



SOCIAL SECURITY
Office of the Commissioner

12/17

Diana —

Here's our review
of cases described by
the SSI Coalition as
well as those cases
mentioned in various newspaper
articles.

Please call to discuss.

THKS.

Brian

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.

TO: Brian Coyne
Richard Green

FROM: Diana Fortuna DF

DATE: December 16, 1996

Diane Gavro
Can you review &
let me know your
thoughts on this ASAP
Tks.
Brian Ge

Attached is a piece from the SSI Coalition that includes several examples of children at the 3 moderates and 1 marked/1 moderate level. You may already have seen it. I am sending it to you for two reasons:

1. I thought perhaps the examples here would be helpful to you as you try to figure out examples. If so, Brian, could you please forward to whoever is appropriate at SSA?
2. I was curious as to whether SSA thinks these examples are accurate. As you know, it appears that most of the children that the press has identified as at risk of losing benefits would in fact qualify at the 2 marked/listings level. Therefore, I thought it would be useful to take a look at these cases to see whether the advocates are accurately describing them. I would appreciate a call back from someone at SSA on this question.

Thanks.

Please fax to Richard Green
at 5-0851

and
② Brian Coyne at 358-6076

Returns Diana F

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 ♦ PAX 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 (IPA) 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; 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 IPA 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

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."¹

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 HAS 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

¹ 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 STANDARD¹

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;²
- ♦ many children with a combination of physical and mental impairments, none of which singly meet the Listings of

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.

² 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 intrauterine exposure to cocaine and alcohol and HRV 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.

* * * * *

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, swings 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

Justin
father
buried,
intention
not for
applies,
185

W. Allen
vs
43% per
Zebly

admitted

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.

* * * * *

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.

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

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Hunter Steinitz
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Neville Barnhill

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.

Yo. Wednesday

Your boss
a beast?
Contest:
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Eugene'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 Charol Johnson 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 totaling \$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.

See SSI Next Page

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, La'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 prickler."

The first-grader is laying out the components of her "One Touch II" gadget, which identifies her blood-sugar level. Her fingertips are callused 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 rejection. 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 of 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.

Not to *Zebley*, each of a child's conditions would be considered on its own merits, explains Dr. Scullin, Director of Social Services of United Cerebral Palsy (UCP), 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, forty thousand of them in Pennsylvania.

A review of SSI by the Department of Health and Human Services reports that, in fact, an estimated 1.1–1.4 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 UCP'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 when recipients would otherwise be institutionalized.

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



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

► of services which parents of children with disabilities approved under a revised program could choose 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?" ■

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.

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PITTSBURGH POST-GAZETTE

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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 birth was what to name her.

Patti was 36 years old and felt good. Her morning sickness had abated early in her pregnancy. Sonograms and amniocentesis, the chromosomal abnormality test that also reveals the baby's sex, gave both mother and unborn daughter a clear 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 the 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 occurrence in preemies.

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

Mark, who had never experienced the birth of a child, thought nothing of the 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 the hide of an elephant.

A doctor told the new parents: "Your baby has a skin disorder. It's called 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 1992 through friends, she was, and still is, a Pittsburgh police officer - first in 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 father'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 Side

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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, restricting 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 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 walk 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 has 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 diligent professional help in movement and speech - which has cost more than \$300,000 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 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 support these services. But there's a catch: No child can be turned down.

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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 what 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 receive 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 Rep. 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 with at least one of the 15 topical ointments - all every two hours. The humidifier 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 child, 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 special 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 her skin smooth and less itchy.

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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-month-old body cannot afford to lose any nutrition.

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

(END)

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/CC† 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 Comp-ton 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 60 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, non-profit 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 immi-

grants 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

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 27 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.

SPECIAL ALERT



American Academy of Pediatrics



Department of Government Liaison • The Homer Building • 601 Thirteenth Street, N.W. • Suite 400 North • Washington, D.C. 20005
202-347-8600 • 800-336-5475 • FAX: 202-393-6137

November 22, 1996

TO: Interested Pediatricians

FROM: Phil Ziring, MD, Chair, AAP Committee on Children with Disabilities

RE: Supplemental Security Income (SSI) Program for Children

This memo is to alert you to several changes to the Supplemental Security Income (SSI) program for children which are part of the new welfare reform law (PL 104-193). It is anticipated that these changes will result in a sharp increase in the number of requests to physicians for medical information about these children. In the next few weeks, the Social Security Administration (Social Security) will announce new rules for these program changes. The Academy will continue to update you as the new SSI standards are developed and implemented.

Key changes to SSI:

- Establishes a new definition: A child is considered disabled if he or she has a "medically determinable physical or mental impairment which results in marked and severe functional limitations, which can be expected to result in death or which has lasted or can be expected to last for at least 12 months";
- Eliminates the "Individual Functional Assessment (IFA)" standard;
- Changes the way Social Security considers certain behavior problems caused by a child's mental or emotional condition.

What does this mean for children?

These provisions apply to new claims filed beginning August 22, 1996, and to all claims that have not been finally adjudicated (including cases pending in the courts) prior to that date. Social Security is required to review the cases of children who currently receive SSI as a result of the IFA to determine whether they meet the new definition of disability. It is estimated that 275,000 children will require review under the new rules.

What does this mean for pediatricians?

In late November, Social Security began notifying families of children whose cases will be reviewed. In addition to the Social Security notice, families are receiving information from disability and social service groups urging them to provide as much medical and other evidence about their child's disability and to take their child in for medical care if they have not been doing so regularly.

