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Folder Title:
SSI [Supplemental Security Income] Disability

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PRESERVATION

IMPACT OF THE PERSONAL RESPONSIBILITY ACT ON CHILDREN AND FAMILIES WITH DISABILITIES

While the current House plan is weak on work, it is very tough on children. Cutting school lunches and getting tough on disabled children and children in foster care is not my idea of welfare reform. We all have a national interest in promoting the well-being of our children and in putting government back in line with our national values... In the end I believe we can work it out together, as long as we remember the values this debate is really about. The dignity of work, the bond of family, and the virtue of responsibility are not Republican values or Democratic values. They are American values -- and no child in America should ever have to grow up without them.

President Bill Clinton
Letter to Speaker of the House Newt Gingrich and Minority Leader Richard Gephardt, March 20, 1995

The House Republican's Personal Responsibility Act, which passed in the House on Friday March 24, ends numerous federal-state entitlement and discretionary programs -- including Aid to Families with Dependent Children (AFDC), Emergency Assistance (EA), child care, child welfare, and nutrition assistance -- and replaces them with block grants to states. It cuts funding for Food Stamps and significantly reduces the number of disabled children eligible for the childhood SSI program and converts most of the program into a block grant. **This could result in your state and its residents receiving significantly less federal funding for these programs. It is important that you are aware of these changes and what they may mean for you, your children and your family.**

Title VI of this Act would deny Supplemental Security Income (SSI) to many currently eligible persons and future applicants -- particularly disabled children, many of whom would be denied all benefits due to eligibility placed on them by the proposal. These reductions would result in $14.5 billion less federal funding for childhood SSI cash benefits over the five years and would result in approximately **177,000 disabled children losing all SSI benefits and Medicaid**, and approximately **613,000 losing cash SSI benefits.** (The latter group would be eligible for Medicaid, and block grant services at the state discretion.)

Under the Personal Responsibility Act:

- **Children who currently receive SSI because of an Individual Functional Assessment would lose all benefits (cash and Medicaid) six months after enactment**, because the IFA is repealed. Of the approximately 813,000 children found eligible between 1991 and 1994, a preliminary estimate of over 251,000 (31 percent) would be eliminated from the rolls. (although it is possible that up to 30% of those cut would be re-determined eligible by meeting the listing of impairments.)

  The Personal Responsibility Act makes the assumption that children who qualify for SSI under an IFA are not as severely disabled as those who meet one of the SSA impairment listings. This is an arbitrary cutoff of children; these children may have multiple disabilities which add up to a very severe functional disability.

- **It's the luck of the draw for future applicants.** If future applicants look like current recipients, only 1/5 of applicants would receive cash benefits.

- **Current recipients and new applicants who would today be found eligible under an IFA would no longer be eligible for Medicaid,** unless their families are eligible through some other means.

  Health services provided to children through Medicaid in many cases prevent a mild or moderate disability from becoming severe. Furthermore, without Medicaid coverage for their child, the parents of children with disabilities are vulnerable to losing their private insurance coverage, or reaching lifetime limits or paying drastically higher rates.

- Cash benefits and Medicaid would only be available for children who meet the medical listings AND are institutionalized, or who would be institutionalized if they do not receive personal assistance services. **This could lead to inappropriate institutionalization of people with disabilities.**

- The definition of personal assistance services is unclear; it: (1) likely does not include children under the age of six because it is developmentally appropriate for most young children to need help with basic activities of daily living; and (2) could narrow the number of children who will qualify for cash benefits.

  Personal assistance services are defined as hands-on, stand-by, or cueing assistance with activities of daily living (eating, toileting, bathing, dressing and transferring) and, as appropriate, the administration of medical treatment.

Under the new block grant:

- **Cash payments to recipients would not be permitted.** States would have to allow all eligible children to apply for services.

  Based on an assessment of the child, states would determine: (1) which services are offered under the block grant, (2) the amount and scope of each service; and, (3) which children receive each service.

- **Less money is spread among more children.** Only 1/5 of children who currently receive cash would continue to receive cash. For the majority of children who are severely disabled enough to meet the listings, their cash benefits would be cut-off.

- **It is possible that administrative costs will increase, while availability of services will decrease.** While a lot of money and other resources would be required to assess children's service needs, it is possible that a substantial number of those assessed needs would not be met by this program.

A child could be found, for example, to need speech therapy, but there is no guarantee that: (1) the state would include speech therapy in its offered services under the block grant; or (2) even if speech therapy were included, that this particular child would get the services in the needed amount.

cc Carol Rasco
Ken Apfel
Keith Fontenot
Richard Green
Debbie Fine
-Diana Fortuna
(Note no cc's)

November 2, 1995

Alice M. Rivlin, Director
Office of Management and Budget
Old Executive Office Building
17th Street & Pennsylvania Avenue N.W.
Washington, DC 20503

Dear Ms. Rivlin:

The undersigned organizations write to express our disappointment with a recent Administration position that discriminates against children receiving Supplemental Security Income (SSI) benefits because of severe mental and emotional disorders.

In an October 18 letter to Congress outlining the Administration's position on the welfare reform bills, you recommend that any eligibility changes in the children's SSI program should apply only to future applicants. We applaud that portion of the recommendation which would protect all current child recipients. However, the letter then recommends that if conferees apply the new rules to current recipients, they should apply "only to those children eligible as a result of maladaptive behavior."

We believe that this recommendation demonstrates a shocking willingness by the Administration to base its policy decisions on stigma rather than on medical knowledge about the nature of children's mental illness. It also is discriminatory because it singles out children with mental and behavioral impairments for separate treatment.

Contrary to anecdotal reports, it is not possible to obtain SSI benefits on the basis of maladaptive behavior alone. To qualify, the child must have a medically determinable impairment and must demonstrate significant limitation in age-appropriate behavior in at least one other functional area. Furthermore, maladaptive behavior in SSA's medical listings is defined as "behaviors destructive to self, other, to animals or property, requiring protective intervention." Clearly, application of this criterion is limited to children with severe disorders.

By focusing on children with "maladaptive behavior", the Administration simply perpetuated stereotypes and misinformation about children with mental illness. We urge you to withdraw your recommendation on this issue. Children with mental and emotional disorders will be the beneficiaries.

Sincerely,

Rhoda Schulzinger
Bazelon Center for Mental Health Law

Joe Marnes
Bazelon Center for Mental Health Law

Martha E. Ford
The Arc
Co-Chairs Social Security
Task Force, Consortium for Citizens
with Disabilities

Al Guida
National Mental Health Association
Co-Chairs, Mental Health Policy
Committee, Mental Health Liaison Group

American Academy of Child and Adolescent Psychiatry
American Association for Marriage and Family Therapy
American Association of Children's Residential Centers
American Association of Psychiatric Services for Children
American Association of Private Practice Psychiatrists
American Humane Association
American Managed Behavioral Healthcare Association
American Psychiatric Association
American Psychological Association
American Rehabilitation Association
Association of Maternal and Child Health Programs
Bazelon Center for Mental Health Law
Child Welfare League of America
Children's Defense Fund
Federation of Families for Children's Mental Health
International Association of Psychosocial Rehabilitation Services
Learning Disabilities Association
National Association of Developmental Disabilities Councils
National Association of Homes and Services for Children
National Association of Psychiatric Health Systems
National Association of Psychiatric Treatment Centers for Children
National Association of Protection and Advocacy Systems
National Association of School Psychologists
National Association of Social Workers
National Association of State Mental Health Program Directors
National Depressive and Manic Depressive Association
National Easter Seal Society
National Mental Health Association
National Organization for Rare Disorders, Inc.
National Organization of State Association for Children
The Arc
Spina Bifida Association of America
United Cerebral Palsy Associations
World Association for Psychosocial Rehabilitation

SSI disability

EXECUTIVE OFFICE OF THE PRESIDENT

23-Oct-1995 04:11pm

TO: (See Below)

FROM: Diana M. Fortuna
Domestic Policy Council

SUBJECT: Big complaint by Bazelon

I just got a call from Rhoda Schulzinger of Bazelon, who was bouncing off the walls because she had just seen the language of the welfare reform conferee letter from Director Rivlin. She was upset because we said all the eligibility redeterminations should be prospective except, if necessary, those kids eligible as a result of maladaptive behavior. She says the Arc and the American Psychiatric Association are similarly upset.

At first she said the term maladaptive behavior was meaningless in a technical sense, and said she couldn't imagine SSA agreed with it, but as the conversation went on it became apparent that she knows more or less what we meant and that she doesn't want those particular children singled out.

I pointed that our position would keep more kids on the rolls than theirs would; she said she was offended if I meant by that to suggest that they don't care about this issue or sold out; that they have been working on this for a year and begging us to take a stand on this during that time. Ironically, they would prefer we had sold out all the current IFA kids rather than made this distinction.

We need to check with Judy Chesser and SSA and make sure that our words reflect exactly what we meant, but I suspect they did. The core of it is that we made a decision at SSA's suggestion that, if Congress wouldn't agree to make all the cuts prospective, this was the group that we would agree to let go -- partly because this group caused so much controversy, especially in Congress. And, given the tabloid press reports and Bazelon's emphasis on mental health issues, they have spent a lot of time trying to convince people that maladaptive behavior problems can be very severe. She said our position was "a red flag to the Neanderthals on the Hill" who don't understand this issue; and that singling out maladaptive behavior is like singling out "firesetters." (I'm still not sure what that's supposed to mean.)

(Richard Green points out that we are simply saying kids with

maladaptive behavior should be put through the hoops of the new eligibility process; and that, if their disability is severe enough, they will be found eligible.)

Where do we go from here? This will certainly make it harder to try to get them to coordinate their position with ours, Ken. Also, we should think carefully about where we are before we let the Chater letter out the door.

Distribution:

TO: Kenneth S. Apfel
TO: Carol H. Rasco

CC: Richard E. Green
CC: Jack A. Smalligan
CC: Deborah L. Fine
CC: Jeremy D. Benami

National Journal's CongressDaily

May 8, 1995

SSI

SECTION: HUMAN RESOURCES

LENGTH: 640 words

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

BODY:

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

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

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

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

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

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

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

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

---- *URGENT ALERT* ----

SENATORS SHOULD SAVE SSI!

WHAT'S HAPPENING IN WASHINGTON D.C.:

The House of Representatives has approved legislation (the Personal Responsibility Act; bill # HR-4) which makes drastic changes to the Children's Supplemental Security Income (SSI) program. SSI provides small cash payments to low-income people with mental and physical disabilities, including children.

If approved by the Senate, this bill would:

- ☹ Retroactively eliminate the Zebley decision as a basis for SSI eligibility;
- ☹ Eliminate all SSI benefits, including Medicaid, for 27% of the children currently enrolled in the program;
- ☹ Replace cash payments for services and treatments with state-run programs;
- ☹ Cut funding for services and treatments by 25%.

ATTACKS ON CHILDREN RECEIVING SSI ARE UNFOUNDED!

- ☞ Kids' SSI saves tax dollars by allowing families to raise disabled children at home rather than in state-financed institutions. Institutionalizing a child costs $60,000 per year, while an average SSI benefit is less than $5,000 per year.
- ☞ Repeated studies have universally found no evidence of widespread fraud or abuse in the SSI system.

WHAT YOU CAN DO:

ACTION IS NEEDED IMMEDIATELY!

- ☎ **Call your Senators today!** You can reach their Capitol offices through the Senate switchboard at (202) 224-3121. Tell them that the proposed changes to SSI will hurt children and must be taken out of the Personal Responsibility Act. Specifically, they should:
- ▸ Retain cash benefits. Parents - not the government - need to have the right to make decisions about a child's treatment and services.
- ▸ Keep the Individualized Functional Assessment (IFA). Children should not have to fit a "list" to receive benefits.
- ▸ Locate and punish real cases of SSI fraud and abuse, but not make rash, sweeping changes to the program.

SST - Marty Ford 2/27

1) no admin person at mark up for this piece E last week (Sub Cmte)

2) CDF Welfare Reform PC on Wed at 9AM
Karen Higgenbotham + daughter (from LA)

3) need a chaos Tues-Wed to impact Thurs mark-up

4) #1 issue for the Arc
80,000 kids w/mental retardation

5) flex friendly rule solution through SS - talk liaison
don't cut off →

HHS - #'s for press conf
admin - statement that day

Cons

letter?

6) 8 fams w/ deaths on SSI at mark up

House Sht - wk 3/20

go through

U.S. Department of Health and Human Services

The Office of Disability, Aging and Long-Term Care Policy
Room 424-E, Humphrey Building
200 Independence Ave., SW
Washington, D.C. 20201

FAX (202)401-7733

TO: Debbi Feiv *FAX NUMBER:* 456-2983

NUMBER OF PAGES: 5 + cover *DATE:* 3/31/95

FROM:

Michele Adler ☐	Nancy Eustis ☐	Brooke Lindsay ☐
Kathleen Bond ☐	Andreas Frank ☐	Cheryl McDuffie ☐
Darlene Bostic ☐	Mary Harahan ☐	Robyn Stone ☐
Floyd Brown ☐	Jennie Harvell ☐	Tammy Terrell ☐
Robert Clark ☐	Ruth Irwin ☐	Brenda Veazey ☐
Pamela Doty ☐	Ruth Katz ☒	
John Drabek ☐	Crystal Kuntz ☐	

REMARKS/COMMENTS

PERSONAL RESPONSIBILITY ACT, TITLE VI:

SUPPLEMENTAL SECURITY INCOME REFORMS

SSI Restriction to Disabled Children: Restriction of Cash benefits

Proposal

The functional impairment test using the Individual Functional Assessment (IFA) for determining disability is repealed. Children who currently receive SSI by virtue of an IFA would lose all benefits (cash and Medicaid) six months after enactment. Children who are currently SSI eligible because they have a disability that meets or equals the listings of impairments would continue to receive cash benefits and Medicaid. For applicants after enactment, cash benefits and Medicaid would only be available for children who meet the medical listings AND are institutionalized or would be institutionalized if they do not receive personal assistance services required because of their disability. *Personal assistance services are defined as hands-on, stand-by, or cueing assistance with activities of daily living (eating, toileting, bathing, dressing and transferring) and, as appropriate, the administration of medical treatment.* A child who is overseas as a dependent of a member of the U.S. Armed Forces and who is eligible for the block grant services but not cash benefits under the new criteria would be eligible for cash benefits until they return to the United States.

