

Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science

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Since its initial description, the concept of autism has been firmly rooted within the conventional medical paradigm of child psychiatry. Increasingly, there have been calls from the autistic community and, more recently, nonautistic researchers, to rethink the way in which autism science is framed and conducted. Neurodiversity, where autism is seen as one form of variation within a diversity of minds, has been proposed as a potential alternative paradigm. In this review, we concentrate on three major challenges to the conventional medical paradigm – an overfocus on deficits, an emphasis on the individual as opposed to their broader context and a narrowness of perspective – each of which necessarily constrains what we can know about autism and how we are able to know it. We then outline the ways in which fundamental elements of the neurodiversity paradigm can potentially help researchers respond to the medical model’s limitations. We conclude by considering the implications of a shift towards the neurodiversity paradigm for autism science. **Keywords:** Autism; ethics; medical model; neurodiversity; social model of disability.

Introduction

Science is not static. As Thomas Kuhn (1962) explained, science progresses through a series of phases from what Kuhn called ‘normal science’ – the accepted orthodoxy of the moment – to periods of crisis, when scientists begin to contest the hitherto-accepted paradigm itself. This period ends, ultimately, in a shift from one paradigm to another. In the field of autism science, the conventional medical paradigm is – and has long been – the accepted orthodoxy in this field, conceptualising autism in terms of biologically derived functional deficits, and thus placing limits or boundaries on what we can know about autism and how we are able to know it (Kuhn, 1962). The vast majority of autism researchers have been trained to understand autism as a disorder of brain development, an undesirable deviation from the norm.

There have been ‘rumblings’ in autism science, however, of the sort that Kuhn described. In a context of social change, with many challenges to established power structures, autistic advocates and autism scientists have increasingly called to replace the conventional medical paradigm and consider autism instead through the lens of *neurodiversity*, where autism is seen as one form of variation within a diversity of minds (Singer, 1998; Walker & Raymaker, 2020). These calls, stemming originally from autistic¹ activists (Pripas-Kapit, 2020; Sinclair, 1993) have increasingly found at least partial adherents from within autism science (Baron-Cohen, 2000; Gernsbacher, 2007; Happé & Frith, 2020; Mottron, 2011; Nicolaidis, 2012), suggesting that

researchers could be on the brink of thinking about autism in a fundamentally different way. Doing so could radically change how we approach knowledge construction within autism science and the way that we support autistic people and their families in our practice.

In what follows below, we proceed in two major sections. First, we outline the major ways in which the conventional medical paradigm is being called into question. Second, we outline the fundamental elements of the alternative view, the neurodiversity paradigm. We briefly trace its history, describe its core tenets and ask whether the neurodiversity paradigm could potentially overcome the challenges faced by its medical counterpart. We then conclude by considering the implications of a shift towards the neurodiversity paradigm for autism science.

The conventional medical paradigm

The conventional medical paradigm, also known as the medical model of disability (Llewellyn & Hogan, 2000; Marks, 1997), approaches autism as a disability primarily rooted *within* individuals. Within the medical paradigm, disability is seen to arise as a direct consequence of a person’s biological make-up and functioning. Specifically, disability is defined as ‘any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being’ (World Health Organisation, 1980, p. 143). As demonstrated in this definition, the conventional medical paradigm implicitly assumes the existence of a typical or ‘normal’ level of ability that is held up as the ideal ‘state of health’; those who enjoy this state are taken as the normative standard and any

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other is unfavourably compared with it (Akhtar & Jaswal, 2013; Medin, Bennis, & Chandler, 2010).

In line with this perception of disability as an undesirable feature of the individual, treatment of disability under the medical paradigm typically aims to bring an individual's abilities into line with the accepted norm. Treatments and/or interventions are therefore applied to the disabled person, with the goal of altering the individual's impairment/s in order to remediate or eliminate disability and enhance functioning.

Widespread understandings of autism have firm roots within this medical paradigm (Evans, 2013; Fletcher-Watson & Happé, 2019; Silberman, 2015). The first published descriptions of the constellation of traits we now call autism were authored by a psychiatrist (Kanner, 1943) and a paediatrician (Asperger, 1944) working within the conventional medical paradigm of their time. Today, autism is listed in both the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the International Classification of Diseases (ICD-11) as 'Autism Spectrum Disorder', a neurodevelopmental disorder. In both manuals, Autism Spectrum Disorder is described as a series of 'persistent deficits' demonstrated by autistic children, young people and adults, involving deficits in social communication and interaction, and restricted, repetitive and inflexible patterns of behaviour, interests or activities.

This manner of characterising autism focuses solely on the autistic person and their perceived 'deficits'. Consequently, one key aim of autism science has been to identify the specific neurodevelopmental mechanisms – at the genetic, neurobiological and cognitive levels – that might explain the behavioural manifestations of autism. The implicit argument is that such scientific progress is an essential precondition for any further translational efforts to inform treatments and interventions for autistic children, helping to 'guide brain and behavioural development back toward a normal pathway' (Dawson, 2008, p. 776).

This approach has yielded a number of scientific breakthroughs that have dramatically advanced our understanding of autism (see Happé & Frith, 2020, for review). But challenges have been increasingly loud of late, in part due to the rise in autistic self-advocacy and the neurodiversity movement, and in part due to the relative absence of 'hard facts', or universal scientific truths about autism, at any level of explanation (see Verhoeff, 2015, for discussion). As Professor Sir Michael Rutter put it: 'it seems decidedly odd that after more than half a century of both research and clinical experience with Autism Spectrum Disorders, there continue to be arguments on the nature of autism' (2014, p. 55). For some, it is time to consider whether we should be approaching autism science and practice in a radically different way.

