Chapter 4
The Social, Cultural and Discursive Construction of Autism as a Mental Health Condition and Disability: Different Perspectives

> *The language that we use has the power to reflect and shape people's perceptions of autism.*
>
> *(Kenny et al., 2016, p. 442)*

In Chap. 3, we outlined the clinical and medical position of autism, setting the context for the discursive and inquiring position we take throughout the book. In Chap. 2, we presented a more social constructionist argument for understanding how autism came to 'be', challenging the language of impairment and the social construct of normality. In so doing, we considered some of the critical models of disability for understanding how and where autism fits on the spectrum of disabling conditions. The clinical position, whereby autism has been constructed medically as a neurodevelopmental condition, a brain disease, potentially explained by psychobiology and genetics, characterized by impairments, and positioned on the clinical manual (DSM-5), strongly asserts that autism is a mental health condition, a disorder, a disability, requiring psychiatric input and treatments that are both pharmacological and talking/behaviour therapy based. Such positions based on the medical model, posit autism as the responsibility of psychiatry and mental health services more broadly, with such practitioners assuring diagnosis and treatment is done within the realm of clinical responsibility. Ostensibly, therefore, based on such psychiatric assertions, one could argue that autism is a mental disorder and thus constitutes a psychiatric disability. Indeed, this position is accepted by some, and the pathways of care, access to services and supports, and the way in which those diagnosed with autism are treated, are in some ways contingent on this prevailing view. However, there are many critics of the medical ideology of autism, and we have already included and alluded to various scholarly positions thus far in the book. We move forward through these debates here in this chapter.

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Introduction

It is important to recognize that the perspective of autism as a disability, and as a classified psychiatric condition, is not accepted by all. Instead, this is a position that has been challenged from within and outside of the autistic community, and widely discussed in academic circles as well as clinical ones. The very language and rhetoric of disability as ascribed to autistic people has been unpacked and critiqued, with different arguments being presented. Such different ways of understanding autism are associated with different levels of stigma and framings of difference (Botha et al., 2020), which we discuss later in Chap. 7.

Notably, some of the tensions enveloping the positioning of autism have emerged through the rise and standpoints of the various critical disability models we introduced in Chap. 2. In this chapter, we aim to build upon those challenges and critiques, focusing more specifically on the social construction of autism as a disability; that is, the construction of autism as being characterized by impairments across the key dimensions as attributed to the neurodevelopmental explanation. In so doing, (and as noted throughout) we take a broad social constructionist position, considering the value of both macro and micro social constructionist ideologies, while working to maintain a balanced view, ultimately recognizing that there are tensions in the field and differing perspectives, even amongst those who identify as autistic. Indeed, there are those within the autistic community that challenge the disability rhetoric as ascribed to their position within society, but there are others who report to feel its disabling effects and counter the critical position, being more closely aligned with the medical argument.

In this chapter, we seek to respect the different viewpoints in the field, across academic and clinical spheres, as well as those from within the autistic community. We do this by recognizing the validity of some of the points within the different perspectives and explaining the tensions that exist between them. For clarity, in our own work, we generally take a data-driven, person-centred, social constructionist position on the issue, favouring the viewpoints of those talked about and/or participating in research and recognizing the constructed nature of any personal profile. Indeed, we feel that it is crucial that the voices of the autistic community are given credibility, and that families living with, and professionals working with autistic people are heard and attended to. We challenge the boundaries of socially constructed normality and question the power of classification systems and psychiatry broadly to position those as disabled against their autonomous constructions. To complement the arguments made within this chapter and its general focus, we provide some fairly straightforward analysis of data whereby autism is simultaneously positioned as a psychiatric disability and conversely not as a psychiatric disability, as the very tensions that play on the academic stage are mirrored between different members of the autistic community and those engaged with them.

Autism Across Time and Place

To appreciate the social positioning of autism, and to better understand the different viewpoints of autism as a disability (or not) – that is, a psychiatric disorder in DSM terms – it is helpful to think about the way in which autism as a concept has evolved and developed in societal thinking. Autism is not a natural category, rather its existence came to be as a psychiatric diagnosis (Evans, 2013), as well illustrated in the previous chapter. Over time there has been an evolution of autism (O'Reilly et al., 2019b), evolving from a mental disorder to a cognitive condition (Chapman, 2019). This evolution has developed through technocratic power structures, where the power to define the meaning of autism has traditionally been held by non-autistic medical professionals and researchers (Evans, 2013).

In Chaps. 2 and 3, we described some of the history of the development of this label and its implications for those given it. In its early construction, the condition had relatively clear boundaries (Kanner, 1949), but over time it became described as a spectrum condition, and changes of meaning have led to the boundaries of autism becoming blurred. Since its early inception, autism has been a subject of significant controversy (Orsini & Davidson, 2013), and in recent times this has mostly focused on the notion of an 'autism epidemic.' However, as we previously reported, the increasing prevalence of diagnoses of autism has created some tension (Eyal et al., 2010), and there have been some concerns that this increase is not related to 'new' scientific discovery, but instead a shifting cultural and social practice relating to the social construction of what counts as abnormal development (Timimi et al., 2011). The language of an epidemic might justify policy intervention but does not communicate any fundamental truths about autism as the narrative of the epidemic is not the only way autism is understood (Orsini & Davidson, 2013).

Over the last century, there have been changes in the scientific and medical community's understanding of autism and thus what we understand about autism is constantly in flux (Kenny et al., 2016). Indeed, autism is of interest among researchers, scientists, the public, and the media, and perhaps unsurprisingly this interest is made visible in its multiplicity of meanings (Orsini & Davidson, 2013). A focus of such interests has reflected the very discourses used in science and lay discourse to describe those labelled with autistic. As we noted in Chap. 1, there has been some tension about how to refer to the autistic community in writing. We illustrated there that our adoption of 'autistic person' reflects the current debates about identity (Bottema-Beutel et al., 2021). This reflects changes sparked by the efforts of the broader disability rights movement (Kenny et al., 2016), as self-advocates generally prefer to have their identity prominent, as the 'autistic person' (Bagatell, 2010; Ortega, 2009; Vivanti, 2020). Thus, the autistic community have certainly shaped the broader public discourses about the condition, using the Internet to provide a rich commentary regarding their first-hand experiences and sharing their insights and challenges (Orsini & Davidson, 2013).

As we have noted, our perspective is that *autism is a social construct*. We caution here, though, as we have already a couple of times earlier in our writing, that in positioning autism this way we are *not* denying the embodied 'realities' of those with autism or their families, and neither do we diminish any experiences, distress or stress, or difficulties that those families and individuals report (see O'Reilly et al., 2015a). Indeed, we recognize and acknowledge that for some families, the diagnosis of autism is distressing, and that some parents report that working with services is the most difficult thing they cope with in this adversity (Hodge & Runswick-Cole, 2008). Furthermore, although it may be the case that families of children with mental health needs (including autism) feel that the child's behaviour can impact negatively on family functioning and may even feel burdensome, meaning that a label (and by default an explanation) is desirable, there may nonetheless remain some sadness, distress or challenges felt by those families (O'Reilly, 2021).

