Observations

Is It Time to Give Up on a Single Diagnostic Label for Autism?

That was the ruling by the editors of the authoritative *Diagnostic and Statistical Manual* in 2013, but it remains controversial

By Simon Baron-Cohen on May 4, 2018

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Five years ago, the American Psychiatric Association (APA) established autism spectrum disorder (ASD) as an umbrella term when it published the fifth edition of the *Diagnostic and Statistical Manual* (*DSM*-5), the primary guide to taxonomy in psychiatry. In creating this single diagnostic category, the APA also removed the subgroup called Asperger syndrome that had been in place since 1994.

At the 2018 annual meeting of the International Society for Autism Research (INSAR), there will be plenty of discussion about diagnostic terminology: Despite the many advantages of a single diagnostic category, scientists will be discussing whether, to achieve greater scientific or clinical progress, we need subtypes.

THE ADVANTAGES OF A SINGLE DIAGNOSTIC LABEL

The APA created a single diagnostic label of ASD to recognize the important concept of the spectrum, since the way autism is manifested is highly variable. All autistic individuals share core features, including social and communication difficulties, unusually narrow interests, a strong need for repetition and, often, sensory issues. Yet these core features vary enormously in how they are manifested, and in how disabling they are. This variability provides one meaning of the term spectrum, and the single diagnostic label ASD makes space for this considerable variability.

The term spectrum also refers to the heterogeneity in autism. There are huge disparities in many areas, such as language development or IQ, and in the presence or absence of co-occurring medical conditions and disabilities. This heterogeneity is also part of what is meant by a spectrum. And some autistic people also have very evident talents. This is another sense of the term spectrum, and the single diagnostic label makes room for this source of diversity, too.

There have been other benefits of the ASD label: It allows the clinician to describe the person without shoehorning them into a rigid subgroup. Its flexibility also allows for individuals who previously transitioned between different subgroups. And it reduced the risk that service providers might exclude a person because they didn't meet the eligibility criteria based on a rigid subtype. So, the consensus among clinicians is that the addition of the word "spectrum" was helpful and long overdue. Most clinicians therefore find it useful to have the flexibility of the very broad single diagnostic label.

Among proponents of a single diagnostic label, there is some debate about whether we should call it ASD (autism spectrum disorder) or ASC (autism spectrum conditions). This is because some people find the word "disorder" potentially stigmatizing, and argue that the word "condition" is equally effective in signaling a medical diagnosis. But leaving this point aside, many scientists are debating what got lost when subgroups were dropped.

THE DOWNSIDES OF A SINGLE DIAGNOSTIC LABEL

One main reason given by the APA for deleting Asperger Syndrome (AS) was that diagnosis was unreliable. With hindsight, we can see that differentiating AS from classic autism was not the problem. The problem was differentiating AS from high-functioning autism (HFA), a term used by some to refer to autistic people with a history of language delay but with an IQ in the average or above-average range.

Most everybody now agrees that the terms high- versus low-functioning were stigmatizing and therefore should be avoided, but the clear contrast between AS and classic autism might have had value and perhaps should have been retained and likely could have been distinguished with high reliability. And for many, the term AS had even become part of their identity; it felt like more than just a diagnosis.

A widely held view is that medicine makes more progress by identifying subgroups, and AS versus classic autism were two very useful subgroups, because they are quite different in terms of likely levels of independence and educational and occupational attainment. Many parents, such as Alison Singer in her keynote speech in the 2017 INSAR annual meeting, also argued that by lumping AS and classic autism together, the breadth of autistic individuals is not adequately represented—that the single diagnostic category benefits neither subgroup.

For those who may think we should revert to two major subgroups, it is no longer clear that AS would be the right name for one of these, given recently published research about Hans Asperger colluding with the Nazi eugenics program during World War II. Those in the autism community who identify as having AS, and others, are actively discussing this difficult question.

But the main argument against a single diagnostic label is that the inclusion of subtypes will likely lead to greater scientific progress in understanding the precise causes of the heterogeneity, and greater translational progress in understanding what kinds of interventions and support are needed, and for whom.

A MODERATE PROPOSAL

One obvious way forward would be to do what other medical diagnoses (such as Diabetes) have done, and introduce a typology of subgroups, as in type 1 and type 2. So, it's not about either having a single diagnostic label or subgroups. One can have both. Under this approach, we could keep the single umbrella category called the autism spectrum and within this have type 1, type 2, etc.

This could maintain the *DSM*-5's flexibility, so that a person could transition freely between subtypes as they change across their development. Type 1 could be mapped on to what was formerly known as AS, and type 2 on to what was formerly known as classic autism. Other subtypes will undoubtedly follow, such as the syndromic forms of autism that are due to rare genetic mutations, to become type 3 and so on.

Some may worry that this simply reintroduces the high- versus low-functioning distinction. Others will say it avoids the stigmatizing language while recognizing the value of marking the significant differences within the spectrum. Some may argue that this places too much reliance on IQ tests that frequently underestimate the intelligence of autistic people, who might be mistakenly subtyped as type 2 when they are really type 1.

But by allowing flexible transitioning, there may be ways to get around this concern. Clinicians will need to have a very flexible notion of intelligence, and not stick rigidly to any specific test, such as a verbal IQ test.

Interestingly, the *DSM*-5 does already have the option to recognize subtypes, referred to as "specifiers," and invites clinicians to use these to capture co-occurring conditions. But there may be value in explicitly recognizing subgroups within the autism spectrum, while keeping the helpful concept of specifiers. An individual could have type 1 autism with ADHD, or type 2 autism with language impairment, for example.

There will be others who argue that we should only subtype on the basis of biology, not psychology, since in other medical conditions such as diabetes, subgrouping into type 1 and type 2, etc., is based on discovering different causal/mechanistic factors, which have different prognostic or therapeutic implications.

I can't wait to be at the INSAR 2018 annual meeting this year to listen to the arguments about whether we should subtype the autism spectrum, and if so what is the most useful way to do so. And to learn about the latest cutting edge scientific research that can be harnessed to improve the lives of autistic people and their families.

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