A focus on deficits

The conventional medical approach searches for impairments and functional deficits in autistic people and often has the unintended consequence of drawing attention away from the particular strengths of autistic people and focusing entirely on limitations, whether perceived or real. It detracts, in other words, from an account of what autistic people *can* do and stresses what they *cannot*. It does so despite longstanding recognition that autistic people might excel at particular activities in individual instances (Frith & Happé, 1994; Hermelin & Frith, 1971; Hermelin & O'Connor, 1975; Mottron & Belleville, 1993; Shah & Frith, 1983). An increasing number of studies show that while autistic people outperform nonautistic people on a variety of tasks (e.g. Muth, Honekopp, & Falter, 2014; Remington & Fairnie, 2017; Samson, Mottron, Soulieres, & Zeffiro, 2012), these strengths are very rarely considered in the profile of autism (American Psychiatric Association, 2013). When mentioned at all, these tend to be referred to as 'islets of abilities' among a sea of deficits (Shah & Frith, 1983). The adoption of a predominantly deficit-focused view therefore tends to present autism as a lack or absence of something that someone ought to have, an undesirable individual experience (Dinishak, 2016; Robertson, 2010).

The problem goes deeper than this, however. In a number of cases, conventional autism research describes ways in which autistic people *outperform* nonautistic people in scientific tasks yet interpret those achievements as somehow revealing a problem. That is, data that in fact reveal strengths in autistic people are paradoxically – and bizarrely – interpreted in a negative way, as a consequence of a 'deficit' or 'impairment' (Dawson & Mottron, 2011; Dinishak, 2016; Gernsbacher, Dawson, & Mottron, 2006; Robertson, 2010). One of the authors of this review has previously fallen foul of this deficit-focused bias herself. She examined the extent to which autistic children were susceptible to perceptual aftereffects – a change in subjective perceptual experience following prolonged exposure to a stimulus (Webster, 2011). In that study, she initially reported that autistic children showed a significantly *reduced* perceptual after effect for faces compared with nonautistic children of similar age and ability, as if that was a sign of a functional deficit (Pellicano, Jeffery, Burr, & Rhodes, 2007). Yet it soon became clear the same data could be read in almost exactly the opposite way: autistic children's face recognition following adaptation was actually *more accurate* than that of nonautistic children. Whereas nonautistic children were led astray by their preconceptions, the autistic children's perception corresponded more to physical reality than to expectations (i.e. it was more veridical; Pellicano & Burr, 2012).

Other authors make similar observations with regard to a range of autistic social and nonsocial

'deficits' which could equally be seen as 'strengths' (Bertilsson Rosqvist & Jackson-Perry, 2020; Dawson, Soulières, Gernsbacher, & Mottron, 2007; Gernsbacher et al., 2006; Mottron, 2011; Robertson, 2010). Even when autistic people show enhanced performance on visuo-perceptual tasks, like the Block Design task from the Wechsler Scales of Intelligence (Wechsler, 2008, 2014) or on the Embedded Figures Test (Witkin, Oltman, Raskin, & Karp, 1971), such strengths are invariably characterised as a by-product of a deficit in higher-order cognition (e.g. Frith & Happé's 'weak central coherence', 1994). As Dawson and Mottron (2011) write:

Autistics, like non-autistics, have genuine difficulties in many areas, and like non-autistics, require assistance in areas where their performance is weak... But autistics uniquely are seen as pathological when displaying significant or dramatic strengths, creating for autistics a nearly insurmountable disadvantage or disability not faced by non-autistics (p. 34)

This tendency to interpret autistic performance negatively is seen further in the research literature on autistic intelligence, which demonstrates that it is often the research design itself that is the cause of the issue. For many years, researchers interpreted autistic people's low scores on, or noncompletion of, standard intelligence tests (e.g. Wechsler Scales of Intelligence) simply as confirmation of intellectual disability. In fact, however, once strength-informed intelligence tests (e.g. Raven's Progressive Matrices) were substituted for the conventional ones, those deficits disappeared (Courchesne, Girard, Jacques, & Soulières, 2015; Courchesne, Meilleur, Poulin-Lord, Dawson, & Soulières, 2019; Dawson et al., 2007).

Such negative interpretations and the research design that reinforces them have consequences beyond research itself. Autistic scientist, Michelle Dawson, has long argued that the habit of casting autistic people as 'less than' has resulted in autistic people being subject to medical and other interventions that are not as fully supported by evidence as they should be. This is particularly the case with one dominant intervention, Applied Behavioural Analysis (Dawson, 2004). Even as recently as 2019, autistic people have been subjected to 'aversive' treatments in behavioural intervention research (Verriden & Roscoe, 2019), including electric shocks as punishment at the highly controversial Judge Rotenberg Educational Center of Canton, Massachusetts, which is still open for business despite having been condemned for torture by the United Nations Special Rapporteur on Torture (Neumeier & Brown, 2020). The persistent focus on deficits serves to support these dehumanising attitudes; seeing autistic people as 'less than human' (Goffman, 1990; see also Cage, di Monaco, & Newell, 2019) legitimises the use of electric shock in this instance.

