Slattery Comm.

National Commission on Childhood Disability

801 Pennsylvania Avenue, NW, Suite 625, Washington, DC 20004
Tel: (202) 272-2228 Fax: (202) 272-2233

OVERVIEW

Chair:
The Honorable Jim Slattery

Members:
Polly Arango
Family Voices

Adrianne Asch, Ph.D.
Wellesley College

Dolores Berkovsky, M.S.N., L.M.S.W.
St. Teresa's Home, Catholic Charities

Wade F. Horn, Ph.D.
National Fatherhood Initiative

Jennifer Howse, Ph.D.
March of Dimes Birth Defects Foundation

Sharman Davis Jamison
Parent Advocacy Coalition Educational Rights Center

Dan Johnson
Madison, Wisconsin

Paul Marchand
The Arc

James M. Perrin, M.D.
Massachusetts General Hospital

M. Carmen S. Ramirez
Schools Are For Everyone

Carol Rank
Kansas Disability Determination & Referral Service

H. Rutherford Turnbull III
Beach Center on Families & Disabilities, University of Kansas

Barbara Wolfe, Ph.D.
University of Wisconsin

Staff Director:
Elaine Fultz, Ph.D.

Congress established the National Commission on Childhood Disability in 1994 as part of the Social Security Independence and Program Improvements Act (Public Law 103-296). The task of the Commission is to examine the Supplemental Security Income (SSI) program for children with disabilities, assess the appropriateness of its eligibility criteria, and review the impact of the program on disabled children and their families. The 14 Commission members were appointed by the Secretary of Health and Human Services. The Commission is chaired by Jim Slattery, a former representative of the second congressional district of Kansas.

A major impetus for the creation of the Commission was a recent three-fold increase in the number of children receiving SSI. Between 1989 and 1994, SSI child beneficiaries increased from 290,000 to 890,000, raising program costs to nearly $5 billion. This increase has been attributed primarily to three causes: a liberalization of eligibility criteria required by the 1990 Sullivan v. Zebley Supreme Court decision; the Social Security Administration's expansion of its listings of childhood mental impairments; and increased outreach efforts by SSA. The Commission will examine these causes along with others in an effort to address the seven issues in its statutory mandate:

1) the appropriateness of the present SSI definition of disability and the advantages and disadvantages of using an alternative definition;

2) whether the need by families for assistance in meeting high costs of medical care for children with serious physical or mental impairments might appropriately be met through expansion of federal health assistance programs, regardless of whether they are eligible for disability benefits under title XVI of the Social Security Act;

3) the feasibility of providing benefits to children through non-cash means, including but not limited to vouchers, debit cards, and electronic benefit transfer systems;

4) the extent to which the SSA can involve private organizations in an effort to increase the provision of social services, education, and vocational instruction with the aim of promoting independence and the ability to engage in substantial gainful activity;

5) alternative ways of providing retroactive supplemental security income benefits to disabled children, including the desirability and feasibility of conserving some portion of such benefits to promote the long-term well-being of such children;

6) the desirability and methods of increasing the extent to which benefits are used in the effort to assist disabled children in achieving independence and engaging in substantial gainful activity; and

7) the effects of the SSI program on disabled children and their families.

The Commission is mandated to report its findings and recommendations to the House Committee on Ways and Means and the Senate Committee on Finance by November 30, 1995. However, the Commission has accelerated its timetable and hopes to submit its report by late summer.

CHILDHOOD DISABILITY COMMISSION MEMBERS

Polly Arango National Director of Family Voices, a national coalition that speaks for children with special health needs. The mother of a child with multiple disabilities, Ms. Arango is active in national health reform for children with disabilities.

Adrienne Asch, Ph.D. Professor in Biology, Ethics and the Politics of Human Reproduction at Wellesley College, Wellesley, Massachusetts. A noted ethicist and social psychologist, Dr. Asch has researched legal and ethical problems in health care delivery and participated in the Project on Implications of Population Screening for Cystic Fibrosis. Dr. Asch has written extensively on disability, bioethics and health care, stigmatization of the disabled, home care, rehabilitation, imperiled newborns, and reproductive technology.

Dolores Berkovsky, M.S.N., L.M.S.W. Director of Children's Services for Catholic Charities of Fort Worth, Texas. Ms. Berkovsky is responsible for a large continuum of grassroots child and family services, including programs that promote family preservation, adoption of children with disabilities, and out-patient assessment and treatment services. Ms. Berkovsky is also involved with families and children at the state level, where she is instrumental in child and family advocacy committees such as the Children's Community Research Group.

Wade F. Horn, Ph.D. Director of the National Fatherhood Initiative, a group that promotes father restoration in American families. A clinical child psychologist, Dr. Horn is a nationally recognized expert on Attention Deficit Hyperactivity Disorder and served as the National Executive Director for the organization, Children and Adults with Attention Deficit Disorders, in 1993. Dr. Horn also served as the Commissioner for Children, Youth and Families in the Administration for Children and Families during the Bush Administration.

Jennifer Howse, Ph.D. President of the March of Dimes Birth Defects Foundation. Previously, Dr. Howse served as Associate Commissioner for the Office of Mental Retardation and Developmental Disabilities for the state of New York. She has also served as the Executive Director of the Greater New York March of Dimes, and the Pennsylvania State Commission for Mental Retardation.

Sharman Davis Jamison Speech therapist, member of the National Advisory Committee of the Howard University Research and Training Center, and the President's Committee on Employment of Persons With Disabilities. The parent of an adult daughter who is autistic and deaf, Ms. Jamison develops and implements parent training throughout the country, and provides advice to parent training and information centers regarding disability issues.

Dan Johnson Director of the Office for Persons With Physical Disabilities in Madison, Wisconsin. Mr. Johnson is responsible for the development and coordination of programs for persons with physical disabilities in Wisconsin. He provides planning and definitions of program policy, goals, and objectives to ensure the delivery and coordination of services essential for independent living and self-sufficiency.

Paul Marchand Director of the Association for Retarded Citizens (ARC). Mr. Marchand is a leading spokesperson for children with disabilities, especially those with mental disorders.

James M. Perrin, M.D. Associate Professor of Pediatrics at Massachusetts General Hospital in Boston, Massachusetts. Dr. Perrin has written extensively on the organization of services for children with chronic physical disorders, and co-authored Home and Community Care for Chronically Ill Children and Chronically Ill Children and Their Families.

M. Carmen S. Ramirez President and Founder of Schools Are For Everyone. Ms. Ramirez has extensive community volunteer experience in issues affecting children with disabilities, including minority and non-English speaking families. She was appointed by Governor Ann Richards to serve on the Texas Continuing Advisory Commission for Special Education. Ms. Ramirez also serves on the Governing Commission of the Texas Parent and Training Information Center for Latino Parents of Children With Disabilities.

Carol Rank Director of the Kansas Disability Determination and Referral Service. Ms. Rank works closely with Kansas' State Services for Children With Special Health Care needs and other agencies to further understanding of the requirements for the children's SSI program.

Jim Slattery Former United States Representative from Kansas and partner in the Wiley, Rein and Fielding law firm of Washington, D.C. Mr. Slattery was elected to the House of Representatives in 1982 and served six terms. He served 12 years on the Energy and Commerce Committee, where he was active on environmental, health care, railroad and telecommunications issues. Mr. Slattery also served for 6 years on the House Budget Committee and the House Veterans' Affairs Committee. His primary interests included deficit reduction, health care access in rural areas, and Medicaid coverage for children from low-income families.

