



Q&A:

Autism Spectrum Disorder (ASD) and Changes in the DSM 5

produced by

Debbie Dorfman and Cathy Costanzo
Center for Public Representation (CPR)
with a grant from the Training and Advocacy Support Center (TASC)

June 2013

Q: What is Autism Spectrum Disorder (ASD) and what will the changes to the diagnosis of ASD in the DSM 5 likely mean in practice and service delivery?

A: Autism Spectrum Disorder (“ASD”) is a “range of complex neurodevelopment disorders, characterized by impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior disorder.”¹ Previously, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (“DSM IV TR”) divided autism spectrum disorders into five separate categories. DSM 5, released at the American Psychiatric Association’s Annual Meeting in May 2013, will group these separate categories, under one umbrella diagnosis entitled “Autism Spectrum Disorder.”²

¹ “Autism Fact Sheet,” National Institute of Neurological Disorders and Stroke, National Institutes of Health available at: http://www.ninds.nih.gov/disorders/autism/detail_autism.htm (last visited February 8, 2013).

² American Psychiatric Association (“APA”) NEWS RELEASE Jan. 20, 2012, Release 12-03, available at <http://www.dsm5.org/Documents/12-03%20Autism%20Spectrum%20Disorders%20-%20DSM5.pdf> (last visited Feb. 13, 2013). Rett’s disorder will be removed from the single diagnosis of autism spectrum disorder under the DSM V. Sally Ozonoff *Editorial Perspective: Autism Spectrum Disorders in DSM-5-An historical perspective and the need for change*, 53 J. CHILD PSYCHOLOGY & PSYCHIATRY 1092 (2012).

Introduction

According to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, autism spectrum disorders were divided into five separate categories. These categories were autistic disorder (*a.k.a.* “classic autism”); Asperger’s disorder (*a.k.a.* “Asperger’s Syndrome,”); Rett’s disorder (*a.k.a.* “Rett’s syndrome), childhood disintegrative disorder (“CDD”); and pervasive developmental disability not otherwise specified (“PDD NOS”). Each condition was defined by its own set of diagnostic criteria in the DSM TR IV.

Although these separate conditions have individual diagnostic criteria, each have several features in common. These include: problems with verbal and nonverbal communication, social interaction and skills, and “restricted, repetitive, and stereotyped patterns of behavior.”³

The diagnostic criteria for ASD, however, was dramatically changed when the new Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (“DSM 5”) was published in May 2013.⁴ DSM 5 groups these separate conditions, except for Rett’s disorder, under one umbrella diagnosis entitled “Autism Spectrum Disorder.”⁵ Once grouped, these disorders will be viewed and diagnosed on a continuum from “mild” to “severe”.⁶ Under the DSM IV TR, clinicians were required to diagnose each condition, based upon the answer to “yes” or “no” questions, whether the individual meets each diagnostic criteria for

³ Judith Coucouvanis, Donna Hallas, & Jean Nelson Farley, *Autism Spectrum Disorder, in Child and Adolescent Behavior: A Resource for Advanced Practice Psychiatric and Primary Care Practitioners in Nursing* (eds. Edilima L. Yearwood, Geraldine G. Pearson, and Jamesetta A. Newland, Wiley-Blackwell (2012). The severity of these symptoms vary depending upon the individual and hence the specific categories of autistic disorders were developed. See *id.* Additionally, with the exception of Rett’s disorder, these conditions are primarily seen in males.

⁴ American Psychiatric Association (“APA”) NEWS RELEASE May 17, 2013, available at <http://www.psychiatry.org/advocacy--newsroom/news-releases>, “American Psychiatric Association Releases DSM-5.”

⁵ American Psychiatric Association (“APA”) NEWS RELEASE Jan. 20, 2012, Release 12-03, available at <http://www.dsm5.org/Documents/12-03%20Autism%20Spectrum%20Disorders%20-%20DSM5.pdf> (last visited Feb. 13, 2013). Rett’s disorder will be removed from the single diagnosis of autism spectrum disorder under the DSM V. Sally Ozonoff *Editorial Perspective: Autism Spectrum Disorders in DSM-5-An historical perspective and the need for change*, 53 J. CHILD PSYCHOLOGY & PSYCHIATRY 1092 (2012).

