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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. list	Clearance List (partial, DOB, SSN) (1 page)	10/18/1996	b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12021

FOLDER TITLE:
Children's SSI [Supplemental Security Income] Regulation #2 [1]

2018-0525-S
ry2239

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

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RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
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WHITE PAPER ON NEW DEFINITION OF CHILDHOOD DISABILITY FOR SUPPLEMENTAL SECCURITY INCOME

ISSUE: The welfare reform law provided a new general definition of childhood disability for the Supplemental Security Income (SSI) program intended to tighten eligibility requirements. Both the Congress and the Administration proposed tightening the requirements with virtually identical language. However, the statutory language is not precise. The Office of General Counsel at the Social Security Administration (SSA) believes that SSA has substantial discretion in drawing the eligibility line.

The President's FY 1997 Budget Request proposed the new childhood disability provision as part of a larger welfare reform bill with estimated savings of $8.4 billion over the six-year period from FY1997-FY2002 and $1.9 billion in FY 2002. These savings were based on OMB's understanding at that time of where SSA would draw the line in tightening the eligibility requirements. SSA also advised CBO of its intentions. When the legislation was enacted, the provision was scored at these levels.

Given the potential for SSA to exercise discretion in this area, this paper provides four options for drawing the eligibility line that differ considerably in terms of how many children will lose benefits. Option 1 represents the position on which the official scoring was based. Thus, from a budgetary perspective, choosing any of the other three options, each of which represents looser eligibility requirements than Option 1, has costs over the six-year period and in 2002, the target year for balancing the budget. Attachment 1 is a chart summarizing the impacts of each of the four options.

The decision will affect both current recipients and new applicants. Under any of these options, current recipients would not begin to lose benefits before July 1997. However, soon after a decision is made, SSA can begin to process new claims. Approximately 1,500 cases per day have been held since enactment in August, pending a resolution of this issue. In addition, there is a statutory deadline of November 20, 1996, for SSA to promulgate rules codifying the new definition, although implementation can begin prior to such codification. The first three options we have identified can be implemented immediately. The fourth can, in part, be implemented immediately, but also would require legislation.

BACKGROUND: Under SSI, an individual under the age of eighteen with physical or mental impairments of sufficient severity may be determined disabled for purposes of receiving means-tested cash benefits. Prior to enactment of welfare reform, a child was considered disabled under the law if he or she had an impairment of "comparable severity" with that of an adult. This lack of statutory specificity in the mid-1970s gave SSA considerable flexibility to implement the law. In response to a 1990 Supreme Court decision (*Sullivan v. Zebley*), SSA established an additional step (known as the Individualized Functional Assessment or IFA) to the disability determination process that it had established that allowed for a determination of disability at a lower level of

severity than was in place prior to that decision.

Prior to the establishment of the IFA in 1991, there were 300,000 children on the rolls. Today, approximately one million children are receiving benefits. The growth has been attributed mainly to a combination of the effect of the *Zebley* decision and an expected expansion in the number of children with mental impairments on the rolls as a result of changes to SSA regulations. If there had been no change in the law, SSA estimates that the rolls would have grown to 1.3 million by FY 2002.

Since the IFA was put in place, there has been a perception by many that the standard of severity had been lowered too far. This perception has been reflected, in part, by media reports on children receiving "crazy checks," i.e., SSI payments for exhibiting behavioral problems significant enough to qualify for benefits under these lower standards. Although neither SSA nor GAO has found any evidence of unqualified children being found eligible, the appropriate threshold for eligibility clearly became an issue.

Under the new welfare reform law, a child is disabled if he or she has an impairment which results in "marked and severe functional limitations." The new law also explicitly eliminated the IFA. By this action, Congress most clearly signaled its intention that the eligibility standards should be tightened.

To understand the options better, a rudimentary discussion of the determination process is helpful. The specialized terms used in the options have become familiar enough to Congressional staff to allow them to appear in letters sent to the President by a number of Senators and advocacy groups. Attachment 2 provides a brief description of the disability determination process and the terms used in describing standards of severity.

OPTIONS: Below is a brief description of each option.

Option 1 -- Significantly tighten eligibility -- eliminate the IFA and make no other changes.
An estimated 190,000 children currently on the rolls would lose benefits by September 1997. This option is consistent with the assumptions in the FY 1997 President's Budget and, therefore, has no cost in FY 2002 or over the six-year period from 1997-2002.

SSA would clarify the current procedures and regulations related to the determination process and eliminate the IFA as required by the new law. Except for elimination of the IFA, determination procedures would be essentially unchanged. The level of severity would be what is known as "Listing level" or "two marked" (see Attachment 2).

Analysis: **Option 1** is arguably closest to Congressional intent, as shown by the amount of savings scored by CBO and OMB during the debate on this issue and at the time of enactment. It is also the option with the largest impact and does not take advantage of SSA's existing regulatory authority to make changes to the disability determination process independent of the

welfare reform bill.

Option 2 -- Tighten eligibility by eliminating the IFA, but modifying current process. An estimated 145,000 children currently on the rolls would lose benefits by September 1997. This option would cost $0.6 billion in FY 2002 and $2.0 billion from FY 1997-2002.

After eliminating the IFA, SSA would modify the current process by adding a fifth "domain" to the four mental disorder-oriented domains currently used for the "functional equivalence" evaluation described in Attachment 2. The fifth "domain" would be a "motor domain." The addition of this physical disorder-oriented domain would ensure greater consideration of limitations caused by combinations of physical impairments. The level of severity would be "Listing level" or "two marked," with the "motor domain" essentially providing an additional opportunity to have a "marked" limitation in a second domain. In addition, SSA would put in place a standard form that adjudicators would be required to fill out when making their determinations. SSA believes that this form would promote greater uniformity in decision making and lead to more allowances than would otherwise occur.

Analysis: **Option 2**, by adding a "motor domain" and promoting the greater discipline and uniformity in the process that would result from the standard form, would be consistent with a policy to tighten eligibility and help ensure that a significant number of severely disabled children are found eligible, without lowering the standard of severity below that explicitly identified in the Conference Report as appropriate under the Listing. Independent of the passage of the welfare reform legislation, these are changes that make programmatic sense, at the same time that they have the effect of reducing the number of children who would lose benefits compared to the first Option.

Option 3 -- Tighten eligibility some by eliminate the IFA, modifying the current process, and adding a new additional step with a lower severity standard. An estimated 45,000 children currently on the rolls would lose benefits by September 1997. This option would cost $1.5 billion in FY 2002 and $6.6 billion from FY 1997-2002. .

After eliminating the IFA, a new additional step at a "lower-than-listing level" of severity would be included in the determination process. SSA's General Counsel believes that the legislative history can be read to allow for such a new step. In order to distinguish this option from the process prior to the new law, the severity standard would be higher than the IFA standard. The standard proposed by the advocates of "one marked and one moderate limitation" accomplishes this purpose in a manner that can be immediately implemented.

Analysis: **Option 3** would put SSA in the position of defending a much lower threshold than was anticipated by either the Administration or the Congressional conference committee at the time of enactment. However, SSA believes it would be legally defensible to create a more lenient test that would drop fewer children from the rolls. Given that SSI cash benefits link these children to Medicaid coverage, and that the welfare reform bill simultaneously makes many other

changes to the welfare system that could affect these families, it could be argued that it is appropriate to err on the side of SSA using its legal discretion to keep more children on the rolls. At the same time, Option 3 risks going so far that it might revive the "crazy check" stories that appeared in the media. To that extent, there is much less risk to Option 2 in terms of criticism from Congress.

Option 4 -- Tighten eligibility as in Option 2 and propose legislation to phase in the new rules for current recipients. An estimated 145,000 children currently on the rolls would lose benefits by 2002 as a result of continuing disability reviews. This option would cost $0.6 billion in FY 2002 and $3.9 billion from FY 1997-2002.

Under the new law, current recipients who are on the rolls as a result of the IFA are to be reviewed under the new definition no later than one year after enactment (August 1997). No child currently on the rolls would begin to lose benefits before July 1997. Under Option 4, the eligibility rules would be tightened as in Option 2 and legislation would be proposed to phase in the new rules for current recipients, such that those children on the rolls as a result of the IFA would not be subject to immediate review. These children would be reviewed under the new rules at the time of their regularly scheduled continuing disability reviews.

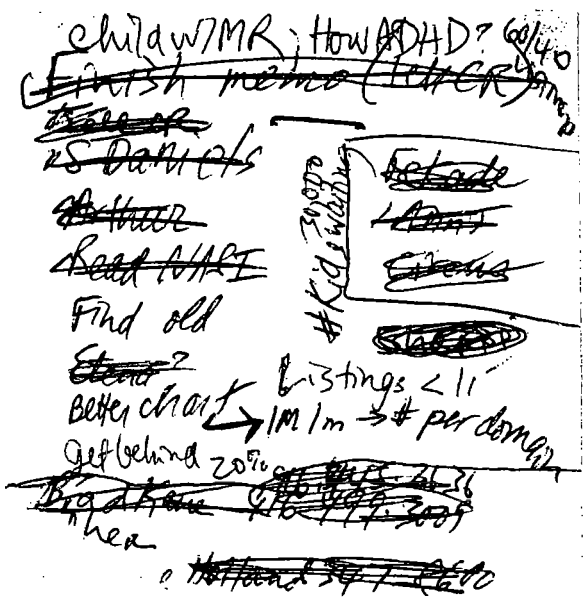
Option 4A -- Tighten eligibility as in Option 2 and propose legislation to "grandfather" current recipients from coverage under the new rules. No children currently on the rolls would lose benefits. This option would cost $0.8 billion in FY 2002 and $4.8 billion from FY 1997-2002.

As a variation on Option 4, the eligibility rules would be tightened as in Option 2 and legislation would be proposed to "grandfather" current recipients, such that those children on the rolls as a result of the IFA would never be subject to the new rules, also eliminating any requirement for immediate review.

Analysis: The number of children affected differs significantly between Options 2 and 3. Despite repeated efforts, SSA has so far been unable to identify an option that could be developed and implemented immediately that falls between these two in terms of the effect on children currently on the rolls. **Option 4** could serve as a compromise solution in terms of how quickly children currently on the rolls would lose benefits. **Option 4A** would be even more protective of children currenty receiving benefits. However, both of these options would require legislation, passage of which would be uncertain.

In this paper and the first two attachments, the options have been discussed in terms of the number of children who could lose benefits and the costs of the options in relation to savings anticipated at the time the bill was enacted. Attachment 3 provides a brief summary of which interested parties might provide support or opposition for each option.

Attachments (3)



def mod evalt'd
rel to mtd
"combined effect"
dof + 1 hand
episodic
upgrade mtd

20,000
* Vachon mtg
* Are they getting ready for likely outcomes?
* 1M2m diff than thought
* Brian pt re algo in Rege repealed on 1/1/m
* meaning of severe
* Only MA

Attachment 1

COMPARISON OF OPTIONS FOR DETERMINING SSI CHILDHOOD DISABILITY UNDER WELFARE REFORM

	SEVERITY STANDARD FOR DISABILITY	REDUCTIONS IN NUMBER OF CHILDREN RECEIVING SSI PAYMENTS		SSI AND MEDICAID COSTS FROM 1997-2002	EFFECT OF OPTIONS ON OUTLAYS IN 2002	
		CURRENT RECIPIENTS REMOVED FROM ROLLS BY SEPTEMBER 1997 (down from 1.0 million before welfare reform)	IN 2002 (down from 1.3 million before welfare reform)		Additional Eligible Children	Additional SSI and Medicaid Costs
Option 1	Significantly Tighten Eligibility	**190,000**	**250,000**	**0**	**0**	**0**
Option 2	Tighten Eligibility; Modify Determination Process	**145,000**	**185,000**	**$2.0 billion**	**65,000**	**$0.5 billion**
Option 3	Add New Step with Lower Standard than Options 1 or 2	**45,000**	**50,000**	**$6.6 billion**	**200,000**	**$1.5 billion**
Option 4	Same as Option 2, but Slow Phase-in of Current Recipients	**0**	**175,000**	**$3.9 billion**	**75,000**	**$0.6 billion**
Option 4A	Same as Option 2, but "Grandfather" Current Recipients	**0**	**110,000**	**$5.8 billion**	**140,000**	**$0.8 billion**

New

Attachment 2
DISABILITY DETERMINATION PROCESS

The disability determination process involves first identifying whether a child's impairment can be found to "meet or equal" the numerous impairments in SSA's 100-page tabulation of medical impairments (known as the "Listing of Impairments"). If a child's specific impairment (1) is not found in the Listing and (2) is not found by an evaluating physician or psychologist to "medically equal" an impairment in the Listing, the individual may still be determined to be "disabled."