Rud Turnbull Co-director of the Beach Center on Families and Disabilities at the University of Kansas. Mr. Turnbull is a nationally known expert and author in disability policy issues. He has served in national leadership positions in several organizations, including the Association for Retarded Citizens, the American Association on Mental Retardation, the Association for Persons With Severe Disabilities, and the American Bar Association Commission on Mental and Physical Disability Law.

Barbara Wolfe, Ph.D. Director of the Institute for Research on Poverty at the University of Wisconsin, where she is also a member of the faculty of the Department of Economics, the Department of Preventive Medicine, and the LaFollette Institute of Public Affairs. Since the 1970s, Dr. Wolfe has written a number of publications regarding health care issues including a 1994 article, "Reform of Health Care for the Nonelderly Poor." Dr. Wolfe also co-authored a recent book, Succeeding Generations: On the Effects of Investments in Children.

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SSI for Children

The enactment of the Supplemental Security Income (SSI) program in 1972 marked a milestone in the development of federal policies for children with disabilities. Previously, disabled children, like those without disabilities, were eligible for cash benefits only if their families qualified under a state Aid to Families with Dependent Children (AFDC) program. SSI provides benefits to children in their own right, provided they meet both the medical and financial requirements.

SSI is a means tested program funded entirely from federal general revenues. In 1995, the maximum federal benefit is $458 per month. All but seven states and one territory supplement the federal SSI payment.

A child is found disabled under SSI if he or she suffers from a physical or mental impairment comparable to one which would render an adult unable to work.[1] In calculating a child's financial eligibility for SSI, a portion of the income and resources from other family members is deemed to the child. Generally, a disabled child in a family of four can qualify for a full benefit when family income is under $20,200 and can qualify for a partial benefit when income is under $30,900.

Children undergo a sequential evaluation to determine their medical eligibility for SSI. Originally, the Social Security Administration (SSA) established different evaluation processes for adults and children. Both included a comparison of the claimant's impairments and those specified on the medical listings created by SSA. If a child's impairment(s) did not meet or equal the severity of those in the listings, he or she was denied benefits. Adults who did not meet or equal the listings, on the other hand, were given a functional assessment to determine the extent to which the impairment(s) affected their ability to be employed, given their age, education, and work experience.

[1] The statutory definition of a disabled person is one who is "unable to engage in any substantial gainful activity by reason of any medically determined physical or mental impairment which can be expected to last for a continuous period of not less than 12 months (or in the case of a child under the age of 18, if he suffers from any medically determinable physical or mental impairment of comparable severity)." P.L. 92-603.

In the 1990 *Zebley v. Sullivan* Supreme Court decision, the Court found that SSA's process did not satisfy the requirement in the Social Security Act that children's eligibility standards be comparable to those for adults. To provide comparability, SSA created an Individualized Functional Assessment (IFA) for those children who did not meet or equal the medical listings. Under the final court settlement, SSA agreed to readjudicate all claims that were denied from January 1, 1980, to February 11, 1991, using the new functional criteria. As a result of the reajudication, approximately 135,000 new beneficiaries entered the program.

A second factor which has contributed to SSI program growth is SSA's revision of its listings of childhood mental impairments. These listings were revised and expanded in compliance with the 1984 Disability Benefits Reform Act to reflect advances in evaluation, treatment, and technology. The new listings were finalized in 1990, the same year as the *Zebley* decision.

Third, in response to a 1989 Congressional mandate and a requirement in the *Zebley* decision, SSA has expanded its outreach activities. In an effort to identify eligible children, the agency has published and distributed pamphlets, conducted demonstration projects at children's hospitals, and contracted with local school districts and special education programs.

Increased outreach efforts, along with the revised listing of mental impairments and the Individualized Functional Assessment, have contributed to an unprecedented growth in the enrollment of children in the SSI program. The number of SSI beneficiaries under the age of 22 increased from 296,300 at the end of 1989 to 892,000 at the end of 1994, increasing program expenditures for children to nearly $5 billion.

While 1994 witnessed a significant change in this trend,[2] the post-*Zebley* expansion has nevertheless raised questions about the appropriateness of the IFA and the mental impairments listings. Since SSI cash benefits are greater than those available through AFDC, critics argue that less stringent eligibility criteria and the subjectivity in the definitions of several mental impairments allow parents to "coach" children to appear disabled. Critics also point to cash payments as a disincentive for families to actively seek treatment.

Responding to these concerns, Congress passed legislation in 1994 creating the National Commission on Childhood Disability. The Commission is now examining the SSI childhood program, assessing the appropriateness of its eligibility criteria, and reviewing the impact of the program on beneficiaries and their families. The 14 member Commission must submit its report to Congress by November 30, 1995. Given the high level of Congressional interest in these issues, the Commission is working to complete its report in late summer.

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[2] After rising from 38 percent to 55 percent in the wake of *Zebley* (1992-3), SSA's childhood benefit allowance rate for 1994 fell to 32 percent.

Public Law 103-296

Social Security Independence and Program Improvements Act of 1994

SEC. 202. COMMISSION ON CHILDHOOD DISABILITY.

(a) ESTABLISHMENT OF COMMISSION.—The Secretary of Health and Human Services (in this section referred to as the "Secretary") shall appoint a Commission on the Evaluation of Disability in Children (in this section referred to as the "Commission").

(b) APPOINTMENT OF MEMBERS.—(1) The Secretary shall appoint not less than 9 but not more than 15 members to the Commission, including—

(A) recognized experts in the field of medicine, whose work involves—

(i) the evaluation and treatment of disability in children;

(ii) the study of congenital, genetic, or perinatal disorders in children; or

(iii) the measurement of developmental milestones and developmental deficits in children; and

(B) recognized experts in the fields of—

(i) psychology;

(ii) education and rehabilitation;

(iii) law;

(iv) the administration of disability programs; and

(v) social insurance (including health insurance); and

(C) other fields of expertise that the Secretary determines to be appropriate.

(2) Members shall be appointed by January 1, 1995, without regard to the provisions of title 5, United States Code, governing appointments to competitive service.

(3) Members appointed under this subsection shall serve for a term equivalent to the duration of the Commission.

(4) The Secretary shall designate a member of the Commission to serve as Chair of the Commission for a term equivalent to the duration of the Commission.

(c) ADMINISTRATIVE PROVISIONS.—(1) Service as a member of the Commission by an individual who is not otherwise a Federal employee shall not be considered service in an appointive or elective position in the Federal Government for the purposes of title 5, United States Code.

(2) Each member of the Commission who is not a full-time Federal employee shall be paid compensation at a rate equal to the daily equivalent of the rate of basic pay in effect for Level IV of the Executive Schedule for each day (including travel time) the member attends meetings or otherwise performs the duties of the Commission.

(3) While away from their homes or regular places of business on the business of the Commission, each member who is not a full-time Federal employee may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons employed intermittently in the Government service.

