NATIONAL
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INSURANCE

Background Paper for Children's Committee for the Disability Policy Panel
SSI Eligibility Criteria for Childhood Mental Disorders

Virginia Reno
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The Federal Supplemental Security Income (SSI) program provides means-tested cash assistance to low-income persons with limited financial assets who are age 65 or older and to persons of any age (including children) who are blind or disabled. The Federal benefit, for an individual with no other countable income is $446 a month and is reduced $1 for $1 if the person has countable income. For children, SSI benefits depend on the amount of the parents' income and resources. Children in families with incomes over about $25,000 to $30,000 are not eligible for SSI. Most children receiving SSI are in families with incomes well below those levels.

Issues of Concern

Questions have been raised regarding several categories of disability for children, especially categories experiencing substantial growth in the past few years. These include, but are not limited to, ADHD, personality disorders, and learning disabilities.

Issues for discussion:

1. What are the trends in childhood disability benefits based on mental disorders in general, and these categories in particular? *(This note provides some recent data.)*

2. What are the criteria for allowing benefits to children based on mental disorders, in general and for specific disorders? *(The criteria in regulations are included.)*

3. Are there professional diagnostic criteria for these conditions that can be consistently applied? Are there ways to determine severity within these diagnostic criteria?

4. Are the current guidelines for determining eligibility for these conditions appropriate? The guidelines include both diagnostic criteria and functional criteria that are part of the mental impairment listings as well as an individualized functional assessment. Does this three step process properly determine disabling conditions among school-age children and adolescents?

1776 Massachusetts Avenue, NW
Suite 615
Washington, DC 20036-1904
Telephone (202) 452-8097
Facsimile (202) 452-8111

5. If not, what should we recommend be done to improve the criteria for determining disability in these cases? What enhancements would help SSA procedures in determining disability in these cases?

6. In what ways are these conditions disabling?

7. Are these conditions that create additional financial burdens for households beyond medical expenses or special education expenses?

8. What guidelines should there be about disability reviews for these conditions? When and how?

This paper has information on questions 1 and 2 as background for discussing the other questions. Part I briefly described policy changes that contributed to the recent growth in childhood SSI claims and allowances. Part II outlines the process used to determine disability in adults and in children. Data on primary diagnosis of children receiving SSI is presented in Part III. Part IV is an overview of the criteria for allowing benefits to children based on mental disorders. It describes the mental disorders medical listings (which are made of medical diagnoses in paragraph A and functional assessment in paragraph B) and the additional individualized functional assessment (IFA) that was introduced following the Supreme Court's decision in *Sullivan v. Zebley*. Part V summarizes findings about allowances based on mental disorders and raises questions about the logic of the fit between the functional criteria used in paragraph B of the listings and the IFA. Part VI describes the assessment of "functional equivalence" to the medical listings, which also was added following the Zebley decision and is the basis for allowance mainly for children with physical impairments. Part VII concludes with the key question for discussion.

Appendix A includes the regulations specifying the criteria for meeting Paragraph A and B of the mental disorders listings. Appendix B has the Zebley regulations[1] which describe criteria for the individualized functional assessment (IFA) and for the assessment of "functional equivalence" to the medical listings for physical and mental impairments.

I. Recent Policy Changes

The growth in the number of children receiving SSI benefits can be traced to at least three recent policy changes: updates of the childhood mental disorders listings in December 1990; publication in February 1991 of regulations resulting from the Supreme Court decision in

[1] The regulations implementing the Supreme Court's decision in *Sullivan v. Zebley* are officially called the Childhood Disability Regulations. In this paper we call them the Zebley regulations to more clearly distinguish them from the Childhood Mental Disorders listings.

Sullivan v. Zebley in February 1990; and outreach activities by the Social Security Administration and private groups to enroll eligible children in the SSI program.

Mental Listings Update

The update of the childhood mental disorders listings in December 1990 was based on the same conceptual framework used to update the adult mental listings in 1985. The change for adults was required by Court decisions in the early 1980s and by legislation enacted in 1984 that required that the new mental impairment criteria focus on evaluating the person's ability to perform substantial gainful activity in a competitive work place environment. The new childhood listings emphasized functional criteria (like the adult mental listings published in 1985), and included new listings for certain specific conditions, such as attention deficit hyperactivity disorders, autism and emotional disorders in infants.

Zebley Decision

The U.S. Supreme Court decision in *Sullivan v. Zebley* in February 1990 expanded SSI eligibility criteria for children. When the SSI program was enacted in 1972, the law provided that children would be considered disabled for SSI purposes if they suffered from "any medically determinable physical or mental impairment of comparable severity" to that which would make an adult disabled.[2] Before the Zebley decision, childhood disability had been determined using only medical listings. A special set of medical listings had been developed for children, and children were found disabled if their condition met or equalled conditions found in either the medical listings for adults or the special childhood disability listings.

For adults whose impairments do not meet the medical listings, there is an additional step. The adult's "residual functional capacity (RFC)" is evaluated and used to determine whether the claimant is able to do his past work, or any other work which exists in significant numbers in the national economy. There was no counterpart assessment for children to the "residual functional capacity" assessment for adults. In *Sullivan v. Zebley*, the Supreme Court found that this did not meet the statutory requirement for determining "comparable severity." The Zebley regulations, issued in February 1991, specified that children whose impairments did not meet or equal the medical listings would undergo an individualized functional assessment (IFA), as called for in the Supreme Court decision, to determine whether their impairments substantially reduce their ability to function independently, appropriately, and effectively in an age-appropriate manner.

Outreach

Finally, widespread publicity following the Court's decision, and concerted efforts by SSA

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[2] Section 1614(a)(3)(A) of the Social Security Act.

and by private groups, sought to enroll eligible children in the SSI program. Legislation enacted in 1989 stipulated that SSA should have an ongoing outreach initiative to enroll children in the SSI program. SSA as well as private foundations and interest groups launched SSI outreach activities, notable among them the SSI Children's Campaign of the Bazelon Center for Mental Health Law, which was supported in part by private foundations, including the Pew Charitable Trusts, and by SSA.

II. SSA's Current Disability Assessment for Children

The determination of disability for children is a four-part sequential process that parallels the five step sequential process for adults. It is based on the process for adults because the Social Security Act defines disability for children for SSI purposes as of "comparable severity" to that which would disable an adult.

Sequential Process for Adults

1. Is the applicant engaging in substantial gainful activity (generally earning $500 a month or more)? If yes, **deny**. If no, go on to step 2.

2. Does the applicant have a severe impairment or combination of impairments? If no, **deny**. If yes, go on to step 3.

3a. Does the applicant have a condition that MEETS the medical listings? If yes, **allow**. If no, go on to step 3b.

3b. Does the applicant's condition(s) MEDICALLY EQUAL the medical listings? If yes, **allow**. If no, go on to step 4.

4. Assess the person's RESIDUAL FUNCTIONAL CAPACITY. Given that residual capacity, is the applicant able to do past relevant work? If so, **deny**. If not, go on to step 5.

5. In light of his/her age, education, work experience and residual functional capacity, can the person do other work that exists in significant numbers in the national economy? If no, **allow**. If yes, **deny**.

Sequential Process for Children

1. Is the child engaging in substantial gainful activity? If yes, **deny**. If no, go on to step 2.

2. Does the child have a severe impairment or combination of impairments? If no,

deny. If yes, go on to step 3.

3a. Does the child have a condition that MEETS the medical listings? If yes, **allow**. If no, go on to step 3b.

3b. Does the child's condition(s) MEDICALLY EQUAL the medical listings? If yes, **allow**. If no, go on to step 3c.

3c. Is the child's condition(s) FUNCTIONALLY EQUIVALENT to the medical listings? If yes, **allow**. If no, go on to step 4.

4. Do an individualized functional assessment (IFA). Under the IFA, does the child's impairment so limit his or her ability to function *independently, appropriately and effectively in an age-appropriate manner* that it is of comparable severity to impairment(s) which would make an adult unable to engage in SGA? If yes, **allow**. If no, **deny**.

Steps 1 and 2 are used to deny claims for both adults and children. Their purpose is to ease the cost and burden (to the government, private health care providers and others who are asked to provide evidence of disability) in cases where the claim would not be allowed. At Steps 3a, b, and c, benefits are allowed if the child's condition meets the medical listings, or is found to be medically or functionally equivalent to the listings. Step 4 was added as a result of the Supreme Court's decision in *Sullivan v. Zebley*. Step 3c also was added as part of the Zebley regulations.

III. Types of Impairments of SSI Childhood Beneficiaries

SSI Children Today -- A Profile

In June 1994, children under 18 receiving SSI benefits based on disability numbered 782,000 (Table 1). The most common primary diagnosis was mental retardation, accounting for 43 percent of all SSI child beneficiaries. The second most common diagnostic category was mental disorders other than mental retardation, which accounted for 22 percent of all SSI children under age 18. Impairments of the nervous system (such as cerebral palsy, epilepsy and other nervous system disorders) and sensory impairments (such as vision and hearing disorders) were the primary diagnosis for 13 percent of the SSI children. Respiratory disorders account for 3 percent. Diseases of the circulatory, digestive or musculoskeletal system, infectious diseases, neoplasms, and endocrine and metabolic disorders, combined were the primary diagnoses for 5 percent. Congenital anomalies and other disorders were the primary diagnostic codes for 13 percent of SSI children.

The difference in disabling conditions among age groups reflects the dynamic nature of

childhood disability. Often it is difficult to have a precise diagnosis for newborns or very young children. Among infants and toddlers, under the age of 3, about half (52 percent) have as their primary diagnosis congenital anomalies (Down syndrome, congenital heart anomalies, or multiple dysfunctions) or other disorders (such as very low birth-weight, growth impairments). Among children of elementary school age, nearly half (47 percent) had mental retardation as their primary diagnosis, while among teenagers, 55 percent had that as their primary diagnosis.

Mental impairments other than mental retardation were most common among school-age children, accounting for roughly 1 in 4 beneficiaries between the age of 6 and 17. Mental and emotional disorders other than mental retardation have increased significantly in recent years. In December 1991, (shortly after both the new mental disorders listings and the Zebley rules were put in place) they accounted for 12 percent of all childhood disability beneficiaries. In June 1994, they accounted for 22 percent.

Table 1. – Children under 18 on the SSI Rolls: Percent Distribution of Primary Diagnosis by Age, June 1994

Diagnostic group	Total	under 3	3-5 years	6-12 years	13-17 years
Total number	781,980	59,170	114,480	359,560	248,770
Total with diagnosis	650,710	47,590	97,470	305,420	200,230
Total percent	100.0	100.0	100.0	100.0	100.0
Infectious and parasitic diseases	0.4	1.3	0.8	0.3	0.1
Neoplasms	1.7	1.5	2.4	1.8	1.1
Endocrine, nutritional, and metabolic	1.1	1.6	1.6	0.8	1.1
Mental retardation	43.5	8.1	27.5	46.7	54.7
Other mental and emotional disorders	22.2	7.4	15.7	24.2	25.9
Diseases of the:					
Nervous system and sense organs	12.7	16.1	19.8	12.6	8.7
Circulatory system	0.7	2.9	1.3	0.4	0.4
Respiratory system	2.7	7.0	5.2	2.2	1.3
Digestive system	0.3	1.2	0.8	0.2	0.2
Musculoskeletal system and connective tissue	1.2	1.2	1.6	1.1	1.2
Congenital anomalies	4.6	19.4	8.3	3.3	1.5
Other	8.8	32.2	14.8	6.4	3.8

Source: *Children Receiving SSI*, SSA, June 1994.

Types of Mental Disorders for Children with Recent Allowances, 1992 - 1994

The number of children entering the SSI rolls reached all-time highs in 1992 and again in 1993 and declined somewhat in 1994. Children with mental disorders, particularly disorders other than mental retardation, continue to increase as a proportion of those entering the rolls.

Table 2 shows detailed diagnostic codes for children with mental disorders who were allowed benefits in 1992 - 1994. The data exclude members of the Zebley class, whose prior denials of benefits were redetermined, so as to show only new benefit claims. The data also do not include benefit allowances on appeal. The 1994 data are based on actual numbers recorded through November 28, 1994 and are estimated for the full year by multiplying the actual numbers by 12/11.[3]

Allowances based on mental retardation declined slightly from 39 to 37 percent, while those based on other mental disorders rose from 23.8 percent to 31.5 percent. New coding conventions were introduced in February 1994 to add four specific new codes. The new codes do not represent a change in policy. Rather, they were introduced to more precisely classify the nature of the child's disabling condition. Specific codes for "learning disorders" and "speech and language delays" together accounted for about 3 percent of allowances recorded in 1994, which may account for the slight decline in the proportion of cases classified as mental retardation.

Similarly, "conduct disorders" and "oppositional defiant disorders" accounted for about 2 percent of all allowances, and may account for the decline in allowances based on "personality disorders" from 5 percent to 3 percent. These three groups of behavioral disorders account for about 5 percent of allowances in all three years.

The most rapid increase in allowances is for those based on attention deficit hyperactivity disorder which rose from 6.9 to 11.3 percent of allowances between 1992 and 1994. The actual number of such allowances is estimated to be about 20,000 in 1994, about the same as in 1993. During that period, however, the total number of allowances for all other types of disorders is estimated to have declined by about 30,000. *(See footnote number 3.)*

All other mental disorders are a relatively stable proportion of allowances, about 12 percent -- with each particular diagnosis accounting for a small proportion of cases. The disorders include organic mental disorders, schizophrenic/paranoid functional disorders, mood disorders, autism, anxiety-related disorders and developmental emotional disorders in infants. The mood disorders category, including depression, manic syndrome and bipolar disorder, was the largest of these, accounting for 3.5 percent of allowances in 1994.

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[3] This may underestimate the annual data for 1994, because of lags of a few days or weeks in entering decisions in the data system, the data as of November 28 may represent less than 11 months of decisions.

Table 2. – Entrants to the SSI Childhood Disability Rolls, 1992-1994
Percent Distribution by Detailed Mental Disorders Codes
Initial DDS Allowances on Childhood Initial Claims

Code	Disorder	1992	1993	a/1994
total	Total initial allowances	196,036	218,502	183,263
	Total with diagnostic codes	195,808	218,324	183,112
	Total percent	100.0	100.0	100.0
total	**Physical (nonmental) disorders**	**37.1**	**34.7**	**31.5**
total	**Mental disorders**	**62.9**	**65.3**	**68.5**
Mental disorders by specific codes				
3180	Mental retardation	39.1	38.9	37.0
total	**All other mental**	**23.8**	**26.4**	**31.5**
total	**Learning and communication disorders**	**na**	**na**	**3.0**
3152	Learning disorder (child)	na	na	1.8
3152	Speech and language delays (child)	na	na	1.2
total	**ADHD and behavioral disorders**	**11.8**	**14.4**	**16.6**
3140	Attention deficit hyperactivity disorder (ADHD)	6.9	9.2	11.3
total	Behavioral disorders	5.0	5.1	5.3
3010	Personality disorders	5.0	5.1	3.2
3120	Conduct disorders (child)	na	na	1.1
3138	Oppositional defiant disorder (child)	na	na	1.0
total	**All other mental disorders**	**11.8**	**12.2**	**11.9**
2940	Organic mental disorders	2.0	2.1	2.0
2950	schizophrenic/paranoid functional disorders	0.7	0.7	0.8
2960	Mood disorders (children)	2.9	3.2	3.5
2990	developmental disability including autism	1.9	2.0	2.2
3000	Anxiety-related disorders	2.2	1.9	1.4
3030	Substance dependency -- alcohol (child)	0.1	0.1	0.1
3040	Substance dependency -- drug (child)	*	0.1	0.1
3060	Somatoform disorders	*	*	*
3070	Eating and tic disorders	0.2	0.1	0.1
3150	Developmental emotional disorder (infant)	1.7	2.1	1.8

Source: Calculations based on data provided by Office of Disability, SSA
a/ 1994 data are through November 28, 1994 and are estimated by multiplying by 12/11.
na = not available. These conditions were first coded separately in February, 1994.
* = fewer than one-half of 1 percent.

Basis for Allowance

As indicated in Part II, benefits can be allowed based on a finding that the child's impairment meets the level of severity in the medical listings (step 3a) or is found to be medically or functionally equivalent to the level of severity indicate by the listings (Steps 3b or c). Those not allowed on those bases may be allowed at Step 4, using an individualized functional assessment (IFA) of the child's ability to function *independently, appropriately and effectively in an age-appropriate manner.*

This last step was the basis for allowance for 42 percent of childhood allowances based on mental impairments, but only about 7 percent of those based on physical impairments (Table 3). Overall, *meeting the listings* was the basis for allowance for about half of children with mental or with physical impairments. Those with physical impairments were more often allowed based on a finding of *medical or functional equivalence* to the listings.

The individualized functional assessment of ability to function independently, appropriately and effectively in an age appropriate manner seems to be used primarily for children with mental disorders. In fact, of those allowed based on the IFA, 93 percent had mental disorders, while 7 percent had other disorders, as shown below:

Percent of Allowances that Are Mental or Other Disorders by Basis for Allowance
Childhood Disability Allowances, January - November 1994

Basis for allowance	Total number	Type of Disorder	
		Mental (percent)	Other (percent)
Total	167,991	68	32
Meets the listings	87,369	68	32
Medically equals	13,974	39	61
Functionally equals	14,377	13	87
IFA	52,271	93	7

Mental impairment allowances that are most likely to be based on the IFA are:

-- Attention deficit hyperactivity disorder (61 percent);
-- Impairment that are not specifically listed in the mental disorders listings, including:
  - learning disorder (88 percent);
  - speech and language delay (67 percent);
  - conduct disorder (63 percent);
  - oppositional defiant disorder (64 percent);
-- Anxiety-related disorders (56 percent); and
-- Mood disorders (51 percent).

Table 3. -- Basis for Allowance of Childhood Disability Claims by Detailed Mental Diagnostic Codes, 1994
Percent Distribution by Basis for Allowance

Code	Disorder	Total		Based on Medical Listings			IFA
		number	percent	Meets	Med. Equals	Func. Equals	
total	Total initial allowances	167,991	100	52	8	9	30
total	**Physical (nonmental) disorders**	**52,960**	**100**	**53**	**16**	**24**	**7**
total	**Mental disorders**	**115,031**	**100**	**51**	**5**	**2**	**42**
Mental disorders by specific codes							
3180	Mental retardation	62,188	100	63	2	1	32
total	**Learning and communic. disorders**						
3152	Learning disorder (child)	2,941	100	8	2	2	88
3152	Speech and language delays (child)	2,075	100	8	12	12	67
total	**ADHD and behavioral disorders**						
3140	Attention deficit hyperactivity disorder	18,934	100	35	3	1	61
total	**Behavioral disorders**						
3010	Personality disorders	5,372	100	48	7	2	43
3120	Conduct disorders (child)	1,771	100	28	7	2	63
3138	Oppositional defiant disorder (child)	1,715	100	26	9	1	64
total	**All other mental disorders**						
2940	Organic mental disorders	3,276	100	56	7	4	33
2950	schizophrenic/paranoid func. disorders	1,380	100	65	6	2	28
2960	Mood disorders (children)	5,901	100	42	5	2	51
2990	develop. disability including autism	3,666	100	66	6	2	26
3000	Anxiety-related disorders	2,340	100	36	6	2	56
3150	Dev./emotional disorders (infant)	3,015	100	31	8	7	53
total	All other mental disorders	457	100	39	7	3	52

Source: Calculations based on data provided by Office of Disability, SSA.

Note: 1994 data are through November 28, 1994.

IV. Criteria for Allowing Benefits to Children Based on Mental Disorders

The criteria for benefit allowances based on the mental disorders *medical listings* are made of up medical criteria in paragraph A and functional criteria in paragraph B. A child must meet both the A and B criteria in order to be allowed benefits based on meeting the medical listings.

Children whose impairments do not meet or equal the medical and functional requirements in the listings can be allowed benefits based on an additional functional assessment that was introduced as a result of the Zebley decision. While the IFA may sound similar to the paragraph B functional criteria in the medical listings, it is a separate step with somewhat more lenient functional criteria than those in paragraph B.

This section briefly describes the A and B criteria of the medical listings and the IFA, as they apply to school-age children.

The Medical Listings of Mental Disorders -- Overview

The structure of the mental disorders listings for children under age 18 parallels the structure of the mental disorders listings for adults but is modified to reflect the presentation of mental disorders in children. The listings are arranged in 11 diagnostic categories:

- organic mental disorders (112.02)
- schizophrenic, delusional (paranoid), schizoaffective, and other psychotic disorders (112.03)
- mood disorders (112.04)
- mental retardation (112.05)
- anxiety disorders (112.06)
- somatoform, eating and tic disorders (112.07)
- personality disorders (112.08)
- psychoactive substance dependence disorders (112.09)
- autistic disorders and other pervasive developmental disorders (112.10)
- attention deficit hyperactivity disorder (112.11)
- developmental and emotional disorders of newborn and younger infants (112.12)

Each listing begins with an introductory statement that describes the disorder addressed by the listing. This is followed by paragraph A criteria, which describes medical or diagnostic findings of the disorders, and paragraph B which describes functional limitations related to the disorder.
A claimant is found to have an impairment that **meets** the listings only if the criteria in both **both paragraphs A and B are met.**

The purpose of the criteria in paragraph A is to substantiate medically the *presence* of a particular mental disorder.

The purpose of the paragraph B criteria is to establish the *severity* of the functional limitation imposed by the impairment.

Mental Listings -- Paragraph A Examples

The opening descriptive statement and paragraph A criteria for ADHD, personality disorders and mental retardation are listed below. They are highlighted here because: ADHD is the most rapidly growing diagnostic group; personality disorders include "behavioral" disorder; and mental retardation may include cases of learning disorders. Appendix A has the complete listings for childhood mental disorders.

Attention Deficit Hyperactivity Disorder (112.11)

Manifested by developmentally inappropriate degrees of inattention, impulsiveness, and hyperactivity. The required level of severity for these disorders is met when the requirements in both A and B are met.

A. Medically documented findings of ALL THREE of the following:

1. Marked inattention; and
2. Marked impulsiveness; and
3. Marked hyperactivity;

AND meeting the paragraph B criteria.

