

Debate about the New DSM-V

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There has been a great deal of buzz about proposed changes in the Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychiatric Association. The proposed changes will collapse the four disorders known as autism, Asperger Disorder, childhood disintegrative disorder and pervasive development disorder-not otherwise specified (PDD-NOS) into one new disorder, called Autism Spectrum Disorder.

The DSM-IV calls for three areas of evaluation, commonly called domains. These areas are communication, social interaction and repetitive behavior. The proposed DSM-V reduces the three to two domains; social/communication deficits and fixated interests and repetitive behaviors, with more stringent criteria.

Additionally, in the proposed DSM-V, diagnosticians are expected to note the amount of support the person needs within each of the two domains. The support levels include support, substantial support, and very substantial support.

It is the implementation of these new criteria that creates questions for researchers, service providers, families and individuals with autism spectrum disorders. This is a complicated issue and we don't have a crystal ball to look into the future to see how it will impact our community. We know from our experience with POW&R that support needs are difficult to predict and can change very quickly in either direction, so we question predicting support needs at the time of diagnosis. We are also concerned about eliminating the term "Asperger" because it connotes a very different picture than autism, which we think assists with clarity.

How Will the New DSM Affect Individuals Who Are Higher Functioning? We know that diagnosis as it is doesn't work very well for those at the high end of the spectrum. Diagnosis is not an exact science. It depends on the tools being used, the knowledge and experience the diagnostician has with autism spectrum disorders; and how the diagnostician interprets the standards. Were the right questions asked? Did the family provide the right information? Has the child been seen in more than one setting? According to Dr. Dan Hoover, formerly of Delaware's Division of Prevention and Behavioral Health and currently with Kennedy Krieger, Delaware's children with Asperger's are equally likely to be under-diagnosed and over-diagnosed. That's unacceptable.

The key to effective treatment and supports is good diagnosis, so something needed to change. While the new standards are more stringent around social interaction and communication criteria, for the first time sensory processing criteria are included, so it's possible now that individuals with sensory issues can receive a diagnosis of Autism Spectrum Disorder. That leads us to be cautiously optimistic.

How will this affect services? The concern that those 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 is real, but it is an issue that is already pervasive in Delaware. Every year about 100 families of children with high functioning autism contact Autism Delaware looking for help to get the education or

services they need. Too often schools do not know how to support these students and families aren't sure how to effectively advocate for services. Teacher and school psychologists' education is just starting to catch up with high functioning spectrum disorders so schools struggle with how to diagnose and educate children.

Children who might be eligible for mental health services from the Division of Prevention and Behavioral Health lose that eligibility at age 18; and the adult mental health system has different eligibility requirements. We are fortunate that the Division of Developmental Disabilities Services changed eligibility to accept individuals with Asperger's about four years ago, but there have been few services available for them to purchase. Providers are starting to emerge, but there is typically no insurance coverage to pay for it, so it's up to families, the education system and state agencies to bear the entire cost.

What will Autism Delaware do? We must stay vigilant and active as these new standards 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 to make sure that children and adults with autism in Delaware who need services do not lose eligibility in the process. More to the point, we need to keep advocating and working to make sure that autism services and supports are available for all those who need them regardless of where they fall on the spectrum. In the meantime, as a parent, it's important to advocate for your child based on his or her needs in each of the domains. It's the need rather than the diagnosis that should drive services, particularly within the educational system.

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