- It is expected that the Social Security notices and information from other groups will cause families great concern and confusion. Families may ask pediatricians for assistance in obtaining documentation about their child's disability to keep their child on SSI;
- More information, such as additional medical evidence of a child's disability, may be needed by Social Security during the review process. If Social Security wants a child to be examined by a doctor, the government will pay for it.

The AAP continues to work with Social Security as they develop the review process and other implementation efforts. If you would like additional information about SSI changes, please contact Elaine Holland, Assistant Director in the AAP Washington Office at 800-336-5475.

def. of chronic: a shorthand: for some children, frequency a problem underrepresents

chronic illness nature comes and goes; nature of disability;

frequency= severity; impairments where not constant/episodic
chronic: underlying pathology constant
at that time, 2 marked;

(where in listings? sub-reg?)

do rereview temporarily?

Most of the children who would lose eligibility under this option have mental impairments, including the behavioral disorders that were the impetus for the changes to the program, such as conduct disorders, learning disabilities, and ADHD. A large number have mental retardation. Others have chronic diseases that are episodic or are fully or partially controlled by medication, such as asthma or hemophilia, or diseases such as cerebral palsy that do not seriously impair more than one area of a child's functioning.

epilepsy,

rare diseases not listed by SSA, or

chuck: janet bendann;

mr: 60-70: marked; likely to have ; what number like to have
rule of thumb over 70 moderate

iq not always predictive

can't generalize on mid-60's; depends on so many other factors,
attention

DRAFT OD**December 12, 1996****Pg 1**

A Phased-in Test of the RTW Ticket for Social Security Disability Beneficiaries

Recommended Option

The Social Security Administration (SSA) recommends a 10-year test of the Return-to-Work (RTW) ticket. The test will be conducted to achieve 3 purposes:

1. Pilot the ticket idea in general to determine whether or not a private market for return-to-work services can be created;
2. Test different models of the ticket and payment systems; and
3. Roll-out the ticket nationwide, based on success of tests and refinements made over the life of the test.

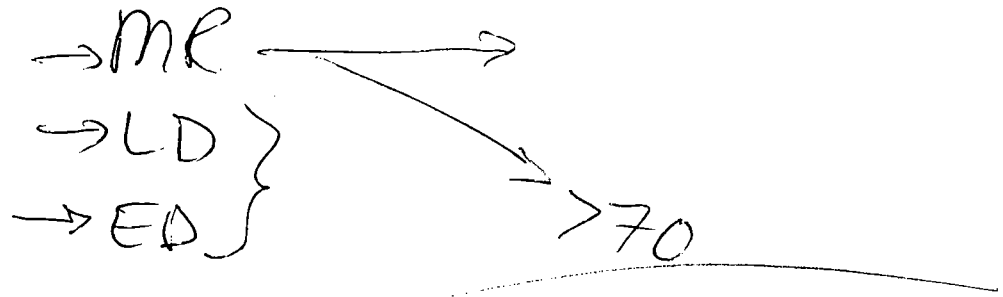
Scope and Timing: The RTW ticket will be tested over 10 years through a series of models with gradually expanding phases. The testing will begin in 5-10 selected States and, at critical decision points, the Commissioner of SSA will decide to either end the test or expand to more States. Ultimately, the models could be operating in as many as 25-35 States.

State VRA Options: The State VR agencies (SVRAs) in each test State will have the option to participate on an equal basis with any other provider or ~~to remain in the current SSA VR program (i.e., receive cost reimbursement after 9 months of Substantial Gainful Activity).~~ Under either system, these beneficiaries whom the SVRAs do not serve will be free to give their ticket to any other provider which is willing to accept them. (11/20/96 #1)

Eligibility for Tickets: Tickets will be given to all new beneficiaries at the time of award, except those awardees who are classified "Medical Improvement Expected" (MIE). MIE cases will be granted a ticket only after the first Continuing Disability Review (CDR) has resulted in a continuation of benefits. Also, beneficiaries who are scheduled for a CDR within 6 months would not be granted a ticket until after the CDR has resulted in a continuation decision.

Payment Formula: SVRAs or private providers will be paid a percentage of disability benefits saved, as a result of beneficiary work, for a specified period of time. Several models will be tested with variations across models in the payment formula (20-50 percent of savings) and the length of the payment period (3-5 years) with the greater risks of longer payment periods being compensated by higher total payments. Providers will be eligible for payment for each month of the payment

motor chronic



Yest:

LP →

[Handwritten signature]

