March 15, 1995 • Philadelphia Weekly

A Disquieting Spring

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

"brittle" (i.e. uncontrolled) juvenile diabetes - "IFA" child

BY DAISY FRIED

HARVEY FINKLE

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

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

The first-grader is laying out the components of her "One Touch II" gadget, which identifies her blood-sugar level. Her fingertips are 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 $403 of public assistance a month, plus $213 worth of monthly food stamps to support her family of three. "I take from Peter to pay Paul," she says. "It's a constant tug o' war. Now why would I fight this long if I had no reason? It is time-consuming. It would be much easier to get a job."

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

In a 1990 decision, *Zebley v. Sullivan*, a conservative Supreme Court decided by a 7-2 margin that policies used to determine children's eligibility for SSI were illegal because the existing listings, created to assess adults' (in)ability 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.

Prior to *Zebley*, each of a child's conditions would be considered on its own merits, explains Joe Scullin, Director of Social Services of United Cerebral Palsy (UCP) of 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.

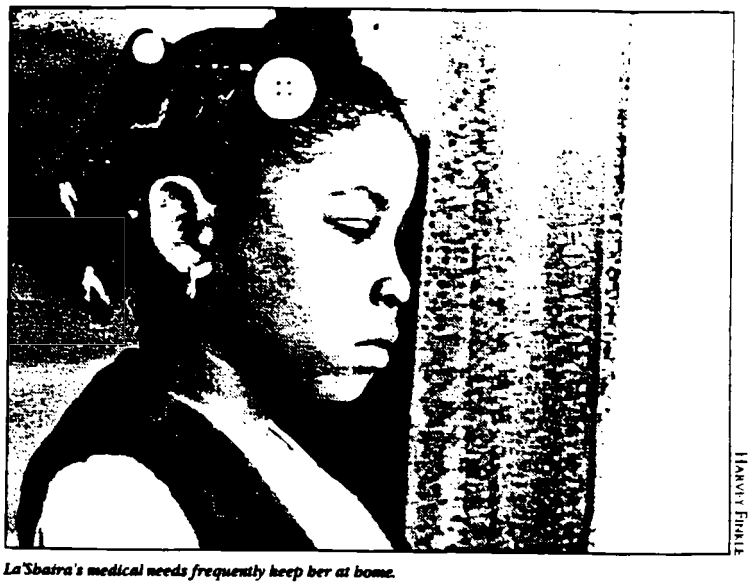
"If there is fraud or misuse, the solution is to enforce, not to cut. The criticism [SSI opponents] are making is a criticism of government, not of the people. They're basically blaming the victim for their own lack of attention," says UPC's Scullin.

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

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

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

3/95 - Phila. Weekly



HARVEY FINKLE

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

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

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

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

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

Personal Responsibility Act did you say?

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

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

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

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

That's not all.

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

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

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

MARCH 27, 1994 STATEMENT TO SSI CHILD DISABILITY COMMISSION

OF

VANESSA COOKE, MOTHER OF

La'SHAIRA COOKE WITH "BRITTLE DIABETES"

My daughter, La'Shaira Cooke, is six years old and suffers from severe, "brittle diabetes" where she is in mild insulin rejection at all times. She began applying for SSI benefits when she was two and was denied SSI repeatedly despite virtually every part of her life being affected by her disease. Five years after first applying a Social Security judge finally awarded benefits, saying my "care for [La'Shaira's] condition was a full time job."

La'Shaira must have her blood sugar checked four times per day. On the three days that the school nurse is at her school she does the blood tests, but on the other two days I must come to school to do the test. If the test results are unacceptable her urine must then be checked for ketones. If unacceptable, she must then be given an immediate insulin injection (in addition to the three daily injections she normally gets). These injections must be given by me, after telephone consultation with her doctor, as the school nurse is not allowed to give injections.

I wear a beeper so I can rush to La'Shaira's school to give her injections. I am too poor to own a car, and must take a cab to school to respond to an emergency. Two hours after an emergency injection my daughter's blood sugar must be again checked, and I must wait at school to administer the follow up test.

Every day La'Shaira must eat special snacks at 10:00 A.M., 2:00 P.M. and at night; in addition, she eats a special homemade lunch in the nurse's office where she can't have access to the free lunch program and be tempted to eat the wrong food or trade food with her classmates. She cannot go on school trips without me (and at an added cost for me). She often becomes nauseous, dizzy or very thirsty or shows other signs of hypo- or hyper-glycemia; in all these cases I am the one who is summoned.

Despite all this high level of care, La'Shaira does not meet Social Security's so-called "Medical Listings" for child diabetes (Section 109.08), in part because of the excellent care I provide. The Listing requires that a child take insulin by injection and that she have "recent, recurrent hospitalizations for acidosis." Although my daughter has been hospitalized occasionally, her history does not meet the vague "recent, recurrent hospitalization" standard of the Listing.

La'Shaira's endocrinologist, in a letter to the Social Security Administration, describes the Medical Listing as "failing to reflect the real concerns and realities of managing the very young diabetic," likening them to locking the barn-door after the cow has been stolen -- being based on the <u>failure</u> to adequately treat and monitor a child with diabetes. Since the care La'Shaira receives has made these episodes too infrequent, according to SSA, she does not "meet" the Listing!

Instead, La'Shaira <u>only</u> qualified for SSI after several appeals because the Zebley "functional assessment" test accurately measured the restrictions she had in motor activity, the personal

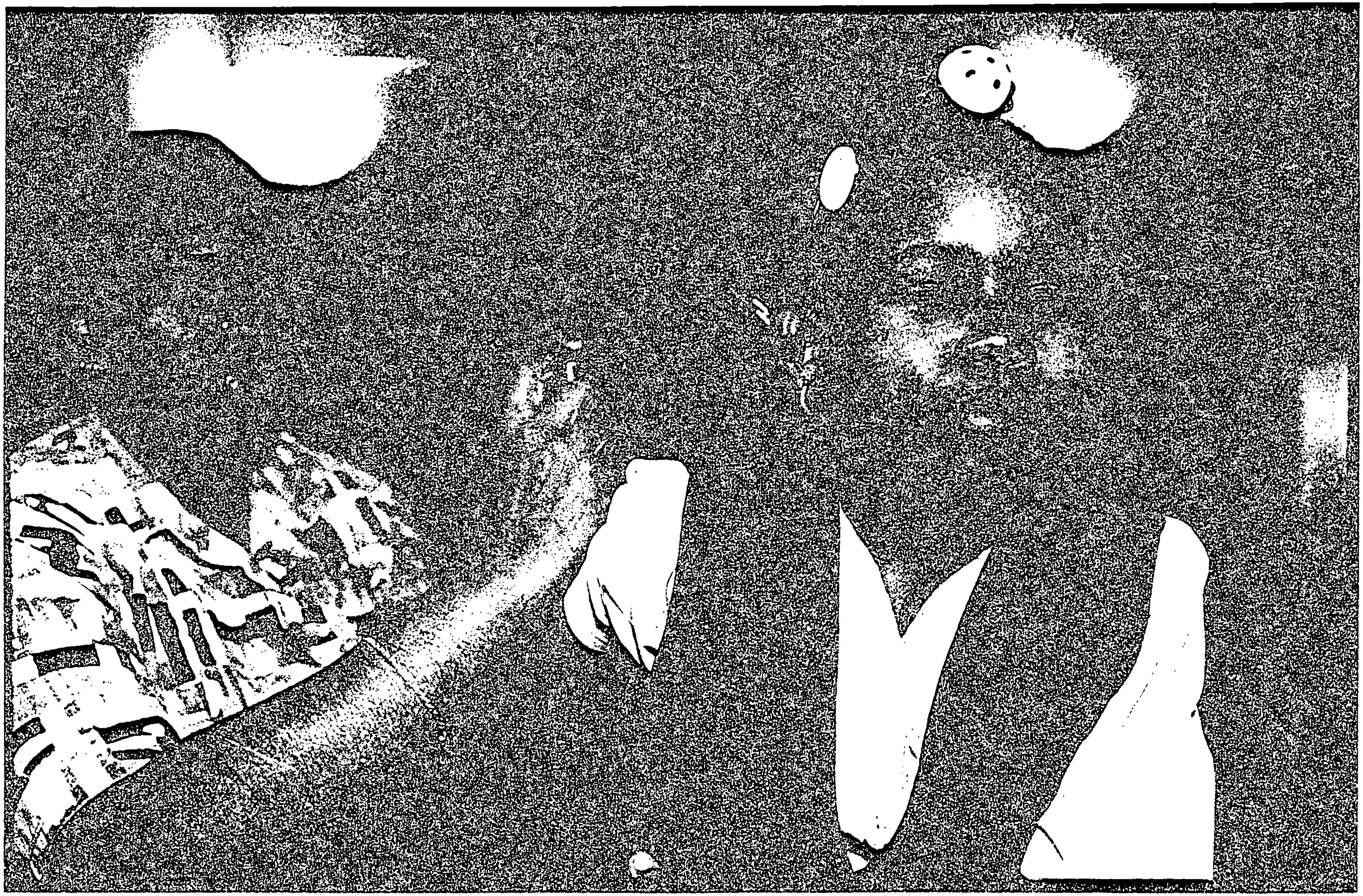
behavior domain, social restrictions and the special "other factor" consideration of the highly unique protective setting for her created by me, her school and her university hospital physicians.

Caring for my daughter makes me unemployable, as I must be ready to drop everything on a moment's notice to respond to frequent crises. Only SSI cash - not "vouchers," not "social services" -- can meet my needs: La'Shaira's special diet far exceeds her foodstamp allotment; beeper maintenance costs $12.80/month, plus our telephone which is essential also; cab fares and other related expenses take up a substantial part of the family budget.

Thank you for allowing me to tell my story.

Address: 300 No. Busti Street
Apartment 503
Philadelphia, PA 19104

Tel: (215) 222-7789



CLINTON WHITE HOUSE STATEMENTS ON THE

SSI CHILDHOOD DISABILITY CONGRESSIONAL PROPOSALS

"...The President made the decision to veto the welfare reform conference agreement because of the excessive cuts in this program and many others....we have advocated grandfathering SSI benefits for the children who would lose coverage as a result of the eligibility changes passed by the Congress."

Letter of Feb. 28, 1996 of Carol Rasco, Ass't to the President for Domestic Policy

"...we want to eliminate the impact of the SSI cuts that impact on children....all of that's been made clear in the letters that we have sent to the conferees."

Interview of Nov. 12, 1995 with Leon Panetta, Chief of Staff, on Face the Nation, ABC-TV

"The Administration supports the bipartisan Senate decision to continue to provide SSI cash benefits for all eligible children. But, we strongly urge the conferees to reduce hardship to disabled children currently on SSI by exempting them now from the new, stricter eligibility rules,. However, if the conferees determine that these rules should be applied to current SSI recipients, the Administration recommends applying them only to those children eligible as a result of maladaptive behavior."

Letter of Alice Rivlin, OMB Director to Senator Bob Dole, Oct. 18,1995

"...The Administration is deeply concerned about the cuts passed by both houses [in the SSI program], particularly those in the House. The House plan would drop approximately 200,000 children from the rolls immediately....The Senate bill is better than the House, but it would still cut eligibility sharply."

Letter of Carol Rasco of Sept.28,1995

The New York Times

Founded in 1851

ADOLPH S. OCHS, *Publisher 1896-1935*
ARTHUR HAYS SULZBERGER, *Publisher 1935-1961*
ORVIL E. DRYFOOS, *Publisher 1961-1963*
ARTHUR OCHS SULZBERGER, *Publisher 1963-1992*

The President's Next Welfare Test

President Clinton will have to work with the Republican Congress to keep his promise to fix the welfare law that he signed over the protests of many Democrats. But his Administration has sole control of the implementation of a potentially punitive provision of the new law. That provision would knock children off disability rolls. How well Mr. Clinton protects those children will provide the first post-election test of his resolve to block Congress's worst impulses.

About one million poor children receive Federal money under the Supplemental Security Income program. Most recipients suffer from well-defined physical or mental handicaps that are so severe that no one disputes their eligibility. But about 300,000 of these children qualify for S.S.I. because of a combination of functional impairments, no one of which may be severe. It is this group that some members of Congress want to drive off the rolls, even though no Federal study has shown a pattern of abuse. They have accused parents of abusing the program, coaching their children to feign "maladaptive behavior" and other handicaps.

The new law eliminates maladaptive behavior as a qualifying handicap. It also vaguely calls for an overall tightening of standards. But, in a flash of good judgment, Congress left the task of issuing new guidelines — due in the next few weeks — to the Administration. That means Mr. Clinton has the authority to protect these children.

The question before the Administration is how many of these 300,000 children with a combination of functional impairments are truly disabled. Within this group, the children the Administration is most likely to rule ineligible are an estimated 50,000 who are less dramatically impaired. They qualify for S.S.I. under current rules because they suffer a combination of three "moderate" functional impairments. The Administration will be tempted to throw all these children out of S.S.I. just to appease Congress's intent to tighten eligibility.

The temptation should be resisted. Jonathan Stein, the general counsel of Community Legal Services, an advocacy group in Philadelphia, points out that these supposedly moderate handicaps can be severely debilitating. As one of many examples, he cites a 6-year-old child with a very low I.Q. of 72 and a mild case of cerebral palsy who cannot walk or talk well. By S.S.I. standards, no one of these mental or physical handicaps is severe. But the combination surely is.

A blanket rejection of aid for children with three non-severe handicaps would cruelly leave the poor parents of these severely handicapped children to fend for themselves. The Administration needs to make finer distinctions rather than simply sweep out broad categories.

The rules that the Administration will soon issue will determine how many vulnerable children are stripped of Federal benefits. Mr. Clinton's obligation, no matter how much anger he provokes on Capitol Hill, is to make sure that every child he separates from S.S.I. is undeserving. Appeasing Capitol Hill's need to find abuse where it may not exist or, worse, saving money on the backs of the disabled might be politically expedient, but it is unfair.

W Post 11/7/96

INSIDE:
SOCIAL SECURITY

Aid for Disabled Children Hinges on New Definition

By Barbara Vobejda
Washington Post Staff Writer

In the coming days, the Clinton administration will answer a question that has prompted enormous anxiety since Congress began debating welfare legislation nearly two years ago: How many children will lose their federal disability benefits as a result of the new law?

Families and advocates for the disabled have known since the welfare law was enacted in August that eligibility would be tightened for the Supplemental Security Income (SSI) children's disability program. But Congress gave the administration wide discretion in determining which disabilities will qualify for benefits, which average about $430 a month.

