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Disagreeing over Neurodiversity

I was saddened to see the letter from Cross and Atherton published in the last issue of the Psychologist. This letter has been one of many recent articles from various outlets to take issue with the concept of neurodiversity. Only, the concept as described in these articles often appear to be simplistic characterisations at best.

The term neurodiversity was coined by the Australian Sociologist Judy Singer more than twenty years ago. Singer’s own views regarding neurodiversity have developed since this time (https://neurodiversity2.blogspot.com/p/what.html), yet were initially based on the principle of biodiversity and the stating of a ‘brute fact’ of the diversity of embodied experiences, and not viewed as a ‘good or bad’ thing as such. Over time growing numbers of people, particularly autistic activists identified as proponents of the ‘neurodiversity movement’ or variations of what has been referred to as the ‘neurodiversity paradigm’ (https://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/). The neurodiversity movement has been conceptualised in different ways, but largely refers to the promotion of civil rights for ‘neuro-minority’ or ‘neurodivergent’ populations (as sometimes referred to). Perhaps what causes the most controversy (and also misunderstanding) has been on the notion of the ‘neurodiversity paradigm’. Variations of which often work with variations of a social or post-social model of disability, promoting participation and experiential knowledge.

Unsurprisingly to me, like any such movement there are many variations, personal accounts, disagreements and disputes. Unfortunately though, such a diverse movement have often been (mis)characterised as monolithic and ‘extreme’ (https://aeon.co/essays/why-the-neurodiversity-movement-has-become-harmful). Indeed, the neurodiversity movement has been criticised for being too aligned to a medical model (http://blogs.exeter.ac.uk/exploringdiagnosis/debates/debate-1/), too aligned to (a simplistic mischaracterisation of) a social model (https://www.theguardian.com/commentisfree/2019/aug/26/autism-neurodiversity-severe), as not appropriate for use with those with significant intellectual impairments (http://www.diva-portal.org/smash/get/diva2:457919/FULLTEXT01.pdf), and for ignoring such needs (https://aeon.co/essays/why-the-neurodiversity-movement-has-become-harmful), as well as wanting to stifle scientific research particularly in relation to autism and minimising disability (https://www.tandfonline.com/doi/full/10.1080/09687599.2019.1596199). As an autistic academic and neurodiversity proponent and father to an autistic son with severe learning disabilities who has for many years worked with academics across a range of disciplines from neuroscience to drama, and on projects regarding autistic people with high support needs (https://nationalautistictaskforce.org.uk/), I find such criticisms to be lacking nuance to say the least.

I would agree with the benefits of a diversified approach to autism research as suggested by Cross and Atherton. Yet, it is not the neurodiversity movement that is repressing certain avenues of enquiry, although advocates may well be critical of research and often are. I know of very few autistic people with much power to gatekeep, otherwise I imagine the balance of research funding may well be differently weighted than is currently the case. The approach at least I suggested in my previous article was not to detract from areas of enquiry, but to bolster efforts in social and participatory research in the field, which hitherto has seen very little investment despite some collaborative efforts (http://discovery.ucl.ac.uk/1495583/1/A_Future_Made_Together_1.2_LR.pdf).

As a regular user of social media, I witnessed some of the criticisms that were levied at the work of Cross and Atherton and yes some of them were harsh. Receiving such criticisms is always difficult, and yet in the field of autism rather hard to avoid given the many controversies in the field. Upon reflection however, they may see that engaging more with the autistic community may help to
mitigate against such criticisms before they reach publication and help with the respectful dissemination of findings. The Woods et al. article referred to in the letter was written specifically regarding the growing subfield of ‘critical autism studies’ and how referencing autistic scholars would be a good way of not misrepresenting their views. Indeed, without building up interactional expertise with autistic people (https://journals.sagepub.com/doi/abs/10.1177/1362361314525281?journalCode=auta) such breakdowns in communication are all the more likely, leading to further frustration for all concerned.

As for the benefit of both theoretical and applied research, I could not agree more. The above contentions, misinterpretations and disagreements could all be lessened perhaps, if all concerned worked in a more mutual and participatory manner?