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ABSTRACT

This hearing addresses issues in the reauthorization of the Child Abuse Challenge Grant Program, which provides federal funds to match state funding for child abuse prevention programs, and reauthorization of the Temporary Child Care for Handicapped Children and Crisis Nurseries Act, which provides respite care for families with children with disabilities. Included are statements, prepared statements, letters, and supplemental materials from the following individuals and organizations: (1) three Congressional Representatives: George Miller, Major R. Owens, and Donald M. Payne; (2) Governor of Indiana, Evan Bayh; (3) governmental agencies, including the United States General Accounting Office and the Children's Bureau of the Office of Human Development Services; and (4) private organizations, including the Human Services Research Institute; Texas Respite Resource Network; United Cerebral Palsy Associations, Inc.; Texas Children's Trust Fund; and National Center on Child Abuse Prevention Research. The statement from the Human Services Research Institute summarizes the findings of a national survey of parents' experiences with non-medical respite services. The statement from the United Cerebral Palsy Associations includes statistical data on family support spending by state. The statement from the General Accounting Office includes information on national organizations involved in respite care and federal respite care demonstration grants. (JDD)

# HEARING ON REAUTHORIZATION OF TEMPORARY CHILD CARE FOR HANDICAPPED CHILDREN AND NURSERIES ACT OF 1986 [RESPITE CARE] AND THE CHILD ABUSE CHALLENGE GRANT PROGRAM

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## HEARING

BEFORE THE

SUBCOMMITTEE ON SELECT EDUCATION

OF THE

COMMITTEE ON EDUCATION AND LABOR
HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

HEARING HELD IN WASHINGTON, DC, APRIL 6, 1989

**Serial No. 101-7**

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# HEARING ON REAUTHORIZATION OF TEMPORARY CHILD CARE FOR HANDICAPPED CHILDREN AND CRISIS NURSERIES ACT OF 1986 [RESPITE CARE] AND THE CHILD ABUSE CHALLENGE GRANT PROGRAM

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THURSDAY, APRIL 6, 1989

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON SELECT EDUCATION,
COMMITTEE ON EDUCATION AND LABOR,
*Washington, DC*

The subcommittee met pursuant to notice, at 9.50 a.m., in Room 2261, Rayburn House Office Building, Hon. Major R. Owens [Chairman] presiding.

Members present: Representatives Owens, Payne, Jontz, Bartlett and Smith.

Staff present: Maria Cuprill, Wanser Green, Laurence Peters and Richard Horne.

Chairman OWENS. The meeting of this subcommittee will come to order.

Last year, despite the fact that these super planes continued to malfunction, one hundred B-1 bombers were delivered at a cost to the government of $27.1 billion dollars.

The programs we are considering today add up to less than $10 million dollars--less than one-tenth of the cost of just one of these aircraft—and yet this "kinder and gentler" administration wants to zero out funding for the Child Abuse Challenge Grant Program and freeze the Temporary Child Care for Handicapped Children and Crisis Nurseries program at current levels, effectively cutting its budget.

On the other hand, the administration wants to be kinder and gentler to the thrift industry. We are now obligated to spend billions of dollars to bail out the bad business judgment of scores of savings and loan investment managers, but where are the dollars to add credibility to the administration's compassion for the abused children in this country?

The incidence of child abuse in this country is a national scandal. Despite a slight decline in the total child population, the number of child maltreatment reports in the United States rose by 180 percent between 1976 and 1985.

A survey conducted by the House Select Committee on Children, Youth and Families found a disturbing 37 percent increase in child abuse deaths between 1984 and 1986.

Our response must be to do everything we can to insure that all children can live without fear. Laws dealing with child abuse prevention should be unanimous, bipartisan and bicameral—and yet we open this hearing today with the understanding that the administration will not support the reauthorization of the Child Abuse Challenge Grant Program.

We are also here to begin the process for the reauthorization of the Temporary Child Care for Handicapped Infants and Crisis Nurseries Act.

It has been reported that at least 25 percent of child abuse cases involve children with disabilities. Respite care should be part of a family support program to give parents some relief from the day-to-day demands of caring for a child with a disability. It is important that we not allow money for this program to be frozen below inflation levels.

If the administration's budget were to be guided by truly humane and rational priorities, the programs we are considering today for reauthorization should receive increases based on the dramatic rise in the incidence of child abuse in recent years.

The federal government has since the 1970s played a key role in moving the states to accept more of their responsibilities in the area of child abuse and child welfare.

The 1986 amendments to the Child Abuse Prevention, Adoption and Family Services Act, for example, were a key catalyst in inducing states to change their laws to better administer children's justice. Similarly, the Challenge Grant Program, through its state-matching requirements, has sustained child abuse prevention programs in states that would have otherwise directed their over-burdened resources to meeting the increased demands of child abuse treatment.

If the federal government reneges on its commitment to maintain trust funds that have now been started in 47 states and to establish the remaining trust funds, a powerful message is sent: prevention programs are an optional extra rather than central to the states' efforts to combat the growing rise in child abuse.

In short, when it comes to the increased needs of families and children, the federal government cannot and must not flinch from its leadership role. We still have a very long way to go to meet the challenges ahead as we attempt to build upon these fledgling programs.

This hearing, which happens to fall at the beginning of Child Abuse Prevention Month, is also our beginning as we focus our attention, confront these issues and take concerted steps in the right direction.

[The prepared statement of Hon. Major R. Owens follows:]

# OPENING STATEMENT

CHAIRMAN MAJOR R. OWENS

## HEARING ON THE REAUTHORIZATION OF THE "TEMPORARY CHILD CARE FOR HANDICAPPED CHILDREN AND CRISIS ACT OF 1986" AND THE CHILD ABUSE CHALLENGE GRANT PROGRAM

APRIL 6, 1986

LAST YEAR, DESPITE THE FACT THAT THESE SUPER PLANES CONTINUED TO MALFUNCTION, ONE HUNDRED B-1 BOMBERS WERE DELIVERED AT A COST TO THE GOVERNMENT OF $27.1 BILLION DOLLARS. THE PROGRAMS WE ARE CONSIDERING TODAY ADD UP TO LESS THAN $10 MILLION DOLLARS--LESS THAN ONE-TENTH OF THE COST OF JUST ONE OF THESE AIRCRAFT. AND YET, THIS "KINDER AND GENTLER" ADMINISTRATION WANTS TO ZERO OUT FUNDING FOR THE CHILD ABUSE CHALLENGE GRANT PROGRAM AND FREEZE THE TEMPORARY CHILD CARE FOR HANDICAPPED CHILDREN AND CRISIS NURSERIES PROGRAM AT CURRENT LEVELS, EFFECTIVELY CUTTING ITS BUDGET.

ON THE OTHER HAND, THE ADMINISTRATION WANTS TO BE KINDER AND GENTLER TO THE THRIFT INDUSTRY. WE ARE NOW OBLIGATED TO SPEND BILLIONS OF DOLLARS TO BAIL OUT THE BAD BUSINESS JUDGMENT OF SCORES OF SAVINGS AND LOAN INVESTMENT MANAGERS, BUT WHERE ARE THE DOLLARS TO ADD CREDIBILITY TO THE ADMINISTRATION'S COMPASSION FOR THE ABUSED CHILDREN IN THIS COUNTRY?

THE INCIDENCE OF CHILD ABUSE IN THIS COUNTRY IS A NATIONAL SCANDAL. DESPITE A SLIGHT DECLINE IN THE TOTAL CHILD POPULATION, THE NUMBER OF CHILD MALTREATMENT REPORTS IN THE UNITED STATES ROSE BY 180 PERCENT BETWEEN 1976 AND 1985. A SURVEY CONDUCTED BY THE HOUSE SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES FOUND A DISTURBING 37 PERCENT INCREASE IN CHILD ABUSE DEATHS BETWEEN 1984 AND 1986. OUR RESPONSE MUST BE TO DO EVERYTHING WE CAN TO ENSURE THAT ALL CHILDREN CAN LIVE WITHOUT FEAR. LAWS DEALING WITH CHILD ABUSE PREVENTION SHOULD BE UNANIMOUS, BIPARTISAN, AND BICAMERAL. AND YET, WE OPEN THIS HEARING TODAY WITH THE UNDERSTANDING THAT THE ADMINISTRATION WILL NOT SUPPORT THE REAUTHORIZATION OF THE CHILD ABUSE CHALLENGE GRANT PROGRAM.

WE ARE ALSO HERE TO BEGIN THE PROCESS FOR THE REAUTHORIZATION OF THE TEMPORARY CHILD CARE FOR HANDICAPPED INFANTS AND CRISIS NURSERIES ACT. IT HAS BEEN REPORTED THAT AT LEAST 25 PERCENT OF CHILD ABUSE CASES INVOLVE CHILDREN WITH DISABILITIES. RESPITE CARE SHOULD BE PART OF A FAMILY SUPPORT PROGRAM TO GIVE PARENTS SOME RELIEF FROM THE DAY-TO-DAY DEMANDS OF CARING FOR A CHILD WITH A DISABILITY. IT IS IMPORTANT THAT WE NOT ALLOW MONEY FOR THIS PROGRAM TO BE FROZEN BELOW INFLATION LEVELS.

IF THE ADMINISTRATION'S BUDGET WERE TO BE GUIDED BY TRULY HUMANE AND RATIONAL PRIORITIES, THE PROGRAMS WE ARE CONSIDERING TODAY FOR REAUTHORIZATION SHOULD RECEIVE INCREASES BASED ON THE DRAMATIC RISE IN THE INCIDENCE OF CHILD ABUSE IN RECENT YEARS.

THE FEDERAL GOVERNMENT HAS SINCE THE 1970'S PLAYED A KEY ROLE IN MOVING THE STATES TO ACCEPT MORE OF THEIR RESPONSIBILITIES IN THE AREA OF CHILD ABUSE AND CHILD WELFARE. THE 1986 AMENDMENTS TO THE "CHILD ABUSE PREVENTION, ADOPTION AND FAMILY SEVICES ACT," FOR EXAMPLE, WERE A KEY CATALYST IN INDUCING STATES TO CHANGE THEIR LAWS TO BETTER ADMINISTER CHILDREN'S JUSTICE. SIMILARLY, THE CHALLENGE GRANT PROGRAM, THROUGH ITS STATE-MATCHING REQUIREMENTS, HAS SUSTAINED CHILD ABUSE PREVENTION PROGRAMS IN STATES THAT WOULD HAVE OTHERWISE DIRECTED THEIR OVER-BURDENED RESOURCES TO MEETING THE INCREASED DEMANDS OF CHILD ABUSE TREATMENT. IF THE FEDERAL GOVERNMENT RENEGES ON ITS COMMITMENT TO MAINTAIN TRUST FUNDS THAT HAVE NOW BEEN STARTED IN 47 STATES AND TO ESTABLISH THE REMAINING TRUST FUNDS, A POWERFUL MESSAGE IS SENT: PREVENTION PROGRAMS ARE AN "OPTIONAL EXTRA" RATHER THAN CENTRAL TO THE STATES' EFFORTS TO COMBAT THE GROWING RISE IN CHILD ABUSE.

IN SHORT, WHEN IT COMES TO THE INCREASED NEEDS OF FAMILIES AND CHILDREN, THE FEDERAL GOVERNMENT CANNOT AND MUST NOT FLINCH FROM ITS LEADERSHIP ROLE. WE STILL HAVE A VERY LONG WAY TO GO TO MEET THE CHALLENGES AHEAD AS WE ATTEMPT TO BUILD UPON THESE FLEDGLING PROGRAMS. THIS HEARING, WHICH HAPPENS TO FALL AT THE BEGINNING OF CHILD ABUSE PREVENTION MONTH, IS ALSO OUR BEGININING AS WE FOCUS OUR ATTENTION, CONFRONT THESE ISSUES, AND TAKE CONCERTED STEPS IN THE RIGHT DIRECTION.

Chairman OWENS. I yield to Mr. Payne for an opening statement.

[Whereupon, due to audio difficulties, Mr. Payne's oral opening statement was not recorded.]

[The prepared statement of Hon. Donald M. Payne follows:]

## Statement on Child Abuse and Crisis Nurseries
### The Honorable Donald M. Payne

Mr. Chairman. As you know, the incidence of child abuse has risen sharply over the past decade. The heinous example of New York City Attorney Joel Steinberg has made the nation acutely aware of the pervasiveness of child abuse. And although awareness is generally heightened, funding for services like respite care, which provides temporarily relief for parents and other caretakers who are under the stress of unemployment, drug addiction or any number of other personal problems, remains far below their recommended levels.

Today I am pleased to be here to lend my support for two bills that I would consider essential to the care and protection of children who have fallen under the emotional and physical weight of domestic violence or physical disabilities: the Child Abuse Challenge Grant Program and the Temporary Child Care for Handicapped Children and Crisis Nurseries Act.

In the past, we assumed that a greater frequency of child abuse must be countered proportionally with increase in treatment and crisis intervention. Most of the federal funds were used for treatment, and little was left for prevention. We now believe that prevention is equally important in stopping this type of domestic violence. As legislators, we obtain the most effective tools to assist community leaders in balancing the scales between treatment and prevention.

Through continued support for the challenge grant, temporary child care demonstration projects and crisis nurseries for abused children, we would be able to provide more resources to state, local and research facilities designed to improve methods of preventing child abuse.

More specifically, the challenge grant and crisis nurseries programs offer us the unique opportunity to further the efforts begun under P.L.98-473 to assist the children and families affected by domestic violence. While it not only sends a signal to the nation that Congress unilaterally intends to take a more active role in child abuse programs, it also conveys a message of solidarity by establishing a federal, state and local partnership designed to improve prevention methodology. More importantly, it assures the people most in need of services the chance to receive quality assistance.

In addition, Congress has another opportunity to expand its support for state and local agencies' child care initiatives through the Temporary Care for Handicapped Children Act. This legislation would provide temporary non-medical care for children with special needs to alleviate the social, emotional and financial stress among those children and their families. By increasing access to programs through an increase of federal funds, we essentially preempt the opportunity for neglect and abuse.

Frankly, Mr. Chairman, I must say that I am pleased to be a member of a subcommittee that will be taking the lead during the 101st Congress on issues important to the family It is an issue that will only grow in importance as America enters the 21st century. Therefore, you can be assured of my continued support on this kind of legislation well into the future.

Chairman OWENS. Our first speaker will be Ms. Betty Stewart, Associate Commissioner of the Children's Bureau of the Office of Human Development Services.

## STATEMENT OF BETTY STEWART, ASSOCIATE COMMISSIONER, CHILDREN'S BUREAU, OFFICE OF HUMAN DEVELOPMENT SERVICES.

Ms. STEWART Thank you, Mr. Chairman and members of the subcommittee.

I am Betty Stewart, Associate Commissioner of the Children's Bureau. Thank you for this opportunity to discuss our implementation of the Child Abuse Prevention Challenge Grant Program and the Temporary Child Care for Handicapped Children and Crisis Nurseries Act.

Several years ago, some states began to recognize the importance of funding child abuse prevention activities and creatively establishing children's trust and prevention funds. By 1984, about twenty states had established such trust funds to support child abuse prevention activities.

The Challenge Grant Program was enacted by Congress in 1984 to provide an incentive through federal matching funds to challenge additional states to establish trust funds or other funding mechanisms, including appropriations, targeted only for child abuse and neglect prevention activities.

We believe that this program has been successful in achieving its goal of creating ongoing resources at the state level for child abuse prevention activities.

In Fiscal Year 1986, thirty-three states received federal Challenge Grants totaling $4.85 million. In Fiscal Year 1987, forty-four states were funded, for a total of $5 million.

In Fiscal Year 1988 forty-two states—every state which applied for a Challenge Grant—received an award. The Fiscal Year 1988 grant awards ranged from $4,768 to West Virginia to $956,709 to California, for a total of $4.787 million.

Federal Challenge Grant funds represent a small percentage of monies now available for child abuse prevention activities at the state and local levels. Based on state applications submitted in Fiscal Year 1988, Children's Trust and Prevention funds collected and made available for child abuse and neglect prevention activities included an aggregate of approximately $31.3 million in non-federal funds.

These funds are raised through a variety of methods including state income tax check-offs; birth certificate surcharges; increased fees on marriage licenses, divorce filings or death certificates; the sale of heirloom birth certificates; and state appropriations. Over one-third of the trust funds also receive direct donations from private sources.

Recently, the Department delivered to Congress a report on state Challenge Grant Program activities for grant awards made in Fiscal Year 1986. These funds were used by state and local agencies and organizations for a wide range of child abuse prevention programs such as community-based programs on parenting, child care and child development; personal safety training for children; support groups and counseling for families at risk; and educational programs to increase public awareness of child abuse. Examples of some of these activities include the following.

In California, many counties have established local child abuse and neglect prevention councils. These councils have conducted culturally sensitive and ethnically appropriate training sessions for parents, established support groups among at-risk populations and developed curricula for preschool through elementary school levels.

In Michigan, health care providers have been working with young mothers in infant care classes and providing child care literature in prenatal clinics. The Visiting Nurse Association is providing a group of high risk mothers with intensive, individually designed services and support during a critical time frame in the development of the mother/child relationship.

In New York, the Buffalo North American Indian Culture Center developed a child abuse and neglect prevention program for Buffalo urban Indian families to eliminate barriers which prevent Indian youth and families from participating in existing community services.

In North Carolina, a support program for teen mothers in Hertford County has provided pre- and postnatal care, made referrals for related services, taught parenting skills to young mothers, fathers and significant others, and coordinated educational services to allow teen mothers to remain in school.

In Louisiana, efforts have been made to recruit volunteers from churches, service groups, university students and the public for community programs, and a toll-free 24-hour "Helpline" has been established to provide counseling and information to families at risk before an abusive incident occurs.

In Maine, a ten-week course for primary and secondary school teachers regarding child abuse and neglect was conducted, with credits for the course being sanctioned by the state university system. A six-month public awareness campaign entitled "Child Abuse and Neglect is a Preventable Problem" was conducted.

In Oklahoma, family life skills and child abuse prevention curricula were coordinated and promoted in public and private schools. A review of child abuse data was conducted. A resource lending library was developed. Presentations were made on child abuse prevention to civic and community groups and a training conference on child abuse prevention, intervention and treatment for professionals was organized.

The Children's Trust Fund of Texas has undertaken a demonstration project in three Texas cities to prevent child abuse by adolescent parents. In addition, a public service announcement has been completed on shaken infant syndrome with distribution scheduled for Child Abuse Prevention Month.

In Connecticut, a statewide "Child Awareness in the Schools" project was developed to help elementary and middle school personnel and parents become more involved in preventing child abuse and neglect, become more knowledgeable in identifying signs of child abuse and neglect and become more aware of information regarding the resources available for families in stress. Training materials were printed in both English and Spanish.

This is just a small sample of the hundreds of innovative child abuse and neglect prevention programs being carried out at the state and community levels through the State Children's Trust and Prevention Funds.

In order to encourage coordination among the states and to assist them in identifying and implementing effective prevention programs, the National Center on Child Abuse and Neglect, NCCAN, funded a grant to the National Committee for Prevention of Child Abuse National Committee, an internationally recognized leader in child abuse prevention activities.

Under this grant, the National Committee provided, by means of a regular conference call, a forum for states to share information on cost-effective planning and identification of innovative programming; coordinated an annual conference of Children's Trust and Prevention administrators; provided technical assistance in developing effective public awareness campaigns by exchange of brochures, videocassettes and public service announcements that have proved effective; and conducted an annual survey of Children's Trust and Prevention Funds administrators to gather information on the Funds' structure, revenue sources, size and expenditure patterns.

In December 1988 NCCAN convened a national conference in Washington for Challenge Grant Program grantees which provided states an opportunity to share information in such areas as teen parenting programs, parent self-help groups and building community networks to prevent child abuse and neglect.

The announcement requesting applications for the Fiscal Year 1989 Challenge Grant Program awards was published in the *Federal Register* on March 30. We expect to receive applications from at least forty-five states this year. We anticipate that almost all states will have trust funds or other funding mechanisms for child abuse prevention activities in place by the end of 1990.

We believe this program has been very successful in encouraging states to establish Children's Trust Funds or other funding mechanisms for child abuse and neglect prevention activities.

The Challenge Grant Program has accomplished the purpose for which it was established. For these reasons, the Department did not request funds for this program in Fiscal Year 1990.

The Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986 directed the Department of Health and Human Services to establish demonstration programs to states to assist private and public agencies and organizations in providing two types of services: in-home or out-of-home temporary nonmedical child care for handicapped children and children with chronic or terminal illnesses, and crisis nurseries for abused and neglected children, children at risk of abuse and neglect, or children in families receiving protective services.

In Fiscal Year 1988, the first year for which funds were appropriated, $4.787 million was available for these two demonstration programs. Through a competitive award process, 32 grants involving 28 states were funded.

Sixteen states received grants to demonstrate temporary child care programs for handicapped or chronically ill children and sixteen states received grants to demonstrate effective crisis nurseries.

Four states, North Carolina, Florida, Illinois and California, received grants in both demonstration areas.

The average amount of each grant is $150,000. The grants were awarded in August and September of 1988 and are in the early stages of implementation.

Some of the projects funded included the following. The Arkansas project is one that will provide respite care and other services through existing parent support groups in fifteen rural counties of Arkansas. Parents will be the respite care providers. Each provider will be trained and certified by the St. Vincent Medical Infirmary.

The Chronic Illness Respite Care Project, operated by the New York State Department of Social Services, is one that will identify and train respite care providers of minority backgrounds to provide respite care for children with AIDS who live with their own parents or with foster care families. A manual will be produced and disseminated in order to encourage the development of additional programs in other parts of New York state.

In addition, we have directed resources to provide for networking and information exchange among these grantees. For example, North Carolina is facilitating the exchange of information among all grantees and other sources of expert information on these programs. In this way we hope to enhance the impact of the demonstration programs across the states and local communities by providing information about common issues of concern and in comparable form. In order to coordinate and share information, we are also sponsoring a meeting of all of these grantees in late May.

As you know, last year Congress reauthorized the Temporary Child Care for Handicapped Children and Crisis Nurseries Act for one year and subsequently appropriated $4.94 million dollars for FY 1989. An announcement requesting applications for the FY 1989 grants to states will be published in the *Federal Register* by the end of this week.

Preference for these grant awards will be given to states that did not receive grants in FY 1988.

The Secretary currently has the authority to operate temporary child care and crisis nursery activities under Section 426 of the Social Security Act. In Fiscal Year 1990 the Secretary will continue to fund similar demonstration projects under the child welfare research and demonstration program.

Therefore, the Reagan administration budget did not request the reauthorization of the Temporary Child Care for Handicapped Children and Crisis Nurseries Act in FY 1990. However, an amount equal to the FY 1989 appropriation for temporary child care and crisis nurseries was added to the Fiscal Year 1990 budget request for the child welfare research and demonstration program.

Under the Bush administration budget proposals for Fiscal Year 1990, the funding for these activities are contained in the residual freeze category, which includes numerous programs across the government.

The freeze is flexible in that it allows for negotiations between Congress and the administration to determine appropriate funding priorities.

In closing, we appreciate the opportunity to share with you our view of our successful implementation of these programs. I will be happy to answer your questions.

[The prepared statement of Betty Stewart follows:]

**DEPARTMENT OF HEALTH & HUMAN SERVICES**

Office of
Human Development Services

Office of Assistant Secretary
Washington D C 20201 000

STATEMENT OF

BETTY STEWART

ASSOCIATE COMMISSIONER OF THE CHILDREN'S BUREAU

ADMINISTRATION FOR CHILDREN, YOUTH AND FAMILIES

OFFICE OF HUMAN DEVELOPMENT SERVICES

DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

SELECT EDUCATION SUBCOMMITTEE

OF THE

HOUSE EDUCATION AND LABOR COMMITTEE

U.S. HOUSE OF REPRESENTATIVES

April 6, 1989

Mr. Chairman, Members of the Subcommittee

I am Betty Stewart, Associate Commissioner of the Children's Bureau. Thank you for this opportunity to discuss our implementation of the Child Abuse Prevention Challenge Grant Program and the Temporary Child Care for Handicapped Children and Crisis Nurseries Act.

Child Abuse Prevention Challenge Grants

Several years ago, some States began to recognize the importance of funding child abuse prevention activities and creatively established Children's Trust and Prevention Funds. By 1984, about 20 States had established such trust funds to support child abuse prevention activities. The Challenge Grant Program was enacted by Congress in 1984 to provide an incentive through Federal matching funds to "challenge" additional States to establish trust funds or other funding mechanisms, including appropriations, targeted only for child abuse and neglect prevention activities. We believe this program has been successful in achieving its goal of creating ongoing resources at the State level for child abuse prevention activities.

In FY 1986, 33 States received Federal Challenge Grants totaling $4.85 million. In FY 1987, 44 States were funded for a total of $5 million. In FY 1988, 42 States, every State which applied for a Challenge Grant, received an award. The FY 1988 grant awards ranged from $4,768 (to West Virginia) to $956,709 (to California) for a total of $4,787 million.

Federal Challenge Grant Funds represent a small percentage of monies now available for child abuse prevention activities at the State and local level. Based on State applications submitted in FY 1988, Children's Trust and Prevention Funds collected and made available for child abuse and neglect prevention activities an aggregate of approximately $31.3 million in non-Federal funds. These funds are raised through a variety of methods including State income tax check-offs, birth certificate surcharges; increased fees on marriage licenses, divorce filings, or death certificates; the sale of heirloom birth certificates, and State appropriations. Over one-third of the trust funds also receive direct donations from private sources.

Recently, the Department delivered to Congress a report on State Challenge Grant Program activities for grants awards made in FY 1986. These funds were used by State and local agencies and organizations for a wide range of child abuse prevention programs such as community-based programs on parenting, child care, and child development, personal safety training for children; support groups and counseling for families at risk, and educational programs to increase public awareness of child abuse. Examples of some of these activities include the following:

- In California, many counties have established local Child Abuse and Neglect Prevention Councils. These Councils have conducted culturally sensitive and ethnically appropriate training sessions for parents, established support groups among at risk populations, and developed curricula for pre-school through elementary school levels.

- In Michigan, health care providers have been working with young mothers in infant care classes and providing child care literature in prenatal clinics. The Visiting Nurse Association is providing a group of high-risk mothers with intensive, individually designed services and support during a critical time-frame in the development of the mother/child relationship.

- In New York, the Buffalo North American Indian Culture Center developed a child abuse and neglect prevention program for Buffalo urban Indian families to eliminate barriers which prevent Indian youth and families from participating in existing community services.

- In North Carolina, a support program for teen mothers in Hertford County has provided pre- and post-natal care, made referrals for related services, taught parenting skills to young mothers, fathers and significant others, and coordinated educational services to allow teen mothers to remain in school.

- In Louisiana, efforts have been made to recruit volunteers from churches, service groups, university students and the public for community programs, and a toll-free 24 hour "Helpline" has been established to provide counseling and information to families at risk before an abusive incident occurs.

- In Maine, a 10 week course for primary and secondary school teachers regarding child abuse and neglect was conducted, with credits for the course being sanctioned by the State university system. A 6 month public awareness campaign entitled "Child Abuse and Neglect is a Preventable Problem" was conducted.

- In Oklahoma, family life skills and child abuse prevention curricula were coordinated and promoted in public and private schools. A review of child abuse data was conducted; a resource lending library was developed, presentations were made on child abuse prevention to civic and community groups; and a training conference on child abuse prevention, intervention and treatment for professionals was organized.

- The Children's Trust Fund of Texas has undertaken a demonstration project in three Texas cities to prevent child abuse by adolescent parents. In addition, a public service announcement has been completed on shaken infant syndrome with distribution scheduled for Child Abuse Prevention Month.

- In Connecticut, a statewide "Child Awareness in the Schools Project" was developed to help elementary and middle school personnel and parents become more involved in preventing child abuse and neglect, become more knowledgeable in identifying signs of child abuse and neglect, and become more aware of information regarding the resources available for families in stress. Training materials were printed in both English and Spanish.

This is just a small sample of the hundreds of innovative child abuse and neglect prevention programs being carried out at the State and community level through the State Children's Trust and Prevention Funds.

In order to encourage coordination among the States and to assist them in identifying and implementing effective prevention programs, the National Center on Child Abuse and Neglect (NCCAN) funded a grant to the National Committee for Prevention of Child Abuse (National Committee), an internationally recognized leader in child abuse prevention activities. Under this grant, the National Committee --

- provided by means of a regular conference call, a forum for States to share information on cost effective planning and identification of innovative programming

- coordinated an annual conference of Children's Trust and Prevention Fund administrators,

- provided technical assistance in developing effective public awareness campaigns by exchange of brochures, videocassettes, and public service announcements that have proved effective and

- conducted an annual survey of Children's Trust and Prevention Funds administrators to gather information on the Funds' structure, revenue sources, size, and expenditure patterns.

In December 1988, NCCAN convened a National Conference in Washington for Challenge Grant Program grantees which provided States an opportunity to share information in such areas as teen parenting programs, parent self help groups and building community networks to prevent child abuse and neglect.

The announcement requesting applications for the FY 1989 Challenge Grant Program awards was published in the Federal Register on March 30. We expect to receive applications from at least 45 States this year. We anticipate that almost all States will have trust funds or other funding mechanisms for child abuse prevention activities in place by the end of 1990.

We believe this program has been very successful in encouraging States to establish Children's Trust Funds or other funding mechanisms for child abuse and neglect prevention activities. The Challenge Grant Program has accomplished the purpose for which it was established. For these reasons, the Department did not request funds for this program in FY 1990.

## Respite Care/Crisis Nurseries

The Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986 directed the Department of Health and Human Services to establish demonstration programs to States to assist private and public agencies and organizations in providing two types of services:

- in-home or out-of-home temporary non-medical child care for handicapped children and children with chronic or terminal illnesses; and

- crisis nurseries for abused and neglected children, children at risk of abuse and neglect, or children in families receiving protective services.

In FY 1988, the first year for which funds were appropriated, $4.787 million was available for these two demonstration programs. Through a competitive award process, 32 grants involving 28 States were funded. Sixteen States received grants to demonstrate temporary child care programs for handicapped or chronically ill children. Sixteen States received grants to demonstrate effective crisis nurseries. Four States (North Carolina, Florida, Illinois and California) received grants in both demonstration areas. The average amount of each grant is $150,000. The grants were awarded in August and September of 1988 and are in the early stages of implementation. Some of the projects funded include the following:

- The Ohio Department of Human Services project will extend an existing weekend crisis nursery program to a 24 hour, 7 day a week program. In addition, a State-wide needs assessment and resource inventory will be conducted to determine how the different counties are dealing with respite care and crisis nurseries and to determine where gaps in service exist.

- The Arkansas project will provide respite care and other services through existing "parent support groups" in 13 rural counties. Parents will be the respite care providers. Each provider will be trained and certified by the St. Vincent Medical Infirmary.

- The "Chronic Illness Respite Care Project" is being operated by the New York State Department of Social Services. This project will identify and train respite care providers from minority backgrounds to provide respite care for children with AIDS who live with their own parents or with foster care families. A manual will be produced to encourage the development of additional programs in other parts of the State.

- The Massachusetts Department of Social Services in Boston is forming the "Child Care AIDS Network" to pilot family-based, temporary child care for children with AIDS. Under this project, foster families will be organized into a formal, statewide child care exchange network. Training and support groups, case management, and medical and social service consultation and referral will be provided.

- The California Department of Social Services is using funds to expand the "Children's ARK" (Assistance and Relief for Kids) program to include respite care. This infant and child development program provides a range of child development services for drug-exposed newborns and their families.

In addition we have directed resources to provide networking and information exchange among grantees. For example, North Carolina is facilitating the exchange of information among grantees and other sources of expert information. In this way we hope to enhance the impact of the demonstration programs across the States and local communities by providing information about common issues of concern in a comparable form.

In order to coordinate and share information among grantees, we will also sponsor a meeting of all grantees in late May.

As you know, last year Congress reauthorized the Temporary Child Care for Handicapped Children and Crisis Nurseries Act for one year and subsequently appropriated $4.94 million for FY 1989. An announcement requesting applications for FY 1989 grants to States will be published in the Federal Register by the end of this week. Preference for these grant awards will be given to States that did not receive grants in FY 1988.

The Secretary currently has the authority to operate temporary child care and crisis nurseries activities under Section 426 of the Social Security Act. In FY 1990, the Secretary will continue to fund similar demonstration projects under the child welfare research and demonstration program.

Therefore, the Reagan Administration budget did not request the reauthorization of the Temporary Child Care for Handicapped Children and Crisis Nurseries Act in FY 1990. However, an amount equal to the FY 1989 appropriation for Temporary Child Care and Crisis Nurseries was added to the FY 1990 budget request for the child welfare research and demonstration program.

Under the Bush Administration Budget proposals for FY 1990, the funding for these activities are contained in the residual freeze category, which includes numerous programs across the government. The freeze is flexible in that it allows for negotiations between Congress and the Administration to determine appropriate funding priorities.

In closing, we appreciate the opportunity to share with you our view of the Department's successful implementation of these programs. I would be happy to answer your questions.

Chairman OWENS. Thank you, Ms. Stewart. We have been joined by two additional colleagues, Mr. Jontz and Mr. Smith I wonder if Mr. Jontz or Mr. Smith would like to make an opening statement before we begin?

Mr. JONTZ. Mr. Chairman, I have no opening statement to make. I do want to submit for the record a letter from the Honorable Evan Bayh, Governor of the State of Indiana, with regard to funding for Challenge Grants for child abuse prevention, and if it would be appropriate to insert that into the record at this time, I would like to do that and express my appreciation of the leadership of the governor of our state on this important issue and my agreement with the opinions he is expressing in this letter

Chairman OWENS. Without objection, the letter will be entered into the record.

[The material to be supplied follows:]

OFFICE OF THE GOVERNOR
INDIANAPOLIS, INDIANA 46204-2797

EVAN BAYH
GOVERNOR

April 5, 1989

The Honorable Jim Jontz
1039 Longworth Building
Washington, DC 20515

Dear Jim:

Recently, I became aware that the proposed federal budget eliminated funding for challenge grants for child abuse prevention. I want to share with you a few alarming statistics. Indiana has seen an increase in the number of child abuse and neglect cases through recent years. In 1988, there were a total of 30,763 reported cases while in 1981 there were only 22,844. What is especially frightening about these statistics is that the number of abuse cases has nearly doubled over this same period. In 1981, there were a total of 8,249 abuse cases while in 1988 thre were 16,023.

With these statistics in mind, I urge you to support the retention of these funds in the federal budget. They are essential to programs that will help prevent child abuse and assist its victims, both in Indiana and the nation. To allow this assault upon our future is unconscionable. We must all commit ourselves to ensuring that this nation's abused and neglected children receive the assistance they deserve.

Sincerely,

Evan Bayh

EB:JBD:ab

Chairman OWENS. Mr. Smith?

Mr. SMITH. Thank you, Mr. Chairman. I have a short statement to make. I want to begin by expressing my apologies for being late.

I am going to have to be in and out because Congressman Miller, who I guess was here earlier, has chosen today at 10:30 to organize the Select Committee on Children, Youth and Families, of which I am a member, so I am going to have to go and do that and then hopefully be back to hear this.

I would only say that the Children's Trust Fund in Vermont has made a significant difference in the life of families in our state, as it touches not only children who are subject to problems of abuse but also this largely, until recently, undiscussed or unspoken problem of respite care and all associated services.

