there was malnutrition.

These issues are being addressed, but only partially by the Department. The Department of Agriculture, as you know, has a major role in the alleviation of some of the malnutrition. The forward plan of the Department addresses nutritional issues in what I believe to be a constructive and forward looking fashion, and an attempt is being made to identify through more sophisticated methods than presently available, malnutrition which is incipient.

There is no art in identifying broad malnutrition. The importance is to detect children who give evidence of incipient malnutrition, and this we propose doing.

Mr. OTTINGER. It is very hard to conceive of an administration which calls child health top priority in the health field, says this is going to be the year of the child, and then vetoes a nutrition program. I find in every respect that the actions simply don't follow the words with respect to giving what I consider a most important program the kind of priority and attention it deserves.

I don't want to monopolize all the time. At this point let me recognize my colleague, Mr. Sharp.

Mr. SHARP. Mr. Chairman, I wonder if it could be useful if they could specify what actions have been taken? My concern is that the charge has been made in this hearing and articles in the National Journal that there has been a gross absence of commitment in primarily the Nixon administration, and perhaps that is carried over in

the Ford administration on this very program which has been on the books since 1967. Now that is a very serious kind of charge.

The second is, you heard this morning, if you weren't already plainly aware of it, that there are many serious questions about whether we should implement this particular program, whether it really can do the job we need to do, and maybe what we ought to be doing is drawing up a different program.

You have indicated there are specific actions being taken. I would like to know what those are in terms of implementing them and what should be changed. I don't sit on the authorizing subcommittee, so I may be ignorant of this. I would appreciate if you would clear it for me.

Mr. WEIKEL. You referred to the National Journal articles which were written on the basis of the way the program was prior to 1974. I think a tremendous amount has happened since that time.

As of the end of last July there were approximately five people involved in the implementation of the EPSDT program. As of today there are approximately a hundred people involved in the implementation of that program. I think that clearly demonstrates some commitment on the part of the Department.

As of last July, there was very little in the way of technical assistance available. We are spending $3.5 million with various contractors, many of them professionals, such as the Community Health Foundation, to provide technical assistance to States that have not developed an adequate program. We have a commitment to provide in depth technical assistance to nine States under that contract.

We have contracts with the American Medical Association to determine how we can get more cooperation on the part of the providers. I might indicate that over the past year there has been a tremendous commitment on the part of the AMA and on the part of the Academy of Pediatrics.

We also have a contract with them trying to provide us with technical assistance, working with our regional offices in each of the regional offices, working with the States to try to improve participation of providers in this program.

One illustration, the testimony earlier, was that we should not consider mass screening clinics. In term of implementing the program we would like to have all these children treated in the private practice if that is most cost effective and most beneficial in terms of their health. But in our project that is being sponsored by the AMA in Illinois where the county medical society is intimately involved, where their commitment was to try to get private practitioners to take the children as part of their regular patient mix, they have had difficulty getting physicians to take the patients.

It is not an all black or white situation. There is difficulty involved in providing the proper providers. The reason in that case was not that providers did not want to take patients, they were overloaded with their present population. They did not have capacity to absorb additional children. That is just one example.

I could go on laying out other technical assistance contracts, demonstration contracts, that have been initiated and implemented during the past year.

Mr. SHARP. Could you give us a couple more examples?

Mr. WEIKEL. We have a rural health project that we are involved with in Cuba, N. Mex., where the problem is how can we provide EPSDT service to our rural population as well.

We have a project in San Antonio, Tex., barrio project, attempting to provide health services, that is jointly funded by ourselves and the Robert Johnson Foundation. The Lodge Foundation is involved as well. So we are involved in joint projects.

Mr. SHARP. These are experimental projects?

Mr. WEIKEL. They are a series of research and demonstration projects. There is also a series of five or six specific contracts which have been implemented during the past 6 months to provide technical assistance to the States to improve their program.

Dr. DICKSON. In respect to this question the activities in the past year in the health services administration are pertinent. I would ask Dr. Van Hoek to comment with respect to those.

Dr. VAN HOEK. I would like to address the second question that you raised, which is with respect to how we can improve the delivery of health care services to children. One more program that we administer is title 5 of the Social Security Act, the maternal and child health and crippled children program. This program over the years has directed itself to doing exactly what you heard the pediatricians on the panel prior to us describe as to what the nature of screening, referral, comprehensive care for children should be, and the fact that you have to link the screening program with the delivery system in settings. This is exactly the approach that the maternal and child health and crippled children program has taken in the States.

It is a program formulas grant to the States, currently running at approximately $300 million per year in total, including some research and training funds, and providing services to approximately 8 million mothers and children at the present time, targeted largely to the low-income families.

Mr. SHARP. Can you tell me how that would work from a mother's point of view? What would be her experience on the receiving end?

Dr. VAN HOEK. If eligible as a low-income mother from a low-income family, you can come to one of these projects or programs. It may be operated by the State or local health department. It may be operated under agreement or contract by medical schools, hospitals, group practice programs, or clinic programs. The mother and child receive prenatal care, care through maternity, post-natal care, well child conferences, immunization, subsequent screening as the child grows and complete assessment, not just of vision screening and hearing but complete assessment of the growth and development of the child. Not only that, it either directly or through other arrangements sees that any nutritional problems are met.

There is a significant follow-up component of the programs which is education of the mother and family to maintain adequate nutrition and assistance in carrying out these activities.

Mr. SHARP. Is there a great deal of flexibility as to how the pattern of administration works? In most of these programs it is my impression that is left for local decision. What you people do is scrutinize just to see that they meet general guidelines.

Dr. VAN HOEK. We set minimum standards as to the types of services that are to be provided, how they are organized and carried out is at

the discretion of the program. I would also point out that this program has significantly focused on the training and improvement of nonphysician personnel to carry out many of the programs functions. We are attempting to solve the problems of shortage of physicians or maldistribution of physicians by using other personnel adequately trained to carry out these functions, including nurse practitioners mentioned by an earlier testimony.

Mr. SHARP. Thank you.

Mr. OTTINGER. Mr. Santini.

Mr. SANTINI. Thank you, Mr. Chairman.

I will address my questions to whichever member of the panel wishes to respond.

First of all, I am concerned by the fact that we are looking at what the chairman and Mr. Weinberger and you have acknowledged is a top priority program. As Dr. Weikel appropriately observed, a high priority is indicated by the actions.

Now, in the law enacted in 1967, July 1, 1969, was the effective date. By February 1972, almost 3 years later, for this top priority program, we have implementing regulations. In view of the fact that this is a top priority program that took almost 3 years to get regulations, what was the reason for the delay?

Mr. WEIKEL. I think first of all it was not probably established as a top priority [illegible]969. I think Secretary Weinberger clearly did later establi[illegible] top priority. Former Secretary Weinberger has indicated there is enough blame in terms of the slow implementation to go around to all of us, the Department, the States, and anyone else who was involved. I do not think it benefits us to say who was at fault for the slow implemenation.

Clearly, I think during the past year there has been rapid implementation and we have begun to address some of the real problems that we are confronted with in the implementation of this program.

Mr. SANTINI. Should not the Department be the one to bear the primary blame or responsibility or credit for the success or failure of this particular problem in view of the fact that HEW is the implementing agency?

Mr. WEIKEL. I think that is correct. Also it obviously involves participation with the States. The State governments have the principal responsibility for implementing the medicaid program in EPSDT.

Mr. SANTINI. On that point, Dr. Weikel, Dr. Cohen, former Secretary of HEW, testified yesterday that one of the principal failures of this particular program, and I am sure you have had a report on his testimony, was the fact that HEW has established an adversary confrontation relationship with the States, and that even to the last week of Secretary Weinberger's service he issued two regulations without any consultation with the States. The States are rebelling in response to this program because they feel it is being crammed down their throats as opposed to being implemented as a joint effort between Health, Education, and Welfare and the States concerned

Mr. WEIKEL. I could recite here a litany of our efforts today along with the States. First of all, last August we had a conference where we invited the Governors, representatives of his office, the Director of Social Services of the State agencies, Director of Medicaid, to tell them about the commitment of this Department to implement this program.

We followed that up with a whole series of correspondence to the States. I have personally been involved in numerous conferences with the Health Subcommittee of the American Public Welfare Association that has responsibility within that organization for representing the States in Washington and meeting with them on issues. I have met with them just recently on the new regulations that were proposed to implement the penalty.

I think the record indicates we have worked with the States. We have cooperated with them. Within the Medical Services Administration we are not publishing regulations unless we have previously consulted States about those regulations.

Mr. SANTINI. Your testimony at this point is that every regulation that is implemented concerning——

Mr. WEIKEL. I did not finish.

Mr. SANTINI. It is not every regulation then?

Mr. WEIKEL. In the case of the regulation on the penalty that you were referring to that was published, the revised penalty regulation for EPSDT, that regulation was not discussed in any amount of detail. Small parts of it were discussed with individual people and States, but the regulation itself was not discussed because we felt there was a real need to make some clarification, to clear up some of the confusion that existed with the first penalty regulation that we discovered as a result of trying to implement. We have tried to correct it through that new regulation. Because Secretary Weinberger wanted to correct that before he left, he did publish those without our consulting with the States.

Mr. SANTINI. May I nail down one thing before we go much further? It is your sworn testimony as to all implementing regulations, I appreciate your being as precise as you can on this point—that you confer with the States or consult with the States prior to the implementation of those regulations.

Mr. WEIKEL. Absolutely. So there can be no confusion. I cannot testify as to what happened in terms of the original implementing regulations since I was not involved in the program in any way at that point.

I am saying in recent history there clearly has been a record of consultation.

Mr. SANTINI. What is recent history?

Mr. WEIKEL. Within the last year.

Mr. SANTINI. That is 6 years after the so-called effective date, July 1, 1969.

Mr. WEIKEL. If we are truly interested in whether this program has a potential we can recite past history over the last 5 or 6 years, or we can look at what has been done by the Department to move out aggressively to implement this program.

I also want to make clear that the regulations you are talking about being published in August were clearly not regulations that were just laid on States. That was a notice of proposed rulemaking that the States and every other interested party has 30 days to comment on, after which we will consider their comments. In that interim period I have already discussed those regulations with State officials, with the American Public Welfare Association, and their representatives.

Mr. SANTINI. You feel that the record of Health, Education, and Welfare has been a commendable one in terms of its relationship with the States?

Mr. WEIKEL. In terms of the EPSDT program, I think that is clearly true. I think that we feel the need within medicaid within SRS, and within the Department to have more dialog with the States rather than less.

We clearly can't solve these problems from Washington. We believe they can only be solved by working cooperatively with the States.

I think I can give you a specific list of regulations that have been published within the medicaid program, within SRS and the Department in the past 6 months where the States have been consulted even before the notice of proposed rulemaking.

Mr. SANTINI. Dr. Weikel, I would appreciate your comment, too—as you observe the value of the program is not in screening, it is in children treated—can you advise this committee, in view of the fact that this is the value of the program, how many children were treated?

