



Broadening Our Understanding of ASD in Girls

by Kate Forster

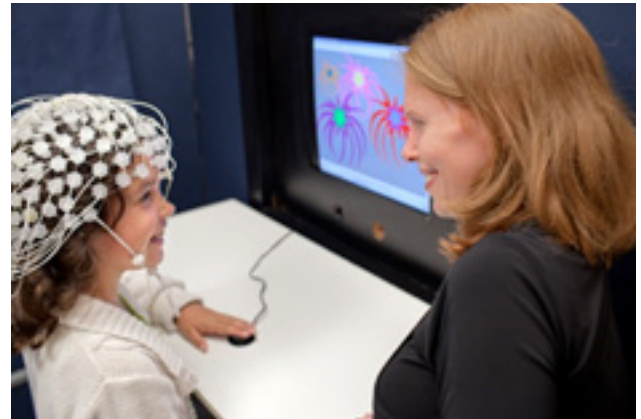
It is widely accepted that boys are four to five times more likely to be diagnosed with autism spectrum disorder (ASD) than girls are, and that for children at the high-functioning end of the spectrum, the gender ratio is estimated to be 10 to 1. However, little is known about why this is the case or about the implications of these statistics as it relates to girls. Is it truly the case that there are fewer girls with ASD, or could it be that ASD manifests differently in girls than in boys, and clinicians are missing the signs?

Most ASD screening and diagnostic tools were developed based primarily on observations of behaviors in boys, and the result is that we know very little about whether and how autism might be different between girls and boys. This could mean that girls with ASD may not be getting the help they need. Few studies so far have explored these questions.

This is what Sara Webb, Ph.D., wants to investigate. Webb is an associate professor in the department of psychiatry and behavioral sciences and a CHDD research affiliate. She is conducting research with CHDD research affiliates Raphael Bernier, Ph.D., and Elizabeth Aylward, Ph.D., and collaborating with colleagues at Autism Centers at Yale University, UCLA, and Boston Children's Hospital/Harvard University in order to expand our understanding of what ASD looks like, particularly in girls. "In most research samples right now, girls make up less than 20%, so it is often the case that conclusions are drawn based on male samples," said Webb. "In our research, we're specifically saying that we're going to combat this bias. We're inviting a large number of girls to be equal participants in our study with the hope to better understand the diverse profiles of girls with ASD." Webb believes that by identifying behaviors that may be specific to girls with ASD, they could then verify whether current screening and diagnostic tools adequately capture these behaviors. This is particularly important with ASD, where the earlier the intervention, the better the outcome.

Three levels of analysis

The study involves 300 girls and 300 boys ages 8 to 18 who have been diagnosed with ASD and their families. To better understand the characteristics of girls who have been diagnosed and how they might differ from boys with the diagnosis, Webb and her team are taking measures using three different modalities and plan to analyze the interaction among them. They are studying and comparing the behavioral characteristics of girls and boys with ASD; they are also looking at brain functioning, and they



Sara Webb wants to uncover the specific characteristics of ASD in girls.

are reviewing genetic profiles. By analyzing the data from these three different types of measures, they hope to get a comprehensive view of how the brain is working and identify any differences in behavior and brain functioning based on diagnosis and gender.

First, families are brought in for a diagnostic procedure, and quantitative measures are taken to understand the symptom characteristics of ASD using standard clinical diagnostic tools. Then, Webb and her team use both electroencephalogram (EEG) and functional magnetic resonance imaging (fMRI) technology as the participant performs a battery of tasks. The EEG shows the temporal characteristics of how the brain is working as the participant completes a task, and the fMRI provides an anatomical view of the areas of the brain that are being activated. “We’re looking at brain correlates of the same skills,” said Webb. “The tasks we chose are the ones we think may potentially show gender differences, such as social attention, language, and reward-processing. Webb and her team are also collecting blood samples for DNA analysis on all of the families in the study, and they plan to look at the different aspects of the genetic contributions within and among the families. She plans to analyze how the genetic findings might differ in the girls versus the boys.

Once all of the data has been collected and analyzed, Webb hopes to gain deeper insights into girls who have the diagnosis. In particular, she hopes to learn whether it is the case that clinicians are not expecting girls to have ASD and are missing the signs. This is certainly possible, according to Webb. “A set of interviews we conducted with the mothers suggests that there may be a gender bias around the way we currently define ASD. The mothers reported very long times to diagnose ASD in their daughters. They also talked about getting a lot of pushback from pediatricians and family members, who dismissed the idea that their daughters might have ASD. From this, we know that there probably are some cultural biases in place that result in girls not getting the attention they need in their struggle with ASD.”



The Psychophysiology and Behavioral Systems lab, from left: Sara Webb, Megha Santhosh, Casey Guiland, Erin Libsack, Emily Neuhaus, Anna Kresse, Sarah Corrigan, and Raphael Bernier.

Another question Webb hopes to answer is whether there are protective mechanisms that affect brain functioning or genetics that prevent girls from having the same types of symptoms as boys or that decrease the severity of their symptoms. “I think there are a number of different reasons why there may be a difference in the ratio of males to females diagnosed with ASD, and with this research, we hope to tease apart whether this truly is a disorder that affects boys more than girls, or whether there is a bias in some other aspect of how we define ASD. By looking at genetics, brain functioning, and behavior in girls diagnosed with ASD and really making sure that we have wide sampling of girls in our research, we will be better able to determine this,” said Webb.

Broad implications for the field of ASD research

Webb believes that understanding gender-based differences in ASD will help researchers and clinicians understand ASD more broadly. “I think this study definitely has implications for this potentially underdiagnosed and underserved population. It’s going to enhance the outcomes for these girls,” she said. When this study is completed, she hopes to follow it up with another grant. “We’re really excited about the potential to follow these participants as they transition into adolescence and young adulthood. These are really big transitions that can be particularly vulnerable periods for typically developing girls, and the vulnerability is even greater for girls with ASD. They have very specific struggles that are different from males. We’re hoping that this study will set the stage for understanding more about how these girls make the transition into and out of adolescence. We really want to gain a deeper understanding of the outcomes for these girls,” she said.

CHDD is an interdisciplinary center dedicated to the prevention and amelioration of developmental disabilities through research, training, clinical service, and community outreach. CHDD includes the University Center of Excellence in Developmental Disabilities and the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center.

CHDD Outlook

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