Thus, we aim to offer a perspective that is congruent with the autonomy of those with lived experiences, a person-centred theoretical position that provides alternative ways of thinking about the medicalized discourses that prevail in positioning autism as a psychiatric disability. In so doing, we explore the mechanisms for appreciating how the dominant ideas of an 'impaired' autistic person have been reified through medical rhetoric and examine how discursive research and social constructionism allows a way of exploring the tensions to challenge this dominant position, while placing the autistic person as the focus. In so doing, we seek to provide a platform for different views to take centre stage, to set autism against the social construction of normality and show how the narrow interpretations of autism risk practices that over-medialize a condition and the negative impact that this may have on those who may not conform to the constructed standards of normality.

Medicalization

We introduced the notion of medicalization back in Chap. 2. Here we defined the concept and considered this argument in relation to the medical model of disability. We showed that medicalization is defined as being the process of reducing human experience and functioning to medical concepts and explanations (Conrad & Barker, 2010), which for some is seen as a form of social control (Conrad, 1979). Because of its prominence and importance in autism and in relation to the notion of whether (or not) autism should/could/is defined as a disability, we return to this concept here and offer further consideration of it. As we have noted in this book, in the field of mental health the diagnostic manuals, such as the DSM, are prominent in shaping how society and practicing professionals within it view and define mental health. Over time, there have been substantial efforts to create and instil more reliable criteria and thereby to promote more consistent diagnostic practices across the world (Karim, 2015). Critics have however argued that the increased number of diagnostic categories designed to conceptualize characteristics and symptoms into definable disorders has increasingly medialized the behaviour of individuals and thus reduced societal expectations and constructs of what is 'normal' (Wykes & Callard, 2010).

The arguments regarding the construction of the normal person have been ongoing for decades, but the increased envelope of abnormality as standardized by the diagnostic manuals has created some serious concern. The growing symptom profile and the increased categories of mental health conditions have raised many questions about the state of society's mental wellbeing. Fundamentally, such medicalization of behaviour and emotions have raised questions about why and how human attributes have become so medicalized, and the extent to which this can be considered acceptable. Thus, the tension in medicalization is that the medical vocabulary justifies and legitimizes medicine to validate professionals' determination of what counts as sickness, and who qualifies as being categorized as disabled (Nettleton, 2013), which in turn determines the levels of support, in terms of economics and services.

It is this frame of reference and the increased medicalization of mental health conditions that has become most prominently associated with the arguments proposed about the domination of medicine and the power of psychiatry. This argument about power is especially pertinent as the medical vocabulary utilized to describe mental health conditions, and more specifically autism, has both justified and legitimized medical science as an epistemic agent (O'Reilly et al., 2015a). Thus, in terms of the social construction of an illness reality, it is the practitioners and scientists who carry epistemic credibility in terms of positioning sickness or disability (Nettleton, 2013). This has important implications for mental health conditions, and specifically for conditions such as autism. This is because the medicalized discourse of mental health is intrinsically tied to our social understanding of normality and abnormality and how members of society view and treat those individuals who fall within or outside of those parameters.

Over time the practice of psychiatry as a branch of medicine has created controversy, and there has been some backlash in the form of anti-psychiatry and critical psychiatry movements (Hopton, 2006; Ralley, 2012; Thomas & Bracken, 2004). One of the central concerns raised about the discipline has been its tendency to medicalize the mind, and this has created some dispute regarding the requirement of medical management of conditions (Szasz, 2010). Indeed, some critics have argued that it is inappropriate to medicalize the field of mental health; for example, some have argued that it is not necessary to frame emotional distress in medical discourse (Chesler, 1972), with contemporary concerns regarding the language and labelling of sadness as clinical depression (National Health Service [NHS], 2014).

Such discourses of medicalization stem from the medical model (as discussed in Chap. 2). However, critics have suggested that the construction of this position as a model is misleading, as the premises it rests upon offer nothing more than a platform of medicalization, rather than a model specifically, and offers little more than positioning elements of disability as medically recognizable (Grue, 2011). It was argued by Grue therefore, that the medical model simply perpetuates the illusion that medicine provides a theoretical, viable perspective of disability. Of course, such a notion is intrinsically tied to the notion of recovery, with the implicit suggestion that illness should be treated and/or cured. The medicalization of mental health conditions is imbued with the idea that impaired individuals should address and cure their flaws to fit into the social ideal. Thus, historically, it became incumbent upon psychiatry to solve the problem, and this led to a rapid rise in pharmacological treatments; for example, increasing the use of methylphenidate for ADHD, and the use of antidepressants for sadness (Karim, 2015). Indeed, such acquisition of labels ostensibly offers a promise of a cure, or at the very least symptom management; yet the medical evidence relies on a socially constructed discourse and frame of reference (Strong, 2012). Furthermore, medial models explaining autism view language and communication as symptoms of a disorder, and yet they ought to be repositioned as contextually meaningful communication (Strong, 2014).

The difficulty in emphasizing curing individuals of their impairment and managing symptoms is the very focus itself. It has been argued that the goal of normalization denies the agency of those with disabilities (Eyal et al., 2010; Grue, 2011), condemning them to life as second-class citizens (Mercer, 2002). More specifically, in relation to psychiatric disabilities (and as we referred to earlier in the book), such positioning places individuals under judgment of being lazy, weak, or belligerent (LaFrance & McKenzie-Mohr, 2013) and thus carries a stigma associated with the labels ascribed to them.

The social constructionist challenge to such conceptualizations has been that the binary of normality-abnormality has functioned to validate classification systems and sustained the myth of a ‘normal’ society (O’Reilly et al., 2015a). Fundamentally, social constructionism critiques a recovery model approach to mental health and the medicalized discourse that surround such modals, noting that classification of illness and the promotion of recovery are not entirely appropriate, as illness is fluid and flexible and individuals’ mental health is on a spectrum. In other words, human experience cannot be reduced to medical evidence, as medicalized notions of mental health are social constructs and reified through language (Strong, 2012).

A Note of Caution

We want to acknowledge at this point that the orientation in our argument presents medicalization as negative; yet, for the sake of balance, we also want to caution the reader that medicalization is not inherently problematic or negative, and neither is psychiatry. Indeed, most psychiatrists have their patient’s best interests at the forefront of their work and are working with practices designed to support and help autistic individuals and their families. Furthermore, some psychiatrists themselves are reflective, take a critical position on labelling and overmedicalizing autism, and work tirelessly supporting these individuals, their families and doing what they can to convey useful information and services that will promote quality of life.

At this point in the book, we would point out that while we take a social constructionist position, arguing for the relevance and importance of language and the voices of autistic persons, we are not specifically aligned with the critical (or anti) psychiatry movement. Indeed, some of our work and time is spent working with professionals to facilitate psychiatrists and other mental health professionals to recognize their best communication practices through reflection and making evidence-based changes where needed. Mental health practitioners play a crucial and important role for autism, and there are ways in which psychiatrists and others can fight for change to improve life quality and promote positive discourses of autism. Our position, is to empower autistic voices, promote qualitative research and move beyond a dominant reliance on outcomes focused work to listen to what autistic persons and those around them really want from science.