⁶ See *Diagnostic criteria for autism-related disorders as set forth in the DSM IV TR*, Copyright 2000 American Psychiatric Association.

each specific disorder on the autism spectrum.⁷

Other changes include an extension of the period of onset of symptoms “until ‘social commands exceed limited capacities,’ as long as symptoms were present in early childhood.”⁸ Again, under the DSM IV TR, depending on the specific individual condition, the age of onset was more limited.⁹

Additionally, the “three symptom domains (social, communication, and repetitive behavior) are merged into two— social-communication and repetitive behaviors.”¹⁰ The presence of repetitive behavior is also required to qualify for a diagnosis of ASD.¹¹ Also, the overall number of symptoms set forth in the ASD diagnostic criteria is reduced from 17 to 12.¹² According to the professional literature, the reason for the reduction of symptoms is to “streamline” the overlapping symptoms and remove symptoms that are “not specific to ASD.”¹³

A “Social Communication Disorder” (“SCD”) diagnosis is also added to the DSM

⁷ *Id.*

⁸ Sally Ozonoff, *Editorial: DSM-5 and autism spectrum disorders-two decades of perspectives from the JCPP*, 53 J. CHILD PSYCHOLOGY & PSYCHIATRY e4 (2012) available at <http://onlinelibrary.wiley.com/store/10.111/j.1469-7610.2012.02587.x/asset/j.1469-7610..2012.02587.x.pdf?v=1&t=hcxsy7sv&s=bfda0952a09b3f3f8e019407451085aa58af3f9> (last visited Feb. 8, 2013); see also APA NEWS RELEASE “Commentary Takes Issue with Criticism of New Autism Definition DSM-5 *Experts Call Study Flawed*,” March 27, 2012, available at <http://www.dsm5.org/Documents/12-15> (last visited Feb. 13, 2013).

⁹ See Diagnostic criteria for autism-related disorders as set forth in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. (DSM IV TR)* 2000. American Psychiatric Association at p. 70 (for example, under the DSM IV TR, a diagnosis of autistic disorder, the age of onset under the DSM IV TR must be before the age of 3 [p. 70]).

¹⁰ Ozonoff, *supra* note 5, at p. 1092; Lorna Wing, Judith Gold, Christopher Gillberg, *et al.*, *Autism spectrum disorder in the DSM-V: Better or worse than the DSM IV*, 32 RES. DEV. DIS. 768, 738 (2011).

¹¹ Ozonoff, *supra* note 5, at 1093.

¹² Ozonoff, *supra* note 8, at e4.

¹³ *Id.* (giving examples of current overlapping symptoms including limited social-emotional reciprocity, limited sharing of interests, and others and symptoms not related to ASD such as delayed development of language.)

5. This disorder is not considered part of the new ASD diagnosis.¹⁴ This new diagnosis of SCD is “intended to provide a label for children with significant social and communication difficulties who do not exhibit the repetitive behaviors of ASD.”¹⁵ The change is intended to eliminate the misdiagnosis of children as having ASD when they have communication disorders but do not engage in the repetitive behaviors that are present in children with ASD.¹⁶

What will the changes to the diagnosis of ASD in the DSM 5 likely mean in practice and service delivery?

The changes in the diagnosis and definition of ASD in the DSM 5 have been discussed and tested over the past several years.¹⁷ There is, nevertheless, significant disagreement among clinicians and advocates as to the merits of these changes, particularly with respect to eliminating the separate disorders and the impact that this will have on the eligibility and delivery for treatment interventions and other services.¹⁸

Proponents of the changes to DSM 5 argue that they will make the diagnoses of these disorders more specific and precise. They suggest that clinicians will have a greater ability to provide effective treatment interventions.¹⁹ For example, some clinicians argue that the adoption of one diagnosis of ASD on a continuum of mild to severe will likely reduce the number of co-morbidity diagnoses and thus

¹⁴ *Id.* at e 6 (This new diagnosis is “intended to provide a label for children with significant social and communication difficulties who do not exhibit the repetitive behaviors of ASD.”).

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ APA Jan. 20, 2012 NEWS RELEASE, *supra* note 5.

¹⁸ Ornoff, *supra* note 5, at 1093; *see also* APA Mar. 27, 2012 NEWS RELEASE, *supra* note 8.

¹⁹ Thomas W. Fraizer, Ph.D., Eric A. Youngstrom, *et al.*, *Validation of Proposed DSM-5 Criteria for Autism Spectrum Disorder*, 51 J. AM. ACAD. CHILD & ADOLESC PSYCHIATRY. 28 (2012); APA Jan. 20, 2012 NEWS RELEASE, *supra* note 5 (The APA states that the changes will “provide a more useful and dimensional assessment to improve the sensitivity and specificity to the criteria” that will lead to more accurate diagnoses.” At the same time, however, recommending that a “relaxed” version of the ASD diagnostic criteria be used to help improve early identification of ASD so that treatment can be provided as soon as possible).