In this third step, he or she can be found to have an impairment that is "equivalent" to the listing by an evaluation of the functional limitations caused by the impairment in a number of "domains" (or functional areas). These four "domains" include personal behavior, social behavior, cognition/communication, and concentration. In these cases, the disability determination hinges on the level of severity of the functional limitation. Individuals are found to have impairments "equivalent" to the Listing if they have "marked" limitations in at least two of the four "domains"-- the "two marked" criteria has become known as "Listing level severity." The IFA essentially added an additional step similar to the step above, but allowing for eligibility if a child had "one marked and one moderate limitation" or "three moderate limitations."

It has proven very difficult to generalize about the children who do or do not qualify at different levels of severity. The most meaningful distinction appears to be from the perspective of the decision maker determining whether or not the child meets the eligibility requirements. The decision maker is typically a State employee working on a claim in a State Disability Determination Service office or an SSA Administrative Law Judge adjudicating an appeal. The attached table identifies some of the key differences between "moderate" and "marked" limitations.

The key point of the table is to illustrate the difficulty of the decision as to whether a child's limitation in a given domain is "moderate" or "marked." The core question is whether a particular problem or limitation is "occasional" or "occurs sometimes" (and therefore is "moderate") or whether the problem is "frequent" or "persistent" or "constant" (and therefore "marked"). The broad range of judgment involved in the determination that a given limitation is "moderate" leads to the vast difference between the estimated effects of Option 2 and Option 3.

pers
social
cognitive

motor

Attachment 2 -- Table

Examples of Moderate and Marked Functional Limitations

CHILD #1 -- MENTAL IMPAIRMENT 14-year old boy with mild **mental retardation** who does not have specific medical findings to meet listings	CHILD #2 -- PHYSICAL IMPAIRMENT 12-year old girl with juvenile **rheumatoid arthritis** who does not have specific medical findings to meet listings
Example of Moderate in Personal Domain: can be on his own only in familiar places; can only handle small amounts of money; has to be reminded of personal care at home **Example of Moderate in Social Domain**: has only occasional difficulty maintaining relationships with children his own age	**Example of Moderate in Motor Domain**: occasional pain and stiffness in knees and ankles limits walking when pain occurs; unable to run; is sometimes symptom-free; sometimes has general malaise from illness and medication **Example of Moderate in Personal Domain**: pain and stiffness in wrist are less frequent and severe; when they occur, cause some difficulty in self-care activities such as eating, dressing, toileting **Example of Moderate in Social Domain**: when symptoms are present, tends to be irritable and avoids interacting with people.
Example of Marked in Personal Domain: gets lost when on his own; can't handle money; requires close supervision at home for bathing and dressing **Example of Marked in Social Domain**: has serious difficulty maintaining relationships with children his age	**Example of Marked in Motor Domain:** frequent pain and stiffness in knees and ankles requires cane to walk; unable to run; is rarely symptom-free; frequent general malaise from illness and medication **Example of Marked in Personal Domain:** frequent pain and stiffness in wrists causes serious difficulty eating, dressing, toileting, etc.; is rarely symptom free **Example of Marked in Social Domain**: Because of frequent illness and symptoms, is depressed, irritable, and socially withdrawn

Attachment 3
IMPLICATIONS OF OPTIONS

Option 1 -- The tightest definition of childhood disability is consistent with assumptions made by both the Congressional Budget Office and the Office of Management and Budget when scoring this provision of the welfare reform bill. It represents the position we believe the majority of the Republican conferees would say was intended by the change in the law. This position is reflected in the language of the conference report.

Option 2 -- The modifications to the regulation envisioned by this option represent the Social Security Administration's best efforts to identify an option that moderates the effects of the legislation without significantly reducing the standard of severity for eligibility childhood disability benefits. The expectation is that a majority of Republicans would not see this proposal as contrary to the spirit of the conference agreement, while advocacy groups would see it as an effort to at least recognize the problems of severely disabled children with multiple physical impairments who would not otherwise qualify for the rolls. However, advocacy groups and Senate moderates could be expected to find either Option 1 or Option2 unacceptable.

Option 3 -- The loosest definition is favored by various advocacy groups. It is also being championed by at least five Senators (Daschle, Conrad, Chaffee, Cohen, and Moseley-Braun). The rationale for this option comes from the position of advocates and some members of Congress that the Congress did not intend to establish a high severity standard, even after eliminating the IFA. While this position relies more on what the conference report does not say than on what it does say, it is not inconsistent with the SSA General Counsel's position that this option is within SSA's regulatory discretion. There would undoubtedly be significant negative reaction to this option from the Republican majority and it could be represented as negotiating in bad faith.

Options 4 and 4A -- Proposing legislation either to slow the phase-in for or to "grandfather" current recipients has not been discussed outside of the Executive Office of the President. The formulation for how long children currently on the rolls who might be found no longer eligible would continue to receive benefits was the last item of negotiation between the Administration and the Republican majority in this title of the welfare reform bill. These proposals would represent an effort to undo that part of the negotiations. To be satisfied with either of these proposals, advocates would have to perceive it as the best they could get under the circumstances. From SSA's perspective, passage of legislation would eliminate one of the thorniest of the implementation issues -- reviewing a large number of children in a relatively short period of time.

EXECUTIVE OFFICE OF THE PRESIDE
N T EXECUTIVE OFFICE OF THE PRESIDE
N T

18-Oct-1996 07:36pm

TO: (See Below)

FROM: William White
Office of Public Liaison

SUBJECT: Background on Children's SSI Meeting

October 18, 1996

TO: KEN APFEL
SKILA HARRIS
DIANA FORTUNA

FROM: BILL WHITE - OPL

SUBJECT: BACKGROUND ON CHILDREN'S SSI MEETING

DATE/TIME: Tuesday, October 22, 1996
2:00 - 3:00 PM

LOCATION: OEOB - Room 476

PURPOSE: To provide an opportunity for the leading disability advocates to voice their opinions on the proposed SSI benefits regulations.

BACKGROUND: Proposed new regulations have generated wide opposition from many groups advocating the rights of children with disabilities. Advocates claim the proposed regulations would eliminate almost one third of the children currently receiving benefits, especially children with mental illness. They say that the regulations are simply a means of cutting costs and cite the flawed studies showing fraud in the system as insufficient justification for imposing the regulations. They will press for a broader interpretation of the

definition of childhood disability.

PARTICIPANTS:		
	Marty Ford (Lead)	Consortium for Citizens with Disabilities / The ARC
	Al Guida	National Mental Health Association
	Mary Lee Allen	Children's Defense Fund
	Craig Obey	Nat'l Assoc. of State Mental Health Program Dir.
	Christine Koyanagi	Bazelon Center for Mental Health Law
	Charlie Barone	American Psychological Association
	Jonathan Stein	Community Legal Services

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Tom Yates SSI Coalition

October 18, 1996

CLEARANCE LIST:
CHILDREN'S SSI MEETING
OCTOBER 22, 1996, 2:00 - 3:00
O.E.O.B., ROOM 476

1.) Mary Lee Allen

(b)(6)

2.) Charlie Barone

(b)(6)

3.) Marty Ford

(b)(6)

4.) Al Guida

(b)(6)

5.) Christine Koyanagi

(b)(6)

6.) Jonathan Stein

(b)(6)

7.) Tom Yates

(b)(6)

[001]

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TO: Kenneth S. Apfel
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CC: Doris O. Matsui
CC: Cheri M. Carter
CC: Lee A. Satterfield

Frank Schuster - CMO
- dsn't know

Janet Bendann - clinical
Barry Eigen - operations

Not adeq
FE deals w/ rare disorders

AAP - res. on who came on

mod in [illegible] fuzzier [illegible]

ADL

motor - gd for yg children

assmt @ age 8

ADL -

Ruth Stein - Jacobi
718.918.5304

MH - asthma - arguable
- higher levels MR -
- behavioral - ADHD, conduct, LD

persistent | marked - mod.

asthma - marked - around yr drugs
acute attacks 1/mo

~~Mod~~ mild - average - 1-2x/fall

Mod - Sept - Dec 2-3 ER visits/mo.

Talk to Brian

SOCIAL SECURITY ADMINISTRATION
USA

OFFICE OF THE COMMISSIONER
BALTIMORE, MARYLAND 21235
(410) 965-3120

TO	FROM
NAME Diana Fortuna	NAME Brian Cayo
TELEPHONE NUMBER	TELEPHONE NUMBER
FAX NUMBER 202/456-7431	FAX NUMBER (410) 966-1463

REMARKS:

Here's a second try on trying to illustrate Childhood disability and the differences between various standards. Call me to discuss. Also, Can you get a Copy to Richard Green. Thks.

BRIAN

COVER AND 5 PAGES

6 page fax

Carol -

Not sure how helpful this is, but here is SSA's latest attempt to define the kids who could lose or keep SSI under various scenarios. It still doesn't do it the way I think it needs to be done but, not knowing when your conversation is supposed to happen, I wanted to send it along to you.

(I thought your remarks today were great!)

Diana

CHILDHOOD DISABILITY - ESTABLISHING THE STANDARD

- Of about 1,000,000 children receiving SSI disability benefits, we must redetermine the eligibility of only about 300,000 children because of the new law. These children had been allowed based on an Individualized Functional Assessment (IFA) or on consideration of maladaptive behavior as a separate area, both of which the new law eliminates when considering eligibility determinations. The remaining 700,000 are not affected by the new law because they meet or equal medical listings. The new law requires that these children be redetermined based on a new difinition of requiring a "marked and severe functional limitation".

- The issue is how to interpret the phrase "marked and severe functional limitation" in the law. The options being discussed are based on assessing various combinations of "marked" and/or "moderate" limitations in broad areas of functioning which are defined in regulations. Generally, limitations in two of the following areas are required:

  1. Cognitive/communicative functioning
  2. Social functioning
  3. Personal functioning; e.g., bathing, dressing
  4. Concentration, persistence, or pace in task completion
  5. Motor functioning (added under some options)

- Moderate and marked limitations fall on a scale of "none," "minimal" (or "mild" or "slight" or "not severe"), "moderate," "marked," and "extreme." "Extreme" in itself is disabling because it meets the medical listings.

- Attached are 4 examples of children with different sorts of impairments. Each child is portrayed with different levels of impairment severity showing what is required to meet each of the options. Note that the impairments chosen for illustration might cause other limitations than those in the examples.

- The first three options are set at the same level of severity (i.e., two marked limitations). The second and third options differ from the first in that they contain a policy enhancement (motor functioning) and procedural enhancements (a form and emphasis chronic episodic impairments) intended to ensure that all limitations are fully considered. The fourth and fifth options are set at lower levels of severity, involving combinations of marked and moderate severity.

Child #1- **Borderline Intellectual Functioning** (14-year-old boy with borderline intellectual functioning who does not have specific medical findings to meet a mental retardation listing.)

2 Marked Limitations Standard -

Marked in Personal: May be left on own for limited periods. Can take school bus but needs some assistance getting to the bus on time. Requires supervision at home for bathing, dressing, toileting.

Marked in Social: Has serious difficulty maintaining relationships with other children and adults. Is alternately withdrawn and physically aggressive.

