

Is the changing definition of autism narrowing what we think of as 'normal'?

September 21 2015, by Jennifer Sarrett



Is normal behavior being pathologized? Credit: Elizabeth Albert/Flickr, CC BY

I first learned about autism in 1997 in my high school psychology course. It was relegated to a small paragraph in a chapter on childhood disorders. The film Rainman had come out a decade earlier, publicizing

the condition to a degree. But autism still wasn't well-known – or well-understood, at the time.

That certainly isn't the case today.

Since then I have been a special educator, an [autism](#) consultant, and, most recently, an autism advocate and researcher. I explore how both culture and ethics influence autism as a concept, diagnosis and lived experience. One thing that is clear is that the way we think about autism has changed.

As the power and recognition of modern psychiatry as a medical field have expanded, so has the way we think about and define different conditions, including autism. The diagnostic criteria for autism have gotten broader, helping it go from a rare disorder to one that affects [one in 68 children](#) in just a few decades.

And this shift isn't unique to autism. The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) – the book psychiatrists use to determine diagnoses – was criticized for lowering the diagnostic thresholds for many conditions. As these broader concepts for psychiatric disorders rapidly gain public recognition and influence, our concept of what is "normal" becomes increasingly narrow.

How autism has changed from DSM to DSM

The first edition of the DSM was published in 1952. It was 130 pages and contained 106 diagnostic descriptions. The most recent edition, the [DSM-5](#), published in 2013, is 947 pages and covers roughly 300 disorders. As the DSM has gotten bigger and broader, so too has the definition of autism.

Before 1980, the word "autistic" appeared in the DSM only as a trait to

describe schizophrenia. But that doesn't mean diagnostic criteria for autism didn't exist. A [1956 article](#) by Leo Kanner (who is credited with "discovering" autism) and Leon Eisenberg focused on two criteria: aloofness and a significant resistance to changes in routines, noticeable in a child by 24 months of age. These traits are still present in diagnostic criteria today, and are sometimes called classic autism or Kanner's autism.

The DSM-III, released in 1980, introduced "infantile autism," officially creating a separate diagnosis for autism for the first time. Seven years later, a revised edition, the DSM-III-R, changed the name to "autistic disorder" and placed it in the category of [Pervasive Developmental Disorders](#) along with other related conditions like Asperger's Disorder and Pervasive Developmental Disorders - Not Otherwise Defined (PDD-NOS).

The DSM-III-R marks the first expansion of the diagnostic criteria for autism. Criteria were broken up into three categories: social interaction, communication and behavior, covering about 16 traits. At least eight of the 16 traits were required for a diagnosis. The manual covered behaviors that occurred outside the psychiatrist's office, such as "absence of imaginative activity," making parental input necessary. The manual also included examples of each of these traits to guide diagnosticians.

The 1994 DSM-IV dropped the number of required traits for a diagnosis from eight to six. And the majority of behavioral examples included in earlier versions of the manual were removed, meaning that physicians had to interpret behavioral descriptions with less guidance.



Credit: AI-generated image ([disclaimer](#))

These changes, along with better educational services and public awareness (thanks in large part to the film *Rainman*), marked a dramatic rise in autism prevalence, jumping from one in 2,500 in the 1980s to one in 250 in the late 1990s. These criteria remained in place for almost 20 years when the DSM-5 was released in 2013.

The DSM-5 changed the diagnostic criteria yet again. Autism and related conditions like Asperger's and PDD-NOS were collapsed into a single diagnosis: "autism spectrum disorder." Three categories of diagnostic traits became two: social interaction and social communication became one category and the behavior category remained. No required number of traits are needed from the [social interaction](#) category for a diagnosis, but two are required from the behavior category.

These changes were initially criticized due to concern that the shift to "[autism spectrum disorder](#)" could reduce diagnoses, and possibly result in fewer children getting needed services. But this diagnostic reorganization seems to me like an even broader diagnostic process.

Despite broader criteria, diagnostic disparities persist

In the case of autism, there is a [higher demand](#) for the diagnosis. Having an [autism diagnosis](#) can result in fairly good education services these days, such as smaller class sizes, in-school therapies, and one-on-one teacher attention for children with the diagnosis. Psychiatrist and researcher Judy Rappaport is [quoted](#) as saying:

... We'll call that kid a zebra if he needs to be called a zebra to get the educational and other services that he needs and deserves.

Even though the criteria for an autism diagnosis have gotten broader, many children who could and should be diagnosed aren't. Studies have shown that many minority children, especially African-American kids, are misdiagnosed with conditions such as [ADD or oppositional defiant disorder](#), which are suggestive of defiant emotional problems resulting from poor or neglectful environments. These discrepancies hold remnants of early claims from the mid-1900s that autism is a disorder of the white upper and middle class.

This discrepancy [has continued](#): 12.3 per 1,000 African American kids are diagnosed with autism and 10.8 per 1,000 Hispanic children, compared to 15.8 per 1,000 among white children.

There are many reasons these racial disparities exist. Persistently vague diagnostic criteria allow for subjectivity in diagnostic practices for autism. And it is also a question of access. Minority children are more likely to come from [lower-income families](#) who simply do not have the

time or money to get a diagnosis. And psychiatric and development disorders are more stigmatized in many [nonwhite communities](#), meaning families are less likely to [seek](#) a diagnosis.

Broad diagnoses change our concept of 'normal'

When the DSM-5 was released, it sparked [a petition](#) signed by over 15,000 psychologists. The petition argued that the manual placed the diagnostic threshold for many conditions too low, making it easier to apply a psychiatric label to a wider range of people. That also means the DSM has the power to make people more eligible for treatment with drugs whose effects, [especially long-term](#), are not fully studied.

Allen Frances, the chair of the DSM-IV task force, [has highlighted](#) the risk that "normal" people are being diagnosed with mental conditions they do not have, thanks to overly broad [diagnostic criteria](#) in the DSM-5. This almost exactly mirrors criticisms over the broadening definition of autism.

And as the definition of autism get broader, it narrows what is considered "normal." People who would not previously have had a diagnosis are now being pathologized. We are constructing a new reality of the disorder that does not accurately represent the most affected population. This could divert attention and resources from the people who need it the most – the significantly disabled.

Rates of people with less significant forms of autism will rise and become the autistic norm, as we see in media portrayals in TV shows like Parenthood and or books like The Curious Incident of the Dog in Nighttime. When this becomes the autistic norm, people who are more significantly autistic appear super-disabled, and then become super-stigmatized.

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