If the administration adheres to a narrow definition of disability, around 200,000 of the nearly 1 million children now in the program would likely lose their benefits. If it accepts a broader definition, the number could fall below 100,000, advocates say.

With benefits for that many children at stake, those in the disabled community see these regulations as critical and have been actively lobbying the administration to cut off as few recipients as possible.

"There is a distinct risk of overkill, putting in jeopardy children even the vocal critics would not want to be terminated" from the program, said Jonathan Stein, a Philadelphia attorney and leading advocate for disabled children. "The administration should be looking for a way that harms the least children."

The decision is before officials at the Social Security Administration and could be announced within a week or two, an SSA spokesman said.

"The agency is meeting at the highest levels now, meeting with the White House" on the new rules, said Phil Gambino, an SSA spokesman. "We're at that last stage."

While much of the attention to the welfare legislation has focused on Aid to Families with Dependent Children, the law also affects several other programs, including food stamps and SSI payments to the elderly and disabled.

Sponsors of the legislation, led by Rep. Jim McCrery (R-La.), had argued that some children who were not seriously disabled were receiving benefits, including some whose parents had coached them to pretend they suffered from mental or behavioral problems.

As a result, Congress instructed the administration to tighten eligibility, but it gave little guidance on exactly how to do that.

"We want to make sure that under the new criteria, only the truly disabled qualify for this benefit," McCrery said. "That's what we're waiting to see, if the administration will indeed write regulations that carry out the intent of the law."

The law eliminates what was known as the "individualized functional assessment," or IFA, a test that was used to determine eligibility if a child's disability was not among a "listing" of conditions.

The new language says that a child "shall be considered disabled . . . if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations."

But that leaves enormous room for interpretation. A Congressional Budget Office estimate based on an earlier draft of the legislation indicated that as few as 10 percent or as many as 28 percent of the nearly 1 million children receiving benefits could be pushed off the rolls as a result of the law.

The language in the final legislation was less strict. At SSA, Gambino said, "we have talked about a range of 100,000 to 180,000 who could lose benefits as a result of the regulations." And advocates believe the range could be slightly larger.

After the regulations are completed, SSA must review the cases of all children who were granted eligibility through the functional assessment, or nearly 300,000 children, and determine if they meet the new criteria. That will begin early next year, with benefit cuts beginning in July.

But no one can say until the new regulations are released how many of those children, or how many new applicants, will be granted eligibility.

"We have no sense of where they might come out," said Marty Ford, assistant director for governmental affairs at The Arc of the United States, an advocacy group. "We're pushing hard because we think kids and families will be devastated by the impact if the Social Security Administration chooses too high a standard."

Under the previous law, Ford said, the standard was already very high. A mentally retarded child, for example, would have to have an IQ of 70 or below to be considered someone with a "marked" disability. An IQ of 74 was considered a moderate disability.

"It's very scary," said Patti Steinitz, a Pittsburgh mother who fears her 2-year-old daughter could lose the Medicaid benefits she receives under SSI. Steinitz said her daughter, Hunter, suffers from a severe disorder that makes it difficult for her to get enough nutrition and makes her very vulnerable to infection. She requires around-the-clock nursing, at an annual cost of more than $160,000.

Steinitz, a police officer, and her husband Mark, a businessman, are ineligible for cash benefits under SSI because of their incomes. But they lost the Medicaid benefit that pays for Hunter's nursing care, Steinitz said, in order to care for their child, "we would have to quit our jobs and go on welfare."

Steinitz appealed personally to President Clinton for his help when he was campaigning recently in Pittsburgh and since has been writing letters to the White House.

Jonathan Stein, whose arguments before the Supreme Court in 19[illegible] contributed to an expansion of the SSI children's program, argues that many lawmakers mistakenly believe that children who qualified for SSI because of the functional test are not seriously disabled.

Of the 300,000 children who receive SSI because of mental retardation, one-third qualified because of the functional test, he said.

"The IFA population is strewn with families who have kids with serious disabilities, and they're all in jeopardy," Stein said.

10/9/96

The Washington Post

AN INDEPENDENT NEWSPAPER

A Choice for the Administration

THE WELFARE bill that Congress passed and the president signed two months ago had to do with more than just welfare. Among the other programs it will affect is a special form of federal aid to needy families with disabled children. For years a kind of backwater in the budget to which no one paid much attention, the program in the 1990s suddenly more than tripled in size. The caseload shot up from 300,000 to about a million, the cost from a little more than $1 billion to about $5 billion.

Partly this expansion reflected a 1990 Supreme Court decision requiring that eligibility standards for children be eased, and partly it was the result of an earlier congressional decision to admit to the program a broader range of children with mental disorders. But critics had begun to contend that it was partly due to abuse as well. They argued mainly on the strength of anecdotal evidence that parents and others were taking advantage of the liberalized rules to obtain disability benefits for children who, while needy, were not in fact disabled, and they said the program had grown in directions that Congress never fully had contemplated.

The House version of the welfare bill therefore proposed sharp cuts in the disability benefits. Rather than give cash to eligible families, it proposed offering most of them only certain services, limiting the cost of those and narrowing the definition of disability. The Senate took a more moderate approach, which prevailed in the bill the president finally signed. The cash payments were preserved, and the disability definition was tightened less.

The new language creates a zone of discretion for the administration. A child will be deemed disabled if he or she has a "medically determinable physical or mental impairment, which results in marked and severe functional limitations." What might those be? The administra will have to say in regulations.

Just about everyone agrees that some th fourths of the children on the rolls are disa enough that they will meet the new test, ever it is phrased. It is the others, abo quarter of a million, whose fate is up in the together with however many might be expe to apply in the future.

Advocacy groups say the final language in bill was deliberately such that the administra need cut off only a minority of these. They among much else, a carefully orchestrated c quy on the Senate floor last year when this of the bill was taking final form. Then-Majo Leader Bob Dole, who took part along with S John Chafee and Kent Conrad, said at one p "I think we can all agree that the children's [as the program is called] needs a tune-up." T hardly argues for wholesale change, they They make the further point that the So Security Administration has already tightened on the program, such that the so-called allowa rate or percentage of applicants granted bene has fallen from an artificial high of 70 percen 1991 to 30 percent today.

Our own sense is that the administration ou to err on the side of giving the extra ben rather than denying it. The poverty rate amo children remains high, and other forms of aid needy families with children already are be cut. Having at home a child with even a relativ modest disability can be an enormous burden a cost for even a family of some means, if o because it often deprives the household of ea ings. A family member who otherwise mi work is required to provide child care inste We have no doubt that people here and there a ripping off this program, just like any oth program. But most aren't, and that ought not the presumption of policy.

LOS ANGELES TIMES EDITORIALS

Don't Penalize Disabled Kids

Washington should seek properly broad criteria for aid

President Clinton can begin making good on his campaign promise to fix the flawed welfare reform law by dealing with the issue of benefits for disabled children. When the Social Security Administration moves to redefine the eligibility criteria, as required under the new law, the White House should encourage a broad definition. The health of thousands of children is at stake.

One million disabled children currently receive some form of federal assistance, primarily for mental retardation, physical disabilities and, increasingly, emotional disorders. Poor disabled children also qualify for cash benefits, about $500 a month in California.

Under the new rules, narrowly tailored eligibility regulations would eliminate as many as 200,000 children from the benefit rolls, according to an analysis by the Congressional Budget Office. But this is a humanitarian issue, and a more generous standard should be adopted, one that could drop fewer than 100,000 children from this program.

Congress set tighter eligibility standards in part to remove from the rolls children who were being coached by parents to mimic emotional ailments or behavioral problems. Such fraud qualified some families for so-called "crazy money." On this point Congress was right. Fraud should not be tolerated. But most recipients are truly needy.

The new law also calls for tighter standards for children with moderate disabilities, which would preserve funds for those considered "truly disabled." Now further fine-tuning of definitions is needed, particularly in the aftermath of a 1990 U.S. Supreme Court decision that broadly extended benefits to thousands of children with mental impairments or multiple moderate disabilities.

The welfare reform law terminates federal disability benefits to legal immigrants, regardless of age or impairment, and the aid never has gone to illegal immigrants. An estimated 50,000 legal immigrant children are expected to lose benefits nationwide; as many as half live in California. Only Congress can restore the program for these children.

The welfare reform law requires the Social Security Administration to formulate new criteria by Nov. 22. President Clinton can influence that decision and should act for the benefit of disabled children. Yes, fraud is a problem. Yes, costs must be cut. But disabled children should not be counted among cost-saving measures.

THE REGION & STATE

PITTSBURGH POST-GAZETTE ■ SUNDAY, SEPTEMBER 22, 1996

Hunter Steinitz, 23 months old, needs constant nursing care which could become unaffordable due to changes in the welfare law

Welfare cuts could be fatal to infant

By Ellen M. Penmutter
Post-Gazette Staff Writer

Hunter is doing remarkably well for a 23-month-old with a genetic disease so rare that victims seldom live past 2 years.

But now, her parents say, Hunter's health could be threatened by cuts in the federal Supplemental Security Income program, which was included in the new welfare law that President Clinton signed in August.

Because of her SSI eligibility, Hunter Steinitz, who lives with her family in Observatory Hill, has received almost $200,000 in nursing care in her lifetime — one of the keys to her survival, say her parents, Patti and Mark Steinitz.

She is not the only one to get such extraordinary help.

There are 315,000 children nationwide, including 15,000 in Pennsylvania, with severe physical and mental disabilities whose care may be in jeopardy under the revamped welfare law, advocates say.

Hunter, who was profiled in the Pittsburgh Post-Gazette in May, has skin that grows so fast it can't shed quickly enough. Her skin becomes so thick that it tightens around her chest and abdomen, and could choke her. It also cracks easily, opening her up to infections.

She needs some type of preventive medical care nearly every hour. Whether it's moisturizing her skin or placing prescription drops in her eyes because her lids do not shut completely. A humidifier needs to be constantly monitored so the air is kept properly moist for Hunter's delicate skin — always bright pink as it grows and sheds.

Hunter requires two baths a day, each one taking up to two hours. Special care must be taken to remove excess skin from her nostrils and ears.

The nurses, made possible through SSI eligibility, help Hunter's family to live an almost normal life. The couple, who also have a teen-age daughter, share the responsibilities on their days off from work.

But, they said, they can't be available 24 hours a day.

"We need the nurses so desperately," Patti Steinitz said. "We have a night nurse every night of the week so we can get some sleep."

The nurses, paid through the state, are provided because of the severity of Hunter's disorder. An evaluation process enabled Hunter to qualify.

But the new welfare law eliminates the assessment process Hunter went through. That process broadly defined a person's disability so that no children would fall through federal cracks.

Critics charged that the rule made it too easy for children to be classified with physical or mental disabilities. They said parents coached their children to feign disabilities.

The General Accounting Office and Social Security Administration, however, determined there was "absolutely zero evidence of widespread abuse."

The new law requires SSA to come up with a new assessment procedure no later than Nov. 22.

SEE **HUNTER**, PAGE B-6

Annie O'Neil/Post-Gazette

Hunter Steinitz — *Within the next few weeks, she will have an operation to insert a tube in her belly so her parents can intravenously feed her the nutrients she needs.*

Inside the Region

— Patti Steinitz, center, and Mary Ann Veremeychic, a nurse with Interim Nursing, play peekaboo with Steinitz's daughter, Hunter.

Hunter is doing remarkably well for a 23-month-old with a genetic disease so rare that victims seldom live past 2 years. But now, her parents say, Hunter's health could be threatened by cuts in the federal Supplemental Security Income program, which was included in the new welfare law that President Clinton signed in August.

Story, Page B-5.

Annie O'Neil/Post-Gazette

Welfare cuts could be fata

HUNTER FROM PAGE B-5

"Children with medically documented disabilities have a better chance of remaining eligible for benefits," said Tom Morgenau, SSA spokesman. That would seem to include Hunter.

But, said Jonathan Stein, general counsel of Community Legal Services in Philadelphia, "No one can give anybody any assurance.

"The fact is there is no standard right now. Since the law went into effect on Aug. 22, there has been no standard," Stein said. "We're in limbo."

Meanwhile, Hunter's parents juggle their schedules to deal with Hunter's condition. Her mother is a Pittsburgh police officer who made about $40,000 last year. Her father is a struggling businessman who recently closed his framing shop on the South Side.

Their income was not taken into consideration in determining SSI eligibility — only their daughter's extreme need for care.

Hunter weighs 17 pounds, 8 ounces now — 12 pounds more than her birth weight. She has a digestive problem that makes it difficult to keep food down.

Within the next few weeks, Hunter will have an operation to insert a tube in her belly so her parents can intravenously feed her the nutrients she sorely needs.

Patti Steinitz's private medical insurance pays for some medicines and care. But it has caps on the amount it will disperse in Hunter's lifetime.

She was born with the disorder as a result of two rare, recessive genes carried by her parents. The condition is present in one to five children of every 5 million babies born in the United States each year. There are only three children, including Hunter, in the United States diagnosed with Harlequin Ichthyosis.

"Without SSSH, her care would decline and leave her at risk for illnesses and death," Patti Steinitz wrote to Clinton a month before he signed the welfare bill.

The SSI changes can also affect Hunter's eligibility for other programs that help with her medical care.

They include the federal Women, Infants and Children program, which provides the nutritional formulas she needs to ensure she gets the 1,300 calories a day her body craves. And because many assistance programs are predicated on SSI eligibility, the new law could also affect whether the state would continue to pay for early intervention services — such as physical therapy — that Hunter now receives.

The toddler, who could barely lift her head her first year, is as active and inquisitive as any healthy child her age because of the constant care she receives, her parents maintain.

"I wish people would understand that this is not something we chose to happen to us," Patti Steinitz said. "It happened. We love our baby. And we're going to do everything we can for her. Everything."

WASHINGTON EDITION

Southern California's Newspaper

Los Angeles Times

Thursday October 17 1996

CIRCULATION: 1,021,121 DAILY / 1,391,076 SUNDAY

DAILY $1.00 AN EDITION OF THE LOS ANGELES TIMES

For Thousands of Children, Aid Rides on a Definition

■ Health: Mentally disabled must be reevaluated to see if they still qualify for benefits under federal welfare reform.

By JOCELYN Y. STEWART
TIMES STAFF WRITER

By this time next year, tens of thousands of disabled children may vanish from federal assistance rolls.

Their disorders will remain the same, their symptoms unchanged. What will be different is the way the government defines childhood disability.

The change is more than an exercise in semantics.