Dawson frames these 'unacceptably low standards' (Cowen & Dawson, 2018, para 146) as human rights issues and calls for researchers and practitioners to ensure basic standards in research and practice are extended to autistic people (see Dawson & Fletcher-Watson, 2021). The relative failure of autism researchers to report potential conflicts of interest in research (Bottema-Beutel, Crowley, Sandbank, & Woynaroski, 2021b) and adverse events or potential 'harms' in nonpharmacological interventions for young autistic children (Bottema-Beutel, Crowley, Sandbank, & Woynaroski, 2021a; Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2021) is consistent with this view (Davis, den Houting, Nordahl-Hansen, & Fletcher-Watson, in press).

Aside from concerns regarding questionable standards in autism intervention, the conceptualisation of autism as a series of deficits and the goal of intervention thus to 'make people less autistic' is morally troubling in itself (Ne'eman, 2021; see also Callanan & Waxman, 2013). Autistic people and their families are regularly presented with the message that being autistic is a tragic fate, with an autism diagnosis presumed to prompt grief and mourning. The language of deficits dominates discussion of autism both in scientific writings and in the popular press (Bottema-Beutel et al., 2021; Kenny et al., 2016). Researchers and others use terms like 'disorder', 'deficit', 'impairment' and 'dysfunction' to describe most deviations from the norm in autistic behaviour, cognition or neurobiology. Researchers commonly use person-first language ('child with autism'), as if autism can be separated from the person, even in the knowledge that many autistic people eschew this terminology (Kenny et al., 2016; Sinclair, 2012) and that it is more likely to contribute to stigma (Bottema-Beutel et al., 2021; Gernsbacher, 2017). Researchers also routinely describe children as 'high-' or 'low-functioning' (Alvares et al., 2020; Kenny et al., 2016), as being 'at risk' of developing autism (Jones, Gliga, Bedford, Charman, & Johnson, 2014; Kolevzon, Gross, & Reichenberg, 2007; Modabbernia, Velthorst, & Reichenberg, 2017; Yudell, Tabor, Dawson, Rossi, & Newschaffer, 2013), and as having the potential to achieve an 'optimal outcome' (Fein et al., 2013; Orinstein et al., 2014; Sutera et al., 2007) – where optimality is equated with no longer meeting diagnostic criteria for autism. Frequently, policy makers and others discuss autistic people in terms of 'burden', in relation to both the economic costs associated with autism (e.g. Knapp, Romeo, & Beecham, 2009; Leigh & Du, 2015) and the experiences of parents and others who care for autistic people (e.g. Marsack-Topolewski, Samuel, & Tarraf, 2021; Picardi et al., 2018).

In the face of this constant negative messaging, especially combined with more generalised discrimination against disabled people, it is unsurprising that considerable stigma is associated with the

autism label. Studies with young autistic people in particular have found that they often construe themselves as ‘different’ to neurotypical people in a negative way (Cribb, Kenny, & Pellicano, 2019; Humphrey & Lewis, 2008; Shattuck et al., 2014; Williams, Gleeson, & Jones, 2019). They label themselves as a ‘freak’, ‘mentally disabled’ and as ‘having a bad brain’ (Humphrey & Lewis, 2008), and often just want to be ‘as normal as possible’, actively hiding their autistic-ness (Cribb et al., 2019). These negative self-appraisals are not unexpected given that young autistic people are more likely to experience social exclusion and bullying (Humphrey & Hebron, 2014; Maiano, Normand, Salvat, Moullec, & Aime, 2016; Schroeder, Cappadocia, Bebko, Pepler, & Weiss, 2014). But they can have damaging effects on their mental health (Cage, Di Monaco, & Newell, 2018; Cooper, Smith, & Russell, 2017; Hedley & Young, 2006), where a disabled/autistic person may come to believe that they are less worthy and act accordingly (Becker, 1963; Milton, 2012). Actively hiding one’s autistic differences through masking or camouflaging (see Pearson & Rose, 2021, for discussion) can also come at serious personal cost, including stress, anxiety and negative self-perceptions (Hull et al., 2017) and burnout (Higgins, Arnold, Weise, Pellicano, & Trollor, 2021; Raymaker et al., 2020) in autistic adults.

The medical model is essentially individualist

The prevalence of deficit-based thinking has the further consequence of focusing attention directly on the individual and away from social and environmental factors that might in fact play a significant role in shaping autistic lives (Engel, 1977). In the conventional medical view, autism and its associated disabilities are seen as something inherent to the individual. Biomedical research thus tends to explain an autistic person’s difficulties not with reference to the context in which the difficulty occurs – home, school, work or broader community – but rather as a characteristic of the individual themselves. Within autism science, this tendency has been further enhanced by the well-established portrayal of the autistic person as being on their own in the world (Broderick & Ne’eman, 2008). Given that autism was originally seen to manifest as withdrawal from the world (Kanner, 1943), it made even more intuitive sense to early researchers to propose that the features that determine the nature of the autistic experience lay with the individual themselves.

Taking this individualistic starting point suggests that the ‘fault’ for difficulties in life resides with the individual themselves, thus the burden of ‘correcting’ perceived difficulties lies there too. The autistic person is perceived to be in some way ‘flawed’ or ‘defective’, with individual treatment required to remediate these shortcomings. In autism research and practice, it is clearly evident that autistic people

are by and large expected to ‘overcome’ their impairment/s in order to achieve a typical level of ability. Treatments and interventions have thus been designed to modify, diminish or enhance autistic children’s behaviours to address these key goals.