It is a problem that I have been working on politically and personally since I was a member of our state senate, which is, God forbid, almost ten years ago. I attach - -I think it is one of those little programs that has made an enormous difference in the lives of individuals who struggle with problems that they did not choose for themselves and struggle to live lives that are whole.

So I attach great significance and real human importance to the deliberations of this subcommittee today as it relates to the Challenge Grants of the Trust and the respite care issues.

Chairman OWENS. Thank you. Ms. Stewart, I think your testimony illustrates how effective the program has been in stimulating activity within the states.

It is a very tiny amount of money. You can't find it in the budget. It is so tiny that we wonder why attention was focused on it as one area that we should cut.

You speak of absorbing this small but critical amount of money into Section 426 of the Social Security Act.

Ms. STEWART. Could I make a——

Chairman OWENS. Yes.

Ms. STEWART. The money I was talking about in terms of 426 is the Crisis Nurseries money——

Chairman OWENS. That is the respite care. The other amount you just want to cut out completely. That will get absorbed anywhere, the money for the Challenge Grants.

The language of Congress was that they wanted to establish and maintain—the federal government would have a role in establishing those Challenge Grant programs and maintaining them.

We certainly succeeded with a very small amount of money in stimulating a lot of activity. The total amount of activity, I think your testimony said, adds up to about $33 million?

Mr. SMITH. Thirty-one point something.

Chairman OWENS. Thirty one million dollars. That isn't even a million dollars per state. Of course, there are some states—I said forty-seven and the correct number, I think, is that forty-four have participated in the program up to now. For the present fiscal year only forty-two are involved, but as many as forty-four out of the fifty, have participated which is a plus. Some have participated to a very small degree and a very small amount of activity is going on. If you take all fifty, you have less than a million dollars that has been generated from the program to date in all fifty states.

What is the great rush to stop the successful program?

Ms. STEWART. Well, I will just repeat and maybe elaborate a little bit on what I said earlier.

We feel that the program has been successful. States that had initially established Children's Trust Funds even before the federal funding was available have maintained those funds.

We have an additional state, the state of Arkansas, who has a trust fund and as of this year now has enough money in that fund that they will be applying for grants this year.

We have two additional states that have legislation pending, I believe Colorado and Mississippi. We have a third state, Wyoming, which expects to introduce legislation in their next session of Congress, so that states have taken advantage of this encouragement to continue.

The other thing is that the amount of money that is coming from state and private sources is much, much greater than what is coming from the federal government. I think that we have viewed—not to say that we don't think prevention is very important, because we have a major focus on prevention activities through our National Center on Child Abuse discretionary funding program, but we feel that this particular program has served its intent and for that reason we do not recommend its continuation.

As I said earlier, this is a part of the flexible——

Chairman OWENS. The fact that the amount of money which is now in the program is much greater than the federal contribution, that is nothing new. Programs in education, programs in health and human services operate that way all the time.

Is there any evidence—did you do any kind of evaluation or do any kind of study or were there statements made or did governors indicate that for some reason this was different—if the federal stimulus was not there they would automatically keep going?

How do we know that if the federal stimulus is not there we won't lose some of the programs that we have?

Ms. STEWART. Well, I don't know that—we certainly have no indication that I know from any governor or any state that if this money is not available that these programs will stop. Many of these programs are now established

Chairman OWENS. Do you have any indication from any of them that they don't need the money anymore? Did anybody say that we would like to see the federal government withdraw its tiny contribution?

Ms. STEWART. That has never happened, as far as I know, for any federal program.

Chairman OWENS. So the administration has decided to do this just on the basis of the great need to save money?

Ms. STEWART. We have decided to do this on the basis that we feel the program has fulfilled its purpose, funds are established, funding mechanisms are in place through the collection of money from birth certificates and other kinds of activities. That is the reason.

Chairman OWENS. On the second part of the consideration today, the respite care, you propose to move it under Section 426. What is under Section 426 already? What kinds of programs are being funded there already?

Ms. **Stewart**. The basic programs that are funded under 426 are a Child Welfare Discretionary separate amount which is specifically targeted toward child welfare training.

That includes areas such as foster care, family-based services, residential care and other areas that have to do with general child welfare programs.

Chairman **Owens**. What is the total budget now before you add this research training and demonstration projects under Section 426? What budget amount?

Ms. **Stewart**. For 1990?

Chairman **Owens**. Yes, what is your current—what is your 1989 budget?

Ms. **Stewart**. I am not sure I can give you that, but I will be glad to provide it.

Chairman **Owens**. Do you know it for 1990?

[No response]

Chairman **Owens**. You don't know it for either year?

Ms. **Stewart**. I don't want to—I'm not sure. Excuse me just a moment.

It is $13 million.

Chairman **Owens**. You have $13 million in that Section already?

Ms. **Stewart**. That is correct.

Chairman **Owens**. Which funds a variety of programs you just indicated?

Ms. **Stewart**. That is correct.

Chairman **Owens**. What guarantee do we have that there will be funding beyond this year for the respite care programs? If we put them under there the secretary has discretion. What guarantees will there be that the same or more money will be spent on this very critical area?

Ms. **Stewart**. The same funds that are available this year have been added to the 426 budget specifically for this program. We are expecting to publish a "Federal Register" announcement within the next week for the next amount of funding, so that we have every intention to continue funding this program at least at the same level.

Chairman **Owens**. If you only put the same amount of money in there, that is already cut. You are not taking that first into consideration at a time when the need is galloping forward and we have every indication that the need is far greater now than every before. Eighteen states do not fund any respite temporary care assistance at this point, yet you are cutting it by just putting the amount of money in the general 426 area of funding that we had before.

You don't recognize the fact that there is an increased need?

Ms. **Stewart**. Our understanding is that these programs are set up to be demonstration, to provide us with information, to provide states and other communities with information about what works in these kinds of programs, what is the most effective, how to establish them, really to develop models that can be spread throughout the country.

The funding of the first round of grants was for seventeen months, because that was the total length that we could fund them because of the way the funding was set up.

We realize that these are programs that require some time and our intention would be to continue funding the ones that we currently have if they are succeeding in their efforts, so that we would over the long run be funding these programs for a period of thirty-four months.

In addition, with the next round of grants we would also want to do the same thing, so that at the end of three years we are going to have probably something like sixty-four demonstrations split between these two areas that will have a life of three years, that will be funded at least in the range of $150 or more, and I think that that is going to provide not just us at the federal level, but states and communities with substantive information about these programs.

Chairman **Owens**. Well, states are very hard-pressed to just take care of the treatment of child abuse, with the great increase of obvious cases, and also many states are having tremendous budget trouble.

You don't feel that we are sort of abandoning the process which is really the least expensive approach to this problem, we would hope: prevention, the prevention sector of the problem.

Ms. **Stewart**. I am sorry, I don't——

Chairman **Owens**. You say that once the demonstration projects have gotten off the ground you feel there is no more federal obligation for participation?

Ms. **Stewart**. No, I didn't say--what I intended to say is that this Act set these programs up as a demonstration. We are very committed to this program. I think that we are doing everything and will continue to administer this program in a way that is going to maximize its effectiveness, not just for the individual programs but for others around the country who are looking toward these demonstrations for information and assistance.

Chairman **Owens**. Have you done any studies or evaluations of what the impact of the programs has been since 1983?

Ms. **Stewart**. Well, this program—we have just funded our first round of grants and they have had about seven months. They are just getting underway. We will learn more at the meeting we are having for all of these grantees in May.

The grantees are required by the law to provide the secretary with information on their programs. One of the things that we will be doing at the May meeting, with the help of our North Carolina grant, is to develop some common data sets from each of the grantees so that we can collect information that will be the same throughout all of these grants and thus give us more information.

I think—from my own knowledge as a practitioner in the past, I think that the respite care and crisis nurseries programs have pretty much been grass roots kind of programs, many of which grew up out of the mental health field and other kinds of areas.

I don't know how much actual research information we have at this point about the extent to which these programs are effective in reducing child abuse. I don't think that we know that.

Certainly from an anecdotal perspective we know that these kinds of programs have great potential to relieve pressures on parents who may themselves be in crisis under the strain and therefore it says to them, you know, we accept that you have a difficult job and you need help. They can receive this help without it being devastating to them and really supporting them.

Chairman OWENS. Thank you. Mr. Payne?

Mr. PAYNE. Thank you, Mr. Chairman. I, too, must apologize. At 10:30 I was asked to sit in on the Committee on Hunger to listen to some testimony that is going to be taken. Shortly after that I will return here.

Although I think you certainly asked the appropriate questions, it just seems to me to be a step in the wrong direction.

As has been indicated, states are having tremendous problems balancing their budgets—most states in the union, including my state of New Jersey, which for the last five or six years has had a tremendous surplus because of economic development and so forth, this year has a tremendous deficit.

For programs like this, it is to be expected that the states would pick up more and more of the costs, I think, that is neither realistic nor reasonable, especially in light of the fact that the federal government is even talking about tapping into resources that state governments usually use as funding sources, such as federal tax on gasoline, as an example.

That has been the purviews of the states, where they have continually raised taxes on gasoline in order to balance their local budgets. Now the federal government is looking into dipping into that, yet still we are asking states to take more and more responsibility.

There is a growing number of children with AIDS. In some urban areas, as high as five percent of the births are to parents who are IV drug users. To see us turning our backs on the people who most need this assistance, even if it is for demonstration programs, to me it seems that the federal government would be looking for ways of providing permanent funding for programs in this important and critical area.

It appalls me that the use of the jargon of flexible freeze, where you find some programs being cut as much as 46 percent because of the manner in which funding comes about, I just think it is a hoax on the American public It is a sin to turn our backs on so many people who are voiceless and who really need the assistance.

I know that you are not the person who sets the budget. There is no question about that. You just happen to be the one here.

Chairman OWENS. Thank you, Mr. Payne. Mr. Jontz?

Mr. JONTZ. I do have some questions, Mr. Chairman, but I would like to yield to Mr. Smith from Vermont, because he does have another obligation, and I would defer to his time situation.

Mr. SMITH. Thank you. I will be uncharacteristically brief. You won the raffle.

Ms. STEWART. I won the raffle?

Mr. SMITH. Yes, that's what we say in Vermont when you get to be the one to bring the bad news.

[Laughter]

Mr. SMITH. I think, you know, there are two issues. Not to get into a debate with my colleagues on the panel, but the issue of whether or not the federal government has been more or less successful at balancing its budget or has a bigger or a smaller problem than even the state of New Jersey, where we have a good Republican governor, or the state of New York, where we have a Democratic governor, I think is one that reasonable people could at least spend a lot of time talking about.

We have got a heck of a problem here and our responsibility is to try to figure out how to make the most sense out of it.

What I am interested in is that at some point in the future we may as a matter of legislative intent say that we want to change this program and turn it into an ongoing federal program to support the two—we are talking about two different bills here—and change the nature of the Challenge Grant Program to an ongoing support program. I think that is something that I would support.

In the meantime you are in the difficult position of having to come and argue what was legislative intent and we are in the position of saying we think this is working, and while we are disseminating good practices around the country we are also serving people.

The state of Vermont—I like the match, I like the challenge, I like the trust. The state of Vermont is outperforming, you know. If we funded this bill more we would get a whole lot more money in Vermont and I suspect the other participating states are in the same situation.

Our state share is way above—or, I will put it differently. Our federal share is way below where it would be if this thing were funded even the way we had hoped it would be.

From my point of view this is a time in which, as we make what are difficult budget decisions, I think we need to at least maintain and, if we can, increase the commitment to a historically just dramatically, tragically underserved subset of the population.

I have one particular question about respite care. Is your office aware of a state initiative program in Michigan through which the parents of disabled children are, in fact, simply given money, because they have a disabled child, for respite care?

The state of Michigan apparently has recognized that the cheapest, most cost-effective way to help families with disabled children or young children with significant problems or disabilities is to simply give them a drawing account which they can use within an annual cycle to either purchase or in other ways provide respite services.

Have you heard anything about that?

Ms. STEWART. I am not personally familiar with that. I will be glad to check with some of my staff to see if they know more about it. It is not anything I have heard of.

Would this include all children in the state who have disabilities?

Mr. SMITH. It is my understanding, and it is cheap and, in fact, the argument of, I think it is, Governor Blanchard's office—he is on your team, isn't he—is that his name? I think it is Governor Blanchard.

Anyway, the argument from the state government in Michigan that I have understood is that it is far and away the cheapest and most effective way to go and that they are very excited.

I think it may, just from the point of view of trying to move the ball down the field a little bit—it is something you ought to have someone in your office check on, because if I got it wrong I need to hear that and if I don't have it wrong I think it is something that the world ought to know about.

Beyond that piece of information, I would appreciate hearing from you and I think the committee—if there are models out there that are working, we need to know about them.

I will rest with my initial statement. One final question. Is there any other program—how do I want to put this? Medicaid reform gave people who were means tested in, or Medicaid eligible, subsidy—some coverage—for respite care.

Is there any other coverage at the federal level other than this bill for people who are not Medicaid eligible, or people who are Medicaid eligible? I mean, what other kinds of programs do we have for respite care?

Ms. STEWART. There may well be other health-related programs. I think the difference in the program is that it is more chronically ill or children with handicaps. It is not a medically oriented program, so that I think there may well be programs that I am not directly familiar with that are related to health needs and respite care or some kind of care that also meets their health and physical needs.

Mr. SMITH. I may be alone in this, and I am a newcomer here, Mr. Chairman, but I find again and again that when we are trying to think about a comprehensive set of services the one place that it doesn't come together is around the child; in other words, the parents of the child don't know what is available.

I guess I am believing that if I don't know what is available comprehensively at the federal level, or what we believe is available, what we are trying to make available, whether it is on the medical side or the social side, how in the world is a parent of a child going to know what is available?

If there is any way to get to the staffs just some overview of the different bits and pieces. I run into this with older Americans all the time. I think it would be very helpful.

Ms. STEWART. I think that one of the major issues of legislation that has impacted particularly on the young child is the Education Act for Handicapped Children, which is very much geared toward providing a comprehensive approach with very strong parent involvement, meeting the needs of these youngsters as it relates to their educational needs.

Mr. SMITH. Well, I think we all know that law pretty well. That doesn't get at what I am asking about.

Ms. STEWART. I understand that, but it does provide for a comprehensive perspective.

Mr. SMITH. Right. If there is some way without breaking the back of your office that we could have some sense of what the different pieces are in the federal pie that together get at the question of respite care and abuse for children, it might help us, rather than continually debating, you know, a straw here and a sliver there and the elephant's tail here. Let's try to get the whole beast assembled and see what it looks like. It might help us.

Anyway, thank you. Thank you, Mr. Chairman. I will try to get back here.

Chairman OWENS. Mr. Jontz?

Mr. Jontz. Thank you very much. Ms. Stewart, I want to read to you just a little bit from the federal statute that I know you are very familiar with.

"The Congress finds that disturbing increases have occurred in recent years in the numbers of younger Americans who are abused. Given the increased demand for treatment and crisis intervention in child abuse and neglect cases, federal funds distributed to the states are most often used for treatment and little is left for prevention.

"Since 1980 some states have begun to recognize the critical needs for prevention efforts and trust funds are being established to allow states to pay for child abuse and neglect prevention activities.

"In recognition of the increased cases of child abuse and neglect, other states have established significant funds for child abuse and neglect prevention activities through direct appropriations and the nation cannot afford to ignore the importance of preventing child abuse."

Do you think all of those statements are true today?

Ms. Stewart. I don't—I mean, I don't find them to be inaccurate

Mr. Jontz. You think those are accurate conclusions? You would agree with those statements which I just read to you? Would you?

Ms. Stewart. I don't disagree with them.

Mr. Jontz. Then you agree with them?

Ms. Stewart. I would.

Mr. Jontz. Fine. Well, as you know, this is from Section 402 of Title IV of Public Law 98-473, which is the section of law with regard to the findings that Congress made in establishing the Challenge Grant Program.

If I understand your testimony, you say you believe that the findings which Congress made in 1984 which were the underpinnings of the Challenge Grant Program are now just as true in 1988 as they were in 1984, when the Congress put these words into law.

Now, let me read you another section from this particular law, Section B.

"It is the purpose of Sections 402 to 409 by providing for federal challenge grants to encourage states to establish and maintain trust funds or other funding mechanisms, including appropriations to support child abuse and neglect prevention activities."

Your testimony used the word "establish" on numerous occasions. Your testimony never used the word "maintain."

Why is that?

Ms. Stewart. As I responded to a question earlier, not only have the great majority of the states established Children's Trust Funds, all of those states that have established such funds have maintained them during this period, including the twenty or so states that already had funds prior to the passage of the legislation.

Mr. Jontz. Well, it seems to me that the word "maintain" envisions some ongoing concern about an effort to continue mechanisms that have been established.

I question whether at this point in 1989 the purpose for which this law was established has really been fulfilled, seeing as how we do have a long way to go in most of these programs and it seems to me the need to maintain the programs is just as great today as what it was in 1984.

Do you think the need to maintain the programs has diminished in any way?

Ms. **Stewart**. I think that many of the states have set up their mechanisms so that they can maintain the programs through various kinds of collections in the states.

Mr. **Jontz**. Well, you know, I really think that what you have presented to us today is a very poor rationale for terminating the Challenge Grant Program, because in fact all of the conditions that the Congress found true in 1984 in establishing this program are just as true today, and the need to maintain the programs and to establish them in some cases where they have not been established is just as great today.

I really find it quite appalling that with the need so great we would have a witness from the administration come forward and suggest that this program, of such modest size, be terminated.

Your experience in dealing with child abuse at the community level may be much larger than mine. I was co-author of Indiana's child abuse law. We are celebrating our tenth anniversary of that law this week. I have seen a great deal of improvement in the response by our state and our local communities to the problem of child abuse, but I also know—and, again, your experience may be much larger than mine and perhaps it contradicts my experience—that the resources that are now available at the local level are far smaller than what the need is.

I can think of a very recent case where I was in a small town in my district and had the opportunity to visit with some nurses who were providing care for a child. They shared with me their frustrations that the federal government was willing to pay for the medical care that they provided on an ongoing basis to this child, but that when they left the house the conditions in the household were so volatile and the parents were so poorly equipped to meet the needs of the child that they feared abuse and neglect was occurring. There was nothing in this small rural community—no services available—to provide any help to those parents from a prevention standpoint.

I am sure this same experience is replicated throughout our country. It is not just in the rural, remote communities where an absence of resources exists. It is in communities of all sizes, I believe.

Whatever money the federal government can spare for this purpose seems to me to be money very well spent, and what's more it seems to me that there is some symbolic purpose in addition to the actual resources that are provided that this particular program fulfills, because I would like to think that the federal government at least recognizes the problem and at least is willing to say, we want to do something to continue a commitment to addressing these very important needs.

I am very discouraged by the sense of priorities that I see here in Washington. My constituents at home don't understand this. They don't understand, and I realize again that you are not responsible for the parameters of the budget overall, but the people at home don't understand why, with the problems of child abuse they see in our local communities, our nation can send billions of dollars around the world and we can spend $4 billion a year on Star Wars, and we have these critical needs here at home and we are saying, well, the states are taking care of this problem and so we are going to get out of providing assistance.

I hope that—I appreciate the position you are in. As Mr Smith said, you won the lottery to come today to make this testimony. I hope you can relay back to the people you deal with in OMB or wherever it is that this message you have brought to us today really is not very well received, because it seems so out of place with the priorities that we hear from people at home as to where they think our federal tax dollars should be spent.

I am a little bit ashamed, if you will, to be engaged in this dialogue, because I am sure that you see the need there and I don't mean to be trying to convince you of the need, because I am sure that you understand it much better than I.

I simply hope that we can get the message back to whoever it is that put together this outlandish set of budget priorities that something is wrong when we have to terminate such a modest program where the needs are so large.

I apologize, Mr. Chairman, for going on at some length, but I do feel very strongly about the need to work in partnership with federal, state and private sectors in addressing this very, very vast problem which is not getting smaller, but rather is getting larger in spite of our efforts. Surely it would be hard to find a better use for a tax dollar than to prevent child abuse and neglect.

I appreciate the patience of the chairman for my comments this morning.

Chairman OWENS. The gentleman's remarks very much need to be placed on the record.

I think it is also in the line of that same comment that it is important to note the fact that mechanisms for funding of these trust funds from one state to another are quite different and in many of them quite uncertain.

Louisiana almost lost its funding for its Challenge Grant Trust Fund. New York has a situation where each year it has to vote on it, and given the fact that there is a budget squeeze this year it is not certain that the funds that have to be appropriated at the state level will be appropriated, or the mechanisms used to collect the money will be allowed only for this purpose.

If you remove the federal incentive, the federal stimulus, as tiny as it is, you are likely to have more difficulty in getting the state shares on a continuous, ongoing basis.

I would like to just clarify one question I asked before. If you don't have the information now, we would like for you to submit it in writing.

Since 1983 you have funded some grants in other programs, in other places within HHS. Grants have been made related to respite care. We would be interested to know what kind of evaluation or reviews have been done on those programs.

I also would like to close with a general question. That is, there has been a 36 percent increase in child abuse and neglect fatalities between 1985 and 1988. Much of this is attributable to the great increase in drug abuse.

With this kind of escalating increase in child fatalities—deaths—does the administration have any kind of response? Is it concerned at all about its role, the federal government's role, in what is an obvious problem?

Ms. **STEWART**. We certainly are very much concerned about child deaths. The actual number of children estimated that we know from the states who died of child abuse last year, I think, was about 1,200 children, which represents a small— but significant in terms of the lives of the children— increase in the past year.

We have been looking at this with researchers in the field and others within the National Center at ways in which we can better understand how to predict the kind of adult behavior that will lead to child deaths. There is really not very much information on this.

We are also looking with researchers and other people from CDC at ways in which we can have better protocols to, in fact, make better determinations, because there is a general feeling that there may be more children who die as a result of abuse but at medical examination their death is determined to be because of the actual physical injury that they suffered.

So there is a lot of work that needs to be done in this area, both in relationship to the responsibilities of the National Center on Child Abuse and others who are very concerned about this whole issue.

Chairman **OWENS**. Thank you. We will submit some additional questions in writing concerning these two very important programs.

We want to thank you for appearing.

Ms. **STEWART**. Thank you.

Chairman **OWENS**. Our next panel consists of Mr. Phillip Strickland, the founder and immediate past Chair of the Texas Children's Trust Fund; and Ms. Deborah Daro, D.S.W., Director of the National Center on Child Abuse and Prevention Research, Chicago, Illinois.

Mr. Strickland, you may begin.

## STATEMENTS OF PHILLIP STRICKLAND, FOUNDER AND IMMEDIATE PAST CHAIR, TEXAS CHILDREN'S TRUST FUND; AND DEBORAH DARO, D.S.W., DIRECTOR, NATIONAL CENTER ON CHILD ABUSE AND PREVENTION RESEARCH.

Mr. **STRICKLAND**. Mr. Chairman, I am delighted that I have the pleasure of having won the lottery on the other side of this issue, for earlier this week I was testifying to a Senate committee in Texas on a highly controversial issue, and it is nice to be before a committee that is obviously very sensitive to this issue, an issue which I think basically should be considered a noncontroversial and certainly a nonpartisan issue.

I am Phil Strickland. I was the first Chair of the Children's Trust Fund of Texas. I was one of the organizers of that Children's Trust Fund.

I have with me Ms. Janie Fields, who is presently the Director of the Children's Trust Fund of Texas, who can help us with any questions that you might have.

I bring to you the perspective of one children's trust fund and a word about what the Challenge Grant money has enabled us to do in that one particular state.

Some of the people who will be before you today will urge you not only to reauthorize the Challenge Grant Program but also to increase the ceiling to $7 million to meet the required 25 percent match.

The recommendation which I want to suggest to you this morning is different from that. It is that the grant be reauthorized and that funding be authorized to $15 million in order to provide a 50/50 match to the eligible state expenditures for trust funds.

I make that suggestion for three reasons, because, number one, these funds deal with one of the most fundamental problems that we are facing in our society today. Second, these funds enable us to have a significant impact on child abuse prevention. Third, these funds provide a huge return on the investment, both economically and in the prevention of pain and suffering by our children.

These funds do, indeed, deal with one of the most fundamental problems that we face in our society. What will life be like, for example, for our children in the year 2000? Do the signs point to children who are growing up happy and content and well cared for and challenged and the product of good education and good parenting?

Will they grow up in a child-oriented society which is concerned about the mental, physical and spiritual health of our children and which is dedicated to producing healthy children?

Or do the signs point elsewhere? Do they point to large numbers of children who live in intense poverty, receive marginal educations and go home to abusive families?

In 1986 by the accounting standards of HHS approximately 1,584,700 children were confirmed by protective services in the various states as being abused or neglected. That, as you know, is the tip of the iceberg.

A large percentage of abuse cases are never reported. If you take just the confirmed cases and project that over the next ten years it will mean nearly 16,000,000 cases of abuse in this country, even without figuring any increase in the rate of abuse That rate, however, has increased from 9.8 children per thousand in 1980 to 16.3 children per thousand in 1986, a 66 percent increase.

The cost is very high. First and foremost, and we can't forget this, it is primarily high in the lives of children who suffer immediate physical pain and often a lifetime of emotional pain as a result of the abuse.

The societal cost of such abuse is also enormously high. According to a recent report prepared by the Texas Department of Mental Health and Mental Retardation and the Texas Department of Human Services, 50 percent of abused children show poor school performance, 50 percent show low self-esteem, 33 percent chronic health problems, 20 percent experience learning disorders, 10 percent become self- destructive.

Sixty-five percent of the inmates in the Texas Department of Corrections were abused as children. Sixty to eighty percent of the adult drug or alcohol abusers in that system were abused and 90 percent of the murderers came from abusive families.

Abuse causes poor school performance and dropouts. Ninety percent of Texas prison inmates are school dropouts. The state also makes a huge investment in simply trying to protect abused children. Funding for child protective services in Texas is currently approximately $90 million a year.

Even with that kind of investment, we are still critically short of case workers and are dealing primarily only with priority one and priority two children in that particular system.

The research is very clear and very clearly substantiates the indisputable connection between child abuse and all kinds of other social problems. The cost of failing to attend to the needs of our children is an enormous cost. The cost of treating our failures in inundating us.

Our prisons are overflowing. Drug crimes engulf us. Our mental hospitals are underequipped to handle the need. Our public health services are taxed beyond their capacities. Child abuse outraces our ability to respond and social services programs reel from overload.

We are investing huge amounts of money to treat our problems. We are investing very little to prevent them.

Second, the funding which you have provided enables us to have a significant impact on child abuse prevention in Texas. Simply put, I suggest to you that we are talking here, not only in Texas but across our nation, about a program that is working.

In Texas most of our funds go into local programs. We are limited to ten percent of our funds for both administration and for broad statewide initiatives. Texas has now received two years of matching funds, $155,000 the first year and $196,000 the second year.

Some of the second year funds have not yet been obligated. In spite of that, the federal challenge funds have enabled us to do the following:

One, to develop a public awareness plan. We have been able to develop a creative strategic plan to accomplish the goals for a public awareness campaign. This campaign includes a public service announcement on the dangers of shaking an infant, which many of you saw as you came in because it was being played on the monitc Ninety of those PSAs have been distributed and will begin to run in Texas in the next couple of weeks.

An eleven-minute slide presentation will soon be available for use by council members and others to increase public awareness regarding child abuse and neglect and what a community can do to help.

Incidentally, we are also currently in negotiation with Boy Scouts in the Houston area, talking to them about the possibility of an interaction with their child abuse prevention efforts, utilizing both the resources of the Children's Trust Fund and the Boy Scouts of America in that area and utilizing specifically the Challenge Grant money to do so.

We have distributed press kits on child abuse all over the state. A sixteen-page definitive brochure on approaches to preventing child abuse and neglect has been prepared for distribution. A child development poster which provides information to parents on child development and immunization schedule as supported by the

American Pediatrics Society has been developed for distribution to parents as they leave the hospital.

The Children's Trust Fund of Texas has also developed a demonstration project utilizing the Community of Caring curriculum developed by the Kennedy Foundation. This is another avenue in which we have sought to leverage, as we speak, the funding which you have provided for us. A child abuse and neglect module for that curriculum was developed and completed by the Kennedy Foundation and the Yale Child Studies Center. Pilot projects are now being done in two cities in Texas. Other pilot projects will soon begin.

We have done professional forums with the funds that you have provided. Two professional forums have been held, bringing together national experts from across the country. The first of these forums looked at the issue of teaching life skills to children. The second looked at personal safety and adolescent parenting programs.

Thirty professionals attended each forum, those professionals from across the country, and the proceedings of those forums are going to be helpful to us in two ways. First, they will provide us and other human services agencies and professionals with research-based evidence on which programs are most effective in preventing child abuse and neglect. Second, these forums are going to help us to establish effective minimum standards for programs which are funded by the Texas Children's Trust Fund.

We have done technical assistance in evaluation and monitoring with the utilization of your federal funds. We have been able to expand our evaluation process.

We are basically doing evaluation currently in three ways. Every program in Texas is internally evaluated. Second, we have a general evaluation of all of the programs Third, we have emphasis-related evaluations being done on groups of programs such as those which deal with hispanic children and those which deal with teenage parents.

The funds have also enabled us to provide broad technical assistance to communities across the state that need help in developing their own child abuse prevention programs, many of which did not receive any actual funding for those programs from the Children's Trust Fund. In other words, we have become in Texas an enormous resource to communities all over the state for how they can, in turn, establish their own child abuse prevention programs.

In a nutshell, you are enabling us to increase enormously the effectiveness of our Children's Trust Fund programs beyond the 32,500 families and the 153,000 children which we served last year.

Incidentally, we also have relied heavily on approximately 52,000 hours a year of volunteer time that is being given through the trust fund programs in the state of Texas.

Your federal Challenge Grant money has also allowed us to do some polling on child discipline attitudes which will give us valuable information regarding how to assist families in understanding effective discipline which does not harm the child.

These funds, Mr. Chairman, provide a huge return on the investment the federal government is making. In light of the impact that child abuse has on our society, I want to suggest to you that $15 million is a minimum investment which the federal government should be making in trying to prevent this massive problem.

I am suggesting that this Congress should put into child abuse prevention in this session approximately the same amount it has budgeted this year for Senate stationery, that we spend as much preventing child abuse as we put into the military budget for the 1990 Goodwill Games, that cleaning up the abuse of our children is worth as much money as we set aside in the EPA budget for cleaning leaking underground storage. This is at least as important as one SH-50 helicopter or one Super Stallion helicopter.

Few investments are ultimately more important in this country than investing in the lives of our children. Few investments in the lives of our children are paying higher ultimate dividends than investments in child abuse related programs through the Children's Trust Funds across this nation.

I urge you not only to reauthorize the Child Abuse Prevention Federal Challenge Grants Act and to do as the initial legislation suggested to maintain these programs, but to consider doubling the match level to 50 percent and to funding it accordingly.

[The prepared statement of Philip Strickland follows:]

# TESTIMONY REGARDING REAUTHORIZATION OF THE CHILD ABUSE PREVENTION FEDERAL CHALLENGE GRANTS ACT -- PL98-473

before the House Subcommittee on Select Education

Thursday, April 6, 1989

Phil Strickland

I appreciate the opportunity to testify before you today regarding the reauthorization of challenge grants for Children's Trust Funds. I am Phil Strickland, director of the Texas Baptist Christian Life Commission. I was also the first chair of the Children's Trust Fund of Texas, and I also chair a broad coalition of approximately 50 organizations in Texas known as the CARE Coalition, which addresses child abuse prevention and treatment issues. I bring to you the perspective of one Children's Trust Fund and a word about what the challenge grant money has enabled us to do in one particular state. You will have other witnesses today who will be able to bring to you a more generic view of the impact of the federal challenge grants on trust funds in general.

Some who will come before you today will urge you not only to reauthorize the challenge grant program, but also to increase the ceiling to $7 million to meet the required 25 percent match. The recommendation which I am going to suggest to you is different: It is that the grant be reauthorized and that funding be increased to approximately $15 million in order to provide a 50-50 match to the eligible state expenditures for trust funds. I make that suggestion because 1) these funds deal with one of the most fundamental problems that we are facing in our society 2) these funds enable us to have a significant impact on child abuse prevention and 3) these funds provide a huge return on the investment, both economically and in the prevention of pain and suffering by our children.

1. These funds deal with one of the most fundamental problems that we face in our society. What will life be for our children in the years to come? Do the signs point to children who are growing up happy, content, well cared for, challenged, the products of good education and good parenting? Will they grow up in a child-oriented society which is concerned about the mental, physical and spiritual health of our children and which is dedicated to produce healthy children?

   Or do the signs point elsewhere? Do they point to large numbers of children who live in intense poverty, receive marginal education and go home to abusive families?

   In 1986, by the accounting standards of HHS, approximately 1,584,700 children were confirmed by protective services in the various states as being abused or neglected. That, in turn, is the tip of the iceberg.

A large percentage of abuse cases are never reported. If you just take the confirmed cases and project that over the next ten years, it will mean nearly 16 million cases of abuse in this country, even without figuring any increase in the rate of abuse. That rate, however, has increased from 9.8 children per thousand in 1980 to 16.3 children per thousand in 1986, a 66 percent increase.

The cost is high. First and foremost, it is high in the lives of children who suffer immediate physical pain and often a lifetime of emotional pain as a result of the abuse. But the social cost of such abuse is also enormously high. According to a recent report by the Texas Department of Mental Health and Mental Retardation and the Texas Department of Human Services,

-- 50 percent of abused children show poor school performance

-- 50 percent show low self-esteem

-- 33 percent experience chronic health problems

-- 20 percent experience learning disorders

-- 10 percent become self-destructive

Sixty-five percent of the inmates in the Texas Department of Corrections were abused as children. Sixty to eighty percent of the adult drug or alcohol abusers were abused, and ninety percent of the murderers come from abusive families. Abuse causes poor school performance and dropouts. Ninety percent of Texas prison inmates are school dropouts (Children; Choices and Changes, Hogg Foundation for Mental Health, Austin, Texas, 1988, page 70).

Recent studies of the patients who are in psychiatric hospitals or psychiatric clinics and community health centers indicate that nearly one-half give histories of varying degrees of neglect or abuse in their early lives.

The state also makes a huge investment in simply trying to protect abused children. Funding for child protective services in Texas is currently approximately $90 million per year. Even with that investment, we are still critically short of caseworkers.

One needs only read the 1987 Massachusetts Committee for Children and Youth Report Preventing Child Abuse: A Resource for Policymakers and Advocates, to find the research which clearly substantiates the indisputable connection between child abuse and a myriad of other social problems. The cost of failing to attend to the needs of our children is enormous. The cost of treating our failures is inundating us. Our prisons are overflowing, drug crimes engulf us, our mental hospitals are underequipped to handle the need, our public health services are taxed beyond their capacities, child abuse outraces our ability to respond, and social services programs reel from overload.

We are investing huge amounts of money to treat our problems. We are investing little to prevent them.

2. The funding which you have provided enables us to have a significant impact on child abuse prevention in Texas. Simply put, we are talking here about a program that works. In Texas, the legislature has developed such confidence in this program that it is now looking for other ways to provide additional funds to the program. Children's Trust Fund programs are working.

