Received: 1 July 2021 | Accepted: 3 July 2021

DOI: 10.1002/aur.2578

LETTER TO THE EDITOR

When diagnosis hampers research

Laurent Mottron (2021) has done the community a great service by courageously calling out the problems we are facing in the diagnosis of autism. I agree with his stark assessment that the autism spectrum, as currently defined by DSM and operationalized by standardized tools, is hampering scientific research.

I can recall the research environment of 50 years ago, when autism was considered a rare disorder. Research was not better in those days. It barely got off the ground. The main challenge was recruiting participants for experiments, and I remember my own desperate efforts to do this. I was eager to embrace a widening of the diagnostic criteria, and I welcomed and promoted the notion of the autism spectrum (Frith, 1991), but I had no idea just how elastic it would become. I had no idea that the boundaries of the spectrum would be so blurred that the terms “disorder” and “deficit” would become meaningless.

However, this blurring of boundaries has not changed my belief in categories as being just as important as dimensions (Happé & Frith, 2020). After all, differences in autistic traits, inherent in normal variation, are one thing, and differences due to neurological glitches are another. We cannot put aside the fact that there is a long history of neurological signs in autism.

The widened criteria were a boon for researchers like me to be able to recruit more participants, and it was a boon to use standardized diagnostic instruments. However, this came at a cost. Larger samples nowadays are likely to be extremely heterogenous, and this leads to a massive increase in statistical noise. For group comparisons, this means weak or null results. Unfortunately, they tend to be blamed on sloppy theories rather than on sloppy subject recruitment. This has battered the belief in the ability to find real group differences on any experimental psychological tests. But, while the group differences of old have vanished, autism has not.

It is still an open question whether autism is a natural entity. There are now calls for abandoning autism as a category and merging it with other neurodevelopmental disorders. I believe this would be a great loss. We know that, despite the multitude of biological causes and the variety of behavioral signs of autism, there remains a recognizable phenotype. In addition, this phenotype is not just in the imagination of some autism experts. Young children can quickly detect the presence of an autistic child at a playground or school. Naïve adults can perceive the subtle signs of oddness or strangeness in able autistic individuals, present in the manner or content of their speech or their motor movements. Of course, such thin slice judgments can be wrong and are subject to various biases. They do not replace a thorough clinical assessment.

I agree with Laurent Mottron that autism at present is a category at the wrong level in the hierarchy, and I am optimistic that we can arrive at an agreed prototype if we try. I believe we can do this best by going straight to the cognitive level, where we might find the proximate causes of the ostensible strangeness of autistic behavior (Frith, 2012). These cognitive causes should explain clusters of social and non-social features, allowing for the fact that the resulting behavior will look different at different ages and levels of ability. The clusters should point to specific problems in neuro-cognitive mechanisms, and it is these that we still have to nail in order to link them to their neural basis.

I am hoping for a systematic attempt to identify meaningful subgroups in the whole of the autism spectrum, not just at the center. Although the search for subgroups has yielded very little so far, it may not have been conducted with a sufficiently strong theoretical basis and has been tied too much to the behavioral rather than the cognitive level. Finding subgroups at the biological level seems just out of reach at present.

There are important questions to be asked about children who are diagnosed early and how they differ from those who are diagnosed late. What about those people who were never recognized as children, but strongly feel they are part of the autism spectrum? Are they possibly in search of a diagnostic category that does not yet exist, but should?

Prototypes can only provisionally be based on behavior, whether through observation, interview, or self-report. This is because behavior is influenced by a multitude of variables that are forever outside our control. I believe that differences at the cognitive level can validate, not just clinical judgment, but also the naïve intuition of what is different and strange, and wonderful, about the nature of autism.

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