Scholars have debated the issue of medicalization extensively, and while critics have tended to assume that a medical positioning on psychiatric disability is intrinsically problematic, there are some caveats to this position. The positioning of medicalization as dichotomized in terms of being inherently ‘good’ or inherently ‘bad’ is inappropriate. Scholars have argued that the view of medicalization as either good or bad lies with the implicit definitions of health and illness, and additionally with the critical assessment regarding the effectiveness of medicine in terms of the physical, social, and psychological wellbeing of the individual (Broom & Woodward, 1996). It is therefore helpful to look at the origins of the concept, whereby founders of medicalization theory, such as Peter Conrad, positioned medicalization as value neutral (Parens, 2013). Consider, for example, the following: “… while medicalization describes a social process, like globalization or secularization, it does not imply that a change is good or bad” (Conrad et al., 2010, p. 1943). It is arguable that to recognize the real distress (where it exists) of individuals and families, the active seeking of support and treatment, the social and economic functions of diagnosis, and the embodiment of psychiatric labels, some medicalization is typically welcomed by society. However, to temper the dominant effects and power of psychiatry in its delineation of normality, social constructionist ideas and critical or social theoretical frameworks must guide the imposition of medicalization. Indeed, there has been an increased concern regarding the decline of trust in the epistemic position of experts. In contemporary healthcare, the consumer has an active role in their healthcare, and patient-centred decision making is at the heart of care, leading to the interesting tension between a rise of medicalization and increased resistance to it (Ballard & Elston, 2005).

Arguably, some balance has been achieved as there is now recognition that medicalization has advanced our understanding of health and illness, and there are perhaps circumstances where this can be helpful. However, there is a risk of over-medicalization, where healthcare is entrenched with the power and control of medicine; yet, as we noted, some have argued, medicalization in and of itself is not inherently bad (Parens, 2013). We argue therefore that some balance in perspective is needed, as it is important (in our view) not to dismiss the role of medicine, that is, psychiatry, in mental health, specifically autism. Yet, such a balanced position needs to be situated within a constant reflective position on what that means, giving attention to the critical ideologies that question and test the impact of the dominance of medicalization. This is eloquently proffered in the following quote from an interview with Professor Tom Strong:

> The upside of medicalisation is that it has served to legitimise concerns that previously were dismissed, such as Post-Traumatic Stress Disorder. The downside is that people have increasingly taken on psychiatric terms as identity terms, accepting with this way of legitimising their vulnerabilities a host of other constraints on their wellbeing. Medicalisation

> increasingly enables a pharmaceutical and technological form of agency that accompanies acceptance of a diagnosis. That means new kinds of iatrogenic 'side effects' as people turn to drugs, neurostimulation, and mental health apps to 'better' themselves.
>
> (Interview excerpt taken from O'Reilly & Lester, 2017a, p. 69).

Medicalization and Autism

Fundamental to our discussion in this chapter is the relevance of broader discussions about mental health in relation to autism, medicalization and autism, and our argument that autism is a social construction. We note that it is a logical proposition based on how the criteria for any condition, but particularly autism, has shifted over time, with variances and differences across the different diagnostic manuals. This is complicated further by the lack of definitive measures, as while there are tools facilitating diagnosis, the diagnosis relies predominantly on the subjective judgment of professionals marking individuals against the criteria provided (Karim et al., 2014). From our perspective, autism should be understood as a social construct not a medical one, and one that is fluid and contestable (Lester, 2014). Despite autism being positioned as a global issue, affecting most corners of the world (Bailey, 2008), there is limited dialogue about the different ways in which the construction of normality or abnormality, as related to autism, are actualized in practice (Lester & O'Reilly, 2016).

While we have talked about the positive and negative polemic of medicalization in general terms, it is important to consider what such a medicalized position means in relation to autism more specifically. The DSM-5, as we noted in Chap. 3, has reconstructed and reconceptualized the meaning of autism in terms of the criteria and the language used to describe it, removing notions such as Asperger's Syndrome from the diagnostics list (see, for example, American Psychiatric Association, 2013). This has attracted criticism for relying more heavily on medicalization than previous inceptions (Strong, 2014). Consequently, there has been some debate regarding whether the broadening of diagnostic criteria has emboldened professionals and policy makers to 'disorder' greater numbers of people without paying sufficient attention to the ontological premises and consequences of the practice (Hagan, 2018). This is because DMS-5 has lowered thresholds for diagnosis and has separated individuals with needs from the optimal society and positioned them as posing a threat to prosperity (Frances, 2013a, b). This is not a construction that sits well with autistic individuals or their families however, and neither is it typically congruent with the perspectives of professionals working with them. Indeed, there is an extensive literature that expresses dissatisfaction with the medicalization of autism, and the medical model which underpins many services for autistic people and their families as this fails to adequately meet their needs (Kapp et al., 2013; Razzaque & Wood, 2015).

Notably, the dominant understanding and conceptualization of autism has predominantly resulted from psychiatry and psychology. Such constructions of autism have grown from a complex history of psychiatry, psychology, and the critical alternatives (Nadesan, 2005). Autism has traditionally been medicalized as it has been discursively constructed through a lens of deficit and popular media perpetuating the search for a cure (Broderick & Ne'eman, 2008). This has led to the unification of the category of autism, which has reified the differences between normality and abnormality (Bilić & Georgaca, 2007). Significantly, the public narratives around autism have produced competing ideas about what constitutes a pathological identity (Avery, 1999). In such a way, autism has been positioned as a biological fact (Glynne-Owen, 2010), and the cultural and social sphere inherent to the language of autism are largely ignored (Nadesan, 2005). Problematically, there has been a striving to 'fix' what is constructed as broken (Broderick & Ne'eman, 2008; Osteen, 2008), leaving autistic individuals and their families constantly negotiating what counts as normal behaviour, with deviations from the norm being called to account (Lester & Paulus, 2014).

It is this ambition to 'fix' autistic people that is at the heart of medicalized practices. Indeed, medicalization has been accused of constructing autistic people as isolated and shackled by their abnormalities. The knowledge drawn upon by mental health professionals and service providers is taken directly from medical, psychological, neurological, and developmental positions of autism as grounded in the criteria posited by DSM-5 (Hagan, 2018). However, parents and autistic individuals do not necessarily utilize the same frames of reference or knowledge as professionals, and notably their relationships with services have often been reported to be stressful and sometimes conflicting (Hodge & Runswick-Cole, 2008). For example, some families and individuals have argued that professionals are clueless about the issues they experience and feel that those professionals are experimenting with treatments (especially for those who are given pharmacological treatment) to manage their behaviour (Bagatell, 2007).

The medicalization of autism should not be considered a single occurrence, as the medical model has been dominant in our society for some time, and we have seen pharmacological treatments rise for a range of conditions, such as Attention Deficit Hyperactivity Disorder and Bipolar Disorder (Martin, 2007; Phillips, 2006). While of course, medication can be crucial to support quality of life for those individuals who take it, and medication is of course not inherently problematic in the context of mental health, rather such pharmacological solutions are foundational for how autism has become embedded within a medical vocabulary (Anderson-Chavarria, 2021). Furthermore, it is often the case that autistic individuals, especially in childhood, experience co-occurring medical and mental health conditions that may require pharmacological intervention, such as gastrointestinal disorders, sleep disorders, and seizure disorders (Meltzer & Van De Water, 2017).

