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**W**HEN WE PUBLISHED "ADHD AND YOUR EXTENDED FAMILY" in the June 2014 *Attention*, very little had been written about the impact of ADHD beyond the immediate family. Based on our initial research and the response to that article, we realized that there was practically no data, but there were many anecdotal stories about how individuals with ADHD interact with their extended family, and how those interactions affected relationships within the extended family. To substantiate this with data, we developed an extensive questionnaire that was sent electronically to CHADD coordinators across the country.

Distributing the questionnaire to CHADD members meant that all responses would come from individuals who either have ADHD or have family members with ADHD. We sought to develop a sense of the population that responded and the extent to which ADHD impacted their lives. We assured everyone that responses would be treated in strict confidence.

### **Demographics and stories**

We received 132 responses, rich with data and stories. The stories were filled with the struggles and sadness so many of us know about, but there were also many stories of success and redemption. Seventy percent of the responses came from the East Coast, twenty percent from the West Coast, and ten percent from other areas. Eighty percent of the respondents were women between the ages of 25 and 70. One-third reported that they have ADHD, while two-thirds said they are not diagnosed with ADHD. Over eighty percent said they live with one or more family members who have ADHD.

Sixty percent reported that there was only one recognized family member with ADHD, whereas forty percent identified at least two or three family members with ADHD. It was not clear from the data or stories how many family members were thought to have ADHD but were undiagnosed.

Of the family members identified as having ADHD, sixty-five percent were sons, and thirty-five percent daughters—twice as many boys as girls. In some families, there were both! Twenty-five individuals with ADHD were identified as spouses or significant others. As expected, when the person with ADHD is actually living within the family unit, the impact of ADHD symptoms is noticed more by the family members around them than by the extended family.

We also saw from the data and stories that extended family members notice more males than females with ADHD symptoms. This is consistent with both their relative numbers, and research data that shows females tend to exhibit less hyperactivity and impulsivity than males.

Ranging from descriptions of significant life struggles to positive stories of reaffirmation and success, the stories we received were touching.

# Research on ADHD and the Extended Family





# On the Questionnaire

In addition gathering information about respondents' location by zip code, gender, and age range, we asked the following questions:

- Do you have ADHD, and if so, how were you diagnosed?
- Do you live with a family member who has ADHD?
- Who in your family has ADHD?
- Does your extended family know that your family member has ADHD?
- How do the other family members, including yourself, respond to the family member with ADHD?
- How does the family member with ADHD engage with the extended family?
- How much time do family members spend interacting with the individual who has ADHD?
- Do other family members tend to "over-function" for your family member with ADHD?
- Does your family member with ADHD have any of these specific behaviors (from a list we provided)?
- In some families, the person with ADHD is recognized for their positive qualities. How is your family member with ADHD viewed by your extended family, according to a specific set of qualities we listed?
- Do your family members think that the person who has ADHD has control over their ADHD behaviors?
- What stories do you have about your family member who has ADHD?

As expected, the overall experience of family members was that the person with ADHD appeared to struggle with finding appropriate ways to engage in social settings, whether the gatherings involved immediate or extended family.

The greatest number of responses focused on the negative behavior patterns of the person with ADHD, pointing either to behavior deficits or bad habits. Out of a long list of negative behaviors, here are the top five:

- acts impulsively without thinking
- has a messy room/house/work space, etc.
- tends to interrupt a conversation
- struggles with time management and punctuality
- gets easily irritated

There were a few isolated comments, such as "we get different responses from different family members at various times," but they were not the norm. The bulk of the responses were mostly negative or mostly positive. Negative responses used words like "frustrated," "impatient," and "annoyed." Positive responses included "supportive," "understanding," and "patient."

In social settings, respondents said that their family member "seems arrogant or aggressive," "is unable to relax," "loses everything," "finishes sentences for me," and "talks constantly."

In speaking for themselves and their extended family, it was clear that people felt there are still many misunderstandings and misinterpretations about ADHD and its related behaviors. Perhaps most importantly, respondents asked how they can deal effectively with extended family.

