The Family Opportunity Act of 2000
Organizations of Support
as of 7/19/00

American Academy of Pediatrics (AAP)
American Academy of Child and Adolescent Psychiatry
Adapted Physical Education Council
American Association for Marriage and Family Therapy
American Association of University Affiliated Programs
American Association of Mental Retardation
American Association of Pastoral Counselors
American Association of School Administrators
American Counseling Association
American Congress of Community Supports
Association of Educational Services Agencies
American Family Foundation
American Federation of Teachers (AFT)
American Group Psychotherapy Association
American Music Therapy Association
American Network of Community Options and Resources (ANCOR)
American Nurses Association
American Occupational Therapy Association
American Psychiatric Association
American Psychological Association
American Therapeutic Recreation Association
American Psychoanalytic Association
American Association of People with Disabilities
American College of Osteopathic Pediatricians
American Academy of Child & Adolescent Psychiatry
American Physical Therapy Association
Anxiety Disorders Association of America
Association of Maternal and Child Health Programs
Autism Society of America
American Congress of Community Supports and Employment Services (ACCSES)
Bazelon Center for Mental Health Law
Brain Injury Association
Consortium for Citizens with Disabilities (representing 115 groups)
Child Welfare League of America
Children's Defense Fund (CDF)
Council of Great City Schools
Children and Adults with Attention Deficit Disorder
Consortium of Developmental Disabilities Councils

Cystic Fibrosis Foundation
DuPont Hospital for Children
Disability Rights Education and Defense Fund (DREDF)
Epilepsy Foundation
Mile High Down Syndrome Association
National Association of Mucopolysacchridosis (MPS) Society
National Association of Children's Hospitals (NACHRI)
National Disability Network
National Downs Syndrome Congress
National Depressive and Manic Depressive Association
National Association of School Nurses
National Association of Pediatric Nurse Practitioners and Associates
National Rural Education Association
National Association of State Directors of Special Education (NASDSE)
Easter Seals
Family Voices
Federation of Families for Children's Mental Health
Federation of Behavioral, Psychological and Cognitive Sciences
Federation for Children with Special Needs
International Association of Psycho-Social Rehabilitation Services
Justice for All
March of Dimes
Mental Health Liaison Group
National Education Association (NEA)
National Council on Independent Living (NCIL)
National Association of Anorexia Nervosa and Associated Disorders
National Alliance of the Mentally Ill (NAMI)
National Association of Developmental Disabilities Councils
National Association of County Behavioral Health Directors
National Association of People With Aids
National Association of Psychiatric Health Systems
National Association of School Psychologists
National Association of Social Workers
National Down Syndrome Society
National Center on Disability and Health
National Association of Psychiatric Treatment Centers for Children
National Association of Protection and Advocacy Systems (NAPAS)
National Association of State Mental Health Program Directors
National Council for Community Behavioral Health
National Mental Health Association (NMHA)
National Therapeutic Recreation Society
National Parent Network on Disabilities

Rehabilitation Engineering Society of North America (RESNA)
Research Institute for Independent Living
National Shaken Baby Alliance
The ARC of the United States
The National Adoption Center
United Cerebral Palsy Association
Voice for Adoption
Washington Business Group on Health
World Institute on Disability

American Academy of Pediatrics

Reply To:
Department of Federal Affairs
American Academy of Pediatrics
The Homer Building
601 Thirteenth Street, NW
Suite 400 North
Washington, DC 20005
202/347-8600
800/336-5475
Fax: 202/393-6137
e-mail: kids1st@aap.org
http://www.aap.org

March 22, 2000

Honorable Charles Grassley
United States Senate
Washington, DC 20510

Honorable Edward Kennedy
United States Senate
Washington, DC 20510

Dear Senators Grassley and Kennedy:

On behalf of the 55,000 pediatrician members of the American Academy of Pediatrics (AAP), I write to express our gratitude for your leadership in developing the Family Opportunity Act of 2000. The AAP is pleased to support this important legislation.

Universal health care coverage for all children should be our National standard and is the goal of the AAP. The Family Opportunity Act of 2000 moves us closer to that objective.

As pediatricians, we know that children with disabilities have specific medical needs that are frequently not accessible through private health care plans. The Family Opportunity Act provides an avenue for middle income families who have children with severe disabilities to buy in to Medicaid health care coverage on a sliding scale. No family of a child with severe disabilities should have to choose between poverty and health care coverage for their child with special health care needs. And Medicaid is the only health care benefit that ensures access to the medically necessary services that a child with a disability's medical condition requires.

In addition, this legislation establishes Family-to-Family Information Centers, which will provide an essential link for families who need assistance and information for their child with disabilities and/or special health care needs. Another important component of this bill is the demonstration provision. This will allow states to develop ways to assist families of children with disabilities before those children become severely disabled.

We are grateful for your efforts on behalf of children with disabilities and their families. The American Academy of Pediatrics welcomes the opportunity to work with you toward passage of this important legislation.

Sincerely,

Donald E. Cook, MD

Donald E. Cook, MD, FAAP
President

DEC:eb

National Association of
Children's Hospitals

LAWRENCE A. McANDREWS, FACHE
President & Chief Executive Officer

N • A • C • H

May 30, 2000

The Honorable Charles Grassley
The Honorable Edward Kennedy
United States Senate
Washington, DC 20510

Dear Senators Grassley and Kennedy:

The National Association of Children's Hospitals (N.A.C.H.) is pleased to support S. 2274, the "Family Opportunity Act of 2000." This bipartisan legislation – if enacted - will break the link between forced poverty and Medicaid by allowing middle-income families with disabled children the opportunity to buy-in to Medicaid health care coverage on a sliding scale.

Ten percent of all children, or nearly 8.5 million children nationwide, experience a disorder or activity limitation as a result of a chronic physical or mental condition. Two percent of all children, or 1.5 million, have a congenital or chronic condition that requires extensive health services. This makes them especially vulnerable to preexisting condition exclusions or other limits on private health care coverage. A study completed by Family Voices and Brandeis University documents that Medicaid is the best benefit package for children with special health care needs – and the only program that can provide the comprehensive services these children require.

But for too long families of children with disabilities have had to choose between access to good jobs and advancement in the workplace, and their children's health care needs. That is why your legislation is so important. N.A.C.H. believes that your bill takes a pragmatic and responsible approach to offering families potential access to Medicaid's comprehensive benefits package, and assistance in accessing current information about services and supports available for their children through Family-to-Family Information Centers.

We greatly appreciate your efforts on behalf of children with disabilities and their families. We welcome and look forward to the opportunity to work with you toward passage of this essential legislation.

Sincerely,

Lawrence A. McAndrews

Lawrence A. McAndrews

cc: David Alexander, M.D., Raymond Blank Memorial Hospital for Children
David Weiner, Boston Children's Hospital
Connie Gardner, Office of Senator Kennedy
Hope Hegstrom, Office of Senator Grassley
Cate McClain, Office of Senator Grassley

duPont
HOSPITAL FOR CHILDREN

1600 Rockland Road
P.O. Box 269
Wilmington, DE 19899
302 651 4000
http://KidsHealth.org

June 8, 2000

The Honorable William V. Roth, Jr.
U.S. Senate
104 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Roth:

The mission of children's hospitals across the country is to provide access to quality health care for all children. In the past, we have sought your support for initiatives that would better enable our institutions to fulfill that mission.

I am writing to you today to urge your support for an important bipartisan bill that will enable families of children with disabilities, both in Delaware and across the country, to fulfill their personal missions: to provide their children with the quality health care services they require. Senators Charles Grassley and Edward Kennedy have introduced S. 2744, the "Family Opportunity Act of 2000," which creates a state option allowing families of children with special health care needs to purchase Medicaid coverage on a sliding scale, regardless of their income level. In effect, it affords to the working parents of children with special needs the same incentive to work hard and achieve as the "Work Incentives Act of 1999" offered to adults with disabilities.

Every day, children in the United States are born with severe disabilities that require specialized health care services. A recent study documents that Medicaid is the best benefit package for children with special health care needs – and the *only* program that can provide the comprehensive services these children require. S. 2744 could help an estimated 250,000 children nationwide, if all states took advantage of it.

But for too long families of disabled children have had to choose between access to good jobs and advancement in the workplace, and their children's health care needs. At a time when our country is experiencing such bountiful economic prosperity, it is a tragedy that families of children with special needs should continue to live at or near the poverty line in order to gain and maintain access to the Medicaid benefits their children need. That is why the Family Opportunity Act is so important. By taking a pragmatic and responsible approach to offering families potential access to Medicaid's comprehensive benefits, the Family Opportunity Act breaks the link between forced poverty and access to Medicaid.

The NEMOURS FOUNDATION

Alfred I. duPont Hospital for Children
Wilmington, Delaware

Nemours Children's Clinic
Wilmington, Delaware

duPont Pediatric Practices
Delaware

Nemours Health Clinic
Wilmington, Delaware

Nemours Children's Clinic
Ft. Myers, Florida

Nemours Children's Clinic
Jacksonville, Florida

Nemours Children's Clinic
Orlando, Florida

Nemours Children's Clinic
Pensacola, Florida

Nemours Center for Children's Health Media

Nemours Education Programs

Nemours Research Programs

Nemours Mansion & Gardens

Partners in Pediatrics
The Nemours Foundation
Clinical Care Health System
Florida Jefferson University

I seek your support for this measure because it will do nothing less than help more disabled children in our community and across the country have access to the best possible treatment and therapies available while making it possible for their parents to fulfill their employment potential. I respectfully urge you to join 35 of your colleagues in supporting S. 2744 and moving it through the Finance Committee.

Sincerely,

Thomas P. Ferry
Administrator/CEO

cc: John Duncan, Office of Senator Roth

AMERICAN
PSYCHOLOGICAL
ASSOCIATION

May 1, 2000

The Honorable William Roth, Chairman
Senate Finance Committee
United States Senate
Washington, DC 20510

Dear Senator Roth:

I am writing on behalf of the 159,000 members and affiliates of the American Psychological Association (APA), the largest association of psychologists worldwide, to urge you to hold a Senate Finance Committee hearing and a mark up on the ***Family Opportunity Act of 2000 (S. 2274)***.