A problematic consequence of the medicalization of autism is that the diagnosis reduces their condition, their experiences, views, and relationships to a standardized measure; that is, a benchmark-driven network of meanings that is constructed through an adherence to the criteria developed for DSM-5 (Hagan, 2018). Hagan (2018) noted that in so doing it places restrictions on the variability and richness of life and experiences, severely impacting familial possibilities. Unfortunately, the medical hegemonic position surrounding autism underpins a legislative requirement for legitimate access to services and support as without the label, there is no system or process for autistic individuals or their families (Bumiller, 2008) and this access to support and services is often something that families actively seek out and make a case for when presenting their child for a mental health assessment (O'Reilly & Kiyimba, 2021).

Indeed, families are pressured by the generalized fear held by society that if they fail to follow medical advice, they will be morally implicated in their child's later negative experiences (Clarke & van Amerom, 2007). Clarke and van Amerom (2007) argued that families are encouraged to acquire an early diagnosis to acquire strategies for treatment, and families who fail to intervene appropriately will share responsibility for their child's poor academic performance, bullying, and the co-occurring conditions remaining undetected. Parents are charged with the responsibility to be advocates for their autistic children, carers for an autistic adult who lacks capacity to act in their own best interests (Hart, 2014), and while they may accept such responsibility, they can face challenges in protecting the rights of their autistic child (Trainor, 2010).

In working toward a better future for their children, parents become crucial agents in the global spread of the medical model as they seek services, support, information, and ways to help their child to function in the world (Brezis et al., 2015) and yet, there are aspects where parents and autistic individuals can celebrate their autism and reject the deficit-focused paradigm of autism. For example, Temple Grandin an autistic author argued that there are characteristics of her autism that she would not want to lose, and she has criticized the medical model for dismissing the perspectives and voices of autistic people (Grandin, 1995). Notably, medicalization of autism potentially negatively impacts on the agency of autistic individuals to engage in the social and political environment from which they are typically excluded because of their perceived deficits (Anderson-Chavarria, 2021). All too often autistic individuals are a focus of public policy and yet are framed as citizens who lack the rights, hopes or aspirations necessary to influence politics and are reliant on the benevolence or goodwill of those around them (Orsini, 2012). Yet, the impact of medicalization on autistic individuals and their families is not well explored, and there is a lack of broader explorations of the meanings from their perspective of normality and abnormality, and of ability or disability (Broderick, 2009).

Research has shown that families and autistic people tend to construct an autistic identity on a spectrum of normality, and grapple with a dilemma as to whether autism constitutes a normal identity (Lester et al., 2015). From our perspective, an overreliance on medical ideas related autism will ultimately lead to a mismeasurement of the autistic experience (Chown, 2013). We suggest instead that there is value in shifting the focus from medicalization to language as that which constitutes social realities; in so doing, it is perhaps possible to explore in greater details the cultural, political, and social makings of autism and the experiences of impairments associated with autism (Solomon, 2011). Indeed, it is so often the case that autistic children and adults have greater levels of competence on the domains of communication and social interaction than is recognized, and it is the ways in which others around them engage that needs to adapt and flex to allow that social competence to emerge (Tuononen et al., 2014; Drewett & O'Reilly, in press; O'Reilly et al., 2019a, b; Stribling et al., 2009).

The Reification of Medicalization Through Research Funds

Although we clearly need a more extensive evidence base and there is a strong requirement for more research in autism, it is important to be mindful of the role that science has played in the reification of medicalization, the projection of vulnerability of a population, and the potential to dehumanise individuals, in the context of autism. It was argued in the early millennium that autism was the most widely researched childhood 'disorder' (Wolff, 2004). Additionally, with the growing awareness of the condition, the greater public scrutiny, and the proposed increased prevalence, it is likely autism remains the most widely researched childhood (and adulthood) 'disorder.' Although much modern research aims to be participatory and inclusive of autistic individuals (Fletcher-Watson et al., 2019), all too frequently, research has historically excluded autistic communities, and dehumanized this population (for a review see Cowen, 2009). Of course, it is not the case that all research in the field of autism has been dehumanizing, yet the pathologizing of autism has led to some dehumanization across certain domains (Botha et al., 2020). For example, and as we discuss later in the book, autistic individuals have been positioned as being an economic burden and costly to society and their families (Lavelle et al., 2014), and are constructed as lacking important human qualities like theory of mind and empathy (Baron-Cohen et al., 1985). Advocates of the autistic community and autistic individuals have spoken out about this dehumanizing rhetoric that continues to be pervasive in autism research and report feeling alienated by it (Rose, 2020), much of which has been underpinned by notions of pathology and psychiatric disability which many object to or at least soften the meaning of. However, such positions and ideas about autism have been strengthened in some ways by the contemporary biological focus.

Indeed, biomedical research focused on autism has increased massively since the late 1990s, since a link was found that connected autism and two chromosomes, 15q and 7q (Schanen, 2006). This created an energy around genetic research and biomedical aetiological explanations for autism, resulting in a significant funding stream levied at research that sought to find further credibility for such genetic explanations. Statistics from the UK demonstrate that research in autism has focused on biomedical issues, with 56% of studies exploring brain, biology, and cognition, 18% focusing on interventions, 15% on aetiology, 5% on diagnosis, and 5% on services (Pellicano et al., 2013). Pellicano et al. (2013) noted that in terms of commitments to research in autism, the United States spends 18 times more money than the United Kingdom; however, in the United States, just like in the United Kingdom, biologically grounded, outcomes-focused research receives a far greater income than other areas. Arguably, such genetic and biomedical work is especially complex for autism, as it is highly unlikely that scientists can discover an 'autism gene' because of the complexity of this condition, and thus pre-natal tests can only be developed based on discernible patterns (Muhle et al., 2004). For some, they position this work as creating a risk or threat to the autistic community, as genetics research can lead to genetic testing, and may put mothers under pressure to terminate pregnancies (Waltz, 2008). Waltz argued that this is especially problematic for autism, as the spectrum is broad, and multiple genes are likely linked; thus, this research focus could potentially threaten the future lives of many. Indeed, for some this research focus has been criticized as reflecting a new wave of eugenics (Orsini & Davidson, 2013).

Furthermore, this genetic focus has been constructed as problematic and critics, including autistic advocates, have expressed concern that such a prioritizing of genetics research is diverting important resources away from those already diagnosed with autism (Pellicano & Stears, 2011). In an important report commissioned by the charity 'Research Autism,' it was reported that there is very much a need for more research that focuses on the agendas and experiences of autistic people and their families (Pellicano et al., 2013). In focus groups with families, autistic individuals, professionals, and researchers, we found that genetics and talk of a cure was a low priority for them, as they much preferred evidence that focused on strategies for behaviour management, coping with adversity, and improving quality of life (O'Reilly et al., 2015b). Evidently, there is a clear difference between the priorities of funding councils, researchers and autistic self-advocates and parents (Pellicano & Stears, 2011). Problematically, therefore, only a limited research base exists that has had any impact on the lives of autistic individuals and their families, and much of the medical research is inconclusive or contested (Timimi et al., 2011).

This means that there is a gap between our knowledge and practice, and the need for advances in research that will benefit from that research (i.e., autistic people, their families, and those who work with them), this is necessary as it is autistic individuals, their families and professionals who argue that research needs to focus on issues that affect autistic individual's day-to-day lives (Pellicano et al., 2013). We argue that it is especially problematic that there is such a small amount of qualitative research that promotes the voices of autistic people and their families and explores their opinions and experiences, and even more problematic that qualitative research is perceived by some funding bodies, governments and academic journals as a lesser form of evidence. Funding has focused on genetics and biomedical experimentation, favouring outcomes focused randomized controlled trials, genetics advancement and pharmacology, and this allocation of monies has encouraged neurophysiological interest and prioritized the medicalization of autism, reifying such discourses in practice and in science. We need more research funding that is aligned with the needs and interests of the autistic community and those who align themselves with autistic individuals and autistic voices. We should be listening to the autistic community about where research funds ought to be prioritized and what research questions need more attention.