   In Texas, most of our funds have to go into local programs. We are limited to ten percent of our funds for both administration and for broad, statewide initiatives. Texas has now received two years of matching funds, $155,000 the first year and $196,000 the second year. Some of the second-year funds have not yet been obligated. In spite of that, the federal challenge funds have enabled us to do the following:

1) Develop a public awareness plan. We have been able to develop a creative, strategic plan to accomplish the goals of a public awareness campaign. This campaign includes a public service announcement on the dangers of shaking an infant. How many of you were aware that shaking a very young infant can cause serious physical harm? Ninety PSAs have been distributed and will begin to run in Texas in the next couple of weeks.

An eleven-minute slide presentation will soon be available for use by Council members and others to increase public awareness regarding child abuse and neglect and what a community can do to help.

Five hundred press kits have been distributed.

A 16-page definitive brochure on approaches to preventing child abuse and neglect has been prepared for distribution over the state.

A child development poster which provides information to parents on child development and an immunization schedule as supported by the American Pediatrics Society has been developed for distribution to parents as they leave the hospital.

2) Adolescent parenting. The Children's Trust Fund of Texas has developed a demonstration project utilizing the Community of Caring curriculum developed by the Kennedy Foundation. A child abuse and neglect module for that curriculum was developed and completed by the Kennedy Foundation and the Yale Child Studies Center. Pilot projects are now being done in two cities in Texas. Other pilot projects will soon begin.

3) Professional forums have been conducted with these funds. Two professional forums have been held bringing together national experts from across the country. The first of these forums looked at the issue of teaching life skills to children, the second looked at personal safety and adolescent parenting programs. Thirty professionals attended each forum, and the proceedings of those forums will be published. The forums will be helpful in two ways. First, they will provide the Children's Trust Fund and other human services agencies and professionals with research-based evidence on which programs are most effective in preventing child abuse and neglect. Second, they will enable us to establish

effective minimum standards for programs funded by the Children's Trust Fund.

4) Technical assistance, evaluation and monitoring have also been enhanced by the utilization of these funds. We have been able to expand our evaluation process, with general evaluations being done of all CTF programs and specific evaluations being done of groups of programs such as those which deal with Hispanic children and those which deal with teenage parents. The funds have also enabled us to provide technical assistance in communities across the state that need help in developing their own child abuse prevention programs, many if not most of which receive no actual funding from the Children's Trust Fund. In other words, you are enabling us to increase enormously the effectiveness of our Children's Trust Fund programs beyond the 32,482 families and the 153,313 children which we served last year. The child abuse expertise of the Children's Trust Fund is being shared with numerous groups across the state which, in turn, are implementing their own prevention programs.

5) Polling on child discipline attitudes is also being done utilizing the challenge grant funds. This polling will give us valuable information regarding how to assist families in understanding effective discipline which does

not harm the child.

3. These funds provide a huge return on investment, both economically and in the prevention of pain and suffering for our children.

In light of the impact that child abuse has on our society, I suggest that $15 million is a minumum investment the federal government should be making in trying to prevent this massive problem. I am suggesting that this Congress put into child abuse prevention in this session approximately the same amount it has budgeted this year for Senate stationery; that we spend as much preventing child abuse as we put into the military budget for the 1990 Good Will Games; that cleaning up the abuse of our children is worth as much money as we set aside in the EPA budget for cleaning leaking underground storage. This is at least as important as one SH-60 helicopter for the Navy or one "Super Stallion" helicopter for the Marines.

Few investments are ultimately more important in this country than investing in the lives of our children. Few investments in the lives of our children are paying higher ultimate dividends than investments in child abuse related programs through the Children's Trust Funds across this nation. I urge you not only to reauthorize the Child Abuse Prevention Federal Challenge Grants Act but to consider doubling the match level to 50 percent and funding it accordingly.

Chairman OWENS. Thank you. Ms. Daro?

Ms. DARO. Thank you very much. I want to thank the committee for holding this hearing and for giving me an opportunity to address them this morning.

I found the comments made this morning already very refreshing. You are all excellent advocates for prevention. I think it is encouraging that I can sit in the audience and I don't know party affiliation without a score card. It says to me that children are becoming a real unifying force in Congress and I am excited about that.

For the past two years it has been my privilege to really work with the Trust Funds and I have come to respect both the staff of the Trust Funds for their unique and very important focus on prevention as well as the role each of those funds play in developing strong prevention networks within their state.

I want to talk briefly this morning about three things. I want to talk about the growth of these funds and what it has meant for the kinds of prevention programs that are now available in communities around this country. I want to talk about the federal Challenge Grants and what it has really meant in furthering the goal of prevention, and finally the importance of sustaining a federal role at this time.

As you know, since 1980 funds have been established in forty-seven states. Twenty-eight of these states have passed it in the last five years. Approximately $21 million was spent last year to support 1,200 programs around the country. They represent the continuum of prevention services, and that is very important to keep in mind.

There is no one prevention program out there. There is no one program that is going to solve the problem of child abuse. What we need is a great deal of diversity and a great deal of flexibility as we look to each community and decide what exactly would you need in your area to prevent child abuse.

The Trust Funds allow that kind of diversity to happen and to grow. In addition to expanding that program diversity, the Trust Funds have also contributed significantly to our knowledge base about what works with prevention.

Prevention is hard to prove. It is probably one of the most difficult issues we face and I face as a researcher. One of the things that is encouraging about the Trust Funds is that it really gives us a natural experiment, if you will. Those 1,200 programs are out there and the Trust Fund administrators want to know what is the most effective program with what kinds of people.

It moves us further. It helps our planning process. We are not just shooting in the dark, if you will, but we are building on some credible evidence about what kinds of programs work best with what kinds of families.

Second, there are questions about how the Challenge Grant money has been used. Some have said, well, are we just putting it into a big pot of money and is it getting absorbed with all the other state efforts?

I think there are at least two unique ways in which these Challenge Grants have furthered the Trust Fund growth and development.

About 50 percent of the states, as we look at how they spend the Challenge Grant monies, do in fact use that money to augment their existing direct service application program. In other words, they are able to provide more services to more people along the lines they had hoped to be able to do that.

It is important to keep that in mind because so many of the funds just simply don't have the resources to fund all of the needs they are able to identify, so the federal Challenge Grants are really making services available to more people than would otherwise be possible.

Second, the other 50 percent of the funds have really pushed beyond their initial parameters. You have given the funds an opportunity to grow in a unique way, a way that simply wouldn't be possible if there wasn't a federal presence.

Some states have used the money to develop new service initiatives, to try to move in an area where their state maybe hadn't been as comfortable moving in before there was federal money available.

Others have been able to develop greater public awareness efforts simply to let members of their state and members of the community know more about the Trust Funds as well as about prevention in general, and finally, as Phil was saying, in the state of Texas, to really further the advancement of the field, to hold forums, to begin to push our knowledge further along than we had been able to to date.

For me, most importantly, the federal challenge grant money has been used to really enhance management and efficiency in the operations of the Trust Funds. Again, as Texas and many other states have, they have strong ceilings on what can be used for administrative costs. That means that there is not as much money for monitoring, for tracking, for training providers as the state might ideally like.

The fact that the federal money is there means that these are the best programs possible that are being delivered for prevention today. I think that bodes well. When states have looked at how many of their programs are still around after they are no longer able to fund them, they find retention rates of 80 to 85 percent of these programs.

As someone who has evaluated federal demonstration programs for most of my professional life, I can tell you that that kind of retention rate doesn't exist in a program that is simply funded and supported with federal funds. When a program is invested at the local level and the state level, those programs are around for years to come.

So you have done such a good job that some people are saying, well, maybe you don't need to do anything more. Well, clearly I disagree with that, and I think from what I have heard this morning you all disagree with it also.

I would like to point out three reasons why I think the federal Challenge Grant should be continued, and I would underscore Phil's suggestion that they be expanded.

First, the Trust Funds, while growing—the resources available for expansion are still woefully inadequate. The funds report to us that they are able to fund no more than 50 percent of the applications that they receive. In some states that funding rate is as low as eight percent.

It is not that these are bad programs. It is simply that they don't have the resources available to support the innovative ideas that people in the field are coming to them with. Filling this unmet need, I think, requires both state initiatives as well as federal initiatives.

Second, I think the Challenge Grant model, to my mind, the way one would want the federal government to work. Child abuse is a local issue. The particulars of how to prevent child abuse most certainly need to be designed at the local level, but providing leadership and resources to see that states move in that direction is clearly a federal responsibility.

For a very small investment the federal government is able to see growth in an area that I think everyone would agree is most necessary.

The Challenge Grants offer more than financial independence. They tell people, public corporations, state legislatures simply that it is important to focus on prevention. It is important to offer these services. It models a leverage of funding, if you will, that many of the Trust Funds have taken to heart and do in their own communities.

There are partnerships between Trust Funds and educational institutions, Trust Funds and health care providers, between Trust Funds and corporations. That kind of modeling is exactly the sort of thing we like to see happen and continue.

I think ending the federal support at this point would endanger that kind of leveraging from continuing and would be particularly hard felt among the Trust Funds that are new and have relatively few resources.

Finally, the Challenge Grants help states sustain a focus on prevention and that is most unique. As many of the members talked about this morning, the state of child welfare is a sad state today. Child abuse reports are up. Child abuse fatalities are up five percent—thirty-six percent since 1985.

We are extraordinarily concerned about that. The demands of current victims will always tug at our heart strings. It is very hard to turn your back on an abused child, an abandoned child, but if we are going to make effective progress we really need to begin to look to prevention, and that is where the Challenge Grants really do send a message, that prevention is important. It says to the field that if we are not doing prevention we are missing the boat in a very important way. Elimination of the Challenge Program or a reduction in its scope might well convey a message to local and state legislators that prevention is no longer a credible to confront child abuse.

Forty-five percent of the resources the Trust Funds have come from state appropriations, so although the private sector is certainly doing its role, we need state legislatures to continue to vote for the message of prevention.

If we were to take a position of eliminating the Challenge Grants, we might well endanger our capacity to make any significant headway in reducing child abuse and neglect in the coming decade.

In many respects child abuse follows the pattern of a disease. If left unattended, even minor disorders can mushroom into serious disorders with serious, sometimes fatal, consequences.

Certainly prevention is difficult. I have talked about the difficulty of measuring prevention. It is almost difficult, as some would say, to do good—the limits of benevolence, as one author once wrote.

Despite these very real problems, the course is one that must be pursued by both the state and federal levels. Intervening after a child has suffered is simply too late for that child, for that child's family or for a society that cares about its future.

Thank you.

[The prepared statement of Deborah Daro follows:]

Written Testimony Prepared by
Deborah Daro DSW
Director, National Center on Child Abuse
Prevention Research
for the U.S. House of Representatives
Committee on Education and Labor
Subcommittee on Select Education
Thursday, April 6, 1989

## Children's Trust and Prevention Funds: The Importance of Sustaining Federal Incentives

### OVERVIEW

The Children's Trust and Prevention Funds are state level governmental organizations which establish permanent funding mechanisms for child abuse prevention programs at a community level. Formed by state legislation, these funds create an opportunity for local communities to assume responsibility for the prevention of child abuse by providing needed expertise and funding. In many states, these funds represent a significant source of funding for those programs providing primary and secondary prevention services.

Since 1986, these state initiatives also have been supported through the Child Abuse Prevention Federal Challenge Grant (PL 98-473) which provides for up to a 25% match for the prevention monies collected by the state. The purpose of this funding, as stipulated in the legislation, is "to encourage states to establish and maintain trust funds or other funding mechanisms including appropriations to support child abuse and neglect prevention activities." Over the past three years, the Federal Challenge Grants have served this purpose as demonstrated by the growth and expansion of trust and prevention funds nationwide.

The purpose of this written testimony is to provide an overview of this developmental process, to highlight the current scope and activities of these funds, and to outline the contribution trust and prevention funds offer the broader field of child abuse prevention research. The final section addresses the major challenges the trust funds face in the coming decade and the need for continued Federal leadership in this area.

## BACKGROUND AND STRUCTURE

The idea of a Children's Trust Fund was conceived in the late 1970's by Dr. Ray Helfer, a pediatrician nationally recognized in the field of child abuse. Dr. Helfer designed the funds as a way of securing support for prevention efforts in an era of diminishing governmental budgets and increased scrutiny of public responsibilities. Since 1980, advocates for child abuse pr ention have established trust and prevention funds in 47 states. Twenty-eight of these funds have been enacted in the past five years (e.g. 1984 - 1988).[1]

The majority of Children's Trust and Prevention Funds incorporate innovative funding models utilizing a variety of public and private sources. The most common public sources include appropriations, state income tax check-offs, increased fees on marriage licenses, birth certificate surcharges, increased cost of divorce filings, increased fees on death certificates, and the opportunity to design and develop heirloom birth certificates for sale. In addition to these mechanisms,

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over one-third of the funds receive direct donations from private sources.

The governing boards of the trust and prevention funds are intended to create public-private partnerships within the states they serve. Board members generally include representatives from those governmental agencies working to prevent child abuse and neglect such as education, social services, mental health, law enforcement, and criminal justice. In addition, private citizens are appointed by the governor and legislative leadership of the state. The responsibilities of the boards vary from state to state, including either or both advisory or administrative duties.

In addition to supporting the expansion of local child abuse prevention service systems, the funds have created new opportunities for applied research. Formal program evaluations are requested from the grantees by the majority of fund administrators. At present, over three-quarters of the fully funded and operating trust and prevention funds are actively engaged in program evaluation activities. In some instances, the findings from these efforts are used to guide future funding decisions or to identify specific areas which programs need to strengthen in order to enhance outcomes. Beyond this immediate use, these evaluative efforts offer a critical resource to the broader child abuse prevention community. By documenting the utility and limitations of multiple prevention strategies, the trust and prevention funds offer the field a much needed experimental laboratory for highlighting successful client level strategies as well as modeling potential systemic changes.

## CURRENT FUNDING LEVELS AND ACTIVITIES

For the past two years, the National Committee for Prevention of Child Abuse (NCPCA) has facilitated communication among trust and prevention fund administrators through annual surveys of their efforts and ongoing conference calls. The most recent survey was conducted in September, 1988. All trust and prevention fund administrators were sent a mail questionnaire soliciting information regarding their fund's structure, revenue sources, size and expenditure patterns. Follow-up telephone contacts with all respondents were made to maximize the response rate.

At the time of the 1988 survey, four of the 46 authorized funds had not yet raised revenues and an additional three had not yet distributed any resources.[2] Forty-two of the state administrators surveyed provided the majority of the revenue and expenditure information requested. However, only a small number of administrators (12) were able to consistently document the number of service units provided or the number of individuals served as a result of fund activities.

Collectively, the Children's Trust and Prevention Funds raised over $27 million in FY 1988 through a variety of funding mechanisms. This figure represents a 17% increase over the documented FY 1987 revenue levels and is significantly larger than the 3% increase in reports of child abuse noted during the same period.[3] Almost 45% of these prevention dollars are generated through direct appropriations from state legislatures; 20% of the dollars are generated by surcharges on existing filing fees such as birth certificates and marriage licenses; and 15% of the dollars are generated through income tax check-off systems. The balance of funding (21%) is obtained through other sources such as private donations or interest income. Of the 42 states covered in the survey, only 14 utilize a single funding source, most commonly direct appropriations or an income tax check off. The majority of the funds rely upon multiple funding sources, a strategy viewed as offering greater opportunity for expanded revenues and for insuring that the viability of the fund is not threatened through a sudden disruption in a given revenue source.

A total of 39 trust fund administrators provided detailed expenditure data. Based on these data, over $21 million was allocated in FY 1988 to support more than 1,200 programs, over 20% more programs than were funded the previous year. The distribution of these programs by prevention service category is as follows:

- 28% are parenting education programs, over 40% of which directly target teens.
- 21% are life skills training for children and young adults, three-quarters of which provide child assault prevention instructions to children and one-quarter of which provide interpersonal skills training or pre-parenting training for teens.

- 12% are support programs for new parents.
- 8% are public information and educational programs
- 8% are services for abused and neglected children.
- 7% are self-help groups and other neighborhood support programs.
- 4% are crisis intervention services including telephone hot lines, respite care programs, and crisis counseling.
- 4% are public awareness campaigns, including the development of public service announcements.
- 8% are other types of prevention services including day care, program evaluation, and community development efforts.

In addition to state funds, the Federal Challenge Grants distributed almost $4.8 million to 43 states in 1988, a slight decline from the 1987 distribution levels. These grants ranged from a high of over $956,000 to California to a low of less than $5,000 to West Virginia. Approximately 50% of the states receiving these funds have used these resources to augment their existing direct service grants program. In these cases, federal funds have allowed states to provide more services in a greater number of communities than would have been possible with merely state-raised revenues. The remaining recipients utilized the federal funding to establish new direct service initiatives, to enhance their public awareness efforts, or to improve their planning and management activities. Specifically, Federal

Challenge Grant monies have been used to support the production of public service announcements; the development and dissemination of parenting materials; the conduct of special interest forums to explore new prevention options; and the establishment of state-wide child abuse prevention networks. Many trust fund administrators also have relied upon federal support to provide the necessary resources for monitoring and facilitating the exchange of information among their grantees and for conducting comprehensive program evaluations. This approach has been particularly critical in states which place strict ceilings on the percentage of funding which may be used for administrative purposes. In short, federal support has allowed local funds not only to expand their direct service opportunities but also to explore innovative program and management opportunities.

## CONTRIBUTIONS TO THE BROADER RESEARCH COMMUNITY

Child abuse trust and prevention funds offer each community in this country a tangible revenue source for expanding primary and secondary prevention efforts. Beyond this critical local function, however, the funds serve as an excellent resource for the broader research community. In addition to expanding services, the funds offer a unique opportunity to contribute to our collective wisdom on how best to prevent child abuse.

Since their initiation, the trust and prevention funds have incorporated research and evaluation efforts into their ongoing operations. The primary users of these efforts include state planning units, city or county level planning units, prevention service providers, and the general child abuse prevention field. Each of these users have different informational needs. State and local service planners are in the business of allocating scare resources among competing users. For them, the critical question is what program models offer the best opportunity to prevent child maltreatment. The choices may be among programs targeting the same client population or service objectives, such as group-based versus home visitor parenting programs, or among programs traveling very different prevention paths, such as parenting programs versus child assault prevention instructions. To assist planners in making these choices, evaluative data is most useful when it assesses program performance in terms of a common set of outcome measures.

In contrast, providers are more interested in knowing that their efforts are successful and that the procedures they are following adhere to prevailing notions of "best practice." The outcome variables identified in studies designed for specific service providers reflect the attitudes or behaviors a given program has targeted for change. Such evaluations are generally less concerned with comparing a program's performance in terms of the success achieved by other types of programs. These evaluative efforts also place special emphasis on documenting the service delivery process in order to determine the extent to which an individual client's experiences parallel what providers believe to be the most effective method for engaging and working with at risk families.

Finally, the broader child abuse prevention field has need for a wide range of programmatic and evaluative information. Like local and state program planners, the prevention community is eager to learn which programs significantly reduce the level of risk for abuse or neglect. Of particular importance is the identification of programs which can easily be replicated across the country. Programs which are successful but which are linked to a unique set of qualifying conditions are of less utility to the prevention field than they are to the specific communities in which they operate.

Beyond these program specific issues, the trust and prevention funds can contribute to the field's collective knowledge in at least three additional ways. First, these efforts can identify evaluation strategies which effectively utilize various administrative data sources. In determining immediate and longer term impacts of prevention services, client progress can be monitored not only through direct follow-up assessments with families but also by tracking clients through existing data sources maintained by state and local health, education and welfare departments. Because each trust and prevention fund is located within their state's bureaucracy, fund administrators generally have better access to these data than programs located outside this structure. Second, the trust and prevention funds can encourage their grantees to test the appropriateness of a wide range of standardized assessment tools for child abuse prevention programs. In those cases where accurate measures of program outcomes are not available, the funds offer the research community an opportunity to work with practitioners in developing useful and reliable alternatives Finally, trust and prevention funds which operate an active evaluation component can demonstrate for the field how evaluative data can be effectively integrated into prevention program planning. Such data can be used in determining future funding priorities or program guidelines as well as in guiding the replication of promising strategies throughout a state.

The identification of promising prevention strategies, the development of more appropriate assessment measures, and the identification of key factors to consider when replicating a program are among the contributions research funded by the trust and prevention funds offer the field in general. Further, this research can serve as a catalyst in identifying changes within broader welfare, health, and educational systems such that these institutional forces strengthen their contribution to the overall child abuse prevention service continuum.

Accomplishing this research mission under current fiscal constraints is a major challenge. Two factors are key to the ability of funds to meet this challenge: 1) determining clear, measurable objectives which will govern all funding decisions; and 2) enhancing the capacity of individual grantees to assess their performance. While contracting with research or program evaluation specialists will offer most states much needed access to expert input into the evaluation process, continued reliance on these experts will significantly reduce the funds available for direct services. Such experts are best used on a transitional basis for the development of new assessment measures and more complex, multi-program evaluation designs. Ideally maintenance of these systems should gradually be transferred to the trust and prevention fund staff. Success lies not in the development of separate program and research agendas but rather in the integration of these two fields such that each is regularly informed and shaped by the other. The Children's Trust and Prevention Funds offer an excellent opportunity to realize this objective, particularly if present federal assistance and leadership in this area continues.

## FUTURE CHALLENGES

As the trust and prevention fund administrators face the coming decade, they must overcome at least three challenges in sustaining th growth and singular commitment to prevention. First, resources, while growing, remain woefully inadequate in most states. Each year, trust and prevention fund administrators are unable to support thousands of qualified programs in their respective states due to a lack of adequate resources. States are generally able to fund no more than 50% of the requests they receive. In some states, this figure is as low as 8%. Filling these unmet service needs will require not only expanded local initiatives but also sustained federal support. Because the average trust and prevention fund grant is less than $25,000, even small revenue increases can have notable impacts on available service levels.

Second, responsibility for raising the revenues necessary for effective child abuse prevention cannot lie solely with the trust and prevention funds. Child abuse prevention is a tall order and one which will require a diversified public and private revenue source. Following the model of incentive funding implicit in the federal challenge grants, local trust and prevention funds have expanded their influence by using their limited funds to leverage additional revenues from local health and education agencies as well as corporate leaders. Trust funds have been successful in securing a greater emphasis on prevention from local hospital administrators, school superintendents, and public health care providers. Further, corporate support has played a key role in establishing effective public-private partnerships in a number of states. Continuation of the challenge grants serves as a vital role model for states to follow in identifying creative revenue enhancement measures.

Finally, sustaining a unique focus on prevention in light of a growing number of serious child abuse cases is problematic. All things being equal, the practical and emotional demands of present victims will always exceed the more amorphous but more rational appeal of prevention. Child welfare agencies in this country face increasing number of reports with fixed or declining revenues. Nationwide, more than 2.2 million child abuse reports were filed in 1988, a figure which translates into over 250 reports every hour. For the past three years, over three children a day have been identified as fatal victims of maltreatment. Unfortunately, increasing reports and child fatalities have not resulted in increased revenues for child protective services. In 1988, only 12 states received increases in their child welfare budgets and the majority of these funds merely provided for cost of living increases. Such stable or declining revenues have meant fewer workers, larger caseloads and fewer services for the victims of maltreatment.[4]

While the opportunities for success and cost savings are significantly greater through prevention than treatment avenues, the painful realities of having too few services for present victims endangers the ability of trust funds to continue their emphasis on prevention.[5] It is in this respect that the federal challenge grant program offers its most significant contribution. Over and above the dollars provided to the states, the challenge grant legislation signals clear support for prevention among our nation's leadership. Elimination of this program or a reduction in its scope might well convey the message to local and state legislators that prevention is no longer a credible way to confront the child abuse problem. Unfortunately, such a position would endanger our capacity to make any significant headway in reducing child abuse and neglect rates. In many respects, child abuse follows a developmental pattern not unlike that of a disease. Left untreated even minor symptoms and discomfort can mushroom into serious, even fatal disorders. Child abuse will not be reduced by defining away its existence. It will be effectively reduced only through a system of early interventions which help parents before they develop abusive and neglectful behaviors. Certainly prevention has its difficulties -- the potential stigma associated with being classified as "at risk", the difficulty in measuring impacts, and the general difficulty of doing good or the limits of benevolence. Despite these very real problems, the course is one which must be pursued at both the state and federal levels. Intervening after a child has suffered is simply too late for the child, for the family and for a society which values its future.

## References

1. The three states which have not yet passed Children's Trust or Prevention Funds are Colorado, Mississippi and Wyoming.

2. Those states which had yet to fully implement their trust funds by 1988 included Alaska, Arkansas, Georgia, Hawaii, Maryland, Massachusetts, and New Hampshire. Pennsylvania, the 47th state to pass a prevention fund, did so in 1989.

3. Daro, D. and Mitchel, L. (1989). Child Abuse Fatalities Continue to Increase: The Results of the 1988 Annual Fifty State Survey. Chicago, IL.: National Committee for Prevention of Child Abuse.

4. Daro and Mitchel (1989).

5. For a discussion on the specific merits of prevention see Daro, D. (1988). Confronting Child Abuse. New York: Free Press.

Chairman OWENS. Thank you both.

Mr. Strickland, I understand you have a plane to catch, so why don't I just ask you a couple of questions first.

We have the odd phenomenon here that an investment has been made that is paying great dividends, and so they want to withdraw the investment. People don't behave that way anywhere else except in this administration.

You have a very successful program and I congratulate you on your enthusiasm and thoroughness in your presentation, but certainly your enthusiasm, I'm sure, went into the program and is part of the reason you have such a successful program in Texas.

What would be the damage if the federal contribution was withdrawn?

Mr. STRICKLAND. Immediately, $250,000 in the practical sense, which translates into many of the things that I have been talking to you about.

If this federal program were withdrawn, you would see the public awareness program basically scratched. We would not do a statewide public awareness program. You would see the evaluation process of the programs and that which we are learning from the evaluation process drastically cut back. You would see the research forums eliminated. You would see the technical assistance that is going to communities all over the state of Texas right now basically eliminated because the funding is not there for any of those programs under the state dollars.

I think there is another effect, though, and that is perhaps rather than just those very specific practical things. That is that you would be sending a very significant message from the federal governments to the state governments that we do not think this really is a priority.

We are having to hang in there to continue in a time of tight dollars even in the state of Texas—particularly in the state of Texas. We are having a continual battle, as most states are having, to see that these programs continue to be well funded.

We don't need the message coming from the federal government to the states that we no longer consider this to be a real priority. This is best going to be done as a federal, state and local kind of partnership, a partnership which this administration and the previous administration have talked about at great length.

I agree with Deborah that this may be one of the outstanding examples of that partnership working, where we have a tremendous number of match dollars, both in-kind dollars and actual real dollars, being invested at the local level and then you have the investment of the state with the federal government.

Your state funding is still fragile It needs to be backed up and underwritten in a sense by the federal government saying this is indeed a priority.

Chairman OWENS. You mentioned several times evaluation, that you have an internal evaluation of each program, et cetera.

Could you expand on that a bit? For the benefit of other programs as well, what approaches are there that can help us to prove the cost effectiveness of the program?

Mr. STRICKLAND. Child abuse prevention is a new science, first of all. We are still learning a lot We don't want to be out there spending dollars, particularly very limited dollars, because we are talking about very limited dollars, on things that don't work.

So we have felt in Texas, and I think that is the feeling shared by many of the other Trust Funds, that one of the priorities is a kind of consistent flow of evaluation to determine as clearly as we possibly can what programs are most effective in ultimately accomplishing what we are trying to accomplish, and that is some children that are not being abused that would have otherwise been abused.

In Texas there basically are three levels of evaluation. First of all, when programs submit an RFP or respond to the Request for Proposals, they are asked to include in their proposal a program of evaluation, a procedure for evaluation, of their own program. That is one of the primary grading ingredients when we grade the particular proposals that are made. We look at what kind of evaluation process they are setting up.

Second, we have done an outside evaluation of all of the programs of the Children's Trust Fund, a kind of generic overall evaluation, program by program, to see which ones of them seem to be functioning well and seem not to be functioning well.

Thirdly, as I mentioned, there is evaluation grouped around basically emphasis areas such as—we have looked at the programs that deal with antivictimization, to see which of these programs, which of these antivictimization programs, seem to be getting the best results. Programs dealing with hispanic children, programs dealing with teenage parents--we are trying to look at them by subject matter, as well.

All of that is apart from the regular reporting procedure and the kind of built-in technical evaluation that goes on as to whether or not they are actually living up to the contract.

Chairman **Owens**. Thank you very much. If you have more time, you might want to participate in answering the next two questions I have for Ms. Daro, which do relate to the same point of evaluation and justification and cost effectiveness.

You say in your testimony that the painful realities of having too few services for present victims endangers the ability of Trust Funds to continue their emphasis on prevention. You also said, I think, somewhere else that one of the hardest jobs in research is to show the value of prevention.

Could you elaborate on that? Are we likely to have any better scientific approach to that in the future, where we can show the ratio of prevention to cases that didn't occur, or something that we can go to the legislators and decision-makers with?

Ms. **Daro**. Okay, I've got you. The first part is the tension between where resources are allocated.

I think our major concern there is because so many of the Trust Funds rely on state appropriations and the state is then drawing that money from a single pot as child welfare demands increase, and we suspect they will increase in coming years. State legislatures are going to find themselves between a rock and a hard place.

Do we give money to current victims or do we continue to fund the Trust Funds in the hopes of doing prevention?

The political realities often of having increasing child deaths, increasing births of cocaine-addicted children in hospitals, hospitals closing and the like, really do force, I think, state legislators to look toward the most immediate problem, rather than being able to have the luxury of foresight, of preventing something down the line.

With respect to monitoring and documenting prevention effectiveness, I think we are very good at this stage in being able to show that certain services produce both measurable cost savings and measurable changes in parenting functioning.

It is a little more difficult to be able to say specifically that these programs reduce child abuse in the future. There have been some experimental designs. The best study to date was done by David Olds in Rochester, New York, which I am sure you are aware of, where he found that providing a home-based home nurse visiter program reduced child abuse rates. His families that received these services had a four percent rate of child abuse and families that didn't receive these services had a nineteen percent rate of child abuse, so there are dramatic differences in child abuse in the future.

The cost savings when people have followed families that have received early interventions over time really show up in several areas. Certainly, it is the welfare caseloads. These are families that are just simply more self-sufficient, so there are fewer dollars needed for welfare.

They are also families that are healthier. Women that get prenatal care and begin worrying about their children while they are pregnant rather than at the point of birth have healthier babies, so the hospitalization costs are less. There are less low-birth-weight babies. So we see it in medical costs, in welfare costs. Then as the child matures we see it in reduced remedial services costs in education.

So the cost savings are really throughout all systems In terms of short-term outcomes for parents that receive early intervention, we see greater knowledge about child development, greater knowledge about different parenting practices, less reliance on the use of corporal punishment and physical punishment as a means of disciplining a child, greater sense of self esteem on the part of parents, and for teen parents, I think most importantly, we see a reduction in that repeat pregnancy rate.

Anyone who has ever said that having two children is as easy as one clearly never had two children. When you are sixteen years old and you have one baby, when you are seventeen you don't need another. By working with these girls early on, what we are able to do is get them off to the right track. They finish school. They don't have that second baby. They are in the labor force by the time they are eighteen and nineteen years old and not on welfare.

I think those savings make a very powerful case for focusing on specifically the area of new parent services.

Chairman **Owens**. So as a result of your work at the National Center, since you have a different perspective, a broader perspective, you have some idea of what would be done with additional money.

If we doubled the amount of money, do we have some models and some approaches now which we could offer state to state which are working to use the additional money swiftly and most effectively?

Ms. DARO. I think so. The National Committee has been working with the Trust Funds The Trust Funds themselves have developed a real partnership among themselves. I think Janie could talk about how the executive directors of these funds meet regularly, they talk regularly, they are constantly trying to further each other's missions

So a good idea in Texas is now available to the other forty-six states that, in fact, have Trust Funds. People are waiting to operate, to move on those good ideas, with additional funding.

So the idea of holding forums to enhance our knowledge base about what would be the most effective way to prevent child abuse, systems of setting up community-based councils to address child abuse, to really galvanize in each local community those key actors that can really make a difference in preventing child abuse, those are going on in some states but not all states have local councils. I think all states would if the funding were available.

Home visitor programs for high-risk parents—there is a wonderful demonstration program going on now in Michigan where they are carefully evaluating, again, the results of working with women who are at risk of potentially abusing their children either due to their age or to a prior history of substance abuse, let's say.

As those programs become better documented and the Trust Funds share among themselves, I think we would see that kind of exchange were the resources there.

Chairman OWENS. A question to either one of you—to what degree can the mass media be utilized in these kinds of efforts, and in order to do that is there a need also for some kind of national mechanism to participate on a greater level to provide the kind of funding and coordination to develop items that can go on public service television and radio, et cetera?

Mr. STRICKLAND A couple of responses. We have looked at, in the process of creating a public awareness program in the state of Texas, a number of public awareness programs around the country that have been designed to try to create a mind-set on the part of people about smoking, for example, about drunk driving and other kinds of behavioral types of adjustments.

We are committed to the fact that a mass media program can have a real impact, in fact that it is one of the most critical parts of having a real impact on this problem.

What we need to do in Texas is somehow to create a mind-set throughout the state and throughout the people of that state that the abuse of a child is not an appropriate thing to do and that one simply does not do that in responding to his or her anger, frustration or whatever it is at the moment.

The particular initial public awareness efforts center around the issue of shaking the child, which is a more common practice than we realized.

Whether or not there ought to be a national mechanism, I think, for doing that or a national kind of campaign—I think that ought to be explored

There are some advantages in tailoring the campaign to the states themselves, perhaps in having some national guidelines for a campaign, some national expertise for a campaign, but at the same time allowing the states to make significant adjustments including, for example, personalities that have an enormous amount of credibility in that state.

Ms. DARO. Yes.

Chairman OWENS. Has your video on shaking children been shown on cable television stations or——

Mr. STRICKLAND. The video is just now going to the stations throughout the state. It will start being shown in about two weeks in the state of Texas.

Ms. DARO. The National Committee for several years has run a national media campaign on a whole range of child abuse efforts. Right now our campaign is focusing on emotional abuse, as you might have heard yesterday.

What public awareness campaigns do, I think—they do three critical things.

One, they raise awareness on the part of that individual parent about, I may be doing something that may be harmful to my child.

Beyond that, they also create, I think, a general demand among the public for more services for families that are at risk of child abuse and a greater interest in just information about the problem and the scope of the problem.

When the public has that kind of interest, it brings pressures to bear on local agencies to really increase services and to keep better records about what is happening. I think both of those are extraordinarily important for getting a better handle on where we are currently in preventing child abuse and how we can move in the future.

Chairman OWENS. Thank you.

Mr. STRICKLAND Mr. Chairman, you were referring to the issue of cost just a moment ago. I was thinking a couple of things.

As I mentioned in my testimony, right now the budget for the protective services in the state of Texas is approximately $90 million a year. I am part of a current effort in our state to try to find another $20 million to $30 million for the protective services budget. With that $90 million a year they are providing services to approximately 60 percent of the children in our state that they have confirmed as abused.

As I mentioned earlier, we are paying an enormous price for treating our problems. An inmate in the Department of Corrections in Texas will cost us somewhere between $35,000 and $40,000 a year to maintain That is equivalent to six children—if we could prevent child abuse on the part of six children in the state of Texas and prevent their winding up a recipient of the services of the Texas Department of Corrections, that is the equivalent of the money that we receive from the federal Challenge Grant.

We must move back to prevention. The social problems are becoming overwhelming. I think in the state of Texas some initiatives that have been taken there in the last couple of years, particularly by the lieutenant governor of our state, show a very strong commitment to moving in that direction.

