Education, Equity, Economy
Series Editors: George W. Noblit · William T. Pink

Jessica Nina Lester
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The Social, Cultural, and Political Discourses of Autism

Springer

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George W. Noblit
University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

William T. Pink
Marquette University, Milwaukee, WI, USA

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Jessica Nina Lester
School of Education
Indiana University
Bloomington, IN, USA

Michelle O'Reilly
University of Leicester and Leicestershire
Partnership NHS Trust
Leicester, Leicestershire, UK

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Foreword

When I was approached to write a foreword for this book by one of the authors (Michelle O'Reilly), I could not have been happier to be given an opportunity to read it before it was published. My reason for this is that in the field of autism studies where the *potential* for offering different perspectives on the subject matter and its study should be myriad, biological approaches still dominate. The field is largely made up of a brain or medically focussed literature that continues to position autistic people as less than human in a variety of ways, and these are etched deep in the mind of the public, tropes such as the highly intelligent, IT obsessed autistic man who is single, and the awkward, friendless woman who lacks empathy. Instead, this book offers a more nuanced and critical understanding of autism, that positions it as socially constructed but does not 'throw the baby out with the bathwater'. The authors also recognise autism as a real phenomenon in the sense that it is made real through subjective and inter-subjective experiences.

Both authors have a considerable track record in scholarship on autism, mental health and qualitative research, especially micro-level interaction empirical studies using conversation analysis and discourse analytic methodologies. What is inspiring about this book though, and why is should be read, is that it masterfully interweaves the authors' substantial research on autism with the theoretical debates that characterise the field. The book centrally deals with important epistemological and ontological questions, such as how we identify autism, what it is and who has the power to define and diagnose. The key questions are considered in the light of their research, and the field more widely, to shine a spotlight on how these discourses have shaped and been shaped by different audiences, autistic people themselves, families, professionals and policy makers. This book has enormous value to the literature because it oscillates between thorny theoretical arguments and empirical research, as well as incorporating less powerful but equally valid (if not more) autistic voices. The neurodiversity versus disability polemic, for example, is brought to life through the real-life illustrations from the research. This work demonstrates the shifting attitudes and perspectives on autism, and its changing relationship to mental health.

As a clinical academic, working as a specialist mental health and autism speech and language therapist and a senior lecturer, I want to thank the authors for an extremely valuable contribution to autism scholarship that is also sensitive to the experiences of autistic people themselves. They have not shied away from the thorny questions, but they have provided a level-headed, interesting and inciteful book that will be very valuable to a very wide readership.

De Montfort University
Leicester, UK
Leicestershire Partnership NHS Trust
Leicestershire, UK

Alison Drewett

Acknowledgments

This book has been many years in the making and thus there are several individuals who have contributed greatly to its completion. First, we are grateful to the series editors, Professors George Noblit and William Pink, who invited us to write this book. In the early days of developing the contours of the book, they offered insightful feedback that served to inspire and shape what we ultimately crafted. Second, we are grateful to Springer's editorial team who worked closely with us in bringing this book to publication. Third, we thank Alison Drewett who provided feedback on several of the chapters and wrote the foreword for the book. Fourth, and perhaps most significantly, we are particularly grateful to the many individuals who have participated in our research studies over the course of many years. Throughout this book, we weave in findings from our previous research, which was only possible because of the willingness and support of our research participants. They have certainly been our greatest teachers along the way. Finally, we are grateful to our partners for their continued support and patience.

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About the Authors

Jessica Nina Lester, Ph.D., is an associate professor of inquiry methodology in the School of Education at Indiana University, Bloomington. Dr. Lester has published over 90 peer-reviewed journal articles, as well as numerous books and book chapters focused on discourse and conversation analysis, disability studies, and more general concerns related to qualitative research. Broadly, her scholarship is positioned at the intersection of disability studies and discourse studies, with a particular focus on mental health and education contexts. She is a co-author of the first edition of *Digital Tools for Qualitative Research,* published with SAGE. She has also co-edited a book focused on performance ethnographies (Peter Lang, 2013), policy, and discourse analysis (Palgrave, 2017), and a book focused on discursive psychology and disability (Palgrave, 2021). She recently co-authored (with Dr. O'Reilly) a book focused on applied conversation analysis with SAGE publications, as well as *Doing Qualitative Research in a Digital World* (co-authored with Trena Paulus). She is a founding member of the Microanalysis of Online Data international network; the associate director of the Conversation Analysis Research in Autism group at the University of Leicester, UK; and the former co-program chair and chair of the Qualitative Research Special Interest Group (AERA). In 2014, Dr. Lester received AERA's Division D's Early Career Award in Measurement and Research Methodology (qualitative methodology). In 2018, she received the Distinguished Early Career Contributions in Qualitative Inquiry Award from the American Psychological Association. She has most recently published in journals such as *Qualitative Inquiry* and *Discourse Studies*.

Michelle O'Reilly, Ph.D., works as an associate professor of communication in mental health and is a chartered psychologist in health at the University of Leicester. At the university, Dr. O'Reilly works in the School of Psychology and the School of Media, Communication and Sociology. Dr. O'Reilly is also a research consultant with Leicestershire Partnership NHS Trust where she supports clinical practitioners in undertaking research, service evaluation, and audit. She has a role in quality improvement as part of the Trust's mission for evidence-based practice. Dr. O'Reilly's research interests are broadly in the areas of child mental health, family therapy, and the sociology of health and illness. She has undertaken a range of work in different areas, including neurodevelopmental conditions, social media and mental health, and self-harm and suicide prevention. Dr. O'Reilly has worked with a broad range of different child groups including, unaccompanied refugee minors, homeless adolescents, children with educational difficulties, children attending child and adolescent mental health services, looked after children, children who are self-harming, and young carers. Her specific interest in neurodevelopmental conditions means she has co-created information videos for parents on autism in a range of different languages (available on the university website) and an information book for parents on the condition (led by Dr. Khalid Karim). Dr. O'Reilly is also the director of an international research group for autism "*Conversation Analysis Research in Autism*," which has a clinical expert panel for advice. Dr. O'Reilly identifies as a qualitative methodologist who has written extensively about, theory, methods, and ethics.

Chapter 1

Introduction to *the Social, Cultural, and Political Discourses of Autism*

This book aims to explore the world of autism and throughout we use the broad term ‘autism’ to capture the wide ranging and various terms that have been and can be used in this context. Over the last 70 years, autism has become part of the Western world’s discourse and everyday imagination, with representations of autism often including an image of an isolated individual disengaged from the social world. Internationally, autism is being increasingly diagnosed, with much of the public understanding surrounding it shrouded in discourses of deficit and illness (Lester, 2014; Lester & Paulus, 2012). The narratives associated with autistic individuals range from descriptions of them as “imprisoned” and “waiting to be reclaimed” (Maurice, 1993, p. 32) to “*not* just a ‘shell’ within which a ‘normal’ child is waiting to get out” (Happe, 1994, p. 6). Popular media has also become a site wherein autism is showcased. From talk shows (e.g., e.g., Winfrey, 2007, “The Faces of Autism” on *The Oprah Show*) to television series (e.g., Trilling & Massin, 2010 on *ABC* television series “Parenthood”), to films (e.g., Garner et al., 2016 on ‘Rainman’ and other films), public stories about autism abound.

Across many of these contexts, metaphors of “medical intervention” and “cure” are generally evoked when talking and writing about autism (Broderick & Ne’eman, 2008, p. 469), which serve to locate autism as something that rests outside of culture (Nadesan, 2005) and as a biological given. Further, much of the heralded research that surrounds autism draws upon positivist epistemologies and medicalized discourses, and has predominately focused on identifying the aetiologies of, and effective interventions for autism (Glynne-Owen, 2010; Rocque, 2010), yet a cause has yet to be identified (DeFilippis & Wagner, 2016). Thus, in many ways, the growing debates and conflicting discourses that surround autism highlight, in explicit ways, the “perceived wisdom of those at society’s centre,” and therefore, we argue, serves as “a [potential] context to understand and transform established belief systems” (Solorzano & Yosso, 2002, p. 156) about the boundaries between normality and abnormality, between ability and disability.

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While we recognize the tensions, arguments and controversies, autism remains medically explained predominantly, and in medical terms autism is constructed as a psychiatric disability (an issue we detail and critically question throughout the book). Defining disability, and equally, what counts as a disability is a complex thing to do, and perhaps unsurprisingly, there are different ideas about what constitutes a disability, and even more tensions as to whether autism might be characterised in that way. However, like Ingstad and Whyte (2007) noted in their writing on the matter, we agree that we are less interested in dry concrete universal definitions of disability (or indeed autism) and much more concerned with how disabled persons construct and identify their own understanding of their disability and their lived experiences in society. Thus, arguably, a person is disabled if they identify as disabled and are considered impaired and treated as disabled by others (Kasnitz & Shuttleworth, 2001).

Like Goodley (2011, p. 641), we recognize that disability can serve as a "platform or plateau through which to think through, act, resist, relate, communicate, engage with one another against the hybridized forms of oppression and discrimination that so often do not speak singularly of disability". In this book, we seek to critically consider how the varying discourses and taken-for-granted practices have served to produce and re-produce varying constructions of autism, and how those discourses have positioned, repositioned, and deconstructed autism as a disability. In that sense, the construction of autism as a disability has been heavily influenced and shaped by socio-political forces, academic ideologies, and disability activists.

Broadly, we locate our collective work related to autism as methodologically qualitative, and theoretically grounded in social constructionism. We acknowledge that it is challenging to engage in qualitative research in a field such as autism. For, as Biklen et al. (2005, p. 14) noted, engaging in qualitative research in a highly medicalized field such as the 'field of autism' is difficult given that "most of the language of the field assumes a shared, normative perspective". Nonetheless, there is a growing body of literature around the everyday experiences and life-worlds of those who identify as and/or are labelled autistic (e.g., Huws & Jones, 2008). This literature is most often positioned within disability studies (e.g., Ashby, 2010; Ashby & Causton-Theoharis, 2009) and/or critical autism studies (e.g., O'Dell et al., 2016). Critical autism studies have advanced our understanding of the lived experiences of autism and have critically questioned much of the taken for granted medical knowledge about autism. These works are a cross-disciplinary endeavour as scholars bring together ideas from critical psychiatry, critical psychology, disability studies, cultural studies, sociology and education, and challenge approaches that limit and potentially damage those with a diagnosis (Runswick-Cole et al., 2016). Such positive and empowering ideas about autism are complemented by more recent literature highlighting the value of discursive approaches for the study of autism (e.g., Lester, 2014; O'Reilly et al., 2016).

This book, which we position at the intersection of disability studies and discourse studies, aims to build upon this growing body of scholarship. Taking up a social constructionist position, we seek to illustrate the social and cultural construction of autism as made visible in everyday, institutional, and historical discourses, alongside a consideration of the bodily and material realities of embodied differences (Oliver, 1996). In so doing, we discuss the social and economic consequences of a disabling culture and explore how autism fits within broader arguments related to normality, abnormality, and stigma.

Importantly, in adopting our social constructionist, language-focused approach to autism, we do not deny the ‘reality’ of autism and neither do we deny that autism is experienced in different ways, rather we centre the voices of those communities where autism is fundamental to identity, lived experiences and opinion. To do this, we provide a theoretically and historically grounded discussion of autism – one designed to layer and complicate the discussions that surround autism and disability in health contexts, schools, and society writ large. In addition, we locate our discussion across two geographic contexts – the United States (US) and the United Kingdom (UK) – and draw upon empirical examples to illustrate our key points. Methodologically, we draw specifically upon both discursive psychology (Edwards & Potter, 1992) and conversation analysis (Sacks, 1992), and thereby position our analytical and methodological focus within a specific micro-oriented approach to discourse analysis.

Over the last decade, we have both written – individually and collaboratively – extensively in this area. Thus, what we seek to do in this book is bring together the various arguments we have offered, tying together what has previously ‘lived’ in seemingly disparate locales. Importantly, we do not position this book as foregrounding empirical findings; rather, we point to our previously published studies (and the related findings) to deepen our discussion and illustrate some of the key theoretical points. Where relevant, then, we draw upon our previously published sole and co-authored journal articles and book chapters. By doing so, we hope that ideas, arguments, and findings that have previously ‘lived’ apart can now be positioned side by side, speaking to and (even) against one another. For indeed, our own thinking and understanding of the constructions and meanings of autism, as well as the lived experiences of autistic people, has evolved over time.

Importantly, we begin this chapter with a discussion of the choices we have made in this book related to language and representation, noting why we have chosen not to use people first language. We also offer a general overview to how we conceptualize three key concepts that are central to the book, *discourse*, *disability*, and *autism*. Second, we individually discuss our positionalities, noting some of our assumptions about disability generally and autism specifically. We also note what brings us to this work. Third, we offer we discuss the theoretical and methodological framing of the book, highlighting the meaning(s) of social constructionism and discursive psychology. Fourth, we overview the datasets that we draw upon across the chapters. And, finally, we provide an overview of each chapter included in the book.

Centring Disability with Language Choices

In writing this book, we recognize that we are producing representations of others, and, writing about others is always a complicated and ethically-laden process. Significantly, representations of all kinds can function to reduce others; for, as Edward Said (1989) noted, representation nearly always entails some sort of violence to the subject. Thus, in choosing whether and how to write about autism and autistic people, we have faced several considerations. For instance, should we use people first language (e.g., person with autism)? How might we avoid reinforcing medicalized conceptions of autism and neurodivergent bodies and minds? How might we centre autistic people's perspectives? Ultimately, what we share in this book is partial (Noblit et al., 2004) and there is much that remains untold (Krog, 1998).

Nonetheless, in making choices about our own language choices, we have sought to foreground disability (and autism more particularly) as an identity (e.g., autistic person). Drawing upon scholarship produced within disability studies, we too view the word "with" (e.g., person with autism) as often locating a disability as an "add-on [identity]" (Aubrecht, 2012, p. 4). As such, throughout the book, we use language that seeks to centre disability as an identity, to take a positive position on the autistic person by recognising the autism as part of the identity, and do not use the alternative description, person with autism. In doing so, we acknowledge that naming of any kind is indeed an "act of power" (Guenther, 2009, p. 412) and that the language we use is not simply a matter of semantics, but the distinction between autistic person, and person with autism has political and practical implications that influence societal perceptions, public policy, clinical practice and where we go next with research (Vivanti, 2020).

Advocates of autistic persons, therefore, promote that autism should not be in second position when referenced, as autism is an integral aspect of their identity (Cascio, 2012). Furthermore, using person first language (person with autism) is viewed by autistic individuals as a form of control and a reification of the dehumanization of autism (Botha et al., 2020). As Sinclair (2013) advocates, saying person with autism suggests something bad or undesirable and it is important to remind autistic individuals that an essential part of their personhood, their autism, is not bad. Hagan (2018) utilized the useful example of creativity, illustrating that we would generally not describe a creative person, as a 'person with creativity,' but as a 'creative person' as this is a term that treats the creativity as part of who that person is and in so doing celebrates and values the positivity of creativity. In that way being creative is seen as a good element of a personal identity. She argued that to use the notion of 'person with autism' suggests a separatism of the individual from their autism, thus implicating the autism as an undesirable aspect of their character and reinforcing medicalization. In her view then, it is far better to celebrate the positivity of autism and claim it as an inherent part of a person's character, thus the autistic person. This is our view too, as we are keen to act in accordance with those who seek to destigmatize autism (e.g., Beck, 2018; Silberman, 2015; Vivanti, 2020), we argue that using the framing autistic person is a step that contributes to positive-identity building practices and encourages improved wellbeing, self-esteem and quality of life for autistic individuals (see Gernsbacher, 2017).

Defining Key Terms

Throughout this book, we offer a multitude of ways in which autism has come to be conceptualized, pointing to varied disciplinary knowledges, histories, and discourses. We nonetheless begin the book by making explicit our own conceptualization of *autism*, as well as *disability* more generally and *discourse*. Given the central place these three concepts play in this book, an initial framing of how we define these terms serve to make visible the positions from which we write. As qualitative writers we value a central quality indicator in the process, that of reflexivity, and recognize the importance of the self in the production of any text, and any research findings.

We conceptualize *autism* as a social construct with multiple and shifting meanings. That is, we view autism as "a concept *developed and applied, not discovered*" (Biklen et al., 2005, p. 12). In defining autism as a social construct, we attempt to move away from highly medicalized definitions of autism as being a biological truth. Rather, we suggest that the emergence, labelling, and treatment of this "disorder" are embedded within institutionalized histories, cultural practices, and discursive practices (Nadesan, 2005), and meaning of any kind is never simply given or guaranteed. With such a definition, it is important to note that in our work generally and this book specifically, we do *not* deny the potential biogenetic aspects of autism or suggest that it is not a 'real' category; we focus on how autism has been made relevant in and through discourses and taken-for-granted practices across time, and what it means, how it is relevant and what consequences it has for those who adopt an autistic identity.

In our writing we are broadly locating autism in the sphere of disability. This is not to reify the notion of autism as a psychiatric disability (a rhetoric we critically discuss later in the book), but rather acknowledging that medically, clinically this is where autism is located. This location cannot be ignored in any text that examines autism and thus our writing also reflects some of the disability discourse in terms of the positioning of autism. There are a range of ways in which *disability* has been conceptualized across time – something which we map out in greater detail in the book. We view disability as both a multidimensional (Altman, 2001) construct and an "extraordinarily unstable category" (Davis, 1995, p. xv). More particularly, we orient to disability as situated and discursively constructed, aligning closely with a disability studies perspective that challenges the idea that disability is a defect or deficiency (Society for Disability Studies, n.d.). Drawing upon a social-relational model of disability (Finkelstein, 2000; Reindal, 2008; Thomas, 1999, 2001, 2004), we recognize that disability can (and, we argue, should) be understood as non-neutral and potentially political, as it is indeed “woven through, and out of, cultural ideas and discursive practices” (Thomas, 2002, p. 49).

Across the empirical work that we draw upon in this book, we have generally taken up a more micro-oriented conceptualization of *discourse*, attending closely to how social realities are produced in and through daily and institutional social interactions. More particularly, we view discourse as action-oriented, and thus generally seek to study what language-in-use is *doing* or *performing*. Second, we view discourse as both constructed and constructive. Accordingly, we examine the actual words, embodied practices, and rhetorical devices use within social interactions, whilst also assuming discourse constructs the social world (Potter, 2004). Third, we view discourse as always already situated. As such, an identity label is assumed to be bound up and embedded within social interactions. Importantly, while in this book we offer empirical examples from studies wherein we took up a more restricted notion of discourse, across many of the chapters, we oriented to discourse more broadly, attending to the institutionalized histories, discourses, and practices (Foucault, 1972) implicated in the construction and continual re-construction of autism. For us, then, the term discourse(s) also refers to broader discourses that make visible the institutionalized histories and practices that organize and socially bound what is said about a topic (Foucault, 1972). For example, the discourses of medicine, education, and childhood psychiatry are all implicated in how autism was and is made real and socially organized. Thus, as Foucault noted, discourses within the broader social process act to legitimate certain versions of the world, privileging and maintaining a given truth about the world/subject.

Our Positionalities

I (Jessica) was formally trained as a special education teacher, with a particular focus in autism spectrum conditions. I certainly hold the credentials and training required to identify and teach disabled children. Many would argue that I have the power to label, name, and “fix” children with presumed “abnormalities.” In my professional work with autistic children and adolescents, I often struggled with and against my own desires to fix and render docile (Foucault, 1991) those who are named “abnormal.” When it comes to autism, these “abnormalities” are often linked to specific, visible behaviours. For instance, some people with autism labels might move their bodies in ways that are unfamiliar to me or others, touch an object repeatedly, or turn away when called upon. Donnellan et al. (2010) suggested that professionals are frequently trained to see such behaviours as “autistic” and worthy of being “targeted...for reduction” (p. 1). I am not an exception to this. Power, indeed, is often located in a class of skilled professionals, with these “credentialed experts” retaining “a sense of their validity by relying on tradition, deference to authority, and inherited privilege” (Brantlinger, 1997, p. 438).

At times, I have been troubled by my own power and normatively laced "ideological inheritance" (Kincheloe & Steinberg, 1993, p. 302), and have come to question the labelling of another person's way of being as "abnormal" or "deviant."

With a niece and a close friend identified as autistic, I am intimately familiar with the ways in which material institutions, professional identities, and cultural values work to frame and constrain the meanings of autism. I have thus engaged in research in this area over the last decade, I assumed that autism, like any other phenomenon, is not knowable as objective truth, but is always open to interpretation. I have sought to question, then, totalizing ideological horizons that work to deny the contingency and contestability of constructs such as autism (Howarth, 2000). For to me, autism is a list of behaviours that is only known as it is made relevant in and through discourse. I assume that the construct of autism and what counts as "intervention" does not rest at any level of static meaning, but rather has shifting signification (Barthes, 1973) and is always already being produced at the intersection of culture and biology.

Over the last decade, I have engaged in frequent conversations with autistic adults who have questioned my taken-for-granted assumptions and reminded me that "when you understand people, when you have committed to them, and when you have learned from them, you advocate for them…where advocating means trying to promote their world view as reasonable" (Noblit, 1999, p. 8). These interactions and unfolding friendships have taught me that the legitimation of the dominant culture's view of what successful functioning looks like is partly "marked by acquiescence and consent" (Charlton, 1998, p. 34). Further, I argue that the goal of intervention should not be to "fix" the individual with an autism label, but rather to collaboratively work to find comfortable and effective ways to increase participation with each other (Donnellan et al., 2010). As Sinclair (1992), who identifies as autistic, suggested:

> If you would help me, don't try to change me to fit your world. Don't try to confine me to some tiny part of the world that you can change to fit me. Grant me the dignity of meeting me on my own terms...recognize...that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build more bridges between us. (p. 302)

It is from this committed and, at times, troubled place that I have engaged in this work. From a place of commitment to autistic people, I recognize anew that I take up many social categories laced with privilege.

I (Michelle) have grappled with the shifting meanings of autism both professionally and personally, as autism has fluidly moved from a deficit-disability position, to one of competence and rights-based. My early interests in autism became important when I was very young, in my pre-teen years as my family became exposed to a range of professionals such as social workers, special education needs teachers, clinical psychologists, psychiatrists and doctors, as my brother received a relatively late diagnosis of Asperger's Syndrome aged 10-years. It was a label I later came to associate with more high functioning autism, of which my brother was not. He had (and still does have) moderate learning difficulties, communication difficulties and all associated 'impairments' of autism, along with an interesting array of co-occurring mental health conditions. He later was re-diagnosed autistic and in his adult years was subjected to 'section' under the UK Mental Health Act, and currently resides in a hospital environment.

The challenge then, in my personal life, of paternalistic best interest principles, to neuro-diverse autonomy claims has been a delicate endeavour as my brother continually expresses a 'desire' to remain institutionalized within the safety of the hospitalized rituals and boundaries, against the government Winterbourne directives to deinstitutionalize individuals and place them back into community support systems. On one hand, to encourage professionals to adopt a neuro-diverse perspective to grant the wishes of my brother to remain in the hospital environment because of his apparent contentment and resistant to change, likely driven by anxiety, against a neuro-typical best interests position that he may be 'better off' in the community is a complex one, and one that I have not fully reconciled intellectually or pragmatically. The social control of the institution asserts a power over my brother's rights pushing him toward a neurotypical life (see Foucault, 1991), and yet his efforts to assert his personal power to remain in the hospital are at odds with the belief system of society that an individual should return to a state of wellness and contribute to the social structure (Nettleton, 2013). The challenge personally then is to decide who knows best? I, as his representative family member to reflect his best interests while trying to align with what he explicitly states he wants, the psychiatrists who continue to detain him under section for his own good and the safety of the community (he is very prone to violent outbursts), or the policy initiatives that seek to place psychiatry in a more positive social light by moving to disempower the institution in response to a range of political movements? In respecting his rights to be deinstitutionalized we may not act in his best interests, may be ignoring his competence to make decisions for himself and may inadvertently disempower him by taking the very deficit medicalized position we seek to challenge.

The difficulty then for me, has always been the balance of the professional and personal and to seek an intellectual and theoretical position that reflexively manages that very balance. Professionally, I undertake a range of neurodevelopmental research and work that is designed to be person-centred and place autistic voices and their families at the heart of key recommendations and messages. In my health service role, I work closely with psychiatrists and psychologists, and am aligned with the mission to provide the best types of support to autistic children and their families. In doing research, I seek to empower and represent autistic children, young people, adults, and their families by presenting and centring their perspectives. This is a complex process and the voices represented sometimes differ and disagree and yet it is this diversity that reflects the very reality of autism as no single autistic voice can represent autism fully, and thus a collection and agenda of listening is very much needed. Autism is now described as a spectrum condition and one where individuals may or may not experience additional mental health conditions that complicate its presentation (Karim et al., 2014). Inevitably, my personal experiences intersect and integrate with my professional ones, and the lines between the two can become blurred. I write transparently (especially in texts such as this), as a reflexive writer recognizing that any text is bounded by the beliefs and experiences of its producer. Thus, the courtesy stigma (see Goffman, 1963) that plagued me in my younger years for being associated with a child with a social disability, is now reverently resisted and ignored, and indeed instead is celebrated. The insider knowledge of the condition and its consequences to family has actually been a significant driver in my career in mental health and my constant ambition to find theoretical and methodological frameworks that do justice to the voices of all on the spectrum, and those members that are important to them. Thus, while in the early days my family sought to 'fix' my brother, looking for treatments and other ways to modify the socially undesirable behaviour just like many other families (Ludlow et al., 2011), over time we now simply accept his different way of life, and promote his perspective and views in any official domain. In turn, I work to reflect that position in my professional work, to ensure that competence, rights-based social frameworks are recognized, and the diversity within autism is hailed and promoted.

Theoretical and Methodological Framing of the Book

Broadly, we theoretically locate the arguments made the book within a social constructionist position (Berger & Luckmann, 1966; Woolgar, 1988). As previously noted, throughout the book, we illustrate key points by drawing upon previously published empirical findings. These published studies – and our collective work more broadly – is methodologically informed by discursive psychology (Edwards & Potter, 1992). While it is not the purpose of this chapter (nor the book) to offer a comprehensive overview of social constructionism or discursive psychology, we briefly provide a discussion of each below. Notably, we encourage readers less familiar with these perspectives to consider turning to seminal readings (many of which we cite here) to gain a deeper understand of how we theoretically and methodologically locate our arguments.

Social Constructionism

In the broadest sense, a social constructionist position is an epistemological position that rejects absolute knowledge and positions language as central for how people go about sharing and developing shared constructs (Andrews, 2012; Zein, 2013). Contemporary discussions of social constructionism tend to emphasize language use and locate knowledge as always situated and linked to human practices (Gergen, 2009). Knowledge, then, is not assumed to just 'exist.' Human experience and perceptions are not conceptualized as fixed but rather mediated culturally, historically, and linguistically. Social constructionism has also been written about as a rubric or broad philosophical position organized around a set of loosely connected perspectives, including deconstructionism, critical theory, post-structuralism, and discourse analysis (Burr, 2003). Various disciplines have promoted social constructionism, with the field of sociology having a significant early influence in the mid-1960s (Andrews, 2012). Social constructionism is frequently described as involving two peaks or positions: macro-social constructionism and micro-social constructionism.