The Family Opportunity Act, as introduced by Senator Charles Grassley, would enable middle-income families of children with disabilities to access health and mental health services for their children, without having to become impoverished. Under current law, many families of children with disabilities risk financial hardship in order to provide health care to their children with special needs. In some traumatic instances, families have been compelled to relinquish custody of a child to a state agency in order to access intensive mental health and support services in a residential facility. APA supports S. 2274, which addresses these concerns by allowing middle-income families with children who have severe mental or physical disabilities to "buy-in" to the Medicaid program. Medicaid benefits would also promote early intervention, access to medically necessary services, and family stability.

Child and family concerns are especially important to our membership. Seven of APA's divisions and significant elements of the organization's governance structure are devoted specifically to children and child development. The work of psychologists has played a pivotal role in our society's understanding of the social, emotional, and physical development of children and youth. In particular, APA members have a long history of involvement in researching and treating mental disorders in children, and APA has long supported efforts to increase access to needed child health and mental health services.

As an organization that shares your commitment to children and families, we urge you to conduct a hearing and mark up in the Senate Finance Committee in a timely manner. If you have any questions, please contact Daniel Dodgen, Ph.D., of our Public Policy Office at (202) 336-6068.

Sincerely,

Henry Tomes, Ph.D.
Director for Public Interest

CC: Members of the Senate Finance Committee

750 First Street, NE
Washington, DC 20002-4242
(202) 336-5500
(202) 336-6123 TDD

Web www.apa.org

National Association of School Nurses

EASTERN OFFICE
[illegible]

WESTERN OFFICE
[illegible]

[illegible]

June 9, 2000

The Honorable Edward Kennedy
United States Senate
Washington, D.C. 20510
ATTN: Connie Garner

Dear Senator Kennedy:

On behalf of the National Association of School Nurses (NASN), I am writing to express our support, as well as our appreciation, for your sponsorship of S. 2274, the Family Opportunity Act of 2000.

We are pleased with the intent of this bill, which seeks to keep families together. It allows those who live near the poverty level to progress in their careers and salaries without fear of losing vital health care coverage for their disabled children. The fact that any family is forced to make a choice between health care coverage and being able to better provide for their children is a tragedy. Congress has witnessed an unintended consequence of well-meaning regulations, and we value your leadership in addressing this matter and in attempting to correct this issue.

Again, NASN, which represents thousands of school nurses who deal with disabled children on a daily basis, is supportive of this legislation and is excited about its potential benefits to families. We are happy to work with you in any way we can to help promote enactment of this important bill.

Sincerely,

Judy Robinson

Judy Robinson, PhD, RN
Executive Director

National Association of State Directors of Special Education, Inc.
King Street Station I, 1800 Diagonal Road, Suite 320, Alexandria, VA 22314
Tel: 703/519-3800 • Fax: 703 519-3808 • TDD: 703/519-7008

June 20, 2000

The Honorable Edward Kennedy
315 Russell Senate Office Building
Washington, DC 20510

Dear Senator Kennedy:

The National Association of State Directors of Special Education (NASDSE), a professional organization representing the state administrators of education programs for children and youth with disabilities in the 50 states and federal jurisdictions, is pleased to announce its support for S. 2274, the "Family Opportunity Act of 2000."

This legislation addresses a critical need for thousands of families with children with severe disabilities. Families with special needs children all too often are forced to make employment decisions based on their need to stay in the income bracket that qualifies their child for SSI and/or Medicaid. Your legislation recognizes the concerns of these families by enabling states to offer Medicaid coverage to children with severe disabilities living in middle-income families through a buy-in program. This legislation also will enable school districts to count these children as Medicaid-eligible for purposes of providing supports and services. This will make Medicaid funds available to schools and school districts to cover a portion of the cost of these services, and enable the school district to allocate a portion of its expenses to Medicaid administrative costs.

NASDSE members are pleased that your legislation also establishes family-to-family health information centers where families can obtain information and support from other families in similar circumstances.

NASDSE thanks you for your continued support for families with children with special needs and we look forward to working with you and your staff for passage of S. 2274.

Sincerely,

Bill East

Bill East
Executive Director

Cystic Fibrosis Foundation

June 1, 2000

David Bowen

The Honorable Edward Kennedy
U.S. Senate
315 Russell Building
Washington, DC 20510

Dear Sen. Kennedy:

On behalf of children with cystic fibrosis (CF), we would like to thank you for introducing your bill to provide medical assistance to families with disabled children. The Family Opportunity Act of 2000, S. 2274, will provide much-needed medical assistance to families who have young children with CF but who do not qualify for Medicaid due to income limitations. The ability for these families to purchase Medicaid coverage will enable them to obtain vital health care for their children.

As a genetic disease, CF affects people regardless of income or insurance coverage. Nearly two-thirds of people living today with CF are children; the median life expectancy has now grown to 32 years. Access to medical specialists who treat CF has been a central facet to the increased lifespan for people with CF from early childhood in the 1950s to the mid-thirties today. Children with CF whose families are unable to afford health insurance, but whose incomes exceed requirements for Medicaid, are denied the opportunity to reap the benefits of improved health care for this disease. These children may be denied a future as well. We appreciate your efforts to make sure that more children with disabilities can access medical care to restore that future to them.

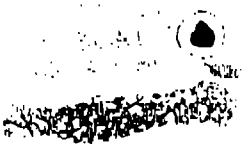
We also support the bill's requirement for families to purchase employer-sponsored insurance. We believe it is critical to create incentives to ensure that the private insurance market will continue to play a strong role in providing comprehensive health insurance for families with disabled children.

We welcome your attention to the medical needs of children with disabilities and we look forward to working with you to secure passage of this bill this year.

Sincerely,

Robert J. Beall, Ph.D.
President and CEO

National Office
6931 Arlington Road Bethesda, Maryland 20814
(301) 951-4422 (800) FIGHT CF (800) 344-4823 Fax: (301) 951-6378 Internet: www.cff.org E-mail: info@cff.org



Children's Defense Fund

March 21, 2000

The Honorable Charles Grassley
135 Hart Senate Office Building
Washington, DC 20510

The Honorable Edward Kennedy
315 Russell Senate Office Building
Washington, DC 20510

Dear Senators Grassley and Kennedy:

The Children's Defense Fund is pleased that you will be introducing the Family Opportunity Act of 2000 to make Medicaid available and affordable for families with children with disabilities. The proposal also creates a Medicaid demonstration program to provide care for children with potentially severe disabilities and to establish family-to-family health information centers to assist and support families of children with disabilities or special health care needs.

Many families with children who meet the federal disability rules cannot qualify for Medicaid coverage, and the critical services Medicaid covers for children with special health care needs, because they earn too much to qualify for the program. At the same time, those families that do qualify for Medicaid stand to lose coverage if they get raises or better paying jobs making their income too high for Medicaid. Your proposed legislation provides relief to families in both these circumstances by giving states the option to let these families buy into the Medicaid program.

The demonstration component of your proposal is important because it would provide care and services for children who are not so severely disabled to meet current disability criteria for Medicaid eligibility but who are likely to become so disabled without medical care.

Building on the current Children's Health Insurance Program (CHIP) and Medicaid, your proposal represents another critical step in providing coverage to a group of families and their children who otherwise are unable to get or afford coverage or whose coverage excludes or limits needed services. The Children's Defense Fund appreciates the bipartisan leadership you are providing on this important issue and stands ready to support your efforts to pass the Family Opportunity Act of 2000.

Sincerely,

Gregg Haifley
Deputy Director, Health Division

25 E Street NW
Washington, DC 20001
Telephone 202 628 8787
Fax 202 662 3510
E-mail
cdfinfo@childrensdefense.org
Internet
www.childrensdefense.org

WASHINGTON BUSINESS GROUP ON HEALTH
--- North Capitol Street, N.E. Suite 800 • Washington, D.C. 20001
202.408.9320 • Fax 202-408.9332

WBGH

March 20, 2000

The Honorable Charles E. Grassley
The Honorable Edward F. Kennedy
United States Senate
Washington, D.C. 20510

Re: Family Opportunity Act of 2000

Dear Senator Grassley and Senator Kennedy:

On behalf of the Washington Business Group on Health (WBGH), a non-profit research organization made up of Fortune 500 and large public sector employers, we would like to express our support for the principles embodied in the Family Opportunity Act of 2000. As you know, WBGH has historically been a strong voice in the employer community and remains so with a membership of 150 of the nations largest and most innovative employers. WBGH's members provide health coverage for more than 39 million U.S. workers, retirees, and their families.

The Family Opportunity Act of 2000 permits states to allow middle-income parents of children with serious physical and mental disabilities to "buy-in" to the Medicaid program. It also provides for demonstration programs where states can choose to cover children who would become seriously disabled absent health coverage. WBGH supports these two important goals. Our employer members know it can be extremely difficult and time consuming for working parents to access the care needed to meet the needs of children with physical or emotional/behavioral disabilities. Lack of adequate health coverage can also interfere with the ability of families recently entering the workforce from welfare to maintain newly-acquired employment. Working parents should not have to choose between access to good jobs and advancement in the workplace and the need to assure that their children receive the health care that they need

We share your interest in increasing the availability of appropriate physical and mental health care for the children of working parents. We also believe that the demonstration projects could provide early intervention to prevent more serious disabilities as children mature. We appreciate this important work and look forward to working with you and your staffs on these vital efforts.

Sincerely,

Mary Jane England

Mary Jane England, M.D.,
President

national down syndrome society
ndss
Education. Research. Advocacy.

March 22

The Honorable Charles E. Grassley
The Honorable Edward M. Kennedy
United States Senate
Washington, DC 20510

Dear Senators Grassley and Kennedy:

The National Down Syndrome Society is a national non-profit organization founded in 1979 to ensure that all people with Down syndrome have the opportunity to achieve their full potential in community life. NDSS works to increase public awareness about Down syndrome and to improve the lives of individuals with Down syndrome and their families through education, research and advocacy.

