

# WITHDRAWAL SHEET

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**Date:** 3/24/04

DOCUMENT NO. & TYPE	SUBJECT/TITLE	DATE	RESTRICTION
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I. Notes	Re: candidates for commission, 2p	nd	P5
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- P1** National security classified information [(a)(1) of the PRA].
- P2** Relating to appointment to Federal office [(a)(2) of the PRA].
- P3** Release would violate a Federal statute [(a)(3) of the PRA].
- P4** Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA].
- P5** Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA].
- P6** Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA].

**RESTRICTIONS**

- B1** National security classified information [(b)(1) of the FOIA].
- B2** Release could disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA].
- B3** Release would violate a Federal statute [(b)(3) of the FOIA].
- B4** Release would disclose trade secrets or confidential commercial financial information [(b)(4) of the FOIA].
- B6** Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA].
- B7** Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA].
- B8** Release would disclose information concerning the regulation of financial institutions [(b)(9) of the FOIA].
- B9** Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA].

C. Closed in accordance with restrictions contained in donor's deed of gift.

PUBLIC LAW 103-296—AUG. 15, 1994

**SOCIAL SECURITY INDEPENDENCE AND  
PROGRAM IMPROVEMENTS ACT OF 1994**

**(c) DEMONSTRATION PROJECTS.—**

(1) **IN GENERAL.**—The Secretary of Health and Human Services shall develop and carry out demonstration projects designed to explore innovative referral, monitoring, and treatment approaches with respect to—

(A) individuals who are entitled to disability insurance benefits or child's, widow's, or widower's insurance benefits based on disability under title II of the Social Security Act, and

(B) individuals who are eligible for supplemental security income benefits under title XVI of such Act based solely on disability,

in cases in which alcoholism or drug addiction is a contributing factor material to the Secretary's determination that individuals are under a disability. The Secretary may include in such demonstration projects individuals who are not described in either subparagraph (A) or subparagraph (B) if the inclusion of such individuals is necessary to determine the efficacy of various monitoring, referral, and treatment approaches for individuals described in subparagraph (A) or (B).

(2) **SCOPE.**—The demonstration projects developed under paragraph (1) shall be of sufficient scope and shall be carried out on a wide enough scale to permit a thorough evaluation of the alternative approaches under consideration while giving assurance that the results derived from the projects will obtain generally in the operation of the programs involved without committing such programs to the adoption of any particular system either locally or nationally.

(3) **FINAL REPORT.**—The Secretary shall submit to the Committee on Ways and Means of the House of Representatives and the Committee on Finance of the Senate no later than December 31, 1997, a final report on the demonstration projects carried out under this subsection, together with any related data and materials which the Secretary may consider appropriate. The authority under this section shall terminate upon the transmittal of such final report.

**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.

**SEC. 203. REGULATIONS REGARDING COMPLETION OF PLANS FOR ACHIEVING SELF-SUPPORT.**

(a) **IN GENERAL.**—Section 1633 of the Social Security Act (42 U.S.C. 1383b) is amended by adding at the end the following:

“(d) The Secretary shall establish by regulation criteria for time limits and other criteria related to individuals’ plans for achieving self-support, that take into account—

“(1) the length of time that the individual will need to achieve the individual’s employment goal (within such reasonable period as the Secretary may establish); and

“(2) other factors determined by the Secretary to be appropriate.”

(b) **EFFECTIVE DATE.**—The amendment made by subsection (a) shall take effect on January 1, 1995.

**SEC. 204. SSI ELIGIBILITY FOR STUDENTS TEMPORARILY ABROAD.**

(a) **IN GENERAL.**—Section 1611(f) of the Social Security Act (42 U.S.C. 1382(f)) is amended—

(1) by inserting “(1)” after “(f)”; and

(2) by adding after and below the end the following:

“(2) For a period of not more than 1 year, the first sentence of paragraph (1) shall not apply to any individual who—

“(A) was eligible to receive a benefit under this title for the month immediately preceding the first month during all of which the individual was outside the United States; and

“(B) demonstrates to the satisfaction of the Secretary that the absence of the individual from the United States will be—

“(i) for not more than 1 year; and

“(ii) for the purpose of conducting studies as part of an educational program that is—

“(I) designed to substantially enhance the ability of the individual to engage in gainful employment;

“(II) sponsored by a school, college, or university in the United States; and

“(III) not available to the individual in the United States.”

(b) **EFFECTIVE DATE.**—The amendment made by subsection (a) shall take effect on January 1, 1995.

42 USC 1382  
note.

**SEC. 205. DISREGARD OF COST-OF-LIVING INCREASES FOR CONTINUED ELIGIBILITY FOR WORK INCENTIVES.**

(a) **IN GENERAL.**—Section 1619(b)(1)(B) of the Social Security Act (42 U.S.C. 1382h(b)(1)(B)) is amended by inserting “and increases pursuant to section 215(i) in the level of monthly insurance benefits to which the individual is entitled under title II that occur while such individual is considered to be receiving supplemental security income benefits by reason of this subsection” after “earnings”.

(b) **EFFECTIVE DATE.**—The amendment made by subsection (a) shall apply to eligibility determinations for months after December 1994.

42 USC 1382h  
note.

**SEC. 206. EXPANSION OF THE AUTHORITY OF THE SOCIAL SECURITY ADMINISTRATION TO PREVENT, DETECT, AND TERMINATE FRAUDULENT CLAIMS FOR OASDI AND SSI BENEFITS.**

(a) **PREVENTION OF FRAUD BY TRANSLATORS OF FOREIGN LANGUAGES.**—

(1) **OASDI PROGRAMS.**—Section 205(c) of the Social Security Act (42 U.S.C. 405(c)) is amended—

(A) by redesignating paragraph (8) as paragraph (9); and

(B) by inserting after paragraph (7) the following:

“(8) A translation into English by a third party of a statement made in a foreign language by an applicant for or beneficiary of monthly insurance benefits under this title shall not be regarded as reliable for any purpose under this title unless the third party, under penalty of perjury—

“(A) certifies that the translation is accurate; and

“(B) discloses the nature and scope of the relationship between the third party and the applicant or recipient, as the case may be.”

(2) **SSI PROGRAM.**—Section 1631(e) of such Act (42 U.S.C. 1383(e)) is amended by inserting after paragraph (3) the following:

“(4) A translation into English by a third party of a statement made in a foreign language by an applicant for or recipient of benefits under this title shall not be regarded as reliable for any purpose under this title unless the third party, under penalty of perjury—

“(A) certifies that the translation is accurate; and

“(B) discloses the nature and scope of the relationship between the third party and the applicant or recipient, as the case may be.”

(3) **EFFECTIVE DATE.**—The amendments made by this subsection shall apply to translations made on or after October 1, 1994.

(b) **CIVIL MONETARY PENALTIES, ASSESSMENTS, AND EXCLUSIONS FOR TITLES II AND XVI.**—

42 USC 405  
note.

15 - 1-1-95  
(19 experts).

MD - Chair

James Perrin Harvard Med Home & Community Care for  
for E.I. Ch (1993).

William Roper (Bush Admin Dep. Health for PP)  
Pres, Prov. Center for Health Care Research  
(HECKFA Admin)

Jack Shankoff (Brandeis Deans) - directed Early Infant  
Callahan's Study -  
somewhat atypical development.

Psych: Steve Forness - UCLA neuropsych (w/ - - LD, ADD)<sup>+</sup>  
(SIR)

Knutzer - consultant M.H. Services (NY, Vermont)  
Former CDF, Bank of America

Nehas. Shannon Jamison. MA (now Bayshore Center (w/))  
(speech therapy - sent adult @ unfortunatly.  
PCER w/ D. min. - Rep. appointed.

Lan Lucy Mackinay (daughter MR / CDF - Health Div. (N. Carolina)

David Turnbull - Co-director Bayshore Center (w/ 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66, 67, 68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79, 80, 81, 82, 83, 84, 85, 86, 87, 88, 89, 90, 91, 92, 93, 94, 95, 96, 97, 98, 99, 100)  
- MR Factor - MR, WARR, JASH, OBA

Paul Marchand Marty (or Ford) - martyr sibling w/ MR -

Ed. Corpolonga - OK - member, researcher + (Dir of Special)

M. Carmen Ramirez (TS) Hosp. mother of DS child -  
Scholar for cognitive / education experience.

Admin of DPs

Maxine Hayes (WA) AA Int'l MCH Director

"

Mary Jo Iwan (WV) ~~member~~ Neb Dept of SS - - Institute dir...

Carl Rankin - (Acting Dir, KS, Massachusetts Department of Corrections  
(on Baz list)

Social Insurance? Dan Johnson (WI) Pres, Office for Prison of PD.  
(Dept of HSS - development program committee  
PD

Remember/Policy Jennifer Howell, NY Pres, Council of Prison B, - 17  
Depts of - Assoc' Comm.

Paul Newachek - Adjunct Prof. for Health Policy  
Hleds (UC SIF) -

Barbara Wolfe; VWI Pres, Institute for Research  
in Privacy

Ethnicity Adrienne Reich - misspelled name Adrienne,  
Professor of

Sten

Pds-

Duranbenza

Reistle X

ITA:

Alickin

Marghera-Mezinsky

Moody (WI)

Penny (MN)

Shepard (VT)

Stabery (KS)

Smith (IA)

Gov

Navy (IA)

Ruchman (VT) X

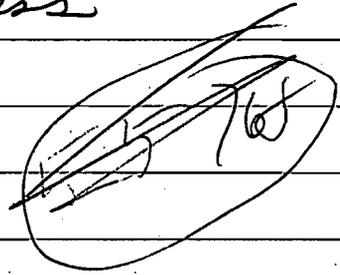
Bernhard Roberts (D-OR) (parent) X

Other

Arminy Thurnburg X

Madeline Will (parent)

Stein - - shut but only has Manly Fred  
also <sup>around</sup> Forness



My suggested deletions: Roper...  
Paul Marshall...  
Carpolanga...  
Newach...  
any of the address...  
Lynn...  
Rant...