Macro-social constructionism has been described as the first peak, wherein the idea of social constructionism was first introduced by Berger and Luckmann (1966). The key concept within their position was that people interact with social systems and over time develop mental representations of social actions, with the social order confining people's actions. More particularly, macro-social constructionism can be understood as maintaining a focus on the power of language (Burr, 2003) and the role that linguistic and social structures play in producing the social world (Gubrium & Holstein, 2008).

Micro-social constructionism has been described as the second peak and often credited to the work of both Gergen, and to Latour; a perspective that emphasizes the micro-level practices and process that construct knowledge (Alvesson & Sköldberg 2010), with knowledge viewed as unstable and co-constructed in the everyday interactions of life (Gubrium & Holstein, 2008). Language, then, is understood to be action-oriented, with social reality constructed in everyday and institutional interactions. In this book, we are primarily informed by a micro-social constructionist perspective and have argued elsewhere that this is a particularly useful perspective for understanding disabilities positioned as 'mental health' or 'psychiatric disabilities' (O'Reilly & Lester, 2017a), particularly autism (O'Reilly & Lester, 2017b). Within this theoretical position, medical knowledge and practices are viewed as socially constructed, with medical diagnoses viewed as inventions not discoveries (Bury, 1986). This position that shapes our own conceptualization of the very meaning(s) of autism.

An Overview of Social Constructionism and Autism

A focus on the social, a focus on language and meaning, and a focus on social interaction and competence, is an important step forward in better understanding autism and the lives of autistic individuals. We argue, therefore, that it is useful to conceptualize autism as a social construct and pay close attention to language and social interaction so as to ascertain a more nuanced and critical understanding of the condition that goes beyond a medical diagnostic classification (O'Reilly & Lester, 2017b). Social constructionist thinking is especially useful for research in the field of autism, and for our knowledge and understanding of the condition. The social construction of autism is clear in the diagnostic labels utilised to describe conditions (Mac Carthaigh, 2020). It is arguable, that critically challenging medicalized ideologies of autism through a social constructionism lens are especially important in advancing the field and improving life for autistic people. As Mac Carthaigh (2020, p. 61) noted:

> Equitable outcomes for people upon whom ASC [autism] labels have been imposed necessitates professional and academic awareness of the lenses through which the condition is

viewed. Consequently, reflection on how ASCs have come to be understood raises questions about whose interests may be served by biomedical narratives, and whether this ‘medical gaze’ hampers the people it professes to help.

Discursive Psychology

Discursive psychology can be thought of as both a methodological and theoretical position (Potter, 2012), one in which discourse is conceived of as that which social life unfolds. In the broader, interdisciplinary field of discourse studies, discursive psychology stands as one perspective that engages a form of discourse analysis to closely examine how psychological matters – such as beliefs, cognition, identities, etc. – are made real in and through talk and text (Potter & Hepburn, 2008). Growing out of the field of social psychology (Edwards & Potter, 1992; Potter & Wetherell, 1987), this perspective turns the idea of talk as representative of inner thoughts on his head – so to speak. Thus, for discursive psychologists, there is an exploration of how the traditionally psychologized constructs, like memory or attention, “are produced, dealt with and made relevant by participants in and through interaction” (Hepburn & Wiggins, 2005, p. 595).

From a discursive psychology perspective, it is talk/text (or discourse) that produces minds, emotions, identities, etc. Tileagă and Stokoe (2016) described discursive psychology as encompassing two type or strands of work, including one more aligned with conversation analysis and one aligned with ‘critical’ perspectives. Conversation analysis is a stand-alone qualitative methodology that arose from the field of sociology in the 1960s and generally examines the sequential organization of everyday and institutional interactions (Sacks, 1992). Notably, discursive psychology and conversation analysis typically prefer naturally occurring data (e.g., therapy talk) versus researcher-generated data (e.g., interviews) (Kiyimba et al., 2019), which is particularly useful for understanding issues related to autism (Lester et al., 2017). In this book, we draw upon several of discursive psychology research studies, most of which were informed to some degree by conversation analysis.

In addition, given the focus on both *what* and *how* things are said a specialized transcription system is used. This transcription system was initially developed by Gail Jefferson and serves to represent nuanced aspects of interaction. Across several of this book’s chapters, we include data extracts from our research – research which was heavily informed by discursive psychology and conversation analysis. All these extracts use symbols drawn from Jefferson’s method (Jefferson, 2004). Appendix A provides an overview of the meaning of symbols and may be useful to refer to as you engage with data extracts in the coming chapters. Hepburn and Bolden (2017) have also produced a text devoted to Jefferson transcription, outlining some of the evolving ways to represent what has been said by participants and just as importantly, how it was said.

Discursive psychology researchers generally take up a particular approach to discourse analysis, one which is often characterized as micro-oriented. Given the narrow scope of this book, we do not offer details on our analytic process here. Rather, we encourage interested readers to turn to the journal articles that we cite, as it is there that we articulate the details of our analytic process.

An Overview of Discursive Psychology and Autism

There has been a considerable growth of critical thinking and advocacy across the evidence base on autism, and the contribution of discursive psychology, and its related language-based methodology conversation analysis, is starting to have an impact. Traditionally the socio-cultural, linguistic, and political conditions that shaped the meaning and existence of autism were often overlooked or minimized (Nadesan, 2005), but the discursive turn (the turn to language) has started to spotlight new ways of thinking about autism that is influencing the voices of autistic individuals, their families and the practitioners who work with them (O'Reilly & Lester, 2017b). Importantly, the discursive researcher advocates the idea that meanings of autism are not a given but acquire multiple intersecting and different meanings in different contexts, time stamps and situations (see Glynos & Howarth, 2008). Discursive research, therefore, can illustrate *how* the concepts of normality – abnormality, neurotypical –neurodivergent, ability – disability are contingent upon the everyday discourses and practices that make them possible (O'Reilly & Lester, 2017a, b).

For the discursive researcher, understanding autism from a discourse position manages to reframe the condition as situated within a broader social history of specific disciplinary knowledge and institutional histories write, develop and shape what is means to be autistic (Rocque, 2007). By taking a discursive psychology approach, means that one can examine the ways in which talk that is produced in everyday or institutional activities, functions to position people and their social actions in various ways (O'Reilly & Lester, 2017b). There is a valuable and developing evidence base using discursive methodologies, and the related methodological approach of conversation analysis, that is informing a more nuanced and critical understanding of autism. For example, on the diagnosis process of autism (Maynard & Turowetz, 2017), inpatient care (Dobbinson, 2016), and autistic children's competence (Lester, 2015; Stribling et al., 2007). Importantly, the value of discourse and conversation approaches for understanding autism is being more widely appreciated and knowledge generated applied to practice (see O'Reilly et al., 2016).

Datasets and Previous Research Endeavours

Across the chapters, we offer empirical examples from our previous research, drawing from four distinct datasets. While one of us individually led the data collection process of each of the studies briefly described below, we have both been involved in the analysis of the data and the reporting of findings.

First, we include findings from a study that took place in the United States, which was led by Lester (Author 1). The data included in this study was part of a larger 2-year ethnography in a paediatric clinic in the Midwest region of the United States. This paediatric clinic offered speech therapy, physical therapy, occupational therapy, sibling support groups, and social skills groups to children (typically 2 years to 12 years of age) diagnosed with developmental disabilities. The corpus of data included: (1) 175 h of conversations that occurred in the clinic's waiting room, therapy sessions with therapists, autistic children, and their caregivers; (2) interview data with parents of autistic children, therapists, and state disability advocates; (3) observational field-notes, totalling 650 pages; and (4) documents used within therapy sessions. Participants included 14 parents of children with a clinical diagnosis of autism (11 mothers and three fathers) and 12 children who identified as and/or were diagnosed with autism. Eight therapists (three speech therapists, one physical therapist, two occupational therapists, one autism specialist, and one support group facilitator) and one state disability advocate also participated in the study.

Second, we include findings from a study that took place in the United Kingdom, which was led by O'Reilly (Author 2). In this study, the first initial assessment appointment that families attend in the Child and Adolescent Mental Health Service were video-recorded amounting in approximately 2458 min(37.5 h) of interactional data. Following referral to this service, usually from a General Practitioner, families were called to an initial assessment to ascertain the nature of their child's 'problem.' Initial assessments were multidisciplinary in nature and the format of assessments was not informed by any specific therapeutic theoretical approach, apart from institutional requirement and assessment guidelines. Children were assessed by a minimum of two practitioners (except one) and all 29 practitioners within the team participated. This included a consultant, staff-grade and trainee child and adolescent psychiatrists, clinical psychologists, assistant psychologists, community psychiatric nurses (CPNs), occupational therapists and psychotherapists. In this research setting, a wide range of different possible conditions were assessed, varying from anxiety or depression to ADHD and Autism. Of the whole data corpus, 10 families presented autism as a possible outcome of the appointment and clinicians were required to validate or refute this possibility.

Third, we include findings from another study that took place in the United Kingdom, which was led by O'Reilly (Author 2). The purpose of this study was to gain a better understanding of the information needs of parents whose child had recently been diagnosed with autism. Although there is a vast array of information available to the public much of it can be inaccessible in terms of the language it uses, it is sometimes contradictory, or parents and carers simply do not know where to start looking. Through the use of short semi-structured interviews, we explored the sort of information parents do have about the diagnosis, where they have found it, whether they had to find it themselves, and most importantly what information they did not have access to that they feel would have been beneficial to themselves and their child. This project aimed to explore what sources of information parents currently use or have used, whether they find that helpful, where they obtain information from, and what additional resources they would prefer. It further explored the diagnosis journey that those parents went through and asked about the challenges they faced when going through the process and their sources of support afterward. There were 15 interviews in total.

Finally, we point to findings from a study that took place in the United Kingdom. This study, which was led by O'Reilly (Author 2), included three focus groups, each with the same nine stakeholders with a view to explore the information needs, fears and challenges that are faced by parents of autistic children. This study also examined the views of how disabling autism as a condition was and the social framework around the condition. Included in the focus groups were, three parents of autistic children (two of these parents are advocacy workers for the Parent Carer Council); two members of the Board of the Leicestershire branch of the National Autistic Society; and a service manager for health Trust for Child and Adolescent Mental Health Services. In addition, a researcher and a Consultant Child and Adolescent Psychiatrist were included.

Overview and Structure of the Book

The book includes six core chapters, as well as this introductory chapter and a concluding chapter. Within Chap. 2, we offer a historical overview of disability generally and 'psychiatric disability' specifically. In doing so, we introduce the concept of medicalization and its influence in the broad area of mental health. We also offer a general overview of the various models of disability and briefly points to sociological theories of inequality and disability. This chapters serves to historically frame our consideration of autism. Next, in Chap. 3, we focus explicitly on how autism has come to be understood within clinical contexts. We highlight the ways in which the medical field orients to and conceptualizes the meaning of autism, and how this has been shaped by diagnostic manuals and practices. Chapter 4 deepens the discussion, providing a historical understanding of how autism came to be. Significantly, this chapter engages the question: Is autism a psychiatric disability, a disorder, or a natural variance of difference? To illustrate the key points, findings from our previous research are summarized. In Chap. 5, we expand our discussion of the meanings of autism by drawing upon findings from the US- dataset, further unpacking the ways in which the meanings of autism are negotiated and made sense of in practice. Notably, we have individually and collaboratively written on this topic quite extensively. Thus, we include in this chapter sections from a previously published paper that focused on how parents and therapists of autistic children talk about the meaning(s) of autism (Lester & Paulus, 2012). This paper was based on the US-based dataset and is one that has deeply shaped our conceptions and understandings of autism over the last decade. It thus captures core ideas related to the shifting and even conflicting ways in which people talk about autism. Chapter 6 examines the ways in which resource allocation, as related to disability, makes visible pervasive inequalities that impact autistic people. We consider in this chapter inequalities face in the contexts of health and education and draw upon previously published findings from the US-based dataset (Lester & O'Reilly, 2016). To illustrate the key points, we draw upon data from the UK-dataset and US-based dataset to illustrate the key points. Within Chap. 7, we engage the concept of stigma as related to autism. In this chapter, we provide a general overview of the literature around stigma. Finally, in Chap. 8, we provide a summary of the key arguments made across the book and point to implications for researchers, community members, and society writ large.

Concluding Thoughts

In this chapter, we have sought to locate this book substantively, theoretically, and methodologically. Substantively, we are focused on unpacking the social, cultural, and political discourses and practices that have contributed to the making of autism. Theoretically, we locate our work in a micro-social constructionist position, focusing explicitly on how social reality unfolds via micro-level processes. And, methodologically, we lean heavily into the tenets of discursive psychology, and, to some extent, conversation analysis. In moving through the next chapters, we encourage readers to situate our arguments in relation to these perspectives.

Chapter 2
Historical and Social Constructions of Disability

Across time, societal perspectives and every day and institutional practices surrounding disabled people has varied. Indeed, the oldest historical documents contain references to physical impairments and behaviours that many people today would classify as a 'disability' or 'disorder' (Braddock & Parish, 2001). In *A History of Disability*, French theorist Henri-Jacques Stiker (1999) wrote of the "fear of the abnormal" and how disability has been with us across time. It is, as he noted, trans-historically disturbing, making visible that "an aberrancy within the corporeal order is an aberrancy within the social order" (p. 40). Notably, long before autism came be a clinical category, there were a multitude of histories, discourses and practices that ultimately shaped its making (Nadesan, 2005). Importantly, then, to better understand how autism has come to be understood clinically (as discussed in Chap. 3), as well as from a more socially and discursively oriented way (as discussed in Chap. 4), it is important to gain an understanding of disability, and more particularly mental health and mental illness (that is, mental health conditions), across time. For as Nadesan (2005) noted, there is a complex web of histories, discourses, and everyday practices that have facilitated the production of autism.

Introduction

From Ancient Greece to contemporary practice, there have been many changes that shape how disability, mental health, and mental illness are talked/written about and understood. The history of autism is one that we argue should not be simply written about as a chronology of events. Rather, it is/was generated within a web of complex and varied structures, discourses, and practices. Thus, we suggest that to understand autism from a social constructionist position requires (at least) some level of familiarity with the histories of how disability, and more particularly mental health (given autism's historically categorization as a 'mental' or 'psychiatric disability')

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have been understood. Equally important is to gain a sense of how models of disability have functioned to offer critical and alternative perspectives on the very notion of mind and body differences. Accordingly, this chapter has two purposes. First, we offer an abbreviated history of mental health and the categorizing of mental 'disorders', chronicling only some of the key historical events and practices. This historicizing should be read as setting the context for understanding contemporary conceptions of autism and not as a detailed historical account. Second, we offer a general introduction to some of the models and theories of disability, specifically those that have arisen in response to medicalized conceptions of disability and note that most of these arose in relation to physical disability with (in some cases) only passing reference or transferability to 'psychiatric disability'. Notably, this chapter does not exclusively focus on the 'making of autism;' rather, it sets the stage for understanding how autism came to be as this is important for contextualizing the place of autism in terms of medicine and alternative theories and movements.

To frame this chapter's discussion, the words of Hayakawa (1957) provide insight into how we make sense of the construct of disability, and more particularly autism:

> The question, "What is it really?" "What is its right name?" is a nonsense question...one that is not capable of being answered...the individual object or event we are naming, of course, has no name and belongs to no class until we put it in one...what we call things and where we draw the line between one class of things and another depend upon the interest we have and the purposes of the classification. (pp. 115–116)

Thus, as we present the landmark events/writings related to the history of mental health and illness, we seek to foreground (at least implicitly) that the history of mental health is very much a history of naming and classifying. Further, we acknowledge we are not capable of isolating *all* of the intersecting contexts that have contributed to the production of the thing we now call 'the field of mental health' (White, 1978).

As Porter (1997) noted, "madness may be as old as mankind" (p. 10), thus in tracing this history, we can turn all the way back to Egyptian writings about 'hysterical disorder' (Sigerist, 1951) and Hippocrates descriptions of treating mental 'distress'. In other words, the history is vast and certainly open to interpretation and the language used has been rich, varied and evolving. As such, what we offer in this chapter is only one of many possible interpretations of the history of mental health, choosing not to view our own interpretation as neutral, realist, or complete. Finally, we have previously written about the social construction of mental health, devoting an entire book to many of the ideas we briefly summarize in this chapter (O'Reilly & Lester, 2017a), as well as social constructionism and autism (O'Reilly & Lester, 2017b). In our book, *Examining Mental Health through Social Constructionism*, we included a chapter that offered a chronology of the historical events surrounding notions of mental health and mental illness. We draw heavily upon this chapter here and encourage interested readers to turn to our previous writing should there be an interested in a deeper consideration of what we offer with brevity here.

An Abbreviated History of Mental Health and Mental Illness

What we offer next is a chronological overview of the treatment of people who historically were thought not to fit within the norms of society. In mapping out the history of mental health and notions of mental illness (a term we are using more in this chapter as it is commonly framed historically as ‘illness’ rather than conditions, which is the more preferred conceptualisation in modern writing), we recognize we are engaging with language choices that many have critiqued as being fairly associated with autism. That is, there is certainly debate on whether autism should/can/must be defined as a mental ‘disorder’ – a mental health condition consistent with a psychiatric framing. Our intent is not to engage these debates within this chapter; rather, we seek to offer context for *how* (and to some extent *why*) autism came to be historically associated to the field of mental health.

Demonology

As early as 5000 BC, people believed to be displaying ‘unusual’ behaviours were thought to be ‘possessed’ by evil spirits or demons. Spiritually grounded claims were commonly proffered to explain unexplained behaviours. Ancient Egyptian and Greek writings frequently cited demon possession as a possible reason for an individual’s ‘unusual’ behaviour, with early Christian beliefs also foregrounding notions of the devil battling in the minds of people (Bone & Marchant, 2016). Archaeological evidence suggests that another treatment of ‘choice’ for those presumed to be in distress was to bore small holes into their skulls – thereby creating a literal exit pathway for the evil spirits (Rosen, 1968). Notably, not everyone believed that demon possession was the cause or explanation for such behaviours. Some people argued that the behaviours associated with mental health conditions were due to natural causes, with some Greek writers suggesting it could be treated through solitude and even drug treatment. Even today, there remain people who believe behaviours associated with mental health conditions are caused by evil spirits. Koenig (2009) noted that religious beliefs and spiritual causes are frequently associated with neurosis and psychotic delusions. Further, Koenig noted that historically and in contemporary times, religious practices have been frequently cited as offering hope and comfort for those experiencing distress.

During medieval times, it was particularly common for ‘unusual’ behaviours (behaviours that would likely be described as ‘mental illness’) to be presumed to have a supernatural basis – particularly demonic possession. Witchcraft and sinful deeds were often cited as what might be underpinning these behaviours, leading to great persecution (and death) of thousands of presumed ‘witches’ (Russell, 1972). Some people thought to be possessed were locked in dungeons (Porter, 2002) or sent to religious institutions for ‘treatment’ (Porter, 1987). For example, St Mary of Bethlehem was a religious asylum in England established in the 1400s to house people described as ‘lunatics’ (Shorter, 1997). The idea of an asylum emerged as a popular practice, with asylums becoming more popularized by the 1600s.

Enlightenment

During the seventeenth and eighteenth centuries, the Age of Enlightenment brought with it a turn toward science resulting in an emphasis on ‘curing’ individuals thought to be mentally ill (Shorter, 1997). John Locke’s idea of the mind as a ‘tabula rasa’ shaped the shift toward viewing ‘lunacy’ as not caused by demons but victims of mistreatment (Bone & Marchant, 2016). During the period, as Foucault (1965) noted, the asylum rose to become the primary way by which people experiencing symptoms were treated. Asylums were thought to be a place wherein people could receive treatment and then return to society. A rising faith in these institutions led to their spread throughout Europe and the United States. Significantly, however, maltreatment (e.g., the use of chains, or ice) within these institutions became prevalent, with what was described as a site for rehabilitation functioning more as a space of isolation for those being treated.

Calls for Reform

Alongside the rise of asylums came grave concerns related to the ways in which people were being treated. These concerns led some people to lead efforts to reform how asylums were structured and functioned. In the mid-1800s Dorothea Dix conducted research on how people experiencing mental health conditions were being treated in the United States. She wrote her findings for the General Assembly of North Carolina, describing people in the asylums as chained to beds and experiencing terrible conditions. Dix called for new facilities and a turn toward more humane practice. Similarly, in England some doctors began to draw upon the idea of Battie about moral management (Porter, 2002), wherein restraints were minimized and efforts to support people toward recovery via praise were emphasized (Johnstone, 1998).

Ultimately, by the early nineteenth century, the ‘reformed asylum’ became a site of praise for the treatment of the ‘insane’ (Shorter, 1997). And, notably, alongside the rise of journals and professional bodies related to the treatment of the ‘insane,’ the field of psychiatry was born (Shorter, 1997) as individuals were described as ill and became the responsibility of medicine. Before 1900s, there were very few psychiatrists and those classified as ‘mentally ill’ were typically sent to asylums or large hospitals (Blashfield et al., 2014). With the advent of the field of psychiatry came frameworks for what counted as ‘normal’ versus ‘abnormal,’ and a ‘science’ surrounding the treatment and classification of mental health conditions.

Failures of Reform

With the twentieth century came questions regarding whether asylums were the solution to ‘mental illness’ (Bone & Marchant, 2016). Part of these concerns were grounded in questions regarding the large number of individuals being placed in asylums. For example, in 1800, there were only a few people placed in St Mary of Bethlehem in London. However, by 1895, London had 16 asylums, and in the United States, over 150,000 patients had been admitted (Shorter, 1997). Debates regarding the inability of asylums to manage such large numbers ensued, with moral therapy even deemed as ineffective. Regardless, these approaches to treatment and classification continued into the twentieth century, with the failures resulting in new conceptualizations for treatment.

Rise of New Models and Deinstitutionalization

Within the field of psychiatry during the early twentieth century, psychoanalytic theory and psychoanalysis became increasingly influential in both the United States and United Kingdom (Porter, 1997). World War I also brought with it an acknowledgement of the need for supporting individuals who experienced trauma (Johnstone, 1998), with this support often coming in the form of psychoanalysis techniques. The emphasis on psychoanalytic theory led to psychological problems being positioned as related to an individual’s mother (Lafrance & McKenzie-Mohr, 2013). Thus, the rise of a mother-blaming rhetoric occurred, a practice we discuss further in relation to autism in Chap. 7. Further, this period saw a rise in psychopharmacology for the treatment of mental health conditions, with the first psychotropic drug (lithium) being utilized in the mid-1940s (Bone & Marchant, 2016). With the rise of pharmacology, increasing critiques were made, particularly as mental health patients were commonly criminalized or left in destitute.

These critiques ultimately led to the deinstitutionalization movement (Lafrance & McKenzi-Mohr, 2013), with asylums increasingly discredited as a useful and humane approach. Today, the asylum – which still exists in varying forms – is often viewed negatively. The media, for example, has persistently positioned asylums and psychiatric hospitals in sensationalized ways, presenting patients within them as dangerous, otherworldly, and frightening (Bone & Marchant, 2016). Significantly, deinstitutionalization remains a contemporary issue, particularly in the age of health austerity (O’Reilly & Lester, 2017a).

Policy and Legislation

During the 1970s and 1980s, a new characterization of disability began to materialize that considered external factors as the source of disability, rather than as individual deficiency (Donoghue, 2003). It was during this time that the disability movement was becoming noticeable in the United States and the United Kingdom. Those with disabilities were beginning to fight institutions for their civil rights and successfully transformed the traditional notions of disability as an individual phenomenon, into a new disability theory which saw those with disability as members of a minority group discriminated against and prevented from being normal members of society. It was seen as a victory for the fight of civil rights with the signing of the 'Americans with Disabilities Act' as this targeted the elimination of discrimination. Arguably, this is a finely crafted piece of legislation but is not reflective of only one political ideology. Rather, it is a combination of various political perspectives. Problematically, however, this Act is still grounded in the medical paradigm. "Instead of defining disability as a result of the barriers and 'handicaps' created by society, the Americans With Disabilities Act reproduces the medical definition by defining it as an inability to perform a 'normal' life activity" (Donoghue, 2003, p. 203). It has been argued that through the maintenance of medical terminology, the idea that disability is an individual problem becomes reinforced by the legislation. Additionally, the Act suggests that the physical limitations of the disabled are what cause people to discriminate. This of course stands in contrast to the minority group perspective which advocates that discrimination is actually a product of the stereotyped notions that exist about those with disabilities.

Similarly, in the UK a range of policies exist designed to protect those with disabilities from discrimination, which began in the 1970s. For example, the Equality Act (currently, 2010) was passed in Law to ensure that there is no unfair treatment based on personal characteristics. Like in the US, the language of the Equality Act is positioned medically, utilizing the notion of 'physical or sensory *impairments'*, and 'mental *illness/disorders'*. More specifically, the UK introduced national legislation, in the form of the Autism Act (2009), and guidance from the National Institute for Health and Care Excellence (NICE), which offered strategy for supporting the need to identify and manage autistic individual's unmet health needs (NICE, 2011). Additionally, the Westminster Commission on Autism (2016) put forward a case for preventative health for individuals with autism.

Despite some of the criticisms and limitations of these types of policies in the US and UK, there is at least an honourable intention of protecting those with disabilities from discrimination and stigma and are an important step in recognizing the campaigning and hard work of different movements and ideologies in working for disabled people's rights.

Classifications Systems

For treatment models to be measured for effectiveness, and for policies to be implemented, required 'objective' ways to classify and demarcate disability to that categorisation of individuals as belonging to certain groups. Thus, there was a development classification systems and practices particularly during the twentieth century, which we discuss below. These classification systems are dependent upon constructions of ‘normality’ and ‘abnormality’ as determined by society. In contemporary practice, notions of normality are generally steeped in criterion-based classification systems, with the language of ‘symptoms’ generally leading to a clinical diagnosis. Endemic to these systems is a medicalized model of human functioning, wherein there is a focus on symptoms and conditions being cured. To cure, however, it is often assumed that one must label or classify first; hence, the rise of classification systems such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Disease (ICD). In this chapter, we present a very general overview of the rise of such systems and offer far more nuanced detailed of these systems as related to autism in Chap. 3.

Diagnosis: An Interpretative Process

In contemporary psychiatry and psychology, diagnosis is central to the practice and understanding of mental health. Fundamentally, the diagnostic process has been conceptualized as functioning to categorize and organize a set of deviant behaviours, actions, characteristics, etc. (Tucker, 2009). While some have argued that diagnosis can lead to appropriate treatment, others have suggested that it may also have negative implications. Positive implications of an autism diagnosis are that the labels can provide a sense of relief as the diagnosis provides an explanation for the idiosyncrasies (Bagatell, 2010), and for professionals, plays a role in avoiding any misinterpretation of behaviour constructed as deviant (Jordon, 2015). Of course, the acquisition of a diagnosis also brings opportunities such as resources (Lauchlan & Boyle, 2007) and increased peer acceptance (Gus, 2000). Indeed, diagnosis has historically been positioned as a primary means by which to gain access to services. This is important for parents and families who seek explanations for behaviour and desire help and support where they are struggling (O’Reilly et al., 2020b).