We are pleased to write in support of the Family Opportunity Act of 2000, which we understand you will be introducing today. Your support for addressing the health care needs of children with significant disabilities through this extremely important legislation is very much appreciated. The Family Opportunity Act of 2000 would help ensure that more children with significant disabilities have access to medically necessary health care The bill's comprehensive approach would allow middle income families to purchase Medicaid coverage for their children with severe disabilities; authorize a demonstration program to allow states to extend Medicaid coverage to children with potentially severe disabilities; and establish Family to Family Information Centers to help families access health services. This legislation will have a direct and positive impact on many children with Down syndrome and their families across the country.

As you well know, a recent family survey of 20 states indicates that many families "are forced to stay impoverished, become impoverished, put their children in out of home placements, or simply give up custody of their children – so that their child can maintain eligibility for health care coverage through Medicaid." Families often are not able to obtain private health insurance for their child with significant disabilities. Many employer health plans and a number of government programs do not cover essential services. Families often incur huge out of pocket expenses for services such as occupational, physical and speech therapy, home and community–based services, and customized durable medical equipment. Medicaid ensures access to the comprehensive, medically necessary services that a child's medical condition requires.

666 Broadway • New York, NY 10012-2317 • 212-460-9330 or 800-221-4602 • Fax: 212-979-2873 • www.ndss.org

The Family Opportunity Act takes a bipartisan, fiscally responsible approach to addressing these critical problems. Each state will decide whether or not to implement the buy-in program. If so, the state will decide its premium rates using a sliding scale based on the families' income. The bill requires parents to take employer-sponsored family coverage (if available) but allows them to buy into Medicaid to "supplement" the employer benefit package. This bill will be cost-effective, since families will not need to receive Supplemental Security Income (SSI) in order for their child with special needs to receive health care coverage. Also, with appropriate, affordable health care, families will be able to keep their children at home – instead of giving up custody, placing them in out of home placements or in institutions at a high cost to the taxpayer.

Making Medicaid available to qualified children with significant disabilities will allow their parents to become employed and rise out of poverty. It will allow families to buy and keep their homes and save to meet the educational and other needs of their children. It will allow children with significant disabilities to receive the health care they need and grow up with their families in their own communities.

We appreciate the many opportunities your respective staffs have provided for our organization and others to work with you in developing this critical legislation. We look forward to continuing to work with you to pass the Family Opportunity Act of 2000

Sincerely,

Arden Moulton

Arden Moulton
President

THE FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

March 22, 2000

The Honorable Charles Grassley
The Honorable Edward Kennedy
United States Senate
Washington, DC 20510

Dear Senators Grassley and Kennedy:

The Federation of Families for Children's Mental Health is pleased to support the introduction of the Family Opportunity Act 2000. The Federation is a national parent-run organization focused on the needs of children and youth with emotional, behavioral, or mental disorders and their families. The Federation's mission is to provide leadership in the field of children's mental health and address the unique needs of children and youth with emotional, behavioral, or mental disorders from birth through transition to adulthood.

This important legislation permits states to allow middle-income families with children with severe mental or physical disabilities to "buy-in" to the Medicaid program. The proposal also provides a demonstration program where states can cover children who without preventive health care will become disabled. Providing the link to the comprehensive benefit of services the Medicaid program provides will promote early intervention, ensure access to all medically necessary services and help restore family security.

We are especially pleased that your intent is to insure children with emotional, behavioral, or mental disorders and their families are able to receive essential mental health treatment, services, and supports. Too often we find that families whose children have emotional, behavioral, or mental disorders are unable to obtain adequate mental health coverage through a private health insurance plan. The Center for Mental Health Services has estimated that two-thirds of all young people are not getting the mental health treatment they need. In some cases, when their own insurance and other resources to pay for medical care are depleted, families have to relinquish custody to the state to access public funds for mental health treatments and support services for the child. The tragic reality of this problem, which is well known to our membership and their children, was recently highlighted by Bill Branigan in the *Washington Post* article enclosed.

The Federation of Families for Children's Mental Health looks forward to continue working with you and your staff to pass the Family Opportunity Act 2000. Thank you for your commitment to the mental health needs of our most vulnerable children and recognizing that the best strategy for helping them is to support their families.

Sincerely,

Trina W. Osher

Trina W. Osher
Coordinator of Policy & Research

CONSORTIUM for CITIZENS with DISABILITIES

Contact: Kathleen McGinley, The Arc, 202-785-3388

March 17, 2000

The Honorable Charles Grassley
The Honorable Edward Kennedy
United States Senate
Washington, DC 20510

Dear Senators Grassley and Kennedy:

The Consortium for Citizens with Disabilities (CCD) is a Washington-based coalition of approximately 100 national consumer, advocacy, provider, and professional organizations. For 25 years the CCD has worked with and on behalf of the 54 million children and adults with disabilities and their families living in the United States. The mission of the CCD Health Task Force is to ensure that individuals with all types of disabilities – including children with disabilities -- have access to needed health care and health-related services and supports.

Therefore, the undersigned members of CCD Health Task Force are very pleased to support your proposed Family Opportunity Act of 2000. We believe that this is an extremely important piece of legislation that – if enacted – will help to ensure that less children "fall through the cracks" and more children with disabilities have access to a broad range of needed health care services and supports.

The most critical provision of your proposed bill for CCD member organizations is the provision that would allow states to offer Medicaid coverage to children with severe disabilities – physical or mental -- who live in middle-income families. Currently, these children are ineligible for Medicaid because their families make too much money. In addition, currently, these children often are un-insured or underinsured because health insurance is not available through an employer; is too expensive; or offers a very limited benefits package. Giving parents with the option of buying into Medicaid and paying on a sliding scale basis would provide children with disabilities in these families with access to the full range of Medicaid services, including those provided through the Early and

Periodic Screening, Diagnosis, and Treatment (EPSDT) program. This provision – along with the demonstration program that would allow states to cover children with "potentially severe disabilities" -- promises improved health; the prevention of future disabilities; and a better chance for these children to live full and healthy lives with their families in their home communities.

CCD member groups believe that your bill takes a pragmatic and responsible approach to offering families potential access to Medicaid's comprehensive benefits package.

- It is a state option, one that we strongly hope most states will choose to adopt.
- It requires parents to pay premiums for this coverage on a sliding scale based on their income.
- It requires parents to take employer-sponsored family coverage (if available) but allows them to buy into Medicaid to "supplement" the employer benefit package.
- It breaks the link between forced poverty and Medicaid, and it builds on the bipartisan Work Incentives Improvement Act passed by Congress and signed by the President last year.

Finally, CCD member groups appreciate the many opportunities they had to work with your respective staffs as this important piece of legislation was developed. We look forward to working with you to pass the Family Opportunity Act of 2000 and seeing it signed by President Clinton this year.

Sincerely,

Adapted Physical Education Council
American Academy of Child and Adolescent Psychiatry
American Congress of Community Supports
American Association of People with Disabilities
American Association of University Affiliated Programs
American Association on Mental Retardation
American Music Therapy Association
American Network of Community Options and Resources
American Therapeutic Recreation Association
Autism Society of America
Bazelon Center for Mental Health Law
Brain Injury Association
Children and Adults with Attention Deficit Disorder
Easter Seals
National Alliance for the Mentally Ill
National Association of Developmental Disabilities Councils

International Association of Psychosocial Rehabilitation Services
National Association of Protection and Advocacy Systems
National Association of School Psychologists
National Council for Community Behavioral Healthcare
National Down Syndrome Society
National Mental Health Association
National Therapeutic Recreation Society
Research Institute for Independent Living
RESNA
The Arc of the United States
United Cerebral Palsy Associations

Mental Health Liaison Group

March 17, 2000

The Honorable Charles Grassley
The Honorable Edward Kennedy
United States Senate
Washington, DC 20510

Dear Senators Grassley and Kennedy:

The undersigned members of the Mental Health Liaison Group (MLHG)— a coalition of national organizations representing consumers, families, advocates, professionals and providers dedicated to expanding the availability of mental health services and improving mental health care in America— are pleased to support the introduction of the Family Opportunity Act of 2000.

The hallmark of the Family Opportunity Act of 2000 is the removal of a barrier that so many families encounter when they earn too much to qualify for Medicaid, are without employer health coverage or their private insurance coverage has inadequate mental health benefits that prevents them from meeting their child's needs. This important legislation permits states to allow middle-income families with children with severe mental or physical disabilities to "buy-in" to the Medicaid program. The proposal also provides a demonstration program where states can cover children who without health care coverage will become disabled. Providing the link to the comprehensive benefit of services the Medicaid program provides will promote early intervention, ensure access to all medically necessary services and help restore family security.

Increasing access to needed health and mental health care is a longstanding priority of the MHLG. Therefore, we commend your bipartisan leadership and the sound approach your proposal takes in fostering access to a wide range of services and supports for children with significant health needs.

Too often we find that the service needs of families with children with serious mental disorders are not being met and obtaining adequate mental health coverage in private insurance plans is extremely difficult. The Center for Mental Health Services has estimated that two-thirds of all young people are not getting the mental health treatment they need. In some cases, families are forced to give up custody of a child with complex health care needs to the state as an avenue to access mental health and support services for the child. The tragic reality of this problem was recently highlighted by a *Washington Post* article.

The MHLG looks forward to working closely with you and your staff throughout the legislative process to pass the Family Opportunity Act of 2000 this session. Thank you for your commitment to the health needs of our most vulnerable children.

