Autism in the Twentieth Century: An Evolution of a Controversial Condition

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INTRODUCTION

Clinically, autism spectrum disorder (henceforth, autism) has been described as a lifelong neurodevelopmental condition characterised by impairments in social interaction, communication, and rigidity in thinking. Additionally, autistic individuals are typically characterised as having executive functioning difficulties (i.e. self-regulation skills), sensory processing problems (i.e. the brain processing information from the senses), difficulties with sleep and food, limited theory of mind (i.e. the ability to see things from the point of view of others), and the possibility of various co-morbid mental health conditions.[1] Despite such descriptions,

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autism, as we now know it, is a relatively new condition. In less than a century, a whirlwind of ideas, movements, and positions have littered the autism literature, with a critical polemic threaded through the narratives of various autistic individuals, political advocates, writers, and academic scholars. Indeed, autism is a by-product of many (even conflicting) disciplinary knowledges, institutional discourses, and histories.[2]

The twentieth century was a significant and powerful century for autism, and for some, it has been classified and understood as a '*twentieth-century disorder*'.[3] Not only were there clinical advances in terms of it being recognised, labelled, and identified and appearing in the classification systems for mental illness, but there was also the rise of pharmacology for treatment and the increased role of psychiatry for identifying and managing autism. Importantly, the twentieth century also saw a rise of critical rhetoric, challenges, political ideologies, and a range of movements, such as anti-psychiatry, critical psychiatry, neurodiversity, consumerism, and social models of disability. All these movements and perspectives made visible a struggle to invent, reconfigure, and reinvent the meaning of autism, with some challenging the position of autism as a mental health difficulty, that is, a psychiatric disability. Indeed, even in the historical present, the classification of autism as a mental health condition is controversial and contested. Later in the twentieth century, autism became redefined as a spectrum, which served to acknowledge the great heterogeneity within the meaning of autism and developed more refined ideas around the so-called impairments associated with it.

In this chapter, we overview some of the historical changes and, in doing so, highlight some challenges of labels and language that shroud those who are named autistic and/or take up this identity label. We also note the shifts in thinking that have challenged the psychiatric and psychological framing of autism. The residue of the twentieth-century tensions that is the genetic revolution, the diagnostic medicalisation, and the empowerment of neurodiversity has spilled over into the twenty-first century, leaving us with an array of critical discourses and challenges around what many now describe as a *spectrum* condition. That is, we are left with a patchwork of different perspectives and ideas regarding what constitutes autism, the language of autism, how autism should be researched, and the most appropriate healthcare pathways and other service provisions for those diagnosed. This chapter explores how this fractured view of one 'mental health difficulty' came to be. In so doing, we thread through our own position, that of social constructionism, not denying the reality of the autistic community, but acknowledging

differences in views and the importance of language and meaning. Indeed, we recognise that for some autism is celebrated, treated as difference, and tensions of medical notions and impairments are proposed, and yet for others, autism is seen as disabling, the diagnosis is stressful, and treatments are actively sought. The range of perspectives that grew from the twentieth century are considered throughout. We do however insert a caveat here and note that the history of autism is vast and spans multiple disciplines and fields, and thus what follows can only ever represent a snapshot of history and inevitably misses out some of the developments that occurred throughout that century and some scholarly contributions. The chapter is only ever intended as a summary.

EARLY HISTORY OF AUTISM

Importantly, the concept of autism did not specifically exist prior to the 1940s, although the notion was introduced by Bleuler in his work on schizophrenia in 1911. However, it was the work of two pioneering practitioners that identified some of the core characteristics that distinguished it as a discrete concept. First, the work of Leo Kanner, following his seminal child psychiatry text in 1935, introduced the world to the condition, autism.[4] Kanner was an Austrian psychiatrist who wrote a paper describing the behaviour he had observed in eleven children. He conceptualised these characteristics as a need for sameness, aloneness, and obsessions. It was common at this time for children with these types of behaviours to be classified as schizophrenic, so Kanner's work was important for distinguishing between the two groups. However, it should be noted here that the credit given to Kanner has created some tension and criticism.[5] Second, was the work of Hans Asperger who was writing in parallel with Kanner and wrote about the characteristics of children in similar ways.[6] Asperger was a German paediatrician who observed the behaviour of four boys who he argued were showing challenges in forming friendships, displayed a general lack of empathy towards others, had clumsy movements, and had difficulties with communication. While this work became considerably influential, it did not reach the mainstream literature until after he died. It was Asperger who noted that children with this syndrome could flourish, and in some cases show signs of genius, and expressed the insight that autism may exist on a continuum.[7] It was this notion that resurfaced, as British psychiatrist Lorna Wing introduced the notion of a spectrum.[8]