Ammon: Rohant

Is Taber really a combination  
brand?

Volvic Hydrogen  
Bergman.

S. Kim

① Thinking of you -- inspiration speech.

② Blood-oath (2 or 3 people in whole county)  
you only

THIS FORM MARKS THE FILE LOCATION OF ITEM NUMBER 1  
LISTED IN THE WITHDRAWAL SHEET AT THE FRONT OF THIS FOLDER.

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TO: Stan Hill  
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- To Keep  
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 Per Your Request  
 FYI

Message:

Public Law 103-296, §202

From: Andie Clark

Janny  
10-27 TB  
20-

For consideration for: COMMISSION ON THE EVALUATION OF DISABILITY IN CHILDREN  
(alphabetical order)

GLEND A ANN MILLER BOND - TN

Glenda Bond is the mother of two sons (ages 19 and 16) with severe disabilities. She has extensive volunteer community service experience dealing with issues facing people with disabilities and their families, including service as President and as Vice President of The Arc - Tennessee. She has been recognized as Volunteer of the Year by The Arc of Cumberland County and The Arc of Tennessee. Ms. Bond is also a special education teacher.

DARA HOWE - TN

Dara Howe is the mother of a ten year old son with significant cognitive, physical, and health-related disabilities. She has had extensive community involvement in disability issues as well as several years of professional experience in coordinating programs for parents and coordinating public awareness for a state-wide coalition of over 30 disability-related organizations. Ms. Howe also serves as President of the Tennessee Health Care Campaign and as Chair of the Governmental Affairs Committee of The Arc of Tennessee.

M. CARMEN S. RAMIREZ - TX

Carmen Ramirez is the mother of a 12 year old son with Down syndrome. She has extensive community volunteer experience in issues affecting children with disabilities and their families, including for minority and non-English speaking families. She is the founder and President of Schools are for Everyone (SAFE) and serves as a member (appointed by Governor Ann Richards) of the Texas Continuing Advisory Committee for Special Education and on the Governing Committee of the Texas Parent and Training Information Center for Latino Parents of children with disabilities, among other activities. Ms. Ramirez received the National Leadership Award in 1994 from the National Council of La Rasa.

DONALD W. REDDEN, JR. - TN

Donald Redden is the father of a teenage son who has severe multiple disabilities. He serves as Executive Director of Developmental Services of Dickson County. Mr. Redden is a former member of the Dickson County School Board and has served in various leadership roles in The Arc of Tennessee, Community Mental Retardation Agencies of Tennessee, southeast division of the American Association on Mental Retardation, Tennessee chapter of The Association for Persons with Severe Handicaps, and the Coalition for Tennesseans with Disabilities.

BARBARA SACKETT - OR

Barbara Sackett is the mother of a woman with Down syndrome. She has worked at the state level since 1978 in the Office of Developmental Disability Services developing programs, budgeting, developing administrative rules, serving as a Title XIX specialist, licensing, and serving as liaison to county developmental disability programs. Ms. Sackett has been active in The Arc since 1960 and served as national President of The Arc from 1988 to 1990. Ms. Sackett also served as a member of the SSI Modernization Project Panel of Experts.

H. RUTHERFORD TURNBULL, III - KS

Rud Turnbull is the father of a 27-year old man who has both mental retardation and autism. He is the Co-Director of the Beach Center on Families and Disability and Professor of Special Education and Courtesy Professor of Law at The University of Kansas. Mr. Turnbull is a nationally known expert and author in disability policy issues and has served in national-level leadership positions in numerous organizations, including The Arc, 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.

Additional name for consideration for: COMMISSION ON THE EVALUATION OF DISABILITY IN CHILDREN

LINDA ROWLEY - WI

Linda Rowley is the mother of a 9 1/2 year old son with severe multiple disabilities who has required extensive hospitalizations and surgeries. She credits the SSI program with allowing her, as a single parent, to keep her son at home and to receive vital services through Medicaid. She returned to school for a college degree and is now able to care for her son in their home community without the use of SSI. In her current position as the Project Director of Wisconsin First Step, an information and referral service for parents of children with disabilities or special health care needs, Ms. Rowley has extensive contact with parents and familiarity with the needs of their children with disabilities. Ms. Rowley is also one of the founders of the Parent Empowerment Coalition.

### H. Rutherford Turnbull, III

Mr. Turnbull is the Co-Director of the Beach Center on Families and Disability and Professor of Special Education and Courtesy Professor of Law at The University of Kansas. His training is in political science (B.A., The Johns Hopkins University) and law (Ll.B., University of Maryland; Ll.M., Harvard Law School).

Mr. Turnbull is the father of a 27-year old man who has both mental retardation and autism.

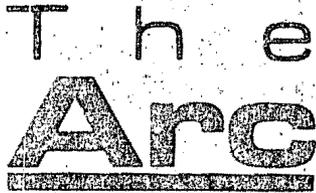
Mr. Turnbull concentrates his research and training in four areas: Special education law and policy, mental disability law and policy, public policy analysis, and ethics as related to disability policy and service provision.

He co-directs the Beach Center, the Center's special education doctoral training program in disabilities and families and the Center's Organization of American States/Inter-American Children's Institute program.

Since developing his specialization in the mid-1970s while professor of public law and government at the Institute of Government, The University of North Carolina at Chapel Hill (1969-1980), Mr. Turnbull authored has over 125 articles, books, chapters, monographs, technical reports, reviews, and commentary related to disability issues. Mr. Turnbull has been "of counsel" on amicus briefs in two disability cases heard by the United States Supreme Court; been the author and draftsman of North Carolina's special education law and limited guardianship law; been the draftsman of P.L. 100-407, Assistive Technology for Individuals with Disabilities Act of 1988 (in his role as special staff to the Senate Subcommittee on Disability Policy); testified about a half-dozen times before the United States Congress on disability legislation; testified before the United Civil Rights Commission on disability policy; testified frequently before the North Carolina and Kansas legislatures on disability law.

Mr. Turnbull has served or currently serves in elected or appointed leadership in the following organizations--President, American Association on Mental Retardation; Secretary, The Arc (Association for Retarded Citizens); Treasurer, The Association for Persons with Severe Disabilities (TASH); Chairman, American Bar Association Commission on Mental and Physical Disability Law; Trustee, David L. Bazelon Center for Mental Health Law (the Mental Health Law Project); Director, Federation for Exceptional Children; Director, Camp Hill Association of North America; Founder and Former President, Full Citizenship, Inc.; and numerous committees and task forces in Kansas and North Carolina, including as counsel to the North Carolina Developmental Disabilities Planning Council and member of the Kansas

Developmental Disabilities Planning Council. He also has  
received national leadership awards from The Arc and National  
Association of Private Residential Providers.



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8-18-94

Stan

Here is a final copy of the draft fact sheet I gave you regarding the SSI children's program.

Also, we are working on a list of suggested people for the childhood disability commission.

Please call if you have any questions.

- Marty

a national organization on mental retardation

# Consortium for Citizens with Disabilities

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For more information, contact one of the Task Force co-chairs: Rhoda Schulzinger, Bazelon Center for Mental Health Law, 202-467-5730/Marty Ford, The Arc, 202-785-3388/Jenifer Simpson, UCPA, 202-842-1266/Tony Young, American Rehabilitation Association, 703/716-4035.

## MEMORANDUM

To: Interested Persons  
From: Social Security Task Force  
Consortium for Citizens with Disabilities  
Re: Children's SSI Program  
Date: May 31, 1994

The Supplemental Security Income (SSI) program provides basic income for low-income children who have a severe disability or chronic illness or who are blind. The SSI program encourages low-income families to stay together and is founded on the principle that families are in the best position to meet the needs of children with severe disabilities.

To qualify for SSI, children must qualify financially and also meet the definition of being blind or having a disability. Although the regulations are complicated, it is critical to understand basic points about the children's SSI program discussed on the attached fact sheet:

- o SSI benefits are intended to pay for food, clothing and shelter for qualified low-income children who are disabled or blind. The cash payment recognizes the family's right and ability to make decisions about how to best spend benefits on behalf of eligible children. (See: What is the purpose of the children's SSI program?)

- o In December 1993, over 720,000 children under the age of 18 who are blind or disabled received SSI benefits. Children with mental retardation are the largest single group representing about 43 percent of the enrollment while another 20 percent have psychiatric illnesses. Almost 15 percent have neurological or sensory conditions and 17 percent have diseases of the endocrine, respiratory, circulatory or musculoskeletal systems. (See: Who receives children's SSI benefits?)

- o Medical documentation of substantial physical and/or mental impairments from a doctor or licensed psychologist must be presented to support all applications. (See: What is the disability determination process for a child?)

- o Families use SSI benefits to pay for daily and extraordinary expenses associated with raising children who have significant mental or physical disabilities. (See: Why is cash assistance critical for eligible families?)

- o A number of factors explain why applications for the children's SSI program increased over the last four years since the U.S. Supreme Court Zebley decision. (See: Why have the children's SSI applications increased over the past few years?)

# Consortium for Citizens with Disabilities

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For more information, contact one of the Task Force co-chairs: Rhoda Schulzinger, Bazelon Center for Mental Health Law, 202-467-5730/Marty Ford, The Arc, 202-785-3388/Jenifer Simpson, UCPA, 202-842-1266/Tony Young, American Rehabilitation Association, 703/716-4035.