The idea of negative implications of diagnosis, of autism or any other mental health condition, have been written about particularly in relation to psychiatric diagnostic categories (O’Reilly & Lester, 2017a; O’Reilly et al., 2020b). Indeed, power and authority are at play within the diagnostic process, as only particular individuals (i.e., medical professionals) are granted the authority to identify, label, and ultimately diagnose the presenting ‘symptoms’. Thus, diagnosis, is itself a ‘powerful social tool’ occurring between the intersection of the illness and disease, the doctor and the patient, and in this way provides a ‘cultural expression’ of what is viewed as normal within a society (Jutel, 2009).

As one example, when it comes to autism, common ‘traits’ are often linked to visible behaviours. For instance, some autistic people may move their bodies in ways that are interpreted as non-normative or evidence of an autistic ‘characteristic,’ with enough evidence resulting in an official diagnosis. Donnellan et al. (2010) noted that professionals are trained to see non-normative behaviours as “autistic” and worthy of being “targeted...for reduction” (p. 1). Power, then, is often located in a class of skilled professionals, with these “credentialed experts” retaining “a sense of their validity by relying on tradition, deference to authority, and inherited privilege" (Brantlinger, 1997, p. 438). From a social constructionist perspective, the diagnostic process is viewed as interpretative and grounded in conceptions of normality-abnormality. As Becker (1963) noted:

> ...social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders. From this point of view, deviance is not a quality of the act a person commits, but rather a consequence of the application by others of rules and sanctions to an "offender." The deviant is one to whom that label has been applied; deviant behaviour is behaviour that people so label. (p. 9)

Further, over time this process has been situated within an increasing reliance upon classification systems; that is, systems by their very nature steeped in assumptions that it is possible to delineate boundaries between 'normal' and 'abnormal' behaviours and ways of being in the world.

Dominant Classification System Relevant to Autism – The DSM and ICD

While there are different classification systems, the two most relevant to conditions such as autism are the DSM and ICD. In contemporary times (as well as in the recent past) the diagnosis of a mental 'disorder' is guided using these diagnostic manuals. The ICD was put out by the World Health Organization and the DSM by the American Psychiatric Association. The ICD has been translated into 43 languages and broadly used to monitor the incidence and prevalence of disease and 'disorder' worldwide. This diagnosis manual classified both physical and mental health problems, while the DSM focuses solely on mental disorders. Notably, the DSM has a long history of describing mental disorders (Lafrance & McKenzie-Mohr, 2013), with presenting 'symptoms' positions as abnormal and warranting some type of specialized attention (American Psychiatric Association, 2013). In Chap. 3, we discuss in detail the way in which autism has come to be represented in the DSM.

Critiques of Classification Systems

From a social constructionist position, there are at least five critiques of classification systems. First, a common critique is that classification systems are presented as ahistorical, universal accounts of human functioning. Social constructionists proffer that 'normal' versus 'abnormal' functioning is a socially constructed reality; thus, classification systems are simply historically constructed artefacts. They are not static accounts of human functioning, but rather human inventions grounded in conceptions of culturally, politically, economically, and socially-defined norms. Second, specific to the DSM, some have argued that it is atheoretical, simplistically locating the 'problem' within an individual and explainable via biological or physiological functions (Caplan, 1995). Third, the classification systems continually change, with some arguing that these changes are simply reflective of the growth in understandings related to human development. Alternatively, some of have argued that these changes in criteria cannot not be necessarily linked to growing understandings of human development (Timimi, 2002, 2004); rather, they are reflective of the ever-shifting ways by which society defined 'normality.' Fourth, there have been claims that the growing classification systems have resulted in diagnostic specificity. Yet, this claim has been questioned, as some scholars have argued that little specificity has ensued but rather a set of "complex dimensional ratings that could never be used clinically" (Frances & Nardo, 2013, p. 171). Finally, it has been noted that there are material consequences to applying labels to people, as stigma is a common occurrence. Lafrance and McKenzie-Mohr (2013) argued that an alternative approach is needed, one that acknowledges "...the social and political realities of people's suffering in a way that prevents them from being relegated to the margins of theoretical understanding" (p. 134). Indeed, the medical 'facts' that form the basis of the classification systems function to sustain the myth of their being such a thing as a 'normal' human (Wykes & Callard, 2010).

Medicalization and the Medical Model of Disability

Medicalization refers generally to the way in which human conditions, symptoms, behaviours, etc., become characterized and ultimately treated as medical problems (and we discuss this in further detail in Chap. 4). Thus, the foundational aspect of the medical model of disability is that the disability is viewed as an illness, a deficit, ultimately as a disease (Retief & Letsosa, 2017). Fundamentally, diagnostic practices and classification systems are based on medicalized conceptions of human functioning. Within such a conception, there is a belief that a *true* 'normal' and 'abnormal' is knowable and/or achievable.

The benefits of taking a medicalized approach to managing 'disorders' classified as mental health concerns has been greatly debated (Szasz, 1963). Notably, medicalizing 'natural' aspects of people's lives has led to grave consequence. Women, for instance, were historically positioned as 'distressed' as their everyday life events (e.g., menstruation, menopause, etc.) were medicalized (Oakley, 1980) and described as evidence of emotional distress (Chesler, 1972). While medicalization is conceptualized as distinct from diagnosis, the two concepts and process are interrelated. In more contemporary times this interrelation has been evidenced in discussions around the overdiagnosis of people's everyday experiences. For example, the *British Medical Journal* published a series of articles examining the harms of overdiagnosis of conditions, such as diagnosing 'sadness' as 'clinical depression.'

Medicalized conceptions of difference and human problems has become embedded within Western society. Such conceptions have been characterized in the medical model of disability, wherein disability is viewed as an ahistorical, permanent biological impairment. Thus, the medical model has focused on identifying the physical, cognitive, sensory, behavioural, and psychological tragedy of the individual (Gilson & DePoy, 2000). In other words, the medical model as the dominant view of disability presumes that the solutions to the problems that are experienced by those with disabilities are within the remit of medical professionals (Mercer, 2002). The medical model as related to disability locates a disability within the individual, with a particular emphasis on identifying a cure or treatment to overcome difficulties (Orsini & Davidson, 2013). In this way, the problem is viewed as dispositional, and anyone whom medicine is unable to 'fix' becomes positioned by the medical field as deficient (Gilson & DePoy, 2000). For mental health conditions, a biomedical framing of the issues offers up a scientific framework for society and allows a biomedical understanding and treatment for the mind (LaFrance & McKenzie-Mohr, 2013).

More broadly, the medical model can be conceived of as an ideological framework that places normalization of bodies and minds as the end goal and the agency of disabled people minimized (Eyal et al., 2010; Grue, 2011). Further, when applied to the field of mental health (wherein autism has been historically classified), the medical model has emphasized disabled people's challenges, and, in so doing, judged them as weak, lazy, resistive, and so on (LaFrance & McKenzie-Mohr, 2013). Muskett et al. (2010) described this model as particularly problematic for the conceptualization of psychiatric disability, as it relies on a conceptualization of psychiatric disability as synonymous with physical disease.

In more recent times, the field of medicine has taken upon a biopsychosocial model rather than the older medical model. In theory, this model is thought to consider biological, psychological, and social aspects of disorder and illness (Santrock, 2007). While some have described the biopsychosocial model as being more closely related to care and the social aspects of disability, this model still relies on notions of causation; that is, that a disorder stems from an individual body and can/should be 'cured.' In addition, some have argued that in reality the biopsychosocial model really just lives within the medical model, as the medical model and the assumptions that go with it persist (Pilgrim, 2002).

Even though this model has been dominant for some time, some have questioned whether it is a model or simply a series of examples of medicalization. Grue (2011) noted, for example, that the model simply promotes reducing various aspects of disability into medically recognizable patterns. Most significantly, this model has been critiqued for positioning disabled people as second-class citizens and promoting segregation of difference from society (Mercer, 2002). Historically, and, even in modern times, this segregation of disabled children is seen in schooling contexts. While there has been movement of inclusion, the very appropriateness of inclusion has been challenged and segregated experiences persist for many disabled children. Notably, many of the models of disability arising from the field of disability studies offer direct critiques to the medical model of disability – several of which we examine in this chapter.

Autism and the Medical Model of Disability

Our next chapter, Chap. 3, is entirely dedicated to clinical and medical understandings of autism, and our Chap. 4, offers a detailed critique of medical framing and medicalization, but we nonetheless introduce the medical model in relation to autism here in this chapter, albeit very briefly for context. Because autism is situated within the American Psychiatric Association (2013) classification system for mental health conditions, this places autism very significantly in the medical domain. In this way, autism has gained social capital and prestige within the biomedical community and has been securely framed as a neurodevelopmental disorder under the remit of biomedical authority (Anderson-Chavarria, 2021). By placing autism as a medical condition and as one where the deficit lies with biological origins, Leach Scully (2008) has argued that this creates a negativity of disability, making disability undesirable.

Biological explanations of autism have grown in popularity, with theories of excess neuron overgrowth (Courchesne et al., 2007), issues of immunology (Silverman, 2012), and the possible connection to gut microbiota (Kelly et al., 2017; Fattorousso et al., 2019). Indeed, there has also been an exponential growth of genetics research, seeking to identify the 'autism gene(s)' and provide an aetiological explanation for the 'brain' disorder. Like many areas of modern western medicine, there has been a rise of geneticization for explaining autism (Anderson-Chavarria, 2021). In other words, there is considerable growth in research on genetics to account for disease and explain the process whereby a biological conditions constitutes a social definition of abnormality (Lippman, 1991). Notably, the most extensive work currently does seem to indicate a genetic cause of autism (Bai et al., 2019). However, genetic research has important social implications because a genetic aetiology creates a socially embedded relationship between the individual and the categories to which they belong (Arribas-Ayllon, 2016), an issue we discuss further in the book.

The Social Model of Disability

The social model of disability is a particularly well-known, strong, and influential model of disability, that is often pitted against the medical model to challenge the deficit-based language associated. For the social model of disability, disability is viewed as socially constructed, and as we have led you through this book, we have provided you with some understanding of how this focus on language and meaning are important for understanding and researching autism. The social model of disability was developed predominantly within the UK and was noted for its orientation to Marxist sociology (Grue, 2011). Indeed, it was the activism of the disability movement in England during the 1960s and 70s where the social model of disability started to address some of the limitations associated with the medical framing of disability (D'Alessio, 2011) and instead recognised how the social environment imposes limitations onto disabled people (Oliver, 1981).

For those that advocate a social model framing of disability, there are arguments that it is society that disables those who have conditions and thus there is a need for societal change and not individual rehabilitation, that we need to move away from dispositional arguments to systemic ones (Barnes et al., 2010). In other words, for the social model of disability, disabilities are explained as a kind of economic and political oppression imposed on individuals who have bodies that fail to conform to the ideology of industrial capitalism (Oliver, 1996). For anyone who has the incapacity to function in the traditional ways expected by society, they become positioned within a hostile environment (Gleeson, 1997). The social model of disability seeks to redress this negative challenge and promote changes to definitions of disability in ways that start to reflect the personal realities of those who are disabled (Oliver, 1981) and to understand the ways in which systemic issues have shaped our understanding of disability.

These radical ideologies of disability have had a profound influence on how we understand disability (Giddens, 2006), and the social model of disability has played a crucial role in shaping social and educational policies. While immensely popular and certainly radical, the social model of disability has nonetheless been critiqued for failing to fully consider culture in relation to disability (Shakespeare, 1994) and for essentially ignoring gender, age, and class differences (Barton, 1993). Shakespeare (2014) called for the social model of disability to be revised and Mike Oliver himself has called for a reinvigoration of the social model of disability in contemporary society, arguing that we need to stop talking about it and do something more proactive (Oliver, 2013). For example, it has been argued that a more active social model needs to be implemented, one that is more aligned with an agenda for change and recognises the longstanding denial of fundamental human rights for those with disabilities [see also the human rights model of disability] (Berghs et al., 2019). Berghs et al. thus proposed we need a 'stronger' social model of disability that focuses on defending and implementing human rights, and yet the idea of this is arguably not new (Riddle, 2020). Riddle proposed that the purpose of a model of disability is to understand the experience of disability and the paradigmatic shift from the medical to the social has empowered and mobilised those with disabilities, and this value is not due to the model's political commitments, but rather it's ontological ones. Clearly, the social model of disability has changed societal attitudes substantially and we should continue to raise questions, challenge ideologies, and use the social model of disability in practice (Levitt, 2017).

Autism and the Social Model of Disability

The social model of disability has been hugely influential and important for autism. The social model of disability rejects a deficit-focused understanding of autism. Instead, as we have noted, the social model of disability frames disabilities as a social construction that are a consequence of societal oppression (Anastasiou & Kauffman, 2013). Such ideologies were juxtaposed with an increased presence and voice of those with disabilities who worked to challenge the medical model of disability and started asking critical questions (Pelka, 2012). Thus, the social model of disability was able to illuminate differences across groups and across individuals and looked beyond the medical and biological, to the individual and person. Yet, there are clear institutional influences on how disability is viewed and managed, with educational systems being particularly important in childhood and an area where performance is impacted and measured (Phillips, 2006). Thus, educational and workplace institutions have the power to determine social normative values in behaviour (Martin, 2007).

For autism, the behaviours and traits that are associated with the condition are not so much medical symptoms, but rather are alternative forms of behaviour that will or will not be tolerated by society (Anderson-Chavarria, 2021). Often the behaviours of autistic persons, like stimming, rocking, or repetitive vocalisations are constructed in negative ways, but this does not necessarily need to be negatively viewed, if embraced as difference and not deficit (Bakan, 2014). However, while the social model of disability provides a mechanism for such a perspective to be culturally embedded and recognises the role that systems play for autistic behaviour, it does risk perpetuating the marginalization of those individuals (Leach Scully, 2008) as the discursive positioning of the autistic person as 'other', potentially alienates autistic individuals and risks dehumanizing them (Hacking, 2009). The consequence of this therefore is that the autistic individual is further disengaged from society and social engagement becomes an even greater challenge (Bagatell, 2007).

Other Models of Disability

Within the field of disability studies, many models of disability have been offered, and while the medical model and social model are arguably the most widely discussed, there are other models that have important implications for autism. As we noted in Chapter 1, the field of disability studies is a particularly pertinent one for our own work. More broadly, this interdisciplinary field "sits at the intersection of many overlapping disciplines in the humanities, sciences, and social sciences" (Society for Disability Studies, n.d.). This is a field that challenges the view of disability as a deficit or defect to be fixed or cured by medical intervention. The field instead proffers that disability can and should be understood in relation to the social, political, cultural, and economic factors that produce it. Notably, the field does acknowledge the potential utility of medical research and intervention, while also calling for a continued examination of the links between stigma and medicalization.

There is a plethora of models of disability with many shared characteristics, as well as some distinct assumptions. Presently, there is not a particular model that is heralded as the *best* model; rather, the models offer unique perspectives informed by a range of theoretical positions. There are various functions to the models of disability, and these were outlined by Smart (2004) as:

- Offering definitions of disability.
- Providing useful explanations about causes and responsibility attributions.
- Identifying individual and perceived needs.
- Guiding the formulation as well as the implementation of policy.
- Shaping the self-identity of individuals.
- Determining which academic fields study disability.

Smart (2004) recognised that models of disability can never be value neutral and also can risk leading to discrimination, stigma and prejudice. All models have their critics and their criticisms, and we do not have space to go into that kind of detail in this book. Some scholars have also noted the incompatibility of the models (Grue, 2011), with some agreement that a more critical orientation to the study of disability is needed (Mulvany, 2000). Broadly, such an orientation is one that includes:

- Challenging viewing disability from a deficit perspective (Barton, 1993).
- Focusing on the rights of disabled people, as well as the potential of generating a collective identity in pursuit of social change (Mulvany, 2000).
- Differentiating between impairment and disability (Barnes et al., 1999; Mulvany, 2000), with disability emerging because of the structures and societal practices that disadvantage some (Oliver, 1990).

The distinction between disability and impairment has been particularly useful within our own scholarship. Drawing upon a social-relational model of disability (Thomas & Bracken, 2004), a distinction can be made between *disability* and *impairment effects*. Disability here is conceptualized as only being relevant when restrictions of activity are placed on one's way of being or doing – these restrictions often coming from environmental and social structures that shape what is and is not possible for people. For instance, in our own research, paediatric therapists have described how some of the autistic children they work with were not 'allowed' to use their communication devices in their schools, resulting in them being excluded and devoid of tools to communicate with peers and others (Lester, 2014). School officials were reported as deeming communication devices as "distractions" and "not really needed" and thus the autistic children resulted in not being able to participate in the social or academic events at the school. So, in this way, the child's impairment became a "the marker for other restrictions of activity which do constitute disability" (Thomas, 1999, p. 43).

More broadly, critical models or approaches to disability are particularly relevant to any discussion of autism, as there have been varied ways that autistic people have described and experienced a diagnosis. For instance, some autistic people have described their struggles associated with the condition (Huws & Jones, 2008), while others have pointed to a desire for a cure (Bagatell, 2010). Celebration of an autistic identity (Baker, 2011) and/or opposition to the call for a 'cure' (Brownlow, 2010) are other perspectives that have been shared as well. The various models of disability offer helpful theoretical understandings of disability that shed light on the varied ways in which people make sense of disability, while importantly standing against the dominating medical model of disability.

What we now offer in this chapter is a general overview of *some* of the other models of disability (other to the medical or social models), acknowledging that what is offered here is not comprehensive and neither is it detailed. Rather, we encourage readers to turn to seminal literature to fully assess the potentiality of critical models of disability as what we present is merely a basic overview for context. For example, a useful overview of a range of models of disability is offered through a discussion piece by Retief and Lesosa (2017) and by Shakespeare (2014), as well as our own writing on the matter in our book on social constructionism and mental health – O'Reilly and Lester (2017a).

The Moral Model of Disability

It has been argued that the moral model of disability, that which sees disability as 'an act of God', is the oldest of all the models (Pardeck & Murphy 2012), with one of the oldest ideas seeing disability as a punishment from God for a sin (Retief & Lesosa, 2017). Thus historically, and arguably even in contemporary society there are those that believe some disabilities are a consequence of a failure to adhere to social morality and thus disability is the punishment for transgressions of the disabled individual or their ancestors (Henderson & Bryan, 2011). It is clear, that there are negative and stigmatising aspects to this model, with potentially destructive implications for those living with a disability, which can lead to some entire families being excluded from social participation in their local communities (Rimmerman, 2013) as they grapple with a courtesy stigma of being associated with the individual (Goffman, 1955).

While there are evidently negative and stigmatising aspects of the moral model of disability, conversely there has also been a perpetuation of the myth of disability as mysticism or a metaphysical blessing (Retief & Lesosa, 2017). From this point of view, the disability is not a punishment from God, but instead is seen to have a special purpose (Neimann, 2005). We have demonstrated earlier that there have been strong connections historically between spirituality, religion and our understanding of mental health conditions and some of this belief still lingers in society today. Some cultures have particularly strong religious ideas around disability (Dunn, 2015), and in those societies individuals with disabilities tend to be marginalised and sometimes are abandoned (Anderson, 2013).

The Identity Model of Disability

The identity model of disability is a well-known model that has some affiliations with the social model of disability, particularly for its underpinning social constructionist ideas and emphasis on language and meaning. The emphasis of this model is on the identity of the disabled individual and the personal experience of the disability. For this model, the disability is very much viewed as part of the individual's identity and sees the disability as a positive aspect of the identity (Brewer et al., 2012). For the identity model, there is a sensitivity to individual experience (Shakespeare, 2014) and a strong rejection of viewing impairment as a tragedy (Cameron, 2008).

The identity model, sometimes referred to as the affirmation model, argues that the disability experienced by the individual shapes their identity, as well as creating a collective identity as belonging to a group (Swain & French, 2000). Swain and French argued that this collective identity can lead to a group expression of anger and can be a mechanism for an agenda for change and civil rights. This model of disability has been influenced heavily by those who belong to the community as they collectively seek to adopt a positive self-image that achieves pride in who they are (Darling & Heckert, 2010). Thus, it is argued that the impact of any destabilizing force might be mitigated by a shared identity construction, as Bloom (2019) argued a group identity formation can create a community with shared ideologies and shared embodied practices, which can create a shared sense of group identity and build a positive sense of community. Thus, the validity and value of the life of the disabled person is reaffirmed (Swain & French, 2000). It is this group collective, however, that has attracted criticism, as arguments have been proposed that this model compels disabled people to identify with a specific group culture (Fraser, 2003).

The Labelling Model of Disability

Labelling theories have been popular in shaping our beliefs and ideas about diagnosis and conceptualisations of disabilities. Labelling theory developed from the American (Chicago/California) ideas about deviance and evolved from the work of Lemert and the symbolic interactionist perspective (Petrunik, 1980). For example, Lemert (1948) considered the difference between primary and secondary deviance; seeing primary deviance as the attributes or experiences of the individual, and secondary deviance being the behaviour that follows on from the real or imagined responses of others to the deviance. So, for labelling theorists then, the focus was much more on the social reaction rather than the perceptions of those who were labelled (Mulvany, 2000). Importantly, labels are not static, rather they are dynamic and socially created through language (Hacking, 2006).

Labelling theory has been particularly influential for the field of mental health, with a central idea proposed that the role of those who are diagnosed with a mental health condition is consolidated by the social reactions from others (Goffman, 1968). In other words, the very label of a mental health condition was presumed to have an incredibly powerful effect on the reactions by society toward that individual (Martin et al., 2007). The labelling model of disability thus argues that those in society learn and adopt a stereotyped imagery of the 'mentally ill' and acclimatise to the pejorative language that has become endemically associated with it (Weinstein, 1983). There has been some backlash against this model (see Petrunik, 1980), as it is argued that adopting a psychiatric definition of illness presumes an existence of a psychopathology which positions the disorder as abnormal (Weinstein, 1983).

The Human Rights Model of Disability

A more recent model of disability is that associated with a rights-based framework. Many activists now argue that we need to consider disability from a human rights perspective and that human rights should be embedded in our thinking about disability (see UN, 2006). From this perspective disability is positioned as a human rights issue. The human rights model of disability has a lot of hallmarks of the social model of disability, although they are distinct models. For example, it has been recognised that while the social model of disability promotes ways to understand the fundamental social and systemic issues that shape an understanding of disability, the human rights model of disability seeks to move beyond explaining disability, to providing a theoretical framework for disability policy that emphasises human dignity (Degener, 2017). Degener also argued that the human rights model of disability foregrounds human rights in terms of civil, political, economic, cultural, and social rights, and unlike the social model of disability recognises that for some with disabilities there is a suffering and pain that needs to be addressed in terms of social justice.

The Economic (and Political) Model of Disability

The economic model of disability views disability as an impairment of contribution to an economic society and a challenge to productivity. The focus of the economic model of disability is on the functioning of the individual, to a society that values economic contributions. Thus, the focus tends to be on the individual's abilities to contribute to the labour market (Armstrong et al., 2006). In such a way, the economic model argues that it is important that there is respect for those with disabilities and a realisation of their civil rights to contribute to the economy (Smart, 2004). Evidence suggests that the economic model of disability is frequently deployed by governments as a reference for developing policies (Jordan, 2010) and yet its emphasis on cost-benefit and economics fails to account for other important aspects of life (Smart, 2004).

The political model of disability also emphasises the economy. This model resonates with the social model of disability and is often described as a socio-political approach (Hahn, 1984). From the perspective of the political model of disability, the disability itself is considered to be a product of the interactions between persons and their environment (Hahn, 1984). Thus, this model of disability moves the disability itself into the domain of power and resources, and the disabilities are seen as conditions that interfere with the individual's capacity to work or contribute to the societal economy (Gilson & DePoy, 2000).

The Predicament Model

It has been argued that autism is a condition that has 'presented a new frontier challenging how society understands disability" (Anderson-Chavarria, 2021, p. 1). Anderson-Chavarria argued that autism tends to be understood either in the context of the medical model of disability or in the context of the social model of disability, and neither can encompass the diverse autistic experience. Anderson-Chavarria recognized that the medical model is inadequate for autism as it focuses to significantly on what the individual cannot do, and should be focusing on their competence, and the social model sees autistic persons as excluded from society as they fail to conform to social norms but does not adequately explain what being autistic means.

Instead, Anderson-Chavarria, proposed that a predicament model may be more appropriate as it facilitates a nuanced, multidimensional understanding of the autistic lived experience and goes beyond a problematic understanding of autism and critiques the oversimplification of ideas of high or low functioning. Thus, by proposing an individualized predicament allows for a more nuanced interaction with what being autistic means without comparing it to the neurotypical standard of normality. In other words, Anderson-Chavarria argued that for autism, the condition is a highly variable and individual experience and may simultaneously be disability and positive difference and thus we need to reclaim the autistic identity and multidimensional understanding of what it means to be autistic. For Shakespeare (2008) the predicament model notes that impairment is not neutral, but neither is it all-defining and a tragedy, and the complexity of impairment is therefore a predicament.

The foundation of the predicament model is that this model of disability recognizes a disability as being biologically based *and* socially constructed, as atypical functionality can, and usually is, made restrictive through a society that does not operate with atypicality at its core (Anderson-Chavarria, 2021). So, while impairments may make life more difficult, they can be overcome and do not have to be viewed by society as unpleasant (Shakespeare, 2008). In other words, those with disabilities may need to actively confront any atypical functional restrictions as they go about their daily business, particularly if they are experiencing pain or biological impairments, and such restrictions of abilities can be thought of as predicaments (Anastasiou & Kauffman, 2013).

For conditions like autism them, the predicament model is especially suitable. The predicament model does well for those conditions where some individuals view their experience as disabling, whereas others view it as a gift or empowering (Anderson-Chavarria, 2021), and this is something we present data on later in the book. Importantly, the experience and impairments of autism are unique and often the barriers can be thought of as systemic, societal, cultural, and thus, the individuality of the autistic person shows how useful a predicament model may be.

The Intersection of Models of Disability

A model of disability should be a means to change society and uphold the human dignity of those with disabilities (Berghs et al., 2019). However, to date no model has offered a *comprehensive* account of disability, but they have all served to offer an important challenge to medicalized conceptions of difference and disability and they have served to advance political and social changes in how those with disabilities are treated (Grue, 2011). It is argued that in the modern world, we need a new approach for understanding disability, one that provides a foundation for research and practice to move forward, one that forms new alliances and makes advances in the agenda of equality in disability (Shakespeare, 2014).

In our own writing, we have not subscribed fully to one particular model; yet our social constructionist position is one that aligns well with the early writings around the social model of disability, our focus on empowerment and voice sits well with the human rights model of disability and our appreciation of the complexity and heterogeneity of autism resonates with the predicament model. From these perspectives, language use is part of the very making of 'disability,' 'normality,' 'abnormality,' etc. Importantly, though, as we have noted before, we do *not* deny the embodied 'realities' of disability. In addition, as we draw upon discursive psychology, we also take a slightly different approach to the study of power as related to disability.