Personality Disorders (112.08)

Manifested by pervasive, inflexible, and maladaptive personality traits, which are typical of the child's long-term functioning and not limited to discrete episodes of illness. The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Deeply ingrained, maladaptive patterns of behavior, associated with ONE of the following:

1. Seclusiveness or autistic thinking; or
2. Pathologically inappropriate suspiciousness or hostility; or
3. Oddities of thought, perception, speech, and behavior; or
4. Persistent disturbances of mood or affect; or
5. Pathological dependence, passivity, or aggressiveness; or

6. Intense and unstable interpersonal relationships and impulsive and exploitative behavior; or
7. Pathological perfectionism and inflexibility;

AND meeting the paragraph B criteria.

Mental Retardation (112.05)[4]

Characterized by significantly subaverage general intellectual functioning with deficits in adaptive functioning. The required level of severity for this disorder is met when the requirements in A, B, C, D, E or F are satisfied.

A. For children (age 3 to attainment of age 18), resulting in at least two of the functional deficits in the generalized paragraph B functional criteria. OR

B. Mental incapacity evidenced by dependence upon others for personal needs (grossly in excess of age-appropriate dependence) and inability to follow directions such that the use of standardized measures of intellectual functioning is precluded; OR

C. A valid verbal, performance, or full-scale IQ of 59 or less; OR

D. A valid verbal, performance or full-scale IQ of 60 through 70 and a physical or other mental impairment imposing additional and significant limitation of function; OR

E. A valid verbal, performance or full scale IQ of 60 through 70 and ... for children (age 3 - 18) resulting in at least ONE of the (noncognitive) functional limitations in the generalized paragraph B criteria; or

F. ... For children (age 3-18), satisfying the cognitive functional limitation in the generalized paragraph B criteria and a physical or mental impairment imposing additional and significant limitations of function.

Mental Listings -- Paragraph B Criteria

The paragraph B criteria for school age children (age 3-18) generally are the same for all listed impairments.[5] These criteria are met if at least TWO of the following functional

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[4] The mental retardation listing uses the generalized paragraph B criteria somewhat differently than do the other mental listings. The paragraph B criteria are used only in certain combinations with the listed diagnostic criteria.

[5] As noted, the mental retardation listing uses the paragraph B in combination with only selected paragraph A criteria.

limitations are met:

a. Marked impairment in age-appropriate **cognitive/communication** function; or
b. Marked impairment in age-appropriate **social functioning**; or

c. Marked impairment in **personal/behavioral** function as evidenced by either:

(1) Marked restriction in age-appropriate **activities of daily living**; or

(2) Persistent serious **maladaptive behaviors** destructive to self, others, animals, or property, requiring protective interventions; or

d. Deficiencies of **concentration, persistence, or pace** resulting in frequent failure to complete tasks in a timely manner.

Appendix A has more complete text of the paragraph B criteria.

Children allowed benefits based on meeting both the medical (paragraph A) and applicable functional (paragraph B) criteria are classified as having **met** the medical listings. In general, those who meet the paragraph B functional criteria, but not all of the paragraph A diagnostic criteria can be found to **medically equal** the listings as long as they have a severe medically determined impairment. As indicated in Table 3, of children allowed benefits in 1994, those allowed based on **meeting the medical listings** account for:

-- 35 percent of those allowed with ADHD, while 61 percent of those allowed with ADHD qualified under the IFA, described below.

-- 43 percent of those allowed with personality disorders, while 43 of those with personality disorders were allowed based on the IFA.

-- 63 percent of those allowed based on mental retardation, while 32 percent with mental retardation were allowed based on the IFA.

Behavior disorders such as "conduct disorder" and "oppositional defiant disorder" are not specifically included on the medical listings, and children allowed benefits in 1994 with these diagnostic codes generally qualified under the IFA. Similarly, "learning disorders" and "speech and language delays" are not listed impairments, and children allowed with these diagnostic codes generally qualified under the IFA.

The Individualized Functional Assessment (IFA) -- Zebley Regulations

If the child's impairment does not meet or equal the medical listings, the IFA required by the Zebley regulations, is used to determine whether he or she nonetheless has an impairment(s)

that would be of "comparable severity to impairment(s) that would disable an adult." That assessment is to determine whether the child can function "independently, appropriately and effectively in an age-appropriate manner."

The functional criteria for the IFA are generally the same kinds of criteria used in paragraph B of the mental disorders listings. They, however, require a less severe level of functional limitation than do the paragraph B criteria. For children age 3 to 16 the assessment is in six areas:

1. Cognitive function;
2. Communication function;
3. Motor function;
4. Social function;
5. Personal/behavioral function; and
6. Concentration, persistence and pace.

As guidelines for a finding of disability based on these areas, the IFA regulations give two examples:

-- **Marked** limitation in ONE area and **moderate** limitation in another.

-- **Moderate** limitation in THREE areas.

The specific examples to illustrate these bases for allowance are:

Example 1:

You are functioning at the marked level on ONE domain or behavior, for example

-- in the domain of **social functioning** you are generally unable to maintain age-appropriate relationships with peers and adults, with frequent serious conflicts with your family, classmates, and teachers; or

-- in the domain of **motor functioning**, your range of motion in your elbows, wrists, and fingers is limited by less than 50 percent and you have difficultly writing, typing, picking up and handling small objects, carrying, reaching, and engaging in physical activities which rely heavily on the use of the upper extremities; AND

you are functioning at the moderate level in another domain or behavior (for example:

-- in the domain of **personal/behavioral** functioning, you are frequently unable to perform self-care activities independently.

Example 2:

You are functioning at the moderate level in three areas, for example:

-- in **cognitive functioning**, you have a valid full scale IQ of 74; and
-- in **social functioning**, you have limited age-appropriate relationships with peers and adults, with occasional serious conflicts with family, classmates, teachers, and others; and
-- in **concentration, persistence and pace**, you are frequently unable to complete age-appropriate complex tasks, and occasionally unable to perform simple age-appropriate tasks adequately.

The regulations say that these examples are only guidelines. "The guidelines illustrate a level of impairment severity that is generally, though not invariably, sufficient to establish comparable severity. ... The examples ... are only guidelines to illustrate severity and are not all-inclusive rules. The determination of your claim is based on all relevant evidence in the case record, using all the principles and guidance in 416.924 through 416.924d on a case-by-case basis." The text of the relevant section of the Zebley rules is at Appendix B.

V. Summary and Observations

A growing proportion of children receive SSI benefits based on mental disorders other than mental retardation. That proportion grew from 12 to 22 percent in the 2 ½ year period ending in June 1994 and it continues to grow. In 1994, 31.5 percent of new allowances were based on those conditions.

Most of the allowances of childhood claims based on mental impairments other than mental retardation are not based on meeting or equaling the listiings. Rather, they are based on the individualized functional assessment (IFA). In fact, the IFA seems to be used almost exclusively for allowance of claims with mental disorders as the primary diagnosis -- over 90 percent of IFA allowances were for such cases.

The reason for this may well be because the IFA uses a functional assessment that is very similar to that used in paragraph B of the mental impairment listings. It, however, permits an allowance based on a somewhat lower threshold of functional limitation than that required to meet or equal the mental listings.

The similarity between the functional domains used in the mental disorders listings and the domains used in the IFA is illustrated in Chart 1. (Chart 1 also shows the functional domains used to assess adults, under the adult mental disorders listings.)

SSA's Functional Assessment of the Severity of Disabling Conditions

Adult Mental Disorders Listings

The required level of severity is met with TWO of the following:

1. Marked restriction in **activities of daily living.**

2. Marked restriction in **social** functioning

3. Deficiencies of **concentration, persistence or pace**

4. Repeated episodes of **decompensation** in work, or work-like settings

Childhood Mental Disorders Listings

The required level of severity is met with TWO of the following:

1. Marked impairment in age-appropriate **cognitive/communication** function.

2. Marked impairment in age-appropriate **social** functioning

3. Marked impairment in **personal/behavior** functioning as evidences by:

   a. Marked restriction in age-appropriate **activities of daily living**; or

   b. Persistent **maladaptive behavior** destructive to self, others, animals or property;

4. Deficiencies of **concentration, persistence or pace.**

Childhood Individualized Functional Assessment (IFA)

"Guidelines" are ONE marked and ONE moderate limitation, or THREE moderate limitations among:

1. **Cognitive** function

2. **Communication** function

3. **Motor** function

4. **Social** function

5. **Personal/behavioral** function

6. **Concentration, persistence or pace.**

The childhood paragraph B criteria find a child disabled if the child has a **marked** impairment in TWO out of the FOUR following areas:

1. Cognitive/communicative function;
2. Social functioning;
3. Personal behavioral function; or
4. Concentration, persistence or pace.

In contrast, the IFA permits a finding of disability if the child has a **marked** impairment in ONE and **moderate** impairment in ANOTHER of the SIX following areas:

1. Cognitive function;
2. Communication function;
3. Motor function;
4. Social function;
5. Personal/behavioral function; or
6. Concentration, persistence and pace.

If the role of the IFA is to permit allowances based on a combination of physical and mental impairments (which, generally, is not the purpose of the criteria in the mental disorders listings), then perhaps the IFA criteria should be qualitatively different, in some significant way, from the functional assessment in the mental listings. As it now stands, it appears that it can serve as a second chance at roughly the same functional assessment used in the mental impairment listings, but with a lower threshold for allowance. That may explain why it is, in fact, so often used to allow benefits for children with mental impairments, and so rarely for children with physical impairments.

In considering the functional consequences of impairments that are not mainly mental in nature, it is noteworthy that the regulations implementing the Supreme Court's decision did more than add the IFA at step 4 of the sequential decision process for children. Those regulations also added Step 3c -- for an assessment of "functional equivalence" to the medical listings. This assessment of functional equivalence was the basis for allowance for about 1 in 4 allowances for physical disorder, but only 2 percent of allowances based on mental disorders (Table 3).

The text of that part of the Zebley regulation follows.

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Focus Group Qualitative Results

Preliminary Report for the Disability Policy Panel

Virginia Reno

November 1994

Background

The Academy's Disability Policy Project contracted with LaScola Qualitative Research, of Washington, D.C., to conduct focus groups with DI and SSI beneficiaries in October 1994. The purpose of the focus groups was to get beneficiaries' perspectives on their past work and prospects for returning to work. For young adult beneficiaries, we wanted to get their perspectives on current or future work and their experience in preparing for the world of work.

Interviews were conducted with four groups of beneficiaries:

1. Young adults -- ages 18-24 -- in current payment status for DI or SSI benefits.

2. Family members of young adults receiving SSI, but not necessarily related to the participants in Group 1.

3. Older adults -- ages 50-61.

4. "Middle" adults -- ages 25-49.

The last two groups of beneficiaries had filed for benefits within the last five years and, therefore, were relatively recent entrants to the DI or SSI rolls.

The interviews were held in the following sites:

Des Moines, IA:	Groups 1, 2 and 3	Tuesday and Wednesday, October 4-5
Portland, OR:	Groups 1, 2 and 4	Thursday and Friday, October 6-7
Manhattan, NY:	Groups 3 and 4	Tuesday, October 11

The following general observations are based on the interviews with young adults and their parents.

Young Adults and Parents

The focus groups with young adults had four participants each, in Portland and

1776 Massachusetts Avenue, NW
Suite 615
Washington, DC 20036-1904
Telephone (202) 452-8097
Facsimile (202) 452-8111

Des Moines, for a total of eight. Because of the high rate of "no shows," the focus groups were supplemented with telephone interviews with six more young people in the two sites. The parents' focus groups included five parents in each site, for a total of ten. Together the young adults and parents portray the extraordinary diversity among young people entering adulthood with a link to the SSI program. In some cases, the young person was from a low-income family and received SSI as a child. In other cases, they began receiving SSI at age 18 when their financial status is considered separately from that of their parents.

The Parents' View

The parents offered a perspective that we could not get from interviewing only young adults, themselves. Some of the parents' adult children had profound health problems or disabilities that ruled out their ability to participate in a focus group and, in many cases, in competitive employment.

> "My son (age 22) couldn't do this [participate in a focus group]. The only thing in his life is love. He knows closeness. He has the ability of a 6-month old." (mother, Des Moines)
>
> "(My daughter) had brain cancer when she was 2. She just turned 20. She is three feet tall and weighs 50 pounds and needs 24-hour care. ... If I had $10 for every time we were told she wouldn't make it through the night, I would be rich. ... When a person needs 24-hour care thank God there are two parents in the household. I would go crazy if I didn't work some. I work six months, then my wife works six months." (father, Portland)
>
> "My son, age 19, had a brain tumor and stroke when he was 11. A good life for him is built around people he knows care. He can sense whether a person likes him or not. Or will be mean or not. He responds meanly if a person is mean to him. I could put him in a foster home. I won't do that. SSI is not enough. (My son) is a sweet, loving teddy bear. He is nonverbal. 24-hour a day care is essential. Many people don't understand that." (mother, Portland)
>
> "My daughter was born with a visual impairment. She had a stroke when she was 3. She will be 19. ... She understands simple commands, simple terms. She gets frustrated. She is nonverbal. We taught her appropriate-type touching. She responds to hugging. We direct her by shoulder rubs." (mother, Portland)

The parents, without exception, wanted their children treated with love and respect, and to be given the maximum responsibility and independence possible. In some cases that meant having the person who cares for their child understand the child's nonverbal signals about what he or she wants or needs.

These parents were not worried about the risk of losing benefits. Now that their children were adults, the child's benefits (and Medicaid) were secure, because the parents' financial status no longer affected the child's eligibility. The parents were concerned about the quality of care available to their children and were deeply concerned about who would fill the caregiver role if the child outlived them. They expressed frustration with the limited amount of financial and other help available. The child's SSI benefit -- at $320 or $445 -- fell far short of what they needed to help pay for their child's care. Several were incensed that there would be far more financial support if they placed their child in foster care. That was unacceptable to them.

The Young Adults' View

The young adults who participated in focus groups or telephone interviews were, through a screening, able to speak for themselves. They showed great diversity in their outlooks on life, their accomplishments, aspirations and adjustment to their disabilities.

Those who had long-term disabilities and had benefitted from well-established support systems were doing fairly well.

The two participants who described themselves as "retarded" or "slow to learn, learning disabled," had established themselves in stable living arrangements and had part-time jobs. One had received a large lump-sum payment (probably a *Zebley* settlement) that he and his mom had used to help pay for their house. The second young man appeared to have entered the SSI rolls at age 18. Both had long-term relationships with social service networks -- a social worker, or skills-trainer, helped them through difficulties with their jobs or other coping situations. They seemed unconcerned about benefit rules, perhaps because they counted on their case workers to keep their records straight. Their aspirations were to "be around good people, have a safe place to live," and they had a sense of accomplishment from their jobs "helping people find things in the store" or "carrying groceries for little old ladies."

A young man who was blind was interviewed by telephone. He was attending college with tuition support from the State Commission for the Blind. He was extremely upbeat, planned to get married soon and looked forward to a successful career as a special education teacher. He had been contacted by the State agency when he reached age 18 about his potential eligibility for SSI. He qualified quickly and is grateful for the support while he gets his master's degree.

Other young adults with long-term disabilities lacked these kinds of stable supports and had not yet found clear direction in their lives. They were concerned about jeopardizing their benefits. Their aspirations were not different from those of people without disabilities -- they wanted a good family, enough income, maybe some children and often mentioned career

goals -- as a musician, hairdresser or interior decorator. They did not yet have a plan for achieving those goals.

A young man in Iowa reported he had a stroke at birth and, because he was paralyzed on one side, did not walk until he was six. In 1987, he started having seizures for which he continues to take medication. He had been denied for SSI in Indiana because his parents made too much money in the steel mills. He fondly recalls a teacher at the "handicapped school" in Indiana who helped boost his horizons and build his confidence to do whatever he set out to do. When his family moved to Texas to find work, he attended regular high school classes. When he had seizures in class, they thought he was asleep and dropped him from school, for which he reported being on a two-year punishment from his step-dad. "That put me lower and lower." His SSI benefits are an important source of security and he is reluctant to risk them. He has yet to obtain his GED, but would like to have a career in art or architectural drawing. He seemed unsure how to go about it.

Other young adults had disabilities with recent onset -- two had head and back injuries from automobile accidents and one had partial blindness and recurring headaches from a shooting accident. Another described herself as diagnosed as "borderline personality" when she was 13 and entered SSI when she was 18. Her husband is her payee.

> A young man, age 18, who had partial blindness and recurring headaches from a shooting accident when he was 16, got on SSI to help pay the hospital bills. He spoke hesitantly about dealing with being treated as "different," from other people or from the way he used to be. It is easier, he said, when you realize that people just want to know how you are doing. They don't think less of you. He was attending the local community college working toward his GED, although doing all the reading is difficult. He believes he can do a job, and hopes that his family will help him find work when he has finished his schooling.
>
> A young man in Oregon had traumatic head injuries as well as other injuries in an automobile accident 18 months earlier. His girlfriend died in the automobile accident. He was volatile and frustrated with his limitations after the accident and with his life as an SSI recipient. He had high expectations about his future and did not want to settle for less than wish for a career as a musician. He had lost several jobs because of his unpredictable behavior.
>
> A young woman in Iowa has sustain traumatic brain injury in an automobile accident just 13 months earlier and had been in a coma for 45 days, during which her initial application for SSI had been denied. Her neurological and speech impairments from the injury were improving, though she continued to have radical mood swings and difficulty remembering things. The consequences of her injuries strained her relationship with her family. "My family is in denial. But my mom stands by me." Her mother participated in the parents group was torn by the stress of coping with her

daughter's unpredictable, often aberrant or self-destructive behavior, and of intervening with the young woman's father and sister, who could not accept the change following the accident. The young woman wanted to be a hair stylist and had taken classes at the community college to rebuild her reading and writing skills. She was unsure about her future and was taking one day at a time.

For many of the young people who were not yet in a "work track," the benefits were, in a sense, a source of security and dependability in an otherwise chaotic and undependable world. They were wary of SSI's benefit rules and, in fact, find them incomprehensible. As one young woman said, "Everything depends on everything: my income, my husband's income, where we live and what we have in the bank. Even if you report everything they want, it takes so long to fix it that you end up owing them money."

Summary Findings

Young people entering adulthood on SSI are an extraordinarily diverse group. The best pay off for investing in supports to encourage a work track appears to be among a subset of the young adults. Among the young adults:

1) Some families are under great stress to meet the needs of their young adult children with significant disabilities who have very limited prospects for competitive employment. The parents want their children treated with love and respect and are worried about the long-term prospects for continuing care for their children.

2) Some of the young adults on SSI are successfully making the transition to work:

   -- Some young people with cognitive limitations were getting the support they needed from families or case workers and had successful part-time jobs. They may continue to rely on SSI and its work incentive provisions as a safety net and seem to have the assistance they need to utilize those work incentives.

   -- Others young adults use SSI as temporary support while they get post-secondary educations and look forward to successful professional careers when they will be completely off the SSI rolls.

3) Other young adults have aspirations for work careers, but have not yet made the connection with the education or other supports they need to prepare for work. They do not understand and are wary of SSI benefit rules.

THE NATIONAL ACADEMY OF SOCIAL INSURANCE

Disability Project Panel

Jerry L. Mashaw, Chair
Sterling Professor of Law
Institute of Social and Policy Studies
Yale University Law School
New Haven, CT

Monroe Berkowitz
Professor of Economics, Emeritus
Rutgers University
Bridgewater, NJ

Richard V. Burkhauser
Center for Policy Research
Syracuse University
Syracuse, NY

Gerben DeJong
Director
National Rehabilitation Hospital-Research Center
Washington, D.C.

James N. Ellenberger
Assistant Director
Department of Occupational Safety and Health
AFL-CIO
Washington, D.C.

Lex Frieden
Senior Vice President
The Institute for Rehabilitation and Research
Houston, TX

Howard H. Goldman, M.D.
Mental Health Policy Studies
Department of Psychiatry
University of Maryland School of Medicine
Baltimore, MD

Arthur E. Hess
Consultant
Former Deputy Commissioner of Social Security
Charlottesville, VA

Thomas C. Joe
Director
Center for the Study of Social Policy
Washington, D.C.

Mitchell P. LaPlante
Associate Adjunct Professor
Institute for Health and Aging
University of California, San Francisco

Douglas A. Martin
Special Assistant to the Chancellor
University of California, Los Angeles

David Mechanic
Director
Institute for Health, Health Care Policy and Aging
Rutgers University
New Brunswick, NJ

Patricia M. Owens
Vice President, Disability Programs
UNUM Life Insurance of America
Brooklyn, NY

James M. Perrin, M.D.
Associate Professor of Pediatrics
Harvard Medical School
Massachusetts General Hospital
Boston, MA

Donald L. Shumway
Director
Division of Mental Health
and Developmental Services
Concord, NH

Susan S. Suter
President
Suter and Associates
Springfield, IL

Eileen P. Sweeney
Director of Government Affairs
Children's Defense Fund
Washington, D.C.

Jerry Thomas
Director
Disability Adjudicative Services
Decatur, GA

United States General Accounting Office

GAO

Report to Congressional Requesters

March 1995

SOCIAL SECURITY

New Functional Assessments for Children Raise Eligibility Questions

GAO/HEHS-95-66

GAO

United States
General Accounting Office
Washington, D.C. 20548

Health, Education, and
Human Services Division

B-257473

March 10, 1995

The Honorable Herb Kohl
The Honorable David Pryor
United States Senate

The Honorable George W. Gekas
The Honorable Gerald D. Kleczka
The Honorable Blanche Lambert Lincoln
The Honorable Nick Smith
House of Representatives

The number of children receiving Supplemental Security Income (SSI) benefits has nearly tripled over the last 5 years from 300,000 to almost 900,000, and benefit payments now exceed $4 billion annually. The Social Security Administration (SSA) awards SSI benefits to disabled children who live in families with low incomes and limited resources. A number of factors have contributed to the growth in children's awards, including outreach efforts by SSA and child advocates, rising numbers of children in poverty, and major changes in the criteria for determining whether children are disabled. Growth has been especially rapid in awards to children with mental impairments.

Particularly troublesome have been allegations that parents coach their children to fake mental impairments by misbehaving or doing poorly in school so that they can qualify for cash benefits. These benefits can amount to almost $5,500 per year for each disabled child.[1] The coaching allegations, which have been widely reported by the media, have created the perception among the public that the program is vulnerable to fraud and abuse. In addition, concerns have been raised that the program could foster lifelong dependence on government assistance if children come to view the label "disabled" as a lifetime entitlement to income and medical benefits. Finally, concerns have been raised about whether the program's eligibility criteria for children are too lenient. As a result of these concerns, reform of the SSI childhood disability program is now the subject of congressional scrutiny.