Respondents submitted hundreds of stories; most were deeply personal. We grouped them into five categories: struggle, stigma and denial, bad parenting, isolation, and success. They bear witness to the true impact of ADHD on the extended family. Edited for brevity, the quotes that follow are representative.

## Stories of struggle

*"Holidays and birthdays are always problematic."*

*"During Thanksgiving dinner at Grandma's house, my son said something rude to his father. My brother-in-law commented that he wouldn't tolerate that behavior from his child, and called my son a smart ass in front of everyone. My son didn't say anything, but regrettably, I did. I retorted with 'I now understand why your daughter lives a thousand miles away.'"*

*"While there are a few core members of our immediate and extended family who are beginning to treat, understand and accept ADHD, we have another side of our family who denies any type of brain disorder, and is totally against medication."*

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### Stories of stigma and denial

*"My extended family often feels embarrassed by my son."*

*"His grandparents made fun of their 'pill popping' grand-son because he was on medication."*

*"I don't enjoy attending family functions at my in-laws due to the fact that they don't understand what ADHD fully is. Taking my son is always a problem. I'm always on edge, worrying if he's going to say something incorrect, hurtful or rude, according to them."*

*"I talk with my extended family members prior to events, informing them of what my boys can handle, and telling them to expect their loud voices and impulsive behavior. Our boys rarely talk to their aunts and uncles because they are either ignored or preached to. I now set boundaries with family events."*

### Bad parenting stories

*"Our extended family members think that our ADHD child isn't parented properly, since he does not like to sit at meals, and cannot follow all the conversation."*

*"My sister cannot stand my daughter. She lives out of state and we rarely visit. My sister feels like ADHD, ODD, etc., all amount to lazy parenting and not enough beatings! [emphasis mine]. Whenever we visit her house, she tries to 'show me' how parenting is done."*

*"Our son's grandparents all disagree with the diagnosis and are very unsupportive. His aunt and uncle know he has ADHD, yet get very annoyed and judgmental about his behavior, and say it's my fault."*

### Isolation stories

*"We are regularly told that ADHD doesn't exist, or that the only reason our kids have it is because we aren't good parents. That if we were more disciplined, they would be fine. We blame ourselves, believing that we were simply failures as parents. We feel pretty isolated, and often say 'It's our family of four against the world.'"*

*"Several members of my family have ADHD. They each go their own way. There is not much 'closeness'—we're a family of loners."*

*"Our son's cousins, aunts and uncles are very intolerant. I find them distancing their kids from my son, as if he was a bad influence."*

*"All my friends have abandoned me due to my son's behaviors. I am a single mom with no family or any other support... I've lost it all."*

### Positive stories

*"Our grandson has such a kind heart and is very loving, so that it is easy to overlook his behaviors that are not as positive."*

*"My ADHD child has not impacted family events for anyone but me. My extended family continues on with what is occurring, and lets me handle his behavior."*

*"With a strong presence of ADHD in our family, extended family gatherings are complex with some people dominating the conversations; others getting lost in the crowd; lots of inattention and constant interruptions. There are varying degrees of frustration, intolerance and understanding, and a lot of advice giving. But it's a lively group, with lots of humor and love."*

### Success stories

*"My extended family is very supportive and accepting of the large number of ADHD individuals in the family, and frequently joke about it. Most of us are very successful; have a lot of energy; and enjoy one another. Like all families, we fight, but we also accept and forgive and understand."*

*"Because of several incidents with my sister when our son was younger, she took years to forgive him and would not invite us to their home. After several 'heart-to-heart' conversations, she came to understand his shortcomings, and could then have conversations with him about what bothered her about his behaviors. He is now 22, and today has a wonderful relationship with my sister."*

*"My son is now 27 and has effectively learned to manage his ADHD. He has become the one member of our extended family that keeps in touch with everyone regularly."*

We are grateful to the CHADD members who shared their information and stories with us. Without them, this work would not have been possible. Based on the positive response and interest in our initial research, we are now working with several academic groups on proposals for a more detailed questionnaire and collaboration on original qualitative studies to further explore the impact of ADHD on the extended family. 🌱



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