Specifically, in this book, and our broader scholarship, we take a micro social constructionism position that examines how social actors within a given interaction make relevant (or not) issues of power and oppression. In other words, we do not presuppose the ways in which power structures are at play; instead, we seek to examine how the discourses of disability and mental health may make evident (or not) power and oppression. In the coming chapters, we return to these ideas and offer an explicit empirical example of how this might be understood more fully. This is particularly important when considering autism, especially as classifying autism as a disability or as a mental health condition is controversial (as we discuss later in the book) and therefore the applicability, translatability, and meaningfulness of models of disability as relevant to autism are questionable and challenging.

Concluding Thoughts

In this chapter, we have sought to provide an historical account – albeit abbreviated – of disability, particularly as related to mental health and the classification of mental 'disorders.' In doing so, we have provided a general overview of some of the key events, many of which gave rise to the asylums and emphasis of 'curing' people experiencing 'distress.' Notably, the narrative offered here is set against a backdrop wherein rapid industrialization and the medicalization of society led to standards for normative development and behaviour. These standards were arguably situated within and generated from/by the advent of psychiatry in the nineteenth century (Shorter, 1997). As Foucault (1995) so aptly noted:

> The power of the Norm appears through the disciplines...Let us say rather that, since the eighteenth century, it has joined other powers – the Law, the Word (*Parole*) and the Text, Tradition – imposing new delimitations upon them...normalization becomes one of the great instruments of power at the end of the classical age. For the marks that once indicated status, privilege and affiliation were increasingly replaced – or at least supplemented – by a whole range of degrees of normality indicating in a homogeneous social body but also playing a part in classification, hierarchization and the distribution of rank. (p. 184)

With the nineteenth century psychiatric standards and nosological frameworks greatly influencing the construction of autism, we turn in the next chapter to unpacking how the condition has historically been understood from a clinical perspective. In doing so, we aim to unpack some of the psychiatric beliefs and "discoveries" that contributed to the emergence of autism in the twentieth century.

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.

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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)

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

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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.
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Mother nine

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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.
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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

`It can become very lonely having a disabled child.`

Mother six

`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.`

Mother three

`There's um a big grieving process.`

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.

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

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

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

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Introduction

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

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

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

Autism Across Time and Place

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

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

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

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

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

Medicalization

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

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

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

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

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

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

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

A Note of Caution

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

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

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

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

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

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

Medicalization and Autism

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

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

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

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

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

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

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

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

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

The Reification of Medicalization Through Research Funds

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

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

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

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

Neurodiversity: A Notion of Natural Human Variation

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Exploring the Tensions in Practice: Findings From our Research

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

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

The Methods

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

Our Findings

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

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

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

The Boundaries of Normalcy and Autism

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

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

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

(Focus group one)

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

The Boundaries Between Ability and Disability

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

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

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

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

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

Mandy: >There is that<

(Focus group two)

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

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

Pete: ↑Right

Joanne: So it is a disability

Pete: No I don[‘t see it (.) well]

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

(Focus group two)

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

Navigating the Severity of Autism

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

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

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

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

Rani: Yea::h

(Focus group three)

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

Negotiating Epistemic Agency

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

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

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

(Focus group two)

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

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

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

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

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

Concluding Thoughts

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

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

Chapter 5
Constructing the Meaning(s) of Autism

As we noted have noted in this book, there have been a range of ways in which autism has been conceptualized and defined. Despite the wide range of the meaning(s) of autism, we have shown that it remains that the construct itself is most often located in deficit-oriented and medicalized discourses (Biklen et al., 2005), yet while autistic people themselves tend to position their autism as biological, they construct the condition as value-neutral, as an internal reality which is inseparable from who they are, the autism is a central feature of their identity (Botha et al., 2020).

As we have highlighted throughout this book, the construct of normality and the labelling of mental health conditions are clearly defined and demarcated by diagnostic manuals. Such scripts do not formulate diagnosis against the background of the individual, and neither do they account for people's lived experiences and actions; instead, a diagnosis is most often formulated against a range of symptoms that can be mapped against a pre-defined list of criteria within a certain time frame (Brinkmann, 2014). Thus, perhaps unsurprisingly, most of the scholarship *on* and/or *about* autism rests on assumptions of autism being linked to particular *labels* and *deficiencies* (Hobson et al., 2010), with the methods often used to study autism designed to identify aetiologies and/or generate interventions to cure the problems.

We have shown in this book so far, that within disability studies communities there has been a growth of the autistic voice. Indeed, there has been a growing body of scholarship that has centred the life stories of autistic individuals (e.g., Ashby, 2010; Ashby & Causton-Theoharis, 2009). Some of this scholarship has also examined how autistic identities are (re)shaped in everyday contexts (Bagatell, 2007). To date, there is also a growing body of scholarship that has drawn upon language-based methodologies and methods, such as various forms of discourse analysis or conversation analysis, to more closely analyse the meanings of autism and the interactional practices that contribute to its very making (O'Reilly et al., 2016). This scholarship sheds light on the ways that the meaning(s) of autism have come to be and are continually in the making.

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Introduction

To illustrate the ways in which meaning(s) of autism are variably performed at an interactional level, in this chapter, we share findings from a previously published paper based on the US-based study described in Chap. 1 (Lester & Paulus, 2012),[1] as well as make connections to the UK-based mental health assessment study. Specifically, the US-based analysis sought to examine the varied meanings and performances of autism within a theoretical perspective that presumed that the social world is built in and through talk. More particularly, the analysis was focused on interview data gathered from 14 parents of autistic children and eight therapists. Throughout the interviews with the parents and therapists, an attempt was made to avoid imposing an a priori definition of autism. Rather, each parent interview began with the question, "What things might you want someone who has just met your child to know about him/her?" and the therapist interviews with "What things might you want someone to know about the children you work with?" In doing so, the hope was to consider what the parents and therapists chose to make relevant about the participating children and actively avoid imposing a researcher agenda upon them. Indeed, this work sought to acknowledge that "identity ascription of any kind, and by academics as much as by anyone else, is always occasioned by some interactional or institutional circumstance" (Rapley et al., 1998, p. 825). Here in this chapter, we present findings from the analysis of the interview data, wherein the analysis was drawing upon discursive psychology and conversation analysis methodological perspectives.

Therapists' and Parents' Orientations to the Meanings of Autism

Early in the process of collecting the US-based dataset, the ways in which the shifting meanings of autism were linked to performances of 'normality', 'abnormality', and even 'exceptionality' were examined. In taking note of the performative component of autism in the interview data, the interpretation of the parents' and therapists' accounts became increasingly complicated. No longer were the parents' and therapists' accounts viewed as solely performing 'normality', 'abnormality', 'disability', or 'ability'. Instead, autism was performed in shifting and even at times contradictory ways and not always as conforming to neat binaries that are so typically employed in traditional ways of thinking about conditions. One of the initial understandings of this aspect of the data is illustrated in the following research reflexivity journal entry:

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[1] A significant portion of this chapter is taken from the previously published Lester and Paulus (2012) article in *Discourse & Society* and falls SAGE's Author re-use guidelines (https://us.sagepub.com/en-us/nam/journal-author-archiving-policies-and-re-use)

> **June 2, 2010 8:30 pm**
>
> In a parent interview today, I (Jessica) was struck by how 'autism' was not separated from the spaces in which the child and parent traversed. 'Autistic' was not how the mom first described her son. Autism was made relevant for a reason. It only came up in the context of certain spaces and events. When discussing the neighbourhood in which they recently moved, the mother said that the neighbours noticed right away that something was 'different' about her son Saturn. She continued, '. . . all we had to do was say, "Okay look Saturn has autism and this is the way it is and he's not ignoring you. He just doesn't know how to address you or to identify with you just yet. But if you give him some time he will".' About school, she said, 'They had never worked with an autistic child. So, I had to tell them what that meant and how to teach him and that he is a very smart boy.' So, as she and her son navigated these spaces, autism was performed in varied ways, for different audiences.

One of the ways in which all the participating parents and therapists performed autism discursively was to reframe the children's (non-normative) behaviours for diverse audiences. While many researchers cast framing and reframing events as a cognitive entity or task (Shmueli et al., 2006), we orient to this concept discursively and suggest that speakers (re)frame events as they work to make sense of them in coherent and believable ways. Thus, much like Edwards and Potter (1992) speak of building accounts in ways that are believable to others, this idea of reframing can be viewed as the way in which the participants re-accounted for an event or behaviour, offering an alternative explanation or account that framed anew an event or behaviour assumed to be problematic.

To illustrate the primary ways in which the therapists and parents, drawn from the analysis of the interview data, oriented to the performative components of autism, three extract are presented, which capture the contradictory, fluid ways in which notions of autism were framed for diverse audiences. The first extract focuses on what many of the therapists referred to as 'looking autistic'. The second extract highlights the elaborate work of performing normality. The final extract presents an account in which the deployment of a disability category is made in relation to others' potential (mis)interpretations. When talking about the meanings and performances of autism, the therapists, in particular, made relevant the subjective nature of being diagnosed with an autism label.

In the below, Megan (*pseudonym), a therapist, pointed to the 'look' of autism and questioned the veracity of the expert's decisions to diagnose Chance (*pseudonym), one of the participating children, with an autism label.

Extract Example

```
Megan:     Chance that little boy his paediatrician diagnosed
           him (.1) and I'm sure to the paediatrician he looks
           very autistic 'cuz he has some of those sensory
           things going on and some of those behaviour things
           and you know (.) language that hasn't developed (.)
           so I think (.1) even, I don't know, even psycholo-
           gists sometimes they they will see a child for one
```

evaluation visit and have to make a diagnosis based on that one visit (.) um (.) and I don't think they always know=

Jessica: =Mm hm=

Megan: =Like if they look autistic and they meet the criteria (.) then they're gunna get a diagnosis basically

In the above extract, Megan began by referencing Chance, whose 'paediatrician diagnosed him'. Her move to name who ('paediatrician') diagnosed Chance is particularly relevant in that across the interview data, both the participating therapists and parents spoke often about the need to educate general paediatricians about the needs, or impairment effects, of children with autism labels. While an autism diagnosis can typically be made by a range of healthcare providers (Allen et al., 2008), specialists in developmental disabilities, such as developmental neurologists or child psychologists, are oriented to in the broader and publicly available discourse as the most skilled autism diagnosticians (Center for Disease Control (CDC), 2010). Thus, Megan's move to make the 'paediatrician' relevant is telling, and points to both the local and broader discourse about who is and is not qualified to name someone autistic.

Megan next stated: 'I'm sure to the paediatrician he looks very autistic', implying that there are specific, visible characteristics, physical markers, or performances that increase the chances of being named autistic. In many ways, Megan's emphasis on the 'look' of autism points to the performative aspects of the body, highlighting the way in which a body might be oriented to and 'read' by experts as autistic or non-autistic, normal or abnormal, and so forth. She then named what it is that 'looks' autistic to the paediatrician, including 'sensory things', 'some of those behaviour things', and 'language that hasn't developed'. As Garland Thomson (1997) noted, within discourse, particular identities are produced and located 'within a hierarchy of bodily traits that determines the distribution of privilege, status, and power' (p. 6). So, it is not surprising that Megan's list ('sensory thing', 'behaviour things', and 'language that hasn't developed') matched, to some extent, the common ways of talking about, producing, and locating autism, with particular 'bodily traits' being noted, including (1) social, (2) communicative, and (3) behavioural deficits. Further, three-part lists often work to discursively create a sense of completeness and representativeness (Bowker & Tuffin, 2007; Edwards & Potter, 1992). Thus, Megan's three-part list functioned to construct autism as something that is prescriptively determined, yet just as ambiguous and open to interpretation as the 'official' diagnostic (and open to interpretation) criteria found within the diagnostic manual (DSM-IV) used by professional diagnosticians (e.g., psychologists or psychiatrists).

Although displaying initial tentativeness about offering any concrete judgment of her own, particularly about an individual (psychologist) who typically holds diagnostic epistemic rights, Megan initially stated, 'I don't know' (Edwards & Potter, 2005; Potter, 1996), and then she introduced the idea that 'even psychologists . . . don't . . . always know'. While psychologists are typically positioned as the key diagnosticians of autism (Allen et al., 2008), Megan oriented to 'even' their diagnostic abilities as being questionable based on only one visit. She undermined the validity of the diagnostic process, suggesting that the psychologist likely cannot really 'always know' because '. . . they will see a child for one evaluation visit'. All the participants who offered critiques of the diagnostic process for disability labels pointed to the minimal time the diagnostician spent with a given child. Such critiques imply that as an 'expert' spends more time with a child, s/he may discover how to more accurately interpret or read the 'look' or 'characteristics' of autism, eventually being better able to determine whether the child is really autistic or not. Megan concluded with an if/then conditional statement: 'Like if they look autistic and they meet the criteria (.) then they're gunna get a diagnosis basically'.

Conditional statements often function to distance speakers from being directly accountable for their statements, as such statements are often constructed and taken up as being factual (Potter, 1996). In this case, her final if/then statement pointed again to what happens when a child 'looks autistic'. Megan oriented to this 'look' or performance of autism in the presence of a diagnostician as inevitably resulting in a diagnosis of autism. In other words, if Chance or any other child 'looks autistic' enough to a diagnostician, he will be discovered as such. As many disability scholars have noted, 'the nondisabled gaze is the product of a specific way of seeing which actually constructs the world it claims to have discovered' (Hughes, 1999, p. 155). Thus, as was made visible in Megan's talk, autism remains '. . . a list of symptoms or behaviours or representations that can be studied and discussed, but it is not knowable as a truth. It must always be interpreted' (Biklen et al., 2005, p. 3).

So, it seems that Megan's account leaves open the possibility that autism is always already open to interpretation and contestation by those 'experts' most often deemed responsible for determining, somewhat subjectively, whether a child really is autistic, as well as those individuals who live or work closely with the child with an autism label. The construct of autism, never located as inherent to the child, is only made real when it is negotiated between the key social actors (i.e., diagnosticians and families/parents) and the child's very performance of the 'autistic look'.

Indeed, in our other work on mental health assessments we have shown that parents are key contributors to the construction of the autistic child as they build their case that the possible outcome of the assessment could be, or even should be autism (O'Reilly et al., 2017). In that work, we showed that parents often directly or indirectly oriented to the possible diagnosis of autism as they presented the behaviours and characteristics of the child, as illustrated in the two extracts below (using pseudonyms):

Extract Example (O'Reilly et al., 2016, p. 73)

```
Mum:  An' (0.40) it just it j- it just pops out at me as as
      being very Aspergecy I mean
```

Extract Example (O'Reilly et al., 2016, p. 74)

Mum: ↓an' it was like I mean it is Mrs C↓ooper ↓the SENCO at the school is ↓b you kn↓ow basically (0.38) been pushing us push (0.62) you know she's felt ↓Mandy's autistic ↓for quite a while ↓now.

Extract Example (O'Reilly et al., 2016, p. 76)

Mum: when he first went big ↓school um:: (.) he had this obsession with (0.77) needing (0.74) what was it five p↓ens three ↓pencils just and it was all I had ↓to check his bag about ↑twenty ↓times before he'd go out coz he used to ↓think somat ↓would be missing.

Performing Normality

The performance of autism is thus an important aspect of the way in which the child is constructed and perceived by those around them. The next extract (as we return to discussing our US study) illustrates the ways in which some parents went about performing their child's normality despite a medical diagnosis of autism. In this extract, Alisha (*pseudonym) constructed her son as 'a very typical little boy', locating who he is in relation to a normative backdrop, which is itself a discursive construction (Locke & Edwards, 2003). The next extract, while highlighting the common pattern of performing 'normality', shows that few parents went about performing 'normal' as elaborately as Alisha did. The extract begins just after the interviewer (Jessica) asked Alisha, 'if others were to meet your son what would be some things that you'd want them to know about him?'

Extract Example

Alisha: um (2) he is very affectionate he has feelings just like everyone else he has likes and dislikes just like any other child um (.) there's a lot of things about him that are very tyvpical (.)

Jessica: Mm hm=

Alisha: =um (.) even how he expresses even though it sometimes doesn't always seem like it in many ways is a very typical little boy=

Jessica: =Mm hm can you talk a little bit about that (.)

```
Alisha:    Um you know he enjoys he loves playing outside he
           loves the trampoline he'd probably live in it if we
           let him um he loves chocolate chip cookies and pan-
           cakes and he loves to watch cartoons he likes to he
           loves to draw (.) um and he you know he works really
           hard in school and he actually gets very good grades
           in school um he's an excellent speller he's a very
           good reader he reads above his grade level even
           though we can't have a conversation=
Jessica:   =Mm hm=
Alisha:    =he (.) he reads wonderfully loves Alvin and the
           Chipmunks you know very typical things that (1)
Jessica:   Mm hm=
Alisha:    =normal kids (.) like and very age appropriate
```

In response to the first interview question ('What things might you want someone who has just met your child to know about him?'), Alisha, like most parents, began by making relevant all that Picasso could do. She began by describing Picasso, her son, as 'affectionate' and having 'feelings'; most parents, and all of the therapists, made similar statements about the children they spoke about. Making emotional qualities relevant was particularly significant in that one of the prevailing assumptions about autism is that people with autism labels inherently lack the ability to relate to others, possessing 'no affective tie to people' (Kanner, 1943/1985, p. 24). Thus, with Picasso constructed as affectionate and having feelings, Alisha resisted or at least distanced herself and her son's identity from the dominating discourses of autism that would likely cast Picasso as possessing a 'genuine defect' in the 'understanding of the other person' (Asperger, 1944/1991, p. 81). Instead, she constructed her son as 'normal', bolstering this claim of normality by describing all that made Picasso a 'very typical little boy'. Further, she worked to normalize and reframe that which could be named an impairment effect – Picasso's communication difference. While Picasso was described by his mother and therapists as minimally verbal, here Alisha reframed his communication as 'in many ways . . . very typical'.

Her use of the phrase 'even though it sometimes doesn't always seem like it' implied that there were communicative differences that other people might name as atypical. Sacks (1984) suggested that 'doing being ordinary' is a common feature in talk, a recurring pattern in everyday social life. To present oneself or the identity of another as an ordinary social participant implies normalcy; thus, Alisha's descriptions of Picasso as enjoying being outside or liking to eat chocolate-chip cookies functioned to discursively define all the specific actions that identified her son as typical and normal (Locke & Edwards, 2003). Further, Alisha's examples of what makes Picasso typical pointed to the cultural assumption that there is a natural set of practices, actions, and behaviours common to all normal children.

With disability categories often positioned as being synonymous with incompetence, particularly when an individual is considered minimally verbal (Biklen et al., 2005), Alisha's description of Picasso as an 'above' par student functioned to counter the presumption of incompetence. While Alisha constructed Picasso as competent, she did not avoid naming what he could not do, stating 'even though we can't have a conversation'. Yet she continued by linking what Picasso could not do to what he could do: 'he (.) he reads wonderfully'. By emphasizing what Picasso can do (i.e., 'reads wonderfully'), Alisha minimized what some would name Picasso's primary impairment effect (i.e., 'can't have a conversation'). Some disability studies scholars have critiqued the ways in which 'most popular representations of autism . . . impose neurotypical formulae or conventions' on people with autism labels, ignoring social differences through the validation of 'neurotypical experiences' (Osteen, 2008, p. 9). Indeed, it is important to acknowledge this tendency and the overarching pattern in the broader discourse to impose and privilege certain social conventions.

Certainly, one might interpret Alisha's account as imposing neurotypicality on Picasso, to the demise of his differences. Yet the very task of negotiating normality, abnormality, autistic, or non-autistic identities is filled with contradiction and is a rather fragile endeavour, far more complicated than the binary constructions of typical versus non-typical or normal versus abnormal, notions which are often critiqued by disability studies scholars (Thomas & Bracken, 2004). Parents may draw upon different rhetorical and discursive devices in different contexts for different purposes. They construct and reconstruct, navigate, and negotiate their child's autistic identity in various ways depending on the institutional or rhetorical business they are performing. For example, our other work has shown that parents will sometimes utilize the device of 'doing being normal', a similar rhetorical function to 'doing being ordinary' but used as a way of contrasting their child's behaviour to that of the typically developing child to highlight the difference when building their case for a need for support and services (O'Reilly et al., 2020b). In this example, then we can see that Alisha, like all the participating parents and therapists, is engaged in the fragile and contradictory task of performing difference, normality, and even autistic or non-autistic identities in fluid and shifting ways. Much like Butler (1990, 2004) argued about the performance of femininity, all aspects of autism are constantly being negotiated, taken up, and reproduced as performative acts that function to reinforce certain discourses and ideologies surrounding autism and disability in the culture at large. These performances often act to position the very notion of an autistic or non-autistic child as being a natural truth, something that is really achievable; yet to achieve typicality or normality is impossible, as it too is a discursive construction, always shifting across time and place.

Across the parent interviews, each parent shared a story or account of a time or place in which they felt compelled to make their child's diagnostic label relevant. Many of these retellings were linked to notions of disability and normative and non-normative ways of behaving and speaking. For the parents, making autism relevant to outsiders was almost always linked to the ways in which the participating children were oriented to by outsiders as troubled or even 'unruly' and 'misbehaving'. At times, autism and other disability labels were used to reframe discursively the child's way of being, accounting for why the children screamed or moved their bodies instead of using words, for example. The label of autism, then, functioned to explain the participating child's non-normative ways of speaking and behaving, even making the non-normative more reasonable and justifiable.

Performance and Disability Categories

In the third and final extract, Nicole (*pseudonym) offers one such account, illustrating how specific events or encounters in public places were linked to the performance of autism as a disability, with the disability category itself functioning to explain her child's non-normative behaviour.

Extract Example

Nicole: When I when I when a stranger sees George I sometimes feel like I have to offer up if he isn't (.) uh if his behaviour's a little bit different that he's autistic and sometimes I want=

Jessica: =hm=

Nicole: =people um to know that um we had an incident yesterday at um at a business where he um had a meltdown in the bathroom because the bathroom door wasn't locking and it was very upsetting to him and then some employees came in and tried to get in and see if he was okay and it was you know you could hear him throughout the whole building so sometimes you know (.) I I want people to know=

Jessica: =mm hm=

Nicole: that he has a a disability

Nicole, responding to the first interview question ('What things might you want someone who has just met your child to know about him?'), emphasized that outsiders or 'strangers' orient to her son George (*pseudonym) in ways that compel her to 'offer up' an explanation. Nicole's use of the word 'sees' pointed to this idea of an autistic 'look' or body, implying that there is something about her son's actions or way of being in the world that automatically positions him as different or non-normative to outsiders. She then shared an example of an event that resulted in George's differences being noted by outsiders. George's meltdown at a business was apparently heard by everyone. While Nicole stated that the bathroom door locks were simply 'upsetting' to her son, she implied that George's meltdown was quite troubling to the store employees. Later in the interview, Nicole returned to this 'incident' and further explained that the business employees came to the bathroom to determine whether they needed to call for further assistance or security.

This event, a 'meltdown' and the response of the business employees, was used by Nicole to account for making relevant and even naming her son's disability. Further, as broad categories that are both open to interpretation, the terms 'autism' and 'disability' functioned to reframe the 'meltdown' as explainable, even justifiable. If a child is constructed as autistic and has a meltdown, the meltdown is oriented to as more justifiable, as autism is then positioned as a disabling entity that caused the meltdown. However, if a child is constructed as non-autistic and has a meltdown, the child may simply be positioned as ‘unruly’ and ‘misbehaving,’ as one father spoke about in his interview. Sacks (1992) reported that a common rhetorical move in discourse is to resist being accountable for an action or situation by defining that action as commonplace, normal, or expected (Edwards, 1997). Indeed, parents frequently use rhetorical discursive strategies to account for their child’s behaviour in ways that construct it as dispositional and thus mitigating any potential challenge that this is due to poor parenting or a failure of discipline (O’Reilly & Lester, 2016; Patrika & Tseliou, 2016). It is possible then that Nicole’s deployment of the terms ‘autism’ and ‘disability’ functioned to distance herself and her son from being responsible for the meltdown, with autism or a disability positioned in that role instead.

A body named ‘a little bit different’, ‘autistic’, or ‘disabled’, much like other bodies, is always already an object of discourse caught up in multiple systems of meanings and representation (Bordo, 1992; Foucault, 1971; Turner, 1984). Normative behaviours in a business space do not typically (if ever) include meltdowns or looking ‘a little bit different’. So, in the above extract, Nicole’s construction of George’s behaviour as ‘a little bit different’ (line 2) also illustrated the ways in which his body might be constructed and oriented to by others as troubled.

In this way, children’s bodies or actions/behaviours themselves are sites of discourse, with their bodies/behaviours often being constructed as autistic, disabled, abled, normal, abnormal, etc. Foucault (1972) suggested that discourses constitute and even regulate the body in certain ways, ‘exercising upon it a subtle coercion... obtaining holds upon it at the level of mechanism itself – movements, gestures, attitudes, rapidity: an infinitesimal power over the active body’ (p. 137).

Concluding Thoughts

In Nadesan’s (2005) historical account of the making and remaking of autism, she spoke about the performative aspect of autism, stating:

> . . . autism has a performative component, as known by every parent who struggled to meet the criteria for government and educational services for their children. For the social services agent, I [as a parent of a child diagnosed with autism] must stress (and even exaggerate) Kamal’s [her son] maladaptive behaviours. For his teachers, I stress Kamal’s high intellect in order to avoid having him labeled as ‘mentally retarded’. For his peers, Kamal performs ‘normality’ in the context of the school playground by stifling his odd interests and masking social awkwardness in order to ‘fit in’ with the other children. (p. 2)

Nadesan’s words capture the social, political, and economic constraints that shape the performative aspects of autism, pointing to how parents of children with autism labels make real varied versions of autism for particular audiences. Similar to Nadesan’s (2005) historical account of the making and the remaking of autism, the findings of this study make visible the performative aspects of autism as the participants made real varied versions of autism for particular audiences. We found that the therapists and parents both oriented to a diagnosis of autism as a subjective matter, as definitions of autism vary and change both officially and unofficially. Rather than equating a diagnosis of autism as a diagnosis of incompetence, we noted that in some situations parents and therapists performed a child's 'normality' (competence) and in other situations they performed the child's 'abnormality' (incompetence). Building upon Rosetti et al.'s work, this study's findings point to the ways in which 'behaviours and actions traditionally linked with incompetence' can and even should be reframed and reinterpreted (p. 364). For example, the idea that a child's look 'or way of moving their body or expressing themselves is read' as plainly pathological, often results in misinterpretation by outsiders (e.g., the child is constructed as 'threatening' or 'incompetent'), something which was made relevant by the participants in this study over and over again. The body, as a site of discourse and performance, can resist and re-invent identities. As Carlson (1996) noted, 'performance can work within society precisely to undermine tradition, to provide a site for the exploration of fresh and alternative structures and patterns of behaviours' (p. 15). Yet few parents worked to perform autism in ways that positioned their children's non-normative behaviours as 'alternative structures and patterns', which could function to redefine and rework all that is named typical or normal development, while many of the therapists did so. Nevertheless, the parents did speak of the ways in which the participating therapists assisted them in making sense of their children's behaviours/actions and communication styles, helping them and their children to redefine all that counted as successful functioning. The therapists, who often explicitly taught the children how their very bodies were oriented to by outsiders, seemed to go about the work of co-constructing and reframing with the children, in particular all that might be oriented to by others as problematic. This discursive work of reframing most often occurred in the one-on-one therapy sessions of the participating children and therapists analysed, and these are explored in a future study (Lester, 2011).