Chairman OWENS. Thank you both.

Mr. STRICKLAND. Thank you.

Ms. DARO. Thank you.

Chairman OWENS. Your testimony will be used as we move forward to fight the battle with the administration to get the reauthorization of these programs.

Our next panel consists of Mr. Franklin Frazier, the Director of Income Security Issues, Disability and Welfare, of the General Accounting Office; Mr. James Knoll, of the Human Services Research Institute, Cambridge, Massachusetts; Ms. Jennifer Cernoch, Project Director, Texas Respite Resource Network; and Ms. Kathy Mandeville, Parent and Chairperson of the New Hampshire Support Task Force, on behalf of the United Cerebral Palsy Associations.

Mr. Frazier, would you like to begin, please?

### STATEMENTS OF FRANKLIN FRAZIER, DIRECTOR, INCOME SECURITY ISSUES, DISABILITY AND WELFARE, GENERAL ACCOUNTING OFFICE; JAMES KNOLL, HUMAN SERVICES RESEARCH INSTITUTE; JENNIFER CERNOCH, PROJECT DIRECTOR, TEXAS RESPITE RESOURCE NETWORK; AND KATHY MANDEVILLE, PARENT AND CHAIRPERSON, NEW HAMPSHIRE SUPPORT TASK FORCE, ON BEHALF OF THE UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

Mr. FRAZIER. Thank you, Mr. Chairman I am Franklin Frazier, with the General Accounting Office. I brought with me today Patty Cole and Ted Boyden to help me answer the questions.

As you know, your committee has requested the General Accounting Office to conduct a study looking at respite care. We have some preliminary findings. We looked at five states. The states we looked at are California, Indiana, Massachusetts, New York and Texas.

It was a very cursory telephone questionnaire, trying to find out at the state and national level what was happening with respite care in those five states.

We found in the five states that respite care is a relatively new concept, generally done at the grass roots level and generally done by profit and nonprofit organizations such as Easter Seals, Campfire, Downs' Syndrome, the Council for the Aging, Visiting Nurses. Those are the kinds of organizations that are primarily providing the services.

We were not able to tell from the national and state level data that we have much about the demographics of the families that are receiving these services. We will probably be talking to you and your staff directly later to see where we should go from here with this particular study.

In terms of federal involvement, we have found very little federal involvement. Since 1983 HHS has granted forty- seven grants, thirty-two of those grants as a result of your Temporary Child Care for Handicapped Children.

In the federal government we have found that the Department of Defense and in particularly the Department of the Army Service has the most extensive program.

At the state level we are finding that the states do have some programs. They have spent about $44 million, for the five states that we looked at, but they vary.

For instance, the state of Massachusetts spent about $18 million on respite care. The state of Indiana, which has a similar population with handicapped children and people, spent $1 million. So they kind of vary all over the place.

Most respite care do not charge families for service, we found in the five states. Again, there is very little information available at the state and national level as far as the characteristics of the families served.

The last finding that we have, as has been implicated here before, we have found very little research that has been done to indicate the correlation between—that there is a strong correlation between respite care and reducing child abuse or neglect.

We believe that a first step toward the evaluation is that we need to collect more uniform data on the type of people who are getting the service and something about the cost.

Mr. Chairman, that concludes my statement.

[The prepared statement of Franklin Frazier follows:]

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# Respite Care: Insights On Federal, State, and Private Sector Involvement

Statement of
Franklin Frazier, Director of Income Security
Issues (Disability and Welfare) Human
Resources Division

Before the
Subcommittee on Select Education
Committee on Education and Labor
House of Representatives

## Respite Care: Insights on Federal, State, and Private Sector Involvement

GAO's testimony focuses on preliminary results from our respite care study at the national and state level. We collected information on federal government and national organization activities and surveyed programs offering respite care in 5 states: California, Indiana, Massachusetts, New York, and Texas. Respite care is temporary relief in the form of child care for family members and other caretakers who are under high levels of stress. Respite care could be targeted, for example, to parents of disabled children, foster parents, and unemployed parents. Its purpose is to relieve temporarily the stress and, in turn, to prevent abuse and neglect and support family unity.

-- Respite care is a relatively new, often grassroots level service. It often is provided through local chapters of national organizations such as the United Cerebral Palsy Association. We have identified 6 such organizations with 257 local affiliates providing respite care services, but have been unable to determine the number of families benefitting from their services.

-- Federal involvement in respite care is minimal, occurring mostly through Department of Health and Human Services demonstration grants. Since 1983, HHS has awarded 47 such grants, but funding totaled only $6.5 million. Information on funding from other HHS sources which could be used for respite care was not available. Within the Department of Defense, the Army has the most extensive formal program for providing respite care for service families.

-- While state governments in the states we surveyed are supporting respite care, with little federal assistance, the programs vary greatly in size and funding. In 1988, for example, Massachusetts spent $18.5 million on respite care compared with Indiana's $1.1 million. (The two states have comparable numbers of children under age 18 and handicapped children, rough measures of respite care target groups.) Overall, the programs are new--most began after 1980--and often provide services in addition to respite care. Most provide care at no charge to the family, but little information is available on the characteristics of families served.

-- Little research has been directed at determining respite care's effects, for example, on reducing abuse and neglect. As a first step toward evaluation, programs need to uniformly collect information on respite care services, recipient families, and costs.

Mr. Chairman and Members of the Subcommittee:

I am pleased to provide you with preliminary information from our respite care study requested by your Subcommittee and the Select Committee on Children, Youth, and Families. My statement addresses the nature of national association and federal involvement in respite care, state-level programs, focusing on California, New York, Massachusetts, Indiana, and Texas, and the extent of respite care research and evaluation.

We collected program data and interviewed national association and federal officials responsible for respite care. In the states I mentioned, we conducted a telephone survey to collect program information. We also surveyed the respite care literature and talked with area experts.

## WHAT IS RESPITE CARE?

Respite care is temporary relief in the form of child care for family members and other caretakers who are under high levels of stress. Respite care could be targeted, for example, to parents of disabled children, foster parents and unemployed parents. Its purpose is to relieve temporarily the stress and, in turn, to prevent abuse and neglect and support family unity. High levels of stress within a family, whether caused by the burdens of caring for a disabled child or such factors as financial worries, are strongly linked with child abuse. Such abuse, neglect, or just the family's inability to cope with the child may lead to the child's placement in an institution or foster care. Respite care seeks to support the family as a whole by providing a break for parents and a safe place for the child for a brief time.

Respite care has several characteristics. It is temporary and is directed at the parent or other caretaker--though the child's needs may require a special skills respite care provider. It can be planned and act as a preventive service before a crisis is reached, but it also can be an emergency service such as a crisis nursery, which specializes in providing short-term crisis care to abused and neglected children.

Respite care as a recognized service is relatively new. As with many social services, it originated at the grassroots level. The need for family support services, such as respite care, became apparent in the early 1970's following the movement to allow disabled persons, particularly children, to remain with their families instead of being placed in an institution. Crisis nurseries began at about the same time. While respite care is most widely used in the disability area, child welfare agencies also may include it among their services.

Currently, most respite care activity appears to be in the private sector, provided through local chapters of national organizations. Federal involvement occurs mostly through demonstration grants such as those funded through the legislation you are considering reauthorizing. Our work in 5 states found that while state governments are supporting respite care, with little federal assistance, programs vary greatly in size and funding. Little research has been directed at determining respite care's effects, such as on reducing abuse and neglect. As a first step, programs need to work toward a uniform definition and collect information on services, recipient families, and costs.

## NATIONAL ORGANIZATIONS: GRASSROOTS EFFORTS

Support for respite care often comes from national organizations or associations involved in social services. These organizations' local chapters frequently are the focus for grassroots activity, since they respond to community needs. We identified at least six organizations that had a total of 257 local chapters with respite care services. However, these organizations did not collect information on how many families have benefitted from these services.

These organizations use different approaches for providing respite care. For example, the National Council on Aging uses its Family Friend Program to match older volunteers with chronically ill and disabled children. The volunteers visit the children at least once a week in their homes providing psychological and social support to the children parents, and other family members.

The National Down Syndrome Society has a respite care program which places these children with volunteer host families for one weekend every six weeks over a one year period. Along with providing regular respite care for the children's parents, the program seeks to foster independence in the children and educate host families and communities about Down Syndrome.

## LIMITED FEDERAL INVOLVEMENT

Federal involvement in this relatively young human service is limited largely to demonstration grants. The extent to which permanent funding sources are used for respite care is harder to identify, but, except for the ACTION agency, appears minimal.

As expected, much of the activity is by the Department of Health and Human Services. The 32 temporary care for handicapped children and crisis nursery grants make up the largest federal source of support for which we could identify funding. Since 1983, HHS has awarded 15 other grants for respite care, only one of which is still active. Total funding for all 47 grants, however, is only $6.5 million. Although other HHS funding sources have been used to provide respite care, information was not available on the amount provided by (1) Medicaid which in some cases finances home and community-based services for disabled individuals, (2) title [illegible] of the Social Security Act -- children with special needs, (3) title IV-B of the Social Security Act -- child welfare, and (4) social services block grant.

The ACTION agency has provided one $25,000 grant for a respite care program. ACTION also has provided respite care through its Foster Grandparent Program, whose 328 local programs hire low-income elderly people to act as foster grandparents to special needs children. The Department of Education has funded three grants, each for $[illegible]0,000, to develop respite care educational materials. The Department of Interior has one respite care project at an Indian reservation.

In the Department of Defense, the Family Support program provides some respite care through its Family Advocacy and Exceptional Family Members (Handicapped) components. Within the Department of Defense, the Army has the most extensive formal program, with respite care being one of several family support services provided. In the United States and overseas, the Army has (1) 99 installation programs, (2) 133 programs located off its installations, and (3) 107 foster care programs. Information on funding and numbers of families served is not routinely collected.

The Navy has programs at six locations worldwide which together spend about $62,000 annually on respite care-related activities. The Air Force and the Marine Corps have no formal programs, but officials told us these services use volunteers, community resources, and nonappropriated funds to support respite care functions. They also use child development centers for respite care on an infrequent basis.

## STATE RESPITE CARE PROGRAMS VARY WIDELY

Our survey of 24 programs in 5 states found extreme variation in number of families served and funding levels. Several states have programs with significant state support. Other programs are much more modest. Overall, most programs are relatively new and, in keeping with the picture of limited federal involvement, receive little federal funding.

### Program Administration

We found multiple agencies, as many as four in a state, administering the programs. Departments of Human/Social Services and Mental Health together administered two-thirds of the programs. Three-fourths of the programs began providing services after 1980.

The 19 programs which could provide funding data spent about $44 million on respite care in fiscal year 1988. Ninety-nine percent of the total was state funding. However, states varied widely in their support for respite care. For example, Massachusetts and Indiana have comparable numbers of children under 18 and handicapped children (a rough measure of respite programs' target population). Yet, Massachusetts spent a total of $18.5 million on respite care, compared with Indiana's $1.1 million.

Most programs paid the providers for respite care services. Other funding mechanisms included cash subsidies to parents, direct service provision, and grants to county or local nonprofit agencies.

## Eligibility

The programs are split among those that serve multiple target populations and those that are narrowly targeted. Each of the five states has at least one program serving families with a broad range of special needs children. The most frequently targeted group is families with mentally retarded children. Some children such as severely emotionally disturbed, abused or neglected, and foster children, are less frequently targeted by individual programs.

Other eligibility criteria center on a child's age and family income. Almost all of the programs allow families to receive respite care from the time a child is born. Some programs place no upper age limits for eligibility. Others end eligibility at ages ranging from 18 and 24 and still others serve only children of certain age ranges below age 18.

Most of the 24 programs have no income ceilings above which a family would be ineligible for respite care services. A few programs have family income ceilings that would allow most middle-class families to qualify for assistance. One serves families in the Supplemental Security Income program, thus coming under its eligibility requ[illegible]ments.

Two-thirds of the programs provide services at no charge to eligible recipients. Programs requiring a family contribution require partial payment based on a sliding scale according to ability to pay, a flat rate, or a formula based on family net worth.

## Service Availability

The 12 programs reporting data on recipient families show great variation in the extent of respite care provision. Programs operated statewide ranged from 3 to 15, 00 families served in 1987 or 1988. Other programs, those operating at a limited number of locations, ranged from 2 to 51 families. Programs could provide very little information on service demand versus availability or recipient characteristics.

Although respite care is designed to be temporary, program rules set few specific limits on the amount of respite care available to eligible families. For example, respite care is generally available year round. Only a few programs specifically limit the number of service hours or days that can be used in a given period. However, some programs reported that available funding could limit the amount of respite care they provide to a family.

Respite care is only one of several services provided to families by most of the 24 programs. Additional services included (1) counseling, (2) homemaker, (3) recreational, and (4) nursing care. A third of the programs provided respite care only.

Most programs provided respite care services in the home. Respite caregivers in the home setting included those skilled in services such as nursing care, homemaker, baby sitting, companionship, and home health care.

Many programs also provided respite care outside the home. most frequently used settings outside the home were private family homes, day care centers, and residential and respite care facilities. The services most frequently provided in these settings were nursing care, personal care, and camping.

The programs surveyed generally do not pay for training respite care providers. However, the state programs required providers to be licensed or certified by the respective licensing authorities for their individual specialty, such as nursing.

## RESPITE CARE RESEARCH AND EVALUATION

We could identify little research on respite care's effects, such as on reducing stress or child abuse and neglect. To date our literature survey has found no significant studies of respite care. The lack of research may be explained by respite care's relatively recent emergence as a needed, available service and the small size and funding of many respite programs. Also, because respite care often is one of several services offered by a program, its effects are difficult to isolate from those of the other services.

We also reviewed the applications for demonstration grants awarded under the 1986 Temporary Child Care for Handicapped Children and Crisis Nurseries Act to determine how evaluations will be done. Only about half of these applications contain detailed plans. The Department of Health and Human Services plans to convene a group of project staff in May to develop a data collection and evaluation strategy for the projects.

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In concluding my remarks, I would like to suggest some areas which should be considered in the evaluation of respite care programs. Our work shows that only limited information is available on respite care program characteristics and recipient demographics. But basic program information is needed to properly plan, provide, and evaluate these services--

notwithstanding the complications brought about by respite care's inclusion as one of many services provided by a program.

Thus, as a first step in the evaluative process, programs need to work toward a common respite care service definition and uniformly collect, analyze, and report in a consistent way such information as:

-- Types and amounts of various services provided as respite care;

-- Number of families receiving services;

-- Recipient demographic data; and

-- Cost of various types of services.

Finally, as part of the evaluation process, programs could survey families to measure their satisfaction with services provided. The types of information I have mentioned would allow better analysis to determine how respite care services are being delivered, to whom, and the extent to which parents and other caretakers feel their needs are being met.

Mr. Chairman, this concludes my prepared remarks. I would be happy to answer any questions.

## NATIONAL ORGANIZATIONS INVOLVED IN RESPITE CARE

Table I.1: Summary of National Organizations Involved in Respite Care

| Organization | Number of Local Chapters Providing Respite Care | Number of States Covered |
|---|---|---|
| Visiting Nurses Association | 87 | 29 |
| Camp Fire | 73 | 30 |
| United Cerebral Palsy Association | 46 | 18 |
| Easter Seal Society | 37 | 26 |
| National Council on Aging | 10 | 9 |
| National Down Syndrome Society | 4 | 3 |
| TOTAL | 257 | |

## NATIONAL ORGANIZATIONS INVOLVED IN RESPITE CARE

Table I.2: Local Chapters of National Organizations With Respite Care Programs by State

| | Easter Seal Society | Camp Fire[a] | UCPA[b] | Down Syndrome | Council On Aging[c] | Visiting Nurses |
|---|---|---|---|---|---|---|
| Alabama | 1 | 1 | 4 | | | 1 |
| Alaska | | | | | | |
| Arizona | | | | | | |
| Arkansas | 1 | | | | | 1 |
| California | 1 | 9 | 4 | 1 | 2 | 7 |
| Colorado | | 2 | | | | 4 |
| Connecticut | 1 | 1 | | | 1 | |
| Delaware | 1 | | 2 | | | 1 |
| District of Columbia | 1 | | | | 1 | 1 |
| Florida | | 3 | 3 | 2 | 1 | 9 |
| Georgia | | 1 | 1 | | | 1 |
| Hawaii | 3 | | | | | |
| Idaho | | | | | | |
| Illinois | 2 | 4 | 2 | | | 6 |
| Indiana | | 2 | | | | 5 |
| Iowa | 2 | 3 | | | | |
| Kansas | | 1 | | | | |
| Kentucky | 1 | | | | | 1 |
| Louisiana | 1 | 3 | 1 | | | |
| Maine | 1 | 1 | | | | 1 |
| Maryland | | 1 | 2 | | | |
| Massachusetts | | 1 | | | | 3 |
| Michigan | 1 | 4 | | | | 7 |
| Minnesota | | 2 | | | | |
| Mississippi | | | | | | |
| Missouri | | 1 | 1 | | | 5 |
| Montana | | | | | | |
| Nebraska | | 1 | | | 1 | 1 |
| Nevada | 1 | | 1 | | | |
| New Hampshire | 1 | 1 | | | | 1 |
| New Jersey | | 1 | 3 | | | 2 |
| New Mexico | | | | | | |
| New York | 1 | 2 | 8 | 1 | | 4 |
| North Carolina | 2 | | | | | |
| North Dakota | 1 | | | | | |
| Ohio | 4 | 1 | 2 | | 1 | 2 |
| Oklahoma | | 1 | | | | 1 |
| Oregon | 2 | 4 | | | | 1 |
| Pennsylvania | 1 | 2 | 4 | | | 6 |
| Rhode Island | | 1 | | | | 2 |
| South Carolina | | | | | | |
| South Dakota | 1 | | | | | |
| Tennessee | 1 | 1 | 1 | | | 2 |
| Texas | 1 | 8 | | | 1 | 5 |
| Utah | 1 | 1 | | | 1 | 1 |
| Vermont | | | | | | |
| Virginia | 3 | | | | | |
| Washington | | 9 | | | | 1 |
| West Virginia | | | | | | |
| Wisconsin | 1 | | 6 | | 1 | 3 |
| Wyoming | | 1 | | | | |
| Puerto Rico | | | | | | |
| Totals | 37 | 73 | 46 | 4 | 10 | 87 |

[a] Special Sitters Program Data Ordered By Local Affiliates
[b] United Cerebral Palsy Association
[c] Family Friends Program

## FEDERAL RESPITE CARE DEMONSTRATION GRANTS

**Table II.1:** Funding for Federal Respite Care Demonstration Grants

| Agency | Number of Grants | Total Funding |
|---|---|---|
| **Health and Human Services** | | |
| **Temporary Child Care** | 16 | $2,348,336 |
| **Crisis Nurseries** | 16 | 2,413,508 |
| **Other** | 15 | 1,753,444 |
| **Subtotal** | 47 | 6,515,288 |
| **Education** | 3 | 90,000 |
| **ACTION** | 1 | 25,000 |
| **TOTAL** | 51 | $6,630,288 |

## FEDERAL RESPITE CARE DEMONSTRATION GRANTS

**Table II.2: Federal Grants For Respite Care Activities By Federal Agency and State**

| | Public Law 99-401 | | | | |
|---|---|---|---|---|---|
| | Section 203[a] | Section 204[b] | Other HHS Grants | Dept. of Education | Action |
| Alabama | 1 | | | | |
| Alaska | | | 1 | | |
| Arizona | | 1 | | | |
| Arkansas | 1 | | | | |
| California | 1 | 1 | 1 | 1 | |
| Colorado | 1 | | 1 | | |
| Connecticut | | | | | |
| Delaware | | | 1 | | |
| District of Columbia | | | 1 | 1 | |
| Florida | 1 | 1 | | | |
| Georgia | | | | | |
| Hawaii | | 1 | | | |
| Idaho | 1 | | | | |
| Illinois | 1 | 1 | | | |
| Indiana | | | | | |
| Iowa | | | | | |
| Kansas | 1 | | | | |
| Kentucky | | | | | |
| Louisiana | | | | | |
| Maine | | | 1 | | |
| Maryland | | 1 | | | |
| Massachusetts | 1 | | 2 | 1 | |
| Michigan | 1 | | | | |
| Minnesota | | | | | |
| Mississippi | | | | | |
| Missouri | | | | | |
| Montana | | | | | |
| Nebraska | 1 | | 1 | | |
| Nevada | | | | | |
| New Hampshire | 1 | | | | |
| New Jersey | | 1 | | | |
| New Mexico | | | 1 | | |
| New York | 1 | 3 | | | 1 |
| North Carolina | 1 | 1 | | | |
| North Dakota | | 1 | | | |
| Ohio | | 1 | | | |
| Oklahoma | | | | | |
| Oregon | | 1 | | | |
| Pennsylvania | | 1 | | | |
| Rhode Island | | | | | |
| South Carolina | | | | | |
| South Dakota | | | | | |
| Tennessee | 1 | | | | |
| Texas | | | | | |
| Utah | | | 1 | | |
| Vermont | | 1 | | | |
| Virginia | 1 | | | | |
| Washington | | 1 | 1 | | |
| West Virginia | | | | | |
| Wisconsin | | | 1 | | |
| Wyoming | | | | | |
| Puerto Rico | | 1 | | | |
| Totals | 16 | 16 | 15 | 3 | 1 |

[a] Temporary Child Care for Handicapped and Chronically Ill Children.
[b] Crisis Nurseries.

## CHARACTERISTICS OF STATE RESPITE CARE PROGRAMS

Table III.1: Summary of Characteristics of Programs in Five States Offering Respite Care

Number of programs = 24

| Characteristic | Number of Programs |
|---|---|
| Administering Agency: | |
| Social/Human Services | 8 |
| Mental Health/Retardation | 8 |
| Health | 4 |
| Welfare | 2 |
| Developmental Disabilities | 1 |
| Education | 1 |
| Year Services Began: | |
| Before 1980 | 4 |
| 1980 and after | 18 |
| Unknown | 2 |
| Geographic Coverage: | |
| Statewide | 16 |
| Limited | 8 |
| Target Group Coverage[a]: | |
| Broad | 9 |
| Limited | 15 |
| Services: | |
| In-Home Only | 5 |
| Out-of-Home Only | 4 |
| Both | 15 |

[a] "Broad" targeting means the program covered the developmentally disabled or all or most of the following groups: Mentally retarded, physically handicapped, chronically ill, abused/neglected, visually impaired or blind, speech or hearing impaired, foster children. "Limited" targeting means the program served only one or two of those groups.

Table III.2: Characteristics of Programs in Five States Offering Respite Care (1988)

| State/ Program No. | Administering Agency | Year Begun | State-wide Services | Target Group Coverage[a] | Funding | Families Served | Services | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | In-Home | Out-of-Home |
| **CALIFORNIA** | | | | | | | | |
| One | Education | 1984 | Yes | Broad | $1,089,000 | b | Yes | Yes |
| Two | Devel. Disab. | 1977 | Yes | Broad | 7,528,496 | b | Yes | Yes |
| Three | Social Serv. | 1983 | Yes | Limited | b | b | Yes | Yes |
| Four | Health | 1985 | No | Limited | 272,000 | 25 | No | Yes |
| **INDIANA** | | | | | | | | |
| One | Human Serv. | 1987 | No | Limited | 150,000 | b | No | Yes |
| Two | Human Serv. | 1988 | No | Limited | 3,044 | 5 | Yes | No |
| Three | Mental Health | 1978 | Yes | Limited | 850,000 | 950 | Yes | Yes |
| Four | Welfare | 1977 | Yes | Broad | 136,696 | b | Yes | Yes |
| **MASSACHUSETTS** | | | | | | | | |
| One | Health | 1985 | No | Broad | 40,000 | 41 | No | Yes |
| Two | Health | 1975 | Yes | Broad | 400,000 | 188 | Yes | No |
| Three | Mental Retard. | 1984 | Yes | Limited | 3,000,000 | b | Yes | Yes |
| Four | Mental Retard. | 1980 | Yes | Broad | 8,000,000 | 6,300 | Yes | Yes |
| Five | Social Serv. | 1982 | Yes | Broad | 7,000,000 | 3,700 | Yes | Yes |
| Six | Welfare | 1984 | No | Limited | 39,427 | b | Yes | Yes |
| **NEW YORK** | | | | | | | | |
| One | Mental Health | 1983 | Yes | Broad | 15,000,000 | 15,000 | Yes | Yes |
| Two | Mental Health | b | Yes | Limited | 237,000 | b | Yes | No |
| Three | Health | 1985 | No | Limited | 118,000 | 35 | Yes | No |
| Four | Social Serv. | 1985 | Yes | Limited | b | b | Yes | Yes |
| **TEXAS** | | | | | | | | |
| One | Human Serv. | 1988 | Yes | Limited | 19,994 | 3 | Yes | No |
| Two | Human Serv. | 1988 | No | Broad | 7,200 | 2 | Yes | Yes |
| Three | Human Serv. | 1985 | No | Limited | 23,880 | 51 | Yes | Yes |
| Four | Mental Health | 1988 | Yes | Limited | b | b | Yes | Yes |
| Five | Mental Health | 1985 | Yes | Limited | b | b | Yes | Yes |
| Six | Mental Health | b | Yes | Limited | b | b | No | Yes |

[a] "Broad" targeting means the program covered the developmentally disabled or all or most of the following groups: Mentally retarded, physically handicapped, chronically ill, abused/neglected, visually impaired or blind, speech or hearing impaired, foster children. "Limited" targeting means the program served only one or two of those groups.

[b] Not available.

Chairman OWENS. Thank you. Mr. James Knoll?

Mr. KNOLL. Thank you, Mr. Chairman. I appreciate the opportunity to testify to the committee about a service which many parents of children with disabilities see as one of the most significant supports they can receive from the public sector.

Today I am speaking on behalf Human Services Research Institute, where I am a senior research analyst, and the readership of "Exceptional Parent Magazine," who are the sources of the information I am sharing with you today.

I might mention that my organization has since 1983 been involved in thirteen studies involving the broad level of family supports for families of kids with disabilities. Five of these have been federal projects and eight have been state projects. That has involved us with providing technical assistance or doing research in at least eighteen states.

In today's testimony I want to highlight some of the major points in a recently completed national survey of parents' experiences with respite services that I have provided an almost complete copy of to the committee.

The survey was distributed in the October 1988 issue of "Exceptional Parent Magazine," the premier national publication for families of kids with disabilities. The findings presented today are based on the return of 2,847 valid returns.

In a time when most discussion related to child care and family support is prefaced by the caveat that all efforts must be sensitive to the changing nature of the family, our sample represents a consistent picture of the normative two- parent household. More than 85 percent of the respondents identified themselves as two parents in the home. The average household had two children.

Sixty-two percent of our respondents had a 1987 taxable income in excess of $30,000. The sample group is also well educated. Fifty percent of the prime caregivers had a college degree or more.

Hence, it is important to note in reviewing our findings that the needs of the single parent, the less well educated or less prosperous family will be somewhat different and almost certainly more intense than the needs found in our sample.

In general, the family member with the disability in our sample was a child nine years of age with a relatively severe degree of developmental or physical disability. The respondents to our survey were almost equally divided between families that had used respite in the last year and those who had not.

Since the differences between the users and nonusers were minor, the major factor which seems to differentiate them is the availability and accessibility of services. We received returns from all fifty states, the District of Columbia and Puerto Rico.

The range within those states of people using respite went from two jurisdictions in Mississippi and Puerto Rico, where no one had access to respite, to the state of Alaska, where all of the respondents had access to respite.

This study clearly demonstrates that respite is a valuable resource for families who are able to utilize it. Fifty-seven percent of the families ranked respite as a high priority for them.

Of the users, seventy-four percent reported that the service made a significant difference in their family in the ability to care for the member with a disability, and thirty- five percent actually said that they would have had to consider out-of-home placement for their child if respite were not available.

Fifty-nine percent of the users indicated that they were satisfied with the respite options that were available to them, and they were also highly satisfied with the actual people who provided services.

When the question shifted to focusing on the broader service system the level of satisfaction dropped significantly. There seemed to be substantial problems working out the details of getting this service. There was a lack of flexibility in the types of respite available, in the scheduling of that service, in arbitrary limits on the use of this service and particularly on the inability of the system to respond to the need for respite in a critical situation.

These all point to services which have not yet taken the concept of family-centered to heart. This experience is also mirrored in the families' evaluation of the degree to which they are really active partners in planning and control of the services which impinge on the lives of their communities.

Only a third of the respite users felt satisfied with their involvement in that broader service system. When we asked families to rank some of the models of respite, they expressed a clear preference for arrangements that are congruent with normative community approaches to providing for child care or sitters.

Parents wanted to be in control and have a provider who was responsible to them. They prefer someone who they know and, failing that, someone who is clearly seen as being the family's employee.

As soon as the respite alternatives began to move out of the local community or to minimize parental control, parents were less prone to endorse them.

The average allocation of publicly subsidized respite is about twenty-four hours or three days a month. The average family uses thirty-three hours of respite a month and they indicated a minimal need of nineteen more hours a month per family of respite.

Some of the findings of our study point to a substantial social cost as parents, usually women, with a wide range of education and talents, are unable to pursue educational and career demands because of the requirements of raising a child with a disability.

With the high level of education observed in our sample we anticipated seeing a large number of two-income families. In fact, almost seventy percent of the families were single income.

When the respondents were asked to identify the opportunity costs associated with raising a child with a disability, over 46 percent indicated that they had foregone either educational or employment opportunities and fully 35 percent said that a member of the household had given up employment in order to take care of the family member with a disability.

The issue of child care in general has come to the front of our national policy agenda because of the economic impact that lack of resources in this area has had. What has not been addressed is the failure of respite or generic day care to provide for the needs of parents of children with disabilities on a day-to-day basis, yet the economic impact on these families is certainly more profound than the case of a parent like myself who might be late for work one day because a day care arrangement falls through.

The image of respite that emerges from the families is one which the public sector regards as an extraordinary resource, made available to forestall family crises. However, families clearly regard it as a necessary and regular part of daily life.

Much of what we see argues for expanding respite so that it loses its specialness and is integrated into a comprehensive system of child care which includes access to day care in general and also includes the range of supports which fall under the umbrella of respite that we see in place today.

To put this project with its emphasis on respite in some sort of context, a final set of questions on our survey asked the respondents to rate various forms of family support according to their level of need.

The highest rating was given to a need for assistance in future planning to assure the long-term wellbeing of the family member with the disability. Second rated was access to specialized services for the family member with the disability. Respite rated third.

Perhaps as a comprehensive, consistent, responsive system of community-based family support including respite becomes the rule across this country, rather than the exception, families can look to the future of their member with the disability with a little more confidence.

Thank you.

[The prepared statement of James A. Knoll follows:]

## Testimony of James A. Knoll, Ph D., to the Subcommittee on Select Education on re-authorization of the "Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986"

April 6, 1989

I appreciate this opportunity to testify to the committee about a service which many parents of children with disabilities see as one of the most significant supports they can receive from the public sector. Today I am speaking on behalf of Human Services Research Institute, where I am employed as a Senior Research Analyst, and the readership of *Exceptional Parent Magazine* who are the source of the information I am reporting to you today.

I have a Ph.D. in Mental Retardation with a concentration in the area of policy analysis. I have been involved in the field of services for children and adults with disabilities for 15 years. During the last five years I have primarily focused on research on the development of effective community-based programs for people with severe disabilities.

In this written testimony I would like to share with the committee a fairly comprehensive overview of the results of a recently completed national survey of parents' experiences with non-medical respite services. One copy of the complete report of this study has been given to the sub-committee staff We will gladly provide additional copies upon request

### SUMMARY OF FINDINGS

The motivation behind this study was to develop a base of information which would enable parents to become better informed consumers of respite services. In this study we have developed a very clear picture of the experience and needs of middle and upper-middle class families as they relate to respite services. Additionally, this sample is most representative of families with relatively young children with a relatively severe level of developmental and physical disabilities.

This study clearly demonstrates that respite is a valuable resource for families who are able to utilize it. The families are essentially pleased with the individuals who provide them with respite. However, they seem to have some substantial problems working out the details of obtaining this support. Lack of flexibility, arbitrary limits on use of the service, the inability of the "service system" to consistently respond to crises, all point to services which have not yet taken the concept of parental empowerment to heart. This experience is mirrored in the families' evaluation of the degree to which they are active partners in the planning and implementation of the programs which affect their families.

There is a clear preference among families for respite arrangements which are congruent with the normative community approaches to providing for child care or sitters. The parents want to be in control and have the provider responsible to them. They prefer someone they know or, failing that, someone who is clearly seen as being their employee. As soon as the respite alternatives begin to move out of the local community or begin to minimize parental control parents become less prone to endorse them.

Some of the findings of this study point to a substantial social cost as parents--usually women--with a wide range of education and talents are unable to pursue educational and career goals because of the extraordinary demands of raising a child with a disability. The issue of day care in general has come to the front of the national policy agenda because of the economic impact that the lack of resources in this area has had. What has not been addressed is the failure of respite or "generic" day care to provide for the needs of parents of children with disabilities on a day to day basis. Yet, the economic impact on these families is certainly more profound than the case of the parent who misses work periodically because day care arrangements fall through. The image of respite that seems to emerge is something which the public sector regards as an extraordinary resource made available to families. However, families clearly regard it as a necessary and regular part of daily life. Some of what we see here points in the direction of expanding respite so it that loses some of it specialness and is integrated into a comprehensive system of day care.

The failure to develop a coherent vision of the needs of parents and their children with disabilities is most evident in the wide variation in state-to-state use of respite. This indicates some major differences in the availability and accessibility of services.

As we look at what parents say they want in the way of information, it seems to fall into two major areas. First they want to be able to exercise control over the services which affect their home life. Second, they want a substantive role in forming or reforming the system of services in a manner which is really responsive to their needs.

When we asked what their major needs are, parents' first two primary concerns are for the overall welfare of their child. Only after their pervasive concern for the future of their child is addressed does respite, or "relief" for them, become a priority. Perhaps as a comprehensive system of community-based supports including respite become the rule rather than the exception parents will be able to look to the future of their child with a little more security.

## A NATIONAL SURVEY OF PARENTS' EXPERIENCE WITH RESPITE SERVICES

"Respite" is the blanket term used to describe a wide range of services for families who care for a child with a disability at home. Its origins are found in efforts to give parents some "relief," some respite, from the day-to-day demands of caring for a child with a disability. Often the mystique of disability has made it impossible for these families to use the typical forms of child care found in our communities. Hence these families have often had to turn to specialized agencies to get the most rudimentary sitter services. With this use of special agencies has come substantial increases in the cost of obtaining child care, therefore many parents have sought assistance from the public sector to assure availability of this service and for some help in meeting their extra expenses. As it has evolved over the last decade respite has come to mean **any service or program which provides care for a person with a disability while the primary care giver is engaged in some other activity**. Under this expansive umbrella, all of the following situations, and more, can be found.

- Beds in an institution can be periodically reserved by parents. These same places are also available if a crisis arises which impairs the family's ability to care for its member with a disability.

- Spaces in local group homes for people with disabilities can serve the same function as institutional programs.

- A variant of these institution and group home based programs is a system whereby individual families take turns using respite facilities according to a pre-set schedule. Family members must confirm these dates at the beginning of the year or loose them.

- A respite house or center is a group home serving exclusively as a respite facility. Usually such programs allow parents to schedule specific periods of time, up to two full weeks, in advance. They also provide emergency respite so that a child living at home does not have to go into an institution during a family crisis.