(d) ASSISTANCE TO COMMISSION.—The Commission may engage individuals skilled in medical and other aspects of childhood disability to provide such technical assistance as may be necessary to carry out the functions of the Commission. The Secretary shall make available to the Commission such secretarial, clerical, and other assistance as the Commission may require to carry out the functions of the Commission.

(e) STUDY BY THE COMMISSION.—(1) The Commission shall conduct a study, in consultation with the National Academy of Sciences, of the effects of the definition of "disability" under title XVI of the Social Security Act (42 U.S.C. 1382 et seq.) in effect on the date of enactment of this Act, as such definition applies to determining whether a child under the age of 18 is eligible to receive benefits under such title, the appropriateness of such definition, and the advantages and disadvantages of using any alternative definition of disability in determining whether a child under age 18 is eligible to receive benefits under such title.

(2) The study described in paragraph (1) shall include issues of—

(A) whether the need by families for assistance in meeting high costs of medical care for children with serious physical or mental impairments, whether or not they are eligible for disability benefits under title XVI of the Social Security Act, might appropriately be met through expansion of Federal health assistance programs;

(B) the feasibility of providing benefits to children through noncash means, including but not limited to vouchers, debit cards, and electronic benefit transfer systems;

(C) the extent to which the Social Security Administration can involve private organizations in an effort to increase the provision of social services, education, and vocational instruction with the aim of promoting independence and the ability to engage in substantial gainful activity;

(D) alternative ways and providing retroactive supplemental security income benefits to disabled children, including the desirability and feasibility of conserving some portion of such benefits to promote the long-term well-being of such children;

(E) the desirability and methods of increasing the extent to which benefits are used in the effort to assist disabled children in achieving independence and engaging in substantial gainful activity;

(F) the effects of the supplemental security income program on disabled children and their families; and

(G) such other issues that the Secretary determines to be appropriate.

(f) REPORT.—Not later than November 30, 1995, the Commission shall prepare a report and submit such report to the Committee on Ways and Means of the House of Representatives and the Committee on Finance of the Senate which shall summarize the results of the study described in subsection (e) and include any recommendations that the Commission determines to be appropriate.

Statement of Congressman Sander Levin

before the

National Commission on Childhood Disability

I want to thank the members of the Commission for giving me the opportunity to come before you today and testify about the Supplemental Security Income program (SSI) for children. This Commission's charge is a vital one. I urge you not to study too long because Congress is moving quickly on this issue. We need the benefit of your study and wisdom. In the recent debate in the House of Representatives over welfare reform, the SSI program was an area of some of the most vigorous debate. Unfortunately, it was an area of some of the worst public policy.

It is obvious that the SSI for children program needs reform. Since 1990, the program has experienced a vast expansion in the number of children who receive benefits. This is widely acknowledged to be the result of several events. First, the 1990 Supreme Court decision *Sullivan v. Zebley*, which resulted in the creation of the Individualized Functional Assessment (IFA) to determine whether or not a child had impairments that cause a substantial reduction in that child's ability to function in an "age-appropriate" manner. Second, the updating and expansion of the childhood mental disorder medical listings in December of 1990, increased the number of mental impairments from 4 to 11, including conditions such as autism and Attention Deficit Hyperactivity Disorder (ADHD) for the first time.

Since these developments, there has been an increase in the abuse of the program. The most common allegation is that children are being "coached" by their parents so that they may qualify for the so-called "crazy check." In an environment of a five trillion dollar national debt and multi-billion dollar deficits, we need to carefully assess the expansion in SSI and to take steps to eliminate abuse. Although in 1994 there was a decrease in the number of new beneficiaries as compared to 1993, the status quo is clearly not acceptable.

In my opinion, the single most necessary reform is to restructure the Individualized Functional Assessment. Some type of functional assessment, whether it be the IFA or a new functional assessment, is necessary for determining the eligibility for SSI for children. The biggest need for a functional assessment was recognized by the Supreme Court in the *Zebley* decision: that there are children who possess a combination of impairments, none of which meet the requirements of the listings, but when taken as a whole render the child incapacitated. The majority of these children are not kids who have "behavior disorders." These are children with medical disabilities, like cerebral palsy or cystic fibrosis. These children must be taken care of.

Both the Democratic substitute in the Ways and Means Committee and on the floor of the House addressed this problem of restructuring the IFA by eliminating maladaptive behavior as a functional domain in both the IFA and the medical listings. In testimony before the Senate Finance Committee on March 27, Jerry Mashaw, Chair of the Disability Policy Panel of the National Academy of Social Insurance, advocated the exact same

approach. This main thrust of the proposal is aimed at getting at the allegations of parents coaching their children so that the child will misbehave in order to receive a monthly SSI check. This proposal would prevent maladaptive behavior, in and of itself, from being evidence of the disabling consequences of the child's impairment. Experts in childhood mental disorders report that maladaptive behavior is not one of the key domains used to assess the functional consequences of childhood disabilities.

I am not saying that these changes will be painless, or that there are not children who currently could receive SSI that would not if these changes were implemented. However, I believe this is the most effective way both to tighten the eligibility criteria of the IFA and attack the mistaken perception that inappropriate behavior is a basis for SSI benefits.

Next, I want to emphasize one reform that I believe should not be implemented. That is the removal of cash benefits. To remove cash benefits from families and replace them with vouchers or some other mechanism to cover only services will, in effect, be taking power away from families and giving it over to bureaucrats, be they state or federal. Who do we think knows best on how best to spend money for a disabled child? A child's parents or some well-meaning bureaucrat?

The House Ways and Means Committee, of which I am a member, heard testimony from Karen Higgenbotham. Mrs. Higgenbotham's daughter Alison suffers from a rare seizure disorder called infantile spasms and receives SSI. In her testimony Mrs.

Higgenbotham detailed some of the ways in which she spends the monthly SSI check for Alison. It goes to pay for the tuition and transportation costs to take Alison to an out-of-town speech therapy program because there was no local program. It went to extra clothes because Alison was consistently incontinent. It went to pay for modifications to their home - such as widening doors, installing door levers, and installing a paved driveway because Alison's wheelchair could not travel over a dirt or gravel driveway.

If we were to move away from cash benefits the Higgenbotham's would no longer have the assurances that they could obtain these much needed items. In a system that covers only services, some of these things may not be covered. In a system of vouchers, would the paving company take the voucher and then trade it in for reimbursement or would the Higgenbotham's pay the expense and hope that they could submit a voucher to the state along with the receipt and get reimbursed? Eliminating cash benefits would add administrative costs to the program and would be an unnecessary intrusion into the lives of families with disabled children.

To ensure that money is being spent properly, we do not need to eliminate cash payments, but rather we need to improve the accounting rules. We should require that parents demonstrate that funds they have been provided are spent for the well-being of the child, and that they are following any course of medical treatment that has been prescribed for the child.

In conclusion, let me reinforce my belief that reform is needed in the SSI program for children. But, reasoned reform is needed, not the hastily drafted, ill-thought out reforms that were passed by the House of Representative late last month within H.R. 4, the Personal responsibility Act (PRA). The PRA denies cash benefits to over 700,000 children. This is simply unconscionable. It also takes away cash benefits from all future beneficiaries, except for those who meet a very strict institutionalization standard. Do we need to restructure the SSI program, in general, and the IFA, in particular? Yes. But, restructuring should not be an excuse for decimating the program and harming hundreds of thousands of disabled children.

