Medicaid savings from kicking disabled kids off SSI

17-Jul-96		1996	1997	1998	1999	2000	2001	2002	2003	sum
Proposal:	House Ways & Means/Senate Finance									
Kids cut from SSI (Kathy's estimate)										
Via IFA repeal		--	-23	-204	-259	-278	-297	-315	-332	
Via CDRs		na	na	na	na	na	na	na	na	
Subtotal		--	-23	-204	-259	-278	-297	-315	-332	
Via 2-tier system		na	na	na	na	na	na	na	na	
Total		--	-23	-204	-259	-278	-297	-315	-332	
Of the first group (kids, mostly poor, who aren't "disabled enough" under new criteria).....										
Cut from SSI		--	23	204	259	278	297	315	332	
Retain Medicaid through AFDC	60%	--	14	122	155	167	178	189	199	
(Of remainder) retain Medicaid via poverty*	62%	--	6	51	64	69	74	78	82	
Resulting %/no. who keep Medicaid	85%	--	20	173	220	235	252	267	282	
Resulting %/no. who lose Medicaid	15%	--	3	31	39	42	45	48	50	
Assumed per capita (federal share)		$820	$880	$960	$1,020	$1,090	$1,170	$1,270	NA	
% growth		NA	7.3%	9.1%	6.3%	6.9%	7.3%	8.5%	NA	
Total Medicaid savings ($ millions)		--	-$3	-$30	-$40	-$46	-$53	-$61	NA	
Rounded		--	-$5	-$30	-$40	-$45	-$55	-$60	NA	-$235
Of the second group (children meeting disability criteria but whose parent's income would be too high for the two-tier system)--										
Cut from SSI		--	--	--	--	--	--	--	--	
Keep Medicaid	25%	--	--	--	--	--	--	--	--	
Lose Medicaid	75%	--	--	--	--	--	--	--	--	
Assumed per capita (federal share)		$820	$880	$960	$1,020	$1,090	$1,170	$1,270	NA	
Total Medicaid savings ($ millions)		--	--	--	--	--	--	--	NA	
Rounded		--	--	--	--	--	--	--	NA	--

TO: DPC Staff

FROM: Antonia Juhasz
Congressman John Conyer's Office, Michigan
(313) 961-5670

DATE: October 21, 1996

SUBJECT: Changes in SSI Disability

Ms. Juhasz has some questions about changes in SSI Disability and was referred to DPC by the Social Security Administration. They told her they were waiting for a new interpretation of a definition before they can act on new legislation.

Chic Regional office

Calendar No. 125

104TH CONGRESS
1st Session

SENATE

REPORT
104–96

THE FAMILY SELF-SUFFICIENCY ACT OF 1995

JUNE 9 (legislative day, JUNE 5), 1995.—Ordered to be printed

Filed, under authority of the order of the Senate of June 8 (legislative day, June 5), 1995

Mr. PACKWOOD, from the Committee on Finance, submitted the following

REPORT

together with

ADDITIONAL VIEWS

[To accompany H.R. 4]

The Committee on Finance, to which was referred the bill (H.R. 4) to amend the Social Security Act to replace the AFDC program with block grants for needy families with children, to replace child welfare, adoption assistance and foster care programs with a block grant for child protection, to make various reforms to the Supplemental Security Income program, to strengthen the child support enforcement program (along with various reforms to other programs under other laws), and which would restore the American family, reduce illegitimacy, control welfare spending, and reduce welfare dependence, having considered the same, reports favorable thereon with an amendment in the nature of a substitute, and recommends that the bill as amended do pass.

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91–331

C. AMENDMENTS OFFERED AND WITHDRAWN

Mr. Conrad offered an amendment to limit educational activities to not more than 50 percent of a State's work participation rates in 1996 and 1997.

Mr. Grassley offered an amendment to provide that a State operate a jobs program in accordance with Part F of the Social Security Act or another work program to be defined by the State.

V. BUDGETARY IMPACT OF THE BILL

In compliance with sections 308 and 403 of the Congressional Budget Act of 1974, and paragraph 11(a) of rule XXVI of the Standing Rules of the Senate, the following letter has been received from the Congressional Budget Office regarding the budgetary impact of the bill:

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, June 9, 1995.

Hon. BOB PACKWOOD,
Chairman, Committee on Finance,
U.S. Senate, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed estimate of H.R. 4, the Family Self-Sufficiency Act of 1995, as ordered reported by the Senate Committee on Finance on May 26, 1995.

Enactment of H.R. 4 would effect direct spending and thus would be subject to pay-as-you-go procedures under section 252 of the Balanced Budget and Emergency Deficit Control Act of 1985.

If you wish further details on this estimate, we will be pleased to provide them.

Sincerely,

JUNE E. O'NEILL, *Director.*

CONGRESSIONAL BUDGET OFFICE—COST ESTIMATE

1. Bill number: H.R. 4.
2. Bill title: Family Self-Sufficiency Act of 1995.
3. Bill status: As ordered reported by the Committee on Finance on May 26, 1995.
4. Bill purpose: To enhance support and work opportunities for families with children, reduce welfare dependence, and control welfare spending.
5. Estimated cost to the Federal Government:

Direct spending

The bill would effect federal outlays in the following mandatory programs: Family Support Payments, Food Stamps, Supplemental Security Income, Medicaid, and Foster Care. The following table shows projected outlays for these programs under current law, the changes that would stem from the bill, and the projected outlays for each program if the bill were enacted.

[Outlays by fiscal years, in millions of dollars]

	1995	1996	1997	1998	1999	2000	2001	1002
Projected spending under current law:								
Family Support Payments	18,223	18,544	19,048	19,534	20,132	20,793	21,477	22,184
Food Stamp Program	25,120	25,930	27,400	28,900	30,390	32,030	33,600	35,100
Supplemental Security Income	24,322	24,497	29,894	32,967	36,109	42,749	39,481	46,807
Medicaid	89,216	99,292	110,021	122,060	134,830	148,116	162,600	177,800
Foster Care	3,540	4,146	4,508	4,930	5,356	5,809	6,290	6,798
Total	160,421	172,409	190,871	208,391	226,817	249,497	263,448	288,689
Proposed changes:								
Family Support Payments[1]	0	−729	−1,192	−1,603	−2,207	−2,559	−3,234	−3,842
Food Stamps	0	238	745	993	1,274	1,511	1,818	2,155
Supplemental Security Income	0	−441	−3,554	−4,482	−4,674	−5,218	−4,646	−5,441
Medicaid	0	−22	−375	−545	−606	−662	−771	−777
Foster Care	0	0	0	0	10	25	35	45
Total	0	−954	−4,376	−5,637	−6,203	−6,903	−6,738	−7,750
Projected spending under H.R. 4:								
Family Support Payments	18,223	17,815	17,856	17,931	17,925	18,234	18,243	18,342
Food Stamps	25,120	26,168	28,145	29,893	31,664	33,541	35,418	37,255
Supplemental Security Income	24,322	24,056	26,340	28,485	31,435	37,531	34,835	41,476
Medicaid	89,216	99,270	109,646	121,515	134,224	147,454	161,889	177,023
Foster Care	3,540	4,146	4,508	4,930	5,366	5,834	6,325	6,843
Total	160,421	171,455	186,495	202,754	220,614	242,594	256,710	280,939

[1] Under current law, Family Support Payments includes spending on Aid to Families with Dependent Children (AFDC), AFDC-related child care, administrative costs for child support enforcement, net federal savings from child support collections, and the Job Opportunities and Basic Skills Training program (JOBS). Under proposed law, Family Support Payments would include spending on the Temporary Assistance for Needy Families Block Grant, administrative costs for child support enforcement, and net federal savings from child support collections.

H.R. 4 would create a new Temporary Assistance for Needy Families block grant and specifies funding levels through fiscal year 2000. CBO's estimates for 2001 and 2002 assume that the level of the block grant will remain the same as in 2000.

Note.—Details may not add to totals because of rounding.

The direct spending costs of this bill fall within budget functions 500, 550, and 600.

Authorizations of appropriations

The bill would increase the administrative costs of the Supplemental Security Income (SSI) program, which are funded by an annual appropriation. Those extra costs stem from provisions of Title III that would require program administrators to verify the citizenship of all SSI recipients and conduct reviews of some disabled recipients.