Social Security Administration officials say about 185,000 children in the United States may lose their monthly checks by next July because of a provision in the welfare reform law that seeks to limit federal assistance.

"We have to start reviewing their cases to see if they meet the new definition of disability," said Tom Margenau, a spokesman for the Social Security Administration.

In California, 75,000 children receive such assistance, second only to New York. Of those, state officials say that more than 17,000 youngsters would be reevaluated and many of them could lose their benefits. Many have just won the right to the aid after a hard-fought court battle.

State and federal officials are not certain which children might be denied aid. The Social Security Administration has the job of converting a small section of the wel-

Please see CHILDREN, B3

CHILDREN

Continued from A1

fare reform law into comprehensive eligibility guidelines.

But the new law is expected to deal its toughest blows to children with behavioral problems and other mental impairments. Those children were accused in congressional hearings last year of faking disorders to qualify for Supplemental Security Income benefits—a charge later determined to be largely unfounded.

The changes also will effectively reverse part of a 1990 Supreme Court decision that opened the door for thousands of disabled children to receive monthly disability checks of about $400, as well as state Medicaid health benefits.

The law is not expected to eliminate children with severe physical disabilities.

But advocates nationwide have expressed concern that the Social Security Administration may be overzealous in its implementation in an effort to trim the budget.

"We are interested in seeing that the agency exercise its discretion in a way that harms the least number of children," said Rhoda Schulzinger of the Bazelon Center for Mental Health Law in Washington, a nonprofit organization that represents the interests of low-income adults and children with mental disorders.

Schulzinger has joined other advocates and health care professionals in writing letters and attending meetings with Social Security officials, hoping to soften the potentially devastating financial blows.

Nationwide, about 1 million disabled children receive SSI. Low-income children are entitled to cash payments in addition to medical benefits. Medical benefits are provided to disabled children regardless of income. Of the 1 million children, nearly 300,000 are expected to be reevaluated under the new law.

For now, many families are not even aware of the changes. Notices will be sent beginning next month.

"We'll have to send them a notice saying you need to come in and reestablish the cause of your disability," said Edward Smallfield, a spokesman for the Social Security regional office in San Francisco.

This particular reform provision has drawn little attention so far, apparently overshadowed by the fate of welfare recipients and legal immigrants who also face new restrictions.

But for many families, SSI is a critical source of support.

Disabled children in California can each receive as much as $533.40 a month, along with Medi-Cal benefits. The amount varies depending on income. For example, a family of three with a monthly income of $2,600 can qualify for assistance. After turning 18, recipients must reapply for SSI benefits under guidelines for adults.

Under the new law, disabled children are eligible for cash and health coverage only if they have a "medically determinable impairment which results in marked and severe functional limitations" that are potentially fatal or last more than 12 months.

"The law is a short law," said Barry Eigen, director of the medical and vocational policy branch of the federal office of disability, referring to the vagueness of the provision. The new law eliminates a test used in recent years to determine eligibility. The government has until Nov. 22 to issue its new eligibility guidelines.

Children who will be reevaluated are primarily those with certain types of mental disorders, and those who qualified for the program based on an eligibility test that came into use after a 1990 Supreme Court decision, Smallfield said.

That year the court determined that thousands of children had been illegally denied assistance because their disorder was not included on a list of eligible disabilities.

The government listing at the time did not include many common childhood conditions such as spina bifida, Down syndrome and autism.

As a result of the Supreme Court decision, children were generally allowed to qualify for assistance if they could not function at a level appropriate for their age.

The eligibility of children was determined from medical reports, as well as documentation from teachers, social workers and child care providers. Each application was reviewed by a disability examiner and by at least one physician working for the agency, said Dr. James Krajeski, a regional SSI medical advisor.

"The bottom line is, is the child or adult able to do either activities consistent with work, or activities consistent with a normal child—going to school and achieving at an appropriate grade level and social level?" Krajeski said.

The Supreme Court decision also required the agency to launch a national outreach campaign. That same year, SSI expanded its list of eligible disabilities to include maladaptive behavior, a category that includes children with personality disorders such as hyperactivity.

After the Supreme Court decision, advocates nationwide began notifying eligible families, some of whom had previously been denied aid.

"We were trying to let families know that the [rules] had been made more flexible and more all encompassing for children," said Rachel Shigekane, managing attorney for the Volunteer Legal Services Program in San Francisco.

As a result, the number of children receiving SSI benefits has tripled from 300,000 to more than 900,000 over the past six years, according to a Government Accounting Office report. Benefit payments exceed $4 billion annually. The rate of new children qualifying on the basis of mental impairments tripled.

Many advocates say the decision to revise the eligibility requirements came in part because of the success of their outreach efforts, as well as the mood in Congress.

The growing number of children raised concerns among lawmakers, fueled by media reports, that some parents coached their children to behave as if they were mentally ill.

"Frankly, the SSI children's program has grown out of control and well beyond helping truly needy children," said Rep. Jim McCrery (R-La.) during congressional hearings on the program last year.

McCrery argued that some children were being placed on medication to treat mental disorders that simply do not exist, and others were not being treated for fear that SSI benefits would stop.

In September 1995, then-Sen. Bob Dole (R-Kan.) said that "children's SSI needs a tuneup" and that he hoped that the changes in the law "will help restore confidence in this program."

Jonathan Stein, a Philadelphia-based attorney who in 1990 argued successfully before the Supreme Court for expansion of federal disability benefits, said the proportion of children allowed into the program, compared with those applying, has already started declining.

Stein, a leading advocate for children's assistance, said the move to restrict the program was based largely on anecdotal evidence of fraud—a belief echoed by many.

"It just never materialized," Eigen said. "Obviously we found out things from time to time. In a program of this size, anything and everything can and does happen, but nobody has ever found any evidence of widespread fraud."

Responding to congressional concerns, a national hotline was set up by the Social Security agency for teachers and other school personnel to report parents who they believed were coaching their children. Nationwide, about 230 children were reported from September 1994 through July 1995. Of those reports, only about half concerned children receiving benefits. The agency recommended further review in 83 cases.

In California, there were six calls.

In another study, federal officials reviewed 1,232 cases in which coaching was suspected. Only 77 of those children had been awarded benefits.

Children's advocates argue that Congress ignored those and similar findings.

"I think these kids just got swept up in the whole rhetoric of welfare reform," said Alice Bussiere of the National Center for Youth Law in San Francisco. "The other problem was there was a significant increase in the number of children. It looked like there was this big explosion of cases, but that was because the Supreme Court decision resulted in a liberalization of the rules."

Supporters of the program acknowledge that implementation of the rules varied from state to state. And some said the program needed to assess disabled children periodically, to see if they still belonged in the program.

But the cure, they argue, is likely to do more harm than good.

"We think the president . . . and the Congress went overboard, way too far," said Marty Ford, of the ARC, a Washington organization representing retarded citizens. "In terms of changing the eligibility criteria, their target went way beyond any of the problems that had been noted or substantiated."

Now that the law has been passed, some worry that federal cost-cutting will come at the expense of innocent children.

"It's part of the Social Security Administration saying we basically have a goal of eliminating people off of our rolls," said Melinda Bird, managing attorney with Protection and Advocacy Inc., a disability rights law firm in Los Angeles.

"It's more a cost goal than based on any evidence that these people aren't disabled—that's distressing."

Social Security officials say that their goal is to implement the law and that they have not targeted a specific number of children.

Even without knowing yet what Social Security officials will do, advocates say they are preparing for the consequences of the agency's decision—and trying to influence it.

A coalition of organizations has submitted recommendations for the new guidelines to the agency. And the Bar Assn. of San Francisco's Volunteer Legal Services Program has started recruiting attorneys to assist families who may need representation in the reevaluation process.

At the same time, advocates do not want to cause unnecessary panic.

"One of our greatest fears is that people will say it's not worth applying," Schulzinger said. "We're deeply worried that families will not be stepping forward for assistance to which they are legally entitled. This is not just a fictitious fear. Prior to the changes [in 1990], that's exactly what happened."

Times researcher Ron Weaver contributed to this story.

A Disquieting Spring

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

"brittle" (i.e. uncontrolled) juvenile diabetes - "IFA" child

By Daisy Fried

Harvey Finkle

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

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

The first-grader is laying out the components of her "One Touch II" gadget, which identifies her blood-sugar level. Her fingertips are 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 $403 of public assistance a month, plus $213 worth of monthly food stamps to support her family of three. "I take from Peter to pay Paul," she says. "It's a constant tug o' war. Now why would I fight this long if I had no reason? It is time-consuming. It would be much easier to get a job."

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

In a 1990 decision, *Zebley v. Sullivan*, a conservative Supreme Court decided by a 7-2 margin that policies used to determine children's eligibility for SSI were illegal because the existing listings, created to assess adults' (in)ability 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.

Prior to *Zebley*, each of a child's conditions would be considered on its own merits, explains Joe Scullin, Director of Social Services of United Cerebral Palsy (UCP) of 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 UPC's Scullin.

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

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

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

3/95 — Phila. Weekly

HARVEY FINKLE

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

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

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

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

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

Personal Responsibility Act did you say?

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

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

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

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

That's not all.

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

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

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

Yo.Wednesday

Your boss a beast? Contest: *Page 33*

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 Jamison knows how to treat her son's severe asthma.

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

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

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

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

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

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

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

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

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

"This program is out of control," said Weldon, a Re-

See **SSI** Next Page

IFA Chi[illegible]
w/ Asthma + Cogn. Dve problems

Pittsburgh Post-Gazette

Founded 1786

Paul Block, publisher, 1927-1941 *Paul Block Jr., co-publisher, 1942-1987*
William Block, co-publisher, 1942-1989; chairman, 1990 -

John Robinson Block
Co-publisher and editor-in-chief

William Block Jr.
Co-publisher and president

John G. Craig, Jr., editor and vice-president
Madelyn Ross, managing editor *Michael McGough, editorial page editor*

Robert B. Higdon, vice-president and general manager

Setting an SSI standard

Clinton can help families with disabled children cope

Hundreds of thousands of families are in limbo, not sure if the SSI money they receive to help care for their disabled children will continue.

Their fate became tied up with the welfare reform bill that was signed into law over the summer. That bill included a provision to tighten eligibility for Supplemental Security Income, but it left the administration considerable discretion in pinning down the details.

Now the needy families who count on the maximum monthly SSI benefit of $458 have to wait until the Social Security Administration defines exactly what the bill means when it says a child is disabled if he or she has a "medically determinable physical or mental impairment, which results in marked and severe functional limitations."

The administration could try to work backward by figuring out how many of the nearly 1 million children eligible for SSI should be lopped from the rolls and craft a definition that accomplishes that.

A more humane and reasonable approach would be to come up with a standard that protects the families of children with a legitimate need; to "tune up" the system as the senators who wrote the bill intended, rather than gut it.

SSI for families of disabled children never received much attention until 1990 when a Supreme Court ruling expanded eligibility, which helped triple the caseload at an annual cost of $5 billion.

Following that explosive growth came charges of broad-based abuse of the system, including accounts of parents coaching children to appear retarded or hyperactive. Numerous investigations into the claims have shown them, at best, to be wildly exaggerated. No broad-based or systemic abuse was uncovered.

•

In the meantime, the Social Security Administration has been much more re strained in awarding the benefits. Today, 7(percent of applicants are rejected compare(with a 70 percent acceptance rate five years ago.

The House wanted to clamp down much more tightly on the program, but the more moderate Senate approach prevailed. Most of the children receiving SSI will be eligible no matter how the definition is drawn. But that leaves about 250,000 families who don't know whether they will still qualify.

It was that now-defunct assessment that led to SSI eligibility (and therefore Medicaid eligibility) for 23-month-old Hunter Steinert of Observatory Hill, whose disability is so rare that it is not listed on the standard directory of qualifying medical conditions. Hunter's skin grows so fast that her body cannot shed it quickly enough. Without costly and exhausting around-the-clock medical treatment, Hunter will not survive.

Other children ruled eligible under the old assessment may have had several problems, each of which on their own would not be enough to constitute a severe disability. The old standard allowed consideration of the cumulative effect. Those families may not need the hundreds of thousands of dollars of care that Hunter requires. But they may spend thousands of dollars in special transportation or clothing or nutrition or day-care costs that they can't afford on their own.

The Social Security Administration should not merely rubber-stamp what was done in the past. But in defining what constitutes "marked and severe functional limitations," it should strive to remember that this is one of those areas in which government can and must be part of the solution. Its role here is not to save money at any cost but to help deserving families with disabled children cope.

Loss of Benefits Would Hit Family Hard

Support: Grandparents care for 12-year-old who struggles with hyperactivity and autism. Medi-Cal and SSI payments cover cost of drugs and special programs.

BY JOCELYN Y. STEWART
TIMES STAFF WRITER

SAN DIEGO—She is the mother of six children and the grandmother of 13 others. She spent decades as a health care worker, taking care of people unable to take care of themselves.

But even a lifetime of mothering could not prepare 61-year-old Patricia Jaynes for Alex.

"I call my grandchildren angels," Jaynes said. "They all teach me something about myself. And Alex is one special angel."

Jaynes' 12-year-old grandson, Alex, suffers from attention deficiency hyperactivity disorder and autism, conditions that make it difficult for him to learn and socialize.

He is one of the 75,000 disabled children in California who receive monthly Supplemental Security Income checks and Medi-Cal health care benefits—and one whose SSI benefits may soon be cut. A provision of the welfare reform law redefines childhood disability and will require the children enrolled in the SSI program to be reevaluated. Only low-income families are eligible for the cash assistance.

Advocates say they fear that many youngsters with emotional and mental disabilities will be among those cut from the program. Losing the benefits, they say, would strike a serious blow to caregivers like Jaynes, who receives about $500 a month from SSI.

"If we were able, I wouldn't accept [the help]. We would take care of him on our own," Jaynes said. "But we're not able to do that."

Tens of thousands of other families also depend on the monthly checks and Medi-Cal benefits to care for their children, advocates say.

Aside from helping pay for child care, food and shelter, the benefits help low-income families buy special formulas or food, make home modifications to accommodate the needs of a disabled child, and pay for special toys and learning materials.

Jaynes and her 75-year-old husband offered to care for Alex after the boy's mother became so ill with cancer she could no longer care for him.

The grandmother quickly found that few of the child-rearing methods that worked with other children seemed to help Alex. Raising him has taken patience and prayers, she said.

The 12-year-old has difficulty expressing himself. He becomes easily upset and is unable to play with other children for very long. He has difficulty learning and is enrolled in special education classes at a public school.