In our October 21, 1994, briefing, you asked us to report on SSA's new way of assessing children's impairments using the individualized functional assessment (IFA) process mandated by the Supreme Court in Sullivan v.

[1]Benefits generally are provided without regard to the number of SSI recipients in the household. SSA estimated in March 1994 that 125,000 children receiving SSI lived in households with at least one other SSI recipient.

Zebley. The new IFA process permits the award of benefits to children with impairments that are less severe than the impairments that previously could justify an award. We assessed (1) the IFA's impact on the SSI rolls, (2) its implementation by SSA, and (3) its vulnerability to coaching.

To develop the information in this report, we (1) reviewed SSA's childhood disability program policies, procedures, and records, and discussed the IFA process with SSA program officials on the national, regional, and local level; (2) interviewed officials in state disability determination services (DDSs); (3) reviewed SSA's study of decisions made on childhood cases involving behavioral and learning disorders; and (4) attended a June 1994 SSA training course designed to address the problems raised in the study. We also discussed eligibility issues with officials of the Department of Health and Human Services' (HHS) Office of Inspector General (IG), which recently issued two reports on the SSI childhood disability program. (See app. I for more details on our scope and methodology.)

Results in Brief

Changes in the regulations governing childhood eligibility for SSI have had a significant impact on the growth and composition of the childhood disability rolls. In particular, awards have been made to more than 200,000 children who did not meet SSA's listing of impairments but instead qualified for benefits based on the less restrictive IFA criteria. These awards account for about $1 billion a year in benefit payments. About 84 percent of the children qualifying based on IFAs have mental impairments, and about one-half of the awards for behavioral disorders, including attention deficit hyperactivity disorder, are based on the IFA criteria.

In our analysis, we found fundamental flaws in the IFA process. Specifically, each step of the process relies heavily on adjudicators' judgments, rather than objective criteria from SSA, to assess the age-appropriateness of children's behavior. As a result, the subjectivity of the process calls into question SSA's ability to ensure reasonable consistency in administering the SSI program, particularly for children with behavioral and learning disorders.

In addition, rapid program growth, particularly in the award of benefits to less severely impaired children, may also have contributed to the public concern that parents could be coaching their children to fake mental impairments in order to qualify for benefits. Studies that we reviewed, however, have found little evidence that coaching is widespread, but they relied solely on documentation in case files and, therefore, cannot rule out

coaching. Although coaching allegations are troublesome, substantiating them and measuring the extent of coaching is virtually impossible.

Background

Since 1974, the SSI program, under title XVI of the Social Security Act, has provided benefits to low-income blind and disabled persons—adults and children—who meet financial eligibility requirements and SSA's definition of disability. SSA determines applicants' financial eligibility; state DDSs determine their medical eligibility. DDSs are state agencies that are funded and overseen by SSA. To meet the financial test, children must be in families with limited incomes and assets.

In 1994, children's federally administered SSI payments totaled $4.52 billion. Depending on the family's income, an eligible child can receive up to $458 per month in federal benefits; 27 states also offer a supplemental benefit payment. Because SSI is an individual entitlement, no family cap exists on the amount of benefits received in a household. With SSI eligibility usually come other in-kind benefits, most notably Medicaid and Food Stamps.

The Social Security Act defines a disabled child as a person under age 18 who "suffers from any medically determinable physical or mental impairment of comparable severity" to one that disables an adult. The statute defines adult disability in terms of an inability to work either in a former job or in any other job in the national economy. Specifically, adult disability is defined as the inability

> "to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last a continuous period of not less than twelve months."

Because children are not expected to work, however, this definition is not applicable to measure disability in children.

At a DDS, childhood disability determinations are made by an adjudication team consisting of an examiner and a medical consultant. For mental impairments, the consultant must be a psychiatrist or child psychologist. The examiner collects all medical evidence—physical and mental—either from medical sources who have treated the applicant or from an independent consultant if more medical information is needed. The examiner supplements the medical information with accounts of the

child's behavior and activities from the child's teachers, parents, and others knowledgeable about the child's day-to-day functioning.

Working together, the DDS adjudication team determines whether the applicant's medical condition matches or is equivalent to an impairment found in SSA's listing of medical impairments.[2] If so, benefits are awarded. If, however, the applicant's condition is not severe enough to meet or equal the severity criteria in SSA's medical listings, the team uses the evidence to perform an IFA. If the IFA shows the child's impairment substantially reduces his or her ability to function age-appropriately, benefits are awarded. If not, a denial notice is issued, and applicants are informed of their appeal rights.

SSI Childhood Eligibility Criteria Have Undergone Major Changes

During a 2-month period, SSA issued two sets of new regulations that significantly changed the criteria for determining children's eligibility for SSI disability benefits.[3] One set of regulations, issued in accordance with the Disability Benefits Reform Act of 1984 (DBRA), revised and expanded SSA's medical listings for evaluating mental impairments in children to incorporate recent advances in medicine and science. The second set of regulations was issued in response to the Sullivan v. Zebley Supreme Court decision, which required SSA to make its process for determining disability in children analogous to the adult process. Both sets of regulations placed more emphasis on assessing how children's impairments limit their ability to act and behave like unimpaired children of similar age. Both also emphasize the importance of obtaining evidence from nonmedical sources as part of this assessment.

DBRA Regulations Changed SSA's Medical Listings for Assessing Mental Impairments in Children

SSA issued new regulations in accordance with DBRA on December 12, 1990. These new regulations revised and expanded SSA's medical listings for childhood mental impairments to reflect up-to-date terminology used by mental health professionals and recent advances in the knowledge, treatment, and methods of evaluating mental disorders in children. The new medical listings for mental impairments provided much more detailed and specific guidance on how to evaluate mental disorders in children than the former regulations, which were published in 1977. In particular, the new medical listings placed much more emphasis on assessing how a

[2]SSA's listing of medical impairments describes impairments—in terms of signs, symptoms, and laboratory findings—that are presumed to be severe enough to disable an individual.

[3]For a complete description of these changes, see Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations (GAO/HEHS-94-225, Sept. 9, 1994).

child's mental impairment limits his or her ability to function in age-appropriate ways. SSA made this change because mental health professionals consider functional factors particularly important in evaluating the mental disorders of children.

The former medical listings for mental impairments emphasized the medical characteristics that must be met to substantiate the existence of the impairment. Specific areas of functioning sometimes were and sometimes were not mentioned as a factor in this determination. In contrast, the new medical listings provide much more detailed guidance on assessing the functional aspects of each impairment. The standard for most impairments is divided into two parts: medical and functional criteria, both of which must be satisfied for the applicant to qualify for a benefit.

The functional criteria are described in terms of the age of the child and the specific areas of functioning—such as social, communication/cognition, or personal/behavioral skills—that must be assessed. The new medical listings emphasize the importance of parents and others as sources of nonmedical information about a child's day-to-day functioning. In general, the childhood mental listings require children over 2 years old to have marked limitations in two of the four areas of functioning to qualify for benefits. Further, when standardized tests are available, the listing defines the term "marked" as a level of functioning that is two standard deviations below the mean for children of similar age.

The new medical listings also classified childhood mental disorders into more distinct categories of mental impairments. Previously, there were 4 impairments listed—mental retardation, chronic brain syndrome, psychosis of infancy and childhood, and functional nonpsychotic disorders—now there are 11. Several of the newly listed impairments, such as autism and other pervasive developmental disorders, mood disorders, and personality disorders, describe impairments that were previously evaluated under one or more of the four broader categories of childhood mental impairments. Several other impairments are mentioned for the first time, such as attention deficit hyperactivity disorder and psychoactive substance dependence disorders.

Zebley Regulations Added Separate Functional Assessment Process

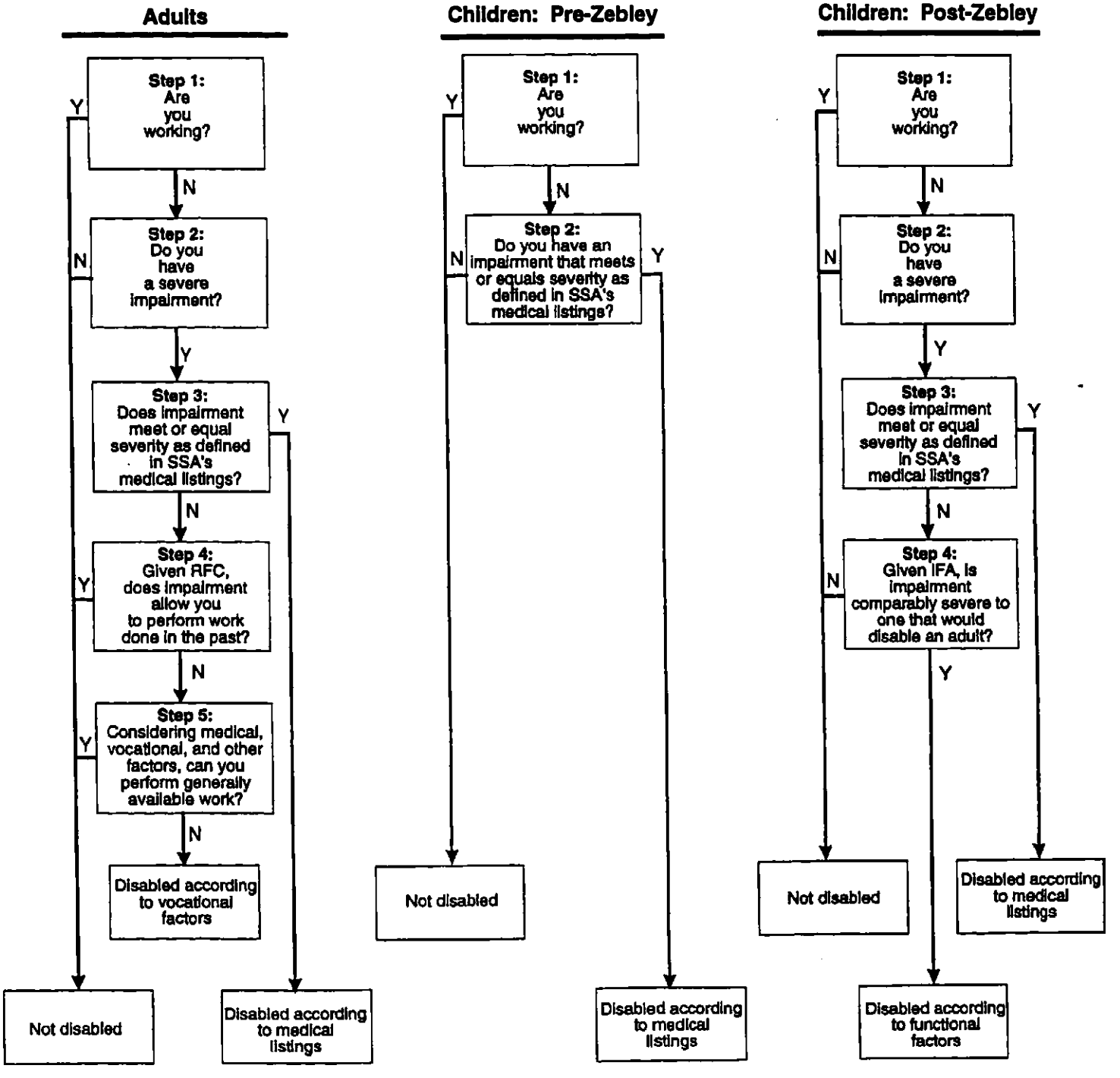
On February 20, 1990, the Supreme Court ruled that SSA's process for determining disability in children under 18 years old violated the Social Security Act because the process held children to a more restrictive

disability standard than it did adults. In its opinion, the Court found that the process for children

"does not account for all impairments 'of comparable severity' [to adults], and denies child claimants the individualized functional assessment that the statutory standard requires . . . ."

To determine adults' eligibility for disability benefits, SSA uses a five-step sequential evaluation process. Before Zebley, it used only a two-step process to determine children's eligibility for benefits. (See fig. 1.) Children were awarded benefits only if their impairments met or equaled the severity criteria in SSA's medical listings. All other children were denied benefits. In contrast, adults whose conditions were not severe enough to qualify under the medical listings could still be found eligible for benefits if an assessment of their residual functional capacity (RFC) showed that they could not engage in substantial work. No analogous assessment of functioning was done for children who did not qualify under the medical listings.

Figure 1: Disability Evaluation Process for Adults Versus Children



To eliminate this disparity, the Court mandated that for those children who do not qualify for benefits under the more restrictive medical listings, SSA must add a less restrictive individualized assessment of how the child's impairment affects his or her ability to function in age-appropriate ways—that is, to act or behave in ways that children of similar ages normally do—before it could decide whether the child was eligible for benefits. The Court said that although a vocational analysis does not apply to children because they are not expected to work, SSA could make

"an inquiry into the impact of an impairment on the normal daily activities of a child of the claimant's age—speaking, walking, dressing and feeding oneself, going to school, playing, etc."

Although the Court required the functional assessment, it did not define the degree of limitation necessary to qualify for benefits, except by analogy to the adult definition of disability.

To implement the Zebley decision, SSA convened a group of experts in April 1990 to help formulate new regulations using age-appropriate functional criteria. Included were experts in general and developmental pediatrics, child psychology, learning disorders, and early and adolescent childhood education as well as advocates from groups such as Community Legal Services in Philadelphia (plaintiff's counsel in the Zebley case), the Association for Retarded Citizens, and the Mental Health Law Project. SSA also consulted with its regional offices and the state DDSs.

Building on the functional criteria added to the listings after DBRA, SSA issued regulations implementing the Supreme Court's decision on February 11, 1991.[4] According to these regulations, for the child to be eligible for disability benefits, the IFA must show that the child's impairment or combination of impairments limits his or her ability "to function independently, appropriately, and effectively in an age-appropriate manner." Specifically, the impairment must substantially reduce the child's ability to grow, develop, or mature physically, mentally, or emotionally to the extent that it limits his or her ability to (1) attain age-appropriate developmental milestones; (2) attain age-appropriate daily activities at home, school, play, or work; or (3) acquire the skills needed to assume adult roles. Although SSA officials describe these as state-of-the-art

[4]Final regulations incorporating voluminous public comments were issued on September 9, 1993. These regulations, which were not substantially different from the February 1991 interim final regulations, have a September 9, 1997, sunset date, after which time they will no longer be effective, unless the Secretary of HHS extends, revises, or reissues them.

criteria for assessing children's functioning, they concede that many of these concepts are not clear cut.

As a result of these regulations, DDSs now perform IFAs to assess the child's social, communication, cognitive, personal and behavioral, and motor skills, as well as his or her responsiveness to stimuli and ability to concentrate, persist at tasks at hand, and keep pace.[5] Like the DBRA regulations, the IFA process requires DDSs to supplement medical information with information about the child's behavior and activities from the child's teachers, parents, and others knowledgeable about the child's day-to-day functioning in order to make these assessments. Generally, if the IFA shows that a child has a moderate limitation in three areas of functioning or a marked limitation in one area and a moderate limitation in another, benefits are awarded. In contrast, the more restrictive functional criteria under SSA's mental listings require two marked limitations.

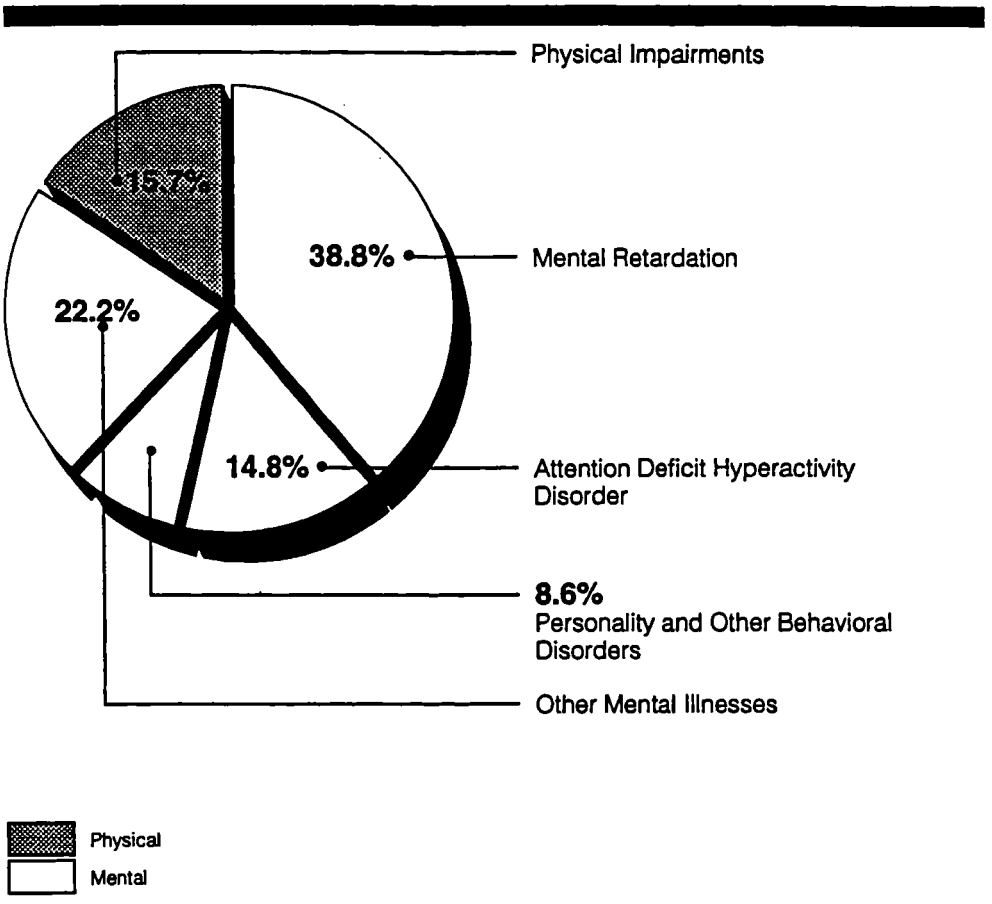
In addition to measuring functioning as part of the IFA process, the Zebley regulations added the concept of functional equivalence to SSA's medical listings. Before Zebley, a child qualified for benefits only if his or her impairment met or was medically equivalent to the severity criteria in the listings. After Zebley, a child could qualify if his or her impairment was functionally equivalent to an impairment in the medical listings, as long as there was a direct, medically determinable cause of the functional limitations. The regulations provide 15 examples of conditions—such as the need for a major organ transplant—presumed to be functionally equivalent to the listed impairments.

IFA Process Has Had a Major Impact on the Rolls

Of the 646,000 children added to the SSI rolls from February 1991 through September 1994, about 219,000 (one-third) were awarded benefits based on the less restrictive IFA process. If all 219,000 children receive the maximum benefit, their SSI benefits would cost about $1 billion a year. About 84 percent of these children had a mental impairment as their primary limitation, and about 16 percent had physical impairments. (Fig. 2 shows a breakdown of the impairments.)

[5]Social, communication, cognitive, and motor skills are assessed for children of all ages; personal and behavioral skills are assessed for children 1 year old and older. The ability to concentrate, persist at tasks at hand, and keep pace are assessed for children 3 years old and older; responsiveness to stimuli is assessed in children under 1 year old.

Figure 2: Most IFA Awards Go to Children With Mental Impairments

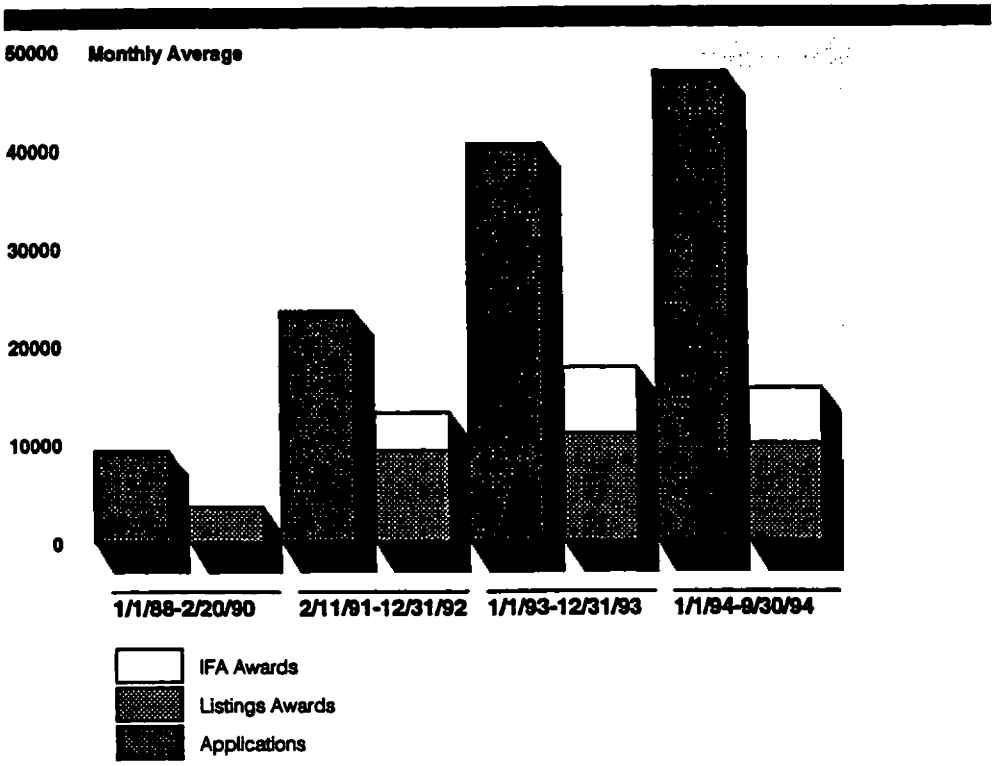


Source: Analysis of SSA's 831 file.

Figure 3 shows the substantial increase in the number of awards. Much of this increase was due to the implementation of new medical listings for mental impairments. The IFA process also added to the growth in the rolls and accounted for a substantial portion of new awards. Figure 3 also shows that the average monthly number of applications jumped dramatically after Zebley and has continued to grow. Many observers attribute this increase in applications to the publicity surrounding Zebley, as well as to increased outreach by SSA, some of which was congressionally mandated.