Mr. WEIKEL. That is clearly one of the problem areas in administering the program. When the program was originally implemented there was too much emphasis, I believe, speaking as a professional, on the screening component. The only data required from the States was oriented around the number screened and the number that are referred. We recognize this problem, and we have begun to do something about it.

We have changed our reporting requirement. We are in the process of getting that cleared through the Office of Management and Budget, and we are requiring them not only to report screening data but to develop some mechanism for following up to make sure that the children are treated.

One of the major provisions of the revised penalty regulation is require documentation on the part of the States to determine whether or not the children were treated.

Mr. SANTINI. Your answer is that we cannot assess the value of the program because we don't know how many children have been treated 6 years after the program was to be implemented?

Mr. WEIKEL. That is correct. I think the mechanisms are in place clearly to correct that.

Mr. SANTINI. Congressman Metcalfe testified, with regard to the actions on this top priority program:

> In 1972 I requested the U.S. General Accounting Office to investigate the EPSDT programs to determine the extent of its implementation in my home State of Illinois and throughout the Nation. In January of 1975 the GAO issued a report. Their findings and conclusions made it clear that despite the law, and despite the obvious human need that program can serve, HEW has all but ignored the existence of ESPDT for more than five years.

Is that an accurate conclusion?

Mr. WEIKEL. I think in our comment on that the Department indicated we did not have any real problem with that conclusion.

Mr. SANTINI. You agree with that conclusion?

Mr. WEIKEL. Yes, sir. The Department officially responded to that effect.

Mr. OTTINGER. I am going to have to cut the gentleman off, but we will get back to you. I think you are doing a good job.

The administration has vetoed a health bill that would provide for the training assistance to medical schools, additional assistance to medical schools, to provide the doctors that are needed. Then it vetoes the Child Nutrition program. They have announced that we should not bother to pass a national health insurance program, all that costs too much money.

We had strong evidence in these hearings that the States were not responding enthusiastically at least in part because they are suffering severe financial stringency, and they are not anxious to put up a very substantial share of the funding that is required. How would the Department look upon our increasing the Federal share 100 percent, or perhaps 90 percent, and could we anticipate a veto if we went ahead and did that?

I think the Secretary probably ought to answer that as it is a question of departmental policy.

Mr. SOPPER. Mr. Chairman, obviously you are making a proposal which the Department would have to consider and discuss in the context of its place in the executive branch. We cannot tell you now what the President would do if the Congress were to send him legislation which would change the EPSDT program.

Mr. OTTINGER. Is it your opinion that the inability of the States to finance the program is a problem?

Mr. WEIKEL. I would like to comment on the different types of implementation of this program. If you look at the medicaid program historically, that has been a program that has had principally one objective, providing payment or paying bills for low income individuals who are eligible to providers from whom they receive services. The EPSDT program gave the States an entire different set of responsibilities that they never had before, they could look at a single bill in isolation and say that is a valid bill, and pay it.

With the implementation of the EPSDT program it put on a different set of responsibilities, responsibility for outreach, and followup, a responsibility to make sure that children get in to be treated. That was not the responsibility that the traditional medicaid agency had prior to the enactment of the EPSDT. That is quite different.

The reason I mention that is that funding is only one of the problems I think that the States have.

We are addressing the need for outreach. The need for followup, and tracking through some of our technical assistance, some of our changes in reporting, and some of our other contracts to develop tracking systems for the States. So, money is only one problem.

I am sure if you asked the States if they wanted more money the answer would be yes.

Mr. OTTINGER. What is needed here is a comprehensive health program for children as I see it here. Perhaps if the administration was not prepared yet to go for a national health insurance program that covers everybody it might at least, as has been suggested in testimony here, go for a national health insurance program that covered children in their early childhood years. The testimony I think was that it would be very desirable to have this from birth to 6 years old.

Can you give us any indication of how the Department would view this?

Dr. DICKSON. No, sir. I have no comment to make on that. I heard the proposal.

Mr. OTTINGER. Can we get some comment from the Department on those two questions in writing?

Dr. DICKSON. Yes, sir.

[The information requested was not available to the subcommittee at the time of printing—November 18, 1975.]

Mr. OTTINGER. Counsel, I will give you an opportunity for some questions.

Mr. SEGAL. Last year there was an indication that there were 13 million EPSDT eligible children. Is that correct?

Mr. WEIKEL. Yes.

Mr. SEGAL. Approximately 1.5 million were screened?

Mr. WEIKEL. That is correct.

Mr. SEGAL. Therefore, that would leave approximately 11 million or 11.5 million not screened?

Mr. WEIKEL. Who were not screened that year; that is correct. There is a total of 3 million children screened to date.

Mr. SEGAL. Could I ask, Mr. Chairman, that we insert in the record at this point a preliminary report that was done by the staff by requesting States for information on EPSDT.

Mr. OTTINGER. Without objection, that will be so ordered. I think if you are going to question the witness about it, you had better make it available to the witness.

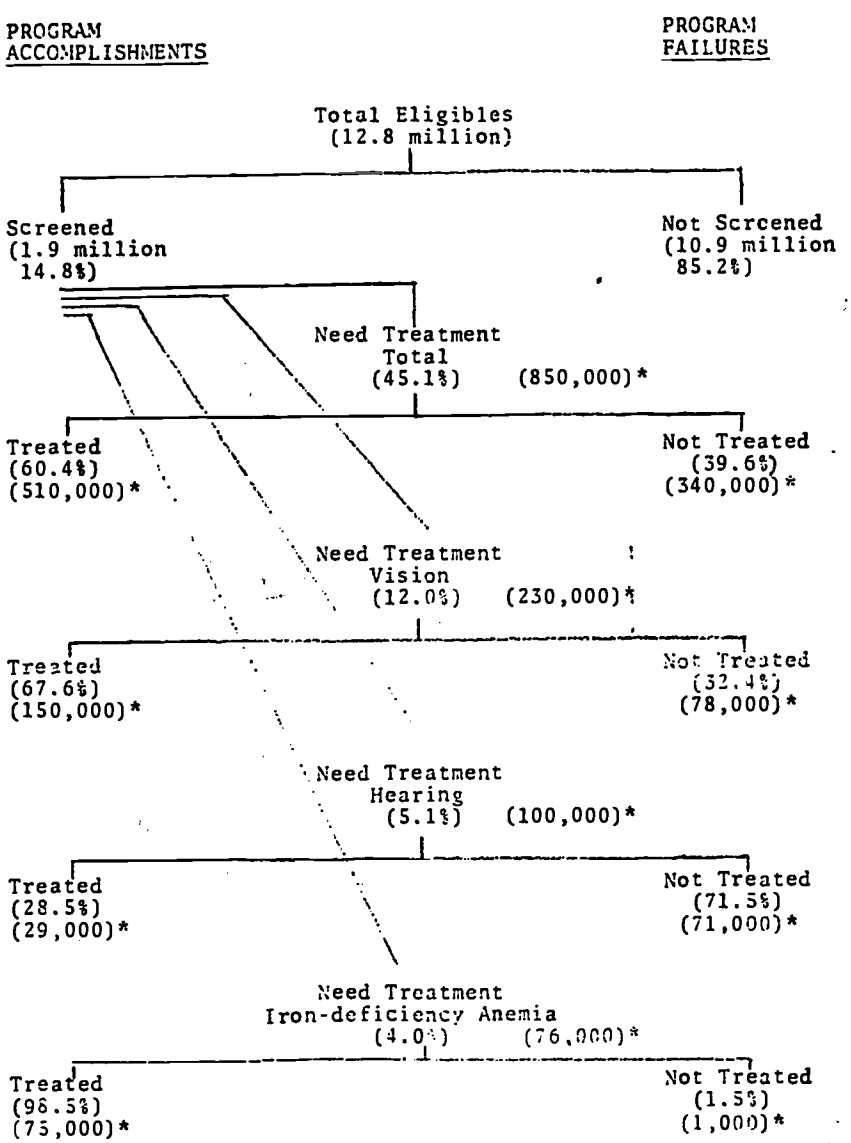
[The document referred to follows:]

60-800—75——9

PRELIMINARY REPORT OF THE RESULTS OF A QUESTIONNAIRE SENT TO STATE MEDICAID AGENCIES CONCERNING EARLY AND PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT (EPSDT)

(Prepared by the Staff of Oversight and Investigations Subcommittee, Committee on Interstate and Foreign Commerce)

EPSDT - FY 1975



*Staff estimates

EARLY AND PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT

On September 10, 1975, the Subcommittee on Oversight and Investigations of the House Committee on Interstate and Foreign Commerce surveyed the States for certain basic statistical information on the Early and Periodic Screening, Diagnosis, and Treatment program (EPSDT) required under Title 19 [Medicaid] of the Social Security Act. A total of 35 States responded. The results of that survey form the basis for this preliminary report on EPSDT.

The following sections examine the number of children eligible for screening, and the number screened, needing treatment, and treated for general conditions and for specified visual, hearing, and anemia problems. The report focuses on children receiving such services, and more importantly, on children who are not receiving such services when they should be.

Eligible population

Based on the responses of 31 States providing information on the eligible population, an estimated 12.8 million children were eligible for EPSDT at some time during fiscal year 1975. The methodology used in arriving at this estimate is as follows:

Data on quarterly eligibles was provided by 30 States, indicating a quarterly average of 4,084,545 eligibles during FY 1975. These States included approximately 45% of Medicaid recipients under 21 years of age during May, 1975 (excluding New York for the reasons noted below). Assuming that the same ratio holds true, 4,084,545 would be 45% of eligibles in FY 1975, yielding an average quarterly estimate of 9.1 million eligible children;

Eight States provided information on both the quarterly eligibles and the total yearly number of eligibles. In these States, the yearly total was 1.28 times higher than the quarterly average. Multiplying this 1.28 yearly turnover factor times the 9.1 million average quarterly number of eligibles yields an estimated 11.6 million eligibles at some time during FY 1975; and

New York reported 1.2 million eligibles during the year, and no quarterly number, and thus has been excluded from the above computations. Adding the 1.2 million New York eligibles to the 11.6 million yields a nationwide estimate of 12.8 million children eligible at some time during FY 1975.

General screening package

Data on the general screening package was reported by 34 States, with a total of 1,162,589 screenings reported in those States. These 34 States included approximately 61% of Medicaid recipients under 21 in May of 1975. Assuming that the same ratio holds true for the entire fiscal year, an estimated total of 1.9 million children were screened during FY 1975.

States were also requested to provide information on the number screened specifically for visual, hearing, and iron-deficiency anemia problems. In general, for most States, vision and hearing screens reported were the same as total general screening. Fewer States reported screening for iron-deficiency anemia. The results of screening for these specific problems are as follows:

33 States reported 1,115,223 screenings for vision;
33 States reported 1,111,060 screenings for hearing; and
20 States reported 886,971 screenings for iron-deficiency anemia.

Public accountability questions

Since the total eligible population was estimated to be 12.8 million, approximately 10.9 million children were eligible for screening services but were not screened during FY 1975.

What are the consequences of 10.9 million children not receiving this basic preventive health care?