- A licensed respite provider will take a person with a disability into his or her home for any prearranged period of time ranging from a few hours to a week.

- A respite agency will arrange for its employees to care for the person with a disability either in the family home or the provider's home.

- A Licensed Practical Nurse may be sent by a home health care agency on a weekly basis to provide "respite" for a child with severe disabilities while the parent does the family's grocery shopping.

- A "regular" day care center may accept children with disabilities.

- A neighborhood center's after-school program provides special staffing so that each of its activity groups can include one child with severe disabilities.

- A neighbor, recruited and trained by the family itself, is certified by a state agency as a respite provider for that family.

- A drop-in weekend day center with limited space offers respite care for children with disabilities on a first come, first served basis.

- A college student spends three hours every afternoon after school with a young man with autism enabling both of his parents to retain their full time jobs.

Listing all of these possibilities together creates the illusion of a comprehensive system of respite services which should be sensitive to meeting any need a family may have. While a survey of services across the nation is able to identify individual instances of just about any type of respite a family may desire, the reality is that in most areas families have few, if any, alternatives. If respite services exist, they are likely to be limited to one or two possibilities which are presented to families on a take it or leave it basis.

The approaches to funding respite services are almost as diverse as the services themselves. In areas of the country where there is little public support for respite care, families and not-for-profit agencies must carry most of the cost. On the other extreme, there are states which provide families with cash support, a certain amount of pre-paid free respite, and publicly subsidized services which are available to families at a greatly reduced cost should they use up their allotted amount of respite. Between these extremes there is a wide range of funding mechanisms. These include partially subsidized private services, public agencies with a co-payment provisions, voucher systems, and systems where the public contribution is negotiated between the family and the case manager on an individual, as-needed basis.

## Respite in Context

This tremendous diversity in respite services results from the fact that these services are only now finding their form. The uncertain nature of this development process mirrors the changing public policy environment in which it is occurring.

Less than 20 years ago the only publicly funded "support" available to a family who had a child with a disability was institutionalization. Since then, the public outcry against the abuse so often associated with institutional life and an awareness of the trauma inflicted on families in the name of helping them has fostered a rejection of institutionalization as a mode of service for children with disabilities. Moreover, there is increasing recognition that the great majority of families reject out-of-home alternatives in favor of continued care at home, especially during the child's early years. Taken together, these circumstances have prompted a deepening concern that families and their members with disabilities receive the supports they need

As a result, the newer models of service emerging over the last 15 years are presented as being "family-centered" and "community-based" In reality, most state and local systems are only beginning to come to grips with the implications of this kind of rhetoric. Public policy is actively seeking to define the most useful role the public sector can play in assisting families to care for children, including those with the most severe disabilities, at home. States pay over $100.00 a day to support a child in an institution while still questioning the advisability of programs which provide in-home supports to families.

## Parents in the Policy Arena

Parents of children with disabilities need to take an active role in these policy discussions which so directly affect their lives They must be able to define their own vision of what they need and communicate that vision to their representatives. On the local level, parents need to be active participants in the development and evaluation of the services they actually receive. Only then can they be assured of the appropriateness and quality of these services

Parents and other primary care providers are faced with the need to be informed, intelligent, and active consumers of services. But given the day-to-day demands of caring for a child with a disability, where can they turn for the information they need to fulfill this role?

**Intent of this Project**

The primary intent of this project was to lay the groundwork for developing a range of materials that will provide parents with the information they need to take a formative role in the area of family supports and respite services. In keeping with a focus on parental empowerment, this project called on parents of children with disabilities to inform our efforts. We needed them to tell us what they already know, what they need to know, and the most effective ways of getting the products of this project back to parents.

Our primary means for achieving this end was a **national survey of parents** who are caring for children with severe physical disabilities, chronic illness, emotional disturbance, and developmental disabilities at home to determine a) their experience with respite services, b) their perception of what they need to know to be more effective consumers of respite services, c) their perception of the need for additional services to meet the needs of their child and family, and d) the form materials should take in order to be most accessible to them.

## METHOD

This survey was designed as a way to listen to families and to develop a profile, now largely lacking, of what their experience of respite has been and what they need to know to improve this experience. The potential results of this effort would be two fold 1) to identify the types of information which will assist parents to be come empowered consumers of respite services and 2) to contribute to the national base of information and thus ensure that the voice of parents is heard in the formulation of policy and the design of services.

To achieve this goal, a 46 item questionnaire was designed. The majority of the items on this form were forced choice and rating scales. Several fill-in-the-blank items were also included in the survey. These latter items usually solicited the number of hours of service available and used or the cost of services. The survey was divided into 7 major sections: 1) description of the household and care giver, 2) description of the family member with a disability, 3) availability and use of respite, 4) satisfaction with respite, 5) problems with respite, 6) desirable information, and 7) desirable forms of family support services.

The respite survey was shrink-wrapped with the October 1988 issue of *Exceptional Parent Magazine*, the premier national publication for parents of children with disabilities. A pre-paid return mail envelop was attached to the form. This mode of distribution insured that the form would not be missed by subscribers -- it was the first thing they saw on receiving their periodical. The form had a cover letter from the editors explaining the purpose of the survey. This was reiterated in the editor's column inside the magazine. The October issue had a distribution of 22,943 copies. This issue was received by all subscribers by mid-October. The November issue of the magazine carried a prominent reminder to subscribers to return the completed surveys. December 12, 1988 was the final return date for all usable questionnaires. By that date, 2,847 completed and useable forms were received. This represents a return rate of 12.41%, an excellent showing for an unsolicited mailing.

## RESULTS

### HOUSEHOLD CHARACTERISTICS

In a time when most discussions related to child care and family supports are prefaced by the caveat that all efforts must be sensitive to the changing nature of the family, our sample seems to represent a consistent picture of the "normative" two parent household. It should be pointed out that the list of primary descriptors for the household ("two parent," "single parent" "foster home," "shared household,") were not mutually exclusive. More than 85% of the respondents identified their household as having "two parents in the home." The average household had 4.1 people. The average number of children in a household was 2.57 (ranging from no one under 18 years of age (n=186) to 17 (n=1)).

A majority of the households are supported by a single income (69.2%, n=1970). Of the households sampled 19.5% have more than 1 full time income and approximately 32% obtain some part of the household income from part time employment. 62.4% of the respondents report a 1987 taxable income in excess of $30,000.00.

The vast majority of the returned questionnaires were completed by the mother of the person with a disability (n=2483, 87.2%) In most cases, the mother is also the primary care giver. This sample group is very well educated--50.1% of the primary care givers and 54% of other adults have at least a college degree with over 26% of the other adults having some graduate education.

With the high level of education observed, we anticipated seeing larger numbers of two income households. When the respondents were asked to identify some of the opportunity cost associated with care of the family members with a disability, the data reveal that this probably would have been a realistic expectation if someone in the family had not had a disability. Over 46% of the households report that someone has not pursued employment or education because of the demands of care. In 35.5% of cases a member of the household has actually given up employment because of the presence of a family member with a disability. Additionally, a substantial number of households report that the need to be concerned about care for a person with a disability has influenced some aspect of a family member's employment experience.

### FAMILY MEMBERS WITH A DISABILITY

The family members with disabilities in our responding households ranged in age from under 1 to 86 years of age The average person was a child 8.8 years of age Only 9.9% (n = 282) of the sample was 18 years of age or older

*Type of Disability* Respondents were asked to select the condition or conditions which best described their family member from a list of eight types of disability In the following list the type of disability is followed first by the total number of respondents who selected that condition and second by the number who selected <u>only</u> that condition.

| | | |
|---|---|---|
| Medical Condition | 1120 | 16 |
| Physical Disability | 1733 | 168 |
| Developmental Disability | 2197 | 278 |
| Speech Impairment | 1477 | 4 |
| Hearing Impairment | 324 | 8 |
| Visual Impairment | 699 | 5 |
| Emotional Disturbance | 422 | 15 |
| Other | 635 | 103 |

As is apparent from this list the majority of the sample described their family member as having more than one disabling condition 1132 respondents selected 2 or 3 conditions, 925 identified 4 or 5, 168 indicated the presence of 6 or 7, and 7 respondents checked all 8 options

*Level of Disability* Of greater interest than the frequency with which a type of disability was identified is the measure of the severity of that condition Our respondents were asked to rate four classes of disability (intellectual, physical, medical, behavioral) on a four level severity scale ("slight" indicating this type of condition was essentially not a problem, "mild," "moderate," "severe") 74 7% of the sample indicated moderate to severe intellectual disability and 65 6% identified the same range of physical disability As far as medical involvement was concerned, 32 1% of the sample saw their family member as having a moderate to severe level of need [illegible] the area of behavior problems, 6% of the sample report a severe problem while 25 9% report moderate level of disability in this area A summary score was developed to gain a measure of each household's overall level of disability across categories This rating, with 44% of the sample at the moderate level and 24 8% at the severe level, reflects the trend of the sample toward identifying a relatively severe level of disability

*Functional Limitations* An effort was then made to translate the level of disability into functional terms Respondents were asked to rate their family member's need for assistance in seven activities of daily living on a three point rating scale Respondents were asked to indicate if the family member needed complete, some, or no assistance in toileting, eating, bathing, grooming, dressing, communicating, moving around the home, and travel in the community With the exception of eating, communicating, and movement in the home, these variables show a consistent pattern Approximately 60% of the sample needs complete assistance, 30% needs some help, and about 10% needs no help These trends are reflected in the overall assistance variable which averages each respondents ratings in these areas Translated to low, moderate, and high needs, this variable finds 16 7%, 28 1%, and 55 [illegible]% of the sample, respectively, at these levels

*Out-of-home Activity* A major hypothesis that guided the design of this survey was the expectation of a relationship between the amount of programming and recreation engaged in by the person with a disability and the household's need for or use of respite We asked the respondents to tell us how many hours per week their family members were engaged in an educational or work/vocational program and in recreation, either as part of a 'program' or informally with friends The modifier attached to these questions was that these activities take place outside of the home

Based on the pre-supposition that the type and amount of out-of-home activity would be related to the age of the person with a disability, we examined these data with an eye to different age ranges The 29 2% of our sample under 5 years of age (n = 831) we found received an average of almost 12 hours of education activity each week. Only a relatively small percentage of this age group (12 2%, n = 101) is not receiving any educational intervention

For the 60 9% (n = 1734) of the sample in school age range, 5 to 18 years, we see that they are in school for an average of 25 48 hours a week. 97 9% of this age range gets some educational programming In this same age range an average of 5 8 hours of out-of-home recreation was reported. If the substantial percent of individuals in this age group who are not involved in out-of-home recreation activity is not considered, the average amount of recreation increases to 7 46 hours In the school age group the average individual is involved in out-of-home activities for 30 23 hours a week.

Almost 10% of the sample is 18 years of age and over (n=282) 64 9% of this group is involved in an average of [illegible] 16 hours of work/vocational programming per week. When the large number of people indicating no hours of vocational activity is excluded, the average hours increase to 21 5 A substantial number (n=153, 54%) of people in this age range are engaged in some sort of educational activity for an average of 16 44 hours a week. In this same age range, 81 3% are engaged in a mean of 5.58 hours of out-of-home recreation each week When we consider only those who actually engage in recreation, the mean is 7 11 hours The average total amount of out-of-home activity for adults with disabilities in our sample is about 34 hours.

## RESPITE USERS COMPARED TO NON-USERS

The survey form was designed based on the premise that only a small number of people who are not currently using respite would take the time to complete the form. This assumption was a major error on our part In fact the respondents were almost equally divided between respite users (n=1412, 49 6) and non-users (n=1391, 48.9%) (there were 1 5% (n=44) missing responses to this item) This result indicates the importance of this topic to families--especially those who are presently not using or having difficulty accessing services There is no other obvious explanation for the high degree of participation by people who have not used respite in the last year Since the survey was designed to gain information from respite users, a majority of the items could not be completed by non-users If we had any inkling of the high level of participation from the non-user group we would have designed an additional section focused specifically on the issues which they confront Unfortunately, we missed this great opportunity

An important question we are able to address is the identification of any independent variables which seem to differentiate respite users from non-users Statistical tests were conducted which explored the relationship of all independent variables, described thus far, to use or non-use of respite

The tests of our hypothesis that there was a relationship between out of home activity an use of respite revealed only one statistically significant relationship

The non-users of respite reported access to significantly more hours of vocational programming than users of respite ($t = -2.00$, $df = 1346$, $p =< .05$).

An examination of the relationship between use/non-use of respite and the descriptive variables such as age, level of disability, functional limitations, household characteristics, and opportunity costs revealed a number of statistically significant but relatively minor difference between the two group. These difference emerged only because the size of our sample was large enough to assure that there was little likelihood that these difference could be attributed solely to chance. In summary these differences reveal that respite users are slightly more likely to indicate that a) their family member with a disability is more severely disabled and needs greater assistance in most daily activities and b) that there has been an opportunity cost associated with the care needs of their family member. However, we need to reiterate the magnitude of these differences is relatively small, in reality non-users and users of respite form very similar groups.

The major characteristic which seems to differentiate user and non-user groups is where they live. Questionnaires were returned from all 50 states, Puerto Rico, and the District of Columbia. Given the almost equal split between users and non-users in the sample as a whole, we would expect that if we were dealing with a system of services which had some degree of national uniformity the proportion of users to non-users within a particular jurisdictions would roughly mirror the national percentages. As Figure 1 clearly shows there is wide variation in the percentage of respite users from one jurisdiction to another. Both Mississippi (n = 17) and Puerto Rico (n = 4) have no respite users, while Alaska (n = 13) has 100% and the District of Columbia (n = 4) has 75% users. If the distribution of states is split at the 50% user mark, we find that we received 51% of our replies from the 21 "user" areas and 62.5% of all respite users come from these jurisdictions. On the other side of this arbitrary cut off, only 37.5% of the users are found in the 31 "non-user" jurisdictions from which we got 49% of our respondents.

## EXPERIENCE WITH RESPITE

The centerpiece of the survey was the section which asked the respondents to describe their experiences with their local system of respite services. The non-users of respite were directed away from responding to these items. All percentages reported in this section are based on the valid responses elicited from the 1412 respondents to our survey who used respite during the last year.

As I pointed out earlier, the possible forms or model of respite services are seemingly endless. This perception is largely confirmed by our review of the literature. In an effort to organize this diversity, we presented respondents with a 13 item typology of respite services as a basis for their answers. This typology, presented in Table 1, is made up of six in-home alternatives and seven out-of home alternatives. No functional definitions were given of these types other than the identifiers as found in Table 1. The sole exception to this was an effort to elicit information on the use of generic day care by specifying 'community day care provider" on the survey form.

### Availability of Respite

Respondents were asked to identify the models of respite that are available in

FIGURE 1

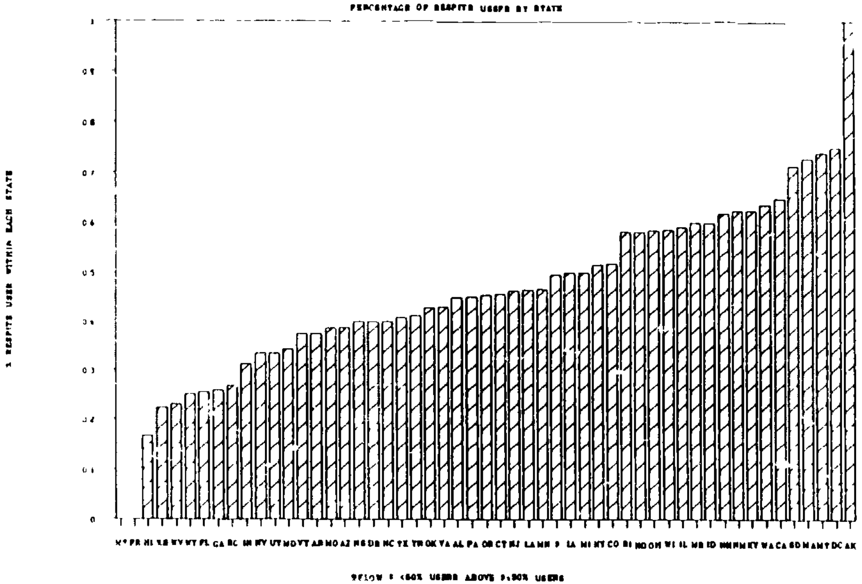
PERCENTAGE OF RESPITE USERS BY STATE
% RESPITE USER WITHIN EACH STATE
1
0.9
0.8
0.7
0.6
0.5
0.4
0.3
0.2
0.1
0
NV PR HI NE WV WY FL GA SC IN NY UT MO VT AR MO AZ NE DE NC TX TN OK VA AL PA OR CT NJ LA MN IA MI MT CO RI ND OH WI IL MS ID NH NM KY WA CA SD MA MT DC AK
BELOW < 50% USERS ABOVE > 50% USERS

TABLE 1

AVAILABILITY, UTILIZATION, & DESIRABILITY
OF VARIOUS RESPITE MODELS AS REPORTED BY RESPITE USERS

| MODEL | AVAILABILITY REPORTED BY % OF USERS | UTILIZATION REPORTED BY % OF USERS IF AVAILABLE | DESIRABILITY RATING *IF NOT* AVAILABLE |
|---|---|---|---|
| IN-HOME | | | |
| FAMILY, FRIEND NEIGHBOR | 62.25% | 76.68% | 1 |
| TRAINED RESPITE PROVIDER | 44.69% | 52.61% | 2 |
| LICENSED PRACTICAL NURSE | 16.71% | 32.63% | 8 |
| FORMAL RESPITE AGENCY | 42.14% | 45.71% | 7 |
| OTHER PERSON | 17.99% | 68.50% | 10 |
| OTHER APPROACHES | 5.38% | 71.05% | NA |
| OUT-OF-HOME | | | |
| FAMILY, FRIEND, NEIGHBOR | 42.14% | 61.85% | 3 |
| PRIVATE HOME | 26.42% | 40.48% | 6 |
| RESPITE CENTER | 22.80% | 36.65% | 4 |
| GROUP HOME | 5.17% | 5.48% | 9 |
| INSTITUTION | 6.94% | 12.24% | 12 |
| DAY CARE PROVIDER | 13.46% | 32.11% | 5 |
| OTHER | 1.42% | 80.00% | 11 |

their community The responses to this question are found in the first column of Table 1 For both in-home and out-of-home respite the most available form is the largely informal network of family members, friends, and neighbors In the in-home category, a trained provider and a respite agency are listed as most available forms of respite after the informal network We interpret the "Other Person" that is available in 17 99% of the cases to be essentially a sitter with no specialized training The fact that a Licensed Practical Nurse (LPN) is identified in only 16 71% of the responses may indicate a lack of need and knowledge rather than availability It is unlikely that most people would think of this highly professionalized approach as viable unless they needed it because of a family member's medical condition Idiosyncratic approaches to in-home-respite were reported 5 38% of the time

For out-of-home respite care, private homes (again the untrained "sitter") and respite centers are indicated as the next most available forms after the informal network Community day care is perceived as available in 13 46% of the cases We were surprised to find that group homes and institutions were only available 5 17% and 6 94% of the time respectively A small number (1 42%) of the respondents reported unique approaches to out-of-home respite

**Utilization of Respite**

The second column in Table 1 reports the percentage of time a particular approach to respite is reported as used **when it is identified as available** It should not be surprising that the approaches that are dependent on individual arrangements are the one most frequently used when they are available Interestingly, trained respite providers and agencies are only used about 50% of the time LPNs, respite centers, and day care providers are all used about the same amount of the time The least used options are institutions and group homes It ather surprising that the institutional option is used about twice as often as group homes

The figures on Table 2 take this rate of utilization one step further and present the average number of hours that each respite option was used in one month The second column of this table indicates the number of respondents who used that option Although used by a relatively small portion of the sample, the Licensed Practical Nurse were, on average, used for the greatest number of hours In summary, 90% of all respite users utilize an average 28 27 hours of in-home-respite per month This figure seems to indicate that where it is available, families are making good use of respite

The high average hours of use associated with private homes, respite centers, group homes, and institutions suggest that these out-of-home options are usually used for overnight stays The few hours of monthly use of community day care is interesting This seems to indicate that very few parents of children with disabilities are able to use day care in order to work on a regular basis The average monthly use of out-of-home respite is 22 3 This represents the usage of 34 9% of all respite users The figure of 43 7 hours a month of average use for all forms of respite indicates that these families are making use of both in-home and out-of-home options in the same month

The data indicate that 479 user households (37%) used only one type of respite option A nearly equal number (n=472) used 2 types of respite 23% of

## TABLE 2

## AVERAGE HOURS OF VARIOUS MODELS OF RESPITE USED IN ONE MONTH AS REPORTED BY RESPITE USERS

| MODEL | AVERAGE NUMBER OF HOURS USED | PERCENT OF RESPITE USERS |
|---|---|---|
| IN HOME | | |
| FAMILY, FRIEND NEIGHBOR | 14 75 | 55 682% |
| TRAINED RESPITE PROVIDER | 18 77 | 27 516% |
| LICENSED PRACTICAL NURSE | 37 28 | 6 412% |
| FORMAL RESPITE AGENCY | 17 65 | 22 565% |
| OTHER PERSON | 30 91 | 14 610% |
| OTHER APPROACHES | 25 07 | 4 789% |
| AVERAGE IN-HOME USAGE | 28 27 | 90 097% |
| OUT-OF-HOME | | |
| FAMILY FRIEND NEIGHBOR | 12 90 | 30 357% |
| PRIVATE HOME | 26 45 | 12 825% |
| RESPITE CENTER | 31 48 | 9 821% |
| GROUP HOME | 45 01 | 0 325% |
| INSTITUTION | 44 75 | 1 299% |
| DAY CARE PROVIDER | 2 48 | 12 744% |
| OTHER | 5 85 | 4 383% |
| AVERAGE OUT-OF HOME USAGE | 22 30 | 34 903% |
| AVERAGE USE OF ALL TYPE OF RESPITE | 33 25 | 100 000%<br>(n = 1232) |

308 respondents used both in home and out-of home respite

Their average usage was 43 70 hours

respite users employ 4 or 5 alternatives Three respondents report using 6 or 7 different models of respite within one month. The average household used two types of respite In some cases, this reflects a use of several forms of the same type of respite, rather than the use of one in-home and one out-of-home model. In fact, 38% of users report multiple forms of in-home respite, while 27% used several out-of-home options.

Of respite users, 83% indicated that some part of the respite they used was at least partially subsidized by some source of public funds When we asked how this publicly supported respite was allocated, 59% of users indicated that the had an average allocation of about three days of respite per month (24 82 hours) Twenty four percent said that they did not know what the allowable allocation was and 16 2% reported that respite was allocated on an "as needed" basis. In response to questions about the need for additional respite, 40 93% of respite users said they needed an average of 18.3 more hours of in-home respite each month 16 61% of the users felt they could use 20 4 more hours of out-of-home respite each month

**Preferred Models of Respite**

The final column of Table 1 shows the desirability rating of certain forms of respite among respite users in areas where that approach is currently **not available.** The rating score reflects the ranking of these approaches based on the number of times each was selected as desirable These ratings seem to demonstrate a clear preference for less formal and individual relationships with providers (family, friends, and neighbors and individual trained providers) Respite centers and day care providers are ranked closely together as the next most preferred options followed by private homes Formal agencies and LPNs seem to fall together as a grouping of professionalized approaches which are not quite as desirable as the more informal approaches These are followed by group homes The somewhat ill-defined options of "other person" in-home and "other" out-of-home are found next in the ranking The sample sees respite services in an institutional setting as the least desirable option This mirrors the relatively low rate of utilization observed for this option

**Experience with Providers**

In the next group of variables we examined parents' experience with respite providers We found that there is wide variability in the amount of control that parents have over selecting the person who will be their actual provider Surprisingly in 23% of the cases some care giver have **no** input into the selection of the respite person Most care givers feel that the individuals providing respite services are relatively well qualified About 72% of the respondents feel that providers are well or very highly qualified

An additional set of questions explored the degree of flexibility of providers around being sitters for siblings without disabilities in addition to providing respite for the member of the family with a disability 57% of the responding respite users indicated that their providers were willing to watch other children In most cases (52.74% of users) there was an additional charge for this services which averaged $2 82 per hour

*Cost* From a public policy perspective two important questions are 1) how much do these services cost the public sector, and 2) how much does this thing called respite cost families over and above the typical costs of baby-sitting and child care? This study did not take a detailed look at this issue but, from the perspective of the family, we did collect some relevant information Respondents were asked about the reimbursement rate for publicly subsidized respite The majority of respondents left this item blank or checked a box that indicated that they did not know The 719 replies we did receive indicated an average rate of $5 85 an hour. There were many different answers ranging from three respondents who indicated there was no public rate to single individuals who cited rates of $32.00, $35.00, $40 00, $50 00, and $90 00 an hour

To the question which asked how much money had been spent out of pocket for publicly subsidized respite during the last month, 998 individuals responded 610 of these households encountered no expenditure. On the other extreme were 23 households which spent in excess of $200 00 including two whose monthly bill for respite was more than $1000 00 The average monthly cost for households that had some additional expense was $57 14. A final fiscal question asked the respondents for the hourly rate they pay for respite which they pay for completely on their own. The average hourly rate reported by 7?7 respondent was $4 36

*Scheduling* In conversations with parents, project staff have been told that respite agency requirements for advance scheduling were a major problem for many families Three questions in the survey addressed this issue The image of respite care that emerges is not of one that is particularly flexible or responsive to the shifting demands of everyday life 71% of users report that they must schedule respite at least four days in advance In 18 8% of the cases this lead time is more than two weeks 53 8% of users indicate that the existing scheduling requirements usually meets their needs However, this means that 46 3% of the respondents work with a system which does not respond to their needs

Perhaps the real test is whether the system of respite is able to respond, not so much to the day-to-day shifts of schedule, but to major crises 46 7% of respite users report that the system that they use cannot usually meet their needs in a time of emergency Only 27% of the sample report sufficient flexibility to respond to a crisis An almost equal number (26 6%) indicate that they have never encountered a crisis in which they needed emergency respite support

*Problems* In another series of items, respite users were asked to identify which of 15 possible problems with respite they had encountered Table 3 presents these problems rank ordered according to the frequency with which they were selected. No single problem was encountered by a majority of the users However, about 40% of them indicated that limited allocation of respite time and the need to leave their family members with a disability with a stranger were problems for them The scheduling issue discussed in the previous section was cited by 26 98% of the users A quarter of the respite users had encountered problems with the quality of services that were available and almost 23% had unique problems which fell outside the categories provided on the questionnaire Given that respondents to this item were already respite users, it is not surprising that some problems were cited infrequently Issues such as source of referral, cost, waiting list, eligibility criteria, lack of public supported services, failure to qualify for services, and lack of transportation could be expected to rate much higher with non-users

*Satisfaction* A series of items endeavored to gain a sense of the respondents' satisfaction with the system of respite services, their perception of the value of

TABLE 3

PROBLEMS ENCOUNTERED BY FAMILIES USING RESPITE SERVICES

| PROBLEM | PERCENT OF USERS REPORTING THIS PROBLEM |
|---|---|
| TOO LITTLE TIME ALLOCATED | 40.8% |
| RELUCTANT TO USE STRANGERS | 39.5% |
| TOO LITTLE TIME TO MAKE ARRANGEMENTS | 27.0% |
| POOR QUALITY OF AVAILABLE SERVICES | 25.4% |
| OTHER REASONS | 22.7% |
| LACK OF REFERRAL INFORMATION | 20.5% |
| AVAILABLE SERVICE TOO EXPENSIVE | 18.8% |
| DISABILITY DID NOT FIT ELIGIBILITY CRITERIA | 18.3% |
| EXTENSIVE WAITING LISTS | 18.3% |
| ADDITIONAL COST FOR OTHER CHILDREN | 17.8% |
| LACK OF PUBLICLY SUPPORTED RESPITE | 14.9% |
| AVAILABLE SERVICE INAPPROPRIATE | 14.2% |
| FAMILY DID NOT QUALIFY FOR SUPPORT | 12.0% |
| LACK OF TRANSPORTATION | 6.8% |
| PROBLEM WITH THE PERSON WITH A DISABILITY | 6.3% |

respite, and their sense of the degree to which the system of service will improve over the next few years Respite users are, in general, fairly satisfied with the respite options which they use 59 3% of users indicate that they more satisfied than not, while 20 6% of fall at the other end of the satisfaction distribution This high level of satisfaction is paralleled by the impact that families attribute to respite services 74% of the families reported that this service has made a significant difference in their ability to care for person with a disability at home On the other extreme, 17 2% of the respondents were neutral in their evaluation of the value of respite and 8 9% tended to minimize its affect 34 6% of the respite users indicated that without respite services they would have considered out-of-home placement for their family member

When we explored whether the respondents feel that they have adequate input into planning services and sufficient control over the services, only 37 3% and 32.6% of respite users, respectively, expressed satisfaction with these aspects of the service system This low level of satisfaction with the system is echoed in the range of responses to a question which asked for an evaluation the potential for positive growth in the community's system of family supports Only 3 9% of the sample indicated a high expectation for change 12 9% of the respondents were optimistic, while 45 3% had limited expectations 37 9% of the sample had essentially no expectation of change for the better

**Why Respite?**
A final group of survey items asked users to identify the reasons they used respite Table 4 displays the results of this section The frequencies reflect the percentage of users who identified a particular reason for using respite As we review the results, it is very difficult to separate the first two reasons listed -- clearly time for socializing can be a major way to alleviate stress The next two items in the listing make an interesting pair in their complementary concern for a member of the family other than the care giver Specifically the use of respite as a method for expanding the social experience of the person with a disability is intriguing Respite can and is used to fulfill the role that social networks and community involvement provide for children without disabilities The relatively low rating of respite as child care for parental employment leads us to wonder if that might not be a function of the relatively prosperous nature of our sample In a less affluent group, we would expect to see a greater need for respite for longer periods of time during the workday

## NEEDS FOR INFORMATION AND SERVICES

Both respite users and non users were asked to complete the balance of the items on the survey These items dealt with the content and format of materials which may be developed as a result of this project and entailed prioritizing respite within the framework of other forms of family support

**Information Needs**
Table 5 ranks 13 types of information in the order of their rating by all respondents Over 90% of the respondents rated each of these options on a 5 point rating scale (1 least preferred to 5 most preferred) The scores in the rating column reflect the average scores associated with these items While the spread on all of the items is only one point, it is interesting to note that items seem to fall

### TABLE 4

### REASONS FOR USING RESPITE REPORTED BY RESPITE USERS

| REASONS FOR RESPITE | REPORTED BY % OF USERS |
|---|---|
| TIME FOR ENTERTAINING/SOCIALIZING | 75 92% |
| RELIEF FROM EMOTIONAL STRESS | 73 51% |
| TIME & ATTENTION TO OTHER FAMILY MEMBERS | 59 21% |
| SO FAMILY MEMBER CAN HAVE CONTACT WITH OTHERS | 42 85% |
| VACATIONS | 42 21% |
| TIME FOR HOUSEHOLD ROUTINES | 41 29% |
| EMERGENCIES | 39 59% |
| TIME FOR EMPLOYMENT | 29 46% |
| ILLNESS IN THE FAMILY | 27 97% |
| ASSISTANCE BEFORE OR AFTER SCHOOL | 23 65% |
| OTHER | 12 18% |

### TABLE 5

### INFORMATION DESIRED BY FAMILIES TO ASSIST THEM IN IMPROVING SERVICES IN THEIR COMMUNITIES

| TYPE OF INFORMATION | AVERAGE RATING |
|---|---|
| SOURCES OF FUNDING FOR SERVICES | 4 563 |
| HOW TO RECRUIT, TRAIN & SUPERVISE PROVIDERS | 4 452 |
| VARIOUS RESPITE ALTERNATIVES | 4 251 |
| UNDERSTANDING OF THE SERVICE STRUCTURE | 4 136 |
| HOW TO ADVOCATE AND LOBBY FOR CHANGE | 4 106 |
| KNOWLEDGEABLE POPLE TO CONTACT | 4 065 |
| HOW TO EVALUATE SERVICES | 4 030 |
| HOW TO WORK WITH PROVIDERS | 3 999 |
| DESCRIPTION OF MODEL PROGRAMS | 3 998 |
| AVAILABLE FAMILY SUPPORT OPTIONS | 3 950 |
| HOW TO ORGANIZE | 3 [illegible] |
| CONTACT WITH OTHER FAMILIES | 3 660 |
| DOCUMENTATION OF RESPITE S VALUE | 3 639 |

### TABLE 6

### TYPES OF SUPPORT SERVICES DESIRED BY FAMILIES

| TYPE OF SUPPORT | AVERAGE RATING |
|---|---|
| FUTURE PLANNING | 293 |
| SPECIALIZED SERVICES | 772 |
| TEMPORARY IN HOME RESPITE | 3 559 |
| SUPPORT FOR THE WHOLE FAMILY | 3 356 |
| ADEQUATE HEALTH COVERAGE (INSURANCE) | 3 335 |
| FINANCIAL ASSISTANCE | 3 331 |
| INFORMATION AND REFERRAL | 3 090 |
| DAY PROGRAMMING | 3 012 |
| TEMPORARY OUT OF HOME RESPITE | 2 954 |

into related clusters The first three reflect a functional perspective on the knowledge necessary to organize, manage, or at least fully understand respite services The next three items are concerned with the skills and knowledge needed to achieve systemic change The next pair of items focused on working with and evaluating direct service This is followed by information on two types of best practices The next pair both deal with grassroots organizing The least desired information is documentation on the value of respite This is not surprising since all of the respondents to this survey have clearly demonstrated the high value which they place on respite They do not need further research to confirm their own knowledge

**Support Needs**
To put this project with it emphasis on respite in context, the final series of items on the survey asked respondents to rate nine forms of family support services, including in-home and out-of-home respite, according to their level of need for that support. Again the ranking was on a five point scale with a higher score indicating a greater degree of need. Each item was ranked based on its average rating by all respondents Table 6 presents the results of this ranking

It is important to point out that although "respite" was the focus of this survey and respondents are very interested in this topic respite is not their most pressing need In fact out-of-home respite (as opposed to in-home respite) received the lowest need rating of any item The highest rating was given to a need for assistance in future planning to assure the long term well-being of the family member with a disability This was followed by a need for specialized services which addressed the disability related needs of the person In-home respite was ranked as the third highest priority item Supports which address the needs of the entire family (sibling counseling, etc ), adequate [illegible] th insurance coverage, and financial assistance to meet some of the costs associated with their specialized needs are found clustered together in the center of the ranking A need for information and referral to services and a need for day programming round out the ranking

Respectfully submitted by

James A Knoll, Ph D
Human Services Research Institute
2336 Massachusetts Ave
Cambridge, MA 02140
(617) 876-0426

Chairman **Owens**. Thank you. Ms. Jennifer Cernoch?

Ms. **Cernoch**. Mr. Chairman and members of the committee, I am Jennifer Cernoch, Project Director of the Texas Respite Resource Network.

The Texas Respite Resource Network was established in 1985 as a grant project of the Texas Planning Council for Developmental Disabilities in response to the tremendous need for respite care services in the state of Texas.

As a state information clearinghouse and technical assistance network, Texas Respite addresses issues relating to respite care and we identify, initiate and improve multifaceted respite resources.

Since our inception, we have broadened our focus to include the implementation of three model pilot projects that I will talk about in a minute. By default we have become the national data center to provide technical assistance to parents, agencies and programs throughout the United States, because currently there is no such service.

