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IPS

## IMPACT OF MEDICAID CUTS ON HOME AND SCHOOL-BASED SERVICES TO CHILDREN

In addition to the services that Medicaid provides to children in hospitals and doctor's offices, Medicaid also pays for many other services for children at home and in the schools, especially children with disabilities. These programs would come under particular pressure in states attempting to cope with a Medicaid block grant.

- o Infants and Toddlers with Disabilities: The Department of Education funds state efforts to identify infants and toddlers with disabilities and get them into treatment ("Part H"). Early intervention and therapy for these very young children is critical to maximize what they can accomplish later in school. A total of 165,000 infants and toddlers now get help through the Part H program, and many of these services are paid for by Medicaid. For example, Medicaid funds 62% of the Part H program in Arkansas, 32% in South Carolina, 25% in Massachusetts, and 41% in New York State.

Under a block grant, states would be under severe pressure to discontinue such services.

- o School Health Programs: Many schools use Medicaid and other resources to stitch together school health programs, particularly in at-risk neighborhoods. Medicaid's entitlement to basic preventive services for children ("EPSDT") is often used to develop comprehensive health programs. Under a block grant, states may choose to discontinue these programs.

- o Support for Families and Children at Home: Many families, both poor and middle class, receive support from Medicaid for their disabled children at home. Such programs have been developed over the past decade as an alternative to placing children in institutions. Medicaid will pay for equipment like wheelchairs or communication devices; therapy, including teaching parents to perform needed therapies at home; respite care for parents who need an occasional break in caring for a disabled child; and home modifications needed to allow a child to live at home.

Without these services, some parents may have to give up their jobs or seek institutional placement for their children.

- o Special Education Related Services: Many school districts bill Medicaid for medically-related services such as speech therapy and physical therapy, to which children are entitled as part of the special education program. If states choose to discontinue Medicaid for these therapies, these costs would be borne by local school districts.

Add to first paragraph in first section ("Eliminates Medicaid coverage", etc.)

Services to children with disabilities would be particularly at risk.

Add as second bullet to "impact of cuts on Children with Disabilities":

States would be under great pressure to eliminate Medicaid funds for children with disabilities. Medicaid services allow these children to remain at home, through equipment like wheelchairs and communication devices, therapy at home, respite care, and home modifications. Without these services, parents will be forced to give up their jobs or seek institutional placement for their children.

## **BULLETS FOR CONFERENCE CALL WITH DISABILITY ADVOCATES**

### **Supplemental Security Income**

- o Republicans in the Senate propose to eliminate benefits for over 150,000 disabled children currently on the rolls and some 200,000 more over the next five years. The House goes even further, eliminating cash benefits for as many as one million children with disabilities between now and the year 2000. The House would replace some cash benefits with block grants to the States worth 25% less than the dollars that would have gone directly to needy families.
- o The President proposes to preserve cash benefits for children. The President's budget proposal assumes modest savings through some tightening of SSI eligibility requirements in relation to current definitions of disability for children; those savings are considerably less than the Senate Republicans' proposal and are closer to the level of savings in Senator Conrad's alternative. Specific policies have not been finalized.
- o Under the House and Senate proposals, an individual will no longer be considered disabled for the SSI program if alcoholism or drug addiction is a contributing factor material to the individual's disability. The President's budget proposal assumes some savings from reductions in payments to individuals whose disabilities are based on alcoholism or drug addiction.

### **Education Programs**

- o The President's proposal will assure continued funding for priority education programs serving individuals with disabilities, rejecting congressional cuts.

JUDGE DAVID L.  
BAZELON  
CENTER  
FOR  
MENTAL  
HEALTH  
LAW

# STEALING HOPE

What Congress Is Doing  
to Families of  
Children with Severe Disabilities

DECEMBER 6, 1995

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## The Impact of the Welfare Reform Conference Agreement on Children with Severe Disabilities

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*If children with severe disabilities lose their SSI benefits, many families will simply not have the resources to care for them at home and will turn to state and local governments for assistance.*

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**T**he welfare reform conference agreement currently before Congress should be rejected because it steals too many families' hopes for their children who have severe disabilities. If the proposed changes to the children's supplemental security income (SSI) program become law, almost one million low-income children with serious disabilities would be denied access to the program or receive reduced benefits.

The conference agreement would have a devastating effect on families who struggle to help their children who have disabilities achieve the greatest possible independence. The SSI program is based on the premise that families can best decide how to meet their own children's needs. The cash benefit encourages lower-income families to stay together to help their children thrive and mature as productive adults.