How many of these children were screened in previous years? For example, if 3 million children were screened in all previous years, does than mean almost 8 million eligible children have *never* been screened under this program?

Can one expect a greater proportion of eligibles to be screened in the future years? How many?

What is the Department of Health, Education, and Welfare doing to increase the pace of screening?

Number needing treatment

States were asked to provide the number screened who were identified as needing treatment.

32 States reported the total number needing some form of treatment as a result of the general screening package. Of the 1,098,400 screened in those States, 495,471, or 45.1% needed treatment.

32 States reported the number needing treatment for vision problems, with 12.0% (133,589 of 1,113,261 screened) needing such treatment.

32 States also reported those needing treatment for hearing problems, with 5.1% (56,747 of 1,110,778 screened) needing such treatment.

13 States reported those needing treatment for iron-deficiency anemia, with 4.0% (24,417 of 608,821 screened) needing such treatment.

Assuming that the percentages of those needing treatment would apply to the entire eligible population of 12.8 million, the following can be derived:

45.1%, or 5.8 million children, need some form of medical treatment;
12.0%, or 1.5 million children, need treatment for vision problems;
5.1%, or 650,000 children, need treatment for hearing problems; and
4.0%, or 510,000 children, need treatment for iron-deficiency anemia.

Public accountability questions

What are the consequences of as many as 5.8 million children actually needing some form of medical treatment when only 1.9 million are being screened each year?

How can the Department of Health, Education, and Welfare justify its actions in implementing EPSDT when the program falls so far short of the need?

Number treated[1]

A small number of States were able to report the number of those needing treatment who were actually treated.

9 States reported all treatments as a result of the general screening package, with 60.4 percent (80,454 of 133,117 needing treatment) actually receiving treatment.

5 States reported the number receiving treatment for vision problems, with 67.6% (8,357 of 12,368 needing treatment) actually receiving treatment.

5 States reported the number receiving treatment for hearing problems, with 28.5% (622 of 2,186 needing treatment) actually receiving treatment.

3 States reported the number receiving treatment for iron-deficiency anemia, with 98.5% (8,401 of 8,527 needing treatment) actually receiving treatment.

Applying these percentages to the total number of children reported as needing treatment in this survey yields the following:

60.4% of the 495,471 children reported as *needing treatment*, or approximately 299,000 children, actually received such treatment. Approximately 196,000 were identified as needing medical treatment but *were not treated;*

67.6% of the 133,589 children reported as needing treatment for vision problems, or approximately 90,000 children, actually received such treatment. Approximately 43,000 children were identified as *needing treatment* for vision problems but *were not* treated;

28.5% of the 56,747 children needing treatment for hearing problems, or approximately 16,000 children, actually received such treatment. Approximately 50,000 were identified as *needing treatment* for hearing problems but *were not treated;* and

98.5% of the 24,417 children needing treatment for iron-deficiency anemia, or about 24,000 children, actually received such treatment, while approximately 400 did not.

Public accountability questions

How can one justify identifying medical problems and then not treating them?

Why are so few States able to report important link between screening and treatment? Do the other States not know how many were treated?

How can the Department of Health, Education, and Welfare assure that the treatment component of EPSDT is being carried out, when most States cannot even provide information on treatment, and those that do provide such information indicate that only 60.4% of the total problems identified are actually being treated?

[1] Because of the limited number of States responding these figures must be used with caution in considering national extrapolation.

Additional data needed

Data on the numbers screened, and numbers needing treatment for specified conditions appear to be adequate at the present time. However, the remainder of the data on EPSDT needs marked improvement.

Information on the eligible population can only be described as grossly inadequate. The Subcommittee staff encountered similar problems on the eligible population in the survey of surgery under Medicaid. It is imperative that the Department of Health, Education, and Welfare develop accurate information on the number of Medicaid eligibles.

The survey requested information on the number of those informed of the the availability of screening services, and the number requesting and declining such services. A number of States were unable to identify those informed, and most States were unable to identify those requesting and declining such services. Such information should be kept up to date at the Federal level, and must be kept at the State level since States are required to inform eligibles, and must be able to identify requests for screening in order to provide service.

Public accountability requires that a data collection system be available that will link treatment to screening.

Mr. SEGAL. I have a couple of additional questions. Let us focus on those who were not screened, the 11 million approximately.

We have heard testimony over the past couple of days that a number of disorders such as vision disorders and hearing disorders and anemia are prevalent among the population. Would you say that an estimate of 10 percent of those children screened would be likely to have a vision disorder? I think it might be appropriate to hear from our pediatricians who are here.

Mr. WEIKEL. I will tell you what we have discovered in the 3 million children we have screened. That is somewhere in the neighborhood——

Mr. OTTINGER. Excuse me. I heard you say before that you screened about 1 million children.

Mr. WEIKEL. I think I said previously we screened through July 1 of 1974, 1.5 million. We screened during the past year, in fiscal 1975, 1.5 million, for a total of 3 million children screened.

Mr. SEGAL. Since 1969 there have been 3 million screened?

Mr. WEIKEL. There have been 1.5 million children screened during the last fiscal year.

Mr. OTTINGER. 1.5 million during the past fiscal year.

Mr. WEIKEL. That is correct. I think that clearly demonstrates some increased growth in the implementation of this program.

Mr. SEGAL. Using the figure that you indicated that there were 8 percent of those who had been screened had visual problems, would you think then it would be a fair extrapolation to look at the 11 million who had not been screened and assume that 800,000 of them would have visual disorders?

Mr. WEIKEL. No, sir. First of all, we at this point unfortunately do not know how many of the remaining 11 million children have received services that are equivalent to screening through being treated by a neighborhood health center.

Mr. SEGAL. Could we have Dr. Lowe answer that question on his professional judgment?

Dr. LOWE. I would have to defer to Dr. Weikel. There are good figures on the prevalence of a large variety of important defects in children. This would be one of them. I think it is an opportunity to gain hard numbers on the prevalence of visual defects. I am afraid I can't assist you.

Mr. SEGAL. Have you seen any studies on visual disorders and the percentage of children that have been determined to be having defects or disorder problems?

Dr. LOWE. Yes, sir; there are studies and the National Center of Health statistics has prepared some. The problem is that these figures tend to be distorted because children with very obvious defects show up before children with more subtle defects. The caveat I think that Dr. Weikel inserted is one that should be kept in mind.

Mr. SEGAL. What about the National Academy of Science study? Would that be a study that you would consider appropriate in any way? What of the epidemiology of the study's results?

Dr. LOWE. I am not sufficiently familiar with the study to comment.

Mr. WEIKEL. I am familiar with the study.

Dr. KRETCHMER. The answer is yes.

Mr. SEGAL. 11 million individuals who are not screened, if they were screened what percentage might you expect would have visual disorders?

Dr. KRETCHMER. I have no idea really. I think what Dr. Lowe said is quite true. As you screen you are going to get a minimum figure which is comprised of those children who have outstanding disorders. That is a minimum figure. Then a maximum figure builds up as you begin to count minimal or mild disorders. I don't think there are sufficient data now available that would give an accurate percentage figure of visual disorders which one could expect.

There are data, for example, on mental retardation.

Mr. SEGAL. Could you cite those, please?

Dr. KRETCHMER. Yes. The data on mental retardation, which have been gathered primarily by the National Foundation as well as other foundations, would indicate that about 7 percent of the children would fall into an area from mildly to severely retarded. This is a figure, by the way, that was given to you yesterday also.

Mr. SEGAL. That is right. So, you would expect out of that population of unscreened; namely, 11 million, that 770,000 of them might very well be mildly to severely retarded?

Dr. KRETCHMER. Yes; or with some kind of learning disability; that is right.

Mr. SEGAL. Could I ask one more question along that line? As part of the methodology for the study that we did of the State agencies it was determined out of 1.9 million screened there were 12 percent that had visual disorders. Is there someone here who feels that is an inappropriate figure to have be determined by the States?

Dr. LOWE. With your permission I would like to go back to the question on mental retardation because I think it would be helpful to clarify one point. The prevalence of mental retardation is a function of the age at which you make the assessment. The best single study, for example, done in Maryland shows that if you detect mental retardation at birth you start with about 1.5 to 2 percent. If you move up through various ages you can reach 7 to 10 percent. But it is not valid to extrapolate that figure to a population age under 5.

Mr. OTTINGER. In the National Academy of Sciences study I take it the conclusion was that the screening process simply was not valid, the screening that is being done is inadequate, and the followup that is being done on that is even more inadequate. That seems to be con-

firmed by the GAO study as well. Is this piecemeal approach to the problem worth it? Is it worth our putting more efforts in a simple screening program?

Mr. WEIKEL. I would like to comment on that. I think I am aware of the National Academy of Sciences study you are talking about. That was predominantly funded by the Department. I was one of the officers to that particular contract. As I recall that contract, it did not pertain to the effectiveness of screening under the early and periodic screening, diagnostic and treatment program but screening per se, whether done in the school program, neighborhood health clinic, or in a private physician's office. It is not an indictment of the EPSDT program. It says something on a broader basis about our ability to screen and pick up some of these conditions.

To answer your question in terms of tracking, yes, there have been problems in terms of tracking and following up to make sure the children are actually treated. Again I think the States over the last year have made significant progress in putting into place systems that will begin to track.

There are two particular approaches that can be used. I can discuss those in detail if you would like to follow up and track children.

Mr. OTTINGER. Why don't you discuss them briefly and perhaps comment as well on Dr. North's suggestion on supplying vouchers?

Mr. WEIKEL. I have not thought about that approach at all, and I refer not to comment at this time.

In terms of followup treatment there are two approaches. One involves a case management of an individual, to have responsibility on the part of the Government or administering agency to make sure the child goes into screening or goes to a physician that provides screening and treatment. This program does not mandate and does not encourage separate screening clinics despite what some of your previous witnesses have testified to.

Then after the individual is screened, whether it is by a private physician who will follow up on the diagnosis and treatment, that case worker would need some verification that the treatment is provided. Some States are presently implementing that system.

The second system of tracking and followup comes about as a result of a claims process, a process for paying medicaid claims. In that process the physician reports a procedural code. If the State runs a patient profile, they obtain the patient's name, the names of the providers that are servicing that patient, and the names of every service provided, every diagnosis, every treatment that is provided, every service provided for that individual patient. Through that mechanism we can check back to see whether a condition was identified during screening and whether he is receiving subsequent treatment.

Mr. OTTINGER. Are any of these things being done now?

Mr. WEIKEL. Yes, sir.

Mr. OTTINGER. On a universal scale?

Mr. WEIKEL. On a universal scale the answer is no because we have 53 States and jurisdictions operating this program and they have their own methods. Some of the methods are nonexistent. I don't want to imply there are 53 States and jurisdictions that have a tracking system and followup. Texas has put in a patient profiling system. They have had that in recent years, but now they have a means of identifying

whether the child received treatment as a result of screening. The State of Michigan has put a system in place involving more of a case management system which involves the public health department.

Mr. OTTINGER. I recognize Mr. Wunder, the minority counsel.

