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Defining Autism: Social Influences and the Need for the New Classification by Madeline R. Greaves

The diagnosis of Autistic Spectrum Disorders (ASD) is rising, and the explanation is difficult to identify. Multiple factors play a role in diagnosis beyond the presenting symptoms. First, society is simply more aware of ASD than before, due to increased exposure. However, greater awareness alone does not give the full picture. Second, having a child with ASD within a community increases the likelihood of more diagnoses. Lastly, despite parents' resistance to labeling their children, they may feel pressured to accept a diagnosis in order to receive services that teachers or mental health professionals deem necessary. Despite the diagnostic criteria in the DSM-IV-TR, social influences could have had an effect on diagnosis. Moreover, the method of diagnosis may not depend solely on symptomology. Mental health professionals may consider other factors, such as IQ, when deciding which subtype of autism best fits the child. As a result, diagnostic labels for ASD have diminished meaning, as many children could fit the criteria for multiple subtypes. This calls into question the reliability of diagnosis and the real possibility that social pressure could lead to the misdiagnosis of ASD, causing unnecessary stress for the children and their families. With the release of the DSM-5, the impact of societal influences should lessen.

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aving a child diagnosed with a mental disorder can bring great stress to the child and her or his family. Autism is a particularly confusing diagnosis and is affecting more families with time. The incidence of autism diagnosis is on the rise. For over a decade, the Centers for Disease Control and Prevention (CDC) have tracked those diagnosed with autism spectrum disorders (ASD) every two years. In 2000, the CDC estimated that one in 150 children had an ASD; that number rose to one in 88 by 2008 (CDC, 2012). Although the reasons for this dramatic rise are not known, one theory is that parents feel pressured to accept an ASD diagnosis in order to receive available services, despite their reservations over labeling the child (Hodge, 2005). This pressure can come from trusted individuals, such as schoolteachers, counselors, and physicians. The diagnosis can cause both emotional and financial strain on a family that is seeking treatment for their child. Thus, it is essential that the diagnosis be valid.

The diagnostic criteria for autism were previously listed in the *Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision* (DSM-IV-TR; American Psychiatric Association, 2000). Despite its wise usage, the term autism spectrum disorder is not listed in the manual. Instead, the condition is split into multiple disorders, including Autistic Disorder and Asperger's Disorder. Some of these disorders were not operationalized to allow for reliable diagnosis (Mandy, Charman, Glimour, & Skuse, 2011). As such, the ambiguity resulting from these vague diagnostic criteria may have been susceptible to social pressures.

The DSM-5 (American Psychiatric Association, 2013) reclassifies the multiple disorders into the spectrum known as ASD. With this change, children with previous diagnoses are reevaluated when treatment is renewed. Under the new guidelines, children who may have been previously pressured into the diagnosis may no longer qualify. This would, in theory, lessen the effects of social influences on diagnosis. Although autism affects many children, the social influences referred to above could have played a role in the diagnoses under the DSM-IV-TR criteria. The new classification of autism in the DSM-5 may reduce the role of social pressure on diagnosis.

Possible Explanations for Increased ASD Diagnosis

A re-examination of the diagnostic criteria can be crucial as more children are identified with some form of ASD. One must ask about the reasons for the rise in diagnosis. Given that information spreads rapidly, it is possible that the general public, as well as mental health professionals, are simply more aware of the condition and are, therefore, more likely to consider the diagnosis than before (Langan, 2011). Nevertheless, this is not a sufficient explanation to explain the increase in ASD prevalence. Indeed, mental health professionals are not always the first to bring up the possibility that a child may have a form of autism.

Other, well-meaning people may share concerns with parents about a child's development, especially if those people have knowledge of ASD (Russell & Norwich, 2012). Coming from individuals the family trusts, the comments may have greater impact. Despite any doubts or qualms parents may have regarding an ASD diagnosis, a certain amount of social pressure could lead to their

child being tested. Ultimately, this scenario can be problematic because of vague diagnostic criteria, as children may be unnecessarily diagnosed.

Increased Awareness: Only Part of the Story

The current access to information in the Western world allows knowledge to spread rapidly. At the same time, the range of autistic disorders has been depicted in Western media. Langan (2011) argued that a cultural fascination with ASD has developed through the popularity of various novels and films portraying the disorder, such as *Rain Man*. Not surprisingly, parents who find their child's behavior to be similar to that in a media portrayal may be persuaded to arrange for their child to be tested.

On the other hand, increased media exposure can perpetuate false notions about ASDs. Consider the notion that an ASD is caused by vaccinations (Wakefield et al., 1998). Although the study originally linking the two has since been retracted, the belief persists. In a survey of parents living in Los Angeles County who had children with autism, almost half believed that vaccinations had led to the child's diagnosis (Bazzano, Zeldin, Schuster, Barrett, & Lehrer, 2012). Accordingly, it seems that increased awareness is only effective when it involves accurate information. Still, mental health professionals, not parents, are the ones who ultimately make the diagnosis, and they presumably are aware of the true nature of the spectrum of conditions. When the CDC noted the increase in children with autism, their officials concluded that increased awareness alone did not fully explain the increase (CDC, 2012). Therefore, there would need to be another factor to explain this trend.