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May 8, 1995

The Honorable Maxine Waters
330 Cannon House Office Building
Washington, D.C. 20515

Dear Maxine:

Thank you for sending me a copy of the letter you sent to President Clinton regarding the National Commission on Childhood Disability, which I chair.

I regret that the Commission was unable to hold a public hearing in California as we had planned. Unfortunately, the Senate Finance Committee has scheduled markup on welfare reform in May. Members of the Commission concluded it was essential to spend what limited time we have to finalize our recommendations before the Senate acts on welfare reform. I certainly wish we had until November 1995 to complete our work, as the legislation establishing the Commission provides, but this is not the case. We are attempting to do the best job we can in the time available.

I want to point out the critical differences between the Commission recommendations and those in the House welfare reform bill. Under the House bill, SSI cash benefits would be terminated to all children unless the child suffers from an impairment which meets or equals one specified in the Social Security Administration's (SSA's) Medical Listing of Impairments, AND the child is either institutionalized or would be institutionalized if not receiving personal assistance necessitated by the impairment. Also, within 90 days of enactment, the House bill would terminate cash benefits to all children on the SSI rolls who became eligible through the Individualized Functional Assessment (IFA). No such provisions exist in the Commission recommendations.

By contrast, the Commission recommendations preserve the basic structure of the SSI cash program for disabled children and their families, while addressing

the problems that have brought this program into crisis. We do so by preserving the concept of individualized functional assessment of disability, but increasing the stringency of SSA's functional eligibility criteria for children. We also recommend eliminating the double counting of maladaptive behavior in SSA's current eligibility procedures.

The Commission is not alone in recommending that a limit be placed on family benefits. One option to limit benefits is set forth in a proposal by the Bazelon Center for Mental Health Law. This proposal would relate to the poverty level for a family of specific size and would result in benefits of 100 percent for the first disabled child, 85 percent for the second child, 65 percent for the third child, and 45 percent for the fourth and any additional children.

Finally, the Commission recommendations enhance the SSI program in several ways. The Commission proposes eliminating the six-month limit on spending retroactive lump-sum benefits, continuing Medicaid for children who leave the SSI rolls due to medical improvement but continue to need treatment, disregarding minor siblings' earnings in determining a disabled child's eligibility, and expanding eligibility for disabled children of overseas military personnel. The House bill contains no benefit improvements.

I want to add that all Commission members have approached their work with a high level of expertise and concern. By accelerating our schedule and devoting extensive time to the charges of the Commission, we have accomplished a great deal in a short period. The Commission is working to identify and address the real problems that threaten the existence of SSI cash benefits for children.

As you can quickly see, any suggestion that our recommendations are similar to those in the House bill is simply not true. If you or your staff need any further information, please call me personally, or call Elaine Fultz, the Commission Staff Director. I can be reached at 429-7264, and Elaine can be reached at 272-2228. We would be happy to provide you with additional information.

Sincerely,

Jim Slattery
Chairman

MAXINE WATERS
MEMBER OF CONGRESS
35TH DISTRICT, CALIFORNIA

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cc Janet Murguia
cc Ken Apfel
FY 96
FY 1
—Diana Fortuna

May 2, 1995

The Honorable William J. Clinton
President
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20500

RE: SSI Childhood Disability and
National Commission on Childhood Disability
Cancellation of West Coast Hearing

Dear Mr. President:

I write quite upset at learning that your commission chaired by Jim Slattery has canceled its only West Coast public hearing set in Los Angeles for May 19 (as well as its only Mid-west hearing set for June 2). The Commission thus is ignoring the views of two-thirds of the nation who don't have proximity to Washington, D.C. as well as my state of California which, with over 70,000 disabled children on SSI, has almost 1 of every 10 of the nation's children on SSI. I was upset about the composition of the commission from the beginning, but its recent actions are even more upsetting.

What makes these cancellations and Commission's rush to judgment so problematic are the "Preliminary Recommendations" that the Commission voted on in Baltimore a week ago. Despite their "preliminary" nature and the absence of key members not in attendance as well as abstentions for lack of vital information not before the Commission, the chairman, Mr. Slattery, chose to take these recommendations to the Congress in informal discussions--giving them a very "final" spin. I understand the Senate Finance Committee is pressing to complete its welfare-SSI bill in May, but why have a Commission if it is jettisoning reasoned deliberations and fact-finding, and ignoring the families and professionals working with these families in two-thirds of the nation! I think my initial concerns were well founded.

Because Mr. Slattery has chosen to run with these "preliminary recommendations," you should know some of their deficiencies:

1. The draft would define SSI as only for "extra costs" families must meet, not also the basic needs of children (food, clothing and shelter) that the program has also attempted to address successfully for over 20 years. This is a radical step backward destroying the safety-net for 900,000 poor, disabled children.

2. The draft would eliminate the Zebley decision's individualized Functional Assessment (IFA) test, which has worked very well to provide fair and realistic evaluations of children (and has been tough enough to deny well over one million children since its use in 1991). The draft would substitute a "functional equals" to the Child Listings test that is the House Republican test of "meets" or "equivalent" to the Listings, effectively ending SSI for the 25-30% of children on SSI (a quarter of a million children, over 20,000 in my state) who are there due to the IFA test that all the national medical and disability groups sought to be established.

3. It would "cap" benefits for multiple child households instead of a more equitable declining benefit scale, and then inject this unfair and unworkable judgment of determining what the "extra costs" would be for multiple child households.

4. Finally, it would toss the SSI children's program back to HHS which has no experience in direct administration of a benefit program like this, and where it would get less attention and be at greater risk of being "block granted." Connections with other services can be obtained with the program at SSA.

I hope you will immediately intervene to correct this situation, as well as support constructive, moderate and middle-of-the-road reform efforts such as the Senator Kent Conrad bill which improves the program without hurting disabled children.

Sincerely,

MAXINE WATERS
Member of Congress

cc: Carol Rasco, Director, Domestic Policy Council
The White House
Secretary Donna Shalala, HHS
Commissioner Shirley Chater, SSA
Jim Slattery, Chair, Commission on Childhood Disability
Elaine Fultz, Staff Director
Commission on Childhood Disability

POLICY OPTIONS
COMMISSION ON CHILDHOOD DISABILITY

On Friday, April 21, 1995, the Commission on Childhood Disability discussed several issues on the attached list of policy options. Based on this discussion, Chairman Jim Slattery plans to meet with members of the Senate Finance Committee and staff during the week beginning April 24, 1995 to offer preliminary recommendations for the Senate's forthcoming actions on the childhood disability provisions in H.R. 4, the Personality Responsibility Act of 1994. (He indicated that he would emphasize that these are preliminary recommendations which require further discussion by the Commission.)

The following is a summary of the actions the Commission took on those issues discussed:

- *Cap family benefits so that payments do not rise significantly above poverty guidelines for families of various sizes.* (#1)

Agreed to cap family benefits, including multirecipient families.

- *Require continuing disability reviews (CDRs) for SSI children under age 18 and establish a revolving fund to cover their costs.* (#2)

Agreed to recommend CDRs on children under age 18 every two years unless SSA decides that there is a likelihood that the impairments will not improve. Discussion of the revolving fund issue was deferred.

