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Chapter 1: Neurodiversity past and present – an introduction to the neurodiversity reader [Chapter head]

By Damian E M Milton

The term ‘neurodiversity’ originated initially in 1998 from the work of Australian sociologist Judy Singer, who proposed it as a new category for intersectional analysis, and to suggest it as a banner term for emerging social movements for civil rights for people with various devalued, medically labelled neurological conditions. She based it on the concept of Biodiversity, and its broad argument that the more diversity within an ecosystem, the more resilient and sustainable it would be. She did not define the term, thinking it self-evident, and moved onto the main body of her thesis, which included an evaluation of the social versus medical models of disability, and also explored the notion that perhaps an “ethnicity” or “minority” model was better suited to conditions like “Asperger Syndrome” and “ADHD”. This idea was taken further by others, albeit often taking an approach more aligned with the social model of disability (or variations thereof – for example see Oliver, 2013).

Walker (2014) suggested using the terms ‘neurodiversity’, the ‘neurodiversity movement’ and the ‘neurodiversity paradigm’. Here neurodiversity is stated as a ‘brute fact’ that all brains are to a degree unique, with the embodied development of people being differently disposed in their experiences and actions. In contrast to an individualised medical model of disability, which contrasts ‘normal’ development with that of ‘abnormal’, traditionally framed in terms of deficiency and dysfunction, such a view would not place value judgements of such diversity. The ‘neurodiversity movement’ as a term having been adopted by those arguing for the equal human rights of those deemed divergent from the idealisation of neuro-normativity. It is perhaps the concept of the ‘neurodiversity paradigm’ however that has created the most controversy (and misunderstanding) in this history, described by Walker as:

‘1.) Neurodiversity is a natural and valuable form of human diversity.

2.) The idea that there is one ‘normal’ or ‘healthy’ type of brain or mind, or one ‘right’ style of neurocognitive functioning, is a culturally constructed fiction, no more valid (and no more conducive to a healthy society or to the overall well-being of humanity) than the idea that there is one ‘normal’ or ‘right’ ethnicity, gender, or culture.

3.) The social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human diversity (e.g., diversity of ethnicity, gender, or culture). These dynamics include the dynamics of social power inequalities, and also the dynamics by which diversity, when embraced, acts as a source of creative potential.’ (Walker, 2014).

The immediate antecedent to the development of the neurodiversity movement could be said, however, to have been the coming together of primarily autistic people who were challenging the dominant ways in which autism had been classified, often referred to as the autistic rights and/or self-advocacy movement. Through both online and in-person encounters, a small but highly influential community began to grow, such as through the online networks of ANI (Autism Network International) and InLv (Independent Living on the Autism Spectrum), and the setting up of the Autreat conference in the US (and later the Autscape conference in the UK). These networks included pioneers such as Jim Sinclair, Mel Baggs, Donna Williams, Martijn Dekker and Judy Singer (among others). A seminal essay in this development was ‘Don’t Mourn For Us’, written by Sinclair (1992), in which concerns were directed to the parents of young autistic children.

‘Grant me the dignity of meeting me on my own terms – recognise that we are equally alien to each other and that my ways of being are not merely damaged versions of yours.’ (Jim Sinclair)
Such work was followed by the publication online of satirical guidance in the form of the Institute for the Study of the Neurologically Typical (Tisoncik, 2019), coining the term ‘neurotypical’ and framing such ‘normalcy’ in terms of medicalised symptomology. This was followed by campaigns critiquing the work of non-autistic-led major autism organisations and campaigns that framed autism as a tragedy and even epidemic.

This burgeoning of autistic culture and community has thus been central to the formation of the neurodiversity movement, which can be seen both historically and within this collection. Yet the concept of neurodiversity was never meant to apply to just autistic people, and in more recent years more and more disability advocates have found interest (and sometimes critique) in this movement and related concepts. Over 20 years since its inception, the neurodiversity movement could be said to be ‘coming of age’ with a wealth of books, blogs, films and events, and an ever-growing international reach. One can even see progression into what might be thought of the mainstream media, especially in the UK with pro-neurodiversity television series such as ‘The Autistic Gardener’ and the children’s programme ‘Pablo’.

Since its inception, the autistic community and neurodiversity movement has also provided a space for neurodivergent scholarship to emerge. Early examples of this can be seen in the work of Dinah Murray (see Murray et al, 2005) and Wenn Lawson (2010) regarding the topic of ‘monotropism’ or an ‘interest model of mind’ (captured in the next two chapters of this collection) and Scott Robertson (2010) regarding autism and quality of life. Other notable examples being the setting up of the Autonomy Journal (Arnold, 2012), the AASPIRE group (Raymaker et al, 2019), work relating to what has been called the ‘double empathy problem’ (Milton, 2012; Milton et al, 2018), influence through mainstream research conferences (Robison, 2019), general texts on autism theory (Chown, 2016), critical work on autism interventions (Milton, 2014; Kupferstein, 2018) and more recently regarding autism and culture (McGrath, 2017; Yergeau, 2018; Rodas, 2018). This can also be seen throughout this collection and particularly the first section of this book.

In recent times, neurodiversity and related concepts have come under criticism from various stakeholders. Whilst some criticism may be more well founded (e.g. Russell, 2019), much of this criticism has reduced these concepts to simplistic mischaracterisations (for a discussion of which, see Milton, 2019).

This collection involves three sections. First there are a set of articles that explore various conceptualisations of neurodiversity or aspects thereof. The second section concentrates more on the lived experience of being ‘neurodivergent’, whilst the third section reflects on the implications of neurodiversity and related concepts on practice. No collection such as this can be exhaustive of relevant topics, and it is suggested here that this volume be seen as complementary to other such collections, particularly that of the Loud Hands collection (Bascom, 2012), the two autism and intellectual disability annuals also published through Pavilion Publishing (Milton and Martin, 2016; 2017), and the superb recent collection edited by Steven Kapp (2019) reviewing the history of the autistic community and the neurodiversity movement (including articles from many of the pioneers of the neurodiversity movement). This book has thus attempted to collate work which seeks to explore key issues and yet also point to the future and where the neurodiversity movement may go from here, including chapters from a number of ‘up-and-coming’ voices.

References [B-head]