2 Marked Limitations Standard, with Motor Functioning and Functional Equivalence Form -

Motor domain does not apply to this example. Use of form will help ensure potential for problems such as in the social area are explored.

2 Marked Limitations Standard, with Motor, Form, and Emphasis on Chronic Episodic Impairments -

Marked in Personal: Same as above.

Marked in Social: Has some social skills and appears to get along for awhile, but always becomes abusive after a time and relationships fail. Emphasis on chronic episodic problems helps focus attention on long-term consequences, not just on "good" days.

1 Marked and 1 Moderate Limitation Standard -

Marked in Personal: Same as above

Moderate in Social: Has difficulty maintaining relationships with children his own age, but does have some friends and relates reasonably well with authority figures and other adults.

Three Moderate Limitations Standard -

Moderate in Personal: Can be on his own in familiar places. Able to travel on school bus without assistance. Eats on his own, needs some supervision for bathing and dressing; toileting not usually a problem.

Moderate in Social: Same as above

Moderate in Concentration, Persistence, and Pace: Needs one-on-one supervision for complex task completion.

Child #2- **Behavioral Disorders** (13-year-old child with Attention Deficit Disorder who does not have specific medical findings to meet listings)

2 Marked Limitations Standard -

Marked in Concentration, Persistence, and Pace: Does not persist, serious difficulty in task completion; needs close supervision. Does not complete homework, in-class assignments, chores, or games.

Marked in Social: Has serious difficulty maintaining relationships with other children and adults, is alternately withdrawn and physically aggressive.

2 Marked Limitations Standard, with Motor Functioning and Functional Equivalence Form -

Motor domain does not apply to this example. Use of form will help ensure potential for problems such as in the social area are explored.

2 Marked Limitations Standard, with Motor, Form, and Emphasis on Chronic Episodic Impairments -

Marked in Social: Same as above.

Marked in Concentration, Persistence, or Pace: Can maintain focus on tasks for awhile in low-stress situations, but when left on her own, or as stress builds up even slightly, ability to sustain attention disappears. Emphasis on episodic problems helps focus attention on long-term consequences, not just on "good" days.

1 Marked and 1 Moderate Limitation Standard -

Marked in Concentration, Persistence, and Pace: Same as above

Moderate in Social: Has difficulty maintaining relationships with children his own age, but does have some friends and relates reasonably well with authority figures and other adults.

Three Moderate Limitations Standard -

Moderate in Social: Same as above

Moderate in Concentration, Persistence, and Pace: Needs one-on-one supervision to complete complex tasks, but sticks with schoolwork and chores.

Moderate in Personal: Can be on his own in familiar places. Able to travel on school bus without assistance. Eats on his own, needs some supervision for bathing and dressing; toileting not usually a problem.

Child #3- Physical Impairment (12-year-old girl with juvenile rheumatoid arthritis who does not have specific medical findings to meet listing)

2 Marked Limitations Standard -

Marked in Personal: Frequent pain and stiffness in wrists causes serious difficulty in eating, dressing, toileting; is rarely symptom-free.

Marked in Social: Because of frequent illness and symptoms, is depressed, irritable, and socially withdrawn.

2 Marked Limitations Standard, with Motor Functioning and Functional Equivalence Form -

Marked in Motor: Frequent pain and stiffness in knees and ankles. Uses a cane. Can't run. Rarely symptom-free; i.e., usually has some pain, stiffness, or feeling of illness from condition or medication.

Marked in Personal: Same as above

Note: Marked (or any other level) limitations in the Social (or any other) area would not be required since physical problems limit new motor area along with personal area.

2 Marked Limitations Standard, with Motor, Form, and Emphasis on Chronic Episodic Impairments -

Marked in Motor: At times, symptoms are diminished, but they are always present to some degree and recur in severity over time with some frequency. Emphasis on episodic problems helps focus attention on long-term consequences, not just on "good" days.

Marked in Personal: Same as above

1 Marked and 1 Moderate Limitation Standard -

Marked in Motor: Same as above

Moderate in Personal: Less frequent and severe pain and stiffness in wrists; when they occur, causes some difficulty in self-care activities such as eating, dressing, toileting.

Three Moderate Limitations Standard -

Moderate in Motor: Pain and stiffness in knees causes some limits in walking, but can get around without cane; difficulty in running.

Moderate in Personal: Same as above

Moderate in Social: Because of physical problems and symptoms, has difficulty in maintaining relationships with children, but does have some friends and relates reasonably well with adults.

Child #4 - Communication disorder and physical impairment (6 1/2-year-old girl with developmental articulation (speech) disorder and sickle cell disease).

2 Marked Limitations Standard -
Marked in Communicative: Speech is easily understood only by family members; child must frequently repeat herself to be understood by others.

Marked in Personal: Sickle cell disease causes fatigue, muscle weakness, and joint pain which seriously limit her self-care activities (of dressing, bathing, toileting).

2 Marked Limitations Standard, with Motor Functioning and Functional Equivalence Form -
Marked in Motor: Sickle cell disease causes fatigue, muscle weakness, and joint pain which seriously limit her physical activities (e.g., walking, climbing stairs, playing outdoor games).

Marked in Personal: Sickle cell disease causes fatigue, muscle weakness, and joint pain which seriously limit her self-care activities of bathing, toileting, dressing.

NOTE: With physical limitations divided between a Motor Area (gross and fine motor skills) and a Personal Area (self-care abilities), it would not matter in this example if the communicative area (or any other) were not marked (or any other level) in severity.

2 Marked Limitations Standard, with Motor, Form, and Emphasis on Chronic Episodic Impairments -
Marked in Motor: Attacks of sickle cell disease occur intermittently with some periods of relatively symptom-free activity, causing periodic fatigue, muscle weakness, and joint pain seriously limiting her self-care activities. Emphasis on chronic episodic problems helps focus attention on long-term consequences, not just on "good" days.

Marked in Communicative: Same as above.

1 Marked and 1 Moderate Limitation Standard -
Marked in Motor: Same as above.

Moderate in Communicative: Mispronounces many words and sometimes has to repeat herself to be understood by people outside the family.

Three Moderate Limitations Standard -
Moderate in Motor: Sickle cell disease resulting in occasional fatigue and muscle weakness which limits her physical activities.

Moderate in Communicative: Same as above.

Moderate in Social: Is ridiculed by some children because of her speech, so she does not talk in the classroom and in group play situations.

MATRIX - EXAMPLES FOR DIFFERENT APPROACHES ON CHILDHOOD

	1. Functional Equivalence (FE) as in Existing Regulations	2. FE, plus Motor Domain and Form	3. Same as 2., Plus Emphasis on Chronic Episodic Impairments	4. 1 Marked plus 1 Moderate
Physical Girl with Juvenile Rheumatoid Arthritis. Does not meet a listing.	Marked in two areas: Personal (Pain in wrist causes difficulty eating, dressing, etc.; pain in legs requires cane to walk even short distances) and Social (depressed, irritable, and socially withdrawn.)	Additional allowances. Two marked without considering social. Motor (requires cane to get around and can't carry school books) and Personal (serious limitations in self care such as dressing, eating, etc.) Some additional allowances could result due to form.	Additional allowances. Would focus attention on long-term consequences of impairments, not just "good" days.	Additional allowances. Only one marked limitation needed; second area could be moderate (e.g., Personal - pain in wrist causes some difficulty in personal care.)
Mental Retardation Child with mild mental retardation. Does not meet a listing.	Marked in 2 two areas: Personal (Needs close supervision of bathing, dressing and eating) and Social (serious difficulty maintaining relationships.)	Addition of motor area would have no effect. Some additional allowances could result due to form.	Effects of MR not usually episodic - additional allowances unlikely	Additional allowances. Only one marked limitation needed; second area could be moderate (e.g., Social - difficulty getting along with peers; has some friends. Relates reasonably well to adults).

Behavioral Disorders - Child with Attention Deficit Disorder (ADD). Does not meet a listing.	If impairment does not medically equal a mental listing based on marked limitations in two areas of functioning (e.g., Social functioning and Concentration, persistence, or pace), impairment unlikely to functionally equal a listing either.	Addition of motor area would have no effect. Some additional allowances could result due to form.	Additional allowances possible if, e.g., child's behavioral and attentional problems are sometimes worse, sometimes better. Would focus attention on long-term consequences of impairments, not just "good" days.	Additional allowances. Only one marked limitation needed; second area could be moderate, e.g., Concentration, persistence or pace marked (serious difficulties in task completion); Social moderate (considerable difficulty getting along with peers; has some friends. Relates reasonably well to adults).

Cover + 1 page fax

TO: Carol Rasco

FROM: Diana Fortuna

DATE: December 18, 1996

FYI, attached is what Richard Green of OMB was able to work up as examples of the children's SSI cuts. He was planning to do 2 similar sheets -- one for a child with mental retardation and one for a child with other mental/behavioral impairments, but I told him I wasn't sure he should bother because I didn't think the format was so great.

DRAFT

	CHILD #3 -- PHYSICAL IMPAIRMENT EXAMPLE 12-year old girl with juvenile **rheumatoid arthritis** who does not have specific medical findings to meet listings stays on the rolls if:
Option #1 Assumed Policy 2 marked	**Marked in Personal Domain:** frequent pain and stiffness in wrists causes serious difficulty eating, dressing, toileting, etc.; is rarely symptom free **Marked in Social Domain**: because of frequent illness and symptoms, is depressed, irritable, and socially withdrawn
Option #2 OMB/DPC two marked with motor domain and severe episodic limitations	**Marked in Motor Domain:** frequent pain and stiffness in knees and ankles requires cane to walk; unable to run; is rarely symptom-free; frequent general malaise from illness and medication **Moderate in Personal Domain**: pain and stiffness in wrist are less frequent and severe; when they occur, cause some difficulty in self-care activities such as eating, dressing, toileting **Marked in Social Domain**: because of frequent illness and symptoms, is depressed, irritable, and socially withdrawn
Option #3 one marked and one moderate	**Moderate in Motor Domain**: occasional pain and stiffness in knees and ankles limits walking when pain occurs; unable to run; is sometimes symptom-free; sometimes has general malaise from illness and medication **Moderate in Personal Domain**: pain and stiffness in wrist are less frequent and severe; when they occur, cause some difficulty in self-care activities such as eating, dressing, toileting **Marked in Social Domain**: because of frequent illness and symptoms, is depressed, irritable, and socially withdrawn
Standard prior to welfare reform -- 3 moderates	**Moderate in Motor Domain**: occasional pain and stiffness in knees and ankles limits walking when pain occurs; unable to run; is sometimes symptom-free; sometimes has general malaise from illness and medication **Moderate in Personal Domain**: pain and stiffness in wrist are less frequent and severe; when they occur, cause some difficulty in self-care activities such as eating, dressing, toileting **Moderate in Social Domain**: when symptoms are present, tends to be irritable and avoids interacting with people.

SOCIAL SECURITY ADMINISTRATION'S EVALUATION OF DISABLED CHILDREN MENTIONED IN VARIOUS NEWSPAPER ARTICLES

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A

Divider Title: _____

Neville Barnhill

There is very little evidence from the article on which to base a definitive statement about his disability. However, Neville would be found disabled under Listing 110.06 if he has been diagnosed with Non-Mosaic Down Syndrome. Even if he has Mosaic Down Syndrome, a form of the disease from which a range of limitations from mild to very severe can result, the little information provided would tend to imply that he would be found to medically or functionally equal a listing (e.g., "...he has virtually lived in a hospital since he was born.") and therefore, eligible for benefits.

(There is even less detail in this article about 2 of Neville's siblings, barely more than diagnoses. These children could easily be found to meet, medically equal or functionally equal a listing with more detailed information.)

Los Angeles Times
F/CCt SUNDAY, AUGUST 25, 1996

Broad Reach of Welfare Reform Stirs Anxiety

By SAM FULWOOD III
TIMES STAFF WRITER

WASHINGTON—When President Clinton delivered on his campaign promise to "end welfare as we know it," he also led millions of Americans who depend on federal assistance into a new world that nobody knows.

