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Testimony for Hearing on Supplemental Security Income Benefits for Children
Subcommittee on Human Resources
Committee on Ways and Means
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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/2010/12/12/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/

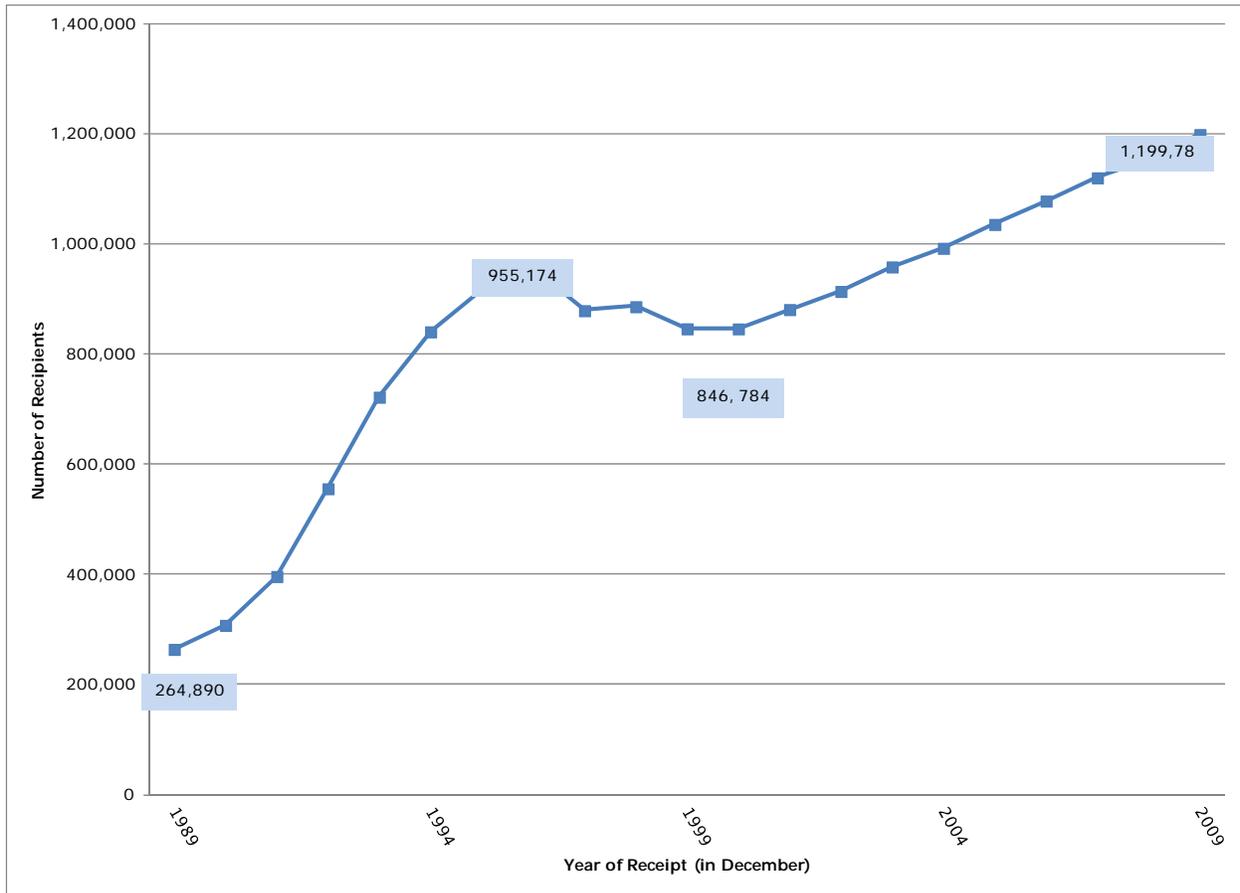
⁴ <http://www.npr.org/2011/08/18/139722024/benefits-for-severely-disabled-children-scrutinized>

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 Auxter et al. (1999).

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

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

¹¹ Tabulations based on data from http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2009/sect04.html#table19.

¹²http://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%3d&tabid=432>

¹⁴ Duggan and Kearney (2007).

¹⁵ Davies et al. (2009).