6. Basis of estimate: CBO estimates the enactment of H.R. 4, as amended by the Committee on Finance, would reduce outlays for direct spending programs by $1.0 billion in 1996 and $7.8 billion in 2002. The bill would also increase the administrative costs of the Supplemental Security Income (SSI) program, which are funded by an annual appropriation. These estimates incorporate the economic and technical assumptions from CBO's March 1995 baseline and assume an enactment date of October 1, 1995. The remainder of this section outlines the methodology used for the estimates. The attached tables detail the estimates for each title of the bill.

eligible for foster care benefit into the foster care program. AFDC administrative data for 1993 suggest that roughly 500,000 children (5 percent of all children on AFDC) fall into this category because they live in a household without a parent. CBO assumes a number of legal and financial barriers would prevent states from transferring a large share of such children and estimates states would collect an additional $10 million in foster care payments in 1996, rising to $45 million in 2002.

Title III: Supplemental security income

Title III of H.R. 4 would reduce spending in the Supplemental Security Income program for three distinct groups of participants: legal aliens, drug addicts and alcoholics, and disable children. Net savings are estimated to equal $5.1 billion in 2002 (see Table 2).

Legal aliens.—In general, legal aliens are now eligible for SSI and other benefits administered by the federal government. Most aliens, other than refugees, do not collect benefits during the first few years in the U.S., because administrators must deem a portion of a sponsor's income to the alien during the period when determining the alien's eligibility. H.R. 4 would eliminate SSI benefits altogether for most legal aliens. Exceptions would be made for groups that make up about one-fifth of aliens on the SSI rolls: refugees who have been in the country for less than five years, aliens who receive a Social Security benefit based on their own earnings, and veterans of the U.S. military. All other legal aliens now on SSI would be removed from the rolls on January 1, 1997.

CBO bases its estimate of savings on administrative records for the SSI program. Those data suggested that there were about 700,000 non-citizen beneficiaries in 1994, or 12 percent of all recipients of federal SSI payments in that year, and that their numbers might be expected to continue to grow in the absence of a change in policy. The administrative records, though, are of uncertain quality. They are not likely to reflect changes in citizenship status (such as naturalization) that may have occurred since the recipient first began collecting benefits. It has not been important for agencies to keep citizenship status up-to-date so long as they have verified that the recipient is, in fact, legally eligible. That problem is thought to be particularly acute for SSI, where some beneficiaries identified as aliens have been on the program for many years. Recognizing this problem, CBO assumes that about one-fifth of SSI beneficiaries coded as aliens are in fact naturalized citizens.

CBO estimates the number of noncitizen recipients who would be removed from the SSI rolls by projecting the future caseload in the absence of policy change and subtracting the three groups (certain refugees, Social Security recipients, and veterans) exempted under the bill. CBO also assumes that some of the remainder will be spurred to become naturalized. The rest, estimated by CBO at approximately one-half million legal aliens, would be cut from the SSI rolls. Multiplying by the average benefits paid to such aliens—assumed to equal 1994 levels plus subsequent cost-of-living adjustments, or about $4,700 per alien in 1997—yields annual federal budgetary savings of between $2 billion and $3 billion a year.

Removing these aliens from the SSI rolls has indirect effects on two other programs: Medicaid and food stamps. In most states,

Medicaid is automatically available to anyone on SSI. Although H.R. 4 does not explicitly bar legal aliens from Medicaid, some aliens who lose SSI would thereby lose their only route onto the Medicaid program. CBO assumes that most aliens who lose SSI disability benefits could keep Medicaid eligibility under other terms of the program, only about half of those aliens who lose SSI old-age benefits, however, would be able to requalify as medically needy. Savings in Medicaid of $0.2 billion to $0.3 billion a year would result. H.R. 4 is silent about legal aliens' eligibility for food stamps, a program that is outside the jurisdiction of the Finance Committee. Under current law, legal aliens who lose cash income and who also get food stamps would automatically receive larger benefits under that program. CBO assumes that only a fraction of the SSI loss would be made up at the state and local level through general assistance programs. For aliens participating in food stamps, food stamp benefits are estimated to increase by about 33 cents for each dollar of cash income lost. Extra food stamp costs would be approximately $300 million a year.

These estimates, and other CBO estimates concerning legal aliens, are rife with uncertainties. First, administrative data in all programs are of uncertain quality. Citizenship status is not recorded at all for about 8 percent of SSI recipients, and—as previously noted—some persons coded as aliens are certainly naturalized citizens by now. Second, it is hard to judge how many noncitizens would react to the legislation by becoming citizens. At least 80 percent of legal aliens now on the SSI rolls are eligible to become citizens; the fact that they have not been naturalized may be attributable, in part, to the lack of a strong financial incentive. Heretofore, all legal immigrants have not been barred from most jobs, from eligibility for benefits, or from most other privileges except voting. Because the naturalization process takes time and effort, CBO assumes that only about one-third of those whose benefits would otherwise be eliminated will become citizens by the year 2000.

Drug addicts and alcoholics.—For many years, the Social Security Administration (SSA) has been required to identify certain drug addicts and alcoholics (DA&As) in the SSI program, when the substance abuse is a material contributing factor to the finding of disability. Special provisions apply to those recipients: they must comply with treatment if available, they must have representative payees, as (as a result of legislation enacted last year) they can receive a maximum of 36 months' benefits. About 100,000 recipients classified as drug addicts and alcoholics received benefits in December 1994.

CBO assumes that, under current law, the DA&A caseload would grow to about 190,000 by 1997, fall in 1998 (as the first wave of terminations under last year's legislation occurs), then resume climbing gradually. Under H.R. 4, awards to DA&As would stop immediately, and those already receiving benefits would be removed from the rolls on January 1, 1997, unless they had another seriously disabling condition.

Estimating the number of DA&As who already have or will soon develop another disabling condition is a thorny issue. A sample of 1994 awards with a primary diagnosis of substance abuse found

that two-thirds identified a secondary disabling condition (predominantly mental rather than physical). That fact must be interpreted with caution. In order to be worth noting, the secondary condition must be quite severe—but not necessary disabling in its own right. On the other hand, there is no requirement to record secondary conditions; some of the one-third for whom none was recorded undoubtedly had them. And the health of many DA&A recipients certainly deteriorates over time, with or without continued substance abuse. Thus, CBO assumes that only about one-quarter of DA&A recipients would be permanently terminated from the program; the rest could requalify by documenting that they have another sufficiently disabling condition. Multiplying the number of recipients terminated times an average benefit yields savings of $200 million to $300 million a year in SSI benefits.

Besides saving on benefits, the Social Security Administration would also be freed from the requirement to maintain contracts with referral and monitoring agencies (RMAs) for its SSI recipients. Those agencies monitor addicts' and alcoholics' treatment status and often serve as representative payees. Savings are estimated at about $150 million to $200 million a year in 1997 through 2002. Savings in 1996, however, are uncertain, as SSA will likely have to pay cancellation penalties on the contracts to be terminated.

The legislation would also eliminate Medicaid coverage for DA&As terminated from the SSI program, resulting in another $100 million a year or so in savings. And because former SSI recipients would experience a reduction in their cash income, food stamp costs under correct law would increase slightly—by approximately $30 million a year.

Disabled children.—H.R. 4 would restructure the SSI program for disabled children. Under current law, low-income children can qualify for the SSI program and its federal cash benefits of up to $458 a month in two ways. They may match one of the medical listings (a catalogue of specific impairments, with accompanying clinical findings), or they may be evaluated under an individualized functional assessment (IFA) that determines whether an unlisted impairment seriously limits a child from performing activities normal for his or her age. Both methods are spelled out in regulation. Until the Supreme Court's decision in the *Zebley* case in 1990, the medical listings were the sole path to eligibility for children. Adults, in contrast, could receive an assessment of their functional and vocational capacities even if they did not meet their own set of listings. The court ruled that sole reliance on the listings did not comport with the law's requirement to gauge whether children's disorders were of "comparable severity" to impairments that would disable adults.

H.R. 4 would eliminate childhood IFAs and their statutory underpinning, the "comparable severity" rule, as a basis for receipt. Many children on the rolls as a result of an IFA (roughly a quarter of children now on SSI) would be terminated, and future awards based on an IFA would be barred. Thus, the program would be restricted to those who met or equaled the listings. The bill would also remove the reference to maladaptive behavior—behavior that is destructive to oneself, others, property, or animals—from the

personal/behavioral domain of the medical listings, the only place where it appears as a basis for award.