Few pieces of legislation ever have the sweeping impact of the welfare legislation that Clinton signed. And few stir up as much anxiety.

Not only prototype "welfare families"—those headed by young, single mothers—will feel the new law's sting. So will many others, including unemployed middle-

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aged people, children with disabilities and legal immigrants of many descriptions.

Congressional budget-cutters expect to save taxpayers $55 billion over six years by tearing apart the welter of welfare programs that have accumulated in the 61 years since the enactment of Aid to Families With Dependent Children. The legislation's supporters said its tough-love provisions will make self-respecting and productive citizens out of the millions of Americans now trapped by their dependency on the federal dole.

Many people on the receiving end of the programs, by contrast, are terrified of what the future might hold.

What follows are snapshots of four individuals representing categories of Americans whose lives will not be the same in the uncharted territory that awaits them.

Middle-aged unemployed

Sharon McGee scours her Compton neighborhood for empty bottles and cans to earn spare change. On weekends, she stages yard sales outside her apartment. She has not worked full time since suffering a breakdown following the death of her mother in 1985.

McGee, 44, who is unmarried and has two adult children, manages to get by, with a little help from Washington. But she is worried that on Oct. 1, she will no longer qualify for the $315 in food stamps she now receives each month. Assessing her options, the former building manager said, half-seriously, that she is contemplating a life of crime.

"I know there's easy money in selling drugs, so that's what I may have to do to eat," she said, laughing sardonically. "When the police stop me, I'm going to say: 'Washington said I had to fend for myself the best way I could.' I'll tell them this is Washington's survival technique."

The legislation that Clinton signed is not as harsh as the House-passed bill, which would have let the states define eligibility for food stamps. The new law keeps that responsibility in Washington, although it still threatens people like McGee—adults with no dependent children and no steady jobs.

The legislation's fine print says able-bodied people between the ages of 18 and 50 who have no dependents will qualify for food stamps for only three months of every three years unless they work—or participate in job-training programs—at least 20 hours a week.

The goal is to force people like McGee into self-sufficiency. But because the legislation provides no additional funding for jobs programs, McGee and others like her fear that they are more likely to forgo food than find work.

She said she has applied, without success, for a host of jobs in which she could use her typing and bookkeeping skills. But since recovering several years ago from severe clinical depression made worse by alcohol abuse and a prescription drug addiction, she said, "nobody is going to hire me."

Not long ago she applied for a job as a waitress. "The owner said when I called him that I was overqualified and that he was looking for someone younger," she said. "So tell me, how am I going to eat if they take away my food stamps?"

Immigrants

Aida Ulloa doesn't speak English.

She is in the United States legally. But she is not a citizen and, at age 74, she is unlikely ever to learn the language well enough to pass the citizenship exam.

That puts her in the class of people who stand to lose the most from welfare reform: legal immigrants. She stands to lose what she calls *la ayuda*—the help—a mixture of federal support payments that includes $470 a month in Supplemental Security Income for elderly poor people, $77 a month in food stamps and health insurance under the Medicare and Medicaid programs.

A sad-eyed woman, Ulloa looks like someone's grandmother. But she never had children and has no living family members. She left Cuba shortly after her husband died in 1989 and the Castro government confiscated their home and what remained of his shoe factory.

"I came to America to get away from the Communists," she said in a small voice amplified by an interpreter at the Little Havana Activities and Nutrition Center of Dade County, Fla., a private, nonprofit immigrant service organization. "In Cuba, the government took away all that I had. I thought I would do much better here."

Ariela Rodriguez, who directs the Little Havana center, described Ulloa as "a typical case, like so very many others we see here." She said many of the Cuban immigrants are elderly and single, people who will never learn enough English to become citizens but have nowhere else to go.

"The old people came here as part of the family reunification," Rodriguez said. "They didn't come to get anyone's job. But once they got here, the families didn't have any way to support them. So, as soon as they could, the family or some sponsor got them hooked up with public assistance. They did the best they could."

To become citizens, immigrants must pay about $100 for photographs, fingerprinting and paperwork—plus the dreaded citizenship exam. "The exam is done in English," Rodriguez said. "If you're over 65 and have been here 15 years or more, then it's in Spanish."

Many fail the test because they do not have the language skills. "After flunking twice they have to start all over again and pay the fee again," Rodriguez said. "Many can't retain their English between the exam periods. They're in legal limbo. Those people are going to lose [welfare benefits] because they're not citizens."

Ulloa is one of them. She arrived in the United States on a visitor's visa and was permitted to stay under federal laws protecting Cubans escaping the Castro regime.

She secured a place to stay with a friend of friends from Cuba, and she even found a minimum-wage job at a factory, stitching together slippers. After providing her with five years of self-sufficiency, the factory closed.

Unable to find another job, she retired and lived off federal assistance for the poor. She did not qualify for Social Security benefits because she had worked only half of the minimum 10 years before her forced retirement.

"The [governmental] process here is very difficult to comprehend," she said. "But what I do understand scares me because it means I'm going to lose *la ayuda*."

In the meantime, she continues to study English and "pray for a miracle" when she takes the citizenship examination.

Disabled children

Eleven years ago, when Sharon Barnhill's newborn son, Neville, was hospitalized with Down's syndrome, a doctor offered some grim advice: It would be better for all concerned if Neville died.

It was advice that Barnhill could

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not accept. But in his 11 years, Neville has already undergone both heart and brain surgery, and he has been confined to a hospital for a host of infectious diseases.

"I have never agreed with that doctor," Barnhill said recently, "but I understand where he was coming from because Neville has virtually lived in a hospital since he was born."

Barnhill, a single mother who lives in the Chicago suburb of Blue Island, has two younger children, and both of them also have severe health problems. Tiffany, 7, has cerebral palsy and requires therapy and leg braces. Jarel, 3, is autistic and requires frequent hospital stays for a disorder that prevents food from staying in his stomach.

Barnhill never married. The father of Tiffany and Jarel stayed with her and the children for a few years but, Barnhill said, "he retreated to drugs to cope with all the stress" of raising a family of disabled children.

She holds down two jobs and earns $30,000 a year—enough for an ordinary family of four to get by but scarcely enough for hers. She gets a little help, in the form of about $2,750 a year to defray some of Neville's and Jarel's medical costs, from the federal SSI program, which was established about 25 years ago to help three categories of poor people: the elderly, the blind and the disabled.

To Barnhill, the SSI program is worth far more than $2,750 a year. Eligibility for SSI also qualifies Neville and Jarel for federally subsidized health insurance under the Medicaid program.

The welfare reform law tightens SSI eligibility for the 800,000 disabled children who do not qualify for benefits. It remains unclear which children will be cut off, according to social workers advising parents in Barnhill's situation.

It is Barnhill's nightmare that Neville and Jarel may no longer qualify—which would cost her not only $2,750 a year but also the Medicaid benefits. "If the SSI people called and said that they were keeping their check but that I could continue to get the [medical] assistance, that would be fine with me," she said. "But when the SSI ends, I won't have medical coverage."

In that case, she said, she will have only one option left.

"Parents like me will have no choice but to put their children in an institution," she said in a strong, matter-of-fact voice. "I'll probably have to decide which one. But that's no choice I'd wish on any parent."

Welfare mothers

Shirley Smith is among the first welfare applicants to be put on notice. The clock is ticking. Two years and then it's time to go to work.

She swears this will not be a problem.

Smith comes from a long line of working people, no welfare recipients among them. She remembers accompanying her mother to her job as a cook in a veterans home and greeting her father when he finished his shift at the foundry. Her siblings, seven in all, toil as security guards, government clerks, housekeepers.

And Smith, 36, worked steadily, most recently as a cook in an Illinois restaurant. But then her daughter got in trouble, and Smith wound up as legal guardian of her two grandchildren.

That is why she found herself this week in a place she never expected to be: sitting in a Los Angeles welfare office, waiting for her name to be called on a bullhorn so that she could apply for Aid to Families With Dependent Children.

"I don't know how much you get in California," said Smith, who moved to Los Angeles because she has relatives here who can help take care of the two children, 3-year-old Yolanda and 11-month-old Yondale. "But I know it's not the $200-plus a week I got when I was working. Plus, you feel good inside taking your butt to a job everyday."

Under the welfare legislation signed by Clinton, Smith and 2.7 million other poor parents and children in California will be forced off the welfare rolls within two years of their first benefit check, which now averages $594 a month in Los Angeles for a family of three.

Beginning in October, the federal AFDC program will cease to exist and states will have vast new authority to run their own welfare programs. But the new law mandates that states must move recipients from welfare to work in two years or less and limit each family to five years of aid in a lifetime.

The legislation includes funding for child care for former AFDC families and the guarantee of continued health care under Medicaid. But there is no new money for job training or placement.

Smith said she has no quarrel with the strict time limits—if the government helps people learn a trade or prepare for the workplace.

"It may sound cruel, but let's get real here about the two years," she said. "You can get trained in several different things in that amount of time. But before they cut everybody off, they better give them some training. If you think crime is bad now, just wait. People won't wait around and let their kids starve."

Smith said she has done everything in her power to avoid coming to this bleak government office on Beverly Boulevard, noisy as a train station, with its metal detector, speckled linoleum floors and falsely cheerful signs that say, "We're all part of Team America" and "Tomorrow's Success Begins Today."

Squeezed between other women with babies on their hips and diaper bags on their shoulders, most of them Spanish-speaking, Smith explained that she had quit her job in the Midwest because she had no one to care for the little ones.

In Los Angeles, she is living with a younger brother who works nights as a security guard. He is willing to mind the children during the day once Smith finds a job, which she said she has been seeking since June.

"As long as it's legal, I'll work," she said. "Not everybody wants to sit around and collect—or not me anyway. That's why it took me so long to come down here. You're talking to somebody who's been searching."

Smith said she has applied for restaurant, housekeeping, warehouse and security jobs, "but nobody calls back or they're not hiring." She hopes something will turn up before long.

In the meantime, she said, not even assistance from relatives can help her make it if she does not get her AFDC check.

"I don't want to walk up to anybody and say, 'Give me your purse,' " she said. "But I can't starve, and I can't let these babies starve."

Times staff writer Jane Gross in Los Angeles contributed to this story.

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B

Divider Title: _____

Hunter Steinitz

Hunter would be eligible for benefits since her impairment functionally equals examples 5 or 7 in our regulations. She needs very frequent therapy and prolonged amounts of time for care. There is also a medical need for 24-hour-a-day supervision.

ID:STEINITZ FR:PERLMU-LMU;09/18,16: VER00DAY LH
17:08 18-SEP-96

PITTSBURGH POST-GAZETTE

DATE: Sunday, May 5, 1996
BYLINE: ELLEN M. PERLMUTTER

A LIFE IN THE BALANCE

THE BATTLE TO TRIM MEDICAL SPENDING COULD UPSET THE NETWORK OF CARE USED TO TREAT LITTLE HUNTER STEINITZ, WHO SUFFERS FROM A RARE SKIN DISEASE

The biggest worry Patti and Mark Steinitz had before their daughter's birt was what to name her.

Patti was 36 years old and felt good. Her morning sickness had abated earl in her pregnancy. Sonograms and amniocentesis, the chromosonal abnormality te that also reveals the baby's sex, gave both mother and unborn daughter a clea bill of health.

They wanted a name that began with the letter H to remind them of Mark's late mother, Henrietta. They found the answer scrawled on a blackboard at a children's shoe store.

Hunter.

An unusual name for a girl, they admitted, but they liked it. It was Oct. 15, 1994, and Hunter Elizabeth Steinitz was due in five weeks.

That night, though, Patti's water broke. And she had no contractions.

''Something's wrong,'' Patti told her husband, as they dressed to go to th hospital. ''Something has to be wrong.''