## FACT SHEET: CHILDREN'S SSI PROGRAM

### 1. WHAT IS THE PURPOSE OF THE CHILDREN'S SSI PROGRAM?

Congress intended SSI benefits to pay for food, clothing and shelter for qualified low-income children with disabilities and children who are blind. The cash payment recognizes the family's right and ability to make decisions about how to best spend benefits on behalf of an eligible child.

Families raising children with significant physical, developmental or mental disabilities have higher expenses and often have less income. Although public or private health insurance covers some medical costs, families face extraordinary additional out-of-pocket expenses. The needs of a child with a serious disability frequently require a parent to remain home and forego paid employment. Some parents remain underemployed by taking a part-time job to have more time at home. Other parents must refuse better job offers to protect current health benefits or remain in a school district that has the necessary services for their child. All these factors decrease family income in both one and two-parent households.

### 2. WHO RECEIVES CHILDREN'S SSI BENEFITS?

To be eligible for SSI, a child must meet two sets of eligibility criteria: financial and disability. Only **after** the child is found financially eligible does Social Security consider whether the child is blind or whether the child's disability or chronic illness is severe enough to qualify.

In January 1993, almost 68 percent of children receiving SSI received the maximum federal payment of \$434. Another 7 percent received at least \$380 which was 87 percent of the maximum federal benefit. This means that three-quarters of the children receiving SSI benefits were living in very low-income families because in a means-tested program, people with the lowest income receive the highest benefits.

In December 1993, over 720,000 children under the age of 18 who are blind or disabled received SSI benefits. About 43 percent of these children have mental retardation. An additional 20 percent have psychiatric illnesses such as autism or severe emotional disorders. Almost 15 percent have neurological or sensory conditions including blindness and about 5 percent have congenital anomalies. The remaining 17 percent have disabilities such as diseases of the endocrine, respiratory, circulatory or musculoskeletal systems.

### 3. WHAT IS THE DISABILITY DETERMINATION PROCESS FOR A CHILD?

#### Medical Proof

A child must present medical documentation of a severe medical or psychological impairment to begin Social Security's disability review process. The impairment must be identical or equivalent to one appearing on a specific list of qualifying impairments or must significantly interfere with the child's ability to develop or function in an age-appropriate manner in multiple areas of normal childhood activities. The disability examiner is required by law to evaluate each application to document whether benefits should be awarded or denied.

#### Functional/Developmental Documentation

The disability examiner must also consider functional information from people who observe the child over a period of time such as parents, social workers, child care providers, clergy and school personnel. By collecting evidence from many sources, the examiner can verify the extent of a child's disability or chronic illness.

#### Comprehensive Decisionmaking

To make a decision, the disability examiner is required to review all available information about the child's daily functioning. Any test results must be consistent with other evidence about the child's daily behavior and activities. If there are inconsistencies, the examiner must get more documentation to resolve the differences.

### 4. WHY IS CASH ASSISTANCE CRITICAL FOR ELIGIBLE FAMILIES?

SSI benefits enable parents to meet the complex needs of a child with a severe disability, helping the child learn, gain independence and, as an adult, be productive. The basic purpose of SSI is to pay for food, clothing and shelter. The benefits may also be used to pay for the child's extraordinary daily expenses or disability-related expenses which may include the following:

- o utility bills (electric bills for 24 hour/day respirators, rental costs of back-up generators to prevent power lapses, battery charges for communication devices or power wheelchairs; water bills for above average bathing and laundry usage)
- o telephone calls to medical providers, pharmacists, social service providers and schools
- o specially trained child care providers since neighborhood babysitters are often unable or unwilling to care for children with disabilities
- o public or private transportation costs for numerous trips (often long distances in rural areas) to obtain medical treatment and services
- o adapted clothing (e.g. replace buttons with velcro fasteners, specially fitted shoes, modify openings or specially designed clothing for persons with limited movement)

- o clothing, laundry & household cleaning supplies (e.g. children who require frequent clothing changes or whose disability requires more frequent household cleaning)
- o specially equipped vehicles to transport children who use wheelchairs
- o home repairs (e.g. special safety equipment such as protective coverings for kitchen appliances, extraordinary wear-and-tear from wheelchairs)
- o home modifications/adaptations including environmental control equipment (e.g. widen doorways, change doorknobs to levers, add ramps, modify controls & switches, install bathroom railings and special bathing and toileting equipment)
- o respite care
- o personal assistance services (including wages and taxes)
- o service and repairs for assistive technology (e.g. power wheelchairs, prosthetics, hearing aids)
- o adapted toys and learning materials (e.g. special tricycle for a child with a physical disability)
- o assistive technology for school homework (e.g. computers with voice output, touch screen or modified keyboard)
- o special telecommunication services/devices (e.g. TTY)
- o co-payments and deductibles for routine medical visits, specialty consultations, medication, biological products, physical/speech/ occupational therapy, orthotic devices and wheelchairs customized for children not covered by Medicaid, private insurance or school districts
- o over-the-counter items not customarily paid for by public or private insurance such as special creams for skin conditions, diapers for older children, wigs, special formulas/items for managed diets
- o family support services (e.g. marriage, family or individual counseling)

## 5. WHY HAVE CHILDREN'S SSI APPLICATIONS INCREASED RECENTLY?

A number of events over the past few years explain the increase in children's SSI applications. The rising rate of poverty and unemployment among American families means that more and more children are eligible for this means-tested program. The number of children living in poverty is the highest in almost 30 years.

Congress, in 1989, directed the Social Security Administration (SSA) to conduct outreach, for the first time, to potentially eligible families with children who are disabled to encourage them to apply for benefits. The next year, SSA published and began to

implement new rules for children with mental and emotional disabilities. The new rules were designed with help from a panel of experts convened by Social Security that included child development specialists, psychiatrists, educators, mental health advocates and agency staff. The new rules more clearly defined mental impairments and established more rational and understandable standards for evaluating them.

The U.S. Supreme Court issued its decision in 1990 in the Zebley case requiring SSA to change its childhood disability determination process to evaluate the child's level of functioning in addition to his or her medical condition. Members of the expert panel advising Social Security as the agency developed the new childhood disability process estimated that over 1 million children would meet financial and disability criteria. Part of the Zebley case required Social Security to notify 452,000 children who were illegally denied benefits between 1980 and 1990 that they had a right to have their cases reevaluated. To date, more than 135,000 Zebley children have received benefits. Besides notifying the class members by letter, SSA also did public service announcements and national outreach to potentially eligible children.

To augment Social Security's outreach efforts, several major foundations funded the Children's SSI Campaign coordinated by the Bazelon Center for Mental Health Law. The campaign works with state agencies, advocates and professional groups across the country to notify potentially eligible families about changes in the SSI program and how to apply.

Both Social Security and the Children's SSI Campaign publicized new financial eligibility rules, issued in November 1992, that calculate the financial eligibility of working families more equitably than before. Thousands of children whose parents are employed who were previously denied because they were over the income limits are now eligible for this means-tested program.

This statement was prepared by the following members of the Social Security Task Force:

American Association on Mental Retardation  
American Council of the Blind  
American Network of Community Options and Resources  
American Occupational Therapy Association  
American Rehabilitation Association  
The Arc  
Bazelon Center for Mental Health Law  
Children and Adults with Attention Deficit Disorders  
Epilepsy Foundation of America  
Federation of Families for Children's Mental Health  
National Association of State Directors of Developmental Disabilities Services  
National Association of State Mental Health Program Directors  
National Association of Protection and Advocacy Systems  
National Community Mental Health Care Council  
National Parent Network on Disabilities  
United Cerebral Palsy Associations

As of May 31, 1994

DRAFT MEMORANDUM

To: Interested Persons

From: Rhoda Schulzinger, Bazelon Center for Mental Health Law, 202/467-5730  
Marty Ford, The Arc, 202/785-3388  
Jenifer Simpson, United Cerebral Palsy, 202/842-1266  
Tony Young, American Rehabilitation Association, 703/716-4035

Re: Children's SSI Program

Date: March 14, 1994

The Supplemental Security Income (SSI) program provides basic income for low-income children who have a severe disability or chronic illness. The SSI program encourages low-income families to stay together, promotes work and is founded on the principle that families are in the best position to meet the needs of a child with a severe disability.

To qualify for SSI, a child must meet the requirements of both financial and disability regulations. Although each set of regulations is very complicated, it is critical to understand some basic points about the children's SSI program. The major points are discussed, in more detail, as answers to five questions in the attached fact sheet:

1. SSI benefits are intended to pay for food, clothing and shelter for qualified low-income children with disabilities. The cash payment recognizes the family's right and ability to make decisions about how to best spend benefits on behalf of an eligible child. (See: What is the purpose of the children's SSI program?)
2. In December 1993, over 720,000 children under the age of 18 who are blind or disabled received SSI benefits. Children with mental retardation are the largest single group representing about 43 percent of the enrollment while another 20 percent have psychiatric illnesses. Almost 15 percent have neurological or sensory conditions and 17 percent have diseases of the endocrine, respiratory, circulatory or musculoskeletal systems. (See: Who receives children's SSI benefits?)
3. Medical documentation of physical and mental impairments must be presented to support all applications. (See: What is the disability determination process for a child?)
4. Families use SSI benefits to pay for daily and extraordinary expenses associated with raising a child who has a significant mental or physical disability. (See: Why is cash assistance critical for eligible families?)
5. A number of factors explain why applications for the children's SSI program increased steadily over the last four years since the U.S. Supreme Court Zebley decision. (See: Why have the children's SSI applications increased over the past few years?)

