

**SUPPLEMENTAL SECURITY
INCOME BENEFITS FOR CHILDREN**

HEARING
BEFORE THE
SUBCOMMITTEE ON HUMAN RESOURCES
OF THE
COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES
ONE HUNDRED TWELFTH CONGRESS
FIRST SESSION

OCTOBER 27, 2011

Serial No. 112–HR9

Printed for the use of the Committee on Ways and Means



U.S. GOVERNMENT PRINTING OFFICE

72–280

WASHINGTON : 2012

For sale by the Superintendent of Documents, U.S. Government Printing Office
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**SUPPLEMENTAL SECURITY
INCOME BENEFITS FOR CHILDREN**

THURSDAY, OCTOBER 27, 2011

U.S. HOUSE OF REPRESENTATIVES,
COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON HUMAN RESOURCES,
Washington, DC.

The Subcommittee met, pursuant to call, at 9:05 a.m., in Room B-318, Rayburn House Office Building, Hon. Geoff Davis [Chairman of the Subcommittee] presiding.

[The advisory announcing the hearing follows:]

ADVISORY

FROM THE COMMITTEE ON WAYS AND MEANS

SUBCOMMITTEE ON HUMAN RESOURCES

FOR IMMEDIATE RELEASE
Thursday, October 27, 2011
HR-9

CONTACT: (202) 225-1721

Chairman Davis Announces a Hearing on Supplemental Security Income Benefits for Children

Congressman Geoff Davis (R-KY), Chairman of the Subcommittee on Human Resources of the Committee on Ways and Means, announced today that the Subcommittee will hold a hearing on Supplemental Security Income (SSI) benefits for children. **The hearing will take place on Thursday, October 27, 2011, in B-318 Rayburn House Office Building, beginning at 9:00 a.m.**

In view of the limited time available to hear witnesses, oral testimony at this hearing will be from invited witnesses only. Witnesses will include the U.S. Government Accountability Office (GAO) and other experts on SSI benefits for children. However, any individual or organization not scheduled for an oral appearance may submit a written statement for consideration by the Committee and for inclusion in the printed record of the hearing.

BACKGROUND:

The Supplemental Security Income program supports adults who are aged or unable to work due to disability with monthly cash benefits of up to \$674 per person in 2011. The program also provides monthly payments to disabled children. Currently, there are 1.2 million children receiving SSI benefits at an annual cost of about \$10 billion, not including Medicaid expenses.

In November 2010, *The Boston Globe* ran a three-part series on increases in children's payments under the Supplemental Security Income program, identifying two areas of concern: a lack of program integrity efforts by the Social Security Administration (SSA) and allegations that psychotropic drugs may be improperly prescribed to children with certain mental and behavioral impairments (especially Attention Deficit Hyperactivity Disorder or ADHD) in order to improve their chances of collecting SSI disability payments.

The series prompted Chairman Davis and a bipartisan, bicameral group of Members of Congress to request that GAO review: trends in the rate of children receiving SSI benefits due to ADHD, depression, and other mental impairments; the role of medical evidence, such as the presence of medication, in SSA disability determinations; and the impact of SSA's not completing continuing disability reviews on current recipients of SSI benefits. While final results and recommendations from GAO are not expected until 2012, the hearing will include testimony from GAO on their preliminary findings as well as from other experts on SSI benefits for children, among related issues.

In announcing the hearing, Chairman Geoff Davis (R-KY) stated, **"The SSI program provides financial support for families with a disabled child. But as currently constructed, the program makes no effort to ensure that benefits are used to help children overcome their disabilities and lead productive lives. As a result, too many children on SSI drop out of school, experience poor employment outcomes, and continue receiving year after year of disability payments as adults. This hearing will review how the SSI program is currently coming up short and possible remedies."**

FOCUS OF THE HEARING:

The hearing will focus on oversight of SSI benefits for children, including trends, program growth, and recipient outcomes.

DETAILS FOR SUBMISSION OF WRITTEN COMMENTS:

Please Note: Any person(s) and/or organization(s) wishing to submit for the hearing record must follow the appropriate link on the hearing page of the Committee website and complete the informational forms. From the Committee homepage, <http://waysandmeans.house.gov>, select "Hearings." Select the hearing for which you would like to submit, and click on the link entitled, "Click here to provide a submission for the record." Once you have followed the online instructions, submit all requested information. Attach your submission as a Word document, in compliance with the formatting requirements listed below, **by the close of business on Thursday, November 10, 2011**. Finally, please note that due to the change in House mail policy, the U.S. Capitol Police will refuse sealed-package deliveries to all House Office Buildings. For questions, or if you encounter technical problems, please call (202) 225-1721 or (202) 225-3625.

FORMATTING REQUIREMENTS:

The Committee relies on electronic submissions for printing the official hearing record. As always, submissions will be included in the record according to the discretion of the Committee. The Committee will not alter the content of your submission, but we reserve the right to format it according to our guidelines. Any submission provided to the Committee by a witness, any supplementary materials submitted for the printed record, and any written comments in response to a request for written comments must conform to the guidelines listed below. Any submission or supplementary item not in compliance with these guidelines will not be printed, but will be maintained in the Committee files for review and use by the Committee.

1. All submissions and supplementary materials must be provided in Word format and **MUST NOT** exceed a total of 10 pages, including attachments. Witnesses and submitters are advised that the Committee relies on electronic submissions for printing the official hearing record.

2. Copies of whole documents submitted as exhibit material will not be accepted for printing. Instead, exhibit material should be referenced and quoted or paraphrased. All exhibit material not meeting these specifications will be maintained in the Committee files for review and use by the Committee.

3. All submissions must include a list of all clients, persons and/or organizations on whose behalf the witness appears. A supplemental sheet must accompany each submission listing the name, company, address, telephone, and fax numbers of each witness.

The Committee seeks to make its facilities accessible to persons with disabilities. If you are in need of special accommodations, please call 202-225-1721 or 202-226-3411 TDD/TTY in advance of the event (four business days notice is requested). Questions with regard to special accommodation needs in general (including availability of Committee materials in alternative formats) may be directed to the Committee as noted above.

Note: All Committee advisories and news releases are available on the World Wide Web at <http://www.waysandmeans.house.gov/>.

Chairman DAVIS. Good morning, thank you for joining us today. At today's hearing we are going to review Supplemental Security Income, or SSI, benefits for children. SSI provides monthly Federal payments of up to \$674 to 1.2 million low-income disabled children across the United States. In all, SSI provides about \$9 billion in payments to children each year, averaging about \$8,000 per child. That \$9 billion nearly matches the amount taxpayers spend for welfare checks under the Temporary Assistance for Needy Families program.

It is one of several reasons *The Boston Globe* published a series last year that called the children's SSI program "the other welfare." As that series detailed and we will hear today, SSI benefits for children are not only significant in size and expense, but they are also growing rapidly, with nearly a 50 percent rise of children receiving payments over the last decade. This growth has been driven by mental and behavioral impairments, which include attention deficit, hyperactive disorder, autism, learning disabilities, and speech and language delays. Boys are twice as likely to receive monthly disability payments as girls, and over 60 percent of children on SSI at age 18 continue collecting payments as adults over a period that can span decades.

Especially troubling in *The Boston Globe* series were allegations that some children are being placed on dangerous psychotropic medications in order to increase their chances of qualifying for SSI checks.

That is one reason why I, along with our colleague Congressman Richie Neal from Massachusetts, who has joined us today, and Senators Susan Collins, Tom Carper, and Scott Brown asked the Government Accountability Office to review this program. From GAO's preliminary findings we have already learned that medication is merely one factor of many that are used to make a determination.

GAO's review goes on to cover a broader array of issues important to the oversight rule of the Subcommittee, including trends for disabilities under which children qualify, the role of medical evidence in determining eligibility, and SSA reevaluations of children in the years after they start collecting benefits.

We are privileged to be joined by Katie and Will Bentley of Covington, Kentucky, part of the congressional district I am honored to represent. Will is a child who receives SSI benefits. We need to keep the interest of children like Will and their families squarely in mind as we consider ways of how to improve this program and how it serves them.

A review of the hearing's testimony revealed all of our witnesses today propose changes in how SSI works with a common goal of doing a better job helping children and families overcome the disabling conditions that led them to apply for SSI in the first place. For example, as several experts have noted, SSI today offers monthly checks without any requirements that benefits be spent on helping the child to overcome his or her disability. Some question whether that may create a financial disincentive to overcoming the disability, because that would mean the checks come to an end.

Other recommendations focus on expecting teenagers on SSI to remain in school in order to qualify for payments. A disturbing 30 percent of older teens on SSI drop out of school, which only adds to the barriers they face in going to work and leading productive lives.

Still other recommendations go to the basic architecture of the SSI program, a largely Federal program that since its inception in the 1970s has spent \$160 billion while being run from the Social Security Administration headquarters in Baltimore.

We look forward to all the testimony today and working with our colleagues across the aisle to improve how this program serves the

children and families who depend on it as well as ensuring that the program efficiently and effectively uses taxpayer dollars.

One of the things that I would like to emphasize in this hearing, and my friend and Ranking Member Lloyd Doggett and I worked very hard during the course of this Congress so far in addressing the programs that we have, is to look at processes. In many cases the processes within the Federal Government are broken. The information systems don't communicate with one another, it is often difficult to identify data that is helpful in helping the people that are being served by the safety net, and to find errors inside of that. That is part of the underlying motivation as we go forward in this hearing today. We are here to gather facts, to get information and hopefully to gain insight how to better improve that program, to improve the process and to better serve both our taxpayers and recipients of the benefits.

Without objection, each Member will have the opportunity to submit a written statement and have it included in the record at this point as well. And with that, I will now defer to my friend Lloyd Doggett from Texas, the Ranking Member.

Mr. DOGGETT. Thank you very much, Mr. Chairman. And the objective that you mentioned in your opening statement of helping families deal with these great challenges that they encounter with a child or children with disabilities is a shared goal that we have. And seeing that the Supplemental Security Income program, or SSI, is administered in an efficient and effective way is a goal that we share. It is one of the reasons that Mr. Neal and others have joined to ask the Government Accountability Office to take a look at the reports that were raised by *The Boston Globe*.

On the other hand, when we have studied unemployment we have had some Members almost suggest that the main problem with unemployment is the unemployed and that they can be blamed for the situation. And we ought not to follow a course along those lines as it relates to children with disabilities.

SSI assists families who are dealing with a child with a disability, physical, mental or both. And only about a tenth of the children in the country with such disabilities receive SSI and the benefits amount to about \$600 a month. These are benefits that help offset the cost of caring for severely disabled children.

SSI is particularly important in my home State of Texas where we have so many poor children generally and particularly poor disabled children, about 130,000 in the State who are receiving benefits. Two such children live near where I do in central Texas in Bastrop County, Tyler and Noah Roberts. They are 5-year-old twins. When you look at their photos you see two very beautiful little boys, but they are little boys who have severe autism. One is nonverbal and engages in behaviors like flapping his arms, spinning and throwing tantrums. The other is verbal but has severe anxiety, intestinal and sensory problems. These are serious conditions that have greatly impeded their mother's ability to maintain a regular work schedule, and she depends on SSI to keep food on the table and a roof over their heads.

I have seen situations just like this in the work that my wife has done. Before I came to Congress she headed an early intervention program working with infants and very young children who had se-

vere disabilities across the Texas hill country. This is not an isolated case. It is an example of the challenges that families face that we need to be assisting, not blaming them for the problem that they have.

There has been some growth in the SSI program since 2001 largely in response to the growing number of children that live in poverty in this country. Just because more families like the Roberts are receiving SSI benefits to help raise their children with autism and other significant problems doesn't mean they should be targeted for cuts. During the last decade almost 5 million more children have fallen below the poverty line. One could reasonably assume that the increase would have an impact on a program designed to help low-income families with disabled children.

While we hear suggestions that the program has changed, the Congressional Research Service concludes that the rate of children on SSI as a percentage of children living in poverty is about the same now as it was in 2001.

Further, we have increased efforts to identify childhood disabilities. The Center for Economic and Policy Research found that the number of children receiving screening and diagnostic services under Medicaid rose from a little over 5 million to over 20 million children from 1998 to 2008. Nevertheless, there has not been an increase in SSI approval rates for children with mental impairments. According to the Social Security Administration, the percentage has actually dropped from 2001 to 2010.

There are a number of steps that we can and should take to improve the administration of SSI, and I hope we will explore those in the hearing. First, I think Congress needs to make good on its pledge to provide adequate resources to conduct continuing disability reviews to ensure that SSI recipients maintain their eligibility for service. And President Obama's administration has nearly doubled the number of those reviews compared to the last year of President Bush.

Second, if we are serious about improving outcomes for children receiving SSI, I look forward to discussing other supports we can offer these families as they work with their children and they seek employment opportunities for unemployed disabled children.

We are, as the Chairman indicated, joined by the Bentley family, by Katie and her son Will, who receive SSI. They are accompanying Jonathan Stein, who is testifying. Despite the severe impairments that Will faces, Mrs. Bentley and her husband were reluctant as many families are to even apply for SSI. They wanted to support Will on their own. But after Mrs. Bentley had to close her business to care for Will the financial burden was heavy and she took the benefits that she is entitled to take. Since Will has been receiving these benefits his outcomes have improved remarkably. According to Mrs. Bentley, the life altering value of SSI is worth so much more than its monetary value. It is truly priceless in her words.

Mr. Chairman, we can all agree on the need to improve and strengthen SSI outcomes, and I look forward to working with you on reform, but let's reject any direct cuts in assistance to the disabled in the name of helping them. However great our Nation's fiscal challenges may be, we ought not to balance the budget on the backs of disabled children.

Thank you.

Chairman DAVIS. I thank you very much, Mr. Doggett. We are also pleased to be joined by our colleague on the Ways and Means Committee, Representative Richie Neal of Massachusetts, who joins me and others in requesting the GAO review showing concerns of families and about how they access SSI benefits for children and ultimately how the program might be improved.

Mr. Neal, do you have any comments before we get to hear from our witnesses?

Mr. NEAL. Thank you, Mr. Chairman. Just a couple of thoughts if I could, just a brief statement and I find myself in agreement with what you said and with what Mr. Doggett said. I think that is the path forward, to have deliberative effort here.

I want to thank you first for allowing me to give some brief opening comments even though I am not a Member of the Subcommittee. And I am very pleased the Subcommittee through you and Mr. Doggett has called the hearing to examine the state of SSI in America. SSI for children is a program that has been brought to my attention as well as New Englanders by an illuminating and powerful three-piece and three-part series by Patricia Wen of *The Boston Globe*, but also anecdotally by educators, parents and health care professionals, in Springfield, Holyoke and other cities and towns in Massachusetts with high populations of SSI recipients.

The *Globe* map that I would encourage all of us to take a look at that demonstrated a clear concentration of SSI recipients in the older cities in Massachusetts speaks to the issues that you have raised and the issues that Mr. Doggett has raised. But I also believe that the role of the Federal Government is to aid the most vulnerable amongst us. The SSI program was created to do just that, originally to provide financial support for children with severe physical disabilities and to evolve as our health care system has evolved to support children who suffer from behavioral and mental health issues as well.

I have met with the Social Security Administration and the Administrator, Michael Astrue, about my concerns with SSI. I requested the Administration meeting with President Obama as well as SSI administrators and I would suggest to this Committee that we include an Institute of Medicine study to examine the concentration of SSI recipients in the old cities of Massachusetts. And why? Simply to get to the bottom of the issue as to the role that the program plays in helping those who need it and to avoid the potential for stigmatizing children when it becomes the first option that is suggested from health professionals.

I have asked the GAO along with the Members of the Subcommittee to conduct an objective and balanced analysis of the SSI program and to specifically look into provocative topics like suspected overprescribing of medications and the lack of a periodic review of the health care progress for children. I think everybody would agree with that, that is not a system that we review sufficiently the progress that children might be making. I am interested in what the report concludes. You should know I have drawn no conclusions and would be anxious to hear from the Institute of Medicine.

The Social Security administrator has indicated that that study would cost about \$10 million. I think that is a reasonable expenditure so that we might determine how we go forward. Supplemental Security Income for Children is an important program for the very vulnerable and neediest of the population, but oversight of the program is necessary as well to ensure its mission in assisting those vulnerable children remain intact while abuse might be examined and identified and where possible eliminated.

I also want to emphasize that I have not again drawn any conclusions, but I want to tell you the series that *The Boston Globe* outlined is a powerful reminder of the responsibilities that we have to these children.

I thank you and Mr. Doggett for allowing me to participate this morning.

Chairman DAVIS. Thank you, Mr. Neal. Before we move on to our testimony I would like to remind each of our witnesses that they need to limit their oral statements to no longer than 5 minutes. Without objection, all of the written testimony will be made part of the permanent record.

On our panel this morning we will be hearing from Dan Bertoni, Director of Education, Workforce and Income Security, the U.S. Government Accountability Office; Richard Burkhauser, Professor, Department of Policy Analysis and Management at Cornell University. Dr. Burkhauser will also be testifying before another Subcommittee this morning and so will need to leave before the end of the hearing, but we certainly appreciate his taking the time to join us and including your testimony in the record. He is also joined by David Wittenburg, Senior Researcher from Mathematica Policy Research; Jonathan Stein, General Counsel to Community Legal Services in Philadelphia and also representing the SSI Coalition for Children and Families; and Elizabeth Roberts, Child and Adolescent Psychiatrist joining us from Murrieta, California.

Mr. Bertoni, please proceed with your testimony.

STATEMENT OF DANIEL BERTONI, DIRECTOR, EDUCATION, WORKFORCE, AND INCOME SECURITY, U.S. GOVERNMENT ACCOUNTABILITY OFFICE

Mr. BERTONI. Mr. Chairman, Ranking Member Doggett, Mr. Neal, Members of the Subcommittee, good morning. I am pleased to discuss our preliminary observations on children with mental impairments and supplemental security—

Chairman DAVIS. Could you make sure that the light is on there?

Mr. BERTONI. It is on.

Chairman DAVIS. Okay, maybe the mic needs to be a little closer, thank you.

Mr. BERTONI. In 2010, SSA paid over \$9 billion in SSI benefits to more than 1.2 million children. In prior work we reported that the number of children on SSI had increased substantially due in part to program changes that expanded eligibility for those with mental impairments. And despite modifications intended to address this growth, the number of children on SSI with such impairments has continued to rise.

My testimony draws on our ongoing work, presents our observations on trends in the rate of children receiving SSI, the role medical and non-medical information plays in the disability decision process and steps SSA has taken to review the continued eligibility of children.

In summary, we found that the number of children who applied for SSI benefits due to mental impairments increased 60 percent over the last decade, and such cases now comprise a growing majority of all child beneficiaries. Moreover, between fiscal years 2000 and 2010 the number of children found eligible for benefits increased for almost every mental impairment category with the most prevalent being ADHD, speech and language delays, and autism. However, over the last decade the average allowance rate for all children with mental impairments has held steady at about 46 percent.

Several factors may have contributed to trends in the roles, including agency and advocate outreach, increased diagnoses of certain mental impairments, and the number of children living in poverty. However, it is unclear how any single factor or combination of factors have driven such trends.

During our field work DDS examiners noted that they rely on a combination of medical and non-medical information such as treatment records, prescribed medications, school records and teacher assessments in determining a child's eligibility. In short, the decision is based on the totality of information rather than any one piece in isolation.

Examiners obtain evidence such as psychological tests and physician's notes to assess children with alleged mental impairments and when such evidence is inconclusive they may purchase an independent consultative exam of the child.

With regard to the role of prescription medication, DDS examiners in various locations told us it is generally given no more weight than any other information, and in some cases if medication improves functioning, it can be a factor in denying a claim. However, certain field offices acknowledge that some parents may believe that medicating their children will improve their likelihood of receiving benefits. In going forward we plan to conduct an indepth case file review to assess the relative weight medication and other evidence plays in SSI decisions.

In regard to non-medical information, we found that some DDSs face challenges in obtaining school records and teacher assessments, which can be a critical source of information for assessing a child's functioning over time, partly due to the school's and teacher's reluctance to complete such assessments. And finally, although SSA is required to periodically conduct continuing disability reviews, or CDRs, of children on the rolls, such reviews decreased substantially over the last decade, from more than 200,000 to about 126,000. And those for children with mental impairments decreased from 84,000 to only 13,000 last year.

We identified over 400,000 child SSI cases with mental impairments that were overdue for a CDR, with thousands of cases exceeding their scheduled dates by several years. Of the CDRs SSA did conduct last year the average benefit cessation rate was 24 per-

cent, with personality disorders and speech and language delays having higher rates of rescission at 34 and 33 percent respectively.

SSA has acknowledged the importance of conducting CDRs but has primarily attributed its failure to do all required reviews to resource constraints and competing workloads. Thus the program continues to be exposed to substantial overpayments.

The recently enacted Budget Control Act of 2011 authorizes additional funding for SSA to do more CDRs and SSI redeterminations, and the agency is currently assessing how it will use such funding should it be appropriated.

Plus, it is not yet known whether SSA will use this funding to do additional childhood CDRs or target its efforts toward those mental impairments with the highest potential cessation rates as a means of best leveraging its limited resources.

Mr. Chairman, this concludes my statement. I am happy to answer any questions that you or other Members of the Subcommittee may have. Thank you.

[The prepared statement of Mr. Bertoni follows:]

GAO

United States Government Accountability Office

Testimony

Before the Subcommittee on Human
Resources, Committee on Ways and
Means, House of Representatives

For Release on Delivery
Expected at 9:00 a.m. EDT
Thursday, October 27, 2011

SUPPLEMENTAL SECURITY INCOME

Preliminary Observations on Children with Mental Impairments

Statement of Daniel Bertoni, Director
Education, Workforce, and Income Security



GAO-12-196T

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Highlights

Highlights of GAO-12-196T, testimony before the Subcommittee on Human Resources, Committee on Ways and Means, House of Representatives

Why GAO Prepared this Testimony

The Social Security Administration's (SSA) Supplemental Security Income (SSI) program provides cash benefits to eligible low-income disabled individuals, including children, as well as certain others. Children may generally qualify for SSI benefits if they meet certain financial requirements and are deemed to have a qualifying medically determinable physical or mental impairment of a specified duration or severity that results in a functional limitation. In 2010, SSA paid more than \$9 billion to about 1.2 million disabled children. Over the past decade, the overall number of children receiving SSI benefits has continued to rise.

In this statement, GAO discusses initial observations from its ongoing review and examines (1) the trends in the rate of children receiving SSI benefits due to mental impairments over the past decade; (2) the role that medical and nonmedical information, such as medication and school records, play in the initial determination of a child's medical eligibility; and (3) the steps SSA has taken to monitor the continued medical eligibility of these children. To examine these issues, GAO analyzed program data, interviewed SSA officials, conducted site visits to SSA field offices and state disability determination services (DDS) offices, and interviewed external experts. This work is ongoing and GAO has no recommendations at this time. GAO plans to issue its final report in April 2012.

View GAO-12-196T. For more information, contact Daniel Bertoni at (202) 512-7215 or bertonid@gao.gov.

October 27, 2011

SUPPLEMENTAL SECURITY INCOME

Preliminary Observations on Children with Mental Impairments

What GAO Found

The numbers of children applying for and receiving SSI benefits due to a mental impairment has increased over the past decade and now comprise a growing majority of all child beneficiaries. While more than half of child applicants are denied each year, children with mental impairments, such as autism, have represented a growing share of those medically allowed for benefits—increasing from 60 to 67 percent between fiscal years 2000 and 2010. Factors including but not limited to the rising number of children living in poverty and increased diagnosis of certain mental impairments may have contributed to such growth. However, the relative effects of these and other factors on program growth are not fully known at this time.

Number of Children under Age 18 Receiving Federally Administered SSI Payments, by Mental and Physical Impairment Group, December 2000–December 2010



Source: GAO analysis of SSA data from the Supplemental Security Record.

Generally, DDS officials reported that they rely on a combination of key medical and nonmedical information—such as medical records and teacher and parent assessments—in determining a child's medical eligibility and that they consider the totality of information related to the child's impairments, rather than one piece of information in isolation. For example, SSA and DDS officials said that they consider a child's use of prescribed medications in the context of other information including school records and teacher assessments, which are critical in evaluating the child's functioning over time. Yet, despite the importance of such nonmedical evidence, GAO's work shows that examiners sometimes face challenges in obtaining this information partly due to teachers' reluctance to complete the assessments.

SSA is required to periodically review the medical eligibility of certain children receiving SSI benefits, but GAO's work shows that SSA has conducted significantly fewer childhood continuing disability reviews (CDR) in recent years. Between fiscal years 2000 and 2010, the number of childhood CDRs and age 18 reviews overall fell from more than 200,000 to about 126,000 (a 38 percent decrease), while childhood CDRs for those with mental impairments dropped from more than 84,000 to about 13,000 (an 84 percent decrease). SSA officials have acknowledged that the agency is not conducting childhood CDRs in a timely manner mostly due to resource constraints. However, SSA recognizes the importance of conducting CDRs and has recently estimated that the CDR process yields a savings-to-cost ratio of \$12.50 to \$1.

United States Government Accountability Office

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to discuss our preliminary observations on children with mental impairments in the Supplemental Security Income (SSI) program. Administered by the Social Security Administration (SSA), SSI is a nationwide federal assistance program that provides cash benefits to eligible low-income disabled individuals, including children, as well as certain individuals who are aged or blind. In 2010, SSA paid almost 8 million recipients about \$50 billion in SSI benefits, of which more than \$9 billion was paid to about 1.2 million disabled children. During the early and mid 1990s, the SSI program experienced a period of unprecedented growth for children due, in part, to legal developments that expanded program eligibility for children with mental impairments. For example, from the end of 1989 through 1996, the number of children receiving SSI benefits more than tripled from 265,000 to about 955,000. Since that time, the number of children receiving SSI benefits has continued to rise, especially for those with mental impairments. Our prior work has shown that accurately diagnosing some types of mental impairments is a complex and often subjective process for SSA, which can sometimes be vulnerable to fraud and abuse.

My statement today focuses on initial observations from our ongoing review and examines (1) the trends in the rate of children receiving SSI benefits due to mental impairments over the past decade; (2) the role that medical and nonmedical information, such as medication and school records, play in the initial determination of a child's medical eligibility; and (3) the steps SSA has taken to monitor the continued medical eligibility of these children. To examine these issues, we collected agency data on the overall number of initial disability determinations and allowances, the number and types of mental impairments, and the number of continuing disability reviews of children conducted by SSA. We assessed the reliability of the data presented in this statement and found potential limitations with the extent to which primary and secondary impairment codes within SSA's 831 disability files—the file that contains data on disability determinations—may be complete. However, because the 831 disability files are used by SSA to reflect the decisions made regarding medical determinations, we determined that these data were sufficiently reliable to describe certain trends among children in the SSI program. In our ongoing work, we will conduct a case file review of a random, generalizable sample of select SSI child mental impairments cases decided in fiscal year 2010, which will potentially assist us in better understanding the extent of this limitation. We also conducted in-depth interviews with SSA management and line staff at SSA headquarters and

six SSA regions—Philadelphia, Pennsylvania; Boston, Massachusetts; Atlanta, Georgia; Dallas, Texas; Chicago, Illinois; and San Francisco, California. Our work included site visits to 9 field offices within these regions, as well as 11 state disability determination services (DDS) offices (state agencies under the direction of SSA that perform medical eligibility determinations and continuing disability reviews of SSI applicants). We selected these sites on the basis of their geographic location, as well as the volume of SSI applications and benefit allowances for children with mental impairments. In addition, we interviewed numerous external experts from the medical and disability advocacy communities and reviewed relevant federal laws and regulations. We plan to issue our final report in April 2012 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained will provide a reasonable basis for our findings and conclusions based on our audit objectives.

Background

Since 1974, the SSI program, under Title XVI of the Social Security Act, as amended,¹ has provided benefits to low-income blind and disabled persons, including adults and children² as well as certain aged individuals who meet financial eligibility requirements and SSA's definition of disability. For children, a disability is a medically determinable physical or mental impairment that results in certain functional limitations, and is expected to result in death or which has lasted or can be expected to last for a continuous period of at least 12 months.³ Families of children receiving SSI payments are generally required to use the benefit to meet

¹Pub. L. No. 92-603, § 301, 86 Stat. 1329, 1465.

²For purposes of the SSI program, the term "child" means an individual who is neither married nor (as determined by the Commissioner of Social Security) the head of a household, and who is (1) under the age of 18, or (2) under the age of 22 and (as determined by the Commissioner of Social Security) a student regularly attending a school, college, or university, or a course of vocational or technical training designed to prepare him for gainful employment. 42 U.S.C. § 1382c(c).

³42 U.S.C. § 1382c(a)(3)(C)(i) and 20 C.F.R. § 416.905.

a child's current and future needs, including food, clothing, and shelter.⁴ The maximum payment for a child receiving SSI benefits is \$674 per month regardless of the severity of the child's impairment.⁵ As of December 2010, the average monthly child benefit was \$597.

To apply for benefits, the child's parent or guardian usually submits an application to SSA either in person at a local SSA field office, by telephone, or by mail. SSA's field offices are responsible for processing these applications and for verifying the child's and legal guardian's nonmedical eligibility requirements, including income, resources, and living arrangement information. After initial verification, the field office transmits the case file to their state disability determination services office for a medical evaluation.⁶ To aid in evaluating whether a child is medically eligible, DDS offices review various medical and nonmedical information about the child, such as physician notes, psychological tests, school records, and teacher assessments.⁷ In certain situations, such as when

⁴Typically, a disabled child's SSI benefit is paid on behalf of the child to a "representative payee," such as a parent or guardian. The "representative payee" is responsible for using benefits received only for the child's use and benefit in a manner and for the purposes he or she determines, consistent with SSA guidelines, to be in the child's best interests. 20 C.F.R. § 416.635(a).

⁵All but five states and the Commonwealth of the Northern Mariana Islands supplement federal SSI benefits with additional payments. Fourteen states and the District of Columbia have state supplements that are either partially or wholly administered by SSA, and 31 states self administer their supplements.

⁶The medical evaluation is conducted under applicable legal requirements and SSA policy and assesses whether the child has a physical or mental impairment that is severe and that meets or medically or functionally equals impairments that are included in SSA's listing of impairments, and that meets the duration requirement. If these requirements are met, the child is found to be disabled for purposes of SSI. 20 C.F.R. § 416.924(a). The listing of impairments for children describes the impairments that cause marked and severe functional limitations. (See app. I for additional information about the listing of mental disorders for children.) If a child has a severe impairment that does not meet or medically equal any listing, DDS will decide whether the impairment results in limitations that "functionally equal" the listings. Under functional equivalence, a child can be found medically eligible for benefits if the child's impairment limits his or her functional ability to the same degree as described in the listed impairment. Functional equivalence is based on the principle that it is the functional limitations resulting from an impairment that make the child disabled, regardless of the particular medical cause. It was added as a basis for eligibility for children in response to the U.S. Supreme Court's decision in *Sullivan v. Zebley*, 493 U.S. 521, that SSA's use of medical listings of impairments for children—without conducting a functional analysis—was incomplete.

⁷20 C.F.R. § 416.913.

the evidence is not sufficient to support a decision as to whether a child is disabled, the DDS may purchase a consultative examination to assist in making the decision.⁸ If there is evidence that indicates the existence of a mental impairment, DDS makes every reasonable effort to ensure that a qualified psychiatrist or psychologist has completed the medical portion of the case review.⁹

After it makes its initial determination, the DDS returns the case file to the field office, where SSA completes any outstanding non-disability case development, computes the benefit amount, and begins paying benefits if the claimant was determined disabled. If the claim is denied, a claimant has 60 days to request that SSA reconsider its decision. If the claimant is dissatisfied with the reconsideration, he or she may request a hearing before an administrative law judge, whose decision may then be reviewed by SSA's Appeals Council. When these administrative review options have been exhausted, the claimant may request judicial review by filing an action in a federal district court.¹⁰

After SSA determines that a child is disabled, the agency is required by law, in certain circumstances, to conduct periodic reviews, known as a continuing disability review (CDR), to verify a child's continued medical eligibility for receiving SSI benefits.¹¹ SSA is generally required to perform CDRs (1) during the first year after birth for babies whose low birth weight is a contributing factor to the determination of disability¹² and (2) at least once every 3 years for all other children under age 18 whose conditions are considered likely to improve.¹³ DDS offices determine when

⁸20 C.F.R. § 416.919a(b). A consultative examination is a physical or mental examination or test purchased from a treating source or another medical source, including a pediatrician, for an individual at SSA's request and expense. 20 C.F.R. § 416.919.

⁹20 C.F.R. § 416.903(e).

¹⁰For more information about the administrative review process for disability determinations, see 20 C.F.R. § 416.1400 et seq.

¹¹SSA conducts two types of reviews to ensure that participants are eligible for benefits—CDRs and redeterminations. CDRs verify claimant's medical eligibility, while SSI redeterminations verify their financial eligibility and ensure that the beneficiary is receiving the right amount of SSI benefits. 20 C.F.R. §§ 416.989 and 416.204.

¹²42 U.S.C. § 1382c(a)(3)(H)(iv).

¹³42 U.S.C. § 1382c(a)(3)(H)(ii)(I).

beneficiaries will be due for CDRs on the basis of their potential for medical improvement, and select and schedule a review date—otherwise known as a “diary date”—for each beneficiary’s CDR. At the time of these reviews, the child’s representative payee generally must present evidence that the child is and has been receiving medically necessary and available treatment for his or her impairment. SSA is also required to redetermine the eligibility of children against the adult criteria¹⁴ for disability after they reach age 18.¹⁵

Number of Children Applying for and Receiving SSI Benefits Due to Mental Impairments Has Increased

The numbers of children applying for and receiving SSI benefits due to a mental impairment has increased over the past decade and now comprise a growing majority of all child beneficiaries. While not all such children who are deemed medically eligible ultimately meet SSI’s financial eligibility requirements,¹⁶ our preliminary analysis of medical allowances suggests that the growth in the number of child beneficiaries is roughly proportionate to the growth in the number of applicants. Furthermore, SSA data showed that the agency has denied a majority of child applicants each year.¹⁷ Between fiscal years 2000 and 2010, the average medical allowance rates for children with physical and mental impairments were about 37 and 46 percent, respectively (see fig. 1).

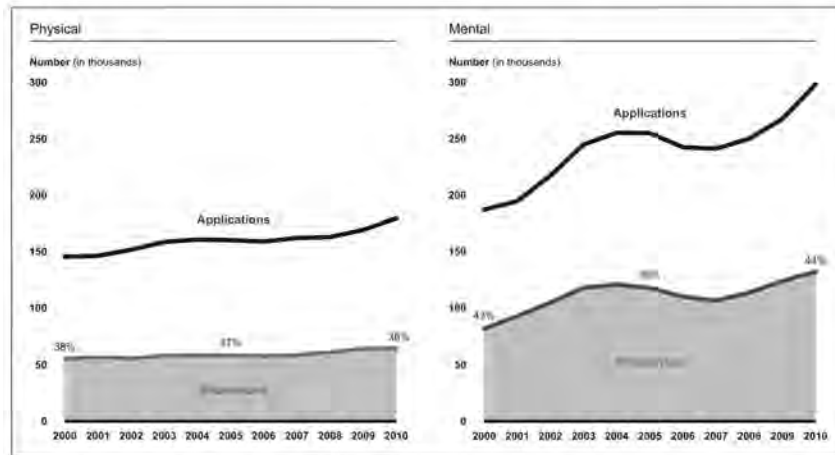
¹⁴Adults are considered disabled if they are unable to engage in substantial gainful activity by reason of a medically determinable physical or mental impairment expected to result in death or last at least 12 months. 42 U.S.C. § 1382c(a)(3)(A).

¹⁵42 U.S.C. § 1382c(a)(3)(H)(iii).

¹⁶Although a child may be found medically eligible for benefits due to a physical or mental impairment, SSA must verify the child’s financial and other non-medical eligibility. If these other criteria are not met, the child will not receive SSI benefits.

¹⁷Data and references to “applications” or “applicants” throughout this statement reflect SSI benefit claims where an initial disability determination was made each year. Some claims may have more than one determination if selected for a quality review or if the disability claim is updated during the same year.

Figure 1: SSI Applications and Allowances for Children under Age 18, by Mental and Physical Impairment Group, Fiscal Years 2000-2010



Source: GAO analysis of SSA data from the SSI Disability Files.

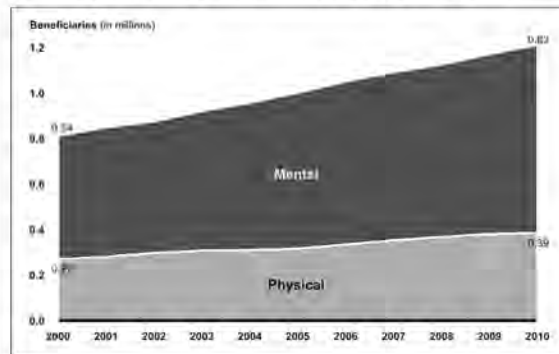
Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination. Data represented as "applications" reflect SSI benefit claims were an initial disability determination was made each year. Some claims may have more than one determination if selected for a quality review or if the disability claim is updated during the same year. Such determinations are reflected in the data presented above.

SSA data show the number of child applicants with mental impairments increased 60 percent between fiscal year 2000 and fiscal year 2010, from 187,052 to 298,264, while the total number of SSI child beneficiaries with mental impairments on the rolls grew 52 percent from 543,000 to 827,000 (see fig. 2).¹⁶ Our preliminary research suggests that several factors may

¹⁶The number of adults receiving SSI benefits has also steadily increased over the past decade. As of December 2010, 6.7 million adults were receiving SSI disability benefits up from 5.8 million as of December 2000.

have contributed to the increased number of child applicants and beneficiaries, including but not limited to SSA's and child advocates' outreach efforts, improved access to health insurance for children, the rising number of children living in poverty, and increased diagnosis of certain mental impairments. However, the relative effects of these and other factors on program growth are not fully known at this time.

Figure 2: Number of Children under age 18 Receiving Federally Administered SSI Payments, by Mental and Physical Impairment Group, Dec. 2000–Dec. 2010



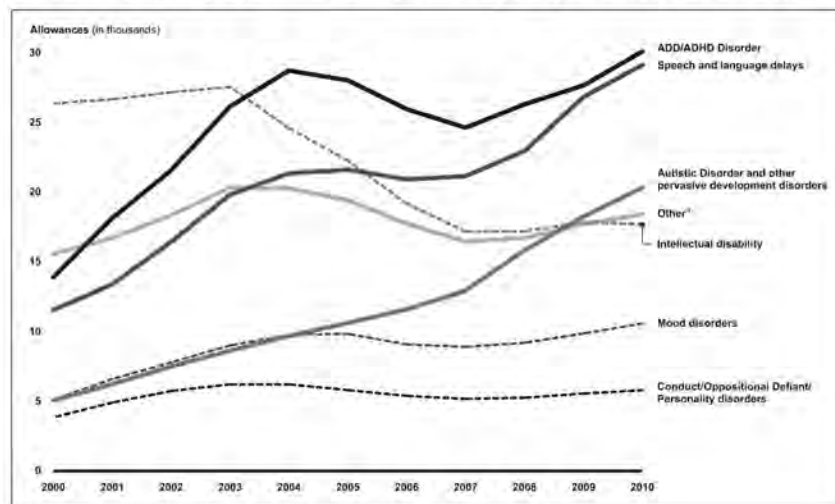
(Source: GAO analysis of SSA data from the Supplemental Security Record.)

Note: The above figure does not include those diagnostic groups that SSA reported as "unknown." SSA data showed that as of December 2000, "unknowns" totaled 33,042 children (0.04 percent), and as of December 2010, 26,417 children (0.02 percent).

While it is unclear how various factors are contributing to growth at this time, SSA data show that since fiscal year 2000, children with mental impairments have represented the majority of all child applications and medical allowances for SSI benefits. For example, in fiscal year 2010, about 62 percent of all SSI child applicants had a mental impairment as a primary diagnosis, and about 67 percent of those applicants were medically approved for benefits. For those applicant children with mental impairments, SSA data also suggests that the number of children found medically eligible for benefits has increased for almost every mental impairment category—such as speech and language delay and mood

disorders—between fiscal years 2000 and 2010, with the exception of intellectual disability as most notable (see fig. 3).¹⁹

Figure 3: Medical Allowances for SSI Children with Mental Impairments, by Primary Impairment, Fiscal Year 2000-2010



Source: GAO analysis of SSA data from the R31 Disability File.

Note. The information highlighted in this figure is based on the primary impairment code recorded in the disability determination.

^aThe "other" category includes borderline intellectual functioning, learning disorders, developmental and emotional disorders in newborns and younger infants, psychoactive substance dependence disorder, somatoform disorders/eating and tic disorders, anxiety disorders, schizophrenic, delusional, schizoaffective and other psychotic disorders, and organic mental disorders.

¹⁹In accordance with Rosa's Law, "intellectual disability" has generally replaced the term "mental retardation." Pub. L. No. 111-256, 124 Stat. 2643.

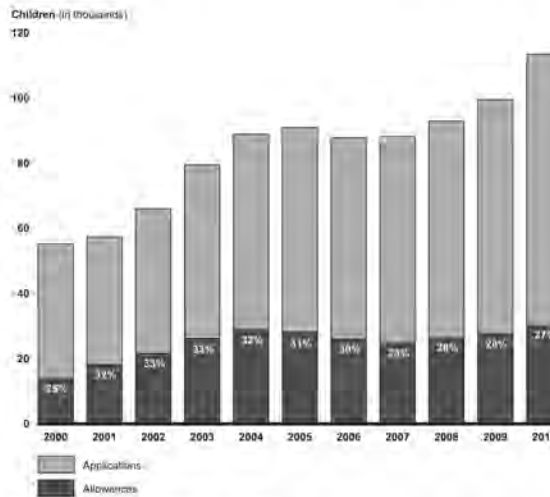
As part of our preliminary work, we examined individual mental impairments to determine which impairments had the highest number of applications and medical allowances. SSA's data on disability determinations is based on the primary impairment as designated by the DDS.²⁰ SSA's policy operations manual directs DDS examiners to code the primary impairment as the most severe condition that rendered the child disabled. In instances where multiple impairments are present, the secondary impairment is generally the next most severe following the primary. However, SSA officials have acknowledged that primary impairment codes are sometimes missing or inaccurately coded.²¹ In addition, the primary impairment code listed may be only one of several impairments that led DDS examiners to find the child medically eligible for benefits. In our ongoing review, we plan to conduct an in-depth case file review to determine the extent to which a secondary impairment was present for the most prevalent impairments and the extent to which the secondary impairment, or combination of impairments, influenced the eligibility decision. SSA data show that for fiscal year 2010, the three most prevalent primary mental impairments among medical allowances were for (1) attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD), (2) speech and language delay, and (3) autistic disorder and other pervasive development disorders (autism). The following information provides a brief summary of each of these three impairments as they compare to the incidence of all mental impairments, as well as in terms of the proportion of applications and medical allowances:

ADD/ADHD. Between fiscal years 2000 to 2010, applications for this condition as a primary impairment more than doubled, from about 55,000 to 113,000. Also, the number of children found to be medically eligible increased by more than 100 percent, from 13,857 to 30,108 (see fig. 4). By December 2010, about 212,000 such children were receiving SSI benefits, and they comprised 26 percent of child recipients with mental impairments.