On Oct. 17, after two days of bed rest at Magee-Womens Hospital, doctors induced labor.

Specialists arrived at the delivery room. They anticipated that the baby would require immediate attention for underdeveloped lungs, a common occurren in preemies.

Hunter weighed 5 pounds, 3 ounces, and doctors immediately whisked her to table across the room.

Mark, who had never experienced the birth of a child, thought nothing of t commotion. Patti was uneasy. She had an 11-year-old from a previous relationship, and the birth had been nothing like this.

They put Hunter into an incubator and rolled it over to the delivery table where Patti still lay.

Hunter's skin was neon pink and covered with white, tough scales - like th hide of an elephant.

A doctor told the new parents: ''Your baby has a skin disorder. It's calle Ichthyosis. We don't yet know what type, but we know it's severe.''

The infant looked so raw that Patti wanted to know how much it hurt.

''She looked like nothing I'd ever seen before,'' Patti said. ''She had bulging eyes. That's what I remember. Mark didn't know what to expect, but I knew. I knew. My baby wasn't well.''

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It seemed surreal for Patti, who grew up on the North Side and only two years before was living a life as a single mom. When she met Mark in June 199 through friends, she was, and still is, a Pittsburgh police officer - first i Oakland, then on the South Side for 10 years before being transferred to the North Side station. Mark, who was living in Monroeville, had gone into his mother's picture framing business with her, which he is now in the process of closing since her death. The couple live in Observatory Hill on the North Sid

(MORE)

The condition that afflicted their daughter was rare. Few people have heard of Harlequin Ichthyosis, also known as Harlequin fetus. A genetic disorder caused by the mating of two rare, recessive genes carried by both parents, the condition is present in just 1 to 5 of every 5 million babies born in the United States each year.

Hunter's skin grows so fast it cannot shed effectively. It thickens easily, becoming scaly. Her body has trouble regulating its temperature. Dehydration can occur. The extra skin can tighten across her abdomen and chest, restrictin breathing. The skin can crack, opening her up to infections.

The Foundation for Ichthyosis and Related Skin Types Inc., knows of two other children in the United States with the same disorder, a girl and a boy i San Diego and Houston.

No child with Harlequin Ichthyosis has lived beyond her teens; most die within a few months of birth.

Yet because of the concentrated efforts by her parents and professionals, the cheerful, active 18-month-old has defied all medical and social presumptions.

She loves the book, ''The Little Engine That Could.'' She can crawl and wal as uneasily as any toddler.

Two weeks ago, she amused a visitor with her royal Queen's wave. The gentle twist of a raised right wrist that comes so easily to everyone else, Hunter ha to be taught. The skin is so tight around her wrist that mobility can be painful.

''Hi! Hi!'' she shouts into a telephone receiver with gusto. Then she laughs, straight from the belly.

Her tremendous progress is a result of concentrated health care and diligen professional help in movement and speech - which has cost more than $300,000 i federal, state and private insurance funds during Hunter's young life.

More than half of the total, which accounts for Hunter's nursing care, is paid mostly by federal and state Medicaid funding.

Patti's private health insurance with an HMO pays for Hunter's visits to si specialists, hospitalization, medical procedures and for some medications.

That doesn't include the electric and water bills, which have tripled since she was born, and the $100 a month for over-the-counter topical ointments.

And now, as federal and state governments race to cut their outlays for medical services, the consequences for children like Hunter are becoming all too apparent.

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First, the Republican-controlled Congress wants to restrict the definition of disability. If the categories of eligible medical assistance are restricted Hunter could lose her disability classification.

She could also lose her medical assistance because Pennsylvania may use parental income as part of the criteria. While specific salary levels have not been determined, advocates fear that the Steinitz's income of just under $47,000 last year could be too high for eligibility.

Then there is the early intervention program for which children like Hunter receive special services, such as physical, speech and occupational therapies.

Pennsylvania receives $12.5 million a year from the federal government to upport these services. But there's a catch: No child can be turned down.

(MORE)

Gov. Ridge, however, wants the state to determine whether a child is eligible. He also wants to cap spending for the children who receive the services. That's because it costs the state $42.5 million more a year than wha it receives from the feds to provide the services, or about $8,000 a year for each of the estimated 16,000 Pennsylvania children who receive the services, according to the state Welfare Department.

''It's going to double in a five-year period, and it has a lot of people concerned, which is why the governor wants out - because we can't control the cost per child,'' Nancy Thaler, deputy secretary of the state Department of Public Welfare's Office of Mental Retardation, said at a hearing in Oakland.

It's not that parents like Patti and Mark view government help as a bottomless pit.

They see it as a means of helping families help their children become productive adults.

''Which way does the government want it?'' asked Patti.

''We'll have to quit our jobs and go on welfare. I don't see any other way out.'' That is not an option they want to explore.

At stake, too, could be other federal funding that enables Hunter to recei the nutritional supplements her 17-pound body craves. She has digestive problems not directly related to the Harlequin disorder, but ones that interfere with her getting enough essential nutrition.

In recent days she has worried doctors because she has been unable to keep her food down.

''Nobody can understand what we go through,'' Patti recently told state Re Don Walko, D-North Side. ''I fight for her every day. I fight with the insurance company. I'm always fighting with someone.''

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It took seven weeks for Hunter to make her first trip home. After three weeks at Magee, including the first nervous meetings between Hunter and her older sister, Dana, she spent another four weeks in a transitional unit in Shadyside.

Every midnight a nurse arrives at their 2 1/2 -story home to administer medicated eyedrops, take Hunter's temperature and pulse, and rub her body wit at least one of the 15 topical ointments - all every two hours. The humidifie must be monitored also.

''We deal with 12 hours a day spent on Hunter's care alone,'' Patti said. ''We juggle two full-time work schedules, Hunter's routine and doctor appointments.

''Thank God I have a wonderful boss who allows me flexibility in my work hours to care for Hunter. Even so, my husband and I take days off work for doctor appointments, and I take days off to spend time with my forgotten chil Dana, who loves her sister so much.

''Dana is also acting out. Her grades have dropped in school and she is angry with me over things I cannot change. I cannot fix Hunter so that we can live a normal life.

''I don't know if parents of normal children can appreciate as much as we how truly thrilling Hunter's accomplishments are.''

Her voice choking, she added:

''She played with her first friend last week.''

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More than anything in the world, Patti and Mark strive for normalcy in the frenzy around them.

For now, Mark is home Sundays and Mondays. Patti is off Thursdays and Fridays. On the other days, nurses take over.

Once a week, medical personnel come to the house to evaluate Hunter's progress. Other days, there are a variety of therapists working with her coordination, dexterity and other physical motions.

Every day, Hunter must be bathed in the morning and evening - each bath an up to two-hour event so her skin can be carefully smoothed and the extra skin peeled from inside her nose and ears.

''The evening bath has become a joint effort. It's something we do together. It's normal, though for me normalcy has changed a lot,'' Mark said.

While Mark fills the tub and spreads oversized bath towels on the floor in Hunter's bedroom, Patti makes a game with Hunter to climb the stairs to the second floor. She switches on lively music and spreads a plethora of lotions, ointments and other medications around her.

Hunter bounces to the music. She loves the warm water, the only part of the day when her skin doesn't itch. She squeals at the water pic, grabbing at the sensation of the waterfall that squirts into her ears. She drinks from it and gurgles.

Often, Dana joins in, splashing water on her baby sister.

Mark holds her; Patti gently scrapes away the peeling skin. She uses a pecial instrument for her ears and nose. Hunter becomes pinker and pinker as her new skin glistens in the bath water.

Afterward, looking shiny from the ointment and petroleum jelly covering her, Hunter proceeds with her nighttime ritual of saying goodnight to her lamp and her clock and her stuffed animals.

While Mark empties the bathwater, Patti gently rocks Hunter and puts her into the crib. It's 10 p.m.

In two hours, the overnight nurse will arrive and her parents can go to bed.

And then begin their day again, tomorrow.

CAPTION: PHOTO: Eighteen-month-old Hunter Steinitz was born with a rare skin disorder called Harlequin Syndrome. Hunter's skin grows so fast it cannot shed effectively. Here Hunter's mom, Patti, clears away loose skin in the outer ear during one of the two daily baths that Hunter gets to keep her skin supple.

PHOTO: Patti Steinitz recently visited with state Rep. Don Walko, D-North Side, to explain how the potential cuts in state and federal funding would effect children with disabilities. ''Nobody can understand what we go through. I fight for her every day. . . . I am always fighting someone.''

PHOTO: Hunter and her mom, Patti, visit with neighbor Rita Formhals. Patti feels that the love and constant stimulation at home have helped with Hunter's development.

PHOTO: Patti shares a tender moment with Hunter during one of the child's two daily baths. Bath time can be a relief to Hunter because the warm water makes r skin smooth and less itchy.

(MORE)

PHOTO: Annie O'Neill/Post-Gazette Photos: Once a week, Hunter is visited by Sharon Clougherty, center, a child therapist, and Rebecca Klaw, right, both from ARC Allegheny.

PHOTO: Hunter's father, Mark Steintz, gives his energetic 18-month-old a dose of Propulsid, a drug that helps her stomach to empty more quickly, Her 17-pour bady canot afford to lose any nutrition.

PHOTO: Hunter gets more than 15 topical mediciation to keep her skin form becoming infected or too dry.

(END)

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Divider Title: _____

La'Shaira Cooke

Children with insulin dependent diabetes mellitus usually do not require the kind of parental supervision described in this article. The article does not provide the kind of specific information that would be required to determine if the level of supervision provided by Ms. Cooke is medically necessary or not, e.g., specifically, how "often" in the last year was there a need for the school nurse to administer additional insulin injections and for La'Shaira's mother to go to the school for this purpose because the nurse was not available. If this level of supervision is shown by the evidence to be medically necessary or prescribed by La'Shaira's treating physician, then she would be eligible for benefits since her impairment would meet functional equals example number 7 in our regulations, i.e., requirement for 24-hour-a-day supervision for medical or behavioral reasons.

A Disquieting Spring

For this Philadelphia mother and daughter, the dissolution of Supplemental Security Income spells disaster.

BY DAISY FRIED

Vanessa Cooke and her six-year-old daughter, L'Shaira, must remain strong.

"Here go my needles," says six-year-old La'Shaira Cooke, at a table near a window of the small apartment where she lives with her mother and sister on the fifth floor of a West Philadelphia high-rise. "Here go my MPH. Here go the things to put in my machine. Here go my pricker."

The first-grader is laying out the components of her "One Touch II" gadget, which identifies her blood-sugar level. Her fingertips are calluused like a guitar-player's from the pricks she gives her fingers everyday to draw blood for testing.

A little more than four years ago, after La'Shaira was diagnosed with diabetes, her mother, Vanessa Cooke, began applying for Supplemental Security Income (SSI): federal cash grants of about $450/month for low-income children with disabilities. After repeated denials, her application was approved this January.

But Vanessa and La'Shaira have yet to see a cent, and Vanessa fears they may never receive any money. If the Republican Congress—which alleges that SSI is rife with parental fraud—has its way, cash grants to disabled children will be virtually eliminated.

Since she was 22 months old, La'Shaira has been in danger of insulin reflection. Her mother has had the full-time job of (1) making sure her blood sugar is checked four times a day, (2) giving her immediate insulin injections in addition to her three regular daily injections if anything is out of whack, (3) regulating her special diet, and (4) monitoring her blood sugar.

Despite such vigilance, La'Shaira's condition has never been under control. Vanessa carries a beeper, and is often summoned to school when La'Shaira's blood sugar deviates from the norm. She cannot afford a car, and so she depends on cabs or public transportation. The demands of her daughter's illness disallow Vanessa, who has a high school degree and some college, to get a job.

"I'm capable," she says, "but who would hire me when I always have to be running off to La'Shaira's school? I have my priorities. Taking care of La'Shaira is what I do."