Respite care is typically defined as any type of relief care allowing families the opportunity to take a break from the caretaking of their children with disabilities Respite can include temporary relief ranging from a few hours to intermittent custodial care ranging up to a few months.

This temporary relief may be provided either in the family's home or in out-of-home settings in the family's community. There are many types of models of respite care programs, but one of the most important things to remember is that respite care is a service oriented toward the whole family. It is not a program specifically designed as a treatment plan, recreational activity or day care services for children with special needs

Respite is part of the overall support system that families need to maintain their children at home Respite is a necessity, not a luxury in our society.

In 1980 respite care was the need most frequently requested by families of children with developmental disabilities and special health care needs As we progress toward community-based family-centered care programs, respite becomes a vital service for families.

However, most communities are currently not able to provide this important service to families. Lack of funding, as always, becomes a major stumbling block in the provision of respite care services.

Many states and local communities have now realized the importance of respite care, but the need for services far outweighs the actual provision of the care. Most respite care programs report to us across the country that they have a waiting list for services, or many are having to limit families to the number of hours that are available.

Through out networking efforts in Texas alone, we have identified approximately 105 respite options to meet the needs of nearly 270,000 Texans with developmental disabilities. Calculations from these statistics would indicate that each respite program should serve over 2,500 families

These figures are overwhelming With limited funds available, most respite programs can serve approximately 200 families in their geographic area, and that is a lot In Texas alone this would leave over 240,000 families unserved.

In addition to these figures, the Texas Respite Resource Network has received over 1,500 calls and letters from families, agencies and governmental entities during the past three years since our inception seeking respite care services, general information and technical assistance Approximately 60 percent of these calls originate outside of Texas.

As an example, we assisted a family in New Jersey who desperately needed respite care services after writing a letter to the White House Through our networking efforts the family was referred to a program within their area and they are currently receiving services.

These limited statistics and examples indicate the tremendous need for services and the lack of services therein. The benefits of respite care far outweigh the cost of any program development

In the few studies that have been conducted to date, it has been generally purported that respite care has proven to be an effective means of reducing family stress and preserving family unity. In addition, respite care costs approximately one-fourth to one-third the cost of institutionalization.

From a preventive perspective, respite care assists in keeping families together and minimizing possible abuse and neglect situations.

For families respite spells relief -relief from the twenty-four-hour-a-day caretaking of their child, relief to spend time with other family members, relief to overcome that sense of isolation, relief to run errands or take a vacation, activities that are part of our daily lives.

For the majority of families with children with special needs a qualified, trained provider is a must for them to participate in these daily life activities that we all participate in

Because of the disabilities of their children, families are not able to hire a sitter from the neighborhood and many of them do not have extended family to care for their children.

Respite traditionally is not medical intervention services provided by many home health care agencies, but rather for relief care

In addition, respite should not be confused with daily child care, of which there is also a need in our country Respite is that temporary relief.

In the three model pilot programs that we have developed through Texas respite, one of our programs, called Respite Care of San Antonio is a very innovative program providing respite services in the family's home or through host families.

In the short time that this program has been in operation, approximately fifteen months, over 170 families have registered to use the service and approximately twenty new families register every month.

Respite Care of San Antonio, supported by a consortium of funding entities, is an excellent example of a broad-based continuum of respite care options.

However, because our funds are limited, families are only able to use the service 240 hours per year, or ten days out of 365 calendar days a year

Families use this service for a variety of reasons As an example, one family uses the service on Sunday mornings to attend church services. This is an activity that they have not been able to do as a family, as a whole family, in over thirteen years.

Another family used the service to attend their daughter's high school graduation Finally, one family used respite care to obtain one night's worth of sleep without interruption, something that they had not had in a number of months

The second model program that we have started through Texas Respite is called the Respite Station This is a unique hospital-based respite care program offered as a joint venture between Texas Respite and Santa Rosa Children's Hospital.

The Respite Station offers families of children with severe medical conditions living at home a safe environment for the provision of respite care

This model was implemented as a cost effective means of providing relief care to an ever-growing large population of children with severe medical problems that are many times unserved

In our third model program, Family Respite Care is an in-home service offered to families of children with chronic mental illness

I have mentioned these model programs to you as examples of creative initiatives in the provision of continuums of respite care options for families and to indicate the effectiveness to you of consortiums of funding from government agencies, state revenue, private sector and community resources All of these resources put together are important for the delivery of quality respite care services

In conclusion, I would like to say that respite care is a vital and necessary component of family support systems It cannot stand alone. Please know that for these families respite care is truly a gift of time

Thank you for the opportunity to present this information on behalf of our families

[The prepared statement of Jennifer Cernoch follows ]

**Texas Respite Resource Network**

Jennifer M Cernoch Ph D
Respite Director

# Testimony on Reauthorization of the Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986

Before the
Subcommittee on Select Education
United States House of Representatives

April 6, 1989

Testimony of

Jennifer M Cernoch, Ph D
Project Director
Texas Respite Resource Network

[illegible]
THE [illegible] CARE CENTER
[illegible]
[illegible]

**Mr. Chairman and Members** of the Committee. Good **Morning.**

I am Jennifer Cernoch, Project Director of Texas Respite Resource Network Texas Respite Resource Network (TRRN) was established in 1985 as a grant project of the Texas Planning Council for Developmental Disabilities in response to the tremendous need for respite care services As the state information clearinghouse and technical assistance network, TRRN addresses issues relating to respite care and identifies, initiates and improves multi-faceted respite resources Since our inception, Texas Respite has broadened its focus to include the implementation of three model pilot programs in respite care and to provide technical assistance to parents, agencies, and programs throughout the United States These additional activities have been developed to better meet the needs of families

Respite care is typically defined as any type of relief care allowing families the opportunity to take a break from the caretaking of their children with disabilities Respite can include temporary relief ranging from a few hours care to intermittent custodial care ranging up to a few months This temporary relief may be provided on an emergency basis or on a periodic or regular basis either in the family's home or in out-of-home settings based in the family's community There are many types of models of respite care programs, but one of the most important things to remember is that <u>respite care is a service oriented towards the whole family</u> It is not a program specifically designed for children with disabilities as a treatment plan, recreational activities, day care services Respite is part of the overall support system that families need to maintain their children at home Respite is a necessity, not a luxury

In 1980, respite care was the need most frequently requested by families of children with developmental disabilities and special health needs As we progress towards community-based family-centered care programs, respite becomes a vital service for families However, most communities are not able to provide this important service to families. Lack of funding, as always, becomes a major stumbling block in the provision of respite care services. Many states and local communities have now realized the importance of respite care, but the need for services far outweighs the actual provision of respite care Most respite care programs report a "waiting list" for services or many are having to limit families in the number of hours that are available Through the networking efforts of TRPN in Texas, approximately 105 respite options have been identified to meet the needs of nearly 270,000 individuals with developmental disabilities Calculations from these statistics would indicate that each respite program should serve over 2,500 families These figures are overwhelming With limited funds available, most respite programs can serve approximately 200 families in their geographic area. In Texas alone, this would leave over 240,000 families unserved In addition to these figures, Texas Respite Resource Network has received over 1,500 calls and letters from families, agencies, and governmental entities during the past three years seeking respite care services, general information, and technical assistance in the establishment of respite care services Approximately 60% of these calls originate outside of Texas As an example, TRRN assisted a family in New Jersey who desperately needed respite care services after writing a letter to the White House Through networking efforts, the family was referred to a program within their area These limited statistics and example indicate the tremendous need for services and the lack of services therein

The benefits of respite care far outweigh the costs of any program development In the few studies that have been conducted to date, respite care has proven to be an effective means of reducing family stress and preserving family unity In addition, respite care costs approximately one-fourth to one-third the cost of institutionalization From a preventative perspective, respite care assists in keeping families together and minimizing possible abuse and neglect situations For families, respite provides relief from the 24 hour a day caretaking of their children with disabilities relief to spend time with other family members relief to overcome the sense of isolation relief to run errands or take a vacation activities that are a part of our normal daily lives For the majority of families of children with special needs, a qualified trained provider is a <u>must</u> for them to participate in daily tasks and activities. Because of the disabilities of their children, families are not able to hire a sitter from the neighborhood and many do not have extended family to assist in the care of the children A qualified trained provider, who the family trusts, is necessary for the provision of care Respite is **not** medical intervention services provided by many home health care agencies, but rather, relief care for the family In addition, respite should not be confused with daily child care of which there is a need also in our country Respite is <u>temporary</u> relief provided to the whole family so that they can enjoy daily life activities

In the three model pilot programs developed through TRRN, Respite Care of San Antonio is an innovative program providing respite services in the family's home or through host families In the short time that this program has been in operation (15 months), over 170 families have registered to use the service and approximately 20 new families register every month Respite Care of San Antonio, supported by a consortium of funding sources, is an excellent example of a broad-based continuum of respite options However, because of limited funds, families are only able to use the service 240 hours per year or 10 days out of 365 days Families use this service for a variety of reasons As an example, one family uses the service on Sunday mornings to attend church services An activity that they have not been able to do as a family in over 13 years Another family used the service to attend their daughter's high school graduation Finally, one family used respite care to obtain a night's sleep without interruption. The second model program, The Respite Station, is a unique hospital-based respite care service offered as a joint venture between TRRN and the Children's Hospital, Santa Rosa Health Care Corporation The Respite Station offers families of children with severe medical conditions living at home a safe environment for the provision of respite care This model was implemented as a cost effective means of providing relief care to a very large population of children that are many times unserved The third model program, Family Respite Care, is an in-home service offered to families of children with chronic mental illness I have mentioned these model programs as examples of creative initiatives in the provision of continuums of respite care options for families and to indicate the effectiveness of consortiums of funding from governmental agencies, state revenue. private sector, and community resources All resources are important for the delivery of quality respite care services

In conclusion, I would like to say that respite care is a vital and necessary component of family support systems It is a tremendously needed service for families Respite care is truly a gift of time

Thank you for the opportunity to present information on behalf of families of children with disabilities

Chairman OWENS. Thank you. Ms. Kathy Mandeville?

Ms. MANDEVILLE Mr Chairman and distinguished members of this committee, my name is Kathy Mandeville and I am a mom. I am from Bedford, New Hampshire, a community just outside of the city of Manchester.

I am pleased to be here representing the United Cerebral Palsy Associations. UCPA is a national organization of nearly 200 affiliates in forty-five states, advocating on behalf and providing a range of community support services to individuals with cerebral palsy and other severe kinds of disabilities and to their families.

I come to you as the mother of a ten-year-old son with multiple handicaps, as well as the Chairperson of the New Hampshire Family Support Task Force.

The Task Force was a legislatively created committee in New Hampshire whose mission it was to study the needs of families caring for severely disabled children at home and to make recommendations to the New Hampshire legislature on what family support services were necessary to enable the developmentally disabled child to remain in the home and not to be taken away or placed elsewhere.

That Task Force met for sixteen months and released its findings this past January. I have brought with me the summary report of those recommendations for your information and a copy is also attached to my testimony for the record

I am married and the mother of three children. I have a picture of our family which I will share with you. We are a feisty group. James is ten and he is our child with disabilities Elizabeth is seven and Margaret is four-and-a- half There is never a dull moment around our house.

The life event that brings us together in this room today was James' birth ten years ago Richard and I had been married for about five years. I was the nurse consultant for prenatal services for the state of New Hampshire and had recently been recognized for my efforts in the prevention of birth defects for the March of Dimes.

Richard had recently been named president of the local two-year community college in Manchester and we were anxiously awaiting the birth of our first child.

James was born and was very beautiful. He was also very lethargic at birth. He seemed to perk up some, but about four hours after birth he started having seizures that went on for a full twenty-four hours.

The first week brought us the knowledge that he had suffered significant trauma to his brain, but that he would live. The second week told us that whatever damage he had had was probably going to be permanent and extensive.

At this point, by age three, we were describing him as a child with cerebral palsy and I did not know what cerebral palsy was at that point. Cerebral palsy means that those areas of the brain that tell the muscles what to do are some way damaged, and James has cerebral palsy and he has interference with his body moving and acting in a functional way throughout his entire body

He is described as being profoundly retarded To me that sounds like somewhere between a cantaloupe and a rock James is not that. He has far more of an affect and an ability to hear what is happening and to know what is happening and to understand some words.

He is a very beautiful child His head circumference, his brain growth and what he looks like is that of a very attractive child, but whose head is about that of a six or eight month old, so he has a fancy term called "microcephaly."

He is totally dependent. Last fall he weighed a grand total of 29 pounds, which was the most he had weighed, and he had turned ten in November.

It was only after a long period of time that we discovered in retrospect that the crying periods that he had had over the years were due to heartburn. If any of you have a packet of Tums in your pocket you know what heartburn is. It is not an uncommon kind of thing to have children who have cerebral palsy to experience something called reflux, meaning that the acid in their stomach washes into their esophagus, and we discovered that in fact his esophagus had the appearance of something like raw meat.

We had been trying to feed him for several years meals that took half-an-hour to an hour at a time and he had to be held at the time to do this, and we were also adding other children to our family at the same time, so you can imagine how exciting "arsenic hour" was between the hours of three and six o'clock in the evening, when things were busy anyway

We were fortunate in being able to have him undergo a procedure last fall in Boston whereby they were able to prevent acid to go up his esophagus anymore, so that he is no longer in probably constant pain that he had for years.

We also decided to do something called a gastrostomy, which was in an artificial way feeding him from a tube in his tummy. It doesn't look as bad as we thought it might. It is less frightening than we thought it was.

James is weighing close to forty-five pounds now, and that is just since November. He has been totally transformed, but it has added an additional dimension to the kind of care that James needs and receives.

It was not until I had the opportunity of accompanying Richard on a business trip when James was about two-and-a-half that the need for care for James for more than a few hours at a time became an issue or even a remote consideration.

We had heard of the term respite care—and, remember, this was about eight years ago—from a doctor when James was a few months old What we heard in our hearts was that respite care was for families who were exhausted, were at the end of their ropes, had problems, were unable to cope with their child or whose marriage was on the brink of collapse. Those words were not said, but those words were heard.

Since we had no other child care options and we desperately needed to get away together as a couple, we looked into a place in New Hampshire two hours from our home, a small residential care facility that also offered temporary care. You may be aware of a place called Cedar Crest, which is not far from the Vermont border.

We were able to get state funds to help pay for Jamie's ten days there, and it was only through the friend of a friend of a friend that we found out that even there might have been some help for that.

I was going only because Richard's expenses were being paid because it was a business trip, so that my expenses would be minimal. To add on to that the additional expenses of taking care of James at probably a hundred dollars a day would have been more than we would have ever looked into. Without that help there is no way we could have afforded that kind of skilled care

We learned, having been away for even two days, that in fact we had been exhausted. Our energies had gone into paying the bills and taking care of James and not much else. We came back feeling relaxed and renewed and we were anxious to see him again.

Respite care became the single most important support to our family in the next several years and is becoming even moreso. The opportunity for Richard and I to go out together for a few hours occasionally was and is extremely important. Respite care made it possible for me to maintain some professional activities—I am a nurse by background—and memberships in community organizations, in Junior Women's Club and being a school volunteer. in garden club, in whatever I could come up with, that allowed me to feel some degree of accomplishment and success and identity.

To go from an active professional career to being at home with a child who is very difficult to feed, screamed in his car seat and wheelchair for his first two years of life, was not getting any better for all the energy and effort we were putting into him, created an incredible amount of frustration, anger, guilt, depression and sense of powerlessness during those early years To have someone care for James so that I could just get away and out was extremely important.

The Family Support Task Force, whose mission it was to determine the needs of families caring for people with disabilities in our state, recommended strongly that increasing the amount of respite and respite care options was very important to families in our state.

We heard from over 350 families who have children who have significant disabilities. We heard from many families and small groups by phone, in personal interviews, in testimony offered before our committee, which was composed of two parents, of which I was one, and the others in charge of services in our state such as special education, mental health area agencies, et cetera.

We heard of incredible situations, from families like ours who do have insurance and do have an intact family and do have neighbors and do have friends, to families where there were single parents caring for children with disabilities, many working mothers and fathers with several children and this happened to be the last child, from a few families whose children demand twenty-four-hour medical and other kinds of supervision, to families whose children are physically fine but the kids without supervision would be spreading feces all over their rooms or going through mattresses or up and down the streets looking in mailboxes.

When you hear things like that and people , to you, how do you get along, you think, I'm getting along fine with what we have but how do you cope?

For many of these families respite care only happens in emergencies. The purpose of respite care is to help prevent burn-out and family disintegration

In some areas it is doing that In many areas it is little more than a band-aid, because it is only seen as crisis intervention. As many people have said before you today, and as I think you understand, it is not supposed to be saved for a crisis when everything is falling apart. It is a band-aid at that point It is supposed to be preventive relief.

As a mother and the chairperson of New Hampshire's Task Force I strongly support the need for accessible, flexible parent-controlled, parent-directed respite care options, but it is also is very important for me that you understand the greater concept of family support.

Family support is the provision of those services that insure ordinary families faced with extraordinary circumstances that come with having a child with severe disabilities that they get the help they need without having to give up parental responsibilities and control and without creating dependency on agencies and professionals.

Family support services are designed to enhance my ability to care for my family, deter unnecessary placement of our children out of our homes and to return people living in institutions back to their neighborhoods and to their families.

I am told that for a child like James, if we had him cared for outside of our home, it would probably be anywhere from $65,000 to $90,000 a year We are not asking you to pay for that We want our kids at home and we are willing to do a lot of that work.

Examples of family support might include such things as information referral, service coordination, temporary relief with respite, connection with other families—just to know you are not the first person or the only person in this world to go through this is very important—parent education, family counseling, homemaker services, adaptive equipment, home alterations—these are all examples of family support—transportation and access to typical community resources.

I don't want to be isolated and segregated. I want to bring James, as we are able to, to our own town pool James may not need the town pool, but need the town pool I need to see other moms with kids and my other children need to be with their friends. We don't want to have a pool down the street for handicapped kids. We want to be a part of our normal communities. These are the kinds of normal situations we are talking about.

We want access to our libraries and to our parks and day care centers, but we don't want them separate We want to have them as normal.

Family support must be family-centered and flexible enough to respond to the unique needs and circumstances of each individual family and their changes over time as determined by that family. Respite care is important, but for a family without other support its effects are short-lived

The funding which the Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986 provides to states on a competitive demonstration grant basis is encouraging. However, much more needs to be done.

As Americans we claim that the cornerstone of our society is the family. We take great pride in that New Hampshire takes great pride in that. Yet the most recent financial data for Fiscal Year 1988 on state expenditures identified in state agencies for persons with mental retardation or developmental disabilities, collected by Dr. David Braddock at the University of Illinois in Chicago, is very, very depressing.

Out of $11.4 billion dollars spent on these states for services, the great majority on a variety of out-of-home living situations, only $177.9 million is spent on a variety of family supports

Now, it sounds like a lot of money, but when I saw the list of states and what percentage that represented of their entire budget, it represented that on an average a meager 1.56 percent of their total budgets was directed to family support.

In days past it is my understanding—this is not my background. If I wanted special ed, I would have majored in it, so it is something that I have come into only by being a parent. It is my understanding that children like James would have been placed at the turn of the century and in the thirties and forties. I would like to know where all the money that would have been used to care for him, in that we have our kids at home right now, has gone.

Yet where do most individuals with disabilities reside? They reside with us. A copy of this data, with state- by-state comparisons, is in the testimony that has been offered to you.

The vast majority of families want to care for their children with disabilities in their homes. It is better for the family, it is better for the child and it certainly better for government funds.

We need help to do it. We can't do it alone. I urge you to continue your support and leadership and to assure that we will be able to keep our families from becoming disabled, as well

We recommend the following items for the reauthorization process:

One, to make the program permanent and to reauthorize the program for three years.

Two, to increase the authorization level to $20 million.

Three, to set guidelines assuring that the program is family-centered and flexible rather than bureaucratic. We have wonderful examples in our state of New Hampshire of how we have done that. It is very simple. It doesn't have to be complex. It really doesn't We can get from point A to point B on a local/regional level and do it well on a cost effective basis.

Four, to move forward toward a state formula grant program rather than a competitive grant award, assuring some services in every state, with a requirement with a state financial match. In New Hampshire, from the little I have been up at the state legislature, the word "federal" is a dirty word. If they have a choice they would rather not get involved. They are not reaching out and I really feel that the federal government must take some leadership in making sure that states like New Hampshire and other states really want to dance and to play and to be a part of this kind of a program and not have a choice about it.

To expand the service capacity in the program, to move beyond respite care as the only fundable service, and to grasp and to embrace a concept of child support.

There are three things that I just want to speak to very briefly in relation to prior testimony. One has to do with this issue of temporarily funding this program.

I would like to think that people that I have met up in the state of New Hampshire Division of Mental Health, who are the people who direct most of the services for our families, would be able to put their time and energy more in helping families and myself rather than perpetually writing federal grants trying to justify that, again, we need the money every year.

I would like them helping us and having people finally buy the concept, say it works, and have them helping us instead of having to write reports back to the federal government, going through the same information, saying "we need it again."

I as a parent want to have the security in knowing that a respite program in my area is going to be there next year and not insecure. I am not going to invest in something of my time and energy and taking advantage of that service if I don't think it is going to be there the year after. I need that security to know it is going to be there.

Second, some thoughts on cost effectiveness. The cost effectiveness, I think, is obvious. James is not in a crisis nursery because we have built-in supports in our community. My marriage is intact. Rich is a wonderful friend and a wonderful human being and a good husband. The amount of strain that can go on and does go on periodically with having a child like James is incredible.

I was humbled often in hearing testimony from families, to hear about the numbers of times that marriages broke up after a child with a disability was born. Families with disabilities are at risk for splitting up and this is an expense, not just in money but a human expense.

Having these kinds of programs allows me to be an active member of our community. My husband is on the school board. I am a school volunteer. We both are involved with service clubs. We both have friends. We are not just sitting in our house feeling sorry for ourselves.

Having that kind of support allows that to happen. It even allowed me to go skiing this year for the first time in ten years. It allowed me to tear a tendon in my ligament and allowed me to be on crutches and have a cast on my foot before you, but it allowed me to have fun with my friends and that gave me energy back.

It allows our children, our other children—and most of us have more than two kids. When you have a kid with a disability and then you have a normal kid, you figure out how easy it is to have a normal kid and then you worry about their having a child they can really relate to, so often we have three and four and five kids in our families—we weren't busy enough.

It allows them to grow up without resentment and without anger. It allows them to grow up to be compassionate and accepting of families and other people with disabilities

It allows James to stay in our home and neighborhood and be loved and to be, in return, a loving child who attracts people to him and isn't just a child who just sits in a corner with no eye contact and drips on his bib and is incapable of attracting people to him.

Because he has been loved in a relaxed environment he can give back love. He will attract people to himself in his very limited way for the rest of his life when I am not around, and that is very important.

Finally, in relation to child abuse and neglect, if you want to help the kids and prevent child abuse and neglect you help the parents. That is how you help the kids.

I grew up in New York City and we often during the summer and during the spring would have on the news appeals for people to contribute to the fresh air fund, and there were three of us growing up in our family and we were all fairly close in age and lived in a two-bedroom apartment

My mother would say, "The kids don't need fresh air camp—it's the mothers who need fresh air camp. Get the mothers off to camp. Give them some time with each other. Make them a meal they don't have to clean up."

That is what will help the kids. I am more patient with my children. I am more reasonable, I am more able to control my behavior w[illegible] have had time with my friends, when I have had twenty [illegible] of peace to myself, when I am able to understand age-ap-p[illegible]e behavior for a two-and-a-half year old or from my child who has disabilities That helps me to be more sensitive and helpful with my children and for me to be a parent who is not abusive and neglectful. We are all capable of that. It is not something that just exists in our cities.

It also allows me to go off and get information about James' particular disabilities and that allows me to understand him and to help him.

In closing, I would like to leave you with a portion of the Center on Human Policy statement in support of families and their children, the complete text of which is included in a copy of the "Family Support Bulletin," which is now reaching over 7,000 subscribers throughout the nation

"All children, regardless of disability, belong with families and need enduring relationships with adults. Families should receive the support necessary to maintain their children at home Family support should build on existing social networks and natural sources of support.

"Family support should maximize the family's control over the services and supports that they receive. Family support services should encourage the integration of children with disabilities into the community."

I really appreciate this opportunity. I appreciated hearing from your original testimonies, people on the committee, that you have an understanding of this, as well, and as a mother and as a member of this country I will help you in any way to further clarify and help on behalf.

Thank you.

[The prepared statement of Kathy Mandeville follows:]

STATEMENT

RESPECTFULLY SUBMITTED

TO THE

UNITED STATES HOUSE OF REPRESENTATIVES

EDUCATION AND LABOR COMMITTEE

SELECT EDUCATION SUBCOMMITTEE

on the

REAUTHORIZATION OF THE

**"TEMPORARY CHILD CARE FOR HANDICAPPED CHILDREN AND CRISIS NURSERIES ACT OF 1986"**

April 6, 1989

PRESENTED BY
KATHY MANDEVILLE
Bedford, New Hampshire

PARENT,
AND CHAIRPERSON
NEW HAMPSHIRE FAMILY SUPPORT TASK FORCE

on behalf of

UNITED CEREBRAL PALSY ASSOCIATIONS, INC

Accompanied by
Allan I Bergman, Deputy Director
United Cerebral Palsy Assocs., Inc.
1522 K Street, N.W., Suite 1112
Washington, DC 20005

UCPA Governmental Activities Office Washington DC

Mr. Chairman, and distinguished members of this Committee: My name is Kathy Mandeville and I am from Bedford, New Hampshire, a community just outside the city of Manchester. I am pleased to be here representing United Cerebral Palsy Associations, Inc. UCPA is a national organization of nearly 200 affiliates in 45 states, advocating on behalf of and providing a range of community support services to individuals with cerebral palsy and other severe disabilities and their families.

I come to you as the mother of a ten year-old son with multiple handicaps as well as the Chairperson of.the New Hampshire Family Support Task Force. The Task Force was a legislatively-created committee whose mission it was to "study the needs of families caring for severely disabled children at home" and "to make recommendations to the New Hampshire legislature on what family support services were necessary to enable the developmentally disabled child to remain in the home environment." That Task Force met for 16 months and released its findings this past January. I have brought with me the summary report of those recommendations for your information and a copy is also attached to my testimony for the record.

I am married and the mother of three children; James, who is ten; Elizabeth, seven and Margaret who is four. The life event that brings us together in this room today was James' birth ten years ago. Richard and I had been married for about 4 years. I was the Nurse Consultant for pre-natal services for the State of New Hampshire and had recently been recognized for my efforts in prevention of birth defects by the March of Dimes. Richard had recently been named President of the local two-year community college in Manchester and we anxiously awaited the birth of our first born. James was born and was very beautiful but was also very lethargic. He seemed to perk up some but about four hours later started having seizures that continued for the next day. The first week brought us the knowledge that he had had significant trauma to his brain, but that he would live.

The only childcare help that we had in those first two years came from two or three people. A grandmotherly woman who liked babies and two energetic teenagers.

It was not until I had the opportunity of accompanying Richard on a business trip that the need for care for James for more than a few hours became an issue or even a remote consideration. We had heard of the term "respite care" from a doctor when James was a few months old. What we HEARD in our HEARTS was that respite care was for families who were exhausted and unable to cope with their child, or whose marriages were on the brink of collapse. Since we had no other childcare options, and we desperately needed to get away together as a couple, we looked into a place in New Hampshire, two hours from our home -- a small residential care facility that also offered temporary care. We were able to get state funds to help pay for Jamie's ten days there. Without that help, there is no way that we could have afforded that kind of skilled care. We HAD been exhausted. Our energies had gone into paying the bills and taking care of James -- and not much else. We came back feeling renewed and anxious to see him.

**Respite care became** the single **most important** support to our **family in the next** several **years and** is **becoming** even **more so.** The opportunity for Richard and I to go out together for a few hours occasionally was and is extremely important. Respite care made it possible for me to maintain some professional activities and memberships that allowed me to feel some degree of accomplishment and success. To go from an active professional career to being at home with a child who is very difficult to feed, screamed in his car seat and wheelchair for his first few years of life and was not getting "better", created an incredible amount of frustration, anger, guilt, depression and sense of powerlessness during those early years. To have someone care for James so I could just get out and away was very important.

The Family Support Task Force, whose mission it was to determine the needs of families caring for people with disabilities, recommended strongly that increasing the amount of respite and respite care [illegible] ions was very important to families in our state. We heard from over 350 families -- in small groups, in phone and personal interviews and in testimony offered before us. There were a number of single parents caring for children with disabilities, many working mothers and families without health insurance. We heard from a few families who have children who require 24-hour monitoring and care -- the parents take turns going out. For many of these families, respite care only happens in emergencies.

THE PURPOSE OF RESPITE CARE IS TO HELP PREVENT BURN-OUT AND FAMILY DISINTEGRATION. In some areas, it is doing that. In many areas, it's little more than a band-aid because it is only seen as "crisis intervention" rather than ongoing "preventative relief."

As a mother and the Chairperson of New Hampshire's Task Force, I strongly support the need for accessible, flexible respite care options, but it is also important to me that you understand that while respite care is critical, it is only one facet of the greater concept of FAMILY SUPPORT. Family Support is the provision of those services that ensure ordinary families faced with the extraordinary circumstances that come with having a child with severe disabilities get the help they need without having to give up parental responsibilities and control and without creating dependency on agencies and professionals. Family support services are designed to enhance the care-giving capacity of families, deter unnecessary out-of-home placements, and return persons living in institutions back to a family setting.

Examples of family support might include such things as information and referral, service coordination, temporary relief or respite, connection with other families, parent education, family counseling, homemaker services, adaptive equipment, home alteration, transportation and assistance in access to typical community resources, including physicians, dentists, recreation centers, parks, libraries, day care centers, etc. **Family support** MUST be FAMILY-CENTERED AND FLEXIBLE enough to respond to the unique needs and circumstances of each individual family and to their changes over time, as determined by the family. Respite care is important, but for a family without other support, its effects are short-lived.

The funding which the "Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986" provides to states on a competitive, demonstration grant basis is encouraging; however, **much more needs to be done! As American's we claim** that the cornerstone of our society is the family! Yet the most recent financial data for FY 1988 on state expenditure identified in state agencies for persons with mental retardation/developmental disabilities collected by Dr. David Braddock at the University of Illinois at Chicago is very, very depressing. Out of $11.4 billion spent by these states on services--the great majority on a variety of out of home living situations--only $177.9 million is spent on a variety of family supports--A meager 1.56% of their total budgets! Yet, where do most individuals with disabilities reside? The answer is with their families. A copy of these data with state-by-state comparisons are attached to my testimony.

The vast majority of families want to care for their children with disabilities in their own homes. It is better for the family; it is certainly better for the child; and it is certainly a better investment of government funds. But we need help to do it I urge you to continue your support and leadership and to assure that we will be able to keep our families from becoming disabled as well.

We recommend the following items for the reauthorization process:

1) to make the program permanent and reauthorize the program for 3 years;

2) to increase the authorization level to $20 million;

3) to set guidelines assuring that the program is family centered and flexible, rather than bureaucratic;

4) to move toward a state formula grant program rather than a competitive grant award assuring some services in every state with a requirement for a state financial match;

5) to expand the service capacity in the program to move beyond respite care as the only fundable service.

In closing, I would like to leave you with a portion of the Center on Human Policy statement in Support of Families and Their Children, the complete text of which is included in a copy of the Family Support Bulletin (attached to my testimony), a UCPA publication now reaching over 7,000 subscribers throughout the nation.

- All children, regardless of disability, belong with families and need enduring relationships with adults.
- Families should receive the support necessary to maintain their children at home.
- Family supports should build on existing social networks and natural sources of support.
- Family supports should maximize the family's control over the services and supports they receive.
- Family support services should encourage the integration of children with disabilities into the community.

Thank you for the opportunity to give testimony on Family Support and Services. I will be glad to answer any questions you may have.