Kanner and Asperger laid a foundation therefore for understanding the behaviours of these children, and Kanner particularly argued that no single factor could explain it. However, the influence of psychoanalysis was strong during this time, and therefore, there was also a powerful promotion of the idea that there were psychodynamic causes.[9] This domination of psychoanalytic theory at this time formed the basis of a culture that blamed mothers for their child's psychological problems.[10] A hugely influential theory in the 1960s, long since discredited, was that autism was associated with a certain style of parenting, with a cold and unavailable mother leading the child to shut down emotionally.[11] Bettelheim referred to this as the '*refrigerator mother*'[12] and resulted in many mothers feeling to blame for their child's condition. This has been argued to be particularly problematic, given that evidence suggests that Bettelheim faked his medical credentials.[13]

Nonetheless, there is some persistence of mother-blaming even today,[14] despite the neurodevelopmental positioning of autism[15] and despite the extensive criticism.[16] Historically it has always been women who have carried this parental burden, as they were argued to fail to conform to the idealised view of motherhood.[17] There was a shift in thinking as psychoanalytic views lost some favour, and science took over as the predominant explanatory framework, and yet the blaming rhetoric underwent a subtle shift as mothers were not blamed via their parenting skills and style, but via their genes. The genetic and medical revolution in psychiatry positioned the aetiology of autism and other mental illnesses as having a biological origin.[18] This is something we return to shortly.

Contextualising Children

An important advancement during the first half of the twentieth century that has important implications for the development of an understanding of autism was the view of children and childhood in relation to the role of psychiatry and psychology. As Steve Taylor observes in Chapter 4, a significant period of history for child mental health was the introduction of a universal education system. In Europe and North America in the late nineteenth century, there was a new formalisation of public and private education.[19] Karim reported that it was this formalisation of education that provided a platform for adults to recognise physical and mental health conditions in the young, which subsequently in the twentieth century led to the creation of sub-disciplines such as educational psychology,

social care, and developmental psychology. The increase in the social surveillance of children with the advent of compulsory education indeed engendered the necessary social conditions for the creation of autism.[20] Further, developmental psychology was especially influential and is generally credited as beginning with the work of Wilhelm Preyer in 1882 and G. Stanley Hall through his introduction of the first American Journal of Child Psychology in 1891.[21] Notably, such work at the time, into the early twentieth century was heavily influenced by the notion of the 'normal' child, underpinned by psychoanalytic ideas of childhood, which was strengthened by the specialised work of Anna Freud, Melanie Klein, and Jacques Lacan, amongst others.

The field of psychiatry also recognised the relevance and importance of treating children separately from adults, and it was in 1935 that the first child psychiatry textbook was produced by Leo Kanner. This was in parallel with the US work by Douglas Thom who developed the Boston Habit Clinic designed to help parents manage their child's everyday difficulties. This was considered necessary as following the Second World War there was recognition that children too needed help with their mental health.[22] Child psychiatry therefore became a separate sub-discipline of medicine, and one that recognised that specialist attention that was developmentally appropriate was needed, with the foundation of the American Academy of Child and Adolescent Psychiatry happening in 1953.[23] By the 1960s and 1970s, therefore, specific treatments designed for children had been developed within psychiatry and psychology.[24] Furthermore, during this period, family therapy emerged and gained popularity as it viewed the child as part of a complex social system.[25] However, it was the focus on pharmacological treatments for children that raised controversy in the later part of the twentieth century and continues today.[26] Thus, by the late twentieth century, child mental health was treated as distinctive and separate by a range of health services, including psychiatry, nursing, psychology, and education. Such services for children relied on childhood being constructed as a series of stages, with a separate focus on adolescence.

DIAGNOSING AUTISM: THE INTRODUCTION OF STANDARDISED MANUALS

A crucial historical moment in conceptualising autism was the development of standardised manuals. We present an overview of the main diagnostic manual, the Diagnostic and Statistical Manual of Mental Disorders (DSM)

to demonstrate some of the key shifts in thinking about autism. While we recognise that there was some influence of the International Classification of Diseases (ICD), this system was much broader and contained physical illness, whereas the DSM was designed specifically for mental illness. The DSM was designed so that those working in the field of mental health were able to classify the full range of mental health conditions based on standardised criteria for diagnosis.[27] In other words, the DSM defined what does and does not constitute an illness and by default implies what constitutes normality and therefore a 'healthy mind'.[28]