States are required to redetermine eligibility for cash benefits and for services under the block grant at least every 3 years unless it is determined that the child's condition cannot improve. For all children who receive cash benefits or services, within one year of the child's eighteenth birthday, states are required to redetermine eligibility for SSI. A continuing disability review (CDR) would be required after one year for low birth weight babies.

In addition, the Commissioner of SSA is required to submit two reports to Congress: (1) an annual report on the listings of impairments, including recommendations for any necessary changes; and (2) by October 1, 1998, a report on SSA's eligibility redetermination activities related to individuals who turn age 18.

The SSI payment amount for institutionalized children would be $30, regardless of whether their medical costs are predominantly covered by private insurance or Medicaid. Also, all children in 209(b) states who have a disability and meet or equal the listings, but do not qualify for Medicaid, would continue to receive cash benefits until September 30, 1996; after that date, only those who meet the "institutionalized/otherwise institutionalized: criteria would get cash.

A review of the appropriateness of the mental impairments listing by the Childhood Disability Commission is required.

Disability determinations would take into account whether a family has transferred a child's assets or trusts anytime during the three year period before applying for SSI.

Discussion

The IFA process evaluates a child's functional status in the domains of cognition, social/behavioral skills, communication, motor skills, concentration, persistence and pace. It was established in response to the Supreme Court decision in the *Zebley* case, which recognized that some children do not meet the listing level of impairment, but nonetheless have impairments in daily living. This proposal makes the assumption that children who qualify for SSI under an IFA are not as severely disabled as those who meet one of the SSA impairment listings. Children who qualify for SSI under an IFA may, in fact, have multiple disabilities, which add up to a very severe functional disability. This is an arbitrary cutoff of children; there should be a thorough examination of the eligibility criteria to ensure that children with severe disabilities receive the services and cash support they need.

Of the 812,411 children found eligible between 1991 and 1994, a preliminary estimate of over 251,000 (31 percent) would be eliminated from the rolls because they became eligible for SSI by virtue of an IFA.; SSA estimates that 40 percent of those children, upon further review, might be determined eligible for benefits based on a listing. This bill would prohibit children in that 40 percent group from continuing to receive cash under the *grandfathering* provision, even though they could have met the listings all along, but happen to have become eligible via an IFA. In addition, the bill appears to deny cash benefits to children who are covered by the grandfathering provision, but lose eligibility for financial reasons for a month or more, then return to the rolls. When they come back into the program, they would only receive cash if they meet the listings and require or would require institutionalization.

Current recipients and new applicants whose impairment does not meet or equal the listings but would today be found eligible under an IFA, would also not receive Medicaid, unless their families are Medicaid eligible through some other means. In many cases, the health services provided through Medicaid can prevent a mild or moderate disability from becoming severe. For many poor children, parents have private health insurance, a child's disability can threaten the private coverage; lifetime limits can be reached quickly when a child with a disability is part of the family, or insurance companies can raise rates or fail to renew policies.

Children in institutions and participating in Medicaid typically receive only a $30 personal needs allowance per month and Medicaid. This proposal appears to maintain that provision. Furthermore, the bill would correct a loophole in current law regarding children in medical institutions whose families have private insurance. The bill would require that these families receive the same cash benefit amount as those who are covered by Medicaid (i.e. $30 personal needs allowance per month).

The proposal also provides SSI cash benefits and Medicaid for those children who have an impairment which meets or equals a listed impairment and who would be institutionalized if they did not receive personal assistance services because of a disability. Personal assistance services is defined as a need for "at least hands on, stand by, or cueing assistance with activities of daily living" (e.g., eating toileting etc.) or need for help with the administration of medical treatment. This definition of personal assistance services raises concerns: (1) it is

not applicable to and cannot be operationalized for children under the age of six because it is developmentally appropriate for most young children to need help with basic activities of daily living; and (2) it could narrow the number of children who will qualify for cash benefits. a related concern is that the definition of a need for assistance with medical treatment is unclear -- is it meant to include, for example, children who need assistance taking medication? If so, that would likely be a large percentage of children with disabilities. Earlier versions of the bill referred to a need for personal assistance services but did not define the term; using the undefined reference, CBO estimated that approximately 30 percent of children who have disabilities that meet or equal the listings would receive cash under this provision. This estimate will change with the inclusion of the personal assistance definition and the addition of the "need for assistance with medical treatment" language.

Furthermore, institutionalization or a need for institutionalization is not a proxy for severe disability; numerous other cultural, economic, legal, educational, and family factors, besides severity of disability, play into a decision to institutionalize a child or keep the child at home. Generally, as community services become increasingly available, the rate of institutionalization of children drops. More importantly, most people in the disability community maintain that it is never appropriate to institutionalize a child.

The Social Security Independent Agency and Program Improvements Act of 1994 required that a percentage of children turning age 18 undergo a continuing disability review. This bill eliminates that requirement, replacing it with a *de novo* eligibility review for all children who are SSI cash recipients within a year of their eighteenth birthday. Presumably, most children who are eligible for block grant services, but not for cash, would also want to reapply at age 18, because they might be able to start receiving cash benefits under the adult SSI program. In that case, SSA would be in a position of *de facto* having to review almost 100 percent of children turning age 18; that would likely require extensive new DDS resources and personnel.

The review of the childhood mental impairment listings by the Childhood Disability Commission could be lost to timing. The Commission is required to complete its work and submit a report to Congress by November 1995; the Commission's Chairman has expressed a desire to submit the report even earlier, by July or August. For the Commission to include the review of the mental impairment listing in its work, this bill would have to be enacted into law very soon. Charging SSA with this review might be more effective.

Block Grants for Medical and Non-Medical Benefits for Disabled Children

Proposal

Children who qualify for SSI cash benefits would be eligible for services, using existing delivery systems where possible, under a new block grant. In addition, children considered disabled under the medical impairments listing but not eligible for cash benefits would be eligible for Medicaid and additional medical and non-medical services (including services that are authorized under Medicaid), under a block grant. This block grant would be an entitlement to states. The Commissioner of SSA is authorized to specify the services that

they be made available under the block grant. Cash payments to recipients would not be permitted under the block grant. States would have to allow all eligible children to apply for services under the block grant and provide each applicant with an opportunity to have an assessment to determine the need for services. However, states would have discretion to determine: (1) which services would be offered under the block grant, based on a list of promulgated by the Commissioner of SSA; (2) the amount and scope of each service; and, (3) which children receive each service. The value of services would not be taken into account in determining an individual's eligibility for other cash assistance programs.

Prior to using block grant funds for authorized services, states would have to make every reasonable effort to use other state and federal funds and payments from private entities which are legally liable. In fact, states would have to maintain their non-federal spending on services to this population; the maintenance of effort (MOE) amount would be based on a two year period prior to October 1, 1995, and increased annually for inflation. States would be allowed to spend the MOE dollars on any allowable services included in the Commissioner's list -- i.e., the MOE is on dollar amounts, not specific services or programs.

A state's allotment of the block grant funds would equal the product of 75 percent of the average qualifying child's annual cash SSI benefits in the state and the number of children in the state who meet the listings but don't receive cash benefits. States that do not participate in the block grant program would be prohibited from using Social Security Numbers for other purposes, e.g., driver's license applications, general assistance applications, etc.

Discussion

This proposal represents an immediate and direct cut in the funding available to assist SSI eligible children with disabilities and their families. Less money is spread among more children. The amount of the block grant is based on three-quarters of the SSI payments that would have gone to children who meet the listings but do not qualify for cash (i.e., are not institutionalized or in need of institutionalization absent personal assistance services). However, block grant services are to be made available to <u>all</u> children who meet the listing, regardless of whether or not they receive cash. Based on the approximately 813,000 children who entered the SSI rolls between 1991 - 1994, the amount of the block grant would be 75% of the payments made to 48 percent of the children (those who meet the listings but not the institutionalized/otherwise institutionalized criteria) of the total group. [Note: The remaining 31 percent entered the rolls via an IFA.] In fact, it is likely that the most disabled children (i.e., those receiving cash benefits) would receive a disproportionate share of services under the block grant. This population is not even included in the state allocation formula.

Another concern is created by the fact that eligible children would have to be offered the opportunity to apply for block grant services and to be assessed to determine their service needs, although states would determine which services would be proved and who would get those services. A child could be found, for example, to need speech therapy, but there is no guarantee that: (1) the state would include a speech therapy in its offered services under the block grant; or (2) even if speech therapy were include, that this particular child would get the services in the needed amount. While a lot of money and other resources would have to

be expended to assess children's service needs, it is possible that a substantial number of those assessed needs would not be met by this program. Furthermore, questions arise regarding what constitutes "services under the block grant." For example, is one hour of service per child per year sufficient to meet the requirement? What if a state opts to offer only a limited array services? Given the cut in funding, coupled with the new need for state administrative expenditures to manage the block grant, it is possible that this requirement could be interpreted in a restricted fashion.

The proposal indicates that the block grant is the payor of last resort, although it gives no guidance regarding how determinations would be made about whether services could be covered under Medicaid in their block grants. If states do opt to include certain Medicaid services, which program is the payor of last resort -- Medicaid or the block grant? States would have an incentive to use this program first given that there is no matching requirement (as there is under Medicaid). It is possible that states would seek to restrict their Medicaid programs, replacing some services with 100 percent federally funded SSI block grant services.

Proposal

The proposal establishes a new block grant for aid to the aged, blind or disabled in Puerto rico, U.S. Virgin Islands, Guam and American Samoa. This provision would be budget neutral. The amount would be set at $18.1 million per year for Puerto Rico, $474 thousand for the Virgin Islands, and $901 thousand for Guam.

Discussion

Puerto Rico, U.S. Virgin Islands, Guam and American Samoa do not currently operate an SSI program, rather benefits are provided to this group through a block grant that serves the low income aged, blind and disabled. This provision is necessary because the new Title I transitional assistance prohibits funds to be used for SSI recipients.

Proposal

States would no longer be required to maintain state supplementary payments to recipients.

PERSONAL RESPONSIBILITY ACT, TITLE VI:

SUPPLEMENTAL SECURITY INCOME REFORMS

SSI Restrictions to Disabled Children: Restriction of Cash benefits

Proposal

The functional impairment test using the Individual Functional Assessment (IFA) for determining disability is repealed. Children who currently receive SSI by virtue of an IFA would lose all benefits (cash and Medicaid) six months after enactment. Children who are currently SSI eligible because they have a disability that meets or equals the listings of impairments would continue to receive cash benefits and Medicaid. For applicants after enactment, cash benefits and Medicaid would only be available for children who meet the medical listings AND are institutionalized or would be institutionalized if they do not receive personal assistance services required because of their disability. *Personal assistance services are defined as hands-on, stand-by, or cueing assistance with activities of daily living (eating, toileting, bathing, dressing and transferring) and, as appropriate, the administration of medical treatment.* A child who is overseas as a dependent of a member of the U.S. Armed Forces and who is eligible for the block grant services but not cash benefits under the new criteria would be eligible for cash benefits until they return to the United States.

States are required to redetermine eligibility for cash benefits and for services under the block grant at least every 3 years unless it is determined that the child's condition cannot improve. For all children who receive cash benefits or services, within one year of the child's eighteenth birthday, states are required to redetermine eligibility for SSI. A continuing disability review (CDR) would be required after one year for low birth weight babies.

In addition, the Commissioner of SSA is required to submit two reports to Congress: (1) an annual report on the listings of impairments, including recommendations for any necessary changes; and (2) by October 1, 1998, a report on SSA's eligibility redetermination activities related to individuals who turn age 18.

The SSI payment amount for institutionalized children would be $30, regardless of whether their medical costs are predominantly covered by private insurance or Medicaid. Also, all children in 209(b) states who have a disability and meet or equal the listings, but do not qualify for Medicaid, would continue to receive cash benefits until September 30, 1996; after that date, only those who meet the "institutionalized/otherwise institutionalized" criteria would get cash.

A review of the appropriateness of the mental impairments listing by the Childhood Disability Commission is required.

Disability determinations would take into account whether a family had transferred a child's assets or trusts anytime during the three year period before applying for SSI.

taking medication? If so, that would likely be a large percentage of children with disabilities. Earlier versions of the bill referred to a need for personal assistance services but did not define the term; using the undefined reference, CBO estimated that approximately 30 percent of children who have disabilities that meet or equal the listings would receive cash under this provision. This estimate will change with the inclusion of the personal assistance definition and the addition of the "need for assistance with medical treatment" language.

Furthermore, institutionalization or a need for institutionalization is not a proxy for severe disability; numerous other cultural, economic, legal, educational, and family factors, besides severity of disability, play into a decision to institutionalize a child or keep the child at home. Generally, as community services become increasingly available, the rate of institutionalization of children drops. More importantly, most people in the disability community maintain that it is never appropriate to institutionalize a child.