Mr. WUNDER. Thank you, Mr. Chairman.

Dr. Weikel, would it be fair to say about the Department's position in regard to this program that, yes, you acknowledge there have been problems and, yes, you acknowledge there have been delays but you are now taking affirmative action to alleviate the problems and delays that existed in the past?

Mr. WEIKEL. I think that is clear.

Mr. WUNDER. Would it also be fair to say that the screening of 3 million children in the last 2 years evidences the Department's position to take a more affirmative action?

Mr. WEIKEL. The screening of a million and a half children during the past year indicates the affirmative action. The 3 million screened was from the beginning of the program in 1969. So that we have screened 3 million throughout the entire program; one and a half million since last July indicates affirmative action.

Clearly those of us who are involved in administering the program are not satisfied with the one and a half million. We believe we have to get up to a maximum implementation of the program which is somewhere in the magnitude of screening on an annual basis of 3 to 4 million children, but never more than that. It must be remembered in this program we are not screening every child very year. That is not a requirement of the program. It would be a waste of the taxpayer's money. We are moving up to get the programs implemented so that we will get the maximum screened and treated.

There is another caveat, this program cannot be one of coercing the recipients to bring their children in. It has to be a voluntary program on the part of the recipient coming in for the service. We are aware that we are screening the recipients right now. We are getting the easiest recipients, those who happen to be most health conscious, into the program.

As we go down the road it will be much more difficult, require much more outreach service, which is very costly to the Federal Government and the State to get a larger number screened. Congress should be aware of that potential difficulty. We don't expect these figures to jump up magically because we must still depend on the cooperation of the parent or guardian to get the children in despite the caseworkers going out and Public Health nurses trying to tell about the importance of preventive health and getting screened.

Mr. OTTINGER. If I may intrude here, on cost effectiveness there is no dispute on your part at all, is there, that the cost of providing the tests or diagnoses of diseases that children may have, insipient diseases that they may have, is just a fraction of the cost of treating those problems when they became acute if they are not diagnosed?

Mr. WEIKEL. We believe, I think, that this program is cost effective. Early intervention in some of the types of diseases we are talking about has implications not only for future health costs but also for cost of education, through special education classes, for example.

We think it is cost effective. We would not conclude by that that every possible clinical test or evaluation that would be included in the

screening package is in itself cost effective. We think the total program can be cost effective.

Mr. OTTINGER. Have you done any actual computations projecting what the costs of a complete program that would cover every child would amount to, versus the present cost of treatment?

Mr. WEIKEL. First of all, I would start with this caveat. Our cost data in terms of data that has been reported specifically from the States is very poor. We have not previously asked for the States to report the cost of doing a screen or the cost of treatment because of the conditions identified during screening. That has to do with our reporting system.

We have corrected that now. In the reporting, as soon as we get the form cleared, we are requiring them to report to us the cost of screening and the cost of treatment for conditions identified.

Mr. OTTINGER. Are you getting also the cost of institutionalization of children who are retarded, and particularly being able to categorize those who might not have had a retardation problem had they been properly identified?

Mr. WEIKEL. I don't really know methodologically how I would get that. We can tell you how much we are spending in the intermediate care facilities for the mentally retarded. How much of that could have been prevented would require a massive clinical evaluation which I don't think we are prepared to do, nor are the States.

Mr. OTTINGER. Do you have the figure for how much is presently being spent under medicaid for the mentally retarded?

Mr. WEIKEL. For the ICFMR I don't have it at my fingertips. As I recall, the total budget for the intermediate care facilities is approximately $2.2 billion. I think it would be roughly a quarter of that, let's say in that neighborhood. But we can supply that to you.

[The information requested was not available to the subcommittee at the time of printing—November 18, 1975.]

Mr. OTTINGER. Thank you, Mr. Weikel.

Mr. Wunder.

Mr. WUNDER. Thank you, Mr. Chairman.

The point I was trying to make is that in the last year you have screened as many people in that program as you have screened in all the previous years combined.

Mr. WEIKEL. That is correct. Not only that, but the screening data includes none of the equivalents to screening. It says nothing about all those medicaid recipients who are getting services from the private pediatrician, practitioners, from the neighborhood health clinic, et cetera.

Mr. WUNDER. Are there any statistics or data that would indicate whether or not, or what percentage of the remaining 11.5 million who have not been screened have received comparable treatment?

Mr. WEIKEL. We do not have good data on that. We are at the present time again working with the States to try to improve that. We have developed a number of papers on the subject of the equivalence to screening. That has been reviewed with the States. Every State has received copies of that document and asked whether they have additional thoughts on how we can measure equivalence, what areas have not been included for those who have criticized us for not involving the private practitioner, which we want to include in this program.

We are telling the States if they can document to us that a certain number of individuals are being treated in the neighborhood health center or receiving screening services in their school system then this is equivalent to EPSDT screening. Someone mentioned earlier the State of Massachusetts where they mandate a requirement that their children be screened prior to admission to school.

I think every year some of the States have that requirement for up to age 12, some of them through high school. But we are telling the States that if the requirements, if the school health program in that case meets the requirements of the EPSDT screening criteria, and the element of the various tests laid out in their screening package and State plan meet our criteria, then that is acceptable. They can count those as an equivalent of having been screened, but they must have mechanisms available to follow up the children.

We are not going to count screening if they only demonstrate screening has been done with no ability to follow up.

Mr. OTTINGER. Mr. Sharp.

Mr. SHARP. Thank you, Mr. Chairman.

I would like to ask if, under present authority, that you have could you let contracts to try the voucher system, to demonstrate it?

Mr. WEIKEL. I don't honestly know.

Mr. SHARP. Can you find out and let us know if you have the legal authority under which you might experiment with this program?

Mr. WEIKEL. Yes.

[The information requested was not available to the subcommittee at the time of printing—November 18, 1975.]

Mr. SEGAL. What about section 222 and section 402?

Mr. WEIKEL. Section 222, as I understand it, I do not believe would cover it. Section 402 I frankly don't know what it is.

Mr. SHARP. Dr. Weikel, my concern is this: It seems to me apparent from the testimony we get that one of the essential problems we have throughout so much of the Federal Government, this particular program as well as the problem of our bureaucratization, everyone agrees with that, that in itself has to be one of the essential concerns of those of us with any responsibility in the Federal Government. Yet it worries me that maybe we are not being experimental enough, that we are not trying to find better ways—perhaps you people are and I am not aware of it—in which to simplify, not complicate but simplify the ways in which we urge people to take a service, the ways in which you provide it.

I guess I want to tell you that I think one of the chief responsibilities we have is to do some of these experimentations in order to find in the next few years the best simplest method. I am worried about all the questions about data, that we will end up with body counts as we did in Vietnam, and we will miss the forest for the trees.

Mr. WEIKEL. I am afraid there is no best, simple method. The best, simple method is to get them treated by a private practitioner or pediatrician and seen on a regular basis. If we don't have an adequate number of pediatricians in a geographic area it is impossible.

To answer your question, I think we have a number of demonstration projects looking at various components. Whether it is the screening, whether we can do that in private practice versus a clinic, the tracking system, we are experimenting with that. We are experiment-

ing with Outreach. We have one project in Portsmouth, Va., where we have involved Public Health nurses going out and talking to the recipient's family, talking about health education, the importance of preventive medicine. That has been effective. It is also very costly.

Mr. SHARP. Do you know of any instance in which a project has not been entered into of this sort that someone in the Department has recommended because of fear that it might develop into a full-fledged program?

What I am indicating here is an ideological opposition to experimenting with some organizational procedure because whatever you don't want it to work.

Do you know of any discussions within the Department where the policy decision was that?

Mr. WEIKEL. What is the question?

Mr. SHARP. Any time a policy was made in which an element of consideration was that we should not try that because the AMA is not going to like it or because some philosophy about distribution is violated.

Mr. WEIKEL. Clearly I can say without fear of contradiction during the past year when I have been associated with this program that I know of no discussion of that consideration within the Department. There have been discussions about the cost of the program and some of the States' concerns about the cost of implementing this program within that. It is not that it does not agree with somebody's philosophy, et cetera. I know of no demonstration projects that have been turned down even on a cost basis. We have one demonstration project here in Washington that we have implemented that I personally feel is very costly because it is putting into place all of what we think should be the ideal system in EPSDT if you are going to deliver it through a clinic, not through private practitioners. But that is one experiment. That is costing three-quarters of a million dollars.

Dr. VAN HOAK. I believe we have a number of programs already in existence which are not intentionally designed as research, but can provide us with information. What we need to do is more effective evaluation studies of impact. We can make comparisons between the ESPDT program and some maternal and child health programs where the mechanism of financing is different in one case, one in essence providing an insurance program and in another you are giving a formula grant to the State and allowing it to organize services.

There are other different approaches to organizing health care such as the health maintenance organization program which we need to evaluate in terms of its effectiveness. There are a number of programs under way which should give us answers to lead to some decisions on your part.

Mr. SHARP. Generally my philosophy is that we are better off trying a variety of things and we will probably always have a variety. I am not advocating a system.

Second, the question of HEW enforcement of these kinds of things. My State is one of those that may take penalties on this and if they are guilty, they should pay the penalty. My only concern is that the penalty tends to play in the hands of those who don't like the program anyway. It simply says we are going to cut you back on funds.

Very frankly, we suspect that some people in our State Department

of Welfare in Indiana are delighted. They are opposed to providing services. So the penalty system works against the program instead of for it.

There has been some suggestion in hospital utilization review and this program that you may have some effective people in regional offices and you may have some who aren't doing a darn thing about the program.

One area of the country may not be getting the benefit of the program and discipline; another area may be getting more discipline than it deserves, and action is taken by HEW in order to see that uniform enforcement is carried out in this country.

Mr. WEIKEL. I think those of us who are administering the program are very concerned about the implementation of the penalty for the reason you mention. It is a double-edge sword. It does have the potential of impacting negatively on recipients. It is because of that that I think the present Secretary, Secretary Mathews, has ordered a study examining the whole question of penalties. Those of us who are involved in administering the program are concerned with trying to develop positive incentives for the States, and providers and recipients for that matter, but in this case specifically, the States, to implement the program aggressively.

Mr. SHARP. When do you expect to have a proposal on penalties?

Mr. WEIKEL. The study on penalties I think is scheduled to be completed somewhere in the beginning of January. That is just an estimate.

Mr. SHARP. It will probably take a legislative proposal to change it.

Mr. WEIKEL. It clearly would take a legislative proposal if there is to be a change in the penalty situation. On the other hand, you know sometimes we need some incentive to get the programs implemented. Whether that should be a positive incentive, providing additional funds or a negative penalty, I think we could clearly discuss.

Mr. SHARP. What do they do to see to it that various regional offices are doing roughly the same kind of enforcement?

Mr. WEIKEL. Whenever you have more than one individual involved in anything, it is difficult to get uniformity. We do take certain steps but we are concerned as well, and I think the Secretary is concerned, at these charges of lack of uniformity from one region to another in the implementation of the penalty. We basically take steps to lay out what they are supposed to look for.