Even as it repealed the "comparable severity" language, the bill would create a new statutory definition of childhood disability. It states that a child would be considered disabled if he or she has "a medically determinable physical or mental impairment which results in marked, pervasive and severe functional limitations [and can be expected to last 12 months or lead to death]." That language appears to be intended to preserve SSI eligibility for some of the most severely impaired children who now qualify by way of an IFA. The exact implications of this language would remain to be clarified through regulation (and perhaps court interpretation) and are difficult for CBO to estimate definitively.

CBO estimated the savings from these changes by judging how many present and future children would likely qualify under the new criteria. CBO relied extensively on SSA program data and on analyses conducted by the General Accounting Office and the Inspector General of the Department of Health and Human Services. Approximately 900,000 children now collect SSI benefits, and CBO projects that the number would reach 1.35 million in 2002 if policies were unchanged. CBO assumed that more than half of children who qualify through an IFA would be rendered ineligible under the proposed criteria-specifically, those who fail to rate a "marked" or "extreme" impairment in at least two areas of functioning. CBO chose that assumption because the bill's key phrase—marked, pervasive and severe functional impairments—might reasonably be interpreted to mean limitations in several different areas of functioning, a tighter standard than the one that now allows some children with "moderate" limitations onto the program. CBO also assumes that the provisions on maladaptive behavior would bar a small percentage of children from eligibility for benefits. Overall, approximately 21 percent of children who would be eligible under current law would be rendered ineligible. Because of the room for regulatory interpretation, however, that figure is uncertain. A tight interpretation might bar up to 28 percent of children; a loose one might trim the rolls by about 10 percent or even less.

CBO estimates the savings in cash benefits relative to current law by multiplying the number of children assumed to lose benefits by the average benefit. That average benefit was about $430 a month in December 1994 and would grow with inflation thereafter. Children already on the rolls would be reviewed under the new criteria but could keep their benefits through December 1996 even if found ineligible. CBO assumes that children who do not meet the new criteria could be removed from the rolls even if their medical condition has not improved since award—as is clearly intended by the bill—even though current law generally requires that SSA document such progress before it terminates a beneficiary. New awards would be affected immediately. Total savings in cash benefits would equal $0.2 billion in 1996 and $2.1 billion in 2002.

H.R. 4 would make several other changes to the SSI program for disabled children, notably by stepping up requirements for continuing disability reviews (CDRs). Savings from that requirement are embedded in CBO's estimate. The bill also requires that representative payees (usually parents) develop a treatment plan for the

child and demonstrate to SSA's satisfaction that they followed that plan. Noncompliance would lead to appointment of another representative payee, not to termination of benefits. The bill also mandates several studies of disability issues.

The proposed cutbacks in children's SSI benefits would affect spending in other programs. Food stamp outlays would increase, under current law, to replace a portion of the cash income lost by the children's families. Effects on two other programs, however, are omitted from CBO's estimate. Under current law, approximately half of the disabled children losing SSI benefits would be likely to end up on the AFDC programs; but because that program would be abolished in Title I and replaced by a fixed block grant to the states, no extra spending would result. The cutback in children's SSI benefits would have only negligible effects on the Medicaid program. Most children removed from SSI would still qualify for Medicaid-either through their eligibility for the program of temporary assistance to needy families (the successor to the AFDC program) or their poverty status.

Administrative costs.—Several provisions of Title III would affect the administrative costs of the SSI program. Those costs are funded out of an overall discretionary appropriation that limits administrative expenses of the Social Security Administration. The most significant burdens would be those involved in checking citizenship status and conducting continuing disability reviews (CDRs). Title III would presumably require SSA to check the citizenship status of all SSI beneficiaries—those coded as citizens as well as those identified as aliens—to verify their continued eligibility for benefits. CBO estimates the one-time cost of that effort at about $50 million; some savings would materialize in later years, though, as SSA would need to sift through fewer applications from legal aliens. The disability-related provisions would, in CBO's judgment, involve approximately $300 million in nonrecurring costs (principally in 1996) as SSA reviews drug addicts and alcoholics and disabled children for continued eligibility, and about $100 million a year thereafter because of the permanent requirement for additional CDRs. SSA would save small amounts of money (less than $5 million a year) from processing fewer benefit checks. Extra administrative costs are expected to total $0.3 billion in 1996 and $0.1 billion a year thereafter.

Title IV: Child support enforcement

Title IV would change many aspects of the operation and financing of the federal and state child support enforcement system. CBO estimates that the change in spending relative to current law would fluctuate between net costs or net savings of $100 million annually over the seven-year estimation period (see Table 3). The key provisions of Title IV would mandate the use of new enforcement techniques with a potential to increase collections, eliminate a current $50 payment to welfare recipients for whom child support is collected, allow former public assistance recipients to keep a greater share of their child support collections, and authorize new spending on automated systems. Similar to current law, the bill would require that states share with the federal government child

support collected on behalf of families who receive cash assistance through the Temporary Assistance for Needy Families Block Grant.

New enforcement techniques.—Using reports on the performance of various enforcement strategies at the state level, CBO estimates that child support collections received by families on cash assistance in 2000 would increase under the bill by roughly 12 percent over current projections (from $3.5 billion to $3.9 billion). Most of the improvement would result from the creation of a new-hire registry (designed to speed the receipt of earnings information on noncustodial parents) and provisions that would expedite the process by which states seize the assets of noncustodial parents who are delinquent in their child support payments. Some states have already applied the proposed enforcement techniques, thereby reducing the potential of improving collections further. CBO projects that the additional collections would result in savings of roughly $0.2 billion in 2000 to the federal government through shared child support collections, as well as reduced spending in food stamps and Medicaid.

Elimination of the $50 passthrough.—Additional federal savings would be generated by eliminating the current $50 passthrough. Under current law, amounts up to the first $50 in monthly child support collected are paid to the family receiving cash assistance without affecting the level of the welfare benefit. Thus, families for whom noncustodial parents contribute child support get as much as $50 more a month than do otherwise identical families for whom such contributions are not made. Eliminating the $50 child support payment beginning in 1996 would save the federal government between $0.1 billion and $0.2 billion annually.

Distributing additional child support to former AFDC recipients.—H.R. 4 would require states to share more child support collections with former recipients of public assistance, reducing federal and state recoupment of prior benefit payments. When someone ceases to receive public assistance, states continue to collect and enforce the family's child support order. All amounts of child support collected on time are sent directly to the family. If a state collects past-due child support, however, it may either send the amount to the family or to use the collection to reimburse itself and the federal government for past AFDC payments. The proposal, which would take effect in fiscal year 2000, would require states to send a larger share of arrearage collections to families, which would reduce recoupment by federal and state governments. Based on a survey of child support directors, CBO estimates that this provision would cost the federal government $0.3 billion in 2000 and $0.4 billion in 2001 and 2002.

Additional provisions with budgetary implications.—A number of other provisions would increase federal outlays. First, H.R. 4 would fund further improvements in states' automated systems at an estimated annual cost of $0.1 billion. Second, the bill would provide about $50 million annually to provide about $50 million annually to provide technical assistance to states and to operate a computer system designed to locate non-custodial parents. Third, the bill would change federal cost sharing in enforcing child support. Although individual states would see their share of federal funds

THE SSI COALITION
FOR A RESPONSIBLE SAFETY NET

SUPPLEMENTAL SECURITY INCOME FOR LOW INCOME ELDERLY AND PEOPLE WITH DISABILITIES

PROPOSAL FOR A NEW CHILDREN'S SSI DISABILITY STANDARD

The welfare reform bill passed by Congress and signed by President Clinton requires the Social Security Administration (SSA) to reformulate the Supplemental Security Income (SSI) standard used for determining whether children are disabled. As set forth below, we believe that President Clinton and SSA should adopt a new standard that ensures that children with marked functional limitations are not terminated from SSI or denied on SSI applications in the future.

To that end, we are proposing a new SSI disability test for children that keeps the first three steps currently used in the sequential evaluation, and adds a fourth step that specifically considers the child's functional limitations in determining disability, but that is stricter than the standard embodied in the Individualized Functional Assessment (IFA). Specifically, the new test will deny disability to children with only moderate functional limitations. The disability standard used previously allowed children with only moderate functional impairments to qualify for SSI disability benefits.