"He'll say, 'I don't like myself, I'm so stupid,'" Jaynes said. "Nobody says that to him, but he's hearing something that registers that. And that breaks my heart."

Even sleep is a challenge. There have been times when he has not slept for two days.

"He'll just tear up the whole house," Jaynes said. "He's looking for something. His mind is just traveling, he's searching. Like he's trying to find a gold mine."

The Jayneses use SSI money to take Alex on outings. They buy him books, and have enrolled him in a program for children with similar disabilities.

Recently, Jaynes received a letter saying two of the three medications that Alex takes will no longer be covered by Medi-Cal. So the SSI money they receive each month will help pay for the medicine.

Through a support group, Jaynes has met working parents she is especially worried about.

"If all these other programs shut down, I don't know what's going to happen," she said. "There are people out there who are not just laying on welfare. That's what people want to think, but that is not true."

Because of the changes in Aid to Families With Dependent Children, many fear there will be little relief for poor families of disabled children who become ineligible for federal assistance.

"These are the parents who are least able to get out into the job market," said Thomas Yates, an attorney with the SSI Coalition in Chicago.

Even families with working parents will suffer from the loss of benefits, said Richard Van Horn of the Mental Health Assn., a nonprofit organization based in Los Angeles County. Many work at low-paying jobs with little or no health insurance. Mental health coverage is often unavailable.

"If there is any [mental health] coverage, they'll run out very quickly—then they're out of luck," Van Horn said.

Parent groups at the Exceptional Children's Foundation in Los Angeles usually focus on the emotional hardship that comes with caring for a disabled child.

But lately parents' thoughts have turned to other issues.

"Virtually every week we have to debrief about rumors and facts of welfare reform law and immigration law changes," said Karen Gilman, social worker for the foundation's infant development program.

The worries are legitimate, she said. "We do have kids who will one day be rendered ineligible for the SSI they're currently receiving."

TOM DASCHLE
SOUTH DAKOTA

United States Senate

Office of the Democratic Leader
Washington, DC 20510–7020

October 4, 1996

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

You have an opportunity to implement the recently enacted welfare reform legislation in a manner that treats low-income disabled children fairly. In crafting a new definition of disability for children under the Supplemental Security Income (SSI) program, Congress provided the executive branch with great latitude to interpret the statute. Knowing of your long-standing commitment to these children, I know you will use that latitude wisely.

My staff and I were deeply involved in crafting with Senator Dole, Senator Chafee and Senator Conrad the compromise language that ultimately became the basis for the new law. We made a conscious and sustained effort to ensure that the Social Security Administration was granted considerable discretion to implement regulations that would tighten the program without dropping truly disabled children from the rolls. This understanding is confirmed by the views of the Congressional Budget Office (CBO) at the time; CBO told Congress that the new policies could cut between 10 to 28 percent of the children from the program, depending upon SSA's regulatory interpretation.

A great deal of effort went into forging a bipartisan compromise over reforming this program. In the end, we reaffirmed that a functional assessment of a child's abilities was critical in evaluating childhood disability. The legislative history makes clear that, to accomplish this, SSA should establish a functional assessment beyond the "Listings of Impairments." The new definition of disability, requiring that qualifying impairments be "marked and severe functional limitations," explicitly does not establish the listings level of severity, or any equivalent measure, as the basis for determining childhood disability. For SSA to interpret the statute otherwise would be a tragic mistake with potentially devastating consequences for thousands of this nation's most vulnerable children.

Certainly, the new statute requires SSA to eliminate the old Individualized Functional Assessment. It does not, however, compel SSA to adopt the very strict level of the listings. A better approach, which we envisioned when crafting the compromise language, would require one marked and one moderate disability in order to qualify. This approach is supported by several respected organizations representing children with disabilities with whom we consulted in the process of developing the new definition. Such an approach meets the statutory requirement that the test determine eligibility only for "marked and severe functional limitations" without requiring the listings level of severity.

I trust that you will do everything you can to strike a balance that ensures only those children who are severely disabled receive SSI benefits, without denying those who are truly deserving. Thank you for your consideration of this legislative history in interpreting the new law in the best interest of America's most vulnerable children.

With best wishes, I am

Sincerely,

Tom Daschle
United States Senator

cc: The Honorable Carol Rasco
The Honorable Shirley Chater

JOHN H. CHAFEE
RHODE ISLAND

CHAIRMAN, COMMITTEE ON
ENVIRONMENT AND PUBLIC WORKS

COMMITTEE ON FINANCE

JOINT COMMITTEE
ON TAXATION

SENATE ARMS CONTROL
OBSERVER GROUP

United States Senate

WASHINGTON, DC 20510-3902

WASHINGTON OFFICE:
WASHINGTON, DC 20510
(202) 224-4521
TDD: (202) 224-7746

PROVIDENCE OFFICE:
10 DORRANCE STREET
SUITE 221
PROVIDENCE, RI 02903
(401) 528-5294

TOLL FREE NUMBER
IN RHODE ISLAND
1-800-[illegible]

INTERNET ADDR
[illegible]

September 17, 1996

The Honorable Bill Clinton
President of the United States
The White House
Washington, DC 20500

Dear Mr. President:

Your administration has a key role to play in the implementation of the children's Supplemental Security Income (SSI) provisions that were included in the welfare reform bill enacted last month. While we are all interested in ensuring that only children who are truly disabled receive SSI benefits, we are equally concerned that those children who are, in fact, severely disabled remain eligible for the program. The Social Security Administration (SSA) has the difficult responsibility of striking a balance between these two goals.

The statutory language was intended to give SSA substantial discretion in drawing the eligibility line for this program. Clearly, the new law cannot be read to allow SSA to continue the current level of severity which drew so much criticism. At the same time, the new definition was never intended to "gut" the program and, in fact, affirms the importance of functional assessment as part of an effective evaluation of childhood disability.

The debate over this issue was heated at times, but, ultimately, we reached a compromise on the definition of childhood disability in September, 1995. That definition became part of the overall Congressional compromise on SSI, and was included in the first two versions of welfare reform approved by Congress and then finally in the bill enacted in August. The compromise is notable in two ways. First, it preserves a broad functional approach, beyond the "Listings of Impairments," in measuring childhood disability. Second, it specifically does not establish the listings level of severity, or any equivalent level of severity, as the measure to be used in assessing childhood disability.

The enclosed Senate colloquy between those of us involved in this compromise is important in understanding the meaning of the new definition. This colloquy was not entered into lightly. Rather, it was the subject of much negotiation and was key to the final language of the definition regarding "physical and mental impairment, which results in marked and severe functional limitations" after dropping the requirement that the effect of the impairment also be "pervasive".

It is certainly appropriate for SSA, as the regulatory agency, to adopt a disability test that is stricter than the old Individualized Functional Assessment (IFA), but which is not at the very strict level of the "Listings." The proposal put forward by several disability advocates and organizations with considerable expertise – a one marked/one moderate level – is an acceptable and reasonable approach that fulfills the statutory demand for a test that allows benefits only for marked and severe functional limitations, but does not require that these limitations be pervasive.

The Congressional Budget Office (CBO) has also acknowledged that SSA would have a great deal of flexibility in meeting the requirements of the new law. The enclosed Senate Finance Committee report shows that CBO estimated that the new definition of childhood disability could bar anywhere from 10-28 percent of children from the program, depending upon the regulatory interpretation of the new definition.

I know that you will do everything in your power to ensure that children with severe disabilities who are truly deserving are not harmed by the changes in the new welfare law. Thank you in advance for your attention to this matter. Please do not hesitate to contact me if I may be of any further assistance.

Sincerely,

John H. Chafee

JHC:bd

cc: Secretary Shalala
Commissioner Chater

United States Senate

SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

October 8, 1996

The Honorable Bill Clinton
President of the United States
The White House
Washington, DC 20500

Dear Mr. President:

The recently enacted welfare reform legislation included changes to the eligibility standard for low-income children who receive Supplemental Security Income (SSI). The legislation eliminated the Individual Functional Assessment, an eligibility standard formulated for children as a result of the Supreme Court decision in Sullivan v. Zebley. The Social Security Administration (SSA) is now in the process of carrying out a directive to draft a new definition that will permit a child to receive benefits if he or she has a "medically determinable physical or mental impairment, which results in marked and severe functional limitations."

As Chairman of the Senate Special Committee on Aging, I have worked to ensure that the SSI program is not vulnerable to false claims for disability benefits from disabled adults, immigrants, and children. However, I am concerned that as SSA carries out its mandate to revise the disability criteria, children with severe disabilities may be denied eligibility unfairly.

Congress intended that the new eligibility guidelines should be more strict than the Individual Functional Assessment; however, Congress recognized that the revised standard should continue the use of criteria which take into account functional limitations. In addition, there was no explicit directive that the new standard equal the level of severity generally found in the Listing of Medical Impairments.

Evidence of congressional intent can be found in a colloquy between Senator John Chafee and Senator Bob Dole (Cong. Rec. S13613). My colleagues noted that a definition requiring a "marked, severe, and pervasive impairment" was rejected by the conferees. When this language was proposed, the Congressional Budget Office (CBO) calculated that the number of children who would be affected could be anywhere from 10 to 28 percent of the children currently on the program. Upon further consideration, the term "pervasive" was dropped from the definition because the term implied some degree of impairment in almost

all areas of a child's functioning or body systems. With the deletion of the term "pervasive," it is clear that Congress is not demanding a drastic change in the level of severity required to demonstrate eligibility for benefits. In choosing a more lenient definition, it is also clear that the number of children who ultimately lose benefits will be lower than the range cited by CBO.

The SSI program provides critical health services and financial support for families with disabled children. While the program has experienced problems, I believe that SSA has initiated steps to implement safeguards which protect against potential abuses. I know that you will do whatever you can to encourage a standard that will promote confidence in the program and will direct help to those who need it most.

With best wishes, I am

Sincerely,

William S. Cohen
Chairman

cc: Carol Rasco, Director
Domestic Policy Counsel
Shirley Chater, Commissioner
Social Security Administration

KENT CONRAD
NORTH DAKOTA
202-224-2043

COMMITTEES
AGRICULTURE, NUTR
AND FORESTRY
FINANCE
BUDGET
INDIAN AFFAIRS

United States Senate

WASHINGTON, DC 20510-3403

September 4, 1996

President Bill Clinton
The White House
1600 Pennsylvania Ave NW
Washington, DC 20500-0005

Dear Mr. President:

I am writing regarding the Supplemental Security Income (SSI) provisions of the new welfare law. As you know, there are approximately 1 million children on SSI. For this reason, it is imperative that the Social Security Administration (SSA) implement the new law with great care and in a manner which ensures that disabled children are not harmed.

The SSA has significant latitude in interpreting the new law which for the first time in the history of the 25 year old program requires the implementation of a broad functional limitations test to evaluate children, retaining the central tenants of the earlier Functional Assessment test. Over 275,000 of the 1 million children on SSI will soon be subjected to new reviews under this law. The Congressional Budget Office has told Congress that with the discretion afforded the SSA under the new law, policies could either cut close to 30 percent of the total 1 million, or cut well below 10 percent -- depending on the SSA's interpretation of the law.

The Senate debate and the legislative history of the final SSI reforms make it clear Congress did not call for or intend for a radical overhaul of the program. In fact, in a colloquy with Senator Chafee and me on September 14, 1995, Senator Dole referred to the SSI program as simply in need of a "tune up."

The intent of Congress in mandating reforms was to remove from the SSI program children who are not truly disabled. I thus urge you to instruct the SSA to carefully develop policies that do not harm disabled children who rely on SSI, but only impact the much smaller group intended by Congress. Additionally, I encourage you to pay careful consideration to the recommendations of nationally recognized experts of this program, such as the Community Legal Services of Philadelphia, The Arc (formerly Association of Retarded Citizens), and the Judge David L. Bazelon Center for Mental Health Law, in developing a comprehensive functional test at a severity level that impacts the fewest number of disabled children.

On a related matter, Congress did not explicitly make the new law retroactive to claims pending on the date of enactment. Consequently, I urge that you clarify that the new law is prospective. That is, families who properly received benefits under existing rules prior to passage of the new law should not now be asked to repay these benefits as a result of this change.

Also, for families at risk of termination, I request that you instruct the SSA to provide parents with the following: (1) adequate information and appropriate assistance regarding the medical and functional evidence of disability required to receive benefits: and (2) appropriate assistance in finding legal representation to appeal their cases. It is also important that the SSA continue benefits in cases of appeal until the Administrative Law Judge hearing and decision are final -- an essential protection given the lives and health of children are at stake and the risk of error is great in mass reviews under a complex, new law.

I appreciate your attention to these matters and look forward to hearing from you.

Sincerely,

KENT CONRAD
United States Senate

KC:wmah

cc: Carol Rasco, Director
Domestic Policy Council
Shirley Chater, Commissioner
Social Security Administration

CAROL MOSELEY-BRAUN
ILLINOIS

COMMITTEES
BANKING, HOUSING, & URBAN AFFAIRS
FINANCE
SPECIAL AGING

United States Senate

WASHINGTON, DC 20510 1303

September 25, 1996

The Honorable Bill Clinton
President
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mr. President:

I am writing regarding the Supplemental Security Income (SSI) provisions of the new welfare law. As you know, the Social Security Administration has a key role in the implementation of the children's SSI provisions. While I fully support efforts to ensure that only children wh are truly disabled receive SSI benefits, I hope that there will be adequat safeguards to ensure that those children who are, in fact, severely disabled, will not be unduly harmed by the new rules.

The Congressional Budget Office has told Congress that the new welfar law could result in anywhere from a ten percent to a twenty-eight percent reduction in SSI caseloads. This demonstrates the considerable discretior that the SSA will have in implementing the broad functional limitations test used to evaluate children.

In developing policies to implement the new SSI provisions, I encourage you to carefully consider the recommendations of several nationally recognized experts of this program, including the SSI Coalitior located in Chicago. The proposal put forth by the SSI Coalition is simila to that put forward by several other disability advocates--that is, a "one marked/one moderate" functional disability test. This standard is an acceptable and reasonable approach which fulfills the statutory demand for a test that allows benefits only for marked and severe functional limitations, but does not require these limitations to be pervasive.

Mr. President, I know that you, too, are keenly interested in implementing the welfare bill in a way that will adequately protect children with severe disabilities. I appreciate your thoughtful consideration of this matter and look forward to hearing from you.