Neurodiversity: A Notion of Natural Human Variation

Such scientific endeavour to promote an understanding of autism in psychiatry (i.e., in medical terms) has been increasingly challenged, and the spread of critical rhetoric has been expedited through the availability of the Internet and the rise of social media. For autism, an important movement directly challenging medicalization and framing the autistic identity in alternative ways, has been the notion of neurodiversity. This is a concept that can be traced back to Australian sociologist, Judy Singer and journalist Harvey Blume, who introduced this term (Armstrong, 2010). It became a popularized term by a group participating in civil rights movements in the late 1990s (Masataka, 2017). Such popularization arose mostly on the internet in response to the perceived marginalization of autistic people (Ortega, 2009). There was a move to establish a culture whereby autistic people have pride in their minority identity and provide mutual support in self-advocacy as a community (Baker, 2011). The Internet was thus an important mechanism for autistic people to navigate the social and communicative exclusion commonly faced, as this mitigated neurotypical ways of using non-verbal cues and subtle communicative exchanges (Davidson, 2008).

Neurodiversity broadly denotes the idea of forms of diversity rooted in 'differently wired brains' (Ortega, 2009), and while it has become strongly associated with autism (Jaarsma & Welin, 2012), it is important to note that it is also applied to other brain-related conditions, such as ADHD, dyslexia, bipolar and Alzheimer's Disease (Orsini, 2012). For autism, neurodiversity has been positioned by Jaarsma and Welin (2012) as having two parts or propositions:

- Autism is a natural variation among humans and being either neuro-diverse or neurotypical represent different ways of existing as humans.
- Neurodiversity is a claim connected to the notion of rights, political issues, and non-discrimination.

It was claimed by Jaarsma and Welin (2012) therefore that when these two points are connected together it forms the neurodiversity movement. That is, a movement associated with the struggle for the civil rights of those who have a diagnosis of a neurodevelopmental disorder (Fenton & Krahn, 2007). Baron-Cohen (2017) summarized the key messages of neurodiversity as such:

- That there is not a single way for the brain to be normal, as there are different ways for the brain to be wired.
- We need more ethical, non-stigmatizing language and terminology to describe people who are different and/or who have disabilities.
- There is a need for a framework that does not pathologize people and does not disproportionately focus on what the person struggles with and instead we need to take a more balanced view and focus on what the person can do.
- Genetic and biological variation is intrinsic to a person's identity and their sense of self, and respect should be given to other forms of diversity, such as gender.

In such a manner, this neurodiversity movement has become a counter narrative to the deficit model, positioning neurodiversity as a bio-political category concerned with the prevention of discrimination and is a movement that fights for the rights of autistic persons and denies the language of disorder (Runswick-Cole, 2014). This can be an important difference for parents, as Runswick-Cole (2016) advocates in disclosing her identity as a mother of an autistic child. The neurodiversity movement strongly advocates the need for a platform for autistic individuals to speak out (Silberman, 2015) and parents of autistic children can learn a lot by listening to those who already have a diagnosis (Nicolaidis, 2012).

From this neurodiverse perspective, society is thought to be organized around ‘neurotypical’ values and placed in contrast to positioned wherein autism is positioned as a deficit (Brownlow, 2010). Such a contrast is important, as social constructionism has shown that abnormality is only possible when it is positioned in contrast with something else, something argued to be ‘normal’ (Lester & Paulus, 2012). In other words, society can only understand the pathological identity when positioned against the corresponding state of normality (Canguilhem, 1989). Indeed, as we noted earlier in this chapter, such a contrast, and such orientation to neurotypical values, mean that normalization has become a goal for society, to be achieved through symptom reduction and cure (Baker, 2011). However, normalization is certainly not a solution that will make disabilities disappear and thus normalization requires a complete recasting of the goals of treatment, and this has created a discontent, leading psychiatry to question what the objectives of treatment should be, that is cure, symptom management or the reduction of distress (Eyal et al., 2010). Eyal et al. (2010) argued therefore that the goals of psychiatry are ill defined, and normalization has potentially been a cover for professional interest. Furthermore, the desire for normalization has ignored the presence of advantageous behaviours and has tended to ignore the role society plays in determining what is and is not appropriate (Baker, 2011). Some parents of autistic children have even positioned autism as a gift (Lester & Paulus, 2012).

A very important aspect of neurodiversity is the role that autistic people themselves have played in its promotion. Autistic self-advocates often view their autism as a natural part of their identity (Kapp et al., 2013). There are autistic self-advocates who within the neurodiversity movement have celebrated autism as inseparable from their identity, actively challenging efforts to identify aetiology and cure (Baker, 2011). This celebration of autism as inseparable from one’s identity has been particularly important in response to fears that seeking a cure will lead to the genetic prevention and possible eradication of autism (Pelllicano & Stears, 2011). Given autism is associated with neurodevelopmental factors, it has been argued that it should be celebrated as part of natural human variation (Armstrong, 2010). Thus, those advocating for neurodiversity argue that autism is a human specificity involving different ways of communicating, sensing, and socializing, and that such human difference should be respected (Jaarsma & Welin, 2012). Such positioning is important, as the impairments associated with autism have created some questions about what it is to be human, as humans are commonly considered to be social beings with language, and thus if a person fails to conform to that ideological notion, they are positioned as impaired (Waltz, 2008).

It is important, however, to recognize that neurodiversity is a controversial concept (Jaarsma & Welin, 2012). For some, neurodiversity is a political movement that fails to reflect autism from their perspective. For example, some parents of autistic children actively pursue treatment for their child, champion the notion of recovery and cure, or seek a more 'normal appearance,' thus aligning with more medicalized ways of thinking (Chamak, 2008). Of course, the neurodiversity movement has acknowledged that some deficits associated with autism can cause distress and agree that some effort to ameliorate such issues is useful (Ne'eman, 2010), and they do not oppose all types of intervention (Runswick-Cole, 2014). For example, those promoting neurodiverse ways of thinking are often happy to promote wellbeing and adaptive functioning to support the autistic person in developing reliable communication that does not necessarily rely on speech (Kapp et al., 2013). Clearly, parents of autistic children should have the right to provide early interventions for their child, making their own choices about promoting their child's potential and likewise autistic adults should have the freedom to try different treatments (Baron-Cohen, 2017). However, the dichotomizing of disability with neurodiversity can lead to confusion for autistic individuals as they are required to embrace a disability identity to access services and supports, but may not consider some or all of their autism experience as disabling, leaving them stuck in a perpetual position of incongruence desiring a rejection of part of the diagnosis they dislike while simultaneously utilising elements that celebrate their uniqueness or talent (Jones et al., 2015).