The welfare reform law made modest changes to the children's SSI program. The new law makes three changes to the SSI children's disability standard:

- SSI disability benefits are available only to children with "marked and severe" functional limitations;
- the Individualized Functional Assessment test is eliminated; and,
- references to maladaptive behavior in the personal/behavioral domain in mental impairment listings are eliminated.

Despite these changes, much of the current children's SSI evaluation scheme remains as before. This reflects Congress' intent, despite the sound and fury of the debate over the children's SSI program, to fine tune, but not radically overhaul, the program through the changes made in the final welfare reform bill that was signed by President Clinton. And, key to the fine tuning is that Congress agreed that functional limitations must be considered in determining whether children are disabled.

To that end, SSA must ensure that any disability standard adopted to implement the changes in the welfare reform bill provides:

- that functional limitations are adequately considered in determining disability; and

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- that children who have marked functional limitations are not terminated from the SSI rolls.

SSA should adopt a new four step disability standard that keeps the first three steps and replaces the IFA test with a new marked and severe functional limitation test. The SSI children's test should consist of the following four steps:

1. **SUBSTANTIAL GAINFUL ACTIVITY TEST:** Is the child working in a job (engaging in substantial gainful activity)? If yes, the child is not disabled. If no, go to the second step.

2. **SEVERE IMPAIRMENT TEST:** Does the child have a severe impairment or combination of impairments? If no, the child is not disabled. If yes, go to the third step.

3. **LISTINGS TEST:** Does the child have an impairment that meets, or medically or functionally equals, the impairments described in the Listings of Impairments at 20 C.F.R. Part 404, Subpart P., App. 1? If yes, the child is disabled. If no, go to step four.

4. **MARKED AND SEVERE FUNCTIONAL LIMITATIONS TEST:** Does the child have an impairment(s) that results in marked and severe functional limitations. In determining this, the child's functioning is assessed in domains derived from the Listings (used at step three) that also factor in physical functional limitations. The domains applicable depend on the age of the child and are broken into three age groups: birth to age 1; age 1 to age 3, and age 3 to age 18 (the age breakdowns follow the Listings).

A child will be found to have marked and severe impairments and be found disabled for SSI if she or he has: a) impairments that prevent the performance of substantially any function or functions in one domain; b) a marked impairment in one domain, and a moderate impairment in another domain; or c) a combination of impairments in various domains that causes substantial reduction in the child's ability to function independently, appropriately, and effectively in an age-appropriate manner.

For more information, or to receive a more detailed proposal, contact Thomas Yates at the SSI Coalition For A Responsible Safety Net, 205 W. Monroe, Chicago, IL 60606-5013, Phone 312.460.8402.

THE SSI COALITION
FOR A RESPONSIBLE SAFETY NET

SUPPLEMENTAL SECURITY INCOME FOR LOW INCOME ELDERLY AND PEOPLE WITH DISABILITIES

DRAFT--SEPTEMBER 4, 1996

Proposal For A New Children's SSI Disability Standard

By Thomas Yates

Set forth below is a proposed standard for determining children's SSI disability that integrates the changes mandated by the welfare reform bill.

The standard, set forth in section C below, uses the present disability sequential evaluation, set forth at 20 C.F.R. §§ 416.924(b)-(f), as the starting point. The proposed standard keeps the current first three steps and adds a new fourth step that requires assessment of functioning in several areas, and then applies a threshold standard that is stricter than the standard embodied in the Individualized Functional Assessment ("IFA"). Specifically, the new test will deny disability to children with only moderate functional limitations. The current disability standard allowed children with only moderate functional limitations to qualify for SSI disability benefits.[1]

A. The Definition of Children's Disability

1. New Statutory Definition of Childhood Disability:

Section 211 of the welfare reform bill replaces the current definition of childhood disability which read:

> An individual shall be considered to be disabled for purposes of this subchapter if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last for a continuous period of not less than twelve months **(or in the case of an individual under the age of 18, if he suffers from any medically determinable physical or mental impairment of comparable severity).**

with the following:

(i) An individual under the age of 18 shall be considered disabled for the

[1] See 20 C.F.R. § 416.924e(c)(1)(ii) & (2)(ii)(children with moderate impairments in three domains could be found disabled under the IFA).

purposes of this title if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted for a continuous period of not less than 12 months; and

(ii) Notwithstanding clause (i), no individual under the age of 18 who engages in substantial gainful activity (determined in accordance with regulations prescribed pursuant to subparagraph (E)) may be considered to be disabled."

2. Changes to Regulatory Childhood Disability Standard:

In addition to the change in the statutory standard, the new law requires the Commissioner to:

i) eliminate references to maladaptive behavior in the domain of personal/behavioral function in §§ 112.00C.2 and 112.02B.2.c.(2)(""B" criteria") in Appendix 1 to subpart P of part 404, Title 20 of Code of Federal Regulations; and

ii) discontinue the IFA set forth in 20 C.F.R. §§ 416.924d and 416.924e.

B. Congress Affirmed Use Of Almost All Of The SSI Regulations Governing Determination Of Children's Disability

As noted above, Congress let stand all of the SSI children's disability regulations finally adopted in 1993 except for the reference to maladaptive behavior in the personal/behavioral domain in the "B" criteria in the Listings, and the IFA test. These modest changes reflect Congress' intent to fine tune, rather than radically overhaul the SSI children's disability program.

Indeed, during the Senate's consideration of welfare reform, Senator Dole stated on the floor of the Senate that "I think that we all agree that the children's SSI needs a tune up...." and that the changes were made to respond the "allegations that some children on SSI are not truly disabled." Congressional Record ("Cong. Rec.") at p. S.13613 (Sept. 14, 1995).

Senator Dole concluded his remarks by noting that:

It is my expectation that this program will continue to serve children with severe disabilities, and that includes properly evaluating children too young to test, children with multiple impairments, and children with rare or unlisted impairments that nevertheless result in marked and severe functional

limitations.

Id.

As noted, Senator Dole describes the bill as providing a "tune up" for the program, a description falling far short of the radical overhaul that would significantly alter the evaluation process or degree of severity required to show disability under the new law. In those same remarks on the Senate floor, Senator Dole affirmed the need to have a program in which Congress can "obtain a realistic picture of how an impairment affects each child's abilities." Id. This succinct statement is a ringing affirmation that a broad functional evaluation of a child be provided and that it be personalized for each child--evaluations that the Listings or Listings-equivalence are impossible to render.

Indeed, Senator Dole's statements are consistent with the Social Security regulations left standing by the new Act, especially 416.924a (age as a factor of evaluation); 416.924b(functioning in children), 416.924c (other factors that we will consider), e.g. "... we will consider all of your mental and physical limitations that result from your impairment(s). We will evaluate the extent to which you can engage in age-appropriate activities in an independent, appropriate, and effective manner...." 20 C.F.R. § 416.924(a).

Finally, with regard to the degree of severity required to show that a child is disabled, Senator Dole additionally stated that the Senate was eschewing a much higher severity level by avoiding a statutory criterion that the functional limitations be "pervasive." Cong. Rec. at S. 13613. He made clear that the Senate chose not to use a term like "pervasive" that would imply "some degree of impairment in almost all areas of a child's functioning or body systems."

Although this statement is not totally dispositive of what the disability threshold test should be, it nonetheless clearly rejects sole reliance on Listings-level severity standard. The Social Security POMs, which provide interpretative support to the regulations states as follows:

> The Listing of Impairments describes, for each of the major body systems, examples of impairments which are considered ... severe enough to prevent a child from functioning independently, appropriately, and effectively in an age-appropriate manner.

POMS § DI 25215.010.B.

This is analogous to the threshold that Senator Dole made clear was rejected--disability based on "some degree of impairment in almost all areas of a child's functioning or body systems."

C. A Proposed New Children's SSI Disability Sequential Evaluation

As is set forth below, the Social Security Administration ("SSA") should change its present children's disability sequential evaluation by discarding the IFA and replacing it with a new fourth step that requires assessment of functional limitations caused by medical impairments and sets a disability threshold that is stricter than that embodied in the IFA. The new standard should be as follows:

1. Is the child engaging in substantial gainful activity? If yes, the claim is denied. If no, proceed to step two.[2]

2. Does the child have a severe impairment or combination of impairments? If no, the claim is denied. If yes, proceed to step three.[3]

3. Does the child have an impairment(s) that meets, or medically or functionally equals, the impairments described in the Listings of Impairments at 20 C.F.R. Part 404, Subpart P, App. 1? If yes, the child is disabled. If no, proceed to step four.[4]

4. Does the child otherwise have an impairment(s) which results in marked and severe functional limitations? If yes, the child is disabled. If no, the child is not disabled.