Sincerely,

American Academy of Child and Adolescent Psychiatry
American Association for Marriage and Family Therapy
American Association of Pastoral Counselors
American Counseling Association
American Family Foundation
American Group Psychotherapy Association
American Mental Health Counselors Association
American Psychiatric Association
American Psychiatric Nurses Association
American Psychoanalytic Association
American Psychological Association
ANAD—National Association of Anorexia Nervosa and Associated Disorders
Anxiety Disorders Association of America
Association for the Advancement of Psychology
Bazelon Center for Mental Health Law
CHADD—Children and Adults with Attention-Deficit/Hyperactivity Disorder
Federation of Behavioral, Psychological and Cognitive Sciences
Federation of Families for Children's Mental Health
International Association of Psychosocial Rehabilitation Services
NAMI— National Alliance for the Mentally Ill
National Association of Protection and Advocacy Systems
National Association of Psychiatric Health Systems
National Association of Psychiatric Treatment Centers for Children
National Association of School Psychologists
National Association of Social Workers
National Association of State Mental Health Program Directors
National Council for Community Behavioral Healthcare
National Depressive and Manic Depressive Association
National Mental Health Association

National Parent Network on Disabilities

Advocating for Individuals with Special Needs and Their Families

March 17, 2000

Dear Congressman,

The National Parents Network on Disabilities (NPND) works with the parents and families of individuals with disabilities and special health care needs. The mission of NPND is to speak as a collective voice representing the perspectives, strengths, needs, diversity, and interests of parents and family members of people of all ages with a disability or special health care need. NPND shares information and resources in order to promote and support the power of parents to influence and affect policy issues concerning the needs of people with disabilities and their families.

NPND's supports the Family Opportunities Act. We applaud the bipartisan efforts in bringing forth a bill that would promote the well being of children with disabilities, which will help maintain the family structure and allow families to move forward in assuring financial stability.

The Family Opportunities Act would:

First, provide families the option to buy into Medicaid. Families, who have the task of raising a child with disabilities and special health care needs, find themselves in difficult situations. These families cannot survive without Medicaid. Families' level of income has prevented them from receiving the medical support needed to maintain their child at home. The Family Opportunities Act would remove the inequities and the disincentives that families' have faced in the past. The opportunity to buy-into Medicaid would allow families' to take care of their children, advance their income, and be cost effective in meeting the needs of their child. The Family Opportunities Act is a tremendous step to assuring that the family can move forward. They can advance their economic situation and receive the Medicaid their son or daughter needs to survive.

Second, the establishment of demonstration projects would allow states to develop projects to implement the law. It is important for states to have the opportunity to pilot new laws that would address the social and economical needs of their own states.

Third, the establishment of Family-to-Family Health Information Centers is a positive way to support families to use the new law to negotiate the complex medical system. Be this private insurance, health care providers, or Medicaid, they become entrapped in a maze of paper and complex terminology. Families have enough to do just caring for their own child and family. The philosophy of family-to-family supports has been well demonstrated to be cost effective and beneficial to families. It promotes family independence and is a way to help families untangle the maze of complex systems. The Family-to-Family Health Information Centers would establish essential assistance to help

1130 17th Street, NW, Suite 400 * Washington, DC 20036 * (202) 463-2299 * FAX (202) 463-9405 * npnd@cs.net

the family new to this situation. in dealing with th. complexity of the medical field. help cope and negotiate the system. at the same time educating and assisting the medical field.

NPND pledges its strong support of the Family Opportunities Act and would urge all Congressional Members to endorse and pledge their bipartisan support of this important piece of legislation.

Sincerely,

Patricia McGill Smith
Executive Director
National Parents Network on Disabilities

Jacqueline L. Golden
Project Manager

WORLD INSTITUTE DISABILITY

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SUITE 100
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CA 94612-1500
USA

TELEPHONE
510 763 4100

FAX 510 763 4109
TTY 510 208 9493

April 18, 2000

The Honorable Charles Grassley
The Honorable Edward Kennedy
United States Senate
Washington, DC 20510

Dear Senators Grassley and Kennedy:

The World Institute on Disability applauds the development and introduction of the Family Opportunity Act of 2000. Once again, bipartisan policymakers have collaborated with the Americans who will be affected by legislation to craft provisions that, in this bill, will keep us healthier and more productive while keeping families united with their children who have disabilities.

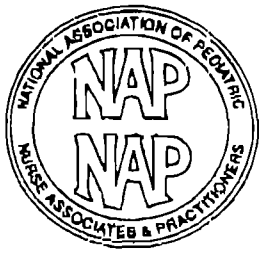
The World Institute on Disability (WID) is a non-profit public policy center dedicated to the promotion of independence and full inclusion in society of people with disabilities. Founded in 1983 by leaders of the Independent Living/Civil Rights Movement for people with disabilities, WID is committed to transforming policy into action. WID's Board of Directors and staff, over half of whom are people with disabilities, consist of well-know national leaders in the disability field as well as leaders in industry, government, and social services.

As was noted at the Press Conference in Washington announcing the introduction of this bill, the Family Opportunity Act of 2000 has modeled its provisions on structures found in the popular Ticket to Work and Work Incentives Improvement Act of 1999. We are especially proud to have worked with your respective staffs and offered technical advice to consumer groups both in Iowa and Massachusetts in the course of that initiative.

We want to paraphrase a policy principle we have long subscribed to during the development of TWWIIA:

"With respect to public program policy and outcomes, the work activity of one family member, with or without a disability, shall not do harm to the worker or to other family members." Work or increased success at work in America should never make any family member worse off or in jeopardy of losing the only healthcare available. While this happens all the time today, the new Medicaid buy-in available in FOA can solve this terrible problem.

Furthermore, we have learned from decades of work in the Independent Living Movement that peer counseling between people with disabilities is an indispensable



National Association of Pediatric Nurse Associates & Practitioners, Inc.

April 21, 2000

The Honorable Charles Grassley
United States Senate
135 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Grassley:

On behalf of the more than 5,800 members of the National Association of Pediatric Nurse Associates and Practitioners (NAPNAP), I would like to provide our sincere thanks and enthusiastic support for S. 2274, the *Family Opportunity Act of 2000*. We believe this legislation will greatly improve health coverage for children with special needs and protect the household income of their families.

The current income limitations which exist for families with special needs children creates a terrible choice for families who must decide whether to live near the poverty level in order to obtain adequate health care for their child or improve their income and risk losing the health care services their child receives. The fact that any family is forced to make this choice is a tragedy, indeed.

NAPNAP believes S. 2274 is legislation written with the best interests of children and families in mind. We applaud you for sponsoring this important legislation and for your leadership on this issue. We pledge our support to work closely with you as this legislation moves toward enactment.

Sincerely,

Barbara Kelley

Barbara Kelley, EdD, RN, MPH, CPNP
President

1101 Kings Highway, North, Suite 206 / Cherry Hill, New Jersey 08034-1912
E-mail: napnap1@aol.com Internet: www.napnap.org
856-667-1773 / Toll Free: 877-662-7627 / FAX 856-667-7187

aauap

American Association of University Affiliated Programs for Persons with Developmental Disabilities

April 28, 2000

The Honorable Edward M. Kennedy
315 Russell Senate Office Building
Washington, DC 20510

Dear Senator Kennedy:

On behalf of the American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP), I would like to commend you for the introduction of S. 2274, the Family Opportunity Act of 2000.

This critical piece of legislation is a huge step forward for families of children with disabilities and serious health conditions. As you well know, families of children with disabilities have incredible financial burdens and have too often been made to make painful choices regarding their children's health care. Families are forced to become poor, give up meaningful careers, or even worse -- split their family apart by giving up custody of their child, in order to stay financially afloat.

The AAUAP is an association that aids families in many ways including providing training to professionals in the field of developmental disabilities, conducting state-of-the art research on disability, disseminating research findings to institutions and families about disability, and providing direct services to help individuals with disabilities live in the community. The AAUAP feels strongly that families should be given opportunities to maintain their family structure and to care for their own children without leaving them destitute.

S. 2274, which builds on the concept of the Work Incentives Improvement Act passed by this Congress, is an excellent step toward helping families. By offering parents an opportunity to buy-in to Medicaid and expanding State Medicaid programs, many more children will be able to receive the health care they deserve. In addition, the UAPs are particularly interested in the Family to Family Health Information Centers provision of this bill. Many UAPs already serve as a clearinghouse and meeting place for families to gain access to and have explained to them the often very complex systems of health services in our local communities. UAPs also help parents to meet other families with similar concerns and to gain information on the latest of what science has to offer regarding their child's conditions. The UAPs stand ready to implement this provision of the bill and provide any assistance necessary.

8630 Fenton Street, Suite 410 • Silver Spring, Maryland 20910 • (301) 588-8252 • FAX (301) 588-2842 • TDD (301) 588-3319

Again, the AAUAP thanks you for your leadership on this important legislation. Please feel free to contact George Jesien, Ph.D., AAUAP's Executive Director or Donna Meltzer, AAUAP's Legislative Director for any assistance needed in moving this legislation forward.

Sincerely,

David M. Mank, Ph.D., Director
Indiana Institute on Disability and Community
President, AAUAP

March of Dimes
Saving babies, together

March of Dimes
Birth Defects Foundation

1901 L Street, NW Suite 200
Washington, DC 20036
Telephone (202) 659-1800
Fax (202) 296-2964

00 JUL 17 09:09:14

July 12, 2000

The Honorable Charles E. Grassley
United States Senate
Washington, DC 20510-1501

Dear Senator Grassley:

On behalf of more than 3 million volunteers and 1600 staff members of the March of Dimes, I want to commend you for introducing the "Family Opportunity Act of 2000" (S. 2274).

As you know, the March of Dimes is committed to increasing access to appropriate and affordable health care for women, infants and children. The Foundation is therefore pleased to support especially the provisions of the "Family Opportunity Act of 2000" that give states the option of expanding Medicaid coverage to children with disabilities who would be eligible for SSI disability benefits but for their family income or resources. Too often the high cost of medical care forces parents to impoverish themselves in order to maintain Medicaid eligibility for a child with special health needs. The March of Dimes applauds your effort to help states give parents of these medically fragile children the opportunity to remain in the workforce without placing their children at risk of being uninsured.

In addition, we appreciate inclusion in S. 2274 of the provisions that authorize the establishment of 'Family-to-Family Health Information Centers.' These Centers, staffed by parents of children with special needs and professionals skilled in working with these children are an important resource for health providers as well as families. Approval of the "Family Opportunity Act of 2000" will reassure millions of families that they can continue to rely on the Centers for help with the often daunting task of navigating an increasingly complex health care system.