Suggesting that performative acts of normality elide differences (Osteen, 2008) ignores the challenge of living in a society that is politically, socially, and economically structured to privilege those who speak and act in normative ways. So, while some of the parents' discourse functioned to construct their children as 'normal' in many ways, they produced such constructions within a social and political context that privileges highly verbal people who behave in normative ways (e.g., people should not flap their hands to communicate excitement, but instead should use words or widen their eyes with surprise, expressing themselves in more 'acceptable' or normative ways). If the parents had constructed their children as minimally verbal or quite inept, perhaps the competency and even humanity of the child would be jeopardized or at least questioned by outsiders, particularly individuals who are unfamiliar with the particular communicative style (Rocque, 2010). As Lewiecki-Wilson (2003) noted, 'we [the majoritarian culture] often demand some verbal response from another as proof of their humanness' (p. 157). Nelson's (2004) official statement to the United Nations pointed to the ways in which individuals with autism labels are misunderstood and excluded, stating that ‘we [people with autism labels] experience discrimination in various forms, often because of our different use of language and communication . . .’ (p. 1). Thus, it is important to interpret the discursive practices of the participating parents and therapists in relation to the exclusionary practices and policies that they and their children encounter daily.

Chapter 6
Mental Health, Autism, and Issues of Inequality and Resources

> *The burden and inequalities in mental healthcare throughout the world are critically important health issues, and taken together present immense ethical challenges.*
>
> *(Ngui et al., 2010, p. 235)*

Globally, governments face challenges investing in health, and this is a crucial area for most countries. Despite voiced commitments to supporting health, many healthcare systems across the world are plagued by complex financial difficulties, because of the growth of chronic illnesses, disabilities, and aging populations. There has been a longstanding understanding that growing economies are associated with healthier and longer lives, with economic booms boosting mortality rates and austerity reducing them (Frakt, 2018). Within individual country economies, there can be diversity in health outcomes, and even in affluent societies there is a persistence of health inequalities (Szreter & Woolcock, 2004). Nonetheless, broadly and overall, economic growth in affluent countries has been associated with better nutrition, stronger public health infrastructures, and more effective medical technology; thus, in countries where there is greater wealth, people tend to live longer, and childhood mortality rates are lower than those countries that lack this financial position (Frakt, 2018). Notably, inequalities, resources (economic, social and familial), and provision of services are all important issues when considering autism.

Introduction

Our intention in this chapter is *not* to provide a critical sociological polemic, and neither is it to fully engage with the rhetoric of capitalist societies in relation to health. Nonetheless, through our focus on resources, inequalities and autism, some of our positions and arguments, as well as our engagement with some of the

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politically driven literature on autism, will touch on broader social arguments related to autism.

It is important to appreciate where autism fits in with the broader resource context and as a benchmark for considering the impact on individuals, families, and communities. However, in providing this broader context this may seem that we are buying into the positioning of autism as a mental health condition, as a disability; yet, this is not necessarily the case, as our critical questioning of this argument demonstrated in previous chapters. Indeed, the boundaries of autism being classified as a mental health condition and a disability are fluid and are only partially accepted as relevant to some autistic people. Regardless, within a social constructionist and person-centred framing, the challenges and inequalities on a broader level of the economy, parity of esteem, and resource implications in an age of austerity are especially pertinent in terms of autism. Therefore, the contextualization offered in this chapter is important for understanding the critical positions and ideas in the field.

Furthermore, as we have noted on various occasions throughout the book, while we take a somewhat critical questioning position through our social constructionist stance, we do not deny the reality of conditions in the lives of those impacted. Like Thomas et al. (2018) noted, we argue that it is important to recognize the ways that scientific knowledge and the narratives of illness are invested with meaning to be tools for the pursuit of political agendas. In other words, the personal experiential realities of autistic people, their families and communities, and their meanings and understandings of resources, inequalities or marginalization perceived or felt by them are important to acknowledge through a social constructionist lens, as is any celebration of identity and rejection or questioning of medicalization.

Health Inequalities

Research and knowledge regarding health inequalities has grown significantly in recent times, with a visible increase in publications concerning issues of inequality and health, although most of this is produced by higher-income country authors (Cash-Gibson et al., 2018). The global pandemic in the form of COVID-19 has particularly highlighted the impact of health inequalities, within and across countries. Indeed, there has been significant attention paid to the challenge of vaccine inequalities, as certain countries struggle to immunise their population (Vaughn, 2021). Of considerable concern, is that research is showing that the pandemic has disproportionately impacted historically disadvantaged groups and has certainly widened inequality (Perry et al., 2021). This is congruent with other work that has shown that natural and man-made disasters create a greater health burden on the most disadvantaged in societies (Waters, 2016). Given that autistic people and their families, have historically been part of those disadvantaged groups, clearly, we need to pay attention to this issue.

It has been argued that health and equality are tied to the efficacy of social capital. Three related approaches in terms of inequality, health, and economy have therefore been developed and reported by Szreter and Woolcock (2004):

1. first a 'social support' position that informal networks are central to welfare,
2. second an 'inequality' position that argues that economic disparities have compromised a sense of social justice and inclusion, leading to increased anxiety and reduced life expectancies,
3. third a 'political economy' position that views the primary determinant of poor health outcomes as a politically and socially mediated exclusion from material resources.

Szreter and Woolcock argued that a more comprehensive approach to social capital is needed, distinguishing between bridging, building, and linking social capital. However, the hold of social capital has been argued to be incompatible with the neoliberal political agenda that is rising in many Western countries, and this has broader implications for health and health inequality (Ferragina & Arrigoni, 2017).

Neoliberalism is argued to be intensifying in many Western countries, and consequently citizens have been repositioned as consumers of public services with consumer rights (Peters, 2000). Arguing in the context of New Zealand, Peters acknowledged that there has been a shift in social welfare and education, with substantial cuts to social welfare and support – a position which is mirrored in many other countries. For the UK and the US, it was during the 1970s and 1980s that saw a rise in neoliberalism, with Margaret Thatcher's model of economic policy promoting privatization of public services, reducing public spending and Ronald Regan aligning with Thatcher's ideas, favouring the dismantling of social welfare systems (Evans, 2017). Thus, a neoliberal position in Western economies sees social policies as 1) concerning domestic, personal and sexual life, 2) focusing on issues such as education and social reform (Richardson, 2005), 3) opposing what is viewed as excessive intervention by the State, and 4) repositioning responsibility with individuals (Goodley, 2011).

Such neoliberal political doctrines can lead to increased income inequality and reduced social cohesion, thereby undermining the welfare state, and promoting the class structures of advanced capitalist societies. This in turn impacts health and health care (Coburn, 2000, 2004). In other words, "neoliberalism is sustained by identifying the responsible compliant citizens 'us' – and those who fail to live up to the neoliberal type – 'them'." (Runswick-Cole, 2014, p. 1118). Clearly, this individual accountability rhetoric has important implications for both health inequalities, but also for those with disabilities, including psychiatric disabilities, and autism.

Socioeconomics, Health, and Disability

As we have previously noted, historically wealth and poverty are correlated with quality of life, health, and mortality, and this is across and within nations. Evidence has consistently demonstrated that wealthier individuals tend to have better health outcomes and live longer when compared to those from lower socio-economic indices (White, 2009), and poorer individuals are more likely to experience chronic conditions (Nettleton, 2013). Contemporary health policies across the globe have recognized the importance of addressing these inequalities and have aimed to address poverty, with efforts to empower people through health education and access to necessary medications and services (Russell, 2014). Despite these endeavours, children living in poverty may still be exposed to a range of adverse circumstances (e.g., poor physical health) (Brooks-Gunn & Duncan, 1997). For children with disabilities, the effects of living in poverty can have even more damaging effects (Park et al., 2002).

Notably, the relationship between health inequality, poverty, and disability is bidirectional, in that, those from lower socioeconomic indices are more likely to experience disabilities, and those with disabilities are more likely to experience social and economic disadvantage. For example, evidence from Western countries, such as the UK and the US, demonstrates that families of children with a disability are more likely to experience financial difficulties, exacerbated further by the likelihood that these will be single parent families or families from minoritized groups (Emerson, 2003). Furthermore, disabled children have been found to be more likely to live in households with lower parental educational levels when compared to children without disabilities, with education being associated with income (Montes & Halterman, 2008). Thus, the income of parents of disabled children was on average 32% lower than other parents (Parish et al., 2004). For example, in the UK, the average income was shown to be £15,270 per annum, compared to the mean income of £19,968 per annum, which is 23.5% lower. Furthermore, 21.8% of these families have an income lower than 50% of the UK mean (The Papworth Trust, 2016). Juxtaposed with this, is the reality that the annual cost of raising a disabled child is three times higher than raising a child without a disability (ibid.).

Aside from the likelihood that disabled people are more likely to experience financial hardship, related to this is the (im)possibility of employment. For example, statistics from the UK demonstrate that only 46% of disabled adults in Britain are working, compared to 76% of the general population, with those with a mental health condition at an even greater disadvantage with only 17% in employment (Office for National Statistics [ONS], 2014). There are several factors which underpin this situation, including that ill health is itself a barrier, but also there is a lack of job opportunities, increased family responsibilities, difficulties associated with transportation, lower educational attainment, increased anxiety, and limited confidence (Russell, 2014). Stigma, which we discuss in Chap. 7, is another potential factor. For parents of disabled children, there is also an increased demand on time for care and a lack of affordable childcare, limiting employment opportunities (Shearn & Todd, 2000).

There are social inequalities in healthcare that partially relate to discourses of accountability, moral positioning of disability and employment, and the rhetoric of blame and medicalization. The neoliberal position that is rising in capitalist societies constructs illness and disability as an individual problem, and risks framing this as ‘bad luck’, orienting individuals as objects of charity or pity and viewing disability in comparative terms (normal versus abnormal) (Ramanthan, 2010). Clearly, people's responses to disability or illness are not simply determined by a disability or illness nor their biological symptoms; rather, the social, cultural and ideological context in which they live play a significant role (Nettleton, 2013). Even still, neoliberalism positions individuals as responsible, and indeed accountable, for their lifestyle choices which may contribute to a disability profile.

Neoliberalism and The Sick Role

Accountability for one's health has been embedded in mental health discourses, and the rhetoric of blame is one that has been problematic in society for a significant time. The current economic climate is especially challenging for those with mental health conditions, as the notion of self-responsibility is imbued through neoliberalism. Furthermore, government policies reflect this neoliberal oriented position by actively encouraging the uptake of employment and simultaneously placing restrictions on entitlements to welfare (Thomas et al., 2018). Through this, moralizing narratives have been created, constructing and promoting the ideology that individuals are responsible for their own health and their mental health (ibid.). In so doing, these moral positions encourage individuals to be active agents and not passive recipients of care (Ellis et al., 2017).

Through such moral positions, disabled people are constructed as morally weak and stigmatized for not taking up employment (Thomas et al., 2018). This is because increasingly around the world, and especially in the West, independence and self-sufficiency are valued as traits, and parents are considered to be 'good parents' if they raise independent children (Kane; 2016; Lavee, 2015; Tabatabai, 2020). Problematically, then, the narrative of neoliberalism idealizes independence and self-sufficiency which is narrowly constructed in economic terms (Reich, 2014; Shuffelton, 2013). In other words, we live in a society whereby our identities are organised and managed as consumers (Giroux, 2012) and for those that struggle to, or cannot manage this independent consumer identity, they are subject to stigma and challenges, and can be especially judged if they fail to contribute to the labour market.

In relation to mental health, as we showed earlier, only 17% of the British population with mental health conditions are employed (Office for National Statistics [ONS], 2014), but in the general population, mental health related issues accounted for approximately 17.6 million days of sick leave, reflecting 12.7% of the total sick leave in the UK (ONS, 2016). For others, the nature of their mental health condition, or the disability they experience leaves them reliant on welfare and support from the State. To mitigate moral accountability of any support required, therefore, those with disabilities arguably adopt a 'sick role' which is claimed to be a survival strategy to enable the legitimate claiming of welfare support (Hansen et al., 2014) or to justify absenteeism from work.

For context it is important to appreciate the theoretical framework around these ideas regarding the construction of a 'sick role' and mental health as a way of managing the moral work of the patient. The notion of the 'sick role' was presented through sociological research and was underpinned by functionalist theory. Functionalist theory highlighted the importance of the social aspects of health and how people adopt a certain health identity when diagnosed with illness (Nettleton, 2013). This position is often contrasted with interpretivism, which focused on how individuals made sense of their illness experiences and how their interpretation of their health affected their behaviour (ibid.). Specifically, it was Parsons (1951) who introduced the concept of a 'sick role', and when legitimized by the medical profession allowed the sick person to negate moral responsibility for being unable to fulfil their social obligations. However, such moral accountability was only legitimized if the person cooperated with medical assistance and worked toward recovery (Nettleton, 2013). Yet not all illnesses are curable, and not all conditions are granted the privileges of illness and thus the legitimacy of the illness is questioned and the illness itself stigmatized (Freidson, 1970). Thus, an individual (i.e., a patient) must have a doctorable reason for needing medical assistance to acquire a legitimate 'sick role' and must strive towards recovery and cure (Seale et al., 2013).

In a neoliberal society therefore, social harmony is sought, and this is achieved through the social control function of medicine, as the goal of medicine is to return people to a state of wellness. Through this functionalist theory then, sickness is seen as a social condition, and not just a biochemical one (White, 2009). We would point out here that the functionalism argument has received some criticism due to its reductive nature (Donoghue, 2003) and because this idea is better suited to individuals with acute sickness and does less well in explaining chronic illnesses and disabilities (White, 2009). Nonetheless, the broader polemic represented by these ideas of legitimacy and moral positioning in illness does chime with the neoliberal rhetoric currently imbued within the social expectations of disabled people and is also congruent with medicalization and the responsibility of psychiatry to treat the mentally unwell.

Inequality and Mental Health

These inequalities in relation to disability and health are possibly nowhere as profound as in relation to mental health and so called psychiatric disabilities. As we have noted previously in the book, the boundaries for viewing autism as a mental health condition are fluid and reflect different perspectives in the field and the spectrum nature of the condition itself. Nonetheless, while there are tensions in the construction of autism as a disability, the social inequalities and health challenges are connected with the autistic community in many different ways, and we link this to the broader discourses of inequality and mental health in a loose and general way, because of the wider relevance.

Globally there are significant inequalities in mental health, especially in terms of access to mental health care and treatment (Mills & Fernando, 2014). There is also a well-established association between poverty and mental health (Burns, 2015), with poverty often described as contributing to mental ill health, and mental health conditions leading to or exacerbating poverty (Thomas et al., 2018). Indeed, some have argued that the onset of the economic recession in 2008 is correlated with the increase in prevalence of mental health conditions (Barr et al., 2015) and there is disproportionate prevalence of mental health conditions in lower income groups (Saxena et al., 2007). However, there is a lack of clarity regarding the causal relationships between poverty, inequality, limited education, and employment, and a need to ascertain which aspects of poverty are key drivers of mental health conditions (Burns, 2015). Burns noted that the neoliberal political doctrine has increased inequality and reduced social cohesion, and thus inequality in mental health is related to broader political endeavours and structures.

The Cost of Mental Health

> The economic burden of mental disorders is great.
> (Ngui et al., 2010, p. 239)

Almost one third of countries do not have a specific mental health budget, and of the 101 that do, 21 one of them spend less than 1% of their total health budget on mental health, and many more spending a very small percentage (Saxena et al., 2007). For instance, in the UK, the National Health Service (NHS) spends as little as 6.6% of its total budget on mental health (Campbell, 2014), although figures reported do vary slightly depending on the publication. Nonetheless, the spending is small, and this has been described as “chronic underinvestment in mental health care across the NHS in recent years” (Mental Health Taskforce, 2016, p.10). Globally, this lack of investment in mental health is a serious problem and equates to less than 2 US dollars per person in wealthy countries, and less than 0.25 US dollars in low-income countries (World Health Organization, 2013). Such minimal investments lead to a serious shortfall in attending to mental health and recognizing the impact of mental health conditions at an individual, community, societal, and global level. The cost of mental health conditions to a country however are significant, in terms of loss of productivity due to illness, welfare payments, physical health costs as related to the mental health condition, and so forth. For example:

- In the U.S the indirect costs associated with mental health conditions was estimated to be over $79 billion (Mandersheid et al., 2007).
- In Canada, the economic burden of mental health conditions was estimated at $34 billion (Patra et al., 2007).
- In Europe, mental health conditions are estimated to cost between 3–4% of the gross national product (World Health Organization, 2005a).
- In the UK, the costs are estimated at £105 billion (figures for 2010), which is more than the cost of obesity and cardiovascular disease together (Lamb, n.d.).

The real economic costs are likely to be higher from when these estimates were put forward, given that prevalence rates are rising globally (Bor et al., 2014) and the impact of COVID-19 on mental health is likely to be profound, leading to a greater demand for services (Holmes et al., in press). Consequently, the lack of congruence between the resources for mental health and the global burden they create has been described as alarming (Ngui et al., 2010).

Indeed, this is a position we agree with. The inequality of mental health is especially concerning when considering the impact that mental health has on individuals, their families, and countries. It is simply unacceptable that those with mental health conditions are failing to receive the supports, services, and/or treatments they need, and that there are delays in seeking help and achieving diagnosis for those that benefit from them. While in this book we are focusing on autism, the broader arguments related to mental health inequality are important and these figures reflect a global inadequacy for managing mental health in society or for those who experience financial hardship due to living with autism. Poor mental health across a nation has an impact on employment rates, welfare spending and mortality, and generally intersects with the criminal justice system with higher rates of mental health conditions present in the system (Mental Health Network, 2014). The literature also demonstrates that autistic people are overrepresented in the criminal justice system (Cashin & Newman, 2009), raising a plethora of critical questions and concerns. Importantly, mental health conditions account for nearly half of those claiming disability/incapacity benefits (London School of Economics and Political Science, 2012) and the rates of mental health conditions is highest amongst poorer groups, including those who are less well-educated and those living in rural communities (Saxena et al., 2007). This is clearly an important issue as there is a great deal of inequality in terms of access to mental health care and health outcomes (Ngui et al., 2010).

Notably, it has also been well-established that disabled children access the healthcare system far more than other children (Lin & Lave, 2000). For example, children with disabilities had almost eight times higher expenses for inpatient hospital care, and three times the average expenditure on physician and non-physician expenses, with prescribed medications being five times higher and three times higher for other medical expenses (Newacheck et al., 2004). Children with mental health conditions particularly levy a significant cost (Belfer, 2008); as there is an increased cost to society in terms of educational provisions, social services, and the criminal justice system (Knapp, 2000).

Parity of Esteem

> The demand for mental health services exceeds supply everywhere, and perhaps always will. (Taylor, 2014, p. 733)

There is indeed significant demand on mental health services, and significant unmet mental health need. This is particularly striking when compared to physical health.

For example, it has been shown that 92% of people with diabetes receive treatment for their condition, and yet only 28% of those with mental health conditions do (Mitchell, 2013). Thus, while there are health inequalities generally with poorer people being disadvantaged, and mental health inequalities, with those from lower socio-economic groups having greater levels of mental health need, there is also a disparity between physical and mental health. For some, this has been conceptualized as 'parity of esteem', with a drive to create equality in terms of access to services, quality of care, and allocation of resources between physical and mental health (Parkin & Powell, 2017). Parity of esteem is an important objective for healthcare provider and government and can be addressed through different perspectives, as Mitchell et al. (2017, p. 197) argued:

> Parity of esteem can be viewed from the perspective of patients (the right to equal standards of quality of care in both mental and physical health), from the perspective of clinicians (equal focus on both mental and physical health) and from the perspective of commissioners (providers should devote the same time and resources to improving mental health as they do to physical health).

In other words, parity of esteem refers to a wider ideology to value mental health in the same way as physical health to address inequalities related to mortality, morbidity, and delivery of care (Mitchell et al., 2017) and in research (Morton & O'Reilly, 2019).

Over time, some countries have started to take the issue of parity of esteem seriously in their healthcare policy and delivery. For example, in the US, parity became law in 1996 under the Mental Health Parity Act (MHPA) and in 2008 under the Mental Health Parity and Addiction Equity Act (MHPAEA) (Mitchell et al., 2017). Similarly, in the UK, the Equality Act of 2010 did place a legal responsibility on health services to make reasonable adjustments to not disadvantage those with mental health conditions (ibid.), and in 2011 the mental health strategy for England adopted the recognition that there is 'no health without mental health' (World Health Organization, 2005b). Despite this however, implementation of parity and real change across healthcare systems and governments has been painfully slow to be realised. As Hilton (2016, p.135) noted:

> When high-tech and low-tech specialties compete for the same pot of money, the latter are disadvantaged. Western society demands state-of-the-art high-tech clinical practices for physical illnesses, and these are readily adopted and funded. It places less value on low-tech innovations, the mainstay of treatment in psychiatry. Changing this balance requires a mind-shift of professionals and public, but achieving a change in expectations and behaviours can take years.

Some scholars have added weight to these ideas suggesting that parity in healthcare for those with mental health conditions ought to be viewed as a basic human right (Fleischacker et al., 2008).

This notion of human rights is especially important in current healthcare, because evidence suggests that those individuals diagnosed with a mental health condition, tend to receive medical, surgical and preventative care that is inferior, and this is exacerbated by high levels of stigma, medication side-effects and lower help-seeking behaviours (Mitchell et al., 2017). Advances in parity are hugely important as improving mental health and investing in mental health support has a great deal of benefits to the economy and the individuals, as it has potential to reduce physical illness symptoms, lessen demand on physical healthcare, increase employment for adults of working age and improve independence for older adults (Hilton, 2016). Indeed, the importance of addressing parity of esteem is further related to the relationship between physical and mental health. For example, research suggests that 46% of those diagnosed with a mental health condition also have a long-term physical health condition, and likewise, 30% of those with a long-term physical health condition also have a mental health condition (Naylor et al., 2012). Furthermore, individuals with severe mental health conditions can die 10–20 years prematurely and have a high rate of physical illnesses (Mitchell et al., 2017). Indeed, mental health conditions can have the same effect on life expectancy as smoking and can have a greater effect than obesity (Hilton, 2016).

COVID-19 and Autism

In considering the intersections between physical and mental health, it is important to recognise the impact of COVID-19. It would be remiss of us not to consider COVID-19 in this chapter given the significant global impact of the pandemic, which is still ongoing at our time of writing this book. Indeed, the impact of COVID-19 is likely to be more significant and challenging for autistic individuals, who have challenges in managing change and uncertainty (Wigham et al., 2015). Research suggests that the fundamental characteristics of autism may impact on those individuals as they try to function in a society that imposes a range of public health measures designed to reduce the spread of the disease. For example, inflexibility, desire for sameness and routine, and challenges in social interaction associated with autism (American Psychiatric Association, 2013) may make it more difficult for autistic individuals to adapt to public health measures such as social isolation, quarantine and working from home/ home schooling. For example, this was outlined by Eshraghi et al. (2020, p. 481):

> Autism spectrum disorder is often accompanied by anxiety, dyspraxia, learning disabilities, epilepsy, fragile X syndrome, Down syndrome, and immune system alterations. Individuals with autism can also have different types of behavioral challenges including deficits in social communication, attention-deficit hyperactivity disorder, irritability, and aggression. Such common comorbidities can present additional challenges for individuals to cope with during the COVID-19 pandemic, making it more difficult to receive needed therapies, practice physical distancing, and adjust to disrupted daily routines.

The public health measures implemented across the globe, can be especially challenging for autistic individuals, as they may find it difficult to wear a mask or may not understand why it is needed, and may not fully comprehend the benefit of vaccination (Eshraghi et al., 2020). Additionally, autistic individuals have been thrown into a chaotic environment with a constant state of flux and increased demands of living in society, and those without a supportive network of friends and family may be at greater risk (den Houting, 2020).

There are further challenges for autistic individuals if they contract the virus as this may need to be tested to confirm this, may need healthcare support, and in some circumstances may need hospital visitation. Emerging research is highlighting that autistic individuals may be at greater risk from contracting COVID-19, and while some of this may be explained for those with lower functioning by a limited comprehension on how to safeguard their health, there are other important factors. This is especially true for those who are residing in institutional residential care settings, as they live in closer proximity to others, tend to share facilities, and may be excluded from support that is needed (Ne'eman, 2020; Ramgopal, 2020). However, autistic individuals have a wide range of factors that may mean they are at greater risk associated with COVID-19, regardless of their residential status.

Research indicates that autistic individuals have a tendency toward a pro-inflammatory state which puts them at greater risk of more severe symptoms (de Sousa Lima et al., 2020). Furthermore, there is an evidence base that autistic individuals have co-occurring conditions (which we discussed earlier in the book), and are at greater risk for overall poor health when compared to the general population (Dunn et al., 2019), including sensory impairments and physical disabilities (Kinnear et al., 2020), and type 2 diabetes (Chen et al., 2016) all of which are associated with risks for poor recovery from COVID-19 (Cariou et al., 2020). This is further problematised in the context of treatment for the virus. Research has illustrated that the intensity and sensory challenges in an emergency department of a hospital can create distress for an autistic individual, and this is exacerbated by a lack of staff knowledge about autism, long waiting times, and insufficient engagement with parents or carers (Postorino, et al., 2017). It is further problematic that some autistic individuals, especially autistic children need someone to stay with them during the hospital visit or stay, and this is challenging in the current environment (Eshraghi et al., 2020).

There are also systemic issues that may impact on autistic individuals. It is likely that family and community challenges will directly and indirectly affect the autistic community. For example, it is plausible, that the pandemic has increased parental anxiety, concerns regarding employment, economic uncertainty, reduced access to health care and services, and increased waiting lists for interventions that autistic people need (Smile, 2020). Having an autistic child in a family can be stressful, and no doubt the pandemic has added a degree of disruption to family life, exacerbating these stresses (Manning et al., 2020). Manning et al. argued that COVID-19 has disrupted services, impacted finances, and parents of autistic children have found the consequences of the pandemic very difficult to manage. Despite the increases stressors and challenges associated with the pandemic, however, research has indicated that some families did experience some aspects of the pandemic, such as lockdown in positive ways. For example, where parents were able to accommodate their child's needs, were resourceful and creative, they were able to maintain a positive outlook, although there were some concerns about their abilities to home educate and about the possible longer-term impacts (Latzer et al., 2021). Thus, the pandemic has illuminated how important it is that there is meaningful collaboration between autistic individuals, families, caregivers, healthcare professionals and other stakeholders who are all invested in the wellbeing of the autistic community during this time (Baweja et al., 2021).

Autism, COVID-19, and Inequalities

The pandemic has created new ways of living, new challenges, and a wide range of changes across societies, and as we stated earlier in the book, has likely created and exacerbated inequalities in for the most disadvantaged. There is a risk that during the pandemic the inequalities that are embedded within society have disappeared from public view (Blow, 2020) and for autistic people, the difficulties they face no longer acquire public attention as advocacy organizations, community groups and researchers have been more challenged in making visible these crucial issues in ways they did previously (Ne'eman, 2020). Furthermore, autistic people are at higher risk of vulnerabilities (Griffiths et al., 2019) and health inequalities (Hirvikoski et al., 2016), which are likely to be magnified in the pandemic, although the full extent of the impact is unknown (Cassidy et al., 2021). The contributory factors for exacerbating inequalities for autistic individuals are multi-factorial and should be consider systemic (Spain et al., 2021). Systemic inequalities already exist for autism including, ethnic, socioeconomic, cultural, and structural inequalities (Singh & Bunyak, 2019).