²⁰The recorded primary impairment code identifies the primary impairment used in the medical determination for an individual's eligibility for Title XVI disability benefits. It appears in the Social Security Administration's 831 and 832/833 Disability files.

²¹According to SSA officials, the error rate for impairment coding is estimated between 5 to 8 percent.

Figure 4: Applications and Medical Allowances for Children with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder as a Primary Impairment, Fiscal Year 2000–2010



Source: GAO analysis of SSA data from the SSI Disability Files.

Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination. Data represented as "applications" reflect SSI benefit claims where an initial disability determination was made within each year.

While children with ADD/ADHD represent the single largest primary diagnostic group, SSA data show that the majority of ADD/ADHD applications over the years have been medically denied. Some of the examiners we interviewed said that they rarely find a child medically eligible for benefits solely on the basis of an ADD/ADHD impairment alone, but more commonly in combination with another impairment, such as asthma or oppositional defiant disorder. Nevertheless, SSA officials suggested that the increase in both applications and medical allowances for children with ADD/ADHD might be attributable to an increase in

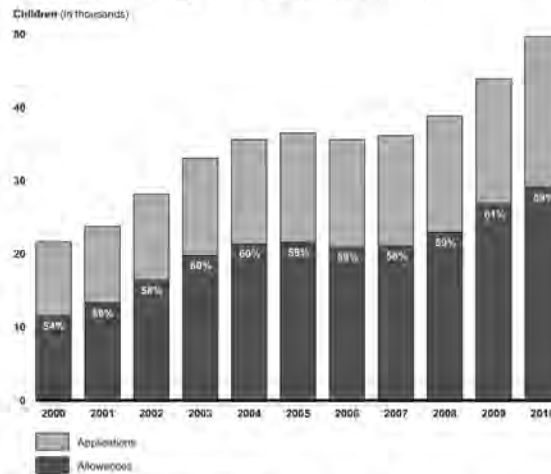
diagnosis over the last decade, and cited a National Institute of Health survey finding that ADHD diagnoses had increased, on average, by 3 percent from 1996 to 2006 and by 5.5 percent, on average, from 2003 to 2007.²² SSA officials also noted a 2008 medical study reporting that ADHD is one of the most commonly diagnosed childhood neurobehavioral disorders.²³

Speech and language delay. During the last decade, both applications and medical allowances for children with speech and language delay have increased overall, but the proportion of applicants found medically eligible has remained relatively stable over time. Between fiscal years 2000 to 2010, applications for this impairment more than doubled, from 21,615 to 49,664 while the number of children found to be medically eligible nearly tripled, from 11,565 to 29,147 (see fig. 5). As of December 2010, about 174,000 (21 percent) children with mental impairments were receiving benefits due to a speech and language delay. While some DDS officials expressed the view that increases could be attributed to increased school testing and screening programs, SSA officials said further study was needed to better understand these particular increases.

²²Centers for Disease Control and Prevention/National Survey of Children's Health, "National Health Interview Survey, 2004-2006."

²³Pastor, P.N., Reuben, C.A., "Diagnosed attention deficit hyperactivity disorder and learning disability: United States, 2004-2006" *Vital Health Stat* 2008: 10 (237).

Figure 5: Applications and Medical Allowances for Children with Speech and Language Delay as Primary Impairment, Fiscal Year 2000–2010



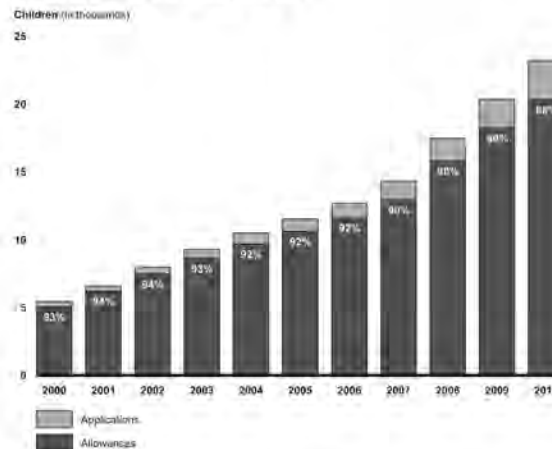
Sources: GAO analysis of SSA data from the SSI Disability Files.

Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination. Data represented as "applications" reflect SSI benefit claims where an initial disability determination was made within each year.

Autism. Between fiscal years 2000 and 2010, autism applications more than quadrupled from 5,430 to 23,203, and medical allowances increased similarly from 5,050 to 20,319 (see fig. 6). As of December 2010, about 95,000 (11 percent) children with mental impairments were receiving SSI benefits due to autism. DDS examiners have generally found the vast majority of those children applying for SSI on the basis of autism medically eligible for benefits. SSA officials attributed the increase in the number of autism applications and medical allowances over the years to greater incidence of autism among children and explained that some children who may have previously been diagnosed as intellectually disabled are instead being diagnosed as autistic. According to one study

SSA cited, the prevalence of autism in children has increased from 0.6 per 1,000 live births in 1994 to 3.1 per 1,000 live births in 2003, while the prevalence of intellectual disability decreased by 2.8 per 1,000 live births in 2003.²⁴

Figure 6: Applications and Medical Allowances for Children with Autism as a Primary Impairment, Fiscal Year 2000–2010



Source: GAO analysis of SSA data from the EY Disability Files.

Note: The information highlighted in this figure is based on the primary impairment code recorded in the disability determination. Data represented as "applications" reflect SSI benefit claims where an initial disability determination was made within each year.

²⁴Shattuck, P.T., "The contribution of diagnostic substitution to the growing administrative prevalence of autism in the U.S. Special Education data," *Pediatrics*, 2006 117: 1028-1037.

Examiners Report Using a Combination of Key Information Sources in Determining Medical Eligibility

In our preliminary work, DDS officials reported that they rely on a combination of key medical and nonmedical information—such as medical records, prescribed medications, school records, and teacher and parent assessments—in determining a child's medical eligibility.²⁵ Several DDS officials said that when making a determination, they consider the totality of information related to the child's impairments, rather than one piece of information in isolation.²⁶ With regard to the medical information used by examiners, SSA generally requires DDS examiners to assist children and their parents or guardians in obtaining medical records in an effort to develop at least a 1-year-long medical history prior to applying for benefits.²⁷ According to many of the DDS officials we interviewed, examiners attempt to obtain medical evidence, such as psychological tests, physician's notes, and mental health records, for children with alleged mental impairments. If such evidence is not available or existing evidence is inconclusive, some DDS officials we spoke with said that they will purchase a consultative examination for the child. This examination is intended to provide the additional medical evidence, such as results of a physical examination and laboratory findings, needed for a determination. However, many DDS officials told us that such examinations are only a "snap-shot" in time and do not provide a longitudinal view of the child's functioning over time. For this reason, some DDS officials said that information from a treating source with a long-standing relationship with the child, such as a physician, is more useful.

In response to concerns among many about the role medication plays in the determination process, we asked SSA and DDS officials how information about a child's use of prescribed medications is used, and they told us it is generally given no more weight than any other medical or

²⁵See 20 C.F.R. § 416.913.

²⁶See 20 C.F.R. § 416.924(a).

²⁷20 C.F.R. § 416.912(d).

nonmedical information in determining a child's medical eligibility.²⁸ Several DDS officials told us that when making determinations for children with mental impairments, medication is considered in the context of other sources of information as "just one piece of the puzzle." To the extent that medication improves functioning, some DDS officials told us they could potentially find that the child is not disabled under program rules. Despite this fact, certain field office and DDS officials acknowledged they believe some parents are under the impression that medicating their children will improve their likelihood of being found eligible for benefits. However, other DDS officials said they think a number of parents may avoid medicating their child prior to a consultative examination so that the child misbehaves and appears more disabled.

To better understand the role of prescribed medications, in March 2011, SSA conducted an analysis to determine the effect reported use of medications has on determinations for children with three different mental impairments and concluded that no effect existed. To conduct this review, SSA compiled reports of medication usage for all fiscal year 2010 initial determinations for children with ADD/ADHD, oppositional/defiant disorder, or conduct disorder impairments.²⁹ For each impairment, SSA calculated the share of allowance and denial decisions for those claims with and without related medications. SSA subsequently noted that for the children examined, those with reports of related medication were more likely to be denied than to be allowed. Although SSA's analysis indicates that allowance and denial rates were similar for children with ADD/ADHD who were and were not taking related medications, children with related medications were somewhat more likely to be allowed for oppositional/defiant disorder and conduct disorder than those without

²⁸ SSA regulations require that, when evaluating the effect of a child's impairment on his or her functioning, examiners consider the effects of treatment, including medication, the child is receiving. Specifically, they are required to consider the effects of medication on the child's symptoms, signs, laboratory findings, and functioning. If it appears that the child's symptoms are reduced by medications, they are required to consider (1) any functional limitations that persist, despite the medication; (2) whether the medications create any side effects that cause or contribute to the child's limitations; (3) the frequency of the child's need for medication; (4) changes in the child's medication or the way it is prescribed; and (5) any evidence over time of how the medication helps or does not help the child to function compared to other children the same age who do not have impairments. 20 C.F.R. § 416.924(b)(9)(i).

²⁹ SSA excluded from its analysis any medications that were not related to the three impairments. For example, a claim for a child with ADD/ADHD who was only taking asthma medication would not be classified as having a related medication.

medications. Because only about one-third of those allowed for these three impairments had reports of related medication, SSA concluded that medication usage does not affect the allowance of child claims for these impairments. However, SSA's analysis did not control for other factors, such as DDS location or claimant age, which may also affect allowance rates. Without a more in-depth analysis, the effect of the underlying causes of such differences is unknown. Although we did not independently validate SSA's findings, as part of our ongoing review, we plan to conduct a case file review of a random, generalizable sample of initial determinations decided in fiscal year 2010 for the most prevalent mental impairments—ADD/ADHD, speech and language delay, and autism. As part of this effort, we will identify what sources DDSs reported using to determine the child's medical eligibility and how they reported weighing various sources if material inconsistencies could not be resolved. This case file review should allow us to verify testimonial evidence from interviews with field office and DDS officials.

In addition to medical evidence, SSA policy directs DDS offices to use available evidence from nonmedical sources to evaluate the severity of the child's impairment and functioning as part of the eligibility determination. These sources include parents, day care providers, teachers, and others knowledgeable about the child's day-to-day behavior and activities. SSA field office staff may also provide observations about the child, if the child is present when the parent submits the application, in person, and the field office may notify the DDS if multiple siblings apply for benefits at the same time. Several DDS officials told us school records and teacher assessments (standardized questionnaires)³⁰ are especially critical, because these assessments provide information on the child's functioning over time and are generally more objective than parent assessments. Because parents may be unable to accurately assess the extent of their child's impairment, nearly all the DDS officials we interviewed said that information from the school, including the teacher assessment, was critical for making accurate determinations. According to some DDS officials, parents may primarily observe their child in an unstructured home environment after the child's medications have worn off, and they may not know what behaviors are developmentally normal, whereas teachers are generally in a position to compare the child to other

³⁰The standardized SSA teacher questionnaire includes checkboxes and multiple choice questions and is organized into sections that cover broad domains of functioning, such as acquiring and using information and attending and completing tasks.

children and provide neutral observations on how the child relates to peers, responds to medication, and performs in school. Several DDS officials told us that they compare all the information they collect to identify inconsistencies and decide how much weight to assign the various sources. For example, some officials told us examiners assess the credibility of parents' assessments of children's functioning by comparing it to physicians' and teachers' statements.

Despite the importance of nonmedical information in determining a child's medical eligibility, our preliminary work shows that examiners sometimes face challenges obtaining complete information. For example, some DDS offices reported difficulty obtaining school records or teacher assessments, which they partly attributed to school and teacher concerns about the time involved to compile this information, potential liability issues, or confusion about how such information is used in the disability decision-making process. In addition, DDS examiners told us that they do not routinely receive information on multiple siblings receiving SSI benefits within the same household even though they are directed to be alert for such cases. SSA's policy operations manual states that disabilities may occur in more than one member of a family or household, but notes prior case experience has shown this type of situation is an indicator of potential fraud or abuse, particularly where certain mental impairments are involved. For example, SSA recently investigated a case in which parents applied for SSI benefits on behalf of their four children, alleging that they all suffered from ADHD and conduct issues.³¹ However, investigators found that the school guidance counselor had never observed the children exhibiting symptoms of ADHD despite seeing them daily and that a doctor had rescinded an order authorizing the school to administer ADHD medication to the children. In this instance, SSA subsequently denied the siblings' applications for SSI benefits. Based on our interviews, it appears that SSA field offices do not consistently notify DDS examiners when an applicant's siblings are already receiving SSI benefits, nor are they always made aware of concurrent sibling applications. Without such information, DDS examiners may be limited in their abilities to identify potential fraud or abuse in the program.

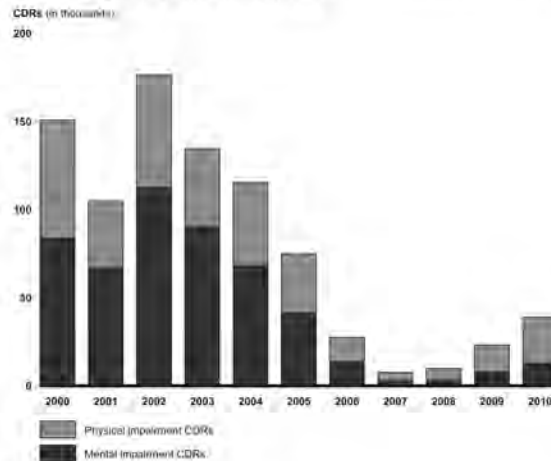
³¹SSA's Office of Operations and the Office of the Inspector's General Cooperative Disability Investigations Unit, which is responsible for investigating questions of fraud in SSA's disability programs, conducted this investigation.

SSA Has Conducted Significantly Fewer CDRs for SSI Children with Mental Impairments

SSA is required to periodically review the medical eligibility of certain individuals,³² though our preliminary work shows that SSA has conducted significantly fewer CDRs for children receiving SSI benefits in recent years, including those with mental impairments. Between fiscal years 2000 and 2010, childhood CDRs for those recipients under age 18 and age 18 redeterminations overall fell from more than 200,000 to about 126,000 (a 38 percent decrease); and more specifically, childhood CDRs for those with mental impairments declined from more than 84,000 to about 13,000 (an 84 percent decrease) (see fig. 7). SSA officials attribute the decrease in CDRs overall primarily to resource limitations and a greater emphasis on processing initial claims and reducing the backlog of requests for appeals hearings in recent years. While SSA did increase the number of CDRs it performed after receiving additional funding specifically targeted for CDRs between fiscal years 1996 and 2002, CDRs decreased once the funding expired.

³²Under Title XVI of the Social Security Act, SSA is required to (1) perform CDRs at least every 3 years on all children recipients under age 18 whose impairments are likely to improve (or, at the Commissioner's option, recipients whose impairments are unlikely to improve) (42 U.S.C. § 1382c(a)(3)(H)(i)(I)) and (2) redetermine, within 1 year of the individual's 18th birthday, the eligibility of any individual who was eligible for SSI childhood payments in the month before attaining age 18, by applying the criteria used in determining initial eligibility for individuals who are age 18 (42 U.S.C. § 1382c(a)(3)(H)(iii)).

Figure 7: Number of Childhood CDRs Conducted for SSI Recipients under Age 18, by Primary Impairment, Fiscal Years 2000-2010



Source: GAO analysis of SSA data from the CDR Worksheet.

SSA has conducted fewer childhood CDRs in recent years. As of August 1, 2011, SSA had not yet conducted CDRs for about 434,000 SSI recipients under age 18 with mental impairments who had reached their scheduled CDR date (see fig. 8).³³ Of these recipients, about 343,000 (79 percent) had exceeded the scheduled date by at least a year, with about 205,000 (47 percent) exceeding their date by 3 years and 24,400 (6 percent) exceeding by 6 years. SSA data also indicate that while age 18 redeterminations are conducted in a more timely manner, about 8 percent

³³About 845,000 child recipients with mental impairments were receiving SSI benefits as of Aug. 1, 2011.

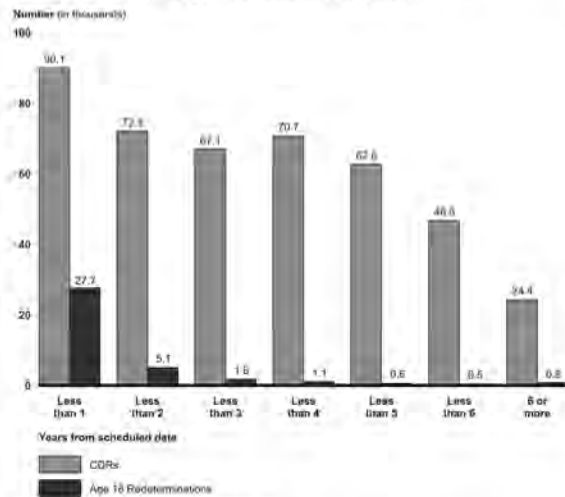
of these reviews are also overdue by 3 years or more.³⁴ In September 2011, SSA's Office of the Inspector General also reported that SSA had not completed all childhood CDRs and age 18 redeterminations in a timely manner. When reviews of benefits are delayed or not conducted, some beneficiaries may receive benefits for which they are no longer eligible. The Inspector General estimated that SSA had paid about \$1.4 billion in SSI benefits to approximately 513,000 recipients under age 18 who should not have received them.³⁵ SSA has recently estimated that the CDR process yielded a savings-to-cost ratio of roughly \$12.50 to \$1 in fiscal year 2009, and that those CDRs conducted for adults and children combined in fiscal year 2009 will save federal programs an estimated \$4.6 billion.³⁶

³⁴SSA informed us that 95.6 percent of the age 18 redeterminations are released to the field offices for processing by SSA headquarters within 2 months of the recipients' 18th birthday, and most all of them were released by no later than their 19th birthday.

³⁵The Inspector General estimated that SSA did not complete 79 percent of childhood CDRs and 10 percent of age 18 redeterminations on the basis of the results of 275 cases of physical and mental impairments they reviewed (Social Security Administration Office of the Inspector General, "Follow-Up: Childhood Continuing Disability Reviews and Age 18 Redeterminations" (A-01-11-11116), Sept. 23, 2011.)

³⁶This estimate represents the combined savings to the SSI, Disability Insurance, Medicare, and Medicaid programs from CDRs conducted for the SSI and Disability Insurance programs, as in some cases eligibility for those programs confers eligibility for certain Medicare or Medicaid benefits, as well.

Figure 8: Pending Childhood CDRs and Age 18 SSI Redeterminations for Recipients with Mental Impairments, by Time Lapsed, as of August 1, 2011



Source: GAO analysis of SSA data from the CDR Worksheet Files.

Of those reviews conducted for child recipients in recent years, the vast majority were for age 18 redeterminations and low-birth weight babies. SSA is generally required by law to conduct age 18 redeterminations, within 1 year after a child turns 18, and within 12 months after the birth of a child who was allowed benefits because of low birth weight. In fiscal year 2010, 87 percent of CDRs conducted for child recipients were done in these two areas, and SSA subsequently terminated benefits for about 52 percent of age 18 recipients and 60 percent of low birth weight recipients. The remaining 13 percent of CDRs conducted were mostly reviews of children with mental impairments. Of those CDRs conducted for children under age 18 with mental impairments, SSA terminated benefits for about 24 percent of recipients in fiscal year 2010, and

personality disorders³⁷ and speech and language delay had the highest cessation rates (34 and 33 percent, respectively).

SSA and DDS officials have acknowledged that the agency is not conducting reviews for child recipients in a timely manner, and in some cases, they have not conducted required childhood CDRs prior to a child's age 18 redeterminations. SSA officials said that they would like to conduct additional childhood CDRs, but added that due mostly to funding constraints they are not able to do so. From 1996 to 2002, Congress provided funding to SSA to conduct additional CDRs for both Social Security disability and SSI beneficiaries. Since this funding expired, the number of CDRs SSA has conducted overall has dramatically declined.³⁸ The recently enacted Budget Control Act of 2011³⁹ authorized an increase in funding for CDRs and redeterminations under both the SSI and the Social Security Disability Insurance programs, starting with an additional \$623 million in fiscal year 2012 and reaching an additional \$1.3 billion in each of fiscal years 2017 to 2021. At the time of this statement, SSA was evaluating how to use this funding for CDRs, should it be appropriated, and it is not yet known to what extent the agency would (a) increase the number of childhood CDRs in the future or (b) target such CDRs toward those mental impairments with the highest cessation rates.

Mr. Chairman and Members of the Subcommittee, this concludes my prepared statement. I will be happy to respond to any questions.

³⁷ Personality disorders are manifested by pervasive, inflexible, and maladaptive personality traits, which are typical of the child's long-term functioning and not limited to discrete episodes of illness. 20 C.F.R. pt. 404, subpt. P, app. 1

³⁸ In part to reduce the CDR backlog, the Obama Administration proposed to increase the overall number of CDRs for adults and children in the SSI program in fiscal year 2012. The proposed fiscal year 2012 budget requests \$562 million for conducting, in part, SSI CDRs and SSI redeterminations (for child and adult recipients combined), an increase of \$298 million over FY 2011. SSA estimates that if granted, this level of funding would result in almost \$4.2 billion in savings to the SSI program alone over the next 10 years.

³⁹ Pub. L. No. 112-25, sec. 101, § 251(b)(2)(B), 125 Stat. 240, 243-44.

**GAO Contact and
Staff
Acknowledgments**

For further information related to this statement, please contact me at (202) 512-7215. Individuals who may key contributions to this statement include Jeremy Cox, Assistant Director, James Bennett, Edward Bodine, Sue Bernstein, David Chrisinger, Alex Galuten, Monika Gomez, Jason Holsclaw, Kristen Jones, Sheila McCoy, Luann Moy, and Paul Wright.

Appendix I: Listings for Mental Disorders for Children under Age 18

The structure of the mental disorders listings for children under age 18 parallels the structure for the mental disorders listings for adults but is modified to reflect the presentation of mental disorders in children. Under federal regulations, when a child is not performing substantial gainful activity and the impairment is severe, SSA is required to examine whether the child's impairment meets, medically equals, or functionally equals any of the impairments contained in the listings. The actual listings go into further detail about the level of severity necessary for this step of the determination, but the general listings for mental disorders in children are arranged in 11 diagnostic categories.¹ These categories include:

Organic mental disorders: Abnormalities in perception, cognition, affect, or behavior associated with dysfunction of the brain. The history and physical examination or laboratory tests, including psychological or neuropsychological tests, demonstrate or support the presence of an organic factor judged to be etiologically related to the abnormal mental state and associated deficit or loss of specific cognitive abilities, or affective changes, or loss of previously acquired functional abilities.

Schizophrenic, delusional (paranoid), schizoaffective, and other psychotic disorders: Onset of psychotic features, characterized by a marked disturbance of thinking, feeling, and behavior, with deterioration from a previous level of functioning or failure to achieve the expected level of social functioning.

Mood disorders: Characterized by a disturbance of mood (referring to a prolonged emotion that colors the whole psychic life, generally involving either depression or elation), accompanied by a full or partial manic or depressive syndrome.

Mental retardation: Characterized by significantly sub-average general intellectual functioning with deficits in adaptive functioning.²

¹For purposes of this appendix, we have provided basic information about the 11 mental disorders for children included in SSA's listings. For additional information about these listings, refer to 20 C.F.R. pt. 404, subpt. P, app. 1.

²Although for most purposes SSA refers to intellectual disabilities rather than mental retardation, its medical listings have not been updated to reflect this change.

Appendix I: Listings for Mental Disorders for
Children under Age 18

Anxiety disorders: In these disorders, anxiety is either the predominant disturbance or is experienced if the individual attempts to master symptoms; e.g., confronting the dreaded object or situation in a phobic disorder, attempting to go to school in a separation anxiety disorder, resisting the obsessions or compulsions in an obsessive compulsive disorder, or confronting strangers or peers in avoidant disorders.

Somatoform, eating, and tic disorders: Manifested by physical symptoms for which there are no demonstrable organic findings or known physiologic mechanisms; or eating or tic disorders with physical manifestations.

Personality disorders: Manifested by pervasive, inflexible, and maladaptive personality traits, which are typical of the child's long-term functioning and not limited to discrete episodes of illness.

Psychoactive substance dependence disorders: Manifested by a cluster of cognitive, behavioral, and physiologic symptoms that indicate impaired control of psychoactive substance use with continued use of the substance despite adverse consequences.

Autistic disorder and other pervasive developmental disorders: Characterized by qualitative deficits in the development of reciprocal social interaction, in the development of verbal and nonverbal communication skills, and in imaginative activity. Often, there is a markedly restricted repertoire of activities and interests, which frequently are stereotyped and repetitive.

Attention deficit hyperactivity disorder: Manifested by developmentally inappropriate degrees of inattention, impulsiveness, and hyperactivity.

Developmental and emotional disorders of newborn and younger infants (birth to attainment of age 1): Developmental or emotional disorders of infancy are evidenced by a deficit or lag in the areas of motor, cognitive/communicative, or social functioning. These disorders may be related either to organic or to functional factors or to a combination of these factors.

According to SSA, these listings are examples of common mental disorders that are severe enough to find a child disabled. When a child has a medically determinable impairment that is not listed, an impairment that does not meet the requirements of a listing, or a combination of impairments none of which meets the requirements of a listing, SSA will

Appendix I: Listings for Mental Disorders for
Children under Age 18

make a determination whether the child's impairment(s) medically or functionally equals the listings.³ This determination can be especially important in older infants and toddlers (age 1 to attainment of age 3), who may be too young for identification of a specific diagnosis, yet demonstrate serious functional limitations. Therefore, the determination of equivalency is necessary to the evaluation of any child's case when the child does not have an impairment that meets or medically equals a listing

³See 20 C.F.R. §§ 416.926 and 416.926a.

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Chairman DAVIS. Thank you, Mr. Bertoni.
Dr. Burkhauser, please proceed with your testimony.

**STATEMENT OF RICHARD V. BURKHAUSER, PH.D., PROFESSOR,
DEPARTMENT OF POLICY ANALYSIS AND MANAGEMENT,
CORNELL UNIVERSITY**

Mr. BURKHAUSER. Thank you for the opportunity to submit a summary of my research on the SSI disabled children's program contained in my new book with Mary Daly.

In 1974, the SSI disabled children's program provided benefits to a small subpopulation of poor families with age-eligible children. Only about 10 per thousand poor children received such benefits. Program caseloads grew modestly to 20 per thousand by 1989. Between then and 1996 the number more than tripled to 65 per thousand, fell modestly for a year, and then increased to 80 per thousand in 2007.

Based on our reading of the evidence, this dramatic growth is not a result of a growing health epidemic of poor children, but rather the consequence of several policy decisions that have turned a modest program for disabled children into a more general welfare program that in large part serves the same poor single mothers in the TANF population.

Seventy-one percent of SSI families are headed by single mothers or other non-two-parent families. Increasingly, their children have medical conditions that are difficult to objectively measure and they are coming onto the SSI program via increasingly subjective evaluations by SSA gatekeepers.

So why has the SSI caseload risen? Is it a health epidemic? While it is difficult to obtain information on the underlying health of poor children, we find no evidence of worsening health in this population. While the number of poor children has increased, the number of children in that population receiving SSI benefits has increased even faster; hence, the 400 percent growth in their share among poor children previously mentioned.

Is it program policy factors? I believe it is and I focus on three policy effects. The first is TANF and SSI interactions. The typical SSI applicant family is headed by a poor single mother who is eligible for TANF. Because SSI benefits are larger than TANF benefits and have no work requirements, it is in the interest of these single mothers to apply and economists have shown that the greater the difference the more likely they are to do so. States also have an incentive to move their TANF families to the SSI program, thus cost shifting their payments to the Federal Government. This becomes a more realistic option, the lower the standard for establishing SSI eligibility and the more subjective SSI's eligibility decisions are.

So here is where the second change comes in. Eligibility standards were both lowered and made more subjective in the wake of the Zebley case, and this explains much of the increase in SSI caseloads between 1989 and 1996. As part of welfare reform, Congress modified definitions of disability for children, creating a new stricter standard. This reduced caseloads per child, but only for 1 year.

Here is where the third change comes in; that is, a change in the way SSI gatekeepers interpret these rules. The outcome of applying more subjective criteria to determine eligibility can be seen in the

percentage of SSI awards for two conditions: Mental retardation and other mental conditions. These two conditions represent extremes between medically measurable and more subjectively determined outcomes.

In 1983, approximately 37 percent of new beneficiaries qualified based on mental retardation, and only 5 percent based on other mental conditions. Today over 55 percent of new beneficiaries claim other mental conditions.

In sum, the research findings provide plausible evidence SSI program growth has primarily been driven by policy changes rather than the declining health of poor children. But what policy caused, new policies can change, but only if they are fundamental changes.

The SSI program closely resembles more general welfare programs and thus can be changed using many of the same principles applied in moving from AFDC to TANF. This would mean moving SSI from the Federal Government to the States. This devolution would, like TANF, hold States accountable to Federal guidelines regarding outcomes of children with disabilities. Like TANF, SSI could be funded by block grants and States could be asked to comply with broader goals.

Devolution to the States would also solve three major problems with the current program. First, on equity grounds, placing responsibility for all welfare families with the States would reduce the difference in treatment of poor families based on the often subjective decision of whether their children meet the SSI standards.

Second, devolving the SSI program to the States would limit State incentives to shift the cost of managing welfare caseloads to the Federal Government through the SSI.

And third, devolution to the States, who have far more experience than SSA in transitioning poor single mothers in the workforce, would allow these single mothers to work now and eventually allow their disabled children the opportunity to work after the children age off the SSI rolls.

Thank you for the opportunity for speaking today.

[The prepared statement of Mr. Burkhauser follows:]

Supplemental Security Income—Disabled Children: Time for Fundamental Change

Testimony Prepared for:
Ways and Means Subcommittee on Human Resources
Rayburn House Office Building, Room B-318
Washington, DC
October 27, 2011

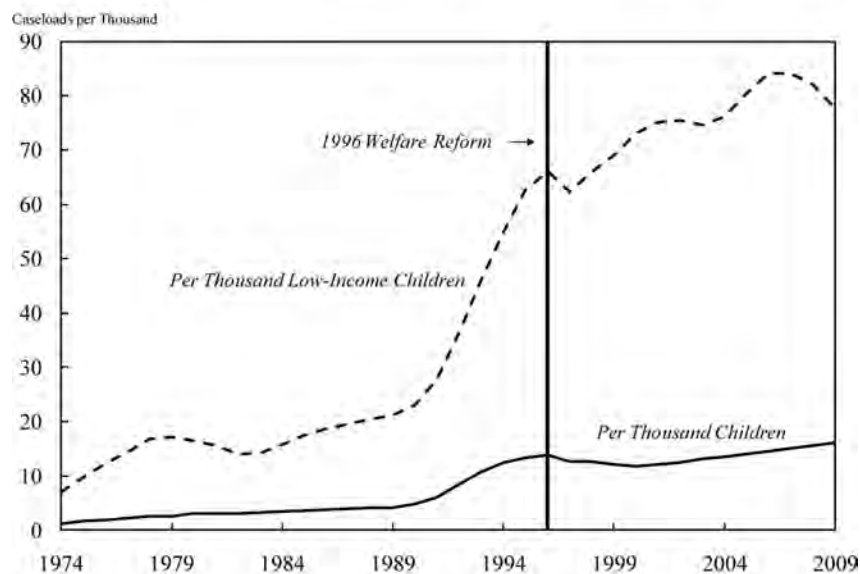
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This is a condensed version of Chapters 6 and 7 from: Richard V. Burkhauser and Mary C. Daly. 2011. *The Declining Work and Welfare of People with Disabilities: What Went Wrong and a Policy for Change*, AEI Press: Washington DC

Since 1974 the Supplemental Security Income-disabled children program has provided benefits to poor families with age-eligible disabled children. Based on our reading of the evidence however this program has increasingly become a more general welfare program that in large part targets a population of able-bodied single mothers that overlaps with the TANF (Temporary Assistance for Needy Families) population. And, whose children have medical conditions that are increasingly difficult to objectively measure and are coming onto the program via increasingly subjective evaluations by Social Security Administration gatekeepers.

This has resulted in substantial program growth both in terms of caseloads and expenditures. The SSI-disabled children program serves only children living in low-income families, so to get an accurate picture of its growth it is important to adjust these measures relative to the potentially eligible population. Two such adjusted measures, an age-based metric and an income-based metric, are shown in figure 1.

Figure 1. SSI-Disabled Children Caseloads per Thousand Children and per Thousand Low-Income Children over Time



Source: Social Security Administration 2009a; and U.S. Census Bureau 2010.

This figure reports the levels and trends in the number of children receiving SSI-disabled children benefits per thousand children under eighteen (age eligible), and the number of

children receiving SSI-disabled children benefits per families in poverty (income eligible). These measures provide rough estimates of the changing importance over time of the SSI-disabled children programs to the general population of low-income families with at least one child. The SSI-disabled children caseload as a percentage of the age-eligible population has grown over time, with especially large increases since 1989. Considering the caseloads relative to the population meeting both the age- and income-eligibility guidelines, the growth in caseloads is even more rapid. Program growth was rapid in the 1970s at the program's beginning, and it was followed by relatively slow growth through most of the 1980s. In 1990, caseloads jumped following the Supreme Court decision that expanded eligibility, and continued to rise until 1996. Caseloads per thousand children fell for one year in 1996 before trending upward again. By 2006, over eighty children per thousand age- and income-eligible children were receiving SSI-disabled children benefits. The rate has fallen somewhat in the wake of the recession, but that owes to the outsized increase in the number of low-income children associated with the economy's downturn.

Why Have SSI-disabled Children Caseloads Risen?

There are several possible explanations for the increase in SSI-disabled children program growth that can be broadly classified into two groups: (1) those that are exogenous to the program—changes in the underlying severity of disability among children and (2) those that are endogenous to the program—Welfare Reform, the size of SSI benefits relative to AFDC/TANF benefits, specific changes in SSI-disabled children program rules and their interpretation and implementation over time. Economists have examined each of these possible explanations and generally concluded that although each played some role, factors that are endogenous to the program had the largest impact on both the growth and fluctuations highlighted in figure 1.

Health. Defining and measuring disability in children is difficult and complicated. That said the limited information on trends in child health and functional limitation point to little change over time. We report data on self-assessed health, specifically the percentage of children under age eighteen assessed by parents to be in poor or fair health. Although there is some fluctuation over time, we find no notable upward trend in the prevalence of poor or fair health over time. We also report the percentage of children ages five to seventeen with an activity limitation by poverty status. Again, the key finding is that there has been little change over time in functional limitations among any of these populations, including those who may be income-eligible. While these data are limited, they provide little indication that changes in child health can explain the enormous variation and growth in the SSI-disabled children rolls relative to the age- and income-eligible population observed in figure 1.

Welfare Reform and the Size of SSI-Disabled Children Benefits Relative to AFDC/TANF benefits. The SSI-disabled children program provides cash benefits to families with low income and a disabled child. But the program might more accurately be called the *Aid to Families with Disabled Children* since it does not directly provide services to children with disabilities, nor tie benefits to the purchase of services for the

disabled child. Rather it is much closer in design to a general welfare program in which benefits are income tested but also require the child of able-bodied parents to have a disability.

Hence the disabled child's interests are represented by the parents and, to a lesser extent, by the state. While this is reasonable, it means that the decision to apply for SSI-disabled children benefits can be based as much on the family's economic circumstances as on the child's disability and specific needs for care. Indeed, Rupp and Ressler (2009) find that the probability that a parent with a disabled child is working is driven by variables other than the severity of the child's impairment. Thus for those who are working at the time of the child's health shock, a parent or parents will be forced to decide whether to leave or reduce employment to care for the child. For the vast majority of Americans with long work histories, stable jobs, health insurance, and family income well above the minimum income protection of the SSI-disabled children program, it is highly unlikely that they will turn to this program for assistance.

For the minority of Americans with intermittent work histories, low-paying or unstable jobs, no health insurance, and family incomes near the SSI minimum guarantee, however, the benefits offered first by temporary welfare (AFDC/TANF) and eventually by the SSI-disabled children program are a possible alternative path given a child's unexpected health shock. In such cases, the child's impairment will certainly affect this decision, but so will the likelihood that the child will be eligible for SSI-disabled children program benefits and their future earnings and private access to health care. As Hemmeter, Kauff, and Wittenburg (2009) and Loprest and Wittenburg (2007) show, however, such children are much more likely to live with a single parent, and less than half of those single parents are employed. Thus, the majority of the families of SSI-disabled children benefits likely do not have a working member at the onset of the child's impairment. For a parent who is not working at the time a child experiences a health shock, decisions need to be made that will be affected by the child's health and likelihood of being found eligible for SSI-disabled children benefits. In addition, the family must determine whether there is a financial gain to qualifying for SSI over staying on the more general welfare program.

Wiseman (2010) estimated the relative financial gain for the average single-mother family on AFDC in 1996 if a mother were able to qualify her child for the SSI-disabled children program. In such a case, she would have nearly doubled her cash transfers. The gain was highest in states like Texas, where AFDC benefits were relatively low compared to SSI-disabled children benefits, but gains were still fairly large in states like California and New York, which had higher AFDC benefits but also offered state supplements to the federal SSI-disabled children payment. After welfare reform, the average gains were even larger. This understates the long-term gains to such single mothers because, under TANF, the mother is guaranteed only five years of benefits and is under other pressures to work. Under the SSI-disabled children program, benefits continue until the child turns eighteen, and the parent is not expected to work.

Evidence suggests that a large fraction of the children enrolling in the SSI-disabled children program in the 1990s previously participated in the AFDC program. Empirical

research examining the degree to which these relative gains produced this shift from AFDC/TANF to the SSI-disabled children program has found it to be significant (Garrett and Glied 2000; Kubik 1999). While it is difficult to identify the effect of this type of incentive, one paper (Kubik 1999) finds that reported disabilities by newly awarded SSI-disabled children—particularly mental impairments, which are the most difficult to objectively evaluate—were higher in states with lower AFDC benefits, where the relative gains from movement onto the SSI-disabled children program were higher.

States will also make decisions that influence whether a family that is either applying for state welfare benefits or already on them chooses to apply for SSI-disabled children benefits. Like the parent, the state will consider the child's health and the likelihood the child will be accepted into the program. The state will also consider whether the parent is a good candidate for employment. In the case of single mothers, it is in the interest of the state not only to encourage their AFDC/TANF population to apply for SSI benefits, but also to provide resources for them to do so. States will have an incentive to move their TANF families to the SSI-disabled children program in order to shift the responsibility of providing cash transfers for those adults to the federal government and reduce any cost the state would absorb in trying to encourage employment. While AFDC/TANF single mothers who are able-bodied are not candidates for the SSI-disabled adults program, their income maintenance would be guaranteed by the federal government if their child were eligible for the SSI-disabled children program.

Although the SSI-disabled children program was intended as an income-support program for families headed by parents who were unable to work because of their child's disability, it appears to have grown into an income maintenance program for low-income families with a qualifying child. This has altered the incentives for these families and the states in ways that likely affect outcomes including caseloads, costs, and ultimately the long-run economic status of the child. At each point in the process that leads parents to apply for SSI-disabled children benefits, decisions have to be made by both parents and the states that provide services to these families before they move further along the path to long-term benefits. The eligibility rules facing SSI-disabled children and how the system is financed influences the behavior of parents of disabled children and the states in which they live in their response to a child's health shock.

Changing Program Rules. When the SSI-disabled children program was originally considered, Congress recognized the potential difficulties of applying the standard SSA disability definition to children. Thus, under the original legislation, Congress wrote that a child should be considered disabled if "he suffers from any medically determinable physical or mental impairment of comparable severity" to a disabling impairment in an adult. Between 1974 and 1989, the child disability determination process did not include a functional assessment or account for the equivalent of adult vocational factors and the program experienced only modest growth.

This changed in 1990, when the U.S. Supreme Court decided the case of *Sullivan v. Zebley*. The Court ruled that to meet the standard of equal treatment, a functional limitation component parallel to that of adults must be included in the initial disability

determination process for children. In response, the Social Security Administration added two new bases for finding children eligible for benefits: (1) functional equivalence, which was set at the medical-listing level of the disability determination process; and (2) an individualized functional assessment (IFA), which was designed to parallel the vocational assessment provided for adults. By allowing applicants who did not meet the medical listing to be found disabled if their impairments were severe enough to limit their ability to engage in age-appropriate activities, such as attending school, the IFA lowered the level of severity required for children to be eligible for SSI benefits (GAO 1994, 1995).

In 1996, as part of welfare reform, Congress modified the definition of disability for children. Legislators replaced the comparable severity (to adults) criteria with a definition of disability that is unique to children. Under the new definition, a child's impairment—or combination of impairments—is considered disabling only if it results in marked and severe functional limitations, is expected to result in death, or has lasted or can be expected to last at least twelve months. The new focus on assessing the severity of impairments among children was reflected in changes in the evaluation process. The legislation removed the IFA, replacing it with criteria based on functional equivalence or evaluations of the extent to which impairments meet or exceed medical-listing-level severity. In practice these changes meant that although functional limitations continued to include behavior-related limitations, they no longer covered the same breadth of functioning included in the IFA. For example, Congress specifically removed maladaptive-behavior disorder from the functional-listing criteria. Thus, the post-1996 standard represents a broader measure of disability than originally applied to children but a narrower standard than the one used between 1990 and 1996.

Applying Changing Rules. Figure 1 clearly shows that changes in rules for children applying for SSI had a noticeable effect on caseloads, but the way SSI administrators interpreted these rules also had an impact on the rolls. The outcome of applying more subjective criteria to determine eligibility can be seen in the percentage of SSI-disabled children awards by two conditions: mental retardation and other mental conditions. These conditions represent extremes of the distribution between medically measurable and more subjectively determined. Mental retardation is a longstanding diagnosis with objective measurable criteria that can be applied consistently across evaluators. Mental impairments other than mental retardation are more difficult to measure objectively.