Vanessa receives $405 of public assistance a month, plus $213 worth of monthly food stamps to support her family of three. "I take from Peter to pay Paul," she says. "It's a constant tug o' war. Now why would I fight this long if I had no reason? It is time-consuming. It would be much easier to get a job."

The SSI program was created in 1974 to aid low-income blind and disabled persons. Allocations of aid were made based on a list of eligible disabilities.

In a 1990 decision, *Zebley v. Sullivan*, a conservative Supreme Court decided by a 7-2 margin that policies used to determine children's eligibility for SSI were illegal because the existing listings, created to assess adults' inability to work, failed to cover all disabling illnesses and abnormalities. *Zebley* showed that needs varied with each individual case.

To deal with the huge variables, the Social Security Administration (SSA), which administers SSI, instituted the Individual Functional Assessment (IFA), where state examiners and physicians look at a child's limitations in various areas of development and functioning vital to a child's life. IFA is especially helpful when children have a combination of mental and physical impairments that, prior to *Zebley*, each of a child's conditions would be considered on its own merits, explains Jay Scullin, director of Social Services of United General Hospital in Philadelphia.

"If you had a child who was mildly retarded, but whose IQ did not meet the mental retardation guidelines for disability purposes, and who also had mild cerebral palsy, the child would not receive assistance. After *Zebley*, with the IFA, the child's conditions would be considered cumulatively," says Scullin.

It was thanks to IFA that a municipal judge finally found that La'Shaira Cooke's "special diet far exceeds her food stamp allotment, beeper maintenance, cab fares and other related expenses take up a substantial part of the family budget."

IFA is the particular bugaboo of legislators who want to dismantle SSI. Pennsylvania's own Senator Rick Santorum called SSI a "travesty" in a May 1994 *Washington Times* piece, stating that "abuses of the program have been encouraged by recent changes in the rules under which children's SSI eligibility is determined. Essentially, children can now qualify if they cannot engage effectively in age-appropriate activities." He also alleged that "there is no assurance that the cash will actually be used to help the disabled child."

In 1987, 300,000 children received SSI cash grants. After *Zebley*, awards to children skyrocketed, largely because eligibility was opened up. In February of 1995, children receiving SSI checks numbered 892,500, some forty thousand of them in Pennsylvania.

A review of SSI by the Department of Health and Human Services reports that, in fact, an estimated 1.3—1.4 million kids meet SSI's disability and income criteria.

Since 1991, because of strict regulations, about a million children have been *denied* SSI under IFA.

A just-released report by the United States General Accounting Office, a body whose staffing and funding depends upon Congress, says that "measuring the extent to which coaching may actually occur is extremely difficult," and calls evidence of fraud "scant."

The report adds that studies by the SSA's Office of Disability found that less than half of 1% of all child applications *might* reflect coaching, and that most of the suspicious applications had been denied benefits anyway.

Community Legal Services lawyer Jonathan Stein calls the GAO report "shoddy and irresponsible": it never looked at actual cases itself, and recommends, despite all lack of significant findings, that Congress "could eliminate IFA and direct the Social Security Administration to revise functional criteria under medical listings" without proposing the preferable step of amending or revising it.

"After *Zebley*, you essentially had the birth of an entirely new program. Any new program will need fine-tuning. Areas of weakness are natural," explains Stein. But he says this doesn't mean congress should take an axe to the program itself.

"If there is fraud or misuse, the solution is to enforce, not to cut. The criticism [SSI opponents] are making is a criticism of government, not of the people. They're basically blaming the victim for their own lack of attention," says UPC's Scullin.

In May of 1994, then-Representative Santorum authored a House bill recommending not only that IFA be struck as a method of assessing children's needs, but also that cash grants be eliminated in favor of vouchers that could only be applied to medical necessities.

That bill went nowhere, but influenced a new bill, a small piece of what some advocates for the disabled call the "Contract on America." The new bill goes to vote under "House Bill 4," the so-called "Personal Responsibility Act," in the House of Representatives the week of March 20. Besides regressing eligibility requirements, it calls for the elimination of cash grants except in extreme cases where recipients would otherwise be institutionalized.

Cash subsidies would be replaced by block grants to states, which could then be applied to a limited list ➤

La'Shaira's medical needs frequently keep her at home.

➤ of services which parents of children with disabilities approved under a revised program could chose from.

Robin Bolduc, disability rights advocate with a Public Interest Law Center of Philadelphia, whose daughter has Down's syndrome, explains what's wrong with block grants.

"Each family with disabled kids has unique support needs. If you block the grant and have states provide families with a list of services, and their needs aren't on the list, they're out of luck. It's also a set amount of money. If more children are identified as eligible, oops, too bad, 'out of money, you'll have to wait.' And states would have the option of taking 20% of the grant and moving it into a project they like better," she says. Most states that have tried service-driven programs in various other mental retardation programs have already switched to family-driven cash grants, which are not only more flexible, but also cheaper, Bolduc says.

"With a block grant, the state has to subcontract with service providers. That creates administrative costs at the state level. Then, the service provider has its own administrative costs, so by the time you're done, the dollar that gets to the kid goes through two layers of administrative costs."

Personal Responsibility Act did you say?

"Families are saying 'we want to take responsibility for making decisions about raising our children. [The Republicans] are saying, no, the state will decide," says Bolduc.

The varieties of needs of the disabled are legion and extend beyond the scope of simple medical care. Sometimes, mothers like Vanessa Cooke just need money to cover some of what they could make if they could work. UCP's Joe Scullin names a few others: accessible housing, wheelchair-accommodating vehicles, child care for a special needs child. Over-the-counter nutritional supplements, diapers for older children. Special clothing for children with ostomy products and catheters "all over their stomachs." Specially-adapted toys. Tutoring assistance. Three-digit monthly electric bills for children on respirators.

"And that's just off the top of my head," Scullin says.

La'Shaira Cooke can't eat lunch with her schoolmates. She might eat something she isn't supposed to. Eligible for subsidized lunches, she can't take advantage of them: she eats special meals brought from home in the school nurse's office instead. Three days a week, the nurse is in school and tests La'Shaira's blood sugar. Vanessa Cooke does it the other two days. Vanessa can never go far from the neighborhood for long when La'Shaira is at school—she never knows when she'll have to rush in for an emergency.

That's not all.

"La'Shaira cannot participate in the little parties they have in school. I have to go on all her field trips, because what if something happened and I couldn't get there? She cannot go to camp. Next year she will be eligible for Juvenile Diabetes Foundation camp, but I don't know if I'll be able to afford it. I have no idea whether they have scholarships or if La'Shaira would get one. She cannot go to visit her friends because she might eat something she shouldn't. Her friends can come here, but I start with her first injection when she wakes up in the morning and she gets her last injection as close to midnight as possible. Once in a while, it's okay. But I am too tired to have more little kids here most of the time. La'Shaira gets lonely."

When, if, La'Shaira gets her money, Vanessa wants to take her to a museum. Vanessa chooses her words carefully because La'Shaira is sitting right next to her, folding up a piece of paper to make a fan.

"By now, she should have some set dosage, some target range. Her readings have all been high lately. Her prognosis is not good. I don't know what is going to happen. I would like for her to go to a museum now. Who's to say if she'll be able to go later on?" ◼

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Eugene Jamison

There is no information in the article beyond the comment that he has severe asthma, so no definitive statement can be made about whether he would be entitled to benefits under any standard.

YoWednesday

Your boss a beast? Contest: *Page 33*

[redacted]'s severe asthma makes it difficult for his mother to work; the family uses SSI to supplement their income ALEJANDRO A. ALVAREZ / DAILY NEWS

BREATHING ROOM

Would loss of SSI fund devastate disabled poor?

by **Mary Flannery**
Daily News Staff Writer

There's only one way that Carol[redacted] knows how to treat her son's severe asthma.

"Stay on top of it," she said. "I know the problem isn't going to go away."

Her son's condition may not disappear. But the $490 in Supplemental Security Income she receives monthly in his behalf may be wiped out.

Proposed legislation to dismantle the children's portion of SSI, a cash-assistance program for poor people older than 65 and disabled people of any age, is part of the package of welfare cuts, known as the Personal Responsibility Act of 1995, under consideration in Washington.

Most public attention has focused on cuts to the food-stamp, school-lunch and welfare rolls. Changes to SSI would also severely impact poor children and their families, according to advocates.

Under the current law, SSI makes monthly payments totalling $8 billion to 890,000 poor children with chronic mental or physical disabilities, including spina bifida, Down syndrome and autism, or a combination of problems. Nearly 8,800 Philadelphia children receive SSI.

Advocates estimate that proposed cuts would mean two-thirds of children on SSI today would receive no benefits or services. Of the 5.3 million adults receiving SSI, only those disabled because of drug addiction or alcoholism would be excluded. (The funds come from general tax revenues, not Social Security taxes.)

Parents of disabled children use SSI money at their discretion – to buy diapers for incontinent teen-agers, for electric bills run up by a ventilator, to pay for parking at a hospital. For some parents, the SSI benefit is a substitute for wages, allowing them to work reduced hours to care for their children at home.

Critics of SSI point out that children can qualify because of behavioral problems, including Attention Deficit Hyperactivity Disorder, which they say varies greatly in severity and can be "coached" by parents. Also, while SSI regulations call for a review of a recipient's disability every three years, the agency itself admits reviews do not occur on schedule, which means that payments can continue indefinitely.

U.S. Rep. Curt Weldon, a co-sponsor of the Personal Responsibility Act, called SSI "well-intentioned but a boondoggle" in a telephone interview last week.

"This program is out of control," said Weldon, a Republican from Delaware County. "It has to stop. This is not what SSI was designed for."

But SSI is how Carol Jamison, 26, copes with her son's asthma. She works three shifts a week as an $8.52-an-hour mental-health aide in a group home in Olney, cutting down her work hours to care for Eugene.

She gives Eugene, 5, three medications daily and clears his airways with a nebulizer spray three times. Sometimes, medication must be given every four hours around the clock, and she sets her alarm to comply.

Eugene's father is not involved in his son's life and Jamison has trouble finding dependable baby sitters who will keep Eugene on his medication regimen.

"The reason why Eugene is on SSI is that he requires a lot of attention and no one wants to (baby-sit) him," Jamison said. "Even with working three days, I have to call out sick sometimes to care for him. I can look in his eyes and know he'll be getting an attack. That's when I get him to the doctor right away."

There are two ways children can qualify for SSI: If they have one of the severe mental or physical conditions listed by SSI rules, or if they qualify through an Individual Functional Assessment, which determines a child's functional ability.

This assessment became part of the SSI qualifying routine after a 1990 Supreme Court decision in a class-action lawsuit. The original case, Sullivan vs. Zebley, was filed against then-Health and Human Services Secretary Louis M. Sullivan on behalf of an Upland, Delaware County boy, Brian Zebley, born with mental and physical disabilities. Weldon said he was unaware this case originated in his district.

Since the Zebley decision, the SSI rolls have grown by 500,000 children. Approximately 30 percent of the increase came about because of functional assessments. The rest of the increase, according to the U.S. General Accounting Office, occurred because of improved outreach to disabled children, a dramatic increase in the number of children in poverty and the expansion of the definitions of mental impairments in children.

In Eugene's case, he qualified because of the combination of his asthma and speech and developmental delays that required psychiatric intervention.

Under the proposed Personal Responsibility Act, individual functional assessments would be eliminated, not only for future SSI applicants, but for the 225,000 -- one quarter of children on SSI -- who currently receive benefits as a result of functional assessment.

Nor would they automatically be qualified for Medicaid.

Children now qualified under the medical listings would continue to receive SSI benefits. For new applicants, states would receive block grants to set up medical and non-medical services, such as therapy or the purchase of wheelchair ramps. These children, according to the bill's provision, would receive no cash assistance. Cash would go only to new SSI applicants so disabled that they would be institutionalized without this aid.

Advocates do not deny abuses exist under the current program. Parents may continue to receive SSI after a child dies. Stories of parents "coaching" their children to qualify for SSI have been reported in the media, although a 1994 federal review found no evidence of coaching.