The development of the DSM and the role of psychiatry have to some extent influenced how 'normal' is viewed, and the American Psychiatric Association decided to unify the diagnostic processes with the creation of DSM-I. Notably, however this single manual was not published until 1952.[29] This first edition represented an important paradigmatic change about the conceptualisation of mental illness and was a milestone in the creation of diagnostic categories. This first version contrasted two core groups of conditions, those caused by organic brain dysfunction and those with aetiology in environmental circumstances.[30] The second version, DSM-II, was developed quite quickly because of concerns about inconsistencies in the first. This version had 193 diagnostic categories, was heavily influenced by psychoanalysis, and launched in 1968.[31] This version of the DSM transformed psychiatry from a field that was concerned with pathology, to one that was more concerned with the boundaries of normality.[32] During this time, the rise of psychopharmacology was influencing more biological and neurological explanations of mental illness. Consequently, the diagnostic criteria were proposed as ways to ensure that standardisation could be achieved.[33]

The notion of standardisation underpinned new changes to the system, and in the resulting DSM-III, there were substantial changes from DSM-II. DSM-III contained criteria which identified categories but moved to a multi-axial system for diagnoses,[34] and while the revision began in 1974, it was not published until 1980.[35] This version held nearly 500 pages and 265 categories.[36] The USA was especially influential here with its insurance health system, as they demanded more precise diagnostics and were more reluctant to fund long-term therapies like psychotherapy.[37] What is especially relevant to our discussion in this chapter is that it was the advent of DSM-III in 1980 that recognised autism as a distinct conceptual category, almost 40 years after its inception by Kanner.[38]

It was this point in the twentieth century, with the inclusion of autism on the DSM-III that the work of Kanner and Asperger were revived by two British professionals who coined the notion of autistic spectrum disorder[39] and the triad of impairments became part of common clinical discourse.[40] This triad consisted of three core characteristics of autism;

1. Impairments in social interaction
2. Impairments in communication
3. Restrictive repetitive patterns of behaviour.

This was later reconfigured in the twenty-first century as a dyad of impairments and reconstructed as autism spectrum disorder, but the notion of the spectrum has been maintained.

A quick succession of revisions occurred after this with DSM-III-*R*, to DSM-IV, and DSM-IV-*R* which each reflected a round of changes. Again, relevant to our discussion, is that DSM-IV saw the inclusion of Asperger's Syndrome and this was viewed as distinct to autism.[41] Those with Asperger's Syndrome were seen as having normal or higher levels of intellectual ability, and those with the diagnosis often argue that this is fundamental to their identity.[42]

DSM 5: Autism in the Twenty-First Century

DSM-5 is the first of the manuals in the twenty-first century and reflects the modern revision from DSM-IV-*R*. Notably, this version was represented with numbers rather than Roman numerals. This new version, DSM-5, has created a great deal of controversy and was created during a period of critical thinking around mental illness more generally. The development of DSM-5 began at the end of the twentieth century and unlike its predecessors was subject to public scrutiny because of the rise of the internet.[43] By 2010, the first draft was posted online and returned over 8000 comments, with 2000 further comments in 2011 on the revision.[44] By this point, the DSM had grown to 947 pages and 541 diagnostic categories.[45]

This new version of DSM had some important changes for autism. While the notion of the spectrum was maintained, other changes were more controversial. For example, this version saw the removal of Asperger's Syndrome as a distinct classification. Indeed, Asperger's Syndrome had a short shelf-life in terms of official diagnosis, as it was

not formally recognised until the 1990s and was then removed in 2013, being subsumed under the general category of autism spectrum disorder. The rationale for its removal was to reflect the shift from a categorical system to a dimensional one.[46] This however has caused great unrest in the autistic community,[47] as new interest groups have emerged claiming that classifications are a blueprint for their identity and not just an arbitrary means for classifying conditions.[48]

The criteria for diagnosing autism also shifted, as there was a move away from a triad of impairments, to a dyad of impairments, as we noted earlier. Thus, there were now just two domains of difficulties—social communication and restrictive and repetitive patterns of behaviour.[49] However, Wing et al. argued that there were relevant clinical reasons why social interaction and communication were treated separately on the triad, and therefore, collapsing them into one domain was viewed as inappropriate.[50]

The shifts in diagnosis and classification from the original version in 1952 to the latest version in 2013 have shaped and impacted on the meaning of autism and the language used to describe it. Autism is a condition that has invoked a great deal of debate and controversy in terms of the language and labels used and adopted and this has not been straightforward. As Kenny et al. noted,

> Tensions surrounding the language of autism are attributable, in part, to the very different ways that autism touches people's lives; some experience it personally, others through their children and others still might only encounter autism in some aspect of their lives – at school, at work, in the community or through friends and family.[51]

The terms used and the language adopted around autism have changed over time, with a range of different conceptualisations of the condition, including, autism, autistic spectrum disorder, autism spectrum disorder, autism spectrum condition, Asperger's syndrome, pervasive developmental disorder, and high functioning autism.[52] The different labels used are loaded with category rich inferences, and these can have different meanings for different individuals and their families.