Also, some of the increase in awards may have been attributable to the close scrutiny of the IFA process by courts and disabled child advocates, which some believe may have resulted in some DDSs feeling pressured to increase their award rates during the 1991-1992 period. (App. II provides a chronology of their actions.) Before the IFA process was introduced in 1991, the national award rate for all types of childhood cases was 38 percent, but the award rate jumped to 56 percent in the first 2 years after the IFA and DBRA regulations were issued. More recently, during 1993 and 1994, the award rate has dropped dramatically. The national award rate for 1994 was 32 percent—lower than it was in the 2 years before Zebley.

Figure 3: IFA and Changes in Medical Listings Both Contribute to Growth in the Rolls



Source: Analysis of SSA's 831 file.

IFA Process Has Been Difficult to Implement Consistently

Our review indicates that the IFA process has been difficult to implement consistently and reliably, particularly for children with mental impairments, because the process requires adjudicators to make a series of judgment calls in a complex matrix of assessments about

age-appropriateness of behavior. SSA and IG studies of children with mental impairments have borne out these difficulties. Although SSA has tried to add rigor to the IFA process through guidance and training, we believe that problems will likely continue because of the difficulties inherent in using age-appropriate behavior as an analog for the adult vocational assessment of residual functional capacity.

IFA—A Complex Process That Relies Heavily on Adjudicator Judgment

Determining disability for children with impairments that are not severe enough to match a listed impairment can be a highly subjective process. SSA designed the IFA process to provide DDS adjudicators with a structure to help them make uniform and rational disability determinations for children with less severe impairments. Even so, the necessity to assess a child's ability to function age-appropriately requires DDS adjudicators to make a series of judgments, which we believe raises questions about the consistency and reliability of DDS decisions. SSA and IG studies and our analysis document problems throughout the IFA process, especially for mental impairments. (See app. III for a more detailed discussion of the problems that SSA and the IG identified.)

Extensive evidence needed: To make disability determinations, DDSs use information from both medical and nonmedical sources, including teachers, day care providers, parents, and others knowledgeable about the child's day-to-day behavior and activities. For the functional assessment, observations are needed about the child's behavior over a long period of time, so evidence-gathering can be a considerable task. SSA found in its 1994 study that the lack of sufficient supporting documentation was the most common problem in its sample of childhood disability decisions.

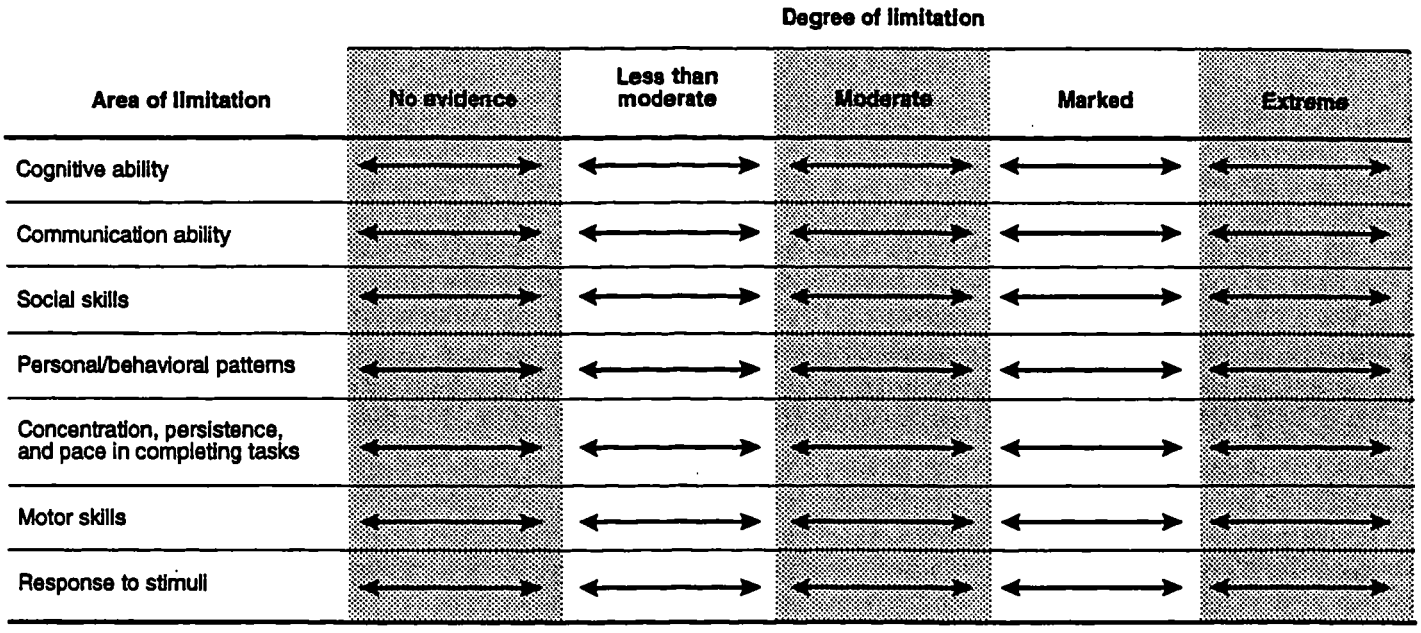
School officials in particular are an important source of nonmedical data on children's behavior over time. Each DDS develops its own questionnaires for eliciting the data, and inquiries are made on virtually every applicant because this information is also used to assess functioning under the medical listings. We estimate that the process now results in about 500,000 inquiries to schools each year, a substantial reporting burden. Some parties believe that the open-ended questionnaire design in many states and the burden on school officials faced with many inquiries may be contributing to poor quality data from this key source.

Difficulty classifying limitations: If an IFA is needed, a disability adjudicator must classify the child's limitations in the appropriate areas of functioning, as shown in figure 4. This is a complex judgment because some areas are

closely interrelated and impairments may or may not affect functioning in more than one area. If, for example, evidence indicates that a child gets in fights at school, the adjudicator must determine whether the specific behavior is evidence of a limitation in social skills, personal and behavioral skills, or some combination of these. SSA found that in cases of incorrect awards a common mistake that adjudicators made was to count the effect of an impairment in two areas when only one was appropriate. This resulted in the impairment seeming more severe than it actually was.

Problems defining degrees of limitation: Once the areas have been identified, the adjudicator must judge the degree of limitation. Because only certain conditions—such as low intelligence quotient (IQ)—can be objectively tested and determined, SSA has defined the severity of limitations by comparison with expected behavior for the child's chronological age. Figure 4 shows the degrees of limitation adjudicators use to assess children 3 through 15 years old. SSA's guidance defines a limitation in the moderate category as more than a mild or minimal limitation but less than a marked limitation. The terms "mild" and "minimal" are not defined, but SSA guidance describes an impairment in the marked category as one that "seriously" interferes with a child's ability to function age-appropriately, while a moderate limitation creates "considerable" interference. Within each category, adjudicators are expected to be able to differentiate the degree of limitation. For example, a moderate rating can range from a "weak moderate" (just above a less-than-moderate) up to a "strong moderate" (just below a marked limitation).

Figure 4: Structure of the IFA Process



Limited guidance for summing the result: Because the IFA process is inherently subjective, SSA cannot provide an objective procedure for summarizing the IFA results. Therefore, SSA instructs adjudicators to step back and assess whether the child meets the overall definition of disability. As an example to guide adjudicators, SSA has said that an award may generally be granted if a child has a moderate limitation in three areas. However, SSA officials stress that this statement assumes "three good, solid moderates," and they characterize it as a general guideline, not a firm rule. Also, they stress that other possible combinations of ratings, such as two strong moderates, could justify finding a child disabled, depending on the individual child's circumstances. In the end, officials stress that adjudicators are expected to award or deny benefits based on an overall judgment, not on any specific sum of severity ratings.

SSA and IG Studies Highlight IFA Difficulties

SSA's 1994 study of 325 childhood awards highlighted the difficulties in using the IFA process to reliably identify disabled children, particularly

children with behavioral and learning disorders.[6] In the study, SSA's Office of Disability selected cases of 325 children with behavioral and learning disorders who had been found eligible. The majority were found eligible based on IFAs. These cases had been decided by DDS adjudicators, based on their understanding of existing guidance from SSA. Then, SSA's regional quality assurance staff had reviewed the decisions and found them accurate. The study involved a third group of experts in the Office of Disability who reviewed the same cases and found inaccuracies in the decisions. Based on their findings, we concluded that about 13 percent of the awards reviewed by SSA had been made to children who were not impaired enough to qualify. Also, another 23 percent of the awards had been made without sufficient supporting documentation.[7]

A January 1995 IG report focused on IFA-based awards to children with mental impairments. IG staff, with assistance from the Office of Disability, reviewed 129 IFA-based awards for mental retardation, attention deficit hyperactivity disorder, and other behavioral or learning disorders. The IG found that 17 (13 percent) of the awards should have been denials and another 38 (29 percent) had been based on insufficient evidence. The IG attributed this to DDS adjudicators' difficulty interpreting and complying with SSA's IFA guidelines for assessing the severity of children's mental impairments. Many adjudicators reported that they found the SSA guidelines unclear and not sufficiently objective. The IG stated that this group of children had less severe impairments than those children determined disabled based on the medical listings, making the assessment of their impairments' effect on their ability to function age-appropriately more difficult.

We observed firsthand the difficulty that adjudicators face in making the judgments required by the IFA process for children who have behavioral and learning disorders. In June 1994, we attended 1-day training sessions for DDS adjudicators and SSA's regional quality assurance staff from across the nation. The Office of Disability presented the findings from its 1994 study and discussed the policies and procedures that DDS and quality assurance staff had misapplied. In this training, Office of Disability staff presented case studies of children included in the 1994 study. After those in attendance reviewed the evidence for each child's case, they were asked to assess the degree to which the child's impairment limited his or her functioning. The attendees' opinions were tallied and in all cases they were split. During discussions of each case, attendees often voiced

[6]The study's sampling methodology does not permit the results to be projected to the universe of childhood cases or to any subset of the universe.

[7]See appendix III for details on the study and how we calculated these percentages.

differing views on why they believed, for example, that the child's limitation was less than moderate or moderate, or whether a moderate limitation was a good, solid moderate, or a weak moderate. In some cases, the opinion of the majority of attendees turned out to be different from the conclusion of the Office of Disability.

In addition to the national training in June 1994, SSA took other steps to correct implementation problems, including (1) issuing numerous instructional clarifications and reminders, (2) requiring DDSs to specially code certain types of mental impairments and all decisions based on three moderate limitations (to facilitate selecting samples of cases for further study), and (3) establishing more rigorous requirements for documenting awards that are based on three moderate limitations. The Office of Disability plans to do a follow-up study to assess the effectiveness of its remedial efforts.

Some experts believe that further steps could be taken to improve the IFA process. For example, experts we contacted commented on the need for more complete longitudinal evaluations by professionals. They pointed out that more complete examinations—sometimes including multiple visits and observations of both parents and children—would help to address concerns about the adequacy of information from schools and medical sources and provide higher assurance of good decisions. They stated that because professionals are trained to identify malingering in mental examinations, the expanded examinations might also help relieve concerns about coaching. They agreed that such examinations would raise the program's administrative costs considerably, but because a child can receive almost $5,500 a year in benefits (which can continue for life) they believed that the costs would be justified.

SSA's efforts and experts' suggestions are geared toward improving the process rather than addressing the underlying conceptual problems with the IFA. The difficulties so far in implementing the IFA bring into question whether these types of incremental actions can ensure consistently accurate decisions for children with mental impairments, especially behavioral and learning disorders.

Extent of Coaching Unknown

The rapid growth in awards to children with mental impairments—particularly behavioral and learning disorders—has contributed to the public perception that the SSI program for children is vulnerable to fraud and abuse. The media have reported allegations that

parents coach their children to fake mental impairments by misbehaving or performing poorly in school so that they can qualify for SSI benefits. Critics believe that cash payments and Medicaid act as incentives for some parents to coach and, therefore, they are concerned about the extent to which parents can manipulate the disability determination process. However, we believe that measuring the extent to which coaching may actually occur is extremely difficult.

Unless parents admit to it, coaching is almost impossible to substantiate. The nature of the parent-child relationship makes investigating coaching allegations difficult. Many communications between parent and child take place at home, out of the view of outside observers. In addition, the variability of children's behavior makes knowing whether a child's behavior is the result of coaching difficult. Behavior can vary naturally among children of the same age—or in the same child over time—as they go through stages in development or respond to changes in their home or school environment. If a child started misbehaving in school, investigators would need baseline evidence to establish that the child had not misbehaved extensively in the past. Finally, even if investigators could identify a sudden change in behavior, they would have to rule out other reasons for the change, such as changes in the child's household or neighborhood environment. In short, knowing whether the child is performing poorly or misbehaving because of coaching or for other reasons is difficult.

Because coaching is difficult to detect, the extent of coaching cannot be measured with much confidence. In recent studies, SSA and the HHS IG reviewed case files and identified scant evidence of coaching or malingering.[8] In the rare instances where they found evidence of possible coaching or malingering, most of the claimants had been denied benefits anyway. (App. III summarizes the results of the SSA and IG studies, including their scopes and methodologies.)

Actions to Reduce Program's Possible Vulnerability to Coaching

To protect program integrity, SSA has taken several steps to help provide assurance that the process can detect coaching or malingering and then make the appropriate eligibility determination. In June 1994, SSA began requiring DDSs to report to SSA's regional quality assurance units any case

[8]SSA considered possible coaching to be involved in any case in which the child reported or an information source suspected that the parent or other caregiver had told the child to misbehave or perform poorly. SSA also looked for evidence that the child had malingered; that is, deliberately provided wrong information or did not put forth his or her best effort during testing, regardless of whether coaching was suspected.

with an allegation or suspicion of coaching. Such cases include those in which teachers, physicians, or psychologists indicate that (1) the child's behavior was atypical of the child's customary school behavior, (2) the child was uncooperative during testing, or (3) the child's behavior deteriorated without explanation during the 6-month period preceding the application. According to SSA, its regional quality assurance units review all alleged cases of coaching. As of mid-January 1995, DDSs nationwide had reported alleged coaching in 674 childhood cases—or less than one-half of 1 percent of all childhood applications filed during the period—and fewer than 50 of these children had been awarded benefits.

Along with this new requirement, in August 1994, SSA required DDSs to send applicants' schools a set of questions specifically designed to elicit the teacher's views on whether the child had been coached. Additionally, each SSA regional office has established toll-free telephone numbers for the exclusive use of teachers and school officials to notify the regional quality assurance unit of coaching allegations. In mid-November 1994, SSA instructed DDSs to begin distributing these toll-free numbers to schools. Also, SSA has instructed its field offices and telephone service centers to report to the regional quality assurance units any allegations of coaching received from the general public. As of mid-January 1995, from all of these sources, SSA had received a total of 42 telephone calls with allegations of coaching involving 54 individuals. According to SSA, each allegation from teachers, school officials, or the general public is reviewed if the child was awarded benefits.

Conclusion

Childhood disability decisions based on the IFA process are among the toughest that DDSs must make. Particularly in assessing behavioral and learning disabilities, the level of judgment required makes the IFA process difficult to administer consistently. Moreover, the high level of subjectivity leaves the process susceptible to manipulation and the consequent appearance that children can fake mental impairments to qualify for benefits. Indeed, the rise in allegations of coaching may reflect public suspicion of a process that has allowed many children with less severe impairments to qualify for benefits. Although scant evidence exists to substantiate that coaching is a problem, coaching cannot be ruled out and its extent is virtually unmeasurable.

We believe that a more fundamental problem than coaching is determining which children are eligible for benefits using the new IFA process. Our analysis documents the many subjective judgments built into each step of

the IFA process to assess where a child's behavior falls along the continuum of age-appropriate functioning. Moreover, studies by SSA and the IG of children awarded benefits for behavioral and learning disorders illustrate the difficulties that SSA has experienced over the last 4 years in making definitive and consistent eligibility decisions for children with these disorders.

SSA's efforts have been aimed at process improvements rather than reexamining the conceptual basis for the IFA. Despite its efforts, too much adjudicator judgment remains. Although better evidence and more use of objective tests where possible would improve the process, the likelihood of significantly reducing judgment involved in deciding whether a child qualifies for benefits under the IFA is remote. We believe that more consistent decisions could be made if adjudicators based functional assessments of children on the functional criteria in SSA's medical listings. This change would reduce the growth in awards and target disability benefits toward children with more severe impairments.

Matter for Consideration by the Congress

Given widespread concern about growth in the SSI program for children and in light of our findings about the subjective nature of the IFA process, the Congress could take action to improve eligibility determinations for children with disabilities. One option the Congress could consider is to eliminate the IFA, which would require amending the statute. The Congress could then direct SSA to revise its medical listings, including the functional criteria, so that all children receive functional assessments based on these revised criteria.

We did not request official agency comments from SSA on a draft of this report. However, we discussed the draft with SSA program officials, who generally agreed that we had accurately characterized the IFA process and the results of studies. SSA officials had some technical comments, which we have incorporated where appropriate.

Please contact me on (202) 512-7215 if you have any questions about this report. Other major contributors are Cynthia Bascetta, Ira Spears, Ken Daniell, David Fiske, and Ellen Habenicht.

Jane L. Ross
Director, Income Security Issues

Contents

Abbreviations

DBRA	Disability Benefits Reform Act of 1984
DDS	disability determination service
HHS	Health and Human Services
IFA	individualized functional assessment
IG	Inspector General
IQ	intelligence quotient
RFC	residual functional capacity
SSA	Social Security Administration
SSI	Supplemental Security Income

Scope and Methodology

To develop the information in this report, we (1) reviewed SSA's childhood disability program policies, procedures, and records, and discussed the IFA process with SSA program officials on the national, regional, and local level; (2) interviewed officials in state DDSs; (3) reviewed SSA's report on its 1994 study of children with behavioral and learning disorders; and (4) attended a June 1994 SSA training course that was based on findings from its study. We also discussed eligibility issues with officials of HHS' IG, which recently issued two reports on the SSI childhood disability program.[9]

To develop SSI childhood program award rate data, we obtained SSA's computerized records on the results of initial determinations and reconsideration disability decisions made by DDSs for children under 18 years old from 1988 through September 1994.[10] These records exclude the results of disability decisions made by administrative law judges. From these records, we determined (1) the overall award rate for children, (2) the percentage of IFA awards that were based on mental impairments versus physical impairments, (3) the average monthly number of childhood applications, and (4) the average monthly number of awards that were based on IFAs versus medical listings. These data, as applicable, were determined for the following periods: (1) 2 years before the Supreme Court's Sullivan v. Zebley decision (Jan. 1, 1988, through Feb. 20, 1990); (2) 2 years after the IFA process was implemented (Feb. 11, 1991, through Dec. 31, 1992); (3) January-December 1993; and (4) January-September 1994. Because no IFA process existed before the Zebley decision, no pre-Zebley awards were decided based on IFAs.

We excluded children who had applied during 1988 through February 10, 1991, from the universe of children on whom decisions were made from February 11, 1991, through September 30, 1994. We did this to minimize the extent to which data in these comparison periods reflect the result of cases readjudicated as part of the settlement in the Zebley class action lawsuit. We were not able to identify or exclude Zebley classmembers for whom benefits had been denied or terminated from 1980 through 1987 from any of the comparison periods. According to SSA, Zebley

[9]See Concerns About the Participation of Children with Disabilities in the Supplemental Security Income Program (A-03-94-02602), Department of Health and Human Services, Office of Inspector General (Oct. 13, 1994); and Supplemental Security Income: Disability Determinations for Children with Mental Impairments (A-03-94-02603), Department of Health and Human Services, Office of Inspector General (Jan. 26, 1995).

[10]The childhood program statistics presented in this report were developed using the same basic methodology used in Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations (GAO/HEHS-94-225, Sept. 9, 1994). This report focused on the growth in awards after SSA changed the disability criteria for children.

classmembers are more likely to have physical impairments than the general population of new SSI child applicants.

We performed our work from May 1994 through February 1995 in accordance with generally accepted government auditing standards.

Efforts to Affect Implementation of the Zebley Decision

January 1991

One month before SSA issued regulations implementing the new IFA process, the Zebley plaintiff's counsel submitted interrogatories to SSA asking, among other things, why nine DDSs with the lowest award rates for children had such low award rates.[11]

SSA regional officials were tasked with answering some of the counsel's interrogatories and, in some instances, the officials informed the states that they were the subject of the counsel's inquiry. Also, from time to time thereafter, SSA officials shared state-by-state award rate data with state DDSs. Some SSA regional officials stated that they believed some DDSs could have felt pressured to increase their award rates.

February 1991

In the month that SSA issued regulations implementing the new IFA process, a federal district court ordered SSA to perform special quality assurance reviews of disability applications denied under the new regulations. The court order required SSA to do quality assurance reviews of denials made by 10 state DDSs that, according to SSA, Zebley plaintiff's counsel had identified as denial prone due to their low award rates.[12] Based on its own studies, SSA had argued before the court that low award rates were not reliable indicators of whether special corrective action was needed to avoid incorrect denials, but the court required SSA to implement the special quality assurance reviews for these 10 states.

Under the court order, during the first month after the new regulations were in effect, SSA had to review the lesser of 100 or all denials for each denial-prone state. SSA reviewed only 25 denials for other states. A subsequent March 1991 court order required SSA, after the first month, to review at least 1,000 denials per month nationwide. SSA's sample of 1,000 denials included 15 percent of the denials from each of the 10 denial-prone states.

By memorandum in February 1991, SSA informed all DDSs of the special quality assurance requirements and identified the 10 states that had been classified as denial prone. The court order required that SSA send the results of the quality assurance reviews monthly to the Zebley plaintiff's counsel.

[11]The nine states were Alabama, Arkansas, Colorado, Louisiana, Mississippi, Nebraska, South Carolina, West Virginia, and Wisconsin.

[12]The 10 states were Alabama, Arkansas, Colorado, Louisiana, Mississippi, Nebraska, New Mexico, South Carolina, West Virginia, and Wisconsin.

June 1991	The Zebley plaintiff's counsel wrote to the SSA Commissioner citing a "disturbing pattern" of low allowance rates in eight states and asked the Commissioner to take remedial steps.[13]
December 1992	In a newsletter to legal aid societies, the Zebley counsel listed 13 DDSs whose cumulative allowance rates were at 50 percent or below.[14] The counsel encouraged legal aid society representatives in those states to contact the DDS directors and "confront them with their sub-par performance."

[13]The eight states were Connecticut, Kentucky, Louisiana, Nebraska, New Mexico, Texas, West Virginia, and Wisconsin.