- *Exclude retroactive lump-sum benefits from countable income indefinitely and require that their use be related to the child's disability and/or to enhancing his or her independence.* (#3)

Agreed, without discussion.

- *Disregard siblings' wages in determining eligibility of a disabled child.* (#4)

Agreed. (This proposal related to a witness' testimony about the adverse effects of an ineligible child's work activities on the amount of the recipients' SSI payment under the deeming rules.)

- *Continue Medicaid for children who lose cash benefits due to medical improvement, but require continuing treatment.* (#5)

Agreed, without discussion.

- *Place limits/conditions on the payment of cash benefits such as providing temporary eligibility, health coverage and services instead or cash for some disabilities, or treatment initially and cash subsequently; or require treatment as a condition of eligibility.* (#7)

These proposals raised the most discussion and concerns. Without agreeing to any of the specific options listed, the Commission agreed to make the following recommendation:

> Require participation in appropriate or recognized services or treatment, which is available and affordable and likely to improve the impairment, as a condition of eligibility.

- *Tighten SSI eligibility criteria to* (#8):

  -- *reduce the weight given to maladaptive behavior.*

Agreed to limit the consideration of maladaptive behavior to the appropriate domains, without double weighting.

  -- *restructure the functional domains in the listings and/or individualized functional assessment (IFA) to eliminate overlapping.*

Agreed. Commission members also suggested the use of a panel of experts to revise/refine the criteria which could include combining some of the current domains.

  -- *increase stringency of criteria for IFA allowances to the listings level.*

Agreed to use of a functional equals standard instead of the IFA evaluation criteria.

At the Chairman's suggestion, the Commission also discussed at great length whether the SSI program for children with disabilities should remain with the Social Security Administration or moved to another agency within the Department of Health and Human Services. During the discussion, it was suggested that the Administration for Children and Families, which currently handles several programs for children, could be the appropriate component for housing the program. In the end, though several

members abstained because of the lack of sufficient information to make a decision, most of the members supported the suggestion.

The remaining policy options will be discussed at subsequent meetings. (Because of the urgency to send recommendations to the Senate before it takes final actions on H.R. 4, the Commission members also agreed not to hold public hearings in Los Angeles, CA and Kansas City, MO.)

Attachment

TA to Elaine
SSA, HCFA, ASPE OK'd

Analysis of Preliminary Recommendation #7

- **Preliminary recommendation requires treatment as a condition of eligibility for SSI** childhood benefits when the treatment is readily available in the child's community, affordable to parents, and likely to result in improvement of the child's condition.

- **Some Commission members have proposed an alternative treatment recommendation** that would require treatment when it is readily available, financed by Medicaid or other third party sources, and developed by qualified professionals in collaboration with the family. The alternative proposal also includes due process safeguards for families prior to a child losing SSI eligibility as a result of this treatment requirement.

- **This preliminary recommendation, and the alternative, must be viewed in coordination with two other preliminary recommendations.**

  - First, the Commission clarified on May 6 that the purpose of SSI assistance for children includes using cash for both basic needs (food, clothing, shelter) and for specialized needs arising from the child's disability. **Commission members agreed that parents do not have to spend the SSI dollars in ways that address or improve the child's condition.**

  - Second, the Commission has agreed to the preliminary recommendation that total benefits to a family cannot exceed the cost of meeting a child's disability related needs. **This recommendation directly conflicts with the treatment and purpose recommendations.**

- **The preliminary recommendation on treatment is also complex in and of itself, and potentially leads to several implications that must be addressed.**

  - Operationalizing the treatment requirement would result in the need to establish new administrative structures and in expanded administrative costs.

  - This may be perceived by states as a new Medicaid mandate -- particularly tricky when the possibility of Medicaid turning into a block grant is factored into the equation.

  - Protections against fraud and abuse would have to be added because the treatment recommendation could be gamed.

  - Equity issues could emerge if the treatment requirement is only applied to certain disabilities; on the other hand, if it is applied to all disabilities, the costs could skyrocket.

- Depending on the details which the Commission adds to the recommendation, and whether it is decided to go with the preliminary recommendation or the substitute, a series of questions arise. The rest of this document outlines some of these questions.

- **Does this apply to all children entering the SSI rolls, or only children in certain categories?** Would all children with a disability that could be improved by treatment be included, both physical and mental, or some targeted group of children such as children with certain mental impairments?

  - If the goal of the recommendation is far narrower than to require all beneficiaries to receive treatment -- i.e., to prevent coaching and malingering -- then the recommendation should explicitly say this.

- **Does "improvement" mean eligibility for SSI cash benefits ends?** If so, there's an explicit disincentive to improve, however, it should be pointed out that this is an improvement over current policy.

- **Who will make the determination that treatment is indicated and specify the components of the treatment plan?**

  - **Who would pay for the plan development -- Medicaid?**

- **How would the assessment and treatment prescription be coordinated with other benefits and services the child receives?**

  - Would the same entity that determined the potential for improvement and prescribed the treatment be responsible for tracking the receipt of services, ensuring/enforcing that the child remains in treatment, approving changes in the treatment plan, and deciding whether treatment has been effective? Can the child's physician certify compliance?

  - Who determines when the child has either improved or when there has been enough "treatment" and improvement is no longer possible?

- **Perverse incentives.** Does the system have perverse incentives?

  - If the case manager certifies that the child has improved or that there is no longer any possibility of improvement, then the case manager loses the case?

- **When would cash benefits start?** The recommendation indicates that the treatment requirement is a condition of eligibility. This could mean that cash benefits will not start until it is determined that treatment is viable and the child is in treatment. Is this what was intended? Some sort of presumptive eligibility may be needed so cash benefits start once financial and disability determinations are made.

  - Also, how is treatment paid for unless the child is on SSI and thus eligible for Medicaid?

  - Should cash be deferred until treatment has been tried?

- **How is treatment defined?** Is it medical care only? For example, does treatment include psycho-social analysis or speech-language classes at school? Medical treatment is costly and a low-income family on SSI would not be able to afford the cost out of pocket. If Medicaid or another third party payor is not available to cover the costs, then the family should not be penalized.

- **Serious Medicaid implications.** There are some serious potential cost implications for Medicaid, depending on how this recommendation is fleshed out. There may be political issues as well, with states charging that this is yet another "unfunded mandate."

  - Medicaid will finance the lion's share of the required treatment. Will the Medicaid system have any say in the amount, scope, or duration of services included in the prescribed treatment regimen?

  - The recommendation may increase utilization, since it requires people to actually use their Medicaid coverage for specific services that they may not be using now.