For example, we have laid out in great detail what our regional office people should look at in making the penalty survey. We have had training sessions, bringing together all the regional people involved in the EPSDT program to tell them what we are looking for. I think there is a record there of having made some attempts to bring about uniformity.

Mr. SHARP. I think that is fine but I seriously believe that tougher management has to be exercised in almost all of these agencies. I share your frustrations with trying to do some of that.

Mr. OTTINGER. The gentleman's time has expired.

Mr. Santini was just getting warmed up, so we will let him warm up again.

Mr. SANTINI. The able questioning of other members of the committee has taken some fuel out of my fire, Mr. Chairman.

I will follow up with some of the questions and concerns I did have.

I would like to ask you, Mr. Dickson, in my questioning yesterday directed to Dr. Cohen he responded in part to a question that I posed with regard to attitudes within the Department of Health, Education, and Welfare, about the program we are examining today. He commented on an attitude that existed there. He said, and I quote now from page 76 of the transcript of our committee hearings of yesterday:

Dr. COHEN. The major responsibility in my opinion to Mr. Dwight——

Is there a Mr. Dwight on the scene at the present time?

Mr. WEIKEL. There is not.

Mr. SANTINI (continuing).

Who was the SRS Administrator during the period of time who came from California, previous experience, came from the Budget Bureau and was made the Administrator of this program.

He had a completely different conception of what the Federal Government's role and responsibility was. As, for instance, take a specific problem in the Outreach; searching out these children who are eligible. He said no, that is not the Federal Government's responsibility to try to go out and beat the bushes to see who is eligible. Allow the States to do what they want.

I would ask you in view of the fact Mr. Dwight is no longer there, is there any residue of that profound administrative judgment remaining in Health, Education, and Welfare?

I would ask you, Dr. Dickson, to answer that question.

Dr. DICKSON. I don't believe so.

Mr. SANTINI. That the Health, Education, and Welfare now views its role as at least in part to communicate the availability of the services that they are statutorily directed to implement. Is that true, Dr. Dickson?

Dr. DICKSON. Yes.

Mr. WEIKEL. I would like to comment on that further.

Mr. SANTINI. I was afraid of that.

Dr. DICKSON. Only if you would like to get the answer.

Mr. WEIKEL. I think it is important that the record is clear.

Mr. OTTINGER. Let's have Dr. Dickson reply first, if he can.

Mr. DICKSON. I could not hear you, sir. Excuse me.

Mr. OTTINGER. I just said to avoid conflict among the panel that you should reply first and then Dr. Weikel.

Dr. DICKSON. Yes. What was the question?

Mr. SANTINI. Health, Education, and Welfare then views as one of its primary responsibilities the communication to those whom the services are intended to reach the information that is necessary for them to obtain them.

Dr. DICKSON. That is my understanding.

Mr. SANTINI. Is that the policy of the Department?

Dr. DICKSON. Yes, it is.

Mr. WEIKEL. Yes, it is clearly the policy of the Department. I have some video tapes here, if you would like to see them, and some radio spot announcements that we have distributed throughout the Nation asking television stations and radio stations to play them. These spot announcements tell recipients where they should go for service or to ask about receiving service.

These are being played around the country. They have been developed by the administration. We have numerous manuals that we have

provided to the medical societies who are involved in participating in the program from whom we are trying to get to greater participation. We have various brochures announcing the program.

Mr. SANTINI. The record is clear, you are right, Dr. Weikel.

Mr. WEIKEL. I think it is a good record.

Mr. SANTINI. You have the tapes?

Mr. WEIKEL. Yes.

Mr. SANTINI. To play on radio. You have the brochures that are given to doctors?

Mr. WEIKEL. Yes, sir.

Mr. SANTINI. And you do have regular public service television announcements?

Mr. WEIKEL. That is correct.

Mr. SANTINI. When was this information program put into effect?

Mr. WEIKEL. This information program has been operating over the last year. The video tapes were available prior to the past year. I can't tell you when the first one was available but they have been sent out several times during the past year to all television stations around the Nation.

Mr. SANTINI. Do you contemplate any further efforts?

Mr. WEIKEL. Yes, sir. We have an active program in the public information field trying to make recipients aware of this. Also within the Medical Services Administration we have appointed someone to be head of consumer affairs to be more of an advocate for recipients, including this program.

Mr. SANTINI. Dr. Dickson, the point of inquiry that I was developing before was, as Dr. Weikel characterized it, the value of this program was in the number of children treated.

We don't have any information on the number of children treated, so we don't have any basis for judging the value of the program at this point. Why not include a question in the multitude of forms that asks the question, "Was there any treatment?", which is the basis on which we value the program. Why not include a question which says something to this effect. That is not really expert bureaucratese but was there any treatment in the forms the States receive and doctors receive?

Dr. DICKSON. I don't know the answer to that.

Mr. SANTINI. Dr. Weikel, do you have an answer?

Mr. WEIKEL. I should. I am in charge of the program.

Clearly the new reporting requirements do require that.

Mr. SANTINI. When are the new reporting requirements in effect?

Mr. WEIKEL. As soon as they are officially cleared through the Office of Management and Budget.

Mr. SANTINI. They are not in effect now.

Mr. WEIKEL. They are not. I did not imply they were in effect. They have been developed by the Department and they are in the clearance process. We must get clearance before we can use any reporting form.

Mr. SANTINI. Can we get any rough idea when we might expect this question to be in the field?

Mr. WEIKEL. We would expect it within the next month or so.

Mr. SANTINI. Finally, Dr. Dickson, what concerned me particularly

yesterday was testimony by Dr. Cohen that we have approximately 210,000 children in our State mental or comparable facilities in this country, and he concluded that 10 percent of those children that are in those mental facilities today, or 21,000 children, need not have been there if they had had proper screening diagnoses and treatment after the effective date of this particular program.

Would you care to comment on the accuracy or validity of that conclusion?

Dr. DICKSON. Yes. I would like to have Dr. Lurie answer that statement, if I may.

Mr. SANTINI. You do not have any individual response to it?

Dr. DICKSON. I don't know the answer to it, no.

Mr. OTTINGER. Would you identify yourself.

Dr. LURIE. Yes. Ira Lurie, from the National Institute of Mental Health.

Mr. OTTINGER. Would you stand to be sworn.

Do you solemnly swear that the testimony you are about to give is the truth, the whole truth, and nothing but the truth, so help you God?

Dr. LURIE. Yes; I do.

Mr. OTTINGER. Please proceed.

Dr. LURIE. Would you repeat the question, please.

Mr. SANTINI. Yesterday in his testimony before this committee Dr. Cohen testified that in our country today it was his estimate that there were 210,000 children presently housed in State facilities for the mentally retarded, or comparable facilities; that it was his estimate that had the proper screening, diagnoses and treatment been implemented at the time that was intended by Congress to be implemented; that 10 percent of that 210,000, or 21,000 children, would not be in those facilities if this program had been implemented at the time designated by Congress.

Dr. LURIE. I am not sure I can respond directly to the numbers. I would assume that given proper screening in the area of mental health and behavioral disorders that a certain percentage of those youngsters would not be in institutions.

In many ways we don't have facilities beyond institutions. That is a very difficult kind of question. We have estimates which are kind of soft in terms of their data.

Mr. SANTINI. We are trying to measure the impact of the dereliction here in the hopes that we can avert it in the future with some constructive action.

Dr. LURIE. One of the major programs in HEW is the Community Health Centers Act in which a large number of children have been diverted from such institutions over the last 10 or 12 years. Under the new legislation each one of these centers across the country, in order to fulfill requirements, was to have children's services which would be able to move more and more of these children into proper kinds of services. It is not a matter of screening that children with emotional problems end up in institutions. They have already been screened by some force. What puts them in institutions is lack of services which HEW through NIMH has been working on actively.

Mr. OTTINGER. Am I correct in my recollection that the administration proposed that the Community Health Centers be closed out?

Dr. LURIE. That was the last administration. I am not sure what the administration is doing on that.

Mr. SOPPER. Mr. Chairman, the administration's position is not that they should be closed out but that the 500 or so community mental health centers that have received Federal assistance should continue to receive Federal assistance through the entire grant cycle, which the statute stipulates, but that the Federal Government should not begin to support any new community mental health centers, that is, the consent had been demonstrated to be successful and that States and local facilities ought to decide on their own whether or not they want to continue the priority and set up community mental health centers in the model that the Federal Government has supported, not that the 550 should be closed.

Mr. OTTINGER. The Federal funding for them should be ended, is that correct?

Dr. LURIE. That there should be no new Federal funds for new community mental health centers but that those who have been getting assistance should get assistance throughout the period of their grant cycle.

No center, for example, that was in the third year should be terminated. It should receive the full 8-year funding that the statute entitles it to.

Mr. OTTINGER. What was the percentage cutback recommended by the administration for neighborhood health centers and community health centers this year as opposed to last year?

Dr. LURIE. I think Dr. Van Hoek can answer that.

Dr. VAN HOEK. [illegible]ximately 20-percent reduction based on the premise that State [illegible]l resources and third party payment would pick up the differen[illegible]he total cost of operating the centers.

Mr. OTTINGER. Anybody in the administration, I suppose they don't really care but certainly, speaking for the city of New York with 9 million people, the State of New York with better than 18 million people, the chances that they are going to be able to come up with additional resources to pick up this kind of cost are rather slim.

I think that is being seen throughout the country with the economic recession. So the effect of what the administration is doing is to say that we are going to cut back our priority in this area. Isn't that so?

Mr. Santini, do you have another question?

Mr. SANTINI. The Maguires testified yesterday about their children suffering from that particular ailment, that with proper screening and diagnoses and treatment they would not be in that facility—it was simply a transfer of bodies—if that had been detected.

Apparently it is a subject of a sizable law suit now. That is the kind of human problems we want to reach out and try to resolve.

Thank you, Mr. Chairman.

Mr. OTTINGER. Mr. Segal.

Mr. SEGAL. I would like to ask a couple of legal questions relating to the imposition of the penalty.

On June 2 of this year the Secretary announced seven States were out of compliance, and in July an eighth State was added. Were all of these for the first quarter of fiscal year 1975, namely, July through September of 1974?

Mr. DICKSON. Yes; they were.

Mr. SEGAL. Have all other States been ruled in conipliance for that time period?

Dr. DICKSON. Please repeat that.

Mr. SEGAL. Were all other States ruled in compliance? In other words, were the eight the universe of those who were penalized for that one quarter?

Dr. DICKSON. I don't believe so.

Mr. SEGAL. There may be additional States penalized?

Dr. DICKSON. There may be, is that what you said, for the first quarter?

Mr. SEGAL. Yes.

Dr. DICKSON. The answer to that is yes.

Mr. SEGAL. Were these penalties imposed on the States where the press announcement said that penalties would be assessed?

Mr. WEIKEL. The penalty announcement——

Mr. SEGAL. I think a yes or no answer——

Mr. WEIKEL. I don't think a yes or no is clearly indicated because there is a precedence. There is such a thing as due process to the States. We announced to the States that we were assessing the penalties against them, but the States have 30 days in which to ask for an appeal. If they ask for an appeal, you have to go through the appeals process prior to the time that the actual reduction is made.