[14]The 13 states were Arkansas, Connecticut, Louisiana, Maine, Mississippi, Missouri, Montana, Nebraska, New Mexico, South Carolina, Tennessee, Texas, and West Virginia.

Studies Done by SSA and the Inspector General

1994 Study by SSA's Office of Disability

SSA considers behavioral and learning disorders to be the most susceptible to coaching and malingering. In 1994, SSA's Office of Disability in Baltimore reviewed a national sample of 617 school-age children who had applied due to behavioral and learning disorders. Because the sample was small, the findings of the study cannot be projected to the universe of childhood disability claims or to the subset of specific impairments studied.

Scope and Methodology

The 617 children were selected from those who had applied due to such impairments as attention deficit disorder, attention deficit hyperactivity disorder, personality disorder, conduct disorder, learning disorder, oppositional defiant disorder, anxiety disorder, developmental delay, behavior disorder, speech and language disorders, borderline intellectual functioning, and adjustment disorder. According to SSA, these types of disorders constitute about 20 percent of all childhood disability applications. SSA excluded cases involving extremely severe mental disorders, such as psychotic disorders and mental retardation.

SSA selected the 617 cases from final DDS decisions that SSA's regional quality assurance staff had already reviewed for accuracy. The 617 cases in the sample consisted of 325 awards and 292 denials that DDSs adjudicated during October 1992 through July 1993. SSA reviewed case file documentation for the 617 cases.

Coaching

In its review of case file documentation, SSA considered coaching to be involved in any claim in which the child reported or an information source suspected that the parent or other caregiver had told the child to act or respond in a manner that would make the child appear more functionally limited than he or she actually was. In addition, SSA looked for evidence indicating that the child had malingered; that is, deliberately provided wrong information or did not put forth his or her best effort during testing.

SSA found only 13 cases that showed any evidence of possible coaching or malingering, and only 3 of these cases were awards. In all cases, the evidence indicating possible coaching was provided by medical professionals or psychologists who performed consultative examinations for SSA. None of the evidence indicating possible coaching or malingering was provided by schools. The three questioned awards involved children who may have malingered during IQ testing. In these cases, however, the awards were based on factors other than the results of the testing. For example, one child with an oppositional defiant disorder appeared to

malinger during IQ testing administered by a consultative examiner, but the award was based on other problems stemming from the disorder, not the results of the testing.

Incorrect Awards

Of the 325 awards reviewed by SSA, SSA found that 8.6 percent (28) should have been denials and another 27.7 percent (90) should not have been made without obtaining more supporting documentation. We asked SSA, based on experience in its quality assurance program, to estimate how many of the 90 cases with insufficient documentation would have been denials if all documentation had been obtained, and SSA estimated that 13 (or 4 percent of the 325 awards) would have been denials. Thus, we concluded that a total of 41 awards (12.6 percent of the 325 awards) should have been denials. By contrast, of 292 denials reviewed in the study, SSA found that only 1.4 percent (4) should have been awards, and another 1.4 percent (4) should not have been made without obtaining more supporting documentation.

Combining all decisional and documentational errors for the 617 denials and awards in SSA's study, the overall error rate for this group of cases was 20.4 percent.[15] This is about twice the maximum acceptable error rate of 9.4 percent that SSA allows for decisional and documentational errors combined for all initial disability decisions made by an individual DDS.

According to SSA's Office of Disability, a primary reason that DDSs made awards that should have been denials was that DDSs had frequently overrated—but rarely underrated—the severity of children's functional limitations. Such overrating occurred primarily because DDSs had (1) compared the child with the perfect child rather than the average child, (2) based the limitation on a single incident rather than behavior over time, (3) not considered the child's ability to function while on an effective medication regimen, and (4) based the limitation on the child's life circumstances rather than the effects of a medically determinable impairment.

DDSs also had mechanically applied SSA's guidelines on how to make awards using the results of the IFA process. SSA's guidelines instruct DDSs that they generally should award benefits to children who have moderate limitations in any three of the areas of ability assessed in the IFA process. SSA found, however, that DDSs had used this instruction as a rule rather

[15]The overall error rate for the 617 cases was computed as follows: (28 award decisional errors + 90 award documentational errors + 4 denial decisional errors + 4 denial documentational errors)/ 617 = 0.204.

than a guideline. DDSs had automatically made awards to any child with three moderate limitations, regardless of how strong or weak the moderate limitations were. SSA stated that its guideline assumed "three good, solid moderates." SSA found that, when DDSs had identified two moderate limitations, they sometimes made special attempts to find a third moderate limitation even though the evidence did not support it.

DDSs had also "double-weighed" the effects of impairments in more than one of the areas of ability assessed in the IFA process, making the impairment seem more severe and pervasive than it actually was. For example, in some cases children displayed a lack of self-control by exhibiting more than one inappropriate behavior, such as fighting, aggressive behavior, disrespectful behavior, lying, oppositional behavior, and stealing. Although all these behaviors should have been rated only in the personal/behavioral area, DDSs had rated some behaviors in the personal/behavioral area and others in the social abilities area, giving the child moderate limitations in two areas rather than only one. This meant that the child needed only one more moderate limitation to have the three moderate limitations needed for approval.

SSA also found that DDSs had sometimes based decisions on old evidence when current evidence indicated children had improved and that DDSs had sometimes assessed limitations that could not be attributed to medical impairments.

Inspector General Study

As the IG reported in January 1995, IG staff reviewed the case files for a sample of 553 children whose applications were adjudicated by DDSs in 1992. Of the 553 children, 298 had been awarded benefits by 10 DDSs—Connecticut, Illinois, Kentucky, New York, North Carolina, North Dakota, Pennsylvania, South Dakota, Vermont, and Wisconsin. The remainder of the 553 cases consisted of a nationwide sample of 255 denials. Of the 298 awards, 129 (43 percent) had been decided based on an IFA, and 195 of the 255 denials (76 percent) had been decided based on an IFA. The IG targeted its study at cases involving mental retardation, attention deficit hyperactivity disorder, and other learning and behavioral disorders. Based on its review of these cases, IG officials told us that they had found no evidence of coaching.

As the IG reported, when the IG staff had questions about the accuracy of a DDS disability determination or about the sufficiency of the evidence supporting a determination, the IG provided the case file to SSA's Office of

Disability in Baltimore—the same staff responsible for conducting SSA's study of 617 childhood disability claims. The Office of Disability reviewed the accuracy of each of the questioned cases. The IG staff also visited the 10 DDSs to obtain their opinions on the adequacy of the SSA guidelines used to make disability determinations.

Of the 129 awards reviewed that were based on IFAs, the IG reported that 17 (13 percent) should have been denials and another 38 (29 percent) were based on insufficient evidence. The IG attributed this problem to DDSs having difficulty in interpreting and complying with SSA guidelines for obtaining and evaluating evidence concerning the severity of the mental impairments of children on whom IFAs are conducted. The IG stated that these children have less severe impairments than those children determined to be disabled based on the impairment listing, making the assessment of the effects of their impairments on their ability to function age-appropriately more difficult. In discussions with employees of the 10 DDSs, the IG reported that many expressed concern that the SSA guidelines for determining disability for children with mental impairments were not sufficiently clear or objective.

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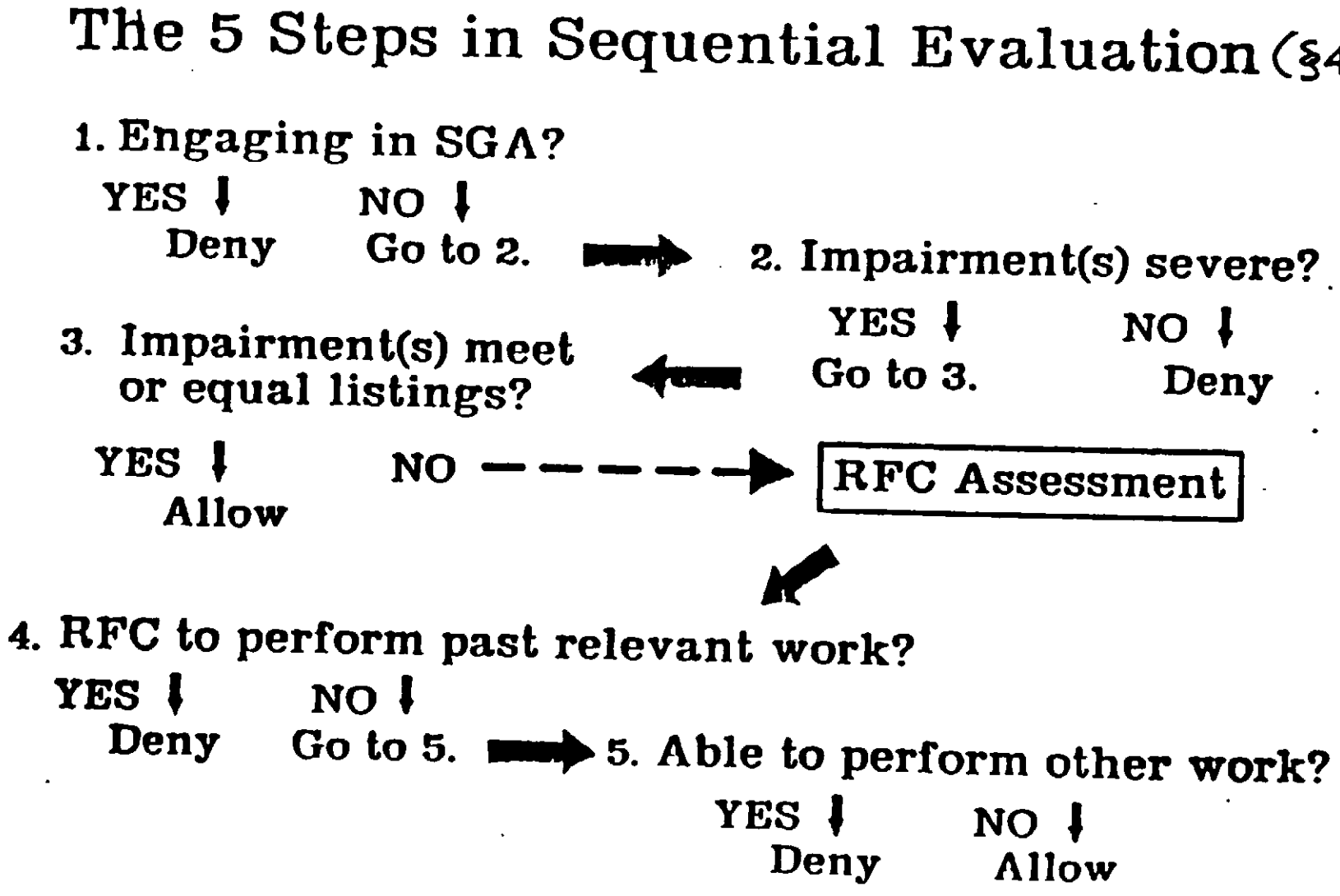
Basic Definition of Disability (§1614(a)(3)(A)+(B))

The inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

To meet this definition an individual's impairment or combination of impairments must be so severe that he or she is not only unable to do past work, but cannot, considering age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy.

The 5 Steps in Sequential Evaluation (§416.920)



Definition of Disability (§1614(a)(3)(A)) for Children

The Act provides that a child under age 18 will be considered disabled for purposes of eligibility for SSI: "if he suffers from any medically determinable physical or mental impairment of comparable severity" to that which would make an adult disabled.

Initial Sequential Evaluation (§416.924) Process for Children

1. Substantial gainful activity?

YES ↓ Deny

NO ↓ Go to 2. → 2. Severe impairment or combination of impairments?

YES ↓ Go to 3.

NO ↓ Deny

3. Meets listing?

YES ↓ Allow

NO ↓ Equals (medical) listing?

YES ↓ Allow

NO ↓ Equals (functional) listing?

YES ↓ Allow

NO ↓ Proceed to IFA

IFA

4. Comparable severity?

YES ↓ Allow

NO ↓ Deny

Age Categories (§416.924a(b))

Newborn and Young Infants	0 - 1
Older Infants and Toddlers	1 - 3
Children (3 - 18)	
• Preschool	3 - 6
• School-age	6 - 12
• Young adolescents	12 - 16
• Older adolescents	16 - 18

(6)

DOMAINS AND BEHAVIORS BY AGE GROUP (§416.924d(c))

Although some domains are common to all ages, the age-appropriate functions assessed in those domains are different for each age group (e.g., social functioning in a preschool-age child is very different from social functioning in an older adolescent).

All Ages (0-18):

- Cognition
- Communication
- Motor Abilities
- Social Abilities

Newborns and Young Infants (0-1):

- Responsiveness to Stimuli

Older Infants and Toddlers; Children (1-18):

- Personal/Behavioral Patterns

Children (3-18):

- Concentration, Persistence, and Pace in Task Completion

Allegations of Coaching

- Of great concern to SSA are the allegations and anecdotal information we have received from members of the educational community and others that children with "mild" impairments were being coached by their parents to act abnormally to qualify for SSI payments.

- As a result of these allegations, SSA conducted a study in 1993 of over 600 childhood disability cases (617 to be exact) involving children with conduct and learning disorders.

- The study focused on claims involving conduct and learning disorders because these impairments seem the most likely to be susceptible to coaching. Also, they are the ones most often cited by those who allege that children with "mild" impairments are being improperly granted disability.

- First of all, SSA found no evidence of widespread coaching. Even when coaching or malingering was an issue (13 cases), the cases were generally denied (10 cases) or the allowances were based on factors not affected by the suspected malingering.

- We also learned that the disability rules and guidelines were, generally, being applied correctly and that proper decisions were being reached. However, a number of issues were identified which necessitated clarification. To address these issues, we issued a series of 13 technical reminders (Disability Digest Articles) to all adjudicators as the issues arose. In addition, national training was conducted in June 1994 on the results of the study and the issues that were identified.

- However, because SSA continues to receive these allegations, and because of congressional and press interest, and because there are allegations that coaching/malingering situations are not being reported, we are taking the following steps:

  - We provided the State disability determination services with instructions for identifying, developing and evaluating cases in which coaching may be a factor. Such cases are referred for a special review.

  - 800-numbers were established to permit teachers and other school personnel to make confidential reports to SSA on an individual basis.

  - We prepared a communique to all SSA employees that informs them of their role in detecting when coaching has occurred. The communique informs employees of the 800-numbers that are available for use by school personnel and the procedures to follow when reports or other indications of coaching are received.

- Two open letters - one to parents and another to teachers - have been developed. These letters inform the readers about the SSI program and their role in providing the information used in deciding a child's claim. Both letters refer to the allegations of coaching.

  -- Parents will be told that children are expected to put forth their best effort on any testing and that, in this regard, we can deny a claim for failure to cooperate and that any parent who coaches a child to do otherwise is breaking the law.

  -- The letter to teachers informs them of the 800-numbers that can be used to confidentially report incidents of coaching.

- A brochure for school professionals that describes SSI childhood disability benefits has been published which reminds teachers to notify SSA if they have any knowledge that the child has been coached to function poorly. A similar brochure for health professionals asks that lack of effort on testing be reported.

- Operating instructions have been issued requiring that requests for information from teachers and other school personnel specifically ask whether the source has any knowledge that a child has been coached.

- Additional instructional transmittals added new coding provisions which will help better identify specific categories of childhood cases (learning disorders, conduct disorders, etc.) for further study.

- A followup study is planned to review the same kinds of cases on which the 600-Case study focused in order to test the effects of our remedial actions (technical clarifications, national training) on adjudicative accuracy nationwide.

- Unconnected with allegations of coaching or the 600-case study, we are about to begin a study of childhood claims involving physical impairments. The study will focus on Congressional and other groups' concerns that children with physical impairments are not treated as fairly under our evaluation process as are children with mental impairments.

Briefing on Childhood Disability Issues

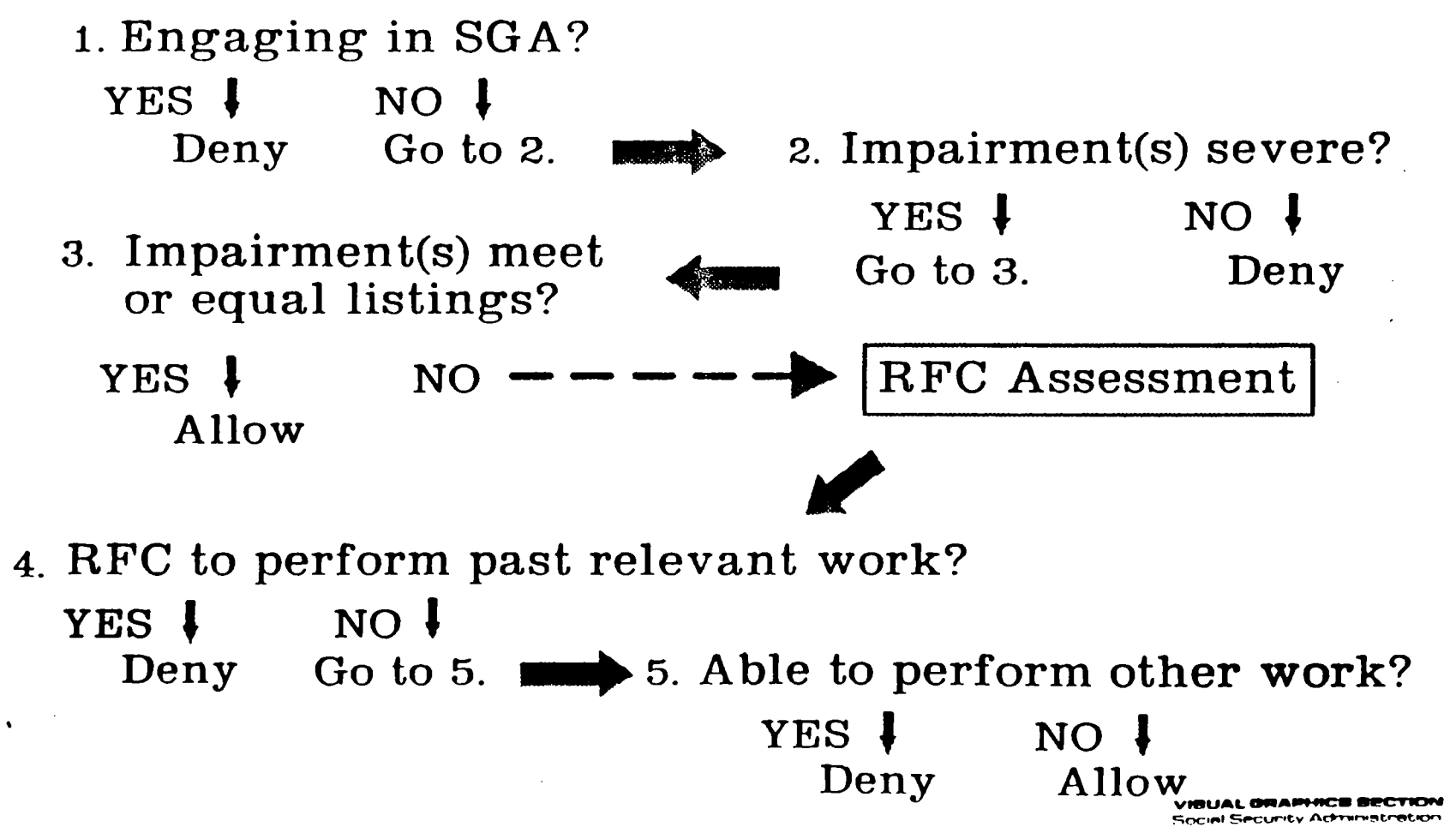
May 18, 1994

Definition of Disability for Children

The Act provides that a child under age 18 will be considered disabled for purposes of eligibility for SSI: "if he suffers from any medically determinable physical or mental impairment of comparable severity" to that which would make an adult disabled.

VISUAL GRAPHICS SECTION
Social Security Administration

The 5 Steps in Sequential Evaluation



Sequential Evaluation Process

For Adults

The 5-step sequential evaluation process used to determine if an ADULT is disabled considers in turn:

1. Whether the adult is doing substantial gainful activity;

2. Whether, in the absence of substantial gainful activity, his or her medically determinable impairment is severe;

3. Whether, if the impairment(s) is severe, it meets or equals in severity an impairment in the Listing of Impairments;

4. Whether, in the presence of a severe impairment, the individual retains the capacity to do his or her past relevant work, considering his residual functional capacity;

5. Whether, if past relevant work is precluded, the individual retains the capacity to do any other work, considering his residual functional capacity and the vocational factors of age, education and work experience.

To meet this definition an individual's impairment or combination of impairments must be so severe that he or she is not only unable to do past work, but cannot, considering age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy.