## **FACT SHEET: CHILDREN'S SSI PROGRAM**

### **1. What is the purpose of the children's SSI program?**

SSI benefits are intended to pay for food, clothing and shelter for qualified low-income children with disabilities. The cash payment recognizes the family's right and ability to make decisions about how to best spend benefits on behalf of an eligible child.

Families raising children with significant physical, developmental or mental disabilities have higher expenses and may have less income. Although public or private health insurance covers some medical costs, families face extraordinary additional out-of-pocket expenses. The needs of a child with a serious disability frequently require a parent to remain home and forego paid employment. Some parents remain underemployed by taking a part-time job to have more time at home. Other parents must refuse better job offers to protect current health benefits or remain in a school district that has the necessary services for their child. All these factors may decrease family income in both two-parent and one-parent households.

### **2. Who receives children's SSI benefits?**

To be eligible for SSI, a child must meet two sets of eligibility criteria: financial and disability. Only after the child is found financially eligible does Social Security consider whether the child's disability or chronic illness is severe enough to qualify.

In January 1993, almost 68 percent of children receiving SSI received the maximum federal payment of \$434. Another 7 percent received at least \$380 which was 87 percent of the maximum federal benefit. This means that three-quarters of the children receiving SSI benefits were living in very low-income families because in a means-tested program, people with the lowest income receive the highest benefits.

In December 1993, over 720,000 children under the age of 18 who are blind or disabled received SSI benefits. About 43 percent of these children have mental retardation. An additional 20 percent have psychiatric illnesses such as autism or severe emotional disorders. Almost 15 percent have neurological or sensory conditions including blindness and about 5 percent have congenital anomalies. The remaining 17 percent have disabilities such as diseases of the endocrine, respiratory, circulatory or musculoskeletal systems.

### **3. What is the disability determination process for a child?**

#### **Medical Proof**

A child must present medical documentation of a medical or psychological impairment to begin the disability review process. The impairment must be identical or equivalent to one appearing on a specific list of qualifying impairments or must significantly interfere with the child's ability to develop or function in an age-appropriate manner in multiple areas of normal childhood activities. The disability examiner is required by law to evaluate each application to document whether benefits should be awarded or denied.

#### **Functional/Developmental Documentation**

The disability examiner must also consider functional information from people who observe the child over a period of time such as parents, social workers, child care providers, clergy and school personnel. By collecting evidence from many sources, the examiner can verify the extent of a child's disability or chronic illness.

## Comprehensive Decisionmaking

To make a decision, the disability examiner is required to review all available information about the child's daily functioning. Any test results must be consistent with other evidence about the child's daily behavior and activities. If there are inconsistencies, the examiner must get more documentation of the child's development and functioning to resolve the differences.

### **4. Why is cash assistance critical for eligible families?**

SSI benefits enable parents to meet the complex needs of a child with a severe disability, helping the child learn, gain independence and, as an adult, be productive. The basic purpose of SSI is to pay for food, clothing and shelter. The benefits may also be used to pay for the child's extraordinary daily expenses or disability-related expenses which may include the following:

1. utility bills (electric bills for 24 hour/day respirators, rental costs of back-up generators to prevent power lapses, battery charges for communicative devices or wheelchairs; water bills for above average bathing and laundry usage)
2. telephone calls to medical providers, pharmacists, social service providers and schools
3. specially trained child care providers since neighborhood babysitters are often unable or unwilling to care for children with disabilities
4. public or private transportation costs for numerous trips (often long distances in rural areas) to obtain medical treatment and services
5. adapted clothing (e.g. replacement of buttons with velcro fasteners, specially fitted shoes, modified openings or specially designed clothing for persons with limited movement)
6. clothing, laundry & household cleaning supplies (e.g. children who require frequent clothing changes or whose behavioral disorders require more frequent household cleaning)
7. specially equipped vehicles to transport children who use wheelchairs
8. home repairs for children with significant conduct disorders (e.g. replacing broken windows and other damages, buying special safety equipment such as protective coverings for kitchen appliances, extraordinary wear-and-tear from wheelchairs)
9. home modifications/adaptations (e.g. widening doorways, changing doorknobs to levers, adding ramps, modifying controls & switches, installing bathroom railings and special bathing and toileting equipment)
10. respite care
11. personal assistance services (including wages and taxes)
12. service and repairs for assistive technology & power wheelchairs
13. adapted toys and learning materials (e.g. special tricycle for a child with a physical disability)

14. assistive technology for school homework (e.g. computers with a touch screen or modified keyboard)
15. special telecommunication services/devices (e.g. TTY)
16. co-payments and deductibles for routine medical visits, specialty consultations, drugs, biological products, environmental control equipment, orthotic devices and wheelchairs customized for children not covered by Medicaid, private insurance or school districts, physical/speech/occupational therapy
17. over-the-counter items not customarily paid for by public or private insurance such as special creams for skin conditions, diapers for older children, wigs, special formulas/items for managed diets
18. family support services (e.g. marriage, family or individual counseling)

##### **5. Why have children's SSI applications increased recently?**

A number of events over the past few years explain the increase in children's SSI applications. The rising rate of poverty among American families means that more and more children are eligible for this means-tested program. The number of children living in poverty is the highest in almost thirty years.

Congress, in 1989, directed the Social Security Administration (SSA) to conduct outreach to potentially eligible families with children who are disabled to encourage them to apply for benefits. The next year, SSA published and began to implement new rules for children with mental and emotional disabilities. The new rules were designed with help from a panel of experts convened by Social Security that included child development specialists, psychiatrists, educators, mental health advocates and agency staff. The new rules more clearly defined mental impairments and established more rational and understandable standards for evaluating them.

The U.S. Supreme Court issued its decision in 1990 in the *Zebley* case requiring SSA to change its childhood disability determination process to evaluate the child's level of functioning in addition to his or her medical condition. Part of the *Zebley* case required Social Security to notify children who were illegally denied benefits between 1980 and 1990 that they had a right to apply for back benefits. To date, about 135,000 *Zebley* children were added to the SSI rolls. Besides notifying the class members by letter, SSA also did public service announcements.

To augment Social Security's outreach efforts, several major foundations funded the Children's SSI Campaign coordinated by the Bazelon Center for Mental Health Law. The campaign works with state agencies, advocates and professional groups across the country to notify potentially eligible families about changes in the SSI program and how to apply.

Both Social Security and the Children's SSI Campaign publicized new financial eligibility rules, issued in November 1992, that changed the way the financial eligibility of working families is determined. Thousands of children whose parents are employed who were previously denied because they were over the income limits are now eligible for this means-tested program.

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For more information about the children's SSI program or information presented in this fact sheet, contact any of the following members of the Consortium for Citizens with Disabilities: Rhoda Schulzinger, Bazelon Center for Mental Health Law, 202-467-5730/Marty Ford, The Arc, 202-785-3388/Jenifer Simpson, United Cerebral Palsy, 202-842-1266/Tony Young, American Rehabilitation Association, 703/716-4035.

(March 1994)

...Robert Packwood and of the

# Social Security to cut 1,000 management jobs

*Reduction expected to come by attrition*

By Nelson Schwartz  
Contributing Writer

WASHINGTON — In its first major shake-up in more than a decade, the Social Security Administration plans to cut more than 1,000 management jobs within two years — mostly at its Woodlawn headquarters — in an effort to streamline the agency's bureaucracy.

The job cuts, Social Security officials insist, will be made through attrition and voluntary reassignments, not layoffs or forced retirements.

Administrators said the reductions would affect only management staff, not the front-line employees who deal with millions of Americans

at district offices across the country. In fact, officials said, some employees may be added at the district offices.

Commissioner Shirley S. Chater said she hoped the changes would trim SSA's oft-criticized bureaucracy and make the agency more efficient.

The goals of SSA's streamlining plans are to create a leaner agency structure, Ms. Chater said in a statement yesterday, and empower employees to better serve the customer and become more involved in decision-making.

The changes are prompted by orders from President Clinton to reduce management staffs at federal agencies, and by the recommendations last year of Vice President Al Gore's National Performance Review, which is trying to make the

See SSA, 12A

# Moving 'further away' from health accord, Clinton complains

as sweeping as Mr. Clinton's own.

But every time I have reached out to Senator Chafee and other Republicans, Mr. Clinton said, they have moved further away.

Over shadowing Mr. Clinton's attempts to find common ground with moderate Republicans is the call from national GOP leaders to deny Mr. Clinton any victory on health care this year that might help the Democrats in the congressional elections, this fall.

Sight unseen, Republicans should oppose whatever version of the bill Democratic leadership to the House, and Senate floor next month, William Kristol, a Republican consultant, advised in a memo to party leaders this week.

Those stray Republicans who decide themselves by believing that there is still a mainstream middle solution are merely pawns in the Democratic game, Mr. Kristol wrote. Health care reform is now about politics, and absolutely nothing else. Not all congressional Republicans have reached that point of view.

"I won't vote against it just because I'm a Republican," said Mr. Gilchrist, who favors a more modest approach of incremental reforms being prompted by his party.

A bipartisan group of House members is trying to put together a somewhat broader approach that it hopes to offer as an alternative to the Democratic leadership plan when the health care legislation comes up for a House vote in two weeks.

But we're going to have a bill of a scuffle over that," said the House Republican leader, Robert H. Michel of Illinois, who noted that Democratic leaders might be fearful of giving moderate Democrats an alternative to the Clinton-style bill.

In the House, Democratic leaders are preparing to try to pass their bill, but they are convinced that the cause they are convinced that the Republicans are nothing but spoilers.

reporters yesterday. They simply want to kill the bill.

