

**Testimony Submitted to the
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**

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Introduction

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) appreciates the opportunity to submit written comments regarding the hearing on October 27, 2011 by the Subcommittee on Human Resources on Supplemental Security Income (SSI) for low-income children with severe mental and/or physical disabilities. CHADD is the leading national advocacy and support organization representing people with ADHD and co-existing disorders.

CHADD is a member of the SSI Coalition for Children and Families, which is led by the Judge David L. Bazelon Center for Mental Health Law and comprised of national and grassroots organizations representing children and families with mental and physical disabilities. Over 80 national organizations have signed on to support the SSI Coalition's efforts to preserve SSI for low-income children with disabilities, including those with ADHD.

Background

ADHD is a chronic, neurobiological, highly heritable disorder and is the most common mental health disorder affecting children.^{1,2,3} A recent study by the Centers of Disease Control found that approximately 9.5% of children aged 4-17 have been diagnosed with ADHD, according to parents, although prevalence rates vary depending on diagnostic criteria, information source, age, gender, cultural background, and geographic location.⁴ Symptoms often persist into adulthood, affecting approximately 4 to 5% of adults.^{5,6} Research has linked ADHD to problems in brain development and maturation and specific neurotransmitters that are required for brain cells to communicate efficiently.^{2,7}

Although all children may be inattentive, impulsive, and overactive to some extent at times, a diagnosis of ADHD is only made when the following criteria are met:

- (1) A significant number of symptoms are observed (6 of 9 listed symptoms).
- (2) Symptoms persist for at least six months.
- (3) Symptoms appear before age seven.
- (4) There is significant impairment in a child's ability to function in at least two areas of life.
- (5) Other possible causes are ruled out.⁸

Therefore, a diagnosis of ADHD is made only when symptoms are extreme, pervasive, and persistent and cause significant impairment in daily living at home, at school or work, and/or in the community.

ADHD requires a comprehensive, multimodal approach to treatment, including parent training in the management of ADHD, behavior management techniques, school accommodations and supports, and medication, when appropriate.⁹ Multimodal treatment can be highly effective in decreasing the symptoms of ADHD and improving a child's functioning at home, at school, and in social situations, especially when certain co-existing conditions are present.^{1,2}

Children and teens with ADHD who go untreated are at high risk for school failure and drop-out, social and relationship problems, involvement with juvenile justice, substance abuse, and teen pregnancy.¹⁰ Children with ADHD have double the risk of accidental injuries as their peers,¹¹ and teens have two to four times as many car accidents.¹² In addition, research by the National Institutes of Mental Health (NIMH) indicates that two-thirds of children with ADHD have at least one other co-existing condition, which also may be severe, such as bipolar disorder, depression, anxiety, learning disabilities, and autism spectrum disorders.¹³ When multiple co-existing conditions are present, academic and behavioral problems, as well as emotional issues, may be even more debilitating and warrant more intensive treatments and supports.

Comments

CHADD endorses and supports the testimony submitted to this committee by the Judge David L. Bazelon Center for Mental Health Law and other SSI Coalition partners. In addition, CHADD would like to specifically respond to three areas of concern expressed in the January 14, 2011 letter from Congress to the Government Accountability Office that prompted the request for an examination of SSI regarding children with ADHD and mental impairments.

1. "An increasing share of SSI benefits is provided to families of children with various types of mental impairments," and "the number of children receiving SSI benefits for...ADHD and depression has increased rapidly."

As the GAO testimony to this committee indicated, it is true that the number of children applying for and receiving SSI for mental impairment, including ADHD, has increased over the past decade. However, as the GAO found, the growth in beneficiaries remains proportionate to the growth in applicants, and the majority of applicants with

ADHD as a primary diagnosis are denied SSI benefits. According to the GAO testimony and data from the Social Security Administration,¹⁴ the growth in the mental impairments category in recent years is due mainly to legal and policy developments that expanded eligibility for children with mental impairments and redefined diagnostic categories and not to unethical or illegal actions by families.

ADHD does represent the largest group within the SSI category of Other Mental Disorders, but this is to be expected, since ADHD is the most common mental disorder in children. As previously stated in this testimony, the percentage of children diagnosed with ADHD has also increased in recent decades to approximately 9.5% of children aged 4-17, based on parent reports. However, only 4% of those children diagnosed with ADHD--the most severely impaired and lowest income children—qualify for SSI.¹⁵ The GAO reports that the majority of applicants with ADHD as a primary diagnosis, over 72%, are denied benefits, putting children with ADHD in the bottom quartile of approval rates. Furthermore, Social Security examiners told GAO interviewers that children rarely qualify for SSI based on ADHD alone; rather, most children with ADHD approved for SSI have other conditions in addition to ADHD, which compound problems and further impair functioning.¹⁶

2. "...The number of children prescribed drugs to treat ADHD...has dramatically increased....Some families, in an effort to make their children eligible for SSI benefits and increase their household income, have resorted to medicating their children with powerful psychotropic drugs."

