THE PRESIDENT HAS SEEN
12-17-97

THE WHITE HOUSE
WASHINGTON

'97 DEC 16 PM 7:04

December 16, 1997

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Mathews
Reed
Fortuna
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MEMORANDUM TO THE PRESIDENT

THROUGH: Sylvia Matthews

FROM: Bruce Reed
Diana Fortuna

SUBJECT: SSA Report on Implementation of Children's SSI Cutoffs

The Social Security Administration intends to release a report this Thursday on its implementation of the new definition of childhood disability for SSI. This report follows Commissioner Ken Apfel's promise, at his confirmation hearing in September, of a "top to bottom" review of SSA's process for redetermining the eligibility of children.

As you know, the welfare law tightened the definition of childhood disability for SSI, and required the Social Security Administration to redetermine the eligibility of approximately 288,000 children, out of about one million children now on the rolls. These reevaluations have led to almost 140,000 terminations to date. (At the time the welfare law was enacted, CBO estimated that 180,000 children would lose SSI; when SSA announced its interpretation of the law, it projected that 135,000 children would become ineligible.) Advocates charge that SSA has done a poor job on these reevaluations, causing eligible children to be dropped from the rolls.

The report concludes that SSA did a generally good job of redetermining eligibility for these children. The report, however, identifies three areas of concern and announces actions to address them.

First, SSA will review the cases of all children "coded" as mentally retarded who were cut from the rolls and have not appealed. This action addresses SSA's finding that some of these children may have been terminated incorrectly. Second, SSA will review a portion of every state's unappealed terminations, choosing the kinds of cases most needing review in each state and focusing heavily on states that SSA has found to have a relatively high error rate. This review will allow SSA to give special attention to states with the highest error rates, without singling them out as "bad actors." Third, SSA will offer all 70,000 families who did not appeal its termination decisions a new opportunity to do so. These actions, and the problems they address, are further described in an appendix attached to this memo.

In all, SSA will review the cases of 48,000 children dropped from the program. (Another 70,000 have appealed.) As a result of these actions, SSA now projects that approximately 100,000 children ultimately will lose SSI benefits.

With the report, SSA also plans to release case studies of a random sample of 151 children who have lost benefits. This document is intended to explain to the public what kinds of children are no longer eligible. Most of the children have mental disabilities other than mental retardation, including learning disabilities and attention deficit disorder. Over a third have improved since they were first found eligible. The majority are teenagers; only a handful are age six or younger.

Advocates will probably have a mixed reaction to the report -- generally pleased about the actions, but still arguing that SSA's regulation interpreting the statute is needlessly strict. The report does not address the latter issue. The Republican leadership in Congress has been extremely supportive of SSA's implementation of the law to date, but probably will criticize this report on the ground that it bends over backwards to restore benefits.

SSA Report on Childhood Disability Process

SSA's report examined three areas of concern raised by advocacy groups:

I. Mental Retardation

Advocates' Charge: Too many children with mental retardation were cut from the rolls.

SSA Finding: Of the 136,000 children terminated to date, 42,000 were "coded" as mentally retarded (MR). However, most of these children do not actually have MR, because until recently SSA's systems did not have all the necessary codes. Instead, most of these children have other mental disorders, such as learning disabilities or "borderline intellectual functioning" (which falls short of full-fledged MR). Some unknown subset of the 42,000 do have MR, but either their impairments are not severe enough to qualify them for SSI, or they were denied incorrectly.

Even with these terminations, approximately 350,000 children coded as MR will remain on the rolls, out of the total of one million children on SSI.

SSA Action: SSA will review all cases terminated that were coded as MR, to ensure that all those decisions were made properly.

II. State Variations in Cutoffs

Advocates' Charge: Errors in cutoffs appear likely, since termination rates varied widely by state, from 32% in Nevada to 82% in Mississippi. Also, SSA may not have acquired all documentation, such as school records, needed to judge a child's disability. Finally, some states were disqualifying too many families for failure to cooperate without making adequate efforts to reach them.

SSA Findings: SSA data show that on average 93% of termination decisions were both accurate and complete (i.e., they included all required documentation). This exceeds SSA's required level of overall state performance for SSI, which is 90.6%. However, 10 states had accuracy/completion rates below 90%. Another 9 states had accuracy/completion rates below the national average. (SSA's experience is that about one-third of the errors identified in these measures will ultimately prove to be accurate decisions that simply lacked documentation.) SSA found that many inaccurate decisions stem from an overly strict interpretation of the new rules for children who exhibit maladaptive behavior.

Claims that SSA did not acquire all needed documentation were determined to be largely unfounded. However, SSA found wide state variations in the percentage of children cut off because their families did not cooperate with the redetermination. In a study of such cessations, SSA found that 68% of the cases did not include documentation that all required efforts to contact the family had been made.

SSA also performed a regression analysis to determine whether wide state-to-state variations in overall termination rates should be expected because of legitimate factors, such as the child's age and impairment and whether the child was initially added to the rolls based on the less strict criteria eliminated by the welfare law. SSA found that these factors would lead you to expect the cutoff rate to vary from 40% in Idaho to 78% in Mississippi. While this regression analysis does not fully explain the actual state-by-state variance, it does convince SSA that most of the variance among states is due not to errors, but to characteristics of the children.

SSA Action: SSA will review a portion of the decisions in all states, focusing more on states with lower accuracy rates. All cases terminated as a result of failure to cooperate will be reviewed. SSA will also provide more training on maladaptive behavior.

III. Appeal Rights

Advocates' Charge: Too few families are appealing because SSA's notice to families was confusing, and workers discouraged appeals. Also, SSA discouraged families from requesting that benefits be continued during the appeal, and didn't do enough to publicize free legal services.

SSA Finding: SSA found that its workers did not discourage appeals, although this may have occurred in isolated instances. At the same time, a survey conducted by SSA confirms that many families did not understand their appeal rights.

SSA Action: All 70,000 families of children who were terminated and did not appeal will be given a new opportunity to do so. In addition, all families of children who appealed but did not request continuation of benefits during the appeal will also be given a new opportunity to make that request. SSA will also publicize the availability of free legal services for families.

Wednesday, February 5, 1997
For Immediate Release

Phil Gambino / Tom Margenau
410-965-8904 Fax 410-966-9973

News Release

Statement of
Shirley S. Chater, Commissioner of Social Security
on the
Release of New Childhood Disability Guidelines to Comply With Welfare Reform Provisions

"Today we are announcing the publication of regulations containing the guidelines we will use to determine if children with disabilities meet the new definition of disability outlined in the SSI provisions of the new welfare reform law.

Because disability is a very complex issue, formulating regulations to implement the law was an enormous task for SSA. The major challenge was to ensure that the intent of Congress was met while working within the framework established by Congress to add additional criteria to the rules to ensure continued benefit eligibility for severely disabled children and their families.

We have crafted policy guidelines that, I believe, meet the letter and spirit of the law while protecting the rights of children and families. I want to thank the many dedicated Social Security managers and employees who worked long and tirelessly to make this happen.

With the implementation of these new rules, we estimate that about 135,000 children will no longer be eligible for SSI benefits. This is consistent with the lower-range estimates made by the Congressional Budget Office.

SSA has notified about 263,000 children and their families that this change may affect them. We expect that approximately one-half of these children will continue to receive benefits when evaluated under the new rules. Although you may have seen news articles alleging

- More --

OPTIONAL FORM 99 (7-90)

FAX TRANSMITTAL # of pages ▶ 9

To Diane Fortuna
Dept./Agency
Fax # 202-456-7028
From Susan Daniels
Phone # 202-358-6044
Fax #

NSN 7540-01-317-7368 5099-101 GENERAL SERVICES ADMINISTRATION that children with impairments such as Downs Syndrome, severe mental retardation, autism, or many rare diseases will lose benefits. the new rules provide guidelines for evaluating severe impairments such as these to ensure that such children remain eligible for SSI benefits. In addition, these new rules include more guidance to ensure careful evaluations of children with physical impairments as well as children with severe impairments that re-occur despite periods of remission.