Anything else is naive to assume at this point. In the Senate, though, the fate of the president's bill appears to rest on the goodwill of a few Republicans who might be willing to resist the pressure from Minority Leader Bob Dole to join Mr. Clinton in a compromise.

Mr. Dole, a potential challenger to Mr. Clinton in 1996, not only wants to deny the president a victory on this centerpiece legislation, but he also wants to delay the issue until next year, when the Republicans expect to have greater numbers in both the House and Senate.

Senator Chafee and his fellow Republican moderates, John C. Danforth of Missouri and Dave Durenberger of Minnesota, are willing to resist the pressure. But they aren't willing to vote for a health care bill as sweeping as Mr. Chafee's original proposal of last year.

A fourth Republican, James M. Jeffords of Vermont, the only GOP co-sponsor of Mr. Clinton's original bill, has been meeting with the Chafee group and other moderates who are crafting an alternative to the Democratic leadership bill being developed by Majority Leader George J. Mitchell.

Mr. Dole, an original co-sponsor of Mr. Chafee's bill who is now backing a very modest package of reform.

forms, is casting his resistance to compromise as a desire for more time to study the Democratic leadership proposal.

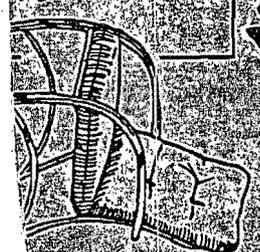
Senator Dole yesterday demanded a week to study Mr. Mitchell's as yet unfinished version of the bill before the measure comes up in the Senate for debate. Other Republicans have begun calling for the Senate to go home for its August recess before taking up the legislation.

**Stellini**

**In-Store**

**Patio Furniture**

**Warehouse Sale**



7/29

150,000

Under the Authority of no sliding scale

0-3

pre-school count  
440,000

Birth to 3

Part 14 -- vol. part

Change fees

sliding fee sched.  
cant be changed  
only 12 states using  
sliding scales

Further grant  
by all end of summer,  
expert

37-38 states Oct 1

are col, Del, Pt. Down, NY, Ohio, Va, VT, Ill., Ky, Md, Minn, NC, W.V.

Free

\$400

approx Part B

subsidizing much more  
only 2 states (NC 300,000, MD 150,000)

(Formerly incentives)

Req -- no fed. law prohibit  
change

2-4% just Part B  
19% of total cost

pre-school grants  
750-800

Family counseling  
JP / not med  
only dia

3-5

over 40 states PT / OT / Family counseling  
18 PIP procedures states  
child funds (not Part B)

Family Support

Statement --

local options --

more programs  
multiversal preschool 1200

larger law (increases  
downward extension  
universal and  
state → local  
historical)

Last Number -- state flexibility  
infant + toddler

Phil's opposed -- barriers to  
services  
Admin costs / months

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## FROM THE DIRECTOR

Thanks to efforts by people like you through the Children's SSI Campaign all across the country, more than 720,000 children with a chronic illness or disability now receive Supplemental Security Income (SSI). That's almost a 61-percent increase since the campaign began over two years ago!

We're delighted that children with disabilities now have a fair shot at getting the benefits Congress established for them two decades ago. Expansion of the program, however, has brought with it greater scrutiny.

Some people are asking legitimate questions about the program's operation. But other criticisms are more far-fetched. Just last month, *The Washington Post* printed an article repeating some of the particularly shrill charges.

The truth is that the lives of hundreds of thousands of children have improved—sometimes very dramatically—by receiving SSI benefits.

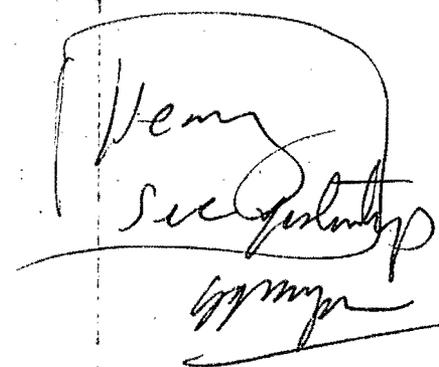
We all need to counter the misunderstandings some articles convey about the basic purpose of the children's SSI program and its stringent eligibility criteria.

Now that we have successfully identified hundreds of thousands of eligible families, we believe it is

time for the Children's SSI Campaign to shift its focus from state outreach efforts to the future of the children's SSI program itself. Our goal is to safeguard the integrity of the program and ensure that proposed solutions address problems that are real, not merely perceived.

We believe that any proposed changes must serve the interests of the children for whom this program is designed. Each of the groups involved in the campaign will continue working with you to improve the children's SSI program so that it can better serve low-income children with disabilities.

Rhoda Schulzinger, Director  
Children's SSI Campaign



MARCH 1994

## CONTENTS

- 2 Basic facts about SSI for children: Why it's important, how children qualify, what kinds of disabilities they have, how families use the benefits, and why more children are applying
- 3 Activities in the campaign's target states and where families can call for information
- 4 Information for school personnel: Questions teachers ask about their role in determining a student's eligibility
- 5 A list of state-specific booklets
- 6 How low-birthweight babies and children with HIV infection can obtain SSI benefits quickly
- 7 How legal services programs can help local outreach efforts
- 7 Readers report valuable outreach strategies

Application tips for families and advocates

A free videotape and posters

Wendell Pinnus: staffing at WHS -- kids needs  
 Charter?  
 List of membership  
 # Pinnus providing non-act facts

budget -- Enrollment Comm'n really independent  
 staff - option to make it locally? academe center  
 financial needs of DP kids  
 point of view  
 Cooper/National Academy of Science (consult)  
 reasonable options

Berry removed as in demand  
 small district  
 a former as well as very good  
 person  
 Fed 2016

4 Ellwood -- logic of program  
 -- not someone replaced  
 -- kids need help  
 Humility is the key / what's best for DP kids

5. Heumann -- financial resources -- additional expenditures of DPs;  
 will monitors cost more  
 6. Oberster's deputy -- no one has the staff; need to reframe Q's re  
 not kids sitting away

AAA/DEA  
 Reinventing  
 Est. Parent  
 Int'l  
 CTR  
 PCMR  
 NCD  
 in new appointees

# Childhood Disability

# Commission

1 Cards Q: larger or smaller commission  
 include Educator  
 (include + caregiver)

Principles  
 parent piece important / close to  
 reports upon adults  
 (what people actually are)  
 push 0 to 3 - home  
 Heumann: FICC rule / since lag  
 from people in school family year?

2 Rivlin: what do we want  
 "Why reorg"  
 "Coordination"  
 "Quality of services"

If no more \$ than  
 spend now, why would  
 you spend existing  
 for disabled kids  
 More than SSI alone; Fed. state  
 fiscal

working closely w/ Comm'n to validate  
 staff resumes to Comm'n

\$5,000 - 1259.209 per year  
 - phoned down  
 various scenarios being to; don't know what a year  
 spends so much money there?

# Background

# Key Legislative Requirements

- Examine the effect of SSI definition of disability; examine alternative definitions of disability
- Examine Federal health assistance programs for those experiencing high medical costs
- Feasibility of providing benefits through noncash means
- Secretary appoints 9 to 15 members; designates chair  
*appt by Jan. 1  
rapid growth*
- Commission's study due to Congress by November 30, 1995

# Scope of the Commission

- Scope of the Commission should be broad
- Commission needs to examine what works, examine changes that are either outdated or expansive
- Need broad-based, balanced, diverse, and objective membership
- Include parents, former child recipients who are now adults, lawyers, physicians, academics

Primus

Wendell

to many mothers / public  
(private costs of raising d. child about  
same as non-disabled)?

Charter: Budget neutral?  
Set of options? or  
Set of recommendations?

list from Tammy and others

Charter

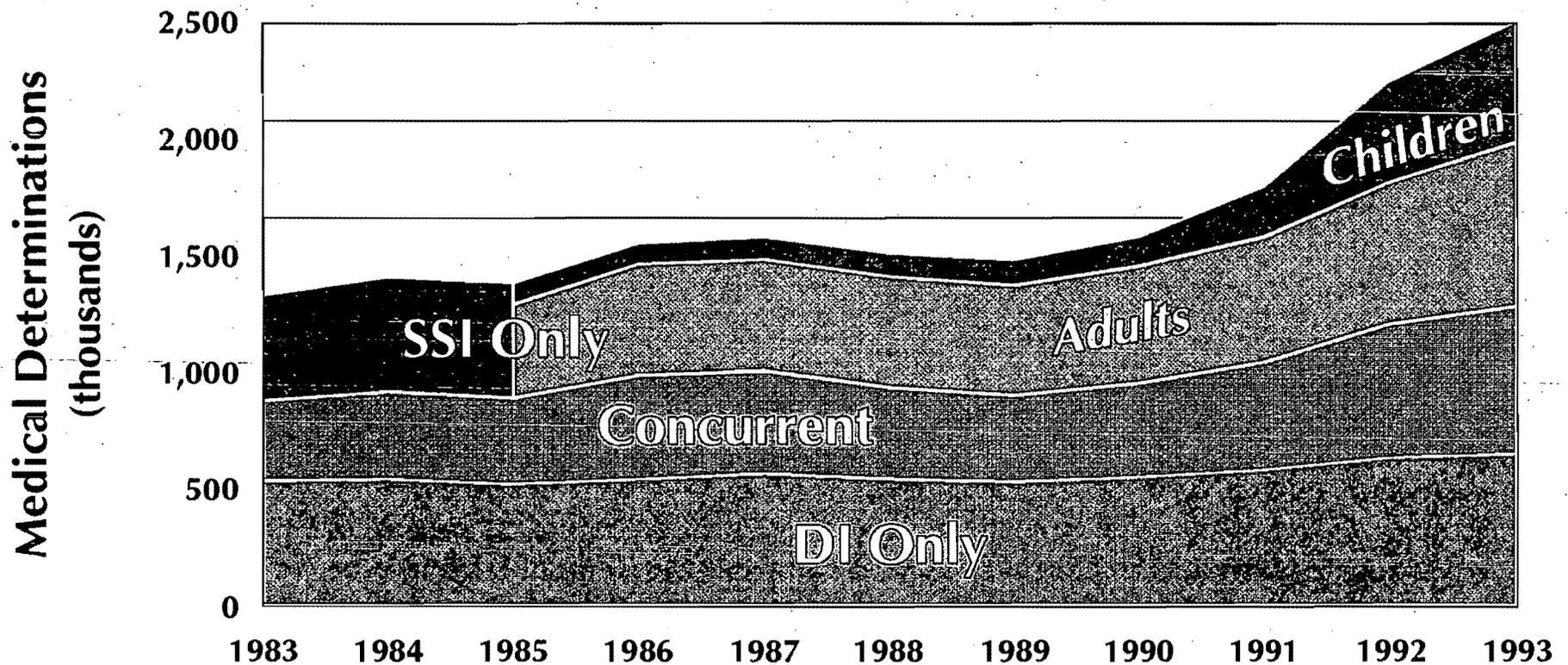
1972 - Zebby - equal  
functional, not vocational standard  
use-appropriate activities (over)