VISUAL GRAPHICS SECTION
Social Security Administration

Basic Definition of Disability

The inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

VISUAL GRAPHICS SECTION
Social Security Administration

16-18

Older Adolescents (Age 16 to Attainment of Age 18)

	Functional Domains/Behaviors	Work-related Mental/Physical Functions
Cognitive	Ability to progress in applying the skills involved in reading, writing, and mathematics, conceptual growth, reasoning, and problem-solving abilities	Mental Functions: Capacity to do the following on a sustained basis (i.e., 8 hours/day, 5 days/week) o To understand, carry out, and remember simple instructions o To use judgment o To make simple decisions o To take necessary safety precautions o To respond appropriately to supervision and peers (by being able to accept instructions and criticism, by not requiring special supervision, and by not being unduly distracted by your peers or unduly distracting to them in a school or work setting) o To deal with changes in your routine school or work setting
Communicative (Includes speech and language)	Ability to communicate pragmatically (i.e., to meet your needs) and conversationally (i.e., to exchange information or ideas in your school classes, with peers or family)	
Motor	Ability to engage in the physical activities involved in physical education, sports, social events, and self-care appropriate to your age	Physical Functions: Capacity to perform on a sustained basis (i.e., 8 hours/day, 5 days/week) o The types and ranges of exertional and non-exertional activities that we evaluate for adults o E.g., sitting, standing, walking, lifting, carrying, pushing, pulling, reaching, handling, manipulating, seeing, hearing, and speaking.
Social	Ability to develop friendships, to relate to peer groups, and to reconcile conflicts between yourself and peers or family members	
Personal/Behavioral	Ability to help yourself in taking care of your personal needs and safety, to respond appropriately to authority and school rules, and to learn new skills	
Concentration, Persistence, and Pace	Ability to engage in an activity, such as studying or practicing a sport, and to sustain the activity for a period of time and at a pace appropriate to your age	

DOMAINS/BEHAVIORS OF CHILD DEVELOPMENT/FUNCTIONING (continued)

	Birth to Attainment of Age 1	Age 1 to Attainment of Age 3	Age 3 to Attainment of Age 6	Age 6 to Attainment of Age 12	Age 12 to Attainment of Age 16
Responsiveness to stimuli Ability to:	Respond appropriately to visual, auditory, or tactile stimulation				
Personal/Behavioral Ability to:		Help yourself or to cooperate with others in taking care of your personal needs, in adapting to your environment, and in learning new skills	Help yourself or to cooperate with others in taking care of your personal needs, in adapting to your environment, in learning new skills	Help yourself or to cooperate with others in taking care of your personal needs and safety; to understand authority relationships and school rules; to develop a sense of responsibility for yourself and respect for others; & to learn new skills	Ability to help yourself in taking care of your personal needs and safety, to respond appropriately to authority and school rules, and to learn new skills
Concentration, Persistence, and Pace Ability to:			Engage in an activity, such as dressing or playing, and to sustain the activity for a period of time and at a pace appropriate to your age	Engage in an activity, such as playing or reading, and to sustain the activity for a period of time and at a pace appropriate to your age	Engage in an activity, such as studying or practicing a sport, and to sustain the activity for a period of time and at a pace appropriate to your age

1st 2 pgs - birth to age 16

DOMAINS/BEHAVIORS OF CHILD DEVELOPMENT/FUNCTIONING

	Birth to Attainment of Age 1	Age 1 to Attainment of Age 3	Age 3 to Attainment of Age 6	Age 6 to Attainment of Age 12	Age 12 to Attainment of Age 16
Cognitive Ability to:	Begin to organize and regulate how you feel and ways you react to your environment	Understand by responding to increasingly complex requests, instructions or ques., by referring to yourself & things around you by pointing and eventually by naming, & by copying things or imitating actions shown to you by others	Understand, reason, and solve problems, and to use acquired knowledge and concepts	Progress in learning the skills involved in reading, writing, and mathematics	Progress in applying the skills involved in reading, writing, and mathematics, conceptual growth, reasoning, and problem-solving abilities
Communication (includes speech and language) Ability to:	Communicate with intention through visual, motor and vocal exchanges	Communicate by understanding, imitating, and using an increasing number of intelligible words, eventually forming two-to-four word sentences	Communicate by telling, requesting, predicting, and relating information, by following and giving directions, by describing actions and functions, and by expressing your needs, feelings, and preferences in an increasingly intelligible manner	Communicate pragmatically (i.e., to meet your needs) or conversationally (i.e., to exchange information or ideas in your classroom with peers or family)	Communicate pragmatically (i.e., to meet your needs) and conversationally (i.e., to exchange information or ideas in your school classes, with peers or family)
Motor (includes gross and fine motor skills) Ability to:	Explore your environment by moving your body, & manipulate your environment by using your hands	Move in your environment using your body with steadily increasing dexterity, independent of support by others, and your ability to use your hands to do or get something that you want or need	Move and use your arms and legs in increasingly more intricate and coordinated activity, or your ability to use your hands with increasing coordination to manipulate small objects during play	Engage in the physical activities involved in play, physical education, sports, and self-care appropriate to your age	Engage in the physical activities involved in physical education, sports, social events, and self-care appropriate to your age
Social Ability to:	Form and maintain relationships with your primary caregivers	Express normal dependence upon, and emotional bonding with, your primary caregivers as well as increasing independence from them	Respond to your social environment through appropriate self-control and increasingly complex interpersonal behaviors, such as sharing, cooperating, helping and relating to a group	Play alone, or with another child, or in a group; to develop friendships, and to relate to your siblings and parents or caregivers	Develop friendships, to relate to peer groups, and to reconcile conflicts between yourself and peers or family members

Generic Definitions of Domains/Behaviors
Childhood Disability
Regulation Section 416.924c

Cognitive: Refers to the ability to learn through perception, reasoning, or intuition, and to retain, use, and manifest acquired knowledge in action or communication.

Communicative: Refers to the ability to receive, comprehend, and express messages in order to meet one's needs or to obtain or convey information; with respect to speech, refers to audibility, intelligibility, and efficiency of speech production.

Motor: Refers to the ability to use one's body and extremities in gross and fine motions in order to relate to the physical environment and serve one's own or others' physical needs or purposes.

Social: Refers to the ability to form, develop, and sustain relationships with other people on a personal and social basis, to respond appropriately within one's own social role or to the social roles of others, and to conduct oneself according to the manners and mores of one's social group.

Responsiveness to Stimuli: Refers to physical and emotional behaviors in reaction to visual, auditory, or tactile stimulation, manifesting an infant's sensitivity to stimuli within a range of "normal," "hypersensitive" (excessive response, as in over-excitability or fearfulness), or "hyposensitive" (minimal or absent response, as in withdrawal or apathy).

Personal/Behavioral: Refers to activities and behaviors entailed in self-help (e.g., feeding, dressing, maintaining personal hygiene), self-regulation (e.g., maintaining proper nutrition, sleep, health habits, regulating mood), self-improvement (e.g., increasing self-help behavior through learning of new skills), self-protection (e.g., taking necessary safety precautions), and self-control (e.g., adapting to changes in environment or activity, controlling impulsive or aggressive behaviors that could otherwise result in harm to oneself, others, animals, or property).

Concentration, Persistence, and Pace: Refers to the ability to sustain focus on, and attention to, an activity or task, and to perform the activity or complete the task at a reasonable (or age-appropriate) rate.

Activities of Daily Living (ADLs)

These are activities that involve continuity of purpose and action, and goal or task orientation; i.e., they are the practical implementation of skills mastered at earlier ages.

ADLs are important indicators of functional limitations in children age 6 to attainment of age 18.

ADLs may also be used to describe the functioning of younger children, e.g., preschool age children.

Domains of Development or Functioning

Domains are broad areas of activity (development or functioning) that can be identified in infancy and traced throughout children's growth and maturation into adulthood, i.e., motor, cognitive, communicative, social, and personal/behavioral.

The term, "developmental domains," is generally used to discuss functioning in younger children (birth to attainment of age 6).

The term, "functional domains," is generally used to discuss functioning in older children and young adolescents (age 6 to attainment of age 16).

Behaviors

This term refers specifically to:

- an infant's physical and emotional responses to stimuli; and
- a child's capacity for concentration, persistence, and pace in completion of tasks after attainment of age 3.

Terms To Know for Adjudication of Child Claims

Individualized Functional Assessment (IFA)

An IFA is an assessment of the impact of a child's impairment(s) on his or her physical and mental functioning, including, when applicable, the child's ability to function on a sustained basis appropriate to his or her age.

Age-Appropriate Activities

This is a comprehensive term that refers to what a child is expected to be able to do at his or her age. It may refer to:

- any discrete behavior of an infant or young child (e.g., the age at which an infant can turn its head from side-to-side, or an older child is able to utter two-word sentences); or
- any global behavior of an older child or adolescent (e.g., reading).

Information about a child's own activities creates a profile of the child's level of functioning, which makes possible a comparison between the profile and the activities that are age-appropriate for that child.

Age-appropriate activities may be described in terms of achievement of developmental milestones, activities of daily living, or other similar terms.

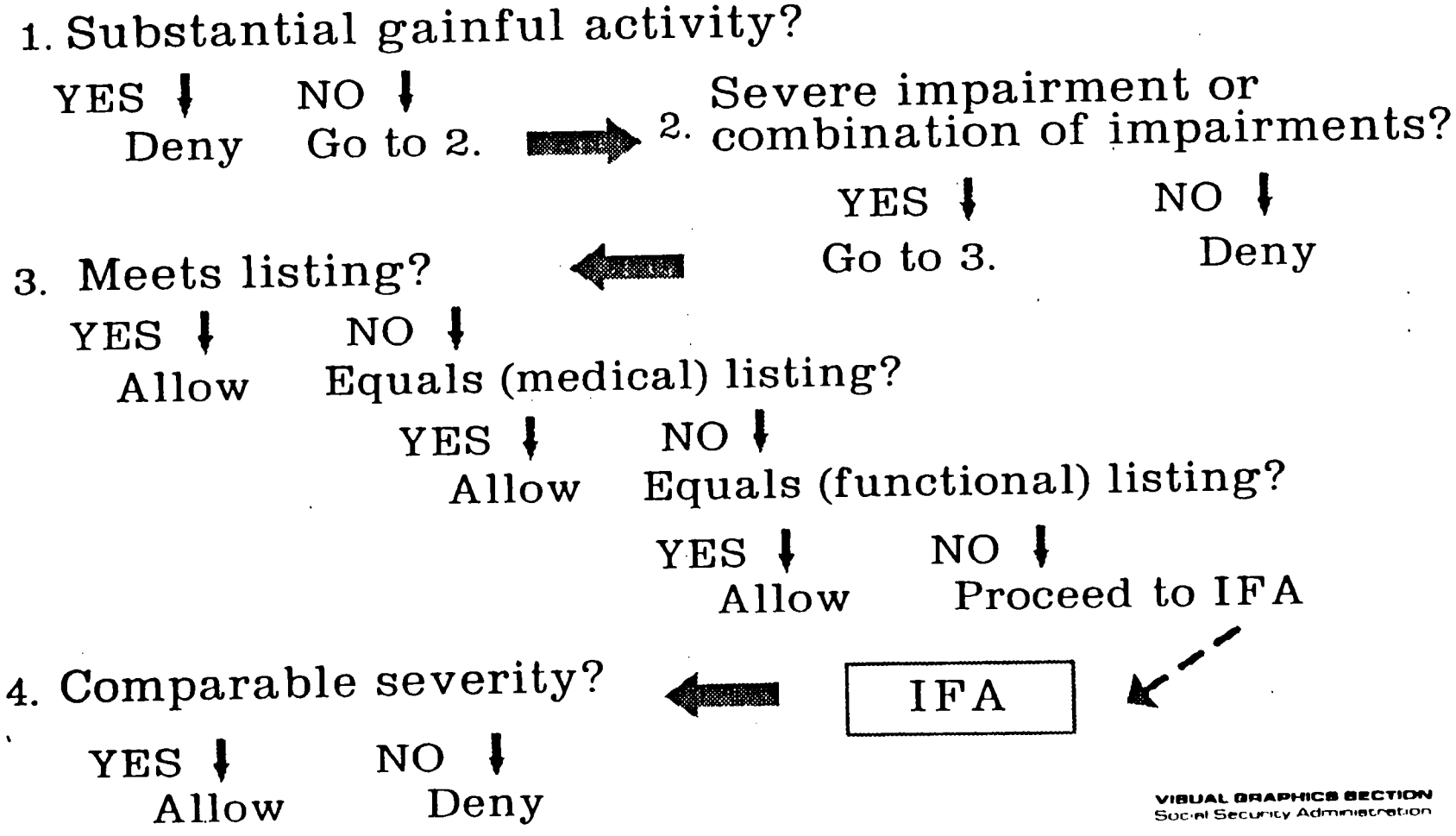
Developmental Milestones

These are a child's expected principal developmental achievements at particular points in time.

Failures to achieve developmental milestones are important indicators of impaired functioning from birth to attainment of age 6.

Developmental milestones may also be used to evaluate functioning of school-age children.

Initial Sequential Evaluation Process for Children



VISUAL GRAPHICS SECTION
Social Security Administration

SEQUENTIAL EVALUATION PROCESS FOR CHILDREN

The new sequential evaluation process for CHILDREN consists of the following steps:

1) Is the child engaging in substantial gainful activity?

2) Does the child have a "severe" impairment or combination of impairments?

3) Does the child have a medically determinable impairment(s) that meets or is equivalent in severity to any impairment in the Listing of Impairments, including an impairment(s) that is functionally equivalent to a listing?

4) Does the child have an impairment(s) that so limits his or her physical or mental abilities to function independently, appropriately, and effectively in an age-appropriate manner that the limitations are comparable in severity to those which would disable an adult?

DEFINITION OF DISABILITY FOR CHILDREN

The Act (Section 1614 (a)(3)(A) provides that a child under age 18 will be considered disabled for purposes of eligibility for SSI, "if he suffers from any medically determinable physical or mental impairment of comparable severity" to that which would make an adult disabled.

"Comparable severity", as defined in the regulations, means that a child's physical or mental impairment(s) so limits his or her ability to function independently, appropriately, and effectively in an age-appropriate manner that the impairment(s) and limitations resulting from it are comparable to those which would disable an adult. Specifically, the impairment(s) must substantially reduce (or if the child is under age 1, be reasonably expected to substantially reduce) the child's ability to:

- grow, develop, or mature physically, mentally, or emotionally and, thus, to attain developmental milestones at an age-appropriate rate; or
- grow, develop, or mature physically, mentally, or emotionally and, thus, to engage in age-appropriate activities of daily living in self-care; play, recreation, and sports; school and academics; vocational settings; peer and family relationships; or
- acquire the skills needed to assume roles reasonably expected of adults.

DEVELOPMENT ACTIVITIES

As a result of the Supreme Court's decision, SSA developed and published interim final rules for evaluating disability in children. These rules were formulated with assistance from:

-- Experts representing a wide range of specialties in the assessment of child development and childhood disability, including:

- general pediatrics
- developmental genetics
- developmental pediatrics
- infant development
- family and support systems
- behavioral pediatrics
- pediatric psychiatry
- pediatric neurology
- child psychology
- pediatric special education
- home and community care
- physical and occupational deficits
- early childhood education
- pediatric rehabilitation
- learning disorders
- chronic illness and somatics
- communication disorders

-- Representatives from more than two dozen advocacy groups interested in childhood disability

-- We were assisted as we drafted our new policies by representatives from four advocacy groups:

- Community Legal Services, Inc. (the Zebley plaintiffs' attorney)
- Association for Retarded Citizens
- Mental Health Law Project
- National Senior Citizens Law Center

-- Within the SSA community, we solicited opinions and advice from our own regional office staffs and the State agencies, the agencies in the individual States that make the disability determinations under the Act.

HISTORY

DATE	EVENT
01/74	SSA had responsibility for SSI claims since 01/74. Adjudication of childhood cases was based on reference to the Listing of Impairments. Special listings were published for use with individuals under age 18 with focus on childhood impairments or special manifestations found in children.
02/20/90	Zebley suit alleging that SSA regulations were too restrictive given the "comparable severity" standard of the statute was appealed to the Supreme Court. On 2/20/90 the Court found SSA's listings-only approach was too restrictive and that every claimant should be given an individualized functional assessment.
05/90	Court-approved interim standard was implemented while new regulations were being developed.
02/11/91	SSA consulted with childhood experts and developed regulations which were cleared through class counsel. Interim final regulations were published with a comment period ending 4/12/91, which was later extended to 7/8/91.
03/14/91	Settlement agreement established the eligible class from 1/1/80 to 2/11/91.
04/91	Cases began to be reviewed under the interim final rules.
07/91	Notices released to 459,000 potential class members.
07/91	Major public information and outreach campaign mounted to locate class members.
07/91	Interim final comment period ends 7/8/91. Over 400 comments received from 42 commenters.
08/91	Began readjudication of retroactive cases.
08/91 - 07/92	Final regulations developed based on public comments and cleared through SSA and DHHS.
08/92	Met with OMB with proposed final regulations. They requested some (unknown) additional changes.

09/15/92	OMB approved sending final regulations to CLS, but did not give final approval to the regulations.
12/92	Revisions made based on CLS comments, but regulations were put on hold pending appointment of new Secretary.
3/23/93	Regulations signed by Mr. Enoff.
5/21/93	Regulations signed by Secretary; package sent to OMB.
7/13/93	Of the 318,000 respondents to the class member notices released in 7/91, 36,000 are still awaiting a decision on their claim. Decisions are expected to be issued by 9/30/93.
9/9/93	Final regulations published in the Federal Register.

GENESIS OF THE STUDY

SSA has received allegations from members of the educational community and others that:

- Some parents were "coaching" their children to "act up" in school, do poorly on tests, and fail subjects so that these children would qualify for SSI;

- Children were "malingering" at CEs in order to obtain benefits; and

- Benefits were erroneously being paid to children with "mild" impairments; i.e., learning disorders, behavioral disorders, and Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD).

To determine the validity of these allegations, SSA conducted a 600-case postadjudicative study of both allowances and denials in which the child's behavior or learning difficulties could have had an impact on the decision.

STUDY GOALS AND RESULTS

The goals of the study were to determine:

- What types of evidence were being obtained and whether that evidence, both medical and functional, is sufficient to establish both the existence (or nonexistence) and the severity of the alleged impairment(s).

- The behavioral characteristics exhibited by the children.

- If there is widespread "coaching" or "malingering."

- If children with "mild" impairments are being found disabled.

- If findings of disability and non-disability are being made in accordance with the rules and guidelines contained in the title XVI childhood disability regulations, the Program Operations Manual System (POMS), and other policy issuances.

The study determined that:

- There was a wide range of evidence in file that supported the decisions reached. Where evidentiary problems were cited, it was not because there was an absence of evidence, rather because the evidence in file was not sufficiently detailed or timely.

  In general, denials in this group of targeted impairments were better documented than allowances. Additional information should have been obtained in 27.7% of the allowances, but only 1.4% of the denials. Most of these cases required clarification of general descriptions of the child's behavior. Although all cases in which the child's behavior was germane to the decision contained some description, they did not always provide sufficient information to determine whether, and the extent to which, a child's behavior was outside the range of "normal."

- Children in this group exhibited a wide array of inappropriate behaviors.

- There was no evidence of widespread "coaching" or "malingering."

- In general the rules and guidelines were being applied correctly and correct decisions were reached. However, a small number of children with "mild" impairments were found disabled due to various kinds of misapplications or misunderstandings about the rules and guidelines.

No. 661

ISSUE BRIEF

NATIONAL HEALTH POLICY FORUM

SSI for Children: Looking at Enrollment Concerns and Program Intent

Monday, January 23, 1995
1:00 to 4:30 pm - Discussion
Quality Hotel Capitol Hill
415 New Jersey Avenue, NW
Federal Ballroom

less vouchers
more pennies program
block grant

Fed list of acceptances

Chassen
- elim IFA
- restrict mental imp.
McCreary/Klocka
Fed optional benes?
$3k cert. items

A workshop featuring

Barry Eigen
Deputy Director
Division of Medical and Vocational Policy
Office of Disability
Social Security Administration

Linda Dorn
Deputy Director
Michigan Disability Determination Service

Sue Smith
Executive Director
Georgia Parent Support Network

Lawrence Thompson
Principal Deputy Director
Social Security Administration

James Perrin, M.D.
Associate Professor of Pediatrics
Harvard Medical School

Registration: Please call **Dagny Canard at 202/872-1392** as soon as possible.

The George Washington University
WASHINGTON DC

SSI for Children: Looking at Enrollment Concerns and Program Intent

The Supplemental Security Income (SSI) program for children is facing increasing scrutiny from Congress. Over the past four years, federally mandated program changes have led to rapid increases in both enrollment and costs. As the program has grown, it has been dogged by allegations that undeserving children are feigning behavior disorders to get onto the rolls and that some parents are not using the cash grant to help their children.

Once a small, highly restrictive, unpublicized program, SSI for children has recently undergone many changes. Since 1990, following a Supreme Court decision that found the rules unfairly denying enrollment to many disabled children, the eligibility criteria have been revamped. The Social Security Administration (SSA) has also expanded the number of qualifying mental impairments, including for the first time separate categories for Attention Deficit Hyperactivity Disorder (ADHD) and several other disorders characterized as behavior problems. Finally, Congress has required the agency to more aggressively publicize SSI to poor families with disabled children.

Is the SSI program for children now out of control? While more children are certainly applying and attempts at "gaming" may be on the increase, government studies have found that few children who do not meet the definition of disability are getting on the rolls. Nonetheless, the allegations have drawn attention to an entitlement program that has more than tripled in cost since 1989 and have caused some in Congress to question whether SSI should remain a no-strings-attached cash grant or whether the money should be targeted to help children become independent adults.

SSI was designed to provide income for poor people who were not able to work (the blind, the disabled, and the elderly) and whose Social Security benefits were either nonexistent or too meager to live on. In folding disabled children into the program, the Congress, after some dispute, agreed that poor disabled children "were the most disadvantaged of all Americans" and that they deserved "special assistance" to help them become "self-supporting members of our society." Now some lawmakers believe that providing vouchers for medically related services is a better way to help poor disabled children than giving their families cash.

The voucher concept is opposed by family advocates, who view the SSI money as making it possible for families to cover what they say are much higher daily costs of keeping disabled children at home and out of expensive institutions—costs of providing special foods, clothing, shelter, child care, transportation, and recreation for children with serious disabilities.

While Congress in August established a DHHS-based commission to study the potential for making a variety of program changes, action may come sooner than the commission's November 1995 deadline. A proposal to change SSI for children into a voucher program for services is expected to emerge from the new, Republican-controlled House in the first 100 days of the new session and may be attached to the Personal Responsibility Act that is part of the GOP's "Contract with America." As of this writing, the voucher proposal has not been drafted, but it is expected to cover a broad range of medically related services, including home modifications to accommodate disabled children. The contract, which Speaker of the House Newt Gingrich (R-Ga.) has pledged to move quickly, proposes another, perhaps more drastic change for SSI—eliminating the program's entitlement status.

In this Forum session, speakers will clarify the SSI eligibility determination process for children, review recent program history that has contributed to child enrollment increases, and discuss how parents view the program and use the money. It will also examine

ISSUE BRIEF/No. 661

Writer/Researcher:
Jane Koppelman

National Health Policy Forum
2021 K Street, NW, Suite 800
Washington, DC 20052
202/872-1390 Fax 202/785-0114

Judith Miller Jones, Director
Karen R. Matherlee, Co-Director
Michele Black, Associate Director/Editor

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the capacity of SSA to administer the program, given new congressionally mandated responsibilities to conduct more child reviews, and will raise issues of disability definition and alternatives to the SSI nonrestrictive cash payment for children.

SSI CHILD PROFILE, PROGRAM RULES

In June 1994, more than 847,000 children received SSI, at a total annual cost of about $4.6 billion. Almost two-thirds of child recipients were disabled because of a mental disorder, the most common being mental retardation, which accounted for 44 percent of all SSI children. Another 22 percent had psychotic and neurotic disorders. Diseases of the nervous system and sense organs comprised the other major impairment categories—accounting for another 13 percent of child recipients.