The most ubiquitous of these treatments are those that are based on a behavioural model, especially Applied Behavioural Analysis (ABA) (Vismara & Rogers, 2010). The ambition of ABA to render autistic children ‘indistinguishable from their normal friends’ (Lovaas, 1987, p. 8) at the very least obscures any distinctive autistic strengths. These treatments are controversial for a range of reasons (e.g., Dawson, 2004; Ne’eman, 2021; Wilkenfeld & McCarthy, 2020) but, for the purposes of this paper, it is helpful to concentrate on the treatment of one behaviour, stimming. Seen through the lens of the conventional medical model, there has been a tendency to perceive so-called repetitive motor stereotypies such as hand-flapping (American Psychiatric Association, 2013) as an individual problem, with no clear purpose or function, and which prevent the child from learning adaptive or other skills and interacting with their peers (Asperger, 1944; DiGenaro Reed, Hirst, & Hyman, 2012; Kanner, 1943; Lilley, 2018). Given these presumed negative outcomes – and that stimming behaviours like hand-flapping are considered conspicuous and stigmatising, particularly for children in mainstream classroom settings – it is often regarded as ‘essential that researchers continue to assess and treat motor stereotypy either as the target behaviour of the intervention or as a collateral behaviour’ (Tereshko, Ross, & Frazee, 2021, p. 3); to demonstrate ‘calm’ or ‘quiet’ hands.

These treatments persist despite a dearth of evidence that these stimming behaviours are harmful to autistic people or their peers. In fact, it now seems likely that they often serve a regulatory, soothing function for autistic people (e.g. Joyce, Honey, Leekam, Barrett, & Rodgers, 2017; Kapp et al., 2019). Moreover, the interventions designed to quash these behaviours might well do more harm than good (Bascom, 2012; Dawson, 2004; Jaswal & Akhtar, 2018; Lilley, 2018). It is surely at least plausible to suggest that attention would be better directed towards *social* interventions that aim to shift the negative perceptions of stimming among nonautistic people, rather than to efforts to prevent autistic people from stimming in the first place.

Excluded voices, narrow perspectives

One further critique of the conventional medical paradigm is its tendency to detract attention from autistic people’s own understanding of autism and of their own lives. As autistic self-advocate Donna Williams put it, ‘right from the start, from the time someone came up with the word “autism”, the condition has been judged from the outside, by its

appearances, and not from the inside according to how it is experienced' (Williams, 1996, p. 14). Along these lines, some researchers have even suggested that a lack of 'theory of mind' in autistic children, young people and adults (Baron-Cohen, Leslie, & Frith, 1985) impairs their ability to reflect on their own mental states (Lombardo, Chakrabarti, Bullmore, & Baron-Cohen, 2011), thus questioning the veracity of autistic people's accounts of their own experiences (Frith & Happé, 1999).

Consequently, researchers have often avoided attending to first-person testimony, preferring to privilege reports from parents, teachers or other informants, or laboratory-based observation over considering the perspectives of the person themselves (Jaswal & Akhtar, 2018; Mazefsky, Kao, & Oswald, 2011; McGeer, 2004; Milton, 2012). The claim that autistic people cannot understand their own minds can also have damaging effects, including to autistic people's autonomy, self-determination and perceived credibility (Gernsbacher & Yergeau, 2019). As Jim Sinclair (1993, p. 298) wrote:

The results of these assumptions are often subtle, but they're pervasive and pernicious: I am not taken seriously. My credibility is suspect. My understanding of myself is not considered to be valid, and my perceptions of events are not considered to be based in reality. My rationality is questioned because, regardless of intellect, I still appear odd. My ability to make reasonable decisions, based on my own carefully reasoned priorities, is doubted because I don't make the same decisions that people with different priorities would make.

As well as shaping research findings, this lack of attention to autistic people's perspectives also has the consequence of ensuring that autistic people themselves have almost no say as to *what* gets researched in autism science, *why* or *how*. Over the last two decades, international investment in autism science has grown extensively (Office of Autism Research Coordination, 2017; Pellicano, Dinsmore, & Charman, 2013). In 2016 alone, US\$400 million was spent on autism research in the United States, United Kingdom, Australia and Canada – although the United States contributed the vast majority (92%) of that investment (Office of Autism Research Coordination, 2019). Similarly, the number of papers published on autism has increased 10-fold (Dawson, 2013; Office of Autism Research Coordination, 2012), far surpassing publications on related topics in child psychology and psychiatry. According to PubMed, there were 6,539 journal articles published on autism in 2020 alone.

Autistic people themselves have had almost no say in shaping that research agenda. The conventional medical approach to autism assumes that priorities for autism research centre on questions of identifying, treating and potentially preventing autism; and that answers to these fundamental questions will

'only be found when there is a better understanding of the neurobiological basis of autism' (Insel & Daniels, 2011, p. 1361). As noted by Bertilsdotter Rosqvist and Jackson-Perry (2020), 'in a condition as highly medicalised as autism, whose parameters are laid out in medical practitioners' diagnostic manuals, it follows that the testimony which may be assumed to be the most accurate, which holds the highest level of credibility when discussing autism... issues from medical science' (p. 3).

It is not, surprising, then, that the vast preponderance of autism research worldwide focuses on the underlying genetic causes and biology of autism (den Houting & Pellicano, 2019; Office of Autism Research Coordination, 2019; Pellicano, Dinsmore, & Charman, 2014b; Singh, Illes, Lazzeroni, & Hallmayer, 2009). This focus is in sharp contrast to the stated research priorities of community members – autistic people, their family members, educators, clinicians and other professionals – who have consistently called for research on areas that are of more immediate, practical concern or for basic science research that may be more straightforwardly translated into applications (Frazier et al., 2018; Jose et al., 2020; Pellicano et al., 2014b; Robertson, 2010; Roche, Adams, & Clark, 2021; Warner, Parr, & Cusack, 2019). In the words of one parent, 'when it comes down to it, it's not real life ... [research] is always missing the next step' (Pellicano et al., 2014b, p. 5).

