

The DSM-V debate

The American Psychiatric Association is updating its *Diagnostic and Statistical Manual of Mental Disorders* (DSM), and a great deal of buzz surrounds the proposed changes in the fifth edition. The changes collapse the four disorders—autism, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder—not otherwise specified (PDD-NOS)—into one: autism spectrum disorders (or ASDs, for short).

While DSM-IV called for three areas of evaluation, commonly called domains (communication, social interaction, and repetitive behavior), DSM-V reduces the domains to social/communication deficits and fixated interests/repetitive behaviors and has more stringent criteria. DSM-V also calls for diagnosticians to note the amount of support the person needs within each domain: support, substantial support, or very substantial support.

Implementing these new criteria creates questions for researchers, service providers, and families and individuals with ASDs. The answers are complicated by the autism community's inability to see how the new criteria will impact us in the future. From Autism Delaware's experience with POW&R, we know that support needs are difficult to predict and can change very quickly, so we question any prediction of support needs at the time of diagnosis.

How will DSM-V affect individuals who are higher functioning? We know that the diagnosis *as is* doesn't work very well for people at the high end of the spectrum. Diagnosis is not an exact science; it depends on the tools being used, the diagnostician's knowledge and experience with ASDs, and how the diagnostician interprets the standards: Were the right questions asked? Did the family provide the correct information? Has the child been seen in more than one setting?

According to Dr. Dan Hoover, formerly of the Delaware Division of Prevention and Behavioral Health Services and currently with the Kennedy Krieger Institute, children with Asperger's syndrome are as likely to be under-diagnosed as over-diagnosed. This is unacceptable. The key to effective treatment and supports is good diagnosis, so this issue must be addressed.

The DSM-V standards are more stringent around social interaction and communication criteria and include sensory-processing criteria for the first time. Individuals with sensory issues may now receive an ASD diagnosis. This leads the autism community to be cautiously optimistic.

How will this change affect services? The concern is that people on the high end of the spectrum won't be included in the diagnosis and, thus, won't be eligible to receive the services they need. It's an issue that's already pervasive in Delaware. Every year, about 100 families with children with high-functioning autism contact Autism Delaware™, looking for help in getting needed education or services.

Too often, no services are available. And education for teachers and school psychologists is only starting to catch up with high-functioning spectrum disorders, so schools struggle with how to diagnose and educate. Children who might be eligible for mental health services from the Delaware Division of Prevention and Behavioral Health Services lose this eligibility when they turn 18, and the adult system does not recognize the same eligibility standards.

We are fortunate that, about four years ago, the Delaware Division of Developmental Disabilities Services changed eligibility to accept individuals with Asperger's syndrome. Unfortunately, few services were available. Providers are now starting to step up to this population, but no insurance typically covers these services. As a result, the entire cost is borne by the family, education system, and state agencies.

What will Autism Delaware do? We must be vigilant and active as the standards in the new DSM-V continue to be developed and implemented. We are hopeful that better understanding and more specific diagnosing criteria will improve the landscape for people with autism, but we will be monitoring the process to make sure that Delaware's children and adults with ASDs who need services do not lose eligibility. In other words, we need to keep advocating and working to ensure that services are available for all who need them, regardless of diagnosis.



Helping People and Families Affected by Autism

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