We thank you for your leadership and stand ready to work with you and Senators Kennedy, Jeffords and Harkin to obtain Senate approval of this important bill.

Sincerely,

Marina Weiss

Marina L. Weiss, Ph.D
Senior Vice President
Public Policy and Government Affairs

Talk to Jeanne + Chris

MEMORANDUM

TO: Becky Ogle and Marsha Scott

FROM: Bob Williams (ASPE), Henry Claypool (HCFA), Sheila Foran (OCR) and Lorinda Daniel (SAMHSA)

RE: Possible Directives/Announcements from the White House Regarding Actions HHS Will Take to Aid States' Compliance with the ADA and the Olmstead Decision

DATE: July 10, 2000

The purpose of this memorandum is to outline our collective thoughts regarding possible directives/announcements the White House could make regarding actions HHS will take to help states comply with the ADA and the Olmstead decision. This memo incorporates thoughts and ideas from all four HHS components involved in implementing the Olmstead decision and in planning ADA anniversary events (HCFA, OCR, ASPE and SAMHSA).

1. DIRECT HHS TO DEVELOP AND PUBLISH A REGULATION ALLOWING STATES TO USE SECTION 1902(R)(2) TO EXPAND MEDICAID ELIGIBILITY BY PROVIDING MORE LIBERAL INCOME DISREGARDS THAN WOULD OTHERWISE BE ALLOWED. This would help level the playing field between institutional and community services by allowing States to offer community services to those with low to moderate incomes. States already cover those with similar incomes, if they go into a nursing home.

. STATUS: Discussion between HCFA and OMB (Tim and Jeanne) are taking place and there is said to be a desire to move ahead. Cost estimate: $785(?) million over 5.

. IMPORTANCE FOR PEOPLE AND STATES: States that take this up would be able to offer people more of a real choice between going into an institution and living in their own homes and communities with needed supports. States like Connecticut and North Carolina have pushed for this change to be made. Absent legislation this is the most this Administration can do to afford States the tools they need and want to offer more people with disabilities of all ages the choice and supports to live meaningful lives in their communities.

2. ANNOUNCE $50 MILLION TO FUND SYSTEM CHANGE/CAPACITY BUILDING GRANTS TO HELP STATES WORK WITH THEIR DISABILITY/AGING COMMUNITIES TO PURSUE AFFORDABLE STRATEGIES FOR IMPLEMENTING OLMSTEAD. These grants would be the same as those called for in part of MiCASSA.

. STATUS: After meeting with ADAPT Nancy Ann forwarded this proposal to Chris and Jeanne. New Spending: $250 million/5 years. Resources not identified.

. IMPORTANCE: These grants would fund States to enhance their capacity to provide by working in close coordination with its disability community to develop and implement a

comprehensive, effectively working plan as encouraged by Olmstead. The disability community recognize that to be effective the grants need to be funded and awarded in FY2001.

3. ANNOUNCE INCREASED FUNDING FOR HHS OFFICE FOR CIVIL RIGHTS ACTIVITIES RELATED TO THE AMERICANS WITH DISABILITIES ACT, INCLUDING THOSE PERTAINING TO THE OLMSTEAD DECISION.

. STATUS: OCR's FY 2000 budget is $22 million, which is the same as OCR's budget was in 1980, when HHS was created, and the same as OCR's budget in 1993, when President Clinton entered office. The FY 1980 budget supported 550 employees nationwide, while today's budget supports 225.

. IMPORTANCE: OCR's enforcement responsibilities have increased substantially over the past ten years, with passage of the Americans with Disabilities Act. The Supreme Court's decision in Olmstead has increased OCR's ADA workload exponentially, not only due to a large volume of complaints but because of the comprehensive manner in which OCR is seeking to resolve the complaints. OCR has received more than 120 complaints alleging that states and other public entities have failed to provide services to people with disabilities in most integrated settings. OCR is attempting to resolve these complaints by working with all parties in the states to build comprehensive, effectively working plans for placing qualified persons with disabilities in the most integrated setting appropriate.

The Department has played a key role in the development of Olmstead planning coalitions across the nation. In some states, special governor's commissions have been established to head these coalitions. In others, particular disability groups have taken up the challenge of coalition building. In all, some twenty states are engaged in various stages of Olmstead planning.

4. ANNOUNCE CREATION OF A NATIONAL MENTAL HEALTH COALITION TO PROMOTE COMMUNITY-BASED CARE.

. STATUS: SAMHSA will support creation of this coalition. Key organizations and constituencies will come together to work in partnership with the States to develop a plan for the coalition, working with consumers.

. IMPORTANCE: This technical assistance effort will link with the Private Industry Councils (PICs), looking at employability, housing authorities, case managers, professional organizations, social security services and others to ensure wrap-around, integrated, community-based services. Particular attention will be paid to including organizations that address the two most critical issues consumers face in trying to live in the community -- finding adequate and affordable housing and identifying employment opportunities.

5. GIVE HIGH VISIBILITY TO THE CHANGES MADE IN MEDICAID POLICY TO BETTER ENABLE STATES TO HELP PEOPLE MAKE A SUCCESSFUL TRANSITION FROM NURSING HOMES AND OTHER INSTITUTIONS INTO THE COMMUNITY.

. STATUS: Changes will be announced in a State Medicaid Director letter. See attached.

. IMPORTANCE: People with disabilities who want to and are able to move out of nursing homes and other institutions often face tremendous barriers to making such a transition. State Medicaid programs face similar barriers of their own. The guidance and policy clarifications in the State Medicaid Directors letters HHS will issue to State Medicaid Director on July xx will help eliminate many of these barriers.

6. GIVE HIGH VISIBILITY TO THE CHANGES MADE IN MEDICAID POLICY TO BETTER ENABLE STATES TO MAXIMIZE THE PERSONAL DIGNITY AND AUTONOMY OF PERSONS WITH DISABILITIES THROUGH SELF DETERMINATION AND CONSUMER DIRECTED SERVICES.

. STATUS: Changes will be announced in a State Medicaid Director letter. See attached.

. IMPORTANCE: Approaches for increasing consumer choice and control over their Medicaid services and supports are having a significant impact on people with developmental disabilities, physical disabilities, and serious mental illness of all ages, including elderly individuals. The new guidance clarifies how all States can use Medicaid to design and implement strategies for enabling people with disabilities to have a say in how the services they support on most to live their lives get provided. THIS IS ALSO LINKED TO THE TASK FORCE'S PROPOSED INITIATIVE ON PEOPLE WITH SIGNIFICANT DISABILITIES AS WELL AS THE PROPOSED ACCESSHOUSING 2000 INITIATIVE.

NOT FOR DISTRIBUTION:

CHANGES AND CLARIFICATIONS HHS IS MAKING IN MEDICAID POLICIES TO HELP STATES CARRY OUT THE SUPREME COURT'S OLMSTEAD DECISION:

In its January letter to States on the Olmstead decision, HHS pledged to begin to review and modify, where necessary, relevant federal Medicaid regulations, policies and previous guidance to assure that they are compatible with requirements of the ADA and facilitate States' efforts to comply with the law.

Toward this end, HHS is issuing two additional letters and related guidance to State Medicaid Directors which provide needed policy clarifications and in some instances, reflect significant changes in policy to support community integration. These letters are responsive to specific issues that have been identified as barriers by both States and the disability community. The letters will support States' efforts:

. expanding access to home and community based services;

. assisting people with disabilities make a successful transition from nursing homes and other institutions into the community; and,

. maximizing the personal dignity and autonomy of persons with disabilities.

Along with the letters, the Department is releasing a set of Questions and Answers regarding the ruling. The Q&A's like the policy clarifications HCFA is issuing are responsive to the questions and concerns that States and the disability community brought to HHS as a result of our invitation to do so in the January letter.

EXPANDING ACCESS TO HOME AND COMMUNITY BASED SERVICES: This letter describes the ways in which States can use the Medicaid program to work toward achieving the following 4 goals:

1. HELPING PEOPLE WITH DISABILITIES MAKE A SUCCESSFUL TRANSITION FROM NURSING HOMES AND OTHER INSTITUTIONS INTO THE COMMUNITY:

People with disabilities who want to and are able to move out of nursing homes and other institutions often face tremendous barriers to making such a transition. State Medicaid programs face similar barriers of their own. The guidance and policy clarifications in the first letter HHS just issued to State Medicaid Director on July xx, will help eliminate many of these barriers.

Accessing Waiver Services: HCFA explains the quickest way a State can begin using Medicaid waiver funds to help a person move out of a nursing home or institution back into their community;

thus cutting down on undue delays.

Community Transition Expenses: HCFA details how Medicaid can be used to pay for services and one-time expenses related to assisting a person to move from institution to the community. This can include paying for up to 6 months of case management to identify and obtain needed services for the person by the time he or she leaves the facility; accessibility assessments and modifications to the home or apartment the person is moving into; and a security deposit on an apartment and other typical moving costs.

Avoiding Reinstitutionalization: HCFA will now allow States to use Medicaid to continue to pay for personal care for a period of up to two weeks, while a person with a disability is hospitalized or absent from his or her home. This will enable a State to help individuals avoid losing their attendants and risk unnecessary institutionalization. Doing this extends the policy of making similar payments to retain the bed of a Medicaid nursing home resident who is hospitalize or otherwise absent to those receiving community services.

2. EXPANDING THE AVAILABILITY AND QUALITY OF HOME AND COMMUNITY BASED SERVICES:

The first letter HCFA recently sent to State Medicaid Director also addresses some of the fiscal and programmatic challenges State face in increasing the availability and quality of home and community based services for people with disabilities of all ages. Some of these can only be addressed over the long term by way of the issuance of new regulations and/or changes to the law itself. HHS is committed to working with States and others identifying and giving serious consideration to best way of effectuating such regulatory and statutory reforms. We believe, however, we have identified and made a series of immediate changes in existing guidance or HCFA's interpretation of the Medicaid statute that States and the disability community will find helpful.