The relationship between autism scientists and community members has a long and fraught history (Pellicano & Stears, 2011; Silberman, 2015; Silverman, 2011). But the mismatch between what is currently being researched, what community members want from research and who gets to make these decisions may well be contributing to the growing distrust of mainstream autism science by the broader community (Bagatell, 2010; Dawson, 2004; Lory, 2019; Milton, 2012). Pellicano, Dinsmore, and Charman (2014a) have shown that autistic people and family members in the United Kingdom report overwhelmingly negative experiences of autism research. Family members described feeling disappointed and frustrated at being 'mined' for information and having little or no opportunity to learn about the resulting scientific discoveries and what they might mean for them. Autistic adults reported feeling objectified ('we are a bit like monkeys in a zoo') and their experiential expertise perceived as being disregarded by researchers ('whatever I say, is this really going to influence anyone?'; also see Milton & Bracher, 2013).

Ultimately, autism research has been characterised by a narrowness of perspective. By prioritising research on causation, we have failed to understand the nature of autistic people's life experiences. Imposing nonautistic, medically driven priorities has had the grave consequence of diverting resources away from existing autistic people and the

areas that matter most in their lives (Pellicano & Stears, 2011; Robertson, 2010).

Neurodiversity: is it time for a paradigm shift?

These three difficulties with the conventional medical approach to autism – an overfocus on deficits, an overwhelming emphasis on the individual as opposed to their social context and a narrowness of perspective – have provoked an increasingly strong reaction in recent years. In the early 1990s, autistic activists began to advocate for a shift in attitudes towards autistic people. They drew encouragement from the broader disability rights movement that itself gained force during the late 1970s and early 1980s, and achieved landmark progress during the early 1990s with the introduction of the Americans with Disabilities Act in 1990, the Australian Disability Discrimination Act in 1992, and the British Disability Discrimination Act in 1995 (Oliver, 1996; Swain, French, & Cameron, 2003). Perhaps most notable in this early autistic advocacy is the work of autistic advocate Jim Sinclair, whose foundational essay ‘Don’t mourn for us’ remains poignantly relevant even today (Pripas-Kapit, 2020; Sinclair, 1993).

In 1998, autistic sociologist Judy Singer and journalist Harvey Blume coined the word ‘neurodiversity’ (Blume, 1998; Singer, 1998), supplying a collective framework for autistic and neurodivergent advocacy. The term ‘neurodiversity’ (see Box 1 for terminology) and the associated paradigm were embraced by autistic advocates, and over time became ubiquitous within – and synonymous with – the broader neurodivergent community. Throughout the 2000s, autistic-led advocacy organisations (e.g. the Autistic Self-Advocacy Network) were founded, providing for the first time an authoritative voice for the autistic community in neurodiversity advocacy efforts.

Autistic scholars and allies have worked to promote awareness of the neurodiversity paradigm

within academia (den Houting, 2019; Nicolaidis, 2012; Robertson, 2010). A cursory search of the PubMed database using the keyword ‘neurodiversity’ indicates some success in this regard. During 2010, just one relevant manuscript was published. A decade later during 2020, 33 manuscripts were published. Most recently, autistic scholars have sought to progress the scholarship of neurodiversity in its own right, through the emerging disciplines of critical autism studies and neurodiversity studies (Bertilsdotter Rosqvist, Chown, & Stenning, 2020; Kapp, 2020; Walker & Raymaker, 2020). Framed within the neurodiversity paradigm, each critique explored above is seen as a significant failure requiring urgent attention to put right. Below, we trace the ways in which those who advocate neurodiversity seek to do so.

Diversity, not deficits

In and of itself, *neurodiversity* refers to the broad diversity that exists in human neurobiology. There are countless ways in which the human brain and mind can develop, both structurally and functionally. Many of these fall within a range that can be considered as ‘typical’ neurodevelopment, while some fall outside of that range and can be considered to ‘diverge’ from the norm (Ecker, Bookheimer, & Murphy, 2015; Jumah, Ghannam, Jaber, Adeeb, & Tubbs, 2016). Neurodiversity encompasses this entire spectrum, including both typical and divergent neurodevelopment (Singer, 1998; Walker, 2014). The neurodiversity paradigm refers to a particular set of beliefs and attitudes regarding this diversity (Walker, 2012) and rejects the view that divergence from the norm is a flaw requiring correction.

This stance can be broken down into two key assumptions. The first of these is the assumption that typical neurodevelopment is neither superior nor inferior to divergent neurodevelopment. Neurotypicality does not represent ‘correct’ neurodevelopment any more than English represents the ‘correct’ language to speak, or that one element of an ecosystem can be seen as prior to any other. Indeed, diversity in neurodevelopment is itself valuable, in much the same way that linguistic diversity is valuable in contributing to a culturally rich landscape or biological diversity can strengthen the health of all of the component parts of a system (see Amundson, 2000, for discussion). The second key assumption within the neurodiversity paradigm is the belief that even if diversity were not to serve this collective purpose, *all* people deserve to be treated with dignity and respect, independently of how they diverge from a putative norm, and should be valued for who they are and as they are.