Mr. SEGAL. Could you cite the regulations that say that that must be the case?

Mr. WEIKEL. That has been the practice of the agency.

Mr. SEGAL. For audit exceptions?

Mr. WEIKEL. For any audit exception.

Mr. SEGAL. Is this an audit exception or a mandatory statute calling for a penalty?

Mr. WEIKEL. This is a mandatory statute calling for a penalty.

Mr. SEGAL. Do you treat it the same way as an audit exception?

Mr. WEIKEL. We believe the State should have an opportunity to appeal in case there has been some error made.

Mr. SEGAL. How can they appeal a penalty that has not been imposed?

Mr. WEIKEL. They have been notified that unless there is an appeal request made officially of the Department within 30 days the penalty will be taken and there will be a reduction in their Federal grant the next quarter, and they have all been notified of that by letter.

Mr. SEGAL. Again you have no regulation that cites that such a penalty will be held in abeyance while there is an appeal process for something that has not been imposed?

Mr. WEIKEL. As of August 18, 1975, there is in the Federal Register a notice of proposed rulemaking.

Mr. SEGAL. So you have nothing in effect?

Mr. WEIKEL. There is nothing in effect in terms of the whole reconsideration process other than the traditional practice of the Department and agency in terms of disallowances or audit exceptions. That is correct.

Mr. SEGAL. With respect to the question on staffing you indicated before that there were 100 positions that were made available. Was that in the regional and central offices for EPSDT?

60-800—75——10

Mr. WEIKEL. That is a combination of regional office, central office within the Medical Services Administration, plus any of the personnel within the Social and Rehabilitative Services offices.

Mr. SEGAL. I think you might want to amend your previous statement because that was in relation to the program of EPSDT and not in relation to the Social and Rehabilitative Service.

Mr. WEIKEL. Social and Rehabilitation Service does have responsibility for the EPSDT program. The Medical Services Administration is one of the programs within the Social and Rehabilitative Services.

Mr. SEGAL. That is right. But that was not the question posed to you. The regional offices were listed in a letter from Secretary Weinberger to GAO in response to a letter of theirs indicating that 56 positions in the region had been assigned to work on EPSDT. Is that a fact that it is still in effect?

Mr. WEIKEL. That is correct.

Mr. SEGAL. Is that 56 full-time equivalents?

Mr. WEIKEL. No, the individuals assigned there were on a full-time basis, the 56 people in the regional offices. The regional offices in addition to that had been reporting 10 people prior to being given the 56, that were working on a part-time basis.

Mr. SEGAL. You mean full-time equivalents among the 56?

Mr. WEIKEL. Fifty-six.

Mr. SEGAL. Working full-time on EPSDT programs?

Mr. WEIKEL. That is correct.

I know what you are leading to—the 20-percent figure that was reported in the work plans of the regional offices. I want to make very clear that those work plans have not been accepted on the part of the central office as they were reported from the regional office.

Mr. SEGAL. I would like to ask specifically about a couple of States.

The State of Indiana—one of those listed to be penalized—their director of the program, Wayne Stanton, indicated that HEW has now completely approved their program. He also indicated that Indiana has the most comprehensive medicaid program in the Nation.

Has Indiana been cleared?

Mr. WEIKEL. Indiana has been assessed the penalty.

Mr. SEGAL. You have proposed to assess the penalty?

Mr. WEIKEL. We are in the due process of application of that penalty. They have appealed that, and that appeal is being considered. After that appeal is completed, the penalty will be assessed. It is during that reconsideration process that the determination will be made whether or not their program was in compliance not at the present time, but during the first quarter for the year when the penalty was assessed.

Mr. SEGAL. Why should they be able to put in a press statement, "At Indiana's request, including Governor Bowen's personal intervention, the threatened fiscal penalty was later subject to reconsideration," and then further on a statement that I quoted to you before, that they were absolved of this?

Mr. WEIKEL. I can't speak for the State in this case. I can tell you they are referring to a study that was done, an evaluation of their third and fourth quarter compliance. That report was submitted to our office.

I have informed the regional office in Chicago that that report is inadequate based on our standards, and, therefore, additional work needs to be done in the State of Indiana. I think Indiana, as we do with every State, had an opportunity to review the results of the regional office evaluation. They obviously took that and decided on that basis that they should make a press release. I think that is Indiana's choice. We are still considering the situation.

Mr. OTTINGER. We have been joined now by my esteemed colleague from New York who is a member of the subcommittee that deals with this situation, as well as this subcommittee.

I recognize the gentleman from New York, Mr. Scheuer.

Mr. SCHEUER. Mr. Chairman, I have a few questions. I suppose that we will be breaking in 6 or 8 minutes. I will ask unanimous consent to submit the questions to these gentlemen.

Mr. OTTINGER. Without objection, it is so ordered.

Mr. SCHEUER. And I hope they will be included in the permanent record.

[Testimony resumes on p. 153.]

[The following letter and enclosure was subsequently received for the record:]

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
OFFICE OF THE SECRETARY,
Washington, D.C., November 5, 1975.

Hon. JOHN E. MOSS,
Chairman, Oversight and Investigation Subcommittee, Committee on Interstate and Foreign Commerce, U.S. House of Representatives, Washington, D.C.

DEAR CHAIRMAN MOSS: Thank you for your letter of October 21, 1975. I am pleased to provide you with the information requested by Representative James H. Scheuer for the record of the October 8 hearing on child health.

Please let me know if you need additional information.

Sincerely,

STEPHEN KURZMAN,
Assistant Secretary for Legislation.

Enclosure.

Question 1. How can the Department of Health, Education, and Welfare (DHEW) penalize states retroactively to July 1, 1974 when the regulations were not issued until August, and the states were allowed no lead-time to meet the regulation requirements?

Answer. The penalty provision was enacted in October 1972, giving states 20 months lead-time until the effective date, July 1, 1974. Further, the nine states that have been determined out of compliance with the penalty provision for the first quarter of FY 1975 failed to meet very basic and minimal criteria under the penalty statute. The final regulations contained no new or unusual requirements about which the states had not otherwise been informed, through the legislation, proposed rules, and regional office correspondence.

Question 2. Is it appropriate for DHEW to penalize States for failing to inform families in writing by September 30, 1974, when Federal regulations indicate that this must be done within a year from July 1, 1974, the time the regulations became effective?

Answer. This interpretation of the regulation conflicts with section 403(g)(1) of the Social Security Act. This section clearly contemplates that the penalty be taken for the first quarter of FY 1975 if a State fails to undertake its basic responsibility to inform all AFDC families of the availability of EPSDT services *during* that quarter. Indeed, the statute could be read to require States to repeat this function with regard to all AFDC families in *every* succeeding quarter. Short of this stringent standard, however, a reasonable reading of the statute requires at least that each AFDC family be properly informed by no later than the end of the quarter in which it becomes part of the caseload. The regulation which must be read consistently with the statute, speaks to a State's responsibility to *renotify* each AFDC family no less than annually after the initial notification. It cannot be read to excuse a State from complying with the underlying statutory requirement.

To argue that the regulation authorized a State to wait until June 30, 1975, to accomplish its initial notification would be to ignore the existence of section 403(g)(1) of the Act through the first three quarters of FY 1975, and would legitimize a State's practice of keeping its AFDC caseload uninformed of the EPSDT program for a full year after a Congressional dictate that States have their programs fully operative or be penalty liable.

Question 5. In applying these penalties to the states, what evidence is there that DHEW has applied a standard methodology so that all states irrespective of DHEW region or political party of the Governor of the state, are treated equitably?

Answer. A penalty reporting form with instructions for its completion was issued to all HEW regional offices in August 1974 in order to assure that gathering of information related to making determinations regarding penalty states would be uniform in all states. (See Attached Form.)

In addition, based on our initial experience with the penalty determinations, we are in the process of issuing a more detailed revised reporting format to the regional offices.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
SOCIAL AND REHABILITATION SERVICES.
Washington, D.C., August 8, 1974.

To: All SRS Regional Commissioners.
Subject: Field Staff Information and Instruction Series FY 75–4 EPSDT Penalty Reporting Form.
Cleared by: OFO.

The directives of the guidelines for imposition of the penalty (MSA–PRG–32) (45 CFR 205.146(c)), call for the Regional Offices to collect information for a narrative report to be used to determine whether the penalty should be applied to a particular State.

The first quarterly report for FY 1975 (July 1–September 30, 1974) is to be a one-time report requiring detailed information on existing State EPSDT programs, should be completed during September and October, and must be based on actual State practice during the first quarter of FY 1975. Subsequent quarterly reports will be updates and modifications to the program described in this first report.

Attached is the penalty reporting form with a covering explanation of the contents of the reporting form, giving instructions for its completion and an outline of questions to be answered in the narrative. All of the questions for the narrative must be addressed in the report submitted by the Regional Offices.

Please submit the first report by November 15 to Division of Program Monitoring MSA, Room 4628, Switzer Building.

Subsequent reports should be submitted within 30 days of the end of the quarter.

ALBERT J. RICHTER,
Associate Commissioner.

Attachment.

EPSDT NARRATIVE REPORT

Explanation of report form

The guidelines for the penalty provision (45 CFR 205.146(c)) call for a narrative report to be submitted by the Regional Offices describing actual methods of implementation in the States during the first quarter of FY 1975, which will be used for initial determinations on application of the one percent reduction in AFDC funds. This first report should describe fully the State's method of achieving full compliance. Subsequent quarters' reports will describe only program modifications and corrections.

This report form was developed to facilitate the preparation of the narrative report requested in the guidelines. It is divided into four sections:

Section I—Statistical Data.
Section II—Instructions for Narrative.
Section III—Validation Visits.
Section IV—RO Assessment.

Section I.—Statistical Data

This section requests information on the number of individuals eligible and the number receiving EPSDT services in the program. We have asked for a break-

down by AFDC and others of the total number of eligibles and number of eligibles informed. (The only informing requirement for the penalty is the AFDC). For the other data requested (screened, referred, and diagnosed/treated), we did not request a breakdown because of the limitations of State reporting systems.

Section II.—Instructions for Narrative

This section provides instructions for a narrative report on State activities to be completed through interviews with staff of the title XIX and other responsible agencies. The Section is further divided into three subsections:

A. Informing Procedures.
B. Screening Arrangements.
C. Diagnosis and Treatment Arrangements

Each subsection includes:

1. Statement of requirements to avoid imposition of penalty
2. Instructions for information to be included in the narrative
3. Instructions for documentation to be submitted with the narrative report

Because of the diversity of methods the States are using to implement the EPSDT regulations, the report form must, of necessity, be general to allow for the differences. We have tried to give as explicit instructions as possible within that limitation. Except where otherwise indicated, each question must be answered. The inability to do so may be considered indicative of a problem in a State.