Although it is claimed that other programs would provide assistance, families believe otherwise because they have found no alternative to SSI cash benefits. Many SSI children are not eligible for food stamps, and the future of that program is unclear. Some SSI children would qualify for welfare, but assistance through that program is being drastically reduced. Congress' block grant proposal for Medicaid further threatens essential health care for children with disabilities. Special education provides certain "related" services, but excludes medical services needed by children with severe disabilities, especially preschoolers. Furthermore, school districts vary widely in their ability to meet current demand.

If children with severe disabilities lose their SSI benefits, many families will simply not have the resources to care for them at home and will turn to state and local governments for assistance. Without the federal benefits that parents now spend on behalf of their children, states' costs to serve children with severe disabilities will inevitably increase. As an especially tragic consequence, some families may be forced to surrender

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custody to guarantee proper care for their children, either through the foster care system or in state institutions.

Overall, about 25 percent of children would be dropped from SSI on January 1, 1997, or denied future eligibility. Cash benefits would also be cut by one fourth for 65 percent of the children found eligible after January 1, 1997. For children who are already in the program based on a qualifying medical impairment, these changes would take effect when each child undergoes a mandatory evaluation of continued eligibility.

Almost a million low-income children with serious disabilities would be denied access to SSI or receive greatly reduced benefits. The Congressional Budget Office estimates that benefits to 335,000 children would be dropped or denied; another 658,000 children would receive reduced payments by 2002.

The conference agreement would cut program costs by \$13.2 billion over seven years. This is almost identical to the original House cut of \$13.4 billion. In contrast, the Senate bill cut \$8.4 billion.

### **PROGRAM CHANGE**

The conference agreement eliminates the Individual Functional Assessment (IFA).

### **IMPACT**

Although various studies (GAO, HHS/IG, NASI) found that allegations of widespread program abuses could not be substantiated, the conference agreement severely tightens eligibility for the program—much more than disability and children's advocates believe is warranted. The conference agreement eliminates almost 160,000 of the 934,000 children now eligible. Only children whose impairments can meet restricted listings of medical conditions would qualify.

Children who may no longer qualify include those who: have more than one impairment if each impairment by itself is not enough to qualify through medical listings, children who have a disorder that narrowly misses the listings-level description, children who are too young to test for the listings and children who have rare disorders that are not listed.

## **PROGRAM CHANGE**

The conference agreement creates a new payment scale with two levels of benefits depending on the child's disability. For children under six to receive full benefits, they would have to prove that their ability to function age-appropriately is severely limited and that, without personal assistance, they would require specialized care outside the home. Children over six, to receive full benefits, would have to prove that they need (a) personal care assistance for at least two activities of daily living (eating, toileting, dressing, bathing and mobility) or (b) administration of medical treatment beyond help with medication or (c) continual 24-hour supervision to avoid causing harm to self or others and that if they did not receive such assistance, they would require full- or part-time specialized care outside the home.

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*A two-tier system has an obvious disincentive because children who have struggled to achieve greater independence would be penalized by a 25 percent reduction in benefits they would have otherwise received.*

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## **IMPACT**

Most children would receive 75 percent of the benefit they would now receive, based on family income. Only children who meet a new "personal care" standard would receive 100 percent of their benefit. CBO estimates that 65 percent of children would receive reduced benefits and only 35 percent would qualify for full payment. These changes would apply, within three years, to children now eligible for benefits as well as all children who qualify in the future.

Within the two-tier benefit system, only the need for "continual care to avoid harm to self or others" applies to most children with mental illness. The "continual care" criterion sets a higher standard for one group of children compared to the regular, time-consuming but intermittent, care associated with activities of daily living. In addition, a two-tier system has an obvious disincentive because children who have struggled to achieve greater independence would be penalized by a 25 percent reduction in benefits they would have otherwise received.

## **PROGRAM CHANGE**

The conference agreement creates two categories of benefits. This is both unwarranted and discriminatory.

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*The agreement would significantly increase SSA's costs by adding an additional evaluation to determine the benefit level.*

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### **IMPACT**

The proposal makes false distinctions between children with serious disabilities based on the nature of their impairment. Since only children who meet the highly restrictive medical listings will qualify for benefits, all eligible children need the full assistance of the SSI program. The only rationale for different payment levels for children who have proven they have severe impairments is the desire to cut program costs. There is no programmatic justification.

### **PROGRAM CHANGE**

The conference agreement proposes a standard that does not reflect a family's need for assistance.

### **IMPACT**

SSI is a means-tested program that only allows families with very limited income to qualify. But even among these families, the program adjusts benefit levels according to income. Establishing a two-tier system will harm families who depend on the assistance to offset income lost because a parent must remain unemployed or underemployed to provide care.

### **PROGRAM CHANGE**

The conference agreement creates a more complex and costly disability determination process. Children would first have to prove that their condition meets the eligibility standard and then a second review would determine the size of their benefit.