[MORE]

These media reports have fueled Congress' desire to reform SSI, said Weldon.

"There's a feeling across the country that by going to the doctor, you can get your kid qualified for a full disability," said Weldon.

"I think in many cases there is deliberate abuse of the system. We must revise the guidelines to make sure we care for people who have needs. But the government should not be the end-all for people who say, 'Don't worry about taking care of your own needs, we'll take care of them for you.'"

"If a child has a serious disability, there should be a way to take care of it. But I don't know if SSI is the proper way."

Weldon, a father of five and a former teacher, said he knows children can have emotional problems. "But this government cannot fund every kid who has a dysfunctional problem. We can't do it. We don't have enough money. It gets down to reason and common sense."

Those who serve disabled children are angered and worried about the proposed changes. Reform the system rather than destroy it, they say.

"Being able to make a functional assessment is a strength of SSI, not a weakness," said Mary Ellen Caffrey, director of Ken-Crest, a Philadelphia-area agency that provides family services for people with mental or developmental disabilities. "A lot of problems are non-categorical."

"There's no known disease for kids who have a tracheotomy ... A tracheotomy is a functional problem. It interferes with a child's playing just like with an adult working.

Caffrey fears that without SSI income, families may not be able to afford to seek treatment.

Brian Zebley, born brain-damaged and partially paralyzed, attended years of special classes and had several operations on his leg. Three years ago, he was "mainstreamed" into the seventh grade in the Interboro School District. Today, he's a member of the Interboro High student council. He walks unassisted. He attends special ed classes but is following the standard curriculum.

At the time of the Supreme Court ruling, Brian was no longer receiving SSI benefits because his father's wages exceeded the SSI income ceiling.

"SSI helped us subsidize our income until my wages were substantial enough to support the family adequately," said John Zebley.

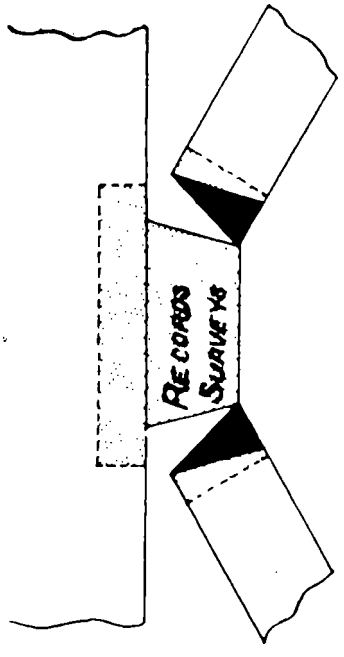
"People think you are stealing money from the government because you have a handicapped child. But they don't walk in your shoes."

Carol Jamison isn't sure what she'll do if Eugene loses his SSI benefit.

"If I work full time," she said, "what will I do if he gets sick?"

How to use these separators

Look for your reference letter. The far left column designated "TAB" will indicate proper tab position for that number or letter. Cut off and discard all tabs except the one you wish to retain. Example: Position number "10" would be found behind the fourth tab. Position letter "C" would be found behind the third tab.



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THIRD	100	93	86	79	72	65	58	51	44	37	30	23	16	9	2
FOURTH		94	87	80	73	66	59	52	45	38	31	24	17	10	3
FIFTH		95	88	81	74	67	60	53	46	39	32	25	18	11	4
SIXTH		96	89	82	75	68	61	54	47	40	33	26	19	12	5
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Form **SSA-69** (10-79)

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Evaluation of Children's SSI Coalition Letter

SOCIAL SECURITY'S EVALUATION OF THE CHILDREN LISTED IN THE SSI COALITION'S LETTER

Jonnie; age 3; developmentally disabled; moderate cognitive, communicative, and motor limitations.

As described by the Coalition, the communicative limitation is probably marked. If there is in fact also a moderate motor limitation, the impairment(s) would functionally equal listing 111.07B.3. Other listings that might be met or equaled include 111.09A and 110.07D.

Janie; age 31 months; developmentally disabled; moderate communicative, motor, and personal/behavioral limitations.

Similar to Jonnie above - as described, the communicative limitation is probably marked, and the impairment(s) may well meet or equal 111.07B.3. or various other listed impairments.

Harry; age 4; severe lead poisoning; moderate limitations in cognitive and motor development and in concentration, persistence, and pace.

No conclusion at all can be drawn from the sketch provided. Typically, lead poisoning affects multiple body systems, and if sufficiently severe would meet or equal listing 110.07A.

Tommy; age 6; post-traumatic stress disorder due to sexual abuse; moderate limitations in social and personal/behavioral functioning and in concentration, persistence, and pace.

Descriptions of problems are insufficient to judge if one or more might be at the marked level. If any two were marked, impairment(s) would equal 112.02B2.

Brandon; age 3; loss of one eye due to retinoblastoma; moderate motor, social, and personal/behavioral limitations.

Probably should have been denied even under our prior standard. It would be very unusual for the loss of an eye, by itself, to result in a disabling level of limitations.

Alfred; age 14; attention deficit hyperactivity disorder and borderline intellectual functioning; moderate cognitive, social, and personal/behavioral limitations.

Depending on the frequency and the severity of the problems described, limitations in social and/or personal/behavioral functioning may be marked. If both are marked, would equal 112.02B.2.

Shannon; teenage; depressive disorder, mental retardation, impaired adaptive behavioral functioning; moderate limitations in cognitive and social functioning, and in concentration, persistence, and pace.

May well have a marked or even an extreme cognitive limitation - clinical diagnosis of "moderate" mental retardation describes a level of limitation we consider marked or extreme. If so, her impairments presumably meets 112.05D.

Jason; age 8 ½; psychiatric disorders; moderate cognitive, social, and personal/behavioral limitations.

Based on description, child may have major depression, which could depress cognitive functioning beyond the measured IQ. Also, personal/behavioral functioning may be at marked level. If cognitive limitation is actually marked, would probably equal 112.05D; if functioning in another area is marked would also meet or equal 112.02B.2.

Isabella and Elizabeth; age 4; communicative and cognitive problems; marked communicative and moderate cognitive limitations.

As described, the communicative limitation is extreme, and impairments would functionally equal 111.09A.

Sarah; age 9; cerebral palsy and double hemiplegia; marked motor limitation and moderate limitation in concentration, persistence, and pace.

Based on the description of her motor problems, her impairment probably meets 111.06. Based on the description, the limitation in concentration, persistence, and pace may actually be marked, which could support functional equivalence to 112.02B.2.

Justin; hemophilia; moderate motor and marked social limitations.

As described, his impairments would meet 107.08A, but the time period during which the bleeding was uncontrolled is unclear. Treatment may now prevent a disabling level of limitations.

Rashavie; age 3; severe asthma and communicative and language delays; marked communicative and moderate personal/behavioral limitations.

Based on the description, the communicative limitation may actually be extreme; the personal/behavioral limitation may actually be marked. Probably meets or equals 110.07D, 112.02B.2., and/or 111.09A. or B.

Kimberly; age 11; cognitive delay, urinary incontinence, and trichotillomania; marked cognitive and moderate personal/behavioral limitations.

As described, her impairments would meet listing 112.05D.

Susie; age 3; developmentally delayed; marked communicative and moderate motor limitations.

As described, her communicative limitation is probably extreme, and might functionally equal 111.09B. Even if not, her limitations, as described, would probably functionally equal 111.07B.3.

Jennie; age 17 months; hydrocephalus, tests HIV positive, exposed to drugs in utero; marked motor and moderate social limitations.

As described, her motor limitation appears extreme, and the social limitation is probably marked. Would meet or equal various listings, e.g., 110.07A and 112.02B.1.

THE SSI COALITION
FOR A RESPONSIBLE SAFETY NET

SUPPLEMENTAL SECURITY INCOME FOR LOW INCOME ELDERLY AND PEOPLE WITH DISABILITIES

205 West Monroe Street ♦ Chicago, IL 60606-5013
Telephone 312.223.9600 ♦ FAX 312.263.3846

OCTOBER 22, 1996

WHO ARE THE CHILDREN WHO WILL BE CUT OFF CHILDREN'S SSI DISABILITY BENEFITS WHEN THE DISABILITY STANDARD IS AMENDED TO DEFINE CHILDREN WITH "MARKED AND SEVERE FUNCTIONAL LIMITATIONS"

The Clinton Administration is considering at least two radically different standards that the Social Security Administration (SSA) will apply to determine disability for children seeking Supplemental Security Income (SSI) benefits.

The first standard, drafted by advocates for children with disabilities, defines disability for children seeking SSI that, while eliminating the Individualized Functional Assessment (IFA) test:

- recognizing the statutory mandate for a "functional limitations" test, provides a new step that explicitly considers a child's functional limitations and sets forth different areas in which to measure that child's functioning;[1] and
- provides that children with at least one marked impairment and one moderate impairment in different areas (or domains) of functioning will be found disabled.

This standard ("one marked and one moderate impairment test"), strikes a middle ground between the extremes of Listings-level severity and the former IFA test. It will permit the Social Security Administration to terminate SSI eligibility for children currently eligible based on three moderate impairments, and comport with Congress' wish that the children's disability standard be

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[1] These areas are modelled on the "B" criteria of the children's mental impairment listings that were approved by Congress when it modified the children's SSI program, and are further refined to assure fairness in evaluating children with physical impairments. See National Academy of Social Insurance, Report of the Committee on Childhood Disability of the Disability Policy Panel at 29 (1996).

"fine-tuned."[2]

Contrary to this fine-tuning approach, the second proposal, akin to the rejected House version of the law, would require children to show that they meet or equal the extreme severity thresholds set forth in the Listings of Impairments. Children with mental impairments or combinations of mental and physical impairments would essentially be required to show that they had two marked impairments in the "B" criteria of the mental impairments listings. This proposal ("two marked impairments test") will lead to loss of eligibility for up to one third of all children currently receiving SSI. It is also much closer to the earlier House bill that was rejected in the final compromise provisions on SSI.

In assessing what standard should be applied and then determining what effect that any new standard will have on the number of children receiving SSI, it must be recognized that SSA has already greatly restricted the actual eligibility process for finding children disabled for SSI. See § A.

Below are set forth examples of children who stand to lose SSI eligibility under the alternative tests. Under either test, children with severe problems will be denied SSI eligibility.

In § B(1), children who were found disabled with three moderate impairments--who would be terminated from SSI under the one marked and one moderate impairment test--are profiled.

In § B(2), children who were found disabled with one marked impairment and one moderate impairment--who would be terminated from SSI under the two marked impairments test--are profiled.

A. SSA WAS ALREADY GREATLY TIGHTENED UP ELIGIBILITY AS SHOWN IN THE DENIAL RATE FOR CHILDREN'S SSI CLAIMS UNDER THE OLD STANDARD THAT INCLUDED THE IFA TEST

SSA has already significantly tightened up the eligibility process. SSA data show a 43% allowance rate in 1989, the year before the Supreme Court decided Sullivan v. Zebley, which led to the creation of the IFA test. After a surge in the allowance rate in 1991, that was fueled also by the congressionally mandated outreach program for children, and issuance of newly revised mental disorder Listings, the allowance rate has steeply declined. By April 1996, the allowance rate had fallen to 31%, well below the 1989 43% allowance rate, the year before the Zebley reforms were

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[2] See colloquy language between Senators Chafee, Conrad, and Dole, who along with Senator Daschle, shaped the compromise final language of the new law. Cong. Record at S 13613-14 (Sept. 14, 1995).

implemented. This hardly bespeaks an out-of-control program in need of drastic cutbacks.

B. PROFILES OF CHILDREN WHO WILL BE CUT OFF SSI UNDER A NEW DISABILITY STANDARD[1]

It is important to remember that, no matter which test is adopted, a significant number of children, all with serious disabilities, will be cut off. The question is, given Congress' mandate to "fine-tune" the program, where the disability line should be drawn.