This second assumption implies that, in contrast to the common misconception that the neurodiversity

Box 1 Terminology

Neurodiversity: The range of natural diversity that exists in human neurodevelopment.

Neurotypical: A person or people whose neurodevelopment falls within the range usually considered to constitute ‘typical’ development.

Neurodivergent: A person or people whose neurodevelopment falls outside of (or ‘diverges’ from) the range usually considered to constitute ‘typical’ development (e.g. a group of autistic people is a group of ‘neurodivergent’ people).

Neurodiverse: A collective term for groups including mixed neurodevelopment (e.g. a group of autistic and nonautistic people is a ‘neurodiverse’ group).

movement is only of interest to autistic people with less complex support needs (commonly termed 'high functioning'; Fenton & Krahn, 2007; Jaarsma & Welin, 2012), the neurodiversity paradigm is explicitly inclusive of *all* autistic and neurodivergent people, including those with the highest and most complex support needs (Grinker, 2020; den Houting, 2019; Ne'eman, 2021). In practice, neurodiversity advocates have long recognised that it can be a challenge to ensure that all autistic people's interests are taken into account, not just those who are more able to influence decision-making or to make their voices heard through research, activism or protest (Ballou, 2018). But, fundamentally, those who support neurodiversity accept that a person's value must not be contingent on their ability to 'contribute' to society, economically or otherwise (Kittay, 2017). As such, the neurodiversity paradigm also broadens the standard understanding of what constitutes a 'meaningful' life. It insists that an autistic person's life may be rich and fulfilling despite bearing little resemblance to the conventional ideal. In conventional research, well-being and quality of life are often presented as objective constructs comprising outcomes including employment, independence, and relationships. Neurodiversity, on the other hand, encourages us to be open to a wider range of potential conceptualisations of a good life. Measured according to neuronormative standards, that is, many autistic people are assumed to have poor quality of life, but this view can change if autism-specific values, goals and needs are taken into account (Lam, Sabnis, Migueliz Valcarlos, & Wolgemuth, 2021). Indeed, when autistic people have been involved in determining outcomes that are relevant to their quality of life, they have identified unique factors including other people's knowledge and acceptance of autism; sensory processing differences; supporting other people and positive autistic identity (McConachie et al., 2020). This contrasts sharply with deficit-based framings of autism as an unwelcome encumbrance (e.g. autism as a 'shell' or 'prison'; Broderick & Ne'eman, 2008) from which an otherwise 'normal' person can be freed through intervention.

The neurodiversity paradigm thus promotes autism acceptance, urging autistic people and others to embrace autism as an inherent and integral part of an autistic person's identity and experience of the world. The potential value of this acceptance mindset to autism is further supported by recent research indicating that greater autism acceptance is associated with better mental health, in both autistic adults (Cage et al., 2018) and mothers of autistic children (Da Paz, Siegel, Coccia, & Epel, 2018). Similarly, and consistent with evidence regarding identity development in the broader disabled population and the general population, a positive sense of autistic identity is also associated with better mental health (Cooper et al., 2017).

Neurodiversity highlights the need for social responses

None of this is to suggest, of course, that autistic people do not require supports to enable them to achieve their goals. The neurodiversity paradigm does, however, lead us to understand the nature of the obstacles that many autistic people face in a fundamentally different way to the conventional medical paradigm. Neurodiversity is closely aligned with the social model of disability. Seen this way, any 'disability' is not best understood as the result of an individual's unique characteristics, but rather as a result of an environment that does not effectively accommodate those characteristics (Oliver, 1996; Union of the Physically Impaired Against Segregation, 1976). The physical and social environments within which we all live are generally designed to meet the needs of those who fall within the typical range of neurodevelopment; these same environments are often suboptimal, and even hostile, for neurodivergent people and need to be adjusted if such people are to lead good lives.

Traditional, mainstream school settings are an example of one such environment: they are often physically large, noisy and chaotic, require frequent transitions within and between classes throughout the school day, and entail a host of implicit social rules and expectations. Physical environments, like schools, that are designed with neurotypical needs in mind can leave autistic people in sensory discomfort and distress, and social environments governed by neurotypical rules are often similarly inaccessible. These inaccessible contexts can render autistic people less 'able' than their neurotypical peers – that is, disabled – in myriad ways.

Such examples are only small instances of the ways in which the institutions that govern society at a structural level are typically controlled by and designed for neurotypical people, often with devastating effects for autistic people. Autistic people are disproportionately formally excluded (expelled) from school (e.g. *Ambitious about Autism*, 2014; Brede, Remington, Kenny, Warren, & Pellicano, 2017), experience frequent bullying and other forms of victimisation (Brown-Lavoie, Vecili, & Weiss, 2014; Maiano et al., 2016), are either unemployed or underemployed at greater rates than other disabled people (Chen, Leader, Sung, & Leahy, 2014; Scott et al., 2019), are at greater risk of physical health conditions (Croen et al., 2015) and have increased vulnerability to mental ill-health (Lai et al., 2019), including high rates of suicide (Cassidy et al., 2014; Kirby et al., 2019). They are also more likely to experience premature death (Hirvikoski et al., 2016). A growing body of research describes the substantial barriers that autistic adults face in accessing physical healthcare, which include such diverse factors as inaccessible sensory environments; providers'

knowledge about and attitudes towards autism; and the complexity of healthcare systems (Mason et al., 2019; Nicolaidis et al., 2015). Similar barriers exist across a range of domains, including access to mental healthcare (Adams & Young, 2020), employment (Harmuth et al., 2018) and leisure activities (Askari et al., 2014). According to the neurodiversity paradigm, responding to these facts does not require us to ‘change autistic people’ but rather to challenge the societal factors that influence these outcomes (Howlin, 2000; Howlin & Magiati, 2017; see Mandy et al., 2016, for an example).