### **IMPACT**

The agreement would significantly increase SSA's costs by adding an additional evaluation to determine the benefit level. As with other eligibility decisions, benefit levels will be appealable, which will also add significant administrative costs. The National Commission on Childhood Disability recognized significant problems with tiered cash benefits, including the absence of a mechanism to classify disabilities according to extra costs and the need for a more expensive eligibility process.

## The Faces of Children with Severe Disabilities Harmed by the Welfare Reform Agreement

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Here are several examples of children with severe disabilities who would lose SSI benefits entirely under the conference agreement—children who became eligible through an Individualized Functional Assessment (IFA). Except for Tamara's, these children's names have been changed to protect their privacy. Additional accounts of children who receive SSI, many of whom are threatened by the conference agreement, appear in the Bazelon Center's booklet, *SSI—Lifeline for Children with Disabilities*. To get in touch with their families, contact Rhoda Schulzinger or Lee Carty at 202/467-5730.

### **Eddie**

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*His mother, who is a single parent, works as a mental health counselor, but Eddie's asthma was so severe she was forced to take leave from her job to care for him.... Eddie's physician credits her diligent care with reducing his need for repeated hospitalizations.*

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Eddie is five and lives in Pennsylvania. By his second birthday, he had been hospitalized three times for severe asthma attacks. He did not begin to walk or talk until he was two. His mother, who is a single parent, works as a mental health counselor, but Eddie's asthma was so severe she was forced to take leave from her job to care for him. She got a nebulizer, which she uses for his bronchodilator treatments three times per day. When his asthma flares up, Eddie takes steroids and has to use the nebulizer every four hours. His mother watches Eddie's condition carefully, rushing him to the doctor at the first sign of an attack. Eddie's physician credits her diligent care with reducing his need for repeated hospitalizations.

Eddie also has a speech impairment with a severe delay in auditory comprehension and difficulties with speech articulation and vocabulary. His pediatrician referred him to a child psychiatrist just before he turned four because he had begun to bite people without provocation, isolate himself from others, throw uncontrollable tantrums and wet and soil himself. The child psychiatrist diagnosed a Mixed Development Disorder.

It took almost two years after his application for Eddie to qualify for SSI because his asthma did not meet the listings.

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*At the time of her SSI application, Maria was cared for by her aging grandparents, both of whom were in ill health... Recently, Maria's grandfather died and SSI helps her grandmother continue her care.*

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Although Eddie's speech and developmental impairments were both found to be severe, neither individually met the speech or mental disorders listings.

Eddie qualified for SSI through the IFA because the combined impact of his asthma, speech impairment and development disorder limited his ability to function in age-appropriate ways.

Eddie is now in a half-day kindergarten program, but often has to stay home because of his asthma. His mother has returned to work but cannot find anyone to take care of Eddie after school because people are afraid to have responsibility in case he has an attack. As a result, she can only work 28 hours per week. She also has to miss work whenever Eddie's asthma keeps him home from school. Having Eddie's SSI benefits to supplement her earnings makes it possible to buy food and clothing despite the reduction in her earnings due to Eddie's special needs. The SSI benefits also enable her to buy some of the special things Eddie needs, including nutritional supplements, reading aids and books, and educational games and puzzles.

### **Maria**

Maria lives in West Virginia. She's a very active five-year-old with microcephaly (a congenital brain defect) and an accompanying attention disorder. Maria qualified for SSI through the use of the functional assessment. She has many behavioral, feeding and communication difficulties.

At the time of her SSI application, Maria was cared for by her aging grandparents, both of whom were in ill health. SSI helps this family by giving Maria access to medical assistance, which allows the family to receive behavioral support as well as the services of a nutritionist. With the SSI cash assistance, the family was able to make desperately needed modifications to their home so it could be safe for this very active little girl. Recently, Maria's grandfather died and SSI helps her grandmother to continue her care.

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*Leanne is now eight and has been able to attend school only 25 days this school year. ...She has a permanent I.V. line in her chest and needs an I.V. pump 12 hours a day, resulting in very high utility bills. Her frequent infections and surgeries have resulted in hospitalizations about once a month over the past two years.*

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## **Teri**

Teri is nine and has cerebral palsy. Her gait is almost spastic and she has major gross and fine motor skills limitations. Teri cannot ride a bike, jump rope, go down stairs one foot after the other, tie her shoes, button her blouse or zip up her coat. She cannot brush her teeth or shower by herself and cannot chew certain food without choking. Her social skills are limited and she has a lot of trouble making friends. Teri also has learning disabilities, developmental delays and is deaf in one ear.

Teri was denied SSI benefits when she first applied. After her family appealed, she was accepted under the IFA guidelines.