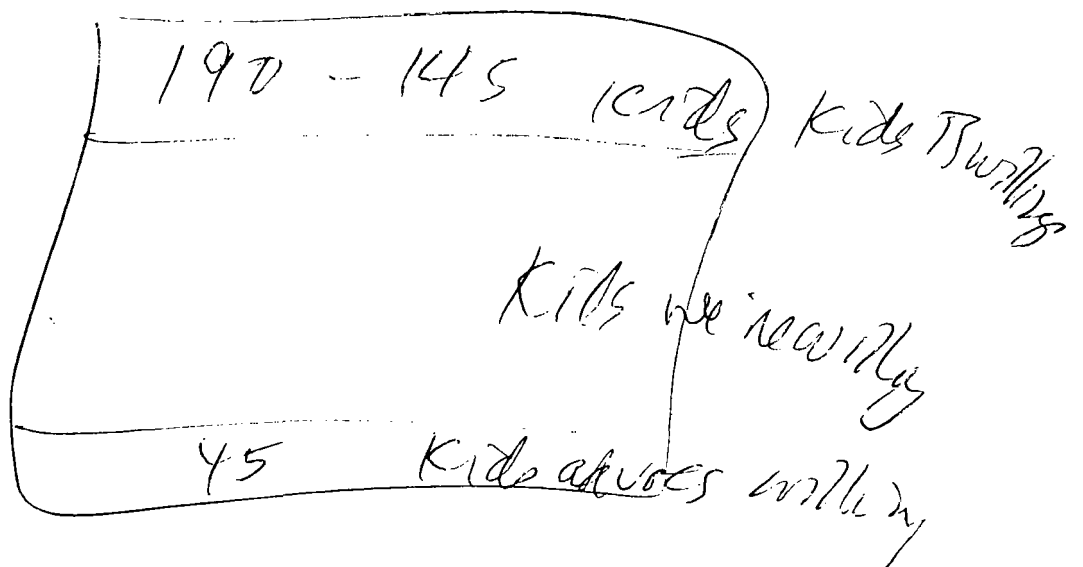
LP - outside #13

P - don't know what, but merits

Wants to know more re kids
*who are they?
- Gore / M#

Welf Thuro - then or defer

Shirley must be conf.



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

02-Jan-1997 02:58pm

TO: Jill Pizzuto
TO: Diana M. Fortuna

FROM: Carol H. Rasco
 Domestic Policy Council

SUBJECT: Meeting with POTUS

I have put into Stephanie Streett to meet with the President as directed by Leon and Erskine on a budget issue. I have told Stephanie I will not be in until 10:30 a.m. on Monday or perhaps not there until 2;30 on Monday. This meeting needs to take place as soon as possible next week. I asked her to contact you to set it up and told her I would be taking Diana Fortuna with me.

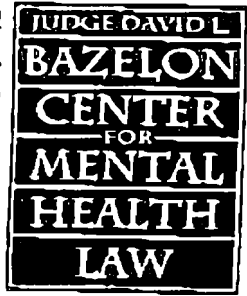
Diana: This will answer your question of last email. Once we know the time you and I should discuss how to present this to him; I have told scheduling it will not be more than 10 minutes. It is not a decision meeting, simply a meeting to explain to him how it will be handled. I have asked scheduling not to list yours or my name on the meeting time. I would prefer NO one know we are going into this meeting. (Jill: it should not even show up on my schedule as a meeting with POTUS. Put it as a meeting with Nancy Hernreich in her office.) I do not intend to include OMB or anyone else since it is informational, not decision. This is how Leon suggested it be done and I agree.

Silly that we have to be this cautious but regrettably we do.

Thanks.

FAX

Suite 1212
1101 Fifteenth Street N.W.
Washington D.C. 20005
Voice: 202/467-5730
TDD: 202/467-4342
Fax: 202/223-0409
e-mail: hn1660@handsnet.org
<http://www.bazelon.org>



PLEASE DELIVER THIS FAX MESSAGE IMMEDIATELY

TO: Diana Fortman
FAX #: 456-7028 No. of pages, including this: 3
FROM: Rhoda Schulzinger
DATE: 12/30/96 Transmitted by: _____

COMMENTS:

Here's letter from Rep Jon Fox showing a different
Republican perspective. Will you still be working
on this issue with the change of command?

Rhoda

NOTE: If problems occur during transmission, please call 202/467-5730.

JON D. FOX
13TH DISTRICT, PENNSYLVANIA

INTERNATIONAL RELATIONS

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Congress of the United States
House of Representatives

Washington, DC 20515-3813

December 27, 1996

The Honorable William J. Clinton
President of the United States
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mr. President:

I write at a critical time in the implementation of the recently enacted welfare legislation as your Administration is soon to publish policies implementing the new Supplemental Security Income childhood disability standard. I encourage you to implement this law so that the maximum number of children with disabilities will be served.

As you know the new statutory test qualifying children who have marked and severe functional limitations does for the first time put into law a requirement that the actual functional impacts of childhood disabilities be evaluated by the Social Security Administration.

In this regard, Congress has ordered a functional test for children, one that first came into the program via the U.S. Supreme Court in the Sullivan vs. Zebley ruling. This decision was urged by every major national child disability and medical organization and obtained through the advocacy of our local Community Legal Services of Philadelphia.

But the exact severity threshold of the new test was not precisely established by the Congress. It was specifically left open-ended so that it could be established by the administrative agency that knew these children best.

Knowing that there may be various competing proposals available for implementation, I wish to emphasize some guiding factors that, at the least, reflect congressional intent in this area.

The great majority of the children who qualified for SSI in recent years have had quite serious disabilities. Indeed, SSA reports that of the over 250,000 children who qualified under the functional test ordered by Zebley, and now discontinued, fully 100,000 are diagnosed with mental retardation. Others have autism, sickle cell anemia, cerebral palsy, tuberculosis, diabetes, muscular dystrophy, serious burns, etc. A new test cannot jeopardize these children's access to SSI and the Medical Assistance that comes with it.

This program in 1996 is far different than the one publicized in the early 1990's. SSA has

WASHINGTON OFFICE
510 CANNON BUILDING
WASHINGTON, DC 20516
(202) 225-6111

DISTRICT OFFICES

NEW TOWN
LUAN SQUARE SHOPPING
CENTER
1789 MARKLEY STREET
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(610) 272-0400

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already taken major steps to tighten up the program, as seen by the dramatic fall in the childhood initial claims rate. It fell from 70% in 1991 to 30% in 1996, a percentage said to be lower than the adult allowance rate.