In 1983, approximately 37 percent of new beneficiaries qualified based on mental retardation and only 5 percent had other mental conditions. By 2003, over one-half of all new beneficiaries listed other mental conditions as their qualifying diagnosis and that grew to over 55 percent in 2009.

Part of the explanation for this increase is a specific change in the eligibility criteria—an SSA-based easing of criteria for meeting or exceeding the medical listings for mental impairments and a *Zebley*-based expansion to include functional limitations. But following this change in criteria, the share of new beneficiaries based on a mental condition has continued to grow at a rate much closer to the rapid rate that immediately followed the *Zebley* decision. The increase in the share of new beneficiaries with other

mental conditions since *Zebley*, and especially since the efforts to limit entry in 1996, suggests that gatekeeper discretion in determining these outcomes is another driver of SSI-disabled children caseload growth. This influence can be seen in the rise in awards based on functional criteria. The percentage of SSI-disabled children awards based on meeting or equaling the medical listings has declined substantially, and the percentage of children awarded benefits based on functional listings has risen accordingly.

These figures show that changes in program rules (especially the *Zebley* decision), and the subsequent administration of these rules, are affecting the patterns of program growth in figure 1. Hence, the growth in the SSI-disabled children rolls does not seem consistent with changes in the underlying health conditions among children. Rather, it appears to be based on increases in applications and acceptances onto the rolls that revolve around program eligibility rules and their implementation.

In sum, the research findings above provide plausible evidence that SSI-disabled children program growth has primarily been driven by factors other than the declining health of poor children. Loosening of program rules in the wake of the *Zebley* case has made it more difficult for gatekeepers to judge eligibility and welfare reform has increasingly made it in the interest of poor single mothers who have children with some impairments to apply for the more lucrative SSI-disabled children benefits often with the assistance of states attempting to reduce their TANF costs.

Unintended Consequences and Long-Term Costs

We have argued above that the rise in SSI-disabled children caseloads and costs are primary policy driven. Some would agree with us that this is the case but that while it is costly to provide benefits to the poor via this program, these funds none the less provide additional resources to a poor population. While that is certainly the case, we argue that the current program has one additional unintended consequence that makes it a much less than ideal program for integrating poor children with disabilities in the mainstream society as they age out of the program and hence made be detrimental to the long term interests of these children. Hemmeter, Kauff, and Wittenburg (2009) find that nearly two-thirds of these children transition directly to the SSI-adult disability rolls. Once this transition is complete, very few attempt to work thereafter. Moreover, of those who do not move directly onto the rolls, only about 60 percent are employed at age nineteen (Hemmeter, Kauff, and Wittenburg 2009). Thus, most SSI-disabled children beneficiaries age out of this program into what is likely to be a permanent life on the SSI-disabled adults program or, in the event of denial of SSI-disabled adult benefits, turn to other forms of social welfare. This outcome is costly both to the beneficiaries who live their lives at or near the poverty threshold and to taxpayers who are funding the benefits.

The Case for Fundamental Change

The SSI-disabled children program closely resembles general welfare programs in the United States and, thus, can be changed using many of the same principles applied in moving from AFDC to TANF. This would mean moving jurisdiction of the SSI-disabled

children programs from the SSA to the states. Unlike the previous periods when SSI-like programs were in state hands, this devolution would, like TANF, hold states accountable to federal guidelines regarding outcomes of people with disabilities. Like TANF, the SSI-disabled children program could be funded by block grants from the federal government, and states could be asked to comply with broad goals. At the same time, states would be allowed and encouraged to innovate and create work based alternatives to long-term cash support for applicants with disabilities.

Following welfare reform, and in keeping with the changing views about the integration of children with disabilities into the schools, we urge that families of children in the SSI-disabled children program be placed under the case management of state welfare agencies and that states use the same mix of supports (for example, child care and job training) and requirements (such as potential loss of benefits for noncooperation) to encourage working-age adults in these families to work. States would be able to use their funds to better target the special needs of the children with disabilities in these families. States would also be able to use these funds to provide services, rather than cash, to children with disabilities directly. These services could be refined to match the specific needs of the local population and, ideally, to improve the long-run ability of these children to enter the labor force.

These types of changes would move toward solving a number of problems with the current program. First, on equity grounds, placing responsibility for all welfare families with the states would reduce the difference in treatment of poor families based on whether they have children who meet the SSI-disabled children standards. Second, devolving the SSI-disabled children program to the states would limit states' incentives to shift the costs of managing welfare caseloads to the federal government through the SSI system. Finally, because states would carry the full burden of children with disabilities who remained in their welfare population once they reached working age, they would have a much greater incentive to provide the education, training, and accommodation necessary to enable children with disabilities to enter the workforce as adults.

Can States Manage the SSI-disabled Children Program? State welfare agencies now have over a decade of experience in moving welfare mothers and other welfare clients into the workforce. Although this would be a significant change from the last thirty years, and one that states may not want to undertake in a time of severe budget pressures, we argue that it makes sense to integrate the SSI-disabled children population into the broader state-run social safety net for low income residents. Providing states with block grants to use for all of their low-income populations has the potential to generate more experimentation and work-oriented programs, including rehabilitation, job training, and accommodation efforts focused on individuals with disabilities. If augmented by the same federal commitments given to low-income single mothers, such as the EITC, child tax credits, and health insurance, states will likely be willing and efficient managers.

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Chairman DAVIS. Thank you very much, Dr. Burkhauser. Dr. Wittenburg, if you could give your testimony.

**STATEMENT OF DAVID WITTENBURG, PH.D.,
SENIOR RESEARCHER, MATHEMATICA POLICY RESEARCH**

Mr. WITTENBURG. Thank you, Chairman Davis, Ranking Member Doggett, and Members of the Subcommittee, for the opportunity to testify on how we can improve efforts to provide supports to child SSI recipients.

I have written several reports about the outcome of these youth. And I will make three points about this program related to issues raised in recent media reports, including *The Boston Globe* series.

The first point is about the importance of the child SSI program as an anti-poverty tool. A key indicator of the program's effect on poverty is that on average the child's SSI benefit check currently accounts for approximately half of the income of the family.

A second related point is about the strong individual and State incentives that encourage families to apply for SSI over existing State welfare programs like TANF. This point, that goes to Dr. Burkhauser's point just made, that families might be enticed to apply for SSI on behalf of their child because the Federal SSI benefit on average is \$200 larger than State TANF benefits. Because TANF is funded by a block grant, States can also financially gain because every dollar saved by a transfer of a TANF recipient to SSI remains within the State. For these reasons a low-income parent who has a child with even a moderate disability has a financial incentive to apply for SSI, and could even be encouraged to do so by a State worker.

The caseload trends illustrate this gradual federalization. Since 1989 child SSI caseloads have increased by 350 percent while the corresponding State welfare caseloads have dropped by more than 50 percent. There is evidence of direct transitions across the programs. A key question is whether this movement increasingly toward using child SSI supports for low-income families is appropriate.

This question leads to my third point, which is the most important point in my testimony, and is illustrated on the slide above. A major concern is the program's effects on the outcomes of young adults. And this slide shows between the ages 19 to 23 former child SSI recipients reported first of all substantial dropout rates. Two in five did not have a high school diploma and were not actively attending school. Low employment rates, almost four in five are not currently working. Most disconcerting, high arrest rates, one in five had been arrested. And unfortunately these arrest trends are consistent with other reports that indicate 30 to 50 percent of incarcerated youth with disabilities could qualify for other services.

Finally, reliance on SSI benefits is a long-term option. Just over three in five are receiving SSI after age 18. Taken together, these poor outcomes suggest a need to rethink the current policies. Any approach though should balance the outcomes needed above with also providing income supports that keep low-income families out of poverty.

One approach to reforming policy and to reverse the outcome shown on this slide is to pilot the addition of education and/or work

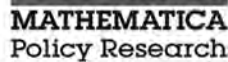
requirements for continuing SSI eligibility. This option maintains the current structure of the child program but alters the potential adverse incentives children face regarding school and work. The infusion of education requirements would also make the child SSI program more consistent with the Individuals With Disabilities Education Act, which provides free and appropriate education services to youth with disabilities.

A second more ambitious approach is to look at the broader safety net and consolidate service delivery to more specifically meet the diverse needs of youth with disabilities and their family. This option is especially important given the fact that the line between TANF and SSI has become blurred. Improving program design requires rethinking of existing programs and designing new approaches that should be tested to build a consensus on what works. Such rethinking could include local, State, Federal or even private providers who provide a more integrated set of reports.

While we do know some information to approach the problem, the exact model for reform is not known at this time because it has not been tested. So we should not rush to a solution. Experimentation, however, can lead to innovation of promising practices, service delivery and effective policy. For this reason I suggest the use of congressional authority to invest in major demonstrations which will highlight models that could improve health and social outcomes and potentially save significant tax dollars. Failure to do so only delays our ability to develop policies to improve the lives of youth with disabilities. Youth are worth the investment, and the outcomes I outline today indicate that we should be more aggressive in efforts to help them reach their full potential.

Thank you and I would be pleased to take your questions.

[The prepared statement of Mr. Wittenburg follows:]



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Testimony for Hearing on Supplemental Security Income Benefits for Children
Subcommittee on Human Resources
Committee on Ways and Means
U.S. House of Representatives

October 27, 2011

Thank you, Chairman Davis, Ranking Member Doggett, and members of the Subcommittee, for this opportunity to testify on how we can improve efforts to provide supports to children who receive Supplemental Security Income (SSI) benefits. In my work as a senior researcher at Mathematica Policy Research, I have written several reports about the outcomes of these youth. My testimony today builds off this research and I have structured my comments to address several concerns regarding the child SSI program raised in recent media reports.¹ The research findings do confirm some concerns raised in the media. There is a need for reforms, but they should be viewed in the context of other programs that serve low-income families with children.

I'd like to make the following three points regarding the child SSI program:

1. **Risks of harm to long-term development of youth.** The most important point of my testimony is that, as child SSI recipients near age 18, parents and their children face incentives to behave in ways that are not necessarily in the best interest of the child. These incentives may adversely affect parents' choices regarding their child's education, health care, and later employment.
2. **Federalization of welfare.** Strong financial incentives exist for both individuals and states to shift low-income families with children with even moderate disabilities from state to federal programs. The result has been to increase the federal government's role in providing support for this population, primarily via SSI, and to reduce the states' role. This raises questions about both the purposes of the block-granted state Temporary

¹http://www.boston.com/news/local/massachusetts/articles/2011/12/12/with_ssi_program_a_legacy_of_unintended_side_effects/ and <http://www.npr.org/2011/08/18/139722024/benefits-for-severely-disabled-children-scrutinized>

Assistance for Needy Families (TANF) programs that serve low-income families and the federal child SSI program that provides benefits to low-income children with disabilities.

3. **Importance as an anti-poverty program.** The child SSI program provides an important source of cash benefits to many low-income children, especially children living in single-parent families and other (non-two-parent) family households. Poorly designed policy reforms would put such children and their families at substantial risk.

Policymakers should not stand still in light of the substantial growth of the child SSI program and the poor young adult outcomes of the recipients. If past history is any indication, Congress should take steady action in revising the program.

I propose two options for addressing these issues:

1. **Test adding education and/or work requirements for continuing eligibility for some child SSI recipients.** One option is to add school and work requirements as a condition of eligibility for some segment of child SSI recipients to receive ongoing benefits. This option maintains the current general structure of the program, but alters the potential adverse incentives children face regarding school and work.
2. **Congressional authorization to test initiatives that integrate state and federal supports to promote long-term adult outcomes, such as employment.** A second option is to test consolidating federal and state supports into a more coherent safety net that customizes cash, health, and employment supports to meet the unique needs of low-income families with children with disabilities. This option would take some time to develop, but its potential for payoff in terms of building consensus of “what works” in supporting youth with disabilities could lead to substantial long-term reductions in government spending.

My testimony begins by providing context on the issues facing the child SSI program and then reviews the three key points about the child SSI program to support my proposed two policy options. In describing the child SSI population, I draw from multiple survey and administrative data sources. In some cases, the data I use come from the 2000 National Survey of SSI Children and Families (NSCF),² which allows for a detailed examination of the living circumstances and outcomes of the population unavailable elsewhere. Although the child SSI program has grown since 2000, the general eligibility requirements have remained the same, indicating that the general experiences of former child SSI recipients I cite in 2000, particularly their adult outcomes, should be very similar to those of current recipients.

²Rupp et al. (2005).

CONTEXT ON THE ISSUES

A. Debate Over Problems in the Child SSI Program

The recent media reports have raised specific concerns about the growth of the child SSI program, potential abuses in the system, and effects of the program on teenagers' decisions to pursue education and work activity. Potentially most disconcerting were the reports that growth was related to adverse incentives for families to overmedicate their children with psychotropic drugs in order to qualify for the benefit.³

These media reports have raised concerns among both Republicans and Democrats, who have since requested that the Government Accountability Office investigate the program's practices.⁴ Currently, a House budget report suggests that eliminating incentives to overmedicate children could save the SSI program \$1.4 billion over 10 years, though details on how those savings would arise are not publicly available.⁵

Disability advocates have noted that the media reports distort the characteristics and needs of children who qualify for benefits. The Bazelon Center for Mental Health Law, a nonprofit organization that supports the rights of people with mental illnesses, argues that these benefits are central for protecting the income of families. They note:

*"The SSI cash benefit (and the Medicaid coverage that accompanies it) enables these families to access the services necessary for children to live with their families in their community, not in institutions. These benefits are also essential to preventing families from falling deeper into poverty."*⁶

B. A History of the Growth and Changing Incentives in the Child SSI Program

The history lessons of the child SSI program are especially relevant as Congress considers making changes to the program and underscore the importance of not taking rash action. This is not to say that the concerns raised by the *Boston Globe* series, particularly about the overmedication of youth, should be treated lightly. However, as I will describe in more detail below, several major changes were made in 1996 to the child SSI program in a hasty fashion based on allegations of fraud that government reports found to be untrue. These changes likely contributed in part to the poor outcomes of former child SSI recipients as adults that appear later in my testimony.

³http://www.boston.com/news/local/massachusetts/articles/2010/12/12/with_ssi_program_a_legacy_of_unintended_side_effects/

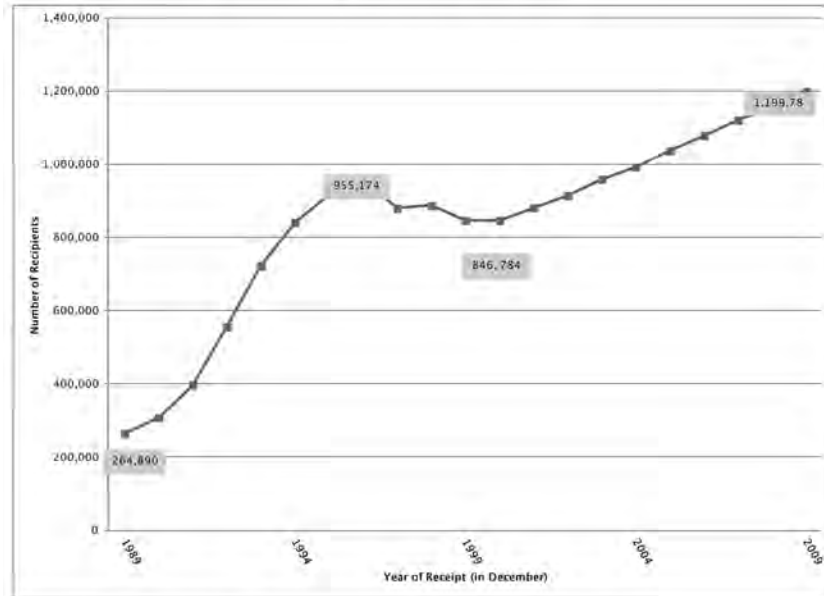
⁴ <http://www.npr.org/2011/08/18/139722024/benefits-for-severely-disabled-children-scrutinized>

⁵ <http://budget.house.gov/UploadedFiles/fy2012FullReportText.pdf>

⁶<http://www.bazelon.org/Where-We-Stand/Access-to-Services/SSI-SSDI-Disability-Benefits/Childrens-SSI-Disability-Benefits-Threatened.aspx>

As shown in Exhibit 1, the child SSI program in 1989 was relatively small, with 265,000 recipients. The small size partly reflected the restrictive “listing-only” approach to eligibility, in which children could qualify only if their medical impairment met the medical listing definitions for the adult program.

Exhibit 1. Expansion of the Child SSI Program Between 1989 and 2009



Source: Statistics from SSA administrative records on child SSI recipients.⁷

From 1989 through 1995, the child SSI program more than tripled in size following major changes in its eligibility definition. The 1990 Supreme Court decision, *Sullivan v. Zebley*, argued that SSA’s “listing-only” approach was too restrictive. Following the change, the SSI program expanded using a broader definition that generally assessed whether a child could function “independently, appropriately, and effectively in an age-appropriate manner.”

⁷ <http://www.ssa.gov/policy/docs/statcomps/supplement/2010/7a.pdf>

In some parallels to today's concerns over the growth in the child SSI program, media reports circulated that children were coached to behave inappropriately in order to obtain SSI benefits.⁸ Although the claims turned out to be unsubstantiated, the child SSI program went through a major change in redefining eligibility requirements.

In 1996, the Personal Responsibility and Work Opportunity Reconciliation Act instituted an age 18 redetermination and revised the child SSI eligibility definitions, which are the basis of current policy for assessing disability claims. The changes made the eligibility policy more restrictive, though the new eligibility requirements are not nearly as restrictive as the "listing-only" approach that existed before the Zebley decision. To meet the disability criteria, a child must have "a medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months" (U.S. Code 42 2007). As in previous years, once on the rolls, recipients must continue to satisfy the strict income, asset, and disability eligibility criteria to continue receiving benefits. The 1996 changes also included the requirement that the eligibility of all child SSI recipients be redetermined under adult definitions at age 18. As I will show in more detail below, this requirement has important effects on the incentives of youth and their families to pursue activities, such as employment, that might jeopardize long-term benefits.

Currently, the child SSI program provides a cash benefit amount and, in most states, categorical eligibility for Medicaid. In 2011, the federal SSI benefit amount was \$674 a month (approximately \$8,088 per year) and several states provide additional supplements to the benefit.⁹

While the growth in the mid-1990s could potentially be explained by eligibility expansions, the child SSI program has continued to expand significantly over the past decade without any major eligibility changes. From 2000 through 2009, the program has expanded by 40 percent from 847,000 in 2000 to 1.2 million recipients. During this same period, the overall size of the population under age 18 remained relatively unchanged.¹⁰ As has been well documented, a substantial amount of that growth was due to an increase in the number of beneficiaries with mental disorders, who now comprise more than half of the child SSI caseload.¹¹

The growth of the program is important, given that the annual cost of providing SSI benefits to children is \$10 billion and the long-term costs could be substantially larger.¹² While data on the long-term outcomes of child SSI recipients will not be available for several years, if a child becomes eligible for the adult SSI program, she could be eligible potentially for a lifetime of benefits.

⁸ Auster et al. (1999).

⁹ <http://www.ssa.gov/ssi/text-benefits-ssi.htm>

¹⁰ http://www.childtrendsdatabank.org/sites/default/files/53_fig01.jpg

¹¹ Tabulations based on data from http://www.ssa.gov/policy/docs/statcomps/ssi_ast/2009/sec04.html#table19.

¹² http://www.boston.com/news/local/massachusetts/articles/2010/12/12/with_ssi_program_a_legacy_of_unintended_side_effects/

IMPORTANCE AS AN ANTI-POVERTY PROGRAM

Disability advocates argue that the child SSI program is an important policy tool in fighting poverty because of its income supports and linkages to Medicaid coverage in most states.¹³ They note that families caring for a child with a disability have many additional expenses relating to the disability, such as out-of-pocket health care costs and accommodation supports. Additionally, they argue that SSI also helps to replace lost income when a parent must stay home to address the child's very significant needs.

A. Child SSI Benefits and Related Supports Are Important for Low-Income Families

The research findings do support the claims that the child SSI program is an important anti-poverty program and its expansions reduced poverty in the 1990s. One estimate indicates that expansions of the child SSI program in the 1990s reduced the probability that a child lived in poverty by 11 percentage points. By 2006, researchers estimate that there were 160,000 fewer children in poverty than there would have been absent the large expansions of the child SSI program in the early 1990s.¹⁴

A key indicator of the program's effect on poverty is that the child's SSI benefit check represents approximately half the income for the family.¹⁵ While the SSI benefit alone is not enough to move a family of three out of poverty, as I will explain in more detail later, the benefits are relatively generous in comparison to TANF benefits.

The categorical linkages of SSI to Medicaid also play an important role in providing safety nets of supports to ensure that health needs are met. SSI recipients report relatively few unmet medical needs and out-of-pocket medical expenses because over 90 percent report that they receive Medicaid coverage.¹⁶ Medicaid has been found to be equal if not better than some private plans at serving the health needs of children because it provides specialized supports, such as early screenings, and has low co-payments that protect vulnerable families from excessive expenses.¹⁷

The combination of both cash and health supports illustrates why advocates strongly support the child SSI program in protecting at-risk families. However, as I will detail below, these protections to lift families out of poverty also come at a potentially high cost to a child's long-term outcomes.

¹³ <http://www.bazelon.org/LinkClick.aspx?fileticket=pO2Q6DljPso%5d&tabid=432>

¹⁴ Duggan and Kenney (2007).

¹⁵ Davies et al. (2009).

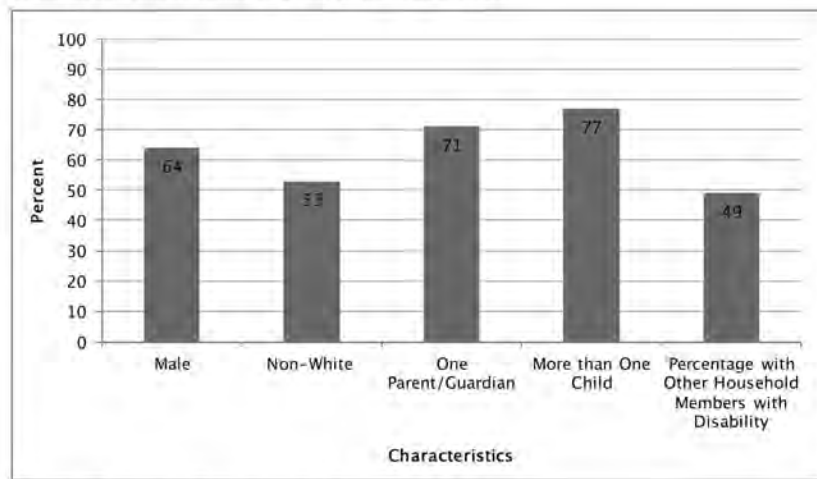
¹⁶ DeCesario and Hemmeter (2009).

¹⁷ Dubay et al. (2007).

B. Parental Employment and Caregiving Decisions Influenced by Both Child and Household Characteristics

The health and other needs of child SSI recipients are heavily influenced by their disabilities, as well as their demographic and family characteristics. As shown in Exhibit 2, in 2000, two-thirds of child SSI recipients were male and approximately half were non-white. Of particular importance is that 71 percent lived in a single parent/other guardian family and almost 80 percent lived in a household with another child. Additionally, almost half of the households include another family member with a disability. For parents, the implication of these characteristics is that they often have to take care of multiple children and, in a substantial number of cases, two people with a disability.

Exhibit 2. Child SSI Recipients Age 0 to 17 in December 2000



Source: Davies et al. (2009) using data from the NSCF.

Not surprisingly, the employment and health caretaking activities of parents of child SSI recipients vary, in part based on the severity of the child's disability and these other circumstances. To supplement their incomes, 55 percent of parents reported working and their incomes represent 39 percent of total household income.¹⁸ Parents with higher education levels, living in two-parent households, and with fewer children were more likely to work relative to others.¹⁹

¹⁸ Davies et al. (2009).

¹⁹ Rupp and Ressler (2009).

Over one-third of parents reported providing home health services, with significant variations in the time reported to take care of youth.²⁰ Specifically, parents of youth with more severe health needs reported providing more in-home health care. The challenges of providing home health care were especially difficult for single mothers who had children with severe disabilities and few options for outside support.

The characteristics underscore both the diversity of child SSI families and their unique health care needs to address a child's disability. Some families need income supports to cover the needs of the youth, as well as those of other youth in the household. A substantial minority of families may also need the SSI check to substitute for employment in order to provide home health care to their youth, though the majority of parents do not report these intensive services.

FEDERALIZATION OF WELFARE

What is driving the large expansion in the SSI caseloads?

While there have been advances in the ability to detect and diagnose childhood disorders, such as autism, there have been relatively limited changes in the reported functional status of youth in the previous decade.²¹ Hence, it seems unlikely that changes in the underlying health of the population can be driving these trends.

Given the characteristics shown in Exhibit 2, a likely explanation appears to be a major transition in serving low-income families by states to federal programs. As shown in Exhibit 2, 71 percent of child SSI recipients live in a single parent/other guardian household. Presumably, based on their low incomes and assets and the high number of single-parent households, most of these families would be eligible to receive TANF.

As has been noted in the media, an important issue is that SSI benefits have several advantages over existing state welfare benefits from TANF. While both TANF and SSI provide means tested support, SSI benefits are relatively larger than TANF benefits and do not include work requirements or time limits. In 2008, the national average monthly TANF benefit was approximately \$200 lower than the average SSI benefit.²² For these reasons, a low-income mother who has a child with a moderate disability may have a financial incentive to apply for SSI over TANF to obtain the larger benefit and escape TANF work requirements and time limits.

The incentives for individuals to apply for SSI in lieu of TANF are not new and, in fact, there is strong evidence that families have been making these financial choices to apply for SSI for more than 20 years.²³ Parents living in states that pay low TANF benefits have more financial incentive to

²⁰ Rupp and Ressler (2009).

²¹ Burkhauser and Daly (2011).

²² Wiseman (2011).

²³ Schmidt and Sevak (2004); Wiseman (2011); Stapleton et al. (2001); and Wamhoff and Wiseman (2005).

apply for SSI and, not surprisingly, the movement from TANF to SSI is substantially larger in states where the difference between the SSI and TANF benefit checks is large.²⁴

States also stand to gain financially from moving youth from state TANF programs to federally funded SSI, which is especially important today as states scramble to balance their own spending. Because TANF is funded by a block grant, every dollar saved by a transfer of a TANF recipient to SSI remains with the state. The clearest example of these incentives may be the fact that most states now have special administrative procedures for supporting SSI application by adults and children who appear potentially eligible, and some use contractors for this purpose.²⁵

The changes in the relative sizes of the TANF and child SSI caseloads illustrate the movement toward federalizing supports for low-income populations with children. The number of children covered who received TANF and the Aid to Families with Dependent Children (AFDC), the program TANF replaced in 1996, changed substantially between 1989 and 2009. From 1989 to 2009, the number of children who lived in families receiving AFDC/TANF benefits dropped by more than 50 percent (from 7.4 million to 3.2 million children), while the child SSI program increased by 365 percent (from 265,000 to 1.2 million children).²⁶

Exhibit 3 shows the changing number of children who received AFDC/TANF and child SSI benefits over the past 20 years. In 1989, there were 115 child AFDC recipients and 4 child SSI recipients per thousand children under age 18 in the United States. By 2009, those ratios had changed substantially as there were 45 child TANF recipients and 16 child SSI recipients per thousand children in the United States. This figure shows that some significant responsibility for serving low-income families has shifted from TANF to SSI, even though TANF continues to serve a broader target population of low-income children.

The general transition of youth from state to federal benefits raises questions of whether these trends are reversing the intention of welfare reform legislation in 1996. This issue is especially important given that the transitions from TANF to SSI vary by state, as states with less generous benefits generally have higher transitions from TANF to SSI.²⁷

A key question is whether child SSI benefits are most appropriate for serving the long-term outcomes of children. I address this last issue by looking at the adult outcomes of youth.

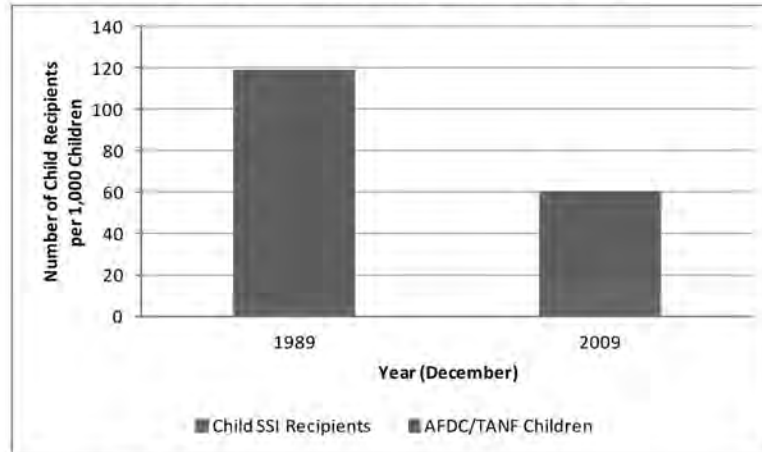
²⁴ Schmidt and Sevak (2004).

²⁵ Wiseman (2011).

²⁶ SSI data for 1989 and 2009 from <http://www.ssa.gov/policy/docs/statcomps/supplement/2010/7a.pdf>; 1989 AFDC data are available from http://www.acf.hhs.gov/programs/ofa/data-reports/caseload/afdc/1989/fycyrom189_ek.htm; 2011 TANF data are available from http://www.acf.hhs.gov/programs/ofa/data-reports/caseload/2009/2009-children_tan.htm.

²⁷ Schmidt and Sevak (2004).

Exhibit 3. Number of Child SSI and Child AFDC/TANF Recipients Per Thousand



Source: Administrative data from the ACF and SSA.²⁸

RISKS OF HARM TO LONG-TERM DEVELOPMENT OF YOUTH

In part three of the *Boston Globe* series (“For teenagers, a difficult balancing act”), one teenager noted being afraid to apply for SSI because of its long-term implications:²⁹

A fear of becoming dependent on the check is why Eliseo Ramirez, a 15-year-old New Bedford High School student, has virtually begged his mother not to apply for SSI benefits for him, even after a state social worker suggested she do so.....Eliseo said he has seen troubled classmates qualify for SSI, then lose their ambition to get part-time jobs or strive for better things in their lives. Some, he said, have drifted into the underworld of drug dealing because they didn't want any above-board income.

Unfortunately, the observations about Eliseo’s fellow students’ troubles are not uncommon. The “loss of ambition” noted above manifests itself in the transition experiences into adulthood for many teenage SSI recipients who have no work experience, have had problems in schools, and have an arrest history.

²⁸ SSI data for 1989 and 2009 from <http://www.ssa.gov/policy/docs/statcomps/supplement/2010/7a.pdf>; 1989 AFDC data are available from http://www.acf.hhs.gov/programs/ofa/data-reports/caseload/afdc/1989/fvcv/mal89_ch.htm; 2011 TANF data are available from http://www.acf.hhs.gov/programs/ofa/data-reports/caseload/2009/2009_children_mn.htm. Population data on youth ages 0 to 17 taken from http://www.childtrendsdatabank.org/sites/default/files/53_fig01.jpg.

²⁹http://www.boston.com/news/health/articles/2010/12/14/teenagers_in_ssi_program_face_a_cruel_dilemma/?page=full

At age 18, approximately two-thirds of beneficiaries remain on adult SSI benefits, though the probability of remaining on benefits varies substantially by recipient characteristics, especially impairment.³⁰ In general, children who have characteristics that are most similar to adult SSI medical listings are more likely to stay on SSI after age 18. These characteristics include mental retardation, sensory disabilities, schizophrenia or psychoses, and having entered the program before age 5. Beneficiaries with mental and emotional impairments, such as affective disorders and other mental disorders (for example, ADHD) noted in media reports are relatively more likely to be off SSI at age 18.³¹ Interestingly, there is also evidence that children who became eligible after several appeals are substantially less likely to retain benefits than those who qualified without an appeal. This finding makes intuitive sense in that those whose applications were initially approved might have impairments more similar to the adult SSI disability criteria than children who had to appeal their application several times before becoming eligible.

The trends in redeterminations are important because they provide an indication of the types of beneficiaries who might stay on adult benefits after age 18. This information could be used to make better use of agency resources by targeting continuing disability reviews to those most likely to leave the program.³²

In Exhibit 4, I illustrate the challenges that former child SSI recipients face in adult life after their age 18 redetermination based on research that is summarized in several reports.³³ For comparison, I also present data on activities of all youth in the same approximate age ranges from various data sources.

Unfortunately, the characteristics of child SSI recipients between the ages of 19 and 23 are very disconcerting for their long-term adult prospects. Key areas of concern include:

- **High rates of inactivity:** 57 percent were not enrolled in education programs, not receiving vocational rehabilitation (VR) services, and not employed.
- **Substantial school dropout rates:** 39 percent did not have a high school diploma and were not currently attending school. By comparison, only 11 percent of all young adults ages 16 to 24 had dropped out of school and not received a diploma.
- **Low employment rates:** 22 percent were employed in a job, compared with a 69 percent employment rate for all adults ages 20 to 24.
- **Low postsecondary enrollment rates:** 6 percent were enrolled in some form of postsecondary education after graduating from high school, compared with 41 percent of all youth ages 18 to 23.
- **Low rate of enrollment in vocational rehabilitation:** Only 13 percent ever participated in vocational rehabilitation services.

³⁰ Hemmeter et al. (2009).

³¹ Hemmeter and Gilby (2009).

³² Hemmeter and Gilby (2009).

³³ Loprest and Wittenburg (2007); Rangarajan et al. (2009); Wittenburg and Loprest (2007).

- **High rate of arrests:** Approximately one-fifth had been arrested. Unfortunately, these trends are consistent with other reports that indicate 30 to 50 percent of incarcerated youth have disabilities that could qualify them for other services, such as special education services.¹⁴

Exhibit 4. Relatively Poor Outcomes of Child SSI Recipients Compared to Other Youth

Characteristics	All Youth Age 16 and Older (%)	Former Child SSI Beneficiaries, Ages 19 to 23 ^a (%)
Schooling		
In school or graduated ^b	89	62
Dropped out/out of school	11	39
Employed		
2000: currently employed (ages 19 to 23)	n.a.	22
2006: currently employed (ages 20 to 24)	69	n.a.
Other Activities		
Graduated high school; enrolled in postsecondary education	41	6
Ever participated in VR	n.a.	13
Inactive: not participating in education or VR and not employed	n.a.	57
Ever Arrested	n.a.	22

Sources: Data from Loprest and Wittenburg (2007), who generated estimates using the 2001 NSCF. Average monthly employment rates of young adults ages 20 to 24 during calendar year 2006 are based on calculations using data from the Current Population Survey.¹⁵ Dropout rates are based on findings from Kaufman et al. (2001) and postsecondary education enrollment rates are from Wagner et al. (2006).

^aIncludes youth who are in school or who have graduated from secondary school.

^bIncludes respondents from a 1996 cohort of child SSI recipients age 19 to 23 in calendar year 2000.

n.a. = not available

¹⁴ National Council on Disability. "Addressing the Needs of Youth with Disabilities in the Juvenile Justice System: The Current Status of Evidence Based Research." 2003. Available at [http://www.ncd.gov/newsroom/publications/2003/juvenile.html].

¹⁵ http://www.bls.gov/data/home.htm

Youth who transition off SSI after age 18 generally have higher employment rates than those who stay on, but their long-term economic prospects are still poor. Presumably, these youth have less severe disability characteristics relative to those who stay on SSI after age 18. In part, this difference is reflected in the higher employment rates of those who leave the program. However, at age 18 few former child SSI recipients were earning more than their child SSI payment amount.³⁶ Additionally, approximately half of these former SSI recipients had dropped out of school and approximately one-third had been arrested.³⁷ The outcomes were particularly poor among youth who had a child impairment of another mental disorder, as these youth reported significant social problems.³⁸ These findings indicate that some youth no longer on SSI after age 18, particularly those with behavioral disorders and mental disorders, are likely not prepared for life without SSI. In part, this might explain why approximately one-quarter of those who initially have their benefits ceased at age 18 come back to appeal or reapply for benefits later.³⁹

The problems illustrated above are compounded by a fragmented system of supports that changes as the youth ages into young adulthood. Programs that serve youth, such as school programs, are not available to adults. Additionally, the adult service system itself includes many programs and mixed incentives for work, and providers often do not make systematic efforts to share information about those whom they serve or ways to improve access for youth with disabilities.

POLICY OPTIONS

A fundamental challenge to reforming the child SSI program is that Congress must balance both the income and other protections (such as related health coverage) provided by SSI with the adverse incentives outlined above. For example, simple benefit cuts or eligibility restrictions might result in caseload reductions and even increases in employment among youth, though they could also increase poverty. At the same time, not reforming the child SSI program and related service systems could lead to increased costs to taxpayers and potential long-term harm to youth who try to continue to qualify for benefits.

A related issue is whether services other than an SSI benefit check might be more helpful to youth with disabilities and their families who, as noted above, have differing income and health care needs. The data on reported home health care and out-of-pocket expenses indicate that, while some youth need intensive supports, including home health care, the majority do not need such supports.⁴⁰ This variation raises a question about whether a single benefit check for all youth with disabilities is appropriate, or whether supports could be better tailored to meet their unique needs.

³⁶ Hemmeter et al. (2009).

³⁷ Loprest and Wittenburg (2007).

³⁸ Hemmeter et al. (2009).

³⁹ Hemmeter and Gilby (2009).

⁴⁰ DeCesaro and Hemmeter (2009) and Rupp and Ressler (2009).

The ongoing Youth Transition Demonstration (YTD) and the planned Promoting Readiness of Minors on SSI (PROMISE) demonstration should provide insights on factors that could address these issues, given their focus on employment outcomes and more integrated services. The YTD projects are being implemented in several sites across the country and will provide a rigorous evaluation of the effects of employment-related services, benefits counseling, and work incentives on adult outcomes for youth between the ages of 14 and 25 receiving disability benefits.⁴¹ The delivery of intensive employment supports along with enhanced work incentives through program waivers provide a clearer direction for youth participants to focus on employment. The YTD services, which were designed to address many of the problems outlined in Exhibit 4, should provide evidence on whether employment-based interventions can improve the outcomes of existing recipients. The final evaluation of YTD will be complete in 2014, though interim evaluation reports are currently available and more will be forthcoming in 2012. Unfortunately, at this stage, it is still too soon to make an early assessment of YTD impacts.

PROMISE, which is still under development, is a joint effort by the Department of Education, Social Security Administration, and the Departments of Health and Human Services and Labor.⁴² Information on the nature of the interventions is unclear at this point, though PROMISE will pilot demonstrations in a select number of states to improve the coordination of services provided to child SSI recipients in an attempt to improve their employment prospects and reduce program dependency.

A. Short-Term Approach to Reforming Child SSI: School or Work Requirements for Ongoing Eligibility

To address the problems identified in Exhibit 4, the child SSI program could follow the lead of TANF by including school requirements and/or work requirements for child SSI recipients for continuing eligibility. These requirements would reduce incentives for individuals to emphasize their disability as a condition for eligibility and build incentives for child SSI recipients to pursue human capital development activities, such as employment, rehabilitation, and education. Congress might consider adding other incentives for those who fulfill these requirements, such as temporarily extending benefits beyond age 18.

This change would also bring the child SSI program more in line with the Individuals with Disabilities Education Act (IDEA), which provides an Individualized Education Program specifying school services for youth with disabilities up to age 21. Under IDEA, all youth with disabilities must be provided a free appropriate education that prepares them for further education, employment, and independent living.⁴³

The exact details of such a requirement would need to be further specified and ideally pilot tested to understand its potential implications for both SSA operations and recipients. Key questions remain about who could be targeted for these requirements and how SSA would process the

⁴¹ <http://www.mathematica-mpr.com/disability/ytd.asp>

⁴² <http://www2.ed.gov/about/overview/budget/budget12/justifications/i-specialed.pdf>

⁴³ <http://www2.ed.gov/about/offices/list/ocr/docs/edlite-FAP1504.html>

reviews. For example, one potential target group might be recipients who are more likely to have an age 18 redetermination end in a cessation of benefits; this group might include youth with specific characteristics identified above (such as those who were determined eligible after several appeals) and those referenced in media reports (such as those classified as “other mental disorders”). Independent of the age 18 redetermination, another group might be youth who have a high probability of receiving a Continuing Disability Review. Conversely, as in TANF, some recipients and their families could be exempted based on their circumstances, such as a youth who is homebound.

If successful, such a change could lead to an increase in long-term employment of former child SSI recipients and their parents and a decline in dependency on benefits. Depending on the design, in the short term the program would likely result in savings as people either comply with the new eligibility requirements or fail to comply and leave the program. However, policymakers should be more focused on long-term cost considerations, especially if youth use services to make permanent transitions off of SSI.

B. Long-Term Approach to More Fundamental Reforms: Testing Demonstrations at the State Level

A limitation of the short-term approach above is that it does not address the key issues of federalizing welfare and, in particular, the lack of coordinated supports available to youth. These issues will limit the ability of programs to effectively customize services needed by many youth that either are being inefficiently delivered or are completely unavailable. Additionally, this short-term approach would continue to move the burden of paying for income supports from states to the federal government.

The need for a more integrated set of supports is especially great among the majority of child SSI recipients who are falling behind in their early education and employment experiences. Such supports would also be helpful for families whose children have intensive caretaking needs, though these youth comprise a smaller share of the caseload.

An integrated set of supports would also need to emphasize common long-term outcomes, such as employment. A key problem is that existing service systems can have competing goals that work in opposite directions. For example, the child SSI eligibility rules described above arguably discourage continuing education, even though other broad initiatives, such as IDEA, attempt to provide a free and appropriate education to all youth.

This idea of flexible supports was raised by Dr. James Perrin, a Massachusetts General Hospital pediatrician, during his interview with the *Boston Globe*:⁴⁴

“Families with children with disabilities have real needs for additional income - but perhaps that money should be linked to meeting the specific needs of the child’s disability and, where possible, to supporting that child’s transition to productive adult life.”

⁴⁴http://www.boston.com/news/local/massachusetts/articles/2010/12/12/with_ssi_program_a_legacy_of_unintended_side_effects

The notion outlined in Dr. Perrin's comments echoes the potential for integrating supports to meet a specific outcome.

There is a logical argument for starting at the state or local level where several services are currently being provided to youth with disabilities. These services include schooling, health coverage, employment supports through VR and One Stop agencies, and other specialized supports.

