Chapter 3
What Is Autism? A Clinical Understanding

Across the globe, autism operates within a rapidly changing environment, and as a society, we are frequently exposed to messages about new discoveries or ideas about it. The media regularly reports stories about autism, proffering ideas about diagnosing and treating autistic children (e.g., see, Falco, 2009, for an example of this). Indeed, there has been extensive media coverage of autism, meaning that this condition has gone from being almost invisible to the public eye – now dominating a range of contexts and disciplines (Karim, 2017). The increased visibility of autism has prompted a surge in the attention given to discussing and studying autism. This increased awareness and spotlight on autism has resulted in a growing body of research focused on examining the aetiology, neurophysiology, genetics believed to underpin autism, as well as the behaviours of autistic individuals and programme of intervention. Many scholars have suggested that this increase in attention is a great and important stride forward for autistic people, their families, and the broader communities. However, the increased visibility of autism has also created challenges, critiques, and broad explorations of the very meaning(s) of the condition, the implications of it, the discourses that shroud it, and the location of autism within the field of mental health and disability studies (Lester & O'Reilly, 2016).

Indeed, throughout the twentieth century, autism as a concept, as a condition, and as a neuro-diverse movement has shifted in meaning and consequence (for an overview see O'Reilly et al., 2019b). In this book, we broadly explore and unpack the various positions and issues pertinent to autism. More specifically, within this chapter, we focus on the traditional, clinical language surrounding autism, which pervades the medical sciences and underpins a great deal of the research related to autism. Understanding this clinical and medical perspective serves as a foundation for understanding some of the more social and critical perspectives about autism, which we examine more fully the chapters that follow.

J. N. Lester, M. O'Reilly, *The Social, Cultural, and Political Discourses of Autism*, Education, Equity, Economy 9,
https://doi.org/10.1007/978-94-024-2134-7_3

Introduction

A clinical definition is important to our understanding of autism, and for the purpose of this chapter we open with definitions of autism that are very much grounded in medical concepts and ideas. These concepts originated in the practice of psychiatry wherein the diagnostic criteria tend to govern decisions. There are considerable challenges and critiques to conceptualizing autism in medical terms where it is generally framed as a 'mental illness' or 'disorder,' in other words, as a psychiatric disability. While we take up a critical orientation to the very notion of autism as a 'mental illness' or 'disorder,' it would be remiss of us not to provide contextualization from the field of psychiatry and medicine, where some of the most heralded meanings of autism as a 'disorder' and as a concept have been developed. This is because when a child or adult is diagnosed and categorized by the medical or at least a clinical profession as being autistic or having the characteristics of autism, it is within the clinical criteria, or the medicalized understanding of what autism is that this label is being applied and positioned.

Thus, while we ourselves see some tensions in the medicalized position of autism, and the labelling process more generally, it is first important to understand the medical context; that is, it is helpful to make sense of the psychiatric positioning of autism before engaging with any of the critiques or arguments that more critically engage autism as a category. What follows in this chapter is a discussion of the clinical definitions of autism. Again, and quite importantly, we do not necessarily subscribe fully to these definitions but we do argue that understanding these definitions is important when making sense of how historically autistic people have been located within a distinct clinical category.

Medically Defining Autism

Within clinical contexts, autism is typically defined as a lifelong neurodevelopmental condition or disorder, which presents from a young age (although it might not be recognized until later in life) (Karim et al., 2014). A neurodevelopmental condition is defined as occurring when the brain has not developed or matured in ways that fundamentally impacts how an individual reacts to the outside world, and consequently affects certain behaviours and emotional responses (Karim, 2017). In other words, autism is often described as a condition marked by impairments in the brain or nervous system, originating from a developmental cause rather than causes such as infections or tumours. Autism has also been described as a spectrum condition, and this has resulted in some scholars arguing that it is difficult to determine how children will develop over time or to make a longer-term prognosis (Karim et al., 2014). Notably, this understanding of autism has emerged across time and geographic space – it is not an ahistorical entity, as noted in Chap. 2. We thus offer next a discussion of the early history of autism, particularly within the field of medicine and mental health.

Early History of Autism

To appreciate the concept of autism within the field of medicine and mental health more broadly, we provide a brief history of how autism – as a 'condition' – came to be understood. This history is important as it provides an understanding how those with the condition came to be labelled in that way, and points to the changes that have happened in psychiatry and related fields in terms of categorizing this condition. It is recognized that the concept of autism was initially attributed to two medics working during the same time who first described the characteristics clinicians now recognize to be autism.

First, there was the work of Leo Kanner (1943a, b) who wrote a seminal paper introducing the world to autism. Kanner was an Austrian American child psychiatrist and in his paper, he described patterns of behaviour observed in 11 children who displayed a need for sameness, aloneness, and obsessive behaviour. Kanner distinguished these children from those described as having schizophrenia at that time. Notably, he included within his description many strengths, such as 'high intelligence.' Second, there was the work of Hans Asperger (1944) who at the same time as Kanner, wrote about characteristics of children in similar ways to those of Kanner. Asperger was an Austrian paediatrician interested in the characteristics of four boys who he noted were displaying difficulties in forming friendships, had a lack of empathy, tended to get absorbed in special interests, had clumsy movements, and got involved in conversations that were generally one-sided. Like Kanner, he attended to the perceived social differences of the children. Asperger's patients were all described as being highly verbal and intelligent, while also tending to talk extensively about a unique subject of interest (see Silberman, 2015 for further detail about Kanner and Asperger and their role in the history of autism).

It was Lorna Wing, a British autism researcher, who introduced Asperger's work to the English-speaking world in 1981, changing the term "autistic psychopathy" to "Asperger's Syndrome." It was not until Wing's 1981 publication that Asperger's work became better known and researched within the medical community, being recognized by some as related yet distinct from what Kanner had described as infantile autism. Popularly called "The Little Professor Syndrome" (Osborne, 2000), Asperger's Syndrome was conceptualized as a less severe form of autism. Ultimately, it was Asperger's work that was used to justify the construction of a "spectrum" of related but unique syndromes ranging in severity.