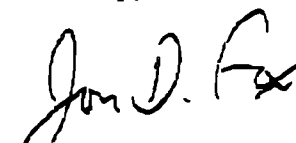
The unfounded criticisms of the program have been refuted by major investigations of the General Accounting Office, HHS Inspector General, and SSA's own investigation. Each agency concluded that the "coaching to get benefits" allegation was not true, and that the program did not have any evidence of systemic fraud or abuse.

The real experts in this field are groups such as The Arc, formerly the Association of Retarded Citizens, and child advocates like Community Legal Services. I understand that these groups have made sound proposals to you to increase the reliability and accuracy of actual decision-making that can only strengthen the program and also address governmental concern for more accountability in the program.

I urge you to give these proposals your most serious consideration as they will not only promote accountability but also be of tremendous assistance to the great majority of children whose very lives often depend on access to SSI and the Medical Assistance that comes with it.

In advance, I thank you for your leadership and utmost concern for the well-being of this nation's disabled children.

Sincerely,


Jon D. Fox
Member of Congress

JDF:klm

DRAFT

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DRAFT

WELFARE REFORM AND SSI CHILDHOOD DISABILITY ISSUE

Q: Under the welfare reform law signed by the President on August 22, 1996, the Social Security Administration was to issue regulations establishing a new medical eligibility standard for children with disabilities and publish the standard in the Federal Register by November 22, 1996. Why hasn't the SSA complied with the law?

A: The welfare reform law did change the statutory medical definition of disability for children under the SSI program. The statutory language stated that the child's disability must impose "marked and severe" functional limitations on the child. It was left to the Social Security Administration to specifically define this new eligibility standard through implementing regulations.

Since the passage of welfare reform, SSA has been involved in a very intensive discussion over the policy and legal issues surrounding the interpretation of this new law. Disability is a complex issue, and drafting regulations to implement this new law is an enormous task. It is taking some time to work through these issues. I am confident that the final result will be a set of regulations that meet both the letter and spirit of the law, ensuring that all children and families affected will be treated fairly and appropriately.

Q: When will the new childhood disability medical standard be announced and published in the Federal Register?

A: The new disability standard will be published as quickly as possible. However, because this new medical standard will have a direct impact on thousands of low-income disabled children, it is essential that we take whatever time is necessary to ensure that the new guidelines are appropriate. We must ensure that they meet the letter and spirit of the law and yet protect SSI entitlement for those disabled children who we all agree should receive benefits under the program.

Q: It is my understanding that about 100,000 new applications for SSI disability benefits from disabled children are being held by SSA and cannot be processed until this new disability standard is published. Aren't you concerned about the negative consequences this has for low-income families with disabled children?

A: Absolutely. I am concerned about the impact this will have, as I stated previously. We are also concerned about the equally adverse consequences of rushing too quickly to establish a new medical standard without carefully considering all the policy and legal issues that might arise under this new standard.

DRAFT**PHOTOCOPY
PRESERVATION****DRAFT**

SSA will move as quickly as possible to expedite the processing of those claims as soon as the new standard is established.

Q: As you know, the advocates are saying that the Administration has a great deal of leeway in setting the new standard and are arguing for a more liberal interpretation where fewer children would lose benefits. On the otherhand, many Republicans on the Hill have said they are watching the Administration closely to ensure that the new standard follows the statutory intent of welfare reform. What effect will either have on the Administration's final decision?

A: We will always welcome the advice of various constituencies. But, in the end, we must take actions that are consistent with the law and in the public interest. In this case, we will carefully consider all the various policy and legal issues and arrive at a medical standard that is most appropriate based on the letter and spirit of the law.

Q: The President has repeatedly stated that there were parts of the welfare reform law that he objected to and would like to seek changes to. Will the Administration attempt to circumvent the welfare reform law by developing a new medical definition of disability for disabled children not consistent with congressional intent?

A: Absolutely not. However, we will use whatever administrative discretion that is granted to us by the statute to ensure that the implementing rules for the legislation protect the entitlement of those low-income disabled children who are eligible under the law.

Q: How many disabled children currently receiving SSI benefits will SSA have to re-review once the new disability standard is established?

A: SSA will be required to redetermine the medical eligibility of approximately 300,000 children who currently receive disability benefits under the SSI program.

Q: I understand SSA will begin sending notices next week to the 300,000 children whose cases must be re-reviewed under the new standard. How can SSA send notices to these children informing them of the review process when the new medical standard hasn't been finalized?

A: Under the law, SSA is required to send notices by January 1, 1997 stating that a certain case will be reviewed in the near future. Although the final rules of the new medical standard have not been finalized yet, we believe it is appropriate and fair to inform those who might be affected by the new law as early in the process as possible.

won't lose pens @ earliest
Lm Summer

005/005

DRAFT

DRAFT

Q: Is that the same person that was in the car with the...

A: The [redacted] will [redacted] all the [redacted] Policy
Council [redacted] [redacted] [redacted] [redacted]
[redacted] [redacted] [redacted] [redacted] [redacted] [redacted]
[redacted] [redacted] [redacted] [redacted] [redacted] [redacted]

Jere

Jeremy?

Q: How did you react to the new law?

[illegible]

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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

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 HAS 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

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 STANDARD³

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

³ 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 intrauterine 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.

* * * * *

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 an 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.

* * * * *

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.