However, an intervening entity is needed to encourage state and local agencies to consolidate supports in a coherent manner. This entity might also come from the state or local level, though it could also be provided federally and even privately by grantees who organize services through cooperative agreements.⁴⁵ The exact set-up of this type of integration might vary depending on the agencies within a given state, locality, or even region. In summary, there are multiple ways in which the coordination could occur, though a key factor is confirming that a mechanism is in place to ensure agencies work together for common outcomes on behalf of the youth and their families.

One element of this approach is to ensure proper planning, which is challenging given that many states are currently facing their own budget difficulties in providing supports. For example, a simple block grant to states might be effective in some states, but not in others because states have different capacities. The experience from TANF is especially noteworthy given that many states are struggling to serve TANF recipients with their existing block grants because they had used block grant monies in previous years for other state purposes.⁴⁶

The key to overcoming the current problems states might face is to develop a focused demonstration period to build an evidence base and political consensus to support a major structural change. Congressional authority to sponsor major demonstrations in several areas would be especially useful in assessing the potential for different types of approaches to integrating services and promoting key outcomes. This type of varied approach is currently being used by SSA in YTD, which includes a mix of state agencies and private service providers who are coordinating and delivering employment and other services to youth. This type of approach could also be tested under the PROMISE demonstration, which already has buy-in from multiple federal agencies.

A more comprehensive approach would share similarities with the vision outlined by Douglas Besharov in his testimony before you on September 8, 2011, which attempts to integrate these services for all low-income and at-risk families. This type of demonstration would go beyond those in YTD and PROMISE and test the provision of coordinated services and benefits within a single funding stream. For example, this type of integration might take YTD a step farther by providing participants a benefit check from an independent entity that also provides other supports. Federal legislation would need to authorize and encourage this type of demonstration, define demonstration objectives, establish requirements consistent with those objectives, guarantee the cooperation of pertinent agencies, ensure that the demonstrations proceed without undue risk to participants, and establish evaluation requirements that will maximize learning.

⁴⁵ Mann and Stapleton (2011).

⁴⁶ <http://www.cbpp.org/cms/index.cfm?fa=view&id=3554>

While ambitious, there is evidence that a more flexible set of programs at the state level have the potential to influence key outcomes. For example, the Cash and Counseling demonstration provided consumer-directed funds to people with disabilities that were used to purchase goods and services to meet their personal care needs. The unique aspect of the demonstration was its flexibility in service provision, including allowing participants to manage their own budgets, and its clear focus on promoting participants' health outcomes. The evaluation found positive effects of the program in several areas, including the health of participants and a reduction of unmet medical needs.⁴⁷ The success of the demonstration led to a further expansion of the program into Medicaid programs in 15 states.⁴⁸

SUMMARY

In a recent media interview, Suzanne Poe—a mother with a child who is 4 and is eligible for SSI based on ADHD—summarized the perspective of a parent who was struggling to make ends meet:⁴⁹

"The reason I applied for disability was not because that's what I want to live on for the rest of my life or my kid's life. I want to achieve things in life. I want my family to be self-sufficient."

Poe says, "Right now, that isn't happening."

Unfortunately, Suzanne Poe has summarized many of the problems that face child SSI recipients and their families. Many families need the cash support to pay bills, but the program becomes a poverty trap in which the only way to remain eligible is to show your child has a long-term disability. This type of requirement dampens recipients' expectations for their own future, especially whether to make attempts to become more independent in fear of jeopardizing the family's source of income.

If one looks at the SSI program in isolation and observes the major child SSI caseload expansions, the natural instinct is to assume that all the new claims of disability cannot be legitimate. This is especially true when there have been no major changes in the eligibility requirements since 1996.

However, when viewed in the context of the overall safety net, a clearer picture emerges that explains some of the reasons for the growth in the child SSI program. The total number of children receiving TANF or SSI is substantially lower today than it was two decades ago. For example, approximately 7.6 million children lived in an AFDC family or received a child SSI benefit in 1989, compared to 4.4 million children who receive the equivalent types of support today.

⁴⁷ Brown et al. (2007).

⁴⁸ http://www.bc.edu/schools/gssw/orcpds/cash_and_counseling.html

⁴⁹ <http://www.npr.org/2011/08/18/139722024/benefits-for-severely-disabled-children-crucial>

The key question is whether the child SSI program is the best source of support for most youth. Despite the positive effects on short-term poverty, the answer appears to be “no,” based on the poor long-term outcomes of child SSI recipients. After age 18, many recipients are inactive, meaning they are not working, going to school, or receiving any rehabilitation services. For these reasons, their long-term prospects are grim.

I suggest two potential approaches to deal with this issue. The first is to institute school and work requirements for eligibility for at least some SSI recipients, particularly those most likely to be off benefits after age 18. This change would put a new emphasis on key activities to develop the youth's long-term outcomes. However, this approach is limited in that it does not deal with the broader safety net issues that are driving these trends, including the transitions from TANF to SSI. The second approach attempts to address the broader safety net issue by proposing a series of focused demonstration projects at the state and local levels that would better integrate supports. This approach would take a more holistic view of all safety net services and integrate supports to promote long-term outcomes of youth.

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Chairman DAVIS. Thank you, Dr. Wittenburg.
Mr. Stein, you may proceed.

**STATEMENT OF JONATHAN M. STEIN, GENERAL COUNSEL,
COMMUNITY LEGAL SERVICES OF PHILADELPHIA, AND
MEMBER, SSI COALITION FOR CHILDREN AND FAMILIES**

Mr. STEIN. Good morning. I am Jonathan Stein, General Counsel at Community Legal Services in Philadelphia, where I have represented children with disabilities and their families for most of my 43 years of practice. CLS is a member of the SSI Coalition for Children and Families, 80 organizations that share the belief that SSI is a critical lifeline for children with severe disabilities, our Nation's most vulnerable children and youth.

I first would like to introduce you all to Will Bentley, and his picture is up there on the wall. Will is an 8-year-old boy who lives in Covington, Kentucky with parents and sister. Nearly from birth Will's parents knew something was wrong. Will was very slow in learning to speak and had trouble eating and drinking because he wasn't able to keep liquid in his mouth. His parents enrolled him in First Steps, Kentucky's Early Intervention program, where he learned to sign with his hands so that he could communicate with his family.

At age 3 Will began to have frequent violent seizures. His diagnoses grew to include developmental delays, speech delays, Sensory Integration Disorder, Anxiety Disorder, frequent bouts of depression, among others. Taking Will to all his needed medical and therapy appointments became a full-time job for his mother, Kate.

Katie Bentley was forced to shut down her small business to stay home and care for Will and the family suffered a huge loss of income. In Katie's own words, "My husband and I really wanted to support Will on our own, but we quickly learned that the dream we had of our own family would never become a reality. I surrendered my career and we adapted our lives so that Will's needs could be met. Before he was granted SSI in 2010 we barely could even afford the gas to drive him to his therapy appointments with his specialist. Now SSI allows us to focus on Will's needs."

And as she further says, "At one time Will was unable to do anything for himself, he couldn't even feed himself. Now he has learned to write his name, and a few days ago Will learned to zip his own jacket, and is even learning to read. The wealth of support that comes from SSI and Medicaid is a dream come true for us," says Katie Bentley.

Helping children with severe disabilities like Will lead their fullest lives possible requires access to treatment and support services as well as financial support to replace lost income when a parent must stay home to care for the child. SSI is a key ingredient to helping them get the care and support they need.

Sensational and ill-informed media accounts as in *The Boston Globe* and elsewhere have relied almost entirely on anecdotal observations and half truths. So let's instead consider some facts.

Fact, only the most severely impaired children qualify for SSI. Fewer than 10 percent of all children in the Nation with disabilities receive SSI. And this is because of the extraordinarily strict SSI disability standard, an objective standard, unlike Mr. Burk-

hauser's characterization of it as subjective. Just 39 percent of children who apply are awarded SSI, a figure that has remained essentially unchanged for well over the past decade.

Fact, SSI was established by Congress to aid children and adults with physical as well as mental impairments. As a nation we have made great strides toward achieving parity between mental and physical disabilities. Any debate over whether mental impairment, such as ADHD or autism, are as "legitimate" as physical disabilities represents a significant and shameful step backward.

Fact, ADHD is a neurobehavioral disorder with clear medical diagnostic criteria recognized by the National Institutes of Health and a myriad of other respected organizations. Only the most severe cases of ADHD qualify for SSI. Just 26 percent of children with ADHD who apply for SSI are approved. Thus three out of every four children with ADHD are denied. In fact, the allowance for ADHD has been declining in recent years.

Fact, a prescription for medications would never on its own make a child eligible for SSI. In fact being on medications can actually make a child less likely to be found eligible for SSI if they lessen the severity of the child's impairments. Moreover, SSA data show that children with ADHD who are taking medications are no more likely to be approved for SSI than those not taking medications. And the fact is there is nothing in the GAO report that cites a study to be contrary to that.

We look forward to hearing, though, GAO's findings when it has completed its study and expect they will match SSA's own findings.

Fact, growth in the children's SSI program in recent years is due primarily to increasing poverty. As the number of poor children in this country has reached tragic new heights, over 16 million U.S. children now live in poverty versus 11 million a decade ago. More low-income children obviously are financially eligible for SSI. Yet the share of children in poverty who receive SSI has remained unchanged for the past 10 years, 7.5 percent.

I am nearing my end, Mr. Chairman.

Chairman DAVIS. We are well past that.

Mr. STEIN. Might you just give me one more minute.

Chairman DAVIS. No. If you could sum up briefly with one sentence.

Mr. STEIN. Okay. I will be saying the following: I would urge the Subcommittee not to take hasty action, and to wait for the GAO study and then seek a study from the Institute of Medicine or the Association of University Centers on Disability. And I would say, as I have said earlier, this is a critical lifeline for families like the Bentleys. And if any Members of the Subcommittee have any questions of Mrs. Bentley, who is sitting behind me to the right, she is also available to respond to questions.

Thank you.

[The prepared statement of Mr. Stein follows:]



Thursday, October 27, 2011

Chairman Davis, Ranking Member Doggett, and other distinguished Members of Subcommittee, thank you for the opportunity to testify today regarding the children's SSI program.

I am Jonathan Stein, General Counsel at Community Legal Services in Philadelphia, where I have represented children with disabilities and their families for most of my 43 years of practice. Today I am also here in my capacity as a member of the SSI Coalition for Children and Families.

The SSI Coalition for Children and Families, and supporting organizations, is a network of over 80 consumer, service provider, advocacy, and professional organizations, which have come together to advocate on behalf of families caring for children with severe mental and physical disabilities and impairments. The SSI Coalition believes that SSI serves as a critical lifeline for our nation's most vulnerable children and youth, making it possible for families to stay together rather than needing to send children with disabilities into institution-based care.

As recently as the 1960s, children with disabilities were stigmatized. It was expected that parents would put children with intellectual disabilities (formerly known as mental retardation), or physical or other mental impairments, into institutions. Over the past fifty years, a network of services and supports has developed to enable parents to care for their children with special needs at home. This network is neither perfect nor complete, but it has allowed millions of children to remain at home with their families and in their communities. Most people would agree that this makes for better outcomes for children.

The advent of the children's SSI program in 1972 marked a critical point in the expansion of services and supports for children with disabilities. Many families face extreme hardship when disability strikes. The extra expenses they incur and the income lost when a parent reduces his or her hours, or leaves a job altogether, to stay home to care for a child with a severe disability can be crushing. For many families with a disabled child, SSI means the difference between living above and below the poverty line, and between being able to provide for their disabled child, and having to go without basic necessities. In 2010, about 1.3 million U.S. children and their families were helped by SSI. SSI also provides access to Medicaid coverage in most states.

Before I go into the complexities of the SSI program, or delve into facts and figures, I'd like to introduce you to Will Bentley. Will is an eight-year-old boy who lives in Covington, Kentucky with his parents and sister. Nearly from birth, his parents knew something was wrong. Will wasn't able to keep liquid in his mouth, and he was very slow in learning to speak. His parents enrolled him in First Steps, Kentucky's Early Intervention program, and he learned to sign so that he could communicate with his family. At age three, Will began to have violent seizures. His doctors were unable to determine the cause, or to make them stop. An MRI eventually showed lesions on his brain, and he began seeing a neurologist. His seizures became more frequent and dangerous, and affected his short-term memory. His diagnoses grew to include: partial seizure disorder, developmental delays, dysgraphia (inability to write and use one's

hands due to delayed motor skill), Sensory Integration Disorder (Will does not interpret things that he touches, smell, or hears correctly, and his level of pain is extremely high), Anxiety Disorder, and Apraxia (a speech delay that impairs the use of his muscles to form words and plan an activity or how to say a sentence).

His mother Katie became overwhelmed—she was forced to shut down her small business to take a much lower-paying job, so that she could have the flexibility she needed to stay home with Will. The anti-seizure medications that Will was prescribed were incredibly expensive—over \$700 per month, and not covered by the family's insurance. Taking Will to all his needed appointments became a full-time job in itself – his medical team grew to include an Allergist, an ENT physician, a Developmental Pediatrician, an Immunologist, and a Psychologist.

Eventually Will's need for constant care became so great that he was unable to cope and would lie lifeless and cry if he was left with strangers or at day care; he would get sick and could not eat for days, and in turn would have more seizures. Katie had no choice but to leave her job to stay home to care for Will. That is when she applied for SSI benefits for Will. In Katie's words:

"I had never applied for SSI before because my husband and I really wanted to support Will ourselves. We quickly learned that the dream that we had of our family would never be. I surrendered my career and we adapted our life to living it so that Will's needs were met. Before he was granted SSI in 2010, we could barely even afford the gas to drive him to his therapies and appointments with his specialists. Now, SSI allows us to focus on what Will needs."

Here is how Katie describes the difference SSI has made in Will's life:

"At one time, Will was unable to do anything for himself. He needed assistance with nearly every self-help skill. He could not even feed himself. Now he has learned to write his name. We work on skills like dressing himself, feeding himself... Today Will learned to zip his own jacket. Within the past few months, Will learned to read. For a parent with a child with a disability, the wealth of support that comes from SSI and Medicaid is a dream come true."

Helping children with severe disabilities, like Will, to reach their potential and lead the fullest lives possible, requires a comprehensive approach, including access to treatment and supportive services, as well as financial support to replace lost income when a parent must stay home to care for the child. For children with severe disabilities, living in low-income households, SSI is a key ingredient to helping them get the care and support they need.

As a Member of the SSI Coalition for Children and Families, I appreciate the opportunity to discuss the following issues this morning as part of my testimony:

- What SSI is used for, in families with a child with severe disabilities;
- How children with physical and mental impairments are determined eligible for SSI;
- How medications are considered as part of that process;
- Trends in children's SSI enrollment in recent years, highlighting the mental impairment categories; and

- How the SSI program can be strengthened to better support children with severe physical and mental disabilities.

1. How SSI Benefits Are Used by Families with a Child with Disabilities

SSI provides a modest cash benefit, up to a maximum of \$674 per month, but significantly less for many children, where there is other countable income in the household. The average children's benefit was just \$592 in 2010. SSI provides critical income support for families who experience lost income due to caring for their child with disabilities. It's not uncommon for a parent to lose her job after one too many days taken off or afternoons of early departure for doctors' appointments, or when the school calls to say the child must be taken home or to the hospital.

Indeed, research shows that families caring for children with disabilities are significantly more likely to experience material hardships, such as food insecurity (e.g., skipping meals because of lack of money, or running out of food), and housing and utility hardships (e.g., being unable to pay rent; or having utility service shut off) than families whose children are not disabled.¹ SSI thus helps to cover the child's portion of ongoing living expenses and basic necessities.

Families also use SSI for purposes such as: transportation to and from doctors' appointments and supportive services (especially in rural areas); specialized child care; adaptive equipment (such as the special bowl that Will used as a small child) and reading aids; special diets and activities that help in overcoming or minimizing the effects of impairments; diapers for larger children and adolescents who are incontinent or not fully "potty-trained"; among others.

2. The SSI Disability Determination Process for Children

The SSI program was established in 1974 to aid any person unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment expected to result in death, or that has lasted or can be expected to last for a continuous period of at least 12 months.² Children with impairments of comparable severity were also included.

The current eligibility standard was tightened considerably as part of "welfare reform" in 1996, which in fact resulted in over 100,000 children being terminated from the SSI rolls. To qualify under the current eligibility standard, a child's impairment or combination of impairments must either fall under one of the 14 types of disabilities included in SSA's Listing of Impairments (e.g., Disorders of the Musculoskeletal System), or result in "marked and severe functional limitations."³

Because of the impossibility of listing every impairment that could conceivably afflict the human condition, as well as the medical reality that many children have multiple medical impairments that combine to severely limit their functioning, children with disabilities who do not "meet" a Listing may alternatively qualify for SSI by "functionally equaling" the Listings. What this means in practice is that the child's level of functioning is

¹ See, e.g., Susan Parish et al., 2008. "Material hardship in U.S. families raising children with disabilities."

² Social Security Act, as amended by Public Law 92-603, enacted 1972.

³ 20 CFR §416.906.

significantly impaired relative to his or her peers. This standard is quantified to require explicitly that the child's level of functioning in multiple "domains of functioning" be at least two standard deviations below the mean.⁴ Pediatricians, child psychologists, and other medical professionals are well versed in making this determination, and it is their medical opinion that is given greatest weight in determining a child's eligibility for SSI.

An example of how functional equivalency is used can be seen in the case of four-year-old Adrien. Adrien has the following medical impairments: developmental delay, for which he received intensive Early Intervention therapies from approximately age one, when the delay was first diagnosed, through age three; failure to thrive, due to persistent chronic diarrhea resulting from *C. difficile* infection; and sensory delays related to an eating disorder (he had developed an aversion to many foods and essentially refused to eat). The last two medical impairments are of course related—his food aversion was linked to the effects of having chronic, severe diarrhea as a toddler. However, when applying for SSI, despite this constellation of profound medical impairments, Adrien did not meet any one particular Listing. Instead, SSA found that he functionally equaled the listings, because he exhibited marked limitations in two domains. He had a marked limitation in "Interacting and Relating with Others" due to language delays that were documented as at least two standard deviations below the mean, by testing done by speech pathologists in the state Early Intervention program and by the Chicago Public Schools. He also had a marked limitation in "Health and Physical Well-Being" due to his body weight's being at the 3rd percentile due to his chronic diarrhea and eating disorder.⁵

Because of the high level of severity required to qualify for SSI, most applicants are denied, and a minority of children who apply are awarded benefits – just 39%. The share of applicants found eligible for benefits has remained at that level for more than ten years.⁶

A mere diagnosis of a disability or medical condition is not enough to qualify for SSI. Nor is a parent's or teacher's opinion that a child is disabled sufficient to demonstrate eligibility. Rather, the SSI disability determination process considers a great many factors, both medical and functional, following what SSA calls its "whole child approach." In evaluating a child's functioning, SSA considers the child's activities at home, at school, and in the community. SSI program rules require review of a combination of medical, professional, and lay evidence of a child's disability – evidence that spans a far more significant period of time than just a single examination.⁷ There must be documented medical evidence of the impairment(s) and their severity for a finding of disability.

Whether a child has Autism or Cerebral Palsy, ADHD or lobar holoprosencephaly, his impairment will be evaluated using the same process and eligibility standard. There must be medical documentation of any type of impairment and its severity, for a child to qualify for SSI, whether she has a physical or mental impairment (or both). The "net accuracy rate" for initial SSI disability determinations is over 97%, indicating a very high

⁴ 20 CFR §416.926a.

⁵ 20 CFR §416.926a.

⁶ Social Security Administration, *SSI Annual Statistical Report, 1999-2010*.

⁷ 20 CFR §416.924

level of reliability in examiner's disability decisions.⁸

3. The Limited Role of Medications in the SSI Disability Determination Process

A prescription for medications of any kind is just one factor among many considered in determining eligibility, and would never on its own make a child eligible for SSI.

Moreover, the SSI children's disability determination process takes into account not just the fact of treatment but also the effects of treatment. Thus, to the extent that any treatment (including psychotropic or other types of medications) improves a child's functioning, the child is evaluated in terms of that improved functioning. Accordingly, putting a child on medication often lessens her chances of being found disabled and eligible for SSI.

Indeed, recent Social Security Administration data show that taking ADHD-related medications did not increase a child's chances of being found eligible for SSI. An analysis of all applications of children with a primary diagnosis of ADHD in 2010, showed that children with ADHD taking related medications were no more likely than those not taking medications to be found medically eligible for SSI.⁹

To the extent that there might be any misunderstanding by parents or caregivers as to how medications are considered when SSA evaluates a child for SSI eligibility, we encourage SSA to engage in outreach and education for families with children with disabilities who may consider applying for SSI. SSA makes available a variety of resources, including web-based and hard copy brochures, targeting parents and caregivers of SSI children; these provide logical opportunities to increase awareness among caregivers on the childhood disability determination process and standard, including the limited role of medications in that process.

4. Trends in Children's SSI Enrollment

- a. Growth Is Explained by Increases in Child Poverty, Improved Access to Children's Health Insurance, and Early Identification and Treatment of Children with Disabilities.

About 1.3 million low-income children with severe disabilities received SSI in 2010. The number of children on SSI is a small fraction, just 5 to 10% of U.S. children with a disability.¹⁰ This is because SSI serves only those children with the most severe disabilities and limitations, and whose families meet the very low income and asset limits.

⁸ Social Security Administration, Annual Report to Congress of Continuing Disability Reviews for FY2009.

⁹ Data referenced are from SSA Structured Data Repository (SDR), and include all Title XVI (SSI) child initial determinations from FY 2010 with the impairment code 3140 (Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD)) as well as the medication reported at the time of application for these claims were identified. Data and analysis were prepared by SSA's Office of Disability Policy (ODP).

¹⁰ See *Child Trends Analysis of National Health Interview Survey*; Boyle, Coleen, et al., Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008, *Pediatrics*, May 23, 2011, using data from the National Health Interview Survey; National Survey of Children with Special Health Care Needs (2005-06); ChildStats.gov, *America's Children in Brief: Key National Indicators of Well-Being* (2010); Census Bureau, Current Population Survey, ASEC, Table 3, Historical Poverty Tables, People.

For a variety of reasons, primarily the increasing number of children living in poverty, more children receive SSI today than at the program's inception in 1974. There has also been modest growth in the program in more recent years. In 2001, about 11.7 million children lived in poverty (16.3% of all children); by 2010, that figure had jumped to 16.4 million (over 22% of children).¹¹

Comparing the number of children receiving SSI with the number of children in poverty, the share of poor children on SSI has remained nearly unchanged for over a decade (7.52% in 2001, vs. 7.56% in 2010).¹² Thus, as our nation's count of poor children has sadly climbed, more children with disabilities have become financially eligible for SSI—but the share of poor children on SSI has remained the same.

Another factor that accounts for growth in children's SSI is the dramatic increase in access to children's health insurance, through Medicaid, the Children's Health Insurance Program (CHIP). Between 1998 and 2008, child enrollment in Medicaid increased from about 22 million to over 32 million.¹³ The rise in children receiving services through the Early Periodic Screening Diagnosis and Treatment (EPSDT) program, which is part of Medicaid, was even more dramatic during that same period – climbing from about 6 million to nearly 21 million children.¹⁴ Likewise, enrollment in CHIP has increased from about 1.38 million in 1999 to nearly 5 million in 2009.¹⁵ Access to health insurance has enabled tens of millions of children to access health care, enabling early identification and treatment for disabilities and impairments.

b. Trends in Mental Impairments Category: Decline in Intellectual Disability (Formerly Mental Retardation) Is Matched by Corresponding Increase in Other Mental Health Impairments, Due to Advances in Childhood Diagnosis.

As noted above, Congress intended that SSI aid individuals, including children, with physical as well as mental impairments. There are over a dozen mental impairment codes, ranging from intellectual disability (formerly mental retardation) to Autism to mood disorders to ADHD, to name just a few. Overall, the mental impairments category has remained remarkably stable over the past nearly twenty years – with very little variation from the 65-70% range, and essentially no long-term change during the period 1994-2009. Indeed, exactly the same share of children received SSI for mental impairments in 1994 as in 2009: 66%.¹⁶

¹¹ U.S. Census Bureau, *Profile of General Demographic Characteristics: 2000*, <http://censtats.census.gov/data/US/01000.pdf>; U.S. Census Bureau, 2010 Demographic Profile Data, http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_DP_DPDP1&prodType=table; U.S. Census Bureau, *Historical Poverty Tables – People: Table 3*, <http://www.census.gov/hhes/www/poverty/data/historical/hstpov3.xls>.

¹² Social Security Administration, *SSI Annual Statistical Report, 2009*, Table 4; and U.S. Census Bureau, *Current Population Reports*, as compiled by the Federal Interagency Forum on Child and Family Statistics, available at <http://www.childstats.gov/americaschildren/tables/pop1.asp?>; U.S. Bureau of the Census, *Current Population Survey, Annual Social and Economic Supplements. Historical Poverty Tables – People (Table 3)* available online at

<http://www.census.gov/hhes/www/poverty/data/historical/people.html>.

¹³ HHS, HRSA, Maternal and Child Health Bureau, *Child Health USA 2000*, and *Child Health USA 2010*.

¹⁴ *Id.*

¹⁵ Kaiser Commission on Medicaid and the Uninsured (2009).

¹⁶ Social Security Administration, *SSI Annual Statistical Reports, 1994-2010*.

What has changed, however, is the diagnostic grouping within this overall category. The share of children receiving SSI for intellectual disabilities (formerly mental retardation) has steadily declined (from 42.6% to 12.7%), while the share of children receiving SSI for other mental impairments has increased (from 23% to 53%).

Medical research suggests that this shift in diagnostic breakdown within the SSI program (and in other programs, such as special education) may be reflective of general trends in childhood mental health diagnostic practice. Since the early 1990s, the diagnostic label of mental retardation, and later intellectual disability, has given way to more specific, precise diagnoses such as Autism, ADHD, and speech and language delay.¹⁷ More precise diagnosis is generally viewed as an advance in childhood mental health treatment, as it facilitates better-tailored treatment for children with disabilities.

Moreover, over the past decade, allowance rates for most individual mental impairment categories have either remained stable or declined. For instance, the allowance rate for children's ADHD claims has steadily declined from 32.6% in 2002 to just 26.5% in 2010.¹⁸

c. Facts on Childhood ADHD.

ADHD is a neurobiological disorder that affects 7 to 9% of school age children.¹⁹ While all children experience difficulty sitting still, paying attention, controlling impulsive behavior, or regulating their emotions from time to time, for children with severe ADHD, these problems can be so pervasive and persistent that they interfere with a child's ability to lead a normal life. Research indicates that ADHD is caused by problems with the brain's maturation and low levels of specific neurotransmitters that are needed for neurons to communicate efficiently. Genetics is also a key factor, as ADHD is a highly heritable disorder. Finally, children born prematurely are also at increased risk of ADHD.

A diagnosis for childhood ADHD is only made when:

- 1) A significant number of symptoms (6 of 9) are observed;
- 2) Symptoms are persistent for a period of at least six months;
- 3) Symptoms have appeared before the age of seven;
- 4) There is significant impairment in a child's ability to function in at least two areas of life; and
- 5) Other possible causes are ruled out.²⁰

¹⁷ See, e.g., Bishop et al., Autism and Diagnostic Substitution: Evidence from a Study of Adults with a History of Developmental Language Disorder, *Developmental Medicine and Child Neurology*, 50, 1-5 (2008); King and Bearman, Diagnostic Change and the Increased Prevalence of Autism, *International Journal of Epidemiology*, 38: 1224-1234 (2009); Shattuck, The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education, *Pediatrics*, 117, 1028-1037 (2006). See also Mike Stobe, Autism 'epidemic' may be all in the label, Associated Press, Nov. 4, 2007.

¹⁸ Social Security Administration, Office of Disability Policy, Title XVI Childhood Disability Data Analysis March 31, 2011.

¹⁹ Centers for Disease Control and Prevention (2003). Prevalence of diagnosis and medication treatment for attention-deficit/hyperactivity disorder. *Morbidity and Mortality Weekly Report* 54: 842-847; Centers for Disease Control and Prevention (2010). Increasing Prevalence of Parent Reported Attention-Deficit/Hyperactivity Disorder Among Children -- United States, 2003 and 2007. *Morbidity and Mortality Weekly Report* 59: 1439-1443.

²⁰ American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders: DSM IV* (4th ed., text, revision). Washington, D.C.: American Psychiatric Association.

Yet only the most severely impaired children are eligible for SSI. Thus, only 4% of children in the U.S. who have been diagnosed with ADHD receive SSI benefits,²¹ and many of these children also have additional, severe co-occurring mental impairments, such as intellectual disability, learning disability, or speech delay. Research by the National Institutes of Mental Health (NIMH) indicates that two-thirds of children with ADHD have at least one other co-existing condition.²² When multiple co-existing conditions are present, academic and behavioral problems, as well as emotional issues, may be even more debilitating.

ADHD has long had one of the lowest SSI allowance rates of any impairment category. While it has always been lower than average SSI overall allowance rates, the allowance rate for children's ADHD claims has steadily declined from 32.6% in 2002 to just 26.5% in 2010.²³ This is well below the average allowance rate of about 41%. The vast majority, over 71%, of childhood ADHD claims were denied in 2010, with only the most severe cases approved for SSI benefits.

Additionally, it should be noted that SSA's data do not provide a full picture, because they capture only the "primary diagnosis" code—meaning that a child with multiple disorders who applies for SSI will be coded and tracked only by the disorder that is listed by SSA as the "primary" diagnosis. Thus, SSA data on ADHD do not capture which claims included additional co-occurring disorders, no matter how seriously they contribute to the child's functional limitations.

5. Recommendations for Strengthening SSI to Better Support Children with Severe Impairments

I am very pleased that today's conversation is about how to improve outcomes for children with severe disabilities on SSI. It should come as no surprise that youth with disabilities face diminished employment outcomes, greater risk of dropping out of highschool, and especially for those with mental impairments, greater risk of delinquency. Discussions like today's about how we can better support youth with disabilities to improve their chances at seeing better outcomes are vital to ensuring a better future for this population, and for our country. We can all agree that providing the support needed so that children and youth with severe disabilities can reach their potential and have the greatest chance of reaching self-sufficiency must be one of our nation's foremost priorities. I very much appreciate the opportunity to testify about how SSI can be strengthened to better support that mission.

a. Strengthen SSI Work Incentives to Better Support Transition-Age Youth

The SSI program as currently structured does provide considerable work incentives, especially for youth who are able (or want to try) to do some work. Under current program rules, the first \$85 of earnings each month are not counted against an SSI grant. After that, only half of earnings are counted against the grant. This means an SSI recipient, child or adult, always receives more income if she works than from receiving

²¹ Author's analysis based on ADHD prevalence data from CDC Vital Health and Statistics Report (2007) and SSA data on mental impairments prepared by SSA's Office of Disability Policy (July, 2011).

²² MTA Cooperative Group. (1999) A 14-month randomized clinical trial of treatment strategies for attention deficit hyperactivity disorder. *Archives of General Psychiatry*, 56, 12.

²³ See source cited in note 15.

the grant alone—the amount she receives from earnings plus the grant will be greater than the amount of just the grant. For recipients under age 22, the Student Earned Income Exclusion is even more generous, allowing SSI recipients under age 22 who are regularly attending school to exclude all earnings up to \$1,640 per month, up to a yearly maximum of \$6,600.²⁴ (The purpose of the Exclusion is to help youth access internships and the other early work experiences that are so important to preparing for adult employment.) Additionally, in most states, Medicaid coverage is continued if the child ceases to receive the SSI cash benefit due to earned income, so long as certain criteria are met.

An additional work incentive is found in the Section 301 program, which enables teenagers to continue receiving SSI benefits while they finish school and transition into special state-run vocational rehabilitation programs. This encourages them to complete school and enables them to begin working, build skills, and develop a connection to the workforce while transitioning off of SSI assistance.²⁵

However, SSI's work incentives must be strengthened to more effectively support transition-age youth seeking to try work. As a preliminary matter, more effective outreach is needed to ensure that SSI youth are aware of the available work incentives. One study revealed that just 22% knew of the Student Earned Income Exclusion, and less than a third were aware of the option to keep their Medicaid coverage under the 1619(b) provision.²⁶ Greater awareness of available work incentives could be achieved through better outreach by SSA, as well as individualized benefit counseling for SSI youth, to explain the projected impact of earnings on their SSI and Medicaid coverage.²⁷

Additionally, we echo Wittenburg and Loprest, among others, who recommend expanding the Student Earned Income Exclusion to exclude all income earned by qualifying youth, to further enable SSI youth to try working with no risk to their benefits. While this change would come at a cost, it would result in long-term program savings if it succeeded in supporting youth to transition to work.²⁸

b. A Comprehensive Approach, Including Better Access to Services and Improved Interagency Cooperation, is Urgently Needed.

At younger ages, research suggests that whether and how well a family is able to provide for a child may be the most important determinant of that child's likely outcomes

²⁴ For more on the Student Earned Income Exclusion, see Social Security Administration, *Spotlight on the Student Earned Income Exclusion* (2011), <http://www.ssa.gov/ssi/spotlights/spot-student-earned-income.htm>.

²⁵ The Section 301 Program provides for continued payment of SSI benefits for individuals in a vocational rehabilitation or similar program. See Social Security Administration, "SSI and SSDI Employment Supports," *The Red Book 2011*, <http://www.ssa.gov/redbook/eng/ssdi-and-ssi-employment-supports.htm#5>.

²⁶ Wittenburg, David and Pamela J. Loprest, "Early Transition Experiences of Transition-Age Child SSI Recipients: New Evidence from the National Survey of Children and Families," *Journal of Disability Policy Studies* 18, 3 (2007): 176-187.

²⁷ See id at 184.

²⁸ See id at 184.

later in life.²⁹ To that end, SSI provides critical financial support to families struggling to meet the needs of children with severe disabilities, and is thus a key ingredient in setting children up to have the best chance of success. At older ages, research indicates that youth with disabilities benefit greatly from a comprehensive approach that addresses the unique challenges that they face in transitioning to adulthood, and to the world of work.³⁰

Such pilot initiatives as the Youth Continuing Disability Review Project, the Opening Doors to the Future Project, and the Transitional Employment Training Demonstration, have all shown that transition-age youth have unique needs that defy a one-size fits all approach. Rather, youth at that stage require a tailored, comprehensive, and integrated approach that combines healthcare/medical services, educational supports, and employment supports. The results from these and other pilot initiatives demonstrate significantly better outcomes for youth provided with such an integrated, holistic approach to transition support.³¹ To this end, better interagency collaboration appears critically needed, across the Social Security Administration, the Department of Health and Human Services, the Departments of Education and Labor, and the Centers on Medicare and Medicaid Services.

Additionally, expanding vocational education/rehabilitation programs to children younger than age-18, and ensuring that they have access to such programs (whether by prioritizing SSI youth, or providing waivers that enable direct funding for Vocational Rehabilitation agencies to work with schools) is recommended.³²

Many of the above policy options are part of the Youth in Transition Demonstration (YTD) projects currently underway across the country. The PROMISE program, as well, seeks to explore how best to support transition-age SSI youth. The SSI Coalition for Children and Families has applauded SSA for its efforts in these projects, and Congress for funding these important initiatives. We encourage that they continue to be funded and their results to be implemented as nationwide policy.

c. SSA Urgently Needs Adequate Funding to Perform Continuing Disability Reviews on Schedule.

SSA is required by law to conduct periodic Continuing Disability Reviews (CDRs) to ensure that only those individuals who remain disabled continue to receive benefits. CDRs remain critical to SSI program integrity, and we strongly encourage Congress to provide SSA with adequate administrative funding such that it can comply with its legal obligation to perform on-time CDRs.

For SSI recipients under age 18, for whom eventual improvement is considered likely to occur, SSA is required by law to conduct a full medical CDR every three years; in cases where children are found disabled due to low birthweight, SSA must review children at age one.³³ Failure to cooperate with the CDR process can result in termination of

²⁹ Davies, Paul S., Kalman Rupp and David Wittenburg. "A Life-Cycle Perspective on the Transition to Adulthood Among Children Receiving Supplemental Security Income Payments." *Journal of Vocational Rehabilitation*, 30, 3 (2009): 133-151.

³⁰ See source cited note 22.

³¹ See id.

³² See id at 184-185.

³³ Personal Responsibility and Work Opportunities Reconciliation Act of 1996, Public Law 104-193

benefits. All CDRs performed in children's cases are full medical reviews, evaluating whether there has been "medical improvement," and if so, whether the child continues to meet the eligibility standard for disability.

Between 1996 and 2002, SSA remained "current" in completing on-time medical CDRs for children, thanks in large part to funding authorized as part of the "welfare reform" law of 1996. However, due to a decline in funding for CDRs since 2002, SSA has fallen short of completing its CDR obligations on time.³⁴ According to SSA, as of July 2011, over 140,000 childhood CDRs had been performed for FY 2011, with just over half of reviewed children being found to remain eligible. While this figure does not represent the total number of CDRs that were called for based on existing law, it does reflect steady improvement since 2006.³⁵

CDRs are considered to be enormously cost-effective, yielding an estimated \$10 or more in savings for every \$1 spent in conducting the review. Quality Assurance review of medical CDR decisions in SSI cases shows them to be accurate more than 97% of the time. Actuarial projections suggest that funding SSA to carry out its mandate to conduct CDRs as required by law would yield significant savings. We applaud Congress for including additional program integrity funds for CDRs, as part of the Budget Control Act. SSA must be funded adequately to carry out its statutory obligations in conducting on-time CDRs where required.³⁶

In closing, thank you for the opportunity to testify about how we can work together to strengthen SSI to better serve youth with severe disabilities. I, Community Legal Services, and the SSI Coalition for Children and Families look forward to the opportunity to work in partnership with lawmakers to strengthen SSI to help our nation's most vulnerable children and youth achieve their fullest potential and become contributing members of society.

Respectfully,

Jonathan M. Stein, Esq.

On behalf of Community Legal Services of Philadelphia, and as a Member of the SSI Coalition for Children and Families.

Members of SSI Coalition for Children and Families.

Rebecca Vallas
Thomas Yates
Linda Landry
Richard Weishaupt

³⁴ Social Security Administration, *Annual Report to Congress of Continuing Disability Reviews for FY 2009*.

³⁵ Data obtained from SSA Office of Quality Assurance, June, 2011.

³⁶ See id.

Chairman DAVIS. I appreciate that, Mr. Stein. I wish we had unlimited time for all of our witnesses. It is simply a constraint with the overall schedule of the Congress today. I am personally looking forward to meeting with the Bentleys again after the hearing concludes.

We are going to move on now to Dr. Roberts. You are recognized for 5 minutes.

**STATEMENT OF ELIZABETH J. ROBERTS, M.D.,
CHILD AND ADOLESCENT PSYCHIATRIST**

Dr. ROBERTS. Thank you, Chairman Davis, Mr. Doggett, for inviting me to speak today.

As a child psychiatrist, I have treated hundreds of children who are receiving the Supplemental Security Income. And what I have observed in the cases that I have been treating is an alarming abuse of the SSI system, but more importantly I have observed what a devastating effect the abuse of the SSI system can have on child and family. Because diagnosing a child with a psychiatric condition is based almost exclusively on the verbal report of the child's parent, it is easy for a doctor to arrive at the wrong conclusion. There are no blood tests, CAT scans, MRIs, SPECT scans, and what have you, that can accurately diagnose a mental disorder.

The misdiagnosis of children with psychiatric conditions and the consequential overmedicating of these kids has become a problem of epidemic proportions in the United States. And when you add the financial incentive of getting your child diagnosed and treated with a mental illness, the pursuit of SSI benefits for children has become an irresistible attraction of poor families. If this abuse of SSI were only a waste of taxpayer dollars, that would be bad enough, but the fraudulent use of SSI is hurting children both emotionally and physically. The best way that I can think to elucidate this problem is to give you examples of children I have actually treated.

In 2002, I met an 18-year-old girl who had been assigned to me at the Riverside County Mental Health Clinic for a psychiatric evaluation. For the purpose of this testimony I will refer to her as Sarah. Sarah explained to me that she was required by the SSA to be reevaluated if she wanted to continue to receive her benefit check. She told me that since she was 14 she had been abusing every street drug imaginable, methamphetamine, cocaine, LSD, marijuana, alcohol, and others.

It was at 14 that she started abusing drugs and this is when her mother took her for an evaluation at the county mental health clinic. When she was high on speed she was hyperactive and agitated. When she was drunk, she was depressed. She only experienced her mood symptoms while she was using or withdrawing from drugs.

Prior to the time that Sarah started using drugs, she had no serious mood problems, aside from being belligerent and demanding with her mother. Regardless, her psychiatrist diagnosed her with bipolar disorder. And with this diagnosis her mother was able to secure SSI benefits. And though she was prescribed psychiatric medications for her mood disorder she told me she never took the medications consistently and usually refused them altogether.

Furthermore, Sarah explained that she continued to abuse street drugs for the next 4 years. She described her own behaviors as defiant and rebellious and wild throughout those drug-soaked teen years from 14 to 18 years old. Sarah presented her history with pride and impunity.

At 18 Sarah moved out of her mother's house, starting to cash and keep her SSI benefits of over \$800 a month. I guess kids get more in California than they get elsewhere. Though she abused drugs excessively she was an otherwise beautiful, physically healthy, able-bodied, trim, attractive, smart, Caucasian blonde girl.

Sarah reported it to me in this first session that she established the practice of cashing her SSI check each month, checking into a cheap motel, buying up all the meth with the SSI funds that she could afford. And then she and her boyfriend would use drugs continuously until the money ran out. And when the motel evicted them for nonpayment, they would sleep on the streets and pan-handle for money until the next SSI check arrived.

With the start of each month Sarah and her boyfriend would cash the SSI check and repeat the same routine. When I confronted her with the fact that using the SSI funds to do drugs was destroying her own life, she stated that she didn't care and that she was having fun. She told me that in spite of the fact that she was perfectly capable of working, her bipolar diagnosis entitled her to the SSI money and that she had every intention of continuing to use that money to finance her drug use.

When I pointed out to Sarah that people worked hard, paid their taxes to support programs such as SSI for the benefit of the truly needy, like Will Bentley, she responded by telling me people who work and pay taxes are chumps. Furthermore, I explained to her the abuse of the SSI system was fraud. She went on to provide me with the following advice: If working people had half a brain they would figure out her scam and take advantage of the system as she had.

