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Saving SSI for Children with ADHD

By Soleil Gregg, MA

WITH ALL OF THE GAINS MADE for people with ADHD over the past twenty-five years, it's hard to remember a time when those disabled by ADHD were not eligible for special education services, accommodations in classrooms and the workplace, and Social Security disability. But recent questions in Congress regarding children with ADHD and Supplemental Security Income (SSI) under Social Security have pointed out that such gains should not be taken for granted.

The questions about ADHD and SSI were prompted by allegations of fraud in a series of *Boston Globe* articles, which reported that low-income families were having their children diagnosed with ADHD and giving them "psychotropic drugs, simply to secure [SSI] benefits." Concerned that a substantial number of children were being misdiagnosed with ADHD and unnecessarily medicated by parents and doctors, several congressional groups have requested investigations by the U.S. Government Accountability Office (GAO), focusing on medications and children with ADHD and other mental impairments in Medicaid, the Children's Health Insurance Program (CHIP), and foster care. At one point, language was in the House Budget Committee's report to remove "incentives for parents to place their children on medication solely to receive SSI benefits," and some wanted to eliminate ADHD from SSI altogether as part of spending cuts. The loss of disability status in one federal agency could jeopardize eligibility in others.

Certainly, fraud in any program should not be tolerated, but the *Globe* articles presented no hard evidence that fraud exists in SSI or is specific to ADHD—only a few anecdotes. In fact, the number of children who are approved for SSI for ADHD is relatively small, given current knowledge of the incidence of ADHD. Recent SSI data showed that

nearly seventy-one percent of children who applied for SSI for ADHD were denied, ranking ADHD in the lowest quartile of approval rates for childhood mental disorders.

SSI is intended only for those with great financial need and the most severe impairment. Social Security's definition of disability is quite restrictive, requiring the physical or mental condition to *very seriously* limit the child's activities and to be long-term in nature or to result in death. In addition, the



child's family must have "little or no income and resources." Most children with ADHD therefore would not qualify for SSI, but for those who do, SSI can supply much needed services and supports for the child and family and provide access to care and treatment that would be unavailable otherwise.

To save SSI for children with ADHD and other mental disorders, CHADD began working with the SSI Coalition for Children and Families, spearheaded by the Bazelon

Center for Mental Health Law, to address congressional concerns. In July, CHADD and other Coalition members met with Senate

Finance Committee staff, and CHADD arranged additional meetings with key members of Congress. Representing CHADD and families with ADHD were CEO Ruth Hughes and a mother, Suzanne Poe, whose young son receives SSI for ADHD and who was willing to come to Washington on a moment's notice and share her family's experiences. Several other families also stepped forward to assist CHADD, and their comments were included in handouts for the congressional visits. These meetings were very successful. The proposal to take ADHD out of children's SSI is now off the table, and ADHD is no longer a target in budget negotiations.

We are not out of the woods yet, however. There are still discussions about limiting the SSI program overall, and many programs will surely face cuts in future budgets. In addition, we have learned that Kathleen Sebelius, Secretary of the U.S. Department of Health and Human Services, has a special interest in medications for mental disorders in children enrolled in Medicaid and CHIP.

CHADD will review the GAO reports when they are released. We will keep you posted on events as they unfold and alert you about what you can do to help protect rights and services for people with ADHD. Rest assured that CHADD will do its very best to educate policymakers on Capitol Hill about the challenges facing children, adults, and families with ADHD and work to preserve the hard-fought gains we've made over the years.

Soleil Gregg, MA, is past secretary of CHADD's board of directors and past chair of the public policy committee and editorial advisory board for *Attention* magazine. She represents families with ADHD for CHADD on AACAP's Pediatric Pharmacology Initiative and is a member of the SSI Coalition. She is a retired education consultant and worked as a disability and policy specialist at one of the regional educational research laboratories and regional technical assistance centers. The mother of two grown children with ADHD, she is also an adult with ADHD.

The families speak

Read what some families have to say about the benefits of SSI for children with ADHD. Even for those of us fortunate enough to have adequate resources, caring for a child with ADHD can be emotionally and financially draining. Therefore, these stories should resonate with any family facing the daily struggle of helping a child with ADHD.



Hulston Poe

I can't express how much it has helped to have SSI for my son. It has relieved so much stress. I had medical coverage for him before getting SSI, but it only paid for limited treatment. Having SSI has opened doors to treatment options from other medical specialists and support services that he didn't have access to before. He's now on a medication that seems to work, and he's much happier—I can see the light in his eyes again. I can also afford good daycare that meets his needs, so I don't have to worry that I'm leaving him in an unsafe situation when I attend my college classes. Life is still a struggle because of my son's challenges, but having SSI has really taken the pressure off. —**Suzanne Poe, Des Moines, Iowa**

The youngest of my three children receives SSI and Medicaid for multiple mental health disorders. His father is now out of work and unable to pay child support, so SSI has been a lifesaver in getting treatment for my son. He is in day-treatment and summer programs at school which are partly funded by Medicaid, so if he didn't receive SSI, he wouldn't be eligible for these programs. He sees three counselors and a psychiatrist, so SSI helps with transportation expenses and my time off work to take him to appointments. SSI has also made it possible for me to attend parenting classes to learn behavior modification techniques, which have helped tremendously. My son goes to daycare after school while I'm at work but was expelled from a larger, more affordable daycare program. He now attends a more individualized daycare program, which I can only afford because of SSI. —**Amy Bond, Chesapeake, Virginia**

I am a grandparent raising a grandchild with illnesses that impede his development and intellectual functioning. After many therapies and changes in his treatment, my family had to seek aid from SSI. Without the support from SSI, it is sad to say that I would have to think twice about helping even my own grandchild. We have expended all of our resources trying to help him. Without SSI, it would be impossible to care for such a high-needs child. He is fourteen years old but is well below grade level in school and functions emotionally at times like he is seven. The constant wear on the family emotionally caused us to seek and start a support group to help other families. Now we are educated about the level of care that is involved for my grandson, but it took almost five years to learn that. Caring for a child with special needs like his is not an easy task. —**Deborah Allen, Miami, Florida**

My twelve-year-old son has received SSI since 2004, and it has been a major plus for his care and treatment. SSI helps my son go to programs he couldn't attend otherwise and covers the cost of his medicines, doctors, and counseling. Access to good medical treatment is the biggest benefit. He now has great health insurance through his school instead of Medicaid; many doctors in my state don't accept Medicaid patients, so his treatment options before receiving SSI were limited. He also now has one-on-one tutoring, and a counselor comes to school to meet with him there. I've seen a breakthrough in him because of that. SSI has been a tremendous blessing for my son and my family. —**Rhonda Osborne, Jackson, Mississippi** 🗣️