COMMUNITY
LEGAL SERVICES, INC.

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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

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[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

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[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.

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[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]

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[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]

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[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

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[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

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[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-employments-supports.htm#6.

[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 encourages 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

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[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]

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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,

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[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.