## Next Steps

- HHS has established a group to start the process. Along with SSA, includes senior representatives from ACF, HCFA, PHS, ASPE and ASMB. We plan to include the Department of Education.
- Compiling a list of potential Commission members and chair.
- Developing a full plan outlining tasks, designating staff, and specifying budget needs.
- Establishing a mechanism for communication and coordination with other Federal agencies and outside groups.

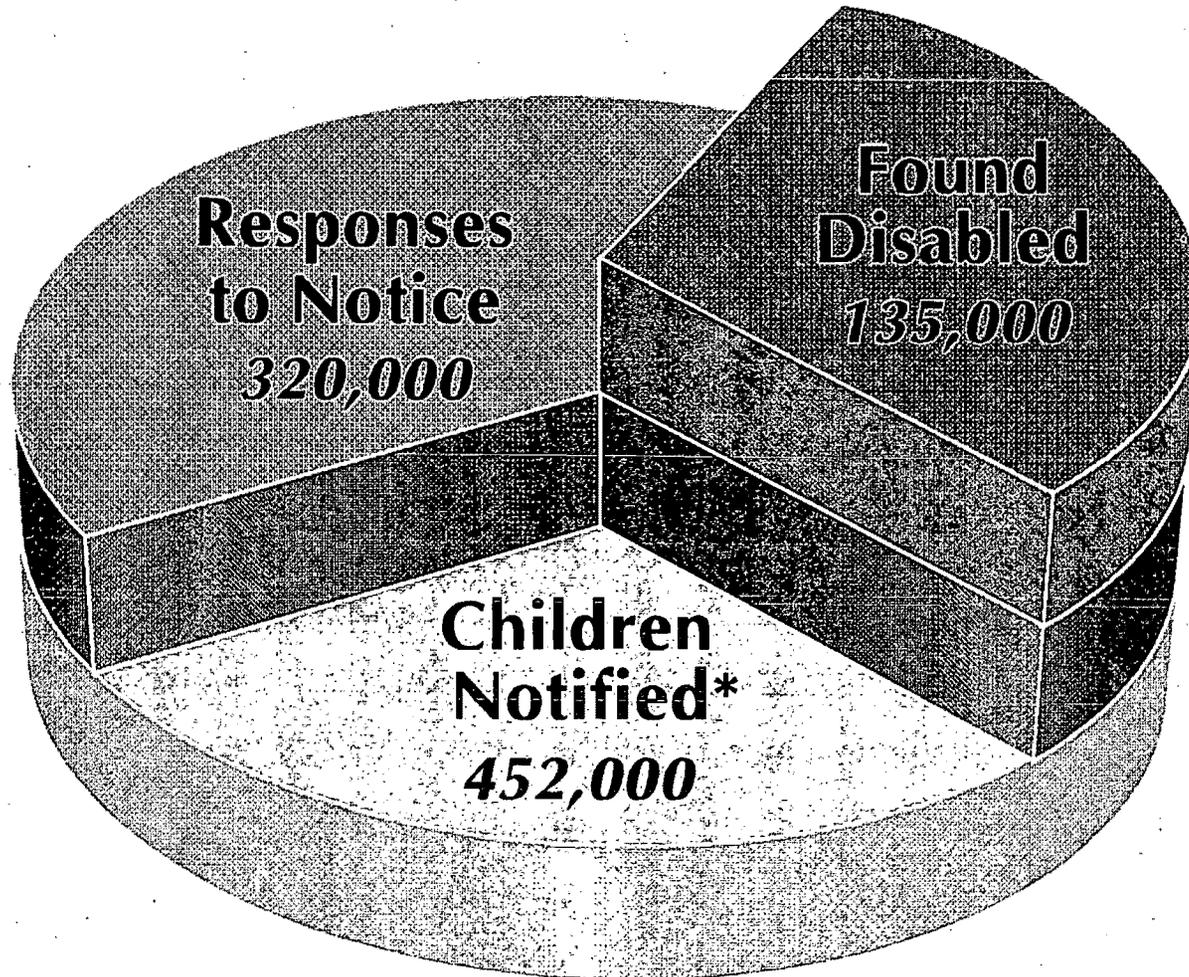
# Children and SSI

# Medical Determinations, FY 1983-1993 (DI, SSI & Concurrent) plus Zebley-Related SSI Timeline



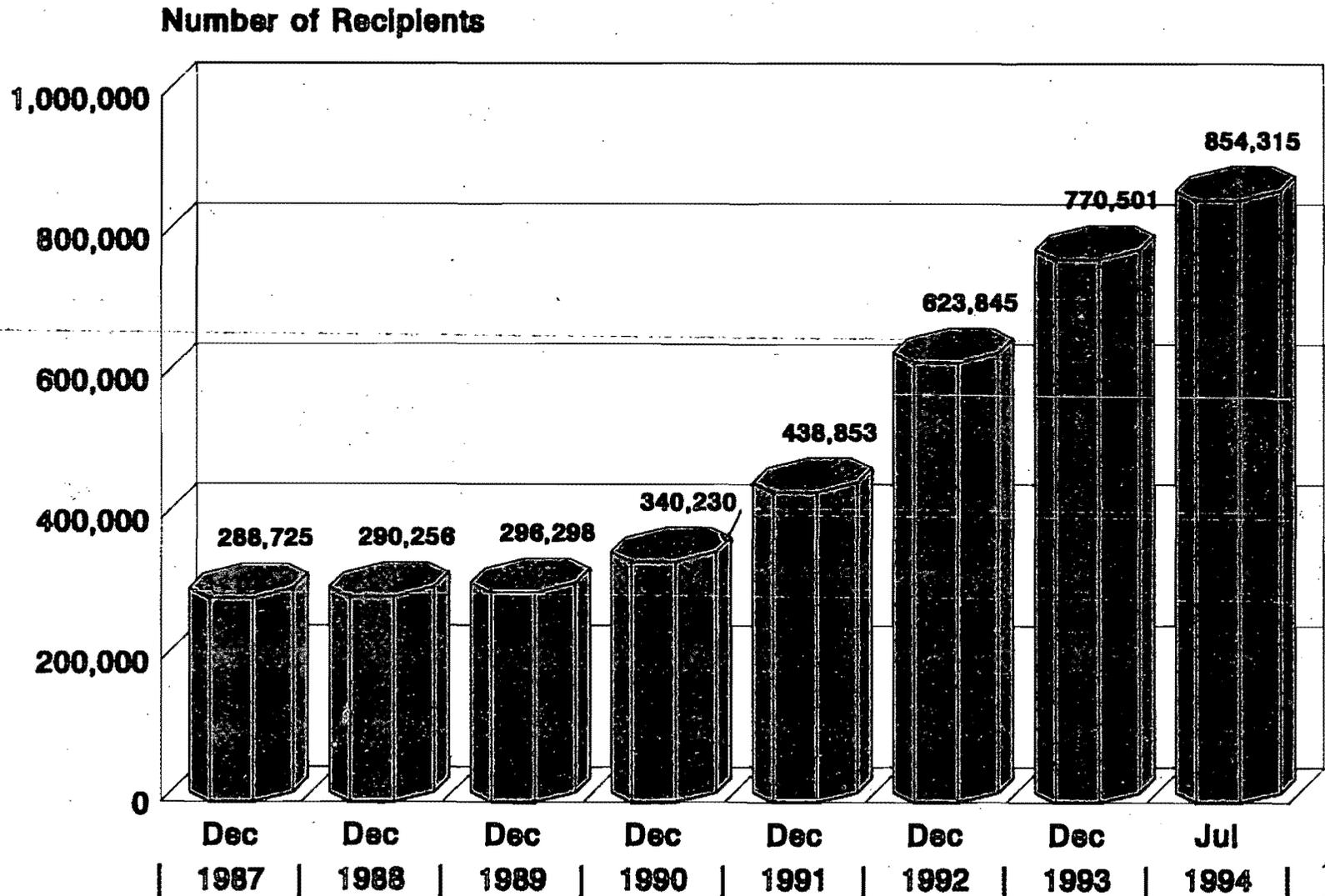
<p>2/90 Supreme Court rules against SSA's "listings-only" approach to childhood disability claims (Zebley).</p> <p>5/90 Court-approved interim standard implemented pending development of new regulations.</p>	<p>4/91 Began reviewing cases under new interim final regulations (published 2/11/91).</p> <p>7/91 Released notices to 452,000 potential class members; began public information/outreach campaign.</p> <p>8/91 Began readjudication of retroactive cases.</p>	<p>7/93 Of 318,000 respondents to class member notices, only 36,000 remained to be decided.</p> <p>9/93 Final regulations published.</p>
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# Zebley Class Outcomes