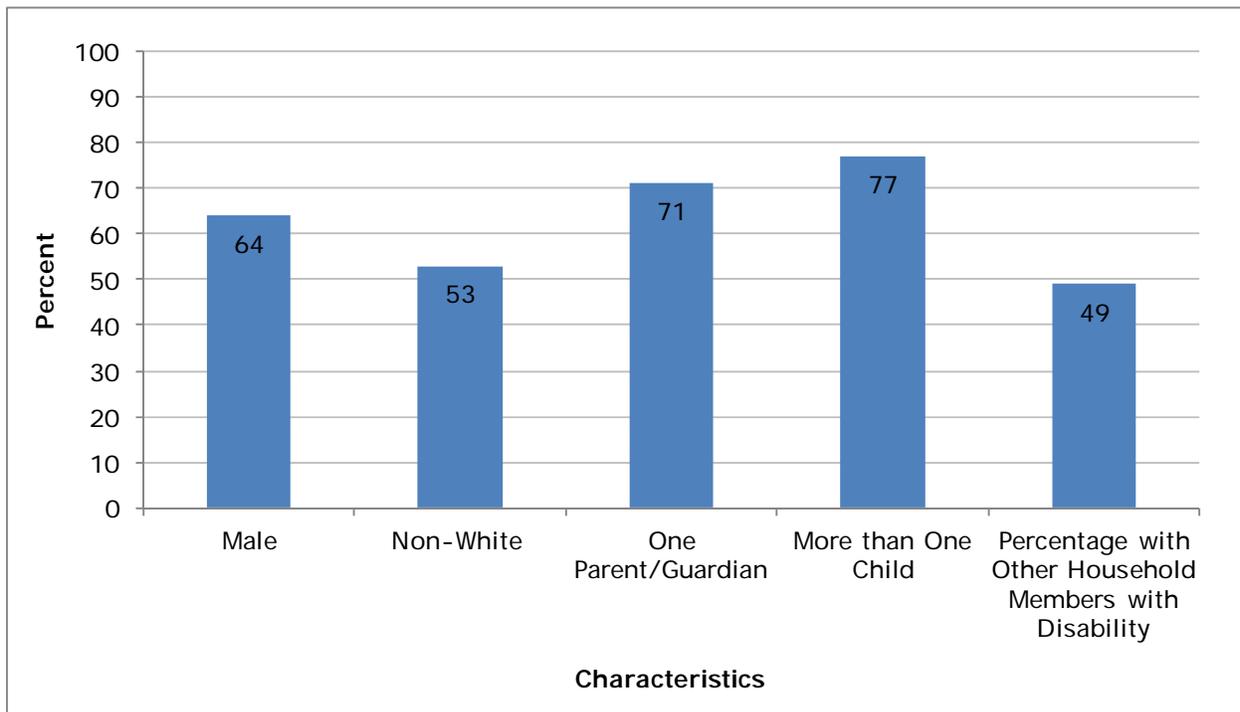
¹⁶ DeCesaro and Hemmeter (2009).

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.

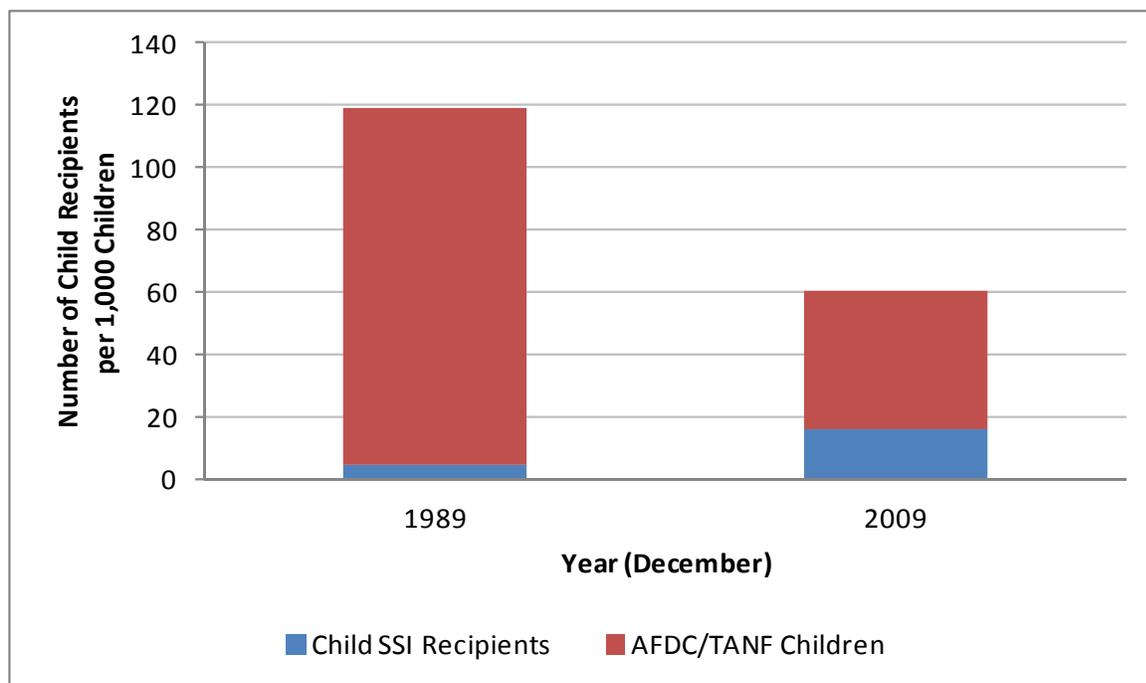
²⁴ Schmidt and Sevak (2004).

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/fycytototal89_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/fycytot89_ek.htm. 2011 TANF data are available from http://www.acf.hhs.gov/programs/ofa/data-reports/caseload/2009/2009_children_tanf.htm. Population data on youth ages 0 to 17 taken from http://www.childtrendsdatbank.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.³⁴

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 ^b (%)
Schooling		
In school or graduated ^a	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.³⁵ 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

³⁴ 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.htm].

³⁵ 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-specialled.pdf>

⁴³ <http://www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.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=3534>

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/nrcpds/cash_and_counseling.html

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

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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