   In determining whether the child has marked and severe functional limitations, follow the following three steps:

   a. Assess all medical and nonmedical evidence of the child's medically determinable impairments, including assessment of the factors set forth at 20 C.F.R. § 416.924c, and pain and other symptoms as required by 20 C.F.R. § 416.929;[5]

   b. Determine if the child has deficits in development or functioning

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[2] This step remains the same as the current first step of the children's sequential evaluation.

[3] This step remains the same as the current second step of the children's sequential evaluation.

[4] This step remains the same as the current third step of the children's sequential evaluation.

[5] These factors must likewise be assessed at steps two and three. Their inclusion here is not meant to imply that they are not relevant at the two previous steps.

as follows:

i. For a child from birth until attainment of age 1, determine if the child has deficits in development or functioning attributable to an impairment(s) in any of the following areas:[6]

A. age-appropriate cognitive functioning;

B. age-appropriate communicative functioning;

C. age-appropriate ability to sustain social interaction on an ongoing reciprocal fashion;

D. age-appropriate motor development;

E. age-appropriate physical stamina and basic physical functioning (including, but not limited to, breathing, digestion, and elimination); and

F. age-appropriate responsiveness to stimuli.

ii. For a child from age 1 to attainment of age 3, determine if the child has deficits in development or functioning attributable to an impairment(s) in any of the following areas:[7]

A. age-appropriate cognitive functioning;

B. age-appropriate communicative functioning;

C. age-appropriate social functioning;

D. age-appropriate gross and fine motor development; and

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[6] These criteria are drawn from 20 C.F.R. Part 404, Subpart P, App. 1, § 112.12 with the exception of the criterion covering physical stamina and basic physical functioning.

[7] These are drawn from the "B" criteria contained in the mental impairment listings for children age 1 to attainment of age 3, 20 C.F.R. Part 404, Subpart P, App. 1, § 112.02, with the addition of a physical impairment criterion to assess physical stamina and basic physical functions.

E. age-appropriate physical stamina and basic physical functioning (including, but not limited to breathing, digestion, and elimination).

iii. For a child from age 3 until the attainment of age 18, determine if the child has deficits in development or functioning attributable to an impairment(s) in any of the following areas:[8]

A. age-appropriate cognitive functioning;

B. age-appropriate communicative functioning;

C. age-appropriate social functioning;

D. age-appropriate personal/behavioral functioning, as evidenced by restrictions in activities of daily living;[9]

E. age-appropriate gross and fine motor functioning;

F. age-appropriate physical stamina and basic physical functioning (including, but not limited to breathing, digestion, and elimination); and

G. age-appropriate concentration, persistence, or pace.

c. A child shall be considered to have "marked and severe functional limitations" if she or he has:

1. impairments that prevent the child from performing substantially any function (e.g. walking, breathing, taking care of personal needs) contained in any one of the criteria set forth above in Nos. 4(b)(i), (ii), or (iii)(depending on the

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[8] These are drawn from the "B" criteria contained in the mental impairment listings for children ages 3 to the attainment of age 18, 20 C.F.R. Part 404, Subpart P, App. 1, § 112.02B, with the addition of two criteria for assessment of physical impairments.

[9] Maladaptive behavior can no longer be considered in assessing functional limitation in the personal/behavioral domain.

age of the child);[10] or

2. a marked impairment in one of the areas in 4(b) above and a moderate impairment[11] in another;[12] or

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[10] This threshold criterion is consistent with SSA's approach in the listings that makes impairment in one area, if severe enough, disabling. Numerous listings base disability on functional impairment in one area, e.g.: **Listing 101.03** (inability to walk or stand is markedly reduced); **101.03C** (inability to perform age-related personal self-care activities); **102.08B3 and Disability Digest 94-6** (Communicative impairment attributed to hearing impairment in children under age 5); and **110.07D** (multiple body system impairment with significant interference with communication due to speech, hearing, or visual impairments).

[11] "Marked" and "moderate" impairments remain the same as they are currently defined in the children's disability regulations. For children from birth to attainment of age 3, "marked" and "moderate" are defined in terms of the ratio of developmental milestone age to chronological age. 20 C.F.R. Part 404, Subpart P, App. 1, §§ 112.02(B)(1)(a)-(d); and 112.12. For children age 3 to the attainment of age 18, the terms are defined in terms of the number of activities affected and the severity of the limitations in affected activities. 20 C.F.R. Part 404, Subpart P, App. 1, § 112.00(C).

[12] Use of the one marked impairment and one moderate impairment test is consistent with Congress' goal to fine tune the SSI children's disability standard. See p. 2, supra. In amending the statutory standard to limit SSI payments to children with an impairment which results in a marked and severe functional limitation, Congress sought to eliminate payments to children with only moderate impairments. Here, a child cannot qualify unless she or he at least has a marked impairment in functioning.

Moreover, in amending the SSI children's disability standard, Congress approved of the use of the Listings at step three in the disability process. And the one marked impairment and one moderate impairment test is a disability severity threshold that is consistent with that used, in some instances, in individual Listings.

For example, a child can meet or equal **Listing 112.05(C)** with the equivalent of one marked impairment and one moderate impairment. Under Listing 112.05(C), a child is considered disabled if s/he has an IQ of 70 or less and another significant physical or mental impairment. The IQ of 70 is considered a marked impairment--the POMS provide that when standardized tests are used as the measure of a child's functional abilities, a valid score that is two standard deviations below the norm for the test (e.g. an IQ score of 70 on the WISC-R) will be considered a marked restriction. 20 C.F.R. Part 404, Subpart P, App. 1, § 12.00C & POMS § DI 25220.020.C.1.b. In addition, a child need only show another significant physical or

3. a combination of impairments in the various areas set forth in No. 4(b) above that causes substantial reduction in the child's ability to function independently outside of the home within age-appropriate norms; or causes substantial reduction in the ability to function independently, appropriately, and effectively in an age-appropriate manner.

With this proposal, children who have only moderate functional limitations are excluded from SSI eligibility, e.g. children who qualified with moderate functional limitations in three domains in the IFA test. See 20 C.F.R. § 416.924e(c)(1)(ii) & (2)(ii)(children with moderate impairments in three domains could be found disabled under the IFA).

D. This Proposed Standard Satisfies Congress' Goal Of Fine Tuning The SSI Children's Disability Standard.

1. Congress intended only to "fine tune" the children's SSI program, not completely revamp it. Moreover, the new law continues to require a functional assessment of the child in determining disability.

2. Reliance solely on the Listings does not satisfy Congress' mandate that a functional assessment in necessary in determining disability. Many of the individual listings do not include a description of the functional limitations caused by the impairments described in those listings. Without such functional limitations defined, there is no way for adequate assessment of those children who have disabling

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mental impairment, which is defined to be an impairment with at least moderate effects on the child's functioning.

See also **Listings 101.03** (Walking is markedly reduced in speed or distance with deficits in musculoskeletal function (of no set severity level)); **110.07** (Marked interference with communication due to speech, hearing, or visual impairment with a serious hereditary, congenital, or acquired disorder (of no set severity level)); **111.07B** (Cerebral palsy with more than slight limitation in motor dysfunction (moderate impairment), and IQ of 70 or less (marked impairment); **111.09 & Disability Digest 93-11** (Marked communication impairment (functioning at two-thirds of chronological age) and documented causally-related neurological disorder (of no set severity level)); **112.05(F)(1)**(for children age 1 to attainment of age 3, marked deficit in cognitive/communicative function (two-thirds of chronological age) and other significant physical or mental limitation (moderate impairment); and **112.05(F)(2)**(for children age 3 to attainment of age 18, marked impairment in age-appropriate cognitive/communicative function and other significant physical or mental impairment (moderate impairment)).

functional limitations unless there is a fourth step that requires assessment of functional limitations for all types of impairments.

3. SSA has already tightened up the disability allowance rates for children seeking SSI disability benefits. As the data below demonstrates, allowance rates are already so low that a de facto fine tuning has been achieved.