President Clinton has made it very clear that he wants to minimize any adverse consequences that this legislation might have on disabled children and their families. The President has proposed in the budget that Medicaid coverage continue for children who lose their SSI benefits as a result of this change in the definition of disability, so that the medical needs of these needy children and families continue to be met.

As this agency has always done, SSA will work with families to obtain evidence to substantiate the child's medical condition and if additional evidence is needed, SSA will pay for any consultative examinations that may be required. Also, the parents or guardians for all children have the right to appeal any decision we make. And in most cases, benefits can continue throughout the appeals process, until the child's representative has had the right to present his or her case in person before an administrative law judge.

Finally, I have asked my staff to develop plans to track the effects of the implementation of this law. If we discover that changes are necessary or desirable in the law, we will recommend revisions and improvements to the President.

We must now begin the challenging process of implementing these new guidelines in a fair and consistent manner across the country."

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SSA Press Office
2/5/97 9:00 a.m.

Talking Points

Welfare Reform and New Regulations Published Today Regarding Supplemental Security Income Payments for Disabled Children

Background

One provision of the Welfare Reform law passed last year changed the SSI definition of disability for children. The new law established a new definition of disability and ordered SSA to discontinue the use of an individualized functional assessment (IFA) process established after the landmark 1990 Zebley Supreme Court decision. This provision was included in welfare reform because Congress was concerned about the rapid growth in the program as the number of children on the benefit rolls grew from 350,000 to 965,000 between 1990 and 1996.

Following the law's passage, SSA had the enormous challenge of formulating regulations to implement the law, making sure the intent of Congress to tighten eligibility standards was met while ensuring that severely disabled children and their families would be protected under the new law. Today, SSA published in the Federal Register the new rules for determining disability for children.

Key Points

--Because disability is a complex issue, SSA faced a very challenging process to carefully develop policy guidelines that meet the letter of the law (a congressionally-mandated tightened definition of disability for children) and the spirit of the law (ensuring that severely disabled children are found eligible for benefits).

--Out of approximately 965,000 disabled children currently receiving benefits, SSA estimates that about 135,000 children will potentially lose monthly benefits that average about $425 per month. This number is consistent with the lower-range estimates made by the Congressional Budget Office. I understand that most of those affected can be broadly categorized as children with certain mental impairments, such as less severe learning disabilities or behavioral disorders.

--Although you may have seen news articles alleging that children with impairments such as Downs Syndrome, severe mental retardation, autism, or many rare diseases will lose benefits, the new rules provide guidelines for evaluating severe impairments such as these to ensure that such children remain eligible for SSI benefits. In addition, these new rules include more guidance to ensure careful evaluations of children with physical impairments as well as children with severe impairments that re-occur despite periods of remission.

--President Clinton has made it very clear that he wishes to minimize any adverse effects this legislation may have on children and families. Towards this end, the President has proposed that Medicaid coverage continue to children who lose their SSI benefits as a result of welfare reform, so that the medical needs of these needy children and families continue to be met. In addition, SSA is going to track the effects of the implementation of this law. If they discover that revisions or improvements in the new law are needed, they will recommend such changes to the President.

--SSA is committed to implementing the new rules in a fair and consistent manner across the U.S. SSA will obtain any evidence needed to substantiate a child's medical condition. In addition, parents or guardians of affected children will have the right to appeal any decision SSA makes and, in most cases, benefits can continue throughout the appeals process.

Possible Questions and Answers

By statute, the new eligibility standard for disabled children was to be published in the Federal Register by 11/22/96. Why did it take so long to issue these regulations?

A: Because these new rules will have a direct impact on thousands of low-income disabled children, it was essential that SSA take enough time to ensure that the new guidelines meet both the letter and spirit of the law in protecting the SSI eligibility for severely disabled children. Working within the general framework established by the Congress, SSA had to carefully examined all its eligibility criteria and, where desirable, add additional functional criteria to the standards to ensure that SSI eligibility for children with severe disabilities will be protected.

Q: How many disabled children will lose monthly payments? Who are the children that will loose benefits?

A: It is estimated that out of approximately 965,000 children currently on the rolls, about 135,000 children will no longer be eligible for SSI payments. (This number was in the low-range of the CBO estimates.) Those affected are children who were allowed benefits based on the individualized functional assessment (IFA) that was eliminated by the welfare reform law. Many can be broadly categorized as children with certain mental impairments, such as less severe learning disabilities and behavioral disorders.

Q: Was the President involved in the decision of the new disability standard?

A: Since the passage of welfare reform, the White House has been working with agency officials to ensure that all affected agencies implement the new law consistently and properly. As a result, SSA consulted with the White House in establishing the new standard, particularly to discuss policy and legal issues that arose. However, as the agency head, the Commissioner of Social Security has made the final decision on behalf of the President. The President fully supports that decision.

Q: How much money will be saved by the new rules? Was the budget a major consideration in establishing the new rules?

A: I understand that program savings of about $4.8 billion is estimated in the 6-year period starting with FY 1997. SSA has stated that budget implications were not a major consideration in establishing the new rules. SSA relied on the Statute itself as well as its legislative history.

Q: The advocates are arguing that the new standard is too strict and that Congress gave the agency much leeway in the Statute to establish a more lenient standard? Why such a strict interpretation?

A: It is my understanding that it was very clear from the welfare reform law and the legislative history that Congress meant to establish this severity standard in the new law. These new rules meet that legislative intent while including important additional elements to ensure that severely disabled children continue to be eligible for benefits.

Q. Is the President concerned about the affect of the new law on low-income disabled children? If so, what is he going to do about it?

A: Yes, the Administration is concerned and has taken several steps to limit any adverse consequences of the law. First, while meeting congressional intent, SSA worked within the framework established by Congress to add additional criteria to the new rules that ensure continued eligibility for severely disabled children. (The 135,000 number of expected benefit terminations was in the low range of CBO estimates for the law.) Second, the President has proposed that Medicaid coverage continue for children who lose SSI benefits as a result of welfare reform, so that the medical needs of families continue to be met. Third, SSA will be tracking the effects of the implementation of the new law. If they discover that changes are needed in the law, they will recommend such changes to the President.

SSA Press Office
2/5/97 9:00 a.m.

A Fact Sheet on Welfare Reform and SSI Childhood Disability

Background

One provision of the Welfare Reform law passed last year changed the SSI definition of disability for children, completely separating it from the definition of disability for an adult. The basic definition of disability for the Supplemental Security Income program for an adult states that a person must have a condition that is severe enough to prevent him or her from doing substantial work and is expected to last for at least 12 months -- or result in death.

SSA uses a multi-step process to decide if an adult meets this definition of disability. One of the most common steps involves the use of a set of evaluation guidelines that contain a list of impairments for each major body system (including mental impairments) that are so severe they automatically mean a person is disabled. If a condition does not meet the criteria on the list, or cannot be considered equal in severity to a condition on the list, then the agency considers vocational factors (age, education, and work experience) to decide if a person has a condition that prevents him or her from working, thus qualifying that person for disability benefits.

Because children, especially younger children, generally do not work, the vocational steps in the disability evaluation process do not apply to them. So, until 1990, the final decision about a child's disability was based on the criteria in the Listing of Impairments. A 1990 Supreme Court decision ordered SSA to develop another step in the evaluation process, analogous to the vocational rules used for adults, that would consider a child's ability or inability to function in a manner similar to children of the same age. In response to the Court's decision, SSA developed a process known as the Individualized Functional Assessment (IFA).