While there may be positive effects for some autistic children and adults, as home schooling or working from home can be positive (see our section on the internet), there likely remain challenges and vulnerabilities related to coping with unpredictable changes in routine, greater levels of uncertainty, and reduced supports which are likely to exacerbate inequalities for this population (Ameis et al., 2020; Cassidy et al., 2021; Tromans et al., 2020a, b). It is indeed problematic that the vulnerabilities and inequalities related to autism have tended to be ignored by governments, and despite their high levels of need, they have generally been invisible at a political level (Spain et al., 2021). Thus, there are many hidden inequalities and injustices for autistic people, and Pellicano and Stears (2020) outlined these as being:

1. The experience of abuse and exclusion from appropriate care, in health, social care and education.
2. A disproportionate impact on the mental health of autistic individuals, with increased stress.
3. Economic inequality and employment challenges.

We look at each of these domains of inequality in turn, recognising that there is overlap between them and there are degrees of impact and relevance across and within them.

First, it has been highlighted that autistic individuals have been subject to abuse during COVID-19, which is an extreme consequence of the pandemic for some, and for others there has been an exacerbation of exclusion or challenges in accessing support. Given that autistic individuals tend to experience victimization and abuse at elevated rates, they are obviously at greater risk of this during periods of lockdown (Weiss & Fardella, 2018), given that domestic violence has significantly increased in households generally during the pandemic (James, 2020). More broadly, however, are the inequalities related to supports, in education, employment, health and social care. A greater emphasis is needed on designing socioculturally appropriate and diverse programmes and to increase psychosocial supports so as to mitigate any effects of isolation for autistic children (Smile, 2020) and autistic adults. This is particularly important as families of autistic children need support, and autistic adults require their ongoing supports and services to continue. Thus, while some autistic people have received support through video conference or via the telephone, many will have become invisible and received no support at all (Pellicano & Stears, 2020). However, because of the pandemic, many services and organizations providing care, health services or educational programmes across the world were closed which meant that autistic children and adults have received fewer necessary therapy hours (such as occupational therapy or speech therapy), and have had their usual routines severely disrupted, creating difficulties for them and their families (Eshraghi et al., 2020). This reduced access to timely and appropriate healthcare has contributed greatly to the inequalities experienced by autistic individuals (Sharpe et al., 2019). Traditionally autistic individuals have experienced barriers to accessing healthcare and support. Some of those barriers relate to the nature of autism, such as being unable to communicate their difficulties, a limited health literacy, anxiety, social isolation or avoidance behaviours (Thye et al., 2018), but some of those issues relate to insufficient reasonable adjustments to account for autistic individual's needs such as an inflexible approach in care settings, lack of autism leadership, limited clinical understanding of the complex interplay between physical and mental health conditions and diagnostic overshadowing (Buckley, 2017).

Second, concerns have been expressed that the pandemic is having a disproportionate impact on the mental health of autistic individuals, although there is limited evidence currently (Pellicano & Stears, 2020). However, there is evidence growing to suggest that the general population is experiencing increased anxiety, depression and trauma because of increased isolation, uncertainty and lockdowns (Holmes et al., in press; Holt-Lunstad et al., 2015), and these are all mental health conditions that autistic people are more vulnerable to (Rumball et al., 2020). This is especially problematic as the loss of usual routines and structure can be especially anxiety provoking for autistic individuals (Kerns et al., 2014) and autistic populations tend to have higher levels of co-occurring mental health conditions (Hollocks et al., 2019; Karim et al., 2014). Recent evidence suggests autistic individuals have experienced greater stress and anxiety and have reported disruption and distress associated with challenges to employment or schooling, and their social lives (Bal et al., 2021).

Third, there have been considerable economic inequalities for the autistic community, and this is potentially exacerbated by the pandemic. COVID-19 has impacted the economy of most countries, and millions of people have experienced unemployment and poverty, which are set to worsen as the crisis continues, and there is little evidence thus far on the impact on autistic people (Pellicano & Stears, 2020). The impact however is likely to be considerable, as the employment prospects for autistic individuals has traditionally been poor (Nicholas et al., 2019) and so it is reasonable to expect that autistic individuals will be exposed to a downturn in the labour market as the pandemic continues and wanes (Pellicano & Stears, 2020).

Neoliberalism, Economics, and Autism

As we noted previously, the prevalence of autism has increased. We acknowledged that figures suggest a prevalence of approximately 1% of the population (Brugha et al., 2009). This increased prevalence of autism has been argued to have led to greater demands on agencies that provide services for autistic people, including healthcare, social care, and education (Ruble & McGrew, 2007), a demand that is likely to increase as the world works through COVID-19 (Holmes et al., in press). Such an increase in the numbers of people diagnosed with autism has been linked to the demands of the neoliberal market, the consumer driven agenda for medical care and diagnosis (Runswick-Cole, 2014). Thus, there has been a suggestion that this creates an environment whereby people must sell goods or products in the marketplace, including a requirement to ‘sell’ oneself, and for those who are unable to do so adequately they become constructed as a ‘problem’ for medical experts who are unable to return that person into a productive citizen (Timimi et al., 2011).

Such neoliberalist ideas do have consequences for autism. For example, if we accept the neurodiversity position, as outlined in Chap.4, on one hand this promotes equality in a neoliberal society and raises awareness and acceptance of the condition and pushes for autistic people to be viewed as simply different and not in need. On the other hand, this position risks a potentially misleading view that all autistic people can achieve the requirements set out by this political structure (Runswick-Cole, 2014). Furthermore, the politics of neurodiversity can fail to attend to other forms of marginalization that can underpin oppressive practices, such as racism, poverty, and imperialism, as well as the intersections between them (Goodley, 2011). It is imperative therefore to explore the ways in which economics and autism intersect in multiple ways and how advantage and disadvantage, ability and disability, are intrinsically tied.

The Societal Cost of Autism

The costs of autism are felt by autistic individuals, their families, communities, and their government (Horlin et al., 2014). The lifelong nature of autism makes it a particularly important condition to consider in terms of economics. This is because those with a diagnosis are likely to need lifelong care and support and this is across a range of domains, such as education, community services and healthcare. It has been argued by Rogge and Jansse (2019) that we must gain an improved understanding of autism-related costs for three major reasons:

1. Studying the costs of autism can provide a detailed picture of the size of the costs, the nature of the costs, the distribution of the costs for the different parties as well as the cost burden and the negative consequences of policies.
2. Those who have a responsibility to develop and implement policies and who decide on resource allocations require a good knowledge of the consequences and impact of their decisions. By gaining an overview of the total cost of autism decisions can be based on evidence and information.
3. The costs related to autism are not merely service and healthcare costs, there are many indirect costs, such as parental lost productivity and informal care and an understanding of these can assist policy makers to find ways to support families and individuals.

The societal costs of autism are not well known in total or for various points in the life. The societal costs of autism are not well known in total or for various points in the life cycle (Ganz, 2007) and studies have suggested a range of different costs, although notably all are high:

- In Australia, the annual national cost of autism is estimated to be between $4.5 and $7.2 billion (Synergies Economic Consulting, 2007).
- In the US, the cost of autism is estimated to be $61 billion, which represents more than the combined costs of heart disease, stroke and cancer (Buescher et al., 2014), with medical costs making up 9.7% of the lifetime costs (Ganz, 2007).
- In the UK, it is estimated that the cost is £2.7 billion per year for supporting autistic children and £25 billion per year for supporting autistic adults (Knapp et al., 2007).

In the UK, 56% of the cost for autistic individuals is accounted for by services, 42% by lost employment, and 2% for caregiver costs, which is similar in the US, with 79% of costs accounted for by services, 12% by productivity costs, and 9% for caregiver costs (Buescher et al., 2014). Buescher et al. noted that the similarity in costs across the two countries is noteworthy given that they have such different approaches to healthcare provision and funding. It is worth recognizing, however, that despite the approach, intervention strategies for autism are expensive, many of which involve long hours of care and support. The cost is not limited to healthcare interventions, but also reaches to familial resources, time, commitment and emotion (Sharpe & Baker, 2007), as well as other services (e.g., social care, education, etc.). Nonetheless, a recent systematic review of the literature demonstrated that medical and healthcare costs are significantly higher for autism than the general population, and indeed higher than for other mental health conditions, and this is a challenge for families (Rogge & Jansse, 2019).

The Familial Cost of Autism

It is well known that disabled children are more frequently born into low-income families and having a disabled child can lead families into poverty (Belfer, 2008). Autism in particular bears a high cost for families at both an emotional and financial level. As the number of people diagnosed with autism increases, it is essential that resources are available to support parents and other family members (Hall & Graff, 2011), and this is arguably especially important for those who receive their diagnosis in adulthood. Many families spend significantly more money on outpatient care, healthcare, visits to the doctor, prescription medications, and the costs of co-occurring conditions (Liptak et al., 2006), reflecting an average healthcare cost which is 45 times higher compared to those with other mental health conditions (Croen et al., 2006), and as we illustrated, the healthcare cost to the economy for autism is significantly higher too (Rogge & Jansse, 2019).

Reviewing research in this area, conclusions indicated that parents, family members and caregivers of autistic individuals sustain a range of financial impacts and income losses (Rogge & Jansse, 2019). For example, in the US, families also spend more on educational and behavioural services, as well as private tutoring, speech and language services, and occupational therapy (Montes & Halterman, 2008). Evidently, autistic children have medical expenses that are significantly higher than in children without the condition (Ganz, 2007). This is additionally problematic for more vulnerable groups. For example, minoritized groups tend to face cultural, social, and economic barriers that reduce their access to healthcare services. Furthermore, for families with an autistic child the social, economic, and psychological costs of immigration and service access can be especially challenging (Welterlin & LaRue, 2007).

Indirect costs are even more complex. Costs such as out-of-pocket expenses, payments for interventions not covered by insurance or healthcare services, and the loss of parental productivity are more challenging for families (Young et al., 2009). For example, research suggests that families with an autistic child spend an average of $613 per year on out-of-pocket expenses (Liptak et al., 2006), with some families spending more than $1000 (Young et al., 2009). Such costly out-of-pocket expenses can mean that people are more likely to be reluctant to seek treatments as care becomes more expensive (Saxena et al., 2007). In addition, some children with autism have additional co-occurring mental health conditions or intellectual disabilities or learning delays (Karim et al., 2014), and there is a greater likelihood of co-occurring physical conditions like diabetes or epilepsy (Tromans et al., 2020a, b) and these can also bear costs for families. For instance, research has shown that in samples of autistic children with co-occurring intellectual disabilities, there was greater financial difficulties for families compared to families of children with autism alone, with 52% of parents having to stop working or cut their hours (Saunders et al., 2015).

Indeed, it has been reported that the largest cost for families is the loss of income from reduced working hours (Horlin et al., 2014). Families of autistic children (and other forms of disability), frequently face economic challenges because of lower levels of employment and the increased costs of meeting their child's basic needs (Baldwin, 2015). Research has indicated that the average loss of income in the US associated with an autistic child was $6200, that is 14% of income (Montes & Halterman, 2008). Montes and Halterman also showed that this lower income was also lower than expected even when accounting for educational and other demographics. Notably, parents often have lost their jobs so that they are able to care for the autistic child, which creates financial burdens (Sharpe & Baker, 2007). This is also true of fathers, who are less likely to be in full-time employment and more likely to work part-time (Montes & Halterman, 2008).

Problematically, however, the long term-consequences of the high financial costs to families of autistic children are not well researched (Horlin et al., 2014). As we noted earlier in the book, most autism research funding has been levied for biological and genetic studies, and less money has been made available for other areas of focus. We have also shown in this chapter that the ideal of parity esteem between mental health research and physical health research has not been fully realised (Morton & O'Reilly, 2019). The high cost of disability to individuals, families, communities, and societies however clearly deserves much more attention. The specific issues faced by autistic people and their families on an economic level must be addressed. As articulated by Buescher et al. (2014, p.727):

> The high economic burden carried by families is particularly concerning; studies of costs to the health care and education systems from providing care to individuals with ASDs [autism spectrum disorders] should be weighed against these largely unstudied family costs, which also should be compared with those of families with a member with a different (or without any) chronic condition.

Evidently, collectively the evidence is consistently clear that there is a much higher financial burden for families across multiple domains and a lifetime of costs for autism (Rogge & Jansse, 2019). Indeed, this review of the literature indicated that across a range of financial burdens, the costs are higher for autism, and the more severe the autism the higher the costs for families.

The Relational Cost of Autism

Costs however are more than merely financial. Research indicates that parents of children with conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and autism have an increased risk of divorce when compared to parents of children without disabilities (Wymbs et al., 2008). It has been argued that autism is potentially the most taxing type of disability on parents (Seltzer et al., 2001), with parents scoring lower on a range of measures of wellbeing compared to parents of children without disabilities, and to parents of children with other types of disabilities (Abbeduto et al., 2004). It is well documented therefore that there are higher rates of divorce in families of autistic children diagnosed.

Anecdotally, it has been suggested that divorce rates are up to 80% among parents of autistic children, figures widely cited by mainstream media, although empirical research suggests that this is inaccurate and overestimated (Naseef & Freedman, 2012). Empirical research suggests that the rates of divorce of parents of autistic children are indeed higher than in parents of children without disabilities, although nowhere near such a high percentage that is sensationalised through the media. For example, in a survey of 391 parents of autistic children, results showed that there was a rate of divorce of 23.5% against 12.8% in a matched representative sample of parents of children without disabilities (Hartley et al., 2010). Likewise, in a longitudinal study, results showed that 25.2% of couples separated, and 74.8% remained together, with no significant difference in any of the clinical or sociodemographic variables (Baeza-Valasco et al., 2013). Nonetheless, these inaccurate media reporting, presented as fact, promote shock and scepticism about marriage, and promote the rhetoric that autistic children are a burden on married couples (Lashewicz et al., 2018).

This vulnerability to divorce is related to the increased demand on parents and the increased stress of having a child with high needs and the reduction in responsiveness to the spouse's needs (Shapiro et al., 2000); evidence does suggest that these families experience extraordinary levels of stress (Smith et al., 2010). Notably for some families, the marriage may simply be unhealthy and end for reasons unrelated to the autism, but in other cases, the inability of one or both parents to manage the stress of raising their autistic child may lead to the increased likelihood of divorce (Jones & Holmes, 2009). Vulnerability to divorce is also higher in families where parents are less well educated, when they married at a younger age, and/or when they had children early in the marriage (Bramlett & Mosher, 2002; Ono, 2000). Furthermore, there is the issue of persistence of stress, as families face a range of different challenges as the autistic child grows up and transitions between schools and into adulthood. Evidence suggests that as the child grows older that there is a greater strain on marriages, with there being limited difference between the autism and non-autism group when the child was 8 years or younger (Hartley et al., 2010). Hartley et al. showed therefore that rates of divorce remained high during the child's adolescence and early adulthood, whereas in the comparison group it decreased as the child got older.

It is important however to apply some critical questioning to this issue. The research evidence demonstrated here does indeed show that the media and anecdotal sources are probably overestimating the rates of divorce in these families. Indeed, although these parents do seem to encounter high levels of stress, many families were 'courageously coping' with that stress and passionately loving their child while trying to stay together (Naseef & Freedman, 2012). Thus, most parents of autistic children do stay together, despite the increased stress, with some reporting that the experience strengthened their relationship (Walsh & O'Leary, 2013), although others have reported lower relationship satisfaction than couples with typically developing children (Brobst et al., 2008). Nonetheless, stress levels have been found to be considerably lower when parents identified positive experiences associated with raising their child (Kayfitz et al., 2010). As noted by Naseef and Freedman, (2012, p. 11):

> Children with autism are fundamentally just children, and couples raising them are just couples. Any child changes the couple. While the birth of a child brings astounding joy, the partnership takes a big loss in terms of sleep, sex, and privacy.

Thus, although there is stress and various demands on the marriage of parents of autistic children, these can be positive and can strengthen the commitment of the two parties to the relationship (Lashewicz et al., 2018).

Part of the challenge, then, is that there is a limited evidence base on relationship quality, relationship stress, and divorce for parents of autistic children. A recent review of the literature found that in work that included an understanding of relationships, it typically was not the primary research question, and few studies fully explored the factors that did contribute to divorce or separation of the couple (Saini et al., 2015). Saini et al. did find some evidence of relationship strain due to increased isolation, limited chances to spend quality time together as a couple, difference of opinion regarding behaviour management of the child, financial challenges, and lack of service access, but the research is inconclusive regarding how these may contribute to the divorce.

Educational Resources and Autism Inequalities

A significant area of concern and one that does place stress on families, has been the education and academic attainment potential for their children. For parents of autistic children, the abilities of their child are connected to the nature of schooling available. For those children who are more academically inclined, they are likely to be schooled through mainstream education, while other children are more likely to be schooled through special education services. The rise of neoliberalism and the striving toward a society whose citizens are contributing and productive is also tied to the education system, which is positioned as a public resource. Parents are now more active in their choices of school, and academic targets are frequently viewed as important to the future generation and economy. This has an impact on autistic children and their educational direction.

One consequence of changing attitudes toward disabilities more generally has been the inclusion agenda; that is, to include children with a range of disabilities in mainstream education. For instance, in the US, throughout the 1960s public laws were passed to help children with disabilities receive appropriate education, and in 1975 congress passed legislation to support educational services, which have been subject to further amendments and federal funding through the 1980s and 1990s (Crane & Winsler, 2008). Thus, the Individuals with Disabilities Education Act (IDEA) has encouraged educational services to ensure that there are practices, policies, and supports in place for autistic children (Henderson, 2011). Likewise, in the UK, in 2001, the Special Educational Needs and Disability Act made mandatory that teachers make ‘reasonable adjustments’ in the classroom to be inclusive of children with special educational needs (Her Majesty’s Stationery Office [HMSO], 2001 [updated in 2014]). Canada also has similar placements for children with special educational needs in terms of the provision of appropriate education in the mainstream classroom (Starr & Foy, 2012).

The resulting argument in the UK and the US is that the respective legislations have strengthened parental rights to express preferences for educational provision addressing their child’s needs (Whitaker, 2007). Despite these advances, there is still a lack of clarity about how effective social inclusion has been for integrating autistic children into a typical mainstream classroom, and there is a limited understanding of the differences in social involvement at all levels (Rotheram-Fuller et al., 2010). Furthermore, the effectiveness of inclusion, the potential and actual difficulties encountered by some autistic children in the classroom, and the adequacy of the available supports and resources for inclusive education have come under criticism.

It is arguably insufficient for policy makers and governments to simply offer up a rhetoric supporting public education, as the educational community requires sufficient levels of funding and cost-effective mechanisms to support teachers of autistic children (Simpson et al., 2011). It has been suggested that autistic children often require unique and well-resourced considerations to include them in the education system (House of Commons Education and Skills Committee, 2006), with autism arguably being one of the most complex and least understood areas of education (Humphrey & Lewis, 2008). Indeed, this reality is reflected in many educational institutions. For example, research has indicated that schools have struggled to keep up with the developments in autism and the increasing numbers of children diagnosed as autistic (Humphreys & Symes, 2010). In a recent review of the literature, the collective evidence demonstrated that autistic children going into school have complex needs and tend to be less emotionally ready than their neurotypical peers, with greater externalising behaviours and self-regulation difficulties that will impact their school engagement and relationships with teachers (Marsh et al., 2017).

It is also important to acknowledge that the age at which the child is diagnosed autistic also seems to have an impact on their educational involvement and outcomes. Research shows that children who receive their autism diagnosis earlier in life gain access to more interventions, tend to demonstrate improved verbal and cognition at school age and are more likely to attend mainstream school than autistic children who receive their diagnosis much later (Clark et al., 2018). Evidence also suggests that school-based behavioural interventions are important for autistic children, as they seem to improve cognitive, language and daily living skills and thus the earlier these can be provided the better for the child and family (Marsh et al., 2017).

Special Education and Inequalities

Of the 1.3 million children and young people with special educational needs and disabilities in England, 11% of them are diagnosed autistic (Department for Education, 2020). In the US, figures demonstrate that from 1991 to 2009 the number of autistic children in mainstream classrooms rose from 12% to 59% (Snyder & Dillow, 2012) and in England, figures illustrate that 70% of autistic children and young people are in mainstream school, the remainder are in some type of specialist educational setting (Department for Education, 2020). Despite the inclusion agenda and efforts to support autistic children and young people in mainstream schools, it is therefore still (and necessarily the case) that many attend specialist educational settings.

It is often the case that autistic children and young people who require education in specialist settings have additional communication, cognitive, emotional, sensory and/or physical needs, which are usually referred to as 'complex needs' (Richards & Crane, 2020). However, it is important to recognize that the support needs, and profile of autistic students in schools are diverse and wide ranging (Crane et al., 2021). Given that autistic children and their families experience a wide range of inequalities, it is essential that special education provides effective and high-quality support and education (Dowling & Dolan, 2001), yet this is not always provided, and the COVID-19 pandemic (as we showed early in this chapter) has left disabled individuals and their families more vulnerable (Pellicano & Stears, 2020). Given that children and young people attending special education tend to face greater inequalities, that stem from educational policies, attitudes from society and the structures and systems that underpin their life experiences (Dowling & Dolan, 2001), it is probable that COVID-19 has heavily impacted education.

Although the educational rights of children and young people with special education needs and disability have been highlighted during the pandemic (in England at least), the decision-making processes and practices have focused predominantly on those students in mainstream schools (Crane et al., 2021). For mainstream schools, the measures implemented have been complex and challenging, and there has been a lack of clear guidance for schools and some decisions communicated to them at very short notice (Kim & Asbury, 2020). For special educational settings, the challenges have no doubt been greater. Prior to the pandemic these schools were disproportionately disadvantaged, with autistic children sitting on the margins of society and experiencing a great deal of stigma (Mitter et al., 2019). For autistic children with additional disadvantage, such as being from an ethnic minority background (see Perepa, 2019) or experiencing financial hardships (see Baldwin, 2015), the impact of inequalities created or exacerbated by COVID-19 is even greater. This is indeed a global problem, as some reports suggest that in majority world countries (previously referred to as low-income countries), vulnerable children have received no education at all because of lockdowns (Montacute, 2020), and it is arguable that this figure is higher for special education (Pellicano & Stears, 2020).

Teachers' and Parents' Views

In the context of autism and education, we argue it is important to foreground voices, autistic people's voices are central, but those around them also have a role to play. In terms of schools then, teacher's perspectives and the role of parents in education are highly relevant, particularly in relation to the inclusion agenda, and in supporting those in special education. In the context of mental health more generally, research has highlighted that teachers do not see managing mental health as their responsibility, and where they did feel they played a role, it was secondary to academic attainment (O'Reilly et al., 2018a). In relation to unique educational needs, teachers often feel unprepared to meet the needs of those with disabilities and frequently view disabled children as a burden in the classroom, resulting in feelings of guilt and frustration that their time is focused on students with additional needs and not the rest of the class (Cassady, 2010). Such attitudes are potentially stronger when teachers are working with autistic children, given that this condition can create further complex challenges compared to some other conditions. Arguably, it is important that educational systems create and fund mechanisms that provide systematic and sustained support for new teachers to better equip them to help and educate autistic children (Simpson et al., 2011). Problematically, there has been a lack of resources for teaching equipment and training, and teachers have frequently reported lacking the training opportunities to work with autistic children (Lindsay et al., 2013). Teachers often report finding it especially challenging because of some of the unusual behaviour exhibited by autistic children, the aggressive or challenging outbursts that some children display, and the issues of socialization can be disruptive in an inclusive classroom (Cassady, 2010). Some research has also highlighted how autistic children themselves some practitioners that work with autistic children reframe children's non-normative behaviours as communicative and function, pushing against normative expectations that children behave and communicate in a singular way (Lester & Paulus, 2014; Lester, 2015). Furthermore, as we have noted throughout this book, autism is argued to be on a spectrum, and thus autistic children are not a homogenous group. They present with different types of need, different levels of need, and different types of behaviour, which can be challenging or confusing for teachers with limited experience of working with these children.

Notably, this has an impact on parents of autistic children. Parents have reported a feeling that there is a limited understanding of autism in schools by staff and perceived that schools do not listen to them when they try to provide information about the child (Kendall & Taylor, 2016), and some research has also highlighted how autistic children express feeling misunderstood in educational contexts (Lester & Paulus, 2014). Overall, then it is perhaps unsurprising that research shows that many parents are dissatisfied with the academic programs for their autistic children (McDonald & Lopes, 2012; Starr & Foy, 2012). For instance, research has shown that although 61% of parents are generally satisfied with the educational provision, this means that almost 40% are dissatisfied, and even satisfied parents presented a range of concerns that their child's needs were not being met (Whitaker, 2007).

Specifically, parents were concerned about the problem behaviour in the classroom and academic attainment (Azad & Mandell, 2016). Additionally, parents reported feeling frequently frustrated by the ways in which their child's progress was measured and reported by schools (Keen et al., 2016), as it is known that academic performance is affected by factors other than IQ (Jones et al., 2009). Parents also reported that their children experienced resentment, prejudice, and fear from school personnel (Starr & Foy, 2012).

Of specific concern to parents relates to the consequences of this prejudice and resentment, and the ways in which the presumed problem behaviour is treated by schools, which can and often does result in suspension or exclusion from school. It has been argued that schools are failing to meet the needs of autistic children and exclusion is a risk resulting from this; "the increased risk of exclusion, disaffection etc. demonstrated in the existing research base is therefore considered to be a result of the general lack of capacity of schools to address these group needs" (Humphrey & Symes, 2010, p. 78). Research has shown that when compared to children with other disabilities, autistic children are more likely to be excluded (Parsons et al., 2009), with 15.4% of autistic children being suspended at some point, often due to the inability of staff to manage the child's behaviour (Starr & Foy, 2012). Indeed, in our own research on child mental health assessments this has been shown to be a challenge for families, and children themselves. For example, drawing from the UK-based study of mental health assessments (as described in Chap. 1), we include here some of the narrative from a 17-year-old autistic young man about his school life when speaking with the psychiatrist assessing him for co-occurring ADHD.

Example 1: from Family 17

Doctor: So so why do you think (.) what is it (that) your behaviours you think why you're ↓here?
Child: Erm (1.23) coz I get (.) kicked out of ↓everywhere (0.31) (don't I) (.) [I don't] know
Doctor: [oka::y] you get kicked out of ↓everywhere
Child: Umhm
Doctor: Where have you been kicked ↓out of?
Child: Every↓where
Doctor: Is that schools or any ↓othe[r places?]
Child: [yeah (it's) s]cho:ols

Some insight is demonstrated here by the young person that he recognizes that his behaviour is connected to his dismissals from school, and that this is a repetitive pattern. Indeed, this issue of being excluded from school was supported by his mother, who was more precise in describing the problems they faced with school as a family.

