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 and other disabilities. 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.

REFERENCES

—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.