Between 1990 and 1996, the number of children eligible for SSI benefits increased from approximately 350,000 to more than 965,000. About one-third of the children entitled during this period were entitled based on the IFA. In addition, there were anecdotal reports of parents coaching children to qualify for benefits, although studies by SSA, the Office of the Inspector General, and the General Accounting Office did not find any evidence of fraud and abuse.

The Welfare Reform Act

On August 22, 1996, the Welfare Reform Act was enacted. One of its provisions changed the SSI definition of disability for children. The new law states that a child's impairment--or combination of impairments--will be considered disabling if it causes "marked and severe functional limitations." The new law established a new definition of disability for children and ordered SSA to discontinue the use of the IFA.

Because disability is a complex issue, formulating regulations to implement the law was an enormous task. The major challenge was to ensure that the intent of Congress was met while working within the framework established by Congress to add additional criteria to the rules that ensure continued benefit eligibility for severely disabled children. In addition to it's own disability policy specialists, SSA consulted with administration and congressional colleagues. The result is a set of policy guidelines that meet the letter and spirit of the law while protecting the rights of children and families.

The New Disability Standard

Under the welfare reform law, a child's impairment, or combination of impairments, is disabling if it causes "marked and severe functional limitations." Congress eliminated the IFA process and the language in the conference report clearly indicated that SSA should use listing-level severity as the test for entitlement to benefits. The new law and the conference report language also emphasized the importance of functional assessments.

The new rules, therefore, define listing-level severity for functional limitations. The severity of an impairment in the listings is generally shown by a) "marked" limitations in either two broad areas of functioning, such as social functioning and personal functioning; or b) extreme limitations in one area of functioning, such as inability to walk.

The new rules reflect both the letter and spirit of the law. They provide an accurate mechanism to ensure that needy children with severe disabilities continue to qualify for SSI payments while fairly implementing the intent of Congress.

While eliminating the IFA, and incorporating other specified changes in the listings, the new rules incorporate several features that will help to better evaluate children under the new law. The new rules add an area of "motor" functioning to ensure that limitations from physical conditions are not overlooked. The new rules also emphasize the importance of "functional equivalence" by providing guidelines that direct disability evaluators to consider conditions that are not necessarily defined in the listings, but are as severe as a condition in the listings. For example, guidance is included on the evaluation of chronic, episodic impairments in children, which can be severe but difficult to evaluate. Finally, a new form has been created to guide decision-makers through the new rules to ensure consistency in applying the criteria.

Who is affected?

SSA estimates that about 135,000 children, out of approximately 965,000 children who currently receive SSI, will no longer be eligible for monthly benefits. This is consistent with the lower-range estimates made by the Congressional Budget Office.

Most of the children affected by the new definition of disability can be broadly categorized as those with certain mental impairments, such as less severe learning disabilities and behavioral disorders.

Although some news articles have alleged that children with impairments such as Downs Syndrome, severe mental retardation, autism, or many rare diseases will lose benefits, the new rules provide guidelines for evaluating severe impairments such as these to ensure that such children remain eligible for SSI benefits. In addition, these new rules include more guidance to ensure careful evaluations of children with physical impairments as well children with severe impairments that re-occur despite periods of remission.

Implementing the new guidelines

One of SSA's highest priorities over the next several months will be to make sure that the new disability guidelines are implemented fairly and consistently across the country.

SSA was required to notify the parents or guardians of children already getting SSI benefits who are potentially affected by the welfare reform bill by January 1, 1997. Last December, SSA sent letters to about 263,000 children who may have their cases reviewed using the new guidelines.

During February 1997, SSA personnel will be trained on the new procedures. By mid-month, SSA will begin interviewing the parents or guardians of the children affected to get current information about their medical conditions.

If additional medical or other evidence is necessary to determine if the child is still disabled under the new law, SSA will obtain the necessary evidence. The first decisions will go out in March and continue going out throughout this fiscal year.

Under the law, no benefits will be stopped before July 1, 1997. Letters sent to the parents or guardians of children no longer considered disabled under the new law will explain their appeal rights, including the fact that benefits can continue during the appeals process until a face-to-face hearing is held before an administrative law judge.

Administration Safeguards to Ease the Transition for Families

President Clinton has made it very clear that he wishes to minimize any adverse effects this legislation may have on disabled children and their families. The President has proposed that Medicaid coverage continue to children who lose their

SSI benefits as a result of welfare reform, so that the medical needs of needy children and families continue to be met.

In addition, SSA is working on procedures to track the effects of the implementation of this law. If the agency discovers that changes are needed in the new law, they will recommend revisions and improvements to the President.

Source: SSA Press Office
Last updated: 2/5/97
9:00 a.m.

Richard
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160,000 – Kids currently 2002
– new snapshot

70,000 current
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FACSIMILE SHEET####################

SOCIAL SECURITY ADMINISTRATION

Office of the Commissioner
Suite 823, 500 E Street, SW,
Washington, DC 20254-0001

Bruce/
Elena

Perrin

Date: 2/4/97

Number of Pages: 9

From: **Brian D. Coyne**

Chief of Staff

Telephone Number: (202) 358-6013

Fax Number: (202) 358-6076

To: Diana Fortuna

Location/Organization:

Telephone Number:

Fax Number: 456-7431

Message: — Revised Sheets —

- Timeline
- Kids
- outreach?

Tuesday, February 4, 1997
For Immediate Release

Phil Gambino / Tom Margenau
410-965-8904 Fax 410-966-9973

News Release

SOCIAL SECURITY

DRAFT DRAFT

Statement of Shirley S. Chater, Commissioner of Social Security on the Release of New Childhood Disability Guidelines to Comply With Welfare Reform Provisions

"Today we are announcing the publication of regulations containing the guidelines we will use to determine if children with disabilities meet the new definition of disability outlined in the SSI provisions of the new welfare reform law.

Because disability is a very complex issue, formulating regulations to implement the law was an enormous task for SSA. The major challenge was to ensure that the intent of Congress was met while working within the framework established by Congress to add additional criteria to the rules to ensure continued benefit eligibility for severely disabled children and their families.

We have crafted policy guidelines that, I believe, meet the letter and spirit of the law while protecting the rights of children and families. I want to thank the many dedicated Social Security managers and employees who worked long and tirelessly to make this happen.

With the implementation of these new rules, we estimate that about 135,000 children will no longer be eligible for SSI benefits. This is consistent with the lower-range estimates made by the Congressional Budget Office.

Ken

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MR

President Clinton has made it very clear that he wants to minimize any adverse consequences that this legislation might have on disabled children and their families. The President ~~has~~ will proposed ~~legislation~~ in the budget that Medicaid coverage continue for children who lose their SSI benefits as a result of ~~welfare reform~~, so that the medical needs of these needy children and families continue to be met.

? Ken

~~has included~~

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SSA will obtain evidence to substantiate the child's medical condition. Also, the parents or guardians for all children have the right to appeal any decision we make. And in most cases, benefits can continue throughout the appeals process, until the child's representative has had the right to present his or her case in person before an administrative law judge.

pay for exams

Finally, I have asked my staff to develop plans to track the effects of the implementation of this law. If we discover that changes are necessary or desirable in the law, we will recommend revisions and improvements to the President.

We must now begin the challenging process of implementing these new guidelines in a fair and consistent manner across the country."

\# # #

outreach?

SSA Press Office
2/4/97 11:00 a.m.