Budget Neutrality: This new policy guidance offers States a more effective way of demonstrating the cost-neutrality of providing Medicaid waiver services to individuals with HIV-AIDS and other illnesses that can lead to episodic periods of institutionalization. It does this by allowing States to factor in costs incurred between institutional stays occurring in the same year.

Habilitation: HCFA makes clear that habilitation services can be provided to individuals with the full range of developmental, physical and mental disabilities under a HCBS waiver. This is important because habilitation services focus on assisting individuals to acquire, retain and improve skills important for living in the community. Traditionally, however, only people with developmental disabilities have been seen to be eligible for these very flexible and individualized services. This important clarification, therefore, opens the doors for many more to benefit from such services.

Out of State Services: HCFA explains how a Medicaid program can pay for services provided to one of its beneficiary in another state when it is in the person's best interest to do so. Examples of when a Medicaid program should consider paying for such services would the need to access services in rural or other underserved areas, situations when an individual needs to be near their family and young people with disabilities attending college out of State.

3. REDUCING THE UNNECESSARY MEDICALIZATION OF HOME AND COMMUNITY BASED SERVICES:

Some States have traditionally administered home and community based services in ways that have been unnecessarily medicalized and restricted the personal autonomy of individuals with disabilities. HCFA's guidance to State Medicaid Directors addresses these barriers to independence and community participation in two key areas:

Home Health: The guidance informs States that they may longer require that people be "homebound" in order to receive Medicaid home health services. State policies that impose the requirement that one must be homebound to receive Medicaid home health services create unfair barriers to such participation. States can set reasonable limits that do not arbitrarily deny or reduce the amount, duration, or scope of a required service solely because of a person's diagnosis, type of illness, or condition. However, the guidance will ensure that no one loses access to home health services simply by leaving their homes and spending time in their communities.

Nurse Delegation: This guidance makes clear that States may use medicaid to pay for services provided by qualified individuals under the supervision of a nurse or its nurse delegation law. In other words, States are not required to use nurses to perform health related tasks (e.g., catheter care) which others can be trained to do just as well. The guidance codifies what HCFA has permitted many States to do for years. it is hoped that this can help other States to eliminate a layer of the unnecessary medicalization of people's lives which many find extremely intrusive.

MAXIMIZING THE PERSONAL DIGNITY AND AUTONOMY OF PERSONS WITH DISABILITIES:

The second letter addresses approaches aimed at increasing consumer choice and control in respect to Medicaid services and supports are having a significant impact on people with developmental disabilities, physical disabilities, and serious mental illness of all ages, including elderly individuals. The new guidance clarifies how all States can use Medicaid to design and implement what are alternatively known as self determination, consumer directed or participant driven approaches to enabling people with disabilities to have a say in how the services they support on most to live their lives get provided. This letter contains guidance and policy clarifications in the following 4 key areas:

Person centered planning: The guidance specifies how Medicaid programs can support and pay for person-centered planning, which focuses on identifying the strengths, capacities and needs of the individual, from the perspective of the person often with the assistance of family and friends.

Individual Budget: It clarifies ways in which permits the use of individual budgets controlled by the person with a disability or their representative. The budget is set by the State in consultation with the person and their team based on the cost of service to meet a documented need and must meet other safeguards.

Service Brokerage : The guidance describes how Medicaid can fund the use of support brokers in

consumer- directed service systems. A support broker is a personal agent freely chosen by the individual who provides assistance with person-centered planning and obtaining both Medicaid and non-Medicaid funded services.

Fiscal Intermediaries: The guidance describes how Medicaid programs can use fiscal intermediaries to foster self determination and consumer directed services. In a self-directed service delivery model, Medicaid beneficiaries may hire/fire, schedule, and supervise their providers to the extent permitted a State. Fiscal intermediaries help relieve individuals of a number of bookkeeping tasks which can be time consuming to perform and create unnecessary barriers to persons with disabilities controlling their services and thus their own lives as well.

Such tasks include Medicaid billing, check writing for provider-generated bills, administration of personnel issues (e.g., employer of record services, tax withholding, worker*s compensation, health insurance) and the management of other taxes and benefits. Some individuals may choose to perform these functions themselves (with the exception of making payments to providers) but the State cannot require them to do so.

- Becky - who should get these in agencies to speed process
- Lisa Loy

DIRECTIVES

RECOMMENDATION	FORMAT	STATUS	ANNOUNCE
President of the United States			
Tax Credit to Assist Adults with Disabilities with Expenses Related to Work (TF '99)	Budget Proposal	In Congress	Pending
Strong, Enforceable Patients' Bill of Rights (TF '99)	Legislation	In Congress	Pending
Create "Access America for People with Disabilities" Web Site - SSA/DOL (TF '99)	Announcement of Web Site	Done	July 26, 2000
Plan of Action to Address Transportation Services and Systems for People with Disabilities (TF '99)		Being Negotiated	July 26, 2000
Encourage Federal Agencies with Customer Service Call Centers to Explore Ways to Hire People with Disabilities (TF '99)	Executive Order	DPC	
Raise SSI Earned Income Exclusion to Encourage Work Efforts - SSA (TF '99)	Regulatory Change	OMB	July 26, 2000
OPM Hiring Goal	Executive Order	DPC	July 26, 2000
Reasonable Accommodation	Executive Order	DPC	July 26, 2000
Section 504	Executive Order and Memorandum	DPC	July 26, 2000

RECOMMENDATION	FORMAT	STATUS	ANNOUNCE
Vice President of the United States			
White House Conference on Employment of Adults with Disabilities (TF '99)	TBD	TBD	
Increased Funding for HHS/OCR – Irene Bueno	Budget	Discussion - OMB	July 26, 2000
Technology: * Development/Adoption of Information and Communication Technologies Used by People with Disabilities (TF '99)	Budget Proposal	Pending	?
* Technology/General Technology Transfer	Pending - Curtis	Pending - Curtis	July 26, 2000
* Technology/Section 508 PETUS POSSIBLE * Technology Transfer GO	Pending - Curtis	Pending - Curtis	July 26, 2000
Olmstead/Home and Community-Based Services:			
* Medicaid Income Disregards for HCBS	Regulation	Discussion: OMB/HCFA	July 26, 2000
* Systems Change Capacity Building Grants	Grant - $50 Million over 5 Years	Discussion: Jeanne/Chris	July 26, 2000
* Medicaid Technical Assistance Consortia	Partnership - TF, Educ, SAMHSA, HHS/HCFA	Done	July 26, 2000

Chris Terrado Jeanne

RECOMMENDATION	FORMAT	STATUS	ANNOUNCE
First Lady			
Develop Youth to Work Initiative - DOL, Education, HHS, SSA, OPM, TF and Others (TF '99)	First Lady Initiative		
Develop Proposal to Allow MCH/CSHN Healthy and Ready to Work Services to Cover Youth with Disabilities Age 16 and Older - HHS (TF '99)	Executive Order/ First Lady Initiative ???	DPC	
Guidance on Non-harassment of Students with Disabilities - Education	Dear Colleague Letter from Education	Done	July 26, 2000
HHS Secretary Donna Shalala			
Olmstead/Home and Community-Based Services: * Helping People with Disabilities Transition from Nursing Homes to Communities * Expanding Availability and Quality of Home and Community-based Services * Reducing Unnecessary Medicalization of Home and Community-based Services * Maximizing Personal Dignity and Autonomy of People with Disabilities	Letter to Medicaid Directors - Policy Guidance/clarification	Done	July 26, 2000

RECOMMENDATION	FORMAT	STATUS	ANNOUNCE
No Principal Designated Yet			
Create Office of Disability Policy Headed by Assistant Secretary - DOL (TF '99)	Budget Proposal	Congress	
Strengthen Enforcement of Employment-related Nondiscrimination Provisions of ADA and Rehabilitation Act - DOJ, Labor, EEOC (TF '99)	OFCCP Regulation	OMB	
Direct Education, Labor, HUD, Interior, HHS, and SSA to develop inter-agency American Indian Disability Technical Assistance Center *and* utilized Internet tools for outreach, training and technical assistance (building on HUD's websites Native Edge and Code Talk)			July 26, 2000
Direct Interior to establish/develop Information Technology Center at the Southwestern Indian Polytechnic Institute to work on digital divide in Indian country	Part of VP's other technology announcements?		July 26, 2000

Michelle

RECOMMENDATION	FORMAT	STATUS	ANNOUNCE
No Principal Designated Yet *(continued)*			
Direct Workforce Investment Board liaisons re: * Participation of youth with disabilities on youth councils * Need for states to be aggressive in ensuring that WIA structures address concerns of people with disabilities in their programs * Outreach to, and inclusion of, state MR/DD directors and state Medicaid directors on state WIBs	DOL Guidance (TIEN)		
15% set aside for technical assistance to workforce system promoting employment of people with disabilities at minimum wage or above	Letter from Secretary Herman		
WIA - Competitive grant competition focusing on use of Individual Training Accounts by people with disabilities			

fax to John
Rother

NEW RECOMMENDATIONS/HHS

1. HCFA will modify its policies and practices to support the integration of Title XIX beneficiaries with significant disabilities into the American workforce by **issuing new policy guidance** and offering **technical assistance** emphasizing flexible, non-categorical implementation of the Medicaid program **to state Medicaid directors** that:

   (1). Clarifies and encourages the use of existing medicaid coverage options (such as personal care; clinic services; rehabilitative services; and HCB waiver programs) to be used to finance supported employment and other work related services for working-aged recipients with disabilities; [note: this is a particularly urgent issue for persons with psychiatric disabilities who are receiving title XIX financed intensive community supports; it will also positively affect people with mr/dd.]

   (2). Explains options available to states to create a special income eligibility category for Title XIX beneficiaries that provides clear and reasonable incentives to engage in work and increase earnings without jeopardizing Medicaid eligibility.

2. HCFA will revise Medicaid **program manual** and issue **policy guidance** to encourage use of individual budgets that enables customer choice and control.

3. HCFA will develop **strategies** to assist states to provide **incentives** for employment by authorizing higher reimbursement rates for integrated employment outcomes.