I offered Sarah psychotherapy, vocational training, drug rehabilitation. She declined all of our services at the county clinic, and including I offered her medication prescriptions. She said she hadn't been taking them anyway and she refused all our services. She asked that I please just simply complete her renewal application for the SSI benefits. I completed the application, providing the SSA evaluators with all the information I had gathered in this first meeting, and her benefits were denied.

Chairman DAVIS. Dr. Roberts, I just encourage you to wrap up.
Ms. ROBERTS. We are out of time. I am sorry, I didn't notice.
[The prepared statement of Dr. Roberts follows:]

Supplemental Security Income Benefits for Children

by

Elizabeth J. Roberts, M.D.

Child and Adolescent Psychiatrist

October 27, 2011

As a child psychiatrist, I have treated hundreds of children who were receiving Supplemental Security Income. What I have observed in these cases is an alarming abuse of the SSI system, but more importantly, I have observed what a devastating effect the abuse of the SSI system can have on the child and the family. Because diagnosing a child with a psychiatric condition is based almost exclusively on the verbal report by the child's parent, it is easy for the doctor to arrive at the wrong conclusion. There are no blood tests or CAT scans or MRI's or even SPECT scans that can accurately diagnose mental illness. The mis-diagnosing of children with psychiatric conditions and the consequential over-medicating of these kids has become a problem of epidemic proportions in the US. When you add the financial incentive of getting your child diagnosed and treated with a mental illness, the pursuit of SSI benefits for children has become an irresistible attraction for poor families. If this abuse of the SSI system were only a waste of tax-payer dollars, that would be bad enough, but the fraudulent use of SSI is hurting children, both emotionally and physically. The best way to elucidate this problem is to share my clinical experiences with this committee.

In 2002, I met an 18 year old girl, who had been assigned to see me at the Riverside County mental health clinic for a psychiatric evaluation. For the purpose of this testimony, I will refer to her as Sarah. Sarah explained to me that she was required by the Social Security Administration to be reevaluated if she wanted to continue to receive her benefits check. She told me that since she was 14 years old, she had been abusing every street drug imaginable: Meth-amphetamine, cocaine, LSD, Marijuana, alcohol and others. It was at 14, after she had started abusing drugs, when her mother took her to be evaluated at a county mental health clinic. When she was high on speed, she was hyperactive and agitated. When drunk she was depressed. She only experienced her mood symptoms while using or withdrawing from drugs. Prior to the time Sarah started using drugs, she had no serious mood symptoms aside from being belligerent and demanding. Regardless, her psychiatrist diagnosed her with Bipolar Disorder. With this diagnosis her mother was able to secure SSI benefits for Sarah. Though she was prescribed psychiatric medications for her "mood disorder" she told me that never took the medications consistently and usually she refused them altogether. Furthermore, Sarah explained that she continued to abuse street drugs for the next 4 years. She described her own behaviors as defiant, rebellious and wild throughout those drug soaked teen years from 14 to 18 years old. Sarah presented her history with pride and impunity.

At 18 years old, Sarah moved out of her mother's house and started cashing and keeping her SSI benefit check of over \$800.00/month. Though she abused drugs excessively, she was an otherwise beautiful, physically healthy, able-bodied, trim, attractive, smart, Caucasian, blond girl. Sarah reported in this first session with me, that she had established the practice of cashing her SSI check each month, checking into a cheap motel, buying up all the "meth" the SSI funds would afford and then she and her boyfriend would use drugs continuously until the money ran out. When the motel evicted them for non-payment, they would sleep on the streets and pan-

Elizabeth J. Roberts, M.D.

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handle for money until the next SSI check arrived. With the start of each month, Sarah and her boyfriend would cash her SSI check and repeat this same routine.

When I confronted Sarah with the fact that using her SSI funds to do drugs was destroying her own life, she stated that she didn't care and that she was having fun. She told me that in spite of the fact that she was perfectly capable of working, her Bipolar diagnosis entitled her to the SSI money and that she had every intention of continuing to use that money to finance her drug use. When I pointed out to Sarah that people worked hard and paid their taxes to support programs such as SSI for the benefit of the truly needy, she responded by telling me that, "People who work and pay taxes are chumps." Furthermore, I explained that her abuse of the SSI system was fraud. She went on to provide me with the following advice. If working people had, "half a brain they would figure out her scam," and take advantage of the system as she had. I offered Sarah psychotherapy, vocational training and drug rehabilitation. She declined all of our services including refilling her psychiatric prescriptions. She reported that she had not taken any of the medications prescribed to her in the past few years anyway.

She asked that I simply complete her renewal application for her SSI benefits. I completed the application providing the SSA evaluators with all the information I had gathered in this first meeting. Her benefits were denied. I thought I had seen the last of Sarah, but a year later she and her mother returned to the clinic together. The mother demanded that I complete the SSI application again, this time describing Sarah as disabled so that she could start receiving the checks again. Sarah's mother explained that their house had burned down recently, and the family really needed the income to rebuild her home. Of note is the fact that without the SSI funds, Sarah had been forced to curtail her drug use, move back in with her mother and get off the streets. I declined to falsify the application just to secure the funds for the family. The mother became enraged and went directly to the clinic supervisor to complain that the doctor was cold hearted and unfair. Sarah's case was reassigned to another psychiatrist who immediately completed the application as Sarah's mother directed and the girl, once again, received her SSI check.

I wish I could report to this committee that this was an unusual case and did not represent the majority of the families that I treat. For those of us in the trenches, we see what the researchers, the number crunchers, the professors, the staff at advocacy programs, and politicians never see. But the fact is that this case is typical of how the SSI program is viewed by the lower income population whom I serve. They see the SSI program as an opportunity to cash in on a deal, from which everyone else in their community is benefitting. So, they justify to themselves....that if everyone else is benefitting, why shouldn't they cash-in too? The evidence that the financial incentive is foremost in their minds, not the mental health of their children, is revealed when they first present their child for "treatment." Those who lack any scruples, but are not very good at deception, start by telling me that their neighbor, friend or their sister told them that their kid could get SSI if the doctor would "fill out the forms." The childhood SSI program was supposed to be essential financial aid for families with extremely sick children. In reality it is crippling the ambitions and ruining the physical health in many, if not most, of the children currently on the program's rolls.

If the loss of ambition and productivity in SSI participants was the only casualty in this fiasco, I would say that this problem was no more than another example of how government waste leads to unintended negative consequences. But this problem is much more devastating for the children it purports to serve. Children learn, in the process of being evaluated and assigned their SSI benefit, that they are "disabled." This can destroy a child's self-esteem. These children give up on their hopes and dreams because they now see themselves as less of a person than their peers, less capable and less deserving of the lofty aspirations that kids often have. They resign themselves to the role that their parents have assigned them—the disabled patient—all in the service of an entitlement check for their parent's benefit.

This final case is an example of how far this folly can go. Most of the children I see on SSI have been prescribed powerful psychiatric medications by their previous doctor. These medications can have ravaging physical side effects. It is very common amongst children being treated in mental health clinics to be morbidly obese—an effect caused by the most popular psychiatric medications prescribed to children: Abilify, Risperdal, Seroquel, Depakote along with a host of other psychiatric drugs. Worse than the obesity, diabetes, lethargy, sedation, and confused/dulled thinking, that these medications can cause, is the potential for these drugs to kill.

On December 13, 2006, at 4 years old, Rebecca Riley died in Hull, Massachusetts as a direct result of the medications prescribed for her Bipolar Disorder—a diagnosis assigned to her when she was only 2 years old. At the time of Rebecca's death, both parents were unemployed, collecting welfare, food stamps and disability benefits while living in subsidized housing. Rebecca's parents had secured Social Security disability benefits for themselves and Rebecca's two siblings, who were 11 and 6 years old in 2006. All four family members had been awarded their benefits based on diagnoses of mood disorders. The psychiatrist, Dr. Kifuji, who had facilitated the procurement of the siblings' disability benefits and who prescribed the medications that ultimately killed Rebecca, reported that the girl's parents repeatedly pressed her to help the family get Rebecca on the SSI rolls. This would enable the couple to collect a 5th SSI check for the family. Toward this end, the mother, Carolyn Riley, continually complained to the doctor that Rebecca required higher and higher doses of her medications for what Carolyn described as out-of-control behavior. Meanwhile, Rebecca's teachers, neighbors and uncle reported that Rebecca was severely sedated most of the day. At 4 years old, she needed help off and on the school bus, slept on her desk most of the day and only awakened at home to eat meals. Dr. Kifuji would not comply with the mother's demands to assist in getting Rebecca on SSI, though she was willing to continue to prescribe Rebecca the heavily sedating psychiatric drugs that killed her. Both parents went to jail for murder in 2010. Dr. Kifuji did not face charges because she agreed to cooperate with the prosecutor's office.

Though SSI abuse rarely results in the death of the children it serves, the SSI system as it is used for mental health disabilities is causing more impairment in children emotionally and physically than it helps. The side effects caused by the medications used in the treatment of mental illnesses can lead to permanent physical damage. Furthermore, the label of "disability" can have an extremely detrimental effect on the emotional well-being of the child. The childhood SSI program is not working. It is devastatingly corrupt. It is a menace to children and a tragic misuse of public funds. I implore this committee to reform the Supplemental Security Income benefits program for children or end it before any more children are hurt.

Chairman DAVIS. Thank you. And we have the rest of your statement in the record as well for further review. I appreciate everybody's testimony. We are going to go ahead and move now to questions.

In the testimony that we have heard today, it appears there are both short- and long-run recommendations on how to help disabled children better prepare for adulthood and recognizing a wide range of needs within the population of children receiving SSI benefits.

Mr. Bertoni, your testimony indicates that, while mental impairments are the diagnosis for two-thirds of the children receiving SSI, the continuing disability reviews, or CDRs needed to confirm children in this group remain eligible, have dropped by 84 percent in the past decade. On page 21, you display a chart that shows how the reviews are years overdue for nearly all child recipients with mental impairments.

Looking at the short-run, Mr. Bertoni, of the trends involving children on SSI due to mental impairments, what does the evidence suggest SSA should be doing to better manage this program?

Mr. BERTONI. I think at the front end SSA should be concerned and looking at the rise in some of these impairments. Especially in speech and language it appears to have increased precipitously. Many of those—that impairment can be viewed as transient in nature, likely to improve. But at the back end much of their focus has been on age 18 redeterminations and low-birth-weight babies, about 87 percent of all CDRs. So we have 13 percent of all other CDRs that are looking at all other mental impairments.

I think it would behoove the agency to sort of tease out some of these impairments that, number one, are growing in terms of raw numbers, and our own CDRs have shown to have fairly large high cessation rates, speech and language 33 percent cessation rate right now.

Chairman DAVIS. So you are saying in effect, if I could just offer a possible example, and tell me if I am right or wrong, that a person who might have been a young person 3 or 4 years old was diagnosed with this, it is possible without the CDR say coming at a reasonable time, within a couple of years, would remain on SSI all the way until age 18 without reviews.

Mr. BERTONI. Certainly right now the case goes up to 174,000 cases and if they are only doing 13 percent of all mental impairments, I think it is fair to say that very few speech and language delay cases are being reviewed. It is probably fair to say that many of those children are probably on the rolls well beyond a CDR that could possibly have ceased them.

Chairman DAVIS. Thank you. Dr. Wittenburg, the outcomes you describe in your research for older youth on SSI are terrible, quite frankly. No one would want that for their children: high rates of school dropout and low rates of work, training, or other positive activities. Two questions, really. First, what should we do about that? And second, is the Social Security Administration equipped to take the steps needed to improve the outcomes or is this the type of effort that State agencies need to be involved in as we saw with welfare reform?

Mr. WITTENBURG. That gets to the heart of my testimony. I think that is an excellent question, Chairman Davis. I think the

short answer for what can SSA do about it is look into school and possibly work requirements for child SSI recipients as well as young adult SSI recipients to reorientate them around the concept of work is potentially an important step, but the bigger picture that I wanted to focus on is the appropriateness of the child SSI benefit and meeting all the diverse needs of the families.

I think as you heard across all the testimonies today, you have a diverse spectrum of youth here. So when we talk about devolving to the State level, I think that is an interesting concept because that is where the services are provided to these youth, that is where schools and voc rehab is provided, and that is where Medicaid is provided. So there is an interesting potential to bundle services, but I would stop short of saying we should go ahead and block grant that to States because at least in some of the experiences under TANF States have not spent their money for other resources. So if you block grant SSI and TANF, a key question is will some States have enough resources to serve both programs given that they are having difficulties serving just TANF in some States? That is why I suggest a more integrated approach that could occur at the State or other levels that might even include private providers. And that is why experimentation is really important.

Mr. STEIN. Mr. Chairman, may I add to that answer if I could in response to your question?

Chairman DAVIS. Sure. We just have a few seconds though.

Mr. STEIN. Yes, sure. Concerning the whole idea of bad outcomes to which Mr. Wittenburg refers, isn't it really not a surprise that there is a high unemployment rate for disabled children; whether they are on SSI or not, they are not going to be employed in great numbers or may be dropping out of school. What Mr. Wittenburg is not doing is comparing those disabled kids on SSI with other disabled children. Don't they all share similar problems or outcomes that we are not that pleased with but we have to understand come because of severe disabilities? Yes, they will drop out of school, and yes, they will have somewhat lower employment rates than others because of the very severity of their disabilities.

Chairman DAVIS. I appreciate your perspective. The reason we are holding this hearing today is to ask some questions that often don't get asked. We are trying to work in a number of areas related to processes and really understanding how to help these young people the best way possible so they can go back to work. And I think the one mistake we don't want to make is to assume, well, because this has been the issue in the past, we therefore should continue to insist that we won't address the root causes of that. Rather, I think the point of asking is to assure that we look at creative ways to address that and make sure that very worthy young people like Will and his family receive support. And for those who may never be able to make that transition we understand that. But on the other hand, I have seen some great success personally in the professional world with young people, incredible disabilities that had been able to move into meaningful work. I think it comes back to community involvement, working the front lines and asking questions like we are asking today. Whether we all agree with each other or not, there is great benefit.

Mr. STEIN. And we do, Mr. Chairman, have specific recommendations in our written testimony which I won't repeat here.

Chairman DAVIS. Reclaiming my time. You will have plenty of opportunity, I am sure, to share as the other Members of the panel ask questions. And with that I will defer now to Ranking Member Doggett for 5 minutes.

Mr. DOGGETT. Thank you, Mr. Chairman. I would ask to be made part of our record an excellent article in today's *USA Today*, Cutting SSI Would Only Hurt Children, written by Dr. Susan Parish of Brandeis University and Dr. James Perrin, a Professor of Pediatrics at Harvard Medical School.

Chairman DAVIS. Without objection.
[The information follows:]

USATODAY OPINION

Column: Cutting SSI would only hurt children

By Susan L. Parish and James M. Perrin

Printed 10/27/11; Posted 10/26/11



By Win McNamee, Getty Images

Families of the disabled protest possible cuts to federal aid on Capitol Hill.

When did it come to this? Are we a nation that balances our budget on the backs of children with severe disabilities and medical conditions? One that forces families to split up because they can't shoulder the costs of caring for their children with special needs? Given recent proposals to cut children's Supplemental Security Income (SSI), one of which the House has already passed, it seems we are.

SSI serves only low-income children with the most severe mental and physical impairments. Its medical and financial eligibility requirements are so strict that only 1.6% of children in the U.S., and fewer than 10% of kids with disabilities, receive SSI. In fact, the overwhelming majority of children who apply for SSI are denied.

Critics who point to SSI's modest growth ignore the fact that child poverty in this country has soared from 16% to nearly 22% in the past decade. Population growth and improved identification of childhood disabilities have also contributed. Yet, the share of poor children receiving SSI has remained constant at about 7.5%.

Heavy burden on families

Another constant: Raising a child with disabilities causes major expenses for families and keeps many caretakers from having gainful employment. For low-income families who are already struggling, shouldering the costs of raising a child with disabilities can be financially devastating. Medicaid and most private insurers offer limited or no coverage for many services that children with disabilities need. Many plans do not cover therapies to help children function in their families, communities and schools. Many plans also fail to cover adaptive equipment and devices to help with communication, mobility, breathing, movement and other necessary functions.

Research shows that families with a disabled child are more likely to run out of food or skip meals; have their phone service shut off; postpone needed medical care; lack money for rent; and move in

with others to prevent homelessness. More than 70% of low-income families caring for children with disabilities report facing severe material hardships such as these.

What's more, families caring for children with disabilities often find it nearly impossible for both parents to work, and thus to provide the income needed to meet their child's basic as well as special needs. Single-parent families have an especially hard time. Every time a parent misses work to care for a child with special needs, the household suffers lost income. Call in sick enough, and a parent risks losing her job altogether.

A modest monthly benefit

While the benefit amount is modest — families receive just \$593 per month, on average — SSI is a lifeline for families caring for children with severe physical or mental disabilities. It helps to replace lost parental income and can blunt the otherwise crushing expense of out-of-pocket disability-related costs.

Most important, SSI enables families to stay together, helping them avoid giving up their children with special needs to more expensive and less effective institutional care.

Before our leaders in Congress consider cutting SSI for children with disabilities, lawmakers need to consider the effect on low-income, struggling families raising children with disabilities. Research suggests that SSI does a lot of good for these children and families — and that, if anything, improvements in benefits and supports are needed, not draconian cuts.

Congress should look for ways to support our nation's most vulnerable children and families, instead of painting a target on their backs in the name of deficit reduction.

Susan L. Parish is the Nancy Lurie Marks Professor of Disability Policy and director of the Lurie Institute for Disability Policy, The Heller School for Social Policy and Management, Brandeis University. James M. Perrin, MD, is a professor of pediatrics at Harvard Medical School and director of the Division of General Pediatrics and former director of the Center for Child and Adolescent Health Policy at the Massachusetts General Hospital for Children. (The House Ways and Means Human Resources subcommittee will hold a hearing on children's SSI benefits Thursday.)

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Mr. DOGGETT. Just reading a couple of lines from that report, I think we have had testimony in my opening statement to this effect, but "SSI serves only low-income children with the most severe mental and physical impairments. Its medical and financial eligibility requirements are so strict that only 1.6 percent of the children in the United States and fewer than 10 percent of kids with disabilities receive SSI. In fact, the overwhelming majority of children who apply for SSI are denied. Congress should look for ways to support our Nation's most vulnerable children and families instead of painting a target on their backs in the name of deficit reduction."

That certainly summarizes my own feeling about this. I am against scams. I think everybody on this Committee is against scams. I am against them whether they are committed by giant pharmaceutical companies at the cost of tens of millions of dollars to public service programs or they are committed by one young woman who goes off to have drugs with her boyfriend. And it seems to me that the focus ought to be on getting at the scams rather than on denying benefits to many deserving families.

We have one way of getting at scams under the system and that is the disability reviews. Unfortunately, under the Bush administration the resources for those disability reviews were significantly reduced and finally under the current Administration we have begun to increase the review process. That is where the focus ought to be, rather than across-the-board cuts.

I find the testimony of Dr. Burkhauser has left the suggestion that because the States have done such a great job reducing benefits in Temporary Assistance for Needy Families, in cutting the level of those benefits and affording them to fewer and fewer families, let's let them do the same thing for families with children with severe physical or mental disabilities. It is a little like the argument that some people have made that because the States do so little with Medicaid in our nursing homes, let's let them administer Medicare too and save some money at the expense of seniors and individuals with disabilities. I think that is very backward thinking. I know what will happen in Elgin, Texas to this beautiful set of twins who suffer from autism. They will get the same kind of second rate support from the State of Texas that the State of Texas provides through the Medicaid program for those who rely on it who can barely get by and can't get all the prescriptions that their doctors provide to them.

Mr. Stein, what would be the effect as you see it in States across the country for these families if we just turn all this, we use I believe the term devolution, let's give it all back to the States instead of maintaining any Federal program with reference the SSI.

Mr. STEIN. I think there would be terrible consequences, Mr. Doggett. There would be a lack of equity. There would be a lack of minimum standards. There would be the very subjectivity that perhaps Mr. Burkhauser is concerned about.

When you have a national system like the Social Security one for kids and adults, you have national standards, you have quality controls in place. In fact, the quality control accuracy rate for decision-making in child disability cases is something like 97 percent.

Now, there is a kind of myth out there that this is the new welfare; this is almost a defamation of the SSI kids program. And it is the wrong assumption that suddenly when you reduce the TANF rolls, all those kids go on to SSI. I think you have heard a little theme about that by a couple of people at this table. But despite those allegations that SSI is or has become a general welfare program, the truth is that being poor is not enough to qualify for SSI. To get SSI you also have to have a very severe disability, and the Congress in 1996 in the welfare legislation then upped the severity standard greatly.

Mr. DOGGETT. Let me just ask you one other question that has been referred to in testimony I think by Dr. Roberts and by others here. Looking at the testimony that is on file with the Committee today from Dr. James Scully on behalf of the American Psychiatric Association, that testimony indicates in response to this issue of well, aren't the people out there just passing out drugs to these kids so they can qualify for this program. He says that the medication treatment for disorders like ADHD actually reduces the likelihood of eligibility for SSI. Is that correct?

Mr. STEIN. That is exactly true.

Chairman DAVIS. Mr. Stein, I am sorry to interrupt.

Mr. DOGGETT. Continue with another Member.

Chairman DAVIS. Time has expired and part of the reason for needing to expedite is we are going to have a vote coming in the next 15 to 30 minutes. I want to make sure that every panelist has the opportunity. If you could give that response to the Committee in writing we would be very grateful for that.

Mr. STEIN. Yes. I was in mid sentence, Mr. Chairman. May I just complete that sentence?

Thank you for that.

Chairman DAVIS. I tell you what we are going to do. Since the last sentence was a minute and a half long I think we will let it come back in writing. I share equal passion for helping young people and have volunteered and worked in this space for nearly 30 years. So I think that we can have some common ground in this.

With that I would like to recognize the gentleman from Minnesota, Mr. Paulsen.

Mr. PAULSEN. Thank you, Mr. Chair. I will be pretty quick. I want to thank you for holding this hearing. And I want to get back to this issue of the timely reviews. Mr. Stein had noted I think back in January regarding children on SSI that existing law already requires disability reviews every 3 years where improvement is likely. But the data really does suggest that those reviews have not actually been happening recently in years.

For example, the Social Security Administration Inspector General recently reported that although required by statute, SSA failed to complete 79 percent of scheduled child reviews resulting in an estimated 1.4 billion in overpayments. So there is obviously concern about this issue on a bipartisan basis. In fact, in the Budget Control Act which we just adopted in August we provided more resources for these reviews, as well as other program integrity activities to the tune of \$623 million for 2012.

Mr. Bertoni, you also note in your statement and made some comments that SSA does not appear to be conducting childhood

CDRs in a very timely manner. In your opinion, how vital is it for SSA to conduct childhood CDRs? And in what ways could SSA better target those efforts?

Mr. BERTONI. Certainly. The CDRs they are conducting, as I said earlier, are for age 18 redeterminations as well as the low-birth-weight babies, but there is a vast range of other mental impairments that they are not getting to. We do know that many of them are increasing and represent a significant portion of the rolls: Speech delay, 21 percent; ADHD, 26 percent; autism, 11 percent. In excess of 50 percent of the rolls are within those three impairments.

They are getting very few CDRs, and again, some of those cases potentially could have medically improved, the science says that that is a possibility. A number of those are probably listed as medical improvement expected, so I think you are foregoing an opportunity, I think, not just to save taxpayer dollars but to put children who are medically impaired on a different track to a track toward productivity and integration, toward something other than lifelong Social Security benefits.

Mr. PAULSEN. So knowing there is that opportunity there, do you believe that SSA has a plan for how to use the moneys in the Budget Control Act that we just passed a couple of months ago to target these reviews more efficiently and effectively?

Mr. BERTONI. I do know they are concerned about certain trends in the caseload, certain impairments, and they are eyeing it very closely. I do not believe there is a specific plan to get to the existing backlog or what they would do going forward.

Mr. PAULSEN. Mr. Chairman, I just think we are going to have to monitor this because we are all looking at, you know, stretched resources, and there is broad agreement here that these reviews, timely reviews, are critical, so I will yield back my time to move on.

Chairman DAVIS. I thank the gentleman.

I now recognize Mr. McDermott from Washington State for 5 minutes.

Mr. MCDERMOTT. Thank you, Mr. Chairman. It seems to me this hearing has two issues in it, and we can't deal with both of them. One is the effect of poverty on poor kids and what we have done, and Dr. Burkhauser and Dr. Wittenburg both talked about that, we ought to have a hearing about that and what we ought to do about it, but the more important issue here, it seems to me, is what Dr. Roberts says.

Dr. Roberts says that child psychiatrists are fraudulently putting children on SSI. She says in her testimony, because diagnosing a child with psychiatric condition is based almost exclusively on the verbal report by a child's parents, it is easy for the doctor to arrive at the wrong conclusion.

Now, that would imply that you don't examine the kid. I am a child psychiatrist; you are a child psychiatrist. You saw that child, and you made the diagnosis on the basis of reports but also what you saw in front of you. For you to imply that any kid out of the 1.2 million kids that are on SSI in this country were put there by somebody who didn't see the child is an absolute accusation of fraud.

And I know you went on Oprah, and you have been on CNN, so I know you have the ear of the media. That is why I am taking you on, because you are in the media here. And the fact is that I would like to hear, did you ever report a doctor for doing such a thing? Because it is against the ethics of the American Psychiatric Association to make a diagnosis without seeing the patient. You know that. I can't make it—I can't say what I think of Mr. Davis' psychiatric condition because I haven't examined him. Everybody understands that.

Chairman DAVIS. If I could interrupt, I would only agree to that if I could have reciprocity with the gentleman from Washington State.

Mr. MCDERMOTT. Well, I make my point. You don't—the business about making a decision about Miss Schiavo by Dr. Frist. Making a decision about somebody in Florida on a breathing machine when you haven't seen the patient is malpractice, and it is unethical.

So now you are accusing doctors of doing that. Give me an example of someone you know by name that saw a patient or didn't see a patient and signed a paper and said they are eligible for SSI.

Chairman DAVIS. I just, in respect of HIPAA, I would ask that you not name any individuals that you are citing if you have those records.

Mr. MCDERMOTT. Well, you can give me a false name like Sarah, all right?

Dr. ROBERTS. Thank you, Mr. McDermott, for the opportunity. I don't know how you came to the conclusion that I said that because the diagnosis is made primarily on the report by the parent that the child is never seen. Evaluations of children, as it is done in practice—it is very nice that there is so much testimony here that getting a child on to SSI is so difficult and the requirements are so strict and stringent. They are not. In practice—now, I don't know how many people here actually treat children still today in poverty and see and help them apply for SSI every week, because I do. Every week. Filling out SSA forms. And the children—

Mr. MCDERMOTT. How long do you spend with these kids, 2 minutes or 3 or an hour?

Dr. ROBERTS. See, that is the difference. I spend 2 hours or more, and my colleagues spend 20 or 5, and that is the problem.

Mr. MCDERMOTT. Twenty minutes or 5?

Dr. ROBERTS. Five minutes, right.

Mr. MCDERMOTT. How do you know that?

Dr. ROBERTS. How do I know that? Because the doctors tell me that, and the patients who have seen these doctors report that to me. The doctors—

Mr. MCDERMOTT. Have you reported them for an ethics violation for seeing the patient for 5 minutes and then going—

Dr. ROBERTS. It is a common practice, Mr. McDermott, a common practice.

Mr. MCDERMOTT. Common practice?

Dr. ROBERTS. And, yes, I report it to the supervisors at the county, and they tell me forget about it.

Mr. MCDERMOTT. Wow.

Dr. ROBERTS. For example, in the case of Sarah, when I denied her, her mother came back a year later and said, my house burned down; we need the money.

Mr. MCDERMOTT. You have given me one example. You—and, I am sorry—let me tell you—

Dr. ROBERTS. Oh, I can give you hundreds of examples. Hundreds.

Mr. MCDERMOTT. You are trying to draw a general policy.

Dr. ROBERTS. No, I am not.

Mr. MCDERMOTT. Yes, you are.

Dr. ROBERTS. I am not. I am trying to say there is a lot of fraud and abuse in the system, and it needs to be fixed. I am not referring to Will; I am talking about kids like Sarah.

Mr. MCDERMOTT. And what have you done to repair it? Where have you used the organizations that one would use to repair that fraud and abuse? What have you done?

Dr. ROBERTS. I report the—I write books. I write articles. And I report it to supervisors. What else can I do? I testified before a Subcommittee; that is the best I can do.

Mr. MCDERMOTT. Are you a member of the AMA? Are you a member of the American Psychiatric Association?

Dr. ROBERTS. No, I let my membership lapse because they are making statements like they did that completely ignores what happens in the trenches for those of us who are actually treating these children. They make these blanket statements as if everyone is getting a very strict review. They are not. After Sarah was denied—

Mr. MCDERMOTT. You are making the blanket statements—

Dr. ROBERTS [continuing]. Her mother came back in to me.

Mr. MCDERMOTT. Excuse me—

Dr. ROBERTS. No, I am not making a blanket statement.

Mr. MCDERMOTT. It is my time.

Dr. ROBERTS. Oh, sorry.

Mr. MCDERMOTT. You are making statements—

Chairman DAVIS. Actually, it is now my time. Thank you.

Mr. BERG. Our time.

Chairman DAVIS. I appreciate the spirited dialogue on this issue with my friend from Washington, with whom I have worked on many legislative initiatives, and yours, Dr. Roberts, as well. We do have a copy of your book, among others.

Now I would like to defer to the gentleman from North Dakota, Mr. Berg.

Mr. BERG. Thank you, Mr. Chairman.

And I truly do want to thank all the panelists that are here.

Thank the Chairman for pulling this together.

You know, back in September, we had really a hearing on the SSI program for adults. And I am just happy here that we are looking at the same issue with children, and one of the things that strikes me is before we get in the weeds, we have to kind of look at the outcomes. And really, what in the big picture long term are we doing, what are we creating, how are we impacting these people's lives? And so that is kind of the thrust of where I would like to go with the questioning, and you know, we talked about the incentives in September for adults on vocational rehabilitation and how to help them reenter the work force, and I think that should

be a goal is how do we have people feel a part of our society, have them be engaged in work that they enjoy, work that they feel a value to? And so a lot of what I have heard here today seems we have barriers and disincentives to that direction.

And so, Dr. Wittenburg, you know, from your research, you know, there are very low rates of enrollment in vocational rehabilitation services on these youth that are transitioning, and you mentioned several demonstration projects. I guess one of the brief questions is the Youth Transition Demonstration. What is the theory behind that?

Mr. WITTENBURG. That is a very good question, Mr. Berg, and the Youth Transition Demonstration is one of the demonstrations that I am very optimistic about because I feel like it is asking the right questions, which is, how can we promote the long-term outcomes of these youth? It looks at the exact poor outcomes that I put in that slide, and it says, what do we know about best practices in terms of delivering employment supports to youth with disabilities? What do we know about incentives that may affect youths' choices regarding the labor market? And it combines a series of intervention approaches, and I think one of the key points of it, Mr. Berg, is that it is designed to be a customized approach to meet the individual needs of the youth. It is not a standard system.

So the Youth Transition Demonstration is operating in several sites across the country, and sites have developed their own models around these general parameters, and it is a flexible sort of model. It is too early to tell what the impacts of YTD are, but demonstrations like YTD are really important because they are changing the way that we are approaching youth with disabilities, and the way we should be approaching, quite frankly, all the youth because the outcomes of these populations are not acceptable currently.

Mr. BERG. Well, then the next question is a follow up, really relates to the high school graduation.

Mr. WITTENBURG. Yeah.

Mr. BERG. And, I mean, I am just stunned by, again, the statistics where, you know, two out of five don't have a diploma; four out of five are not working; one out of five is arrested.

Mr. WITTENBURG. Yeah.

Mr. BERG. Again, it seems like there are some things that are failing here. So, you know, back to you, and even within the program, where we have people receiving survivor benefits, children, they must remain in school, so I guess my question to you is, you know, does this current policy undermine what we are trying to do and should this be a requirement in the system for the education?

Mr. WITTENBURG. I think that is an excellent question, Mr. Berg, and I do believe that we should be putting requirements in the system that help youth achieve all the outcomes that they need to achieve.

Now, all these requirements are not going to be appropriate for all youth. For example, it may not be appropriate to apply these requirements to say, youth who are homebound, but I think that we can move beyond a one-benefit-fits-all-needs model, and if we can customize supports to better meet the needs of these youth—and I want to be clear, I am not advocating cutting the child SSI program in any way. It provides a vital source of low-income sup-

port. I am suggesting that we rethink the way the benefits are provided so youth, getting back to your question, so that when we come to a youth, they don't say to themselves, look, I am afraid to work because it might jeopardize my benefit status.

Mr. BERG. Right, right.

Mr. WITTENBURG. So—

Mr. BERG. Well, and that is kind of in the bigger picture here; I think the one-size-fits-all strategy from the top down is a problem. I think the States are the innovators, so if States can come up with solutions. And, you know, you talked really about again I think the Federal program restricts innovation at the State level in trying to be more effective and better outcomes for children. And so I guess kind of my question is this integration you talked about with the States, if they have more flexibility, what—I mean, I understand the benefits. What are the issues we should be aware of if we are going to transition more of those decisions down to the State level?

Mr. WITTENBURG. Well, the first issue you should be aware of is we don't know what works, and so part of the history of the SSI program is that it became a Federal program because States were having a problem serving people with disabilities.

Chairman DAVIS. Dr. Wittenburg, if I could suggest, if you could complete that answer for the record, that would be helpful. I hate to be the traffic cop this morning, but knowing that we have this impending vote, I want to make sure that all our Members have the opportunity to question.

Mr. WITTENBURG. I am sorry, Mr. Berg.

Mr. BERG. I yield back.

Mr. WITTENBURG. Okay.

Chairman DAVIS. The chair now recognizes Mr. Lewis from Georgia.

Mr. LEWIS. Thank you, Mr. Chairman, thank you for holding this hearing.

Thank members of the panel for being here.

Mr. Chairman, I would like for Mrs. Bentley to come before the witness table.

Mrs. BENTLEY. Thank you.

Mr. LEWIS. Mrs. Bentley, thank you and Will for being here. Can you tell the Subcommittee something about your son Will's disability and about how SSI benefits have helped you better care for him? Or do you think SSI benefits have made a positive difference for Will? What improvement has he made since receiving SSI? What would happen to Will and your family if you did not have assistance from the SSI program?

Mrs. BENTLEY. Thank you.

Will has a seizure disorder that when he has seizures, and most of the time, they are at night—he does have some during the daytime, but he has them when he sleeps, and he loses skills that he has learned during the day. So if it is in his short-term memory, Will may not get it back for some time. And he was unable to feed himself, unable to communicate. He communicated with his hands. We learned how to tell stories, and then he learned how to talk after we started controlling the seizures somewhat, but they are in the part of his brain that controls speech, so that was huge for him.

For Will to be able to dress himself and be able to read that he can today, he is learning so much, and feeding himself and being able to talk to us and to tell us things. His speech still has delays, but Will can say so much, and he can communicate in so many ways.

Without—with the SSI program and being able to have those benefits, it brought so many things to Will, resources that I couldn't even imagine doing without. I don't think that Will would be where he is at today if I had not had that opportunity. These programs just really are priceless to families, to have the support, the doctors, to be able to buy his medicines and not worry, to be able to take him to therapy and get a good home program that I could use so that when Will is in the community or he is at home, we are able to find ways to help him be a part of that. I am not sure if I have answered all your questions.

Mr. LEWIS. Well, thank you, you have done very well.

Mrs. Bentley, thank you so much.

How would you respond to some of the comments from the witnesses here today, particularly those who claim that the childhood SSI program is not working, that it is devastatingly corrupt, it is a menace to children, and a tragic misuse of public funds? How does that make you feel when you have to read these type of allegations, when you are trying to do the best for your son Will?

Mrs. BENTLEY. It makes me want to ask you guys to come home with me, spend some time with me, some time with Will, and to see how great his life is. The opportunities we are giving him are priceless.

I have huge hopes and dreams for my son, and I am working with him to help do that.

If SSI was not available to our family, I could not do that; I couldn't give him an opportunity.

Some day my son is going to be a productive part of the community. He is not going to be someone who is there just getting a check, and right now that gives us an opportunity for me to be there and really be enriched in his life, not just on the sidelines. I am here with him making sure that he has a future, and I put my career back where it needs to be right now. I can always pick that up later. If I don't make the changes in Will's life today, if I don't invest my time in him, I am never going to change the outcome for him. He is going to be the same way his entire life.

But now I know that Will has a chance because I am not going to quit. I am going to be there for him and every other child that is tucked in my heart today as I come here before you.

Mr. LEWIS. Mrs. Bentley, I appreciate you saying what you said. It is my philosophy, it is very simple, that you cannot give up or give in or give out, and thank you for your standing up for Will and speaking up for this program.

Mr. Chairman, you know, in spite of all of the difficulties that we have as a country, I don't think this is the time to cut this program and try to balance the budget on the backs of the most disabled children, young people in our society. We can do better.

Thank you very much, Mrs. Bentley.

Mrs. BENTLEY. Thank you.

Chairman DAVIS. I thank the gentleman.

And, you know, as we move forward, I think one of the highlights that speaks to me and points all the more to why Congressman Neal and I requested the GAO report in the first place is the Sarahs of the world are the ones who take away the opportunities for the Wills of the world, and nobody, I think, has implied or remotely suggested cutting the budget on the backs of the needy. I think what we are trying to do is understand broken processes so that we can repair them and improve the quality of our systems overall, and that unemotional focus in a very emotional situation, I believe, is critical and nonpartisan in nature. Just as we were able to have such a successful reform in the child welfare reauthorization, I would hope as we move forward with these programs, we can accomplish the same thing.

With that, I recognize Mr. Reed for 5 minutes.

Mr. REED. Thank you so much, Mr. Chairman, and I strongly associate myself with your words because I think, Mrs. Bentley, I am a new Member of Congress, and everybody up here recognizes. My son's name is Will. I have two nephews that have autism, one low functioning, one high functioning, and the system needs to be secured. And I hope you take some comfort in knowing that we all up here recognize the system needs to be here for you and for Will. But what we need to focus on is making sure that the abuses and the program is sustainable and the abuses are weeded out so that it will be here in the future for Will and the future Wills.

And so I come out here from a new perspective of trying to look forward, and when I hear my colleagues who have been here for quite sometime talk about how the Federal Government has done it so well and we shouldn't give it to the States or we shouldn't experiment with things at the State level, I just go to the scoreboard. I mean, I look at Social Security, bankrupt 2036; Medicare, bankrupt 2019; Medicaid, every county in my district, I represent eight counties in New York State, 100 percent of the property tax levy goes to Medicaid. It is driving my seniors out of the homes that their parents built because they can't pay the property tax bill. So I came here to make a difference. I came here not to talk about how President Bush cut the program but President Obama is restoring the program. That partisan stuff, I am tired of it.

So we are here to ask the questions of, how do we strengthen this program, how do we—and I will start backward.

You know, Mr. Stein, I would hope your goal is to have recommendations to us today to remove disabilities so that children can go on and become productive so that they don't have the need for SSI going forward. Give me one recommendation from you, sir, that would enhance that goal of removing the disability, and then I want to go to Mr. Bertoni about how we reform and go after the fraud, and then I want to go to Dr. Roberts to go to the qualifying events to make sure they are objective and not subjective.

Mr. STEIN. Thank you, Mr. Reed.

We have a number at the end of our written testimony. One is improving vocational rehabilitation services for those youth who are under 18 and those who transition after 18 on to SSI. The vocational rehab services are very minimal these days to nonexistent. They could be much more proactive. Vocational Rehabilitation is a State agency, so this is State action.

Mr. REED. So you recommend State action?

Mr. STEIN. We recommend that there be improved and pumped-up and targeted services by State voc-rehab agencies that work with Social Security and with other Federal and State agencies to really assist kids who are older kids and teenagers and those transitioning after 18. Indeed, you know, you don't have an automatic ride onto SSI after 18. One-third of SSI kids are terminated at age 18.

Mr. REED. Thank you.

Mr. STEIN. That is a population that also needs voc-rehab services as well.

Mr. REED. That is a very reasonable recommendation. I appreciate you giving us that thoughtful comment.

Mr. Bertoni, from your perspective, what is one of the top areas we could target to go after the fraud and abuse in the system?

Mr. BERTONI. Aside from the income and asset, there is a lot that can be done on the income and assets with the parents, but that is not the subject of this hearing.

From a medical standpoint, I think really targeting those cases that are most likely to improve, doing the appropriate reviews and identifying those children who can move, as you said, to that different track, that more productive track, is key. If you don't, there is the likelihood if it is not fraud, it could be abuse, whereby folks will linger on the rolls for many years well past their eligibility period, and that is a cost to the taxpayer. So if we don't want to touch the front end, which folks can argue whether it is subjective or not subjective, we really need to look at existing folks, the existing folks on the rolls and making sure that they are truly eligible for benefits, and the way you do that is by doing the reviews that you are required to do.

Mr. REED. The reviews. Now on the front end, Dr. Roberts, any recommendations as to how to make this more of an objective standard?

Dr. ROBERTS. It would be very hard because, like I said, when children are being assessed, it is really their parents' report. I am not speaking of children like Will. I am not talking about the children I have helped on to the SSI rolls who definitely needed the help, their family needed the help, but the system has to be reformed in terms of the way the money is used by those who receive it. Regular reviews are a good start, but if the patient is still being seen very quickly—

Mr. REED. I see my time has expired. Maybe we can talk offline or maybe written recommendations as to creating a more objective standard from the gatekeeper perspective.

Thank you, Mr. Chairman. With that, I yield back.

Chairman DAVIS. I thank the gentleman.

And Mr. Neal, my partner in the original request, will have the last word.

Mr. NEAL. Just a couple of thoughts. First how difficult it is to have these conversations, how really hard it is because they become so charged when we really are trying to discern evidence that might support Mrs. Bentley and her family, and that is what the goal ought to be here. That is the priority.

Now, Social Security is not going bankrupt in 2036. I have not heard one actuarial suggestion that that is the case.

Dr. Wittenburg I believe is correct, the reason that the Federal Government took over the initiative was because the States were ineffectual in their approach, and the suggestion that I offered earlier, and I hope that the Subcommittee and the Full Committee might entertain, is the idea of having the Institute of Medicine take a look at the program. I do think that Mr. Bertoni has raised a reasonable point when he says there is a difference between fraud and abuse. There is a chasm there, and abuse clearly could be perhaps an overworked physician suggesting, well, medication becomes the first option. And there are educators in Springfield and Holyoke, Massachusetts, that I have enormous regard for—I have known them my whole life, professionally and personally—and they have suggested to me that this is a worthwhile examination based upon the challenges they face every day in the classroom. And there is evidence that the rolls have grown, and if it is for children like Will, they should grow. If it is an abusive State, then we have an obligation just to examine it, and I don't think we ought to be afraid of the outcomes that the Institute of Medicine might produce, and I would hope we could all rally around the suggestion and the responsibility we have to ensure that people that need the benefit get it and the people that don't need the benefit are removed from it. That is a simple equation.