The barriers to autistic people’s flourishing include both those that exist in the physical environment *and*, perhaps more importantly, social and attitudinal barriers. The discrimination and stigma described above constitutes a serious obstacle for autistic people, which can only be addressed at the societal and systemic levels by promoting autistic inclusion and equity.

Autistic people should lead the conversation

This point returns us to the issue raised above concerning the exclusion of autistic people themselves from the decision-making that directs the agenda for much autism research. It is possible that this exclusion in part results from the way in which we conventionally conceive the fundamental relationship between autistic and nonautistic people. Milton’s (2012) influential Double Empathy Problem proposes a misalignment between the minds of autistic and nonautistic people, highlighting a lack of reciprocity in cross-neurotype interactions as the source of social communication difficulties between autistic and nonautistic people (Davis & Crompton, 2021; Milton, Heasman, & Sheppard, 2018; Mitchell, Sheppard, & Cassidy, 2021). What such research shows is that *nonautistic* people have difficulties understanding the minds and behaviours of autistic people – and, worryingly, are prone to misperceiving them. Nonautistic people, for example, struggle to understand autistic people’s facial expressions (e.g. Brewer et al., 2016) and have difficulties interpreting autistic people’s behaviour (Sheppard, Pillai, Wong, Ropar, & Mitchell, 2016) and mental states (Edey et al., 2016). Nonautistic people also report an unwillingness to interact with autistic people based on first impression judgements (Morrison, DeBra-bander, Faso, & Sasson, 2019; Sasson et al., 2017) and brief interactions (Morrison et al., 2020).

Consistent with this hypothesis, autistic people have been found to communicate more effectively (Crompton, Ropar, Evans-Williams, Flynn, & Fletcher-Watson, 2020) and develop stronger rapport (Crompton et al., 2020) with other autistic people than with nonautistic people. Emerging evidence also suggests that autistic social interaction may incorporate distinctive features that promote social understanding between autistic people

(termed ‘neurodivergent intersubjectivity’; Heasman & Gillespie, 2019).

The neurodiversity paradigm responds to the apparent lack of alignment between the minds of autistic and nonautistic people by emphasising the importance of self-determination and autonomy: autistic people must be involved in all decision-making that stands to affect autistic people, from the highest levels of policy development to individual support planning; that is, they ‘deserve a full seat at the main table’ (Gernsbacher, 2007, p. 13). With this in mind, neurodiversity advocates assert that autism research and practice must be brought into line with the needs and priorities of the autistic and autism communities, taking a far broader perspective of what matters in autism research as a result (Milton, 2014b; Raymaker, 2020; Robertson, 2010). As discussed above, however, autism science has not, to date, been reflective of community priorities for research.

One strategy for producing autism research that more closely aligns with community priorities is to involve autistic people and their allies directly in the research process, through participatory, codesigned and coproduced research. Community engagement in research has a long history outside of autism, most notably with regard to HIV (Epstein, 1996; Moore, 2008) and Aboriginal and First Nations communities (National Health & Medical Research Council, 1991). Processes that draw on the ‘practical wisdom’ of nonscientists have the potential to make scientific discoveries more thoroughly relevant to communities, more directly tailored to the realities of their everyday lives and more consistent with their values (Chalmers, 2004; Hickey, 2018; Lloyd & White, 2011; Pellicano, 2020).

In the past decade, autism researchers worldwide have begun to engage with the autistic community, consulting with autistic people at all stages of the research process, exploring ways to work with autistic people as partners, and addressing research topics prioritised by the community (see Fletcher-Watson et al., 2019; Nicolaidis et al., 2011; Pellicano et al., 2014a, 2014b; Pellicano & Stears, 2011). Such involvement requires substantial commitment by individual researchers to listen to, and learn from, the experiential expertise of a diverse range of autistic people (Collins & Evans, 2002; Milton, 2014a), and to be willing to share power and control in the research process with nonscientists.

Commitments to autistic involvement in research cannot be left entirely up to individual researchers. They must also extend to institutions, such as funders and universities, to instigate structural and strategic change. Over the last few years, funding agencies in the United States (National Institutes of Health’s Interagency Autism Coordinating Committee), the United Kingdom (Autistica) and Australia (Cooperative Research Centre for Living with Autism; hereafter ‘Autism CRC’) have

responded by attempting to direct research efforts towards issues prioritised by community members, including identifying effective supports, interventions and services for autistic people and their families.

The Autism CRC's attempts in Australia have been particularly successful in this regard. They adopted a whole-of-life approach to autism research, investing in projects across early years, school years and adulthood, as well as a participatory approach, placing the autistic community at the centre of its research efforts. This strategic oversight paid off. Analysis of the funding expenditure of Australian autism research during 2008–2017 showed that research during the initial 5-year period (2008–2012) followed a similar pattern to Canada, the United Kingdom and the United States, including a preponderance of funding allocated to biomedical research, but this pattern shifted in the latter 5-year period (2013–2017) following the creation of the Autism CRC, resulting in a more even distribution of funding on biological research and topics prioritised by the autistic community, such as services and life span issues (den Houting & Pellicano, 2019; Office of Autism Research Coordination, 2019). This demonstrates that it is possible to respond to the call for a more expansive research agenda led, at least in part, by autistic people themselves.