The Social Security Independent Agency and Program Improvements Act of 1994 required that a percentage of children turning age 18 undergo a continuing disability review. This bill eliminates that requirement, replacing it with a *de novo* eligibility review for all children who are SSI cash recipients within a year of their eighteenth birthday. Presumably, most children who are eligible for block grant services, but not for cash, would also want to reapply at age 18, because they might be able to start receiving cash benefits under the adult SSI program. In that case, SSA would be in a position of *de facto* having to review almost 100 percent of children turning age 18; that would likely require extensive new DDS resources and personnel.

The review of the childhood mental impairment listings by the Childhood Disability Commission could be lost to timing. The Commission is required to complete its work and submit a report to Congress by November 1995; the Commission's Chairman has expressed a desire to submit the report even earlier, by July or August. For the Commission to include the review of the mental impairment listings in its work, this bill would have to be enacted into law very soon. Charging SSA with this review might be more effective.

Block Grants for Medical and Non-Medical Benefits for Disabled Children

Proposal

Children who qualify for SSI cash benefits would be eligible for services, using existing delivery systems where possible, under a new block grant. In addition, children considered disabled under the medical impairments listings but not eligible for cash benefits would be eligible for Medicaid and additional medical and non-medical services (including services that are authorized under Medicaid), under a block grant. This block grant would be an entitlement to states. The Commissioner of SSA is authorized to specify the services that may be made available under the block grant. Cash payments to recipients would not be permitted under the block grant. States would have to allow all eligible children to apply for services under the block grant and provide each applicant with an opportunity to have an assessment to determine the need for services. However, states would have discretion to determine: (1) which services would be offered under the block grant, based on a list promulgated by the Commissioner of SSA; (2) the amount and scope of each service; and, (3) which children receive each service. The value of services would not be taken into account in determining an individual's eligibility for other cash assistance programs.

Discussion

The IFA process evaluates a child's functional status in the domains of cognition, social/behavioral skills, communication, motor skills, concentration, persistence and pace. It was established in response to the Supreme Court decision in the *Zebley* case, which recognized that some children do not meet the listing level of impairment, but nonetheless have impairments in daily living. This proposal makes the assumption that children who qualify for SSI under an IFA are not as severely disabled as those who meet one of the SSA impairment listings. Children who qualify for SSI under an IFA may, in fact, have multiple disabilities, which add up to a very severe functional disability. This is an arbitrary cutoff of children; there should be a thorough examination of the eligibility criteria to ensure that children with severe disabilities receive the services and cash support they need.

Of the 812,411 children found eligible between 1991 and 1994, a preliminary estimate of over 251,000 (31 percent) would be eliminated from the rolls because they became eligible for SSI by virtue of an IFA. SSA estimates that 40 percent of those children, upon further review, might be determined eligible for benefits based on a listing. This bill would prohibit children in that 40 percent group from continuing to receive cash under the *grandfathering* provision, even though they could have met the listings all along, but happen to have become eligible via an IFA. In addition, the bill appears to deny cash benefits to children who are covered by the grandfathering provision, but lose eligibility for financial reasons for a month or more, then return to the rolls. When they come back into the program, they would only receive cash if they meet the listings and require or would require institutionalization.

Current recipients and new applicants whose impairment does not meet or equal the listings but would today be found eligible under an IFA, would also not receive Medicaid, unless their families are Medicaid eligible through some other means. In many cases, the health services provided through Medicaid can prevent a mild or moderate disability from becoming severe. For many poor children, especially those with disabilities, Medicaid is the only health insurance coverage they have. Even if parents have private health insurance, a child's disability can threaten the private coverage; lifetime limits can be reached quickly when a child with a disability is part of the family, or insurance companies can raise rates or fail to renew policies.

Children in institutions and participating in Medicaid typically receive only a $30 personal needs allowance per month and Medicaid. This proposal appears to maintain that provision. Furthermore, the bill would correct a loophole in current law regarding children in medical institutions whose families have private insurance. The bill would require that these families receive the same cash benefit amount as those who are covered by Medicaid (i.e., $30 personal needs allowance per month).

The proposal also provides SSI cash benefits and Medicaid for those children who have an impairment which meets or equals a listed impairment and who would be institutionalized if they did not receive personal assistance services because of a disability. Personal assistance services is defined as a need for "at least hands on, stand by, or cueing assistance with activities of daily living" (e.g., eating, toileting, etc.) or need for help with the administration of medical treatment. This definition of personal assistance services raises concerns: (1) it is not applicable to and cannot be operationalized for children under the age of six because it is developmentally appropriate for most young children to need help with basic activities of daily living; and (2) it could narrow the number of children who will qualify for cash benefits. A related concern is that the definition of a need for assistance with medical treatment is unclear -- is it meant to include, for example, children who need assistance

Prior to using block grant funds for authorized services, states would have to make every reasonable effort to use other state and federal funds and payments from private entities which are legally liable. In fact, states would have to maintain their non-federal spending on services to this population; the maintenance of effort (MOE) amount would be based on a two year period prior to October 1, 1995, and increased annually for inflation. States would be allowed to spend the MOE dollars on any allowable services included in the Commissioner's list -- i.e., the MOE is on dollar amounts, not specific services or programs.

A state's allotment of the block grant funds would equal the product of 75 percent of the average qualifying child's annual cash SSI benefits in the state and the number of children in the state who meet the listings but don't receive cash benefits. States that do not participate in the block grant program would be prohibited from using Social Security Numbers for other purposes, e.g., driver's license applications, general assistance applications, etc.

Discussion

This proposal represents an immediate and direct cut in the funding available to assist SSI eligible children with disabilities and their families. Less money is spread among more children. The amount of the block grant is based on three-quarters of the SSI payments that would have gone to children who meet the listings but do not qualify for cash (i.e., are not institutionalized or in need of institutionalization absent personal assistance services). However, block grant services are to be made available to <u>all</u> children who meet the listings, regardless of whether or not they receive cash. Based on the approximately 813,000 children who entered the SSI rolls between 1991 - 1994, the amount of the block grant would be 75% of the payments made to 48 percent of the children (those who meet the listings but not the institutionalized/otherwise institutionalized criteria), but the services of the block grant would have to be made accessible to 69 percent (all those who meet the listings) of the total group. [Note: The remaining 31 percent entered the rolls via an IFA.] In fact, it is likely that the most disabled children (i.e., those receiving cash benefits) would receive a disproportionate share of services under the block grant. This population is not even included in the state allocation formula.

Another concern is created by the fact that eligible children would have to be offered the opportunity to apply for block grant services and to be assessed to determine their service needs, although states would determine which services would be provided and who would get those services. A child could be found, for example, to need speech therapy, but there is no guarantee that: (1) the state would include speech therapy in its offered services under the block grant; or (2) even if speech therapy were included, that this particular child would get the services in the needed amount. While a lot of money and other resources would have to be expended to assess children's service needs, it is possible that a substantial number of those assessed needs would not be met by this program. Furthermore, questions arise regarding what constitutes "services under the block grant." For example, is one hour of service per child per year sufficient to meet the requirement? What if a state opts to offer only a limited array of services? Given the cut in funding, coupled with the new need for state administrative expenditures to manage the block grant, it is possible that this requirement could be interpreted in a restricted fashion.

The proposal indicates that the block grant is the payor of last resort, although it gives no guidance regarding how determinations would be made about whether services could be covered under another program. Furthermore, states are explicitly authorized to include services that could be covered under Medicaid in their block grants. If states do opt to include certain Medicaid services, which program is the payor of last resort -- Medicaid or the block grant? States would have an incentive to

use this program first given that there is no matching requirement (as there is under Medicaid). It is possible that states would seek to restrict their Medicaid programs, replacing some services with 100 percent federally funded SSI block grant services.

Proposal

The proposal establishes a new block grant for aid to the aged, blind or disabled in Puerto Rico, U.S. Virgin Islands, Guam and American Samoa. This provision would be budget neutral. The amount would be set at $18.1 million per year for Puerto Rico, $474 thousand for the Virgin Islands, and $901 thousand for Guam.

Discussion

Puerto Rico, U.S. Virgin Islands, Guam and American Samoa do not currently operate an SSI program, rather benefits are provided to this group through a block grant that serves the low income aged, blind, and disabled. This provision is necessary because the new Title I transitional assistance prohibits funds to be used for SSI recipients.

Proposal

States would no longer be required to maintain state supplementary payments to recipients.

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

04-Apr-1995 11:19pm

TO: Justice for All Mailing List

FROM: Fred Fay Justice for All Moder

SUBJECT: SSI Alert

Justice For All

justice@dimenet.com

----- URGENT ALERT -----

SENATORS SHOULD SAVE SSI!

WHAT'S HAPPENING IN WASHINGTON D.C.:

The House of Representatives has approved legislation (the Personal Responsibility Act; bill # HR-4) which makes drastic changes to the Children's Supplemental Security Income (SSI) program. SSI provides small cash payments to low-income people with mental and physical disabilities, including children.

If approved by the Senate, this bill would:

- Retroactively eliminate the Zebley decision as a basis for SSI eligibility;

- Eliminate all SSI benefits, including Medicaid, for 27% of the children currently enrolled in the program;

- Replace cash payments for services and treatments with state-run programs;

- Cut funding for services and treatments by 25%.

ATTACKS ON CHILDREN RECEIVING SSI ARE UNFOUNDED!

~ Kids' SSI saves tax dollars by allowing families to raise disabled children at home rather than in state-financed institutions. Institutionalizing a child costs $60,000 per year, while an average SSI benefit is less than $5,000 per year.

~ Repeated studies have found no evidence of widespread fraud or abuse in the SSI system.

ltr from LOCA

Bazelon Center
non-medical

all cut effort

Rhoda Shulzinger
Bazelon Center
467-5730 ☆

CDF] families on Tuesday Wed

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

FEB 13 1995

The Honorable E. Clay Shaw
Chairman, Subcommittee on Human Resources
Committee on Ways and Means
U.S. House of Representatives
Washington D.C. 20515

Dear Mr. Chairman:

This letter expresses the Administration's views on the Chairman's mark for welfare reform legislation under consideration by the House Ways and Means Subcommittee on Human Resources.

The Administration shares the commitment of the Congress and the American people to real welfare reform that emphasizes work, parental responsibility, state flexibility, and the protection of children. Last year, the President submitted a bold welfare reform bill, the Work and Responsibility Act of 1994, which embodied these values. It imposed tough work requirements while providing opportunities for education, training, child care and supports to working people. It included a stringent set of child support enforcement provisions. It required each teen mother to live at home, stay in school and identify her baby's father. It increased state flexibility without sacrificing accountability. And it maintained a basic structure of protections for children.

The Administration looks forward to working cooperatively with the Congress in a bipartisan way to pass bold welfare reform legislation this year. The Administration has, however, serious concerns about a number of features of the Chairman's mark that appear to undermine the values to which we are all committed. The Administration seeks to end welfare as we know it by promoting work, family and responsibility, not by punishing poor children for their parents' mistakes. Welfare reform will succeed only if it successfully moves people from welfare to work.

Work

For years, Republicans and Democrats alike have agreed that the central goal of welfare reform must be work. That is still our goal: People who can work ought to go to work and earn a paycheck not a welfare check. The Administration believes that no adult who is able to work should receive welfare for an unlimited time without working. The Administration believes that from the first day someone comes onto welfare, he or she should be required to participate in job search, job placement, education, or training needed to move off welfare and into a job quickly. It is government's responsibility to help ensure that the critical job placement, training, and child care services are provided. Individuals who are willing to work should have the opportunity to work and not be arbitrarily cut off assistance.

The Administration therefore has serious concerns about the Chairman's mark before you:

- It eliminates requirements that recipients participate in job search, education, work or training as a condition of receiving welfare, and ends any responsibility of state welfare systems to provide education, training and placement services to move recipients from welfare to work. The proposed legislation effectively repeals the bipartisan Family Support Act signed by President Ronald Reagan in 1988.

- The proposed legislation includes only minimal and unenforceable requirements that recipients work. The bill requires only that persons on the rolls for more than 2 years engage in "work activities" loosely defined by the state welfare bureaucracy, rather than a real work requirement. The proposed participation standards are very low. In many ways, the work requirements are even weaker than those in current law.

- The proposed legislation provides no assurance of child care to recipients who work or are preparing to work--even if a state requires them to participate. It offers no promise of child care for those who leave welfare for work or for those who could avoid falling onto welfare if they had some help with child care. While it repeals provisions of existing law that provide funding for child care, this bill is silent on whether any additional funds will be available for subsidized child care for low income working families.

- The proposed legislation repeals the current rule that anyone who leaves welfare for work can receive Medicaid for an additional year to ease the transition. This would further reduce health care coverage and make it harder for people to move from welfare to work.

- The proposed legislation would deny all cash assistance to families that have received assistance for more than five years, even if the adult in the family is unable to find a job or prevented from holding a job because of illness or the need to care for a disabled family member. Children would be seriously jeopardized even if their parents cannot find any work.

The Administration supports an alternative approach that would genuinely transform the welfare system into a transitional system focused on work. It would have strict requirements for recipients to participate in and clear responsibilities for states to provide education, training and placement assistance; it would have serious time limits after which work would be required; it would ensure that children would not be left alone when parents were working by providing assistance for child care; it would put parents to work, not just cut them off; and it would ensure that children can expect support from two parents.

Parental Responsibility

The Administration believes that welfare reform should recognize the responsibility and encourage the involvement of both parents in their children's lives. The Administration considers child support enforcement to be an integral part of welfare reform, particularly because it sends a strong message to young people about the responsibility of both parents to support their children. The Administration was pleased that you had agreed to add child support enforcement to your welfare reform bill, and sorry that your proposals are not yet part of the bill now under consideration. The Administration looks forward to working closely with you on this issue in the coming weeks.