KATHY MANDEVILLE
Bedford, New Hampshire

/js

# *For the love of our families, for the sake of us all.*

*A [illegible] to our Granite State neighbors from the Legislature's Task Force on Family Support*

The majority of New Hampshire's children and young adults with developmental disabilities are living at home and being cared for by their families

This was not always the case

Before the turn of the century many children with disabilities did not survive infancy For the most part those who did were cared for by their families They were incorporated into an extended family and were part of the fabric of the greater community

As doctors and other professionals became more involved in the field of disability family centered care began to be questioned These experts believed medical specialists were better able to care for people with disabilities than their families or local communities were

Institutions were built in every state Administered by doctors these places purported to offer the latest in therapies and treatment Thousands of children and adults with disabilities were separated from their families and placed in large, isolated state schools and hospitals from which they never returned

Finally in the 1960s and 70s parents and others who worked on behalf of citizens with disabilities began to expose the shame of institutional care Society began to realize what families who had placed their children in institutions, or who had cared for their children at home in isolation already knew Total and separate care of people with disabilities outside of their family and hometown is not good

Segregation and isolation are not good for the child with disabilities They aren t good for the adult who the child will become or for the family who has responsibility for their child s life well into the adult years

Families of the 1980s are grateful not to be pressured into placing their disabled children but they are not the American households of the 1800s who had extended families and simpler life styles

Today s family may be headed by a single parent It may be an adoptive family or a family with a stepparent and stepchildren The mother of a 1980s family is likely to work outside the home

Recent medical and technological advances have made dramatic improvements in the lives of people with disabilities Families however have not received the same attention or resources in their struggle to care for disabled family members It s time that changed

This Task Force of the Legislature was convened to study what New Hampshire can do to support these care giving families

Please take the time to review our recommendations

# Recommendations of the Task Force

## Legislation necessary for a comprehensive family support network in New Hampshire

- **The Governor and Legislature** need to support legislation and the necessary appropriation to establish a comprehensive statewide family support network

***Purpose***

To assist families in whatever manner needed to obtain and maintain the services and resources which can best help them provide care for their family member at home by

***Process***

Providing accurate information and timely referral to services (a 24 hour toll free telephone number)

Providing assistance which is sensitive understanding individualized family directed and flexible

Assuring that every region of the state has a meaningful family support plan which responsively addresses the needs of families

Assuring ongoing contact with families throughout the years

Providing flexible appropriate service planning implementation and coordination

Assuring family involvement in monitoring program effectiveness

***Structure***

*State Coordinator and State Family Support Council*

Would review the establishment of Regional Family Support Councils and the functions of the Regional coordinator(s)

Would advise the Director Division of Mental Health and Developmental Services on issues raised by the Regional coordinators and Family Support Councils as to the effectiveness of services

Would assist Regional Family Support coordinators and families by providing technical assistance training and necessary resources to support local efforts

*Regional Family Support Councils*

Made up of members of families of people with developmental disabilities within each Community Developmental Services Region (Area Agency) of the state

Would approve the plan for services supporting families in the region

Would advise the Regional Family Support coordinator and the Area Agency on creative strategies and the effectiveness of programs created to provide meaningful support to families

*Regional Family Support Coordinator(s)*

Would exist in each of the 12 Community Developmental Service regions in New Hampshire

Each Area Agency would receive funds to implement the comprehensive statewide family support network

Funding would need to be provided by the Division of Mental Health and Developmental Services through a competitive process to determine which lead agency or organization is most able to meet family needs within each region

*Regional Family Support Coordinator*

Must be responsible for assisting families in fully participating in their community

Must work under the guidance of the Regional Family Support Council

Must communicate requests for local support unmet needs and barriers to the Regional Family Support Council

- **The Governor and Legislature** must expand appropriations to fund all aspects of family support specifically funding to

Work toward the elimination of waiting lists for housing employment health care and other community based opportunities

Increase respite care and respite care options

Support youngsters in transitions from school

Provide flexible assistance (e g vouchers)

Allow families to obtain supports needed to make home and vehicle modifications and purchase special equipment supplies and services not usually available through existing programs

To increase early intervention services in order to serve all children from birth to 3 years of age

- **The Governor and Legislature** must address the need for wage and benefit incentives in order to recruit and retain quality caring people who will provide lasting integrated and productive supports to families and to people with developmental disabilities

## Accessible and reliable information and referral systems for families

- **All State Agencies** providing services to families and people with developmental disabilities must assure that all parents receive in a timely manner written easily understood information informing them of eligibility, safeguards services provided and available rights and appeal processes

- **State and private human service agencies** must

Develop specific strategies that address public and professional awareness of the needs families have in caring for their children with developmental disabilities

Foster and facilitate the use of typical community programs and services and not further isolate families by use of overly specialized and segregated services

Assure that persons with disabilities and their families receive assistance in experiencing the same opportunities to participate in community life as any other citizen

- **State, local and private agencies** must involve and support families during the transitional stages of life to assure that families clearly understand their options in entitlement and

*See **Information**, page 3*

# "When all is said and done, let us ensure

***Information,*** *from page 2*

non entitlement services (Entitlement means an absolute legal right to benefits services or programs as a result of being a member of a defined class of people)

Infants and toddlers receive prompt intervention and coordinated referral services that support the family and the child

Students leaving school have available appropriate services that promote continued learning

Employment programs adequately address the impact that wage earnings have on benefits and that work schedules complement family routines

All services and programs have adequate back up support in the event that transition is unsuccessful

◆ **State, local and private agencies serving families** must document and monitor on an active on going basis all family requests for assistance and all waiting lists for services. Those families and individuals awaiting services must be

- Informed of state and local policy addressing waiting lists
- Regularly informed of their status
- Assured of active interim assistance

There must be assurances that service development plans are responsive to actual unmet needs as reflected by these waiting lists

## An inter-agency work group to obtain a broad base of support for families

◆ **The Developmental Disabilities Council** must convene an inter agency work group to obtain the broadest possible base for state federal and local agencies in supporting families

This group should include appropriate agency representatives (e.g. Division of Mental Health and Developmental Services Bureau of Special Education Division of Public Health Division of Human Services Division of Children and Youth Services Division of Vocational Rehabilitation and others) representatives of the State Family Support Council and family member representing other family groups and organizations

The work group must

Review and make recommendations for increased flexibility and responsiveness in practices rules regulations policies and or laws governing services for people with developmental disabilities and their families

*Examples of regulations and or practices in need of revision include*

- Medicaid program and eligibility requirements
- Developmental disabilities definition eligibility and entitlement issue
- Foster care and adoption alternatives
- Flexibility in financing services

File an annual report on expenditures and advancements made in family support

Review and expand participation in interdepartmental agreements and seek funding options to see that they are carried out

◆ **The Developmental Disabilities Council** must convene a study group that continuously reviews and recommends changes in all state and federal statutes pertaining to developmental disabilities

The results of the review must include summaries of laws responsible government agencies rights and appeal procedures and ways families can use this information to have their needs met. Such information should be made available to all families of people with developmental disabilities

## Quality dental and health services

◆ **A Legislative Task Force** with family state government and private insurer participation must be convened to study the availability and accessibility of quality dental and health services available to people with developmental disabilities and the issues confronting families

Specifically

- The reduction of health and dental reimbursement disincentives [illegible] Medicaid reimbursement rate paper work etc
- Review of all current financial resources available to families of children with developmental disabilities
- Recommend feasible methods of providing affordable and comprehensive health and dental coverage

## Identify and implement funding mechanisms for family support

◆ **State agencies** must receive additional funding identify alternative funding sources and implement new funding arrangements such as vouchers low interest loans and other subsidy programs to allow families to care for their family member with a disability

## Integrated and appropriate public education

◆ **The State Board of Education** must facilitate the development of university and in service curricula and certification standards for regular and special educators that promote

- Integration of all students into regular schools and classrooms
- Inclusion of all students into educational programs
- Involvement of families in the educational process

◆ **The State Board of Education** the **State Department of Education** and **local school districts** must carry out the spirit and original intent of Public Law 94 142 (*Education of the Handicapped Act*) when working with families to provide a free and appropriate public education in the least restrictive environment. That is *all* children with disabilities should attend neighborhood schools with non disabled peers where they receive age appropriate services and supports

◆ **Local school districts** must within their special education curricula provide preparatory life skill training throughout the school years. This training must include

# that more will be done than said,"

*1987 88 Family Support Task Force Motto*

health education socialization recreation/leisure community functioning and vocational and career education Local school districts should work closely with adult service workers to assure a successful transition to integrated and meaningful adult lives

## Legal services and support

◆ **Agencies providing legal counsel** must

Help families clearly understand entitlement versus optional programs

Make available affordable information and assistance on such issues as guardianship wills trusts and estate planning

◆ **The New Hampshire Bar Association** must convene educational seminars designed to insure that its members are aware of the legal needs of families caring for disabled people These seminars should focus on providing accessible affordable and knowledgeable legal services

◆ **The Attorney General's Office** must create an office within its Consumer Protection Division that will assist and respond to the needs of families caring for developmentally disabled children

## Available and accessible public transportation

◆ **The Department of Transportation** and **The Governor's Commission on the Handicapped** must conduct a statewide study of existing public and private transportation resources which address the unique issues of people with developmental disabilities This study should include coordination and sharing of existing resources among education public and private human service agencies

## Improve prevention and medical services

◆ **The Division of Public Health Services** must be active in its efforts to

Identify prevent and minimize the incidence of developmental disabilities

Strengthen its programs for childbearing families (i e pre natal education and services pre school health etc ) and for children with special health needs

Continue to develop and monitor standards of care for people with developmental disabilities and their families

◆ **The New Hampshire Medical Society** must conduct educational programs designed to insure that its members are

Familiar with the needs of people with developmental disabilities and their families

Aware of methods and participate in discussions of issues in providing accessible affordable health care

More able to communicate with people with developmental disabilities and their families

## Active family involvement

◆ **All families, professionals and providers of services** must actively address discrimination practices against people with developmental disabilities and their families This includes all areas of community services including housing employment health and dental care transportation recreation and education

◆ **Families caring for children with developmental disabilities** must

Continue to actively seek out the support they need to provide the care for their children

Expand their involvement in family advocacy groups that speak on their behalf

Continue to actively seek out and support elected officials who are interested and knowledgeable of the special needs of families and who will advocate on their behalf

Increase their efforts to influence national policy regarding entitlement to services that will assure their children's full participation in the community

## Development of process to assure recommendations are implemented

◆ **The Legislature** must establish an oversight committee to ensure that these recommendations are implemented

## The Work of the Task Force

The Task Force used a variety of methods to collect and analyze information about supports for families In the last 16 months the Task Force

*Sponsored numerous regional forums for families*

*Interviewed heard testimony from and reviewed survey responses from over 350 families with disabled members*

*Reviewed data and materials from national studies and other states*

*Joined in survey efforts with other agencies*

*Conducted its own state surveys documenting families requests and their satisfaction with current services*

*Listened to an array of state and private agencies educators pediatricians and administrators describe their services for families*

*Sought the assistance of consultants to focus refine and articulate these recommendations*

It has been with great respect for all families with a severely disabled member that the Task Force has conducted its investigations

### For More Information

**The entire Task Force report, entitled *"For the love of' our families...,"* is available upon request from the New Hampshire Division of Mental Health and Developmental Services by calling (603) 271-5060.**

# These are the families

The people who took part in the surveys and research of the Family Support Task Force are not strangers

They are our neighbors friends and relatives young and old prosperous and poor

They have various (dis)abilities and come from families that are intact families with single foster or adoptive parents

They are native and newcomer they live in every corner of the Granite State

What they ask for is reasonable and humane They dont want to suffer the costs that families fractured by stress must endure

What they deserve is fundamental dignity

*Cory Pierson Jr and his dad team up on the slopes of Mt Sunapee Cory Jr competes in nationally sanctioned ski races for disabled people Dad is current head of Special Families United a support and advocacy group for families with a disabled relative Little Cory says he ll ski better than dad someday No one who knows either Pierson would disagree*

# Every family is unique

The Task Force is indebted to the many family members who opened their lives and hearts through personal testimonies By sharing their stories of how the state can support their efforts to care for children at home they present the most compelling information of all

From all the testimony the Task Force distilled this list of values that embodies families definitions of support The values expressed are not unique They are the needs and desires of all

Families who have children with developmental disabilities are no different

***Every family is unique and its needs change over time***

***All individuals belong in families or family-like settings***

***Families are, or can become, competent caregivers***

***Services should support the everyday needs of the family***

***Each family needs services tailored to build on its natural supports, unique skills and existing community resources***

*Family members, legislators, advocates and state officials, including (third from right) Health and Human Service Commissioner Mary Mongan, joined Governor Sununu last spring when he signed into law a bill that makes some Medicaid funding available for severely disabled children who are being cared for at home Increasing the flexibility of such funds is just one of several recommendations of the Task Force on Family Support Such changes can assist New Hampshire families who provide care to a disabled relative or child*

*New Hampshire's*
*Family Support Task Force*
*c/o N H DMH/DS*
*105 Pleasant St*
*Concord, N H 03301*

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*Concord N H 03301*

# *Should you be reading this report?*

## This summary is for anyone who has a neighbor or is part of a family

**It is for legislators and municipal officials** you who have so much to do with shaping policy and carrying out the everyday business of our communities

**It is for our librarians and teachers,** the people closest to us who distribute information work daily in the commerce of ideas and can expose us to the liberation of thought and the challenge of change

**This is for employers,** to alert you that we are all in the midst of a season of changes that you can help and be helped by reconsidering your personnel needs and practices your accessibility and your opportunity to positively change the face of our community by altering the workplace

**For families with a disabled relative** this is a beacon to alert you that you are not alone that your voice- your concern is part of a chorus It is an appeal for you to join us in our efforts to speak candidly about what you need and what you have to offer

**For those working in the disabilities field** anywhere this is a reminder that what you have done what you do reverberates far beyond those you seek to assist daily

**To doctors and lawyers** this is a reminder that there are particular needs that you can help to fill and that you can be even more able and enabling by becoming more informed about disabilities

**To our community leaders,** civic and religious groups service clubs and business associations this report is an invitation to know us better to see us and our disabled kin for what we are your neighbors

# Why families?

Families are the most beneficial and effective caregivers for providing direct assistance to their children or family member with developmental disabilities They must be supported in their effort to maintain their children or family member at home or in community based family-centered options Families are the only constant in the lives of their children services are not

Support should provide the necessary resources to the family so that it can function optimally as a family unit

### Focus on the Family

The focus should be on the entire family and not just on the individual with a developmental disability

Support services must strengthen the family's existing resources and provide appropriate additional resources when none are available

### Family Needs

The Family Support Task Force in reviewing the issues of families caring for people with developmental disabilities has found the following compelling needs of New Hampshire's families Families need

A consistent easily understood responsive and active referral network that clearly understands the families issues provides information on available services and helps connect families to agencies organizations and individuals that can best provide the support required

Assurance that their relatives with developmental disabilities are active participants in typical community activities such as public education recreational and social activities health care and employment

An active direct role in deciding from among a wide variety of choices which supports and services will best assist them in the care of their children or family members

Active involvement by agencies and organizations in the planning implementation and monitoring of services provided for individuals with developmental disabilities

These are the issues that underpin the recommendations contained in this summary

### *Members of the Task Force on Family Support, appointed by the New Hampshire Legislature.*

*Kathy Mandeville Parent*
*Chairperson*
*The Honorable Frank Tupper*
*Co Chairman*
*The N H House of Representatives*
*The Honorable Charles Bond.*
*The N H Senate*

*Cory Pierson, Parent*
*Special Families United*
*Edward Burke Exec Director*
*N H Developmental Disabilities Council*
*Robert Kennedy, Director*
*Special Education Bureau*
*N H Dept of Education*

*Sandra Pelletier Exec Director*
*Area Agency for Developmental Services*
*Nashua, N H*
*Effie Malley, Director*
*N H Division for Children & Youth Services*
*Donald Shumway Director*
*N H Division of Mental Health &*
*Developmental Services*

## TABLE 6
## Discrete Community Initiative Administered By State MR/DD Agencies, By State in FY 1988: Family Support

| State | Cash Subsidy (1) | | Respite | | Other Family Support | | Total Family Support | |
|---|---|---|---|---|---|---|---|---|
| | Expenditures | Clients | Expenditures | Clients | Expenditures | Clients | Expenditures | Clients |
| ALABAMA | $0 | 0 | $250,000 | 341 | $75,000 | (2) 3,037 | $325,000 | |
| ALASKA | $0 | 0 | $718,900 | 436 | $0 | 0 | $718 900 | 436 |
| ARIZONA | $0 | 0 | $227,800 | 754 | $10,617 400 | | $10 845,000 | |
| ARKANSAS | $0 | 0 | $206,000 | 40 | $0 | 0 | $206,000 | 40 |
| CALIFORNIA | $0 | 0 | $10,791,546 | 10,754 | $19,720 293 | 22,159 | $30 511 839 | 32,913 |
| COLORADO | $0 | 0 | $94 894 | | $195,000 | 65 | $289 894 | |
| CONNECTICUT | $0 | 0 | $836,228 | | $1,067,181 | | $1,903,409 | 1,492 |
| DELAWARE | $0 | 0 | $71,818 | 266 | $8,534 | | $80,352 | 266 |
| DIST OF COLUMBIA | $0 | 0 | $342,896 | 400 | $150,186 | 30 | $493,062 | 430 |
| FLORIDA | $5,100 | 12 | $318,568 | | $10 961,568 | | $11 285 234 | |
| GEORGIA | $0 | 0 | $311,562 | 856 | $300,000 | 200 | $611,562 | 1,056 |
| HAWAII | $0 | 0 | | 400 | | | (3) $115,000 | 400 |
| IDAHO | | | $71,500 | 250 | $42,000 | 122 | $113,500 | 372 |
| ILLINOIS | $0 | 0 | $4,409,600 | 3,147 | $7,905,900 | 8,913 | $12 315 500 | 12 060 |
| INDIANA | | | $333 488 | | $37,054 | | $370 542 | (3) 1,000 |
| IOWA | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| KANSAS | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| KENTUCKY | $0 | 0 | $991,312 | | $1,741 645 | | $2,732,957 | |
| LOUISIANA | $45,743 | 169 | | | | | $45,743 | 169 |
| MAINE | $0 | 0 | $197 306 | 500 | $0 | 0 | $197,306 | 500 |
| MARYLAND | $0 | 0 | | | $4 050,136 | 2,008 | $4 050 136 | 2,008 |
| MASSACHUSETTS | $0 | 0 | $15,000,000 | | $3,900,000 | | $18 900 000 | |
| MICHIGAN | $9,429,251 | 3,288 | | | $5,250,000 | | $14,679,251 | |
| MINNESOTA | $1 062,700 | 410 | | | $1,618,000 | | $2,680,700 | |
| MISSISSIPPI | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| MISSOURI | $0 | 0 | $362,500 | 340 | $174,155 | 160 | $536,655 | 500 |
| MONTANA | $0 | 0 | $269 400 | 557 | $2 575 000 | 1,198 | $2,844 400 | 1,755 |
| NEBRASKA | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| NEVADA | $162,200 | 70 | | | $0 | 0 | $162 200 | 70 |
| NEW HAMPSHIRE | $0 | 0 | | | | | $936,174 | 1 285 |
| NEW JERSEY | $0 | 0 | $5 357,000 | | $3,436 000 | | $8,793,000 | |
| NEW MEXICO | $0 | 0 | $187,770 | 224 | $0 | 0 | $187,770 | 224 |
| NEW YORK | $0 | 0 | $1 000 000 | | $15,536 000 | | $18,536 000 | 20,000 |
| NORTH CAROLINA | $0 | 0 | $1,070 200 | 1 369 | $2 700 | 26 | $1,072 900 | 1,395 |
| NORTH DAKOTA | $460 100 | 255 | $317 100 | (2) 32,400 | | | $777 200 | |
| OHIO | $0 | 0 | $0 | 0 | $3,562 462 | | $3 562 462 | |
| OKLAHOMA | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| OREGON | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| PENNSYLVANIA | $0 | 0 | | | $10 086 219 | 15 639 | $10 086,219 | 15,639 |
| RHODE ISLAND | $320 000 | 75 | $300 000 | | $1 060 000 | | $1 700 000 | |
| SOUTH CAROLINA | $180 000 | 175 | $1,242 100 | 66 | $0 | 0 | $1 422 100 | 241 |
| SOUTH DAKOTA | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| TENNESSEE | $0 | 0 | $104 860 | 187 | $0 | 0 | $104 860 | 187 |
| TEXAS | $1 000 000 | 267 | $1 272 276 | 498 | $7,370 580 | | $9 642 856 | 3,649 |
| UTAH | $154 100 | 21 | $183 000 | | $110 000 | | $447 100 | |
| VERMONT | $0 | 0 | $572 500 | 375 | $16 000 | 45 | $588 500 | 420 |
| VIRGINIA | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| WASHINGTON | $0 | 0 | $1 900 000 | | $566 094 | | $2,466,094 | 900 |
| WEST VIRGINIA | $0 | 0 | $114 850 | | $0 | 0 | $114,850 | |
| WISCONSIN | $723 100 | 533 | $1,077 960 | 2 362 | $723,100 | 533 | $2 524 160 | 3 428 |
| WYOMING | $0 | 0 | $0 | 0 | $0 | 0 | $0 | 0 |
| UNITED STATES | $13,542,294 | 5,275 | $50,504,732 | 24 122 | $112 878 207 | 57,019 | (4) $177 976 407 | (4) 102 835 |

NOTE A blank indicates that data were not available and "0" indicates that a discrete community initiative was not identified

(1) States may provide cash subsidies in addition to these funds reported by state MD/DD agencies as discrete community initiatives

(2) Client hours of service were reported in Alabama and North Dakota not included in totals

(3) Family Support expenditures in Hawaii and clients in Indiana reported as totals only

(4) Family support expenditure and client totals do not equal sum of categories there may also be duplicate client counts

Source University of Illinois at Chicago UAP, 1989

FAMILY SUPPORT SPENDING AS A PERCENTAGE OF TOTAL MR/DD SPENDING FY 1988

| | Total Family Support | | Total 1988 MR/DD Expenditures | Percent Family Support of Total MR/DD Expenditures |
|---|---|---|---|---|
| | Expenditures | Clients | | |
| ALABAMA | $325 000 | | $94 695 432 | 0 34% |
| ALASKA | $718,900 | 436 | $20,266 200 | 3 55% |
| ARIZONA | $10,845,000 | | $77 738 400 | 13 95% |
| ARKANSAS | $206 000 | 40 | $71 371 311 | 0 29% |
| CALIFORNIA | $30 511 839 | 32 913 | $1 137 788 802 | 2 68% |
| COLORADO | $289 894 | | $111 732 777 | 0 26% |
| CONNECTICUT | $1 903,409 | 1 492 | $383 182 056 | 0 50% |
| DELAWARE | $80 352 | 266 | $29,322 358 | 0 27% |
| DIST OF COLUM | $493,082 | 430 | $66 238,000 | 0 74% |
| FLORIDA | $11 285 234 | | $302 578 944 | 3 73% |
| GEORGIA | $611 562 | 1 056 | $218 652 454 | 0 28% |
| HAWAII | $115 000 | 400 | $25,567 528 | 0 45% |
| IDAHO | $113 500 | 372 | $34 573 845 | 0 33% |
| ILLINOIS | $12 315 500 | 12 060 | $476 636 556 | 2 58% |
| INDIANA | $370 542 | 1 000 | $176 350 195 | 0 21% |
| IOWA | $0 | 0 | $127 860 155 | 0 00% |
| KANSAS | $0 | 0 | $96 418 039 | 0 00% |
| KENTUCKY | $2 732 957 | | $72 687 173 | 3 76% |
| LOUISIANA | $45 743 | 169 | $172 470 [illegible]4 | 0 03% |
| MAINE | $197 306 | 500 | $55 107 449 | 0 36% |
| MARYLAND | $4 050 136 | 2 008 | $214 695 908 | 1 89% |
| MASSACHUSETTS | $18 900 000 | | $605 835 795 | 3 12% |
| MICHIGAN | $14 679 251 | | $455 760 259 | 3 22% |
| MINNESOTA | $2 680 700 | | $304 618 737 | 0 88% |
| MISSISSIPPI | $0 | 0 | $70 359 690 | 0 00% |
| MISSOURI | $536 655 | 500 | $177 526 268 | 0 30% |
| MONTANA | $2 644 400 | 1 755 | $33 609 760 | 8 40% |
| NEBRASKA | $0 | 0 | $65 839 307 | 0 00% |
| NEVADA | $162 200 | 70 | $16 793 773 | 0 97% |
| NEW HAMPSHIRE | $936 174 | 1 285 | $63 139 614 | 1 48% |
| NEW JERSEY | $8 793 000 | | $476 633 018 | 1 84% |
| NEW MEXICO | $187 770 | 224 | $37 603 322 | 0 50% |
| NEW YORK | $16 536 000 | 20 000 | $1 806 816 303 | 0 92% |
| NORTH CAROLINA | $1 072 900 | 1 395 | $245 415 000 | 0 44% |
| NORTH DAKOTA | $777 200 | | $65 034 408 | 1 20% |
| OHIO | $3 562 462 | | $480 658 581 | 0 74% |
| OKLAHOMA | $0 | 0 | $101 988 275 | 0 00% |
| OREGON | $0 | 0 | $115 149 531 | 0 00% |
| PENNSYLVANIA | $10 086 219 | 15 639 | $683 270 801 | 1 48% |
| RHODE ISLAND | $1 700 000 | | $82 192 060 | 2 07% |
| SOUTH CAROLINA | $1 422 100 | 241 | $145 674 304 | 0 98% |
| SOUTH DAKOTA | $0 | 0 | $35 680 933 | 0 00% |
| TENNESSEE | $104 860 | 187 | $118 996 451 | 0 09% |
| TEXAS | $9 642 856 | 3 649 | $507 360 399 | 1 90% |
| UTAH | $447 100 | | $63 892 876 | 0 70% |
| VERMONT | $588 500 | 420 | $30 030 440 | 1 96% |
| VIRGINIA | $0 | 0 | $184 297 100 | 0 00% |
| WASHINGTON | $2 466 094 | 900 | $176 346 420 | 1 40% |
| WEST VIRGINIA | $114 850 | | $36 691 521 | 0 31% |
| WISCONSIN | $2 524 160 | 3 428 | $221 824 183 | 1 14% |
| WYOMING | $0 | 0 | $23 626 200 | 0 00% |
| UNITED STATES | $177 976 407 | 102 835 | $11 398 799 [illegible]56 | 1 56% |

Source [illegible] Chicago UAP 1989

## FAMILY SUPPORT SPENDING AS A PERCENTAGE OF TOTAL MR/DD SPENDING FY 1988

| | Total Family Support | | Total 1988 MR/DD | Percent Family Support of Total |
|---|---|---|---|---|
| | Expenditures | Clients | Expenditures | MR/DD Expenditures |
| ARIZONA | $10 845 000 | | $77 738 400 | 13 95% |
| MONTANA | $2 844 400 | 1 755 | $33 609 780 | 8 46% |
| KENTUCKY | $2 732 957 | | $72,687 173 | 3 76% |
| FLORIDA | $11 285 234 | | $302,578 944 | 3 73% |
| ALASKA | $718 900 | 436 | $20 266 200 | 3 55% |
| MICHIGAN | $14 679 251 | | $455 760 259 | 3 22% |
| MASSACHUSETTS | $18 900 000 | | $605 835 795 | 3 12% |
| CALIFORNIA | $30 511 839 | 32 913 | $1 137 788 802 | 2 68% |
| ILLINOIS | $12 315,500 | 12 060 | $476 636 556 | 2 58% |
| RHODE ISLAND | $1 700 000 | | $82 192 060 | 2 07% |
| VERMONT | $588 500 | 420 | $30 030 440 | 1 96% |
| TEXAS | $9 642 856 | 3 649 | $507 360 399 | 1 90% |
| MARYLAND | $4 0[illegible] 136 | 2 008 | $214 695 908 | 1 89% |
| NEW JERSEY | $8 793 000 | | $476 633 018 | 1 84% |
| NEW HAMPSHIRE | $936 174 | 1 285 | $63 139 614 | 1 48% |
| PENNSYLVANIA | $10 086 219 | 15 639 | $683 270 801 | 1 48% |
| WASHINGTON | $2 466 094 | 900 | $176 346 420 | 1 40% |
| NORTH DAKOTA | $777 200 | | $65 034 408 | 1 20% |
| WISCONSIN | $2 524 160 | 3 428 | $221 824 183 | 1 14% |
| SOUTH CAROLINA | $1 422 100 | 241 | $145 674 304 | 0 98% |
| NEVADA | $162 200 | 70 | $16 793 773 | 0 97% |
| NEW YORK | $16 536 000 | 20 000 | $1 806 816 303 | 0 92% |
| MINNESOTA | $2 680 700 | | $304 618 737 | 0 88% |
| DIST OF COLUM | $493 082 | 430 | $66 238 000 | 0 74% |
| OHIO | $3 562 462 | | $480 658 581 | 0 74% |
| UTAH | $447 100 | | $63 892 876 | 0 70% |
| CONNECTICUT | $1 903 409 | 492 | $383 182 056 | 0 50% |
| NEW MEXICO | $187 770 | 224 | $37 803 922 | 0 50% |
| HAWAII | $115 000 | 400 | $25 567 528 | 0 45% |
| NORTH CAROLINA | $1 072 900 | 1 395 | $245 415 000 | 0 44% |
| MAINE | $197 306 | 500 | $55 107 449 | 0 36% |
| ALABAMA | $325 000 | | $94 695 432 | 0 34% |
| IDAHO | $113 500 | 372 | $34 573 845 | 0 33% |
| WEST VIRGINIA | $114 850 | | $36 691 521 | 0 31% |
| MISSOURI | $536 655 | 500 | $177 526 [illegible]8 | 0 30% |
| ARKANSAS | $206 000 | 40 | $71 [illegible] | 0 29% |
| GEORGIA | $611 562 | 1 056 | $218 652 454 | 0 28% |
| DELAWARE | $80 352 | 266 | $29 322 358 | 0 27% |
| COLORADO | $289 894 | | $111 732 777 | 0 26% |
| INDIANA | $370 542 | 1 000 | $176 350 195 | 0 21% |
| TENNESSEE | $104 860 | 187 | $118 996 451 | 0 09% |
| LOUISIANA | $45 743 | 69 | $172 470 424 | 0 03% |
| IOWA | $0 | 0 | $127 660 155 | 0 00% |
| MISSISSIPPI | $0 | 0 | $70 359 690 | 0 00% |
| NEBRASKA | $0 | 0 | $65 839 307 | 0 00% |
| OREGON | $0 | 0 | $115 149 531 | 0 00% |
| KANSAS | $0 | 0 | $96 418 039 | 0 00% |
| SOUTH DAKOTA | $0 | 0 | $35 680 933 | 0 00% |
| VIRGINIA | $0 | 0 | $184 297 100 | 0 00% |
| OKLAHOMA | $0 | 0 | $101 388 275 | 0 00% |
| WYOMING | $0 | [illegible] | $23 626 200 | 0 00% |
| UNITED STATES | $177 976 407 | 2 [illegible]35 | $1[illegible] 398 739 [illegible]6 | 1 56% |

[illegible]

# FAMILY SUPPORT BULLETIN

UNITED
CEREBRAL
PALSY
ASSOCIATIONS

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## SUMMER-1987

# WELCOME

Welcome to the first issue of Family Support Bulletin Our purposes are simple (1) to be your source of current information, research, policy and practice at the local, state and federal levels regarding supporting families (natural, adoptive and foster) to raise their children with severe disabilities and/or chronic health needs in their own home, (2) to solicit your comments articles, successes and failures in family support services from which we can all learn, and 3) to develop a national network of families, friends, providers, government agency officials and elected policy makers committed to assuring the development of consistent policies in the private and public sector supporting families

It is a sad commentary on our society that until the late 1970's, the bulk of our local, state and federal legislation provided funding for children with special needs to live outside of the family home In spite of the advances made in many states nearly one-half of the states today still offer minimal or no financial or service support to families Most insurance companies continue to pay for costly hospitalization while very few will pay for a physician approved plan of health care and in home support usually at thirty-five to seventy percent of the cost of hospitalization Financial policy has become, in many ways, a perverse incentive to break up families

Family support is common sense Family support is sound financial policy Family support is reinforcing the family as the foundation of our society Family support, in the best of systems is the empowerment of families to choices and control over their destiny To these ends we look forward to the next few years of communication, dissemination, debate and consensus building to assure the right for every child regardless of severity of disability or health condition to grow up with the love nurturing, support and relationships that only can be provided in a family home

**Allan I Bergman**
Advocacy Liaison Coordinator

# HSRI/UCPA Receive NIDRR Grant on Family Support Policy

The National Institute on Disability and Rehabilitation Research of the Department of Education has awarded a three-year gran to the Human Services Research Institute in Cambridge, Massachusetts, to identify exemplary models for designing and financing home care for children with severe disabilities and chronic illness The go l of the project is to define flexible yet effective mechanisms, to support and sustain family care for these children In identifying state-of-the-art practices and financing options the Institute will address several major objectives

- To identify the cost of providing home care and the factors which contribute to these costs
- To develop alternative models for financing home care using a variety of public and private sources and
- To evaluate the effectiveness of ano feasibility of alternative financing models following implementation at demonstration sites

The project will include a survey of families to isolate those variables that are critical in assessing the financial burden of providing home care This information will be supplemented with a review of literature in the field intensive case studies of families raising their children at home, and options of health care experts concerning the costs associated with providing home care for children with a variety of chronic illnesses and severe disabilities To maxi ize the impact of the project on families and children HSRI will be working with a network of representatives from national organizations serving families and children with severe disabilities and chronic illnesses Two to five representatives will be selected for each state, based upon the size of the state and the availability of liaisons for the national organizations

The liaison network, the keystone of the information dissemination and policy replication effort, will be organized by Allan Bergman Deputy Director for Governmental Activities at the United Cerebral Palsy Associations Inc Quarterly newsletters conferences and detailed reports concerning costs and public policy strategies will be used to inform the liaison network of project activities and to maximize opportunities to influence home and family support policies within each state

During the second phase of the project states will be asked to submit proposals for the development of demonstration projects using new models for financing and supporting home care The selection of demonstration sites will be based upon the following criteria the involvement of key public and private sector agencies the overall impact of the project on the well being of families the probability of success and subsequent acceptance of the model and the level of commitment of the sponsoring agency

The project will also include several national symposia which will introduce participants to alternative financing models and provide an opportunity for the liaison network and other public and private agency representatives to participate in the critical revie ssues and policies affecting the capacities of families to provide care and support in their own homes

For additional information about this project contact Allan I Bergman, Deputy Director Governmental Activities Office United Cerebral Palsy Associations, 1522 "K" Street, N W Washington, D C 20005 (202 842 1266), or Valerie Bradley, President Human Services Research Institute 2336 Massachusetts Avenue Cambridge Massachusetts 02140 7/876-0426)

# HSRI Announces Availability of Annotated Bibliography On Family Home Care

One of the first products of the federal grant is now available The Annotated Bibliography includes current articles and books as well as published manuscripts addressing various issues surrounding family home care for children with chronic health needs and severe disabilities The bibliography can be purchased from HSRI for $10 00 to cover the cost of duplication and postage Orders with a check should be sent to HSRI 2336 Massachusetts Ave Cambridge MA 02140

# Calendar of Upcoming Conferences

**September 1 -15, Annapolis Maryland**

Supporting People with e Disabilities in the Community sponsored by the Center on Human Policy Community Integration Project, Syracuse University and 4 Maryland agencies For additional information contact Yvonne Wampler (301 40-0123)

**October 14-17, Washington D C**

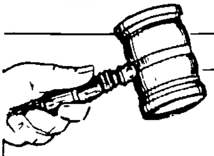
Capitalizing on Our Power annual meeting of the Association for Retarded Citizens of the United States (ARC US) For additional information contact Jim McKenna (817/640-0204)

**October 29-31, Chicago, Illinois**

Back to the Future Annual meeting of The Association for Persons with Severe Handicaps (TASH) For additional information contact Hiroko Roe (206 523 8446)

**October 31, Worcester, Massachusetts**

Family Support Conference II (statewide) For additional information contact Jo Bower Massachusetts Developmental Disabilities Council (617 727 6374)



# United States District Court in Oklahoma Orders Statewide Family Support Services

by Allan I Bergman

On July 24, 1987, Judge James Ellison, in a sweeping court order to close Hissom Memorial Center (a public institution with 450 residents) in the several year old class action suit of Homeward Bound, Inc et. al v Hissom Memorial Center declared a set of values and guiding principles upon which the state must plan its services to persons with mental retardation

The plan states, in part, 'This case brings into public and judicial view the conflict which occurs when bureaucratic remedies to human problems violate societies legal, moral and ethical values. As Americans and citizens of Oklahoma, we believe in rugged individualization the sanctity of the family and in taking care of our own We grow from the experience of living together in the community We admire those who work and we work hard so that our children can have the best life and education possible We have sacrificed to maintain our freedom and a life which is nonrestrictive These values are our heritage which we preserve so that it can be passed down to our children all of our children

'The Quality of life made available in the United States as a result of this value base is the best in the world for those who are allowed to share in it. The American Dream ' rests at the foundation of the values we defend

From the evidence presented it is apparent that these values have been denied to that portion of the citizens of Oklahoma who carry the label of mental retardation Therefore this Order shall include ' Guiding Principles which are intended to direct the remedy developed by the parties as they create community alternatives for persons with mental retardation in Oklahoma

**Guiding Principles**

- All persons are capable of growth and development
- All persons deserve to be treated with dignity
- All persons have value
- All persons must be involved in and carry the primary responsibility of the decisions which effect their lives
- All persons should live and work in the most natural settings
- All children should live with families
- All children have the right to a free appropriate education
- All persons should live in and be a part of the community
- All citizens have the right to fully exercise their rights as guaranteed by the Constitution of the United States

## In Home and Family Support

Historically the public policy of Oklahoma has been that persons with mental retardation will only receive support in living enviroments if the individual leaves home and moves to a state operated institution The state has provided little or no resources to assist a person to stay home but has consistently provided immense financial resource to house people away from their own homes

"The result has been that families have become frustrated with their inability to respond to the family member's needs Institutionalization became the only option Families have experienced severe pain at having to separate their child from home and family For adults with mental retardation this has meant very little or no ability to control their own environment life or pattern of living.