Sincerely,

Carol Moseley-Braun
United States Senator

CMB:arc

cc: Shirley Chater
Carol Rasco

American Academy of Pediatrics

Department of Government Liaison
American Academy of Pediatrics
The Homer Building
601 Thirteenth Street, NW
Suite 400 North
Washington, DC 20005
202/347-8600
800/336-5475
Fax: 202/393-6137
Internet: kids1st@aap.org

October 14, 1996

The Honorable William J. Clinton
The White House
1600 Pennsylvania Avenue
Washington, DC 20500

Dear Mr. President:

The American Academy of Pediatrics applauds your continued efforts to improve health care in the United States. The time has come for our nation to make the health and well-being of children its highest priority. As the public and private sectors continue to discuss the future structure of our health care system, the focus on the health care needs of our children is the next logical step. Indirect approaches will not get the job done. We believe a direct effort to provide for the health for all children is needed to ensure that they receive the care they deserve.

A children's health issue of immediate concern is the implementation of the SSI program changes that were part of the welfare reform law. The Academy is greatly concerned with reports that the Administration may be considering setting too high a standard of severity in determining a child's disability. Cost savings should not and can not enter into decisions regarding functional levels of a child's disability.

The critical piece of SSI -- and one that must not be compromised -- is the need to maintain and maximize the step of functionally equaling the medical listings and strengthen methods to use functional limitations in determining a child's disability. The AAP supports the *SSI Coalition for a Responsible Safety Net* recommendation for a new marked and severe functional limitation test which adds categories for age-appropriate physical stamina and basic physical functioning -- areas the AAP believes were absent from previous assessment methods.

The *SSI Coalition* recommended criteria are stricter than that of the old Individual Functional Assessment (IFA) provision but would enable children with severe disabilities to be eligible for or remain in the SSI program. This addition supports the basic notions in the Supreme Court Zebley decision concerning children with multiple disabilities, which was reaffirmed in the bipartisan colloquy on the Senate floor and in the conference report on the Welfare Reform bill.

We ask that you continue this commitment to children and support the *SSI Coalition's* reasonable level of severity at this critical juncture in the SSI program development.

Sincerely,

/s/

Maurice E. Keenan, MD
President

SSI CHILDHOOD DISABILITY DETERMINATIONS
INITIAL CLAIMS ALLOWANCES, 2/11/91-12/31/94

Impairment	% IFA Allowed
Pulmonary Tuberculosis	38.1%
Thyroid Disorders	25.6%
Diabetes Mellitus	19.9%
Aplastic Anemia	24.8%
Organic Mental Disorders	33.6% (5,474)
Schizophrenic/Paranoid Func Disorders	22.8%
Developmental Disorders, Inc. Autism	28.7% (4,306)
* Mental Retardation	32.6% (101,669)
Multiple Sclerosis	17.0%
Cerebral Palsy	7.3% (1,597)
Epilepsy	18.5 % (1,824)
Muscular Dystrophies	15.9%
Glaucoma	16.7%
Deafness	12.3% (1,807)
Loss of Voice	29.8% (3,418)
Intercranial Injury	24.9%
Burns	28.7%

Source: Report to Congress of the National Commissi
on Childhood Disability , App. 7F (1995)

INITIAL DISABILITY DETERMINATIONS FOR SSI CHILDREN

FISCAL YEAR	ALLOWED	DENIED	TOTAL	ALLOWANCE RATE
1991 (1)	93991	38414	132405	70.99
1992	180597	119933	300530	60.09
1993	214393	215807	430200	49.84
1994	205395	321380	526775	38.99
1995	172433	364272	536705	32.13
1996 (2)	83004	186932	269936	30.75

major drop in SSI allowances under old law

(1) FROM 1/01/91 TO 9/30/91 ONLY

(2) THROUGH 4/26/96

SOURCE: SSA 831 FILES (1991-1994), SAOR (1995-1996)
PREPARED BY: OFFICE OF DISABILITY
DATE PREPARED: MAY, 1996

[Adult allowance rate, about 35%.]

State-by-State Analysis of Changes in Children's SSI Program

State	# Children Receiving Benefits 4/96	# Children to be Reviewed under New Standard
Alabama	28,490	7,487
Alaska	780	256
Arizona	11,480	2,923
Arkansas	19,020	5,988
California	73,680	15,908
Colorado	9,270	2,011
Connecticut	5,170	1,282
Delaware	2,750	678
District of Columbia	2,910	663
Florida	58,350	15,649
Georgia	28,610	5,539
Hawaii	1,010	102
Idaho	3,710	1,334
Illinois	49,350	14,434
Indiana	19,930	5,739
Iowa	7,080	1,989
Kansas	8,430	2,814
Kentucky	22,480	8,017
Louisiana	40,080	12,890
Maine	2,570	432
Maryland	13,020	3,411
Massachusetts	16,350	4,733
Michigan	40,640	15,033
Minnesota	10,650	3,444
Mississippi	24,990	6,636
Missouri	21,180	6,339
Montana	2,170	533

Nebraska	4,420	923
Nevada	2,690	633
New Hampshire	1,890	305
New Jersey	22,260	5,717
New Mexico	7,030	1,553
New York	81,790	26,258
North Carolina	30,040	11,410
North Dakota	1,380	318
Ohio	52,830	16,809
Oklahoma	11,680	1,895
Oregon	6,780	1,525
Pennsylvania	43,800	14,374
Rhode Island	3,140	821
South Carolina	18,090	4,229
South Dakota	2,960	571
Tennessee	25,360	6,049
Texas	57,230	12,728
Utah	4,480	1,098
Vermont	1,610	429
Virginia	22,660	8,610
Washington	11,280	3,338
West Virginia	8,560	2,409
Wisconsin	21,350	7,067
Wyoming	1,200	394
TOTAL	968,660	275,727

Data reflect approvals by state disability agencies for children who are under age 18 before January 1, 1997. Approximately 25,000 additional children have received benefits since 1990 after an administrative hearing; these cases will also have to be screened to see if a redetermination is required.

Data provided by Social Security Administration
Chart produced by Bazelon Center for Mental Health Law
August 1996

Nebraska	4,420	923
Nevada	2,690	633
New Hampshire	1,890	305
New Jersey	22,260	5,717
New Mexico	7,030	1,553
New York	81,790	26,258
North Carolina	30,040	11,410
North Dakota	1,380	318
Ohio	52,830	16,809
Oklahoma	11,680	1,895
Oregon	6,780	1,525
Pennsylvania	43,800	14,374
Rhode Island	3,140	821
South Carolina	18,090	4,229
South Dakota	2,960	571
Tennessee	25,360	6,049
Texas	57,230	12,728
Utah	4,480	1,098
Vermont	1,610	429
Virginia	22,660	8,610
Washington	11,280	3,338
West Virginia	8,560	2,409
Wisconsin	21,350	7,067
Wyoming	1,200	394
TOTAL	968,660	275,727

Data reflect approvals by state disability agencies for children who are under age 18 before January 1, 1997. Approximately 25,000 additional children have received benefits since 1990 after an administrative hearing; these cases will also have to be screened to see if a redetermination is required.

Data provided by Social Security Administration
Chart produced by Bazelon Center for Mental Health Law
August 1996

DRAFT

MEMORANDUM FOR THE PRESIDENT

DRAFT

FROM: Franklin D. Raines
Carol Rasco

SUBJECT: Welfare Reform Administrative Issues in Food Stamps, Supplemental Security Income (SSI) and Medicaid with Significant Budgetary Impact

One of the most difficult resource decisions you will make in the 1998 budget is how to correct the problems you identified in the enacted welfare reform bill within an aggregate spending path that leads to a balanced budget in 2002. The overarching decision is whether to spend more or less for welfare reform fixes than the $13 billion over 5 years now in our 1998 budget planning. This reserve roughly corresponds to the savings from the bill above and beyond the Administration's proposal.

Potential Legislative Fixes. In the near future, we will discuss with you a number of legislative proposals that address the concerns you articulated when you signed the bill. While it is possible to address, in part, all the issues you raised within the $13 billion, more expansive proposals could easily cost much more. For example, bridging the differences on immigrants and Food Stamps could cost as much as $22 billion over five years and $5 billion in 2002.

Additional Near-Term Administrative Issues. In addition to the broader question of aggregate welfare spending, we are raising to your attention three potential -- and time-sensitive -- administrative fixes for Food Stamps, SSI children, and Medicaid. **[All three decisions are on a faster track because they have an immediate impact on benefits to individuals, are subject to statutory deadlines, an/or are important to the state planning process. However, a decision to implement all three at this time would require substantial budgetary resources (ranging from $1 to $10 billion over 1998-2002) and reduce funding available for later legislative changes. In addition to cost implications, there are political implications to softening the impact of the welfare bill administratively in the near-term. These decisions - in particular a decision on SSI children -- may raise expectations in the advocacy community of what welfare fixes the Administration will later propose through legislation, and, at the same time, jeopardize the Administration's ability to sell our legislative proposals to Congress -- such as fixes to the immigrants provisions and welfare-to-work proposals.]** This memo seeks your decisions on the three near-term administrative issues in the context of overall funding for welfare reform fixes in your 1998 balanced budget.

A. NEAR TERM ADMINISTRATIVE DECISIONS

1. Food Stamp Time Limits for Childless Adults

Current Law. The welfare reform bill limited Food Stamps for childless adults to 3 months in 3 years. Individuals are exempt from the time limit if they are: under 18 or over 50 years of age; responsible for the care of a child or incapacitated household member; medically certified as physically or mentally unfit for employment; pregnant; or exempt from the Food Stamp work requirements. This provision is estimated to save approximately $3 billion over 1998-2002. When States fully implement this provision in 1997, almost 800,000 individuals will be ineligible to receive Food Stamps each month. These individuals may only stay on the program if they are working over 20 hours per week or participating in an intensive workfare program. We do not expect States to establish costly workfare slots for this group, given limited State resources and pressures to create jobs for the welfare population. About half of these individuals have no other income other than Food Stamps, putting their average monthly income at $171 or 28% of the poverty level. Over 40% of this group is made up of women.

The law provides an exemption for cities, counties, or states with unemployment rates above 10%, at State request, and allows States to request waivers for any group of individuals residing in an area that "does not have a sufficient number of jobs to provide employment for the individuals." The Administration assumed a very strict interpretation of "insufficient jobs" when the bill passed, but we have the ability to define the criteria for areas with insufficient jobs more broadly as a part of implementation. Since there is substantial latitude in the law for how the Administration interprets exemptions and waivers, the Administration can substantially reduce the numbers of individuals actually denied benefits. **[This is a provision that you explicitly stated you would work to fix when you signed the legislation.]**

[The Food Stamp issue is very time-sensitive because the time limit goes into effect on November 22, 1996, at which time people subject to the time limit will receive notices stating that they are subject to a 3-month clock. If we do not have a final decision very soon on areas to be exempted from the time limit, several hundred thousand people will be threatened with a loss of benefits unnecessarily.] States are already preparing their internal guidance and formulating waiver requests. Oregon, Louisiana, West Virginia, and Washington have already submitted requests.

Option #1 -- Provide waivers only for areas with serious impediments to employment, such as a rural town with only one major employer. While employment may be below 10%, no jobs may be available if the major employer is not hiring. This option would provide relief to few areas. The baseline assumes *de minimis* use of the waiver authority, and this option roughly corresponds to the baseline (i.e., it would not have any costs over 1998-2002). Options #2 and #3 below propose waiver policies that would exempt more people and therefore add costs over 1998-2002.

Option #2 -- Limit waivers to broader geographic-based criteria, such as areas defined as "labor surplus areas" by the Department of Labor (DOL). These are areas with at least two years experience of unemployment 20% higher than the national average. This interpretation could exempt up to 30% of those subject to the time limit who are living in areas with historically high unemployment, albeit under the threshold in the bill. Geographic-based exemptions are arguably an appropriate exercise of the discretion Congress granted. This option would cost $1 billion over 1998-2002 and $0.18 billion in 2002.

Option #3 -- Establish broad waiver criteria in addition to geography. The Department of Agriculture (USDA) and some outside groups have proposed guidance that ranges from exempting areas heavily dependent on declining industries, such as coal mining, to providing waivers to groups of individuals who face fewer employment opportunities due to insufficient job skills, for example, persons without a high school education. The guidance would exempt an individual without a high school diploma from the time limit even though she lives in an area with 4% unemployment. Exempting entire classes of individuals goes beyond what Congress contemplated in providing exemptions to the provisions. While individuals without a complete high school education do face a tougher labor market than others, it is not reasonable to assume that they cannot find employment without regard to local economic circumstances. In addition, some might perceive an exemption for this group to be an education disincentive. **[Rather than an administrative decision exempting a specific group of individuals from this policy, we believe a better way to fix the provision would be through a more comprehensive legislative proposal.]** Highly preliminary estimates show that exempting persons without a high school diploma could exclude 45% of those subject to the time limit. In total, USDA's proposed guidance could exempt between 65 to 75% of those subject to the time limit and therefore cost as much as $2 billion over 1998-2002 and $0.33 billion in 2002. It is unlikely that all States will take full advantage of such broad exemption criteria; however, the Administration would have to defend the position that lack of a high school diploma is a qualification for Food Stamps.

[***Recommendation.*** We recommend Option #2, which would allow States to exempt areas with historically high unemployment relative to the national average, even though it is below the threshold in the bill.]

2. Extension of Waivers Granting Transitional Medicaid Benefits

At the time you signed welfare reform bill, 20 States had waivers that included authority to extend transitional Medicaid benefits beyond the normal 12 months (in some cases up to 36 months). Six more requests are pending. Before welfare reform, the Administration's policy was to establish budget neutrality across the AFDC, Medicaid and Food Stamps programs over the lifetime of the waiver. Typically, costs from additional Medicaid and Food Stamps benefits were offset by expenditure reductions projected to result from decreases in the AFDC caseload.

Since welfare reform replaced AFDC with a block grant, we can no longer project Federal savings resulting from lower AFDC caseloads. OMB and HHS agree that past Medicaid expenditures related to welfare waivers should be forgiven. OMB and USDA also agree that all past and future Food Stamps waivers should continue to be budget neutral. At issue is whether the future costs of extended transitional Medicaid benefits for current and pending Medicaid waivers should continue to be held to a budget neutrality standard. **It is a priority because pressure is growing from 26 States on waivers given enactment of welfare reform. Absent a timely decision, some States could decide to suspend their expanded transitional benefits.**

Option #1 -- Require States to adhere to budget neutrality for current waivers. The Administration could require States that want to continue their waivers to establish that the extension of transitional Medicaid benefits is budget-neutral. Because there are no longer any savings to the Federal government from the block-granted AFDC program, budget neutrality would require that the Federal government pay 0% of the costs (i.e., provide no Federal match) for the extended transitional benefits.

