

July 19, 2011

The Honorable Max Baucus
Chairman
Senate Committee on Finance
Washington, DC 20510

The Honorable Orrin G. Hatch
Ranking Member
Senate Committee on Finance
Washington, DC 20510

Dear Chairman Baucus and Ranking Member Hatch:

The undersigned organizations are writing to ask for your support and leadership in preserving Supplemental Security Income (SSI) for children with disabilities. Inaccurate media accounts that distort the facts about children with mental disorders have already led the House Budget Committee to include damaging cuts to children's SSI in the House-passed FY 2012 Budget Resolution.

SSI is a critical program for very low-income families struggling to meet their children's needs. Studies have consistently shown that the economic burdens on families of children with severe mental health disorders can be even greater than the financial hardships facing families of children with other types of medical disorders. The SSI cash benefit (and the Medicaid coverage that accompanies it) enables families to access the services necessary for children to live with their families in their community. These benefits are also essential to preventing families from falling deeper into poverty.

The monthly benefit is small (on average only \$593 in 2009), but it helps offset the costs of having 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.

SSI provides assistance to children with a medically determinable physical or mental impairment or combination of impairments, that result in "marked and severe functional limitations." The definition of disability and the eligibility standards for the program are already so strict that over 60 percent of SSI applications for children are denied, and only 39% approved.

Of the roughly 1.2 million children with disabilities receiving SSI benefits, slightly more than 53 percent qualify due to psychiatric and other mental impairments, such as pervasive developmental disorders, speech and language delays, and organic mental disorders. Children can have a range of diagnoses, including schizophrenia, bi-polar disorder, depression, attention deficit/hyperactivity disorder (AD/HD) and personality/conduct disorders. However, only about 30-40 percent of potentially eligible low-income children with psychiatric impairments (based on the number who have extreme functional impairments) are actually enrolled in the program.

Some critics of the program claim that some low-income families seek prescriptions for psychiatric medications for their children only to improve the chances that their child will qualify. This allegation is often made about families who have children with AD/HD.

Recent Social Security Administration (SSA) data show, however, that this is not a route to benefits. Children with AD/HD who were taking medications related to that impairment were no more likely to be approved for benefits than those who were not taking medications. In fact, the vast majority of AD/HD claimants approved for benefits were not taking related medications. This is in part because SSA rules take into account the beneficial effects of medication on a child's functioning, and so children on medication are actually more likely to be denied than approved.

Proposals to limit eligibility and reduce benefits would be harmful to these struggling families. Without the necessary services and supports afforded by SSI, these children's functioning would likely deteriorate, and any projected "savings" realized by cuts would quickly be exceeded by escalating costs incurred by child welfare, public safety, juvenile justice, and publicly-funded institutional care.

Some improvements to the program can certainly be made. For instance, the law requires SSA to conduct regular reviews of children receiving benefits to determine whether their condition has improved such that they are no longer disabled. These reviews have been found to be extremely cost-effective, with \$10 in federal savings for every \$1 spent on a Continuing Disability Reviews (CDR). However, SSA lacks the resources to conduct these reviews in a timely manner. We strongly support the Administration's proposal as part of the 2012 budget to increase funding for increased CDRs and other program integrity initiatives at SSA.

Given the importance of the SSI program to so many children and families, expert guidance and thorough study of the program is necessary to ensure that children who need this program are able to access it. As such, we recommend that the Institute of Medicine convene a body of experts to conduct a thorough review of the SSI program for children so that future policy decisions can be made based upon facts and evidence rather than unsupported allegations.

We ask for your commitment and leadership in preserving the SSI disability program for all children. We urge you to oppose any attempt to deny thousands of families the SSI benefits that help them care for their children with severe mental disorders. Thank you for considering our concerns.

ON BEHALF OF:

Alliance for Children and Families
American Academy of Child and Adolescent Psychiatry
American Academy of Pediatrics
American Association of People with Disabilities
American Association on Health and Disability
American Council for School Social Work
American Counseling Association
American Group Psychotherapy Association
American Occupational Therapy Association

American Psychiatric Association
Anxiety Disorders Association of America
The Arc
Association for Ambulatory Behavioral Healthcare
The Bazelon Center for Mental Health Law
Brain Injury Association of America
Center for Clinical Social Work/ABE
Child Welfare League of America
Children and Adults with Attention Deficit/Hyperactivity Disorder
Clinical Social Work Guild
Community Legal Services
Council for Exceptional Children
Depression and Bipolar Support Alliance
Disability Rights Education and Defense Fund
Disciples Justice Action Network
Division for Early Childhood (DEC) of the Council for Exceptional Children
Easter Seals
The Empire Justice Center
Family Voices
Foster Family-based Treatment Association
Health & Disability Advocates
Jewish Council for Public Affairs
IDEA Infant Toddler Coordinators Association (ITCA)
The Jewish Federations of North America
Justice Policy Institute
Learning Disabilities Association of America
Mental Health America
National Advocacy Center of the Sisters of the Good Shepherd
National Alliance to Advance Adolescent Health
National Alliance on Mental Illness
National Association for Children's Behavioral Health
National Association of Disability Representatives
National Association of Councils on Developmental Disabilities
National Association of County Behavioral Health & Disability Directors
National Association of School Psychologists
National Association of Social Workers
National Association of State Head Injury Administrators
National Association of State Mental Health Program Directors
National Center for Youth Law
National Council for Community Behavioral Healthcare

National Council of Jewish Women
National Council of La Raza
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Health Law Program
National Fair Housing Alliance
National Federation of Families for Children's Mental Health
National Foundation for Mental Health
National Latino Behavioral Health Association
National Organization of Social Security Claimants' Representatives
National PTA
National Respite Coalition
NETWORK, A National Catholic Social Justice Lobby
School Social Work Association of America
State Associations of Addiction Services
TeenScreen National Center for Mental Health Checkups
Treatment Communities of America
Union for Reform Judaism
United Cerebral Palsy
The United Church of Christ, Justice and Witness Ministries
U.S. Psychiatric Rehabilitation Association
Witness Justice

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