Medication has been shown consistently by research to be a safe, effective treatment for ADHD, and the practice parameters and guidelines of major medical organizations, including the American Academy of Pediatrics and the American Academy of Child and Adolescent Psychiatry, support the use of medication for severe ADHD in children and adolescents.^{1,17} Therefore, it would be reasonable to assume that the majority of children seen by a doctor for severe ADHD would appropriately be prescribed medication.

Stimulants are the most studied and widely used medications for ADHD, though several non-stimulant medications also appear to be effective for the management of ADHD symptoms.^{1,17,18} Although the number of children taking ADHD medications has increased over recent years, research by the CDC also shows that many children with ADHD who might benefit from these medications are not taking them, so that under-treatment of ADHD remains a problem.⁴

It also must be noted that ADHD medications are prescribed by licensed medical professionals based on professional standards of assessment, diagnosis, and treatment and are not available for families to purchase over-the-counter, so the suggestion that children are frequently and wrongly given powerful drugs to obtain SSI and increase family income does not just cast aspersions on families but also implies collusion in fraud and/or malpractice by the medical profession. However, a prescription for medication alone, including medication for ADHD, does not qualify a child for SSI benefits. The GAO testimony to this committee reports that Social Security Administration looks at multiple

sources of information in assessing a child's impairment and determining medical eligibility, including medical records, school records, and parent and teacher assessments. In fact, the data show that children taking ADHD medications are just as likely to be denied SSI as they are to be found eligible for SSI.¹⁹ According to GAO testimony, the Social Security Administration considers the child's functioning while taking ADHD medication, and if medication reduces the severity of symptoms and improves the child's functioning, the child will be less likely to qualify for SSI.

3. "Such trends raise numerous concerns, including...the extent to which SSA properly monitors the initial and continued eligibility of children with mental impairments, and the implications of placing children on the disability rolls for extended periods of time."

Research shows ADHD to be a chronic, lifespan disorder for many individuals.¹² Approximately 60% of children with ADHD will continue to have ADHD symptoms as adults, with accompanying problems of low educational attainment, low college attendance and completion, low job retention and performance, lower socio-economic status, higher rates of tobacco use and substance abuse, more motor vehicle violations, higher divorce rates, more dependence on social services, more involvement with the justice system, and shortened life expectancy.^{12,20,21} While the goal of treatment in childhood is to improve functioning, prevent or reduce future negative outcomes, and promote self-sufficiency in adulthood, the awareness of the potential for continued negative outcomes points to the importance of maintaining adequate and appropriate services to support a child's successful transition to productive adulthood.

Recommendations

CHADD endorses and supports recommendations set forth in the testimony of the Bazelon Center and other SSI Coalition partners and suggestions for improving SSI, such as supporting transition-age youth in employment, helping families to access services, increasing funds for continuing disability reviews, and authorizing and funding an IOM study of children's SSI. In summary, CHADD would like to reiterate the following points:

- **Investing in SSI for children with ADHD and mental impairments is smart policy.** Investing in children's SSI can prevent or reduce greater demands and dependence on federal and state services in the future, reduce stress on struggling families, and improve child and family functioning and well-being. Because ADHD can be a lifelong disorder, early diagnosis and appropriate treatment and supports can be essential to helping children and teens with ADHD achieve self-sufficiency and avoid progressing to disability status as adults. SSI can make a difference by providing low-income children access to treatment and services that are critical for preventing negative outcomes and promoting success in school and work, so that children with disabilities can become productive, contributing members of society. Children's SSI can also support the employment of adult family members by improving a child's functioning so that family members miss fewer days of work to care for their child and by making it possible for families to afford daycare or after-school care.

- **The budget should not be balanced on the backs of the neediest and most vulnerable children.** Children's SSI provides access to critical treatment and support that benefit not only children and their families but, ultimately, all of society. Caring for a child with disabilities can be emotionally and financially draining for any family, but families with inadequate financial resources can experience significant stress and extreme financial hardship in obtaining the most basic services for their children. Families of children with severe ADHD who receive SSI report to CHADD that SSI has been a godsend, paying for essential services such as medical treatment, counseling, tutoring, transportation to appointments, and specialized daycare so that parents can go to work—all of which were previously unaffordable for them. Budget-cutting measures such as reducing SSI funding, further narrowing eligibility criteria, or making the program a block grant would needlessly burden and harm children with disabilities and their families and could instead increase public costs related to child welfare, public safety, healthcare, juvenile justice, institutional care, unemployment compensation, and adult disability payments.
- **CHADD urges the committee not to reduce support for this vital program.** While CHADD does not condone fraud or abuse and was equally disturbed as members of Congress by allegations in the *Boston Globe* series, particularly those concerning ADHD and ADHD medications, anecdotes and unsubstantiated claims should not be used to make policy and determine Congressional action. Any reforms to the SSI program must be based on facts to ensure the best possible outcomes for this most vulnerable population and for society as a whole.

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