The cash benefits enable Teri's mother to provide for her daughter's special needs. Teri has to wear special clothes and shoes, which are expensive. Neighborhood teenage sitters do not have the experience to take care of Teri, so her mother has to pay more for someone qualified to watch her. The household electric bills are higher than average because Teri must take baths instead of showers and the house must be heated more because she cannot put the covers back on herself at night.

There are also extra costs for the special day camp, swim class and dance class that are critical for Teri's social and motor development. And SSI gives her access to other programs aimed at increasing her independence; she can attend structured socialization groups with the recreation department, ride the transit service for people with disabilities to a computer class and participate in Challenger Little League games.

## **Leanne**

Leanne has a congenital condition resulting in painful urination, frequent, recurrent urinary tract infections and obstruction. SSA found that her medical condition did not meet or equal the severity of the medical listings, but she qualified through an IFA.

Leanne is now eight and has been able to attend school only 25 days this school year. She has had 18 surgeries and still empties her bladder via tubes into a bag outside her body. She has a permanent I.V. line in her chest and needs an I.V. pump 12 hours a day, resulting in very high utility bills. Her frequent

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*Like many parents who must cope with the needs of a child with severe problems, this mother's earnings potential has decreased at the same time that her child's expenses have increased.*

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infections and surgeries have resulted in hospitalizations about once a month over the past two years. Although she lives in Western Massachusetts, Leanne sees medical specialists in two different Boston hospitals and has had many of her surgeries in Boston, resulting in high transportation costs and phone bills.

Leanne lives with her mother and younger sibling. Her mother struggles to support her children on child support plus her limited wages. However, because of Leanne's child's care needs, her mother has been unable to work consistently and feels that her frequent absences have affected her position at work. Like many parents who must cope with the needs of a child with severe problems, this mother's earnings potential has decreased at the same time that her child's expenses have increased. Finding child care is also difficult because of her child's medical needs. The SSI cash assistance is essential to meet Leanne's basic food, clothing and shelter needs and to cover the costs associated with her care and treatment.

### **Patty**

Patty has borderline intellectual functioning. She qualified for SSI through the IFA.

Her teacher reports that Patty acts much younger than her age and responds inappropriately to peers. At 15, she still sucks her thumb. Patty has very limited judgment and cannot do her own self-care activities. The teacher reports that Patty cannot concentrate for more than four minutes at a time, cannot complete assignments and requires constant supervision. At home, she must be constantly prodded to complete chores.

Psychological tests indicate that Patty has numerous complications, including physical problems (failure to thrive), possible organic brain problems, brain functioning limitations and severe emotional trauma. The psychologist noted a significant impairment in Patty's ability to act in age-appropriate ways, partly as a result of previous neglect and abuse.

Patty now lives with a foster family.

### **Tamara**

*Los Angeles Times* reporter Lucille Renwick vividly described several children in a May 22, 1995 article, "Parents Fear Loss

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*"All I know is that if this  
(SSI) gets cut off, we  
might be a homeless  
family with a daughter  
in a wheelchair."*

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of SSI Payments." One was Tamara Baskin of North Hollywood, who has brittle bones, a condition that has stunted her growth, stalling her body size to that of a toddler, and leaving her in a wheelchair most of the time. She has pins throughout her arms and legs to hold them together.

Carol Baskin quit her job as a beautician to take care of Tamara until she could go to school. But school-bus drivers couldn't properly handle Tamara's frail body, so Carol had to become a bus driver herself. While the part-time job leaves Carol five hours a day to take care of Tamara, as a single mother with another child, she can't afford to live on it. "All I know is that if this (SSI) gets cut off, we might be a homeless family with a daughter in a wheelchair," Renwick quotes her.

