

## CHADD'S RECENT SURVEY ON HEALTH INSURANCE COVERAGE AND ADHD

October 2016

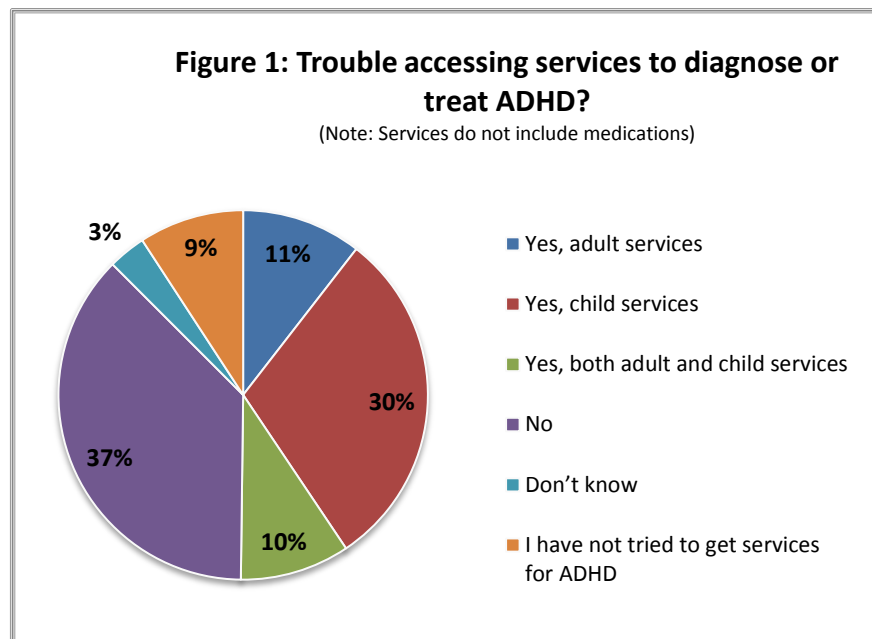
In September, CHADD conducted a survey about health insurance coverage and attention deficit hyperactivity disorder (ADHD) in the United States. More than 1500 people from all 50 states and Washington, D.C. took part in the online survey and answered 15 anonymous questions about their personal experiences seeking access to services and medications for their, or a family member's, ADHD.

**Why ask?** Prior to conducting this survey, CHADD occasionally heard from members about difficulties accessing ADHD specialists, diagnostic and therapeutic services, and medications. We did not know whether these circumstances were the exception or the rule. Although this survey is not scientific,<sup>1</sup> it is helping CHADD to better understand the types of challenges faced by individuals and families with ADHD. And we learned a lot!

**What we learned.** 95% of people taking the survey have a health insurance policy that includes coverage for themselves or a family member with ADHD. Figure 1 shows that over half of these individuals (51%) reported that they had trouble accessing services to diagnose or treat ADHD.

Specific challenges included:

- A limited number of ADHD professionals who accept insurance
- A limited number of ADHD specialists in a geographic area
- Out-of-pocket costs and/or high co-pays or deductibles
- Insurance not covering or only covering a percentage of the costs
- For adults, insurance often only covering medication, but no other services.



About 60% of respondents had issues with medication access with 18% reporting that their insurance denied or refused to cover prescription ADHD medication for themselves or a family member. Additional issues are detailed in figure 2. Many people also described issues because of the controlled substance requirements of ADHD medications such as pharmacies having medication shortages and questions about the legitimacy of their prescription.

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<sup>1</sup> Although helpful in providing new information, surveys conducted in this manner are susceptible to a voluntary response bias, which has a tendency to over-represent those with strong opinions (e.g., those who really like or dislike their insurance coverage).

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Figure 2: Have you had any other trouble accessing ADHD medications under your health care or pharmacy benefit plan?	Response Percent
Yes, it requires "prior authorization"	30.5%
Yes, it requires my doctor to contact the insurer directly	14.1%
Yes, it requires other paperwork	12.9%
Yes, it imposes quantity limits on my medication	29.3%
Yes, it imposes age restrictions on my medication	4.8%
Yes, it requires me to try another drug first	13.0%
Yes, it requires me to use a generic version	25.0%
Yes, it charges a higher co-pay for my preferred medication	26.8%
Yes, it does not cover my preferred medication	10.5%
No, I have not had trouble accessing medications	30.8%

Many people gave examples of their difficulties:

*"I don't have any problems getting the care for my daughter as long as I pay out of pocket. My deductible is so high."*

*"Scheduling appointments is challenging because they book out 3-4 months for new appointments"*

*"My son is allowed only 15 Adderall per month. It works great for him. But the other 15 days he has great difficulty functioning without extreme frustration and mood swings."*

*"When you really need the medication to function properly and you are taking it per doctors instructions, you are not an addict or addicted. You're simply trying to live a normal life. To be discriminated against in this manner is unforgivable!"*

There is still much to be learned from all the survey responses. For example, CHADD will analyze the unique experiences of residents of different states, as well as those covered through different programs, and even different insurance companies.

**Looking to the future.** Once fully dissected, these survey results will be used by CHADD to revisit our priorities and positions relating to health insurance coverage for ADHD treatment. We plan to follow-up this online survey with targeted focus groups and other outreach to better understand some of these issues.

CHADD's leadership, full-time staff, public policy committee, and outside consultants are constantly working to address problems faced by our members and the broader ADHD community. We are engaged in ongoing dialogue with other stakeholders, thought leaders and policymakers about ways to improve federal, state and local health care policies that impact those with ADHD. This survey is helping us to fine-tune our advocacy message, and to back it up with concrete examples of the issues people with ADHD face every day. For this, we thank the more than 1500 of you who took the time to complete the survey and to help us help you!

**Questions?** If you have questions or comments on CHADD's health insurance survey or to bring specific concerns to our attention, please contact CHADD at 1-800-233-4050 or email us at [survey@chadd.org](mailto:survey@chadd.org).