So thank you, Mr. Chairman, and I appreciate very much you allowing me to participate today.

Mr. STEIN. Mr. Neal, may I just add something to your response, which is I think we fully agree with that, and I think the heart of what you are saying is the need not to rush in haste. I think that we need to wait for the GAO study, which is in its "preliminary observation" stage today. We need an Institute of Medicine study, and I think the danger, as Dr. Wittenburg says in his statement, is to rush, like Congress did 15 years ago. He states in two places in his testimony today that there were media reports at that time in the mid-1990s, which were later proved to be totally untrue about abuse, about parents coaching, and all of this, and that fueled changes in the law in this Congress in 1996, changes that he says, at pages 3 and 4 of his testimony, were unwise and made things worse. And he is urging, and I think we all in this room should be in agreement, that this is not a program that we should rush into changing. We should take time—we should look at the studies. We should take our time because the lives and health of too many children are at stake for hasty action.

Mr. WITTENBURG. And if I could just say for the record, I would say that welfare reforms made in 1996 were not evidence-based changes. They were made in haste. So I don't want to put a judgment on whether they were good or bad changes, but certainly, when you look at the outcomes that we are seeing today, I think it does cause us to look at what is going on in the SSI program.

Chairman DAVIS. Does the gentleman yield back?

Mr. NEAL. I did already.

Chairman DAVIS. I thank the gentleman.

And I thank all of our witnesses who came to join us today for this discussion. If Members have additional questions, they will be submitting them directly to you all in writing. What I would ask is that the witnesses submit a copy of their response to the Committee for the record so that it can be shared with all Members and staff. We appreciate your time that you have invested in preparation, especially the Bentleys for coming from my home area in Covington, Kentucky.

And with that, this hearing stands adjourned.

[Whereupon, at 10:31 a.m., the Subcommittee was adjourned.]

[Questions for the Record follow:]

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Congress of the United States
House of Representatives
COMMITTEE ON WAYS AND MEANS
WASHINGTON, DC 20515

SUBCOMMITTEE ON HUMAN RESOURCES

November 1, 2011

Mr. Daniel Bertoni
Director, Education, Workforce, and Income Security
U.S. Government Accountability Office
441 G Street, N.W.
Washington, D.C. 20548

Dear Mr. Bertoni:

Thank you for testifying at our subcommittee hearing on SSI benefits for children. We appreciated your expertise as we seek to understand trends in the number of children receiving SSI due to mental impairments, the role of medication in disability determinations, and the impact of the failure to complete continuing disability reviews on program enrollment.

In order to complete the record of the hearing, please respond to the following questions no later than the close of business Tuesday, November 15, 2011:

1. According to Social Security Administration data, last month the average SSI benefit overall was \$499, while the average SSI benefit for disabled adults was \$517, and the average SSI benefit for disabled children was \$597.

Why do children on SSI tend to receive larger disability benefits than other SSI recipients?

Are there any requirements that a child's SSI benefits, or any SSI disability payments for that matter, must be used to help the individual overcome their disability? If they do succeed in overcoming their disability, what happens to the benefit payments?

2. In our previous hearing on work incentives we found that only 3 percent of SSI adults leave the rolls due to work, while most leave through death, making it sound like SSI is a lifetime commitment.

Is this also a concern for children? What do we know about their durations as children and then as adults?

For example, what is the most common reason children on SSI lose eligibility? Medical improvement? Turning 18? Increased earnings by their parents? Their own earnings? Other reasons, such as the child dies as a result of their disabling condition or other causes?

The Committee relies on electronic submissions for printing of the official record. Therefore, please send an electronic submission in Word format to timothy.ford@mail.house.gov. If you have any questions concerning this matter, please feel free to contact Matt Weidinger or Anne DeCesaro of my staff at (202) 225-1025.

Again, many thanks. We will continue to be in touch with you if we have questions about your preliminary findings.

Sincerely,



Geoff Davis

1. According to Social Security Administration data, last month the average SSI benefit overall was \$499, while the average SSI benefit for disabled adults was \$517, and the average SSI benefits for disabled children was \$597.

Why do children on SSI tend to receive larger disability benefits than other SSI recipients?

While we have not conducted the work necessary to answer this question, SSA attributes the relatively high average payment to children (compared with payments made to blind and disabled adults) in part to a limited amount of countable income. The federal SSI payment is based on the individual's countable income,¹ which for a child, may include the parent or guardian's income. SSA's process of determining how much of this income they will count towards the child's income is called "deeming." SSA will make deductions from deemed income for parents and for other children living in the home. After SSA subtracts these deductions, the agency determines whether the child meets the SSI income and resource requirements and calculates the recipient's monthly benefit payment.

Are there any requirements that a child's SSI benefits, or any SSI disability payments for that matter, must be used to help the individual overcome their disability? If they do succeed in overcoming their disability, what happens to the benefit payments?

Typically, a disabled child's SSI benefit is paid on behalf of the child to a "representative payee," such as a parent or guardian. The representative payee is responsible for using SSI payments only for the child's use and benefit in a manner and for the purposes he or she determines, consistent with SSA guidelines, to be in the child's best interests.² The representative payee of a child also has a responsibility to ensure that the child is receiving treatment to the extent considered medically necessary and available for the condition that was the basis for providing benefits.³ "Treatment that is medically necessary" is treatment that is expected to improve or restore the child's functioning and that was prescribed by a treating source.⁴ SSA is generally required by law to determine the extent to which certain child recipients have medically improved and are still eligible to receive benefits. At the time of this disability review, the child's representative payee generally must present evidence that the child is and

¹Some states supplement the federal SSI benefit with additional payments, making the total SSI benefit levels higher in those states. State supplemental payment amounts may vary based upon an individual's income.

²20 C.F.R. § 416.635(a).

³20 C.F.R. § 416.635(g).

⁴20 C.F.R. § 416.994a(l)(1).

has been receiving medically necessary and available treatment for his or her impairment. If the child is found to have medically improved and no longer meets SSI eligibility requirements, the recipient should no longer continue to receive benefit payments.⁵

2. **In our previous hearing on work incentives we found that only 3 percent of SSI adults leave the rolls due to work, while most leave through death, making it sound like SSI is a lifetime commitment.**

Is this also a concern for children? What do we know about their durations as children and then as adults?

We have not conducted the work necessary to answer this question. However, SSA data suggest that between 1974 and 2010, 918,825 adult SSI recipients first became eligible for benefits before age 18.

For example, what is the most common reason children on SSI lose eligibility? Medical Improvement? Turning 18? Increased earnings by their parents? Their own earnings? Other reasons, such as the child dies as a result of their disabling condition or other causes?

SSA data indicate that between 2006 and 2010 the most common reason SSA terminated SSI benefits for both adult and child recipients was due to "excess income." Of those recipients under age 18 terminated in 2010, about 51 percent were terminated because of excess income. Other reasons for benefit cessation include excess resources, death, or because they are no longer disabled (see table 1).

⁵42 U.S.C. § 1382c(a)(4).

Table 1: Recipients terminated, by age and reasons for termination, 2006-2010

Year	Total	Excess Income	Death	Whereabouts Unknown	Excess Resources	In public institution	Failed to furnish report	Outside United States	No longer disabled	Other
<i>All ages</i>										
2006	735,148	339,110	244,013	10,333	25,947	29,797	9,106	13,369	46,561	16,912
2007	690,504	318,291	242,375	9,615	22,439	30,068	5,911	12,284	32,284	17,239
2008	699,627	324,285	244,412	9,496	24,547	29,613	6,860	13,444	30,671	16,299
2009	732,484	354,770	242,680	10,213	24,147	29,796	8,199	11,340	32,408	18,931
2010	815,946	437,922	241,148	11,397	29,184	27,408	10,163	10,527	34,675	13,522
<i>Under age 18</i>										
2006	65,132	26,241	5,236	2,654	5,257	1,360	3,188	547	17,536	3,113
2007	55,147	25,529	5,488	2,610	4,855	1,420	2,055	522	9,516	3,152
2008	52,703	27,892	5,194	2,595	6,153	1,399	1,451	518	4,478	3,023
2009	53,367	26,085	5,041	3,239	5,773	1,290	3,414	525	4,528	3,472
2010	57,615	29,098	4,824	3,316	6,430	1,123	3,409	481	5,720	3,214
<i>Ages 18-64</i>										
2006	474,074	272,946	105,254	4,612	13,542	27,701	4,762	3,368	29,007	12,682
2007	450,585	258,701	105,573	4,375	11,734	27,902	3,078	3,174	22,751	13,297
2008	460,763	262,551	107,354	4,482	12,499	27,382	4,611	3,153	26,184	12,547
2009	496,049	292,731	109,525	4,613	12,364	27,668	4,109	2,586	27,860	14,593
2010	552,787	351,258	109,559	4,884	15,398	25,472	5,615	2,050	28,942	9,609
<i>Ages 65 or older</i>										
2006	195,942	39,923	133,523	3,067	7,148	736	1,156	9,454	18	917
2007	184,772	34,061	131,314	2,630	5,850	744	778	8,588	17	790
2008	186,161	33,842	131,864	2,419	5,895	832	798	9,773	9	729
2009	183,068	35,954	128,114	2,361	6,010	838	676	8,229	20	866
2010	205,544	57,566	126,765	3,197	7,356	613	1,139	7,996	13	699

Source: Social Security Administration, *SSI Annual Statistical Report, 2010*.

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Congress of the United States
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COMMITTEE ON WAYS AND MEANS
WASHINGTON, DC 20515

SUBCOMMITTEE ON HUMAN RESOURCES

November 1, 2011

Mr. Jonathan Stein
General Counsel
Community Legal Services
1424 Chestnut Street
Philadelphia, Pennsylvania 19102-2505

Dear Mr. Stein:

Thank you for testifying at our subcommittee hearing on SSI benefits for children. We appreciated having the benefit of your experience as we seek to understand caseload trends and outcomes for recipients of program benefits.

In order to complete the record of the hearing, please respond to the following questions no later than the close of business on Tuesday, November 15, 2011:

1. Your testimony points to medical research and "more specific, precise" diagnoses in an attempt to explain the rapidly rising number of reported cases of autism, ADHD and speech and language delay in children receiving SSI. You go on to note, "more precise diagnosis is generally viewed as an advance in childhood mental health treatment, as it facilitates better-tailored treatment for children with disabilities."

What evidence is there that children on SSI are receiving "better-tailored treatment" today? For example, are more children overcoming their disabilities and leaving the SSI program as a result of such "better-tailored treatment"? Are children experiencing shorter durations of disability? Are more going to work as adults? Are there other data showing that children on SSI are receiving "better-tailored treatment," as your testimony suggests?

2. When you testified before this Subcommittee on February 2, 1995 on proposed changes to the SSI children's program, Subcommittee Chairman Clay Shaw of Florida asked you about one family that was collecting \$47,000 in SSI payments per year for two parents and seven children on SSI, or the equivalent of about \$70,000 today.

Here is how you responded to Chairman Shaw: "We have problems with that, and what we would say is – and we have a long list of reforms that we do not have time to get into, but we would say for very large families there should be some sort of family cap or graduated sliding scale of benefits."

The SSI program has not added a family cap or sliding scale of benefits since then, so each child remains eligible for almost \$700 per month in Federal SSI benefits alone today. Do you continue to support adding a family cap or sliding scale for benefits when multiple children are on SSI, as you did in 1995?

The Committee relies on electronic submissions for printing of the official record. Therefore, please send an electronic submission in Word format to timothy.ford@mail.house.gov. If you have any questions concerning this matter, please feel free to contact Matt Weidinger or Anne DeCesaro of my staff at (202) 225-1025.

Again, many thanks. Should we have further questions, we will be sure to contact you.

Sincerely,



Geoff Davis

**BEFORE THE U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON HUMAN RESOURCES**

**WRITTEN RESPONSES TO SUPPLEMENTAL QUESTIONS FROM OCTOBER
27, 2011, HEARING REGARDING SUPPLEMENTAL SECURITY INCOME
(SSI) CHILDHOOD DISABILITY BENEFITS**

**JONATHAN M. STEIN
COMMUNITY LEGAL SERVICES, INC., PHILADELPHIA, PA
NOVEMBER 15, 2011**

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1. Your testimony points to medical research and "more specific, precise" diagnoses in an attempt to explain the rapidly rising number of reported cases of autism, ADHD and speech and language delay in children receiving SSI. You go on to note, "more precise diagnosis is generally viewed as an advance in childhood mental health treatment, as it facilitates better-tailored treatment for children with disabilities."

What evidence is there that children on SSI are receiving "better-tailored treatment" today? For example, are more children overcoming their disabilities and leaving the SSI program as a result of such "better-tailored treatment"? Are children experiencing shorter durations of disability? Are more going to work as adults? Are there other data showing that children on SSI are receiving "better-tailored treatment," as your testimony suggests?

Recent medical studies and reports overwhelmingly suggest significant advances in diagnosis and treatment of mental health disorders. Leading examples include "Evidence-Based Practice in Child and Adolescent Mental Health Services," an oft-cited overview of recent advances in the field;¹ recent reports by the Institute of Medicine, such as *Improving the Quality of Health Care for Mental and Substance-Use Conditions*² and *Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities*;³ and a 1999 report of the U.S. Surgeon General on mental health.⁴

To be clear, however, when I stated that there have been improvements in diagnosis and treatment of mental health disorders, I did not intend to suggest that children who apply for or receive SSI necessarily have access to or receive appropriate levels of what treatment options now exist. Nor did I mean to suggest that there exist such levels of treatment as to be able to "cure" children of all mental and behavioral impairments.

Mental illnesses are complex disorders that affect functioning at home, at school and in the community. Severe disorders typically affect children's behavioral, emotional, and cognitive and academic functioning. When left untreated or treated ineffectively, they can set off a cascade of problems that result in long-term consequences and costs to individuals, families, and society. Even when treatments (whether medication, psychosocial interventions or some combination thereof) are beneficial, it does not mean that all problems in functioning are resolved.

Moreover, as posited by several of the aforementioned leading medical studies and reports on this subject, while we may know *what* to do, that does not necessarily mean that we do it. This is particularly true for low-income children. It should come as no surprise that, as a general matter, children with health insurance get substantially better care—they enjoy better access to behavioral treatments, have better access to appropriate medications, and are more likely to receive care in a "medical home" setting.⁵

However, Medicaid coverage often falls short, especially for children with mental impairments. State Medicaid programs provide incredibly limited coverage of the most effective community-based mental health services for children. Restrictions as to frequency of covered visits and prescriptions can also pose a problem. For instance, a child may receive an initial assessment and diagnosis, but be limited thereafter to follow-

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up therapy visits that are so few and far between as to render treatment ineffective. Likewise, Medicaid coverage rules can prevent a prescription from being refilled as needed in order to adjust and find the right dosage. For all children, whatever health insurance coverage they may have, the profoundly short supply of child mental health specialists (especially child psychiatrists) presents a serious barrier to effective treatment.

In sum, while improvements in diagnosis and treatment of mental health impairments are to be applauded, and mark significant progress on the road to "parity" (between physical and mental health), that alone is not enough. We must also ensure that children have access to effective treatments that will give them the best chance at managing their impairments. What's more, one must take into account the unfortunate fact that for many children, even when the most efficacious treatment is furnished, the improvement that results will be limited to symptom control and some functional improvement, but will not lead the child to no longer be disabled.

SSI is a critical lifeline for low-income families raising children with severe physical and mental impairments. While much is known about what works, in diagnosing and treating children with severe mental impairments, additional study continues to be needed. I would urge the Subcommittee to give serious consideration to commissioning a study by the Institute of Medicine that targets children receiving SSI, to add to what we know about this vulnerable population and how we could more effectively and more efficiently connect children on SSI with appropriate clinical services and treatments. The answer may be improved interagency collaboration and aligned service delivery; IOM would be well situated to study and render recommendations on this point.

2. When you testified before this Subcommittee on February 2, 1995 on proposed changes to the SSI children's program, Subcommittee Chairman Clay Shaw of Florida asked you about one family that was collecting \$47,000 in SSI payments per year for two parents and seven children on SSI, or the equivalent of about \$70,000 today.

Here is how you responded to Chairman Shaw: "We have problems with that, and what we would say is – and we have a long list of reforms that we do not have time to get into, but we would say for very large families there should be some sort of family cap or graduated sliding scale of benefits."

The SSI program has not added a family cap or sliding scale of benefits since then, so each child remains eligible for almost \$700 per month in Federal SSI benefits alone today. Do you continue to support adding a family cap or sliding scale for benefits when multiple children are on SSI, as you did in 1995?

Let me be clear: I do not support a family cap or sliding scale for SSI benefits. My testimony in 1995 referred to a hypothetical family, whose circumstances as described by Chairman Shaw would render it an extreme outlier.

It should be no surprise that some families contain more than one SSI recipient with a disability. Many physical and mental impairments are highly heritable, meaning that shared genetics and environment can increase the likelihood that more than one member of a family will have certain types of disabilities or health impairments.⁶

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Reducing grant amounts paid to families with multiple children with disabilities would be nothing short of devastating to an already struggling group of families and children. Raising even one child with a disability is expensive. Medicaid and private insurance have limited or no coverage of many things that children with disabilities need—such as therapies to help children function in their families, communities and schools; adaptive equipment and devices to help with communication, mobility, eating and breathing; and other material supports.

These high costs lead many families caring for a disabled child to experience serious material hardships such as food insecurity, housing instability, and unmet medical needs. Research shows that families with children with disabilities are more likely to run out of food or skip meals, have their phone service shut off, postpone needed medical care, be unable to pay rent, and have to “double up” with others to prevent homelessness. Over 70% of low-income families that include children with disabilities report facing such material hardships.⁷

Furthermore, the earnings lost when a parent must stay home to care for a child with a severe disability can be significant. For low-income families with a disabled child, SSI can mean the difference between living above or below the poverty line;⁸ being able to provide or going without basic necessities like food; and being able to keep a disabled child at home, or having to put the child in a costly institution to get the care he or she needs.

For families caring for *multiple* children with disabilities, the emotional and financial toll can be magnified considerably. Every child with disabilities has unique needs—such as therapies, medical care, adaptive equipment, medications, and other expenses that may not be covered by health insurance. These sorts of expenses are not shared across multiple children with disabilities. Low-income parents caring for children with disabilities are already hard-hit both financially and emotionally, trying to provide for their children's basic as well as special needs. Reducing the SSI amounts for families with multiple disabled children would only make it harder for these already hard-hit families to care for their children at home instead of in a costly institution. It would also push more already-vulnerable children below the poverty line.

###

As requested by Chairman Davis, I am also including written responses to supplement the oral responses that I was unable to complete during the October 27, 2011, hearing, due to insufficient time.

1. In response to the question posed to Mr. Wittenburg regarding employment and other outcomes of individuals with disabilities who received SSI as children, I stated that it comes as no surprise that individuals with disabilities have difficulty finding and maintaining employment, poor highschool graduation rates, and other disappointing “outcomes.” Mr. Wittenburg testified to poor outcomes of adults who received SSI as children. This statement is both incomplete and misleading.

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as the rates of employment and highschool graduation, etc., for adults with disabilities are low generally—whether or not they received SSI as children. Thus, one must compare the outcomes of individuals with disabilities who received SSI as children with the outcomes of individuals with disabilities generally, in order to isolate whether the receipt of SSI might play any role at all in driving outcomes, good or bad.

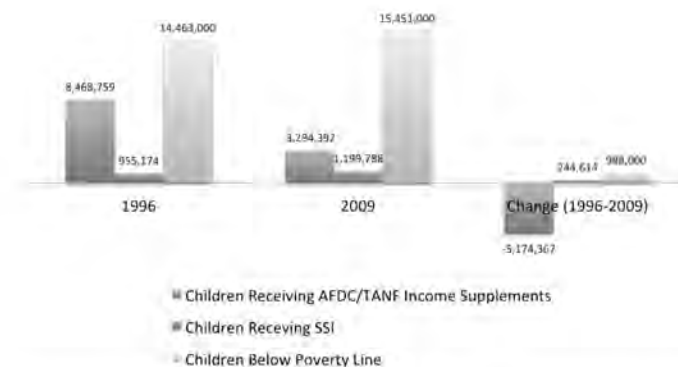
I hope we can all agree on the importance of providing support to individuals with disabilities—children as well as adults—to maximize their likelihood of attaining independence and self-support. There is no question that examining the available data on employment, academic and other outcomes for individuals with disabilities is of great value as we explore how best to support this population. However, we must be clear as we examine those data, not to draw unsupported conclusions. Many individuals with severe disabilities who received SSI as children may have rates of employment, academic success, and other outcome measures, below those of the general “non-disabled” population—but the data reflecting that trend must be compared against individuals with disabilities generally, before we can draw any conclusions about SSI’s role in shaping outcomes.

2. In response to the question posed to me by Ranking Member Doggett regarding what would happen if SSI were to be block-granted, I responded that block-granting SSI would be devastating to countless disabled children and their families. Instituting a block-grant funding structure would result in benefit cuts and children in need having to go without vital assistance. We have seen the result of converting Aid for Families with Dependent Children (AFDC) into Temporary Assistance for Needy Families (TANF), a block-grant funded program. In short, TANF has been largely unresponsive to our nation’s recent rise in poverty during the economic recession; indeed while the number of Americans in poverty climbed from 2006-2008, the TANF caseloads fell dramatically during that period. If SSI is converted to a block-grant program, many children with severe impairments will lose critically needed assistance.⁹

Testimony offered by Mr. Burkhauser and Mr. Wittenberg suggested that SSI provides states with a financial incentive to shift families from their state welfare assistance programs to SSI, and similarly, that it provides families with an incentive to seek SSI over “welfare” for their children because the SSI grant amount is higher. One critical piece of information is missing from this analysis: to qualify for SSI, it is not enough to be poor. One must also have a severe physical or mental impairment or combination of impairments that meets the stringent SSI disability standard. Thus, the alleged potential incentives assumed by Messrs. Burkhauser and Wittenburg (in their written as well and oral testimony) might well explain an increase in *applications* for SSI—but only children who meet the strict disability standard and financial eligibility criteria will receive benefits.

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Indeed, despite concerns around the time of "welfare reform," the increase in the number of children receiving SSI since 1996, when the reforms were implemented, is equal to just one-twentieth of the decline in the number of children receiving AFDC/TANF during that same period.



3. In response to the question posed to me by Ranking Member Doggett regarding "whether medications for disorders like ADHD reduce the likelihood of eligibility for SSI," my time expired after I had the opportunity to say yes, that is correct. To complete my answer to this question, as Mr. Bertoni of the Government Accountability Office (GAO) stated in his "Preliminary Observations" report submitted as written testimony for this hearing, the fact that a child has been prescribed and is taking medications is "just one piece of the puzzle."¹⁰

As any attorney who has represented children in SSI hearings can tell you, a prescription for medications of any kind is just one factor among many considered in determining eligibility, and would never on its own make a child eligible for SSI. Moreover, the SSI children's disability determination process takes into account not just the *fact* of treatment but also the *effects* of treatment.¹¹ Thus, to the extent that any treatment (including psychotropic or other types of medications) improves a child's functioning, the child is evaluated in terms of that improved functioning. Accordingly, putting a child on medication often *lessens* her chances of being found disabled and eligible for SSI.

Recent Social Security Administration data show that taking ADHD-related medications did not increase a child's chances of being found eligible for SSI. An analysis of all applications of children with a primary diagnosis of ADHD in 2010,

Stein, Supplemental Questions on Children's SSI, Nov, 15, 2011

showed that children with ADHD taking related medications were no more likely than those not taking medications to be found medically eligible for SSI. Indeed, the Boston Globe issued a correction on November 6, 2011, after the October 27, 2011, hearing on children's SSI, making clear that their original reporting on this topic was flawed.¹²

¹ Hoagwood et al., Evidence-Based Practice in Child and Adolescent Mental Health Services, *Psychiatric Services*, Sep 2001; 52 (9): 1179-1189, available at <http://ps.psychiatryonline.org/article.aspx?articleid=86400>.

² Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders, Institute of Medicine, "Improving the Quality of Health Care for Mental and Substance-Use Conditions: Quality Chasm Series" (National Academies Press, 2006), available at <http://www.iom.edu/Reports/2005/Improving-the-Quality-of-Health-Care-for-Mental-and-Substance-Use-Conditions-Quality-Chasm-Series.aspx>.

³ Committee on Prevention of Mental Disorders and Substance Abuse Among Children, Youth and Young Adults: Research Advances and Promising Interventions, Board on Children, Youth, and Families, Division of Behavioral and Social Sciences and Education, National Research Council and Institute of Medicine, "Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities" (National Academies Press, 2009), available at <http://www.iom.edu/Reports/2009/Preventing-Mental-Emotional-and-Behavioral-Disorders-Among-Young-People-Progress-and-Possibilities.aspx>.

⁴ Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, U.S. Department of Health and Human Services, "Mental Health: A Report of the Surgeon General" (1999), available at <http://www.surgeongeneral.gov/library/mentalhealth/pdfs/front.pdf>.

⁵ See, e.g., Kaiser Commission on Medicaid and the Uninsured, "The Impact of Medicaid and SCHIP on Low-Income Children's Health," Policy Brief No. 7645-02; see also, Finkelstein et al., "The Oregon Health Insurance Experiment: Evidence from the First Year," NBER Working Paper No. 17190 (July 2011), available at <http://www.nber.org/papers/w17190.pdf> (while this study involves adults, rather than children, the principles involved are the same and the study's results are interpreted by many to reflect the beneficial impact of health insurance through Medicaid on health outcomes, generally).

⁶ See id.

⁷ See, e.g., Susan Parish et al., "Material hardship in U.S. families raising children with disabilities," *Exceptional Children*, 75(1) (2008), at 71.

⁸ Mark G. Duggan & Melissa Schettini Kearney, "The impact of child SSI enrollment on household outcomes," *Journal of Policy Analysis and Management*, 26(4)(2007), at 861.

⁹ Schott, Liz, Center on Budget and Policy Priorities, "Policy Basics: An Introduction to TANF," (Rev. June 2011), available at <http://www.cbpp.org/cms/?fa=view&id=936>.

¹⁰ Bertoni, Daniel, "Supplemental Security Income: Preliminary Observations on Children with Mental Impairments," Testimony Before the Subcommittee on Human Resources, Committee on Ways and Means, House of Representatives (October 27, 2011), at 16.

¹¹ 20 CFR §416.924a(b)(9).

Stein, Supplemental Questions on Children's SSI, Nov, 15, 2011

¹² Boston *Globe*, For the Record (Nov. 6, 2011), available at <http://www.bostonglobe.com/news/nation/2011/11/05/for-record/nrjLTFJoBuOZ5AL2EL62jK/story.html>.

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COMMITTEE ON WAYS AND MEANS
WASHINGTON, DC 20515

SUBCOMMITTEE ON HUMAN RESOURCES

November 1, 2011

Elizabeth Roberts, M.D.
25460 Medical Center Drive
Suite 203
Murrieta, California 92562

Dear Dr. Roberts:

Thank you for testifying at our subcommittee hearing on SSI benefits for children. We appreciated having the benefit of your expertise and on-the-ground experience.

In order to complete the record of the hearing, please respond to the following questions no later than the close of business on Tuesday, November 15, 2011:

1. In your experience, what features in a child's case help determine their eligibility for SSI? What is behind the behaviors that lead parents to promote a psychiatric illness such as ADHD to the evaluating doctor? What causes doctors to sometimes misdiagnose a child?
2. Are SSI payments a factor driving more diagnoses of ADHD and other mental and behavioral disorders in recent years? What should we as policymakers make of all this?
3. In Mr. Stein's testimony on October 27, 2011, he claimed that medical research and "more specific, and precise" diagnoses explain the rapidly rising number of reported cases of Autism, ADHD and speech and language delay among children receiving SSI. In your opinion what is causing this rapidly rising number of children being diagnosed with ADHD and other mental disorders such as Bipolar Disorder and Autism spectrum disorders both in the general public but especially among child SSI recipients?
4. What evidence have you seen that children on SSI are receiving "more specific, and precise" diagnoses and "better-tailored treatment" today, as Mr. Stein contended in his testimony? For example, are more children overcoming their disabilities and leaving the

SSI program as a result of such "better-tailored treatment"? If not, what do we need to do about that?

5. What in your view are the ramifications and consequences for the child whose parent seeks SSI simply because the family needs the extra income and not because the family needs special mental health treatment and educational services for their disabled child?
6. Would you care to comment on the long-term effects on a child's psyche and social functioning, when a child remains on the SSI rolls long after he or she has recovered from the disabling condition simply because a continuing disability review was not completed as required by law?
7. In your opinion, does the legitimate use of the SSI system by some children justify continuing to administer the current program without reforms? Do the benefits for some children justify the risks posed to others if children are wrongly diagnosed and categorized as disabled and possibly mis-prescribed powerful psychotropic medications?

The Committee relies on electronic submissions for printing of the official record. Therefore, please send an electronic submission in Word format to timothy.ford@mail.house.gov. If you have any questions concerning this matter, please feel free to contact Matt Weidinger or Anne DeCesaro of my staff at (202) 225-1025.

Again, many thanks for your excellent testimony. We will continue to be in touch as we have specific questions.

Sincerely,



Geoff Davis

Geoff Davis
 Kentucky Congressman
 Chairman of Subcommittee on Human Resources
 House of Representatives
 Committee on Ways and Means

November 7, 2011

Supplemental Security Income Benefits for Children
 Questions for Child Psychiatrist
 Elizabeth J. Roberts, M.D.

1. **In your experience, what features in a child's case help determine their eligibility for SSI? What is behind the behaviors that lead parents to promote a psychiatric illness such as AD/HD to the evaluating doctor? What causes doctors to sometimes mis-diagnose a child?**

When a child applies for Supplemental Security Income (SSI) based on a mental illness, practice and policy are vastly different in determining eligibility. In spite of the policies outlined in the American Psychiatric Association's (APA) statement to this committee on October 27th 2011, in actual clinical practice, the one most salient feature, and typically the only factor that determines a child's eligibility for SSI benefits, is the doctor's report to the Social Security Administration (SSA). If the doctor's report to the SSA states that the child is functioning at a level significantly below the norm, then his benefits are generally granted. Doctors report to the SSA what the parents report to the doctor during the child's evaluation. Having no other data from which to make a determination about a child's condition, doctors must base their assessment to a large extent on what the parents report. A psychiatrist's encounter with a child during the assessment is usually very brief. When parents exaggerate their child's dysfunction during an SSI assessment, the evaluator can neither substantiate nor refute the claims of the parents. Thus the parent's report of the child's behavior is the primary clinical information that is passed along to the SSA. This is why diagnosing psychiatric illnesses in children is such a subjective process.

For many parents (not all parents) the motivation for seeking a diagnosis of AD/HD for their child is purely for the financial benefits of SSI. Parents have reported to me that SSI benefits are far easier to obtain than welfare benefits. Furthermore, with welfare benefits in most States there is a requirement that parents participate in a vocational training program. Parents have told me they prefer not to work and would rather just get the larger cash benefit provided by SSI, than to have to complete job training. Unfortunately, I have learned through my years of clinical practice, that there is a culture of entitlement in some families, as I am serving third generation SSI beneficiaries.

A doctor's mis-diagnosis of a child in psychiatry happens for a number of reasons. Parents and doctors don't communicate effectively. Doctors use terms that are misunderstood by parents. Parents omit details of their child's symptoms, such as trauma, family crises or drug abuse. In order to qualify for SSI, parents will exaggerated their child's symptoms to portray their child as more mentally ill than the child really is.

2. Are SSI payments a factor in driving more diagnoses of AD/HD and other mental and behavioral disorders in recent years? What should we as policymakers make of all this?

Absolutely, there is no doubt that there is a financial incentive which drives the incredible increase in applications for child SSI benefits based on a mental illness. Regardless of how many claims are denied, the fact remains, that the increase in applications is driven by the desire for money. It is well established amongst those seeking money through the SSI system that mental illness claims are the easiest to get. This perception is rooted in the fact that a psychiatric diagnosis in a child is based on set of behaviors that can be construed in a number of different ways. In other words, the defiant behavior of a belligerent child can easily be portrayed as AD/HD.

A good example of how the SSI payment drives more psychiatric diagnoses in children is the case of a 17 year old High School football player, I will call Joe. Joe's father brought him to me for the treatment of AD/HD. Joe had developed some symptoms of depression after he had broken his arm and was benched for the season. The father, an admitted drug-addict himself, sought amphetamine medications for his son's AD/HD. Although amphetamines are indeed a typical treatment for AD/HD, they are also a controlled and addicting substance. The father also wanted SSI benefits for his son, Joe. The father was very blunt stating that he knew that Joe was NOT disabled, and that his only reason for applying for SSI benefits was because, "The family could use the money." When the SSI benefits were denied, the family never returned for treatment of the Joe's depression or the AD/HD.

3. In Mr. Stein's testimony on October 27, 2011, he claimed that medical research and "more specific, and precise" diagnoses explain the rapidly rising number of reported cases of Autism, AD/HD and speech and language delay in children receiving SSI. In your opinion, what is causing this rapidly rising number of children being diagnosed with AD/HD and other mental disorders such as Bipolar Disorder and Autism spectrum disorders both in the general public but especially among child SSI recipients?

With all due respect to Mr. Stein, an attorney and an SSI advocate, he has only the statements made by administrators and board members of the APA from which to make his claims. Mr. Stein has not completed a degree in medicine, nor has he treated children with psychiatric illness, nor has he completed the evaluation of a child for their SSI benefits. I appreciate his desire to be helpful but he lacks personal experience or clinical insight to make the claims he has made. He is merely repeating what others have said.

For those of us who actually provide psychiatric care for poor families, we have a different explanation for why there has been a rapidly rising number of mental disorders diagnosed in children in the general public and among SSI applicants. The claim that medical research has led to more specific and precise diagnoses completely ignores the clinical realities of how and why children get a psychiatric diagnosis in the first place. I have no doubt that there have been improvements in the tools used to diagnose a child with a mental illness. The problem is that these tools are not often used by the psychiatrists who do most of the SSI evaluations.

The rise of mental disorders among children in the general public is a little more complicated. In a private practice, psychiatrists have to see a certain number of patients every hour to meet the costs of running their clinics and paying their employees. Reimbursement rates from insurance companies are too low to allow for the luxury of lengthy one to two hour evaluation with a child. So, these psychiatrists rush their patients in and out of their offices in 5 to 20 minutes with a diagnosis and a prescription in hand. This has been reported to me by both the families who endure this treatment and the psychiatrists who deliver this kind of service.

Parents play their part as well. Diagnosing a child with a psychiatric illness can meet a number of needs for a family regardless of socioeconomic group. First and foremost, there are, and always have been, a number of children who have legitimate, disabling mental illnesses for which psychiatric treatment is essential, such as Schizophrenia, Autism and many others. However, a psychiatric diagnosis can provide a parent with a rationale for their child's standard, typical poor behavior. The behavior of children who are rude to adults and socially awkward with peers can be explained away with a diagnosis of Asperger's. A defiant, belligerent child who refuses to comply with his teacher's directives can be excused with a diagnosis of AD/HD. And, if a moody, demanding child becomes particularly explosive and throws a tantrum when he doesn't get his way, then a diagnosis of Bipolar Disorder can justify this conduct. Blaming brain chemistry has become an acceptable way for parents to explain away their child's poor behaviors, without having to exam their own failing parenting style.

This in no way means to imply that there are not legitimate cases of psychiatric illnesses in children, of course there are. But, the astronomical rise in the number of psychiatric diagnoses in children in the general public, is better explained, at least to some degree, as the practice of diagnosing a child's every day bad behaviors as a psychiatric illness. On the other hand, for those in a lower socioeconomic group, the diagnosis of a child with a mental illness can be a gateway to financial aid. For these parents, their child's psychiatric diagnosis represents a financial benefit through the SSI program

The vast majority of parents research their child's behavior, before ever visiting a doctor for treatment. Parents search the Internet or ask friends, neighbors and teachers about their child's behaviors before seeking the advice of a doctor. These parents arrive at the doctor's office for their child's first assessment, having already made up their minds about their child's diagnosis. Doctors and therapists know that it is far easier to tell a parent that their child has a chemical imbalance than to tell the parent that they need to change their parenting methods. Accordingly, doctors find themselves agreeing with the diagnosis that the parent provides at the initial assessment rather than argue with the parent.

With or without a mental illness, many psychiatric medications, can improve a child's performance slightly. Though the improvement is minimal, this slight change validates the parent's claim that their child has a mental disorder and justifies the doctor's continued prescribing practice.

4. **What evidence have you seen that children on SSI are receiving "more specific, and precise" diagnoses and "better-tailored treatment" today, as Mr. Stein contended in his testimony? For example, are more children overcoming their disabilities and leaving the SSI program as a result of such "better-tailored treatment"? If not, what do we need to do about that?**

Again, Mr. Stein is not a doctor nor he does not treat children. There is no evidence that he has even encountered the parents whose children have no true mental illness, but who are motivated purely by financial gain, in their pursuit of SSI. Mr. Stein may not be aware that many children, though poorly behaved, do NOT really have a true mental illness, but have nonetheless, been diagnosed with a psychiatric disorder. The child he brought into the hearing room on October 27th 2011 had a physical or neurological illness, a seizure disorder, not a psychiatric illness. My experience in psychiatry is that more often than not, as soon as the poor family receives their check from SSI, they return to our clinic only when absolutely necessary to maintain their benefits. The SSA does not check with the treating psychiatrist for regular updates about the child's compliance with medications or treatment. The families receiving SSI are aware of this lack of supervision by the SSA and know how to meet the minimal requirements to keep the checks coming.

SSI recipients don't receive any "better-tailored treatment" than any other child. In fact, these families often fail to comply with treatment altogether. There is no incentive for a family to end their SSI benefits and therefore no reason for a family to report any improvement in their child's condition. Even when a child does recover from his mental illness, there is no rush to see the doctor for a clean bill of health. These families realize that the child's recovery from the "disabling condition" means that they will lose their benefit check. In the case of Rebecca Riley, described in my written testimony, her parents continued to press Dr. Kifuji to complete the SSI application for Rebecca. In an effort to persuade the doctor that Rebecca was really ill, her parents exaggerated Rebecca's symptoms and kept pushing for ever stronger medication. Oddly, no one else in the family or at the school ever witnessed these symptoms. Rebecca's parents and her two siblings were already receiving four SSI checks amongst the four of them and all based on their psychiatric diagnoses. Tragically, the financial incentive for that fifth SSI check was so powerful that Rebecca's parents kept pushing her medication doses ever higher until they overdosed her and killed her. It is little wonder that the Boston Globe has taken such an interest in the misuse of the SSI program. A child had to die before anyone took notice of what some of us have been warning about for years.

There are many psychiatrists who feel pity for these poor families and will exaggerate the severity of the child's illness or leave out essential features of the child's condition (such as drug addiction) in order to slant the assessment in the favor getting SSI benefits for the family. In the case of Sarah, whom I described in my written testimony, her SSI benefits were reinstated a year later. Because her mother "needed the money to rebuild their burned down home," Sarah was reassigned to a different doctor at that same County clinic. This new psychiatrist was well known for the practice of skewing her reports to the SSA in order to get patients their SSI benefits. This doctor once completed a report for the SSA on a patient she had never met. This doctor merely interviewed the family member who wanted the patient to have a supplemental income source.

5. **What in your view are the ramifications and consequences for the child whose parent seeks SSI simply because the family needs the extra income and not because the family needs special mental health treatment and educational services for their disabled child?**

In the treatment of children with a mental illness, there are no extra costs for "special mental health treatment." These needs are already met through existing programs, such as Medicaid and public schools. Children with mental illnesses need visits with a doctor, medications and special education services. All the care that such a child would need is already provided, at no cost to a poor family, through Medicaid and public schools. But the SSI benefits program has become something else entirely. SSI benefits have become a substitute for a job for many poor parents and their only source of income. Some parents who have become very good at working the system, receive multiple checks for the psychiatric disorders of the various family members, as in the case of Rebecca Riley's family.

When children are incorrectly diagnosed with a mental illness so that their parents can get an SSI check, these children are consequently and needlessly medicated. These medications often have serious, permanent and sometimes deadly side effects. Furthermore, when the SSI system is fraudulently used by some families, other children who really deserve the benefit such as, Will Bentley, may one day find that the funds are exhausted and the program is bankrupt.

6. **Would you care to comment on the long-term effects on the child's psyche and social functioning, when a child remains on the SSI rolls long after he or she has recovered from the disabling condition simply because a continuing disability review was not completed as required by law?**

Children are extremely impressionable and their psyches are deeply impacted by their childhood experiences. If children are falsely led to believe that they are disabled, then they give up on themselves. They come to believe that they are less of a person, unworthy of or incapable of achieving what normal children can. This, in effect, diminishes the child. As adults they carry the self-image of one who cannot provide for himself because he is "disabled." He then becomes a permanent member of the dependent class of citizens who feel entitled to be provided for by government programs their entire lives. When families are acquiring their SSI fraudulently, the child can come to view defrauding the government as justifiable and a clever scam, as Sarah had. The misuse of the SSI system can corrupt a child's incentive to be productive, self-sufficient, independent, self-respecting and law abiding. Disability reviews done at the intervals currently dictated by law are already too infrequent to catch all those who have successfully recovered from their psychiatric illness. Clearly, missing the regular reviews that are required by law, simply exacerbates the problem.

7. **In your opinion, does the legitimate use of the SSI system by some children, justify continuing to administer the current program without reforms? Do the benefits for some children, justify the risks posed to other children who have been wrongly diagnosed and categorized as disabled and possibly mis-prescribed powerful psychotropic medications?**

Clearly, this question answers itself. How can policy makers stand by and watch the destruction of children's lives when they have the power to reform an entitlement program that is hurting so many children. The fact that the Will Bentley's of the world would be inconvenienced by being required to endure a review every year by an independent physician in order to save the lives of the Sarah's and the Rebecca's, seems a small price to pay. Furthermore, the current practice of awarding lawyers a regular portion of a family's SSI check when the attorney sues in court for a

child's SSI benefits, just adds another layer of potential misconduct and abuse of a system already fraught with fraud.