## SSI Children Losing Benefits, 1997-2002

| State             | Currently Eligible Children* | Children Dropped January 1, 1997**<br>Number Percent | Add'l Children Denied Benefits 1997-2002*** | Children receiving Reduced Benefits in 2002**** | Total Children Hurt by Legislation |
|-------------------|------------------------------|------------------------------------------------------|---------------------------------------------|-------------------------------------------------|------------------------------------|
| Alabama           | 27,780                       | 4,680 17%                                            | 5,237                                       | 19,559                                          | 29,476                             |
| Alaska            | 750                          | 130 17%                                              | 146                                         | 526                                             | 802                                |
| Arizona           | 10,960                       | 1,570 14%                                            | 2,039                                       | 9,187                                           | 12,796                             |
| Arkansas          | 18,770                       | 4,690 25%                                            | 4,913                                       | 11,330                                          | 20,933                             |
| California        | 70,540                       | 7,630 11%                                            | 8,944                                       | 55,260                                          | 71,834                             |
| Colorado          | 9,230                        | 1,020 11%                                            | 1,194                                       | 7,204                                           | 9,418                              |
| Connecticut       | 4,990                        | 740 15%                                              | 842                                         | 3,646                                           | 5,228                              |
| Delaware          | 2,500                        | 300 12%                                              | 349                                         | 1,921                                           | 2,570                              |
| D.C.              | 2,820                        | 370 13%                                              | 427                                         | 2,124                                           | 2,921                              |
| Florida           | 55,280                       | 7,050 13%                                            | 8,143                                       | 41,869                                          | 57,062                             |
| Georgia           | 27,280                       | 2,680 10%                                            | 3,165                                       | 21,736                                          | 27,581                             |
| Hawaii            | 960                          | 50 5%                                                | 61                                          | 829                                             | 940                                |
| Idaho             | 3,760                        | 960 26%                                              | 1,000                                       | 2,244                                           | 4,204                              |
| Illinois          | 48,820                       | 9,120 19%                                            | 10,058                                      | 33,232                                          | 52,410                             |
| Indiana           | 19,390                       | 3,350 17%                                            | 3,736                                       | 13,544                                          | 20,630                             |
| Iowa              | 7,050                        | 1,250 18%                                            | 1,389                                       | 4,883                                           | 7,522                              |
| Kansas            | 8,280                        | 1,670 20%                                            | 1,821                                       | 5,485                                           | 8,976                              |
| Kentucky          | 21,380                       | 4,720 22%                                            | 5,066                                       | 13,656                                          | 23,442                             |
| Louisiana         | 40,220                       | 9,510 24%                                            | 10,074                                      | 24,922                                          | 44,506                             |
| Maine             | 2,420                        | 210 9%                                               | 250                                         | 1,968                                           | 2,428                              |
| Maryland          | 12,420                       | 1,850 15%                                            | 2,102                                       | 9,059                                           | 13,011                             |
| Massachusetts     | 15,300                       | 2,640 17%                                            | 2,944                                       | 10,690                                          | 16,274                             |
| Michigan          | 38,630                       | 8,470 22%                                            | 9,100                                       | 24,740                                          | 42,310                             |
| Minnesota         | 10,190                       | 2,000 20%                                            | 2,189                                       | 6,816                                           | 11,005                             |
| Mississippi       | 24,620                       | 5,000 20%                                            | 5,443                                       | 16,258                                          | 26,701                             |
| Missouri          | 20,590                       | 3,840 19%                                            | 4,236                                       | 14,024                                          | 22,100                             |
| Montana           | 2,100                        | 280 13%                                              | 323                                         | 1,577                                           | 2,180                              |
| Nebraska          | 4,370                        | 600 14%                                              | 688                                         | 3,253                                           | 4,541                              |
| Nevada            | 2,480                        | 260 10%                                              | 306                                         | 1,956                                           | 2,522                              |
| New Hampshire     | 1,760                        | 120 7%                                               | 145                                         | 1,473                                           | 1,738                              |
| New Jersey        | 21,050                       | 3,420 16%                                            | 3,845                                       | 14,983                                          | 22,248                             |
| New Mexico        | 6,790                        | 920 14%                                              | 1,056                                       | 5,072                                           | 7,048                              |
| New York          | 78,570                       | 15,540 20%                                           | 16,982                                      | 52,381                                          | 84,903                             |
| North Carolina    | 28,220                       | 6,740 24%                                            | 7,126                                       | 17,405                                          | 31,271                             |
| North Dakota      | 1,310                        | 110 8%                                               | 131                                         | 1,069                                           | 1,310                              |
| Northern Marianas | 110                          | 0 0%                                                 | NA                                          | NA                                              | NA                                 |
| Ohio              | 50,300                       | 6,840 14%                                            | 7,849                                       | 37,534                                          | 52,223                             |
| Oklahoma          | 11,380                       | 1,050 9%                                             | 1,245                                       | 9,158                                           | 11,453                             |
| Oregon            | 6,590                        | 680 10%                                              | 800                                         | 5,205                                           | 6,685                              |
| Pennsylvania      | 42,400                       | 8,580 20%                                            | 9,346                                       | 28,039                                          | 45,965                             |
| Rhode Island      | 2,910                        | 365 13%                                              | 422                                         | 2,213                                           | 3,000                              |
| South Carolina    | 17,240                       | 2,400 14%                                            | 2,747                                       | 12,791                                          | 17,938                             |
| South Dakota      | 2,760                        | 420 15%                                              | 476                                         | 2,002                                           | 2,898                              |
| Tennessee         | 24,040                       | 3,130 13%                                            | 3,609                                       | 18,126                                          | 24,865                             |
| Texas             | 55,300                       | 7,940 14%                                            | 9,059                                       | 40,714                                          | 57,713                             |