'This is further complicated by the Court's finding that institutions, and in this instance Hissom, are the least likely settings in which to achieve growth and development The evidence before this Court is clear that the home, with appropriate supports is the most likely setting in which to achieve individual growth and development

"Therefore the Court concludes that

1) A gatekeeping mechanism must be implemented to insure that persons will not be removed from their natural home except in extreme circumstances
2) All necessary supports and services must be provided to the home so that it can be the living environment most likely to provide for individual growth and development
3) These provisions must apply in the Hissom service area to all children with mental retardation from the date of birth or diagnosis

To effect these ends, within six months of the date of entry of Judgement in this case the State shall develop and submit for the Court's approval a plan implementing the above referenced conclusions Such plan plan include, but not be limited to the following additional provisions

1) In home and family support services shall not cost the family any more than would be the cost of raising a child without mental retardation
2) Necessary and reasonable architectural modification shall be allowed to insure that the home is adequately safe and barrier free
3) Respite including emergency, occasional and regular respite, as well as in home workers shall be available as needed to maintain a balanced nurturing and supportive home environment
4) Specialized services shall be available, as needed
5) Adaptive and augmentative equipment including medical equipment shall be available as needed
6) Parent/family training will be provided on any issue pertinent to positively maintaining the child at home or the adult in his her home

*Continued on page 6*

# UCPA "Think Tank" Identifies Essential Components of Family Support

by Fran Smith

In a national survey conducted during the fall of 1986 by the United Cerebral Palsy Associations, Inc our local and state affiliates identified *Family Support* as one of four priority services for development and expansion. The Community Services Division of UCPA Inc determined that the first step in providing consultation and technical assistance to its affiliates on this service would be to obtain agreement by a group of experts" on the essential components of Family Support

A "think tank was convened in May of this year The participants each have a different involvement in and perspective of, Family Support as it is offered in various parts of the country However everyone agreed on the following essential components

- The support in family support should be defined by the family,
- Families need to be supported in defining their needs as well as having their needs met
- The effectiveness of support services should be determined by their responsiveness to meeting the needs defined by the families
- Family support programs should respect that families are in control and should trust that parents know what is needed
- Services should be delivered regardless of family income,
- Services should not attempt to fit the persons to the program,
- Services should focus on the total family—not just the family member with the disability,
- Parents should be given time to build trust
- Families experience life passages and will need different support and/or services at different points
- Professionals need to be sensitive about and to families—families can be used to train professionals
- Families should have convenient and central access to 'the system"
- The natural supports in the community should be encouraged relatives neighbors and friends
- The system must be label-free and respond quickly
- Special equipment should be designed and built "to live in a family',
- Family support services should include options from an array of services developed and chosen by families

This array of services should include, but is not limited to, companion services, cost support, equipment parent education parent support home modification transportation rent a mom/kid" homework helper tutor information consultant, advocate for access middle of the-night support broker of service and recreational activities and,

- Family support is a service to the entire family to assist the family in meeting its needs in functioning as a family unit within the community

In addition to developing consensus on these components the participants also developed a list of suggestions for methods to replicate family support opportunities for families of persons with disabilities in all parts of the nation

1 Challenge eligibility criteria
2 Humanize the entry procedures—create a user friendly system with non-punitive fees
3 Create a credit card for entry
4 Develop 'model' regulations to include procedures for background checks
5 Use Red Cross, YMCA, Neighborhood Day Care etc —work toward synergism
6 Use marketing skills available locally to promote family support
7 Balance structure and flexibility to individual families
8 Create co-ops for equipment exchange
9 Establish an information base for technology—what is available
10 Develop guidelines of who pays for family support.
11 Establish a feed-back loop for families and providers
12 Examine ways large systems can be responsive to individual cultural and/or religious needs of families

UCPA is using the information gathered during this two day session as a guide to develop materials for distribution to affiliates and to plan a series of Family Support Conferences which will be conducted in a number of states over the next two years The participants in the 'Think Tank were Doreen Croser Assistant Director for Developmental Disabilities Baltimore MD Robert Durgan, Bureau of Children With Special Needs, Bangor ME Kathryn Gill Executive Director UCP of Mobile Respitality Program Mobile AL Judy Hoyt, Parent of Rick and Director of Association for the Support of Human Services Inc Hollard MA Marilyn Krajicek Director of Special Project Curriculum of Denver, CO Augustina Lemon Respite Coordinator UCP of Central Maryland Baltimore MD Michael Smull Director of Special DD Programs University of Maryland Baltimore MD Vonnee Sturgeon Parent and Co-owner of a Public Relations Firm Fresno CA UCPA staff involved in the 'Think Tank were Allan Bergman, Jim Hollahan, Fran Smith and Rachel Warren

# Center On Human Policy

## Issues

### *A Statement In Support Of Families and Their Children*

*Because of the increasing interest in family support services and the belief that children have a right to grow up with families, the Center on Human Policy has developed the following policy statement. We are reprinting it for dissemination and to further thinking in this major new area of public policy.*

**THESE PRINCIPLES SHOULD GUIDE PUBLIC POLICY TOWARD FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THE ACTIONS OF STATES AND AGENCIES WHEN THEY BECOME INVOLVED WITH FAMILIES**

*All children, regardless of disability, belong with families and need enduring relationships with adults*

When states or agencies become involved with families, permanency planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults. As a guide to state and agency practice, permanency planning requires family support, encouragement of a family's relationship with the child, family reunification for children placed out of home, and the pursuit of adoption for children when family reunification is not possible.

*Families should receive the support necessary to maintain their children at home*

Family support services must be based on the principle "whatever it takes." In short, family support services should be flexible, individualized, and designed to meet the diverse needs of families.

*Family supports should build on existing social networks and natural sources of support*

As a [illegible] principle, natural sources of support, including neighbors, extended families, friends, and community associations should be preferred over agency programs and professional services. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.

*Family supports should maximize the family's control over the services and supports they receive*

Family support services must be based on the assumption that families, rather that states and agencies, are in the best position to determine their needs.

*Family supports should support the entire family*

Family support services should be defined broadly in terms of needs of the entire family, including with children with disabilities, parents, and siblings.

*Family support services should encourage the integration of children with disabilities into the community*

Family support services should be designed to maximize integration and participation in community life for children with disabilities.

*When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family*

*Continued on page 6*

## SUBSCRIPTION FORM

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## Human Policy *Continued from page 5*

Consistent with the philosophy of permanency planning, children should live with their families whenever possible When, due to family crisis or other circumstances children must leave their families, efforts should be directed at encouraging and enabling families to be reunited.

*When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued.*

In fulfillment of each child's right to a stable family and an enduring relationship with one or more adults adoption should be pursued for children whose ties with their families have been broken Whenever possible families should be involved in adoption planning and in all cases, should be treated with sensitivity and respect When adoption is pursued the possibility of "open adoption," whereby families maintain involvement with a child, should be seriously considered

*While a preferred alternative to any group setting or out-of-home placement foster care should only be pursued when children cannot live with their families or with adoptive families*

After families and adoptive families, children should have he opportunity to live with foster families Foster family care can provide children with a home atmosphere and warm relationships and is preferable to group settings and other placement. As a state or agency sponsored program, however, foster care seldom provides children the continuity and stability they need in their lives While foster families may be called upon to assist support and occasionally fill in for families foster care is not likely to be an acceptable alternative to fulfilling each child s right to a stable home and enduring relationships

For further information, please contact the Center On Human Policy, Syracuse University 724 Comstock Avenue Syracuse, New York 13244-4230 (315 423 3851)

## *Statewide Services* *Continued from page 3*

7) Intrusion into normal home life shall be minimized and no more support or service shall be provided than is required

8) Normal recreation and leisure opportunities shall be available for the individual with mental retardation and his/her family

9) Transportation shall be adequate to allow involvement in community life and activities

10) Case management (independent of service provider agencies) will be provided to insure access to and coordination of supports and services including participation in education services

Although Judge Ellison s order applies to persons with mental retardation (based on Oklahoma s current state laws) the guiding principles and the requirements for in-home and family support services are equally applicable to all individuals with labels It is encouraging to see a court address the future of society in a proactive manner instead of limiting its order to services to persons currently in the institution As we go to press the State of Oklahoma is alleged to be considering an appeal to this order

**FAMILY SUPPORT BULLETIN** is published by **United Cerebral Palsy Associations, Inc** Community Services Division, 1522 K Street N W Washington D C 20005 (202 842 1266) Leonard Goldenson chairman Jack Hausman vice chairman Robert J MacDonald, president, Michael Morris director Community Services Allan I Bergman deputy director Fran Smith assistant to the director Patricia F Brady staff as a subcontract to the Human Services Research Institute Cambridge Massachusetts

# FAMILY SUPPORT ***BULLETIN***

United Cerebral Palsy Associations

United Cerebral Palsy Assoc
Government Activities Office
1522 K St N W
Suite 1112
Washington DC 20005

This newsletter was prepared by United Cerebral Palsy Associations Inc Community Services Division as a subcontract to the Human Services Research Institute under Grant No G0086C3543 awarded by the U S Department of Education National Institute of Disability and Rehabilitation Research The opinions expressed herein do not necessarily reflect the position or the policy of the U S Department of Education and no official endorsement by the U S Department of Education of the opinions expressed herein should be inferred

Chairman **Owens** Thank you very much, Ms Mandeville Your experience makes you a national resource.

Mr Frazier, did your GAO study help to answer the question, where has all the money gone that would have been available for her son had she put him in an institution?

Mr. **Frazier**. No, sir, I'm sorry We are not going to be able to answer the question.

Chairman **Owens**. You had identified fifteen grants for respite care that had been awarded by HHS before this program was originated and you said all but one of them has been completed.

What kind of information do we have in terms of the results of the achievements of these previous grants?

Mr. **Frazier**. Mr. Chairman, we queried HHS and asked them about the results from their study; however, they were not able to provide any.

They said that most of the grants were very small grants and evaluation wasn't a part of one of the things that they would do with some of the money.

We agreed that they were small and the fact that they were fairly new—they had just completed However, we believe that as a minimum they should have collected some information, some process information such as the kinds of service provided, the cost, the recipient and maybe something about the barriers to getting respite care, but to our knowledge HHS has not collected any evaluation information about those fifteen grants

Chairman **Owens**. Since you have heard the testimony of the people who preceded this panel plus the ones on this panel, are there any other observations you might want to make growing out of your GAO study that might be helpful?

Mr. **Frazier** Sir, we are at the very early part of this study and we don't want to say anything at this particular time that might not pan out, and so, no, sir, right at this particular time we do not want to say anything else.

Chairman **Owens**. Thank you.

Dr. Knoll, I think you mentioned that 34.6 percent of respite users indicated that without the respite services they would have considered out-of-home placement for their children

Mr. **Knoll**. That is correct, yes.

Chairman **Owens**. That is a rather high figure Can you——

Mr. **Knoll** The question on our survey was simply put—if respite services were not available, would you have considered out-of-home placement?

Thirty-five percent of the families indicated that they would.

That certainly—it does seem like a high figure. Families obviously see a real—I think one of the considerations is that families have—their expectations rise after having been exposed to services.

They know that in the past—you know, Ms. Mandeville said that in the thirties and forties kids would have been placed out of the home The reality is that kids are placed out of the home today in some states and that the only option in some states is maybe a little bit of respite In some states the only respite for a family is still some sort of residential placement

Once the families have been exposed to some sort of services they realize that, you know, how did we get along without some of it before?

We are not talking about a lot of stuff. I mean, the average we are talking is three days a month. That isn't a whole lot of service. So the families realize that this has an impact on them.

It may be that that finding may be somewhat inflated, but it does indicate that the service is having an impact on families and that the lack of those services would place a major stress on the families.

Whether they would, in fact, place a child out of the home. that is a major problem with any of this research around the effective programs on families, finding clear outcomes. They don't tend to be sustained over time. You tend to see something indicated as an outcome of services, but the best information in this regard, because the programs are new, is talking with families and really getting a sense of how they see themselves and how they have come to function more as a family, rather than saying that we can point strictly to a clear outcome measure.

Perhaps with time we may be able to develop some of these measures for gauging the value of these services, but the reality is that a community-based family center system of services is brand new. The research community, if you look at the literature, is grappling with all kinds of—in my opinion, some of them very bizarre—measures of seeing how group homes or how family supports are impacting the lives of families, looking for things that you can count.

At this point I think we are still at the stage of saying that we have to sit down and talk to the people with disabilities, talk to their families and understand how they see these services impact on their lives.

Chairman OWENS. I think the "Exceptional Parent Magazine" survey was mentioned a couple of times.

Has any one of you been able to identify in any state or any place the kind of comprehensive system of family support services which have pinpointed as being needed?

Mr. KNOLL. If I can mention, I think what Representative Smith mentioned, the Michigan system, has received a great deal of play nationally because over an extended period of time, I think probably close to ten years, they have been moving in the direction of implementing that statement of policy that Ms Mandeville cited, that no children will be placed out-of-home, that a full range of supports will be available.

The Michigan system is noted for the fact that it does make available a cash subsidy to families with children with severe disabilities, but it is also within a context of a range of services that have developed over time where families have options and respite that are available and have a full range of other kinds of services that are available that are by no means just limited to respite In some places they are called respite, but they can be homemaker services, they can be home modification

I think we have generated a list of up to fifteen options and then you interview the people who are running this program and you say, well. what does this really mean? They will say, well, what it really means is our commitment to whatever it takes to keep the family together

That has meant that they have done some things like—when I was doing some research in that area I asked a budgetary person to explain a contract that I found in a family's file It was for a new furnace.

The reason that the new furnace was there and that the state was paying for the new furnace was that the kid had a severe respiratory problem. The family wanted to bring the child home but they owned the home, it was an old forced-air furnace and there was no way the child could be in that environment.

So family support to that family meant that the state put in a new furnace, and that $7,800 was far and away cheaper than the $250 a day that the child would have cost at an ICFMR- certified unit in that state.

Chairman OWENS. Ms. Mandeville, would you, sort of related to that, care to comment on that "Exceptional Parent Magazine" study, the observation they made about parent- controlled care, and also, I think, it was indicated that parents who worked were given preference over parents who don't work.

From your testimony, the parent at home taking care of that child does a lot of work

Ms. MANDEVILLE Do you want to come home with me?

[Laughter]

Ms. MANDEVILLE. I cannot speak from having read that study. I am very glad to have heard that I did not participate in that study.

What I can speak to is from talking to so many families in our state The kind of supports that families need are as different as the number of families

The areas where the least amount of money has been spent and yet the greatest satisfaction seems to be among the families is when they have talked to someone in their area who is in char the respite care monies or something called a family support worker in their area, who is able to help them plug into existing resources or helps them articulate what their problem is and helps them find things

It doesn't cost much in the long run, because they are not trying to buy something, a brand new service, or reinvent the wheel, but they are just plugging into things that already exist.

In the sea coast area of our state, for example, they have a family support worker There was a family who were renting an apnea monitor for $200 a month The father had to take on a second job just to do that payment

The family support worker who started in that area last year, she got on the phone and in their little family bulletin or the bulletin that goes to all families' houses in their newspaper every week, he put a little blurb in there asking if anybody knew of anyone who had an apnea monitor

A family two towns down had one up in their attic that was sitting there They didn't need it anymore, but they didn't even think about anybody using it. She was able to get that to them.

It is that kind of simple, kind of family-directed, family-involved, sensitive, really hearing what the family's needs are and not trying to get the family to fit into the mold of the agency that really makes the difference

Families want—it isn't a power issue. We are not transferring, as was accused our family early on when we started asking for support and help, that we are having trouble coping with or grieving—we are stuck in grief and we are not accepting the diagnosis, and that is why the anger and frustration is coming out, because we really haven't accepted that James is severe.

Families can deal with grief and they can get used to reality pretty quick, but they want to be heard about what their needs are. In our particular area in Manchester that agency has been very marginal about really helping with respite kinds of needs

Most of the help that I have gotten is because I have put ads in the paper looking for respite people, I have talked to churches, I have talked to neighbors and we have established a circle of people who can help.

I have been able to in the past sometimes get some money out of the respite care program to pay for that person, but they haven't been very savvy about how to get to those people like I can, as a parent.

I think all of us, many of us who are willing to do that kind of thing, we can't get hung up in the bureaucracy. We can't be told that you've got to fill out fifteen forms, leave the application for three weeks, we'll be back to you with three people that you might want to interview. We need to get onto it.

We may have family members living in our area who would be ideal family respite people that can help with our family. We need the kind of flexibility and responsiveness that can really help us plug together, and that is where I think the family is responding That survey would really seem to be saying that—help us be involved. We can make it less expensive for you We can do a lot of the work ourselves, but there may be some mechanical and financial things that we are going to really need you for

When there is a good partnership at the local level those things happen without it being an issue

Chairman OWENS Did you give a figure before for how much it would cost in your son's case if he were put in placement?

Ms. MANDEVILLE. Somewhere between $65,000 and $90,000 a year

Chairman OWENS I thought I heard you say $65,000

Ms MANDEVILLE Yes

Chairman OWENS One final question Ms Cernoch, are there any respite care models that are particularly geared to meet the needs of families that are racially cultured and ethnically diverse that you know of?

Ms CERNOCH Yes, Mr Chairman Across the United States as we have been networking we have helped, for example, the state of New Mexico set up some respite care programs for the Indian reservations We are currently working with an agency here in Washington DC in trying to do some matches within interracial neighborhoods

So, yes, there are a few model pilot programs, but I think, as Ms Mandeville has said, the service needs to be at the local community

I think that local community can judge what types of services are important with the input from the families instead of some agency at the top level deciding, this is the way the program is going to be established, that we are going to run the program from nine in the morning to five in the evening. Suppose she needs it at six in the morning because her other child woke up and had to go to the emergency room?

You have to have that flexibility and working within that local community, which is what we do a lot at Texas Respite is go into the community and assess that community's needs. If it be a cultural need or a racial need or whatever else, that is all taken into account.

There are some model pilot programs out there right now.

Chairman OWENS. Thank you. We have been joined now by the Ranking Member of the committee, Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman Mr. Chairman and members of the panel, I very much apologize for not having been here this morning I have looked forward to this hearing for some time and have reviewed your testimony and I participated with the chairman in inviting some of the witnesses.

The Banking Committee, on which I also serve, began this morning the mark-up, which means the amendment process, for the passage of the FSLIC, so unless Congress resolves the FSLIC crisis I suspect we won't be able to talk about much funding for respite anyway.

Chairman OWENS Even after they resolve it, we had better beware.

[Laughter]

Mr BARTLETT. Even if we do resolve it

I am most impressed with the testimony I had this visit with Ms Cernoch and with what would regard as the premier network in the country, located in San Antonio.

It does occur to me that respite care is both new. It is not a new concept but it is a new concept as far as an organized concept It is a long-time need that families have attempted to fill for themselves and are now beginning to find ways to fill that need on a more organized basis

It is a lifesaver for both the children who are involved as well as the families themselves and the siblings It is also a money saver, and I think much of the testimony that was given here today, particularly by Dr Knoll, would demonstrate that money-saving ability of the enormous savings of allowing children to live at home with that small, little safety valve that respite care can give.

Dr. Cernoch, my question is, you have been running the network now for several years What in your opinion today are the principal sources for funding—not for funding a program, but for funding respite care by parents available in the United States today? What are the principal sources of federal funding, if any, and what are the principal sources of federal funding that should be that are now largely closed?

If you could change federal law in any way, what would you make available? What pot of money would you go after first?

Ms CERNOCH That's like having magic just put in front of me.

Mr BARTLETT This is Congress

[Laughter]

Ms. CERNOCH. Is that on the record? First of all, besides the Temporary Child Care Act of 1986, I am not currently aware of any other type of federal funding that is available except a grant out of the Administration on Developmental Disabilities to the state of Maine to do a statewide respite care service

For families the majority of the funding across the states that we have just looked at and networked informally—most of the funding right now comes either from state revenue dollars, local communities and private foundations.

There is very little in the way of federal dollars to my knowledge, at least, through our informal networking that is available in this area, specifically designed as respite care dollars.

There are federal dollars out there but for some reason it is masked and we can't tap into it. Programs can't tap into it. Families can't tap into it. You know, it might be under a different terminology or something of that nature.

What we have found in our networking is that many times the families particularly that are on Medicaid or some other type of state subsidy dollars can get more support services than a family like Kathy's. It is our middle class Americans out there that desperately need the services. They are a little too poor to qualify for Medicaid but they are not poor enough to sometimes provide these support services.

Mr. BARTLETT. Mr Bergman?

Mr. BERGMAN. If I may, Representative Bartlett. I am Allan Bergman, for the record, with United Cerebral Palsy We have done an exhaustive analysis of the potential—and I want to underline potential—federal funding streams that could be applied to respite or family support services

They are not many but for the record, such as Ms. Cernoch's program, the State Developmental Disabilities Council under the Developmental Disabilities Assistance and Bill of Rights Act can do pilot projects, start-up initiatives leading toward a policy change at the state level, not long-term funding but to get it started. In fact, in most states we believe the DD Councils have played a major role in the state initiatives.

The Title XX Social Services Block Grant Program again potentially could fund but, as I think all the members of this committee know, that has been a capped or limited program for a number of years in terms of any increased appropriations, and most of that does not go to respite. It goes to day care. It goes to day services for seniors and things of that nature

Some of the means-tested programs like the Title IV-E program under the Welfare programs, which has a family prevention, foster family support kind of component to it.

The other major federal stream that could do some family support is community development block grants, which could pay for renovations to the home and adaptations to the home. That, again, is done in some communities in your state, in Austin The United Cerebral Palsy there has a very significant program of renovating peoples' homes so they can live at home So that is a piece of it It is not the respite I would like to clarify, though, for the record, and I think the committee members did earlier, when it was alluded to by the administration that special education is a major component of family support.

P.L. 94-142 certainly looks at the child within the context of a five or six hour school day. It does not look at twenty-four hours, seven days a week. The only piece of that that is available is under the new Part H authority of 99-457, where you did—and we appreciate that—talk about the family support component.

Again, I think it is too early to tell, but potentially some family support services, we think, could be funded under the umbrella of the Infant, Toddler, Family program.

To the best of our knowledge those are the federal funding streams that are potentially applicable other than, as Jennifer pointed out, the Medicaid or medical assistance program, which certainly has the institutional bias and is a means-tested program.

Mr. BARTLETT. One follow-up question. If you were designing a system that provided for long-term funding or day-to-day funding of respite services, leaving aside whether it was—you put in your testimony you would make it flexible, so some would be in specific locations such as your hospital- based, some would be in the family's home and elsewhere

My question is, would you include a portion of that for copayment by the parents?

Ms. CERNOCH. Oh, definitely. In the three model pilot programs that we have developed—Texas Respite was asked to develop these programs to test the feasibility of program structure and cost effectiveness for possible replication not only in the state of Texas but throughout the United States

One of the things, before we set up these pilot programs, instead of us as an agency setting up the parameters we went to the families and said, what do you want? This will be your program

Almost ninety-six percent of families came back and said, I want to pay for part of this service I don't want it as free I don't want for it to be like a welfare program to me I might not be able to pay a lot

In our program I have some families that pay me twenty-five cents an hour, but they are so proud of that payment because they are not getting anything free They don't want charity and they don't want welfare.

We have a $10 registration fee in our programs that we set up not as a money maker, and it doesn't really pay for anything, but it is their membership into the program

I had one mother who has severely handicapped triplets. Two of them are on apnea monitors and one is on a ventilator Two have gastro tubes and one has a tracheostomy.

She came to me and she said, is it $30 or do I just get the bargain of the day at $10 as the registration fee?

We said that we would just charge her $10 She did not have that $10. She paid that $10 off in nine months, giving us like a $1.00 or $1.25 a month, but in the interim she was able to use the respite care services. We didn't deny her the services because she couldn't pay the money

Everybody kept saying to me, she will never pay it This family will never pay it They did It took them nine months, but they paid that $10 That, I think, is so important to the integrity of the family, to be able to pay whatever the copay would allow them to do.

Mr. **Bartlett**. Thank you

Chairman **Owens**. I want to thank the members of the panel We have learned quite a bit that can be useful as we move forward—I m sorry, Mr. Payne

Mr **Payne**. Once again, I am spending the afternoon and morning apologizing. I certainly will not delay the hearing any longer If there are some questions I have, I will submit them in writing

Thank you. Mr. Chairman

Chairman **Owens**. Thank you Thank you again for coming

The hearing is now adjourned.

[Whereupon, at 12:35 p m , the subcommittee was adjourned ]

[Additional material submitted for the record follows ]

TESTIMONY
OF
CONGRESSMAN GEORGE MILLER
Chairman
Select Committee on Children, Youth, and Families

submitted to the
SUBCOMMITTEE ON SELECT EDUCATION

for the hearing on the reauthorization of the
"Temporary Child Care for Handicapped Children
and Crisis Nurseries Act"
April 18, 1989

Chairman Owens and Members of the Subcommittee,

I appreciate the opportunity to submit testimony on behalf of the "Temporary Child Care for Handicapped Children and Crisis Nurseries Act," and urge continuation of these two important child care demonstration programs: temporary child care for handicapped and chronically ill children, and crisis nurseries to provide short-term child care for young children who are potential victims of child abuse and neglect.

The Subcommittee is to be commended for the action you've taken previously to extend these child care programs, which are among the most successful and cost-effective child abuse prevention strategies in operation.

This Committee first authorized these programs as Title II of the Children s Justice Act in August of 1986, and appropriations were approved for FY 1988. The Department of Health and Human Services did not release the funds, however, until the very end of the fiscal year

We've been waiting for almost three years now to see these proven abuse prevention programs approved, funded, and implemented. While we were waiting, the number of child abuse victims, including children who died as a result of abuse, has continued to escalate.

Between 1980 and 1986 alone, according to the Department of Health and Human Service's own study, the actual incidence of child abuse and neglect rose 64% -- and using their revised definition, child abuse rose 150% during this time period.

Just last month, the National Committee for the Prevention of Child Abuse (NCPCA) reported that in 1988, more than two million children were reported as abused or neglected -- a 3% rise just since 1987. My own state of California reported the highest increase -- 26% -- among the 41 states responding to the survey Colorado, Massachusetts, and New York also are among the states with the highest increases in child abuse reports between 1987 and 1988.

The severity of child abuse has also been intensified according to NCPCA. In 1988, reported child deaths from abuse exceeded 1,200, a 5% increase in just one year. In addition, over two-thirds of the states reported that drug and alcohol abuse were predominant characteristics among child abusers. Based on these findings, the National Committee recommended expansion of child abuse prevention services including respite care.

The National Committee's recommendations reaffirm the Select Committee on Children, Youth, and Families' finding that respite and child care play a major role in alleviating stresses that so many families now face, stresses which are often precursors to abuse.

Families with a disabled child are at even higher risk for abuse, especially when social and family supports are absent, which is frequently the case. Even many hospitals, which often have the frequent contact with families of disabled or chronically ill children, are not able to provide or refer for needed respite. In a recent survey of almost 300 children's hospitals and general hospitals with pediatric units in the U S and Canada, only 14% reported that they provided respite care or arranged for respite services in the community.

The Select Committee has also documented that the overburdened social services system is contributing to the escalating child ragedy. Now more than ever, families need support to p the abuse *before* it occurs.

## Cost-Benefits of Respite Care

I have reported previously that respite care is an investment that can reduce family stress and the abuse that may result. In addition, respite services have been shown to prevent more costly institutionalization

New findings from a nationwide survey of parents with disabled family members reaffirm those statements -- that a primary reason families use respite is to relieve emotional stress and that for most of them, respite allows them to continue to care for their disabled family member at home

Crisis nursery services can also save money by avoiding foster care or institutional placements:

** It costs about $1,200 each year to provide crisis nursery care for one child and support services for the family at one program in Oregon The average yearly cost to keep a child in foster care in Oregon is $3,753.

** In California, it has been estimated that an average investment of $400 per month in crisis nursery child care can prevent an expenditure as high as $4800 per month per child for an institutional placement.

## Select Committee Survey Findings

We have waited so long to see these programs put into place. Families have been waiting far longer In our eagerness and concern to see how states would respond, I asked Select Committee staff to survey the 28 states that recently received FY 1988 "Temporary Child Care/Crisis Nursery" funds.

We were delighted to learn of the considerable excitement and creativity with which States are approaching these programs While many of them are still in the process of releasing funds to local programs, most have taken or are planning to take innovative approaches to working with particularly underserved children and families. Nevertheless, most striking was states' overwhelming sentiment that the resources made available through these two programs will be able to fill only a fraction of the enormous need.

Let me tell you more specifically what our informal survey revealed:

## TEMPORARY CHILD CARE

*States are finding that the need for respite services for families of disabled, chronically ill and emotionally disabled children is as great or greater than expected.*

** **Florida:** "The response to a public awareness campaign for families of chronically ill children was overwhelming -- ten times the expected number. We found a number of families in severe stress."

** **Alabama:** "In Birmingham, there is so much need -- families are worn out."

** **Tennessee:** "It is desperately needed. Parents are trapped in their own homes..." Referrals started coming in when the announcement was made that there would be a respite program.

Consistent with the provisions of the Act, many states are serving populations previously not served by respite care programs, including chronically ill or severely emotionally disturbed children, very young children, or families in isolated rural areas.

** The California respite care demonstration, to be based in Los Angeles where there are 10,000 child abuse reports monthly, will intervene early with families who have a disabled or medically fragile infant or toddler to reduce referrals to child protective services and hospital emergency rooms.

** **Florida, Tennessee, Vermont, and Virginia** will be serving families with emotionally disturbed children exclusively or children with multiple disabilities, including emotional disturbance.

** **Massachusetts and New York** will provide respite exclusively to chronically or terminally ill children with AIDS or HIV-related illness.

** **Colorado, Florida, Illinois, Nebraska, New Hampshire, and Virginia** plan to include chronically ill children among those eligible for respite care.

**Arkansas and Colorado** will target respite services exclusively in rural areas, where they have determined the need to be greatest.

CRISIS NURSERIES

States report that the crisis nursery grants are creating ways to respond to parents under stress before damage is done and before removal of children from the home becomes necessary. But they also report that the need is overwhelming, especially for special populations.

** Several of the states with existing but limited crisis nursery or abuse prevention programs reported waiting lists: A program in **New Jersey** has maintained 20 children and **Oregon's** Lane County Relief Nursery has had 90 children on waiting lists; **Ohio** has previously had to turn away one out of every two requests and their new, expanded program filled up immediately.

** In **Los Angeles County**, where the largest increase in reports of child abuse and neglect over the last three years has been among infants under age one, the proposed crisis nursery will address the needs of drug-exposed infants, who are at high risk for abuse, and their mothers "to reduce the need for costly, inadequate, and ineffective out-of-home placement ..."

Allow me to report on some of the innovative ways states are using the demonstration grants for temporary child care and crisis nurseries:

### Training and Developing Parent Support Networks

** A majority of states, **Arkansas, California, Hawaii, Idaho, Illinois, Kansas, Maryland, Massachusetts, Michigan, Nebraska, New Hampshire, New York, North Carolina, Oregon, Pennsylvania, Tennessee, Utah, Vermont, and Virginia** are funding projects which will train professionals, paraprofessionals and/or parents in working with the special needs of the population served. This will not only greatly expand the pool of providers, but will upgrade existing services as well.

** Networks or exchanges to provide respite care through recruitment of neighborhood providers, parents, and foster parents are being developed or strengthened in **Illinois, Massachusetts, Michigan,** and **New Hampshire** so that parents of disabled children will have a peer-support system

** **Arkansas, Hawaii, Idaho, Illinois, North Dakota** and **Virginia** are developing similar parent support and community networks to reduce isolation among families at risk of abuse.

### Variety of Crisis Nursery Services Developing

In addition to parent networks and support groups, states are expanding other services to foster parent responsibility and family strength, thus developing a system of long-term prevention as well as short-term crisis relief

** **California, New Jersey, Oregon,** and **Washington** include intensive training and therapeutic work with parents while their children are in short-term care.

** **California** also has a warmline for parents needing advice and support.

** **North Dakota** will be able to provide case management to families who have not yet been reported to child protective services, to prevent abuse from occurring in the first place.

### Improved Coordination

** **Alabama, Colorado, Nebraska, New Hampshire, North Dakota, Vermont,** and **Virginia** report that the demonstration funds will provide new opportunities for states and local human service agencies to change their delivery systems and the way services are coordinated and integrated to better serve at-risk families

### Future Funding Needs

Finally, states reported on their future funding needs:

In a few of the states, the intent of the legislation -- to more significantly involve states in funding respite care or crisis nurseries on their own -- may be taking hold, but in others, current resources may simply be too limited

** In **Kansas** and **Pennsylvania**, the grants are providing start-up assistance It is anticipated that programs will be continued with state and private funds

** In **Tennessee**, they expect the new respite model to be incorporated into three family support pilots which currently do not provide respite care

However, since most of the temporary child care or crisis nursery programs are targeted to limited areas of a state (only two have statewide programs), large segments within states are left with no services whatsoever.

** **Ohio:** "My problem now is how to continue this program and what to do with the other 87 counties in the state."

** **North Dakota:** "Funding for another quarter of the state could more clearly show the need to the legislature by showing the reductions in cases "

Up until now, states have had limited funds for prevention, and many have been forced to cut back, rather than expand or establish these kinds of services

** **Arkansas:** Respite care is low on the state priority list, but "the need is so great.'

** **Oregon:** Because the Lane County Relief Nursery was considered to be neither prevention nor treatment, it was difficult for them to obtain funding from the state.

** **Alabama:** 'Money for respite care has not been a priority There is some money available, but it is limited

** **Massachusetts:** "It is very difficult to start such a service [respite care for families of AIDS/HIV children] and then have to stop The state is in no position to fund it now Funds are needed both to continue this program and to expand as the number of cases increase "

For many states more time is needed to demonstrate need and/or effectiveness of the programs:

** **Illinois:** "We have not had time to develop credibility and/or plan for the legislature to pick up the respite care program."

** **New York:** 'It takes a year to get a program started and another to demonstrate its effectiveness "

** **Michigan:** 'It takes a minimum of three years to get a program far enough along to be able to demonstrate itself so it can be picked up by the state or other agencies "

** **New Jersey:** "Start-up time for infant child care [for a crisis nursery] is taking much longer than expected It will barely have a solid start when the funding ends '

Child Abuse Prevention Challenge Grants

In addition to to respite and crisis intervention services, states are exploring other innovative approaches to child abuse prevention stimulated by Child Abuse Prevention Challenge Grants (P L 98-473), and I support the program s reauthorization.

Despite its success, however, not all states participate in the program and in many of those states which do, only a fraction of qualified efforts are able to be supported due to limited funding As more and more children are abused, states are forced to devote limited resources to treatment needs at the expense of prevention

I urge you to reauthorize the challenge grant program so that we might preserve and expand upon the critical prevention efforts it has fostered.

Conclusion

I want to thank you for your farsightedness in initially authorizing temporary child care and crisis nursery programs, and for your continued support. What we have now are very promising beginnings, but millions of families still receive no respite services

The General Accounting Office, in a national respite care study requested by this Subcommittee and the Select Committee on Children, Youth, and Families, provided testimony on their very preliminary findings regarding the availability and administration of respite services in five of the largest state but was unable at this stage of the study to discern whether or not the supply was adequate to meet families' needs for services. Evident from these preliminary findings, however, was the minimal involvement of the federal government.

Consequently, I urge you to extend the authorization of the 'Temporary Child Care for Handicapped Children and Crisis Nursery" demonstraton programs for two years at $20 million each year giving priority to states and programs that received funds in FY 1988 and FY 1989. By extending the resources to build on the best of the already initiated programs, states will have a better basis on which to determine the need, demonstrate the impact these services have on saving lives and dollars too, and enable families who had remained unserved because of limited resources to participate in the benefits of respite care. I look forward to the results of these demonstration programs, as well as the final GAO report, so that we will be better able to formulate a comprehensive and far-reaching policy that addresses the unmet needs of families.