The tensions and debates within public and academic communities regarding the most appropriate ways to conceptualise autism has been a consequence of growing disquiet about the role of psychiatry and the influence of medicine, as well as the rise of critical perspective.[53] During

the twentieth century, there was a shift towards person-first language when describing individuals diagnosed with autism, so that the person came first, and the disability came after, that is, person with autism.[54] Over time however, this position has changed and further controversy about descriptive language has been proposed. Disability-first language is now more generally accepted to be the most appropriate way of describing autism, that is, an autistic person. This is because disability-first language adheres to the principle of putting a positive pronoun in front of the noun and thus removes the suggestion that autism is intrinsically negative.[55] This is especially important for the autism community who often view their autism as an accepted and instrumental part of their identity.[56] A good example of this was offered by Hagan who argued that society would not describe someone who was creative as 'a person with creativity', they would be a creative person and as such treats the creativity as part of who they are.[57] Perhaps unsurprisingly then, research has shown that diagnosed individuals tend to favour the concept of 'autistic person', but interestingly professionals still favour 'person with autism'.[58]

The Genetic Revolution

An important contribution to the rise of science and medicine was advances in the study of genetics. Psychiatry and medicine advocated organic causes of mental illness, and geneticists began to seek ways to isolate the gene(s) responsible for autism. This notion of aetiology had important implications for how we view autism and for the position of autistic people in society. The geneticisation of deviance worked to provide accounts for behaviour that failed to conform to social norms and thus provided new ways of thinking about stigma.[59] In other words, those with diagnosed conditions were now constructed as less blameworthy for their condition where it had a biological origin rather than a psychosocial one.[60]

Such a turn to science has had consequences for research and funding. The field of autism research became reenergised by genetics studies. This generally increased pace in the late-1990s, when a link between two chromosomes, 15q and 7q, were identified as connected to autism.[61] Consequently, large funding streams have been provided to further the credibility of genetic explanations, so that the aetiology may be uncovered, and medical treatments created that target the core

symptoms. However, it is arguably concerning that this energy has resulted in a dominance of genetics in the study of autism at the expense of other kinds of necessary and needed research. Statistics from the UK have shown that autism research is now preoccupied with biomedical issues, as 56% of studies have explored brain, biology, and condition, and a further 15% on aetiology, and only 18% on interventions, 5% on services, and 5% on diagnosis.[62] The picture is similar in the USA, which spends 18 times the amount of the UK, but again biologically grounded work receives significantly greater income than other areas.[63]

The inappropriateness of this lack of balance in research funding streams has been positioned from a range of different views. For example, some have argued that autism is an incredibly complex and heterogeneous condition, and it is unlikely that scientists will be able to isolate a single autism gene.[64] Arguably more concerning is the risk or threat perceived by the autistic community in terms of the potential for genetic testing, which may put mothers under pressure to terminate their pregnancy.[65] Waltz noted that for autism this is especially concerning as the spectrum is broad and it is likely that multiple genes are connected, and this termination potential may threaten the lives of autistic people who could be functional in society. Some scholars have extended this argument further by claiming that the genetic focus in autism research reflects a new wave of eugenics.[66]

The diversion of research resources to genetics research is also problematic for those already diagnosed as autistic. Critics and autistic advocates have argued that by prioritising genetics research, necessary finances have been diverted away from those who need support now.[67] Arguably, there is a need for more research which focuses on the agendas that matter to autistic people and their families.[68] In our own work, we found that genetics research and the notion of a cure for autism was a low priority for autistic people and their families, and what they really wanted was more work to help them manage difficult behaviour, challenging sleep patterns, coping with adversity, and improving quality of life.[69] The research base that has an impact on the lives of autistic people and their families is insufficient, and medical and genetic evidence is inconclusive or contested.[70] It seems therefore that the priorities of medical researchers and funding councils are at odds with autistic self-advocates and families.[71] In practice, this means there is a gap between our knowledge and practice, and we need to advance our research to meet the needs of those who would benefit from it most, by focusing on issues that affect people's daily lives.[72] Specifically, we argue

that there is a need for much more qualitative research that promotes the need to listen to the voices of autistic people and their families and allows for an exploration and focus on their views, opinions, and experiences.