EXHIBIT A

Children's SSI Disability Allowance/Denial Rate⁵

YEAR	ALLOWANCE RATE AT INITIAL LEVEL
1989	43%
1990	59%
1991	61%
1992	53%
1993	48%
1994	36%
1995	32% ⁶
1996	31% ⁷

⁵ Report to Congress of the National Commission on Childhood Disability, October 1995, p. 23.

⁶ Initial allowance rate is for fiscal year 1995 (Oct. 1, 1994 through September 30, 1995).

⁷ Data is for fiscal year 1996 and covers period of October 1, 1995 through April 26, 1996.

THE WHITE HOUSE
OFFICE OF DOMESTIC POLICY

Assistant to the President Domestic Policy

To: Diana 

Draft response for POTUS
and forward to CHR by: _____

Draft response for CHR by: _____

Please reply directly to the writer
(copy to CHR) by: _____

Please advise by: _____

Let's discuss: _____

For your information: _____

Reply using form code: _____

File: _____

Send copy to (original to CHR): _____

Schedule ? : ☐ Accept ☐ Pending ☐ Regret

Designee to attend: _____

Remarks: Pls. work w/ OMB
on this -

THE WHITE HOUSE
WASHINGTON

To: Frank Rainie
Carol Rocco

FR: Vicki Radd

Estimate asked that
a draft response letter be
prepared for him.
Thanks.

**COMMUNITY
LEGAL
SERVICES, INC.**

1424 CHESTNUT STREET
PHILADELPHIA, PA 19102
215-981-3700
FAX 215-981-0434

November 16, 1996

Erskine Bowles
Chief of Staff
The White House
17th and Pennsylvania Avenue, NW
Washington D.C. 20500

Re: Pending New SSI
Childhood Disability
Regulations

Erskine
Dear Mr. Bowles:

I write to bring to your attention one of your first and perhaps one of the most important policy decisions you will be participating in at the White House--the new disability test for low-income children under the welfare bill signed by the President on August 22nd. There is considerable discretion the President has to shape a new standard.

Congress ended the former "individualized functional assessment" test, and substituted a new and vague "marked and severe functional limitations" standard, as well as excising the use of a "maladaptive behavior" criterion. Among options being considered by SSA and the White House is something close to the return to a medical "listings" standard, an extreme and limiting test that would exclude 1/3 of the children on SSI with mental retardation (100,000), and children like the "brittle diabetes" child here in Philadelphia in the enclosed clipping.

Disability consumers and advocates put forward some weeks ago a modification of the former test, one which then Majority Leader Dole stated needed but a "fine-tuning". This prior proposal of ours would eliminate children with so-called three moderate levels of disfunctioning in domains of functioning. But even this proposal would constitute overkill in terminating many children who there was a consensus should be protected. (See N.Y. Times editorial of Nov. 11th enclosed.) Clearly, though, it is a proposal far better than a listings or close to listings test.

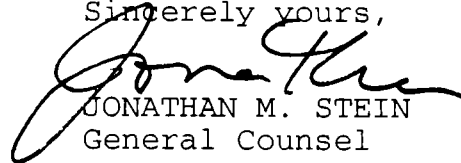
Enclosed you will find a new and revised draft of our proposal which attempts to follow the wise direction of the editorial in the Times which said that, "The Administration needs to make finer distinctions rather than simply sweep out broad categories." The new proposal, summarized in the cover page emphasizes accuracy and reliability in deciding childhood claims

Erskine Bowles
Page Two
November 16, 1996

as well as providing a more restrictive eligibility test. We think this proposal constitutes a good faith compliance with the intent of Congress while exercising the undisputed discretion the Administration has to do the least harm to disabled children.

We would welcome meeting with you at your earliest convenience to discuss this matter, following a very constructive meeting we had several weeks ago with Ken Apfel of OMB and Diana Fortuna of Carol Rasco's staff.

Sincerely yours,



JONATHAN M. STEIN
General Counsel

cc: Frank Raines, OMB Director
Carol Rasco, Dometic Policy Council Director

November 15, 1996

To: Those Concerned with the Adoption of a New
SSI Child Disability Policy

The attached new standard drafted to comply with and implement the new welfare law's SSI child disability provisions, has as its thrust insuring that SSI is provided only to truly disabled children through a revised test that emphasizes accuracy, reliability, and thoroughness in adjudication of claims. This proposal adds to and refines a proposal submitted earlier by a coalition of child disability advocates.

Among its hallmarks are:

1. So-called "moderate" scores in functioning must now, as a result of proposed regulations, be "good and solid moderates" where the disability "interferes considerably" with the child's ability to function like other children that age.

A corollary rule will be that not all "three moderates" will require an allowance of the claim.

2. There will no longer be a binding rule that "one marked and one moderate" will dictate an allowance; and the "solid" moderate rule will also be applicable in these decisions.

3. New rules will avoid any double-counting in domains of functioning that might have given too much laxity in the former IFA.

4. Evidentiary development will be emphasized in many areas, especially to document in a reliable way the underlying medical diagnosis, to provide longitudinal evidence of the history of the child's impairments, and to insure consistency between standardized testing employed and evidence of functional limitations.

5. Fairer evaluations of physically disabled children disfavored by the old IFA are provided by an additional domain relevant to their disabling conditions.