Internal

Talking Points

Welfare Reform and New Regulations Published Today Regarding Supplemental Security Income Payments for Disabled Children

Background

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Key Points

--Because disability is a complex issue, SSA faced a very challenging process to carefully develop policy guidelines that meet the letter of the law (a congressionally-mandated tightened definition of disability for children) and the spirit of the law ~~(protecting the rights of disabled children and their families)~~. NO

ensuring [illegible] severely dis ch are st elig at time of enactment

--Out of approximately 950,000 disabled children currently receiving benefits, SSA estimates that about 135,000 children will potentially lose monthly benefits that average about $425 per month. This number is consistent with the lower-range estimates made by the Congressional Budget Office. I understand that most of those affected can be broadly categorized as children with certain mental impairments, such as less severe learning disabilities or behavioral disorders.

--Although you may have seen news articles alleging that children with severe impairments such as Downs Syndrome, mental retardation, autism, or rare diseases will lose benefits, the new rules provide guidelines for evaluating severe impairments such as these to ensure that such children remain eligible for SSI benefits. In addition, these new rules include more guidance to ensure careful evaluations of children with physical impairments as well as impairments that re-occur despite periods of remission. ch w/ sev.

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is

--SSA has informed the President that they are committed to implementing the new rules in a fair and consistent manner across the U.S. SSA will obtain any evidence needed to substantiate a child's medical condition. In addition, parents or guardians of affected children will have the right to appeal any decision SSA makes and, in most cases, benefits can continue throughout the appeals process. [illegible] ?

Possible Questions and Answers

By statute, the new eligibility standard for disabled children was to be published in the Federal Register by 11/22/96. Why did it take so long to issue these regulations?

in protecting

A: Because these new rules will have a direct impact on thousands of low-income disabled children, it was essential that SSA take enough time to ensure that the new guidelines meet both the letter and spirit of the law ~~and at the same time~~ protect the SSI eligibility for severely disabled children. Working within the general framework established by the Congress, SSA had to carefully examined all its ~~medical~~ criteria and, where desirable, add additional functional criteria to the standards to ensure that SSI eligibility for children with severe disabilities will be protected. ??

elig

Q: How many disabled children will lose monthly payments? Who are the children that will loose benefits?

A: It is estimated that out of approximately 950,000 children currently on the rolls, about 135,000 children will no longer be eligible for SSI payments. (This number was in the low-range of the CBO estimates.) ~~The majority of~~ those affected are children who were allowed benefits based on the individualized functional assessment (IFA) that was eliminated by the welfare reform law. Many can be broadly categorized as children with certain mental impairments, such as less severe learning disabilities and behavioral disorders. ?All?

Q: Was the President involved in the decision of the new disability standard?

A: Since the passage of welfare reform, the White House has been working with agency officials to ensure that all affected agencies implement the new law consistently and properly. As a result, SSA consulted with the White House in establishing the new standard, particularly to discuss policy and legal issues that arose. However, as the agency head, the Commissioner of Social Security has made the final decision on behalf of the President. The President fully supports that

Ken

decision.

Q: How much money will be saved by the new rules? Was the budget a major consideration in establishing the new rules?

A: I understand that program savings of about ~~$5~~ 4.6 billion is estimated in the 6-year period starting with FY 1997. SSA has stated that budget implications were not a major consideration in establishing the new rules. ~~However~~, SSA did rely on the Statute itself as well as its legislative history. ?

Q: The advocates are arguing that the new standard is too strict and that Congress gave the agency much leeway in the Statute to establish a more lenient standard? Why such a strict interpretation?

A: It is my understanding that it was very clear from the welfare reform law and the legislative history that Congress meant to establish this severity standard in the new law. These new rules meet that legislative intent while including important additional elements to ensure that severely disabled children continue to be eligible for benefits. ✓

Q. Is the President concerned about the affect of the new law on low-income disabled children? If so, what is he going to do about it?

A: Yes, the ~~President~~ Adm is concerned and has taken ~~numerous~~ Several No steps to ~~limit~~ minimize any adverse consequences of the law. First, while meeting congressional intent, SSA worked within the framework established by Congress to add additional criteria to the new rules that ensure continued eligibility for severely disabled children. (The 135,000 number of expected benefit terminations was in the low range of CBO estimates for the law.) Second, the President has proposed that Medicaid coverage continue for children who lose SSI benefits as a result of welfare reform, so that the medical needs of families continue to be met. Third, SSA will be tracking the effects ~~progress and development of those children~~ that lose benefits based on the new law. If they discover that changes are needed in the law, they will recommend such changes to the President.

SSA Press Office
2/4/97 11:00 a.m.

RG
(exact capture)

A Fact Sheet on Welfare Reform and SSI Childhood Disability

Richard
for an adult

Background

One provision of the Welfare Reform law passed last year changed the SSI definition of disability for children. The basic definition of disability for the Supplemental Security Income program states that a person must have a condition that is severe enough to prevent him or her from doing substantial work and is expected to last for at least 12 months -- or result in death.

SSA uses a multi-step process to decide if an adult meets this definition of disability. One of the most common steps involves the use of a set of evaluation guidelines that contain a list of impairments for each major body system (including mental impairments) that are so severe they automatically mean a person is disabled. If a condition does not meet the criteria on the list, or cannot be considered equal in severity to a condition on the list, then the agency considers vocational factors (age, education, and work experience) to decide if a person has a condition that prevents him or her from working, thus qualifying that person for disability benefits.

Still
long

Because children, especially younger children, generally do not work, the vocational steps in the disability evaluation process do not apply to them. So, until 1990, the final decision about a child's disability was based on the criteria in the Listing of Impairments. A 1990 Supreme Court decision ordered SSA to develop another step in the evaluation process, analogous to the vocational rules used for adults, that would consider a child's ability or inability to function in a manner similar to children of the same age. In response to the Court's decision, SSA developed a process known as the Individualized Functional Assessment (IFA).

Between 1990 and 1996, the number of children eligible for SSI benefits increased from approximately 350,000 to more than 950,000. Only about one-third of the children entitled during this period were entitled based on the IFA. In addition, there were anecdotal reports of parents coaching children to qualify for benefits, although studies by SSA, the Office of the Inspector General, and the General Accounting Office did not find any evidence of fraud and abuse.

why

The Welfare Reform Act

On August 22, 1996, the Welfare Reform Act was enacted. One of its provisions changed the SSI definition of disability for children. The new law states that a child's impairment--or combination of impairments--will be considered disabling if it causes "marked and severe functional limitations." The new law ordered SSA to discontinue the use of the IFA process and, to establish a new definition ~~of~~ disability for children.

U>

Because disability is a complex issue, formulating regulations to implement the law was an enormous task. The major challenge was to ensure that the intent of Congress was met while working within the framework established by Congress to add additional criteria to the rules that ensure continued benefit eligibility for severely disabled children. In addition to it's own disability policy specialists, SSA consulted with administration and congressional colleagues. The result is a set of policy guidelines that meet the letter and spirit of the law while protecting the rights of children and families.

The new regulations will be submitted to Congress for their review as required under the law. Add: new 6– Mngd immed,

The New Disability Standard

Under the welfare reform law, a child's impairment, or combination of impairments, is disabling if it causes "marked and severe functional limitations." Congress eliminated the IFA process and the language in the conference report clearly indicated that SSA should use listing-level severity as the test for entitlement to benefits. The new law and the conference report language also emphasized the importance of functional assessments. might as well

The new rules, therefore, define listing-level severity for functional limitations. The severity of an impairment in the listings is generally shown by (a) "marked" limitations in either a) two broad areas of functioning, such as social functioning and personal functioning; or b) extreme limitations in one area of functioning, such as inability to walk. *

The new rules reflect both the letter and spirit of the law. They provide an accurate mechanism to ensure that needy children with severe disabilities continue to qualify for SSI payments while fairly implementing the intent of Congress.