1. Significantly Disabled Children Found Disabled With Three Moderate Impairments Will Be Cut Off SSI Under The One Marked And One Moderate Impairment Test

Set forth below are summaries of children who will lose SSI if SSA adopts a standard that provides SSI disability benefits to children with one marked impairment and one moderate impairment, but denies disability to children with only three moderate impairments.

While it is difficult to profile the typical child found disabled with three moderate impairments, certain patterns emerge from reviewing case decisions of these children destined to be cut off SSI:

- many children with cognitive deficits (IQ scores of 71 to 74) qualify through the IFA when those cognitive deficits cause moderate limitations in three of the domains; 100,000 children, or one third of all SSI children with a diagnosis of mental retardation (cognitive deficits) qualified for SSI because of the IFA test;[4]
- many children with a combination of physical and mental impairments, none of which singly meet the Listings of

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[1] The examples that follow are based on real cases collected by Jonathan Stein of Community Legal Services in Philadelphia and Thomas Yates of the SSI Coalition in Chicago. For privacy purposes, identifying information has been deleted, and in some cases, the names have been changed.

[4] We do not know how many of these children qualified with three moderate impairments. We do know that the term "moderate" is not, in a layperson's understanding of the word, a very accurate description for disabling conditions that have such adverse impacts on children's functioning. A child with an IQ of 71, although deemed to have a "moderate" cognitive impairment by SSA, is understood by lay and professional people alike to have a very serious impairment despite the "moderate" tag.

Impairments, qualify because those impairments cause moderate loss of function in three domains; and

- many children experience adverse life circumstances which result in significant functional limitations: e.g. lead poisoning from exposure in unsafe housing; asthma exacerbated by poor air quality; sexual and physical abuse leading to post-traumatic stress disorder; and prenatal exposure to drugs and sexually transmitted diseases that cause moderate impairments in at least three domains.

Jonnie, who is developmentally disabled:

Jonnie, who is 3 years old, was found disabled with three moderate impairments.

Jonnie was found to have a moderate impairment in the cognitive domain based on a McCarthy profile that showed that he was three standard deviations below the norm on measures of understanding numbers and other quantitative words, although the complete results showed him within two standard deviations of the norm.

He also had a moderate impairment in the communicative domain based on substantial deficit in language development. At 3 years of age, his speech consisted of single words, mostly unintelligible, and he could not combine words.

Finally, he had a moderate impairment in motor development because, at 3 years of age, he could not balance on one foot for two seconds, walk backwards, or broad jump. He has minimally decreased tone in his lower extremities with a tendency to plantar-flex and toe-walk bilaterally. He also has difficulty running and climbing stairs.

Janie, who has been developmentally disabled since birth:

Janie, a 31 month old child now living with a relative, was born with intraurterine exposure to cocaine and alcohol and HIV positive. She was found disabled with three moderate impairments.

She has a moderate impairment in communicative development due to a vocabulary limited to five words. She could not combine words, or point to any body parts. She also had a moderate impairment in motor development based on test scores showing her functioning between two-thirds and three-fourths of chronological age in fine motor development and gross motor skills. Finally, she was found to have a moderate impairment in personal/behavioral development because she was not cooperative, could not imitate household tasks, and could not use a spoon to eat.

Harry, who has lead poisoning:

Harry, a four year old child who has severe lead poisoning, was found disabled with three moderate impairments.

Harry was found to have a moderate cognitive impairment based on results from Peabody Picture Vocabulary test and McCarthy Scales. He also had a moderate impairment in motor functioning resulting from the lead poisoning--he frequently suffered from dizziness and headaches that affected his motor abilities. Finally, he had a moderate impairment in concentration, persistence, and pace based on his short attention span.

Tommy, who was a victim of sexual abuse:

Tommy, who is 6 years old, was a victim of sexual abuse and, as a result, suffers from post-traumatic stress disorder. He was found to have three moderate impairments.

Tommy has a moderate impairment in social development; his history of sexual abuse makes it difficult for him to relate to other children. He is physically aggressive with other children, which is linked to the abuse he suffered. He also has a moderate impairment in personal/behavioral development with history of aggressive behavior and sexual acting-out. Finally, he has a moderate impairment in concentration, persistence, and pace based on hyperactivity--he has a very short attention span and difficulty staying on task.

Brandon, who has retinoblastoma (cancer of the eye) and developmental delays:

Brandon, at the age of 16 months, was diagnosed with cancer of the eye. To save his life and prevent the spread of cancer, the cancerous eye was removed. At age 3, Brandon was found disabled with three moderate impairments.

Brandon had a moderate impairment in motor skills and coordination arising from the lack of stereoptic vision. He also had a moderate impairment in social functioning due to difficulties in interacting with other children. Finally, he had a moderate impairment in personal/behavioral functioning due to delays and difficulty in learning to take care of his own needs with his limited sight.

Alfred, who has attention deficit hyperactivity disorder and borderline intellectual functioning:

Alfred, who is 14 years old, has attention deficit hyperactivity disorder and borderline intellectual functioning. He was found disabled with three moderate impairments.

Based on Alfred's full scale IQ of 74, he was found to have a moderate cognitive impairment. He also was found to have a moderate impairment in social functioning because he obsessively talked to imaginary people and played with an imaginary vehicle during class. He also was found to have a moderate impairment in personal/behavioral functioning because he often appeared helpless, and, under stress, regressed to much younger behavior.

Shannon, who has depressive disorder, mental retardation, and impaired adaptive behavioral functioning:

Shannon, a teen-age girl, talked of suicide and lived in isolation from her peers. She was found disabled based on three moderate impairments, in the domains of cognition, social functioning, and concentration, persistence, and pace.

Shannon was found to have a moderate cognitive impairment because she had been diagnosed with moderate mental retardation; she repeated the fifth grade three times. Her moderate impairment in social functioning was based on the fact that she had no friends, played only with children who were much younger, and was diagnosed as suffering from clinical depression. Her depression also caused a moderate impairment in concentration, persistence, and pace.

Jason, who has psychiatric disorders:

Jason, a 8 1/2 year old boy, has behavior problems, problems sleeping, and talks about suicide. Jason has been diagnosed with dysthymia (a type of depression) with borderline intellectual functioning. Jason was found disabled with three moderate impairments.

Jason has a moderate impairment in cognitive functioning based on a full scale IQ of 75; and academic scores placing him in the kindergarten to first grade level. He has a moderate impairment in social functioning based on his anxiety, competitiveness, and overreaction in a school setting, and because he has no close friends and other children leave him alone. Finally, he has a moderate impairment in personal/behavioral functioning due to his need for constant supervision--far more than would be required for an average 8 1/2 year old child.

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These children, who have significant problems, will lose SSI eligibility under the disability definition proposed by the SSI Coalition that ends disability allowances based on three "moderate" impairments.

2. **Additional Children Who Would Be Terminated From SSI Disability If SSA Goes Farther And Adopts The Two Marked Impairments Test**

Below are case summaries of the types of children who will lose disability if SSA adopts a standard that requires two marked impairments. It is the contention of the SSI Coalition and other advocates that these children should remain eligible for SSI because they are seriously disabled. To cut them off will make the test too strict and defeat the purpose of the program. All the children listed below were found disabled with one marked impairment and one moderate impairment.

Isabella and Elizabeth, four year old identical twins with communicative and cognitive problems:

Isabella and Elizabeth, four year old identical twins who now live with an aunt, were born prematurely with respiratory problems to parents who were mentally retarded. At age two, they were found disabled based on a marked impairment in communication and a moderate impairment in cognition. They both were functioning at communication levels less than one half their chronological age, leading to a marked impairment. Also, they both were functioning at cognitive levels more than two thirds, but less than three fourths of chronological age, leading to moderate impairments.

Their aunt could not afford to raise her nieces but for the income of SSI. Without such assistance, the children would have been placed in foster care.

Sarah, who has cerebral palsy:

Sarah, who is, 9 years old, has cerebral palsy and double hemiplegia. She was found to have a marked impairment in motor development based on her cerebral palsy. She is enrolled in a educational program for children with physical disabilities, sways from side to side to walk, takes one step at a time, and cannot stand up from a sitting position on the floor without assistance. Sarah was also found to have a moderate impairment in concentration, persistence, and pace based on her teacher's statements, and needed to work one-on-one with a teacher because she cannot stay on task.

Justin, who has hemophilia:

Justin was 11 when he finally qualified for SSI. He was diagnosed as having bleeding disorders when he was six months old. Over a four year period, his mother has had to rush him to the emergency room 30 times for bleeding joints, hematomas, and other injuries; he had another 60 doctor visits for bleeding problems. While his diagnosis is hemophilia, he did not meet the Listings because medication partially controlled his bleeding and he has had

no permanent joint deformities. Yet, Justin's condition severely restricts his ability to function age-appropriately.

Justin was found to have moderate impairments in motor skills--his joint swelling is so severe that it affects his ability to walk, and makes it impossible for him to participate in physical education or recreational activities. In part, as a result of his exclusion from peers' activities, he was also found to have a marked impairment in social skills--he does not report potentially life-threatening injuries and becomes violent when his classmates do so for him.

Rashavie, who has severe asthma and communicative and language delays:

Rashavie, now three years old, was born prematurely, and had respiratory problems at birth. Since birth, he has had repeated episodes of respiratory distress, has been diagnosed with asthma, and has experienced a variety of developmental delays in almost all areas.

He was found disabled with a marked impairment in communication and a moderate impairment in the personal/behavioral domain. Because of deficits in auditory comprehension and expressive communication, his language was described as almost non-existent. Despite aggressive therapy, Rashavie was found to have a serious delay in communication, leading to the finding of a marked impairment.

In addition, he was given a moderate impairment in personal/behavioral development because he was unable to dress himself, was not toilet-trained, could not feed himself, and was unable to follow simple instructions.

Kimberly, who has cognitive delay and urinary incontinence (enuresis):

Kimberly, who is 11 years old, is three years behind her age group in school. She has great difficulty even in her special education class, and was tested with a full scale IQ of 70. Kimberly also was diagnosed with functional urinary incontinence, trichotillomania (recurrent pulling out of one's hair), and, despite her age, she insists on sleeping with her mother. Kimberly was found disabled because she had a marked impairment in cognitive functioning based on her IQ of 70; and a moderate impairment in personal/behavioral functioning based on her urinary incontinence, and trichotillomania.

Susie, who is developmentally delayed in communication and motor development:

Susie, who is 3 years old, was found disabled with one marked

impairment in the communicative domain and one moderate impairment in the motor development domain.

She has a marked impairment in communicative development: medical evidence shows that she suffered severe delay in expressive language and vocabulary; she was unable to put words together to form phrases and sentences, and she could not refer to herself by name or use the "me" or "mine" concept. She also has a moderate impairment in motor development with history of duodenal atresia for which she has undergone four surgical procedures; she currently has G-tube for feeding and is undergoing medical investigation to discover the cause of recurrent vomiting episodes.

Jennie, who has hydrocephalus, is HIV positive, and was exposed to drugs in utero:

Jennie, a 17 month old child, was born testing positive for cocaine, syphilis, gonorrhea, hydrocephalus and HIV. Since birth, she has undergone several hospitalizations and undergone multiple operations for the hydrocephalus. She has a marked impairment in motor development and a moderate impairment in social development.

Her marked impairment in motor development was based on her inability to perform any of the motor functions appropriate for her age. She cannot sit alone, roll over, bounce actively, pick up small objects with the thumb-finger grasp, or turn while sitting.

She also has a moderate impairment in social functioning--because of her severe health problems, she has not acquired social skills. She is completely unable to engage in interactive play, and cannot play pat-a-cake, peek-a-boo, or hug.

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All these children, who have significant impairments, would lose SSI eligibility if SSA adopts an overly strict standard that finds only children with two marked impairments disabled. Although this may have been close to the intent of the House bill, the views are clearly rejected, in final compromise, by the full Congress that approved the welfare reform law.