4. HCFA will add **premium on federal financial participation** in Medicaid reimbursement to states that adopt a **Medicaid buy-in**. [note: premium could be provided in a variety of ways; the group discussed small financial but there are probably others that HCFA could identify].

5 HHS will create an **Olmstead Watch website** (integrated with Access America Web recommended by the Presidential Task Force 2nd report) that informs the public and multiple stakeholders on post-Olmstead activities, including:

   (1). State compliance plans
   (2). Status of state efforts to move individuals off waiting lists;
   (3). HHS and DOJ monitoring activities and findings;
   .(4). Civil rights information on court cases and decisions regarding Section 188 of WIA, Sections 503, 504, 508 of Title IV WIA and Title II of the ADA
   (5). Civil rights program contacts with state and federal government;
   (6). Examples of state efforts to redirect resources to support integrated employment;
   (7). Federal policy across agencies to support choice and individual budgets; and
   (8). Other research and related data, as appropriate, in order to effectively disseminate information to enable movement to the community and integrated employment for people with the most significant disabilities.

talk to Jeanne + Chris

MEMORANDUM

TO: Becky Ogle and Marsha Scott

FROM: Bob Williams (ASPE), Henry Claypool (HCFA), Sheila Foran (OCR) and Lorinda Daniel (SAMHSA)

RE: Possible Directives/Announcements from the White House Regarding Actions HHS Will Take to Aid States' Compliance with the ADA and the Olmstead Decision

DATE: July 10, 2000

The purpose of this memorandum is to outline our collective thoughts regarding possible directives/announcements the White House could make regarding actions HHS will take to help states comply with the ADA and the Olmstead decision. This memo incorporates thoughts and ideas from all four HHS components involved in implementing the Olmstead decision and in planning ADA anniversary events (HCFA, OCR, ASPE and SAMHSA).

1. DIRECT HHS TO DEVELOP AND PUBLISH A REGULATION ALLOWING STATES TO USE SECTION 1902(R)(2) TO EXPAND MEDICAID ELIGIBILITY BY PROVIDING MORE LIBERAL INCOME DISREGARDS THAN WOULD OTHERWISE BE ALLOWED. This would help level the playing field between institutional and community services by allowing States to offer community services to those with low to moderate incomes. States already cover those with similar incomes, if they go into a nursing home.

. STATUS: Discussion between HCFA and OMB (Tim and Jeanne) are taking place and there is said to be a desire to move ahead. Cost estimate: $785(?) million over 5.

. IMPORTANCE FOR PEOPLE AND STATES: States that take this up would be able to offer people more of a real choice between going into an institution and living in their own homes and communities with needed supports. States like Connecticut and North Carolina have pushed for this change to be made. Absent legislation this is the most this Administration can do to afford States the tools they need and want to offer more people with disabilities of all ages the choice and supports to live meaningful lives in their communities.

2. ANNOUNCE $50 MILLION TO FUND SYSTEM CHANGE/CAPACITY BUILDING GRANTS TO HELP STATES WORK WITH THEIR DISABILITY/AGING COMMUNITIES TO PURSUE AFFORDABLE STRATEGIES FOR IMPLEMENTING OLMSTEAD. These grants would be the same as those called for in part of MiCASSA.

. STATUS: After meeting with ADAPT Nancy Ann forwarded this proposal to Chris and Jeanne. New Spending: $250 million/5 years. Resources not identified.

. IMPORTANCE: These grants would fund States to enhance their capacity to provide by working in close coordination with its disability community to develop and implement a

comprehensive, effectively working plan as encouraged by Olmstead. The disability community recognize that to be effective the grants need to be funded and awarded in FY2001.

3. ANNOUNCE INCREASED FUNDING FOR HHS OFFICE FOR CIVIL RIGHTS ACTIVITIES RELATED TO THE AMERICANS WITH DISABILITIES ACT, INCLUDING THOSE PERTAINING TO THE OLMSTEAD DECISION.

. STATUS: OCR's FY 2000 budget is $22 million, which is the same as OCR's budget was in 1980, when HHS was created, and the same as OCR's budget in 1993, when President Clinton entered office. The FY 1980 budget supported 550 employees nationwide, while today's budget supports 225.

. IMPORTANCE: OCR's enforcement responsibilities have increased substantially over the past ten years, with passage of the Americans with Disabilities Act. The Supreme Court's decision in Olmstead has increased OCR's ADA workload exponentially, not only due to a large volume of complaints but because of the comprehensive manner in which OCR is seeking to resolve the complaints. OCR has received more than 120 complaints alleging that states and other public entities have failed to provide services to people with disabilities in most integrated settings. OCR is attempting to resolve these complaints by working with all parties in the states to build comprehensive, effectively working plans for placing qualified persons with disabilities in the most integrated setting appropriate.

The Department has played a key role in the development of Olmstead planning coalitions across the nation. In some states, special governor's commissions have been established to head these coalitions. In others, particular disability groups have taken up the challenge of coalition building. In all, some twenty states are engaged in various stages of Olmstead planning.

4. ANNOUNCE CREATION OF A NATIONAL MENTAL HEALTH COALITION TO PROMOTE COMMUNITY-BASED CARE.

. STATUS: SAMHSA will support creation of this coalition. Key organizations and constituencies will come together to work in partnership with the States to develop a plan for the coalition, working with consumers.

. IMPORTANCE: This technical assistance effort will link with the Private Industry Councils (PICs), looking at employability, housing authorities, case managers, professional organizations, social security services and others to ensure wrap-around, integrated, community-based services. Particular attention will be paid to including organizations that address the two most critical issues consumers face in trying to live in the community -- finding adequate and affordable housing and identifying employment opportunities.

5. GIVE HIGH VISIBILITY TO THE CHANGES MADE IN MEDICAID POLICY TO BETTER ENABLE STATES TO HELP PEOPLE MAKE A SUCCESSFUL TRANSITION FROM NURSING HOMES AND OTHER INSTITUTIONS INTO THE COMMUNITY.

. STATUS: Changes will be announced in a State Medicaid Director letter. See attached.

. IMPORTANCE: People with disabilities who want to and are able to move out of nursing homes and other institutions often face tremendous barriers to making such a transition. State Medicaid programs face similar barriers of their own. The guidance and policy clarifications in the State Medicaid Directors letters HHS will issue to State Medicaid Director on July xx will help eliminate many of these barriers.

6. GIVE HIGH VISIBILITY TO THE CHANGES MADE IN MEDICAID POLICY TO BETTER ENABLE STATES TO MAXIMIZE THE PERSONAL DIGNITY AND AUTONOMY OF PERSONS WITH DISABILITIES THROUGH SELF DETERMINATION AND CONSUMER DIRECTED SERVICES.

. STATUS: Changes will be announced in a State Medicaid Director letter. See attached.

. IMPORTANCE: Approaches for increasing consumer choice and control over their Medicaid services and supports are having a significant impact on people with developmental disabilities, physical disabilities, and serious mental illness of all ages, including elderly individuals. The new guidance clarifies how all States can use Medicaid to design and implement strategies for enabling people with disabilities to have a say in how the services they support on most to live their lives get provided. THIS IS ALSO LINKED TO THE TASK FORCE'S PROPOSED INITIATIVE ON PEOPLE WITH SIGNIFICANT DISABILITIES AS WELL AS THE PROPOSED ACCESSHOUSING 2000 INITIATIVE.

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CHANGES AND CLARIFICATIONS HHS IS MAKING IN MEDICAID POLICIES TO HELP STATES CARRY OUT THE SUPREME COURT'S OLMSTEAD DECISION:

In its January letter to States on the Olmstead decision, HHS pledged to begin to review and modify, where necessary, relevant federal Medicaid regulations, policies and previous guidance to assure that they are compatible with requirements of the ADA and facilitate States' efforts to comply with the law.

Toward this end, HHS is issuing two additional letters and related guidance to State Medicaid Directors which provide needed policy clarifications and in some instances, reflect significant changes in policy to support community integration. These letters are responsive to specific issues that have been identified as barriers by both States and the disability community. The letters will support States' efforts:

. expanding access to home and community based services;

. assisting people with disabilities make a successful transition from nursing homes and other institutions into the community; and,

. maximizing the personal dignity and autonomy of persons with disabilities.

Along with the letters, the Department is releasing a set of Questions and Answers regarding the ruling. The Q&A's like the policy clarifications HCFA is issuing are responsive to the questions and concerns that States and the disability community brought to HHS as a result of our invitation to do so in the January letter.

EXPANDING ACCESS TO HOME AND COMMUNITY BASED SERVICES: This letter describes the ways in which States can use the Medicaid program to work toward achieving the following 4 goals:

1. HELPING PEOPLE WITH DISABILITIES MAKE A SUCCESSFUL TRANSITION FROM NURSING HOMES AND OTHER INSTITUTIONS INTO THE COMMUNITY:

People with disabilities who want to and are able to move out of nursing homes and other institutions often face tremendous barriers to making such a transition. State Medicaid programs face similar barriers of their own. The guidance and policy clarifications in the first letter HHS just issued to State Medicaid Director on July xx, will help eliminate many of these barriers.

Accessing Waiver Services: HCFA explains the quickest way a State can begin using Medicaid waiver funds to help a person move out of a nursing home or institution back into their community;

thus cutting down on undue delays.

Community Transition Expenses: HCFA details how Medicaid can be used to pay for services and one-time expenses related to assisting a person to move from institution to the community. This can include paying for up to 6 months of case management to identify and obtain needed services for the person by the time he or she leaves the facility; accessibility assessments and modifications to the home or apartment the person is moving into; and a security deposit on an apartment and other typical moving costs.

Avoiding Reinstitutionalization: HCFA will now allow States to use Medicaid to continue to pay for personal care for a period of up to two weeks, while a person with a disability is hospitalized or absent from his or her home. This will enable a State to help individuals avoid losing their attendants and risk unnecessary institutionalization. Doing this extends the policy of making similar payments to retain the bed of a Medicaid nursing home resident who is hospitalize or otherwise absent to those receiving community services.