While eliminating the IFA, and incorporating other specified changes in the listings, the new rules incorporate several features that will help to improve/better evaluate children under the new law. The new rules add an area of "motor" functioning to ensure that limitations from physical conditions are not overlooked. The new rules also emphasize the importance of "functional equivalence" by providing guidelines that direct disability evaluators to consider conditions that are not necessarily defined in the listings, but are as severe as a condition in the listings. For example, guidance is included on the evaluation of chronic, episodic impairments in children, which can be severe but difficult to evaluate. Finally, a new form has been created to guide decision-makers through the new rules to ensure consistency in applying the criteria.

Who is affected?

SSA estimates that about 135,000 children, out of approximately 950,000 children who currently receive SSI, will no longer be eligible for monthly benefits. This is consistent with the lower-range estimates made by the Congressional Budget Office.

Most of the children affected by the new definition of disability can be broadly categorized as those with certain mental impairments, such as less severe learning disabilities and behavioral disorders.

Although some news articles have alleged that children with severe impairments such as Downs Syndrome, mental retardation, autism, or rare diseases will lose benefits, the new rules provide guidelines for evaluating severe impairments such as these to ensure that such children remain eligible for SSI benefits. In addition, these new rules include more guidance to ensure careful evaluations of children with physical impairments as well impairments that re-occur despite periods of remission.

Implementing the new guidelines

One of SSA's highest priorities over the next several months will be to make sure that the new disability guidelines are implemented fairly and consistently across the country.

SSA was required to notify the parents or guardians of children already getting SSI benefits who are potentially affected by the welfare reform bill by January 1, 1997. Last December, SSA sent letters to about 263,000 children who may have their cases reviewed using the new guidelines.

During early February 1997, now SSA personnel will be trained on the new procedures. By mid-month, SSA will begin interviewing the parents or guardians of the children affected to get current information about their medical conditions.

If additional medical or other evidence is necessary to determine if the child is still disabled under the new law, SSA will obtain the necessary evidence. The first decisions will go out in March and continue going out throughout this fiscal year.

Under the law, no benefits will be stopped before July 1, 1997. Letters sent to the parents or guardians of children no longer considered disabled under the new law will explain their appeal rights, including the fact that benefits can continue during the appeals process until a face-to-face hearing is held before an administrative law judge.

Administration Safeguards to Ease the Transition for Families

President Clinton has made it very clear that he wishes to minimize any adverse effects this legislation may have on disabled children and their families. The President has proposed that Medicaid coverage continue to children who lose their SSI benefits as a result of welfare reform, so that the medical needs of needy children and families continue to be met.

In addition, SSA the Administration is working on procedures to track the effects of the implementation of this law. If the agency discovers that changes are needed in the new law, they will recommend revisions and improvements to the President.

Source: SSA Press Office
Last updated: 2/4/97
11:00 a.m.

TO: Diane F.
other
(RTW) list
for briefings

January 29, 1997

NOTE TO KEN McGILL

Subject: OComm List for Use in Inviting National Organizations to Attend Briefings on the SSA Alternative Rehabilitation Provider Initiatives--INFORMATION

The liaison staff in the Office of National Affairs has compiled the attached list of organizations for your use. They believe that these organizations would be interested in being included in briefings on the new alternative provider rehabilitation program initiatives. They have also suggested that Susan Daniels, Associate Commissioner for Disability, would be the most logical SSA spokesperson at these briefings, and we believe she could do an outstanding job of explaining the regulations as well.

Should you have questions, please contact me or Martha Seabrooks in OComm (who compiled the list for the OComm Disability Programs and Welfare Reform Team).

Fred

Fred Crawford

cc:
Charles Fosler
Martha Seabrooks.

Scott Marshall, Director of Public Relations
American Foundation for the Blind
(202) 457-1487
1615 M Street, NW
Suite 250
Washington, DC 20036

Judith Moore, President and CEO
National Industries for the Blind
(703) 9980770
1901 North Beauregard Street
Suite 200
Alexandria, Virginia 22311-1727

Marc Maurer, President
National Federation of the Blind
(410) 659-9314
1800 Johnson Street
Baltimore, Maryland 21230

Leroy F. Saunders, President
American Council of the Blind
(202) 467-5081
1155 15th Street, NW
Suite 720
Washington, DC 20005

National Association of the Deaf;
(410) 587-1788
814 Thayer Avenue
Silver Spring, Maryland 20910

Self Help for Hard of Hearing People, Inc.;
(301) 657-2249
7910 Woodmont Avenue
Bethesda, Maryland 20814

American Society for Deaf Children
(800) 942-2732
2848 Arden Way
Suite 210
Sacremento, California 93825-1373
(though its headquarters is in Sacramento, CA, this office has a representative in the D.C. area and this group is and has been very vocal about the welfare reform and the childhood benefits)

Northern Virginia Resource Center for Deaf and Hard of Hearing Persons
(703) 352-9055

Association of Late-Deafened Adults
(815) 899-3040
10310 Main Street
Box 274

Fairfax, Virginia 22030

Center for the Study of Social Policy
1250 Eye Street NW Suite 503
Washington DC 20009
Tom Joe Director
p 202 371-1565
f 212 371-1472

Center on Social Welfare Policy and Law
275 Seventh Avenue
Suite 1205
New York, NY 10001-6708
p 212 633-6967
f 212 633-6371

Council on Social Work Education
1600 Duke Street Suite 300
Alexandria, VA 22314
Donald W Beless Ph.D., Executive Director
p 703 683-8080
f 703 683-8099

Families, USA Families
1334 G Street, NW
Washington DC 2005
Phyllis Torda
Director, Health and Social Policy
Ronald F. Pollack, President
p 202 628-3030
f 202 347-2417

Family Service America
11700 W Lake Park Drive
Milwaukee, WI 53224
Peter Goldberg CEO & President
p (414) 359 1040

Nat'l Assoc of Public Child Welfare Admin
C/O Amer Public Welfare
810 First Street, NE
Suite 500
Washington, DC 20002-4267
Elizabeth Thielman, Project Manager
p (202) 682-0100
f (202) 289-6555

Nat'l Assoc of Social Workers
750 First Street
Washington, DC 20002-4241
Sheldon Goldstein, Exec Dir
p (202) 408-8600
f (202) 336-8312

Amer Assoc on Mental Retardation*
M.Doreen Croser,Exec. Dir.
444 N. Capitol St., NW, Ste. 846
Washington, DC 20001-1512

Amer Diabetes Association
Myrl Weinberg
Dir.Gov't. Affairs
1660 Duke St., P.O.Box 25757
Alexandria, VA 22314

Arc*
Marty Ford
Asst Dir, Gov Affair
1730 K Street, NW, Suite 1212
Washington, DC 20006

Autism Society of America*
Veronica Zysk
Administrative Dir
7910 Woodmont Ave., Ste. 650
Bethesda, MD 20814

Bazelon Center for Mental Health Law
Rhoda Schulzinger
1101 15th Street, NW, Suite 1212
Washington DC 20005

Brain Injury Association
Alice Demichelis
Legislative Liaison
1776 Massachusetts Ave., NW, Suite 100
Washington, DC 20036

Consortium for Citizens with Disabilities*
Marty Ford
Co-Chair, SSA Task F
c/o The Arc, 1522 K Street, NW, Suite 516
Washington, DC 20005

Disabled American Veterans*
Arthur Wilson
Natl. Adjutant
807 Maine Avenue, SW
Washington, DC 20024

Epilepsy Foundation of America
Paulette Maehara
CEO
4351 Garden City Drive, Suite 406
Landover, MD 20785

Learning Disabilities Assoc of Amer
Justine Maloney

4156 Library Road
Pittsburgh, PA 15234

Muscular Dystrophy Association
Robert Fitzgerald
Human Resources Dir
3300 E. Sunrise Drive
Tucson, AZ 85718