Developing the Triad of Impairments

It was later in the twentieth century that the work of Kanner and Asperger were re-examined, and the characteristics of autistic children were then re-conceptualized by two British professionals – Lorna Wing and Judith Gould. Notably, it has been advocated that the work of Frankl and Weiss deserve some acknowledgement for

this modern understanding of autism as they worked closely with Asperger but were forced to leave Austria for the US (Baron-Cohen et al., 2018). This work led to the re-conceptualized characterization coined 'Autistic Spectrum Disorder' (Wing, 1981a; Wing & Gould, 1979). In providing this new terminology for the condition (Wing, 1981b), the idea of a 'triad of impairments' was created and consisted of:

1. Impairments in social interaction – that is, difficulties in relating to people, making relationships, difficulty reading facial expressions and so forth. This includes impairments such as:
   (a) Being distant with others and failing to pay attention.
   (b) A preference for being alone and withdrawing from social situations.
   (c) Limited social skills.
   (d) Problems in making friends.
2. Impairments in communication – that is, difficulties in understanding or using language, challenges focusing their attention and frequently repeating phrases, and some children having limited speech. This includes impairments such as:
   (a) Echolalia (i.e., repetition)
   (b) Impairments in understanding jokes, irony or sarcasm.
   (c) Misunderstanding facial expressions and common gestures.
   (d) A literal interpretation of colloquial phrases.
3. Restrictive repetitive patterns of behaviour, interests, and activities and impairments in social imagination. This includes impairments such as:
   (a) Problems with imaginative play.
   (b) Difficulty in predicting the actions of others or dealing with hypothetical situations.
   (c) Challenges in imagining how others might think or feel.
   (d) Reacting negatively to new or unfamiliar situations or events.

During the late twentieth century and early twenty-first century, this re-conceptualization was a foundation for thinking about the impairments of autistic children as a triad, while also considering the condition as a spectrum. Notably, in recent times this has more recently been re-conceptualized as a *dyad* of impairments, which we discuss later in this chapter.

Terminology of Autism

Evidently, the terms and language around autism have varied over time and there have been a range of different terms used to describe it, including, autism, Autism Spectrum Disorder, Autistic Spectrum Disorder, Autism Spectrum Condition, Asperger's Syndrome, pervasive developmental disorder, and high functioning autism (Karim et al., 2014). Arguably, each of the different labels that have been

developed and used are loaded with category rich inferences. Perhaps unsurprisingly different groups of people have tended to indicate varying preferences for how to conceptualize and 'name' the condition.

Attempts to standardize the terminology have been generally directed through the DSM, with more recent arguments being that all related concepts fall under the broad concept of *Autism Spectrum Disorder* (American Psychiatric Association, 2013). Other groups of people have questioned the value of using the notion of a *disorder* within the terminology, arguing that it would be more appropriate to utilize *Autism Spectrum Condition* (see, for example, Baron-Cohen, 2017; Dickerson & Robins, 2015). To better understand the changes in concepts and terminology around autism, it is therefore necessary to appreciate the broader changes that have occurred within classification systems and the related diagnostic criteria. The classification systems are highly influential in shaping the language and concepts utilized by mental health professionals, and, ultimately in terms of how individuals become defined and labelled autistic, and we introduced these in the previous chapter.

Classifying Autism

At present, there are a range of approaches to the classification of mental health conditions, which reflect historical and contemporary perspectives found within medicine, public health and social policy; nonetheless, the categorical models (that is, those that determine the presence or absence of a condition) tend to dominate (Volkmar & McPartland, 2014). As we noted previously, the Diagnostic Statistical Manual (DSM) is a frequently used classification system in the field of mental health and maintains a powerful influence on how autism is defined, diagnosed, and treated.

The DSM is now in its fifth edition (DSM-5), having recently transitioned from using roman numerals as was utilized in the other incepts (DSM I, II, III, IV, and IV-R). Broadly, the DSM-5 provides a standardized approach to classifying mental disorders and is utilized in the diagnostic practices of mental health professionals in the United States, as well as many other countries. Historically, the focus of the DSM was so that those working in the field of mental health could categorize the full range of mental disorders, relying upon the outlined criteria for diagnosis (American Psychiatric Association, 2013). In this way, the DSM has generally provided the descriptive text to illustrate what a given 'disorder,' such as autism, is and defines what does and does not constitute a particular 'disorder.' Ultimately, the DSM defines what constitutes normality (Karim, 2017), and draws upon naturalized prescriptions of the individual (Burman, 2008) measuring against so called standardized benchmarks of normality (Brownlow & Lamont-Mills, 2015). For autism, the widespread use of the DSM has had some important implications in terms of the range of concepts used to describe the characteristics presumed to be part of *being* autistic.

The Diagnostic Statistical Manual – The Early Days

The way in which mental health as a construct was broadly conceptualized has shaped the way in which psychiatry has come to recognize what is 'normal', and what falls outside of those parameters. This reality has obvious implications for the inclusion of autism within the DSM. Before 1900, there were very few working psychiatrists, with individuals classified as 'mentally ill' typically sent to asylums or large hospitals (Blashfield et al., 2014) – something we discussed in more detail in Chap. 2. Blashfield et al. (2014) noted that even in the 1900s psychiatrists were aware of the challenges of delineating mental disorder categories and thus tended to classify their patients based on symptom descriptions, but frequently their diagnostic categories overlapped. Despite these challenges and issues in defining mental illnesses, it was not until after World War II that American psychiatrists formally addressed the difficulty. In doing so, the American Psychiatric Association decided to unify the diagnostic processes for psychiatrists and created the DSM I. This was the first official classification system for mental disorders and constituted a single manual developed by the American Psychiatric Association, but notably it was not published until 1952 (Raines, 1953).