2. EXPANDING THE AVAILABILITY AND QUALITY OF HOME AND COMMUNITY BASED SERVICES:

The first letter HCFA recently sent to State Medicaid Director also addresses some of the fiscal and programmatic challenges State face in increasing the availability and quality of home and community based services for people with disabilities of all ages. Some of these can only be addressed over the long term by way of the issuance of new regulations and/or changes to the law itself. HHS is committed to working with States and others identifying and giving serious consideration to best way of effectuating such regulatory and statutory reforms. We believe, however, we have identified and made a series of immediate changes in existing guidance or HCFA's interpretation of the Medicaid statute that States and the disability community will find helpful.

Budget Neutrality: This new policy guidance offers States a more effective way of demonstrating the cost-neutrality of providing Medicaid waiver services to individuals with HIV-AIDS and other illnesses that can lead to episodic periods of institutionalization. It does this by allowing States to factor in costs incurred between institutional stays occurring in the same year.

Habilitation: HCFA makes clear that habilitation services can be provided to individuals with the full range of developmental, physical and mental disabilities under a HCBS waiver. This is important because habilitation services focus on assisting individuals to acquire, retain and improve skills important for living in the community. Traditionally, however, only people with developmental disabilities have been seen to be eligible for these very flexible and individualized services. This important clarification, therefore, opens the doors for many more to benefit from such services.

Out of State Services: HCFA explains how a Medicaid program can pay for services provided to one of its beneficiary in another state when it is in the person's best interest to do so. Examples of when a Medicaid program should consider paying for such services would the need to access services in rural or other underserved areas, situations when an individual needs to be near their family and young people with disabilities attending college out of State.

3. REDUCING THE UNNECESSARY MEDICALIZATION OF HOME AND COMMUNITY BASED SERVICES:

Some States have traditionally administered home and community based services in ways that have been unnecessarily medicalized and restricted the personal autonomy of individuals with disabilities. HCFA's guidance to State Medicaid Directors addresses these barriers to independence and community participation in two key areas:

Home Health: The guidance informs States that they may longer require that people be "homebound" in order to receive Medicaid home health services. State policies that impose the requirement that one must be homebound to receive Medicaid home health services create unfair barriers to such participation. States can set reasonable limits that do not arbitrarily deny or reduce the amount, duration, or scope of a required service solely because of a person's diagnosis, type of illness, or condition. However, the guidance will ensure that no one loses access to home health services simply by leaving their homes and spending time in their communities.

Nurse Delegation: This guidance makes clear that States may use medicaid to pay for services provided by qualified individuals under the supervision of a nurse or its nurse delegation law. In other words, States are not required to use nurses to perform health related tasks (e.g., catheter care) which others can be trained to do just as well. The guidance codifies what HCFA has permitted many States to do for years. it is hoped that this can help other States to eliminate a layer of the unnecessary medicalization of people's lives which many find extremely intrusive.

MAXIMIZING THE PERSONAL DIGNITY AND AUTONOMY OF PERSONS WITH DISABILITIES:

The second letter addresses approaches aimed at increasing consumer choice and control in respect to Medicaid services and supports are having a significant impact on people with developmental disabilities, physical disabilities, and serious mental illness of all ages, including elderly individuals. The new guidance clarifies how all States can use Medicaid to design and implement what are alternatively known as self determination, consumer directed or participant driven approaches to enabling people with disabilities to have a say in how the services they support on most to live their lives get provided. This letter contains guidance and policy clarifications in the following 4 key areas:

Person centered planning: The guidance specifies how Medicaid programs can support and pay for person-centered planning, which focuses on identifying the strengths, capacities and needs of the individual, from the perspective of the person often with the assistance of family and friends.

Individual Budget: It clarifies ways in which permits the use of individual budgets controlled by the person with a disability or their representative. The budget is set by the State in consultation with the person and their team based on the cost of service to meet a documented need and must meet other safeguards.

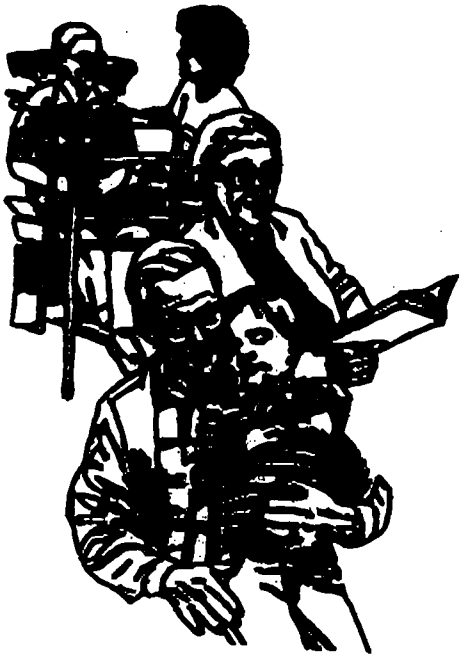
Service Brokerage : The guidance describes how Medicaid can fund the use of support brokers in

consumer- directed service systems. A support broker is a personal agent freely chosen by the individual who provides assistance with person-centered planning and obtaining both Medicaid and non-Medicaid funded services.

Fiscal Intermediaries: The guidance describes how Medicaid programs can use fiscal intermediaries to foster self determination and consumer directed services. In a self-directed service delivery model, Medicaid beneficiaries may hire/fire, schedule, and supervise their providers to the extent permitted a State. Fiscal intermediaries help relieve individuals of a number of bookkeeping tasks which can be time consuming to perform and create unnecessary barriers to persons with disabilities controlling their services and thus their own lives as well.

Such tasks include Medicaid billing, check writing for provider-generated bills, administration of personnel issues (e.g., employer of record services, tax withholding, worker*s compensation, health insurance) and the management of other taxes and benefits. Some individuals may choose to perform these functions themselves (with the exception of making payments to providers) but the State cannot require them to do so.

HEALTH CARE FINANCING ADMINISTRATION



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REMARKS:

DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

Deputy Administrator
Washington, D.C. 20201

DATE: June 29, 2000

TO: Christopher Jennings
Deputy Assistant to the President for Domestic Policy
Executive Office of the President

Jeanne Lambrew
Associate Director for Health and Personnel
Office of Management and Budget

FROM: Nancy-Ann Min DeParle
Administrator

SUBJECT: Proposed Systems Change Grants to States

By way of this memo I am transmitting more detailed information supplementing the conversations I have had with some of you on a grants program that advances our agenda of providing expanded, high-quality services in community-based settings.

As you know, the Supreme Court's Olmstead decision will place increasing demands on all States to significantly expand the availability and quality of personal assistance services and supports (PASS) to people with developmental, physical and psychiatric disabilities of all ages. In all of my meetings with the disability community, I have been told repeatedly that the services currently available in the community do not approach adequacy for meeting the existing need.

I support the attached proposal, largely based on the Systems Change section of MiCASSA, as one step in moving the Department forward in our efforts to ensure the provision of sufficient community-based services.

Rationale for Funding

Section 4 of MiCASSA would fund States to engage in systems change activities designed to build and enhance their capacity to provide personal assistance services and supports (PASS) to people with disabilities of all ages. To be eligible for such a grant a State would need to commit to work in close collaboration with its disability community to develop and implement a comprehensive, effectively working plan. This plan would be modeled after the one that the US Supreme Court indicated a State should consider developing to comply with its Olmstead decision. The disability community rightly acknowledges that, to be effective, these systems change grant monies need to be funded and awarded as soon as possible without being delayed by the larger MiCASSA legislative effort. They are extremely desirous, therefore, of working with Senate Labor HHS Appropriations and the Administration to do this before Congress goes home. They believe this would be a major step in the right direction and have characterized it as such. I believe that this grant money should be a priority for the funding decisions currently faced by the Administration. Funding of these grants this year would be hailed as a significant victory on an issue where the Administration and the millions of Americans with disabilities share a common agenda.

Systems Change and Capacity Building Grants to States

A $50 million grants initiative would be created to support States in partnering with their disability and aging communities to identify mutually agreeable ways to advance community-based care in ways that are realistic, equitable and affordable.

Grants would be awarded to States on either a competitive or funding formula basis. As a condition of the award, a State would commit to actively work with their disability and aging communities on:

developing and implementing comprehensive, effectively working plans for avoiding unnecessary institutionalization;

maximizing each State's use of Medicaid and other funding streams to carry out such plans by increasing both access to and the quality of PASS; and,

providing feedback to HCFA on regulatory and policy changes it can make to improve access to and the quality of such services and supports.

This initiative would be modeled on several different disability grants programs that have sunset. These programs funded States to build capacity and bring about systems change in such discrete areas as early intervention, assistive technology, family support and most recently, developing the Medicaid buy-in under the Ticket to Work and Work Incentives Improvement Act.

Grants made available under this initiative would be used for:

- supporting a Consumer Task Force to assist the State in the development, implementation, and evaluation of its comprehensive, effectively working plan;
- conducting needs assessment and data gathering;
- modifying policies, practices, and procedures that results in unnecessary institutional bias and/or the overmedicalization of long term services and supports;
- interagency coordination and single point of entry activities;
- recruiting, hiring and retaining highly motivated PASS workers by providing them with decent wages and benefits and career advancement opportunities;
- seeding PASS small businesses and cooperatives owned by people with disabilities, their families and PASS workers;
- meeting the needs of aging parents whose sons and daughters with significant disabilities live at home;
- improving the quality of services and supports, especially by equipping individuals with the information and tools necessary to enhance their own safety and well being;
- creating public private partnerships to expand the availability of accessible, affordable housing, transportation and other essential community supports;
- training and technical assistance;
- public awareness;
- facility-to-community transitional costs;
- demonstrations of new approaches; and
- other systems change activities necessary for developing, implementing, or evaluating the comprehensive statewide system of personal assistance services and supports.

Each State's plan and annual benchmarks for accomplishing it would be developed and submitted to HHS with the meaningful participation and support of individuals with the full range of disabilities, families of children with disabilities and other key stakeholders.

New Spending: $50 million.