| State         | Currently Eligible Children* | Children Dropped January 1, 1997**<br>Number    Percent | Add'l Children Denied Benefits 1997-2002*** | Children receiving Reduced Benefits in 2002**** | Total Children Hurt by Legislation |
|---------------|------------------------------|---------------------------------------------------------|---------------------------------------------|-------------------------------------------------|------------------------------------|
| Utah          | 4,420                        | 670    15%                                              | 760                                         | 3,211                                           | 4,641                              |
| Vermont       | 1,450                        | 260    18%                                              | 289                                         | 1,002                                           | 1,551                              |
| Virginia      | 21,500                       | 4,910    23%                                            | 5,235                                       | 13,530                                          | 23,675                             |
| Washington    | 11,140                       | 1,940    17%                                            | 2,161                                       | 7,762                                           | 11,863                             |
| West Virginia | 8,510                        | 1,400    16%                                            | 1,571                                       | 6,032                                           | 9,003                              |
| Wisconsin     | 21,410                       | 4,340    20%                                            | 4,726                                       | 14,149                                          | 23,215                             |
| Wyoming       | 1,140                        | 260    23%                                              | 277                                         | 718                                             | 1,255                              |
| Total         | 934,180                      | 158,675    17%                                          | 176,042                                     | 658,067                                         | 992,784                            |

\* Source: Social Security Administration semi-annual report: "Children Receiving SSI, June 1995"

\*\* Source: Unpublished SSA estimate of impact of the Senate bill prepared by Office of the Actuary.

\*\*\*Derived from CBO estimate of 1,347,000 children on SSI rolls in 2002 if there were no change in law.

The estimate of additional children denied eligibility assumes rate of denial comparable to the rate in 1997.

The state-by-state data should be considered only a rough approximation of the ultimate distribution of cases.

\*\*\*\*Derived from CBO estimate of 1,013,000 children eligible for benefits in 2002 under Conference Report .

Calculation of reduced benefits based on the CBO estimate that 65% of children would receive three-fourths of the benefit they would be eligible for based on their family income.

Prepared by: Bazelon Center for Mental Health Law  
December 6, 1995

# NEWS

FOR IMMEDIATE RELEASE  
December 6, 1995

## ADVOCATES RELEASE REPORT HIGHLIGHTING CONFERENCE WELFARE AGREEMENT'S IMPACT ON CHILDREN WITH SERIOUS DISABILITIES

Advocates for children with disabilities released a new report today highlighting the detrimental impact of the House-Senate conference welfare reform agreement on children with serious physical and mental impairments. Beyond restructuring the welfare system, the agreement now being debated includes a devastating reduction of assistance for families raising children with severe disabilities.

"The conference agreement will steal hope from almost a million children with serious disabilities," said Leonard Rubinstein, director of the Bazelon Center for Mental Health Law. "The President has a responsibility to help these children and their parents so they can stay together as families," he added.

The legislation worked out by the House-Senate conference would fundamentally change the rules for the children's Supplemental Security Income (SSI) program. It would eliminate assistance entirely for some 335,000 children with serious disabilities over the next seven years. In addition, it would create a new payment scale with two levels of benefits depending on a child's disability. Another 658,000 children would receive reduced payments by 2002.

"The two-tier benefit system has no programmatic justification. It is simply a cruel, heartless way to balance the budget at the expense of families who struggle to help their children achieve the greatest possible independence," said Rhoda Schulzinger, senior staff attorney at the Bazelon Center and author of today's report.

As illustrated by accounts of children in the Bazelon Center report, children's SSI enables poor families with severely disabled children to stay together. Often, one parent has to stay home to care for such a child. Families with a limited income face a lifetime of special costs -- diapers for an incontinent teenager, vans with lifts for wheelchairs, soaring electric agreements for 24-hour-a-day respirators, remodeled bathrooms with special safety bars, high gasoline agreements for trips to distant doctors or intensive therapies for severe emotional problems.

Families across the country are frightened at the prospect of losing their children's SSI assistance.

[more]

- The Elledge family in Wyoming lost their home, car and entire savings to pay for their child's care despite having two incomes. "Although we are still facing bankruptcy for the first seven years of Megan's medical costs, we at least have come to the light at the end of the tunnel and will not keep adding to our debt. I cannot imagine where we would have ended up had we not had the help of the Social Security system," says Megan's mother.
- The Bell family in Utah adopted three children, two of them with disabilities. Kim Bell is angry that proposed changes in the program "put me in the position of even having to think about placing my daughters in an institution if we lack the resources to raise them at home."
- The Stehrs in Iowa work opposite hours so the parents can share caring for their son Jon. "We have to have jobs with flexible hours to allow for medical appointments or if Jon gets sick... We have worked hard to stay together as a family. SSI has helped us stay together by reducing some of the financial burden," says Deb Stehr.