The first edition of the DSM represented an important shift in thinking about mental health conditions and the seriousness afforded these conditions in a way that separated mental health from physical health. This first edition represented a milestone in creating diagnostic categories and explaining the behaviour and emotions of individuals. Notably, this first version reflected the conceptualizations of mental health conditions at that time and divided it into two core groups of disorders; (1) those that were considered to be caused by organic brain dysfunction, and (2) those that were thought to reflect environmental circumstances, such as the effects of socio-economic stress and the inability of individuals to adapt to social pressures (American Psychiatric Association, 1952; Kawa & Giordano, 2012).

During this time (the 1950s) the World Health Organization (WHO) also highlighted the importance of more adequately classifying those deemed to be experiencing mental ill health, adding a psychiatric section to its sixth edition of the International Classification of Diseases and Related Health Problems [ICD-6] (Blashfield et al., 2014). Unfortunately, this was not consistently adopted and was ignored by almost all countries (ibid.). In an examination of worldwide psychiatric classifications, it was found that all countries had their own system, and some European countries had more than one (Stengel, 1959).

The second inception of the DSM (i.e., DSM II) came about relatively quickly as the inconsistencies in diagnosis became concerning to many within the field of psychiatry. This second edition was heavily influenced by psychoanalysis and was launched in 1968 (Shorter, 1997). Simultaneously, in 1966, WHO worked to create a consistent system and ICD-8 was created. Notably, the DSM II was almost identical to the ICD-8 in terms of mental health condition categories albeit minor differences (Blashfield et al., 2014). The DSM II had 193 diagnostic categories and consisted of a paper manual of 119 pages. It was this revision which transformed

psychiatry from a discipline that was concerned with pathology, to one that became more centrally concerned with the boundaries of normality (Horwitz, 2002). This version placed an emphasis on categories of illness through a focus on symptomology, rather than on the boundaries of what constituted the 'normal' individual. In so doing, the field of psychiatry became more concerned with diagnosing patients accurately, with psychiatry being expected to mirror other branches of medicine (Shorter, 1997). Notably, it was during this period that there was a rise of psychopharmacology and emphasis on seeking out biological and neurological explanations for the conditions. Aligned with this was the notion that criteria for diagnosis needed to be rigorous and fixed so that standardization could be achieved (Shorter, 1997).

It was this idea of standardization that was an important driving force in the changes made to the system, resulting in the DSM III. The validity of psychiatry had been called into question through research (Szasz, 1963). For example, the infamous experiments conducted by Rosenhan (1973) created embarrassment for the field of psychiatry. In his work, Rosenhan explored the admissions process into psychiatric facilities where individuals deceived staff by providing pseudonyms and reported that they heard voices (but otherwise behaved 'normally'); all were admitted with a diagnosis of schizophrenia. Rosenhan reported that the individuals stayed as inpatients from between seven and 52 days and none of the 'pseudo-patients' were detected, leading to a conclusion that they were unable to differentiate the 'normal' from 'pathological', with some finding it difficult to be released. Blashfield et al. (2014) noted that this controversial study "*stirred up a firestorm of protest*" (p. 30) and such debates created tensions about taxonomies of mental disorders and how they could be classified scientifically.

The changes from DSM II to DSM III were therefore quite substantial. This revision began in 1974 and aimed to make the DSM classification more consistent with the ICD (Mayes & Horwitz, 2005). Further, changes were made in response to demands of insurance companies, in countries such as the United States, who wanted more precise diagnostics to fund longer-term therapies like psychotherapy (Shorter, 1997). Moving from using short, broadly worded definitions to describe the mental health condition categories, the DSM III contained criteria which identified meanings of those categories and also moved to a multi-axial system for diagnosing along five axes (Blashfield et al., 2014). In this way, the DSM III represented a radical shift in the way psychiatry viewed mental health and illness. A consequence of such standardization and tightening of criteria was the promotion of the power of scientific knowledge and seeking of objectivity, reason, and truth (Mayes & Horwitz, 2005). Published in 1980, the DSM III was designed to address these calls for objective, scientific classification.

It was this third version of the DSM that saw an extension of symptomology and ran to almost 500 pages with 265 categories (Shorter, 1997), radically transforming the nature of mental health conditions (Mayes & Horwitz, 2005) and promoting the medicalization of psychiatry (Hale, 1995). Importantly, autism was one of the new categories included, as it had not been previously recognized by the DSM I or DSM II (Volkmar & McPartland, 2014). What is particularly interesting about the third

version of the DSM, is not only its inclusion of autism as a distinctive conceptual category, but how it treated individuals with diagnostic needs. The third version of the DSM represented a legitimacy of the profession as part of medicine, arguing that practitioners treated 'real' diseases (Mayes & Horwitz, 2005), which consequently constructed autism as a psychiatric disability; that is, a medical illness requiring diagnosis and treatment. Such an emphasis on diagnosis and treatment of legitimate illness thus led to billions of dollars invested in psychopharmacological research (Gambardella, 1995) and a translation of the DSM into a range of different languages for consistent global use (Shorter, 1997).

The following changes to the DSM from III to III-*R* to IV (and IV-*R*) were arguably less radical than that from II to III. Nonetheless, there were a range of changes. This was despite some criticism that researchers needed stability to generate helpful work in the field and clinicians needed consistency to perform clinical tasks (Blashfield et al., 2014). In his new role, Allen Frances, as the leader for DSM IV, composed several workshops to synthesize literature and identify databases to create source books and thus DSM-IV grew to 886 pages (ibid.). Such amendments paid more attention to issues like culture and gender, as well as prevalence and family patterns (Kawa & Giordano, 2012). A significant and notable point here was that it was the DSM IV that saw Asperger's Syndrome being classified and conceptualized in terms of its symptoms (Giles, 2013). Giles noted that it was this inception of Asperger's Syndrome as distinct from autism that created some discontent in medical circles, with arguments that they were too similar to differentiate. However, he further reported that it was the non-academic literature evolving during this time, along time with fictional and autobiographical accounts of Asperger's Syndrome that provided the benchmark for the category.