- The only child support provision included in the Chairman's mark is one that allows states to reduce payments to children for the first 6 months if paternity has not been legally established. This provision seems ineffectual and unfair. Even if a mother fully cooperates by giving detailed information identifying the father and his possible location, and even if the state is diligent in pursuing the father, it can easily take 6 months to get paternity legally established. There is no reason why the child should be punished during this period.

The Administration believes that it makes far more sense to deny benefits entirely to any parent who refuses to identify the father or to cooperate in locating him. However, once the mother has done all she can, the family should qualify for aid, and then the state should establish paternity within one year.

The Administration believes that the welfare system should encourage the formation and support of two-parent families. The Administration is therefore concerned about an important omission in the proposed legislation:

- The proposed legislation would encourage the break-up of families by repealing the requirement that states provide cash assistance to two-parent families in which a parent is unemployed or unable to work. It allows states to discriminate against married, two-parent families by treating single-parent families better than two-parent families.

The Administration supports an approach that both encourages the formation of two-parent families and makes sure that both parents take responsibility for children in all cases.

Teen Pregnancy

The Administration and the American people agree that the best reform of welfare would be to ensure that people do not need it in the first place. Welfare reform must send a very strong message to young people that they should not get pregnant or father a child until they are ready and able to care for that child, and that if they do have children, they will not be

able to escape the obligations and responsibilities of parenthood. We must be especially concerned about the well-being of the children who are born to young mothers, since they are very likely to grow up poor.

The Administration therefore has serious concerns about the bill before you:

- The proposed legislation would deny all federal cash benefits for eighteen years to any child born to an unmarried mother under 18, as well as to the parent. This provision appears to punish children for their entire childhood--18 years--for the mistakes of their parents.

- The proposed legislation does not require that teen mothers live at home, stay in school, and identify the child's father. It weakens requirements in current law, and may make the prospects for mother and child even worse.

- The proposed legislation establishes only minimal expectations for states to provide services to unmarried parents, and provides no additional funds to support them.

The Administration supports an alternative approach that would require minor mothers to live at home, stay in school, make progress toward self-sufficiency, and identify the father of the child. The Administration also supports a national campaign to prevent teen pregnancy. It is time to enlist parents and civic, religious, and business leaders in a community based strategy to send a clear message about abstinence and responsible parenting. The Administration also supports a state option not to increase benefits for children born to mothers on welfare. This decision should be made by the state, not the federal government.

State Flexibility with Accountability

The Administration embraces the creativity and responsiveness of states, and the opportunities for real reform when states have the flexibility to design and administer welfare programs tailored to their unique circumstances and needs. Already this Administration has granted waivers to nearly half the states for welfare reform demonstrations. National welfare reform should embody the values of work and responsibility in a way that assures taxpayers that federal money is being spent prudently and appropriately. For reform to succeed, the funding mechanisms for welfare should not put children or states at risk in times of recession, population increase or unpredictable growth in demand.

In this context, the Administration has serious concerns about the proposed legislation:

- The spending cap in the proposed legislation makes no allowances for potential growth in the need for cash assistance because of economic downturn, population growth, or unpredictable emergencies. It could result in states

running out of money before the end of the year, and thus having to turn away working families who hit a "bump in the road" and apply for short-term assistance. It could preclude states from investing in job placement, in work programs, in education and training, and in supports for working families.

- The proposed legislation removes the requirement that states match federal funds with their own state funds. With none of their own money at risk, states will have many fewer incentives to spend the funds efficiently and effectively to improve performance and increase self-sufficiency.

- The proposed legislation provides virtually no accountability. There are no incentives for good performance and virtually no penalties for failure. There is no provision for the recovery of monies paid out fraudulently or in error. There are no mechanisms for ensuring that states are actually spending the money on needy children rather than on state bureaucracies, or for monitoring whether federal money is being used to help parents gain self-sufficiency, require work, and enforce parental responsibility. Indeed, the federal government is forbidden from taking any meaningful steps to ensure program performance and accountability.

The Administration supports proposals that significantly increase state flexibility but also ensure accountability for achieving national goals. The Administration supports a funding mechanism that will not put children and states at risk down the road, and that enables states to succeed in moving people from welfare to work and in supporting working families. The Administration has significant doubts about the ability of a pure block grant funding mechanism to adequately protect both children and states.

Protection of Children

The Administration recognizes that the protection of children is the primary goal both of cash assistance programs and of child welfare and child protective services. Cash assistance programs assist families to care for children in their own homes. Child protection services help those children who are abused or neglected or at risk of abuse by their parents and who need special in-home services or out of home placements to assure their safety. Strengthening families, and where appropriate, preventing removal of children from their homes also are key goals of child protection services. There are problems in a number of areas.

Denial of Benefits to Children on AFDC

The legislative proposals that would reform cash assistance have a number of provisions that would put vulnerable children at greater risk.

- As noted above, the legislation would deny cash assistance to children of unmarried minor mothers for their entire childhood, to children born while the parent was on welfare, and to children whose parent had received welfare for more than five years, whether or not a job was available or the parent was unable to work. The funding caps could have the effect of denying cash assistance to children when states used up their allocated funds, for whatever reasons. Children in low income working families, who may be forced onto cash assistance in times of economic downturn, could be most affected.

Child Protection Services

Some of these children could well come into a system of child protection services that is already seriously overburdened and that is failing to provide the most essential services. Reported child maltreatment and out-of-home placements have both been increasing sharply. Many state systems are in such distress that they have been placed under judicial oversight. The proposed legislation responds to these increasingly serious problems by consolidating existing programs that protect children into a block grant with nominal federal oversight. The Administration has serious concerns about this approach.

- The proposed legislation caps spending for child protection programs at a level considerably lower than baseline projections. This could lead to uninvestigated maltreatment reports, and to children being left in unsafe homes with minimal services. It could also seriously hamper states' efforts to improve their child abuse prevention and child protection systems.

- The proposed legislation eliminates the adoption assistance programs, and leaves it up to states whether they will significantly sustain the subsidies that enable many special needs children to find permanent homes, and whether they will honor commitments to those adoptive families that now receive subsidies.

- The proposed legislation virtually eliminates federal monitoring and accountability mechanisms. It makes it impossible for the federal government to ensure the protection of children.

- The proposed legislation is silent on the formula for allocating funds to the states. Because of serious imbalances among the states in spending on child protection, it is hard to imagine a formula that would not disadvantage either states that have been heavy spenders, or states that are only beginning to improve their systems.

Substantial improvements need to be made in the child protection system and in the federal role in overseeing that system. The Administration supports a careful and thoughtful review of the programs before actions are taken that might seriously harm millions of vulnerable children.

Denial of Benefits to Disabled Children on SSI

The Administration is deeply troubled by the changes proposed in the program designed to help disabled children--SSI.

- The proposed legislation essentially eliminates SSI benefits for children, with the exception of a small group of children currently receiving benefits. Within 6 months, over one hundred thousand disabled children would lose eligibility for SSI benefits--some would lose medical protection as well. And in the future, no child, no matter how disabled, will be eligible for any cash benefits for SSI, except if cash benefits prevent them from having to be institutionalized. These proposals appear to penalize parents who are determined to care for their child no matter what the economic consequences for the family. SSI recipients are among the neediest and most vulnerable children, in the poorest families.

- Some of the money saved is put into a new block grant for services to disabled children, which would require the creation of a new state bureaucracy to decide on appropriate services. This idea is untested, and no one knows what impact it will have on the most vulnerable of children and the parents who care for them. The 5-year cut off in AFDC for all persons along with the elimination of SSI cash for disabled children may leave these children extremely vulnerable.

The Administration sees the need for careful reform in this area, with its potential for serious harm to extremely vulnerable children. Last year the Congress established a Commission on Childhood Disability to look into these issues in consultation with experts from the National Academy of Sciences. The Commission will provide its report to the Congress later this year. The Administration believes prudence dictates waiting for this short time until this bipartisan commission, following a thorough review of all aspects of this important program, has an opportunity to make recommendations.

Benefits to Legal Immigrants

The Administration strongly believes that illegal aliens should not be eligible for government welfare support. But the blanket prohibition of all benefits to legal immigrants who are not yet citizens is too broad, and would shift substantial burdens to state and local taxpayers. These legal immigrants are required to pay taxes. Many serve in the armed forces, and contribute to their communities. The Administration strongly favors a more focused approach of holding sponsors accountable for those they bring into this country and making the sponsors' commitment of support a legally binding contract.

In summary, the Chairman's mark espouses goals for the reform of welfare--work, parental responsibility, prevention of teen pregnancy and state flexibility--that the Administration and the American people share. But the translation of general goals into specific legislation misses the mark in fundamental ways. The proposed legislation does not represent serious work-based reform. It does nothing to move people from welfare to work, and it does not require everyone who can work go to work. It neither holds state bureaucracies accountable nor cushions state taxpayers against recession. It puts millions of children at risk of serious harm. There are alternative approaches to reform that achieve our mutual goals in far more constructive and accountable ways.

The Administration reiterates its commitment to real welfare reform and its desire to work cooperatively with Congress to achieve it.

The Office of Management and Budget advises that there is no objection to the transmittal of this report to Congress.

A similar letter was sent to Representative Harold E. Ford.

Sincerely,

Donna E. Shalala

cc: Members of the Subcommittee on Human Resources

Helping People with Disabilities Achieve Independence

National Easter Seal Society
Office of Public Affairs

1350 New York Avenue N.W., Suite 915
Washington, D.C. 20005
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February 23, 1995

The Honorable Sam M. Gibbons
Ranking Minority Member
Committee on Ways and Means
United States House of Representatives
Washington, D.C. 20515

Dear Representative Gibbons:

We are writing to express our views on the Personal Responsibility Act, as amended by the Subcommittee on Human Resources. The Governors appreciate the willingness of the subcommittee to grant states new flexibility in designing cash assistance and child welfare programs. We are concerned about a number of the bill's provisions, however, that limit state flexibility or shift federal costs to states.

The Governors believe Congress has at this moment an enormous opportunity to restructure the federal-state relationship. The Governors urge Congress to take advantage of this opportunity both to examine the allocation of responsibilities among the levels of government and to maximize state flexibility in areas of shared responsibility. We believe, however, that children must be protected throughout the restructuring process. In addition, although federal budget cuts are needed, the Governors are concerned about the cumulative impact on the states of federal budgetary decisions. The Governors view any block grant proposal as an opportunity for Congress and the president to provide needed flexibility for states, not as a primary means to reduce the federal budget deficit.

The Governors have not yet reached consensus on whether cash and other entitlement assistance should remain available, as federal entitlements to needy families or whether it should be converted to state entitlement block grants. We do agree, however, that in either case states should have the flexibility to enact welfare reforms without having to request federal waivers.

Federal Standards for Block Grants

If Congress chooses to pursue the block grant approach proposed by the Human Resources Subcommittee, the block grants should include a clear statement of purpose, including mutually agreed-upon goals for the block grant and the measures that will be used to judge the effectiveness of the block grant.

Cash Assistance Block Grant

The Governors believe that a cash assistance block grant for families must recognize the nation's interest in:

- services to children;
- moving recipients from welfare to work; and
- reducing out-of-wedlock births.

Although the Governors recognize the legitimate interest of the federal government in setting broad program goals in cooperation with states and territories, they also believe that states should be free from prescriptive federal standards.

We appreciate the flexibility given to states in the bill to design programs, to carry forward program savings, and to transfer funding between block grants. We must oppose, however, Title I's prohibitions on transitional cash assistance to particular families now eligible for help and ask instead that states be given the authority to make these eligibility decisions themselves. Some states may want to be more restrictive than the bill—by conditioning aid on work, for example, sooner than two years—while other states may decide it is appropriate to be less restrictive.

The federal interest should be limited to ensuring the block grant is used to aid low-income children and families. In the past federal restrictions on eligibility have served to contain federal costs given the open-ended entitlement nature of the Aid to Families with Dependent Children program. Such restrictions have no place, however, in a capped entitlement block grant where the federal government's costs are fixed, regardless of the eligibility and benefit choices made by each state.

Similarly, while Governors agree that there is a national interest in refocusing the welfare system on the transition to work, we will object strongly to any efforts to prescribe narrow federal work standards for the block grant. The Governors believe that all Americans should be productive members of their community. There are various ways to achieve this goal. The preferred means is through private, unsubsidized work in the business or nonprofit sectors. If the federal government imposes rigid work standards on state programs, such standards could prove self-defeating by foreclosing some possibilities, such as volunteering in the community that can be stepping stones to full-time, private sector jobs. A rigid federal work standard would also inevitably raise difficult issues about the cost and feasibility of creating a number of public jobs, and the cost of providing child care for parents required to work a number of hours a week in a particular type of job.

Child Protection Block Grant

Governors view the child protection block grant as overly prescriptive and refocus it on achieving broad goals, such as preserving families, encouraging protecting the health and safety of children. We also oppose the mandate

citizen review panels. We believe that it is inappropriate for the federal government to dictate the mechanism by which Governors consult the citizens of their state on state policies.

Block Grant Funding

We appreciate the subcommittee's willingness to create block grants whose funding level is guaranteed over five years rather than being subject to annual appropriations. It is essential, however, that block grants include appropriate budget adjustments that recognize agreed-upon national priorities, inflation, and demand for services. The cash assistance block grant does not include any such adjustments for structural growth in the target populations. While some growth is built into funding for the child protection block grant, it is not clear whether it will be adequate especially given that states are likely to be required by the courts to honor existing adoption assistance contracts. Governors will continue to protect abused and neglected children by intervening on their behalf and we believe that federal funding must continue to be available for these services.