Nat'l Alliance for Mentally Ill
Laurie M. Flynn
Executive Director
2101 Wilson Blvd., Ste. 302
Arlington, VA 22201

Nat'l Assoc of Developmental Dis Coucil
Chris Metzler
Asst Exec Dir
1234 Massachusetts Ave., NW, Suite 103
Washington, DC 20005

Nat'l Assoc of Protection & Advocacy System
Vicki Smith
Deputy Dir
900 2nd Street, NE, Suite 211
Washington, DC 20002

Nat'l Assoc of St Dir of Dev Disabled Servs
Robert M. Gettings
Executive Director
113 Oronoco Street
Alexandria, VA 22314

Nat'l Assoc of St Mental Hlth Prog Dir
Robert Glover
Executive Director
66 Canal Center Plz, Suite 302
Alexandria, VA 22314-1591

Nat'l Down Syndrome Congress*
Michael Leonard
1605 Chantilly Dr., Ste. 250
Atlanta, GA 30324-1146

Nat'l Easter Seal Society*
Randy Rutta
VP Govt Affairs
700 13th St., NW
Washington, DC 20005

Nat'l Mental Health Association
Al Guida
VP Gov Affairs
1021 Prince Street

Alexandria, VA 22314-2971

Nat'l Multiple Sclerosis Society*
Robert Enteen
Public Policy Assoc.
733 3rd Ave.
New York, NY 10017

Nat'l Org of Soc Sec Claimants' Reps
Cathy Thompson
Staff
6 Prospect Street
Midland Park, NJ 07432

Nat'l Senior Citizens Law Center
Ethel Zelenske
Staff Attorney
1815 H Street, NW, Suite 700
Washington, DC 20006

Paralyzed Veterans of America*
Gordon Mansfield
Executive Director
801 18th Street, NW
Washington, DC 20006

FAX COVER SHEET

OFFICE OF LEGISLATIVE & INTER-GOVERNMENTAL AFFAIRS

Number of Pages: cover + 1

Date: 2/5/97

To: Diana Fortuna

From: Jennie Bonney

Fax:

Fax: 202-690-8168

Phone:

Phone:

REMARKS: FYI - here is SSAs write up of the health provisions. I dont have anything on the "ticket."

HEALTH CARE FINANCING ADMINISTRATION
200 Independence Ave., SW
Room 341-H, Humphrey Building
Washington, DC 20201

DRAFT

The Right Incentive: Health Care Security

Additionally, the Health Care Financing Administration will propose to create more health care access for beneficiaries who return to work. For Medicare, the proposal would extend Part-A coverage premium free for those who work beyond the current coverage period during a 4-year demonstration. For Medicaid, States would have an option to extend Medicaid coverage for people who work beyond current coverage levels. States would be allowed to create a sliding-scale premium for those individuals who choose this coverage.

These proposals represent a new opportunity for people with disabilities to make the move from dependence to independence. With greater access to and confidence in the stability of health care and more choice and flexibility in employment services, Americans with disabilities will have greater opportunities for productive and secure lives.

FAx to
Jennie Bonney
FAx 202-690-8168

Jennie - look OK to you?

OPTIONAL FORM 99 (7-90)

FAX TRANSMITTAL

	# of pages ▸ 1
To Jennie Bonney	From Ken McGill
Dept./Agency	Phone # 410-965-3988
Fax # 202-690-8168	Fax # 410-966-8597

NSN 7540-01-317-7368 5099-101 GENERAL SERVICES ADMINISTRATION

Fact Sheet

Social Security Proposes "Ticket to Independence" for Disabled Beneficiaries:

Background: The Social Security Administration (SSA) now pays more than $36 billion a year in disability insurance benefits to 4.5 million disabled workers, and pays $25 billion a year in Supplemental Security Income to more than 5 million low-income people with disabilities. Today Social Security refers disabled beneficiaries to State vocational rehabilitation agencies. SSA reimburses these State agencies for their costs in providing rehabilitation services when the beneficiary works for nine months. Last year SSA paid state VR agencies about $71 million for approximately 6,000 disabled beneficiaries who returned to work.

Proposal: The President's fiscal year 1998 budget proposes a new initiative, in partnership with the private sector, to help more beneficiaries achieve their goals of leaving the benefit rolls and returning to work. SSA will begin in five to ten states to pilot the new approach:

Consumer Choice: Disabled beneficiaries will receive a "ticket to independence" to use with any participating public or private employment or rehabilitation provider of their choice.

Paying for Results: The provider will be paid when the beneficiary works and no longer receives cash benefits.

Health Care Incentives: Disabled beneficiaries will have more secure health care coverage. A demonstration project will extend Medicare beyond the current-law maximum for some beneficiaries returning to work. For SSI beneficiaries who work, States would have the option to extend Medicaid coverage beyond current-law limits as well.

Advantages over current law:

- Creates a public-private partnership between Social Security and private employment/VR agencies with the goal of returning beneficiaries to work.
- Offers potentially significant savings to the Social Security trust funds by helping Americans with disabilities to work.
- Gives beneficiaries the control and flexibility they need in securing VR services.
- Minimizes bureaucratic involvement in the choice of providers and services.

Feb. 4, 1997

OPTIONAL FORM 99 (7 90)

FAX TRANSMITTAL

# of pages ▶ 3

To Diana Fortuna	From Susan Daniels
Dept./Agency	Phone #
Fax # 456-7028	Fax # [illegible]

NSN 7540-01-317-7368

Thursday, February 6, 1997
For Immediate Release

Phil Gambino / Tom Margenau
410-965-8904 Fax 410-966-9973

News Release

SOCIAL SECURITY

SSA Proposes A "Ticket To Independence" For Disabled

Today, when you sign up for disability benefits with Social Security, you may get a referral to a state agency for possible vocational rehabilitation services. In the near future, instead you'll get a "ticket to independence" you can take to a private or public vocational agency in exchange for help in finding work.

The President's fiscal year 1998 budget proposes a bold new initiative to leverage innovation in the private sector to help more beneficiaries achieve their goals, to leave the benefit rolls, and return to work. SSA will begin to pilot this new approach in five to ten states. Here are the highlights:

Consumer Choice: Disabled beneficiaries will receive a "ticket to independence" to use with any participating public or private employment or rehabilitation provider of their choice.
Paying for Results: The provider will be paid when the beneficiary works and no longer receives cash benefits.
The Right Incentives: Disabled beneficiaries will have more secure health care coverage. A demonstration project will extend Medicare beyond the current law maximum for some beneficiaries who return to work. For SSI beneficiaries who work, states would have the option to extend Medicaid beyond current law limits as well.

Shirley S. Chater, Commissioner of Social Security, called the proposal an important step in fulfilling the President's vision of leveraging private sector initiative to better serve its customers. Also, it will help the President achieve his goal of moving people from exclusion and paternalism to inclusion and empowerment. "President Clinton has said he wants people to be less dependent on government," Chater said. "Our plan is to give disabled Americans who want to work a ticket to independence."

-- More --

-- Page 2 --

Recognizing that SSA's current work incentive programs simply were not doing the job -- less than one percent of the approximately 8 million disability recipients successfully return to work each year -- Chater asked her disability managers and staff in 1994 to develop a plan to help disability recipients return to the workplace. After listening to people with disabilities and their advocates, vocational and rehabilitation counselors, as well as employers and other government agencies, SSA developed this unique approach to helping people get off the disability rolls and on the job.

Here's how it will work: Once an individual's disability claim is approved, he or she may be given a return to work ticket which can be presented to any approved provider in exchange for employment
or rehabilitation services. SSA will pay for results. If the beneficiary returns to work and stops receiving disability benefits, the provider will receive a payment.