*\* SSI childhood benefits denied or terminated since 1/1/80.*

# Title XVI Childhood Disability Recipients Growth from December 1987 Through July 1994



*Chart:*

*why rate of ↑*

- Zebley
- outreach program
- mental list liberalized
- GAO says removing children is protection

*most of post 1990 ↑ would have got benefit even w/o Zebley*

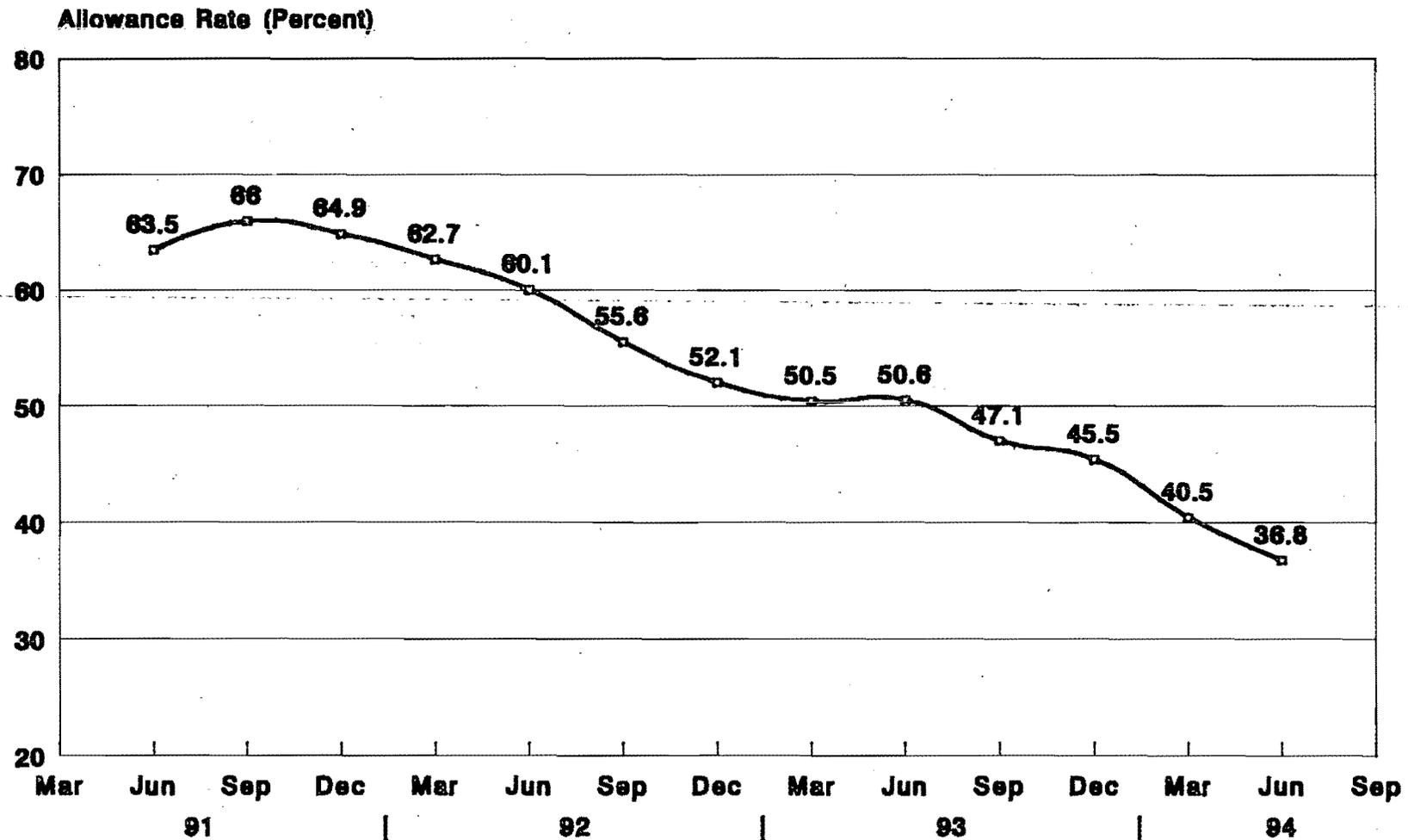
*adversary medical coaching problem no evidence of undue pressure coaching*

- 800 million (re abuse)
- clarifying instructions
- reviews for quality insurance

- teams to AK only a team

- Panel says if child spec on at 7, likely to be in 2 years

# SSI Childhood Disability Claims Initial Level Allowance Rate For 'New' Claims June 1991 Quarter Through June 1994 Quarter



**Overall Allowance Rate For 'New' Claims Under The Revised Criteria Is 50.6 Percent.**

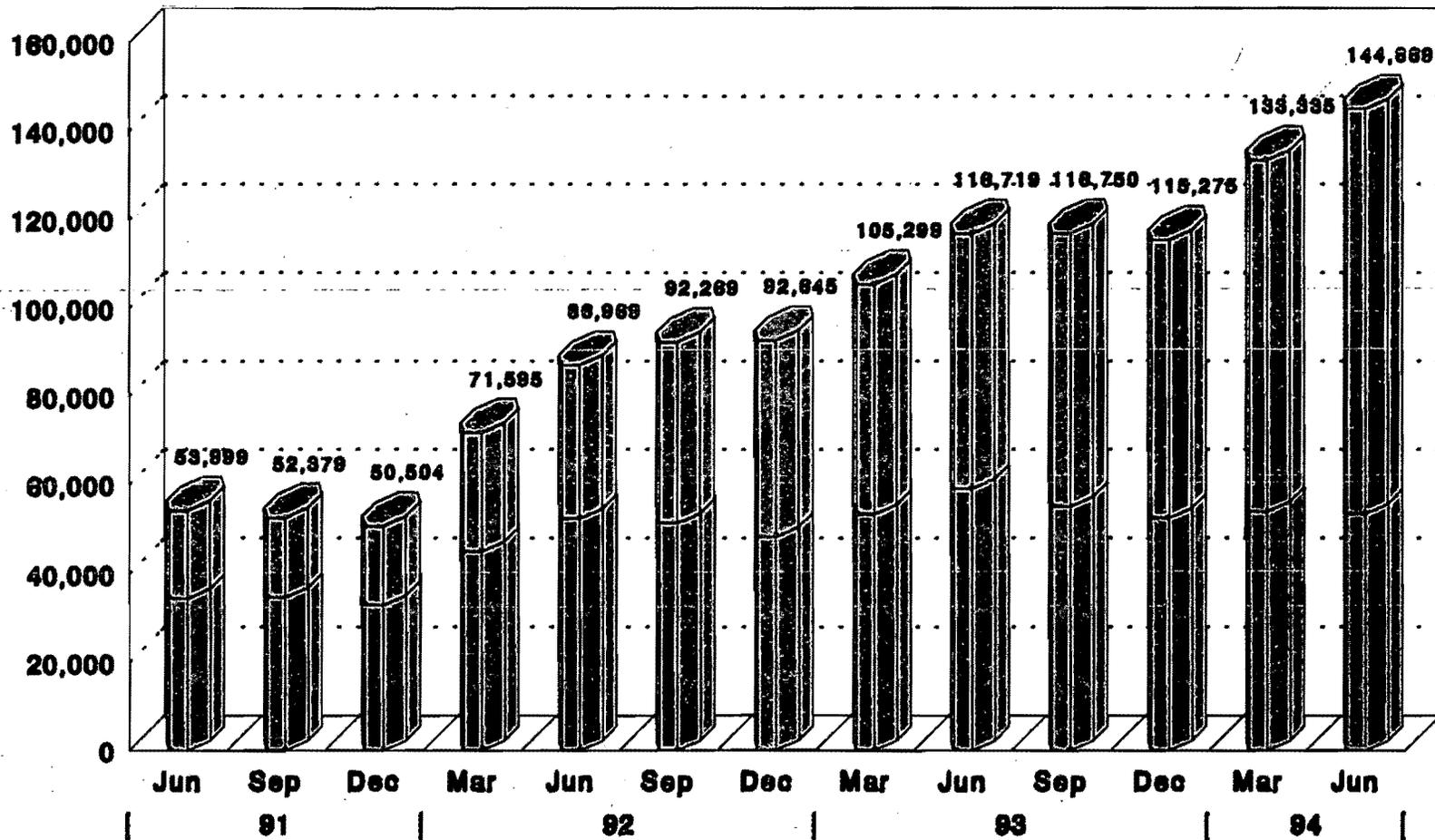
**Pre-Zebley Allowance Rate Was 42.0 Percent.**