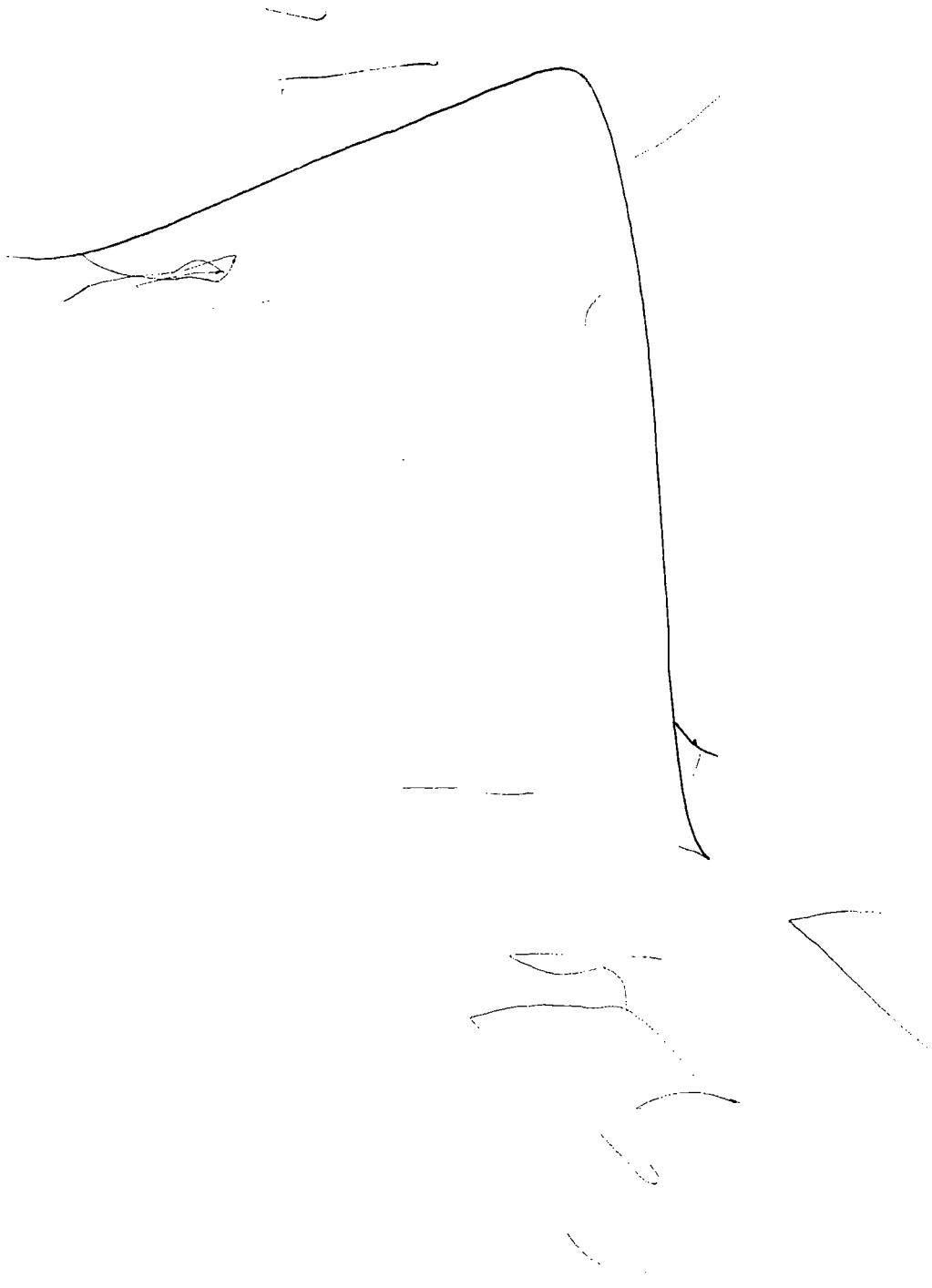
  - **What if Medicaid is block granted or cutback significantly?** How would the federal government enforce the treatment rule? Would states be mandated to provide certain treatments needed by children on SSI?

- **Non-Medicaid covered treatment.** What about other support services such as respite care or family counseling? Medical treatment as well as many rehabilitation and long-term support services could be covered under Medicaid or another third party payor. Other services typically are not covered by such health plans. If other types

of services were covered as a part of the treatment plan, who would pay for these services? Would that payor have some say in the treatment prescription?

- **What about access to treatment within a community?** It is clear that if a provider if not available to conduct the necessary treatment or if no provider exists which accepts Medicaid, the family would be exempt from the requirement. What about the situation where the provider is available but the parent is unable to comply because of work obligations that result in the parent not being able to take the child to the needed appointment? Would the family be responsible for this, using part of the SSI cash benefit to ensure that a child receives the required treatment? Who determines what is "**available**"? How far must someone go to get treatment?

- What if the family disagrees with the decision? Do they have appeal rights?



National Commission on Childhood Disability

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Staff Director:
Elaine Fultz, Ph.D.

March 6, 1995

MEMORANDUM

TO: Members of the National Commission on Childhood Disability

FROM: Elaine Fultz
Staff Director

REGARDING: Background materials for March 10th meeting

As you have been informed, the Commission on Childhood Disability will meet next on Friday, March 10th and Saturday, March 11th, 1995, in Washington, D.C. The meeting will be held in the Montpelier Room of the Washington Court Hotel, 525 New Jersey Avenue, N.W. A tentative agenda for this meeting is attached.

To assist you in preparing for the meeting, I have enclosed:

* A report by the General Accounting Office, New Functional Assessment Process Results in Questionable Eligibility for Children. Please note that the recommendations in this report have undergone revisions since it was distributed in draft to the Commission. This report will be the focus of the Friday morning session.

* A set of documents produced for the Children's Committee of the Disability Policy Panel of the National Academy of Social Insurance. The key item is entitled Background Paper. It will be the basis for the Commission's Friday afternoon discussion of the Individualized Functional Assessment (IFA), to be led by Dr. James Perrin.

* An amendment offered (and defeated) in the House Committee on Ways and Means which would revise the IFA.

* The proposal approved last week by the House Committee on Ways and Means, an accompanying cost estimate, and the amendments which were approved by the Committee. Also enclosed is the Democratic alternative to this proposal which will be offered on the House floor.

I hope that this information is helpful. Please call me at (202) 272-2228 if you have questions.

Enclosures

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Tentative Meeting Agenda

Friday, March 10, 1995

9:00-9:15 - opening comments by Chairman Slattery

9:15-10:45 - invited witnesses from Louisiana and Arkansas

10:45-11:00 - coffee break

11:00-12:00 - General Accounting Office analysis of the Individualized Functional Assessment (IFA) - Jane Ross

12:00-12:15 - Greeting by Social Security Commissioner Shirley Chater, Ph.D.

12:15-1:15 - lunch

1:15-3:15 - approaches to modifying the IFA - James Perrin, M.D.

3:15-3:30 - break

3:30-4:30 - discussion of tiered benefit systems
Eileen Zeitzer, SSA
Caroll McBrine, M.D.
Department of Veterans' Affairs

4:30-5:30 - Commission discussion

Saturday, March 11, 1995

9:00 - 10:00 - task force meetings

10:00 - 10:15 - break

10:15 - 1:00 - Commission discussion

EXECUTIVE OFFICE OF THE PRESIDENT

24-Mar-1995 11:17am - CR to V13:7 ph "how is comm?

TO: Carol H. Rasco

FROM: Diana M. Fortuna
Domestic Policy Council #D do testimony

CC: Jeremy D. Benami

SUBJECT: Background for Slattery lunch

Sorry to send you this long note at the last minute, but here is some background for our lunch with Jim Slattery today. Attending will be you, him, me, and his staffer, Elaine Fultz.