Section II A—Informing Procedures

In light of individual State differences, questions 8 through 11 may not be appropriate for all State reports. If the State is using written materials that give specific information on where screening services are available, then the narrative should address questions 1 through 7. If the written materials give general information, indicating where specific information is available (e.g., contact your caseworker or welfare office, etc., for details on EPSDT services available in your community), the narrative should address questions 1 through 11.

Section II B—Screening Arrangements

The questions request information on the kinds of arrangements the State has made with screening providers so that families requesting screening can receive these services within a reasonable period of time.

Section II C—Diagnosis and Treatment Arrangements

The questions request information on the State's arrangements for referral to diagnosis and treatment providers, provision of those services, and follow-up.

Section III—Validation

In order to assure that services are provided as the narrative describes, visits need to be made by RO reviewer to selected local sites. These visits should be made to county/local welfare offices and local screening or EPSDT providers in at least six counties selected randomly by RO reviewer throughout the State. During these visits, RO staff should determine whether or not the local sites are informing, screening, and following up as outlined in narrative report.

Section IV—Regional Office Assessment

If the State has met the requirements of the penalty regulation, then the RO should check Section IV A of the report form to indicate that the State is in compliance with Federal regulations.

If the RO assessment is that the State has not met the requirements and therefore the penalty should be imposed, Section IV B should be completed in full and the findings reviewed with the State. A recommendation for the penalty should be submitted to the Administrator, SRS, as per instructions in FSIIS–75–(to be issued). Regional Office staff should also complete Section IV C or IV D as appropriate.

Signature

The report is to be signed by the reviewer, the Associate Regional Commissioner for Medical Services (if appropriate) and the Regional Commissioner.

State _____

EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT

PENALTY REPORTING FORM

Date _____ Region _____

Individual completing report _____

SECTION I - Statistical Data

	As of 9/30/74		
A. Eligible	AFDC	Others	Total
Total			
0-5			
6-20			
B. Informed*			
Total			
0-5			
6-20			

	July '73-June '74	July '74-September '74
C. Screened		
Total		
0-5		
6-20		
D. Referred		
Total		
0-5		
6-20		
E. Diagnosed/Treated*		
Total		
0-5		
6-20		

F. Are the figures for number of children screened and referred based on NCSS 116/120 reports? Yes _____ No _____

G. Does the number of children screened, referred, and diagnosed/treated include others in addition to AFDC (e.g., individuals under 21)? If so, please list: _____ _____

*Where data are available.

Section II—Narrative Report Instructions

Section II A—Informing Procedures

Requirements

State must be able to document that all AFDC families have been informed:

1. At least once annually or during the period of eligibility if shorter.
2. In writing (pamphlets, brochures, other written materials, in English and in foreign languages where required).
3. By other methods where written materials are inappropriate.

4. Of what services are available (screening examinations and diagnosis and treatment services).
5. Of where and how services can be obtained.

Description

The report must describe the following:
1. How present recipients and newly eligible recipients are informed of services available and names and locations of screening providers.
2. How the written materials are distributed.
3. How often they are distributed.
4. Who is responsible for distribution (e.g., State XIX agency, State welfare, county welfare, health departments, etc.).
5. Concise summary of information included in brochure.
6. How individuals for whom printed material is inappropriate are informed.
7. Whether foreign language materials are provided and in what localities.

If written materials give general information and refer recipients elsewhere for specific information, then the narrative report must also include the following:
8. Who is designated to povide specific information.
9. How those persons have been prepared to carry out this function (written instructions in administrative handbook, organized training, etc.).
10. How these persons communicate specific information to recipients.
11. Whether these persons or offices have a list of participating providers available upon request.

Supportive Documentation

This must include:
1. Examples of written materials.
2. Instructions or training materials for items 3, 6, 9, and 11 under "Description" above.

SECTION II B—SCREENING ARRANGEMENTS

Requirements

State must be able to document that for all families with eligible children requesting screening services the State has:
1. Informed these families of names and location of screening providers.
2. Informed these families of transportation available.
3. Made agreements with providers to make screening services available to eligible children throughout the State, normally within 60 days of request.
4. Defined screening package and informed screening providers about its contents.
5. Taken steps to assist recipients requesting services to be able to receive them (e.g., transportation, health education, child care, provider availability).

Description

The report must describe the following:
1. What State has included in its screening package (procedures and periodicty schedule for rescreening).
2. Who provides screening services (number and types of providers) and whether these services are available to all recipients throughout the State.
3. What arrangements and/or agreements State has made with these providers.
4. How State informs participating providers of its program requirements for screening (e.g., mandated and optional screening procedures, referral procedures, fee schedule established for screening services, and other case management requirements).
5. How State monitors providers to assure that services are delivered as outlined by State.
6. How State informs recipients of availability of transportation services and assures that transportation is in fact available and provided as needed.
7. How State follows up on individuals requesting screening services to assure that they have had access to these services and to assist those who have not received services to do so.

Supportive Documentation

This must substantiate items 1 through 6 above and include (but is not limited to):
1. State regulations, program standard manuals, staff instructions.
2. Sample provider list.

3. Billing and reporting forms.
4. Other appropriate materials.

SECTION II C—DIAGNOSIS AND TREATMENT ARRANGEMENTS

Requirements

State must be able to document that for children needing diagnosis or corrective treatment for conditions found during screening, the State has:

1. Informed these families of names and locations of providers.
2. Informed these families of transportation available.
3. Made arrangements with diagnosis and treatment providers so that services are available normally within 60 days of a screen. This includes:
   Establishment of referral procedures.
   Provision of diagnosis for all conditions.
   Provision for treatment within limits of State plan except eyes, hearing, and dental, which are mandatory.
   Establishment of agreements with providers so that services are available to eligibles throughout the State.
4. Taken steps to assist recipients requesting diagnostic and treatment services to be able to receive them (e.g., transportation, child care, provider availability).

Description

The report must describe the following:

1. Who provides the diagnostic and treatment services.
2. Whether sufficient providers are available to all recipients throughout the State so that initiation of treatment can begin within 60 days.
3. How families are informed of names and location of these providers.
4. How State informs recipients of the availability of transportation and assures that such transportation is in fact available and provided as needed.
5. How State follows up on children found in need of treatment after screening to assure that they have had access to those services and to assist those who have not received services to do so. (Description of process for notifying the State that treatment has been provided—bills, receipts, follow-up procedures).
6. How vision, hearing, and dental treatment is provided.
7. What limitations to treatment exist, (indicate limits in plan and utilization controls).

Supportive Documentation

This should include:

1. State regulations, staff instructions, provider manuals.
2. Sample provider list.
3. Billing and reporting forms (including case management forms).
4. Other appropriate materials.

Section III Validation Visits

County _____ Welfare Office (identify) _____
Screening or EPSDT provider(s) (identify) _____
Comments including problems encountered during visits _____

County _____ Welfare Office (identify) _____
Screening or EPSDT provider (s) (identify) _____
Comments including problems encountered during visits _____

County _____ Welfare Office (identify) _____
Screening or EPSDT provider(s) (identify) _____
Comments including problems encountered during visits _____

County _____ Welfare Office (identify) _____
Screening or EPSDT provider(s) (identify) _____
Comments including problems encountered during visits _____

County _____ Welfare Office (identify) _____
Screening or EPSDT provider(s) (identify) _____
Comments including problems encountered during visits _____

County _____ Welfare Office (identify) _____
Screening or EPSDT provider(s) (identify) _____
Comments including problems encountered during visits _____

Section IV - Regional Office Assessment

A. _____ State's EPSDT program has met the requirements of 45 CFR 205.146(a)

B. _____ State has failed to meet the requirements of 45 CFR 205.146(a) in the area of:

_____ Informing Procedures
_____ Screening Arrangements
_____ Treatment Arrangements

Description of problems and major obstacles to full compliance:

Concise account of RO efforts to bring State into compliance:

C. _____ State has met requirements of 45 CFR 249.10(a)(3)

D. _____ State has failed to meet requirements of 45 CFR 249.10 (a)(3)

Description of problems and major obstacles to full compliance:

Date _____ _____
Reviewer

Date _____ _____
Associate Regional Commissioner for Medical Services

Date _____ _____
Regional Commissioner

NOTE: Recommendations for application of the penalty should follow procedures outlined in FSIIS FY-75- (to be issued)

Question 4. **Do you feel the current and proposed regulations provide for the most effective methods of informing eligible clients of availability of EPSDT services, i.e., written notification?**

Answer. A good deal of evidence exists from EPSDT demonstration projects that written materials informing families of the availability and nature of EPSDT services are less effective than personal contact and home visits. However, in developing both the current penalty regulation and the proposed revision, the Department has required and proposed only written notification in recognition of the significant increases in staff and administrative resources that many states would have to make to carry out the more effective outreach activi-

ties and to document reliably that all AFDC families had been informed by such methods. Further, it must be recognized that the penalty provision represents only the *minimum* requirements of the program and the Department has not thought it appropriate to consider all methods that would contribute to an optimally effective EPSDT program as penalty issues. However, in the SRS Program Regulation Guide (MSA-PRG-21, June 28, 1972) for EPSDT, the importance of a variety of casefinding and outreach methods is discussed and peronal contact is emphasized. Even though not required by the penalty provision, many states do currently use methods of personal contact for explaining EPSDT in addition to written informing materials. Further, a recent policy clarification makes 75 percent federal matching available, rather than the usual 50 percent for administrative costs, for health related support services, including notification through personal contact and other forms of outreach, for EPSDT.

Question 6. How many childen who were eligible for EPSDT died from complications of communicable diseases that simple immunizations could have prevented for each of the last five years?

Answer. It is not possible to determine the number of EPSDT–eligible children dying from complications of communicable disease. For comparison, the *total* number of individuals under 20 years of age dying as a result of childhood, vaccine-preventable diseaases in the United States was 132 in 1969, 175 in 1970, 145 in 1971, 68 in 1972, and 45 in 1973.

Question 7. The Forward Plan for Health indicates that you will emphasize infant mortality, particularly in the 3,000 counties that have a mortality rate of 33.4 while the rest of the country has a mortality rate of 17.3. Do these 3,000 counties have a disproportionately high percentage of EPSDT eligibles?

Answer. Actually, as the Forward Plan indicates, *ten percent* of the total 3,000 counties in the country have the higher mortality rate you mentioned. Although we do not have data on the number of EPSDT eligibles in the counties with high infant mortality rates, we would assume that such counties do have a relatively high percentage of EPSDT eligibles since infant mortality tends to be higher for low-income populations and in poor rural areas.

Question 8. How many of the approximately 180,000 children who suffer annually from diseases that simple immunization can prevent are EPSDT eligibles?

Answer. During 1974, approximately 96,000 cases of common childhood diseases were reported for which preventive immunizations are available. Although disease occurs across all socioeconomic boundaries, immunity levels are lower in the poverty areas throughout the nation, compared with non-poverty areas, suggesting that disease incidence rates would be greater in these areas. While the disease reporting system does not identify cases according to EPSDT eligibility, a study of selected EPSDT sites indicated that 25 to 81 percent of children receiving screening under EPSDT needed immunization services.