To turn a blind eye to the devastating, and at times deadly unintended consequences of this government behemoth, SSI, is to turn one's back on some children not deemed worthy enough of our concern. I know that your committee, Mr. Chairman, is full of honorable men and women who want to do what is right for children everywhere. Therefore, I implore you to look carefully at what good intentions have wrought.

[Submissions for the Record follow:]

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Statement of

JAMES H. SCULLY, Jr., M.D.
MEDICAL DIRECTOR AND CEO
ON BEHALF OF
THE AMERICAN PSYCHIATRIC ASSOCIATION

For the

House Committee on Ways and Means
Subcommittee on Human Resources

October 27, 2011



The American Psychiatric Association (APA), the medical specialty society representing over 36,000 psychiatric physicians nationwide, appreciates the opportunity to submit the following statement regarding today's hearing on Supplemental Security Income (SSI) Benefits for Children.

The health and well-being of children, particularly those with severe and persistent mental illness, is one of our members' highest priorities. Mental disorders have been estimated by the Surgeon General of the United States to affect up to 20% of children, and severe cases are the leading cause of disability among children. Severe psychiatric disorders in children also bring with them a likelihood of seriously destabilizing effects on family function. Families may experience significant financial hardship due to out-of-pocket treatment costs and necessary specialized services. It is also not uncommon for parents to lose employment or to work fewer hours in order to care for their child suffering from mental illness.

The SSI program acts as a backstop for very low-income families caring for such children, providing a modest benefit that goes toward treatment and support costs as well as lost income. This is why the APA and 80 medical, mental health, and consumer stakeholder organizations have written to Congressional leadership and the Obama administration urging preservation of the SSI program for children with disabling mental illness. While improvements to the SSI eligibility process may be necessary to address program integrity and alleviate concerns over some widely publicized attempts by statistical outliers to take personal advantage of SSI, proposals that limit eligibility and reduce benefits would be harmful to our patient population and ultimately shift costs to other public programs.

Despite media portrayals to the contrary, it is far from easy to gain eligibility to the children's SSI program for mental illness-related disabilities. Diagnoses of mental illness alone are not enough to qualify for SSI; serious functional limitations and severity must be proven from documented medical evidence. The Social Security Administration (SSA) also reviews evidence of the child's activities and functional limitation from home, school, and community settings. Similar to adults with disabling mental illness, co-occurring mental and physical impairments are common in the SSI kids demographic and are taken into account in the SSI eligibility process.

APA is also concerned about the disturbing undercurrent that ADHD diagnoses and typical treatments are scientifically dubious. ADHD is a neurobehavioral condition characterized by excessive restlessness, inattention, distraction, and impulsivity. The disorder can interfere with a child's ability to perform in school and capacity to develop and maintain peer relationships, and markedly increases the chances of school disciplinary problems. Effective treatments are available to help manage the inattention, hyperactivity, and impulsiveness symptoms of ADHD and can improve a person's ability to function at home, at school, and in other places. National Institute of Mental Health research demonstrates that for most young people with ADHD, medication dramatically reduces hyperactivity, improves attention, and increases the ability to get along with others. Only the more severe cases of childhood ADHD causing provable disability qualify for SSI benefits for low income children. Thus ADHD alone is not "easy pathway" to SSI. In fact, nearly 75% of applications citing significant ADHD are denied SSI benefits.

Media portrayals, particularly the *Boston Globe* series highlighted in the hearing advisory, have alleged that medication is an easy pathway to SSI benefits by providing anecdotes of low income parents seeking prescriptions for psychotropic medication, justified or otherwise, in order to gain eligibility to the program. Certainly anecdotal evidence warrants careful review and, where warranted by data, program changes such as more thorough review of applications. As you know, the Government Accountability Office (GAO) is studying the issue for its report that due in the Spring of 2012. Legislation or serious program changes should be avoided until there are full and accurate findings.

Recent data from the SSA has also not corroborated allegations of ADHD abuse. In fact, children with ADHD on medications are no more likely to be eligible for SSI than those who are not. Medication treatment for disorders like ADHD actually reduces the likelihood of eligibility to the program due to the positive treatment effects of the medication, which are taken into consideration in the SSI eligibility process. If there is a pervasive sense among individuals that psychiatric medications are either a prerequisite or easy pathway for SSI eligibility then an education campaign by SSA counteracting these notions may be appropriate.

APA does recognize shortcomings in the program and that improvements can be made. For instance, the law requires SSA to conduct regular reviews of children receiving benefits to determine whether their condition has improved such that they are no longer disabled. These reviews have been found to be extremely cost-effective, with \$10 in federal savings for every \$1 spent on a Continuing Disability Reviews (CDR). However, SSA lacks the resources to conduct these reviews in a timely manner. We strongly support proposals to increase funding for increased CDRs and other program integrity initiatives at SSA. We urge the Members of Congress with interest or jurisdiction to wait for issue of the full report on these matters from the GAO and avoid legislation by anecdote.

The American Psychiatric Association appreciates the opportunity to provide this statement on behalf of the members of the APA. Should you have any questions or need further information, please do not hesitate to contact my staff, Matthew Sturm at (703) 907-7800 or msturm@psych.org.

**Written Statement Submitted to
House Ways and Means Subcommittee on Human Resources**

**Regarding the October 27, 2011, Hearing:
Supplemental Security Income Benefits for Children
with Low-Income and Severe Mental and/or Physical Disabilities**

American Academy of Child and Adolescent Psychiatry
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Mr Chairman and Members of the Committee:

The American Academy of Child and Adolescent Psychiatry (AACAP) is a medical membership association established by child and adolescent psychiatrists in 1953. Now over 8,000 members strong, AACAP is the leading national medical association dedicated to treating and improving the quality of life for the estimated 7-12 million American youth under 18 years of age who are affected by emotional, behavioral, developmental and mental disorders.

I would like to thank the committee for holding this important hearing. Supplemental Security Income (SSI) is a crucial benefit for 1.2 million American children with marked and severe functional limitations. This monthly benefit has provided countless American families with the ability to get their child the treatment they need to become productive members of society who no longer rely on public assistance. All Americans have a vested interest in ensuring the continued success of this program.

Growth of the SSI Program

There has been concern regarding the rate of growth within the SSI program over the last decade, a closer examination of the demographic trends shows that the relative growth in the program has been modest. In the last decade, there has been a 4% increase in child population growth, couple this with a 41% increase in child poverty and the majority of the growth in the SSI program is accounted for.¹ Of all children in America, only 1.6% receives SSI disability support, which equals about 1/10 of children with disabilities across the country.² A majority of children who apply for SSI benefits continue to be turned down, a trend that has been stable throughout the last decade.³

¹ U.S. Census Bureau, "Historical Poverty Tables – People: Table 3," Last accessed October 21, 2011:
<http://www.census.gov/hhes/www/poverty/data/historical/hstpv3.xls>

² Social Security Administration, Annual Statistical Report on The Supplemental Security Income Program, 2009

³ U.S. Government Accountability Office, Supplemental Security Income Preliminary Observation on Children with Mental Impairments 2011

SSI and Psychotropic Medications

There has been great concern that psychotropic medications are being prescribed to children to increase their chances of being approved for SSI benefits. This claim was promoted by a series of articles in the Boston Globe in December of 2010. This claim has been disproven by numerous studies. A recent GAO report cited numerous disability determinations services (DDS) offices who said,

“that when making determinations for children with mental impairments, medication is considered in the context of other sources of information as just one piece of the puzzle. To the extent that medication improves functions some DDS officials told us they could potentially find that the child is not disabled under program rules. Despite this fact... some parents are under the impression that medicating their children will improve their likelihood of being found eligible for benefits.”⁴

As the above GAO report shows, the addition of psychotropic medications does not increase a child's chance of being approved for SSI benefits. Treating a child with medication may reduce their chance of being approved for SSI benefits. As any functional improvement that the medication assists with must be taken into account when determining the eligibility for SSI benefits.

Safeguards Against Corruption

The SSI program has significant safeguards in place to protect the program's integrity and an exemplary performance accountability review (PAR) rate. Prior to receiving SSI benefits, a child must have a medically determinable physical or mental impairment or combination of impairments that result in marked and severe functional limitations. This is determined by first obtaining information from the claimant's treating physician. In the case of a child with mental illness, this physician is often a child and adolescent psychiatrist. The treating source submits reports about the child's impairments including the child's:

- medical history,
- clinical findings,
- laboratory findings,
- diagnosis,
- treatment prescribed with response and prognosis of treatment, and
- a statement providing an opinion about what the claimant can still do despite their impairment(s).

For a child with mental impairments, the statement should describe the child's ability to function independently, appropriately, and in the functional criteria appropriate for the child's age. The treating source is not asked or expected to make a decision on whether the child is disabled. Additional information is received from health care providers, school professionals and other adults caring for the child and includes assessments of the child's functioning in home, school and the community setting over time. The information compiled from the claimant's treatment sources and other information provided by the parents or school system is then evaluated by the DDS. This evaluation is made by a two-person adjudicative team consisting of a medical or psychological consultant and a disability examiner. A comprehensive psychiatric evaluation usually requires several hours to complete and is best performed over multiple sessions.

⁴ Ibid.

In addition to the review process stated above, the Social Security Office of Quality Performance monitors accuracy of initial determination and reports over a 97% net accuracy rate for fiscal year 2009.⁵

In conclusion, the SSI program is a crucial program that helps over 1.2 million poor children with marked and severe functional limitations. While the program itself has been growing in the last decade, the growth is consistent with overall demographic changes (more children and a significant increase in child poverty.) Claims that children are put on psychotropic medications to increase their chances of being accepted into the SSI program do not hold up upon closer examination. The use of medication may even reduce a child's chance of being approved for SSI benefits as any functional improvements that the medication leads to must be taken into account when determining the child's eligibility for SSI benefits. Claims of widespread corruption in the SSI program are also incorrect. However, AACAP recognizes that the SSI program needs to increase the number of continuing disability reviews (CDR) to ensure that children who are no longer eligible for benefits do not continue to receive them. The SSI Office of Quality Performance determined that the SSI program has a 97% net accuracy rate in its initial determinations. We applaud the Congress and the Administration for increasing funding for crucial safeguard mechanisms.

We ask the committee not to rush to make changes to this vital program. Unfounded accusations should not determine the future of the SSI program. Any improvements made to this program should be evidence-based and ensure that we strengthen and not weaken the SSI program. AACAP thanks the committee for their oversight of this vital program.

⁵ Social Security Administration, *Annual Report to Congress of Continuing Disability Review for FY 2009*

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**Comments for the Record
House Ways and Means Committee
Subcommittee on Human Resources**

Hearing on Supplemental Security Income Benefits for Children
Thursday, October 27, 2011, 9:00 AM

By Michael G. Bindner
Center for Fiscal Equity

Chairman Davis and Ranking Member Doggett, thank you for the opportunity to submit comments on these issues. This hearing raises two primary issues, the treatment of young people with learning disabilities and the financial challenges faced by families generally, particularly families in poverty.

Whether educationally disabled youth are over-medicated is to some extent outside of the scope of the Committee on Ways and Means. Generally, it should not be a question for Congress at all, but instead should be debated in the medical community. The governmental response should be centered in the National Institutes of Health and its oversight committees, although the question of appropriate care should be given wide berth by Congress. While treatment of ADHD with nutritional supplements is an interesting field of endeavor, it is not within the purview of this committee.

Secondary to this issue is the role of basic nutrition in learning disabilities. Recent research and common sense both indicate that a diet that is too rich in simple sugars and lacking in protein is likely to aggravate learning disabilities.

Serious attention should be paid to whether federal nutrition aid to both families and schools is more a part of the problem than part of the solution. While high carbohydrate food is cheap, it is likely responsible for both hyperactivity and obesity in America's at risk youth. Reversing bad practice in nutrition is neither cheap nor easy, especially when the role of agricultural subsidies for corn and its associated products, like high fructose corn syrup and import advantages for sugar are brought into the mix. The Agriculture Committees have jurisdiction over these issues and sadly they have been part of the problem rather than part of the solution.

While the Boston Globe article suggests that poor parents are using drug therapy as evidence of disability, the appropriate question is not whether this is an abuse practice, as the state of practice is a medical question. The more appropriate question for this question is much more basic, which is why parents would work so hard to make sure their children qualify for benefits?

The answer to that question is both obvious and uncomfortable. It includes the general approach for delivering these programs through the states and the adequacy of benefits provided from state to state and over time. Furthermore, the multiplicity of programs offered by various committees and agencies yields in consistent results.

The gutting of support for needy families under the auspices of reform has resulted in an epidemic of hunger, which has been made especially difficult during the recent economic downturn. It is no wonder that mothers are gaming the system any way they can.

The fact that it is primarily mothers who must deal with this issue is largely due to requirements which prevent aid to intact families, which is a product of the racism of a prior era that could not fathom providing aid to men, especially African Americans. One would hope that this racism is a thing of the past, however we have our doubts given the state of support for poor families and the level of rhetoric calling for still greater cuts which appears to be driven by more than mere philosophical difference on incentives to self improvement.

We would love to be proven wrong in this area. One way to do this is to use tax policy to provide for adequate incomes for all families.

The United States Department of Agriculture estimates that it should cost \$1,000 per month per child to provide a decent level of subsistence. The federal government could easily guarantee half of this amount using tax reform, with states providing the other half with coordinated tax benefits.

Our proposed tax plan includes expansion of the Child Tax Credit to a refundable \$520 per month per child to be paid out with the wage as an offset to our proposed Net Business Receipts Tax. This tax would function like a Value Added Tax, except that it would be invisible on the receipt, non-refundable at the border and would contain offsets for employers who provide income support to families, health care to employees and retirees and alternative funding for other services now provided by the government, such as elementary and secondary education, remedial literacy for adults, vocational education, mental health services and post-secondary education.

We propose that participants in educational programs targeted at poor families, including secondary education, remedial adult literacy and vocational education, be paid a minimum wage (which would be increased above current levels) and include additional payments of the Child Tax Credit as if they were working in productive employment. This approach is far superior to current programs, especially when such programs push people into work when they are not even literate.

This credit would replace the earned income tax credit, the exemption for children, the current child tax credit, the mortgage interest deduction and the property tax deduction. This will lead employers to decrease base wages generally so that the average family with children and at an average income level would see no change in wage, while wages would go up for lower income families with more children and down for high income earners without children.

This shift in tax benefits is entirely paid for and it would not decrease the support provided in the tax code to the housing sector – although it would change the mix of support provided because the need for larger housing is the largest expense faced by growing families. Indeed, this reform will likely increase support for the housing sector, as there is some doubt in the community of tax analysts as to whether the home mortgage deduction impacted the purchase of housing, including second homes, by wealthier taxpayers.

Likewise, the shift in benefits from categorical and block grant programs to an equal refundable Child Tax Credit will pay for the shift in benefit distribution modalities for families, especially because these families are already eligible for the mix of tax benefits available to workers.

Participants in educational programs should also receive the same level of health insurance as if they were employees of the education provider – thus ending the second class care they receive through the Medicaid program, as well as the need to pay benefits through large, yet underfunded, social welfare bureaucracies at the state level. Public housing should be replaced with residential training programs for both parents and children.

Providing the families of disabled children with the health care services available to workers makes it more likely that health care providers will take the time to consider each case individually, rather than treating them as someone “in the system.” If the subcommittees prefers rehabilitation to permanent disability, it must mainstream medical care and family income levels rather than maintaining income support at what are arguably punitive levels.

Establishing a decent level of income through paid remedial training, increased minimum wages and increased family support through an enhanced refundable child tax credit will also **reduce the need for poor families to resort to abortion services in the event of an unplanned pregnancy.**

Indeed, if state governments were to follow suit in increasing child tax benefits as part of coordinated tax reform, most family planning activities would be to increase, rather than prevent, pregnancy. It is my hope that this fact is not lost on the Pro-Life Community, who should score support for this plan as an essential vote in maintaining a perfect pro-life voter rating.

In the long term, this makes all entitlement services more affordable, as the essential nature of our long-term budget problems are demographic. Providing for more children while giving the poor a way out is the nation’s best long term financial security.

Thank you again for the opportunity to present our comments. We are always available to members, staff and the general public to discuss these issues.

Contact Sheet

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**Hearing on Supplemental Security Income Benefits for Children
Thursday, October 27, 2011, 9:00 AM**

All submissions must include a list of all clients, persons and/or organizations on whose behalf the witness appears:

This testimony is not submitted on behalf of any client, person or organization other than the Center itself, which is so far unfunded by any donations.

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The Diagnosing and Drugging “ADHD” Children—An American Tragedy

by Peter R. Breggin, MD

Psychiatrist, Private Practice, Ithaca, New York

Director, the Center for the Study of Empathic Therapy, Education and Living

The diagnosing of millions of children with ADHD in order to medicate them with stimulants and other psychoactive chemicals is an American tragedy, growing into a worldwide catastrophe. Never before in history has a society attempted to deal with its children by drugging a significant portion of them into conformity while failing to meet their needs in the home, school and society. The ethical scientist or physician, the concerned parent or teacher, must feel stricken with grief and dumbfounded that we have allowed the interests of powerful advocacy groups to completely override the interests of our children.

To make matters worse, on October 16, 2011 the American Academy of Pediatrics overrode the FDA and recommended that children as young as age four be diagnosed with ADHD and given the stimulant methylphenidate (e.g., Ritalin, Metadate, Focalin, Daytrana and Concerta). The scientific literature actually shows that 50% or more of children this young when give Ritalin, Focalin, Dexedrine, Adderall and other stimulants will become obviously depressed, lethargic, weepy--but more manageable. Moreover, it's been proven time and again that the stimulants stunt their growth. In addition studies show that stimulants will permanently change their brain chemistry, cause shrinkage of brain tissue, predispose children to cocaine addiction in young adulthood, stigmatize them with a false diagnosis, and push them toward becoming permanent consumers of psychiatric drugs.

This endorsement of drugging younger children by the American Academy of Pediatrics is an outrage. While focusing on ADHD and stimulants, the endorsement will open the door to every other psychiatric drug. Those weepy children who are having adverse reactions to stimulants will have an antidepressant added to their daily drug dose. When some of them become overstimulated, sedatives will be added to the regimen. When some of them develop drug-induced hallucinations and delusions, or mania, mood

stabilizers and antipsychotics will be added. These new guidelines will encourage prescribers to throw caution to the wind with toddlers, opening a Pandora's box of drug intervention for children. Many young children will have their brains bathed with powerful and often toxic chemicals in the early years of their central nervous system development.

The scientific issues are simple enough. First, ADHD is not a valid medical syndrome. Its three main criteria—hyperactivity, impulsivity and inattention—could never be a valid syndrome. These criteria represent a superficial assessment of external behaviors that tend to disrupt classrooms or require attention at home. The causes of these behaviors are infinite—from boring classrooms and overstressed teachers to chaotic homes and overstressed parents, from children who lack discipline to children with admirable exuberance. Most children who display these behaviors will respond to an educational or home setting where a proper mixture of discipline and nurturing is provided. Others more rarely need special attention to their physical needs because they are malnourished, suffer from head injuries (growing in number from sports concussions), or struggling with a physical illness such as diabetes. Still others are the victims of abuse at home or in school (including the growing problem of bullying). But the vast majority of these children are absolutely normal. All they need is improved adult attention at home and in school.

Second, stimulant drugs simply crush spontaneous behavior. Innumerable scientific studies demonstrate without question that stimulants reduce the self-generated, autonomous behavior of animals and children alike. They also enforce obsessive behavior. The result is a more self-contained and less troublesome child, but the cost is a suppression of the child.

But the potential cost is even greater, since these drugs suppress brain function, cause lasting biochemical imbalances, at times produce atrophy of the brain, and predispose the child to cocaine addiction later in life—all clearly demonstrable in scientific studies (Reviewed in Peter Breggin, *Brain-Disabling Treatments in Psychiatry, Second Edition*, New York: Springer Publishing Company. Chapter 11, "Stimulant-Induced Brain Damage, Brain Dysfunction and Psychiatric Adverse Reactions," 2008).

In short, instead of meeting the normal needs of our children we are suppressing them with drugs. The average parent or teacher, of course, has no idea that what passes for medical treatment is actually a form of medical child abuse. The parent or teacher sees a more manageable child and assumes that this is best for everyone. In reality, the parent and the teacher have been deprived of learning how to assume parental and educational responsibility for the child. And the child is being deprived of the most important learning process of childhood—learning to grow in personal responsibility and self-direction. Instead the child is taught to believe, "I have ADHD" and "I need a pill to help me control myself."

Along with many other concerned scientists, physicians and educators, I have published many books and scientific articles to this subject. The scientific observations in this brief commentary are documented with hundreds of scientific citations in my scientific textbook:

Breggin, Peter. (2008). *Brain-Disabling Treatments in Psychiatry, Second Edition*. New York: Springer Publishing Company.

Chapter 10: From Attention-Deficit/Hyperactivity Disorder (ADHD) to Bipolar Disorders: Diagnosing America's Children, pp. 253-282.

Chapter 11: Stimulant-Induced Brain Damage, Brain Dysfunction and Psychiatric Adverse Reactions, pp. 283-316



**Testimony Submitted to the
House Ways and Means Subcommittee on Human Resources**

**Regarding the October 27, 2011 Hearing:
Supplemental Security Income Benefits for Children
with Low-Income and Severe Mental and/or Physical Disabilities**

**By
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Submitted: November 10, 2011

Introduction

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) appreciates the opportunity to submit written comments regarding the hearing on October 27, 2011 by the Subcommittee on Human Resources on Supplemental Security Income (SSI) for low-income children with severe mental and/or physical disabilities. CHADD is the leading national advocacy and support organization representing people with ADHD and co-existing disorders.

CHADD is a member of the SSI Coalition for Children and Families, which is led by the Judge David L. Bazelon Center for Mental Health Law and comprised of national and grassroots organizations representing children and families with mental and physical disabilities. Over 80 national organizations have signed on to support the SSI Coalition's efforts to preserve SSI for low-income children with disabilities, including those with ADHD.

Background

ADHD is a chronic, neurobiological, highly heritable disorder and is the most common mental health disorder affecting children.^{1,2,3} A recent study by the Centers of Disease Control found that approximately 9.5% of children aged 4-17 have been diagnosed with ADHD, according to parents, although prevalence rates vary depending on diagnostic criteria, information source, age, gender, cultural background, and geographic location.⁴ Symptoms often persist into adulthood, affecting approximately 4 to 5% of adults.^{5,6} Research has linked ADHD to problems in brain development and maturation and specific neurotransmitters that are required for brain cells to communicate efficiently.^{2,7}

Although all children may be inattentive, impulsive, and overactive to some extent at times, a diagnosis of ADHD is only made when the following criteria are met:

- (1) A significant number of symptoms are observed (6 of 9 listed symptoms).
- (2) Symptoms persist for at least six months.
- (3) Symptoms appear before age seven.
- (4) There is significant impairment in a child's ability to function in at least two areas of life.
- (5) Other possible causes are ruled out.⁸

Therefore, a diagnosis of ADHD is made only when symptoms are extreme, pervasive, and persistent and cause significant impairment in daily living at home, at school or work, and/or in the community.

ADHD requires a comprehensive, multimodal approach to treatment, including parent training in the management of ADHD, behavior management techniques, school accommodations and supports, and medication, when appropriate.⁹ Multimodal treatment can be highly effective in decreasing the symptoms of ADHD and improving a child's functioning at home, at school, and in social situations, especially when certain co-existing conditions are present.^{1,2}

Children and teens with ADHD who go untreated are at high risk for school failure and drop-out, social and relationship problems, involvement with juvenile justice, substance abuse, and teen pregnancy.¹⁰ Children with ADHD have double the risk of accidental injuries as their peers,¹¹ and teens have two to four times as many car accidents.¹² In addition, research by the National Institutes of Mental Health (NIMH) indicates that two-thirds of children with ADHD have at least one other co-existing condition, which also may be severe, such as bipolar disorder, depression, anxiety, learning disabilities, and autism spectrum disorders.¹³ When multiple co-existing conditions are present, academic and behavioral problems, as well as emotional issues, may be even more debilitating and warrant more intensive treatments and supports.

Comments

CHADD endorses and supports the testimony submitted to this committee by the Judge David L. Bazelon Center for Mental Health Law and other SSI Coalition partners. In addition, CHADD would like to specifically respond to three areas of concern expressed in the January 14, 2011 letter from Congress to the Government Accountability Office that prompted the request for an examination of SSI regarding children with ADHD and mental impairments.

1. "An increasing share of SSI benefits is provided to families of children with various types of mental impairments," and "the number of children receiving SSI benefits for...ADHD and depression has increased rapidly."

As the GAO testimony to this committee indicated, it is true that the number of children applying for and receiving SSI for mental impairment, including ADHD, has increased over the past decade. However, as the GAO found, the growth in beneficiaries remains proportionate to the growth in applicants, and the majority of applicants with

ADHD as a primary diagnosis are denied SSI benefits. According to the GAO testimony and data from the Social Security Administration,¹⁴ the growth in the mental impairments category in recent years is due mainly to legal and policy developments that expanded eligibility for children with mental impairments and redefined diagnostic categories and not to unethical or illegal actions by families.

ADHD does represent the largest group within the SSI category of Other Mental Disorders, but this is to be expected, since ADHD is the most common mental disorder in children. As previously stated in this testimony, the percentage of children diagnosed with ADHD has also increased in recent decades to approximately 9.5% of children aged 4-17, based on parent reports. However, only 4% of those children diagnosed with ADHD--the most severely impaired and lowest income children--qualify for SSI.¹⁵ The GAO reports that the majority of applicants with ADHD as a primary diagnosis, over 72%, are denied benefits, putting children with ADHD in the bottom quartile of approval rates. Furthermore, Social Security examiners told GAO interviewers that children rarely qualify for SSI based on ADHD alone; rather, most children with ADHD approved for SSI have other conditions in addition to ADHD, which compound problems and further impair functioning.¹⁶

2. "...The number of children prescribed drugs to treat ADHD...has dramatically increased....Some families, in an effort to make their children eligible for SSI benefits and increase their household income, have resorted to medicating their children with powerful psychotropic drugs."

Medication has been shown consistently by research to be a safe, effective treatment for ADHD, and the practice parameters and guidelines of major medical organizations, including the American Academy of Pediatrics and the American Academy of Child and Adolescent Psychiatry, support the use of medication for severe ADHD in children and adolescents.^{1,17} Therefore, it would be reasonable to assume that the majority of children seen by a doctor for severe ADHD would appropriately be prescribed medication.

Stimulants are the most studied and widely used medications for ADHD, though several non-stimulant medications also appear to be effective for the management of ADHD symptoms.^{1,17,18} Although the number of children taking ADHD medications has increased over recent years, research by the CDC also shows that many children with ADHD who might benefit from these medications are not taking them, so that under-treatment of ADHD remains a problem.⁴

It also must be noted that ADHD medications are prescribed by licensed medical professionals based on professional standards of assessment, diagnosis, and treatment and are not available for families to purchase over-the-counter, so the suggestion that children are frequently and wrongly given powerful drugs to obtain SSI and increase family income does not just cast aspersions on families but also implies collusion in fraud and/or malpractice by the medical profession. However, a prescription for medication alone, including medication for ADHD, does not qualify a child for SSI benefits. The GAO testimony to this committee reports that Social Security Administration looks at multiple

sources of information in assessing a child's impairment and determining medical eligibility, including medical records, school records, and parent and teacher assessments. In fact, the data show that children taking ADHD medications are just as likely to be denied SSI as they are to be found eligible for SSI.¹⁹ According to GAO testimony, the Social Security Administration considers the child's functioning while taking ADHD medication, and if medication reduces the severity of symptoms and improves the child's functioning, the child will be less likely to qualify for SSI.

3. "Such trends raise numerous concerns, including...the extent to which SSA properly monitors the initial and continued eligibility of children with mental impairments, and the implications of placing children on the disability rolls for extended periods of time."

Research shows ADHD to be a chronic, lifespan disorder for many individuals.¹² Approximately 60% of children with ADHD will continue to have ADHD symptoms as adults, with accompanying problems of low educational attainment, low college attendance and completion, low job retention and performance, lower socioeconomic status, higher rates of tobacco use and substance abuse, more motor vehicle violations, higher divorce rates, more dependence on social services, more involvement with the justice system, and shortened life expectancy.^{12,20,21} While the goal of treatment in childhood is to improve functioning, prevent or reduce future negative outcomes, and promote self-sufficiency in adulthood, the awareness of the potential for continued negative outcomes points to the importance of maintaining adequate and appropriate services to support a child's successful transition to productive adulthood.

Recommendations

CHADD endorses and supports recommendations set forth in the testimony of the Bazelon Center and other SSI Coalition partners and suggestions for improving SSI, such as supporting transition-age youth in employment, helping families to access services, increasing funds for continuing disability reviews, and authorizing and funding an IOM study of children's SSI. In summary, CHADD would like to reiterate the following points:

- **Investing in SSI for children with ADHD and mental impairments is smart policy.** Investing in children's SSI can prevent or reduce greater demands and dependence on federal and state services in the future, reduce stress on struggling families, and improve child and family functioning and well-being. Because ADHD can be a lifelong disorder, early diagnosis and appropriate treatment and supports can be essential to helping children and teens with ADHD achieve self-sufficiency and avoid progressing to disability status as adults. SSI can make a difference by providing low-income children access to treatment and services that are critical for preventing negative outcomes and promoting success in school and work, so that children with disabilities can become productive, contributing members of society. Children's SSI can also support the employment of adult family members by improving a child's functioning so that family members miss fewer days of work to care for their child and by making it possible for families to afford daycare or after-school care.

- **The budget should not be balanced on the backs of the neediest and most vulnerable children.** Children's SSI provides access to critical treatment and support that benefit not only children and their families but, ultimately, all of society. Caring for a child with disabilities can be emotionally and financially draining for any family, but families with inadequate financial resources can experience significant stress and extreme financial hardship in obtaining the most basic services for their children. Families of children with severe ADHD who receive SSI report to CHADD that SSI has been a godsend, paying for essential services such as medical treatment, counseling, tutoring, transportation to appointments, and specialized daycare so that parents can go to work—all of which were previously unaffordable for them. Budget-cutting measures such as reducing SSI funding, further narrowing eligibility criteria, or making the program a block grant would needlessly burden and harm children with disabilities and their families and could instead increase public costs related to child welfare, public safety, healthcare, juvenile justice, institutional care, unemployment compensation, and adult disability payments.
- **CHADD urges the committee not to reduce support for this vital program.** While CHADD does not condone fraud or abuse and was equally disturbed as members of Congress by allegations in the *Boston Globe* series, particularly those concerning ADHD and ADHD medications, anecdotes and unsubstantiated claims should not be used to make policy and determine Congressional action. Any reforms to the SSI program must be based on facts to ensure the best possible outcomes for this most vulnerable population and for society as a whole.

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Rep. Dave Camp, Chairman of the Committee on Ways and Means
Rep. Geoff Davis, Chairman of the Subcommittee on Human Resources
Members of the Subcommittee on Human Resources
Ways and Means Committee Office
1102 Longworth House Office Building
Washington D.C. 20515

November 10, 2011

Dear Chairman Camp, Chairman Davis, and Members of the Subcommittee on Human Resources:

During the October 27th hearings, your Subcommittee heard accounts of fraud and misuse by SSI beneficiaries and their families, and poor policy implementation by the Social Security Administration (SSA). What was not emphasized was the critical need for comprehensive and integrated services vital to children who have profound and severe disabilities. In this context, I am writing to highlight the distinction between children who have moderate disabilities, such as those described in the *Boston Globe* series, compared to children who have profound intellectual disabilities and severe and persistent mental illnesses. While the *Boston Globe* articles and the October 27th testimony provided to your Subcommittee emphasized the need for accountability and reform, these suggestions were painted with a broad brush. They did not address the importance of developing policy and practice reforms effective at encompassing the diverse levels of services and support needed by a diverse society.

I am the Co-chair of the Clients Rights Committee for FACT Specialized Services, a residential program in North Carolina providing intensive treatment for children dually diagnosed with severe and persistent mental illness and cognitive impairments. As part of its work, the Client Rights Committee regularly interviews parents and guardians of FACT clients to monitor the effectiveness of FACT's client rights policies and practices for those it serves. Repeatedly, the Committee has been presented with horror stories of what these complicated children experienced when they did not receive the intensive therapy and treatment they required, as well as the dramatic positive changes their families observed once these same children were finally provided appropriate treatment.

There are many success stories – Here are two: Once intensive and appropriate care was provided, "John" stopped bouncing through multiple psychiatric hospitalizations and is now successfully living at home, has a part-time job, and is on track for high school graduation. "Pamela," a child dually diagnosed with autism and severe psychiatric illnesses was able to return home and has made the honor roll at school. The success of these children and others is not accidental. Success was possible because of access to appropriate intensive treatment available via SSI funding and Medicaid services.

Unlike the misguided parents of children who have relatively manageable disabilities, and who seek financial stability via their children's SSI payments, most parents who have children with complex cognitive disabilities and mental illnesses would be completely unable to provide the array of services needed by their children without SSI funding and Medicaid services. This is doubly true for parents of children dually diagnosed with both profound intellectual disabilities, and severe and persistent mental illness. In North Carolina, for example, the Day Treatment Program, a Medicaid service used by children whose psychiatric illnesses are so severe as to preclude inclusion in public school classroom, is funded at \$31.41/hour. That's over \$180 per 6-hour school day; a fee unreachable by the vast majority of parents, poor or otherwise. While this intensive service is costly, the success of many FACT clients is due, in part, to its efficacy. In the long run, the Day Treatment Program pays off financially, as its graduates gain psychiatric stability, as well as the necessary behavioral skills to live successful, more independent lives. This clearly is a better outcome for everyone than having children with severe psychiatric illnesses veer from place to place on an expensive and ineffective psychiatric hospital treadmill. This thoughtful approach to Medicaid services can be seen in a variety of effective and evidence-based programs across the country. In fact, SAMHSA has defined specific evidence-based practices, which can aid states in the development of meaningful Medicaid services.

The statistics and incidents reported by the U.S. Government Accountability Office and the experts testifying before this Subcommittee show that misuse of SSI funds, along with decreasing oversight by the Social Security Administration, has generated consequences unintended by those who designed SSI and Medicaid programs. And, while a categorical discontinuance of these funds and services would be catastrophic for children with severe and profound disabilities, it may be less obvious that a one-size-fits-all reform plan could be just as disastrous.

When Dr. Burkhauser testified to this Subcommittee, he pointed out that adolescents receiving SSI sometimes identify these funds as "income maintenance," so lose incentive to remain in school or obtain employment. According to the reported accounts, some parents encourage this SSI "income maintenance" approach, as SSI funding avoids the limitations of AFDC/TANF funds. One solution suggested to the Subcommittee is that SSI funding be tied to school attendance or employment. While such an incentive program might prove beneficial for adolescents with diagnoses of ADHD or language delays, who are capable of functioning in school or on the job, this "incentive" becomes the door to disaster for adolescents who have profound intellectual disabilities and severe psychiatric disorders. It is hard to imagine that a rational response to an actively psychotic adolescent with an IQ of 65 (some persons do not respond to currently available psychotropic medications) would be to remove all services because that teen is unable to attend public school or participate in full-time employment.

My recommendation to this Subcommittee is that it consider the proposed reform measures thoughtfully and carefully. Members of the disability community have strengths and challenges as varied as do members of the larger community. To be

effective, federally funded infrastructure and treatment must be tailored to meet this diversity of need. We know from experience that one size does not fit all, and when this poor approach is taken to develop public policy, the results are anemic programs that bleed shattered lives and wasted funds. Children with severe and profound disabilities can participate as productive members of the community, and often require significant infrastructure and treatment to do so. Those with less complex disabilities may be better served by a completely different approach. And while the percentage of children with dual diagnoses or profound disabilities may be small, lack of meaningful treatment and infrastructure for them results in dismal outcomes for themselves and their families, and expensive "fixes." This Subcommittee has seen the negative result of unintended consequences forged by a one-size-fits-all approach used with prior reform measures. Thoughtful reform will carefully identify children with complex severe disabilities. Effective and meaningful reform will take their needs into consideration when designing solutions to the current SSI and Medicaid policy and practice failures, which will result in a better solution for us all.

Sincerely,

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Statement for the Record

By, Shadi Houshyar, Vice President for Child Welfare Policy

House Committee on Ways and Means Subcommittee on Human Resources

Supplemental Security Income (SSI) Benefits for Children with Low-Income and Severe Mental and/or Physical Disabilities

Thursday, October 27, 2011

Chairman Davis, Ranking Member Doggett and members of the House of Representatives Committee on Ways and Means, Subcommittee on Human Resources, thank you for this opportunity to submit a statement for the record regarding the October 27, 2011 hearing on “*Supplemental Security Income Benefits for Children with Disabilities*.”

First Focus is a bipartisan advocacy organization committed to making children and their families a priority in federal policy and budget decisions. Our organization is dedicated to ensuring the health and well-being of our nation's children, especially those who suffer from severe and chronic mental and physical disabilities. We are especially concerned with preserving the federal safety nets and supports for low income families to ensure that they have the resources they need to properly care for a special needs child. On behalf of First Focus, and as a member of the Supplemental Security Income (SSI) Coalition for Children and Families, I appreciate the opportunity to testify about the importance of this program to so many needy families.

Throughout history, children with disabilities have been stigmatized, and families were often expected to place their children into institutions. Community programs and supports slowly developed as an alternative to institutionalization, allowing these children to remain with their families. While these programs were a life-changing development for many families with special needs kids, they came at a great cost, with many treatments and resources remaining out of the reach of low-income families.

Since its creation in 1972, the Children's SSI program has served as a critical lifeline for low income families of children with special needs. The program provides modest monthly payments—on average \$593—to help replace some of the lost income many families experience when they are forced to reduce work hours to care for their severely disabled child. Even this small amount has allowed low income families to give their children with severe disabilities the care and attention their child requires; care and attention they could not otherwise afford to provide.

Proposals to cut the program, toughen standards of eligibility, or turn SSI into a block grant program, would have disastrous consequences for the thousands of children and families who have depended on SSI, and would risk growing costs in other areas such as child welfare, juvenile justice, and other publicly funded programs. Thus, SSI is a



sound public policy, preventing many families from falling into poverty as a result of the devastating costs associated with a disability diagnosis in addition to keeping children out of publicly funded institutions.

While the SSI program has slowly grown over the last 30 years, this growth is due to the confluence of several external factors impacting the overall pool of eligible children. First, not only has the child population grown as whole, but the number of children living in poverty has also increased from 16.4% in 1974, to 22% of all children in 2010. Despite this growth in child population and increase in child poverty, the proportion of poor children who are on SSI has remained steady for more than a decade (7.52% in 2001 vs. 7.56% in 2010). Moreover, only 1.6% of all children are on SSI, or about one-tenth of all disabled children.

In addition to a growth in the overall child poverty population, the Children's Health Insurance Program (CHIP) has dramatically increased the number of children with access to health care. CHIP has increased child Medicaid enrollment from 22 million in 1998 to 32 million in 2008. This rise in Medicaid enrollment has led to a corresponding rise in access to services and a dramatic jump in the number of children who receive services through the Early Periodic Screening Diagnosis and Treatment program. This rise in participation in screening programs has understandably increased the number of children who are identified as having a disability or impairment.

Moreover, the SSI mental impairments category, a critical part of the SSI program, has remained relatively unchanged over the last 20 years, with the proportion of children eligible for SSI as a result of mental impairments remaining at a constant 66% since 1994. However, as the field has evolved, and diagnostic methods have become increasingly sophisticated, the categories of impairment have expanded and shifted to reflect these changes. Where practitioners would simply use the label "mental retardation" to encompass the universe of mental impairments, more tailored and specific categories of diagnosis have emerged. This shift in the field has led to a more diverse diagnostic breakdown in the SSI program, and more precise diagnoses of Autism, Attention Deficit and Hyperactivity Disorder (ADHD), etc. have replaced the inadequate and outdated mental retardation diagnosis.

The SSI program has extremely stringent standards for eligibility. Only the most severely disabled and poorest children will qualify for the program. The review process is extremely thorough and requires extensive review of medical, school and caregiver records, as well as in person assessments of the child's functioning in their various settings over time. A child must have a medically diagnosable physical or mental impairment, and that impairment must severely interfere with their ability to function. In addition to these rigorous eligibility standards, caregivers must continuously account for their use of SSI funds, and children are subject to Continuing Disability Reviews (CDRs) every 3 years to determine any improvement in condition. Moreover, use of medication does not improve a child's chances of qualifying for the program, and in fact may hinder their chances as medication will improve a child's condition. For example, a recent study of children with ADHD by the Social Security Administration (SSA) found

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that children taking medication were no more likely than their un-medicated counterparts to be found eligible for benefits.

While the SSI program is a desperately needed resource for this country's neediest families, there is definite room for improvement. SSI can be strengthened through enhanced employment opportunities. As it currently stands, the program does offer generous benefits to children who are willing and able to work. As a survey recently revealed, however, just 22% of children on SSI were aware that these incentives existed. The program could improve the employment outcomes of these youth by enhancing their outreach and education efforts on available programs, leading to greater awareness. Moreover, increased funding to improve the provision of continued disability reviews would ensure the integrity of the SSI program by increasing the regularity of reviews. Currently, the program is underfunded and understaffed, preventing regular screening of program participants, allowing individuals who would no longer qualify for benefits to remain on the program. In addition to enhancing the program's integrity, more frequent reviews would prevent unjustified termination of benefits when children are not given their full medical reviews. When adequate funding was provided to conduct CDRs - between 1996-2002 -SSA was current in completing the CDRs as required by law. Once funding was reduced, however, SSA fell behind in their reviews, creating a significant backlog.

In closing, Mr. Chairman and members of the committee, First Focus stands prepared to work with you to ensure that the committee understands the vital role this program plays in the lives of so many of our nation's children. We urge the committee to make only considered, evidence-based reforms that will strengthen and preserve the SSI program so that these children can achieve the best possible outcomes. If you have any additional questions, please contact Shadi Houshyar, VP for child welfare policy at First Focus, at (202) 657-0678.