Jonathan M. Stein
General Counsel
(215) 981-3742)

THE SSI COALITION

FOR A RESPONSIBLE SAFETY NET

DRAFT

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

November 15, 1996

NEW CHILDREN'S SSI DISABILITY STANDARD

By Thomas Yates

In the SSI Coalition Proposal For A New Children's SSI Disability Standard (Draft, September 4, 1996) ("SSIC Proposal"), we, and a coalition of national disability groups, laid out a proposal for determining children's SSI disability, that charted a middle course between the Individualized Functional Assessment test that was rejected by the welfare reform bill and sole reliance on the Listings step (by meeting or equalling its criteria) of the children's disability sequential evaluation.¹

Our proposal set forth a new childhood disability sequential evaluation that retained the current first three steps, see 20 C.F.R. §§ 416.924(c)-(e), and incorporated a new step four that specifically focused on whether a child had medically determinable impairments that caused marked and severe functional limitations.²

The new fourth step is three-pronged. The first prong makes clear that all relevant evidence, both medical and non-medical,

¹ Sole reliance on the Listings was also rejected by Congress. The House of Representatives passed a version of a welfare bill that made the present Listings step the childhood disability standard. The Senate rejected that approach, and substituted a childhood disability standard that found children disabled if their medical impairment(s) caused marked and severe functional limitations. The Senate version was then adopted by the House in the conference bill.

² The SSIC Proposal is significantly different from the discarded IFA test because it tightens the disability threshold test. The IFA provided that generally, but not invariably, children with three moderate impairments would be found disabled, and it disfavored children with physical disabilities. The SSIC Proposal does not so provide; additional restrictions added to that proposal in this document further distance the SSIC proposal from the IFA test.

must be considered in determining whether a child's impairments cause marked and severe functional limitations.

The second prong requires decisionmakers to determine whether children have deficits in development or functioning in up to seven different areas. Those areas, which are modelled on the "B" criteria of the present childhood mental impairment listings, are: cognitive functioning; communicative functioning; social functioning; personal/behavioral functioning; gross and fine motor functioning; physical stamina and basic physical functioning; concentration, persistence, and pace; and responsiveness to stimuli (for infants).

The third, and eligibility determining, prong provided that a child would be found to have "marked and severe functional limitations" if his or her limitations in the areas listed above showed: a) inability to perform substantially any function; b) a marked impairment in one area and a moderate impairment in another; or c) a combination of impairments in the various areas that caused marked and severe functional limitations.

In this document, we supplement that proposal, and in doing so further tighten the disability standard, by addressing the following three issues that are intended to respond to Congressional concerns:³

- ♦ clarifying the disability threshold set by the proposed three tests of disability listed above to ensure that only children with marked and severe functional limitations are found disabled;
- ♦ ensuring that decisionmakers do not double-count functional limitations as they assess a child's development or functioning in the areas listed above; and
- ♦ defining with greater specificity what evidentiary showing is required to show marked or moderate impairments in the relevant areas.

A. Clarifying The Disability Threshold Set By The Three Tests Of

³ We believe these Congressional concerns fall into three areas: a) the old IFA test was deficient because it allowed nearly all children with three moderate impairments to be found disabled (leading to disability findings for children who were not truly disabled); b) there was concern that some functional limitations caused by medical impairments were double-counted in assessing loss of functioning in various areas; and c) there were inadequate safeguards to ensure that adequate and reliable evidence was developed to ensure that children truly had certain impairments (i.e., that children were not malingering, cheating, being coached).

Disability For Marked And Severe Functional Limitations

We propose that a child would be found disabled with marked and severe functional limitations if any of the three following criteria were satisfied:

- ♦ impairments that prevent the child from performing substantially any function (e.g. walking, breathing, taking care of personal needs) contained in any one of the areas;
- ♦ a marked impairment in one of the areas and a moderate impairment in another; or
- ♦ a combination of impairments in the various areas that causes substantial reduction in the child's ability to function independently outside of the home within age-appropriate norms, or causes substantial reduction in the ability to function independently, appropriately, and effectively in an age-appropriate manner.

1. Background: Defining Degrees Of Functional Limitation

SSA assesses the severity of functional limitations caused by medical impairments on a scale of "extreme," "marked," "moderate," "mild," and "minimal." Understanding these gradations is essential to applying the three criteria set forth above, particularly because SSA defines "moderate" to be more severe than it is in common usage. The different gradations are:

SEVERITY OF FUNCTIONAL LIMITATION	DEGREE OF FUNCTIONAL LOSS
Extreme	"Extreme" means loss so severe that child is clearly disabled by the limitation(s); the limitation(s) meets or equals a listing (e.g. marked inability to stand or walk; frequent need for life-sustaining device at home or elsewhere; requirement for 24-hour-a-day supervision for medical or behavioral reasons)

Marked	"Marked" means more than "moderate" but less than "extreme." A marked limitation is one that interferes seriously with the child's ability to function independently, appropriately, and effectively in an age-appropriate manner and, when applicable, on a sustained basis. When standardized tests are used as the measure of a child's functional abilities, a valid score that is two standard deviations below the norm for the test (e.g., an IQ score of 70 or lower on the WISC-R) will be considered a marked restriction.
Moderate	"Moderate" means more than "mild" but less than "marked." A moderate impairment is one that interferes considerably with the child's ability to function independently, appropriately, and effectively in an age-appropriate manner, and when applicable, on a sustained basis. When standardized tests are used as a measure of a child's functional abilities, a valid score that is between approximately one-and-one-half' and two standard deviations below the norm for the test will generally be considered a moderate restriction (e.g. an IQ score on the WISC-R ranging from 71 through 77). The spectrum of what may constitute "moderate" limitation in this age group ranges from limitations that may be close to the "marked" level in severity to limitations that may be close to the "mild" level and, thus, considerably less limiting.⁴
Mild	"Mild" means more than "minimal or no impact" but less than "moderate." A "mild" impairment is one that is "severe," as defined at 20 C.F.R. § 416.924(d); it causes more than minimal limitation in a child's ability to function independently, appropriately, and effectively in an age-appropriate manner.