It is likely that States will continue to provide the transitional benefits waivers only if they believe they can finance them through State savings from the new welfare reform block grant. If transitional Medicaid really has the desired effect, however, States will reap substantial benefits from lower welfare benefits costs.

States may argue that requiring them to re-establish budget neutrality is a "breach of the contract" under which their waivers were granted. However, all Federal Medicaid waivers provide for renegotiation if a change in Federal law occurs. Moreover, this policy is consistent with the consensus policy to enforce budget neutrality in the Food Stamps program after the enactment of welfare reform.

Option #2 -- Modify the budget neutrality policy for the 26 States with waivers or pending applications. The Administration wants to promote welfare-to-work initiatives, of which extended transitional Medicaid benefits policy has been a cornerstone in the past. This option would effectively grandfather all states that were trying to do this prior to welfare reform. This would increase the likelihood that the 20 states with current waivers will continue the extended transitional benefits and that another six would begin them. The Health Care Financing Administration (HCFA) actuaries have not completed their estimate of the costs of this option; however, early information suggests that this option could cost between $160 million and $200 million over 1998-2002.

Option #3 -- Propose legislation. Should the Administration be accused of treating waiver and non-waiver states inequitably, we could propose legislation to create a new optional Medicaid benefit to allow all states to provide extended transitional benefits. In combination with the forgiveness of budget neutrality for grandfathered states, such a legislative proposal could cost between $1.0 billion and $1.4 billion between 1998 and 2002, and between $.2 and $.3 billion in 2002.

[***Recommendation.*** We recommend Option # 2, to grandfather the 26 states that have waivers administratively. We also recommend that you consider *all* welfare reform legislative fixes at the same time, and thus we do not at this time recommend legislation to create a new optional Medicaid benefit for extended transitional benefits.]

3. SSI Childhood Disability Definition

Current Law. The welfare reform bill provided a new, tightened definition of childhood disability for the Supplemental Security Income (SSI) program, consistent with the Administration's proposal. However, the statutory language is not precise, and the Social Security Administration (SSA) has substantial discretion in drawing the eligibility line to implement the new law. The Office of Management and Budget (OMB) and the Congressional Budget Office (CBO) scoring was based on a similar understanding of the impact of the provision at the time of enactment. The SSI childhood disability provision in the final welfare reform bill was scored at $8.4 billion in savings over 6 years and $1.9 billion in 2002, and was estimated to remove 190,000 children out of 1 million from the rolls by September 1997. Since enactment, advocates and some Senate moderates have argued for an implementation policy that is significantly less restrictive. We are asking for your decision on this issue soon so that SSA may begin processing the approximately 7,000 new cases a week that they have held since August **and the statute requires Administration guidance by November 22.**

Option #1 -- Implement the law consistent with the scoring assumptions and understanding at time of passage. This would significantly tighten eligibility compared to the law before the enactment of welfare reform. Under this option, 190,000 of the 1 million children now on the rolls would become ineligible for SSI. This option does not add costs to the baseline.

Option #2 -- Modify the disability determination process to (a) limit the impact of tightened eligibility requirements on children with multiple physical impairments, and (b) require adjudicators to complete a standard form that will promote greater uniformity in decision making and lead to more allowances than would otherwise occur. Both of these changes can be accomplished administratively, were suggested by SSA, and make programmatic sense. Under this option, 145,000 children would be removed from the rolls by next September -- 45,000 fewer children than under Option #1.

To ameliorate the hardship for these children's families, under Option #2 we would also seek legislation to retain Medicaid eligibility for all children now on the rolls who lose SSI. OMB estimates that, under current Medicaid law, 77% of the children who lose SSI would retain Medicaid because of other qualifying factors; new legislation would provide for those children not covered under current Medicaid law. Option #2 would cost $2.4 billion over 1998-2002, including less than $0.5 billion for the legislative proposal. The 2002 cost would be $0.5 billion.

Note that Option #2 is a more lenient policy than the one the Administration and Congress proposed. If we choose this option, we will have to justify changing our policy post-enactment.

Option #3 -- Further ease standard by greater recognition of chronic illness and re-assessment of borderline cases. Option 3 would add to Option 2 two features that are intended to preserve benefits for the children with the most serious disabilities not covered by Option 2: additional recognition of children with chronic or episodic illnesses such as ~~HIV~~, and an added assessment of children on the borderline. While Option 3 would be more complicated to administer than Option 2, SSA believes adjudicators will be able to learn the new procedures. (**Jack Lew noted that we may want to make the Administrative burden argument stronger, as per the discussion with SSA.) Under this option, 100,000 children would be ineligible for SSI -- 90,000 fewer than under Option #1. Option 3 would cost $4.2 billion over 1998-2002 and $0.9 billion in 2002.**

Option #4 -- Provide for a significantly lower severity standard in determining eligibility. This option is supported by advocates, Senator Daschle, and some Senate moderates from both parties. The Senate moderates argue that their explicit legislative strategy during the welfare reform negotiations was to insist on a definition that was ambiguous enough to satisfy the Republican leadership but would still give SSA the latitude to use a more lenient definition. Given that SSI cash benefits link these children to Medicaid coverage, and that the welfare reform bill simultaneously makes many other changes to the welfare system that could affect these families, advocates argue that it is appropriate to err on the side of SSA using its legal discretion to keep more children on the rolls. Under this option, 45,000 children would become ineligible for SSI -- 145,000 fewer than under Option #1.

There would undoubtedly be significant negative reaction to this option from the Republican majority, and it could be represented as negotiating in bad faith. Option #3 would cost $6.4 billion over 1998-2002 and $1.5 billion in 2002.

Option #5 -- Defer the SSI decision and make it with other 1998 budget decisions this December. Unlike the relatively inexpensive and uncontroversial recommendations on the Food Stamps and Medicaid issues, action on the SSI proposals will have potentially significant budgetary and political impact. Choosing a recommended spending option now will reduce the funds available for other welfare fixes by 20-30%, may undermine the expectations of advocates, and/or may portray the Administration as undermining the intent of the welfare bill -- thus threatening the success of future legislative changes to the welfare bill in Congress. ~~Therefore, a decision could be delayed until the end of December when the Administration will be closer to defining an entire welfare reform fixes agenda.~~ Within the context of a broader welfare reform fixes package, this a decision may be less vulnerable to criticism and give the Administration would have additional time to build Congressional support. However, there are a number of very compelling reasons to make a timely decision -- the Administration is required by statute to provide guidance on

November 22, 300,000 current recipients will be notified about potential changes in eligibility this month, and 7,000 SSI applications per week will continue to go unprocessed -- leaving many of those applicants who are otherwise eligible without timely benefits.

[***Recommendation.*** OMB recommends Option #2, using administrative discretion to moderately soften the original policy and retain SSI eligibility for 45,000 children who would otherwise lose benefits, and at the same time seek Congressional support for retaining Medicaid for all children now on the rolls.

DPC staff recommends Option # 3. This option would set the standard at the level that Congress is thought to have intended, expand the number of children who could meet the standard, and provide special protections for children on the borderline. SSA has had difficulty giving us a clear profile of these children, and it is difficult to be confident that SSA's rules reliably discern the most severe impairments. This option would provide extra assurance that children on the borderline will be properly evaluated. The disability community, members of Congress like Senators Daschle and Chafee, and leading editorial writers have made this a major issue, and might not even see this standard as taking adequate advantage of our latitude to assist children with impairments. We should also consider the challenges that many of these low-income families will face under welfare reform.]

B. THE OVERALL 1998 BUDGET ISSUE

In the context of a five-year balanced budget, any resources allocated to welfare reform make the task of reaching balance more difficult. Since the current plan for reaching balance by 2002 is already challenging our ability to find the necessary savings with acceptable policies, it is important to recognize that a decision to spend more than $13 billion over five years will require further offsetting savings if our budget is to reach balance. The fact that administrative actions drive up spending in no way diminishes the need to find more offsets if we want to balance in 2002. At the same time, whether you decide to spend more or less than $13 billion to fix the welfare bill will influence your options on the immediate administrative issues.

Option #1 -- Limit welfare resources to $13 billion. The recommendations in this memo would spend about $3.6 billion over five years on the three near-term administrative issues. With the $9-10 billion remaining in the $13 billion reserve, you would have sufficient resources to propose a repeal of most of the Food Stamp and Medicaid immigrant bans (but not SSI), a legislative fix for the Food Stamp 18-to-50s provision, other changes to mitigate the deep Food Stamp cuts, and expanded contingency funding.

On the other hand, if you choose the highest cost options on the administrative issues, you would spend $10 billion before we even get to a discussion of the larger legislative fixes. This would leave about $3 billion to address the other problems with the bill. These resources would be exhausted by an exemption for immigrant children from the Food Stamp ban and a

limited relaxing of the cap on the Food Stamp shelter deduction. You would not be able to make other legislative fixes within this total.

Option #2. Do not limit resources for welfare reform fixes to $13 billion at this time. If you choose to spend more than the $13 billion reserve, you will sharply limit your ability to meet demands for spending in other areas. Our current outline of the 1998 budget spends $284 billion on non-defense discretionary programs in 1998, about half of which is for your priorities. The other half is allocated to non-priority discretionary programs by cutting these programs 5% below 1997 enacted levels in aggregate. For every additional $2 billion you choose to spend on welfare fixes over five years, we would either need to increase the non-priority cut from 5% to 6% in 1998 (and freeze that level in the out-years), or selectively reduce priority programs. The non-priorities include important government functions such as Veterans Affairs (VA) medical care, tax collection, aviation safety, and the administration of Social Security benefits. Even if we protect your highest priorities -- say, in education and the environment -- we are left with programs such as Ryan White AIDS treatment, the National Institutes of Health, and Women, Infants and Children (WIC). If we look outside discretionary spending for these offsets, we face similarly unpalatable choices in Medicare and Medicaid, farm entitlements, civil service retirement, and veterans benefits.

~~**Option #3 -- Defer the near-term administrative decisions.** You have, of course, the option to defer decisions on one or all of the administrative issues. You would then have the flexibility to make all of the welfare decisions together with the rest of the 1998 budget decisions this December. However, there are undesirable consequences of delaying action on these issues:~~

~~Replaced in SSA section~~

~~-- SSA's backlog of SSI cases has been growing by 7,000 a week since August. However, no new problem will be triggered if you defer a decision on this issue until December.~~

C. DECISION ON OVERALL BUDGET STRATEGY

_____ Option #1. The maximum available for welfare reform fixes is $13 billion, including the decisions below. **(Recommendation)**

_____ Option #2. Spend in accord with the administrative decisions below. Revisit the overall funding levels for welfare reform when we make final 1998 budget decisions.

~~**[DELETE]** Option #3. **Defer the near-term administrative decisions. Make these decisions in concert with 1998 budget decisions this December.**~~

D. DECISIONS ON NEAR TERM ADMINISTRATIVE ISSUES

1. Food Stamp Waiver Guidance

_____ Option #1. Provide waivers only for areas with serious impediments to employment. No additional cost.

_____ Option #2. Limits waivers to geographic-based criteria. Cost: up to $1 billion over 1998-2002; up to $0.2 billion in 2002. **(Recommendation)**

_____ Option #3. In addition to exemptions for geographic-based criteria, exempt all persons without a high school education from time limits. Cost: up to $2 billion over 1998-2002; up to $0.3 billion in 2002.

2. Transitional Medicaid Benefits

___ Option #1. Budget neutrality for current and pending transitional Medicaid benefit waivers. No additional costs.

___ Option #2. Modify budget neutrality policy for the 26 states with ongoing or pending waivers. Cost $0.2 billion over 1998-2002; $0.04 billion in 2002. **(Recommendation)**

___ Option #3. Propose legislation to create a new optional Medicaid benefit to allow all States to provide extended transitional benefits. Cost: $1.0-$1.4 billion over 1998-2002; $0.2- $0.3 billion in 2002. 2. SSI Childhood Disability Definition

3. SSI Childhood Disability Definition

_____ Option #1. 1997 Administration policy. No additional cost.

_____ Option #2. Relax eligibility requirements relative to the Administration's proposals (Option #1) and propose legislation to ensure that all children currently on SSI rolls retain Medicaid coverage. Cost: $2.4 billion over 1998-2002; $0.5 billion in 2002. **(OMB Recommendation)**

_____ Option #3. **Further ease standard by greater recognition of chronic illness and re-assessment of borderline cases than under Option # 2. Cost: $4.2 billion over 1998-2002 and $0.9 billion in 2002. (DPC Recommendation)**

_____ Option #4. Significantly lower standard of severity than options 1 or 2. Cost: $6.4 billion over 1998-2002; $1.5 billion in 2002.

_____ **Option #5. Since the SSI decision differs from the Medicaid and Food Stamp decisions in its significant budgetary and political impact, defer decision and make it with other 1998 budget decisions this December. No immediate**

budgetary cost, but backlog of 7,000 unprocessed cases per week will continue.

11-7

DRAFT

FA in memo - add # kids + $

MEMORANDUM FOR THE PRESIDENT

FROM: Franklin D. Raines
Carol Rasco

RE: Welfare Reform Administrative Issues in Food Stamps, SSI and Medicaid with Significant Budgetary Impact

One of the most difficult resource decisions in the FY 1998 budget and beyond is how we meet the deficit reduction goal while correcting the problems in the Welfare Bill. In the near future, we will discuss with you a number of legislative proposals that address your concerns with the bill. However, three potential administrative fixes to welfare bill for Food Stamps, SSI children, and Medicaid need your immediate decision. This memo summarizes these issues and provides a overall budgetary context for Welfare Reform implementation decisions.

Savings in Welfare Reform and Cost of Fixing the Bill

When you announced you would sign the welfare bill, you expressed general agreement with the concept of the new "TANF" block grant, the successor to AFDC. At the same time, you made clear in your signing statement that you disagreed with the deep budget cuts outside TANF; mainly cuts to Food Stamps and benefits for legal immigrants. CBO estimated that the new bill reduced spending by $14 billion more than your proposal -- even after increasing TANF/AFDC spending by $7 billion over the projected entitlement levels to make the block grant more acceptable to States.