Hello. My name is Gena Pontious. I am Samuel Madonia's mother. Samuel and I are both title 19. We both are on SSI. I have another son Robert Madonia whom I have applied for SSI and is now pending. I was just recently married to Sheldon Pontious whom is not the father to my two oldest sons. Social Security is now cutting not just my SSI but my sons also due to my husband little bit of income that barely holds us above water. With my sons diagnoses, Social Security should know that these children have raging fits and destroy things(clothes, furniture, house products, toys, ECT....) This tends to get very expensive for us financially. I believe that these circumstances should be taken into consideration when calculating our expenses and income. The food prices are going up and Samuel eats equal amounts to the rest of our family (total of 5) being that he is a teenager, and is very picky as to what he eats at that! My husband is killing himself with overtime to make up for the cuts in SSI just for the Social security to cut it even more. I have already stated that I am also on SSI and I am still considering getting a job, however, I can't find daycare for a 14 year old and a 7 year old who destroys things and need to be watch more carefully than centers are capable of. Sometime people's hands are tied and we just need a little more help. I hope that this information is helpful to your cause.

Sincerely,

Gena Pontious

—



November 10, 2011

The Honorable Geoff Davis
Chairman
Subcommittee on Human Resources
Committee on Ways and Means
U.S. House of Representatives
Washington, D.C. 20510

The Honorable Lloyd Doggett
Ranking Member
Subcommittee on Human Resources
Committee on Ways and Means
U.S. House of Representatives
Washington, D.C. 20510

Re: Hearing on Supplemental Security Income Benefits for Children," Oct 27, 2011

Dear Chairman Davis and Ranking Member Doggett:

Thank you for the opportunity to submit a written statement following the October 27, 2011 subcommittee hearing on the children's SSI program.

Greater Boston Legal Services (GBLS) is a non-profit corporation that provides civil legal services to eligible low income clients in 33 cities and towns in eastern Massachusetts. The help it offers ranges from legal advice to full case representation, depending on client need. As part of its mission, GBLS, through its Disability Benefits Project, has represented children with severe disabilities since 1982. In 2007, the Children's Disability Project (CDP) was founded to offer more specialized representation to children in need of these benefits. CDP now assists vulnerable low income families at all levels of the SSI appeals process. CDP works closely with doctors, therapists, and teachers to present the full picture of a child's disabilities to the Social Security Administration. CDP's dedication to our young, vulnerable clients and skilled legal advocacy has garnered local and national recognition. CDP also works with *pro bono* counsel on these cases.

The Disability Law Center (DLC) is the Protection and Advocacy agency for Massachusetts. DLC is a private nonprofit entity that provides free legal assistance to individuals with disabilities throughout Massachusetts. A key mission of the DLC is to help ensure that people with disabilities are able to access the items and services they need to live and work in the community. Access to cash disability benefits and the associated medical coverage is crucial for many to achieve this goal - whether the benefits are needed for a year or longer term or episodically. Since 1983, the Disability Benefits Project (DBP) at the Disability Law

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Center has provided technical back up and support to legal services advocates and private attorneys who represent individuals before the Social Security Administration (SSA). DBP supports high quality representation and advocacy for those seeking Social Security and SSI benefits.

The SSI program is a critical lifeline for the families of our young clients. As *The Boston Globe* reported yesterday, “[p]overty has deepened in Boston’s poorest neighborhoods, widening the gap between the city’s wealthiest and neediest residents,” citing a just released report. The study points to concentrated need in Dorchester, Mattapan, and Roxbury (Greater Boston neighborhoods), where 42 percent of children live in poverty, the densest cluster of childhood poverty in the state, according to the study sponsored by the Boston Foundation.”¹ Families caring for severely disabled children are at greater risk for poverty and privation.² This is what the low income families and children with disabilities served by GBLS face. Our advocacy helps families care for their children with severe disabilities at home. The SSI benefit is low but time and again we have seen that it can make a crucial difference.³

“Michael” is a twelve year old child who has been medically diagnosed as having Attention Deficit Hyperactive Disorder (ADHD), Anxiety Disorder, and a learning disability. His claim for SSI benefits was only approved after an in-person hearing with an administrative law judge. The independent medical advisor present at the hearing found that Michael’s combination of impairments functionally equaled listing level impairments. Michael and his twin brother are being raised by their elderly grandmother, who adopted them after their mother died of cervical cancer. They were born prematurely and Michael’s birth weight was under five pounds.

Throughout his young life, Michael has received services to help him develop and function. His grandmother has worked hard to see that he gets what help he needs. Some services he has received include: Early Intervention, therapeutic treatment, and medication. At school, Michael is in a substantially separate Supportive Academic Remediation (SAR) classroom. He is also helped at the School Achievement Clinic (SAC) at Boston Medical Center. SSI benefits have improved the quality of Michael’s life. According to his grandmother, who is on a fixed income, the first thing that they did with the SSI benefits was to pay off the balance owed on a bed for Michael that she had placed on lay-away. Michael had been sharing a small bed with his twin brother because his bed was broken. Michael’s grandmother does not drive and uses only public transportation to get to all of his medical and school appointments. They have used the SSI benefits for transportation. This eases the worry about travel expenses versus food and clothing. She also uses some of the SSI to pay for Michael’s portion of the household expenses for food and rent. Michael’s grandmother has said: “Without SSI benefits I don’t know how we would have survived.” GBLS has let the family know that when Michael is

¹ “Poverty’s Grip Tightens in Boston; Study Says”, by Meghan Irons, p.1 *The Boston Globe*, November 9, 2011.
<http://www.bostonglobe.com/metro/2011/11/09/poverty-grip-tightens-boston-study-says/pl/XWRN2DkeJg1TE73IG8mM/story.html>

² Susan Parish et al., 2008. “Material hardship in U.S. families raising children with disabilities.”

³ Most families are below the poverty line without the SSI payment, but above the line with it. Off the Charts blog, CBPP, October 26, 2011:
<http://www.offthechartsblog.org/ssi-benefits-vital-to-severely-disabled-children-and-their-families>

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older, he may be able to use the work incentives available to students to help with the transition from school to work.

As noted by the Bazelon Center in its testimony submitted to this Subcommittee on November 3, 2011, "[m]ental impairments are rightly the basis of a large number of SSI claims, consistent with findings that mental disorders are the leading cause of disability in children and that severe psychiatric disorders have some of the worst outcomes with regard to school completion rates and life-long health and economic status." Testimony at 3. Our client "Robert" and his mother illustrate what this means in real life. Robert's mother has been in and out of the work force, depending on the severity of Robert's needs. Now 16, Robert has struggled his whole life. He lives with his mother, and his father is banned from seeing them by a permanent restraining order due to incidents of domestic violence towards his mother. Robert was not the target of this violence but he witnessed it many times. Robert's mother has described him as sad almost all of the time. When he is sad, he won't eat, won't talk, loses sleep, is very pessimistic and has difficulty expressing his anger. He has often said that he wished he was not alive, expressing suicidal ideation every time he is upset. He will stay in his room and cry. Robert has had several psychological evaluations. He has been diagnosed as having Bipolar Disorder and Major Depression.

A major stressor for Robert is in school where there is a climate of bullying. Robert reacts to the bullying by being physically aggressive and the school has had a difficult time dealing with his behavior. Robert says: "If I get called a name, I get so aggravated, I can't control it. I just snap." A discipline record of October, 2007 to June 2008 reveals that Robert had detention or was warned or suspended 21 times. Finally, he was removed from school in April 2008 to be tutored at home. Robert's mother had a job with the school system which she had to leave because she now had to supervise and care for Robert at home. Over the years she has been employed on and off, depending on Robert's condition. At present, Robert is awaiting a 45 day evaluation in order to determine what kind of academic setting is best suited for him. His mother hopes that she can soon work again.

Over the years, Robert's treating sources have searched for treatments to help him, trying different medications sometimes with disastrous results. Originally, he was on Abilify where he had cognitive blackouts. The Risperal gave him hallucinations. He was then started on Lamictal, taken in association with Lithium. Lithium made him angry, so he began a treatment of Lamictal solely, with good results. Later, Robert was put on a generic form of Lamictal where he suffered side-effects of vertigo, dizziness and visual and tactile hallucinations. He had to stay out of school for a week for the medications to be out of his system. Robert's mother wishes there other treatment options for her son but does not know what else to do. "I wish we never had to place him on medication because of the bad side effects on my child."

Robert came to Greater Boston Legal Services four years ago for help with his SSI appeal. His mother has used the benefits for Robert in a variety of ways. For example, when Robert suffered from vertigo he had appointments at Children's Hospital Boston twice per week. The cost of parking, tolls, and gas quickly consumed the family budget. She also uses some of

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Robert's SSI to cover his portion of the household expenses for food and rent. Robert's mother has struggled for years to find a stable school placement for him. He has gone from public school to private school to home tutoring. His challenging behaviors in a school setting make it difficult to find the best setting for him. At present he is in a forty five day evaluation to determine what academic placement will best suit his needs. Robert's mother is hopeful that she can one day return to work full-time. According to Robert's mother: "If we did not have Robert's SSI, we would be homeless because I can't meet his needs on my own." Once he is settled in a school setting, GBLS will refer Robert to the local Work Incentive Planning and Assistance (WIPA) program for help understanding how he can use the SSI work incentives in his transition from school to work.

The SSI work incentives available to low income young adults with severe disabilities can be crucial in making a transition from school to self-sustaining work. "Jean" is a 20 year old diagnosed with a psychiatric disorder and learning disabilities who has a dream of working in criminal justice. As her condition is characterized with ups and downs, she will need a job with some accommodations in order to be self sustaining and will need education to get the type of job where these accommodations and health insurance are available. Luckily, Jean learned about the WIPA program and has been working with a WIPA Community Work Incentive Coordinator (CWIC) who told her about the SSI work incentives she can use, including the Student Earned Income Exclusion (SEIE) and the Plan to Achieve Self Support (PASS). Using these work incentives, Jean has been able to work part-time and retain necessary SSI and Medicaid coverage while attending college at her own speed. She is looking forward to completing her education and moving into a career.

Recommendations

We concur in the testimony and recommendations submitted by the Bazelon Center for Mental Health Law, and by Community Legal Services. We support Representative Richard Neal (D-MA) and SSA Commissioner Michael Astrue in their call for a study by the Institute of Medicine (IOM) concerning this program. Any changes made to this vital program must be evidence based. We support the effort by Congress to add funds to the SSA budget in order for the agency to be able to meet its statutory mandate to perform timely Continuing Disability Reviews (CDRs) on children. Unless funded, SSA cannot meet this mandate, which is a cost-effective way to maintain program integrity. We enthusiastically support all efforts to inform youth of the substantial work incentive programs that are available to them under the SSI program, as well as improvements to those programs. Finally, we oppose any effort to block grant the SSI program. Block granting SSI would cause countless children with severe disabilities to lose the benefits they need to be able to remain in the community with their families, and would result in escalating public costs in child welfare, public safety, juvenile justice and public-funded institutional care.

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Thank you for the opportunity to submit these comments.

Very truly yours,

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Testimony Submitted to:
House Ways and Means Subcommittee on Human Resources

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Re: Hearing on Supplemental Security Income Benefits for Children (October 27, 2011)

Submitted: November 10, 2011

Thank you for the opportunity to submit written testimony regarding the October 27, 2011 Subcommittee on Human Resources hearing on Supplemental Security Income (SSI) for low-income children with severe mental and/or physical disabilities.

The National Health Care for the Homeless Council is a membership organization comprised of providers and consumers from organizations providing health care services to people experiencing homelessness. We are the primary voice for Federally Qualified Health Centers (FQHCs) receiving Health Care for the Homeless (HCH) grants through the Health Services and Resource Administration (HRSA). Last year, FQHCs served nearly one million people experiencing homelessness.

The SSI Task Force of the National Health Care for the Homeless Council is comprised of representatives of numerous organizations who assist individuals experiencing homelessness with SSI/SSDI applications. Our group attempts to eliminate systemic barriers to accessing benefits for people who have a disability and are concurrently experiencing homelessness.

The recent three-part series by the Boston Globe highlighted examples of youth who face challenges to transitioning out of the SSI program. Unfortunately, the series did not paint a full picture of the obstacles that SSI beneficiaries face when attempting to become more self-sufficient. We hope that our written testimony will provide a fuller picture of the social and systemic challenges to self-sufficiency for individuals who are disabled and living in economic hardship.

Past efforts to improve self-sufficiency for child SSI recipients transitioning into adulthood

Studies looking at the transition to adulthood among child SSI recipients find great challenges to long-term self-sufficiency. In addition to health factors that limit substantial gainful activity, non-health factors, particularly education, employment, and social indicators play an important role in the probability of a child SSI recipient being on adult SSI after age 18.¹ This is not new knowledge. Indeed, the Social Security Administration has implemented a number of major demonstration programs over the last two decades to address these challenges. The Transitional Employment Training Demonstration ran from 1985-1987 and attempted to provide time-limited job placement services and on-the-job training to SSI recipients ages 18 to 40 with intellectual disability. Project Network ran from 1992-1994 and tested various approaches to providing case management to SSI and SSDI beneficiaries and SSI applicants, with extra outreach to youth ages 18 to 24. The State Partnership Initiative, which ran from 1999-2004, provided employment and benefit counseling to SSI recipients. Unfortunately, these demonstrations did not realize the results that SSA had hoped to achieve.

In addition to demonstration programs to reduce the number of child SSI recipients transitioning into adult SSI recipients, new regulations implemented as part of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 mandated that child SSI recipients have their eligibility for SSI redetermined under the adult eligibility criteria once they reach age 18. As a result of this law, approximately one-third of child SSI recipients lose eligibility when they turn 18. Youth with mental impairments other than intellectual disability are particularly impacted by this law and are more likely than youth with other disabilities to lose their benefits when they enter adulthood.²

The need for a more pro-active approach to addressing barriers to self-sufficiency

One explanation for the limited success of SSA demonstration programs is that they fail to proactively address the need to build the human capital necessary for succeeding in education and employment. Studies looking at experiences of child SSI beneficiaries transitioning into adulthood find that the family environment and tenuous access to supportive services complicate education and employment.³

In a survey of child SSI recipients who have mental impairments, 45% of the subjects had dropped out of school, 52% reported being expelled or suspended from school and 28% reported a prior arrest. Youth with systems and sensory diseases had a much lower prevalence of reported problems in these categories.⁴ Human capital activities that can mitigate these problems include having a parent who models successful adult labor market participation, quality parental time spent with the child beneficiary, and supports to assist in school participation and success.⁵

Impact on child SSI recipients who are unstably housed or experiencing homelessness

Children experiencing homelessness are more likely to have emotional and behavioral problems and academic delays yet less likely to access the resources needed to address these issues and gain greater self-sufficiency.^{6, 7, 8} Indeed, a study of families living in 18 emergency homeless family shelters in Los Angeles found that almost half (45%) of the children met criteria for special education evaluation, yet less than one quarter (22%) had ever received special education testing or placement.

One study of families living in supportive housing found higher psychological distress among mothers, a factor contributing to less than optimal parenting practices.⁹ Furthermore, the transitional nature of being unstably housed or homeless cause many children living under these circumstances to miss days in school. In addition to poor parenting and tenuous school attendance, youth experiencing homelessness are exposed to precarious living conditions including violence and high-risk behaviors. As such, youth experiencing homelessness are at high risk of school problems, dropping out of school, and arrests. These negative social experiences impact future employment and participation in SSI programs.¹⁰

People with disabilities are disproportionately represented among the homeless adult population. According to the 2010 Annual Homeless Assessment Report to Congress, 37% of people using homeless emergency shelters reported having a disabling condition compared to 24.6% of the poverty population and 15.3% of the total U.S. population.¹¹ Such data makes clear that people who have disabilities face difficulties in accessing income and supports made available through the SSI program. Further restrictions on the SSI program would only perpetuate homelessness among individuals who have a disability and suffers from economic hardship.

Recommendations

The transition of children out of SSI program has been a point of discussion since the adoption of the SSI program in 1972. The issue is not one that can be easily addressed by narrowing eligibility criteria or by adding additional administrative layers. Indeed, such efforts will only add to the growing number of families living in poverty and increase costs to other public systems, including the criminal justice system.

The SSI program provides the income and supports needed by families caring for a disabled child and keeps them from falling into homelessness. Once homeless, the probability of the child becoming dependent on SSI as an adult increases as they are less likely to build the human capital necessary to become successful in education and employment. We believe that the following recommendations will improve self-sufficiency for SSI recipients and prevent homelessness among those transitioning out of the SSI program:

1. Encourage more proactive approaches to help child SSI recipients build human capital.

- Federal agencies through the U.S. Interagency Council on Homelessness can be working together to develop strategies to improve school attendance and facilitate academic growth. This includes addressing transportation issues (the most cited barrier to school attendance), access to after school activities and tutoring, addressing hunger, and ensuring access to housing.¹²
- In order for our Administration to effectively implement programs that address the issues described above, Congress should support increased funding to fully implement the HEARTH Act which reauthorized HUD's McKinney-Vento Homeless Assistance Programs.

- Federal agencies should also work together to determine how best to support parents who are caring for a child who has disabilities. This includes improved access to housing, caregiving supports, employment and academic opportunities for parents, and opportunities to build parental skill sets.

2. Support efforts to streamline eligibility in order to assure immediate access to needed supports.

- Current criteria for SSI eligibility are extremely stringent with more than half of applications for children with mental impairments resulting in denials. Provider documentation of impairment and other evidence of severe functional limitation are reviewed every three years. Further, caregivers of beneficiaries are required to submit annual reports on child impairment, family income, and use of SSI income. Efforts to add even more rigidity to the SSI program would lead to additional costs and administrative burden and compromise efforts that SSA has taken to reduce the disability claims backlog and processing time for appeals.
- Preference should be given to the medical opinion of providers who have established a medical history with an applicant. Physicians and psychiatrists who prescribe medication follow ethical codes that drive their practice. To institute a system that assumes program abuse would no doubt create a trend of inconsistent rulings, many of which will be reversed at the appeals process, and all at the detriment of the families who need immediate assistance.

3. Coordinate efforts among various federal agencies.

- Once adulthood is reached, many services end abruptly even though the need for these services continues. Additionally, many services for children and youth are offered in the school setting and are more easily accessible. As an adult, transitioning to new services can be difficult as services are often fragmented and underfunded. Federal agencies should work collaboratively to ease the transition to adult services.
- Supports available to adults are often poorly funded and have long waiting lists. Congress should ensure adequate funding for services that would improve education and employment for adults.

4. Support programs that prevent homelessness among people transitioning out of the SSI program.

- Youth with mental impairments other than intellectual disability have higher employment rates than individuals who have other disabilities. However, they tend to be in jobs that pay less, have fewer hours, and shorter durations.¹³ The average renter wage is \$14.44; even at this wage, a person must work 51 hours per week to afford a two-bedroom apartment at fair market rent.¹⁴ The U.S. Department of Housing and Urban Development, in its 2009 Worst Case Housing Needs Report to Congress, found that 38% of very low-income households including nonelderly people with disabilities had worst case needs.¹⁵ Congress should support housing programs for people who are transitioning out of the SSI program in order to prevent homelessness.

Case Study

Mr. and Mrs. D., a married couple, and their children moved into a local shelter after losing their home. Though Mr. D. is employed, his income of \$9/hour is not enough to maintain housing while meeting the other basic needs of his family. Unable to afford day-care services for their children, Mrs. D. spends her days caregiving and making sure her children's health care needs are met. Four of Mr. and Mrs. D.'s children have disabilities. Their oldest child, age 7, is diagnosed with speech and developmental delay and has a history of aggression. Their four-year-old child was diagnosed with autism and their 3-year-old and 2-year-old children present with developmental delay.

Mr. and Mrs. D. receive Supplemental Security Income of \$674 for their 4-year-old only. The 4-year old receives special education services at a school for children with autism. He is also receiving mental health care at an outpatient clinic specializing in children with autism. The income is a much needed resource that allows them to secure basic necessities for their child in order to maximize services being provided to him. Mr. and Mrs. D.'s other children are able to access some services including speech and language services and mental health care through the state Medicaid program. Though their children are able to access these services, their family lacks the supports needed to address the "whole-person", this includes supports to ensure that the social and living environment is such that it promotes healthy development.

The social environment and current living circumstance of Mr. and Mrs. D.'s children is likely to impact future success in education and employment. Living in a shelter with other individuals and families experiencing homelessness, they are surrounded by people who live in dire and high stress circumstances. Further, they are exposed to violence and often encounter individuals engaging in high-risk or unhealthy activities. The developmental delays and mental health problems of their children, particularly their children who are not able to access specialized services, will no doubt limit their education and future employment prospects. As such, they are at risk of life long instability and dependency on public programs, like SSI.

The child SSI program ensures adequate access to services and basic necessities, such as housing, for families who might otherwise fall into deeper poverty and even homelessness. In the case of Mr. and Mrs. D. and their children, insufficient access to the program has led to inadequate access to supports and housing instability. These children, with insufficient support to build human capital, are more likely to enter the SSI program later in life and stay on the rolls. However, if we can address their needs (including housing) now, they stand a chance at developing into productive adults.

Conclusion

While we understand the concerns that were raised from the Boston series and agree that self-sufficiency is optimal, we hope that the Subcommittee will consider the full array of challenges that SSI recipients struggle with in order to become self-sufficient. The ability to succeed in education and employment is correlated with support that children receive early in their development. We strongly encourage the Subcommittee to consider a more proactive approach to assisting youth in transitioning out of the child SSI program. Rather than creating policies that make the program harder to access, we

urge you to create policies that will reduce *the need* for the program by ensuring that child SSI recipients have the supports they need to succeed as adults.

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The Honorable Representative Dave Camp, Chairman
The Honorable Representative Sander Levin, Ranking Member
Ways and Means Committee
1102 Longworth House Office Building
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The Honorable Representative Geoff Davis, Chairman
The Honorable Representative Lloyd Doggett, Ranking Member
Subcommittee on Human Resources
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Dear Representatives Camp, Levin, Davis, and Doggett,

Thank you for the opportunity to comment on Supplemental Security Income (SSI) benefits for children, and for your attention to the issues families of children with disabilities face. We look forward to the full report on SSI benefits for children from the U.S. Government Accountability Office in April 2012. I am writing to submit a written statement for consideration by the Subcommittee and for inclusion in the printed record of the hearing on October 27, 2011 related to SSI benefits for children.

As a national nonprofit parent center, PACER Center enhances the quality of life and expands opportunities for all children and young adults, including those with disabilities and their families, so that each person can reach his or her highest potential. PACER operates on the principle of parents helping parents, supporting families and working in collaboration with others since 1978. More than 45,000 parents and others contact us for services each year, and our staff members work with families each day, to ensure that children with disabilities are able to succeed in school and in life. **SSI benefits are a critical factor in that success for many low-income families.**

The SSI program does provide financial support for families of children with disabilities. For many low-income recipients of this benefit, SSI allows families to ensure the best care for their child in the home and community, rather than in more costly institutions. Families contact PACER when faced with the confusing and fractured systems of care for children with disabilities, including education, health care, SSI, and others. It is our experience, working with many thousands of families over more than 30 years that SSI benefits contribute to the household stability that permits low-income children with disabilities to reach their highest potential. Further, certification of disability through SSI is often a critical step in accessing needed state and local services, independent of receiving SSI benefits. **SSI does not fully cover the financial costs of raising a child with a disability, and in no way incentivizes the identification of a disability or the medication of a child.**

In seeking improvements to the outcomes for children with disabilities whose families receive SSI payments, the Committee is undertaking an important conversation. Ensuring the stability of low-income families of children with disabilities, and allowing children to receive timely treatment and services at home and in the community is a critical first step. It is this step that SSI benefits support.

Thank you once again for your work on SSI benefits for children and your commitment to improving lives of individuals with disabilities. Thank you also, in advance, for your consideration of the above-mentioned comments.

Sincerely,

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**Written Statement for the Record
Submitted by**

Marty Ford, Director, Public Policy Office

**The Arc of the United States
Washington, DC**

to the
**Committee on Ways and Means, Subcommittee on Human Resources
U.S. House of Representatives**

**for the October 27, 2011 hearing on
Supplemental Security Income Benefits for Children**

Thank you for the opportunity to submit written testimony on behalf of The Arc of the United States (The Arc) for the record of the October 27, 2011 hearing on Supplemental Security Income Benefits for Children.

The Arc is the largest national community-based organization advocating for and serving children and adults with intellectual and developmental disabilities and their families. Founded in 1950, The Arc includes over 140,000 members affiliated through more than 700 state and local chapters across the nation. The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

The Arc is pleased to join with over 80 national organizations – representing service providers, consumers, and advocates – in supporting preserving Supplemental Security Income (SSI) for low-income children with disabilities.

At the October 27th hearing, the Subcommittee on Human Resources heard from a family from The Arc of Kentucky. Katie Bentley and her son Will are wonderful examples of what SSI does for families. Forced to quit her job to care for her son, Katie and her family rely on SSI benefits and the related medical supports available to Will. As Katie said at the hearing, SSI allows Will to lead an active life in the community, while living at home. SSI is a lifeline for families like the Bentleys, providing essential supports and creating opportunities. Our nation cannot afford to take these opportunities away from children with severe disabilities. ***The Arc urges the Committee to continue to support and sustain SSI benefits for children with disabilities.***

Achieve with us.

Children's SSI Program: Size and Trends

As of September, 2011, SSI provides benefits to approximately 1.3 million children across the United States.¹ As stated at the hearing, this is approximately 1.6 percent of children in the U.S.² This relatively modest participation rate reflects the fact that SSI eligibility is restricted to very low-income children with the most severe physical and/or mental impairments. In 2009, about 40 percent of children who applied for SSI were awarded benefits – a figure that has remained stable for over 10 years.³

Children with mental disorders make up approximately 66.6 % of all children who receive SSI.⁴ As others have noted, over the last two decades the proportion of children with mental disorders receiving SSI has remained relatively steady, but the percent of children receiving SSI in the diagnostic group of intellectual disability has dropped sharply (from 42.6% in 1994 to 12.7% in 2010) while the percent of children diagnosed with other mental disorders has increased (from 23% to 53%).⁵ Reasons for this may include a reflection of general trends in childhood mental health diagnostic practices, but further research is needed.

Children with Significant Disabilities and their Families Face Substantial Challenges

Families with children with significant disabilities often face substantial physical and emotional strain, as well as financial hardship.

In 2010, The Arc conducted a national online survey, called the Family and Individual Needs for Disability Supports (FINDS) Survey, to obtain perceptions of individuals with intellectual and developmental disabilities and their families on a range of life-span issues. Nearly 5,000 family caregivers from all 50 states and the District of Columbia completed surveys.

In the FINDS Survey, 21 percent of families of children with intellectual and developmental disabilities age 0 to 13 reported that over \$1,000 is spent in a typical month on care for their child with a disability.⁶ Seventy-one percent of families reported that caregiving interfered with their work, and 20 percent reported that someone in their family quit their job in order to provide care. These findings are consistent with other national research which has documented sizeable financial and employment difficulties related to caring for a child with significant disabilities.⁷

SSI is a Lifeline

SSI benefits are a lifeline for many families who cannot afford the care and attention a child with a serious physical or mental disorder often requires. Benefits are modest – as of September, 2011 the average SSI children's monthly benefit is only about \$597 (including federally-administered state supplementation) – but nevertheless help families secure essential services and supports for their children.⁸

Families use SSI to meet their out-of-pocket medical costs, to pay for transportation to and from appointments, and for other health-related needs. Families also use SSI to help their children access specialized services such as specialized daycare or therapy tools. Along with Medicaid, SSI

plays a key role in intervening early in a child's development, which can help maximize outcomes, prevent disabilities from worsening, and alleviate the effects of disabilities.

SSI also helps to replace lost income when a parent must stop working or work fewer hours in order to care for the child, respond to crises, or attend frequent meetings with medical providers, schools, and other agencies. Researchers have found that enrollment of a child in the SSI program helps to reduce the probability that the child lives in poverty by roughly 11 percentage points.⁹

Finally, SSI benefits help families care for their children at home. At The Arc, we have heard from many families who tell us that without SSI, they would be forced to consider the unthinkable – an institution or other setting outside the home that could meet their child's needs. The benefits of keeping a child at home do not stop with the child and family: all members of the community benefit when children and adults with disabilities are included in community life.

Recommendations

Given the critical importance of the SSI program in the lives of 1.3 million children and their families, The Arc believes that Congress should preserve and sustain the children's SSI program.

Any consideration of policy changes to strengthen the SSI program for children must be deliberative and fully informed by facts. The Arc recommends that Congress support the proposal for the Institute of Medicine (IOM) to conduct a thorough, data-driven study of the children's SSI program. We recommend that the IOM study include a review of trends in the diagnostic category of intellectual disability, as compared with other mental disorders. The Arc urges the Subcommittee to wait for the completion of the IOM study and the Government Accountability Office report, before any further contemplation of changes to the children's SSI program.

Furthermore, The Arc opposes any effort to block grant the SSI program – a possibility raised at the hearing. Block granting SSI could cause countless children with severe disabilities to lose the benefits they need to be able to remain in the community with their families, and could result in escalating costs in other public systems including publically funded institutional care.

The Arc supports efforts maximize the likelihood that children receiving SSI benefits will transition to a self-sufficient adulthood. We support improving SSI's work incentives, including by expanding the Student Earned Income Exclusion (SEIE). We also support the provision of benefits counseling by SSA to ensure awareness among claimants and families of the SEIE, the Section 301 program (continued payment for youth and adults participating under a Vocational Rehabilitation Program or similar program), and other SSI supports for transition age youth. We also support early and improved access to vocational rehabilitation, for SSI youth under age 18, to ensure maximum preparedness for the world of work as adults.

Finally, The Arc urges Congress to ensure that SSA receives adequate program integrity funds for its continuing disability reviews (CDRs). Without adequate funds, SSA cannot adequately fulfill its statutory obligation to perform on-time, cost effective, CDRs.

Conclusion

The Arc thanks the Subcommittee for its interest in the children's SSI program and for the opportunity to submit a written statement for the record of the October 27, 2011 hearing. We urge the Subcommittee to preserve and sustain this essential benefit for low-income children with significant disabilities and their families.

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⁸ Social Security Administration, *SSI Monthly Statistical Snapshot, September 2011* (Table 7).

http://ssa.gov/policy/docs/statcomps/ssi_monthly/2011-09/table02.html. Accessed Nov. 9, 2011.

⁹ Duggan, M. and Kearney, M.S. (2007). *The Impact of Child SSI Enrollment on Household Outcomes*. *Journal of Policy Analysis and Management*, Vol. 26(4), pp. 861-886.



Statement of the National Alliance on Mental Illness (NAMI)

SUBMITTED TO
HOUSE SUBCOMMITTEE ON HUMAN RESOURCES OF THE
COMMITTEE ON WAYS AND MEANS
WASHINGTON, D.C.

Chairman Davis, Ranking Member Doggett, and Members of the Subcommittee –

The National Alliance on Mental Illness (NAMI) greatly appreciates this opportunity to submit written testimony related to the October 27, 2011 hearing on Supplemental Security Income (SSI) benefits for children.

INTRODUCTION

NAMI is the nation's largest grassroots family and consumer organization dedicated to improving the lives of children, adults and families affected by mental illness. Through NAMI's 1,100 chapters and affiliates in all 50 states NAMI supports education, outreach, advocacy and research on behalf of persons with mental health conditions.

NAMI is also a member of the SSI Coalition for Children and Families, a network of more than 80 family, consumer, professional and advocacy organizations dedicated to advocating on behalf of families caring for children and youth with severe mental and physical disabilities.

The SSI program was established to provide income supports for low income families of children and youth with severe disabilities. Families rely on this funding to help support the needs of their children. NAMI routinely receives requests for assistance from families who are struggling with the hardship that comes with raising a child with a serious mental illness.

Many of these families share the extreme challenges they face in trying to keep their jobs while frequently being called away to come and get their child from daycare programs, schools and other community programs. Most schools and community programs struggle with effectively addressing the needs of children with severe mental illness. Many parents are forced to leave their jobs because of the demanding day-to-day needs of their child, their child's challenges in participating in structured programs, their child's challenges in acquiring basic life skills (like following directions, getting along

with others, controlling and regulating their emotions and more), the need to take their child to therapeutic appointments and more.

ADVANCES IN UNDERSTANDING MENTAL ILLNESS IN CHILDREN

Serious mental illnesses among children and youth are as real and disabling as other physical illnesses such as epilepsy and juvenile diabetes. The National Institute of Mental Health (NIMH) observes that half of all psychiatric illnesses begin by age 14 and calls them “the chronic conditions of the young.” The World Health Organization has identified five of the top ten causes of disability and lost productivity in the world as being caused by psychiatric disorders.

NIMH has invested in multiple research studies that show that the onset of mental illness, including serious mental illnesses that cause severe disability, is most often in early childhood and adolescence¹. We have learned a great deal over the past decade about how to identify mental illnesses in children and youth. Understandably, this has led to an increase in the number of children who have been diagnosed with these conditions:

Psychiatric impairments can affect a child’s learning, growth, socialization, and development as profoundly as it affects an adult’s ability to work. For example, adolescents with psychiatric disabilities have more than double the rate of dropout from high school than the general population. In fact, according to the United States Department of Education, children in the emotional disturbance (ED) category of The Individuals with Disabilities Education Act (IDEA), which includes children with serious mental health conditions, have the highest drop-out rate of any disability group receiving special education services. This is true for children whether or not they are enrolled in the SSI program. This is not a reflection of how well the SSI program works for these children or whether SSI creates disincentives for children to remain in school. Rather, it reflects the reality that our nation’s schools often struggle with how to effectively address the academic and functional needs of students with mental health conditions.

We know this firsthand because NAMI provides an in-service education program for school professionals in nineteen (19) states across the country. We have learned a great deal from working directly with schools and school staff. Many teachers, school administrators and other school staff have candidly shared with us that they struggle with effectively meeting the needs of students with mental health conditions and in the ED category of IDEA. They acknowledge their concern that this impacts the high school drop-out rates of these students. So to attribute the high drop-out rates to the SSI program is contrary to what is actually happening in schools around the country and is a gross oversimplification of a far more complex issue. There are many factors impacting whether students with mental health conditions stay in school and succeed. These include the challenges in accessing effective mental health services because of a critical shortage of child psychiatrists, the lack of training for school professionals to help them understand the effective programs and accommodations that help students with mental illness succeed in school, the different learning styles that many of these students have that are often difficult to address in large schools and classrooms and more.

It is important to recognize that only children suffering with severe mental and/or physical disabilities are eligible for SSI. The review process looks at a child's functioning and not solely at the diagnosis, which is important because children with conditions like Attention Deficit Hyperactivity Disorder (ADHD) may experience very different levels of functioning. Some children with ADHD have very low functioning and struggle with attending and participating in school, in following even basic directions, become involved in substance use and abuse and become involved in the juvenile justice system. Whereas others may have a milder form of ADHD and would not qualify for SSI. This is also true for children with Autism.

Also, many children with a primary diagnosis of ADHD also have co-occurring disorders, including bipolar disorder, depression, anxiety, learning disabilities and autism spectrum disorders." When children have multiple co-occurring disorders, their function is often extremely impaired and they often struggle in the multiple domains of their lives, including in school, at home and in the community. In these cases, low income families need the financial support provided by the SSI program to help provide food, clothing and housing for the child, which becomes all the more important when parents cannot work because they must remain close to home for the child.

Serious mental illness in children often responds well to effective programs, services and treatment. The SSI program is a life line for parents, allowing them to take their children to therapeutic appointments and to see specialists who help children acquire the basic life skills they need to remain at home with their families and out of far more costly institutional settings.

Psychiatric medications, when properly prescribed and monitored, are an important component of psychiatric treatment and have proven effective in reducing disability and fostering recovery among youth with mental illnesses. Health conditions are exacerbated by the consequences of poverty, so getting stable resources to low-income children with mental illnesses is critically important.

Proposals to limit eligibility and reduce benefits would be harmful to these struggling families. Without the necessary services and supports afforded by SSI, these children's functioning would likely deteriorate, and any projected "savings" realized by cuts would quickly be exceeded by escalating costs incurred by child welfare, public safety, juvenile justice, and publicly-funded institutional care.

NAMI SUPPORTS AN IOM STUDY

NAMI joins Representative Richard Neal (D-MA) and Social Security Administration (SSA) Commissioner Michael Astrue in calling for an IOM study to examine the children's SSI program. Given the importance and value of this program to children with severe mental and physical disabilities, expert guidance and a thorough study of the program is needed before any drastic measures are taken to change the program. Convening a body of experts to conduct a thorough review of SSI is the only way that we will understand what is working well and has proven cost effective in the program and how to ensure the program's ongoing integrity. Future policy decisions

about SSI should be made based on facts and evidence rather than unsubstantiated and anecdotal claims.

NAMI SUPPORTS IMPROVEMENTS TO SSI

Before turning to actions that can be taken to improve the SSI program for children, it is important to recognize the safeguards that already exist in the administration of the SSI program. SSI has strict eligibility criteria and standards that result in more than half of the SSI applications being denied every year for children with mental health conditions. Decisions about whether a child qualifies for SSI are only made after a record review and input from multiple sources, including health care providers, school professionals and other adults working with the child. The review process involves determining a child's level of functioning in multiple settings, including home, school and other community settings.

The continuing review process is designed to be rigorous. The SSA is required to conduct Continuing Disability Reviews (CDRs) every three years for conditions that might improve, at age 18 to determine if applicants meet adult SSI criteria and as part of Performance Accountability Reviews. These reviews are absolutely essential to ensuring the integrity of the program. According to the preliminary report released by the U.S. Government Accountability Office (GAO)ⁱⁱⁱ, SSA has struggled to meet the CDR requirements because of limited federal funding. NAMI applauds the recent enactment of the Budget Control Act of 2011 which authorizes increased funding for SSA to conduct CDRs and redeterminations.

NAMI supports improvements to the program to help ensure ongoing program integrity and that children with severe mental illness are receiving the support they need to stay in school, receive therapeutic care to help them develop basic life skills and to work toward leading independent and productive adult lives.

Despite the safeguards that exist in the SSI program, there are certainly areas that can be improved. NAMI calls on Congress to take the following steps to ensure the ongoing integrity of the SSI program for children with severe mental illness:

- Continue to provide adequate funding to allow the SSA to meet their continuing disability review requirements to help ensure the ongoing integrity of the SSI program for children;
- Authorize and fund an IOM study to allow a body of experts to conduct an in-depth review of the program;
- Strengthen the interagency collaboration across federal agencies, including the U.S. Department of Health and Human Services, the U.S. Department of Labor, SSA, the U.S. Department of Education, and the Center for Medicare and Medicaid Services -- to encourage the development of effective cross-agency educational, vocational rehabilitation and supported employment programs for youth and young adults living with severe mental illness. This collaboration should focus on improving educational outcomes, increasing the availability of

supported employment programs and raising awareness about SSI work incentive and other programs that encourage SSI recipients to work.

NAMI urges the committee to avoid drastic changes to the SSI program for children that could ultimately harm children and families. NAMI opposes any changes that would turn the SSI program for children into a state administered program through either a block grant or by adding it to the existing TANF program. This would lead to the elimination of national standards, would not allow vitally important oversight of the program and would place a high administrative cost burden onto states. The more prudent approach is to take an in-depth look at what works in the SSI program and to make any necessary adjustments that will help to improve the program and the young lives that it was originally created to support.

ⁱ NIMH Director's Blog, April 2010, accessed at www.nimh.nih.gov.

ⁱⁱ NIMH Publication: "What Conditions can coexist with ADHD." Accessed at www.nimh.nih.gov.

ⁱⁱⁱ Statement of Daniel Bertoni, Director, Education, Workforce and Income Security, U.S. Government Accountability Office. Submitted on October 27, 2011. GAO-12-196T.

**Testimony Submitted to
House Ways and Means Subcommittee on Human Resources**

**Regarding the October 27, 2011, Hearing:
Supplemental Security Income Benefits for Children
with Low-Income and Severe Mental and/or Physical Disabilities**

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Submitted: November 8, 2011

The National Alliance to Advance Adolescent Health appreciates the opportunity to submit written testimony regarding the October 27, 2011, Subcommittee on Human Resources hearing on Supplemental Security Income (SSI) for low-income children with severe mental and/or physical disabilities. The National Alliance is a non-profit organization that works to improve the lives of adolescents, especially those from poor families, by focusing greater attention and resources on their health needs and on innovative ways to address them. Its aim is to increase adolescents' access to integrated physical, behavioral, and sexual health care that can help them reduce health risk behaviors, identify their health problems earlier, and take on responsibility for managing their health conditions.

As many written testimonies have shown, cuts to SSI benefits for low-income children with disabilities would be nothing short of catastrophic.¹ Studies have consistently revealed that families raising children with disabilities face economic and material hardship at significantly greater rates than families without a child with disabilities. Over 70% of families of SSI children report having been unable to cover rent, food, utilities, transportation, and out-of-pocket medical costs. The SSI cash benefit enables families to access the services necessary for children to remain with their families in their community, rather than being sent to state facilities for institution-based care. Furthermore, these benefits are essential to preventing already hard-hit families from falling deeper into poverty. In short, the SSI benefit is critical in assisting families that struggle financially.

To reiterate statistics from other testimonies, of all children in America, only 1.6% receives SSI disability support. Children's SSI has experienced only modest growth since 2000, and there has

¹ The SSI Coalition for Children and Families, Advocacy Memo, 10/20/2011.

been little change in the percentage of impoverished children receiving SSI in the last decade.² Those children utilizing the SSI benefit are typically from broken or nontraditional homes, with almost 80% of the recipients living in households with one parent or no parent. The more than 150,000 children receiving SSI benefits and residing in households with no parents lived independently, with other relatives or nonrelatives, or in institutions or foster care.³

As the policy statement on SSI by the *American Academy of Pediatrics* makes clear, the SSI program “remains an important source of financial support for low-income families of children with special health care needs and disabling conditions.”⁴ It serves as a critical lifeline for our nation’s most vulnerable children and youth, making it possible for families to stay together rather than needing to send children with disabilities into institution-based care. Without it, more than 1.2 million children with severe disabilities and their families would suffer.

On the behalf of the National Alliance to Advance Adolescent Health and the sixty-eight other national organizations that defend preserving SSI for low-income children with disabilities⁵, we proudly support those low-income children with severe physical and/or mental disorders who receive SSI and their families who continually struggle to care for them.

Respectfully,

Harriette Fox, CEO

² Social Security Administration: “SSI Statistical Report, 2010: Children Under Age 18.” Last accessed October 21, 2011. http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2009/sect04.html#table20

³ “Recipients, by number of parents in the household, December 2010.” SSI Annual Statistical Report, 2010. http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2010/sect04.pdf

⁴ Policy Statement—Supplemental Security Income (SSI) for Children and Youth With Disabilities. *American Academy of Pediatrics* 2009 Dec; 124(6).

⁵ “National Organizations that Support Preserving SSI for Low-Income Children with Disabilities.” <http://www.bazelon.org/LinkClick.aspx?fileticket=ggGdM6QZBT%3D&tabid=498>