Governors also ask that any block grants include funding adjustments to provide for significant changes in the cyclical economy and for major natural disasters. An additional amount should be set aside each year for automatic and timely distribution to states that experience a major disaster, higher-than-average unemployment, or other indicators of distress. While the bill does include a federal rainy day loan fund, we are concerned that this loan fund will prove to be an inadequate means of addressing sudden changes in the need for assistance. States experiencing fiscal problems will not be able to risk taking out federal loans that they may not be able to repay. Furthermore, one billion dollars over five years may not be sufficient if many states experience economic downturns or natural disasters at the same time, as was the case with the last recession or with the midwestern floods. Finally, an unemployment rate in excess of 6.5% may not be a sufficient proxy for identifying increases in need and should not be the sole trigger for increased aid.

We also urge the committee to change the funding base year and formula for the two block grants. We believe that initial allotments to states for the cash assistance and child protection block grants should be the higher of a state's actual funding under the consolidated programs in fiscal 1994 or a state's average funding during fiscal years 1992 through 1994. This change would help protect states with recent caseload growth from receiving initial allotments far below actual need.

Accountability in Block Grant Programs

We believe that block grants should include a clear statement of purpose, including mutually agreed-upon goals for the block grant and the measures that will be used to judge the effectiveness of the block grant. We are concerned, however, that the reporting requirements in both the cash assistance and child protection block grant go far beyond what is necessary to monitor whether program goals are being achieved. We encourage the committee to restrict reporting requirements to outcome and performance data strictly related to the goals of the program, and hope that those reporting requirements can be mutually agreed upon by Congress, the administration, and ourselves.

We agree that states should be required to use the block grant funding to provide services for children and their families. We do have questions, though, about how broadly the bill's audit provisions would be applied. Would the audit process be used, for example, to determine whether the block grant goal of assisting needy children and families was being achieved? We would also suggest that rather than the federal government reclaiming audit exception funds, that these funds remain available to a state for allowable services to families and children.

Implementation

Governors also ask Congress to recognize that moving to a block grant structure raises many implementation issues. Almost every state is operating at least one welfare waiver project. We believe that states with waivers currently in effect should have express permission either to continue their waiver-based reforms, or to withdraw from the waivers, and be held harmless for any costs measured by waivers' cost neutrality provisions. Savings from individual state's waivers should be included in the state's base. Some states have negotiated a settlement to retain access, subject to state match, to an agreed upon dollar amount of waiver savings. Legislative language converting AFDC to a block grant should not terminate these agreements and thereby preclude states from drawing down the balance of these previously negotiated amounts.

Implementation of block grants would also pose enormous difficulties for state information systems, and we are concerned that there may not be sufficient funding or lead time to allow states to update these systems as necessary to implement the legislation. While states that are ready should be able to implement any new block grants as soon as possible, other states should be allowed at least one year after enactment to implement the new programs. We also believe that a consultative process between Governors, Congress and the administration would be necessary to ensure that the transition to a block grant system is made in an orderly way and that children's needs continue to be met during the transition.

Federal Aid to Legal Noncitizens and Federal Disability Benefits

The Governors oppose the bill's elimination of most federal services to legal noncitizens. The elimination of federal benefits does not change any state's legal responsibilities to make services available to all legal immigrants. Policy adopted by the Governors clearly states that since the federal government has exclusive jurisdiction over our nation's immigration policy, all costs resulting from immigration policy should be paid by the federal government. This bill would move the federal government in the opposite direction, and would shift substantial costs to states.

The Governors also oppose the bill's changes to the Supplemental Security Income (SSI) program. We recognize that the program is growing at an unacceptable rate, and that serious problems exist regarding the definition and diagnosis of disabilities. The changes in the bill go far beyond addressing those problems and represent a substantial and unacceptable cost shift to states. The Governors believe that Congress should wait for the report of the Commission on Childhood Disability before acting to change eligibility for disability benefits to children. We

also ask that Congress allow last year's amendments regarding the substance abuse population to be implemented before enacting new changes in that area. If changes in SSI are enacted that deny benefits to hundreds of thousands of families and children, the result may be a sharp increase in the need for aid from the new cash assistance block grant at a time when those funds would be capped.

Thank you for your consideration of our views on the first four titles of Chairman Shaw's bill. We are also reviewing the child support provisions and will be forwarding our comments on them to you separately.

Sincerely,

Governor Howard Dean, M.D.
Chair

Governor Tommy G. Thompson
Vice Chair

Governor Tom Carper
Co-Lead Governor on Welfare

Governor John Engler
Co-Lead Governor on Welfare

Governor Mel Carnahan
Chair
Human Resources Committee

Governor Arne H. Carlson
Vice Chair
Human Resources Committee

Philadelphia Inquirer

EDITORIALS

Dissing the disabled

A plan to cut federal aid to disabled kids is based on false ideas of systematic abuse.

Pretending to attack waste and fraud, a congressional panel has just voted to slash aid for children with mental or physical disabilities.

If the whole Congress agrees to cut this program instead of fine-tuning it, hundreds of thousands of kids will lose help they need.

The political pressure pushing this mean-spirited escapade has been whipped up by shoddy, tabloid-style coverage of scattered abuses.

The feds now give a low-income family up to $458 a month to help care for a disabled child — and that child automatically qualifies for Medicaid. This year, nearly 900,000 children will benefit at a cost of $5 billion. The money must be spent to help the child, but there's flexibility — it could pay for special transportation, equipment or a home computer.

The critics make it sound as if anybody with parental coaching can snare this easy money. What's more, reviving that old lament about "welfare queens," some critics claim families could use the dough to buy a Mercedes.

Neither gripe holds much water.

■

True, eligibility was broadened by a 1990 Supreme Court decision. The court concluded that this aid had been wrongfully denied to children with physical and/or mental problems that didn't quite fit the government's standards for a disabling affliction.

The ruling forced the government to assess more carefully a child's ability to function. The upshot: Financial help started to flow to children with all sorts of problems — cerebral palsy, cystic fibrosis, mental retardation, autism and attention deficits — whose severity hadn't met the standard. This change has been praised by a range of child-advocacy and public-health organizations.

The notion that a lot of these checks are going to standard-issue troublemakers and outright fakers — as hyped on ABC's *Prime Time Live* and in several newspapers — comes from a few anecdotes, not solid evidence of widespread fraud.

The General Accounting Office, a reliable outfit with no record of winking at wasted tax dollars, issued a report debunking claims of systemic fraud. If it were really so easy to qualify, why have more than 800,000 children been turned down for this assistance since 1990?

■

The second criticism — that families have too much leeway for using this money, leading to some abuses — is at least plausible.

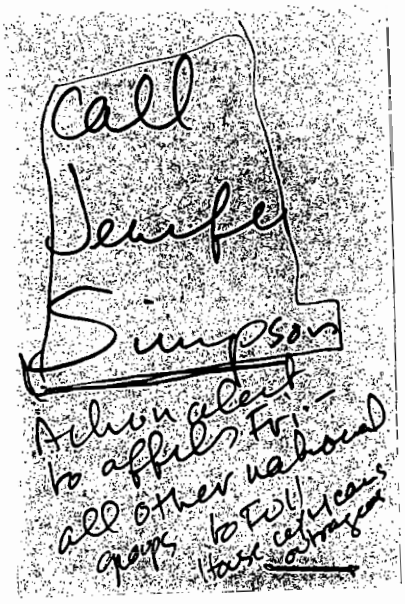
As usual, when it comes to programs for the poor, though, the Republican fix for a blemish will be done not with a scalpel but a meat ax.

Under the bill pending in the House, cash assistance would be terminated in most cases; instead, disabled children would be eligible for a limited list of free services. But it makes more sense to retain a lot of flexibility. In a two-parent family, for example, the money may enable one parent to stay home and care for a disabled child directly.

The House bill's "solution" to the hype about undeserving kids getting aid is to reverse the Supreme Court decision and stop the individualized assessments — thus cutting off aid for at least 200,000 needy children.

If the Senate won't stop this foolishness, President Clinton ought to give it the veto it deserves.

UNITED
CEREBRAL
PALSY
ASSOCIATIONS
Advancing the independence of people with disabilities



MEMORANDUM

To: Debbie Fine - The White House

From: Nancy Flinn, Director of Public Relations, UCPA

Date: February 17, 1995

Re: Childrens' SSI Advocacy – 10 pg

Following are is a press release that was sent out to assist national media covering this respective issues:

Advocates for Children with Disabilities Outraged

The release went out with the UCPA Fact Sheet on Childrens' SSI and state breakdown of recipients.

Jennifer Simpson was on *NPR*'s "**All Things Considered**" and interviewed by Robert Pear of *The New York Times* on Wednesday. All major media, including Associated Press, Knight Ridder, Reuters, *The New York Times*, *Washington Post* and others covering the House mark-up received this release as well as the UCPA fact sheet on Children's SSI benefits.

AS well, this week, the release went out in the packet that all 155 affiliate directors, boards and volunteers receive.

My message to them was the following:

"We encourage you to get these releases into the hands of your local media reporters and editors. Often it raises awareness of the issues you are dealing with as well as provides a resource of information for them to either act on now in creating a story or holding for future use. Media need this information, these releases to help them do a better job at understanding and reporting on issues affecting people with disabilities and you at UCPA as an advocate and service provider."

The Governmental Activities office under the helm of Michael Morris has great expertise that you should tap. Jennifer Simpson is a mom of a young boy, Josh, with cerebral palsy and an expert on this issue. I will talk with you next week on the best way to get you updated on their action plans.

UCPA
UNITED
CEREBRAL
PALSY
ASSOCIATIONS
Advancing the independence of people with disabilities

For Immediate Release:

Contact: Nancy Flinn
(202) 296-9128
(202) 973-7126

ADVOCATES FOR CHILDREN WITH DISABILITIES OUTRAGED
Congress Urged to Leave Kids SSI Benefits Alone

(Wednesday, February 15, 1995) United Cerebral Palsy Associations' leaders are outraged that members of the House Ways and Means Subcommittee on Human Relations have not heard and considered favorably the testimony of real need for the only 'family support' program that is federally available to lower income families - Childrens' SSI Benefits. For many, this cash assistance means the insurance that children with disabilities can live at home with their families and not (at far greater taxpayer cost) in institutions.

Today's mark up of Childrens' SSI Benefits proposal is considered an outrage by parents and advocates who have fought to educate the subcommittee on the real needs met by current SSI cash benefits. The House Ways and Means Subcommittee on Human Resources, chaired by Rep. E. Clay Shaw (FL), is looking at Section 402 of the Welfare Reform proposal and considering changes that will negatively impact low income familites with children with disabilities.

"Threatening the ability of low income families to raise their children at home by eliminating this support makes no sense when considering national emphasis on the value of and need for family unity and the alternative costs of institutionalization," said John D. Kemp, Executive Director of United Cerebral Palsy Associations (UCPA).

The proposal under consideration will do away with the Individual Functional Assessment - IFA and will drop thousands of children with disabilities (an estimated 125,000 to 250,000) and their families. This bill will essentially kick off a quarter of children with disabilities currently on SSI.

Dollars will instead be funneled to the states to be used in block grants for their discretion in serving kids with disabilities. All children would be eligible by qualifying under a medical listing which designates specific categories of disability. A child with cerebral palsy who might have mild speech difficulty, combined with a gait problem, hearing deficiency, and mild cognitive disability wouldn't necessarily qualify under a medical listing because each disability might not be severe enough to qualify. However, the combination of all these disabilities may not qualify the child for SSI benefits under the medical listings only approach.

"What is being proposed is no longer an entitlement for kids but an entitlement for states," said Jennifer Simpson of United Cerebral Palsy Associations' Governmental Activities Department. According to Simpson, mother of a young boy with cerebral palsy and an advocate for children with disabilities, UCPA's national office in Washington receives hundreds of calls from parents in low income families indicating the essential need for SSI Childrens' cash benefits. These parents express fright and alarm at the threat of losing benefits. Families with children with disabilities that are receiving SSI emphasize that the cash benefit's flexibility permits parents to raise their children with serious disabilities at home, saving the enormous expense (to families and taxpayers) of institutional care. The cash benefit covers a range of needs, including replacement of lost or foregone income for parents who must give up work to stay home as caregivers for a child with disabilities.

The maximum monthly benefit is $458, according to the Social Security Administration (SSA) for a maximum of $5,496 per year. Most families receiving benefits are with incomes up to about 150% of poverty ($21,000 p.a.). SSI payments decrease as family income increases. For many children with disabilities, SSI eligibility is the gateway to health care with Medicaid. More boys (524,210) than girls (307,940) tend to be recipients of SSI. 44% of children receiving SSI are eligible because of mental retardation; 22% have psychiatric or neurotic disorders; 17% have diseases of the endocrine, respiratory, circulatory or musculoskeletal system; 15% have diseases or conditions of the nervous system and sense organs. This category often includes children with cerebral palsy and children with vision and hearing disabilities. (Includes 9,300 blind children.)

"The numbers of children living in poverty is greater now than recorded in any year for the last 30 years," said Kemp. "As a result, the need for SSI assistance to children with disabilities is more important now than ever before. Congress, in passage of the historic civil rights ADA, the

Americans with Disabilities Act, promoted a more inclusive and independent America, not one which encourages institutionalization and dependency."

The current proposal for mark up in the House Subcommittee is being met with outrage and extreme disappointment from many in the disability community. More new babies with disabilities are born each year. UCPA statistics show that around 4,000 babies are born with cerebral palsy annually. These new babies may no longer be eligible if they cannot meet medical listings.

UCPA leaders are urging Congress and the public to recognize the real need to support and stabilize Childrens' SSI Benefits. Needs such as those articulated by Karen Higginbotham from Opelousas, Louisiana, who testified before the subcommittee how life with six-year-old Alison, who has cerebral palsy, succeeds at home where special needs can be met, thanks to SSI help. "If Alison were institutionalized, we would be devastated; our son, her brother, would lose his best friend; our state and federal government would pay $60,000 a year for her. What do you think taxpayers want to spend?"