Social Pressures and Parental Concerns

In addition to greater awareness, social influence could lead to more diagnoses of ASD. For example, as previously noted, the comments made by professionals can push parents to pursue an ASD diagnosis. Moreover, a child is more likely to be diagnosed with a form of autism if she or he lives near another diagnosed child (Liu, King, & Bearman, 2010). Because ASD is not contagious, mere proximity does not explain this trend. Rather, the presence of diagnosed ASD in the community may lead parents to specifically pursue the same diagnosis. Once one child is diagnosed, neighbors or other community members may more readily notice developmental delays in their own children or others. Eventually, a mental health professional is consulted and another diagnosis is given. However, not every parent actively pursues the diagnosis.

In a survey of parental perspectives, Russell and Norwich (2012) found that, despite access to reports in the media and in communities, many parents only consider seeking a clinical diagnosis for their child after the idea is suggested by a professional. Additionally, Thomas et al. (2012) found a strong association between socioeconomic status and autism prevalence: the higher the status, the higher the prevalence. The cases in higher-income households also tended to be diagnosed at a younger age. Although families with higher SES may have greater access to professionals, other factors may be involved. Hodge (2005) pointed out that parents may seek an ASD diagnosis in order to access services in schools that may help the child.

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Despite the desire to access services, parents of children thought to have ASDs tend to be reluctant to seek diagnosis. Russell and Norwich (2012) noted that some parents recognize the possibility that children who would simply be considered eccentric in other contexts are more likely to be diagnosed with ASD. Specifically, the researchers reported that "parents of undiagnosed children...differed sharply from those who had been through diagnosis...in the language they used to describe diagnosis, frequently using terms that denoted a violation of the child" (p. 233). In other words, hesitation to diagnosis could be due to the fact that labeling a child as "autistic" may lead to rejection by peers, compounding the social difficulties otherwise associated with ASD.

These concerns continue after diagnosis. Social problems are one of the chief concerns of parents with diagnosed children, and many do not feel their concerns are adequately addressed, at least initially (de Alba & Bodfish, 2011). However, the same researchers found that a majority of parents were very interested in discussing treatment options with physicians. Moreover, although the diagnosis may have led to many concerns, parents did not tend to question the judgment of the professionals. With this lack of parental resistance to diagnosis, it is important that these diagnoses be valid.

Problems with the DSM-IV-TR Diagnostic Procedure

It can be difficult to understand how influences from society can have such an effect on a condition with a clinical definition. However, despite having diagnostic criteria that are clearly listed, there may still be ambiguity in the diagnostic procedure. Disorders may be diagnosed differently as psychiatrists or other professionals try

to make sense of the symptoms (Mazefsky et al., 2012). Consequently, this can create problems for reliable diagnosis. The DSM-IV lists conditions considered to be part of ASD as separate disorders, although the separation may not be distinct (Tryon, Mayes, Rhodes, & Waldo, 2006). For the purposes of this review, the focus will be on Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

Diagnostic Issues with the DSM-IV-TR Criteria

Disorders commonly thought to be part of ASD fell under the umbrella of pervasive developmental disorders. Both autistic and Asperger's disorders were accompanied by similar diagnostic criteria in the DSM-IV-TR (Mayes, Calhoun, & Crites, 2001; Tyron, Mayes, Rhodes, & Waldo, 2006). Both sets of criteria specified that the child was impaired socially and follows an inflexible pattern of behaviors or interests. The main difference between the two diagnoses was language development: it was delayed in Autistic Disorder, but not in Asperger's disorder (APA, 2000). Thus, in the case of conditions so similar, it could be difficult to distinguish them. Sciutto and Cantwell (2005) suggest that, when dealing with highfunctioning children, other factors-such as IQ-often were considered in reaching the diagnosis, leading to diagnoses differing from those stipulated in the DSM-IV-TR. In fact, several children diagnosed with Asperger's Disorder could have also fit the criteria for Autistic Disorder (Mayes et al., 2001; Tryon et al., 2006), which was the precluding diagnosis (APA, 2000).

Meanwhile, children who did not fit either set of criteria or the criteria for any other pervasive developmental disorder often re-

ceived a PDD-NOS diagnosis. Although this diagnosis may have been useful on an individual level as a qualification for receiving services, confusion arose when looking at children with PDD-NOS as a group. Walker et al. (2004) reported that children failed to meet the criteria for other disorders for several reasons, making the PDD-NOS label a difficult one to interpret for the purposes of treatment. Without clear requirements for this category, children could more easily be put into it than other disorders, and it is very possible that some children could have been misdiagnosed.

