Defining neurodiversity for research and practice

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Some of the authors of this publication are also working on these related projects:

Project Health and Wellbeing for a Neurodiverse Age View project
Neurodiversity means a lot of different things to different people. For Singer (1999) and Blume (1998), it was more associated with an ‘ecological society’ where minority minds are valued in light of, and helped to find, their niche. By contrast, Walker’s (2014) influential definition distinguishes between the fact of neurological diversity (a manifestation of genetic diversity), and the neurodiversity paradigm, which is more about depathologising and instead politicising neurodivergence. I myself have analysed it both as a political idea, associated with social models of disability (e.g. Chapman, 2019) and as a scientific concept, indicating a new way of thinking about function and dysfunction (Chapman, forthcoming). Others have used the term in different ways still.

I will only briefly mention how I think neurodiversity differs from the medical and social models, since that is what I have done in my other chapter (Chapter 4) in this volume. In short, I argue that neurodiversity is anathema to the medical model, but also that there is a technical contradiction between neurodiversity and the social model (or at least the traditional version of it). This regards the concept of ‘impairment’, which is measured in relation to a species norm in terms of functional ability, which is part of the social model. The issue is that the very idea of neurodiversity seems to me to include a challenge to the reliance on a species norm for assessing (and valuing) our functional abilities at all, in favour of the notion that diversity itself is normal. And if this is the case, then we must find a way to acknowledge differences in functioning in a way that does not rely on the species-norm–based notion of impairment.

As to what neurodiversity means, I will explain why I am ambivalent about definitions. On the one hand, it is important to try and understand, clarify, and analyse neurodiversity, both as a concept and as a movement. In large part it is important to do this because it is a concept that affects many people, and which can be used or abused, in a multitude of ways. Also, how successful the movement is will, to some extent, depend on how viable its underlying concepts and theoretical basis are. Of course, it is also helpful to define terms for more everyday reasons, in so far as we need to understand what others are talking about for successful communication.

Nonetheless, my own understanding has changed considerably, and it continues to do so. In my own case, I have long counted my autism as part of neurodiversity,
but I see my post-traumatic stress as a genuine mental disorder. This was initially because I see autism as a natural and valuable manifestation of human genetic diversity (albeit disabled by society), whereas my post-traumatic stress is more a set of unwanted ingrained responses to distressing experiences. In framing it this way, I think I was influenced here by all the talk of ‘natural’ variations often heard in neurodiversity proponent circles.

But consider a different example. Some research suggests that some cases of personality disorder are, in significant part at least, responses to early traumatic life events. For this reason, I initially assumed that people diagnosed with disordered personalities would, as with my post-traumatic stress, count them as genuine disorders rather than part of natural and valuable neurodivergence. But I have since been convinced that some individuals given those diagnoses also can find the neurodiversity framing helpful and liberating (or at least some do so). And if the neurodiversity framing is as helpful for those labelled as having disordered personalities as it has been for so many autistic people, wouldn’t it be better to develop a more inclusive concept of neurodiversity rather than exclude them? And why should it matter if any given set of traits is ‘natural’ or not anyway? I rather think the focus on whether things are natural or not often detracts from more important goals.

It is because of such considerations that I both think it is vital to critically analyse, but am simultaneously sceptical of attempts to offer final definitions of, neurodiversity. For on the one hand, we do need to be able to distinguish between minority forms of functioning and genuine pathology; but on the other hand, any attempt at definition risks being harmful or exclusionary. With this ambivalence at defining neurodiversity in mind, I will just say two final things.

First, I think that neurodiversity is likely what philosophers call a ‘moving target’, meaning that the concept will continue to change and ‘move’ due to complex interactions between those who are categorised by it (including both neurotypicals and neurodivergents), as well as the various relevant institutions it challenges and responds to (psychiatry, education, etc.). In short, it will mean different things at different times. Given this, while I certainly think there are better and worse definitions of neurodiversity, and that it is the kind of idea that can be used or abused, I do not think it is the kind of thing we can or should hope for a final definition of.

Second, though, I can say more about what the concept is useful for. Over seven years of working on the subject, I have come to see it being more of an epistemically useful concept than anything else. By ‘epistemic’ I mean relating to knowledge; and in describing it as being ‘epistemically useful’, I mean in terms of helping us access and generate new forms of knowledge. From this perspective, a core function of the concept regards how it helps us imagine the world differently to how it currently is. For instance, it helps us to both reimagine pathologised and dehumanised kinds in a more humane and compassionate way and reimagine the world in a way that is less hostile to such kinds. In turn, by adopting a neurodiversity perspective, we can alter actual relations; all
the way from how we empathise with neurological others on a personal level, to how we design scientific experiments or public spaces. Similarly, within and between neurominorities, it helps us foster not just solidary and resistance, but also grounds the development of shared vocabularies for making sense of our experiences and increasing our understanding of both each other and ourselves. So what starts out first as something epistemically useful, translates into the generation of different social facts, and finally into real world change.

References


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