⁴ In this point, the definition of "moderate" is more severe than SSA has represented that it is. In its Disability Digest No. 94-6 (March 1996), SSA stated that a "moderate" impairment could range from one that is almost "marked" to one that is almost "minimal." This proposal provides a higher low threshold for "moderate" impairments.

Minimal or No Impact	"Minimal or no impact" means that it would not be considered a "severe" impairment. The impairment or combination of impairments causes no more than minimal limitation in a child's ability to function independently, appropriately, and effectively in an age-appropriate manner.
----------------------	--

In making a disability determination, the decisionmaker must review a child's medically determinable impairments and assess the degree of functional limitations, using the definitions set forth above, in each of the relevant areas (e.g. cognition; communication; social functioning; personal/behavioral functioning; motor skills; concentration, persistence, and pace; physical stamina and basic physical functioning; and responsiveness to stimuli for infants).

2. Applying The Proposed Marked And Severe Disability Threshold Tests

In applying any of the three tests of marked and severe disability, the standards set forth are guidelines, not binding rules. Thus, children who meet their terms will generally, but not invariably, be found disabled. In determining childhood disability, SSA must act, on a case-by-case basis, to ensure that only children with marked and severe functional limitations are found disabled.

a. Inability To Perform Substantially Any Function Test

If a child has an extreme functional limitation in any of the areas, see examples set forth in table above, she or he would be considered disabled.

b. The One Marked And One Moderate Test

Generally, but not invariably, a child with one "marked" impairment and one "moderate" impairment will be found disabled. However, not all children found to have one "marked" impairment and one "moderate" impairment are necessarily disabled. Because the term "moderate" represents a range of limitations from just above "mild" to just below "marked," an impairment(s) that imposes "moderate" limitations in an area when paired with another "marked" impairment will not always lead to a finding of disability.

A "moderate" impairment, when paired with another "marked" impairment, cannot be considered disabling unless it is a "good, solid moderate." An impairment, that while in the "moderate" range, is just above "mild" will not be considered to be a "good solid moderate."

Thus, the decisionmaker, in making a decision under this test, must assess the effects of the child's impairments on the various relevant areas, see § 4(b) of SSIC Proposal, and the "other factors" set forth at 20 C.F.R. § 416.924c, and before finding a "good, solid moderate" impairment:

- ♦ take a step back,
- ♦ look at the totality of the evidence, and;
- ♦ consider what the child is able to do and in what ways the child's impairment(s) **interfere considerably** with his or her age-appropriate functioning.

If the impact of the functional limitation interferes considerably with the child's functioning, then it is a "good, solid moderate" impairment that could support, when paired with another "marked" impairment, a finding of disability.

c. Combination Of Impairments In Various Areas Test

Finally, a child could be found disabled at the "marked and severe" functional limitations step if she or he has:

a combination of impairments in the various areas that causes substantial reduction in the child's ability to function independently outside of the home within age-appropriate norms, or causes substantial reduction in the ability to function independently, appropriately, and effectively in an age-appropriate manner.

This test, unlike the first two tests, sets forth no general standard in regard to the number of required marked or moderate functional limitations. It is intended to address those cases of severe disability in which a child evidences impairments in a number of the relevant areas that, taken in totality, cause "marked and severe" functional limitations.

Examples of cases in which children may be found disabled under this test are children with "good, solid moderate limitations" in at least three or more of the relevant areas, determined on a case-by-case basis. *Given that this revised definition*

This test is narrowly drawn to provide SSA decisionmakers with flexibility to make favorable disability determinations for children with functional limitations of equivalent impact to children found disabled with one marked impairment and one good, solid moderate impairment.

6 of "moderate" is more restrictive than that previously used, children with three moderate impairments in areas of functioning will no longer be automatically determined eligible.

B. Decisionmakers Must Ensure That Functional Limitations Are Not Double-Counted In Assessing A Child's Development Or Functioning In The Various Areas

1. Statement of Policy

The areas for assessment of functional limitations⁵ are intended to aid decisionmakers by dividing various areas of a child's functioning or development into different and unique groupings to ensure that functional limitations are not double-counted in determining childhood disability.

Thus, decisionmakers must ensure that any functional limitation that a child has is not assessed in more than one area in determining disability. For example, a child's reading difficulties are evidence of a cognitive limitation, but not a communication limitation--no impairment should be found in communication as a result. In addition, a child's inability to relate satisfactorily to others and his or her difficulty and frustration in not being able to relate satisfactorily to others constitutes a limitation in the social area, not the personal/behavioral area.

Set forth below are definitions of the various areas. Decisionmakers must ensure that any functional limitation caused by medically determinable impairments are assessed in only one area.⁶

⁵ The relevant areas are as follows:

for a child from birth until attainment of age 1: cognitive functioning; communicative functioning; ability to sustain social interaction on an ongoing reciprocal fashion; motor development; age-appropriate physical stamina and basic physical functioning; and responsiveness to stimuli;

for a child from age 1 to attainment of age 3: cognitive functioning; communicative functioning; social functioning; gross and fine motor development; and physical stamina and basic physical functioning; and.

for a child from age 3 until the attainment of age 18: cognitive functioning; communicative functioning; social functioning; personal/behavioral functioning; gross and fine motor functioning; physical stamina and basic physical functioning; and age-appropriate concentration, persistence, or pace.