Example 2:Family 17

```
Mother:   Well he had a hundred an eighty-six ex↓clusions to
          start off with coz of his behaviour
Doctor:   That’s a lot of excl↓usio[ns]
Nurse:                                [Wh]at was (the ↑rate)
Doctor:   Hundred an’ eighty-six ex↓cl[usions]
Mother:                                   [Ye:ah] in one year
Doctor:   Okay (.) what ↑what °what° sort of things were you
          ↓doing to get excluded?
Child:    Messing about
Mother:   Not going into ↓lesson running o:ff
```

Indeed, the problem behaviours displayed in school may be due to a range of different reasons, including anxiety, sensory processing, frustration, and social relationships. In the data segments above, the young person attributed the exclusions from school to be related to his behaviour in a general way, but for the broader population of autistic children there can be a wide range of reasons why they are suspended or excluded from school. For example, autistic children were more likely to be bullied in school than other groups and had lower levels of social support from their peers (Humphrey & Symes, 2010) and this can have a significant impact on their behaviour. In the modern world, of course, much of this now takes place via online platforms and autistic children must navigate the bullying behaviour (cyberbullying) as well as working out their social relationships and social interactions in online spaces (see O’Reilly et al., 2021 for a general overview of social media and mental health).

While the inclusion agenda has some benefits, for some families, the insufficiency of the education system, the bullying, the anxiety, and the reported inability of the school to manage the child’s behaviour has resulted in many parents choosing to take their children out of school. For some parents, they felt that they were left with no choice but to take this option (Parsons & Lewis, 2010). This however can be a problematic action. The acceptance of home education varies between countries (Arora, 2006). For example, in countries like Germany, Spain, Greece and the Netherlands, home education is not permissible by law (Taylor & Petrie, 2000), but in the UK, it is not a legal requirement for parents to send their children to school, although they must provide a suitable education (Kendall & Taylor, 2016). For some parents, they believe that withdrawing their child from the school context is necessary, as the school is described as failing to meet the child’s needs (Parsons & Lewis, 2010), although withdrawing from school is often seen as a last resort (Morton, 2010).

Employment Inequalities

A clear connection between education and employment, as well as income, has long been noted in the literature. Thus, the challenges that many autistic children face in school therefore are likely to have an impact on their likelihood to go into further or higher education, and their employment possibilities. This is important in the broader context of disability, as agency is often not afforded to disabled people, and their success is measured by how independent they are able to be (Tabatabai, 2020), with independence measured by being in paid employment and living away from the family (Sprague & Hayes, 2000). This is important in the neoliberal context as parents become the provider for their disabled child, in terms of income and care (Luxton, 2015).

Some young autistic people have a reasonably stable experience in education, and in further education, and then later in employment and personal relationships (Levy & Perry, 2011); however, it is important to recognize that there is variability in outcomes for autistic adolescents, with many being reported as poor (Howlin & Moss, 2012). It is shown that even for autistic people who are high functioning, they are still frequently disadvantaged in terms of obtaining and sustaining employment (Barnard et al., 2001), and despite many autistic individuals having post-secondary qualifications (Ohl et al., 2017), gaining, and more problematically, sustaining employment is especially challenging for them (Griffiths et al., 2019). While the ‘impairments’ associated with autism may impede some individuals in some areas, research shows that autistic individuals have a huge amount to contribute to employers. For example, autistic individuals tend to pay greater attention to detail than neurotypical peers (Scott et al., 2017), tend to have excellent visual skills (Jiang et al., 2015).

There is no ‘all-embracing’ statistic in terms of how many autistic individuals are currently employed (Lorenz et al., 2016), however, so it is difficult to identify the extent of the problem. Autistic people are at risk of social isolation, marginalization, depression, anxiety, and stress (Attwood, 2003; Ghaziuddin, 2005) which impacts their employment opportunities and retention. For example, research has shown that only 34.7% had attended college and 55.1% held paid employment within 6 years after leaving high/secondary school (Shattuck et al., 2012). Shattuck et al. noted that more that 50% of autistic youth who left high/secondary school in the last 2 years had not managed to progress into employment or additional education. They found that these young people had the highest rates of unemployment compared to other disability categories and had poor postsecondary employment or education outcomes.

Evidently, the employment rates for disabled people are low, and even lower for autistic adults. In the US, it was shown that in those aged 16–65, less than one half of those with a disability (29%) were working compared to those without a disability (64%) in 2010 (U.S Bureau of Labor Statistics, n.d.). Furthermore, when comparing autistic adults with other young adults with a job, the autistic adults were less likely to be employed (NLTS(2), [National Longitudinal Transition Study-2], 2009).

Research indicates that this is because there are many barriers to employment for this group. In a study of autistic individuals, results showed that barriers included organizational and practical problems, including social problems, communication issues, and process-related aspects to job entry (Lorenz et al., 2016). Lorenz et al. conceptualized these problems into three main categories of barrier and argued that these can be overcome:

1. Social problems – those obstacles concerning communication and social interaction.
2. Formality problems – those obstacles related to organizational and practical process-related aspects of entering the job world.
3. Job demand problems – those difficulties in meeting the specific requirements of a job.

Lorenz et al. stated that:

> Our results should encourage individuals with autism, employers and support workers alike to focus on strengths and solutions instead of deficits. While we find it important to address specific problems and barriers that occur, we think that strengths should be identified and fostered at the same time. (n.p.)

Indeed, a strength-based approach is long overdue and may serve to foreground the ways new ways of engagement, participation, and inclusion might be achieved.

The Internet as a Resource: Supporting Social Skills or Isolating Autistic People from the World?

Digital technology has undoubtedly changed the world, the way we communicate with each other, as well as the meaning and face of entertainment. Since the global pandemic, that is COVID-19, has impacted all countries across the world, there has certainly been a greater reliance on digital technology and internet-based activities. For the autistic community, the Internet has heavily impacted them and provided significant opportunities, but also new challenges. During the pandemic evidence shows that some countries have made significant efforts to continue service provision by supporting autistic people online. It seems that some autistic people have welcomed this new delivery of care by having services delivered to them via video technology, with some seeing the pandemic as revolutionising support (Pellicano & Stears, 2020). For example, many health services have delivered their therapeutic interventions online due to COVID, and evidence suggests that although autistic individuals can get distracted at home, with some techniques not being feasible through this modality, there were some advantages, such as improved attendance, and autistic people feeling more comfortable (Kalvin et al., 2020).

For autistic people, face-to-face social interaction can be challenging, and for those who actively seek friendships, communication and social interaction challenges may result in feelings of depression and/or loneliness (Lainhart & Folstein, 1994). Some autistic people may find social interaction and building relationships challenging because of difficulties with non-verbal cues and a need for structure. Arguably, therefore computer-mediated communication is a potential solution, especially for those who may seek greater social connectedness; thus, many autistic people take advantage of online communities to build supportive relationships (Burke et al., 2010), and yet research has indicated that those with any type of mental health condition are at greater risk online (Livingstone, 2013; O'Reilly et al., 2021).

Nonetheless, the Internet provides considerable opportunities for the autistic community to communicate with each other, and with peers and/or colleagues. Computer-mediated forms of communication, such as text-messages, emails, and social media can provide structured environments and their asynchronicity means that the interlocutor has additional processing time (Kruger et al., 2005). This may mean that autistic people can use the Internet at any time of day and in almost any location, with online communities providing support for those with similar interests, self-advocacy, and similar life stories (Burke et al., 2010). Indeed, it was this asynchronicity that was seen to be the positive feature of computer-mediated communication, with email being preferable to online chatting (Benford & Standen, 2009). In this way such computer-mediated communication offers useful opportunities to autistic communities to interact in more structured ways that can be appealing and uniquely benefit them (Gillespie-Lynch et al., 2014). Research has further shown that the social interaction composition is important, as when communicating with friends and family, or for employment/education, autistic individuals preferred face-to-face communication and text-based methods like text messages or email, whereas their least favoured modality was via telephone conversation, and thus organisations that rely on telephone communication can create barriers (Howard & Sedgewick, 2021).

The Internet has been argued to support some autistic people in better dealing with the social challenges they face in offline contexts, as well as to learn about alternative conceptualizations of autism (Jordan, 2010). For example, the Internet is typically one of the main ways that interested autistic people learn about and where preferred, participate in, the neurodiversity movement and express their rights (Bagatell, 2010).

Indeed, it has been well documented that autistic individuals do engage with digital media. There are clearly some social benefits of computer-mediated communication for autistic people which has been classified as being along two key dimensions:

1. Increased comprehension of communication and control over its direction (Benford & Standen, 2009; Müller et al., 2008)
2. Improved social support and contact with similar others from geographically distant locations (Davidson, 2008; Jordan, 2010).

Arguably then, computers (or smart phones/tablets) can reduce discomfort or anxiety that some autistic people feel when engaging in face-to-face social interaction and the Internet provides a form to interact safely from their own familiar location (Bagatell, 2010). In fact, it has been reported that some autistic people feel more comfortable online as they may find writing easier than speaking (Gillespie-Lynch et al., 2014). For example, in a qualitative study with 23 high-functioning autistic adults, participants reported that the Internet reduced emotional, social and time pressures, as well as affording visual anonymity and a more flexible pace of communication (Benford & Standen, 2009). Other research has shown that when compared to neurotypical participants, autistic individuals did see some benefits to computer-mediated communication in terms of control, accessing other groups like them, and the opportunity to express their natural identity, although they did not enjoy the Internet to meet others or maintain connections with friends and families as much as neurotypical participants did (Gillespie-Lynch et al., 2014). Gillespie-Lynch et al. argued therefore that autistic people use the Internet in qualitatively different ways than their neurotypical peers.

Conversely however, it has also been argued that autistic people can see communicating online as a source of vulnerability as some miss the immediate feedback and emotional information provided by non-verbal cues (Benford & Standen, 2009). Furthermore, it is noted that autistic people may not spend as much time communicating online as it may be assumed. Anecdotal evidence suggests that they may spend considerable time watching television, using computers, and engaging with screen-based media such as gaming (Mazurek et al., 2012). In their study of screen-based media through the National Longitudinal Transition Study-2 (NLTS-2), Mazurek et al. demonstrated that 64.2% of young autistic people spent much of their free time using non-social media, like television and video games, and 13.2% spent their free time on social media, such as email and messaging over the internet. Arguably, this is because the promise of computer-mediated communication is not as beneficial as may be thought. For some autistic adults, while benefits such as reduced stress from not having to read non-verbal cues, and the ability to find like-minded individuals was seen positively, sustaining online friendships was difficult for them as participants in the study found it difficult to decide who to trust, what information to disclose, and what social rules applied online (Burke et al., 2010).

It must be remembered that not all autistic people have access to the Internet. As we have recognized throughout this chapter, there is significant inequality in terms of education, employment, and income in groups of autistic children and adults, and thus it is unsurprising that this also links with access to personal devices and the Internet. It is likely that autistic people may be excluded from accessing the Internet and thus denied the opportunity to alleviate their difficulties of social interaction and communication (Benford & Standen, 2009). This is also problematic in terms of a growing reliance on teletherapy as not all autistic individuals have the necessary access to the technology needed to engage, or the required IT skills, and can leave them feeling even more marginalized (Spain et al., 2021).

Furthermore, the evidence base in terms of digital technology, social media, and computer mediated communication in the context of autism is starting to grow, but we still have a limited evidence base. Arguably, in part this is due to the issues we raised early about research funding priorities not being in sync with the needs of the autistic community. For example, a recent systematic review showed that there is very little work in the area of computer mediated communication, digital technology, the Internet and social media in relation to autistic women, transgender autistic people, autistic individuals with low-income levels, and those with co-occurring intellectual disability, and thus the information we have is not fully representative and missing important domains of interest (McGhee Hassrick et al., 2021).

The Market Economies of Disablement: An Empirical Example

To illustrate further the points discussed in this chapter, we conclude by sharing findings from an analysis of the US data, which were previously published (Lester & O'Reilly, 2016). In doing so, we aim to situate this chapter's discussion within the broader political and economic context made relevant by the participants of the US-based study as described in Chap. 1. We specifically focus on the expenses associated with "treating" autism and the process of qualifying for primary insurance and Medicaid coverage, a healthcare program within the US typically for individuals "…with low incomes and limited resources" (Social Security Administration, 2010, p. 16). Further, we position this discussion against the backdrop of schools, as all the children who participated in this study attended public schools during the day and received additional therapies in the afternoon, as they were described as "needing more supports and being better understood at the clinic". This is a particularly relevant point, as children with autism quite often do not receive adequate services in school contexts, thereby necessitating the need to pursue additional clinical interventions (see, for instance, findings from Hess et al., 2008, highlighting the variability in the types of autism interventions in the state of Georgia's public schools).

Across the data, we noted that parents and therapists collectively wanted to provide access for children to receive the care they needed. However, upon closer investigation, we noted that both the insurance market and the government policy actors *both* permeated and defined the therapeutic setting in intriguing ways. Namely, across the data, we noted that: (1) therapists were hypersensitive to the use of discipline specific diagnostic codes; and (2) there was a shared sense between parents and therapists that the insurance company and government policy would likely overrule the decisions to provide services to the child unless aligned to approve disability labels. The permeation of both the governmental policy and insurance companies into the therapy setting therefore incentivized the diagnosis of children with disability labels. When a label of autism did not lead to approval to provide the requested and needed therapy hours, the therapists would then identity discipline specific labels that would prompt the insurance company to cover the cost of compensatory services. For instance, the insurance companies would pay for therapies for a child with an "expressive language delay", a label specific to speech-language pathology, with a child with only an autism label viewed as having too broad of a diagnosis. Consequently, therapists and parents were incentivized to seek out additional disability labels to secure therapies and services for the children.

Insurance Mandates Permeate the Therapy Setting

The very meaning(s) attributed to disability and autism, more specifically, were often associated with "treating" autism and the process of qualifying for primary insurance and Medicaid coverage. Early in the data collection process, Jessica took note of the following in her observational/field notes:

> ***June 2, 2010 8:30 pm***
>
> *I have been struck with the ways in which the therapists moved from 30 minute sessions to filing documents to making insurance notes—their movements appear to be situated between therapy sessions with each child and the insurance note-taking/report-making. There were even discussions between the more experienced and the more novice therapists about how to perform differently for a parent, an insurance provider, and a doctor. The more experienced therapists often said to the new therapists, "You need to write this way when you are writing for an insurance company, but write this way when sharing something with a parent."*

As such, we oriented to the meanings of autism as being bound up in those institutionalized practices that were explicitly tied to a family's insurance policy and/or the state-based healthcare mandates related to autism.

The participating therapists, who seemed to be working at the intersections of the demands of insurance companies/Medicaid requirements and the expressed needs of a child/family, sought to acquire coverage for all of the therapies they provided to the participating children; yet, the state in which The Green Room was located did not have a specific health insurance mandate for autism (American Speech-Language-Hearing Association, 2010). That is, a diagnostic label of autism did not guarantee that an insurance company would offer coverage for individual therapy sessions. In fact, a child needed to be diagnosed with a discipline-specific label (e.g., expressive language delay) to receive services from professionals such as speech pathologists, occupational therapists, and physical therapists. Even in the main office area of The Green Room, the therapists were visually reminded (see Fig. 6.1) of specific diagnostic labels and codes, based on The International Classification of Diseases-10 (ICD-10) (American Medical Association, 2010), that needed to be used when requesting insurance coverage.

While all the participating children held primary insurance policies, only six of them qualified for Medicaid. Based on Jessica's interview with the state advocate and the official government documents (Social Security Administration, 2010), if a child is less than 18 years of age and meets the Social Security definition of disabled, which is not explicitly linked to a diagnosis of autism, and the child's resources fall within the eligibility limits, s/he can qualify for Supplemental Security Income (SSI). In most states, if a child receives SSI payments, they also qualify for Medicaid. In the state in which this study took place, to qualify as "disabled" under Medicaid standards, the child needed to be diagnosed by an official state approved clinician, most often a psychologist, who then determined whether the child was "mentally retarded" and/or exhibited "significant" functional limitations. According to the participating therapists and state advocate, qualifying for Medicaid under the disability category was specific to the child's identified area of need (i.e., cognitive

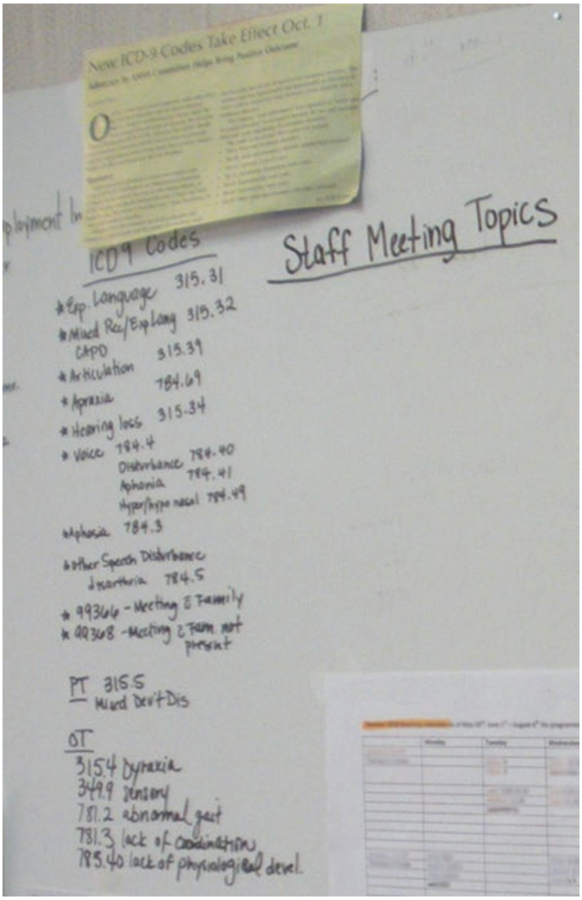

Fig. 6.1 ICD codes for diagnosis

impairment) and not necessarily based on the family's income. Thus, the recommendations of the state-approved assessor were taken into consideration by a state appointed board that then determined whether the child qualified for a medical (developmental disability/mental retardation) waiver. If the child qualified, s/he would no longer receive a bill from The Green Room, or any other therapeutic center, and would then have access to a variety of services, including community help, respite care, and transportation.

While the official government documents that described Medicaid qualification constructed the process as a fairly step-by-step, easy to understand procedure (Social Security Administration, 2010), the participants oriented to qualifying for Medicaid as "confusing" and "frustrating." Megan (*pseudonym), one of the directors of The Green Room, in an email exchange in which Jessica asked for clarification about the process of qualifying for Medicaid, wrote:

> ***December 4, 2010 2:00 pm***
>
> *I think that this process is really confusing for patients/parents/families. Because although it is "Medicaid," the people you speak with are totally separate. I couldn't even tell you who I would refer parents to for questions. We've met with a human services agency about the differences, and some of their caseworkers don't even understand it. Frustrating and confusing.*

When interviewing Ruth (*pseudonym), the state family disability advocate, Jessica asked explicitly about the process of qualifying for Medicaid. Ruth constructed the process as "very judgmental" and "like the luck of the draw," positioning whether a child qualified or not as unpredictable and often "frustrating for the families."

At The Green Room, out of the 70 waiting room conversations analyzed, five conversations occurred in which a therapist encouraged a parent to consider seeking Medicaid coverage, articulating that such coverage would provide them with additional resources and opportunities to access therapies and activities in various community spaces. Drew and Megan (*pseudonyms), the directors of The Green Room, explained why this was important, talking explicitly about "who benefits when a family gets Medicaid coverage," Megan, in response to questions regarding this practice, responded:

> ***December 2, 2010 8:05 pm***
>
> *We both win when the child can have continuous therapy all year. Most insurance plans have a limit on how many visits you get per year. As few as 20...but as much as 90. A child like Noodle, for example, who comes three times a week, runs out of visits in October or November. So her Medicaid waiver allows us to actually bill Medicaid for her November and December therapy (which she would not otherwise receive...and consistent therapy is so very important to her). Medicaid in our state reimburses something like $38 per session (which would be impossible to run a business on solely...unless you were a sole proprietor who had no employees). But I guess you could look at it as being a difference of them coming or not. If they are applying for the waiver, it often means that they cannot afford the out-of-pocket expenses...therefore they would not get services due to finances. With the waiver, kids will get the help they need with the financial stressor removed.*

Her reply pointed to the "market" which surrounds treating children with autism labels, in this case highlighting the benefit of acquiring a waiver. So, although for many families, Medicaid coverage provided services that allowed for qualifying children to participate more fully in the community in which they lived (e.g., funding for an aide to assist a child while s/he attends a local gathering), the state officials and policy makers, those individuals who worked to define what counted as "marked and severe functional limitations" (Social Security Administration, 2010, p. 6), ultimately determined if and how a child could qualify for Medicaid services.

Disability Labels Functioning to Secure Services

Of the six families who qualified for Medicaid, one parent in particular spoke explicitly about the process of qualifying for Medicaid. In the extract below, drawn from the interview data, Lily (*pseudonym) oriented to her son being labelled "mentally retarded" as being related solely to their family's need to acquire Medicaid coverage, moving then to undermine the validity of how the diagnosis of "mental retardation" was determined.

Example

Jessica: Did they diagnose him
Lilly: They did I needed him diagnosed for him to be on Medicaid
Jessica: Okay
Lilly: And the f- um the psychologist who did it wasn't very patient with him
Jessica: Mm hm
Lily: And you know he just kinda fifteen minutes and you know he had figured out he was mentally retarded
Jessica: Mm that's what the psychologist said
Lily: Yeah
Jessica: After fifteen minutes
Lily: Mm hm
Jessica: Mm
Lily: Because he couldn't get answers and stuff from him you know and so I did not like that assessment at all
Jessica: I would imagine not
Lily: Because he is not
Jessica: Mm hm
Lily: I mean he can learn you know
Jessica: Mm hm

In the above extract, Lily began by linking her son's diagnosis of mental retardation to the institutional practice that makes Medicaid coverage possible. She made explicit that she simply "*needed him diagnosed for him to be on Medicaid*," accounting for why she pursued further testing and a diagnosis of mental retardation. Yet, after offering a justification for seeking a diagnosis, she moved to undermine the validity of her son's diagnosis of mental retardation, questioning the very way in which the psychologist determined that her child was "retarded". She reframed her son's failure on the official assessment as not being due to some intrinsic inability, but to the psychologist's impatience and the little time he spent with her son. After Jessica affirmed Lily's dislike of the assessment, stating "*I imagine not*," she moved to clarify why she "*did not like that assessment*." Her next move provided an account of both what her son is and what he can do, with Lily stating, "*because he is not...I mean he can learn you know*." With added emphasis on what her son is "not," as well as what he "can" do, Lily constructed a version of her son as something other than mentally retarded. She worked up the construct "mental retardation" as being indicative of not capable of learning, an attribute from which she distanced her son.

While drawing upon symbolic interactionism and a Foucauldian-oriented analytical framework, Rocque (2007, 2010), who conducted a two-year ethnographic study of autism, described how mothers of children with autism often act as mediators of selfhood, working to actively interpret their child's "odd" behaviours as reasonable and rational for those individuals who "typically are not equipped to understand what mothers believe are the self-expressions of their children" (p. 487). Like the participants in Rocque's (2007, 2010) study, Lily negotiated and maintained in talk a positive identity for her son, accounting for and reframing his performance/behaviour as being due to something outside of him — namely the psychologist's inappropriate, yet necessary, assessment practices. In doing this, she distanced her son's identity from the construct of mental retardation and positioned his very diagnosis of mental retardation as being inextricably linked to the process of acquiring Medicaid, not any real, inherent inability to learn. His multiple and fluid identities, then, as Foucault (1972) would argue, were discursively constructed and reconstructed, shifting continuously in relation to the broader social and political contexts.

Later Lily was asked, "*when you say autism, what does that mean to you?*" she returned to the construct of mental retardation, stating, "*and what it means when I think of autism, I don't think of mental retardation.*" Like many of the participating parents whose children qualified for Medicaid, Lily positioned mental retardation in contrast to autism, with the validity of a diagnosis of mental retardation being perhaps resisted by positioning the diagnosis as necessary only because of the state-based Medicaid requirements. This resistance to and distancing from the label of mental retardation, in particular, points to the common cultural presumption that a "label of 'mental retardation' implies a permanent and severe developmental limitation" (Greenspan & Mann, 2003, p. 639), and carries with it some level of stigma (Major & O'Brien, 2005). Perhaps then by distancing her child from a label that has historically suggested a "permanent...limitation," Lily, like all of the participating parents, worked to construct her child as competent, and as she later stated, as someone who "*can learn you know.*"

In many ways, the complex process of acquiring an official dis/ability label(s), primary insurance coverage, and a Medicaid waiver was imbued with economic and material barriers (Howell, 2004; Johnson et al., 2003; Riebschleger et al., 2010); for some of the participating children, this process acted to restrict and at times prevent them from participating in certain activities, at least until their families could find a way to qualify (i.e., until the child performed as "significantly impaired" according to the officials of the day). Informed by the social-relational model of disability (Thomas, 1999, 2001, 2004), we interpreted these institutionalized constraints as examples of barriers to doing, with disability coming into play as restrictions were placed on the participating children and families. While the therapists, parents, advocates, and even the children themselves, worked across several institutional structures, the power to name, perform, and treat autism was "...never localized here or there...never appropriated as commodity or a piece of wealth," but "...exercised through a net-like organization" (Foucault, 1980, p. 98).

Concluding Thoughts

The very language of autism is clearly important and the very labelling and associated concepts that may be used to describe and position individuals with the diagnosis is important to those individuals and their families. The conceptualizing and diagnosing of autism are a power tool (Jutel, 2009) in the medical armoury, but parents both actively pursue and yet simultaneously resist the framing of the child as autistic (O'Reilly and Lester, 2017). Their pursuit of explanations for the behaviour of the child, to seek out support systems, educational help, financial means and health services is necessary for the legitimization by medicine for those needs and the labels and language of autism can promote that necessary framework. Thus, seeking out an assessment, engaging with services, and learning the language of autism is all necessary as a gateway to an explanatory framework, and associated systems that come with that. Nonetheless, while parents and families may work hard to navigate the autism landscape from diagnosis to service provision, there are inherent inequalities that map against those vulnerabilities and a lack of resources and attention for autism is highly problematic. The range of adversities faced by autistic children and adults, the economic inequalities and greater expenses associated with the condition create a culture of challenges, potential poverty, stigma, and discrimination. In societies that favour neoliberalism and dispositional responsibility, autistic individuals and their families face greater struggles to keep pace with societal expectations. The consequences are far reaching, long lasting and unacceptable.

Chapter 7
Stigma, Disability, and Autism

Autism is arguably one of the most stigmatized conditions included within the Diagnostic Statistical Manual (DSM). Indeed, research indicates that stigma is one of the most significant problems mothers of autistic children face (Dehnavi et al., 2011) and stigma is felt by autistic people as a pervasive part of their existence, as they describe always feeling on the 'outside of the neurotypical world and shunned by society' (Botha et al., 2020, p. 11). In part, this reflects the physically 'normal' appearance of many autistic individuals (rendering it, in many cases, an 'invisible disability'), and in part due to some of the behaviours displayed that fall outside of the traditional social norms and thereby subject to public judgment (Gray, 2002). In other words, some autistic children and/or adults, due to their autism, are likely to display behaviours that in turn can lead to abusive behaviour or negative attitudes from the community around them, leading to embarrassment or a feeling of being judged by others (Broady et al., 2017).