According to UCPA experts, the bigger question is how can all the concerns for welfare reform be addressed without regressing to old pre-ADA policies. "To foster change that would actually go back in time to exclusion, segregation and isolation of children with disabilities would be regressive and not in sync with the world of independence and inclusion we are building, thanks to laws like ADA," said Kemp. "We question the potential for creating new bureaucracies at the expense of children with disabilities if this proposal is enacted. We must assess the difference between the true costs of SSI benefits which are keeping children at home in their families and communities, fostering as much independence and inclusion as possible - and the true costs of the alternatives."

UNITED CEREBRAL PALSY ASSOCIATIONS
Advancing the Independence of people with disabilities

Action Alert

TO: Affiliate Executive Directors and Interested Others

FROM: Jenifer Simpson, Governmental Activities Department

DATE: January 13, 1995

RE: Action Needed to Preserve Cash Benefits in Childrens' SSI Program

On January 27th the House Ways & Means Subcommittee on Human Resources, chaired by Rep. E. Clay Shaw (FL) will hold a hearing about *"reducing or eliminating children's SSI benefits."* Advocates expect the hearing to emphasize the many unsubstantiated stories of abuse in the program and to question the families' need for cash benefits. A complete House bill is likely to be introduced in February that would change the current cash benefit to a voucher program or to eliminate the program completely.

Subcommittee members must receive letters from families and their advocates explaining that children who qualify for SSI cash benefits need this assistance. Letters must emphasize that eliminating the cash benefit or replacing it with a voucher system is detrimental to keeping the child with disabilities at home. The Childrens' SSI program is essentially the only 'family support' program that is federal that is available to lower income families. It must be retained. Letters must be sent to arrive about January 30th.

BACKGROUND: The 104th Congress has begun considering Welfare Reform. Their discussion includes intense scrutiny of the Supplemental Security Income (SSI) cash benefit for eligible children with disabilities in low-income families. A proposal to change SSI for children into a voucher program was introduced, attached to the **Personal Responsibility Act** that is part of the GOP's "Contract With America." The Contract also includes a proposal ***to eliminate the program's entitlement status*** through a limit, or cap, that would reduce the total amount available for the program. Such a cap would force changes in program eligibility rules and could also lower the current $458 maximum benefit level.

ACTION STEPS:

1. Write letters that include the personal story of a family with a child with a disability that receives SSI.
   - Emphasize that the cash benefit's flexibility permits parents to raise their children with serious disabilities at home, saving the enormous expense (to families and taxpayers) of institutional care. If you know the cost of institutional care in your state, mention that.
   - Mention the range of needs that a cash benefit can cover including pointing out that the monthly checks often replace lost or foregone income for parents who must give up work to stay home as caregivers for a child with disabilities.
   - UCPA's Fact Sheet is attached about the Children's SSI program that may

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SUITE 1112
WASHINGTON, DC 20005-1202
800.USA.UCP
VOICE/TT 202.842.1266
FAX 202.842.3519

assist you in your letter writing and which can be attached to your letter.

■ To highlight the impact by state if the Childrens' SSI program were to be eliminated, include a copy of attached pages showing "***Number of children by state/region receiving SSI and the average amount they receive***". Circle the number of children in your state who would lose their cash benefit!

2. Send your letter to your Representative on the Committee (list of committee members below, with address). If your state does not have a committee member send your letter to Rep. E. Clay Shaw (FL), Chairman, and to Rep. Harold E. Ford (TN), the Ranking Member.

■ You may also call the Representative's local district office and ask for the Washington, DC office fax number in order to fax your letter directly to the Representative.

■ Send a copy of your letter to UCPA to assist the national coalition lobbying effort.

3. Send at least one letter to Washington and copy this *Action Alert* to at least one other parent, advocate or relative. Use electronic media or Fax or other means. Encourage multiple letters. Now is NOT the time to sit back and watch a successful federal program get caught in the crossfire. Now is the time to write a letter and be heard!

THANK YOU AGAIN FOR ALL YOU DO TO ENSURE THAT CHILDREN WITH DISABILITIES LIVE WITH THEIR FAMILIES!

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104th Congress HOUSE WAYS & MEANS SUBCOMMITTEE ON HUMAN RESOURCES
(list alphabetical by state)

FLORIDA: . . . . . Rep. E. Clay Shaw, Chairman
MICHIGAN: . . . . . Rep. Dave Camp
. . . . . Rep. Sander Levin
GEORGIA: . . . . . Rep. Mac Collins
WASHINGTON: . . . . . Rep. Jennifer Dunn
PENNSYLVANIA: . . . . . Rep. Phil English
NEVADA: . . . . . Rep. John Ensign
LOUISIANA: . . . . . Rep. Jim McCreary
IOWA: . . . . . Rep. Jim Nussle
TENNESSEE: . . . . . Rep. Harold E. Ford, Ranking Member
CONNECTICUT: . . . . . Rep. Barbara B. Kennelly
NEW YORK: . . . . . Rep. Charles B. Rangel
CALIFORNIA: . . . . . Rep. Pete Stark

Write to: The Honorable Rep. ----
U.S. House of Representatives
Washington, DC 20515

If you are writing to Reps. Shaw or Ford, you can address your letter to the House Ways & Means Subcommittee, Room B317, Rayburn House Office Building, Washington, DC 20515.

If you telephone as well, call (202) 224-3121 in Washington and ask the switchboard operator 'to connect you to Rep.----'s office'. Leave a clear message why you are calling: "*I am calling to protest the proposal to change Children's SSI into a voucher program or to eliminate it.*" Give several reasons why the cash benefit is useful to families with a child with a disability.

Table 3. Number of children receiving Federally administered SSI payments, by Region and State, June 1994[1]

Region and State	Number of children	Average Federally administered payment[2]
Total	832,150	$411.73
Boston	24,960	$423.75
Connecticut	4,340	397.33
Maine	2,240	376.97
Massachusetts	13,230	434.43
New Hampshire	1,420	390.01
Rhode Island	2,430	458.40
Vermont	1,300	455.98
New York	90,030	$423.39
New Jersey	18,750	418.28
New York	71,280	424.74
Philadelphia	76,760	$408.74
Delaware	1,980	378.92
District of Columbia	2,290	397.81
Maryland	10,390	392.04
Pennsylvania	36,270	424.74
Virginia	18,400	391.79
West Virginia	7,430	407.27
Atlanta	199,200	$398.54
Alabama	25,450	402.96
Florida	47,140	400.35
Georgia	24,460	393.24
Kentucky	18,320	404.36
Mississippi	23,480	402.17
North Carolina	24,440	388.34
South Carolina	15,260	391.80
Tennessee	20,650	403.04
Chicago	168,360	$413.28
Illinois	44,640	404.72
Indiana	17,500	395.09
Michigan	34,310	418.97
Minnesota	8,740	394.16
Ohio	43,500	397.17
Wisconsin	19,670	483.08

(continued)

Table 2. Number of children receiving Federally administered SSI payments, by Region and State, June 1994[1] (Cont.)

Region and State	Number of children	Average Federally administered payment[2]
Dallas	123,680	$399.36
Arkansas	18,400	397.37
Louisiana	38,370	404.36
New Mexico	5,880	394.74
Oklahoma	10,350	402.09
Texas	50,680	396.28
Kansas City	35,970	$395.31
Iowa	6,670	379.46
Kansas	6,890	386.54
Missouri	18,590	407.12
Nebraska	3,820	381.36
Denver	18,420	$386.38
Colorado	8,080	391.17
Montana	1,820	392.13
North Dakota	1,110	377.48
South Dakota	2,520	378.29
Utah	3,900	380.77
Wyoming	990	389.35
San Francisco	74,720	$466.11
Arizona	9,520	403.65
California	62,050	479.67
Hawaii	870	370.39
Nevada	2,180	394.66
Northern Marianas	100	387.70
Seattle	20,040	$400.24
Alaska	740	397.68
Idaho	3,280	386.67
Oregon	6,290	384.28
Washington	9,730	415.33

[1] Based on a 10-percent sample file. Recipients with payments due July 1, 1994.

[2] Includes Federally administered State supplementation payments.

United Cerebral Palsy Associations (UCPA) -- FACT SHEET ON CHILDREN'S SSI

How Many Children With Disabilities Receive SSI?

832,150 children with disabilities receive an SSI check (SSA, July 1994).

Overall, this cost $4.6 billion or less than 1 percent of the total federal budget.

Note that 800,000 children nationally have been ***denied*** SSI benefits since 1991. The current average denial rate is about 65%, varying by state.

Children make up but 13.7 percent of the over 6 million total SSI recipients.

Who Are These Children?

Boys are more likely to be recipients, by about three times to two (524,210 boys; 307,940 girls).

7% are 3 years old or less (59,170 babies)
14% are age 3 to 5 (114,480 toddlers)
43% are aged 6 to 12 (359,560 children)
30% are ages 13 to 17 (248,770 teenagers)
6% are between 18 and 21 (or 50,170 young adults)

About 47% are identified as "Black, Hispanic or Other"

99% are U.S. citizens

Almost 80% live with their parent (s)

15% live "in their own household" for payment determination (includes hospitals, nursing homes, residential schools, foster care, or independently).

About 3% live in another (non-parental) household.

Less than 2% were in Medicaid medical facilities (institutions).

Where Are These Children Living?

States with the largest numbers of children receiving SSI were:

New York, California, Texas, Florida, Illinois, Ohio, Louisiana, Pennsylvania and Michigan. Together they accounted for 51 percent of all childhood SSI check recipients (age 21 or under).

For impact by state if program eliminated, see attached pages showing "*Number of children by state/region receiving SSI and the average amount they receive*".

What Kinds of Disabilities Do Children Receiving SSI Have?

- 44% of children receiving benefits were disability eligible because of mental retardation.
- 22% had psychiatric or neurotic disorders.
- 17% have diseases of the endocrine, respiratory, circulatory or musculoskeletal system.
- 15% had diseases or conditions of the nervous system and sense organs (this category often includes children with cerebral palsy and children with vision and hearing disabilities). Includes 9,300 blind children.

How Much Do the Children Get?

Most children on SSI fall at the low end of income eligibility:

68 percent received the maximum monthly benefit of $458, according to SSA, in June 1994. Note that $458 more to the family's budget does not lift them out of poverty (additional $5,496 per year).

Typically, children with disabilities receiving SSI are in families with incomes up to about 150% of poverty (about $21,000 p.a.). As income increases, SSI payments decrease and families become ineligible for benefits at

about 200 percent of poverty level (about $31,000).

For example, a two parent family with two children, one of whom has a disability, receives the full $458 benefit if yearly income is less than $20,220.

Benefit levels are higher in the 36 states that supplement federal payments. The Social Security Administration (SSA) reports that the average SSI monthly payment is $412 when state supplements are included.

Why is SSI Disability Eligibility So Important to Children With Disabilities?

In 31 states and the District of Columbia, SSI enrollment **is the gateway to health care with Medicaid** enrollment automatic. In 7 states SSI children are eligible for Medicaid but must apply separately.

What Do Families Spend the Cash on?

While the basic purpose of the money is 'food, clothing & shelter', it may be used to pay for the child's extraordinary daily expenses or disability-related costs which may include the following, among thousands of possible uses depending on the disability:

--utility bills (electric bills for 24 hr/day respirators, rental costs of back-up generators to prevent power lapses, battery charges for wheelchairs or communication devices;
--telephone calls to medical providers, pharmacists, social service providers & schools;
--respite care or specially trained child care providers who understand the disability;
--public or private transportation costs to obtain routine or specialized medical treatment;
--adapted clothing (e.g., replace buttons with velcro fasteners, specially fitted shoes to accommodate braces, zipper aids);
--home repairs & modifications to accommodate wheelchairs;
--over-the-counter items such as special creams for skin conditions, diapers for older children, wigs, special formulas/items for managed diets;
--marriage maintenance or family or individual stress counseling to maintain family integrity;
--assistive technology, adapted toys, personal care assistance, service and repairs (e.g., for wheelchairs, prosthetics, hearing aids, glasses);

What Accounts for the Rapid Growth in the Program and Is it Likely to Continue?

Child enrollment in SSI more than doubled, rising from about 296,000 in 1989 to more than 770,000 in 1993, to about 847,000 children currently (or less than one million children of the nation's 00 million children).

Six reasons account for the rapid expansion of the program:

1. The number of children overall living in poverty increased by 2.5 million between 1989 and 1993;
2. An overall increase in the number of children with disabilities (since 1960 the proportion has more than tripled);
3. A 1992 regulatory change in how SSA deemed (counted) parental income which had the impact of raising income eligibility levels for working families.
4. A review of denials made by SSA from 1980 onward that was ordered by the U.S. Supreme court in the Zebley decision. The Court ruled that when a child had a condition that did not meet SSA's listings standard, determining whether the impairment was of 'comparable severity' to one which would disable an adult would require a functional assessment. Approximately 460,000 children had been denied since 1980, with some 339,000 responding to SSA's search for them for review. About 131,000 were found eligible.
5. The Court also ordered an Individual Functional Assessment (IFA) as part of the determination of 'comparable severity' for children. The IFA is used to determine the child's ability to engage in age-appropriate activities.
6. Outreach campaigns by SSA and several private foundations helped publicize the program which many income eligible families simply did not know about before.

How Much Abuse and Fraud Is Documented in the Program?
Relatively unpublicized (and unread) government reports refute much of the recent media reports.

