

November 22, 2011

The Honorable Geoff Davis  
Chairman  
Subcommittee on Human Resources  
Committee on Ways and Means  
U.S. House of Representatives  
Washington, D.C. 20510

The Honorable Lloyd Doggett  
Ranking Member  
Subcommittee on Human Resources  
Committee on Ways and Means  
U.S. House of Representatives  
Washington, D.C. 20510

Dear Chairman Davis and Ranking Member Doggett:

The undersigned organizations are writing to thank you for your leadership and commitment to strengthening the Supplemental Security Income childhood disability program to better support low-income children and adolescents with severe physical and mental impairments. We are heartened that the October 27, 2011, hearing focused on strengthening SSI to ensure the best possible outcomes for children and youth with severe disabilities.

As you know, SSI is a critical lifeline for families like the Bentleys, struggling to meet the needs of children who, like Will, struggle with severe disabilities. Studies have consistently shown that low-income families raising children with severe disabilities experience significant financial hardship. The SSI cash benefit (along with Medicaid coverage) enables families to access the services necessary for children to live with their families in their community.

The monthly benefit is small (on average only \$593 in 2009), yet critical to helping offset the myriad of costs of raising a child with a severe disability. Families use these funds for out-of-pocket medical costs, specialized daycare, and 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.

As was stated at the hearing, less than ten percent of children with disabilities receive SSI. SSI's extraordinarily strict eligibility criteria restrict benefits to low-income children with the most severe physical and/or mental impairments. Thirty-nine percent of those who apply receive benefits—a figure that has remained stable for over ten years. Despite its prominence in media accounts on children's SSI, ADHD has one of the lowest allowance rates of any mental impairment, with over 72% of children who apply with a primary diagnosis of ADHD denied SSI.

Given the critical importance of this program in the lives of 1.3 million children and families, we urge the Subcommittee to wait for the GAO to complete its study of children's SSI, to ensure that any policy reforms that are considered are informed by facts, rather than anecdotes, myths, or misconceptions. We also echo the call for a review of the children's SSI program by the IOM, which Representative Richard Neal renewed at the hearing.

Furthermore, as was stated at the hearing, we oppose any effort to block grant the SSI program. Block granting SSI would cause countless children with severe disabilities to lose the benefits

they need to be able to remain in the community with their families, and would result in escalating public costs in child welfare, public safety, juvenile justice and public-funded institutional care.

The children's SSI program can surely be strengthened to better support children with severe impairments, and maximize their likelihood of transitioning to a self-sufficient adulthood. We support improving SSI's work incentives, in particular by expanding the Student Earned Income Exclusion (SEIE), as well as the provision of benefits counseling by SSA to ensure awareness among claimants and families of the SEIE, the Section 301 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.

Furthermore, we urge adequate program integrity funds for CDRs. Without adequate funds, SSA cannot adequately fulfill its statutory obligation to perform on-time, cost effective, CDRs.

We look forward to working together with you and your colleagues to ensure that children with severe physical and mental impairments have the best chance possible at a self-sufficient and rewarding life as adults.

ON BEHALF OF:

Alliance for Children and Families  
American Academy of Child and Adolescent Psychiatry  
American Academy of Pediatrics  
American Association on Health and Disability  
American Council for School Social Work  
American Psychiatric Association  
Anxiety Disorders Association of America  
The Arc of the United States  
Association for Ambulatory Behavioral Healthcare  
Association of University Centers on Disabilities (AUCD)  
Bazelon Center for Mental Health Law  
Center for Civil Justice  
Center for Clinical Social Work/ABE  
The Center for Law and Social Policy  
Children and Adults with Attention-Deficit/Hyperactivity Disorder  
Children's Defense Fund  
Community Legal Services of Philadelphia  
Covering Kentucky Kids and Families  
Depression and Bipolar Support Alliance (DBSA)  
Disability Law Center of Massachusetts  
Disability Rights Education & Defense Fund  
Disciples Justice Action Network  
Easter Seals  
Empire Justice Center

Family and Children's Ministries, Disciples Home Missions of the Christian Church (Disciples of Christ)  
Family Voices  
First Focus  
Foster Family-based Treatment Association  
Health and Disability Advocates  
Jewish Federations of North America  
Justice Policy Institute  
Kentucky Equal Justice Center  
Kentucky Justice Center  
Kentucky Protection & Advocacy  
Learning Disabilities Association of American  
Mental Health America  
National Alliance to Advance Adolescent Health  
National Association of Councils on Developmental Disabilities  
National Alliance on Mental Illness  
National Association of Councils on Developmental Disabilities  
National Association of School Psychologists  
National Association of Social Workers, California Chapter  
National Association of Social Workers, Florida Chapter  
National Association of State Mental Health Program Directors  
National Council for Community Behavioral Healthcare  
National Council of Jewish Women  
National Council of La Raza  
National Disability Rights Network  
National Down Syndrome Congress  
National Down Syndrome Society  
National Fair Housing Alliance  
National Federation of Families for Children's Mental Health  
National Latino Behavioral Health Association  
National Law Center on Homelessness & Poverty  
National Organization of Social Security Claimants' Representatives  
National Organization for Women  
National Respite Coalition  
Public Education Network  
School Social Work Association of America  
TASH: Equity, Opportunity and Inclusion for People with Disabilities  
Treatment Communities of America  
United Church of Christ, Justice and Witness Ministries  
US Psychiatric Rehabilitation Association  
Voices for America's Children  
Youth Law Center, California

Contact for further information: Chris Koyanagi, Policy Director, Bazelon Center for Mental Health Law, 1101 15<sup>th</sup> Street, N.W., Washington, D.C. 20005  
202/467-5730 or [thompson@bazelon.org](mailto:thompson@bazelon.org)