Thus, we suggest that is possible to advocate for autism and neurodiversity, while still supporting the notion for treatment (or at least forms of social, educational/occupational and health supports) and helping autistic individuals navigate impairments without viewing them as deficient. In this way, damaging stereotypes can be challenged and policies that valorise difference favoured over those that seek to correct it (Orsini, 2012). Thus, neurodiversity and the notion of disability are not necessarily incommensurate, as a person can have areas of strength and of difficulty (Baron-Cohen, 2017) as this movement provides a mechanism for a more nuanced understanding of autism that changes in relation to the context and environment of the autistic person (Anderson-Chavarria, 2021). Neurodiversity, then, promotes the intersection of neuroscience, disability, identity, and discourse (Beck, 2018) and embraces the heterogeneity of autism and context-dependent understanding of their abilities and disabilities (Anastasiou & Kauffman, 2013). Therefore, we need a way of moving forward that does not pathologize the struggles faced, but rather promotes a balanced view that maintains a competence paradigm (Baron-Cohen, 2017). Problematically, the construction of autism on a spectrum potentially facilitates an implicit ranking of individuals between high and low abilities, with growing dissatisfaction about this metaphor as it fails to account for diversity in autism (Thomas & Boellstorff, 2017).

Is Autism a Psychiatric Disability, a Disorder, or a Natural Variance of Difference?

The neurodiversity movement has had a significant impact on the way in which we view autism. As we noted at the outset of this chapter, there is a great deal of tension in the scholarly literature, amongst the autistic community, within families, and across services regarding the social and medical positioning of autism, raising a fundamentally important question: Is autism a psychiatric disability? Consequently, this raises other questions, such as: What is a psychiatric disability? Who makes a definition of a disability valid? and What is the function of positioning autism as a psychiatric disability? (O'Reilly et al., 2015a). We argue that the answers to such existential questions are flexibly dependent upon one's points of view and affiliations with different theoretical frameworks, disability models, and personal reflexive attributions. In this chapter, we are attempting to strike a balance between the two views: those who advocate that autism is a psychiatric disability and those who do not. In so doing, we consider the views of those who believe autism is fundamentally a psychiatric disability, and, as positioned so by DSM-5, is a necessary positioning to access treatment, educational support, and psychoeducation. Conversely, we consider the views of those that argue that autism has been misclassified, that the language surrounding impairment and difference has been inappropriately utilized, and that autism is not in all its forms a psychiatric disability and should not be necessary for society to support and help those who are different.

It is arguably possible for autism to be both because it is such a broad category. The diversity of this condition means that the functioning of any autistic person to manage in society without intervention is also diverse, with some individuals requiring a far greater level of support than others. Autism is not a homogenous condition where all individuals conceptualized and diagnosed as such all conforming to a singular set of characteristics or impairments. While the foundational diagnostic criteria may be present in all those classified 'autistic' there is certainly a great level of heterogeneity of lived experiences and degrees of 'impairment' associated with that spectrum.

For some autistic people and their families, being diagnosed with autism is described as a stressful experience, with autism reported as having disabling effects (Huws & Jones, 2008). The stress and difficulties created by common 'symptoms' have been described as leaving some families feeling isolated, stigmatized, and seeking support from agencies. Some children's behaviour is challenging for families to cope with, and some children do not develop language and struggle to communicate with those around them. Some autistic individuals also have co-occurring mental health conditions which can impact their behaviour and their emotions (Karim et al., 2014). As we noted in the previous section of this chapter, some autistic individuals and their families, actively seek a cure for their difference, and certainly look for interventions that will improve family life and functioning.

However, as we have also noted, some members of the autistic community and their advocates have completely contested such a categorization of autism in this way. For example, the group 'Aspies' (which is a self-referential term employed by some diagnosed with Asperger's Syndrome) celebrate the individuality and strengths that the diagnosis affords, positioning the condition in positive terms and advocating a neuro-diverse positioning (see for example: https://aspiesforfreedom.wordpress.com/about/). Aspies seek to promote a more positive view of autism, and position themselves as the experts on the condition (O'Dell & Brownlow, 2005). For those that construct autism in such positive terms, there is an embracing of autism as part of their identity (Baker, 2011), with an active opposition to utilizing funds to search for a cure for the condition (Brownlow, 2010).

What is evident from these differing perspectives is that those who seek treatments and a cure for autism tend to be aligned with the medical model of disability, while those promoting neurodiversity tend to be more aligned with the social model of disability and view disability as being socially, culturally, and linguistically produced (Orsini, 2012). It has been suggested therefore that in pursuing this argument it is useful to closely attend to the language utilized to describe autistic people and how characteristics are attributed with deficit or impairment. Predominantly, in modern services, autism is argued to be a 'disorder.' This is evident from its very ascription of 'Autism Spectrum Disorder' as identified in the DSM-5 (American Psychiatric Association, 2013). If we unpack this concept, we can begin to question its appropriateness in describing autism. By its definition, a 'disorder' is a lack of order or intelligible pattern, and medically is a term used when the causal mechanism is unknown (in contrast to disease when causal mechanisms are identified).

The notion of 'disorder' implies that the natural order has been disrupted and the individual is dysfunctional (Baron-Cohen, 2017). Because of this problematizing of the notion of 'disorder,' some people argue it should be replaced with the concept of 'condition,' that is Autism Spectrum Condition (Kenny et al., 2016) and you may have noticed that throughout this book, wherever suitable for the context we have used the word condition, and not disorder or illness as we also prefer that concept. Thus, the language of disorder is considered too harsh (Baron-Cohen, 2017). As noted by Baron-Cohen (2017, p. 746):

> There is little or no challenge to the use of the term 'disorder' for conditions such as major depression or severe anxiety, or anorexia or psychosis, because these result in the person no longer being able to function, in any environment. Expressed differently, in these conditions, there is plenty of evidence of 'dysfunction'. But the case for not applying the term 'disorder' to autism is that, in an autism-friendly environment, the person can function not just well, but sometimes even at a higher level than a typical individual.

For autism, then, we arguably do not see dysfunction, we see difference (Lai et al., 2017).

Paying further attention to the language employed to conceptualize and categorize autistic persons, a taxonomy has been created. Baker (2011) argued that there are four main conceptualizations of autism that have frequently appeared in the literature, on the Internet and in academic discourse, that of difference, impairment, disability, and perhaps more historically, handicap:

- Baker argued that *difference* is arguably the most generic and innocuous, as all humans embody and experience functional atypicalities, and thus difference is a general category to refer to when there is an absence of connection to a relevant event.

- Baker argued that *impairment* is a category where difference is identified by society and is thought of as sufficiently inconvenient for the individual to require assistance from society. This does not necessarily reduce their social status or their ability to be included in society.
- Baker argued that *disability* is when the person experiences impairment of ‘major life functions,’ and this can vary across time and culture. Diagnosis does not define disability completely, but disability is almost exclusively legitimized by diagnosis.
- Baker argued that *handicap* refers to the interaction between human difference and society and this inevitably produces lower social status. Historically this equated disability with poverty, thus creating handicap, and this was viewed as a problem of the lower social classes.

The field of autism is therefore awash with concepts such as, ‘disorder,’ ‘disability,’ ‘impairment,’ ‘difference,’ and ‘handicap.’ Such language and ascription of terms is challenging for describing autistic persons and considering their identity. On one hand, autism has been framed as requiring medical treatment and on the other we have been encouraged to reframe the disabling construct of autism (Orsini, 2012). Historically, disability is a notion that has been ascribed to those who have a below average level of functioning and require support and treatment (Baron-Cohen, 2017). Whereas difference is used when the person is neurodevelopmentally atypical in contrast to the socially constructed norm, but this does not necessarily affect functioning or wellbeing (ibid.).