The maximum monthly SSI payment of $446 is available to disabled children with family incomes up to about 150 percent of poverty, excluding complex resource criteria. As income increases, SSI payments decline, and families become ineligible for benefits at about 200 percent of poverty. For example, a two-parent family with two children, one of whom is disabled, receives the full benefit if yearly income is less than $20,220. The benefit phases out when family income reaches about $31,000. Most of the children on SSI fall in the low end of income eligibility: 68 percent received the maximum monthly benefit, according to SSA.

Benefit levels are higher in the 36 states that supplement federal payments. Massachusetts, for example, adds $114 to a child's SSI benefit. The average SSI monthly payment, including state supplements, currently is $412, reports SSA.

In 31 states and the District of Columbia, SSI enrollment is the gateway to Medicaid benefits: Medicaid enrollment is automatic. In another seven states, SSI children are eligible for Medicaid but must apply separately.

SSI'S LEGISLATIVE ORIGINS

The birthing of the SSI program is a story of political ironies. That something as liberal as the right to a guaranteed income from the federal government had the blessing of President Nixon, and that Congress approved such a profound change in social welfare policy with little notice or fanfare, is testament to its odd political history.

SSI originally started as a companion to Nixon's Family Assistance Plan (FAP), a sweeping welfare reform proposal that would have replaced the Aid to Families with Dependent Children (AFDC) program with a federally provided uniform minimum income for poor children. Even households with resident fathers would have received the assistance, provided the fathers were either unemployed or had low earnings. Along with FAP, Nixon in 1969 proposed that states be required to pay a federally established minimum income to the poor elderly, blind, and disabled who were on state welfare rolls.

After defeat of the 1969 proposal, the House Ways and Means Committee in 1971 reintroduced FAP and took the companion piece one step further: it proposed that the federal government not only set minimum benefit levels but assume complete payment for three programs that were then state-federal partnerships: Old-Age Assistance, Aid to the Blind, and Aid to the Permanently and Totally Disabled.

The provision was buried in a massive bill, H.R. 1, and sent to the Senate Finance Committee, where most attention was focused on the highly controversial FAP and amendments to Social Security and Medicare. Finance again rejected the FAP. What quietly passed was the nation's first long-term income guarantee—targeted for the poor elderly, blind, and disabled. "When the historic law was enacted, politicians ignored it and most newspapers failed to report it. It is probable that many members of Congress who voted for it did not realize what they had accomplished," wrote Vincent and Vee Burke in *Nixon's Good Deed,* their 1974 book which described the political debate surrounding FAP and SSI.

According to the Burkes, the main reason for designing SSI was to preserve the wage-based Social Security program. The payroll tax had become burdened when Social Security expanded to cover retired low-wage workers and surviving dependents, and there was a call from some sectors to raise the minimum benefit to provide a livable income for the elderly who could not supplement Social Security. SSI provided relief for the poor through the income tax without further pressuring the payroll tax. Observers note that SSI passed chiefly because, unlike assisting the able-bodied population addressed by FAP, guaranteeing an income for those not expected to work—the poor aged, blind, and disabled—sparked little controversy in Congress.

The Inclusion of Children

There is not much written that explains the rationale for the Ways and Means Committee's inclusion

of disabled children in a program designed as an income floor for poor adults who are unable to work. There appears to have been a debate over maintaining the extra payments then made to some AFDC children with "special needs"—payments that supplemented the AFDC cash grant—but that approach was rejected in favor of putting these children under the more generous SSI program. In House Report No. 92-231 the committee said it believed

> that disabled children who live in low-income households are certainly among the most disadvantaged of all Americans and that they are deserving of special assistance in order to help them become self-supporting members of our society. Making it possible for disabled children to get benefits under this program ... rather than under the program for families with children, would be appropriate because their needs are often greater than those of nondisabled children.

The Senate Finance Committee disputed that assumption, claiming in a 1972 committee report that disabled children's needs are greater only in the area of health care expenses and that access to Medicaid through AFDC would be sufficient. "Disabled children's needs for food, clothing and shelter are usually no greater than the needs of nondisabled children," according to the 1972 committee report. In the end, however, the Senate acquiesced to the House version.

In the final SSI statute, the definition of a disabled adult was clearly stated as someone who is unable "to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last a continuous period of not less than twelve months." The law defined disability in children less clearly, depicting an eligible child as one who "suffers from any medically determinable physical or mental impairment of comparable severity" to that which disables an adult.

ZEBLEY DECISION

It was the SSA's longstanding interpretation of "comparable severity" that led the Supreme Court in 1990 to rule that the agency's determination process for children was overly restrictive and in violation of the statute. For years, SSA had employed a different eligibility process for adults than for children. Both groups would initially have to meet financial criteria and be found to have conditions that either were on a prescribed list of medical impairments or were equal in severity to those on the list. (This list is known as the Listing of Impairments and the conditions on it are often referred to as the "listings.") For example, a certain level of impaired pulmonary function may be needed for lung diseases and a certain degree of mobility impairment for orthopedic conditions.[1]

Adults with impairments that did not match or equal any of the listings would be allowed an extra step—an assessment of the impairments' impact on their ability to perform past work or any other kind of substantial gainful work in the economy. Because children were not expected to work, they were not afforded this further inquiry. Child eligibility was determined solely on the basis of the medical listing of impairments.

Before 1990, it had been extremely difficult for some children to qualify for SSI. Many disabling conditions of childhood are rare and were not found in SSA's listings. Frequently, benefits were denied to children with multiple conditions, no one of which equaled the severity of a listed impairment but which, when taken together, would severely impair a child. The result was that some severely disabled children —with cystic fibrosis, Down syndrome, and AIDS, for example—were being denied. Stories of families who had to institutionalize their children at state cost because they could no longer afford to care for them at home were not uncommon.

Brian Zebley, who suffered congenital brain damage, developmental delay, eye problems, and a musculoskeletal impairment, was an SSI cessation case: he was removed from the rolls after SSA ruled he was no longer disabled. In a class action suit brought on behalf of Zebley, the Supreme Court ruled that when a child had a condition that did not meet the listings standard, determining whether the impairment was of "comparable severity" to one which would disable an adult would require a functional assessment. In developing this assessment with a group of experts, SSA decided that children's ability to engage in age-appropriate activities would be the benchmark of eligibility and would be equivalent to the assessment of adults' capacity to work.

As part of the Zebley settlement, SSA was required to review all cases, dating back to January 1980, in which the agency denied or terminated benefits to children, using new eligibility criteria that included an expanded list of mental impairments (discussed below). Of the approximately 460,000 children who

[1]Perrin, James M., M.D. and Ruth E. K. Stein, "Reinterpreting Disability: Changes in Supplemental Security Income for Children," *Pediatrics*, Vol. 88, No. 5, November 1991, p. 1048.

had been denied since 1980, some 339,000 responded to SSA's invitation and were given another chance to apply. As of November 1994, about 131,000 of these children were found eligible.

Zebley Rules

In February 1991, the agency published new rules that eased the requirements for "equaling" a medical listing and dictated the individual functional assessment (IFA) process for children. These rules spelled out the criteria for judging whether a child's impairment(s) caused a substantial reduction in his or her ability to function at an "age-appropriate" level. The IFA does not entail face-to-face contact. SSA evaluators gather information on a child's functioning in a variety of domains—social, communication, cognitive, personal and behavioral, motor functions, responsiveness to stimuli, and ability to concentrate, persist at tasks at hand, and keep pace.[2]

Even before the Zebley Supreme Court decision, members of Congress had criticized SSA for ignoring provisions in the SSI rules that called for the collection of nonmedical evidence in deciding children's eligibility. The Zebley rules gave renewed emphasis to drawing on input from parents, teachers, counselors and other professionals knowledgeable about the child's daily functioning. Physicians were no longer the dominant source of information.

OTHER PROGRAM CHANGES

The SSI program experienced other significant changes in 1990 that expanded the program for children. That year, SSA revised and updated its childhood listings of mental disorders, which had not changed substantively since 1977. Congress mandated the revision for adult impairments in the 1984 Disability Benefits Reform Act to reflect new knowledge in the field, and SSA used the opportunity to review the child listings. The new rules increased the number of mental impairment listings from 4 to 11, including for the first time separate listings for conditions such as pervasive developmental disorders (for example, autism) and ADHD.

Also important was a much greater emphasis on how a child's mental impairment affects his or her ability to function in age-appropriate ways, the measure of which was incorporated months later into the Zebley rules. Previously, SSA had relied predominantly on the medical characteristics of a disability, without special attention to how it affected daily living. Similar to the Zebley rules, the new mental impairment listings called on information from parents and teachers to assess the child's condition.

Another profound change occurred during 1990 and 1991, when three national outreach campaigns were launched to help families become aware of SSI. Previously, the SSA had done little to publicize the program, and many families with eligible children were simply not applying. Congress in 1990 directed SSA to conduct outreach to families of disabled children, and a Zebley court settlement order required SSA to launch a national media outreach campaign. Several private foundations buttressed these efforts by funding the National Children's SSI campaign, an outreach project conducted by advocates.

CONCERN OVER PROGRAM GROWTH, ALLEGATIONS OF ABUSE

By 1993, the combination of the review of denials under Zebley, the new court-ordered IFA process, the mental impairment listings update, and the outreach campaigns had made their impact. Child enrollment in SSI more than doubled, rising from about 296,000 in 1989 (the year before the changes) to more than 770,000 in 1993, while program costs for children increased from $1.2 billion to $4.35 billion during that period. SSA officials also note two other factors that contributed to the expansion: an increase in overall numbers of disabled children (since 1960 the proportion of disabled children has more than tripled) and rises in child poverty (between 1989 and 1993, the number of children living in poverty increased by 2.5 million).

Disability advocates viewed the program trends as the success of congressional mandates and court-ordered actions. Meanwhile, as the SSI child rolls grew, the program became more visible. Particularly noticeable were the families who received multi-thousand dollar lump-sum retroactive awards from the Zebley review; they were required to spend down the awards in six months or lose SSI eligibility. At the same time, some in Congress were receiving a range of complaints about the program. Often generated from the education community, where teachers and counselors were being asked to assess their students, the complaints centered on three basic issues. First, there were allegations that certain children were gaming the system, being coached by their parents to act out in class in order to earn a

[2]Not all domains apply to all children. Their applicability varies by the child's age (for example, responsiveness to stimuli applies only to infants).

behavior disorder label and get onto SSI. There were also claims that the new SSI eligibility rules were too lenient and were allowing children with mild impairments onto the rolls and that parents were not using the money in the best interests of their children.

Battered by sensational media reports of gaming and suggestions that it was driving enrollment increases, the SSI program for children came under attack by some lawmakers. Concern over alleged fraud not only sparked questions of whether the new IFA—in which judgement calls are made about the severity of a child's impairment—was too lenient, but also challenged the fundamental intent and philosophy of the program for children. Critics began to ask whether children with certain mental impairments (particularly those broadly characterized as behavior problems) had higher living costs that merited a monthly cash payment, whether SSI should become a voucher program for services instead of a no-strings-attached cash grant, and whether parents were spending the SSI payment on services or goods that directly benefited their disabled children.

The allegations of abuse have frustrated many state and federal officials who have tried to follow up on the charges. For instance, Maureen Sorbet, who runs an SSI outreach program for the Michigan Department of Social Services, says that when teachers and other school employees who complain of fraud are asked to identify such cases, "they don't come up with names." One SSA official acknowledged that, in a few cases, school staff are reluctant to name names because they do not want to damage relationships they have with their students or fear they would evoke anger from accused families.

"Most people making the allegations are unaware of whether the kids are getting benefits. [They] only know they applied," says Barry Eigen in SSA's Office of Disability. "For example, we are investigating all potential cases of coaching. Of 416 cases referred so far, only 25 were allowed" on the rolls.

Eigen and a number of state officials acknowledge that a small group of "undeserving" children are probably getting on the rolls. The errors are "no different [in SSI] than in other programs," says Bill Shelton, director of Wisconsin's Disability Determination Service (DDS). "The issue is the definition of disability.... A number of people have a basic conflict with the program. They don't think kids should get on [the rolls] with their level of impairment," he says, referring to children with certain behavior problems.

Mental Impairments Controversy

While only 13 percent of child awards between 1991 and 1993 have been for ADHD and other conditions that exhibit themselves as behavior problems, some believe that these conditions have left SSI vulnerable to accusations of abuse. At issue is the subjective nature of determining the point at which poor behavior is severe enough to be classified as an impairment. SSA included these impairments because they were listed in the DSM-III-R,[3] the standard manual used by mental health practitioners. There is, however, dispute among psychiatrists and psychologists over what the threshold of severity should be to merit the diagnoses, and SSA examiners are caught in that same professional bind. According to James Perrin, M.D., a member of a National Academy of Social Insurance panel looking at the program, a related problem is that the SSA criteria taken from the DSM-III-R do not adequately distinguish between the severe and more moderate forms of these disorders; some believe that SSA's rules should be tightened to do so.

RECENT LEGISLATIVE ACTIVITY

Over the past several months a few failed attempts were made in Congress to alter the SSI program for children. Last spring a welfare reform bill sponsored by Republican Sens. Lauch Faircloth (La.), Charles Grassley (Iowa), and Hank Brown (Colo.) included a provision to replace the SSI cash payments for children with a voucher for any medical costs not covered by Medicaid. An earlier version of the bill would have eliminated benefits for children with ADHD. More recently, attempts were made to change SSI as the House marked up its bill to make the SSA an independent agency (the Social Security Administrative Reform Act of 1994). To quell the desires of some members to either eliminate cash payments for children or change SSI to a voucher program for uncovered medical services, the Ways and Means Committee struck a compromise by proposing a commission to look at the issues. The commission was enacted into law in August.

The following are among the major issues that the commission, a panel of DHHS-appointed experts, is required to address by November 1995:

[3] *The Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition (revised),* is a publication of the American Psychiatric Association.

- the appropriateness of the current SSI definition of disability for children under age 18 and the possible need for an alternative definition;
- the feasibility of meeting families' needs for help with the high costs of medical care for seriously physically or emotionally disabled children by expanding federal health programs;
- the feasibility of providing benefits to children through noncash means, such as vouchers, debit cards, and electronic benefit transfer systems;
- the desirability and possible methods of increasing the extent to which SSI benefits are used to help children gain independence and be able to work as adults; and
- the effects of SSI on disabled children and their families.

AVAILABLE STUDIES

Meanwhile, a number of reports have begun to address some of the questions lawmakers have raised. In 1993 SSA reviewed a sample of 617 childhood disability claims of children with behavior disorders and learning disabilities to probe whether children were being coached to feign disability and whether children with mild impairments were being enrolled. These criticized categories of impairment account for about 20 percent of all SSI childhood disability claims.

The study found no evidence of widespread coaching—possible coaching was an issue in only 13 of the 617 cases, and only three of them were allowed. SSA found a small number of children with mild impairments to have been wrongly enrolled—accounting for 8.6 percent of the sample's allowances. It also found that more information should have been collected by those determining eligibility to better substantiate 28 percent of the allowances.

At the time the study was issued, SSA also reported numerous actions it had taken to avert future errors, including national training for DDS determiners, stricter requirements for documenting decisions of cases involving multiple moderate disabilities, and an increase in the number of continuing disability reviews (CDRs) the agency would conduct (for more on CDRs, see page 9).

GAO Report on Enrollment Increases

In September, the General Accounting Office (GAO) released a report examining the rapid rise in the children's SSI rolls. Its findings disputed the conventional wisdom that a less restrictive IFA process mandated by the Zebley decision was responsible for most of the increase. The report found that, since the IFA was established, "70 percent of all awards went to children whose impairments were severe enough to qualify on the basis of SSA's medical standards alone, without the need for a functional assessment."

"The growth in the rolls is the result of huge increases in both applications and awards for children's disability benefits," according to the GAO. "The outreach has been phenomenal," adds Eigen, noting that many children who made it onto SSI without an IFA were not enrolled previously because their families simply were unaware of the program.

Since the Zebley rules were enacted, applications for children with mental impairments have more than tripled and awards to this group more than quadrupled, but two-thirds of these awards have gone to children with mental retardation. It is significant, however, that most decisions for children filing with mental impairments are determined through the IFA. Interestingly, the most criticized categories of mental impairment—those that manifest themselves in poor behavior—represent a small portion of recent awards. From 1991 through 1993, only 13.3 percent (39,400) of all childhood SSI awards went to children with diagnoses of ADHD, personality disorder, autism, or pervasive developmental disorders, the GAO noted. These children have accounted for one-fifth of all awards to mentally impaired children during that period.

DHHS IG Report

In October, the Office of the Inspector General (IG) released an audit requested by Sen. Herb Kohl (D-Wis.) to respond to complaints he was receiving from some in his state's education community over the program. The complaints centered on issues such as the granting of SSI to some children with behavior disorders whose impairments might not prevent them from working as adults, the granting of benefits to children without regard to the financial needs created by their disabilities, and the failure to use SSI payments to help disabled children prepare for work as adults.

The report suggested some confusion in the field over congressional intent. "Under the statute, the 'intent' of the program is to provide cash assistance to children with disabilities. Our review found that the program basically achieves that purpose." The audit clarified that, in enacting SSI, Congress did not

require the cash payment to be used to provide services for children, to identify a financial need created by a disability, or to assess a child's potential to work when an adult. The report also cited SSA's errors found in the IFA process, as well as actions the agency has already taken to prevent future errors. The IG's conclusions were critical; it recommended that Congress revisit the intent of the program as well as the IFA process. In a letter from Inspector General June Gibbs Brown to SSA Commissioner Shirley Chater that accompanied the report, Brown wrote:

> If Congress intended that the SSI program provide only cash assistance to children with mental impairments, then the program is successful.... However, if Congress intended that the SSI program should help children overcome their disabilities, and grow into adults capable of engaging in substantial gainful activity, changes are needed.

HOW PARENTS USE THE MONEY

Media and congressional scrutiny over how parents use SSI payments has led families of disabled children to become more vocal. In a joint statement issued by Family Voices and the Federation of Families for Children's Mental Health, together representing more than 50,000 families with physically and emotionally disabled children, examples of how families spend the money were offered. The list contained many items not covered by Medicaid and included specifics such as over-the-counter nutritional supplements for children with degenerative neuromuscular disorders; additional counseling for a family stressed by a seriously emotionally disturbed child; respite care by a trained babysitter, so parents of a mentally retarded child could go out occasionally; and special day care for a child whose medical condition required 24-hour supervision and whose parents had to work.

Perhaps the only systematic survey on this topic was conducted last spring by the Michigan Department of Social Services, which sent questionnaires to more than 1,900 families with children on SSI. The 28 percent of families responding anonymously reported that, after paying for basic necessities such as food and shelter, families most often spent the monthly SSI checks on special foods, day care services, adaptive equipment, educational aids, toys and recreational activities, transportation to medical appointments, medical bills not covered by other insurance, and clothing and other personal items for the impaired child.

In addition, according to Sorbet, the survey revealed that SSI allowed some parents to forego work and stay home with a seriously disabled child. Joe Manes, analyst with the Bazelon Center for Mental Health Law, notes that parents of seriously emotionally or physically disabled children often forego full-time or even part-time jobs because their children require intensive attention or they cannot find or afford specialized day care. The SSI check helps these families to compensate for their lost income, he notes.

VOUCHERS VERSUS CASH GRANTS

The voucher versus cash grant debate has pitted lawmakers who want more accountability in a burgeoning entitlement program against those who believe that families are better suited than government to decide how the money can help their children. The debate is made more complicated by the reality that each option has serious flaws. The cash grant approach does not address the problem that some parents whose children need specialized services are not spending the money on this care.

Some advocates for a voucher approach believe that it would weed out the "deserving" from the "undeserving" families by restricting the money's use to only medically related services. But the voucher carries its own problems: for one thing, it ignores the reality that some families use the money to supplement lost income. In addition, advocates worry that it would not be flexible enough to meet the varied needs of children and families, particularly in the areas of respite and child care.

Rhoda Schulzinger, director of the Children's SSI Campaign at the Bazelon Center, adds that a voucher program, depending on how it is designed, might not allow low-income families to use SSI to provide for the very basic needs of food, clothing, and shelter for their children. That most SSI children are getting the maximum benefit is evidence of the level of poverty that exists in their families; SSI has helped to keep them afloat, she notes. "What happens if the family car breaks down but [the family is] locked into using vouchers for diapers?"

OTHER ISSUES

Other problems loom as the SSI program for children is reexamined. A serious concern is that once children come onto the SSI rolls they rarely, if ever, exit. Two factors figure prominently in this problem. While guidelines exist for periodic reviews of children (with more frequently scheduled assessments for children whose disabilities are deemed nonpermanent),

until just recently neither the regulations nor the statute have required them, and the SSA has generally not conducted any. Rapid increases in SSI and Social Security Disability Insurance (SSDI) applications have come at a time of agency downsizing: between fiscal years 1985 and 1989, SSA reduced its staff from about 80,000 to about 63,000, according to the National Academy of Social Insurance. In the wake of staff cutting and increased workloads, continuing disability reviews have simply not been a priority. And, while Congress in August mandated that SSA conduct CDRs on at least one-third of the children reaching age 18 in each of years 1996, 1997, and 1998, no money has been appropriated to fund the extra personnel necessary for the task.

Fear of losing Medicaid is also cited as a serious disincentive for parents to encourage their disabled children to improve functioning or prepare for future work. Although many of these children may eventually be able to hold down jobs—thereby overcoming their disabled classification—the jobs may be low-paying and have poor health benefits; this could be a real problem for those who still have severe impairments but, through their own efforts, have lost SSI and consequently, Medicaid benefits.

FUTURE ENROLLMENT TRENDS

A major question for policymakers is whether SSI enrollment for children will continue to grow at such a rapid pace. The answer appears to be no. SSA officials believe the program is reaching the saturation point for child enrollment; it is currently serving between 60 percent and 80 percent of the estimated 1.1 million to 1.4 million children eligible for the program.[4] This estimate is consistent with just-published data from the Institute for Child Health Policy, which found SSI to be serving about 70 percent of all non-institutionalized eligible children.[5] Outreach efforts combined with the one-time Zebley backlog awards created a surge in awards that is not expected to continue.

While the number of applications filed annually since the Zebley decision has more than quadrupled, rising from an annual average of 125,000 between 1987 and 1989 to about 600,000 today, award rates have actually declined recently as the portion of truly disabled children is separated from the rest of the applicant pool. The award rate increased from about 42 percent before 1991 to an average of about 50 percent since then. However, SSA notes that during the period right after the Zebley decision, allowance rates were higher than 50 percent because the volume of applicants had not yet increased sharply. In contrast, the award rate in recent months has been about 35 percent.

