

Appendix 3

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What is autism? How the term became too broad to have meaning any more

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The fashion for celebrating 'neurodiversity' ignores those with debilitating severe autism, which has created a rift in the community

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'I am fluent in four languages and have been able to live abroad. My younger sibling, also diagnosed with autism, requires full-time care. It's apparent that we have very different conditions.' Photograph: Stephen Voss/Alamy

The word autism means a lot of different things to different people. To some, it conjures an image of the socially awkward eccentric who, besotted by a narrow set of interests, eschews small-talk and large gatherings in favour of solitude. To others, it's a profoundly life-limiting disorder that consumes every waking hour of a family's life, a medical disability that entails unpredictable bouts of aggression resulting in torn upholstery, cracked skulls and savage bites. Severely autistic people have a life expectancy of 36 in the United States and 39.5 in Europe, while their

parents and care-givers often experience PTSD and stress similar to that of combat veterans. Mildly autistic people, on the other hand, though far more prone to depression and suicide, can go on to lead productive and fulfilling lives, often blending imperceptibly into the wider population despite their idiosyncracies and social difficulties.

Yet a report this week claimed that the difference between people diagnosed with autism and the rest of the population is shrinking. The autism spectrum is so all-encompassing that experts are now finally starting to question the validity of the term itself. After studying the meta-analyses of autism data, Dr Laurent Mottron, a professor at Université de Montréal, concluded that: “The objective difference between people with autism and the general population will disappear in less than 10 years. The definition of autism may get too vague to be meaningful.”

It is hardly unreasonable to think that a spectrum that encompasses an erudite professor such as Dr Temple Grandin - who has authored several books and can speak in entrancing detail about her condition to packed lecture auditoriums - and severely autistic adults in institutions who have to wear nappies due to incontinence and helmets to protect themselves from involuntary self-injury, is so broad so as to be medically meaningless.

Aside from changing diagnostic practices, the general shift in advocacy in the direction of the increasingly fashionable neurodiversity paradigm has led to what I and many others see as the trivialisation of autism. Neurodiversity posits that conditions such as autism, ADHD, dyslexia and dyspraxia are not so much conditions to be treated but differences to be embraced and even celebrated. Despite the noble intentions of many of its proponents, there are those who feel that neurodiversity excludes those for whom autism confers few if any real cognitive advantages. Despite its claim to be inclusive of all “neurotypes”, its ethos inevitably means that less verbally able autistic people are marginalised from the discussion. Rarely at a neurodiversity event, particularly one that aims to present autism as a competitive advantage in the marketplace, will you find an autistic person with an IQ of lower than 30 who is prone to lashing out and soiling themselves.

The increasing emphasis on autism as neurodiversity has also created a huge rift in the community, particularly between autistic self-advocates and parents. Self-advocates, many of whom possess an above-average intellectual ability as well as great insight into their own condition, celebrate their autism as a core feature of their identity and often promote their neurological difference as a strength. Many who self-identify on social media using the #ActuallyAutistic hashtag insist that autistic people must be at the forefront of all autism discourse and that only autistic people themselves can be considered to be true experts in the condition.

Such an attitude has led to the marginalisation of autistic people who, by virtue of their disability, are unable to speak and rely on others to do so on their behalf. It has also led to the legitimisation in self-advocacy circles of “self-diagnosis”, a practice that may in part account for the increased prevalence of autism and the watering down of the term

itself. Many now self-identify as autistic as though autism were a fashion label rather than a debilitating disorder.

My own life straddles the line between autism's high- and low-functioning polarities. I was originally diagnosed with "upper-end autism", am fluent in four languages and have been able to live and work abroad despite significant social difficulties. My younger sibling, by contrast, who was also diagnosed with autism, will never be able to lead any semblance of a conventional life and will require full-time care until the day he dies. My parents naturally worry about his fate when they are no longer around. Despite sharing the same label, it's apparent that we have very different conditions. It's part of the reason I am reluctant to use the term autism to describe my own comparably mild disability - for fear it will devalue experiences like my younger brother's.

It has become apparent, not just to scientists but to many in the community, that autism needs dividing into separate conditions, starting with the reintroduction of Asperger syndrome, as an important differentiator between mild and severe variants. Contemporary autism discourse and research are both skewed in favour of the verbally able autistic population at the expense of the most vulnerable and, with the growing popularity of the neurodiversity concept, this gap is sure to increase. It's high time that changed and that the lower end of the autism was treated with the seriousness it deserves. The wellbeing of some of society's most vulnerable people depends on it.

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