DSM-5 and the Modern Day

The DSM-5 has arguably been the most controversial conception of the manual. The development of this version began in 1999, and unlike previous inceptions, this one was subject to public scrutiny thanks to the Internet. Further, the American Psychiatric Association invited comments on their website (Blashfield et al., 2014). Notably, it was not until 2010 that the first draft was posted, which returned 8000 comments, and in 2011 a revised version with an additional 2000 comments (ibid.). Blanshfield et al. noted that by opening up the project via the website, this allowed mental health professionals to interact with its development and provided a mechanism for criticism in a way that was unlikely anticipated by the leaders of the development. For example, it has been argued that this new version of the DSM is unnecessarily complex, using dimensional ratings that will be challenging to translate into clinical practice (Frances, 2013a, b); further complicated by the inclusion of many new untested disorders with insufficient data about prevalence, validity, reliability, or responses to treatment (Frances & Nardo, 2013).

As the process unfolded, David Kupfer was appointed as chair and set the goal of creating a 'revolutionary manual' to map the classification of mental disorders to the contemporary molecular biology, cognitive, and affective neuroscience with the inclusion of psychometrics (Blashfield et al. (2014). Blashfield et al. reported that this new version of the DSM had grown to 947 pages, with 541 diagnostic categories, which represented an increase of almost 160 categories compared to DMS IV.

DSM-5 and Autism

The latest inception of the diagnostic criteria, conceptualized within the DSM-5, has had very important implications for autism. The notion of a spectrum condition has been maintained, with the medically accepted label Autism Spectrum Disorder (American Psychiatric Association, 2013), but other changes have been more controversial. The most obvious example of this was the change in the use of Asperger's Syndrome. The first use of the term Asperger's Syndrome was placed in the diagnostic manuals in the 1990s, and yet has been somewhat controversially removed and brought under the general rubric of Autism Spectrum Disorder in this latest version, something we discuss later in the chapter. This contemporary version of the DSM also underwent other major changes for those with autism, especially in recognizing the inclusion of sensory symptoms and changing the age of onset from 'aged 3 years old' to 'early childhood' (American Psychiatric Association, 2013).

Thus, in its current format the DSM-5 classifies autism in terms of core characteristics. There are many aspects of autism thought to affect the thoughts and behaviours of the individual affected, with a range of key features described as making up the condition. While we mentioned the triad of impairments that was historically utilized as a way of characterizing autism, there have been some slight variations on this in more modern descriptions. While still recognizing the triad of impairments, additional characteristics have now been considered. For example, it has been noted that some autistic individuals can have co-occurring learning disabilities or may be extraordinarily intellectually gifted.

A Word About Asperger's Syndrome

Historically, it was the fourth edition of the DSM wherein Asperger's Syndrome was added as a condition to be diagnosed and recognized (American Psychiatric Association, 1995). Asperger's Syndrome is considered a lifelong neurodevelopmental condition, in the same way as autism is, and a disorder that affects how people perceive the world and how they interact with others (Attwood, 2007). Individuals diagnosed with Asperger's Syndrome are thought to display subtle differences from those diagnosed with autism, as they often have normal or high levels of intellectual ability and often feel that this is quite fundamental to their identity

and tend not to have language delay (which is often thought to be the distinguishing feature) (Attwood, 2007). Notably, this is not to say that many people diagnosed with autism are not also thought to have high intellectual abilities; rather, this characteristic has historically and rhetorically been thought to be central to a diagnosis of Asperger's Syndrome.

Accordingly, there is significant overlap in the diagnostic symptoms of Asperger's Syndrome and autism, particularly in relation to what is often referred to as 'high functioning autism.' Notably, there are many individuals diagnosed with Asperger's Syndrome who celebrate their difference and have actively taken offence at the notion of a cure, arguing that Asperger's Syndrome should not be conceptualized as a disability – an argument that has also been made for autism more generally (Lester et al., 2015; O'Reilly et al., 2015a, b). This is an important aspect of the argument about Asperger's Syndrome, because as we have noted, the syndrome has now been subsumed under the broader rubric of Autism Spectrum Disorder in the DSM-5 (American Psychiatric Association, 2013).

Arguably, the rationale for deleting Asperger's Syndrome from the diagnostic manual was thought to reflect the shift from a categorical system to a dimensional one (Bentall, 2009). Consequently, those who would have been previously classified as having Asperger's Syndrome are now instead to receive a diagnosis of Autism Spectrum Disorder, meaning that there will be no qualitative distinction between those with autism and those who are higher functioning (Giles, 2013). Giles (2013) noted that this shift is not as straightforward as may be assumed by professionals, as in a contemporary digital society and consumer driven healthcare environments, new interest groups have emerged who view classifications as a blueprint for their identity and not simply an arbitrary means for classifying patients. This critically- and advocacy-oriented positioning of Asperger's Syndrome and of autism more generally is something we return to later in the book.

As we noted earlier in this chapter, it was the Austrian paediatrician, Hans Asperger, who first wrote about Asperger's Syndrome, describing children whereby their intellectual levels were presumably 'normal,' but they had impairments in communication, and, according to Asperger, failed to demonstrate empathy (Asperger, 1944). Hans Asperger has recently come under some scrutiny and concerns have been expressed about a potential connection with Nazi atrocities, with allegations that he legitimized policies of forced sterilization and child euthanasia. It has been proposed that "Asperger was not just doing his best to survive in intolerable conditions but was also complicit with his Nazi superiors in targeting society's most vulnerable people" (Baron-Cohen et al., 2018, p. 28). However, some arguments have been proposed to suggest that these claims potentially could be refuted (Falk, 2020). Thus, the degree of involvement by Asperger in the targeting of Vienna's vulnerable children remains an open question in autism research (Baron-Cohen et al., 2018). Potentially, however, such politicised rhetoric about such an influential scholar in the field of autism could be damaging for those who bear the label, and arguably the subsuming of Asperger's syndrome as Autism Spectrum Condition may turn out to be a positive step.