He would like to bring you up to date on where he is, share ideas, and get our input on where we'd like to see this issue end up. He will brief us about his activities on the Hill, discuss the political dimensions of the issue, and how much we would like to elevate this issue publicly. He has tried to keep Spencer Rich and someone at the NY Times informed and mindful of the severity of the changes proposed in the House. He has also tried to keep his name out of press, so that his report will be received objectively.

As I've mentioned, he is working hard to have something useful by July or so, so that he can influence the debate on the Hill. That is looking a bit more possible than before, since people now think the Senate may do 2 months of hearings. Slattery just testified before Senate Finance the other day, and he thought it went well, with the Senators looking at the program more thoughtfully than the House has.

As you know, our response to House action on this program has been to say we should wait for Slattery. Behind the scenes, SSA, HHS, and the children's group of the disability policy review have done a lot of talking about what we would propose if the pressure becomes too great. There are two major issues that everyone is trying to address:

1. Were the rules relaxed too much in 1990, so that children are now getting in the program on the basis of "maladaptive behavior" and other problems that either can be coached, or that don't really fall into the realm of a true disability?

2. How do you make a cash program accountable? A voucher plan that would allow families to purchase only certain services or items that benefit the child was everyone's first thought, but

doing a comprehensive list is difficult or impossible, and then you need some bureaucracy to monitor it. Also, cash is often used to allow a parent to stay home and take care of a child. But not all disabilities are severe enough to require this, and the amount of cash is not related to the severity of the disability in any way.

The House bill would address these 2 issues in the following ways:

1. Eliminate the IFA test, which is the functional evaluation established by SSA to determine eligibility to respond to the Zebley decision. The test evaluates a child's functional status in the "domains" of cognition, social/behavioral skills, communication, motor skills, concentration, persistence, and pace.

About 250,000 kids got SSI through the IFA test over the past three years. These kids would lose their cash and Medicaid six months after enactment. Probably 40% of these kids could meet the stricter requirement of the "medical listings" if they reapplied.

SSA feels that we probably went too far in relaxing the rules after Zebley, and that too many children have been allowed in the program because of "maladaptive behavior" and other behavioral problems. There is probably a way not to eliminate the IFA test but strenghten the requirements in the behavioral realm that would target the cases everyone is concerned about. Even Jonathan Stein, the big Zebley advocate, is floating a proposal that would make it impossible to get SSI based solely on maladaptive behavior. We would probably propose to grandfather in all the kids who have already been made eligible through the IFA.

2. After dropping all the IFA kids, the House bill would only give cash to kids who are institutionalized or in danger of institutionalization. Estimates range from 6% to 30% on the portion of kids who would still get cash. The House would take the money saved on the cash side, cut it by 25%, and block grant it to the states for services to these kids. States would choose which children get served and what services they get. (There is some grandfathering here, with only new applicants subjected to the "institutionalization test" in order to get cash.)

We haven't gotten as far in our thinking on this issue. Cash is nice because it involves no bureaucracy and it gives the family flexibility. The question of abuse of cash by families might be moot if we were more certain that only children with real disabilities were getting on the rolls.

Slattery lunch

Be in trtmt
Acct for $

Maladaptive
LFA / elim. mod
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↓ ben middle D

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– R+R – rptg
– trmt

Add 2 Q to SSA eval;

OK, D: – What extra costs: $2 study: $72/mo ⇒ ½ ave pymt today
This is plan
You're eligible

Not micro-acctg, but is therapy happ'g?

Ext.: private gps – SSA lk beyond

National Commission on Childhood Disability

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Staff Director:

Elaine Fultz, Ph.D.

February 24, 1995
Meeting Agenda

8:30 a.m to 9:30 a.m.	- overview of recent action on SSI for children by the House Ways and Means Committee
9:30 a.m. to 9:45 a.m.	- break
9:45 a.m. to 11:15 a.m.	- consideration of the Sullivan v. Zebley Supreme Court decision and the SSA's implementation of the Individualized Functional Assessment
11:15 a.m. to 11:30 a.m.	- break
11:30 a.m. to 12:30 p.m.	- overview of federal programs for children with disabilities
12:30 p.m. to 1:30 p.m.	- lunch
1:30 p.m. to 3:00 p.m.	- profiles of selected disabilities
3:00 p.m. to 3:15 p.m.	- break
3:15 p.m. to 5:00 p.m.	- discussion

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Elaine Fultz, Ph.D.

February 14, 1995

MEMORANDUM

TO: Members of the Commission on Childhood Disability

FROM: Elaine Fultz
Staff Director

REGARDING: the second meeting of the Commission

As you have been informed, the Commission on Childhood Disability will hold its second meeting on Friday, February 24, 1995, at 8:30 a.m. We will meet in Washington, D.C., in Ballroom D of the Loews L'Enfant Plaza Hotel, located at 480 L'Enfant Plaza, S.W. We will complete our business by approximately 5:00 p.m.

To assist you in preparing for the meeting, I have enclosed:

* a draft report prepared by the Urban Institute describing federal programs for children with disabilities and the definitions of disability used in them;

* a recent report by the HHS Inspector General identifying problems in the implementation of the Individualized Functional Assessment; and

* a proposal for revising the SSI program that is being considered by the House Ways and Means Subcommittee on Human Resources this week.

Please note that the Urban Institute study is a working draft which is still being modified. The Institute was willing to share this draft with us because of its relevance to the Commission's work. They have asked us not to share widely and not to quote its contents.

I have also enclosed three documents which relate to the Commission's overall task. These are:

* a study completed in 1981 by Mathematica Policy Research, Inc., of the extra expenses incurred by families of SSI children with various disabilities (a staff summary of the report is also included);

* SSA's 1994 profile of children receiving SSI; and

* SSA's "Disability Evaluation Under Social Security," a publication designed to keep physicians and other health care professionals up to date on changes in agency disability criteria.

Enclosures (6)

National Commission on Childhood Disability

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Elaine Fultz, Ph.D.

8-2-95

Diana,

This is the version of our recommendations that we have provided to Finance and Ways and Means. We are working now on the other pieces of the report. I am sending this to be sure you have the latest version.

Sincerly,
Elaine Fultz

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

09-Mar-1995 11:52am

TO: Carol H. Rasco

FROM: Diana M. Fortuna
Domestic Policy Council

CC: Jeremy D. Benami
CC: Lynn M. Margherio
CC: Julie E. Demeo

SUBJECT: Meeting with Slattery

I just spoke with Jim Slattery of the Childhood Disability Commission to suggest that he meet with you about his work. He thinks that is a great idea, and would like to do so soon. He suggested meeting within the next week or two, which may not work on your calendar, and also suggested the possibility of meeting over lunch. Let me know if you prefer lunch or not, and I will work with Julie to set it up.

It sounds as if he is working full force on this. He is having day long and Saturday meetings with the commission every other week, and he says some of them are complaining he is going too fast. I told him we think fast is good.

Not surprisingly for a former member of Congress, he seems to have a very practical grasp of the situation his commission is in. He wants very much to be a player in this debate, and hopes that his June/July deadline will allow him to influence the debate in the Senate. He said he was responsible for the Spencer Rich story in yesterday's Post that finally attacked the House Republicans for the SSI cuts with some specific examples of kids who would be cut off. He is talking a lot behind the scenes to his former colleagues in the House and Senate, and is scheduled to testify before Senate Finance in about 3 weeks.