Case study of difficult autism diagnosis. With the DSM-IV **process**, a diagnosis for a child could be up for debate. Snyder, Miller, and Stein (2010) discuss Billy, a three-year-old boy diagnosed with autism. Billy was unwilling to play with his pediatrician during a well-child visit, and he does not speak to the teacher or other children in his preschool. In addition, Billy prefers repeating activities, such as playing with the same few cars, over trying new experiences. Despite this, Billy is outgoing in familiar situations, and speaks clearly in complete sentences when with his parents. After a developmental evaluation, he is diagnosed with autism.

When discussing Billy's case, Snyder et al. (2010) agreed that the above information is not sufficient evidence for an Autistic Disorder diagnosis. They argue that increased knowledge of autism in the general population has led to an over-simplification of the condition. Comparing the problem to a similar issue, they state, "As hyperactivity is not sufficient for a diagnosis of AD/HD, limited social interaction does not always mean autism" (Synder et al., 2010, p. S15). Although Billy may have a disorder, the presented infor-

mation is not enough to justify his given diagnosis. This example is not unlike experiences many other parents have faced. As clearly shown here, diagnoses are not always made with adequate information.

Issues with Reliability

It can be difficult to make sense of diagnostic labels that deal with the autism spectrum. Considering the disagreement between diagnoses in some cases, as well as the effect of social influences, this is not surprising. Additionally, autism varies across individuals; symptoms can manifest differently due to multiple factors, such as family history (Mazefsky, Williams, & Minshew, 2008). With this in mind, the task of classifying children into developmental disorders is a difficult one.

Although mental health professionals can often tell if a child has a disorder, the reliability of their judgment is not perfect. Although professionals with more experience tend to be more reliable, reliability can drop when trying to distinguish between Autistic Disorder and another category of ASD (Klin, Lang, Cicchetti, & Volkmar, 2000). Developmental disorders have overlapping symptoms, as previously noted, making them difficult to distinguish (Bühler, Bachmann, Goyert, Heinzel-Gutenbrunner, & Kamp-Becker, 2011). If a mental health professional does not rely solely on criteria listed in the DSM, this may allow other influences—including social influences—to push the diagnostic decision in one direction rather than another.

Even when referring to diagnostic criteria, mental health professionals had problems when dealing with conditions within the au-

tism spectrum. Snow and Lecavalier (2011) compared children diagnosed with Autistic Disorder and those with PDD-NOS and found few differences. Similar findings have been found when comparing Autistic Disorder to Asperger's Disorder (Mayes et al., 2001). Although the condition is varied, there is little difference between the established groups.

Considerations Leading to the DSM-5

As has been discussed, the previous method of diagnosis was in need of revision. The disorders referred to in this article, as well as Childhood Disintegrative Disorder, were incorporated into the new category of Autism Spectrum Disorder (ASD) in the DSM-5 (APA, 2013). The criteria for ASD are stricter than in the DSM-IV-TR. In other words, the subtypes of autism have been eliminated, and at least some of the diagnostic issues resulting from the ambiguity of subtypes may no longer exist. However, this does not suggest that the new criteria will satisfy everyone.

Since this change will redefine autism, those currently receiving treatment or other services for the condition may be required to be reevaluated in order to continue to have access. For children considered to be on the severe end of the spectrum, this will most likely not be an issue. In addition, children without the condition are far less likely to be diagnosed. On the other hand, those with mild forms, such as children formerly diagnosed with Asperger's disorder or PDD-NOS, may not re-qualify for services under the new criteria (McPartland, Reichow, & Volkmar, 2012). Gibbs, Aldridge, Chandler, Witzlsperger, and Smith (2012) noted that children with PDD-NOS are least likely to re-qualify for diagnosis. Under the

new criteria, fewer combinations of symptoms will lead to an autism diagnosis (McPartland et al., 2012), further reducing the inadequacy of a previous diagnosis of PDD-NOS.

With the new criteria in place, social influences should have a diminished role in diagnosis. Although it will take time to determine the full impact the DSM-5 criteria, issues arising from deciding which ASD subtype a child fits have disappeared with the subtypes themselves. With the new dimensional approach, there is less of a need to distinguish one group from another. Higherfunctioning children may not qualify for ASD diagnosis, although some may qualify for other diagnoses that better describe their condition. Despite concerns, the DSM-5 criteria for ASD thus far appear to be effective. The current model is efficient in diagnosis and accurately excludes children without the condition (Frazier et al., 2012). The stricter criteria may lessen social influence in diagnoses, thus reducing the incidence of superfluous diagnoses. The increased reliability and clarity of diagnostic labels may make ASD easier for families to understand and remove unnecessary stress caused by false diagnosis.

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