Though you did not make the explicit connection, many assumed that this $14 billion in additional savings defined the Administration's first available resource to finance fixing the bill. And, in fact, it would be possible to address all of the concerns you articulated at the bill signing within the confines of the additional $14 billion in estimated savings over the President's balanced budget. However, a number of issues on both the savings and the spending sides provide compelling reasons to revisit this assumption. First, there are a range of options to ameliorate the concerns with the bill, and the most expansive proposals cost much more than $14 billion. Second, a number of concerns emerged as we began to implement the bill. Three of these -- Food Stamps for 18-50 year olds, SSI for children, and transitional Medicaid -- need immediate attention, and include options that range in total cost from $0.5 to $8.3 billion over FY 1997-2002.

If you make the near-term administrative decisions in Food Stamps for 18-50 year olds, SSI children and transitional Medicaid that reduce the additional savings assumed in the President's balanced budget, you will have two choices: 1) use less resources to finance the legislative proposals to fix those problems you identified at the welfare bill signing (benefits to immigrants,

the Food Stamps shelter deduction, and improved contingency funding); or, 2) restore the funding cuts you identified at the bill signing, thus putting greater pressure on spending for other budgetary priorities.

In sum, we could readily spend more than twice the $14 billion on legitimate welfare problems, or decide to spend less. And given the deficit goal, all claims on resources -- even those outside of welfare reform, compete against each other. Below is a brief summary of the key concerns and the potential costs involved:

Cost of Administrative and Legislative Welfare Reform Options

Outstanding Issues	**Costs** ($ in billions, 1997--2002)
Administrative/Immediate	
SSI disabled children	$ up to 6.5
Transitional Medicaid	up to 2.0
Food Stamps, 18 - 50s	up to 3.4
Legislative	
Benefits to immigrants	$ up to 19.0
Other Food Stamps	up to 2.7
Total	up to 33.6

Food Stamp Time Limits for Childless Adults

The welfare reform bill limited food stamps for childless adults to 3 months in 3-years (see issue paper in attachment 1). Individuals are exempt from the time limit if they are: under 18 or over 50 years of age; responsible for the care of a child or incapacitated household member; medically certified as physically or mentally unfit for employment; pregnant; or exempt from the food stamp work requirements. This provision is estimated to save approximately $3 billion over FY 1997-2002. When States fully implement this provision in 1997, almost 800,000 individuals will be ineligible to receive Food Stamps each month. These individuals may only stay on the program if they are working over 20 hours per week or participating in an intensive workfare program. We do not expect States to establish costly workfare slots for this group given limited resources and pressures to create jobs for the welfare population. About half of these individuals have no other income other than Food Stamps, putting their average monthly income at $171 or 28% of the poverty level. Over 40% of this group is made up of women.

The law provides an exemption for cities, counties, or states with unemployment rates above 10%, at State request, and allows States to request waivers for any group of individuals residing in an area that "does not have a sufficient number of jobs to provide employment for the individuals." The Administration must decide how broadly to define the criteria for areas with insufficient jobs. The time limit goes into effect on November 22 of this year. States are already

preparing their internal guidance and formulating waiver request. Oregon, Louisiana, West Virginia, and Washington have already submitted requests.

There is substantial latitude in the law for how the Administration interprets exemptions and waivers, and thus for the numbers of individuals actually denied benefits. USDA has proposed guidance that ranges from exempting areas heavily dependent on declining industries, for example coal mining, to providing waivers to groups of individuals who face fewer employment opportunities due to insufficient job skills, for example, persons without a high school education.

We recommend limiting waivers to geographic-based criteria. While individuals without a complete high school education do face a tougher labor market than others, it does not seem reasonable to assume that they cannot find employment regardless of the local circumstances. The guidance would exempt an individual without a high school diploma from the time limit even though she lives in an area with 4% unemployment. Some might perceive an exemption for this group to be an education disincentive. Highly preliminary estimates show that if exempting persons without a high school diploma could exclude 45% of those subject to the time limit. In total USDA's guidance could exempt between 65 to 75% of those subject to the time limit and therefore reduce the savings by as much as $2 billion over FY1997-2002. It is unlikely that all States will take full advantage of such broad exemption criteria, however the Administration would have to defend the position.

While the Administration strongly opposed time limits, exempting entire classes of individuals, such as persons without a high school education, goes beyond what Congress contemplated in providing exemptions to the provisions. We believe that the geographic-based exemptions can provide relief to as many as one-third of all persons affected by the provisions and are more defensible as an appropriate exercise of the discretion Congress granted. This interpretation could exempt up to 30% of those subject to the time limit who are living in areas with historically high, albeit under 10%, unemployment. Savings could be reduced from $3 billion to about $2 billion over the FY1997-2002 period.

SSI Childhood Disability Definition

The welfare reform law provided a new, tightened definition of childhood disability for the SSI program. Both the Congress and the Administration proposed tightening the requirements with virtually identical language. However, the statutory language is not precise, SSA has substantial discretion in drawing the eligibility line to implement the new law and advocates and some Senate moderates have argued for an implementation policy that is significantly less restrictive.

The SSI children's provision in the final welfare reform bill was scored for $8.4 billion in savings over 6 years and $1.9 billion in FY 2002, and was expected to remove 190,000 children from the rolls by the middle of 1997. These savings are similar to the estimates for the proposal in the FY 1997 President's budget. In contrast, the option proposed by advocates would cost $5.8 billion over 6 years, $1.5 billion in FY 2002, and affect 145,000 fewer children currently on

DRAFT

Attachment 1

COMPARISON OF OPTIONS FOR DETERMINING SSI CHILDHOOD DISABILITY UNDER WELFARE REFORM

	SEVERITY STANDARD FOR DISABILITY	REDUCTIONS IN NUMBER OF CHILDREN RECEIVING SSI PAYMENTS		SSI AND MEDICAID COSTS FROM 1997-2002	EFFECT OF OPTIONS ON NUMBER OF RECIPIENTS AND OUTLAYS IN 2002	
		CURRENT RECIPIENTS REMOVED FROM ROLLS BY SEPTEMBER 1997 (down from 1.0 million before welfare reform)	IN 2002 (down from 1.3 million before welfare reform)		Additional Eligible Children	Additional SSI and Medicaid Costs
Option 1	Significantly Tighten Eligibility	**190,000**	**250,000**	**0**	**0**	**0**
Option 2	Tighten Eligibility; Modify Determination Process	**145,000**	**185,000**	**$2.0 billion**	**65,000**	**$0.5 billion**
Option 3	Add New Step with Lower Standard than Options 1 or 2	**45,000**	**50,000**	**$6.6 billion**	**200,000**	**$1.5 billion**
Option 4	Same as Option 2, but retain Medicaid for all current recipients	**145,000**	**185,000**	**$2.5 billion**	**65,000**	**$0.6 billion**

the rolls. A decision is needed on this issue in the near future. SSA has held approximately 7,000 cases a week since August, pending a resolution of this issue.

We have developed 4 options for you to consider. They are summarized on the following table and described in detail in attachment 2. Option 1 is the proposal as understood at the time of enactment by OMB and CBO. Option 2, which SSA Commissioner Chater supports, would limit the impact for children with physical disabilities and would require more documentation of the rationale for disability determinations in all cases, all of which could be done administratively. Option 3 is the advocates position. Option 4 would implement the SSA proposal through administrative action and seek legislation to retain eligibility for Medicaid for all children currently on the rolls who lose SSI. OMB estimates that under current Medicaid law 77% of the children who lose SSI would retain Medicaid; new legislation would provide for those children not covered under current Medicaid law.

- Option 1 not really being Considered
- Collapse pt 2+4

OMB recommends the fourth option, use administrative discretion to moderately soften the policy and retain the eligibility for 45,000 children who would otherwise lose benefits. We would seek Congressional support for retaining Medicaid for all children currently on the rolls. This would avoid the extreme change in policy represented by the advocates' proposal. Whereas the advocate's option would cost $1.5 billion in FY 2002, this recommendation would cost $0.5 billion.

DPC

Extension of Waivers Granting Transitional Medicaid Benefits

When the welfare reform bill was signed, 20 states had welfare waivers that included authority to extend transitional Medicaid benefits, beyond the normal 12 months (in some cases up to 36 months.) Before welfare reform, budget neutrality was established across the AFDC, Medicaid and Food Stamps programs over the lifetime of the waiver. Typically costs from additional Medicaid and Food Stamps benefits were offset by expenditure reductions projected to result from decreases in the AFDC caseload, thus satisfying budget neutrality policy that the Administration has followed in evaluating waivers.

Welfare reform replaced AFDC with a block grant, which technically means that the savings that once were projected to occur -- resulting from lower AFDC caseloads -- can no longer be tracked. OMB and HHS agree that past Medicaid expenditures related to welfare waivers should be forgiven. OMB and the Department of Agriculture also agree that all past and future Food Stamps waivers should continue to be budget neutral. *At issue is whether the future costs of extended transitional Medicaid benefits should continue to be held to a budget neutrality standard.*

As budget neutrality is the Administration's policy rather than a statutory requirement, the treatment of budget neutrality in continuing and pending welfare waivers could be decided administratively. There are two budget neutrality options for those states with current or pending transitional benefits waivers.

Option One: The Administration could hold states accountable for budget neutrality for current transitional Medicaid benefit waivers that continue or new waivers that are granted. Under this approach, the Administration would require states that want to continue their waivers to reestablish that the extension of transitional Medicaid benefits is budget neutral. Because there are no longer any savings to the Federal government from the block-granted AFDC program, budget neutrality would require that the Federal government pay 0% of the costs (i.e. provide no Federal match or FMAP) for the extended transitional benefits.

While states may argue that this is a breach of the contract under which their waivers were granted, the waivers all provide for renegotiation if a change in Federal law occurs. This policy is identical to the policy before welfare reform as the Federal government was *effectively* paying 0% FMAP for these benefits if the waiver was truly cost neutral. This option is also identical to the current policy on budget neutrality for Medicaid-only waivers. States will only continue the transitional benefits waivers if they believe they can finance them through state savings from the new TANF block grant. This policy is consistent with the agreed upon policy on budget neutrality in the Food Stamps program after welfare reform.

Option Two: The Administration could modify its budget neutrality policy in this limited situation, for the 26 state that either had ongoing waivers or pending applications for waivers to provide transitional Medicaid benefits. The Administration wants to promote welfare to work initiatives. The extended transitional Medicaid benefits policy has been a cornerstone of this approach in the past. This option would effectively grandfather all states that were trying to do this prior to welfare reform. This would increase the likelihood that the 20 states with current waivers will continue the extended transitional benefits and that another six would begin them. The HCFA actuaries have not completed their estimate of the costs of this option; however, preliminary OMB estimates suggest that this option could cost as much as $800 million between FY 1997-2002.

Should the Administration be accused of treating waiver and non-waiver states inequitably, legislation could be proposed to create a new optional Medicaid benefit to allow all states to provide extended transitional benefits. In combination with the forgiveness of budget neutrality for grandfathered states, OMB estimates that such a legislative proposal could cost around $2 billion between FY 1997-2002. While a legislative proposal would need to be "paid for" (i.e. offset by savings in another mandatory program), the Administration could grandfather the 26 states that have waivers administratively. Of course, even the administrative action would be reflected in the next Medicaid baseline, slightly increasing the deficit.

Summary of Other Welfare Reform Policy and Budget Issues

The immediate administrative decisions discussed above will compete for resources with the legislative options we will discuss in a few weeks. Below is a brief summary of those issues to provide the full context.

Food Stamps

In the Welfare Reform signing statement, you specifically cited two food stamp provisions as unacceptable. First, the welfare reform bill caps the food stamp shelter deduction, effectively cutting $3 billion in benefits from a million households with high housing costs -- primarily families with children. Remedies for the excess shelter deduction range from increasing the cap over time to removing it entirely. Legislation repealing the cap could cost as much as $0.4 billion in FY 2002 and $2 billion over 6 years. In addition, we are concerned that due to certain freezes in deductions in the Food Stamp benefit calculation that over the long term Food Stamp recipients will only receive 75 to 85% of their COLAs. We are looking at options to ameliorate this problem. These are legislative options and they could be considered as part of the FY 1998 budget. Second, as discussed above, you objected to the Food Stamp cuts for childless adults.

Benefits for Immigrants

The welfare bill profoundly restricts most legal immigrants access to many federal and state assistance programs -- banning them from SSI and Food Stamps until citizenship. In the signing statement, you expressed deep disappointment with the provisions affecting legal immigrants and especially noted the restrictions on Food Stamps and the absence of protections for immigrants who become disabled.

The immigrant provisions in welfare reform saved $25 billion over 6 years. While the Administration has taken some administrative measures to slow the effect of these provisions, a meaningful fix would require legislation. If the welfare bill provisions were repealed and replaced with the Administration's more modest proposal, it would cost approximately $18 billion over 6 years. Exempting immigrants who become disabled after entry and children from the SSI, Food Stamp and Medicaid bans would cost approximately $8 billion over 6 years.

Contingency Fund

In your signing statement you noted that the capped $2 billion contingency fund in the TANF legislation is likely to be insufficient in the event of a recession. (During the recession of the early 1990s, Federal AFDC spending rose by almost $6 billion.) The proposed correction, which the Administration put forth during debates on welfare reform, would enable the contingency fund to expand automatically during periods in which the national unemployment rate rises above 6.5 percent. While this proposal would not necessarily be scored by OMB it would be scored by CBO.

In summary, decisions are needed in each of these areas in the near future. The Food Stamps issue is the most pressing with the time limit going into effect on November 20. Pressure will grow on the SSI issue as more new claims are backlogged awaiting a decision. SSA is holding 7,000 new claims each week, compared to the 1 million children now receiving benefits.

Decision on Food Stamp Waiver Guidance

_____ Option 1: Provide broad guidance for waivers that could exempt all persons without a high school education from time limits.

_____ Option 2: Provide guidance that limits waivers to geographic-based criteria.

Decision on SSI Childhood Disability Definition

_____ Option 1: Policy included in FY 1997 President's budget that would significantly tighten eligibility.

_____ Option 2: Tighten eligibility and modify determination process (SSA recommendation).

_____ Option 3: Add a new step to determination process with lower standard than options 1 or 2.

_____ Option 4: Adopt option 2 and propose legislation to ensure that all children currently on SSI rolls retain Medicaid coverage (OMB recommendation).

Decision on Extension of Waivers Granting Transitional Medicaid Benefits

____ Option 1: The Administration could hold states accountable for budget neutrality for current transitional Medicaid benefit waivers that continue or new waivers that are granted.

____ Option 2: The Administration could modify its budget neutrality policy in this limited situation, for the 26 state that either had ongoing waivers or pending applications for waivers to provide transitional Medicaid benefits.