SSA's return to work policies include other incentives that encourage employment. For example, beneficiaries who try working can keep receiving full monthly disability payments for up to a year after they start a job. And generally, disability recipients who return to work can keep their medicare or medicaid coverage for a number of years after returning to work.

"Many of our customers with disabilities tell us they can work if the incentives are right and if the services they need are available," Chater said. "With this plan, we are creating new ways of helping people find work and achieve their goals."

The return to work ticket and other incentives apply to both disability programs administered by SSA. The Social Security disability insurance program pays more than $36 billion annually to almost four and one-half million people. The Supplemental Security Income disability program pays $25 billion each year to more than five million low-income individuals with disabilities.

# # #

ODCLCA QUICK FAX

(202)358-6030- Voice / (202 358-6074/6075- Fax)

2/4/97

TO: Diana Fortuna

FROM: Judy Chesser

COVER + 11 **pages**

COMMENTS:

This form is produced on reused paper

FAX TO: Diana Fortuna.

Author: William Daly at -SADC
Date: 1/30/97 5:00 PM
Priority: Normal
TO: Frank Jasmine
Subject: disability list

Contacts. for children's regs.

------------------------------ Message Contents ------------------------------

attached

Accreditation Council--People w/Dev.Disabil
Pres., James Gardner, Ph.D. CEO8100 Professional Place, Suite 204
Landover, MD 20785-2225

Alliance of Genetic Support Groups
Joseph Smith
38th and R Streets, NW
Washington, DC 20007

Pres., Joan O. Weiss
Amer. Acad. of Otolarynology-Head & Neck
Joseph Goldstein
One Prince Street
Alexandria, VA 22316

Amer. Assoc. for Counseling & Development
John Jaco
Govt. Relations Office,
5999 Stevenson Ave.
Alexandria, VA 22304

Pres., Doris Cox
Amer Assoc on Mental Retardation
M Doreen Croser
Exec Dir
444 N. Capital Street, NW, Ste. 846

Amer. Assoc. of Univ. Affiliated Programs
Elaina Eklund, Assoc. Exec. Director
8630 Fenton Street, Suite 410
Silver Spring, MD 20910

Pres., William Jones
Amer. Athletic Association of the Deaf
1052 Darling Street
Ogden, Utah 84403

Amer Council of the Blind
Glen Plunkett
1155 15th Street, NW, Suite 720
Washington, DC 20005

Pres., Leory F. Saunders
Amer. Diabetes Association
Myrl Weinberg, Dir of Gov't Affairs
1660 Duke St., P.O. Box 25757
Alexandria, VA 22314

Amer. Fndn. for the Blind*
Scott Marshall
Dir., Govt. Relations
1615 M Street, NW, Suite 250
Washington, DC 20036

Amer. Horticultural Therapy Association
Mary DeRiso
9200 Wightman Rd., Suite 400
Gaithersburg, MD 20901
Pres., Steven Davis

Amer Network of Community Options and Resources
Aause Righter
4200 Evergreen Lane, Suite 315
Annadale, VA 22003
Pres, Joni Fritz

Amer Occupational Therapy Association
Frederick Somers
1383 Piccard Dr., P O. Box 31220
Rockville, MD 20824-1220
Pres., Jeanette Bair

Amer. Red Cross
17th and D Streets, NW
Washington, DC 20006

Amer. Soc. For Deaf Children
Pres., Jeffery Cohen
814 Thayer Avenue
Silver Spring, MD 20910

Amer Speech-Language-Hearing Associati
Dr. Frederick T. Spahr
10801 Rockville Pike
Rockville, MD 20852

Amer. Tinnitus Association
Pres., Gloria E. Reich
P.O. Box 5
Portland, OR 97207

Assoc. for Education & Rehab.of the Blind& Vis Imp
Pres., Kathy Megivern
Executive Director
206 N Washington Street, Suite 320
Alexandria, VA 22314

Assoc. for Persons in Supported Employm
Pres., Wendy Wood
Tammara Geary Freeman, Executive Director
1627 Monument Street, Suite 301
Richmond, VA 23220

The Arc
Marty Ford
Asstn Dir, Gov Affairs

1730 K Street, NW Suite 1212
Washington, DC 20006

Arthritis Foundation
1314 Spriong Street, NW
Atlanta, GA 30309

Assoc. for Persons with Severe Disabilities
Celane McWhorter
206 W. Glendale Ave
Alexandria, VA 22301-2405
Pres., Liz Lindley

Assoc. of Late Deafened Adults
Pres., Bill Graham
P.O. Box 64173
Chicago, Il. 60664

Autism Society of America
Veronica Zysk, Administrative Dir
7910 Woodmont Ave, Ste. 650
Bethesda, MD 20814

Better Hearing Institute
Pres., Joseph Rizzo
5021-B Backlick Road
Annandale, VA 22003

Caption Center
Pres., Larry Goldberg
125 Western Avenue
Boston, MA 02134

Captioned Films/Videos f/t Deaf
Pres., Don Zink
5000 Park Street North
St. Petersburg, FL 33709

Conv of Amer Intructors of the Deaf
Pres., Claire Bugen
P.O. Box 2025
Austin, TX 78768

Catholic Charities USA
Deputy to the Pres., Sharon Daly
1731 King St., Suite 200
Alexandria, VA 22314

Coun. of State Admin of Vocational Rehab.
Joseph Owen, Executive Director
P.O. Box 3776
Washington, DC 20007

Ctr. for BiCultural Studies, Inc.
Betty Colonomos, Director
SSQC. Yenilwarth Ave., Suite 105
Riverdale, MD 20737

Deaf Artist of America, Inc.
Pres , Tom Willard
87 North Clinton Avenue Suite 408
Rochester. NY 14604

Deafness & Communicative Disorders Bra
Pres., Wallace Babington
330 C Street SW Room 3303
Washington. DC 20202

Deafness Research Foundation
Monte H. Jocoby
9 East 38th Street
New York, NY 10016

Deafpride, Inc
Ann Champ-Wilson
1350 Potomac Avenue, SE
Washington, DC 20003

Development Team, Inc.
Shirley Roholley
1615 Thames Street, Suite 300
Baltimore, MD 21231

Disability Rights Education & Defense
Pat Wright
1633 Q Street, NW, Suite 220
Washington, DC 20009
Pres., Mary Lon Breslin

Disabled American Veterans
Authur Wilson\Nat'l Adjutant
807 Maine Avenue, SW,
Washington, DC 20024

Epilepsy Foundation of America
Paulette Maehara, CEO
4351 Garden City Drive, Suite 406
Landover, MD 20785

Gallaudet University
Pres. Dr. I. King Jordan
800 Florida Avenue, NE
Washington, D.C 20002-3695

Gazette International Networking Institute
Joan Headly, Director

4207 Lindell Blvd., #110
St. Louis MO 63108-2915

Goodwill Industries
Kenneth Shaw Dir. of Rehab. Service
9200 Wisconsin Avenue
Bethesda, MD 20814
Pres., David Cooney

HEATH Resource Center
(Higher Educ & Adult Train. for People W/Disa
One Dupont Circle
Washington, DC 20036
Pres., Rhona C. Hartman

Hear Now
Barbara Rocketts
4001 S. Magnolia Way Suite 100
Denver, CO 80237

Int'l Assoc. of Bus., Industry & Rehab
Charles Harles
P.O Box 15242
Washington, DC 20003

Int'l Assoc of Psycho Social Rehab Svc
Ruth Hughes, Ph.D., Executive Director
10025 Governor Warfield Pkwy #301
Columbia, MD 21044-3330

Learning Disabilities Assoc. of Amer.
Justine Maloney
4156 Library Road
Pittsburgh, PA 15234