⁶ This does not mean that a medically determinable impairment (and resulting treatment) cannot cause more than one type of functional limitation. For example, a child with asthma could be

2. Definitions Of Various Areas:

a. Cognition

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

b. Communication

Communication refers:

- ♦ with respect to language, to the ability to receive, comprehend, and express messages using age-appropriate communication skills in order to meet one's needs, or to obtain or convey information; and
- ♦ with respect to speech, to audibility, intelligibility, and efficiency of speech production.

c. Fine And Gross Motor Skills Development

Fine and Gross Motor Skills Development refers to the ability to use one's body and extremities in gross and fine motions in order to relate to the physical environment and serve one's own or others' physical needs or purposes.

d. Personal/Behavioral Patterns

Personal/Behavioral ^{functioning} ~~patterns~~ means age-appropriate activities and behaviors entailed in:

- ♦ self-help (e.g. feeding, dressing, maintaining personal hygiene);
- ♦ self-regulation (e.g. maintaining proper nutrition, sleep, health habits, regulating mood);
- ♦ self-improvement (e.g. increasing self-help behavior through learning of new skills);
- ♦ self-protection (e.g. taking necessary safety

limited in physical stamina as a result of the asthma and limited in personal/behavior functioning because of hyperactivity caused by medications used to treat the child's asthma. Similarly, a child with a history of otitis media with speech and language problems could have functional limitations in both communication (due to the hearing problems) and social (due to his inability to form, develop, and sustain relationships as a result of frustration resulting from the hearing and speech problems).

- ◆ self-control (e.g. adapting to changes in environment or activity).

Social Abilities means the ability to form, develop, and sustain relationships with other people on a social basis in an age-appropriate manner, to respond appropriately within one's own social role or to the social roles of others, and to conduct oneself according to the manners and mores of one's social group.

Concentration, persistence, and pace means the mental ability to sustain focus on, and attention to, an activity or task, such as dressing, playing, reading, studying, or practicing an activity or complete the task at a reasonable (or age-appropriate) rate.

Physical stamina means the physical ability to perform age-appropriate tasks or activities, including play, on a sustained basis at a reasonable (or age-appropriate) rate. Basic physical functioning refers to essential bodily functions such as breathing, digestion, and elimination.

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

In assessing a child's functioning in various areas, decisionmakers must ensure that all relevant evidence is obtained and considered, and that decisions on degree of functional limitations in the various relevant areas are based on reliable indicators of a child's functioning or development. As a general rule, SSA must do the following.

- 9

Reliability

~~_____~~ In some cases, this means developing and considering evidence concerning the child's functioning that ~~_____~~ prior to the date of SSI application.

covers a significant period of time.

- ♦ SSA must, when standardized tests are used to assess functional limitations, develop evidence of the child's day-to-day functioning in the relevant areas addressed by the standardized testing to ensure that test results are valid and consistent with the child's functioning.
- ♦ SSA must, when evaluating behaviors caused by medical impairments that impact functioning, obtain evidence regarding:
 - the nature and intensity of the behavior--more is

7 While standardized intelligence tests are useful in assessing a child's cognitive abilities, they should not alone establish either marked or moderate limitations in cognitive functioning. While low scores on such tests are often indicative of significant cognitive limitations, they must be accompanied by achievement test scores when academic performance is an issue, and by reliable descriptive information about a child's cognitively based functioning on a daily basis. A child may function either above or below the level one would expect based on intelligence test scores alone.

Generally, impairment in cognitive functioning cannot be found unless a child manifests both subaverage general intellectual functioning and deficits in performing cognitively based tasks in an age-appropriate manner on a daily basis.

For example, a child with low IQ scores who nonetheless demonstrates relatively strong cognitive abilities in his or her day-to-day functioning may be found less limited than one would expect based on test scores alone. It is also possible for a child with higher IQ scores to be unable to perform cognitively based tasks in an age-appropriate manner on a daily basis. This child would be found more limited than one would expect based on test scores alone.

In assessing marked and moderate cognitive limitations, a child whose scores on standardized intelligence tests fall two standard deviations below the norm has a marked limitation, assuming the other relevant evidence shows corresponding limitations in day-to-day cognitive functioning. A child whose scores are between approximately one-and-one-half and two standard deviations below the norm for the test has a moderate restriction (e.g. an IQ score on the WISC-R ranging from 71 through 77), assuming consistency with other evidence.

required than a general allegation of the inappropriate behavior--by documenting a detailed description of what occurs, the precipitating event(s), and the setting(s) in which it occurs;

- the frequency and duration of the behaviors so that they can be assessed in longitudinal context and compared to the behaviors exhibited by "normal" children; and
- any interventions attempted to change the child's behaviors and the responses to these interventions.

In assessing any functional limitations resulting from such behavior, the decisionmaker should decide whether the behaviors are consistent with any established impairment, whether there may be an additional underlying mental impairment which must be documented, and how and to what degree an established impairment affects the child's ability to function in an age-appropriate manner.

D. Conclusion

This proposal provides the best approach for SSA to implement the changes mandated by the welfare reform bill, and address the concerns raised by Congress. Its application will allow SSA to make childhood disability determinations that ensure that children with marked and severe disabilities are not improperly denied disability.