Diagnosing Autism Clinically

In making a diagnosis of autism, clinical professionals must make a judgement about the individual as displaying impairments across the core features (Muskett et al., 2013). In other words, diagnosing autism relies on clinical judgements about the child's (or adult's) behaviour, as there are no specific markers to identify the condition (Gray et al., 2008). In making this diagnosis, clinical professionals may also use some tools to facilitate the judgement, such as the structured interview schedules like the Autism Diagnostic Inventory (ADI), and the Diagnostic Interview for Social and Communication Disorders (DISCO), combined with observational tools such as the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 1999). Yet, ultimately the diagnosis is dependent upon the skills of the clinician (Karim, 2017). In addition, best practice requires some consensus from a range of professionals from different agencies, and observations of the child in different settings (National Institute for Health and Care Excellence (NICE), 2011).

Despite the availability of tools and the range of professional perspectives during the diagnosis, the actual procedure and process is challenging (Lord & Corsello 2005). Typically, a diagnosis is made when the child is between 3 and 5 years of age (Goin-Kochel et al., 2006), although parents often report concerns within the first 2 years of the child's life (De Giacomo & Fombonne, 1998) and for some diagnosis can take a much longer time (Crane et al., 2016), not being diagnosed until adulthood. It is recognized that the complexity of diagnosing autism means that it tends to take longer to diagnosis compared to other developmental disabilities (Werner et al., 2005). This is reflected in the concerns that practitioners tend to have about misdiagnosis and labelling, which can contribute to the delays in diagnosing autism (Moh & Magiati, 2012). Waiting times and delays to diagnosis, however, can be particularly challenging for families and can cause stress. Research has demonstrated that it is difficult for children and adults to access an autism assessment (Harper et al., 2019; Lewis, 2017), and it is highly likely that the COVID-19 pandemic is exacerbating barriers to assessment and creating additional challenges for diagnosis because of the mandated distancing, use of personal protective equipment and reduced access to healthcare services (Spain et al., 2021).

Importantly, the DSM-5 has changed the way in which autism is diagnosed clinically. It is noted that there are key features which must be present for a diagnosis to be made. Notably, the original triad of impairments – which included social interaction, communication, and repetitive and restricted behaviours – were collapsed into two broad domains (thus a dyad of impairments) in the new DSM-5 and were listed as:

1. Difficulties in social communication, that is, 'persistent deficits in social communication and social interaction' and these should occur across contexts and time.
2. Restrictive and repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013).

Thus, communication and social interaction difficulties were merged into a single domain, with this category being monothetic (that is, requiring the person to demonstrate symptoms across the three identified clusters within it to be diagnosed), whereas restrictive and repetitive behaviour remained polythetic (that is, the need for evidence of symptoms in two from four symptom groupings) (Volkmar & McPartland, 2014). The reduction from a triad to a dyad has received some criticism. For example, Wing et al. (2011) argued that there are important theoretical and clinical reasons for why social interaction and communication were originally separated and that it is inappropriate to collapse them into the single category of social communication. They further added that the requirement of symptoms to present in early childhood means that it is more difficult for those presenting symptoms in adolescence or adulthood, and thereby places unreasonable demands on clinical professionals to identify problems earlier in life. Furthermore, there are several associated difficulties which tend to occur in those with autism which are now thought to be more clearly recognized, such as executive functioning challenges, theory of mind difficulties, and/or sensory processing difficulties (Karim, 2017) – all of which many have argued are relevant to the diagnosis of autism.

Presumed Difficulties in Communication and Social Interaction

Difficulties in communication are thought to be integrated and overlapping with social interaction difficulties and theory of mind. Although communication and social interaction skills are distinctive, they are often considered together in the context of autism. Clinically, those with autism are argued to have impairments in their communication skills, and in their ability to socially interact with others.

Communication is an essential feature of everyday life and is part of interactions with others. Communication is generally thought of as more than just hearable language, encompassing the many ways in which people express themselves, which includes non-verbal communication, such as using eye contact or using gestures, and other modes of interactions (e.g., sign language). Children develop their language skills over time, with the first few years seeing a significant development of vocabulary and syntactic development (Keenan et al., 2016); however, the clinical literature has highlighted that autistic children often experience challenges with communication skills and in part, this relates to language development. Some autistic children do not develop expressive language skills in the same way as their peers, and for some language development it is significantly delayed (Karim et al., 2014).

For some autistic people, non-verbal communication may be challenging to interpret and express, which can be particularly difficult given this is an important way that people convey meanings. One example of this is eye contact – which is common in many westernized cultures during social exchanges. Some autistic people may struggle with making eye contact, impacting their social interactions which is arguably involuntary and unconscious. Some autistic people can find it challenging to use communication such as gestures, and/or find it difficult to interpret the

body language of others, which can be distressing and upsetting for them (Karim et al., 2014).

In the clinical literature base, communication patterns such as longer than expected pauses or non-responsiveness are often assumed to signal pathology or some kind of communication deficit (Whitehouse & Bishop, 2008). In fact, many assessments used in the diagnosis process favour immediate verbal responses to requests (Newcomer & Hammill, 1977). When individuals fail to display immediate responses, they are frequently presumed to be incompetent (Biklen et al., 2005). Autobiographical accounts of autistic adults have evidenced how autistic people are generally aware of how others interpret their communication differences and may orient to them as incompetent because of a lack of verbal response (e.g., Rentenbach, 2009; Sinclair, 1992).