He thinks we should be "yelling" more about the House Ways and Means proposal, suggesting that it is a good issue to hit them on, although he also agrees that change is needed in the program.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

06-Feb-1995 03:27pm

TO: Diana M. Fortuna

FROM: Carol H. Rasco
Economic and Domestic Policy

CC: Jeremy D. Benami
CC: Lynn M. Margherio

SUBJECT: RE: First meeting of Slattery Commission

After perhaps his second meeting I would like to have a meeting with you, Slattery and myself to get up to speed...if he wanted someone from HHS that would be fine too. Of course this is only if he is comfortable coming to do a briefing but I think based on his phone call to me prior to the first meeting he would be okay on that. Thanks.

CHILDHOOD DISABILITY COMMISSION

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Former Congressman
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HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FOR IMMEDIATE RELEASE
Friday, Jan. 20, 1995

Contact: HHS Press Office
(202) 690-6343

SSA Press Office
(410) 965-8904

CHILDHOOD DISABILITY COMMISSION MEMBERS NAMED

HHS Secretary Donna E. Shalala has named 15 members of the new Childhood Disability Commission, which will review the assistance given to disabled children under the Supplemental Security Income program.

She had announced Jan. 9 that former Rep. Jim Slattery will serve as chair of the commission. The other members will include parents of children with disabilities, advocates for children, educators, psychologists, researchers, attorneys, program administrators, physicians, and others.

The 14 new members are:

- Polly Arango of Algondones, N.M., director, Family Voice
- Adrianne Asch, Ph.D., of Wellesley, Mass., professor in biology, ethics and the politics of human reproduction, Wellesley College
- Dolores Berkovsky of Fort Worth, Texas, director of children's services, St. Teresa's Home
- Anne Ford of New York, N.Y., chairman of the board of directors, National Center for Learning Disabilities
- Wade Horn, Ph.D., of Gaithersburg, Md., director, The National Fatherhood Initiative
- Jennifer Howse, Ph.D., of White Plains, N.Y., president, March of Dimes Birth Defects Foundation
- Sharman Davis Jamison of Minneapolis, Minn., Parent Advocacy Coalition Educational Rights Center
- Dan Johnson of Madison, Wis., director, Office for Persons with Physical Disabilities, Wisconsin Department of Health and Social Services
- Paul Marchand of Washington, D.C., director, The Arc

- More -

- James Perrin, M.D., of Boston, Mass., associate professor of pediatrics, Massachusetts General Hospital
- M. Carmen S. Ramirez of El Paso, Texas, Schools Are for Everyone
- Carol Rank of Topeka, Kan., acting director, Disability Determination and Referral Service
- Rud Turnbull of Lawrence, Kan., co-director, Beach Center on Families and Disabilities, University of Kansas
- Barbara Wolfe, Ph.D., of Madison, Wis., professor and director, Institute for Research on Poverty, University of Wisconsin.

"We chose these people because of their extensive knowledge of programs for children with disabilities and, in many cases, lifelong careers serving children with disabilities and their families. They are among the nation's top experts in this policy area," Shalala said.

The new commission will examine SSI policies and the needs of disabled children, and report its findings and recommendations to Congress this year. The commission was mandated in the "Social Security Independence and Program Improvements Act," passed by Congress and signed by President Clinton last year.

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HHS NEWS

DRAFT

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FOR IMMEDIATE RELEASE
2 n d d r a f t

Contact: HHS Press Office
(202) 690-6343

SSA Press Office
(410) 965-8904

CHILDHOOD DISABILITY COMMISSION MEMBERS NAMED

HHS Secretary Donna E. Shalala has named 15 members of the new Childhood Disability Commission, which will review the assistance given to disabled children under the Supplemental Security Income program.

She had announced Jan. 9 that former Rep. Jim Slattery will serve as chair of the commission. The other members will include parents of children with disabilities, advocates for children, educators, psychologists, researchers, attorneys, program administrators, physicians, and others.

The 14 new members are:

- Polly Arango of Algondones, N.M., director, Family Voice
- Adrianne Asch, Ph.D. of Wellesley, Mass., professor in biology, ethics and the politics of human reproduction, Wellesley College
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- MORE -

Contact members

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- Dan Johnson of Madison, Wis., director, Office for Persons with Physical Disabilities, Wisconsin Department of Health and Social Services
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"We chose these people because of their extensive knowledge of programs for children with disabilities and, in many cases, lifelong careers serving children with disabilities and their families. They are among the Nation's top experts in this policy area," Shalala said.

The new commission will examine SSI policies and the needs of disabled children, and report its findings and recommendations to Congress this year. The commission was mandated in the "Social Security Independence and Program Improvements Act," passed by Congress and signed by President Clinton last year.

More specific on when?

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1/19/95

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Rhoda - elim consid of child's abs to f

Sun 4 part series

AP wire later today

Lack of togetherness in Admin.

DEPARTMENT OF HEALTH & HUMAN SERVICES
Office of the Secretary
Washington, D.C. 20201

MEMORANDUM

TO: Members, Children's Disability Work Group

FROM: Judy Feder

SUBJECT: Meeting, Monday, February 27
Possible Calls from Childhood Disability Commission Staff

This is a reminder that the Children's Disability Work Group will meet in David Ellwood's conference room on Monday, February 27 from 11:00 a.m. to 12:30 p.m. The agenda will include presentation and discussion of draft work plans by each subgroup (i.e., health, education, and SSI).

In addition, for your information, attached is a memo that went to Mary Jo Bane, Shirley Chater, Phil Lee and Bruce Vladeck notifying them that they (or their staff) may be contacted by staff of the Childhood Disability Commission. As you know, the Commission's work is separate from the work of the White House Disability Review - Children's Work Group, although the substance overlaps in many cases. Thus, recognizing that Commission staff have not been involved in the Work Group's deliberations, please be aware that you may be asked for information that you have already provided to the Work Group.

Looking forward to seeing you on Monday.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

MEMORANDUM

TO: Mary Jo Bane, ACF
Shirley Chater, SSA
Phil Lee, PHS
Bruce Vladeck, HCFA

FROM: Judy Feder, Principal Deputy, ASPE

SUBJECT: Inquiries from Childhood Disability Commission Staff

The purposes of this memo are to notify you that you or members of your staff may receive inquiries regarding your programs from the staff of the Childhood Disability Commission and to request your cooperation in providing the necessary information.

This Commission, whose members were appointed by the Secretary in January, will be studying the SSI program for children with disabilities. As part of their work, they will be taking an overarching look at all federal programs that serve children with disabilities. The Commission is expected to forward its recommendations for SSI reform to Congress by November, although it is possible that a report may be developed by June or July. The Chair of the Commission is former Representative Jim Slattery and the Staff Director is Elaine Fultz.

I would appreciate it if you would advise key staff members that they may be receiving calls from Elaine's staff. Please note that Commission staff have not participated in the meetings of the Children's Work Group of the White House Disability Policy Review. Therefore, some of the Commission's questions may duplicate work or briefings that have been provided to the Work Group or to OMB as part of the overall White House Disability Policy Review.

Nevertheless, the Commission's work may assist the Administration in its deliberations related to the SSI program for children. Any help you can give Commission staff will be useful. Thank you.

cc: Members, White House Disability Policy Review, Children's Work Group