The Challenge of Anti and Critical Psychiatry

The dominance of genetics and medicine in the field of autism has caused tensions for scholars and advocates throughout the twentieth century and into the twenty-first. As the different versions of the DSM evolved and changed, and the dominance of genetics and pharmacology grew, there was a notable shift in thinking about psychiatry as a discipline, the conceptualisation of mental illness (and more specifically tensions in classifying autism that way), and the ways in which diagnosed individuals ought to be treated and embedded in society. By the mid-twentieth century, there was a great deal of tension regarding the turn to science and medicine for answers regarding mental illness, and questions were raised about the credibility of categorising illness purely in biological ways and treatment with medications. Notably, movements during this latter half of the century were the anti-psychiatry and the critical psychiatry movement, which gained momentum as new and different critical arguments emerged.

It was during the 1960s that the international anti-psychiatry movement was recognised as such, as was a term coined by David Cooper.[73] This movement was noted to be motivated by anger and the perceived arbitrariness of diagnosis.[74] Those advocating anti-psychiatry called for a paradigm shift in terms of understanding mental illness and argued that patients were being marginalised.[75] Fundamentally those taking this position opposed the use of medication, which was the main form of treatment in the field. Furthermore, they opposed the power of psychiatrists and considered the practices to be coercive (see, e.g., Foucault).[76] The mid-twentieth century therefore saw three critical periods of anti-psychiatry, as noted by Furnham:

1. The early 1950s, where there was a conflict between psychiatrists adopting psychoanalytic perspectives and those new ideas around biology.
2. The 1960s saw a range of influential figures, such as Szasz, Basaglia, Foucault, Laing, and Cooper, from within and outside of psychiatry.

3. In the 1970s and 1980s, American and European sociology joined the debate, particularly in relation to labelling ideas and stigma, and popular media began to spotlight the practices of the profession.[77]

It was thus during the 1980s that anti-psychiatry began to lose its momentum, as psychiatrists began responding to the critique, changing their practices, and working in a more biopsychosocial way. This biopsychosocial perspective of formulating and working with mental illness began to address some of those concerns about treatment of the mentally ill.[78] Thus, anti-psychiatry as a movement failed to establish itself as a mainstream ideology embraced by mental health professionals.[79] A further paradigmatic shift occurred therefore in the 1990s, with a softer critique of psychiatry emerging under a new guise of critical psychiatry.[80] The notion of critical psychiatry was coined by David Ingleby through the collection of essays into a monologue.[81] This recognised the change from focusing on the institution to the community but retained recognition of the difficulties of psychiatry and the political issues surrounding the field. This movement began to gain some acceptance, even amongst those practicing psychiatry.[82]

The focus for critical psychiatry was that psychiatry was a powerful field, and this should be moderated by the voices of service users as central to decisions made.[83] This movement thus proposed two core issues with psychiatry. First, they argued that there are challenges to the scientific basis of psychiatric classification, and second, they noted moral problems that are a consequence of diagnosis.[84] The reliance on science and the turn to genetics were viewed as fundamentally problematic, as the biological basis of mental illness was argued to be overstated as the evidence fails to offer sufficient support for this thesis.[85]

One of the core concerns in the rising movements that had varying degrees of opposition to psychiatry, particularly from those concerned with autism, was that mental illness, and in this case autism, was being over-medicalised and thus ignoring the ecological and systemic frameworks around an individual. The significantly progressive number of diagnostic categories with each version of the DSM was argued to be increasingly medicalising behaviour of individuals, reducing social expectations of normal behaviour.[86] Such an increase of conceptualisations of abnormality created by diagnostic manuals is a cause for concern, particularly in the context of autism, and the medicalisation of autism has been especially contested.