WHITE PAPER ON NEW DEFINITION OF CHILDHOOD DISABILITY FOR SUPPLEMENTAL SECCURITY INCOME

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

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

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

The decision will affect both current recipients and new applicants. Under any of these options, current recipients would not begin to lose benefits before July 1997. However, soon after a decision is made, SSA can begin to process new claims. Approximately 7,000 cases per week have been held since enactment in August, pending a resolution of this issue. In addition, there is a statutory deadline of November 20, 1996, for SSA to promulgate rules codifying the new definition, although implementation can begin prior to such codification. The first three options described in this paper can be implemented immediately. The last one can, in part, be implemented immediately, but also would require legislation.

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

step (known as the Individualized Functional Assessment or IFA) to the disability determination process that it had established that allowed for a determination of disability at a lower level of severity than was in place prior to that decision.

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

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

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

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

OPTIONS: Below is a brief description of each option.

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

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

<u>Analysis</u>: **Option 1** is arguably closest to Congressional intent, as shown by the amount of savings scored by CBO and OMB during the debate on this issue and at the time of enactment. It

is also the option with the largest impact and does not take advantage of SSA's existing regulatory authority to make changes to the disability determination process independent of the welfare reform bill.

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

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

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

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

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

Analysis: **Option 3** would put SSA in the position of defending a much lower threshold than was anticipated by either the Administration or the Congressional conference committee at the time of enactment. However, SSA believes it would be legally defensible to create a more

lenient test that would drop fewer children from the rolls. Given that SSI cash benefits link these children to Medicaid coverage, and that the welfare reform bill simultaneously makes many other changes to the welfare system that could affect these families, it could be argued that it is appropriate to err on the side of SSA using its legal discretion to keep more children on the rolls. At the same time, Option 3 risks going so far that it might revive the "crazy check" stories that appeared in the media. To that extent, there is much less risk to Option 2 in terms of criticism from Congress.

Option 4 -- Tighten eligibility as in Option 2 and propose legislation to provide for retention of Medicaid through age 18 for all current SSI recipients found no longer eligible for SSI cash benefits. An estimated 145,000 children currently on the rolls would lose benefits by September 1997. Under the legislation, those children would still be eligible for Medicaid. This option would cost $0.6 billion in FY 2002 and $2.5 billion from FY 1997-2002.

Eligibility for SSI, with variations in certain States, is categorically linked to eligibility for Medicaid. Under Option 5, legislation would be introduced to ensure that those children currently on the SSI rolls who are found no longer eligible for SSI would retain Medicaid coverage through age 18.

Analysis: **Option 4** could serve as a compromise solution in terms of ensuring the provision of key health benefits to current recipients who are found no longer eligible for cash benefits. Many of these children would already qualify for Medicaid under current law, which provides for coverage for children under age 12 in families whose income is less than 100% of poverty and children under age 6 in families whose income is less than 133% of poverty. Further, this coverage phases up to age 19 by 2002. The legislative proposal in this option would ensure coverage for those current recipients who do not fit the profile of children covered under current law. Those future applicants who would have received SSI under the rules before welfare reform, but not under the tightened eligibility requirements, and are above the age and income levels provided for under Medicaid law would not get Medicaid coverage under this proposal.

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

Attachments (3)

Attachment 1

COMPARISON OF OPTIONS FOR DETERMINING SSI CHILDHOOD DISABILITY UNDER WELFARE REFORM

	SEVERITY STANDARD FOR DISABILITY	REDUCTIONS IN NUMBER OF CHILDREN RECEIVING SSI PAYMENTS		SSI AND MEDICAID COSTS FROM 1997-2002	EFFECT OF OPTIONS ON NUMBER OF RECIPIENTS AND OUTLAYS IN 2002	
		CURRENT RECIPIENTS REMOVED FROM ROLLS BY SEPTEMBER 1997 (down from 1.0 million before welfare reform)	IN 2002 (down from 1.3 million before welfare reform)		Additional Eligible Children	Additional SSI and Medicaid Costs
Option 1	Significantly Tighten Eligibility	190,000	250,000	0	0	0
Option 2	Tighten Eligibility; Modify Determination Process	145,000	185,000	$2.0 billion	65,000	$0.5 billion
Option 3	Add New Step with Lower Standard than Options 1 or 2	45,000	50,000	$6.6 billion	200,000	$1.5 billion
Option 4	Same as Option 2, but retain Medicaid for all current recipients	145,000	185,000	$2.5 billion	65,000	$0.6 billion

Attachment 2
DISABILITY DETERMINATION PROCESS

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

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

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

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

Attachment 2 -- Table

Examples of Moderate and Marked Functional Limitations

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

Attachment 3
IMPLICATIONS OF OPTIONS

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

Option 2 -- The modifications to the regulation envisioned by this option represent the Social Security Administration's best efforts to identify an option that moderates the effects of the legislation without significantly reducing the standard of severity for eligibility childhood disability benefits. The expectation is that a majority of Republicans would not see this proposal as contrary to the spirit of the conference agreement, while advocacy groups would see it as an effort to at least recognize the problems of severely disabled children with multiple physical impairments who would not otherwise qualify for the rolls. However, advocacy groups and Senate moderates could be expected to find neither Option 1 nor Option 2 acceptable.

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

Options 4 -- Proposing legislation to provide for continuation of Medicaid coverage for children currently receiving benefits who are found ineligible for SSI under tightened eligibility rules (see Option 2) would address concerns that loss of Medicaid is as difficult a blow for the families of these children as the loss of SSI cash benefits. The issue of how long children currently on the rolls who might be found no longer eligible would continue to receive benefits was the last item of negotiation between the Administration and the Republican majority in this title of the welfare reform bill. This proposal would represent an effort to ameliorate the final result of that part of the negotiations. However, given the fact that many of these children will be covered by Medicaid under current Medicaid law, it may be seen as a relatively low cost way of partially addressing a key concern of the advocates. At the same time, the advocates would probably not be satisfied by this proposal, in part because it does not ensure Medicaid coverage for future applicants who will not be eligible for SSI under tightened eligibility rules.

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

October 21, 1996

MEMORANDUM FOR FRANKLIN RAINES

THROUGH: Ken Apfel
Barry White
Keith Fontenot

FROM: Matthew McKearn

SUBJECT: USDA Guidance for States Seeking 18-50 Waivers -- DECISION

ISSUE: How broad or narrow should USDA guidance on Food Stamp waivers be, with what related impact on costs? Range of budget impact: $500 million to $2.9 billion.

BACKGROUND

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-438) limits able-bodied adults to three months of food stamp participation in a 3-year period. Individuals are exempt from the time limit if they are: under 18 or over 50 years of age; responsible for the care of a child or incapacitated household member; medically certified as physically or mentally unfit for employment; pregnant; or exempt from the food stamp work requirements. However, the law also permits the Secretary of Agriculture to grant State requests for waivers for any group of individuals residing in: an area with an unemployment rate above 10 percent; or an area that "does not have a sufficient number of jobs to provide employment for the individuals."

As with other aspects of this Act, there is substantial discretion on how tightly or loosely to define the statutory exemptions and the terms of the waivers. An outer bound estimate suggests that as many as 60% of all individuals subject to the provisions could be exempted under the guidance as currently proposed by USDA, if all States were to elect the full range of options, reducing savings from $4.1 billion to as low as $1.2 billion.

The Administration strongly opposed provisions to limit food stamp benefits to households that seek work, but are unable to find jobs, due to the lack of employment opportunities during welfare reform negotiations. Nearly one hour of the budget reconciliation discussions between Sen. Dole, Rep. Gingrich, and the President focused on this issue. Throughout the welfare reform debate, this was one of the main areas of concern to Leon Panetta. The President publicly noted his dissatisfaction with this provision in his signing statement for P.L. 104-438. Most recently, the President underscored the importance of this issue by singling-out the "18-50s" discussion in your October 2 welfare reform implementation memo to question how high

unemployment areas will be defined in guidance.

Likely Adjustments to Savings. At the time of enactment we estimated these provisions would deny benefits to 1.1 million persons monthly and save $4.1 billion over seven years. Actual savings are unlikely to reach this level regardless of the pending guidance for two reasons (see table below). First, USDA does not anticipate having final regulations in place until the beginning of FY 1999. States will thus have considerable discretion to implement the medical exemptions and other provisions, absent regulations, and are likely to interpret the exemptions more liberally, decreasing anticipated savings by approximately $850 million in FY 1997. Second, the scoring estimates inadvertently did not include a factor for the impact of the waiver available to "areas" with unemployment in excess of 10%. If all eligible counties request this waiver it would reduce the number of persons subject to the time limits by 10% and decrease savings by $325 million over 7 years. We propose to the adjust the baseline for this effect. The numbers presented below reflect our outer bound estimate of the impact of waivers if States take full advantage of all provisions. To the extent that States do not, the cost of the waivers decreases proportionately.

Estimated Savings and Impact of Waivers [1]

	($ billion) FY 2002	FY 1997 -2002
Estimate in Baseline	-$0.6	-$4.1
Adjust for error in 10% unemployment	-0.1	-0.3
Loss in savings prior to regulations	---	-0.9
Adjusted Baseline	-0.5	-2.9
Guidance Options		
USDA Proposal	+0.3	+1.8
Net Savings	-0.2	-1.2
Tighten Guidance	+0.1 - +0.2	+0.5 - +1.0
Net Savings	-0.4 - -0.5	- 2.6 - -3.1

Proposed Guidance. The proposed guidance would establish parameters for what States should consider submitting as justification for a waiver. The critical unknown in estimating the potential impact of waiver guidance is how many States will request waivers, or what the "take-up rate" will be. In addition to considering the impact of waivers on participants, States will also weigh the potential administrative burdens. From the standpoint of administrative ease, States are more likely to request waivers if they can exempt entire classes of participants State-wide, or all persons within specific geographic areas. To the extent that USDA guidance limits

[1] These are rough OMB staff estimates. They do not reflect the January 1998 Food Stamp baseline.

waivers to subgroups in specific areas, fewer States may request waivers. States must also weigh conflicting political support that will vary from State to State. Because the implications of these factors remain unknown, the estimates provided reflect outer-bounds that assume States will make complete use of all available waivers. Federal policy (OMB Directive No. 11) requires that all USDA waivers determinations must be based on the use of Bureau of Labor Statistics (BLS) data or BLS standard methodologies. The procedures for determining which areas are eligible for a waiver because they meet the 10% unemployment threshold are straightforward.

USDA proposed six alternatives to document waivers for areas without sufficient jobs: Lack of Jobs in Designated Labor Surplus Areas; Lack of Jobs in States with Extended UI Benefits; Lack of Jobs Based on Education or Skill Levels; Lack of Jobs Due to Lagging Job Growth; and Lack of Jobs in Declining Occupations or Industries. We have concerns with two of the criteria, which are outlined below.

Waivers Based on Education or Skill Level. USDA proposed waivers based on individuals without a high school education because these individuals face a marked lack of jobs appropriate to their skill levels. Data from BLS suggest that the unemployment rate among individuals without a high school diploma is 2.3 times higher than the average unemployment rate. If we assume that waivers are only granted for those States with unemployment rates in excess of 10%, 39 States and the District of Columbia are eligible for States-wide waivers for all individuals without a high school education. Conversely, the data show that large proportions of such individuals do get jobs. Providing waivers for individuals without a high school diploma in these States would exempt over 40% of all recipients subject to the time limits.

Labor Surplus Areas. USDA proposes allowing waivers for approximately 1,300 jurisdictions designated as Labor Surplus Areas by BLS, because their unemployment rate exceeds the national average by 20% for a period of two years. This measure would expand the number of areas eligible for a waiver far beyond the straight 10% unemployment measure. Very preliminary estimates suggest that as many as one-third of all food stamp recipients subject to the provisions live in labor surplus areas. For example, the entire city of Miami, with an unemployment rate of 7.6% would qualify for a waiver.

OPTIONS FOR GUIDANCE CONTENT

Option 1: Approve guidance as proposed by USDA. Savings loss: Approximately $1.8 billion. If States take full advantage of the waiver criteria proposed by USDA it could excluded as many as 60% of the able bodied childless adults from the work provisions, and reduce the law's estimated savings by as much as $1.8 billion over seven years, if all States requested the full range of waivers.

Option 2: Ask USDA to tighten the proposed criteria. Savings loss: Approximately $500 million - $1 billion. Individuals with limited education do face more difficultly in finding employment and probably merit special consideration. However, USDA's guidance could be

interpreted as granting a waiver to these individuals even if they live in a State with as low as 4.4% unemployment. USDA could develop alternative conditions for approving waivers for persons without high school educations. For example, they could tighten the scope of the insufficient education waiver by allowing it only in areas with unemployment rates in excess of an established level or in designated labor surplus areas. A very rough estimate suggests that this would narrow the exemption to 15% of the participants subject to the time limits and reduce savings by $500 over 7 years if all States requested this waiver for all eligible areas in a State.

Similarly, USDA has proposed using Designated Labor Surplus Areas as a sole determinant of "insufficient jobs". Labor Surplus Areas currently must have an unemployment rate in excess of 7.5%, well below the legislated threshold of 10%. This designation would provide waivers to all groups of individuals in a large expanse of areas with unemployment rates well below the 10% threshold -- exempting as many as one-third of food stamp recipient eligible for the waiver.

Option 2 provides relief for some individuals facing limited employment activities because they don't have a high school education, but limits the waiver to areas that have higher unemployment rates. It also suggests that in areas with unemployment less than 10%, waivers should not be granted to all individuals subject to the work provisions.

Option 3: Exclude lack of education or Labor Surplus Area from the list of guidance. Savings loss: Under $100 million. Relatively few areas are likely to meet the remaining four criteria for establishing areas without sufficient jobs. It seems unlikely that these criteria alone will provide any significant relief to large urban areas that may have high unemployment among groups of individuals, while the overall unemployment rate remains low.

PURPOSE OF THE MEETING: We are meeting with you to discuss the options available and come to a resolution. The Administration has committed to providing timely guidance to give States the ability to minimize the disruption associated with implementing the time limits. The clock for the 3 month limit on participation begins December 1 and States need guidance because they are required to notify affected recipients by that date and modify their eligibility systems to track those individuals subject to the time limits.

The guidance also has implications for the Administration's strategy to address provisions of the Welfare Reform legislation that the President opposed. To the extent that the effect of the provisions can be mitigated through administrative action, it reduces the cost of legislative proposals necessary to reverse the policy. However, even broad use of waivers does not address the Administration's fundamental concern that individuals who actively seek work should not lose food assistance because jobs are not available.