



Statement for the Record

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House Committee on Ways and Means Subcommittee on Human Resources

Supplemental Security Income (SSI) Benefits for Children with Low-Income and Severe Mental and/or Physical Disabilities

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Chairman Davis, Ranking Member Doggett and members of the House of Representatives Committee on Ways and Means, Subcommittee on Human Resources, thank you for this opportunity to submit a statement for the record regarding the October 27, 2011 hearing on “*Supplemental Security Income Benefits for Children with Disabilities.*”

First Focus is a bipartisan advocacy organization committed to making children and their families a priority in federal policy and budget decisions. Our organization is dedicated to ensuring the health and well-being of our nation’s children, especially those who suffer from severe and chronic mental and physical disabilities. We are especially concerned with preserving the federal safety nets and supports for low income families to ensure that they have the resources they need to properly care for a special needs child. On behalf of First Focus, and as a member of the Supplemental Security Income (SSI) Coalition for Children and Families, I appreciate the opportunity to testify about the importance of this program to so many needy families.

Throughout history, children with disabilities have been stigmatized, and families were often expected to place their children into institutions. Community programs and supports slowly developed as an alternative to institutionalization, allowing these children to remain with their families. While these programs were a life-changing development for many families with special needs kids, they came at a great cost, with many treatments and resources remaining out of the reach of low-income families.

Since its creation in 1972, the Children’s SSI program has served as a critical lifeline for low income families of children with special needs. The program provides modest monthly payments—on average \$593—to help replace some of the lost income many families experience when they are forced to reduce work hours to care for their severely disabled child. Even this small amount has allowed low income families to give their children with severe disabilities the care and attention their child requires; care and attention they could not otherwise afford to provide.

Proposals to cut the program, toughen standards of eligibility, or turn SSI into a block grant program, would have disastrous consequences for the thousands of children and families who have depended on SSI, and would risk growing costs in other areas such as child welfare, juvenile justice, and other publicly funded programs. Thus, SSI is a



sound public policy, preventing many families from falling into poverty as a result of the devastating costs associated with a disability diagnosis in addition to keeping children out of publicly funded institutions.

While the SSI program has slowly grown over the last 30 years, this growth is due to the confluence of several external factors impacting the overall pool of eligible children. First, not only has the child population grown as whole, but the number of children living in poverty has also increased from 16.4% in 1974, to 22% of all children in 2010. Despite this growth in child population and increase in child poverty, the proportion of poor children who are on SSI has remained steady for more than a decade (7.52% in 2001 vs. 7.56% in 2010). Moreover, only 1.6% of all children are on SSI, or about one-tenth of all disabled children.

In addition to a growth in the overall child poverty population, the Children’s Health Insurance Program (CHIP) has dramatically increased the number of children with access to health care. CHIP has increased child Medicaid enrollment from 22 million in 1998 to 32 million in 2008. This rise in Medicaid enrollment has led to a corresponding rise in access to services and a dramatic jump in the number of children who receive services through the Early Periodic Screening Diagnosis and Treatment program. This rise in participation in screening programs has understandably increased the number of children who are identified as having a disability or impairment.

Moreover, the SSI mental impairments category, a critical part of the SSI program, has remained relatively unchanged over the last 20 years, with the proportion of children eligible for SSI as a result of mental impairments remaining at a constant 66% since 1994. However, as the field has evolved, and diagnostic methods have become increasingly sophisticated, the categories of impairment have expanded and shifted to reflect these changes. Where practitioners would simply use the label “mental retardation” to encompass the universe of mental impairments, more tailored and specific categories of diagnosis have emerged. This shift in the field has lead to a more diverse diagnostic breakdown in the SSI program, and more precise diagnoses of Autism, Attention Deficit and Hyperactivity Disorder (ADHD), etc. have replaced the inadequate and outdated mental retardation diagnosis.

The SSI program has extremely stringent standards for eligibility. Only the most severely disabled and poorest children will qualify for the program. The review process is extremely thorough and requires extensive review of medical, school and caregiver records, as well as in person assessments of the child’s functioning in their various settings over time. A child must have a medically diagnosable physical or mental impairment, and that impairment must severely interfere with their ability to function. In addition to these rigorous eligibility standards, caregivers must continuously account for their use of SSI funds, and children are subject to Continuing Disability Reviews (CDRs) every 3 years to determine any improvement in condition. Moreover, use of medication does not improve a child’s chances of qualifying for the program, and in fact may hinder their chances as medication will improve a child’s condition. For example, a recent study of children with ADHD by the Social Security Administration (SSA) found



that children taking medication were no more likely than their un-medicated counterparts to be found eligible for benefits.

While the SSI program is a desperately needed resource for this country's neediest families, there is definite room for improvement. SSI can be strengthened through enhanced employment opportunities. As it currently stands, the program does offer generous benefits to children who are willing and able to work. As a survey recently revealed, however, just 22% of children on SSI were aware that these incentives existed. The program could improve the employment outcomes of these youth by enhancing their outreach and education efforts on available programs, leading to greater awareness. Moreover, increased funding to improve the provision of continued disability reviews would ensure the integrity of the SSI program by increasing the regularity of reviews. Currently, the program is underfunded and understaffed, preventing regular screening of program participants, allowing individuals who would no longer qualify for benefits to remain on the program. In addition to enhancing the program's integrity, more frequent reviews would prevent unjustified termination of benefits when children are not given their full medical reviews. When adequate funding was provided to conduct CDRs - between 1996-2002 -SSA was current in completing the CDRs as required by law. Once funding was reduced, however, SSA fell behind in their reviews, creating a significant backlog.

In closing, Mr. Chairman and members of the committee, First Focus stands prepared to work with you to ensure that the committee understands the vital role this program plays in the lives of so many of our nation's children. We urge the committee to make only considered, evidence-based reforms that will strengthen and preserve the SSI program so that these children can achieve the best possible outcomes. If you have any additional questions, please contact Shadi Houshyar, VP for child welfare policy at First Focus, at (202) 657-0678.