THE FORUM SESSION

The following are among the questions that surface as policymakers examine the SSI program for children:

- How well do current government programs (for example, special education, Medicaid, and Title V) meet the needs of physically and mentally impaired children?
- What gaps in needs are left by these programs and is the SSI cash grant being used to fill these gaps?
- If a voucher program is considered to replace some or all of the SSI cash grant, how would it be structured to account for the very different service needs created by the individual circumstances of disabled children?
- Which agency would be responsible for administering and monitoring a voucher program, and how costly and labor-intensive would it be to administer?
- To what extent do parents of disabled children make employment decisions that lower family income in order to care for their children? Would a voucher program for child services address this potential loss, and if so, how?

Speakers

Barry Eigen will begin the session with an overview of the SSI eligibility process for children. Mr. Eigen, deputy director of the Division of Medical and Vocational Policy in SSA's Office of Disability, played a large role in drafting the new rules that established the IFA. In 1990, after 15 years in SSA's Office of Hearings and Appeals, he became the first chief of the newly created Childhood Disability Branch in the Office of Disability. His currently drafts and revises regulations and other disability instructions for SSA's various programs for disabled adults and children.

Linda Dorn, deputy director of Michigan's Disability Determination Service, will follow with a state perspective on the challenge of implementing the new regulations, as well as the feasibility of administering

[4]The estimate of all eligible children is based on National Health Interview Survey data of children meeting SSI's disability and income criteria.

[5]This estimate is based on Wave 6 of the Survey of Income and Program Participation (SIPP), a national data set.

a voucher program, if one were to be enacted. Ms. Dorn, who has been with the state DDS since 1975, is currently responsible for serving 159,000 disabled residents both through SSI and SSDI. She also serves on the Michigan Transition Council, a collaborative effort to improve service delivery to disabled people, and has received SSA's Associate Commissioner's Citation for outstanding leadership to the disability program.

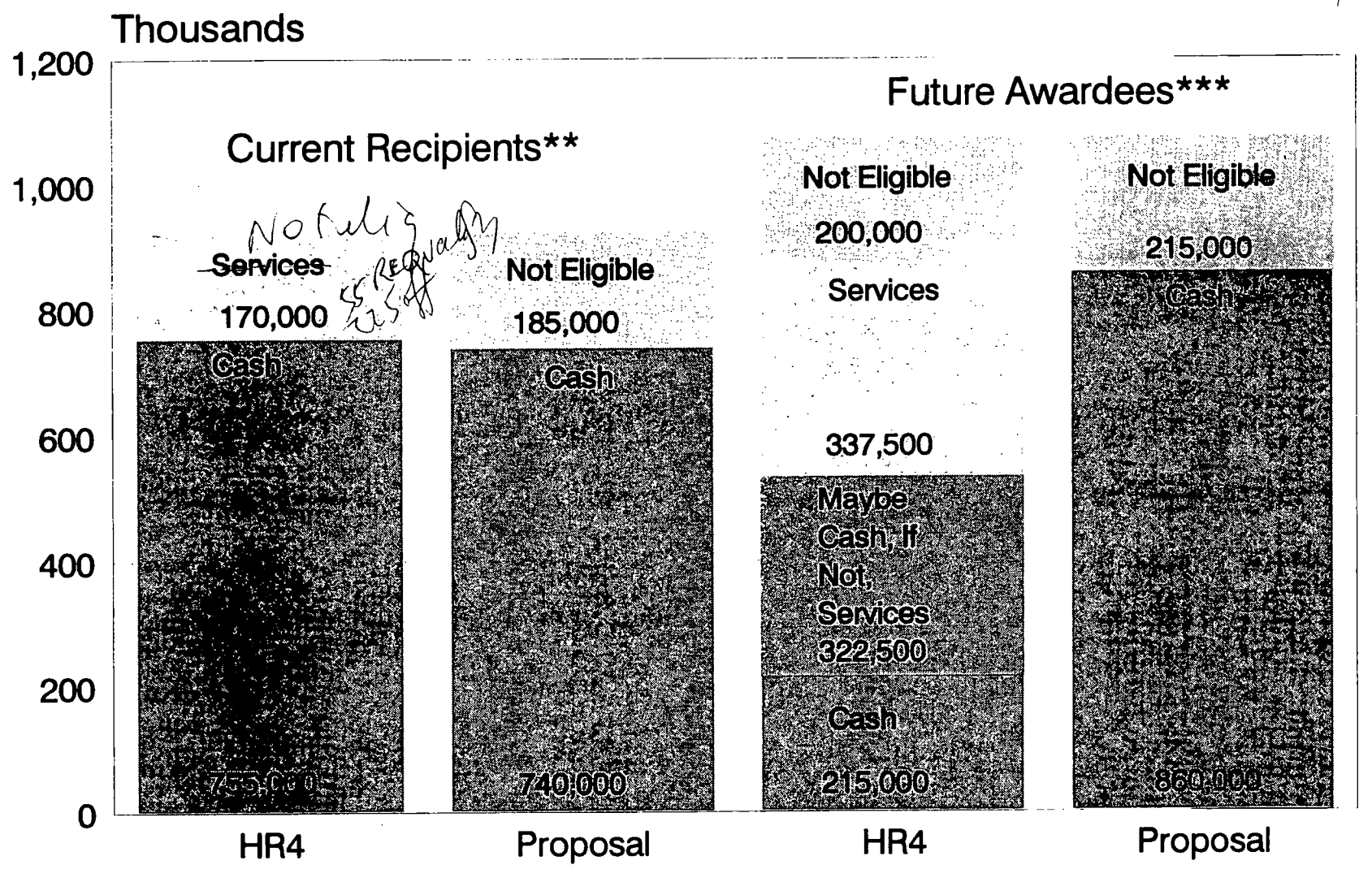
Sue Smith, parent of a child with severe emotional disturbance on SSI, will offer a parent's perspective on how the SSI check affects families. Since 1989, Ms. Smith has been executive director of the Georgia Parent Support Network, a group which provides information for and advocacy on behalf of parents of disabled children in the state. She is also president of the Mental Health Association of Georgia and serves on the executive board of the Federation of Families for Children's Mental Health.

Offering the federal SSA perspective on challenges the agency faces in conducting more CDRs and implementing other potential changes is **Lawrence Thompson**, the agency's principal deputy director. Before joining SSA, he served as assistant comptroller general in charge of the Human Resources Division at the GAO, where he reviewed federal programs involving health, education, labor, and income security issues. Previously, Mr. Thompson was chief economist at GAO and worked for nine years on income security issues at DHHS, including positions as director of social security planning in the Office of the Secretary and associate social security commissioner for policy.

James Perrin, M.D., member of a National Academy of Social Insurance panel looking at the children's SSI program, will discuss some of the panel's preliminary findings, including those that address how to improve the child eligibility process and help children transition off of SSI and into the workforce when adults. Dr. Perrin is associate professor of pediatrics at Harvard Medical School and current committee chair of the American Academy of Pediatrics. For more than 20 years he has served in an advisory capacity to states and the federal government on a range of health issues and has been particularly active in policy development surrounding the needs of chronically ill children.

Comparison of Eligibility Criteria in HR4 to Proposal to Modify the Definition of SSI Childhood Disability*

House Bill 6/5yrs.

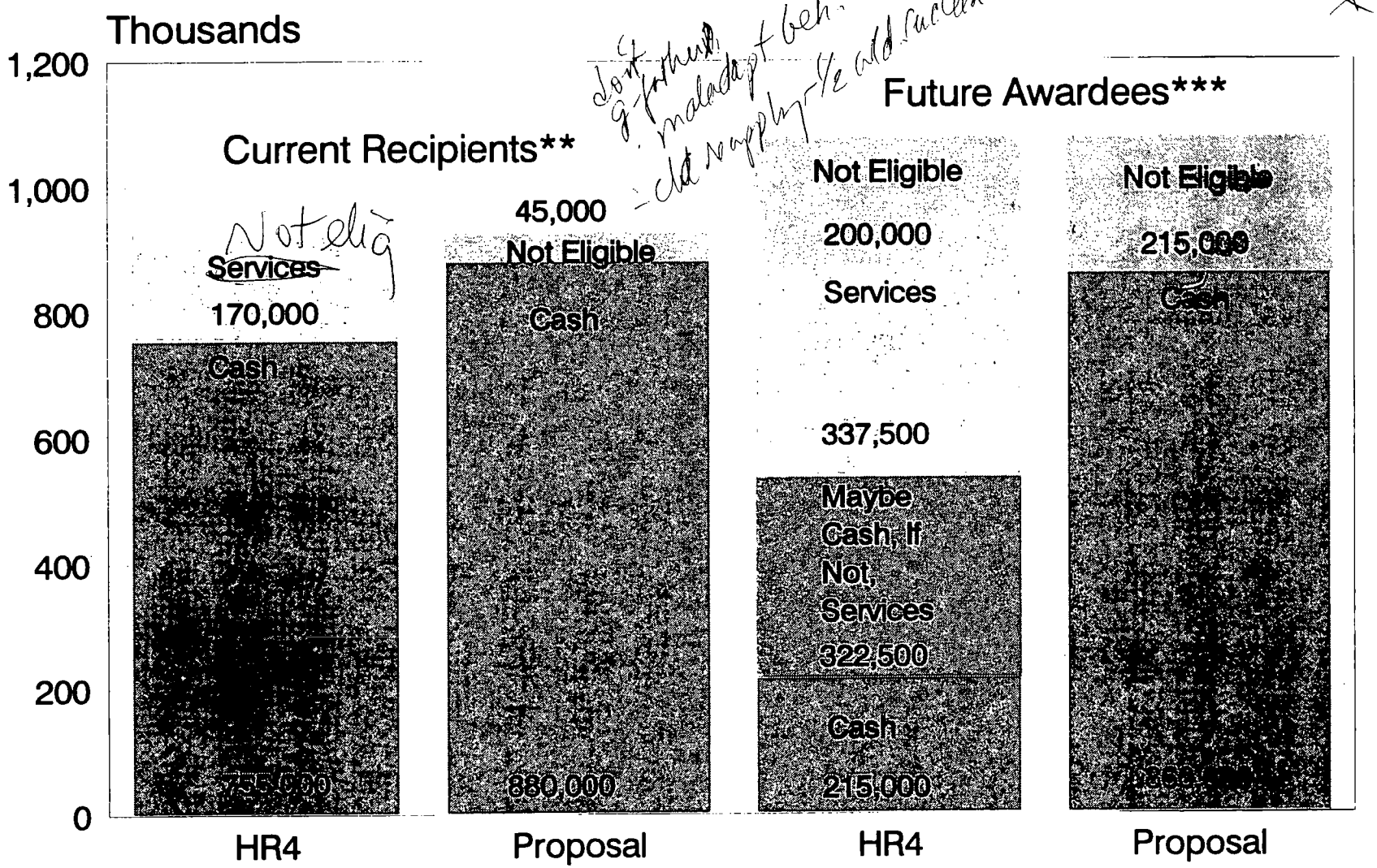


* Differences in implementation timeframes are not considered. Actual cost estimates of effects of legislation differ.

**Estimated recipients as of October 1995.

***Estimated new awardees cumulative from October 1995-September 2000.

Comparison of Eligibility Criteria in HR4 to Proposal to Modify the Definition of SSI Childhood Disability*



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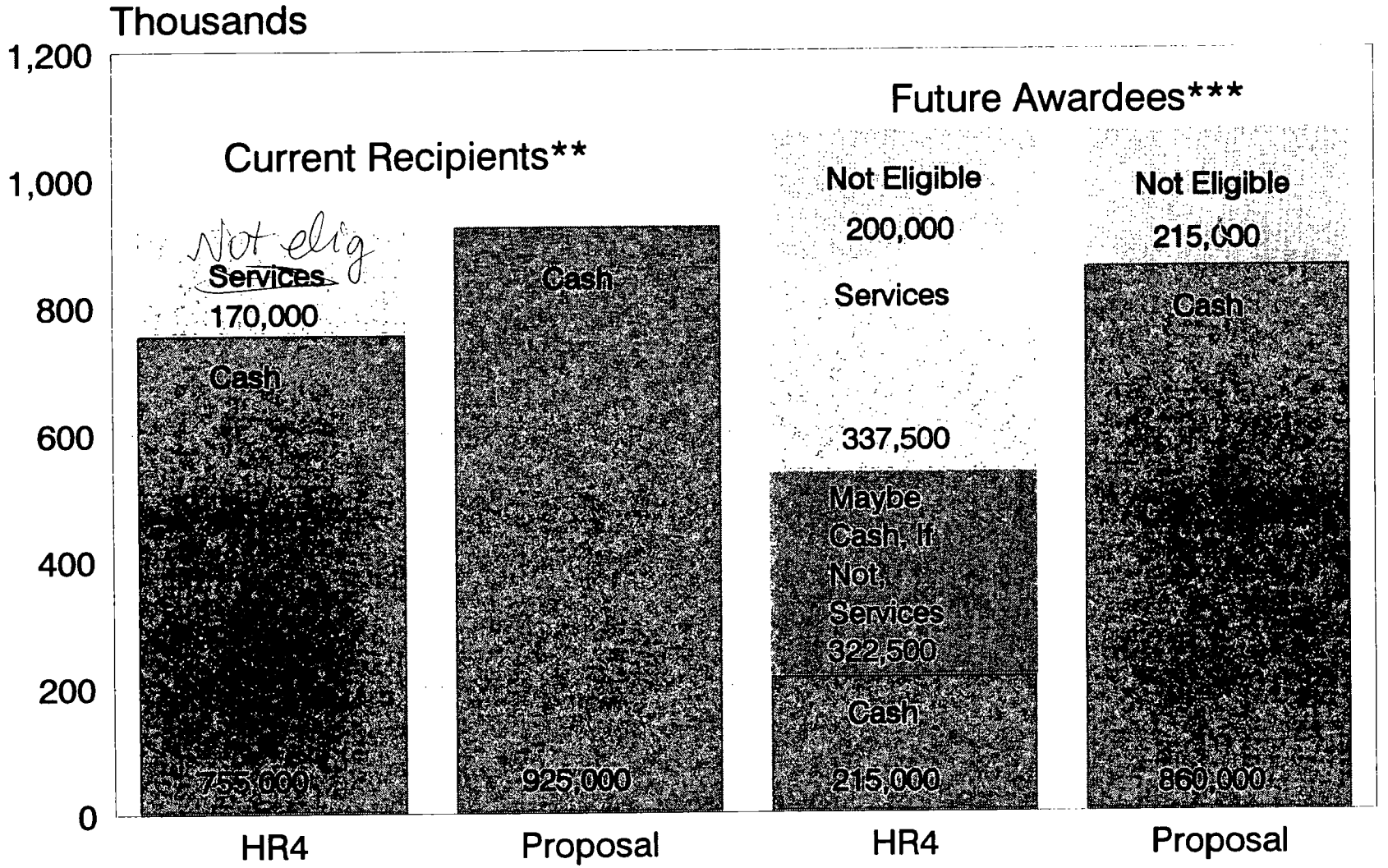

* Differences in implementation timeframes are not considered. Actual cost estimates of effects of legislation differ.

**Estimated recipients as of October 1995.

***Estimated new awardees cumulative from October 1995-September 2000.

w/ IFA

ALTERNATIVE A

CHILDHOOD DEFINITION OF DISABILITY: Comparable severity to that which would disable an adult.

REPLACE NEW DEFINTION= LISTING-LEVEL SEVERITY (2 MARKED LIMITATIONS)

1. Working at Substantial Gainful Activity? ---→Y DENY
   N
   ↓
2. Does the impairment have more than a minimal impact on functioning? ---→N DENY
   Y
   ↓
3. Does the impairment meet the listings? ---→Y ALLOW

Physical listings	Mental listings	
Must meet various criteria	Must meet: "A" Criteria for diagnosis and "B" criteria for severity-- Marked limitation in two domains, or Extreme limitation in one domain: Cognitive/Communicative Social Functioning Personal/Behavioral (Includes Maladaptive Behavior) Concentration, Persistence and Pace	*REVISE LISTINGS* *DELETE*

N
↓

Does the impairment medically equal the listings? ---→Y ALLOW

N
↓

Does the impairment functionally equal the listings? ---→Y ALLOW

NOTE: Can use any functional criteria, see childhood mental listing for general functional criteria.

N
↓

REVISE IFA

4. Individualized Functional Assessment

SEVERITY MET WITH MARKED LIMITATIONS IN TWO DOMAINS, OR EXTEME LIMITATION IN ONE DOMAIN: ---→Y ALLOW ---→N DENY

COGNITIVE/COMMUNICATIVE
SOCIAL FUNCTIONING
ADLs /
MOTOR (INCLUDING STAMINA)
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SECTION: Washington - general news

LENGTH: 934 words

HEADLINE: Panel: Fund Disabled Children

DATELINE: WASHINGTON

BODY:

A yearlong study has contradicted claims that substantial numbers of parents coach their children to act crazy in school so they can collect disability payments.

The National Academy of Social Insurance study released Sunday found instead that the Supplemental Security Income program allows families to care for severely disabled children at home rather than institutionalize them. The academy, a non-partisan research group, recommended tightening eligibility for SSI but continuing its cash payments to families in need.

''Supporting families in their effort to care for their child at home is more efficient, cost-effective and humane than maintaining children in out-of-home settings,'' said the report, written by experts on childhood disability.

SSI costs far less than paying for foster care, group homes, or institutions,the report said. Research cited in the report found the cost of out-of-home care for a disabled child ranges from about $24,000 a year for specialized foster care to $95,000 in a state institution.

SSI pays a maximum monthly benefit of $458. There were 837,000 children on the rolls in December, costing taxpayers about $4.7 billion annually overall.

The number of children who receive SSI has nearly tripled since the late 1980s, in part because a Supreme Court ruling made it easier for children to qualify for aid.

Some lawmakers have charged that children with minor emotional, mental and behavioral problems got on the SSI rolls by pretending to act crazy or by failing tests at school.

In response to those allegations, the House passed welfare reform legislation in March that would replace cash payments to many disabled children with services such as counseling, wheelchair ramps, or diapers. The legislation is pending in the Senate.

''Any evidence of such coaching or 'gaming the system' is extraordinarily thin and appears to be based on anecdotes or perceptions of dubious benefit claims, which upon investigation are found to have been denied,'' the study found. ''The number of such cases reported to Social Security to date is very small.''

Nevertheless, the report recommended that eligibility rules be strengthened when evaluating behavior and mental disorders. The experts also suggested that family benefits be limited when there is more than one disabled child in a household.

National Journal's CongressDaily

May 8, 1995

SECTION: HUMAN RESOURCES

LENGTH: 640 words

HEADLINE: Study: SSI Cuts 'Neither Necessary Nor Practical'

BODY:

Efforts to scale back cash payments of Supplemental Security Income benefits to disabled children are "neither necessary nor practical" and would have a profound negative effect on such children, according a report due to be released today by the Disability Policy Panel of the National Academy of Social Insurance.

The panel, chaired by Yale University law professor Jerry Mashaw, includes experts on disability policy and was assembled at the request of the House Ways and Means Committee during the 102nd Congress.

The report does not explicitly refer to the GOP-sponsored welfare reform bill recently passed by the House or to ongoing efforts in the Senate. But it said the possible use of vouchers or block grants to states would be "either less efficacious" in delivering services to disabled children or would "have such severe implementation difficulties that they would be likely to fail their intended purposes."

The House-passed bill would save some $9.3 billion over five years by changing the criteria under which disabled children qualify for SSI, forcing many recipients off the SSI rolls.

Republican sponsors of the welfare reform measure contend it is unwise to give cash payments to families with disabled children with no assurances or accounting of whether the funds will be spent to benefit the children.

The House bill would still give Medicaid payments to disabled children who currently qualify for SSI and, in addition, would create a block grant for the states to administer SSI programs. "It is neither necessary nor practical to fundamentally restructure SSI for disabled children," the National Academy of Social Insurance report said, adding, "We believe that there is a strong rationale for the payment of cash benefits to families with disabled children. "Particularly for some families with incomes sufficiently low to qualify for SSI, we believe that the margin provided by SSI cash payments is critical to the maintenance of the care of children in their own homes rather than in an institutional setting," the panel maintained.

The report added, "Without these supports, disabled children would be at a much greater risk of losing both a secure home environment and the best opportunity for integration into community life, including the world of work." However, proponents of the House bill argue their intent is to keep disabled children out of institutions. In addition to Medicaid and block grant services, the bill would give some cash payments to groups that work to keep children in their own homes.

The National Academy of Social Insurance panel is scheduled to release its full findings and recommendations this fall.

Under current law, each child in a family is entitled to an SSI check. A study last year by the Social Security Administration, which runs SSI, found 600 households in which there were six or more SSI recipients, including 60 households with 12 or more people on SSI. Not all are necessarily children, because SSI also supports low-income disabled adults and the elderly.

Most importantly, the report said, the SSI childhood disability program must be refocused to emphasize the ''medical recovery, physical and mental development, and job readiness of children with disabilities.''

One of the most persistent criticisms of SSI is that the program merely mails parents a check without requiring that the money be spent on rehabilitation.

The report's bottom line is that cash payments should continue.

''There are myriad special burdens placed on families with severe disabilities,'' said Jerry Mashaw, the chairman of the committee that wrote the report and a Yale University law professor. ''Cash support can ease those burdens, even if it cannot remove them. Low income families, already at the margin, face particular difficulties meeting the added costs associated with their child's disability.''

Children on SSI also receive Medicaid, but the federal health program does not cover some of the diverse needs of families caring for a disabled child, the report said.

Shirley Chater, Social Security's commissioner, said there is no argument children with disabilities living in poverty ''are some of the most vulnerable members of this society. SSI is the only national program for children with disabilities that provides poor families with cash assistance.''

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SSI
New Opportunities for Children with Disabilities

New eligibility rules for Supplemental Security Income (SSI) may enable up to a million children with disabilities in families with limited means to get cash benefits and free health services. This booklet answers parents' and advocates' questions about SSI . . .

- Which children are eligible for SSI?
- Can an eligible child receive free health care?
- Can children with working parents be eligible?
- How does Social Security define "disability"?
- How do children and their families apply?
- What can you do if your child is denied SSI benefits?
- How can children who have been turned down—even years ago—now claim back benefits?