be more accurate.²⁰

Critics of the changes to the definition of autism spectrum disorders argue that merging the separate conditions into one diagnosis will result in reducing the number of people with ASD who are eligible for services.²¹ For example, because of this change, opponents are concerned that children who have been diagnosed with Asperger's will not receive the necessary treatment interventions.²²

Proponents, however, argue that these changes may have precisely the opposite effect. Specifically, they argue that children with Asperger's are often viewed as being substantially different from the children diagnosed with other autism spectrum disorders due to their greater cognitive abilities and, therefore, they are often denied eligibility for services.²³ The change in the DSM 5, therefore, may expand eligibility for services for children with Asperger's because they will be deemed to have ASD.²⁴

²⁰ Ozonoff, *supra* note 8, at e5.; see also Ozonoff, *supra* note 5, at 1093 (noting for example, that "[t]here is ample evidence of inaccuracy of diagnosing Asperger's and autism.)

²¹ Benedict Carey, "New Definitions of Autism will Exclude Many, Study Suggests," NEW YORK TIMES, January 19, 2012 (reporting that a number of recent professional studies on the likely impact of the changes to the DSM to the definitions and diagnostic criteria for ASD will have a significant adverse effect on the eligibility of children with these conditions to receive services. Specifically, the article cites to four out of six studies consistently finding that the relevant anticipated changes in the DSM 5 will result in a reduction of eligibility ranging from 23.4-47.8% for those with ASD, 10.2-23.4 for those with autistic disorder, 50-83% for those with PDD-NOS [only four of the studies included PDD-NOS], and 16.6-75% for those with Asperger's [only two of the studies included Asperger's] available at: http://www.nytimes.com/2012/01/20/health/research/new-autism-definition-would-exclude-many-study-suggests.html?pagewanted=all&_r=0 (last visited Feb. 13, 2013); see also Ozonoff, *supra* note 5, at 1094.

²² Fraizer and Youngstrom, *supra* note 19, at p. 28; see also L. Wing, *supra* note 10, at p. 771.

²³ Ozonoff, *supra* note 5, at 1093 (citing the extensive evidence showing that most children who have been diagnosed with Asperger's meet the DSM IV criteria for a diagnosis of Autistic Disorder); see also Ozonoff, *supra* note 8 at e5; and Susan Dickenson Mayes, Amanda Black, & Cheryl D. Tierney, *DSM-5 Under-identifies PDD NOS: Diagnostic agreement between the DSM-5, DSM IV and Autism Spectrum Disorder Checklist*, 7 RESEARCH IN AUTISM SPECTRUM DIS. 289 (2013) (A recent study found that using DSM 5 criteria to diagnose ASD, only 27 % of the children with PDD NOS were identified as having PDD NOS).

²⁴ *Id.*

Opponents are also concerned that many children currently diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS) will no longer meet the diagnostic criteria for ASD and will therefore lose their eligibility for services.²⁵ They are also worried that if these children are diagnosed with SCD, rather than ASD, they will not be eligible for or receive the treatment that they need. Specifically, because SCD does not yet have exact treatment guidelines²⁶ -- and because there are questions with respect to its validity -- parents, advocates, and clinicians are worried that children previously diagnosed with PDD NOS will no longer qualify for services under ASD and will have no alternatives.²⁷ Supporters of the DSM revisions, however, argue that these children will be more accurately diagnosed and more likely to receive services to meet their needs.²⁸

Conclusion

Advocates need to give careful consideration to whether more versus less treatment is really desirable and whether expanding the group of children who will all be assigned one diagnosis, notwithstanding variations of severity, is stigmatizing and ultimately not in their interest—particularly since they may be entitled to little or no treatment under the DSM 5 changes.

These issues are further addressed in CPR's companion Q&A on the current professionally accepted treatment modalities for Autism Spectrum Disorder for children.

²⁵ Ozonoff, *supra* note 5, at p. 1094. Under the DSM IV TR, children can be diagnosed with PDD NOS even if they do not exhibit repetitive behaviors so long as they meet all the diagnostic criteria for the disorder. Under the DSM 5, however, PDD NOS will be rolled into the ASD diagnosis that will require, as one of the diagnostic criteria, that the child must exhibit repetitive behaviors.

²⁶ See *A Submission to the American Psychiatric Association by the Psychological Society on DSM-5 Draft Criteria, June 15, 2012*, (contacts Professor Simon Crowe and Professor Lyn Littlefield), Australian Psychological Society, at p. 8 available at <http://www.psychology.org.au/Assets/Files/APS-DSM-5-submission.pdf> (last visited Feb. 8, 2013).

²⁷ Ozonoff, *supra* note 13 at e5.

²⁸ *Id.*