Exploring the Tensions in Practice: Findings From our Research

As we noted previously, we have conducted qualitative research exploring a range of perspectives in relation to whether autism is a thought of as a psychiatric disability. The tensions and discourses that are carefully navigated through academic polemic are reiterated and constructed within the viewpoints of those whose lives are affected. For our research, we questioned the discursive resources used by group members to construct and negotiate the autistic identity, to better understand how disabilities might be understood in relation to everyday discursive practices (Lester et al., 2015). To achieve this, we utilized a discourse analytic perspective underpinned by social constructionism. This was considered beneficial for examining how psychiatric categories are reproduced through language (Harper, 1995). Discourse analysis was a particularly useful approach, as it provided a way for us to offer counter-perspectives to the notion of autism as a static construct so that we could explicitly examine how the meaning of autism was negotiated. In other words, we specifically attended to how members made sense of what counts as autism, how epistemic positions were taken up, and how the autistic identity was constructed.

The discourse approach we utilized for our research was that developed by Potter and Wetherell (1987), which is characterized as a commitment to studying talk in social practice, focusing on language and rhetorical organization (Potter, 1997a, b). This meant the utilization of key concepts, such as interpretive repertoires and subject positions. Interpretive repertoires are the everyday common-sense notions drawn upon in talk (Potter & Wetherell, 1987), and subject positions refer to the dynamic and fluid uptake of multiple identities (Davies & Harrè, 1990). Such concepts are analytically central to the study of an autistic identity. We gave specific attention to ideological dilemmas, which refer to the contradictory ways in which people navigate (and talk about) their everyday lives (Billig et al., 1988).

The Methods

The project utilized focus groups with key stakeholders in England representing Paediatrics, General Practice, Psychiatry, Psychology, Mental Health Services, autism charities, families, autistic individuals, and researchers. Three focus groups were carried out with the same group of participants across 6 months so that a depth of understanding could be achieved and meaning in the analysis could be conveyed. In total, there were 13 consenting participants, with some representing more than one role (for example, a child psychiatrist was also a parent of an autistic child). Five of the participants had at least one autistic child, two had autistic siblings, and one was himself autistic (see Lester et al., 2015 for details). Each of the focus groups lasted approximately 2 h and were audio-recorded.

Our Findings

Here we present an overview of our key findings, but direct you to the two publications that have been published in relation to this topic for more detail:

- Lester, J., Karim, K. & O'Reilly, M. (2015). "Autism itself actually isn't a disability:" The ideological dilemmas of negotiating a 'normal' versus 'abnormal' autistic identity. *Communication & Medicine, 11*(2), 139–152.
- O'Reilly, M., Karim, K., & Lester, J. (2015a). Should Autism be classified as a mental illness/disability? Evidence from empirical work. In M. O'Reilly & J.N. Lester, (Eds.), *The Palgrave handbook of child mental health: Discourse and conversation studies* (pp. 252–271). Basingstoke: Palgrave Macmillan.

Analysis of the data illustrated that the participants navigated the very tensions that are reflected through medicalization and neurodiversity. Participants negotiated the boundaries of normality and the autistic identity, navigated the boundaries of ability and disability, negotiated the meaning of the neuro-diverse identity in terms of the severity of the autism, and constructed the relevance of epistemic agents in determining the conceptualization of a 'disorder'.

The Boundaries of Normalcy and Autism

Drawing on a repertoire of normality, participants negotiated the boundary separating normal and autistic identities. In so doing, they navigated an ideological dilemma of the autistic identity, noting that autism is posited as medical and thus ‘disordered’ but that such a construction is to deny autism as a fundamental characteristic of personhood. Specifically, this was expressed emphatically by the autistic participant.

Extract Example (Taken from Lester et al., 2015, p. 142)

Pete: I think th::e (0.4) there is (.) one key difficulties
here (.) which is (.) that need t′ be addressed and
that′s the generalisation (0.4) issue, the fact that
(.) um (.) different individuals ↑a::re (.) affected t′
different degrees in different realms different spheres
at particular times (0.2) different times different
>different different different<

(Focus group one)

In our paper, we noted the importance and relevance of this comment, as it illustrates the complexity of autism, and the blurred boundaries of the diagnostic construction of the condition. Here, Pete (*pseudonym), an autistic individual recognized the difficulties in defining and constructing the autistic identity. Through his repeated and emphasized use of the word ***different***, the repertoire of difference was positioned as important in acknowledging tensions between different perspectives. In this way, a dilemma between normality and abnormality was developed.

The Boundaries Between Ability and Disability

In constructing discourses of difference, the participants navigated the dilemma created in constructing autism in terms of neurodiversity and medicalization, thereby positioning autistic people as both able and disabled. They noted that disabilities are positioned in ways that require services, and the desire to attend to the person through treatment and return to normalcy, but if constructed in ability terms, risks denying the reality of any distress or difficulty and potentially problematizes any seeking of support. Thus, as other research has shown, participants are able to view autism as a disability, but simultaneously demonstrate that the autistic identity does not impede their capacity for quality of life (Botha et al., 2020).

In our paper, we provide evidence of a disagreement between participants that demonstrates an active tension within the real experiences of the autistic community. We present two extract examples here to illustrate the tension that played out within the focus group discussions.

Extract Example (Taken from Lester et al., 2015, p. 143).

Pete: <But it also leads into what was ↑just ↑said> an’ that’s >↑you know< (0.4) ↑autism itself I’m a great believer that ↑autism itself actually isn’t a disability in any way at a::ll (.) in fact there are many areas where I would argue that my autism >is a s↑trength< (.) um

Joy: >Its other people’s ignorance< isn’t it?

Mandy: >There is that<

(Focus group two)

Extract Example (Taken from Lester et al., 2015, p. 144)

Joanne: Well I’m sorry Pete >I kinda disagree< because (0.6) wouldn’t you say that (0.4) <some of th::e> the like from the <triage> of autism (0.2) >the symptoms< (.) ↑a::re a symptom of the condition which is autism

Pete: ↑Right

Joanne: So it is a disability

Pete: No I don[‘t see it (.) well]

Joanne: [WELL I CAN ONLY look at it from my da::ughter’s point o- view (.) ↑she (.) <↑she can’t handle noise> an’ >stuff like that<

(Focus group two)

This disagreement is an important one as it demonstrates the difficulties that participants when navigating the ‘real world’ of autism, as they must negotiate the different ways in which autism can be constructed and the associated issues that this may raise for families. In the first of these two positions, the autistic adult (Pete), positions his autism as ***a strength***, and directly argues against the notion that autism can be construed as a disability, saying that “autism itself actually isn’t a disability.” Discursively, he takes up a subject position (Davies & Harrè, 2001) of non-disabled, and manages any stake and interest (Potter, 1996) he has in taking up a certain identity. However, a direct disagreement is offered by a parent (Joanne *[also a pseudonym]) of an autistic child. Notably, disagreements can be face-threatening (Goffman, 1967) and we see the parent (Joanne) being cautious in offering the tension; yet she does directly argue the counter position claiming, “it is a disability.” The dilemmatic aspect of what autism “is” becomes evident as the parties negotiate how and if autism constitutes a disability, while also resisting these varied constructions of autism.