Thus, the basic understanding of communication, positions it within the domain of psychological ability or competence dispositional to the individual, when it should arguably be considered more systemic and social (Potter & te Molder, 2005). Language, then, including its core elements such as syntax, semantics, vocabulary, and the act of communication are constructed as if indexing stable psychological and cognitive skills (Muskett, 2017). Muskett argues that this psychological, dispositional view of communication is not helpful in the context of autism. He argued, that if an assumption is made that language and communication are stable psychological constructs, then any assessment of autistic individuals will adopt those assumptions and a person's individualized vocabulary assessment of checklist of their social communication is measured as their vocabulary ability or pragmatic competence and not as a reflection of their achievement at a moment in time, within specified parameters.

Social interaction is also important in relation to autism. Social interaction is a central part of human life and interacting with others happens daily. For autistic individuals, it is noted by the DSM-5, that they have impairments in social interaction, in the sense that they may have challenges in initiating and maintaining social interactions, as well as challenges recognizing and responding to social cues (American Psychiatric Association, 2013). Social cues can be subtle and autistic individuals may have trouble reading these social cues from others. Consequently, some have noted that they can have difficulties fitting in with their peer groups, which is especially prominent for children in schools, and for adults in employment or social situations (Humphrey & Lewis, 2008). Of course, there is significant variability in individuals' abilities to engage in social interaction, and such social difficulties may be complete disinterest or disengagement from the social environment to individuals who are motivated to engage with their peers but find it difficult to do this in a socially appropriate way (Karim et al., 2014).

An important aspect of the difficulties in social interaction relates to the challenges of initiating, sustaining, or maintaining relationships with others. Many autistic children, for example, are asked to deal with the complex social environment of school, which can be a challenging arena in general. Research has highlighted how often autistic children struggle to fit into social groups, which can increase their anxiety (Humphrey & Lewis, 2008; Karim, 2017).

Theory of Mind

The clinical literature has frequently described autistic people has having impairments in what is referred to as theory of mind. The concept – theory of mind – was developed by Simon Baron-Cohen and his colleagues and is frequently adopted to explain how autistic people understand and relate to the thoughts and feelings of others (Baron-Cohen et al., 1999). Notably, theory of mind is a psychological term referring to the ability to recognize and interpret the thoughts, beliefs, desires, and intentions of others and this is necessary for individuals to make sense of their behaviour (Baron-Cohen, Mortimore et al., 1999). In many ways, theory of mind links to empathy relating to an ability to relate to others on an emotional level and understand their feelings (Gillberg, 2002). Empathy is thought to be an important skill and essential for forming relationships and necessary for friendship formation. In the modern world of digital relationships and online interaction, empathy is situated as even more important for maintaining and promoting kindness in cyberspace (O'Reilly et al., 2021).

The clinical literature has suggested that autistic people may experience impaired theory of mind, leading to peer difficulties and isolation as neurotypical people may misattribute a lack of theory of mind as stubbornness or argumentativeness (Karim et al., 2014). Significantly, the idea of theory of mind impairments is controversial and has been critiqued within the disability studies literature base. Yergeau and Huebner (2017), for example, noted that there is a "scientific rhetoric" that surround Theory of Mind – one that espouses a "medicalized understanding of autism" (p. 273).

Restrictive and Repetitive Patterns of Behaviour

Historically, a central feature associated with autism is difficulties that individuals may have in terms of their thinking and behaviour. Generally, this has been described as presenting with a rigidity of thinking, literal thinking, obsessive thinking, and need for routine and sameness (American Psychiatric Association, 2013). Life in contemporary society places people under constant pressure to cope with changes – perhaps reflective of a taken-for-granted social expectation. Change at home and school are inevitable and therefore individuals need to be flexible and adaptable to manage and cope with these changes. However, autistic individuals may struggle to adapt to changes, with a lack of flexibility creating considerable stress for them (Karim et al., 2014).

For children specifically, school environments can be also challenging as these are often demanding contexts that favour normative communication and behavioural patterns. For example, the transition between schools, going from younger age group (primary/elementary) to older age group (secondary/high) is especially difficult for children who are identified as 'at risk' or as particularly vulnerable (Yadav et al., 2010). Autistic children are especially vulnerable during this

transition period because of the significant changes they encounter. For many autistic people, there is often a preference for certainty and routine. Rigidity of thinking and literal interpretation of rules can make life difficult. For neurotypical children and adults, the autistic person's strict adherence to rules may be oriented to as frustrating and even lead to misunderstandings.

Presumed Difficulties in Sensory Processing

A common feature generally associated with autism is sensory processing difficulties. In practice, this refers to the difficulties that an individual may have in interpreting the sensations that receive and are exposed to every day. This includes auditory (hearing), olfactory (smell), visual (sight), tactile (touch) proprioceptive (awareness of the body), vestibular (balance), taste, and hunger/thirst. Sensory processing challenges are reported in autistic individuals of all ages and all levels of symptom severity (Leekam et al., 2007), and can impact on their daily functioning (Suarez, 2012) affecting various areas of their lives. Evidence suggests that 95% of parents of an autistic child report some atypical sensory behaviour (Rogers & Ozonoff, 2005). Some autistic individuals have been described as being oversensitive (hyper-sensitive) or they can be under-sensitive (hypo-sensitive) to different sensations (Bogdashina, 2003). Thus, an autistic individual may be hyper or hypo sensitive to some or many of the senses, which can lead to sensory seeking or sensory avoiding behaviours as senses can become overwhelming (American Psychiatric Association, 2013). Autistic individuals have also been described as experiencing difficulties with filtering out background information or alternatively being under-sensitive to all the information that bombards their senses.

Biologically the senses are processed by the brain. The brain constantly processes sensations converting them to a coherent form and filtering out what is significant from the less significant. In so doing, the brain is consistently interpreting the senses and uses previous experiences as a point of reference and this develops as the child grows older (Karim et al., 2014). The clinical literature suggests that for some autistic people the ability to receive and then process the senses is challenging. Ultimately, autistic individuals commonly experience sensory dysregulation which consequently impacts social functioning and there are multiple ways in which this manifests in practice (Thye et al., 2018) and various ways in which it might influence their behaviour in social situations. It has been argued that sensory and social behaviours both arise from an underlying mechanism and as such may have a reciprocal influence on one another as the child develops (Gilga et al., 2014). Indeed, the atypicality of sensory sensitivity may influence the development of social play (Miller Kuhaneck & Britner, 2013), lead to increased withdrawal from peers and social situations (Brock et al., 2012), and can be fundamental to the levels of social impairment in adults (Hilton et al., 2010). In this way, the social and sensory features of autism may be interdependent (Thye et al., 2018).