Allegations about 'Parents Coaching their Children to Act Crazy to Get Money'--
An SSA review of 617 cases of school-related behavior disorder allowances and denials found "no evidence of widespread coaching or malingering...". Of the 13 possible coached cases, ten were denied and the other three allowed were allowed based upon independent, non-coaching bases (medical) for the award.

Myth that 'Anyone can Get SSI If They Know How To Game The System'--
A Government Accounting Office (GAO) report found that 70 percent of the increase after the Zebley 1990 decision was not due to the liberalized Zebley Individual Functional Assessment Rules -- which critics claim as the stage in the process where 'gaming' occurs -- but due to children qualifying for SSI because they met SSA's new Listings of Impairments. This included the December 1990 revisions to the Childhood Mental Disorder Listings which increased the number of mental impairment listings from 4 to 11, including for the first time separate listings for conditions such as pervasive developmental disorders (e.g., autism) and Attention Deficit Hyperactive Disorder (ADHD). It should be noted that Congress had **ordered** the Listings revision six years earlier, in 1984, in the Social Security Disability Reform Act.

This GAO report also confirmed advocates' concerns about the tilting of the individualized functional assessment test in favor of children with mental impairments at the expense of those with physical impairments: *"More than half of the children with mental impairments on whom functional assessments were done (53%) received awards compared with less than one sixth (14%) of children with physical impairments."*

SSA believes that the program has almost reached saturation point as it is currently serving between 60-80% of the estimated 1.1 million to 1.4 million children who are eligible.

When Did the Program Start and Why?
SSI started as part of President Richard Nixon's sweeping welfare reform proposal in 1969, the Family Assistance Plan (FAP) that would have replaced the Aid to Families With Dependent Children (AFDC) program with a federal uniform minimum income for families with poor children.

FAP was defeated but the House Ways & Means reintroduced FAP and an SSI proposal with a new plan for the federal government to set a minimum benefit level and to combine three programs that were then a state-federal partnership, that is, the Old-Age Assistance, Aid to the Blind, and Aid to the Permanently and Totally Disabled programs. FAP was again defeated but the SSI part remained mostly because it guaranteed an income for those not expected to work, i.e., the poor aged, those who are blind and those with disabilities.

Poor disabled children were included because *"... they are deserving of special assistance in order to help them become self-supporting members of our society."* Also, *"... because their needs are often greater than those of nondisabled children."* [House Report 92-231].

Sources: Issue Brief No. 661, Jane Koppelman, George Washington University, National Health Policy Forum, January 23, 1995; "Findings From the Study of Title XVI Childhood Disability Claims, Social Security Administration, Office of Disability, May 1994; "Rapid Rise in Children on SSI Disability Rolls Follows New Regulations," U.S. General Accounting Office, (September 1994); "Zebley Update #9," Community Legal Services, Philadelphia, PA December 20, 1994.

United Cerebral Palsy Associations, Inc., 1522 K Street, NW Washington, DC 20005. Tel: Tels: (800) USA-5UCP or (202) 842-1266. January 1995

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FACSIMILE TRANSMITTAL COVER SHEET

Date: 3/2/94

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Description of Document: FYI/MOST RECENT ACTION ALERT TO FIELD ON KID'S SSI SLASHING

Reply To: J. SIMPSON

Department:

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ACTION ALERT

TO: Affiliate Executive Directors and Interested Others

FROM: Jenifer Simpson, Governmental Activities Department

DATE: February 24, 1995

RE: **Urgent Action Still Needed in U.S. House of Representatives to Preserve Cash Benefits in Children's SSI Program**

On Wednesday, February 15 the House Ways & Means Subcommittee on Human Resources, chaired by Representative E. Clay Shaw (FL), completed its work on the Republican welfare reform proposal, the Personal Responsibility Act (PRA) which is one measure in "Contract With America". They marked up this welfare reform bill on a straight party line vote of 8 Republicans to 5 Democrats amid some rancorous debate and comments by subcommittee members.

Within the PRA, Section 402 approves major and devastating changes to the Children's **Supplemental Security Income (SSI)** program that will impact children with disabilities in low income families across America. The subcommittee's bill establishes a block grant to the states of funds previously sent to families as checks. There would be **no individual entitlement** for eligible children to a check or to the corresponding Medicaid services. Additionally, the legislation would severely **restrict or constrain eligibility for cash benefits.**

The full House Ways & Means Committee is expected to begin its markup of the proposal during the week of February 27 or March 6. House floor action and a vote are expected in late March. Immediate grass roots action is needed with **all** Members of the House of Representatives before the bill is acted upon by the full Ways & Means Committee. UCPA affiliates, disability, low-income and children's advocates, and all interested individuals are urged to ensure that thousands of phone calls are made and letters sent immediately to every Member of the House. Letters and phone calls should continue until mark up of the welfare reform proposal is completed. Details about your message to Congress are below.

SUBCOMMITTEE'S RECENT ACTION DEVASTATES THE CHILDREN'S SSI PROGRAM: The Subcommittee action in Section 402 of the PRA ravages the existing cash entitlement to children with severe disabilities in poor families as follows:

- Section 402 severely restricts eligibility for cash benefits in three ways:

(1) Elimination of the individualized functional assessment (IFA) process for children who do not meet the current medical "listings". The 'Medical Listings of Impairments' are specific disability determination criteria developed by the Social Security Administration based upon (medical) diagnoses which have not been substantially revised since 1979 and do not reflect current and new information about certain disabilities, such as various brain injuries and disorders. Stripping out the IFA process overturns the ruling in the 1990 *Sullivan v. Zebley* U.S. Supreme Court decision and returns the system to its previous emphasis on medical diagnosis over functional impact of disability. This is a step backward in disability policy!

(2) Children currently on the SSI rolls, who qualified on the basis of the medical listings, will continue to receive cash benefits through a "grandfather clause." However, children who are *currently on the SSI rolls who qualified for disability on the basis of the IFA process*, they will lose their cash benefits six months after enactment of the legislation! Since the Zebley decision, about 30 percent of children who are approved for SSI benefits have been found eligible on the basis of the IFA. About 200,000 children will lose their current SSI cash benefits if this measure is enacted!

Advocates believe that a significant number of children with "mild" cerebral palsy combined with other disabilities, children with cystic fibrosis or with behavior or mental disorders, or children who are cancer survivors, as well as significant numbers of babies and toddlers whose disabilities are hard to rate under a Medical Listings approach, may be receiving SSI based on this IFA process. Their parents would no longer receive the benefit and would be asked by SSA to re-apply to see if they qualify for SSI under the (old) medical listings approach. As many realize, making a new application to an understaffed SSA is not easy: this is a significant burden to place on parents of children with severe disabilities.

(3) For new applicants (children who are found eligible on the basis of the medical listings), **cash benefits are completely eliminated** unless the child would otherwise be institutionalized in the absence of the full-time attention of a parent or home health care provider. These newly-eligible children will qualify for services through a block grant made to the states, with the package of services to be determined by the state.

- **Section 402 establishes a block grant to the states of funds previously sent to families as checks. There would be no individual entitlement to funds or the corresponding Medicaid services.**

The block grant received by the state from the Social Security Administration could be spent only on authorized medical and non-medical services. States would decide who to serve and which services to provide from a prescribed list (to be developed by the Commissioner of Social Security).

The states would receive funds based on a formula which essentially allocates an amount equal to only 75 percent of the average SSI benefit for each child who does not receive cash in that state. The funds are intended to cover additional services to children who are eligible for cash

benefits ('grandfathered' or those who 'otherwise would be institutionalized') and those who are disabled by a condition in the medical listings but who are not receiving cash (that is, new applicants found eligible). Children would continue to be eligible for Medicaid in those states which automatically cover SSI-eligible children.

The block grant would create caps at the state level which would force changes in eligibility as states would be forced to choose between raising taxes to meet the additional needs entirely with state funds, cutting benefits across-the board, or denying aid to newly poor families or children found newly disabled.

The legislation does not state which state agency would be involved or how much bureaucracy would be involved for parents in accessing whatever services the state determines. U.S. Health & Human Services Secretary Donna Shalala, in a February 13, 1995 letter to Representative Clay Shaw, Chairman of the House Ways & Means Subcommittee on Human Resources, in reference to putting the SSA funds for Children's SSI into a new block grant for services to children with disabilities, stated "*[this] would require the creation of a new state bureaucracy ... This idea is untested, and no one knows what impact it will have on the most vulnerable of children and parents who care for them.*"

ACTION STEPS:

1. The message to all Members of the House of Representatives is that you are

   "***opposed to the proposal to eliminate the SSI cash benefits for children with disabilities found in Section 402 of the Personal Responsibility Act and to turn it into a block grant to the states***",

   and you are

   "***opposed to the proposal to eliminate the individualized functional assessment (IFA) found in the same measure***".

   Give examples of the importance of the SSI cash benefit to low income families who are trying to raise a child with a significant disability. Mention the range of needs that a cash benefit can include that the monthly SSI check often replaces lost or foregone income for parents who must work part-time or stay underemployed in order to manage their child's care. (A list is attached of what families have told us in the national office they use the money for.)

2. For Members of Congress who are on the House Ways & Means Committee (list attached) discuss the following:

   - While there is some evidence of abuse in the system, all government studies indicate that **there is NOT widespread abuse and fraud**. The vast majority of child beneficiaries are benefitting as intended. Note that the current denial rate is 65 percent by the SSA! Note

that more than 800,000 children who have applied for SSI since 1991 have been denied! The system is working!

- Replacing the cash benefit with services will not address families' basic needs for paying for things such as food, clothing and housing. Point out that low-income families have very restricted resources and that services cannot match the flexibility of the cash benefit in allowing parents to adapt their purchases to their own child's unique and changing needs within the family's circumstances.
- For the problems which do exist in the system, targeted reforms should be adopted rather than wholesale restructuring (or "throwing the baby out with the bathwater"). UCPA and other national disability groups have made several concrete proposals for reforms which would tighten implementation and enforcement.
- Remind the Committee that Congress established a Commission to Evaluate Childhood Disability which is expected to make a report in August or sooner on reforms for Children's SSI. The Congress should allow the Commission to complete its work before considering major restructuring.

Your Action is required now! Write a letter to your Congressional Representative today and make a phone call. Copy this notice and forward it to others! Follow up to be sure calls and letters jam the switchboards and mailboxes in the U.S. House of Representatives.

Let me know in the national office what the Representatives and their staffers are saying back to you.

THANK YOU AGAIN FOR ALL YOU DO FOR CHILDREN WITH DISABILITIES!

To contact your Congressional Representative and/or their staff in Washington, call the U.S. Capitol Switchboard at 202-224-3121. They will connect you to any committee or member office. When writing to Congressional Representatives, address mail to "Representative _____", Washington, D.C. 20515.

HOUSE WAYS AND MEANS COMMITTEE
104th Congress

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WHAT DO FAMILIES SPEND THE CASH ON?

While the basic purpose for use of the SSI Cash benefit is 'food, clothing and shelter', it may be used to pay for the child's extraordinary daily expenses or disability-related costs. These costs are significant to families of children with severe disabilities and may include the following, among thousands of possible uses depending on the disability and the family's individual circumstances or what is not available or cannot be paid for by other service providers:

- utility bills (higher-than-average electric bills for 24 hour/day respirators, battery charges for wheelchairs or communication devices, rental costs of back-up generators to prevent power lapses);
- telephone calls to medical providers, pharmacists, social service providers and schools, including long-distance calls to medical specialists;
- fixing a leaky roof or broken plumbing, buying a washing machine or dryer, replacing broken windows or furniture;
- specially trained child care providers who understand the disability, as neighborhood teen caregivers may lack understanding or training about the particular disability or be unwilling to learn specialized techniques for managing the disability;
- public or private transportation costs to obtain routine or specialized medical treatment;
- adapted clothing (e.g., replace buttons with velcro fasteners, specially fitted shoes to accommodate braces, clothing aids such as zipper reachers or button hookers);

- home repairs for broken or rapidly-worn out items (e.g. children with behavior disorders may routinely break windows, door handles or cause other household damage, children who use wheelchairs bang into screen doors and walls causing excessive wear and tear needing immediate repair);
- greater than average other utility bills (such as water for greater amounts of laundry for children who routinely soil their clothing as a result of disability, or heating oil to maintain necessary higher temperatures in the case of children with chronic conditions);
- modifications to accommodate wheelchairs or other disability (such as door-widening, adding door levers, lowering railings, ramping or other architectural "do-it-yourself" adaptations);
- over-the-counter items such as special creams for skin conditions, diapers or diaper service for older children, wigs, special formulas/items for managed diets, or special food utensils (alternate spoons, knives, forks or cups with adapted handles);
- marriage maintenance sessions or interventions, or family or individual stress counseling to maintain family integrity (this may include counseling or other interventions for siblings who may suffer emotional neglect as a result of the necessary demands and needs of the child with a disability);
- other assistive technology such as adapted toys or household or vehicle controls, and maintenance of them;
- personal care assistance for the child needing help toileting, eating, drinking, washing, dressing, etc., especially when the parent is temporarily incapacitated themself or the parent can no longer physically assist a heavier or taller child;
- respite providers so that the parent(s), or the rest of the family "gets a break". Note that many families with a child with severe disabilities do not "go on vacations" as the logistical effort may be overwhelming;
- service and repairs (e.g., for wheelchairs, batteries, prosthetics, hearing aids, glasses, respirators, special chairs or other seating and positioning devices).

UCPA believes that although each one of these costs may, of itself, be small, ***the incremental costs over time of disability-related expenses causes a significant depletion of resources across household budget categories.***

WHO ARE THESE CHILDREN ON SSI?