INITIAL DISABILITY DETERMINATIONS FOR SSI CHILDREN

FISCAL YEAR	ALLOWED CLAIMS	DENIALS	TOTAL	%
1991[13]	93,991	38,414	132,405	70.99%
1992	180,597	119,933	300,530	60.09%
1993	214,393	215,807	430,200	49.84%
1994	205,395	321,380	526,775	38.99%
1995	172,433	364,272	536,705	32.13%
1996[14]	83,004	186,932	269,936	30.75%

From statistics from SSA Office of Disability, May 1996.

Indeed, the 1996 allowance rate at the initial level, 31%, falls far below the allowance rate, 43%, in 1989,[15] the year before the Supreme Court decision in Sullivan v. Zebley, which led to the creation of the IFA. Prior to Zebley, a child could only be found disabled if she or he had a listings-level disability.

The 1996 31% allowance rate, when compared to 1989 43% allowance rate, is the clearest evidence that the Social Security Administration has already fine tuned the SSI children's disability program to ensure that children with less severe disabilities are denied benefits. To now restrict disability only to those children who can show listings-level disabilities will push the allowance rate far lower, perhaps below 20%.

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[13] The data covers the period from 1/1/91 to 9/30/91.

[14] The data covers the period from 10/1/95 to 4/26/96.

[15] Data from the Report to Congress of the National Commission on Childhood Disability, October 1995, at p. 23.

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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.

Pittsburgh Post-Gazette

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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 restrained in awarding the benefits. Today, 70 percent of applicants are rejected compared 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 Steinetz 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.

American Academy of Pediatrics

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October 14, 1996

The Honorable William J. Clinton
The White House
1600 Pennsylvania Avenue
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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

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."

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 administration will have to say in regulations.

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

Advocacy groups say the final language in the bill was deliberately such that the administration need cut off only a minority of these. They cite, among much else, a carefully orchestrated colloquy on the Senate floor last year when this part of the bill was taking final form. Then-Majority Leader Bob Dole, who took part along with Sens. John Chafee and Kent Conrad, said at one point, "I think we can all agree that the children's SSI [as the program is called] needs a tune-up." That hardly argues for wholesale change, they say. They make the further point that the Social Security Administration has already tightened up on the program, such that the so-called allowance rate or percentage of applicants granted benefits has fallen from an artificial high of 70 percent in 1991 to 30 percent today.

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

COMMUNITY LEGAL SERVICES, INC.

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TELECOPY TRANSMITTAL

Date: 10/27

TOTAL NUMBER OF PAGES: 2 (INCLUDING THIS COVER SHEET)

TO: Diana Fortuna

FIRM: Domestic Policy Council

FAX NO.: (202) 456-7028

FROM: JONATHAN STEIN, GENERAL COUNSEL

DIRECT DIAL: (215) 981-3742

MESSAGE: Diana FYI - note reference to Standa following 9 meetings here.

Please call the direct dial number above if there are any problems with this transmission. The information contained in this fax transmittal is legally privileged and confidential and intended only for the use of the individual or firm named above. If you receive this message but are not the intended recipient, please destroy the fax transmittal and notify us by telephone at the above direct dial phone number. Thank you for your cooperation.

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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

THOMAS DASCHLE
SOUTH DAKOTA
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TELECOPY COVER SHEET

DATE: 10.4.96

TO: Carol Rasco / Diana Fortuna

FAX NO.: 456-7028

FROM: Jonathan Adelstein

Office of Senator Thomas A. Daschle
509 Hart Senate Office Building
Washington,DC 20510
Telephone: (202) 224-2321
Telecopier: (202) 224-2047

MESSAGE: I hope to set up a meeting on this for next week. Senator Daschle is very concerned.

NO. OF PAGES (Including Cover Sheet) 3

TOM DASCHLE
SOUTH DAKOTA

United States Senate
Office of the Democratic Leader
Washington, DC 20510–7020

cc Ken Apfel
FYI.
Diana

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

cc Carol – Do you think I should do anything? -Diana

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JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW

PLEASE DELIVER THIS FAX MESSAGE IMMEDIATELY

TO: DIANA FORTUNA

FAX #: 456-7028 No. of pages, including this: 4

FROM: Rhoda Schulzinger

DATE: 10/2/96 Transmitted by: _____

COMMENTS:

This is the second article on this woman. She had a large picture of Hunter at a rally which the President saw. He told Steve Goodin (sp?) to arrange a meeting with Mrs. Steinitz.

Please share with Carol & Ken.

Rhoda

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

22ND STORY of Level 1 printed in FULL format.

Pittsburgh Post-Gazette

September 22, 1996, Sunday, TWO STAR EDITION

SECTION: LOCAL, Pg. B-5

LENGTH: 871 words

HEADLINE: WELFARE CUTS COULD BE FATAL TO TODDLER

BYLINE: ELLEN M. PERLMUTTER, POST-GAZETTE STAFF WRITER

BODY:

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 child's eligibility 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.

''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, 5 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 (SSI), her care would decline and leave her at risk to 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 state 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.

GRAPHIC: PHOTO (2), PHOTO: Annie O'Neill/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.; PHOTO: Patti Steinitz, center, and Mary Ann Veremaychic, 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. (Photo, Page A-1)

LOAD-DATE: September 25, 1996

cc Carol Rasco
Ken Apfel
Keith Fontenot
Richard Green
– from Diana

What SSI advocates are saying, I have called to complain.

[redacted]

MEMORANDUM

TO: Interested Persons
FROM: Rhoda Schulzinger
RE: Implementation of New Children's SSI Provisions
DATE: 9/27/96

The welfare reform legislation requires the Social Security Administration (SSA) to change the eligibility standard for the children's Supplemental Security Income (SSI) program. Under the new law, children must have a "medically determinable physical or mental impairment which results in marked and severe functional limitations." SSA must determine what level of severity is required to meet this new definition of childhood disability. This is the decision that will determine how many children with severe disabilities will lose SSI benefits as a result of "welfare reform."

The Clinton Administration appears interested in setting a very high standard of severity because they want to avoid Congressional backlash and achieve the greatest possible savings from the children's SSI provisions of the welfare legislation. Disability advocates believe that fear of Congressional backlash and arbitrary quotas to increase cost savings should not be the determining factors in this decision. We believe that the decision should focus on setting a new eligibility standard that will address concerns about program abuses and restore public confidence in a program that provides vital assistance to hundred of thousands of low-income families who want to raise their children with severe disabilities at home.

← this is offensive!

There are approximately 1 million children now receiving SSI benefits. The program changes in the welfare legislation will affect about 276,000 children whose eligibility will be reviewed before they lose benefits. Although SSA has not issued regulations implementing the new definition, their data project that 185,000 children who will be reviewed will lose their benefits – this a 67 percent termination rate. The Administration maintains that its "goal" is only to eliminate 20 percent of the program enrollment (i.e. around 200,000 of the 1 million), but the reduction will have a hugely disproportionate impact on a smaller group of children. Among the children who are likely to lose benefits are those with mental retardation, tuberculosis, diabetes, organic mental disorders, autism, multiple sclerosis, cerebral palsy, epilepsy, brain injuries and burns.

Disability advocates have recommended that Social Security set a standard that will ensure that children with severe disabilities remain eligible rather than one designed to cut an arbitrary number of children to achieve a predetermined cost savings.

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World Wide Web: http://www.[illegible].org, e-mail: [illegible]@[illegible].org

AMERICAN PSYCHOLOGICAL ASSOCIATION
PUBLIC POLICY ACTION NETWORK
!!!ACTION ALERT!!!

September 30, 1995

CLINTON ADMINISTRATION DEBATES CHANGES IN AID TO DISABLED CHILDREN: TENS OF THOUSANDS WILL BE AFFECTED

POLITICAL CONCERNS AT ODDS WITH SOUND POLICY

Background:

As part of the Welfare bill passed by Congress and signed by President Clinton earlier this year, the Social Security Administration (SSA) must make certain changes to the eligibility standards for the children's Supplemental Security Income (SSI) program. Under the new law, children must have a "medically determinable physical or mental impairment which results in marked and severe functional limitations." It falls to SSA to determine how severe a child's disability must be to meet this new definition of disability. This critical decision will have a tremendous impact on tens or even hundreds of thousands of children with severe disabilities and their families.

The APA and many other advocates are concerned that the Clinton Administration may set too high a standard in order to avoid Congressional backlash, and because the more children dropped from the program, the greater the savings which can be applied to the budget deficit. However, fear of Congressional backlash and arbitrary quotas to increase cost savings are not appropriate driving forces behind public policy. This is especially true when the well-being of tens of thousands of children with severe disabilities hangs in the balance.