The concept of medicalisation refers to the process of human experience being reduced to medical terms and definitions.[87] It is this medical vocabulary that validates professionals' determination of what constitutes sickness, and who qualifies as being categorised as psychiatrically disabled.[88] For the critical psychiatrists, psychiatry is a discipline that medicalises the mind as a way of legitimising the requirement of medicine to manage conditions[89] and this perpetuates an illusion that medicine provides a theoretically viable view of disability, which in turn, is tied to the notion of recovery and the restoration of the healthy mind.[90] In other words, this perspective constructs the person's illness as dispositional, and those who are unable to be 'fixed' by medicine are inappropriately labelled as deficient in some way.[91] Such a goal of normalisation denies agency to those with disabilities[92] and risks judgements of laziness, weakness or belligerence.[93] By the end of the twentieth century, healthcare was seen as consumer-driven and patient-centred, and these changes increased the tension between rising medicalisation and increased resistance to it.[94] Furthermore, the DSM-5 was argued to rely more heavily on medicalisation than any of its predecessors,[95] because of lowered thresholds, which separate individuals from the optimal society.[96]

For autism, these arguments are especially pertinent. The autism diagnostic process lacks definitive measures, and while there are tools to facilitate the process, the decision relies mostly on the subjective judgement of professionals applying the criteria, and thus, the power of medicine to define, diagnose, and treat autism has come under criticism.[97] There is therefore an extensive literature that expresses dissatisfaction with the medicalisation of autism as failing to adequately meet the needs of the autistic community.[98] This has been further hindered by the medicalised notions of deficit and cure, as medicalisation has encouraged the search for a cure.[99] Through this, autism has been constructed as a biological fact[100] and the social and cultural aspects inherent to the language of autism have been given less attention.[101] Consequently, autistic people and their families are frequently renegotiating what constitutes normal behaviour and such deviations from the norm are called to account.[102]

The ambition to 'fix' disability is central to medicalised practices, and for many autistic people, this provides a perspective that they are 'broken' in some way.[103] Such ideas are co-constructed by the mental health profession and taken directly from medical, psychological, neurological, and developmental positions of autism as grounded in the criteria created through DSM-5.[104] Importantly, autistic individuals do

not use the same knowledge spheres or frames of reference as professionals, and their relationships with services can be stressful and in some cases conflicting.[105]

It may seem that medicalisation as a concept is negative; yet, notably medicalisation is not inherently problematic. The view of medicalisation as being viewed as good or bad rests on the implicit definitions of health and illness and a critical perspective regarding the effectiveness of medicine to address the well-being of the individual.[106] Indeed, the founders of medicalisation theory, such as Peter Conrad, described medicalisation as value neutral.[107] Furthermore, it must be recognised that medicalisation does serve some function for patients and families. It provides a basis to legitimise concerns that may otherwise be dismissed, and although there are risks that society takes on psychiatric concepts as identity terms, access to support largely relies on medics to confirm the nature of the problems.[108] Thus, the medical hegemonic position on autism underpins a legislative requirement to access services, as without an official diagnosis and label families are not entitled to help.[109] The flip side to this, however, is that parents may fear that if they fail to follow medical advice they will be morally implicated in any later negative experience.[110]

Despite the value neutral nature of medicalisation, it has brought with it a very particular orientation to mental health; that is, one focused on 'fixing' the presumably 'broken' individual. In contrast to this, more social constructionist understandings afford nuanced and layered understandings of difference and disability. More particular to autism, there is a need to shift away from a focus on the medicalisation to language, with its overreliance on medical explanations regarding autism.[111] Such an overreliance might lead to the mismeasurement of the autistic experience.[112] Indeed, this shift has implications for whether autism might be viewed as a natural identity or a dilemma.[113] This focus on language and the social construction of disability and normal identity were encapsulated by a related movement, that of neurodiversity.

Neurodiversity: Empowering Autism

The language that we use has the power to reflect and shape people's perceptions of autism.[114]

A core focus of the neurodiversity movement is on the language we use around autism. This movement rejects medicalised negative concepts

such as 'disorder', 'deficit', and 'impairment' and instead reconstitutes autism as a way of being.[115] The neurodiversity movement therefore directly challenged framing autism in a medicalised way. The notion of neurodiversity can be traced to Australian sociologist Judy Singer and journalist Harvey Blume, and it became popular with civil rights groups in the late-1990s.[116] The popularity of neurodiversity as a movement arose mostly online in response to what was argued to be a marginalisation of autistic people.[117] Thus, this movement sought to establish a culture where autistic people could have pride in their autistic identity and provide mutual support in self-advocacy.[118]

An underpinning principle of neurodiversity was the foundational idea of a 'differently wired brain'.[119] This movement has been instrumental in advocating strength-based discourses for autism,[120] but also for other brain-related conditions.[121] For autism, neurodiversity has two main claims as outlined by Jaarsma and Welin:

1. That autism is simply a natural variation in humans, and being neuro-diverse or neurotypical, reflect different ways of being human.
2. That neurodiversity connects to human rights, political issues, and non-discrimination of autistic people.[122]

