

DEVELOPING A SCREENING TOOL TO IDENTIFY YOUNG WOMEN WITH AUTISM SPECTRUM DISORDER

After years working with individuals with ASDs and their families, the authors realized that young women required a gender-specific screening tool to get the early help they need.

by Debra Eisert, Associate Professor, College of Education and Haidee Copeland, PhD

Consensus is growing among research scientists and clinicians that there is a pronounced gender difference in Autism Spectrum Disorders (see Rivet & Matson, 2011 for a review), and extrapolating diagnostic criteria and assessment instruments to females may be problematic (Rutter, Caspi, & Moffitt, 2003). Autism Spectrum Disorders (ASDs) may exist at a higher frequency than previously expected among young women with average or above intelligence (i.e., high-functioning). The standard reported ratio of males to females is about four to one for all individuals with ASDs, but young women with this disorder may not be recognized until middle school or later, when their limited social communication skills make it difficult to understand the social life of their peers, and to cope with daily life. Researchers and clinicians agree that there are potential problems with how high functioning Autism Spectrum Disorder (HFASD) is recognized among girls and young women (Kopp & Gillberg, 1992). Young women with diagnostic symptoms that overlap with autism may be screened out or identified for a different disorder because their symptoms are milder than boys (Dworzynski, Ronald, Bolton & Happe, 2012; Kopp & Gillberg, 1992). Young girls with ASD might be more easily identified if they also have developmental delays and their symptoms are similar to those of boys.

After years of experience working with individuals with ASDs and their families, the authors became aware of a growing number of young women who, despite years of struggling, are neither diagnosed with, nor receiving necessary services for, HFASD until middle school or beyond. We wondered if the fault might lie with the tools used to screen for HFASD in young women (ages thirteen to twenty-six), as well as the education and training of teachers, parents, and other providers who address the needs of these young women on a regular basis.

The authors decided to develop a short and simple autism-screening tool that could identify females with an increased risk of HFASD, and which might alert professionals to the need for formal evaluation. Parents, teachers, support providers, or young women complete the screen. With the support of the Center for the Study of Women in Society, we reviewed the literature, developed screening items, consulted experts and beta-tested the screen.

The authors used an iterative development process to create and test the tool. We reviewed a variety of autism tools and created a list of sixty common characteristics of HFASD in young women ages thirteen to twenty-six that did not have histories of intellectual delays. Teachers and parents who have experience with young women on the spectrum rated the utility of the sixty items. Based on their input, the original sixty-question screen was refined and reduced to twenty-two questions. A few new items were added based on experts' judgment.

Twenty-five parents and twenty-five teachers were recruited to complete an online scale, rating a young woman with ASD whom they taught or parented. Participants completed the rating so that the utility of individual items for both parents and teachers could be examined. Twenty-four items were retained for the final screen. Both teachers and parents reported



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that they felt strongly that the survey would be an effective screening tool for screening young women with potential HFASD.

We have now developed separate versions for parents, teachers, and youth. The screen is being used in a clinical setting, which serves the needs of transition-aged young people with HFASD and other disabilities. The purpose of this phase is to get expert opinion on the clinical utility when used with a sample of males and females with a variety of disabilities, and to compare it to a screen designed for males and females with a wider age range. The results of this work will help us to refine our screening tool and obtain useful information for seeking further funding. We want to contribute to screening and potential identification of young women with HFASD who need support so that they achieve their own unique life goals. We appreciate the funding provided by CSWS for this work. ■

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—Debra Eisert received a 2013 CSWS Faculty Research Grant in support of this research. She is a psychologist with thirty years of experience working with children and adolescents with disabilities. She is a full clinical professor at Oregon Health Sciences University (OHSU) in the Department of Pediatrics and an associate professor at the University of Oregon in the College of Education. Dr. Eisert is involved in research on the early emergence of autism in infants and toddlers and in gender specific characteristics of autism spectrum disorders.

—Haidee Copeland, who holds a PhD in special education from the University of Oregon, is an educator and an autism research scientist with over thirteen years of experience working with individuals with disabilities, their families, their teachers, and other support staff. She also has “the distinct honor of being the parent of an individual with an autism spectrum disorder (ASD).” Her current research activities have been in collaboration with Dr. Debra Eisert and have focused on identifying gender specific characteristics of ASDs.

Editor's Note: For more information, please contact Haidee Copeland, Ph.D., or Debra Eisert, Ph.D.