In the literature, there is a general acknowledgement that an overload of sensory information can have an impact on behaviour, with some autistic people feeling overwhelmed and thus having sudden outbursts of aggression, or some becoming increasingly withdrawn (Karim et al., 2014). In diagnosing autism and in recognizing the sensory processing difficulties experienced by some individuals, there is no straightforward test and thus history (or in the case of adults by clients themselves) or by observation.

Presumed Difficulties in Executive Functioning

The clinical literature has also described some autistic people as experiencing disorganization and difficulties in managing their lives. These difficulties are generally related to problems with certain cognitive abilities collectively termed 'executive functions.' The executive functions include the organization and planning skills, attention, working memory, problem solving, mental flexibility, verbal reasoning, impulse control, inhibition, and multi-tasking (Chan et al., 2008). Such cognitive skills are thought to be essential to managing everyday life and independent living. Clearly, the need for such skills increases as the individual gets older and greater demands of independence are placed on them. Thus, such skills can become more problematic for some people as they develop and grow through childhood.

In younger children, impairments in executive functions are often described as being less obvious ones, although working memory and impulse control may become evident (Karim et al., 2014). Impairments in the executive functions are likely to cause an individual, and possibly their families, some distress as they may become frustrated as they are challenged to control impulses. Some literature has suggested that some autistic people may find it challenging to organize their work or play, with learning becoming more complex as it becomes more self-directed and begins to involve more organizational expectations (Karim et al., 2014).

Executive functioning is also important for autistic adults. Research has highlighted that autistic adults with impaired executive functioning are more likely to experience greater levels of anxiety (Zimmerman et al., 2017). Furthermore, there seem to be gender differences in executive functioning and autism. For example, the relationship between executive function and social communication are different for males and females and therefore more research needs to be undertaken in this area taking account of gender differences (Chouinard et al., 2019).

Parent Responses to an Autism Diagnosis – Traditional Rhetoric

The complexity and challenges of the diagnosis of autism is not only an issue for clinical professionals, but also for parents who sometimes go through a long and difficult journey in identifying an explanation for their child's differences. In a

recent survey of 1047 parents, it was reported that parents tend to wait an average of 1 year since their initial concern before seeking help and experienced an average of 3.5 years from this first help-seeking behaviour to confirmed diagnosis of autism (Crane et al., 2016). This has not improved over time as similar wait times were reported almost a decade earlier (Siklos & Kerns, 2007). This is arguably problematic as parents spend significant time raising concerns and seeking help before they have more formal support. Furthermore, it is noted that while diagnosis tends to take a long time to be achieved, parents are often noticing concerns about their child as early as within the first 2 years of their lifespan (De Giacomo & Fombonne, 1998).

Such a long wait has a negative impact on parents' stress levels (Osbourne & Reed, 2008), meaning that they are dissatisfied with the diagnostic process with 50% feeling this way (Crane et al., 2016), and negatively impacting on their confidence in the medical profession (Harrington et al. 2006). Indeed, our mental health assessment study (UK) found parents reporting some of the challenges and difficulties they had faced in just getting to the point of having their child assessed by a professional. For example, they used the battle metaphor and expressed exasperation at how difficult it can be in persuading professionals that they need mental health input.

Family 19 (unpublished data extract)

Mother: It's kind of been a battle (.) hasn' it?
Father: Yeah
Mother: Back and forward to the doctors and things like that

Similarly, our UK interview project with parents showed that there was a general belief that more information needs to be available to parents about the diagnostic process and that professionals need to have improved knowledge of autism. They found the process of acquiring help from appropriate sources difficult and emotional.

Mother one

GPs should have information. They may not be clued up themselves but they should be able to hand over several different leaflets for different areas so that parents can first of all make contact with those groups.

Mother nine

Every time we had to go through what we thought the issues were, I can only it was devastating to um talk about what your child is not achieving and really you know to the endth degree explaining all his difficulties whilst you've got a screaming child in the room.

It is also important to recognize that some individuals do not receive their diagnoses until adulthood and can struggle through adolescence and transitioning toward independence (Brugha et al., 2020). Indeed, the prevalence of autism in adulthood is similar to that of children (Brugha et al., 2011), although it is likely that autism is underdiagnosed in adults (O'Regan & Tobiansky, 2014).

For children (and arguably for adults also), shorter waiting times have been identified as being essential for a wide range of reasons, not least as delays can add to

parental stress (Crane et al., 2016), can delay early intervention for the child (Mansell & Morris, 2004), and are correlated with how positive or negative parents' initial reactions are to the diagnosis (Stallard & Lenton, 1992). Parental reactions to the diagnosis of autism are well-documented and such research has predominantly reported the negative reactions they experience. Arguably, such negative reactions can to some extent be tied to how quickly and efficiently the diagnosis was made. Commonly, the literature reports how parents experience a range of emotions when a diagnosis is provided, including grief, guilt, and depression (Myers et al., 2009; Mulligan et al., 2012), as they process the loss of the 'normal' child and come to terms with the extent of the child's challenges and the possible impacts these challenges may have on the child and the family in long term. The parents in our UK interview study, tended to express positive and negative emotions about the diagnosis, but also having a child labelled autistic. For example:

Mother eleven

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It can become very lonely having a disabled child.
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Mother six

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It didn't come as shock it wasn't at that point it wasn't a
particularly useful diagnosis or the information that we had
didn't feel particularly useful.
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Mother three

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There's um a big grieving process.
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Arguments have been presented that these levels of stress are greater for parents with an autistic child than when raising children with other disabilities (Weiss, 2002) and therefore we need a better understanding of parental lived experiences of autism. It has been suggested in the literature that raising a child with autism is stressful for parents for a variety of reasons, including the challenge of navigating a less than inclusive society (Lester, 2015). This is a consistent finding across countries as parents have many concerns about the long-term experiences of their children (Myers et al., 2009). Furthermore, mothers of children with autism seem to experience more direct stress, whereas fathers experience the stress vicariously through the mother (Gray, 2002; Tehee et al., 2009). Notably, the literature has also suggested that parental stress increases as the child grows older, and that this increase in stress tends to be associated with the changes common to navigating complex social and environmental contexts (Warfield et al., 1999). Parental emotions and coping strategies are important, and it is necessary that families have information and support available to them from services.