The APA and others have recommended that SSA set a standard which is reasonably designed to ensure that children with severe disabilities remain eligible, rather than one designed to cut an arbitrary number of children to achieve a predetermined cost savings.

It is critical that the White House receive a large number of phone calls about this issue.

What You Can Do:

Call President Clinton (202)456-1111;

Call Carol Rasco, Director of the President's Domestic Policy Council (202)456-2216

Call Franklin Raines, Director of the Office of Management and Budget (OMB) at (202)395-4840.

Tell them:

Do not set a new standard for disability that will unreasonably and unfairly hurt children with disabilities who are truly dependent on SSI;

The driving force in setting a new standard for SSI eligibility should be the best interest of low income children with severe disabilities, not an arbitrary budget figure; and

The power to hurt these children and their families, or to assist them, is in the Administration's hands.

PLEASE CALL NOW. CALLS ARE IMPORTANT. Also, feel free to forward this message to your colleagues and interested others. And let us know if you make a call. For additional information, or to confirm that you responded, please contact: Charles Barone, Ph.D. at (202) 336-5945, email at cxb.apa@email.apa.org.

***

Public Policy Action Network (PPAN)
American Psychological Association
750 First Street, N.E.
Washington, D.C. 20002
(202) 336-6062

CAROL MOSELEY-BRAUN
ILLINOIS

OCT 1 1996

COMMITTEES:
BANKING, HOUSING, AND URBAN AFFAIRS
FINANCE
SPECIAL AGING

United States Senate

WASHINGTON, DC 20510-1303

September 30, 1996

cc Ken Apfel
F41
—Diana

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 who are truly disabled receive SSI benefits, I hope that there will be adequate 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 welfare law could result in anywhere from a ten percent to a twenty-eight percent reduction in SSI caseloads. This demonstrates the considerable discretion 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 Coalition, located in Chicago. The proposal put forth by the SSI Coalition is similar 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
PSYCHOLOGICAL
ASSOCIATION

PUBLIC POLICY OFFICE
FAX TRANSMITTAL SHEET
Return Fax Number: 202-336-6063

TO: Diana Fortuna DATE: 10/8/96

FAX #: 456-7431

Number of Pages (including cover sheet): 3

Comments: Follow-up to our phone call Friday. I will phone tomorrow to try to arrange a face-to-face meeting. Appreciate your interest in this issue.

SENT BY:

___ Pat Kobor
___ Nina Levitt, Ed.D.
___ Brian Smedley, Ph.D.
___ Elizabeth Baldwin
___ John Palenicek, Ph.D.
___ Lori Valencia Greene
___ Paula Trubisky
✓ Charles Barone, Ph.D. 336-5945
___ Geoffrey Mumford, Ph.D.
___ Jeanine C. Cogan, Ph.D.
___ Jeff McIntyre
___ Eva Vega
___ Barbara Guglielmo
___ Arethea Coles
___ Marci Ejiofor
___ Ly Nguyen
___ Natacha Blain, J.D.

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Web: www.apa.org

AMERICAN
PSYCHOLOGICAL
ASSOCIATION

October 8, 1996

Diana Fortuna
Domestic Policy Council
The White House
Washington, D.C. 20500

Dear Ms. Fortuna:

Thank you again for taking the time to hear the concerns of the American Psychological Association (APA) regarding pending changes to the children's Supplemental Security Income program (SSI).

The new welfare legislation mandates stricter SSI eligibility standards. At the same time, it leaves the Administration considerable discretion as to how the law will be implemented. This decision will have a tremendous impact on tens of thousands of children with severe disabilities, particularly those with mental, emotional or behavioral impairments.

The APA recommends a final standard that ensures that children with severe disabilities remain eligible for SSI. We trust that the Administration shares this goal. However, we also recognize that there are other competing political and budgetary pressures. It is our sincerest hope that the interests of children with disabilities and their families prevail in your final decision.

SSI is an extremely cost-effective way to help parents raise children with disabilities at home. Many costs incurred by these families are not covered by Medicaid or other types of insurance. For example, children with disabilities may require specially-trained daycare providers because others are unable or unwilling to care for them. SSI also compensates parents for lost income when they take time out from employment to attend to their child's special needs. These are parents, already struggling at the economic margins, for whom unpaid leave is not a viable option.

APA endorses the new children's SSI disability standard proposed by a group of disability advocates, including the Consortium for Citizens with Disabilities.

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Web: www.apa.org

This proposal clearly satisfies the new statute by establishing an appropriate required level of severity that falls between the very high presumptive level of the categorical listings and the previous Individualized Functional Assessment (IFA). The proposal we have endorsed is also consistent with the welfare conference report and statements by Congressional leaders, including former Senator Dole, who stated that SSI was more in need of a "tune-up" than a radical overhaul.

None of the many studies of the SSI program suggests the need for wholesale caseload reductions. Reviews of children's SSI cases by both the GAO and the Office of the Inspector General have found that the overwhelming majority of children who were approved for SSI benefits indeed had disabilities severe enough to qualify.

The Administration has both the power and authority to formulate new regulations that tighten eligibility yet maintain support for hundreds of thousands of children with disabilities and their families for whom SSI assistance is critical. We hope that the interests of these children remain paramount in your final decision.

Sincerely,

Henry Tomes, Ph.D.
Executive Director
Public Interest Directorate

Charles Barone, Ph.D.
Senior Legislative &
Federal Affairs Officer

The Arc of the United States
Governmental Affairs Office
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FAX FORM (COVER SHEET)

SENT BY:

___Paul Marchand ___Evelyn Powell

✓ Marty Ford ___Brenda Walker

___Kathy McGinley ___

___Douglas Forand

DATE: 9/23/96

TO: Diana Fortuna

FAX #: 456-7028

NUMBER OF PAGES (INCLUDING COVER SHEET): 3

DOCUMENT DESCRIPTION:

REMARKS:

The Arc — *a national organization on mental retardation*

File Welfare Reform

SPENCER T. BACHUS, III
6TH DISTRICT, ALABAMA

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Congress of the United States
House of Representatives
Washington, DC

August 30, 1996

TO: GAO
FYI

Ms. Connie Rogers
The Arc
Alabama State Office
444 South Decatur Street
Montgomery, Alabama 36104

Dear Ms. Rogers:

Thank you for contacting me regarding welfare reform. It is good to hear from you. As a strong proponent of welfare reform, I am pleased that the 104th Congress recently passed the most sweeping reforms to the welfare system in decades.

Estimates are that passage of this historic legislation will result in savings of $56.2 billion over five years by:

* replacing a number of federal poverty and child care programs with two block grants to the states, allowing states to establish their own criteria for benefits and eligibility;

* limiting benefits for certain able bodied-adults to two years of assistance without work, and limiting their lifetime benefits to a maximum of five years;

* prohibiting most non-citizens who arrive in the U.S. after enactment from receiving federal welfare benefits (except for emergency assistance, federal disaster assistance, and services to protect the public health) during their first five years in the U.S.;

* reforming the federal food stamps and commodity distribution programs in order to streamline and simplify their operations;

* requiring able-bodied adults to work in order to receive food stamp assistance;

* tightening up requirements for receiving SSI benefits.

The old ways of the liberal welfare state have not worked. In fact, they have served to trap people in a cycle of poverty, and a new approach is desperately needed. After input from the nation's governors, as well as experts on welfare, the Republican Congress has delivered on its promise to reform welfare and encourage personal responsibility.

You were particularly concerned with the impact this legislation would have on children with disabilities. Rest assured that benefits for disabled children will not be disrupted, but the processes for gaining and keeping benefits may change. The conference report specifically puts in place more checks to ensure that the children who actually need the benefits receive them, and that if their situation improves or worsens, benefits can be adjusted. There is less room for fraud in this program, and those children who need support will receive the proper help. Certainly, if there is any unintended negative impact on disabled children, it needs to bo identified and corrected immediately.

As well, parents, not the federal government, are given more choices as to who will care for their child. Benefits will be given to the person who is best suited to serve the child. While the states are given more jurisdiction over the program, yearly reports must be made to Congress and the President so that the program can be re-evaluated for efficiency and any needed changes can be made. I believe that this program can work in the best interest of all Alabamians, and I hope that I can count on your continued input as the changes are implemented.