**Prepared by: Social Security Administration**

# SSI Childhood Disability Claims

## Initial Level Determinations For 'New' Claims

### June 1991 Quarter Through June 1994 Quarter



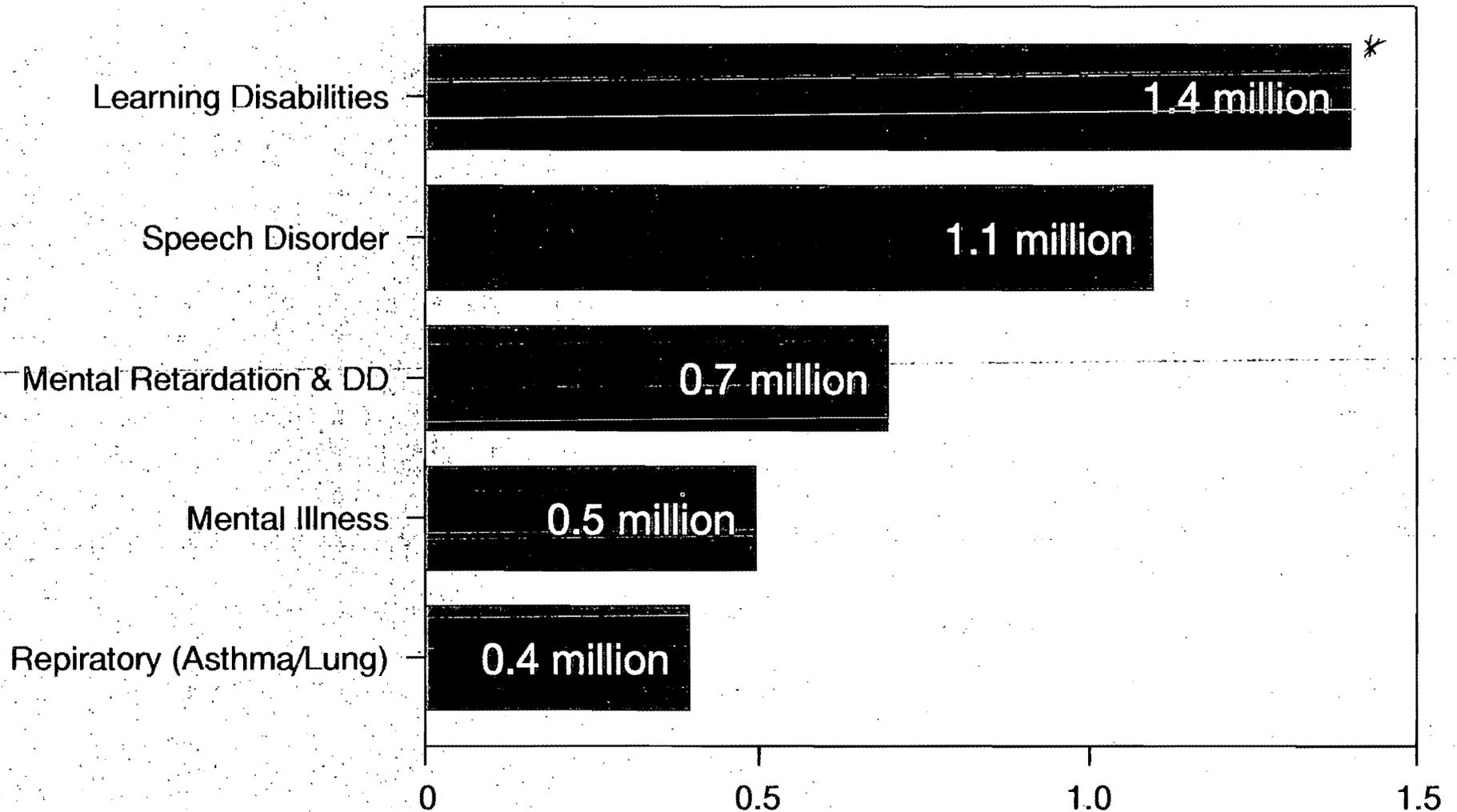
*Ellwood:*  
*leveling off?*  
*at 900,000 -*  
*950,000*  
*permanent*  
*& temporary.*  
*Adverse media:*  
*What is being*  
*produced?*  
*by private*  
*cars?*  
*2nd homes.*

	1991 Jun	1991 Sep	1991 Dec	1992 Mar	1992 Jun	1992 Sep	1992 Dec	1993 Mar	1993 Jun	1993 Sep	1993 Dec	1994 Mar	1994 Jun
<b>Denials</b>	19,711	17,810	17,710	28,705	34,678	40,984	44,423	52,117	57,700	61,736	62,861	79,469	81,527
<b>Allowances</b>	34,288	34,569	32,794	44,890	52,291	51,285	48,222	53,182	59,019	55,014	52,414	53,866	53,342

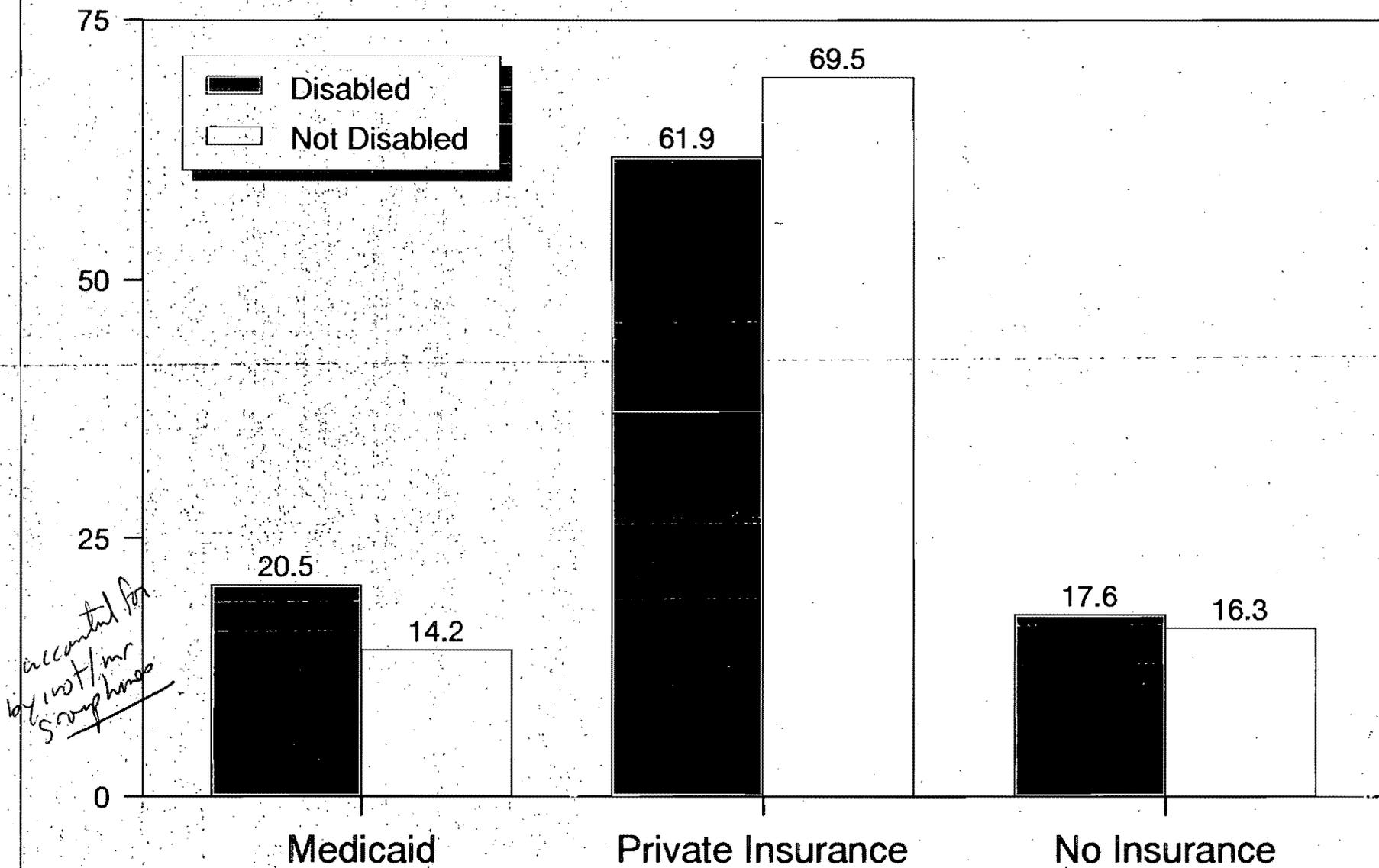
# **Serving the Childhood Disability Population**

# Leading Disabling Conditions

*diverse*



# Percentage Health Insurance by Disability



SOURCE: SIPP, 1990

# Programs Serving Children with Disabilities in DHHS, 1994

## HCFA

- Medicaid
- Medicare
- Home and Community-based Waivers
- TEFRA Waivers

## PHS

- Maternal and Child Health Services
- Disability Prevention Program
- Center for Mental Health Services
- Child and Adolescent Service Program
- Vaccine Injury Compensation Program

## ACF

- Head Start
- Adoption Assistance
- Child Welfare Services Act
- Administration of Developmental Disabilities
- Developmental Disabilities Assistance Act
- Temporary Child Care for Handicapped Children and Crisis Nurseries Act
- Abandoned Infants Assistance Act

## Funding

NA

27 million (FY92)

15 million (FY91)

< 2 million (FY94)

60 million (FY93)

8.4 million (FY94)

35 million (FY94)

12.1 million (FY94)

123 million (FY94)

NA

189 million (FY93)

273 million (FY91)

18 million (FY94)

65 million (FY91)

11.9 million (FY94)

14.5 million (FY94)

**Direct Operating Program Funding Total**

**\$855.9 million**

## Key Policy Issues

- Appropriateness of definitions of disability
- Access to health care and long term supports
- Program interactions between SSI, Medicaid, IDEA, and other federal disability programs
- Balance between service benefits and cash benefits / appropriate
- Subpopulations with unique service needs - sensitivity
- Gaps in knowledge - research initiative -- longer than Comm'n's timeline

(grappled w/ problem, but insufficient attention in health care reform)