Navigating the Severity of Autism

In relation to the disagreements as to what constitutes a disability, the participants considered the spectrum of the condition and positioned the notion of "severity" as being relevant to this tension. In other words, the participants reported that the spectrum of the condition is a key complicating factor when considering the disabling effects faced by those with a diagnosis. Specifically, they reported that those who experience a more severe autism, and may have additional challenges like learning disabilities, are more likely to fit with a conceptualization of disabled, than those who sit at the milder or higher functioning end of society and are able to manage to function in ways similar to their neurotypical peers.

Extract Example (Taken from Lester et al., 2015, p. 146)

Lou: I think because you are lookin′ at autism you are looking at the whole range so >a ↑fou::r year ol::d, with learnin′ difficulties< is goin′ t′ be very different to an eleven year old .hhh er::m (0.2) on the sort of more higher functionin′ end of the spectrum and the

Joanne: cuz you get a diagnosis but (0.4) life goes ↑on

Rani: Yea::h

(Focus group three)

The severity of the condition was argued to be an important factor in constructing an autistic person as disabled or not. In this extract, Lou, a parent of an autistic child, argued that when a person is positioned as high functioning, they are closer to 'normality' than those who are further away. The implication of such a construction is that autism is located at objective points along a spectrum. A dilemma is thus invoked, as the parents have a stake in persuading professionals that services are needed while maintaining a subject position of a normal family life.

Negotiating Epistemic Agency

An important aspect of the argument presented by the participants was regarding who had the authority to speak with expertise about autism. The members of the focus groups had different epistemic rights (i.e., rights to knowledge by virtue of a category or identity), sitting on charity boards, being parents, scientists, or experiencing the condition. In their discussions their identities shifted and varied, as they fluidly presented their epistemic authority.

Extract Example (Lester et al., 2015, p. 147)

Joanne: And if I can speak as a parent and someone who <provides support as well> erm (0.6) I've been listenin' t' this and I find it <exciting> as well if I was a parent (0.2) who had just had a diagnosis erm (0.2) rather than have >an' I've heard these stories< (0.4) rather than have a pa::ediatrician or someone from CAMHS give me a bibliography on a bit of pap↑er (0.4) and say ↑here go and find these ↑books (0.4) if they said to me (0.6) this is a website …… I think that would be absolutely ideal

(Focus group two)

In this extract, the categories (i.e., parent and someone who provides support) invoked by Joanne make visible her expertise to talk about autism, thereby providing a layer of credibility for her version of autism to be accepted by the group. By positioning herself as a "parent" and "someone who provides support," she simultaneously adopted two identities of epistemic authority. Thus, the legitimacy of her knowledge was bound by the performative nature of her account (Horton-Salway, 2004), as her expertise was constructed as both personal – as a parent – and professional – as a practitioner.

Although our analysis here is not intended to be in depth, and simply provides a cursory appreciation of the data, what is demonstrated is the considerable difference and heterogeneity of autism that is offered when considering the following question: Is autism a psychiatric disability? We note here that the participants recognized the range of level of functioning, social impairments, and different experiences of autism as important. This meant that they navigated the task of navigating the autistic identity, which is imbued with contradictions and reflects a complication beyond the binary construction of normal versus abnormal (Lester & Paulus, 2012). To gain more insight around this, we recommend reading the full analysis (Lester et al., 2015; O'Reilly et al., 2015a).

There are clearly ways in which individuals are expected to conform to society's norms. Health policies are discoursed in ways that dictate who can and cannot be supported, positioning and constraining whose voice is most important and privileged (Ramanthan, 2010). As recognized by Waltz (2008, p. 15):

> Our culture currently demands greater degrees of flexibility from people than ever before in human history. Globalisation requires physical, linguistic, and cultural mobility of workers; modern working practices require multi-tasking, lifelong learning, and an affinity for teamwork.

Society is politically, socially, and economically structured to privilege those who function and communicate in normative ways (Lester & Paulus, 2012), and thus disabled people are frequently marginalized.

Concluding Thoughts

We recognize that there are multiple perspectives and 'sides' to the debates around how autism is and should be classified. We see value in considering all 'sides' and engaging with multiple stakeholders. Notably, despite the tensions, autism continues to be medically classified as a psychiatric condition by both the ICD and the DSM. Thus, as we illustrated in Chap. 2, autism in clinical fields is very much viewed as a psychiatric disability, and the diagnostic frameworks position it as such through objectivist, positivist, and realist frameworks, creating a dichotomy between normality and abnormality. We argue however that such a dichotomy is unsustainable, and the critical perspectives that have grown and influenced our understanding of autism cannot, and certainly should not, be ignored. The difficulties experienced by parents and autistic people are important, as they are caught between a medicalized and professional ownership of their diagnosis and the neuro-diverse reclamation of autism as troubled (Cascio, 2012). Thus, many people are caught between aligning with professionals and reinforcing the deficit ideology of autism as they collude with the diagnosis (Hagan, 2018); however, juxtaposed with that, they also may adopt an advocacy position, using autism therapies in ways to create a 'technical infrastructure' designed to support the 'autistic personhood' (Hart, 2014, p. 284). However, the two perspectives, that is "autism as a debilitating disability and autism as neurological difference", do not necessarily have to be positioned as mutually exclusive (Orsini, 2012, p. 808). Orsini noted that it is possible to support funding for autism services, care and support, while agreeing with the reimagining a need to promote the needs of neuro-diverse citizens. Thus, "framing responses to autism in either/or terms" that is, "either it is a neurological difference to be celebrated or it is a disabling condition, can paralyze public discourses in ways that might ultimately be of little benefit to autistic people" (Orsini & Davidson, 2013, p. 3).

In this way, it is recognized that some autistic people do need care. However, it is important that this conceptualization captures the natural variation in the human species, but does not provide a mechanism for the welfare state to deny support to those in need by positioning autism only as a natural variation (Jaarsma & Welin, 2012). Some parents do believe that autism is a positive aspect of their child's identity, but others feel that they need additional supports (Kenny et al., 2016; Lester et al., 2015). Jaarsma and Welin argued that some balance is needed, as neurodiversity should be accepted by society to ensure that autistic people do not suffer stigma associated with deficit, but that those who need supports have the right to access it. In working to resolve this tension therefore, the notion of interdependence has been proposed; that is, autism treatment on the one hand, and supporting neurodiversity on the other hand (Orsini, 2012). We suggest that the notion of interdependence is a useful way to facilitate an appreciation of how neurodivergent individuals might be supported in ways that recognize our attachment to other people without requiring us to position disabled persons as inferior to others (Arneil, 2009). Arneil (2009) argued that adopting a principle of interdependence reduces the binary between rationality and the disability and replaces such a dichotomy with a gradient scale whereby individuals vary in degrees in terms of their dependence on others and their independence. Thus, this critique offered by Arneil provided a way to help detach disability from the deficit model by reconstructing disability as an ‘independent product’ and in this way problematized the asymmetry between providers and receivers of care, positioning the care-receiver as a citizen and not a client. In the next chapter, we complicate the notion of a fixed, ahistorical conception of autism further by drawing upon one of our research studies to illustrate the multitude of ways in which autism is constructed.