



Heterogeneity:

autism adrift

By ANTOINE OUELLETTE

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"Is there a universally accepted term for autism?". To this question, an article in Sur le Spectre (#15, Spring 2023, pages 2 to 5) offered the following food for thought: "Autism, is autistic, neurological/brain difference, neurodivergent, challenges, and neurotypical" are among the terms most commonly used to distinguish autistic and non-autistic individuals. There is therefore no universally accepted way of referring to autism, neither for people who are autistic, nor for the scientific community. This finding is what a study published in November 2022 in the very serious journal *Autism Research* revealed. The study documented the linguistic preferences of more than 650 English-speaking autistic adults worldwide when referring to their condition.

I wasn't surprised by this conclusion, because I myself have the same problem when it comes to describing my condition! Personally, I call myself Asperger's autistic, or simply Asperger's. I've kept the name because

it's the profile that suits me best. I don't see anything offensive about this naming. But this name, that best describes me, in autism is gone!

This designation has disappeared because it seems that, for the same person, the diagnosis of Asperger's was given or a diagnosis of autism (in this case, high-functioning, even if the diagnosis of high-functioning autism never appeared in the DSM). The clinicians agreed that the two disorders belonged to the same family, but it was difficult for them to agree on the distinction between Autistic and Asperger. As a result, there were disparities in diagnosis depending on the person and the country.

In practice, the word autism has come to designate an amalgam of very diverse conditions, causes and presentations, with no links to each other than a set of increasingly imprecise behavioral or personality traits. It ranges from an adult with a vocabulary of about twenty words who is not self-sufficient, even in basic daily tasks, to a person who collects doctorates in cutting-edge scientific disciplines! In my opinion,



Is there a universally accepted term

None of the proposed autism terminology was recorded by 50% of participants.

Article of number 15 pages 2 to 5.

this is insane. This slippage makes it impossible to say anything at the scientific level that is true for all people designated as "autistic". Conceptual flexibility isn't bad in itself, but if you stretch it too far, the elastic breaks: here we are, with a broken elastic.

Inevitably, the fact that one and the same word is used to designate such divergent realities creates tensions and misunderstandings between people. For example, I've been told that the specialists who diagnosed me are "incompetent", because my reality doesn't match that of a family member with the same diagnosis! For my part, I find it impossible to identify with certain autistic profiles, although I may have some similar behavioral traits. I have more in common with neurotypicals than with a non-verbal autistic individual or an individual with a genetic condition. And yet, according to the DSM-5, I am indeed autistic! This confusion has very real human repercussions where in the end, nobody wins.

Tests are available to pinpoint the diagnosis of *secondary autism* (also known as "syndromic"): the diagnosis is then no longer "autism" but, for example, "Angelman

syndrome with secondary autism", or "Fragile X with secondary autism". Of these syndromes, which are numerous, the genetic causes are known, but they resemble me even less than I resemble a non-verbal autistic person without comorbidity. I think it's necessary to clarify the diagnosis, otherwise the word "*autism*" becomes a "*melting pot*" - which, in fact, it has become to a large extent. This poses a major problem for research, because in a cohort of people diagnosed with autism for the purpose of conducting a study, there may be many different conditions. How then can valid conclusions be reached?

These problems will persist as long as people identified with "*pure*" autism (the cause of which is unknown) are lumped together on the same "*spectrum*" with people presenting a wide variety of conditions (some of which can be precisely identified), thus forming a very heterogeneous population. I confess I don't know of any other field where this is done. Here, it's as if we were using the term "*sneeze*", once precise and well-defined, to also designate coughing, sighing, throat clearing, and whistling. Can we really believe that this is progress?! 🌱

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