The Elledges, Bells and Stehrs are some of the families featured in an earlier report by the Bazelon Center, *SSI—Lifeline for Children with Disabilities*, an overview of the program.

The Bazelon Center's new report, *Stealing Hope: What Congress Is Doing to Families of Children with Disabilities*, describes the programmatic changes the conference agreement would make in the children's SSI program. It also includes short descriptions of additional children who would lose benefits under the agreement and lists the number of children who would be affected in each state over the next seven years.

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For more information:

Rhoda Schulzinger at 202/467-5730

Lee Carty at 202/467-5730 or 202/338-2566 (home)



# CRIPPLED CHILDREN'S SOCIETY

OF SOUTHERN CALIFORNIA, INC.

## Headquarters

7120 Franklin Avenue  
Los Angeles, California 90046-3002  
(213) 874-3300 - FAX (213) 850-8062

*Nothing  
Low  
for them*

September 25, 1995

The Honorable Bill Clinton  
President of the United States  
The White House  
Washington D.C.

Dear President Clinton:

On behalf of the Crippled Children's Society (CCS) of Southern California, I am writing to invite you to be our guest of honor at the groundbreaking ceremony on October 13, 1995 at noon for our newest housing complex for low-income people with disabilities in East Los Angeles, California, and to say a few words commemorating this occasion. The "Villa Malaga" housing complex is jointly funded by the Department of Housing and Urban Development (HUD) and the County of Los Angeles. The Crippled Children's Society through the Villa Malaga Housing Corporation, a non-profit board dedicated to bringing this project to fruition, has acted as the project's developer. Your presence at the groundbreaking ceremony, Mr. President, would underscore the Federal government's commitment to working on behalf of the disabled and low-income families in cooperation with local governments and non-profit community-based organizations.

Villa Malaga offers several innovative features. It will not only house adults with disabilities, but will keep families intact in its two and three bedroom units - a first for HUD-funded housing for the disabled. The apartments are also being wired to the information superhighway; the building will contain high speed data networks capable of supporting telecommuting by its disabled residents. The Villa Malaga Board plans a corporate donation program to secure computers for the residents and a computer training program in the community service center which is being built next door. The project will be located in a redevelopment area in predominantly Latino East Los Angeles and will be the first accessible housing for low-income people in the area. Its construction program will include training and job opportunities for local residents, many of them at-risk youth interested in learning a trade.

The Crippled Children's Society, which was founded in Los Angeles in 1926, offers a variety of services. CCS operates 8 service centers throughout Los Angeles and Orange Counties offering programs including physical therapy, day care, adult development, counseling, parent and sibling support groups; 2 summer camps for disabled youth and adults; 3 workshops for vocational training, and 4 housing complexes. Villa Malaga will be the fifth HUD-funded housing project CCS has developed in cooperation with local governments in the Los Angeles area.

The Honorable Bill Clinton  
September 25, 1995  
Page Two

Our greatest reward as a non-profit agency is the difference we make in the lives of our clients and residents. Many residents at our Inglewood, California housing complex, for example, were literally homeless on the street in wheelchairs before moving into CCS' Pacific Rim Apartments. In CCS housing, residents pass through the building's corridors with ease, read books from shelves placed within easy reach of a person in a wheelchair, cook in specially-designed kitchens and take a shower in bathrooms designed to accommodate wheelchairs - all simple things the rest of us too often take for granted. HUD's support makes the housing affordable - residents pay only one-third of their income in rent, an average of \$200.00. It helps people with disabilities become more independent through appropriate housing coupled with support services.

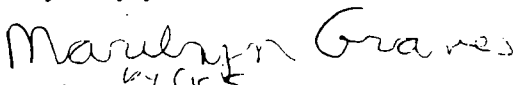
HUD Secretary Henry Cisneros; Congress Members Matthew Martinez, Xavier Becerra, Esteban Torres and Lucille Roybal-Allard; Chairperson of the Los Angeles County Board of Supervisors Gloria Molina and a variety of other dignitaries have been invited to attend. We expect significant media coverage from television, newspapers and radio. Approximately 500 people will attend this gala ceremony.

Enclosed for your information is literature on the Crippled Children's Society's housing and service center programs, and our architect's rendering of the apartment complex. I will send you under separate cover a list of Villa Malaga and CCS Board Members.

We realize that time is short before the groundbreaking ceremony. After several years of working on this project, we just signed the closing documents with HUD today and are now able to set a firm date for the ceremony. Although we hope you can attend in person, in the event your schedule does not permit your presence, we would appreciate a letter expressing your compliments upon this groundbreaking. We also hope you will keep this project in mind when you plan your schedule for the Summer of 1996 when we hope you would be able to participate in the ribbon cutting ceremony upon the project's completion.