This movement therefore became associated with the struggle for civil rights for those individuals diagnosed with neurodevelopmental conditions[123] and as such became a counter-argument for the deficit model to prevent discrimination.[124] This is important, as society tends to be organised around neurotypical values and by contrast autism is positioned as a deficit.[125]

As will be seen in Chapter 8, an important aspect of neurodiversity is that the autistic community were instrumental in its promotion and development. Indeed, there are many autistic self-advocates who have celebrated autism as part of their identity and see their autism as a natural variation.[126] Some of these people have expressed fears that the seeking of a 'cure' may result in the eradication of autism.[127] It was argued therefore that by constructing autism as synonymous with impairments, it raises questions about what it means to be human, and those failing to conform to the dominant ideology are positioned as impaired.[128]

We would note here that not all those in the autistic community advocate a neuro-diverse position, and it is important to have some balance in these arguments. Some neurodiversity movement advocates have

acknowledged that some aspects of autism can cause distress and their amelioration or control is sometimes useful, and they do not oppose all forms of intervention and treatment.[129] Notably, some parents of children with autism do actively pursue treatments for their child and may even seek a cure for the condition.[130] Parents of course should have the right to seek early intervention for their offspring and have the freedom to work in ways they see as best for their child.[131] For those promoting neurodiversity, there is a position of promoting well-being and adaptive functioning to support autistic people.[132] The balance therefore is to support the notion for treatment, support, and services to overcome some of the potentially disabling effects of the condition, while steering away from medicalisation, negative language of deficiency, and damaging stereotypes that reify difference.[133] Neurodiversity as a movement and the construct of an autistic disability do not have to be incongruent, as individuals may have areas of strength and celebrate their identity, while still having some difficulties.[134]

A central underpinning concern that has arisen from medicalisation and from neurodiversity therefore is the way in which autism is classified. While medicalisation advocates the appropriateness of autism as a mental health condition, as reified through its presence on the DSM, neurodiversity tempers this position, critically questioning the 'deficit' associated with such constructions. Ultimately, therefore, questions have been raised as to whether autism should be viewed by medicine, and by society more widely, as a psychiatric disability. The rise of the neurodiversity movement in the latter part of the twentieth century had a significant impact on the way we view autism and contributed greatly to this debate. The construction of autism as a psychiatric category, as a mental health condition, and as a disability is therefore dependent upon different points of view, different theoretical frameworks, subscription to different disability models, and personal experiences and viewpoints.

In our own work, we attempt to strike a balance between recognising the real distress of some families and the severity of symptoms for some children, against the critical and imperative challenges to the notion of deficit and the importance of empowering autistic people. It is important to be aware that for some families the diagnosis of autism is stressful, and the condition can have some disabling effects on the autistic person and their families.[135] For others, a more positive view of autism is necessary and the language surrounding the autistic identity is crucial in challenging deficit, stigma, and unacceptable stereotyping. Arguably, we should not see dysfunction, but we should see difference.[136]

This is a helpful perspective that has been recognised in research with autistic people and those who live or work with them. In our own research on this issue, we considered how the notion of a disability might be understood discursively in relation to autism.[137] Using focus groups with a range of stakeholders, including autistic adults, parents of autistic children, mental health practitioners, researchers, and service managers, we found that the notion of a disability is fluid, contestable, and socially constructed. For example, an autistic adult in the focus groups argued that autism is not a disability:

> I'm a great believer that ↑autism[138] 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.[139]

However, a mother of an autistic daughter, actively disagreed, noting that autism is a disability:

> 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.......So it is a disability.[140]

There was little agreement amongst participants as to whether autism constitutes a psychiatric disability as discussions permeated the boundaries of normality versus abnormality, disability versus ability, and medicalisation versus neurodiversity. While there was some acceptance that, clinically, categorisation and diagnosis were essential for support and service provision, and that some autistic people encountered more severe levels of difficulty than others, there was also an advocacy that autism was a fundamental characteristic of personhood and should not be characterised in limiting ways.