- Boys are more likely to be recipients, by about a 3 to 2 ratio (524,210 boys; 307,940 girls)
- 7% are 3 years old or less (59,170 babies)
- 14% are age 3 to 5 (114,480 toddlers)
- 43% are aged 6 to 12 (359,560 children)
- 30% are ages 13 to 17 (248,770 teenagers)
- 6% are between 18 and 21 (50,170 young adults)
- About 47% are identified as "Black, Hispanic or Other"
- 99% are U.S. citizens
- Almost 80% live with their parent(s)
- 15% live "in their own household" for payment determination (includes hospitals, nursing homes, residential schools, foster care, or independently)
- About 3% live in another (non-parental) household
- Less than 2% were in Medicaid medical facilities (institutions)

FACSIMILE TRANSMISSION COVER SHEET

Administration for Children and Families
Office of Public Affairs
370 L'Enfant Promenade, S.W.
Washington, D.C. 20447

Fax (202) 205- 9688

Date 3/3/95

To : Debbie Fine
Phone 456-2930
Fax 456-2983

From: Patricia Sym
Phone: 401-9261
Cover + _____ **pages**

Message:

Title IV – Supplemental Security Income (SSI)
Disabled Children

Amendment # 4A (Levin)

Eliminate abuses in programs while protecting disabled children.

Specifically, the Levin proposal would significantly restrict childhood disability benefits subject to abuse by:

- **eliminating "maladaptive behavior" as a means of receiving benefits;**

And by directing the Social Security Administration to:

- **significantly tighten the severity threshold in the Individual Functional Assessment (IA) criteria; and**
- **increase the use of standardized tests.**

Eliminating "maladaptive behavior" from the so-called "domains" on which benefits may be based would eliminate the possibility of children receiving benefits because parents have coached them to misbehave. Raising the severity threshold in the Individual Functional Assessment would assure that only severely disabled children would receive benefits, and increasing the use of standardized tests, in combination with the other changes, would help to take teachers and principals out of the business of assessing children.

The Levin proposal is more effective than the Subcommittee bill. Rather than denying benefits to severely disabled children, the Levin proposal eliminates the behavior categories which are subject to abuse in both the listings and the IFA. Thus, the Levin proposal tightens the criteria in the areas where the most growth has occurred -- behavior disorders. According to the General Accounting Office more growth has occurred in these areas of the listings than in the IFA.

The Levin proposal assures that all children with significant disabilities can be evaluated for SSI eligibility based on a strict test of the overall disabling consequences of their impairments. It does not deny a child the chance to demonstrate that a combination of impairments has caused him to be disabled. **The Levin proposal targets and eliminates abuses while protecting vulnerable disabled children.**

Defeated party line vote.

Title IV – Supplemental Security Income (SSI)
Disabled Children

Amendment #6 (Stark)

Require States to provide access to block grant services to all children who meet or equal the listings. No child who meets or equals the listings would be denied the opportunity to apply for services and to have his or her case assessed to determine the child's service needs.

Under the Subcommittee bill, a State has the discretion to decide who among children who meet the listings will receive services. Under this broad authority, States could deny services to any child, regardless of the severity of his or her disability.

SUPPORTS

MC CREERY

PASSED

Title IV – Supplemental Security Income (SSI)
Disabled Children

Amendment # 3 (Levin)

Grandfather cash benefits for children losing SSI due to the repeal of IFA eligibility if those children would meet or equal the listings.

Many of the children who would lose SSI benefits as a result of the elimination of IFAs as a basis for eligibility would have been able to qualify for benefits under the listings, but SSA chose to qualify them under the simpler IFA test. That is because, when a child applies, SSA only asks for, or helps to develop, as much evidence as is needed to qualify the child under the IFA. If SSA had continued to develop the case, the child could have qualified under the listings.

It is inequitable to throw these children off the program while grandfathering those who are currently qualified under the listings. Therefore, the amendment would grandfather cash benefits for children losing SSI benefits due to the repeal of the IFA if those children would meet or equal the listings.

Ensign voted "present" otherwise, party-line vote

Passed

KLECZKA EN BLOC AMENDMENTS TO TITLE IV

Section	Title	Description
2	Studying Mental Listings	Instructs Child Disability Commission to review mental listings for appropriateness.
3 #1	Uninterrupted Grandfather--Eliminating Work Disincentive	Eliminates a potential work disincentive by clarifying that the children temporarily losing financial eligibility retain grandfathered access to cash benefits.
3 #2	Levelling Playing Field for Cash Payments to Institutionalized Children	Provides that children in medical institutions with private insurance will receive the same cash benefit amounts as children with Medicaid coverage.
4	Low Birth Weight Baby Reviews	Requires reviews of continuing disability for low birth weight babies after one year.
8(I)	Assuring Medicaid Eligibility for All SSI Recipients	Clarifies that all children eligible for SSI, whether or not they are receiving block grant services at a given time, are Medicaid eligible.
New Section	Divestiture of Assets	Delays eligibility if applicants have disposed of assets for less than fair market value in order to qualify for child SSI benefits.

KLECZKA AMENDMENT TO TITLE IV SECTION 2
Studying the Mental Listings

Instruct the Child Disability Commission created under Public Law 103-296 to examine the mental listings used by SSA to determine child SSI eligibility. The Commission should conduct this investigation to ensure that the criteria in these listings are appropriate to ensure that SSI eligibility is limited to serious disabilities for which federal assistance is necessary to improve the child's condition or quality of life.

Rationale:

Child SSI recipients should be only the seriously disabled. It has been suggested that some of the current mental listings permit questionable allowances. This amendment is intended to establish a thorough investigation of these listings to ensure that they are all appropriate.

KLECZKA AMENDMENT TO TITLE IV SECTION 3 #1
Uninterrupted Grandfather -- Eliminating Work Disincentives

SSI children receiving cash benefits under the grandfather provision whose financial eligibility is suspended shall continue to receive cash benefits if financial eligibility is restored.

Rationale:

It is common for children to lose financial eligibility for a period of time as family resource situations change. Legislative language from an early draft Committee Print required a child to have been receiving cash benefits continuously since the effective date of the provision in order for the grandfather to apply to them. This would mean that if a child were to lose financial eligibility temporarily, they would never qualify for cash assistance again under the grandfather provision.

This could have unintended negative consequences. For example, it can create a work disincentive. Children of parents who find higher-paying employment will lose SSI eligibility. This could result in the child permanently losing eligibility for cash assistance even if the child regains financial eligibility in the future. This would mean that a parent who takes a more lucrative job could permanently cost their child access to over $5000 per year in cash assistance, regardless of their future financial eligibility. This is a difficult choice for a parent to make and a position in which a government program should not place a parent. A purpose of SSI reform is to remove work disincentives, not create new ones.

This amendment would clarify that a child receiving cash assistance under the grandfather provision would continue to do so if he or she has financial eligibility for SSI suspended and later resumes receiving benefits.

KLECZKA AMENDMENT TO TITLE IV SECTION 3 #2
Levelling Playing Field for
Cash Payments to Institutionalized Children

Provide that children receiving SSI cash assistance, who are in a hospital or other medical institution and for whom private medical insurance covers the cost of the bill, have their monthly SSI benefit amount reduced to the personal needs allowance of $30.

Rationale:

Under the current system, children in hospitals or other medical institutions do not have their parents' resources deemed to them when they are in those institutions. Therefore, these children generally qualify financially for SSI while they are hospitalized. If Medicaid covers more than half the cost of the bill, the child's benefit amount is reduced to $30. However, if the bill is covered by private insurance, this is not the case and the child receives the full benefit amount. Once the child leaves the hospital, the parent's resources are deemed and the child can lose eligibility.

This can amount to a $500 monthly subsidy for families whose resources normally exceed the allowable amounts for the SSI program. This amendment removes the inequity whereby children with the least resources can receive a smaller cash benefit.

Social Security Administration workers in my district have called for this change repeatedly.

KLECZKA AMENDMENT TO TITLE IV SECTION 4
Low Birth Weight Baby Reviews

Require that a review for continuing disability be performed for all children qualifying for SSI due to low birth weight when the child has received benefits for 12 months.

Rationale:

Low birth weight babies can have serious impairments. However, their conditions have the potential to improve rapidly. Currently, reviews of this population lead to cessation of benefits over 40% of the time (as opposed to a 10-12% cessation rate for reviews of the general population in the SSDI program). This amendment would simply require a review at one year to evaluate whether the child's disability continues.

Disability examiners and SSA claims representatives both have suggested this requirement.

KLECZKA AMENDMENT TO TITLE IV SECTION 8(I)
Assuring Medicaid Eligibility for All SSI Recipients

Assure that any child who meets or equals the listings, now or in the future, receives Medicaid except in cases where they would not be eligible under today's system.

Rationale:

The Chairman's mark states that "authorized services provided under the block grant are considered to be SSI benefits." Under the new procedures created by this bill, States are given the authority to determine which of the eligible children will receive services. Therefore, there will be children who are eligible for block grant services but are not receiving any. The Chairman's mark does not make it clear that these children will be eligible for Medicaid coverage. This amendment clarifies that all children eligible for SSI are Medicaid eligible, except for those children who would be not be eligible for Medicaid today.

KLECZKA AMENDMENT TO TITLE IV
Divestiture Of Assets

Delays eligibility for the child SSI program for any applicant whose parents or guardians, in order to qualify a child for benefits, dispose of assets for less than fair market value within 36 months of the date of application.

* Establishment, within 36 months of the date of the application, of a trust in which the child has control over the assets in the trust qualifies as a disposal of assets for less than fair market value.

* The delay (in months) is equal to the amount of the assets divested divided by the SSI standard benefit.

Rationale:

The intention of the SSI program for children is to provide benefits to low-income severely disabled young people. Families should not be allowed to evade financial deeming levels by divesting assets or by placing them in trusts for which the recipient has ultimate control over the assets.

The amendment would apply prospectively to all applicants of the SSI program for children, and the length of the delay would be equal to the amount of the assets divided by the SSI standard benefit. The delay would begin the day the application is filed.

This amendment is similar but not identical to a provision enacted by OBRA '93, which established Medicaid asset divestiture restrictions.

Title IV – Supplemental Security Income (SSI)
Drug Addicts and Alcoholics

Amendment #2 (Rangel)

Retain Medicaid benefits for drug addicts and alcoholics made ineligible for SSI benefits.

Retain Medicaid benefits for drug addicts and alcoholics who are made ineligible for SSI benefits.

cost = # in one 5 years to
458

HCR Republicans vote "no"

All Republicans vote "no"
All Dems " "yes"

Title IV – Supplemental Security Income (SSI)
Drug Addicts and Alcoholics

Amendment #1 (Cardin)

Provide Substance Abuse Treatment to SSI Drug Addicts and Alcoholics.

Create an individual entitlement to an appropriate and adequate substance abuse treatment program for persons who are determined disabled because their drug addiction or alcoholism is a contributing factor material to their disability. The amendment would retain the provision making these individuals ineligible for cash SSI benefits.

Rejected

Rejected

(Cong. Nancy Johnson)

PROPOSED AMENDMENT
TO TITLE IV

BLOCK GRANT FOR THE TERRITORIES OF PUERTO RICO, U.S. VIRGIN ISLANDS, GUAM AND AMERICAN SAMOA

To establish an Adult Assistance for the Aged, Blind and Disabled block grant for the territories of Puerto Rico, U.S. Virgin Islands, Guam, and America Samoa. This block grant would be funded at 1994 Adult Assistance levels as determined by the Secretary of Health and Human Services.

* * *

CURRENT LAW: Under current law, these territories operate an Adult Assistance Program under a capped entitlement which has not been increased since 1988. In addition to Adult Assistance, this capped entitlement funds all AFDC-related programs.

RATIONALE FOR AMENDMENT: The proposed amendment would continue funding for Territorial Adult Assistance (SSI equivalent) through a new Adult Assistance for the Aged, Blind and Disabled block grant. This block grant would be funded at 1994 Adult Assistance levels as determined by the Secretary of Health and Human Services. This block grant is not an individual entitlement.

Passed with
understanding it
will be "Revenue Neutral"

Amendment to be offered by

Mr. Herger

Title IV of the Personal Responsibility Act

Eliminate the maintenance of effort requirement under the State Supplementary Payment (SSP) program.

Explanation of the Amendment:

The amendment will broaden states' ability to manage their supplemental benefit programs which provide state-funded benefits to SSI recipients.

Federal law passed in 1983 prevents states from reducing SSP benefits below 1983 levels, preventing states from reducing benefits to alcoholics or addicts or otherwise altering their programs. Without this amendment, states would still be forced to provide benefits to alcoholics and addicts while federal benefits are denied by this bill.

Current law also prevents states from altering payment categories or reducing administrative expenses associated with the SSP program. California, for example, has 20 payment categories costing the state $60 million to administer. If the state were allowed to combine categories of payments, administrative costs would be reduced as the state could reduce the number of federal checks it must have issued under the SSP rules at a cost to the state of $1.60 per check (a cost that will rise to $5 this fall).

Adopted by VV. Klecza Said Aye

WHAT YOU CAN DO:

ACTION IS NEEDED IMMEDIATELY!

* Call your Senators today! You can reach their capital offices through the Senate switchboard at (202) 224-3121.

Tell them that the proposed changes to SSI will hurt children and must be taken out of the Personal Responsibility Act. Specifically they should:

Retain cash benefits. Parents - not the government - need to have the right to make decisions about a child's treatment and services.

Keep the Individualized Functional Assessment (IFA). Children should not have to "fit a list" to receive benefits.

Locate and punish cases of SSI fraud and abuse, but not make rash, sweeping changes to the program.

For more info call: Chris Koyanagi, Bazelon Center
202-457-5730, 292-898-1670 TTD, 202-223-0409 FAX

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