If you have any questions or require any additional information, please call me at (213) 874-3300 x 315 or Cathy Sandoval, Villa Malaga Board Member at (703) 683-6530. Thank you for your consideration of this invitation.

Very truly yours,

  
Marilyn Graves

Executive Director,  
Crippled Children's Society of  
Southern California

The Honorable Bill Clinton  
September 25, 1995  
Page Three

cc with enclosures:

The Honorable Matthew G. Martinez  
The Honorable Henry Cisneros  
The Honorable Esteban Torres  
The Honorable Lucille Roybal-Allard  
Mr. George Stephanopoulos  
Ms. Patti Solis  
Ms. Araceli Ruano  
Mr. Ray Martinez  
Ms. Suzanna Valdez  
Ms. Janet Murguia  
Ms. Kamiki Gibson  
Ms. Sheryl Cashin  
Ms. Choco Mesa



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The Honorable Al Gore  
Vice President of the United States  
The White House  
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Dear Vice-President Gore:

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HUD Secretary Henry Cisneros; Congress Members Matthew Martinez, Xavier Becerra, Esteban Torres and Lucille Roybal-Allard; Chairperson of the Los Angeles County Board of Supervisors Gloria Molina and a variety of other dignitaries have been invited to attend. We expect significant media coverage from television, newspapers and radio. Approximately 500 people will attend this gala ceremony.

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*Marilyn Graves*  
L.C.S.

Marilyn Graves  
Executive Director,  
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The Honorable Henry Cisneros  
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Mr. Greg Simon  
Ms. Kamiki Gibson  
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## Headquarters

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Los Angeles, California 90046-3002

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September 25, 1995

Mrs. Hilary Rodham Clinton  
The White House  
Washington D.C.

Dear Mrs. Rodham Clinton:

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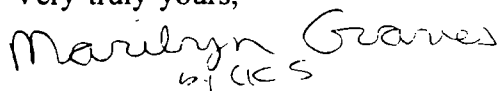
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Mrs. Hilary Rodham Clinton  
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Ms. Choco Mesa



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Crippled Children's Society / Villa Malaga  
4704 Dozier St., E. Los Angeles, CA

Fax Cover Sheet

## Alexandria

112 S. Washington St.

Alexandria, VA 22314

Phone: (703) 739-0783

Fax: (703) 739-0785

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Date

9.30.95

# of pages (incl. cover)

17

To: Suzanna Valdez

From: Cathy Sandowal

Company:

White House  
Office of Public Liaison

Company:

Fax #:

202-456-6218

Fax #:

Phone #:

202-456-2930

Phone#:

703-683-6430

Comments:

Suzanna, Hope you're doing well. Attached is the invitation and material regarding the housing project for the disabled in East L.A. we discussed. We closed with HUD last week. The grand opening ceremony is October 13. I know its late but I'd appreciate whatever

you can do. Originals are in the mail to you. Thanks, Cathy

Catherine J.K. Sandoval  
505 E. Braddock Road # 304  
Alexandria VA 22314  
(703) 683-6530

Ms. Suzanna Valdez  
Associate Director, Office of Public Affairs  
The White House  
Old Executive Office Building, Room 122  
Washington D.C 20500

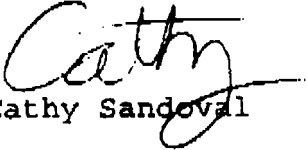
Dear Suzanna:

I hope this letter finds you well. As you may recall, I mentioned to you that I was working on a HUD and local government-funded housing project for people with disabilities in East Los Angeles. After years of working on it, we finally closed with HUD. The groundbreaking ceremony will be in L.A. on October 13 at noon. Enclosed for your information are copies of the letters inviting the principals to address the ceremony. We expect at least 500 people to attend and extensive media coverage. As we discussed, I believe this project fits well with the administration's agenda, assisting the poor and disabled to become more independent through appropriate housing and services. It is a prime example of federal and local government, non-profit and private sector cooperation. The housing complex is also being wired to the information superhighway to support telecommuting by the disabled residents.

Suzanna, I would appreciate any assistance you could give in encouraging one of the principals to attend. I realize time is short before the event but we just today signed the final papers with HUD and were able to set a date for the ceremony. If none of the principals is able to attend, we would appreciate a letter of congratulations upon this groundbreaking. You might also keep this project in mind when setting the California schedule next Summer. We expect to complete construction in June of 1996. It would be great if you and one of the principals could attend our ribbon cutting ceremony upon the project's completion.

Please call if you have any questions or I can send you additional information. Thanks for your help. Take care.

Sincerely,

  
Cathy Sandoval