



For people with intellectual
and developmental disabilities

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**Written Statement for the Record
Submitted by**

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**The Arc of the United States
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**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.

¹ Social Security Administration, *SSI Monthly Statistical Snapshot, September 2011* (Table 2). http://ssa.gov/policy/docs/statcomps/ssi_monthly/2011-09/table02.html. Accessed Nov. 9, 2011.

² Social Security Administration, *SSI Monthly Statistical Snapshot, September 2011* (Table 2). http://ssa.gov/policy/docs/statcomps/ssi_monthly/2011-09/table02.html. Accessed Nov. 9, 2011. And U.S. Census Bureau, American Community Survey, B18101: Sex by Age by Disability Status - Universe: Civilian noninstitutionalized population. Accessed Nov. 9, 2011.

³ Social Security Administration, *SSI Annual Statistical Report, 2010* (Table 69). http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2010/sect10.html#table69. Accessed Nov. 9, 2011.

⁴ Social Security Administration, *SSI Annual Statistical Report, 2010* (Table 20). http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2010/sect04.html#table20. Accessed Nov. 9, 2011.

⁵ Koyanagi, C. (2011). *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*. Washington, DC: Bazelon Center for Mental Health Law.

⁶ The Arc 2010 FINDS National Survey: Technical Report Part 1. Prepared for The Arc of the United States by the University of Minnesota, Research and Training Center on Community Living. Available at <http://www.thearc.org/document.doc?id=3141>.

⁷ For example, see Parish, S.L. et al. (2008). *Material Hardship in U.S. Families Raising Children with Disabilities*. *Exceptional Children*, Vol. 75(1), 71-92; and Witt, W.P. et al. (2009). *The Impact of Childhood Activity Limitations on Parental Health, Mental Health, and Workdays Lost in the United States*. *Academic Pediatrics*, Jul-Aug; 9(4): 263-269.

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.