Conclusion

We are living through a moment of significant change in the way in which people think about autism. That change is reflected in advocacy (e.g. Ne'eman & Bascom, 2020; Rottier & Gernsbacher, 2020), in the media and public debate (e.g. Silberman, 2015), and in arguments about the nature of autism science itself (e.g. Milton, 2014a; Pellicano, 2020; Raymaker, 2020). It is also beginning to be reflected in academic discussions, with a flurry of review papers, perspective pieces and edited books published in the last 12 months alone (Bertilsdotter Rosqvist et al., 2020; Bölte, Lawson, Marschik, & Girdler, 2021; Davis & Crompton, 2021; Kapp, 2020; Leadbitter, Buckle, Ellis, & Dekker, 2021; Mitchell et al., 2021; Walker & Raymaker, 2020). This is a major shift that has revealed fundamental problems in the conventional medical account – and its inability to explain away what Kuhn (1962) called the 'anomalies' at its core – and the possibilities imminent in the neurodiversity paradigm. Some of the commitments at the heart of autism science as we have known it for decades are beginning to wane.

In this review, we have explained that, while the conventional medical paradigm has been a key tool in shaping autism science, it has nevertheless painted an excessively narrow, deficits-based view of autism and excluded the very people it is meant to serve from agenda-setting in research. In so doing, it has placed too many limits on our knowledge of

autism and how that knowledge is derived. This is no longer a tenable approach.

We believe the neurodiversity paradigm presents a compelling alternative. It insists that we make a fundamental shift in our most basic assumptions about the nature of autism, broadening and altering our shared theoretical beliefs, values and techniques. Though the neurodiversity paradigm continues to develop and evolve, in its current conception it appears to offer an important means for advancing autism science. As Kuhn explained, paradigm shifts in science are rarely straightforward and, as such, we cannot predict the future shape of autism research with any real degree of accuracy. It is possible that those committed to the conventional medical paradigm will amend their own understanding. It is likely, too, that there will be further developments in our understanding of neurodiversity. Moreover, there will be adherents of both views who will seek to find some kind of mutual accommodation. We already see sign of that third possibility in the World Health Organisation's International Classification of Functioning Disability and Health (ICF), as described in a recent review by Bölte et al. (2021), and in recent developments regarding the importance of optimising the person-environment fit (Lai, Anagnostou, Wiznitzer, Allison, & Baron-Cohen, 2020; Mandy & Lai, 2016).

In among all this uncertainty, however, here we have established three key lessons from the neurodiversity paradigm as currently conceived, which will remain vital for future autism science. First, while the neurodiversity paradigm does not challenge the notion that autism is biological in nature, it stresses the need to view autistic people, not as a collection of 'deficits' needing to be 'fixed' but as unique and worthwhile individuals, whose lives have meaning and purpose. It also urges us to look beyond the individual, focusing on (immediate – especially, relational – and systemic) contexts and the interaction between contextual and individual factors, to address the negative and disabling effects of being autistic. Second, while autism science has a strong record of collaborative efforts between academics (Goldstein, Tager-Flusberg, & Lee, 2015), including autistic researchers and lay members of the autistic community in these collaborations is still a rare occurrence. This needs to change. We need to develop far more robust mechanisms of participatory codesign and coproduction in autism research, to ensure that autism science is designed in partnership with autistic people themselves. Third, once that more participatory spirit does emerge, then we believe autism science will be more likely to focus on autistic community priorities, ensuring that developments in autism science are translated into effective changes in the real-world challenges that autistic people continue to face. That is, after all, why it matters so much in the first place.

We are at a turning point in the field of autism science. The conventional medical conceptualisation has played a vital role in autism research and practice to date. Nonetheless, it is increasingly clear that if we wish to make progress for the benefit of the autistic and broader autism communities, it is necessary to re-evaluate our fundamentals. There may well be costs to moving from ‘normal’ to ‘extraordinary’ science (Sonuga-Barke, 2020), as well as even more dramatic costs in seeing through the implications of this change. Taking neurodiversity seriously, in other words, would mean both changing the way that we educate the next generation of (autism) scientists, and also demanding substantial real-world changes, overhauling a series of major institutions and practices so that they serve autistic people better. None of this will be easy. Established conventions often remain established long after their original legitimisation has dropped away precisely because agreeing to change – funding it, designing it and implanting it – is often extraordinarily difficult (Pierson, 2000). But, crucially, the costs of *not* changing need to be weighed as well. If the experience of other significant moments of social transformation in recent history teaches us anything, it is that previously inconceivable public

policy shifts can occur when the demand is strong enough.

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Key points

- The way in which autism has been conceptualised remains firmly embedded within a conventional medical paradigm.
- Autism is therefore typically understood as a disorder of brain development – an undesirable deviation from the norm.
- This places serious barriers on our understanding of autism and poses deep challenges in autistic people’s lives.
- Researchers need, therefore, to consider radically new ways of conceptualising autism.
- The neurodiversity paradigm is one such alternative. It encourages research that is focused on autistic community priorities, and on the interaction between contextual and individual factors, rather than exclusively focused on individual factors.
- Such an approach, which also involves autistic young people and adults in the research process, is crucial to ensuring translational research, with real-world implications for improving autistic lives.

Note

1. In line with the social model of disability and the preferences of the autistic community (Bury, Jellett, Spoor, & Hedley, 2020; Kenny et al., 2016), we use identity-first language (i.e. ‘disabled’ and ‘autistic’) in this review.

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