Question 9. On page 35 of the Dr. Dickson prepared statement, dated October 8, 1975, it was indicated that $3.5 billion was spent for those under age 21. Could you please provide a breakdown of these dollars, including:

(*a*) How much was spent for affiictions such as polio, vision, and hearing disorders?

(*b*) How much was spent for institutionalization for mental retardation?

(*c*) How much was spent for hospitalization?

Answer. The National Center for Social Statistics reporting system does not include disease specific information. However, in FY 1973, the latest year for which Medicaid expenditure information for children under 21 is available, the total Federal and State Medicaid expenditures for this population was $3,431,030 for inpatient services in mental hospitals, and $16,456,049 for institutional intermediate care services for mentally retarded people under 21. Total FY 1973 expenditures under Medicaid for inpatient hospital services in general hospitals for people under 21 were $404,797,517.

Question 10. A memorandum of understanding, dated August 28, 1975, between DHEW and the State of California indicates that, regarding AFDC penalties and sanctions, the Secretary will consider a major revision in the penalty structure. Could you please indicate what is meant by this?

Answer. The Department has in progress an in-depth examination of its sanction, enforcement and incentive activities. From this examination, we are considering proposed changes in legislation, regulations and administrative procedures to make sanctions more effective, more rational, more equitable, and less complicated.

The first phase of this study, to be completed early January, 1976, will focus on State-related enforcement mechanisms, with emphasis on formula grant program programs, e.g., Medicaid, Aid to Families with Dependent Children, Social Services (Title XX), and Education for the Disadvantaged (Title I, Elementary and Secondary Education Act).

In our examination, we are attempting to secure relatively wide participation—including State staff, public interest groups, Congressional staff, etc. We intend to reflect in the study a broad spectrum of opinion.

Question 11. Have similar memoranda of understanding, as with California, been established with other States? Would you please forward all memoranda of understanding in existence.

Answer. There have been no similar memoranda of understanding, although we have advised a number of States, interest groups, and private individuals that we are undertaking the study outlined in the response to question 10.

Question 12. Item 9 of the memorandum of understanding, dated August 28, for its noncompliance regarding the early childhood screening program." Could 1975, indicates that DHEW will "sympathetically consider California's appeal you please indicate what "technical noncompliance" means in that statement?

Answer. The Department understands "technical non-compliance" to mean, simply, non-compliance. California officials felt the qualifier "technical" better expressed their position on the compliance questions under discussion, and so that language was included.

Question 13. The audit report of EPDST for Alabama, for the period October 1, 1971 through March 31, 1975, dated August 11, 1975, signed by Emil A. Trefzer, Jr., indicates that 81 percent of all treatment based on a sample analysis was provided after 60 days between the date of screening and the date of diagnosis and treatment. Is this a violation of the regulations regarding the time frame in which treatment must be provided after such treatment is found necessary by screening (45 CFR 205.146 (c) (iii) (B))?

Answer. Under the law, compliance with the EPSDT penalty provision must be determined for each quarter after July 1, 1974. The audit report giving aggregate data for the period of October 1971 through March 1975 would thus not be applicable. Further, even if the 81 percent were true for any given quarter since the effective date of the penalty, the regulations provide that *initial* diagnosis and treatment must be available *normally* within 60 days of the screening. In determining compliance with this provision such considerations as the availability of specialists or the time within which the necessary treatment service is generally available to the population at large in the area are taken into account. Thus we would look beyond a general percentage such as the one sited in the audit report in assessing compliance with this provision.

Question 14. How can you ensure, under the August 20, 1975 Notice of Proposed Rulemaking, that treatment will be given in timely fashion? Section 205.146 (c), (3) seems to allow states to absolve themselves of possible penalty liability, while recipients risk not being provided their required treatment. Should not the states assume a larger burden to insure that treatment be provided within a reasonable time.

Answer. The proposed revision to the penalty regulation provides that States must assure that treatment services are provided or initiated within 60 days of a screening finding that indicates a need for such services except in cases where the State can show that failure to do so is not the result of State inaction. Rather than allowing States to absolve themselves of possible penalty liability this provision would make States liable for inaction in assuring timely delivery of treatment. The exception is provided in order not to penalize States for circumstances beyond their control in meeting the 60 day requirement, such as a severe scarcity of dentists, specialists or other providers or a recipient missing the appointment despite State assistance in scheduling and transportation.

Question 15. Is the Maternal and Child Health program under Title V considered a Departmental priority?

Answer. Yes. The Department's Forward Plan for Health, published in June of this year, states that child health is a "major priority" of HEW. The Department's child health strategy will be focusing on reducing infant mortality and low birth weight and on maternal health services. The MCH program will continue its special support of basic and preventive services of prenatal and postnatal care, infant and preschool health supervision, school health services, and contraception, with emphasis on health assessment, screening, teaching, and care.

Question 16. Why did the President propose to cut the Maternal and Child Health program by $80 million, a 35 percent cut?

Answer. The proposed reduction of $83 million from $295 million in FY 1975 to $212 million in FY 1976 represents a 28 percent reduction for Maternal and Child Health.

The Maternal and Child Health program is not singled out among Federal programs for budget reductions. Such reductions are part of the overall objective of the Administration to limit Federal deficits in an overall attempt to control inflation.

The Maternal and Child Health budget reflects the decision by the Department to require local governments, private institutions, and third-party payors to contribute a greater share of the cost of the health care programs. The effectiveness of special projects over the past two decades has demonstrated to local communities how to reduce the incidence of disorders and handicapping conditions in children. The Department has chosen to advance progressively forward from a focus on demonstration under Title V to promoting and providing needed maternal and child health services through Federal and private sector payment programs.

Mr. SCHEUER. First. Dr. Kretchmer, in connection with our keen interest in doing more in terms of maternal and child health, as I understand it, there is almost nothing that is more important to infant and maternal health than the ability of a mother to space her children. Would that be correct?

Dr. KRETCHMER. Certainly that is one of the most important aspects.

Mr. SCHEUER. I was the author of the 1970 Population Research and Family Planning Act. To put it at its most charitable, Federal support for family planning services and for funding family planning services has been faint-hearted and reluctant.

I feel the Federal Government, instead of looking at the family planning program as perhaps the most cost-effective single program in achieving maternal and child health, had had to be dragged kicking and screaming into the 20th century.

Do you have any explanation as to why the Federal Government is failing to support this most cost-effective of all health programs, and whether there is any intention to do better in the future?

Dr. VAN HOEK. Mr. Scheuer, I am Acting Administrator of the Health Services Administration which administers the family planning programs under title V and title X.

As you know, in the appropriations processes the President in fiscal 1976 recommended 20 percent less for family planning. That was not to indicate that the Department or the administration felt that family planning was not an important service and that we should not continue to support the program but rather within the total Federal expenditures that perhaps the State and local agencies could make up some of that difference in funding to maintain the level of operation.

Mr. SCHEUER. It would take a Martian to believe that New York City and State, as well as other cities and States similarly situated, are capable of filling in the funding gap by substituting their funds for Federal funds. Do you really think such a plan is feasible?

Dr. KRETCHMER. It has to be taken in light of one other factor, and that is that there are other Federal funds available for family planning through title XIX and title XX is which there is preferential matching to the States for the support of those services.

Mr. SCHEUER. All the evidence indicates that there are perhaps 3 to 4 million women of child-bearing years in this country who do not have available to them family planning services. If we are talking

about infant and maternal health there is absolutely nothing, including EPSDT, that will do as much, for as little expenditure of funds, as making family planning information available to mothers.

Now the 1970 act established a 5-year program for bringing family planning services to every single woman of child-bearing years in this country.

Do you feel that we have accomplished this?

Dr. KRETCHMER. No, sir.

Mr. SCHEUER. What plans do you have to accomplish this congressional goal?

Dr. VAN HOEK. It seems to me we have to look at the program from several perspectives. It is not just Federal family planning program legislation and appropriations which can meet the needs of family planning services. In addition to the family planning legislation, we have authority under almost all our other health service programs to provide family planning service.

Our neighborhood health centers, our maternal and child health programs and our direct service programs all provide family planning services to individuals. If there is a gap it may not just be a lack of legislation or appropriation but the way services are organized in the local communities.

Mr. SCHEUER. Mr. Chairman, I ask unanimous consent that the witness may be permitted to complete his answer to my question and also that he be given some additional questions on the penalty of some $21/2 million which has been assessed against New York State. If you would answer these questions for the record I would appreciate it very much.

Mr. OTTINGER. Without objection we will ask the Department to answer those questions for the record.

[See letter dated Nov. 5, 1975, p. 143, this hearing.]

Unfortunately there is a recorded vote.

Mr. OTTINGER. We would like to express our real concern on this committee that the program for child health be carried out. That this has been given the kind of priority which is said to be given by the administration certainly is not reflected by what I understand is a 35-percent cut in the funds for the whole series of maternal and child care programs within the budget.

I hope you will carry that message back as well as our dissatisfaction. The lack of priority for this program is reflected in the top people of the Department not being represented at this hearing.

This concludes 2 days of hearings on "Shortchanging Children." This is the second series of hearings held as part of an overall study of the Subcommittee on "Getting Ready for National Health Insurance."

We have heard distressing testimony of public witnesses who could have and should have been screened and treated in programs mandated by the Social Security Act and funded under medicaid, but who were not. Their loss of good health can never be recovered. Instead of being able to lead normal, productive lives and be future taxpayers to our government, they instead have been mistreated and maltreated and will need to be supported by society. The tragedy is that their ailments could have been avoided if they had received the early diagnosis that is provided for in existing child health legislation.

We have heard from pediatricians and researchers who examined the aspects of the problem and indicated the benefits of early screening and preventive medicine and the huge costs of the absence of such screening treatment. For example, a simple PKU test that costs 30 or 50 cents may save $20,000 a year for an institutionalized mentally retarded victim. Their testimony was convincing both in dollar costs and in human costs. They indicated that are substantial benefits to be gained by such programs as early and periodic screening diagnosis and treatment (EPSDT). There appear to be much better ways to manage such a program than what is currently being done by HEW.

It is clear that wide gaps exist in the execution of this program as intended by the Congress. This is another example of the lack of proper administration of the medicaid program by the Department of Health, Education, and Welfare.

The House of Representatives through rules X and XI has empowered this committee with oversight responsibilities over health programs not supported by payroll taxes.

In order to execute this responsibility in the manner intended, I will transmit to the President of the United States details of the deficiencies and costs found in the implementation or rather lack of implementation of these child health programs. Further the committee will request from the Secretary of HEW a report indicating the steps they intend to take to bring the program into conformity with the statutes of the United States.

In order to protect the consumers of health care in this country we need to close the gaps of the health care delivery system. We must be able to provide quality medical care to all Americans at a reasonable cost. The evidence of why this should be done in the area of child health is overwhelming. The evidence of the gaps in this program are also overwhelming. We have a responsibility to close these gaps. We intend to see that this is done.

The hearing are concluded.

[Whereupon, at 12:45 p.m. the committee was adjourned.]

○