DRAWING CONCLUSIONS: OUR PERSONAL VIEW OF AUTISM IN THE TWENTIETH CENTURY

Our focus has predominantly been the evolution of autism throughout the twentieth century, exploring the various paradigmatic shifts that occurred and polar arguments that developed to influence our thinking around autism. However, these influences, research ideas, medical ideologies, genetic revolution, critical discourses, movements, and personal

advocacies have all influenced our understanding of autism today. We now have a fractured view of a heterogeneous condition with a spectrum of characteristics, and of autistic people being different and reflecting a multitude of identities, views, opinions, and experiences. The twenty-first century is now plagued by the notion of an autism epidemic, and medicalised questions about where such an influx of autistic individuals has come from. This means that parents are thrown into a '*minefield of conflicting information*'.[141] Indeed, the volume of information is a confusing and time-consuming area for parents.[142] Yet, in some ways, this has been positioned as hope for parents, as 'the first decade of the new century was a time of hope for many families, as parents told me they felt optimistic that science was on the verge of finally unravelling the mystery of their children's condition'.[143]

Such 'hope' and challenges related to autism are important as the 'epidemic' of the twenty-first century has become part of the medical rhetoric. There are few epidemiological studies of autism, but it is generally agreed that the prevalence currently stands at approximately 1% of the population.[144] Similarly, in childhood, a total prevalence of 116.1 per 10,000 was presented.[145] Baird et al. argued that the rates of autism are now much greater than was previously seen, and yet the reasons for such an increase in incidence are unclear.[146] The consequences of this growth have meant that services are having to rapidly expand to meet the greater demands.[147] Such an increase has however been controversial, as some have argued that it reflects an exaggeration of the existence of the condition, and others claiming it reflects the broader criteria.[148] It is therefore arguably not a new scientific discovery, but a shifting cultural and social practice regarding the social construction as to what counts as normal.[149]

We conclude our chapter by presenting our perspective on this controversial issue and in so doing recognise the validity in different perspectives. In a personal and professional sense, we acknowledge our own experiences of autism. The lead author (O'Reilly) is an academic psychologist who has a brother diagnosed with autism, currently living in an institution due to the severity of his condition and the expanse of personal need. Furthermore, in addition to the academic position, O'Reilly also works as a research consultant for a Child and Adolescent Mental Health Service and therefore works alongside a multi-disciplinary team of mental health practitioners. The second author (Lester) is a former autism teacher in the USA, has a niece diagnosed with autism, and is now an academic working in educational autism research. The third

author (Kiyimba) is an academic and chartered clinical psychologist, who specialises in trauma, and has worked professionally both with clients with autism, and as a clinical supervisor of mental health professionals working with autism, as well as supervising professionals who are autistic themselves. In outlining this personal position, we reflexively acknowledge that no text can ever be produced without influence and some imposition of the values and experiences of the writer, and our views and motivations are inspired and underpinned by our personal circumstances.

Thus, in our work on autism, we favour social constructionism as a guiding theoretical position, recognising the importance of language, and taking a child-centred and family-centred approach to research. We see the value of balancing the perspectives of psychiatrists, psychologists, other mental health professionals, autistic people, autistic advocates, families, and other stakeholders. The focus, for us, should be on meaning-making, that is, on the language used in different contexts and the impact that this has. In taking this social constructionist position, we do not deny the reality of autistic people or their families. This was eloquently expressed in a recent text by Thomas et al.:

> This is not to deny the reality of mental health issues within people's lives, but rather to acknowledge that if we are to comprehend the ubiquity and impact of mental distress within a contemporary UK context, then we need to recognise the ways that particular types of scientific knowledge and particular narratives of distress have been invested with meaning and authority, and as such, have the potential to become tools for use in the pursuit of broader political agendas.[150]

The twentieth century saw many changes in the scientific and medical community understanding of autism. What we understand about autism is 'constantly in flux'.[151] Autism as a condition has created much interest, amongst researchers, scientists, the public, and the media, and this is likely due to the multiplicity of meanings.[152] We have argued that autism is a social construct. In so doing, we have recognised that for some autistic people, their autism is celebrated, but for other families it is distressing, and they struggle to cope with what they frame as adversity.[153] We have woven a narrative that is congruent with the autonomy of those with lived experiences, have favoured a person-centred position, and explored alternative ways of thinking about the pervasive medicalised discourses that have constructed autism as a psychiatric disability.

We have recognised that there are economic, institutional, and social consequences of adopting different social constructions of autism.[154] Through our exploration of the different arguments, we have shown how the dominant ideas of the impaired autistic person have become reified through medical rhetoric and the genetic revolution. We argued that psychiatry and other mental health professions have an important place for autism but acknowledge that the embracing of biopsychosocial framings of autism within those fields is important. We also noted that social constructionism provides a way for easing some of the tensions and a focus on language sets autism centre stage and challenges narrow interpretations of normality. The neurodiversity movement will be considered in greater depth by Erika Dyck and Ginny Russell in Chapter 8.

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