Muscular Dystrophy Assoc
Robert Fitzgerald
Human Reources Dir.
3300 E. Sunrise Drive
Tucson, AZ 85718

Nat'l Alliance for Mentally Ill
Laurie M. Flynn, Executive Director
2101 Wilson Blvd., Ste 302
Arlington, VA 22201

Nat'l Assoc of Developmental Dis Council
Chris Metzler, Asst Exec Dir
1234 Massachusetts Ave., NW, Suite 103
Washington, DC 20005

Nat'l Assoc of Disability Examiners
Pres., Marty Marshall
2704 Frank Street
Lansing, MI 48911

Nat'l. Assoc of Rehab. Prof. in Private
Bonnie Sheldon
313 Washington Street
Newton, MA 02158

Nat'l. Assoc of Rehabilitation Facilities
Robert E. Brabham, Ph.D., Executive Director
P.O. Box 17675
Washington, DC 20041

Nat'l Assoc of Residential Care Facilities
Barbara B. Jameson, Executive Director
2306 E. Broad, Suite 200
Richmond, VA 23220

Nat'l. Assoc. of Special Education Direc.
Dr. Martha J. Fields
1800 Diagonal Road, Suite 320
Alexandria, VA 22314

National Assoc of St. Dir. of Dev Disabled Servs
Robert M. Gettings, Exec. Director
113 Oronoco Street
Alexandria, VA 22314

Nat'l. Assoc. of State Mental Health Program
Clarke Ross
444 N. Capitol St.,NW, Hall of States
Washington, DC 20001

Nat'l. Assoc. of the Deaf
Nancy J. Bloch, Exec. Dir.
814 Thayer Ave
Silver Spring, MD 20910

Nat'l Black Deaf Advocates, Inc.
Pres., Carl M. Moore
One Lomb Memorial Drive
Rochester, NY 14623

Nat'l. Captioning Institute
Pres., John E. D. Ball
5203 Leesburg Pike
Falls Church, VA 22041

Nat'l. Catholic Office of The Deaf
Pres. Nora Letourneau
814 Thayer Avenue
Silver Spring, MD 20910

Nat'l. Congress of Jewish Deaf
Pres., Barbara Boyd,
13580 Osborne Street
Arleta, CA 91331

Nat'l. Coun on Disability
Speed Davis, Acting Exec. Dir.
1331 F Street, NW, Suite 1050
Washington, DC 20004

Nat'l Coun on Independent Living
Ann Marie Hughey, Exec. Dir.
2111 Wilson Blvd., Suite 400
Arlington, VA 22201

Nat'l. Ctr. For Law and Deaf
Pres., Su DuBow
800 Florida Avenue NE
Washington, DC 20002-3695

Nat'l. Cued Speech Assoc.
Pres. Pamela Beck
1615-B Oberlin Road
Raleigh, NC 27622

Nat'l Down Syndrome Congress
Michael Leonard
1605 Chantilly Dr., Suite 250
Atlanta, GA 30324-1146

Nat'l Easter Seal Society
Randy Rutta, Vice Pres Gov. Affairs
700 13th St., NW
Washington, DC 20005

Nat'l. Fedn. of the Blind
James Gashel, Dir., Public Policy
1800 Johnson Street
Baltimore, MD 21230
Pres., Marc Maurer

Nat'l. Fraternal Society Of The Deaf
Pres., Robert Anderson
1300 W. Northwest Highway
Mt. Prospect, IL 60056

Nat'l. Hearing Aid Society
Pres., Michael K. Stone

20361 Middlebelt Road
Livonia, MI 48152

Nat'l. Industries for the Blind
Robert K. Hanye
524 Hamburg Turnpike, CN 969
Wayne, NJ 07474
Pres., George J. Mertz

Nat'l. Industries for the Severely Hand.
Ken Laureys
2235 Cedar Lane
Vienna, VA 22182
Pres., Elivind H. Johnson

Nat'l. Info. Ctr On Deafness
Pres., Laura DiPietro
800 Florida Avenue NE
Washington, DC 20002-3695

Nat'l Info Ctr for Child & Youths w/Disabls
Suzanne Ripley
Information Service Manager
1875 Connecticut Ave., NW
Washington, DC 20008

Nat'l. Inst. on Deafness & Other Comm Di
Pres., James Snow
9000 Rockville Pike, Building 31, RM 1
Bethesda, MD 20892

Nat'l Mental Health Assoc.
Al Guida, Vice President for Gov. Affairs
1021 Prince Street
Alexandria, VA 22314-2971

Nat'l Multiple Sclerosis Society
Robert enteen, Public Policy Assoc
733 Third Avenue
New York, NY 10017

Nat'l Org for Rare Disorders
Michael Langan
Director of Public Policy
PO Box 8923
New Fairfield, Connecticut 06812-8923

Nat'l. Org. on Disability
Pres., Alan A. Reich
910 16th Street, NW, Suite 600

Washington, DC 20006

Nat'l Rehabilitation Association
Robert E. Brabham, Executive Director
633 South Washington Street
Alexandria, VA 22314

Nat'l. Rehabilitation Info. Center
Phil Bongiorno
8455 Colesville Road Suite 935
Silver Spring, Md. 20910
Pres., Mark Odum

Nat'l. Resource Ctr. on Homelessness & Ment. Ill
Deborah L Dennis, Director
262 Delaware Avenue
Delmar, NY 12054
Pres., Gail Hutchings

Nat'l. Technical Institute for the Deaf
Pres., Dr William E. Castle
P.O. Box 9887
Rochester, NY 14623

Nat'l. Theatre of the Deaf
Pres., David Hays
The Hazel E. Stark Center
Chester, CT 06412

Paralyzed Veterans of America
Gordon Mansfield, Exec. Dir
801 18th Street NW
Washington, DC 20006

President's Comm. on Employment of
People with Disabilities
Richard C. Douglas, Executive Director
1331 F Street, NW, 3rd Floor
Washington, DC 20004

President's Comm. on Mental Retardation
Ashot Mmatazakanian, Exec. Dir
WJ Cohen Building, Room 5325
Washington, DC 20201

Registry of Interpreters f/t Deaf, Inc
8719 Colesville Road Suite 310
Silver Spring, Md. 20910

See Ctr f/t Advancement of Deaf Childr
Main Office P O. Box 1181
Los Almitos, CA 90720

Self Help for Hard of Hearing People
Pres., Howard Stone
7800 Wisconsin Avenue
Bethesda, Md 20814

Spina Bifida Assoc of America
Lawrence Pencak, Exec. Dir.
4590 MacArthur Blvd., NW Suite 250
Washington, DC 2007

Telecommunications f/t Deaf
Pres., Alfred Sonnenstrahl
814 Thayer Avenue
Silver Spring, Md. 20910

The Assoc for Persons w/ Severe Handicaps
Celane McWhorter, Dir Govt. Relations
1600 Prince Street, Suite 115
Alexandria, VA 22314

United Cerebral Palsy Association
John Kemp, Dir. Govt. Affairs
1660 L Street, NW #700
Washington, DC 20036

Vestibular Disorders Branch
Pres., Jerry Underwood
1015 NW 22nd Avenue D-230
Portland, OR 97210

Volunteers of America
Raymond C. Tremont, National Director
3813 North Causeway Blvd.
Metairie, LA 70002
Pres., Clint Chezalher

World Federation of the Deaf
Pres., Liisa Kauppinen
Ilkantie 4, P. O. Box 65
SF-00401 Helsinki, Finland

World Institute on Disability
Judy Heumann
700 Constitution Ave., NW
Washington, DC 20002
Pres., Edward V. Roberts

World Rec Assoc of the Deaf, Inc/USA
Pres., Bruce Gross
P.O. Box 3211
Quartz Hill, CA 93586