Prevalence of Autism – Controversy of the 'Epidemic'

Much of the literature has highlighted that autism is experienced by approximately 1% of the population (Brugha et al., 2009). For example, it was shown that childhood autism had a prevalence of 38.9 per 10,000, and other autism spectrum

disorders at 77.2 per 10,000, meaning a total prevalence of 116.1 per 10,000 (Baird et al., 2006). Baird et al. (2006) noted that a narrower definition of childhood autism provided a prevalence of 24.8 per 10,000. They concluded therefore that the rates of autism are much greater than was previously recognized, although the reason for the increased incidence is unclear. This rapid growth has meant that services have had to rapidly expand to cope with demand (Karim et al., 2014) and an increase in resources is required to support parents and other family members, as well as the child (Hall & Graff, 2011). This increase in prevalence has created some controversy, with some arguing that the existence of the condition has simply been exaggerated (Timimi, 2011), but others have argued that it is simply an alternative way of viewing the world (Beardon & Worton, 2011), others positioning it with the broadening of the criteria (Wykes & Callard, 2010), and a potential reason being increased diagnosis in adulthood.

Gender and Autism

It is commonly acknowledged that more boys are diagnosed with autism than girls. Epidemiological work on adults in England has shown that 1.8% of men had a diagnosis of autism compared to just 0.2% of women (Brugha et al., 2009). Prevalence rates suggested that this is a difference of 4:1 (Attwood, 2007) which is consistent with Kanner's (1943a, b) original work that identified four times more boys than girls with the characteristics. However, there is some variation in the gender differences reported, ranging from 2:1 up to 16:1 (National Autistic Society, 2018). Because of this, autism has been conceptualised as a 'male brain disorder' (Ridley, 2018) and thus autism has become gendered. However, the creation of the male brain and its connection to the incapacity of empathy has reinforced the stereotype that men are less able to empathise than women (Botha et al., 2020).

It has been argued that some of these differences may reflect the spectrum of the condition and that gender difference is more significant in higher functioning individuals. For example, some research has suggested that the condition was 15 times more likely in boys than girls for those with Asperger's syndrome or high functioning autism, and only 2:1 in those with additional learning disabilities (Wing, 1981a). It is clear, therefore, that there is an under-identification in females (Kreiser & White, 2014) as measures of autism have become hyposensitive in identifying autism in females and this is a commonly recognized limitation (Baron-Cohen et al., 2009). Consequently, girls then have reduced access to services and support that may benefit them.

There are a range of reasons why autism is under-identified in girls. First, girls seem more competent in masking their social communication difficulties, partly due to their ability to observe others and imitate social rules: they learn how to mimic 'normal' social interaction styles, but this can have detrimental impact on their mental health (Lai et al., 2017). Second, evidence suggests that the diagnostic tools and assessments themselves are biased focusing on traditionally masculine traits and behaviours (Dworzynski et al., 2012). These gender differences are arguably due to

the diagnostic criteria that reflects a typical male presentation of the condition, and the recognition that girls generally present with a different profile of symptoms (Nichols, 2008). Indeed, there is evidence that male and females diagnosed with autism differ on a neurological and cognitive level (Carter et al., 2007). Evidently, therefore the gender bias in the diagnostic tools available means that current processes are not fully adequate for diagnosing girls with autism and improvements must be made (Hendricx, 2015). Finally, because of the misleading scientific rhetoric reifying autism as a male brain disease, this has led to professional blindness in relation to women's needs (Rutter et al., 2003).

Improvements are arguably crucial as there is an acknowledgement that there are many girls who may be autistic, but because they present differently, they can be more challenging to diagnose. For example, it is not unusual for an autistic girl to have a best friend and form social relationships and therefore this can mask deficits in social interaction (Karim, 2017). Girls, for instance, have been argued to often be less rigid in their thinking style, be less routine driven, and display interests that are more socially appropriate (Nichols, 2008). However, it is hypothesized that as girls age their characteristics associated with autism may become more obvious, particularly as they are exposed to more complex social environments.

Concluding Thoughts

Within this chapter, we have sought to conceptualize autism in relation to the clinically developed and medically preferred language. The clinical understanding of autism has grown centrally from the field of psychiatry, with direct influence coming from the American Psychiatric Association, and influenced heavily by psychoanalysis and psychology. Fundamentally, the DSM, which has evolved since World War II, has defined and constructed what constitutes a mental health condition, with the third version of the DSM defining autism and its characteristics. The latest inception of the DSM, the DSM 5, has reconfigured the meanings and language of autism and removed Asperger's Syndrome as a distinctive category. This, along with many other issues, has caused a great many commentaries and critiques from within and outside of psychiatry. In this chapter, our focus was on providing a general overview of the psychiatrized language that surrounds autism. In doing so, we also considered the process of diagnosis, alongside an introduction to the impact of this process on individuals themselves, parents and families. This chapter has therefore provided a foundation for moving forward in the book, as we have sought to unpack some of the controversies and rhetoric surrounding autism and the language that is imbued in discussions of the clinical 'meaning' of autism. In the next chapter, we offer a range of perspectives on autism steeped in more socially, culturally, and discursively grounded frames.