Again, thank you for contacting me. If I can ever be of any further assistance, do not hesitate to write or call.

Sincerely,

Spencer T. Bachus, III
Member of Congress

STB:aef

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 toddler

By Ellen M. Perlmutter
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 child's eligibility 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-10

Annie O'Neill/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.*

Welfare may prove fatal to ill toddler

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 [SSI], her care would decline and leave her at risk to 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 state 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.

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
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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,

Maurice E. Keenan, MD

Maurice E. Keenan, MD
President

COMMUNITY LEGAL SERVICES, INC.

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

Re: SSI Disabled Children

Fax No. (215) 981-0436

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TO: Diane Fortuna / Carol Rasco

FIRM: Domestic Policy Council

FAX NO.: (202) 456-7028

FROM: JONATHAN STEIN, GENERAL COUNSEL

DIRECT DIAL: (215) 981-3742

MESSAGE: Note current 30% allowance rate (under "current IFA") is even LOWER than pre-1984 1989 year of 43%!!!

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Note also Pittsburgh Post-Gazette editorial - Pa. is a key state!

Please share w/ OMB 955A.

Supplemental Security Income for Children with Disabilities

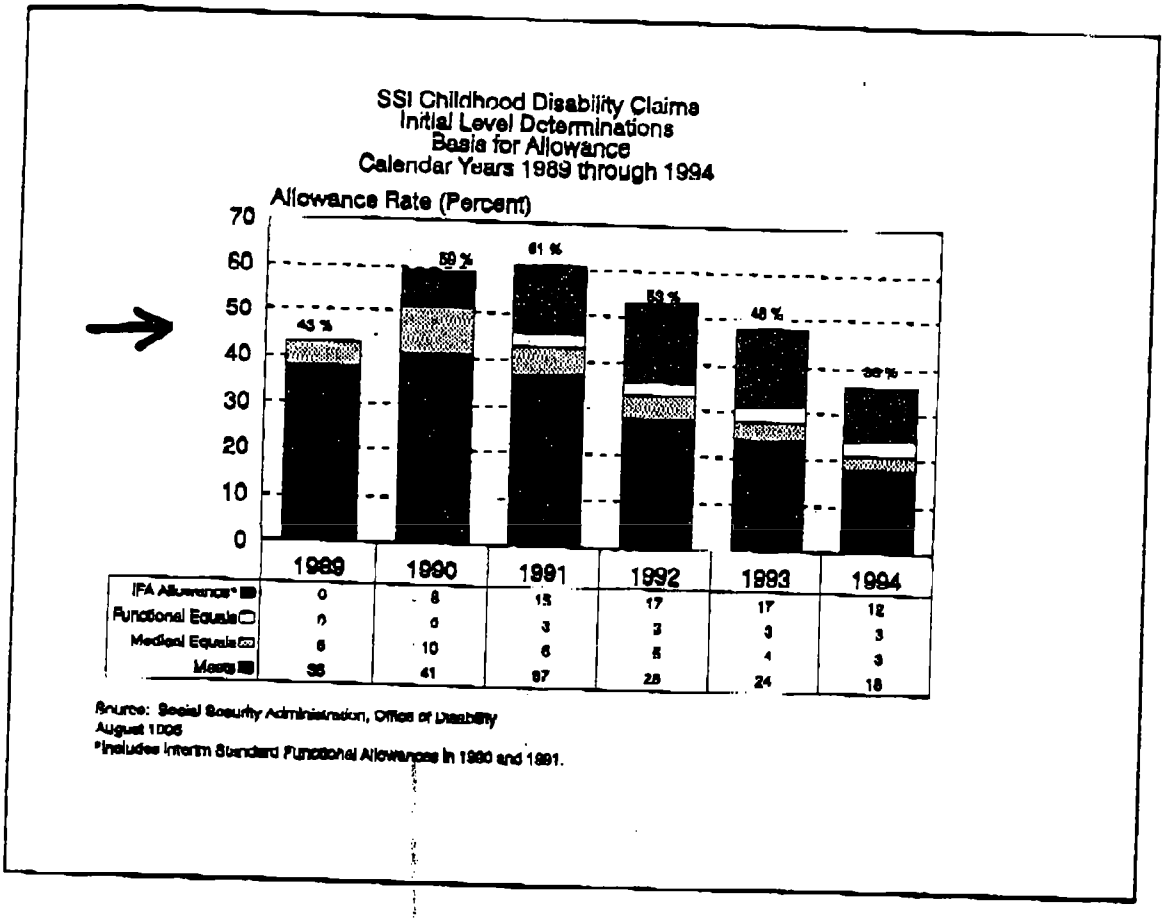
October 1995
Washington, D.C.

Report to Congress of the National Commission on Childhood Disability

Supplemental Security Income for Children with Disabilities

October 1995
Washington, D.C.

Table 1-9.



An additional alleged source of program growth is fraudulent SSI claims. Some observers contend that increasing numbers of parents are successfully coaching their children to feign disabilities in order to receive SSI benefits. Despite the decline in allowance rates to below the pre-*Zebley* rate, the news media has continued to report allegations of coaching.[37] Such coverage has fueled Congressional interest and heightened public concern that fraud may constitute a major source of program growth.

The most comprehensive investigation of these allegations to date was undertaken by SSA itself. The agency's efforts are three-fold. First, in May 1994, SSA examined a sample

[37] For example, T. Hargrove, "Misuse of Aid to Learning-Disabled Children Alleged." *The Atlanta Constitution*, December 30, 1994. J. B. O'Donnell, "Children are Coached to Get Aid, Social Security Admits." *The Baltimore Sun*, April 8, 1995. H. MacDonald, "Teaching Johnny to Fail." *The Washington Post*, June 18, 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

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

(2) THROUGH 4/26/95

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

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 Administration has been much more restrained in awarding the benefits. Today, 70 percent of applicants are rejected compared 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 Steinetz 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

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 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.

AMERICAN
PSYCHOLOGICAL
ASSOCIATION

October 8, 1996

Diana Fortuna
Domestic Policy Council
The White House
Washington, D.C. 20500

Dear Ms. Fortuna:

Thank you again for taking the time to hear the concerns of the American Psychological Association (APA) regarding pending changes to the children's Supplemental Security Income program (SSI).

The new welfare legislation mandates stricter SSI eligibility standards. At the same time, it leaves the Administration considerable discretion as to how the law will be implemented. This decision will have a tremendous impact on tens of thousands of children with severe disabilities, particularly those with mental, emotional or behavioral impairments.

The APA recommends a final standard that ensures that children with severe disabilities remain eligible for SSI. We trust that the Administration shares this goal. However, we also recognize that there are other competing political and budgetary pressures. It is our sincerest hope that the interests of children with disabilities and their families prevail in your final decision.

SSI is an extremely cost-effective way to help parents raise children with disabilities at home. Many costs incurred by these families are not covered by Medicaid or other types of insurance. For example, children with disabilities may require specially-trained daycare providers because others are unable or unwilling to care for them. SSI also compensates parents for lost income when they take time out from employment to attend to their child's special needs. These are parents, already struggling at the economic margins, for whom unpaid leave is not a viable option.

APA endorses the new children's SSI disability standard proposed by a group of disability advocates, including the Consortium for Citizens with Disabilities.

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Washington, DC 20002-4242
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(202) 336-6123 TDD
Web: www.apa.org

This proposal clearly satisfies the new statute by establishing an appropriate required level of severity that falls between the very high presumptive level of the categorical listings and the previous Individualized Functional Assessment (IFA). The proposal we have endorsed is also consistent with the welfare conference report and statements by Congressional leaders, including former Senator Dole, who stated that SSI was more in need of a "tune-up" than a radical overhaul.

None of the many studies of the SSI program suggests the need for wholesale caseload reductions. Reviews of children's SSI cases by both the GAO and the Office of the Inspector General have found that the overwhelming majority of children who were approved for SSI benefits indeed had disabilities severe enough to qualify.

The Administration has both the power and authority to formulate new regulations that tighten eligibility yet maintain support for hundreds of thousands of children with disabilities and their families for whom SSI assistance is critical. We hope that the interests of these children remain paramount in your final decision.

Sincerely,

Henry Tomes, Ph.D.
Executive Director
Public Interest Directorate

Charles Barone, Ph.D.
Senior Legislative &
Federal Affairs Officer