Certain conditions can disrupt individuals' abilities to function in social circumstances and can impact them at home, in the community and in school or work; autism is seen as one such condition. Stigma is therefore a pervasive issue that perpetuates inequality, and has social, cultural, and political implications for autistic individuals, their families, and communities. Clearly stigma needs to be challenged and addressed in society, in health, social care and education. Yet while funding has been invested in campaigns to reduce or eliminate stigma as associated with mental health conditions more widely, these have been largely disappointing (Kaushik et al., 2016). Indeed, Kaushik et al. argued in their review of evidence that we still need a stronger understanding of the stigmatizing processes faced by individuals, especially for children and adolescents, as stigma and mental health is a 'universal and disabling problem' which can lead to intervention avoidance and significant negative impacts.

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Introduction

Broadly speaking, our understanding of stigma in relation to mental health conditions has been informed by social psychology and sociology. Social psychology paradigms ascertain the cognitive and motivation processes leading to peoples' stigmatizing attitudes and behaviours, and sociological paradigms provide explanations of how different political, historical, and economic factors function to produce social structures which promote and maintain discrimination and prejudice (Corrigan & Miller, 2004). For those with mental health conditions, stigma and discrimination are viewed as the most significant obstacles for quality of life and for preventing development of improvements in mental health care (Sartorius, 1998). Indeed, stigma significantly contributes to the burden of experiencing a mental health condition and helps predict decreased life opportunities as well as increasing any impairment (Hinshaw, 2007). For autism therefore, the stigma encountered in a range of environments arguably increases the impact of the core 'impairments', negatively affecting their existing social interaction and communication difficulties, and contributes to the social challenges for both the autistic individual and for their family. Notably, this also connects to our earlier arguments about seeing autism as a psychiatric disability, as a mental health condition, or whether it is viewed as a difference. While we showed that there are tensions in views about this, the challenge of stigma remains.

Stigma research has shown how profoundly negative this can be for individuals with mental health conditions, and the overall negative impact for those with certain diagnostic labels. Stigma can increase the severity of symptoms (Hill & Startup, 2013), has an adverse effect on social functioning (Cerit et al., 2012), impacts employment or education (Thornicroft et al., 2009) and increases the risk of suicide (Thornicroft, 2011).

The focus of this chapter therefore is to critically consider stigma and autism, both in terms of how it manifests and affects the autistic community and their families, as well as unpacking some of the wider issues of how stigma is perpetuated, reified, and embedded in autistic discourses. To achieve this discussion, we also draw upon the broader stigma literature related to mental health conditions more widely, noting that autism remains a DSM clinically diagnosable 'disorder', and is treated socially as a mental health condition, although we have of course already critically questioned this idea throughout the book. However, because of the influence of medicine and psychiatry, and because of the typical classification of autism, the wider mental health and stigma issues become relevant for discussion.

Stigma, Prejudice and Discrimination

It is well-established that stigma and discrimination contribute significantly to social inequality (Heijnders & van der Meij, 2006). However, despite the volume of research and discussions on the matter, defining stigma and its related concepts is not a straightforward endeavour. If we are to appreciate the role and impact of stigma on autistic individuals and their families, it is first important to consider the various ways in which stigma and other relevant concepts have been presented in the wider mental health literature. In other words, stigma is pervasive in the field of mental health and influences public attitudes, feelings, opinions, and actions. Furthermore, the notion of stigma, as related to prejudice and discrimination can have important impacts on those with any mental health condition, not just autism, which can be contextualized as relevant to autism more specifically.

Early work on stigma was heavily influenced by the sociological work of Erving Goffman. In his writing, he defined stigma as a socially discrediting stereotype targeting certain attributes of an individual which leads the person to be positioned as inferior (Goffman, 1963). In this influential work, Goffman provided a general overview of the possible social consequences of being different and considered how a certain attribute could be devalued by society through the process of stigmatization, resulting in isolation and rejection (Goffman, 1963). Goffman did recognize however, that identity is fluid and flexible and individuals could shift away from the stigmatized identity into a more ‘normal’ or socially acceptable one (Wallace, 2010). This however presents a more complicated picture for autism. Autism is a life-long neurodevelopmental condition and therefore while education, intervention, and treatment may lead to some improvements in impairments or characteristics of the condition, the ideology of ‘fixing’ or ‘curing’ the person to return to a more ‘normal’ identity is not entirely plausible. In fact, as we discussed earlier in the book, some schools of thought within the autism literature and community actively resist the very idea that a ‘normal’ or ‘neurotypical’ identity is even desirable.

During this period, the work of Goffman was complemented by the sociological work of Thomas Scheff and his writing on labelling theory. As we noted previously in the book, labelling theory offered a detailed account of the ways in which societal reactions and attitudes can shape and contribute to the construction of societal norms (Scheff, 1966). In this theory, Scheff emphasized the social construction of stigma and acknowledged the power of social responses to labelling (Wallace, 2010), an idea that was also central in the later modified version offered by Link et al. (1989). Those who advocate in favour of labelling theory as an explanation for stigma claim that society learns stereotyped imagery of those with mental health conditions and reiterate the associated pejorative vocabulary (Weinstein, 1983). However, Weinstein in his review of 35 patient attitude studies found that research did not support labelling theory and argued that it has therefore misjudged reactions to diagnosis, as those with conditions seemed to eliminate stereotypes once diagnosed as the labels became personalized and felt more in control of their situations. Thus, once diagnosed with a condition, individuals and their families challenge their false beliefs and uncertainty and seek out measures to manage or overcome the issues faced (Angermeyer & Matschinger, 2003). Indeed, the role of diagnostic labels as a tool of medicine for providing a conceptualization of the illness is central for efficient and accurate communication and treatment (Sartorius, 2002), and therefore the notion of labelling cannot be viewed through a unidimensional lens.

Nonetheless, as Scheff (1966) argued, the rest of society may still stigmatize those with mental health conditions, even if they themselves understand it and challenge attitudes. Research has indicated that community members may foster social distance if they believe the mental health condition to be dangerous (Link et al., 1987) and the modified version of labelling theory argued that it is powerful groups in society that impose negative labels on those considered undesirable and seek to devalue those groups whom they discriminate (Link & Phelan, 2001). Arguably, then, labelling can have both a positive and negative impact and labelling the person is stigmatizing but labelling the illness itself is necessary (Link & Phelan, 2010; Wright et al., 2011).

While the early work of both Goffman (1963) and Scheff (1966) have been highly influential in our understanding of stigma, this work has been critiqued. For example, Goffman's ideas about stigma were argued to fail to consider the structural power relations and inappropriately positioned the stigmatized individual as a powerless victim (Ferrugia, 2009a, b). Furthermore, both theories did position stigma as located within the individual, an idea which has been critiqued (Link & Phelan, 2001). More recent thinking around stigma recognizes the socio-cultural and political context of stigma and the social framework within which it operates (Yang et al., 2007). Problematically, the notion of stigma does not have a clear operational definition (Rose et al., 2007). In more contemporary developments, stigma has become a contested concept, one that is multifaceted and interdisciplinary (Gillespie-Lynch et al., 2015), and the variations in definitions has led to extensive criticism (Hatzenbuehler et al., 2013). This reflects a complex interrelationship involving stereotyping, labelling, discrimination, separation, and power asymmetries (Link & Phelan, 2001).

As our section heading suggests there are three intrinsically connected concepts relevant to our discussion of autism and stigma, as stigma is an amalgamation of three notions. First, is a lack of knowledge, an ignorance about mental health; second is holding a negative attitude toward mental health, prejudice against those with conditions; and third is where people avoid or exclude based on that mental health condition, that is discrimination (see Thornicroft, 2006). In this way stigma connects closely to prejudice and discrimination. Stigma is however broader than simply discriminating against autistic individuals and their families. The literature on stigma and mental health has identified that there are different types of stigma that individuals can encounter. These different types of stigma as outlined by Clement et al. (2015) include:

- Anticipated stigma: which is the anticipation of being treated unfairly.
- Experienced stigma: which is when the individual experiences treatment from society that is unfair.
- Internalized stigma: which is when the individual holds a stigmatized view of themselves.
- Perceived stigma: which is when the individual's hold a perception about the extent others have a stigmatized attitude and express negative behaviour toward them and their condition.

- Stigma endorsement: which is when the individual has their own negative attitude and behaves negatively toward others with mental health conditions.
- Treatment stigma: which is when there is stigma associated with help-seeking and receiving treatment.

These different types therefore link to discrimination in various ways:

- Individual discrimination: this is the behaviour of individual members of a group that intends to have harmful or differential effects on members of another group (Pincus, 1996). This can lead to self-stigmatization which operates via the person's behaviour and beliefs, where the individual in the minority group internalizes the stigmatizing ideas perpetuated in their social environment and believe they are of less value (Dietrich et al., 2004). This is therefore a self-directed prejudice and discrimination where the individual applies negative stereotypes to themselves (Corrigan, 2007).
- Structural discrimination: this refers to institutional policies or practices that operate in ways that disadvantage those from minority groups even if individual prejudice or discrimination are absent (Link & Phelan, 2001). This can lead to institutional stigmatization; this is when service providers such as mental health professionals, GPs or schools reify the stigmatizing practices of society, which goes beyond professionals' attitudes and reflects the policies and practices of those institutions (Mukolo et al., 2010).

These are especially relevant to autistic individuals, and it is important to appreciate the nuances and differences in terms of how these different types of stigma are perpetuated within society, as well as by autistic individuals and their families themselves.

In discussing the various definitions of stigma and discrimination it is important to recognize that stigma not only has an impact on the individual with the mental health condition, but also is relevant to the family members related to that individual (Corrigan & Miller, 2004). For autistic children, parents must manage their help-seeking, education about the condition, tackling the education and health system, with the attitudes and behaviours of their community. Autism sits on a spectrum and the range of behaviours displayed by autistic individuals will vary considerably and can also differ between boys and girls, between men and women. Parents or family members of autistic individuals experience the social interaction, communication and behavioural challenges expressed within different social situations and become targets of people's negative comments and attitudes.

In his early work, Goffman (1963) referred to this as 'courtesy stigma' as he noted that the prejudice and discrimination encountered by individuals are extended to others around them as they are linked to the stigmatized person. It was argued that those who experience courtesy stigma are likely to experience increased social isolation and greater emotional distress (Green, 2001). Thus, while this would suggest that the family becomes 'tainted' by association, it is important to note this does not negate the individual with a condition also assuming a family member role (Corrigan & Miller, 2004). Indeed, for autism a recent literature review illustrated that parents of autistic children do experience courtesy stigma, and yet despite its impact, there is not enough research examining stigma for parents of autistic children (Liao et al., 2019). Research has also illustrated that stigmatization is not always imposed on families, as it can be imposed by families (Moses, 2010).

Service Provision, Attitudes, and Help-Seeking

> A most obvious source of stigmatisation is the careless use of diagnostic labels.
> (Sartorius, 2002, p. 1470)

Across Europe and the US, as many as 74% of people with mental health conditions are not in receipt of treatment or service provision (Alonso et al., 2004; Kessler et al., 2005) and yet despite the high numbers of people not seeking help, the growth of services is still failing to meet demand (Rao et al., 2008). And, as we noted earlier, COVID is likely to have exacerbated demand (Holmes et al., in press) along with the rising prevalence of mental health conditions generally (Bor et al., 2014), and autism specifically (see Eyal et al., 2010 for a discussion). Earlier in the book we demonstrated that it takes an average of 3.5 years for children with autism to acquire a formal diagnosis (Crane et al., 2016), and to access the resources and services they need. We present this as an interesting state of affairs, as help-seeking is not a process that individuals or families particularly want to engage in when they suspect autism, and they find the process challenging and difficult. Stigma is a powerful barrier to help-seeking (Rose et al., 2007) and yet even with stigma preventing large numbers of people seeking an autism diagnosis or entering services, there is many people asking for help who are simply not getting it. We wonder then, what would happen if stigma were reduced – would we see help-seeking reach an epidemic level?

Notwithstanding such ponderings about the state of mental health services, it is clear from the research evidence that the stigma associated with autism does lead to some reluctance of parents, or adults, to seek help from their General Practitioner (or family physician). Research shows that stigma is an important factor that contributes to the decision-making process when considering help-seeking (Phelan & Basow, 2007), which is a reluctance in children and adolescents (Gulliver et al., 2010), and adults of all ages (Bland et al., 1997). Consequently, there are often delays in help-seeking which leads to high levels of unmet need (Schomerus & Angermeyer, 2008).

This is further compounded by the high levels of structural discrimination which serve as a barrier to help-seeking. Research shows that some psychiatrists, family doctors (GPs) and other healthcare professionals can hold pessimistic views of mental health conditions (Jorm et al., 1999; Schomerus & Angermeyer, 2008), and may hold negative stereotypes of those diagnosed individuals (Adewuya & Oguntade, 2007; Nordt et al., 2006). Such perspectives result in discrimination against those seeking help. Furthermore, structural discrimination manifests through the lack of available mental health services, challenges to access services, and insufficient coverage of mental health care by commissioners or insurance providers (Kluge et al., 2007). This is worsened further because as a medical field, psychiatry itself is a stigmatized discipline (Bolton, 2012). It is arguably understandable therefore that individuals or parents of children consider stigma when deciding whether to seek help. Evidence suggests that those individuals who have contact with mental health care services found that stigma was perpetuated (Schulze, 2007), and this stigma persists even if others are aware that the condition is under control and being treated (Pescosolido et al., 2007).

Problematically, then, the perceived possibility of becoming stigmatized negatively influences any willingness by individuals or families to seek help when they suspect the presence of mental health symptoms (Rusch et al., 2009). Typically, when concerns are raised, there are three stages to help-seeking from mental health services, which requires problem identification, active decision to seek help, and choosing the appropriate place to seek help from (Sarker & Huda, 2019). This is important, as help-seeking behaviour is necessary and only arises if the person or parents of the child are aware that there is a difficulty, accept the nature of that difficulty and seek help for it and yet stigma can interfere with this process (Pattyn et al., 2014). Evidence is clear that stigma can be an important factor in preventing individuals or their families from seeking help, which delays identifying and treating those conditions (Corrigan et al., 2014; Pattyn et al., 2014). Indeed, some parents actively avoid the diagnosis of autism for their children as they want to resist a label for their child, which may reduce stigma and prejudice, but also reduces access to therapies and educational services that could improve quality of life (Russell & Norwich, 2012). However, if help is sought, stigma can negatively influence compliance with treatment (Bruce & Link, 2006), while negatively influencing clinical outcomes (Park et al., 2013).

Stigma, Children and Young People

As over 50% of adults with mental health conditions had an onset age before the age of 15 years old (Kessler et al., 2005), it is clear that attending to the issue of help-seeking for children and young people is important (as it is also for adults). Autism however is a neurodevelopmental condition so difficulties can start to show in early infancy. Autism as a clinical condition has an average age of diagnosis of 3.1 years, and yet more commonly is diagnosed later, especially for those who are higher functioning (Mandell et al., 2005), and for some, not until adulthood (Brugha et al., 2011). This reflects the ‘battle’ that many parents report in seeking a diagnosis and support for their child (Russell & Norwich, 2012). For some parents they do not have any idea what the difficulty may be but seek out support because they want help with the child’s behaviour, for others they suspect autism may be the difficulty and want this to be validated. Yet, the process from their initial concerns to eventual diagnosis of autism can be a distressing and difficult journey for some families (Mitchell & Holdt, 2014).

In the case of children and young people there are additional factors that are important when considering stigma. For example, children and young people are very rarely the initiators of help-seeking (Wolpert & Fredman, 1994) and can be difficult to engage in therapeutic treatments (O'Reilly & Parker, 2013), which is compounded further if they do not understand the reasons why they are taken to a mental health clinic (Stafford et al., 2016). Some children may fear going to a mental health clinic as it is an unknown entity for them (Bone et al., 2014), and others may feel embarrassed by the need for such a service (Chandra & Minkovitz, 2006). It is therefore essential that an understanding of stigma and the barriers to familial help-seeking are considered for children and young people, especially for those who eventually acquire an autism diagnosis. This is especially relevant as the role of stigma in child mental health services and research has not been well-conceptualized (Mukolo et al., 2010), and the focus on child mental health stigma is a recent development in academia (Heflinger & Hinshaw, 2010).

Although there are several barriers to families seeking help for mental health conditions in young populations, like mistrust in the system, cultural issues, stigma and financial resources (Gould et al., 2002), understanding young peoples' experiences with labelling and stigma is crucial to appreciate treatment avoidance and poor treatment adherence (Vogel et al., 2007). The role of families of dealing with services and professionals has generally been understated in research, although the wider literature has illustrated that service relationships can be problematic due to stereotyping and professional dominance (Todd & Jones, 2003). Indeed, stigma can increase the burden of care and discourage caregivers from help-seeking (Mukolo et al., 2010). While some progress has been made institutionally in terms of empowering children in mental health to be involved in decision-making, this is not always realized in practice which is problematic (Bone et al., 2014).

In the case of children and young people there are specific concerns that can increase stigma. Young people are susceptible to being viewed as an outsider in school, which is a concern for them (Pescosolido et al., 2007). This may be because young people tend to have less favourable attitudes toward mental health conditions than adults do (Stuart & Arboleda-Florez, 2001) and commonly young people feel that mental health conditions are embarrassing (Barney et al., 2006). Indeed, it is this embarrassment that was a significant barrier for young people not seeking help. Survey research showed that 59.1% saw embarrassment as the main barrier, 42.7% felt they could not trust a counsellor, 34.6% saw stigma as a considerable problem, which meant that 30.3% would not be willing to use a mental health service (Chandra & Minkovitz, 2006). This has been supported by other research that showed that stigma and issues of trust were the main barriers for young people, and they were often fearful of what would happen if they sought help (Gulliver et al., 2010). For children and young people who had accessed services, a third of adolescents described that they had been discriminated against, with peer stigma being especially concerning as it resulted in them feeling socially isolated, and some felt there was substantial stigma even within their families, leaving them feeling blamed or rejected (Moses, 2010). This is particularly important in the contemporary digital world as those with mental health conditions are more susceptible to cyberbullying (Hinduja & Patchin, 2011) and tend to be more vulnerable online (O'Reilly et al., 2021).

It has been suggested that stigma is especially problematic for adolescents. This is because much of the dissatisfaction of healthcare is contextualized by concerns for personal identity (Coyle, 1999) and it is during adolescence that identity is developed and tested (Erikson, 1968). It is therefore argued that adolescents are vulnerable to stigmatizing labels as this is a developmental period marked by identity consolidation characterized by a powerful need for a sense of social acceptance and autonomy (Leavey, 2005). Like adults, when young people are labelled with a diagnosis, they will interpret and respond to those labels in multiple and dynamic ways and therefore they face multiple barriers in identifying with that label (Moses, 2009). It is arguable then, that autistic adolescents are likely to struggle with stigma as they learn to develop their peer relationships and their social interaction challenges can make life more difficult for them.

Autism and Stigma

In autism (specifically Asperger's) research shows that autistic individuals encounter higher levels of overt and relational victimization and have high levels of clinically significant suicidal ideation than their neurotypical peers (Shtayermman, 2009), evidently to some extent connected to stigma and discrimination. This is especially problematic in autistic women and girls, as they seem to experience greater levels of co-occurring depression and/or anxiety (Solomon et al., 2012) and have higher rates of suicide (Hirvikoski et al., 2016).

Families of autistic individuals experience considerable stigma, and stigma is an important factor in predicting how difficult life is for parents (Kinnear et al., 2006). When children display behaviours that are not considered socially acceptable, then this is often interpreted as due to poor parenting and the child is often considered to be naughty (Gray, 2002). As we demonstrated when considering mother-blaming, parents often felt judged about their child and a lack of societal understanding caused parents considerable upset and distress (Broady et al., 2017; Farrugia, 2009a, b) and siblings also often felt neglected or embarrassed (Tehee et al., 2009). Parents reported that there was a general social lack of knowledge about autism, that they felt judged and rejected by others, and that stigma manifested through a lack of support (Broady et al., 2017).

Of particular concern regarding the impact of stigma on autistic individuals and their families has been the role of schools. Schools play a crucial role in shaping children's attitudes, facilitating moral development in children, and are increasingly being placed in a role to educate about mental health. While schools have shown some resistance to taking increased responsibility for child mental health because of a perceived lack of skills and training (see O'Reilly et al., 2018b), there is increasing pressure on them to be inclusive (Department for Education, 2014) and to engage with the mental health agenda (House of Commons Health and Education Committee, 2017). However, despite policy efforts, children with social, emotional or mental health conditions are more likely to be excluded from school (Cole, 2015), and autistic children are the most likely to be excluded (Parsons et al., 2009) as we demonstrated in Chap. 6. What connects these issues for autistic children in school is the experience of stigma, as some mothers of autistic children continue to demonstrate that their children are stigmatized in the education system, despite arguments that the link between stigma and disability is weakening (Lilley, 2013). Indeed, mothers have reported that they are specifically stigmatized in school environments, and they feel compelled to find coping strategies (Gill & Liamputtong, 2010).

It should also be noted that stigma does have some cultural sensitivity. While stigma is pervasive and seems to affect all individuals and families in the area of autism, for some cultures it is viewed as especially negative or at least has considerable impact. For example, African immigrant mothers found autism diagnoses challenging and difficult to manage. Research has shown that this group are reluctant to seek help because they desire privacy due to shame and embarrassment, and they particularly have concerns about being rejected by others and this leaves them feeling stressed and isolated (Munroe et al., 2016). Similarly, Somali parents of autistic children felt discriminated against, felt that their children were stereotyped, and felt isolated and rejected (Selman et al., 2016). Alternatively, however, for some members of some cultures, their faith and religious beliefs provides them with a different perspective as they felt that their child's disability was a blessing from God, although some did see it as a punishment for their sins, which was less positive (Skinner et al., 2001).

It is important to note that autistic individuals and their families are not passive victims of the stigma, and they frequently take steps to challenge and resist stigmatization. In Chap. 4, we considered the neurodiversity movement, that has been instrumental in bringing a voice to the autism community and challenging some of the myths and negative discourses of autism. We do not repeat that argument here, but direct you back to that chapter to consider how neurodiversity challenges stigma and some of the limitations of that movement. Stigma as related to autism is also relevant at more individual and familial levels. We have considered in this chapter pointed to the stigmatizing and problematic aspect of label acquisition, diagnosis, and categorization.

Some people with a diagnosis of autism or Asperger's feel that their diagnosis exacerbates stigma (Linton, 2014). However, Linton showed that some people diagnosed with autism and Asperger's claimed that their diagnosis improved their self-discovery. Furthermore, some mothers drew upon their faith and learning about autism to cope with and resist stigma (Selman et al., 2016). However, the negative framings of autism and the stigma related to it can put autistic individuals under pressure to conceal their autistic identity and mask their behaviour which consequently can negatively impact their mental health (Cage et al., 2018). In a study with autistic people, findings showed that they feel a tension between their own view of autism and that typically understood by society, a tension which created a sense of burden (Botha et al., 2020). Botha et al. reported that their autistic participants believed their autism to be akin to race or sexuality, but instead society tended to position the autistic identity negatively, and yet their autism was central to their identity. Botha et al. (2020, p. 9) argued that autistic individuals felt and experienced the stigma associated with their condition, as they reported:

> Participants discussed how they experienced stigma, infantilization, dis-crimination, dehumanization and powerlessness. Stigma related to gendered stereotypes of autism, assumed incompetency, and violence. Participants described stigma and stereotypes as limiting, and destructive.

Evidently, the diagnosis and label can become a double-sided issue, and this is an argument we have woven through this chapter.

Overall, the picture seems bleak as stigma contributes directly and indirectly to maintaining inequality in autism. Stigma is clearly a powerful force that influences and shapes public reactions to individuals diagnosed with mental health conditions, including autism (notwithstanding possible critiques that autism should not be counted as a mental health condition), impacts their attitudes and behaviours toward those individuals, and affects the beliefs and behaviours of those with autism characteristics. The role of labels and diagnoses is therefore clearly bidirectional. On the one hand there is the risk of stigma, victimization, prejudice, and discrimination, on the other, access to support, funding, services, and treatment. The acquisition of a diagnosis of autism provides families with capital in terms of medicine, education and social care, and accumulating capital can lead to power for accessing resources and yet, the potential medicalizing and labelling may not be helpful in terms of the position of the individual in society, especially if the labels are interpreted negatively in social spheres (Ryan & Runswick-Cole, 2008). In light of this, some effort has been made to alter the autism label, arguing that it is the notion of a ‘disorder’ that is stigmatizing (i.e., autism spectrum disorder), and that we should change our vocabulary to ‘condition’ (i.e., autism spectrum condition) (Baron-Cohen et al., 2009). This is in part why language is so important, as we have consistently referred to throughout this book and as we have said before we have been using the notion of condition, rather than disorder or illness throughout unless in the context of medicine.

Stigma and Medication

It is noteworthy at this point that a common stay of treatment for many mental health conditions is medication (Karim et al., 2014), and this increase in the use of psychopharmacology for children began in the 1970s. The stigma attached to mental health care is related to the concerns that have been raised about utilizing medication for children and the controversies about appropriate treatment programs for this group (Pescosolido et al., 2007). In particular, a condition of controversy is Attention Deficit Hyperactivity Disorder (ADHD). Much of the literature in the field of stigma and medication relates to the condition, ADHD. This is important to arguments about autism in two important ways. First, many autistic individuals are prescribed medication for symptoms such as their anxiety or sleep problems, and second because ADHD is a common co-occurring condition for those with autism and therefore take medication for this (Karim et al., 2014). An issue in relation to this therefore is that medication for mental health is itself stigmatized and there are general negative attitudes toward using medication as a form of mental health treatment in children and young people.

The main negative attitude held is the belief that children are over-medicated (Pescosolido et al., 2007), and this perspective has been reified and reiterated through advocacy groups such as anti- or critical psychiatry, and more extreme groups such as scientology (Ralley, 2012; Desai, 2005). It is argued that there are three main reasons why medication is stigmatized and why there are embedded negative discourses around psychopharmacology and children (see Safer, 2000);

1. These advocacy groups argue that medications are over-prescribed and claim that professionals are succumbing to pressure from parents and schools when many children do not need medication.
2. These advocacy groups argue that alternative forms of treatment are overlooked because medication is favoured and seen as the quick and cheap option.
3. These advocacy groups argue that medication is harmful and subject to abuse. This is compounded by the power held by pharmaceutical companies who have unduly influenced medical research to generate support for medication.

The rhetoric around medication therefore reinforces the stigma and negative attitudes held by society as these arguments sway public opinion about the field of psychiatry. Such discourses perpetuate the belief that medication impacts on children's personality and turns them into 'zombies' and actively work to prevent families from working through the child's problems (Pescosolido et al., 2007). However, what is not thoroughly considered by these advocacy groups is the scientific evidence that shows that professionals spend considerable time considering a diagnosis, rarely prescribe medication as the only form of treatment, and often underestimate the organic aspect underpinning some mental health conditions, like ADHD (Safer, 2000) and autism.

Notably, the rhetoric from such advocacy groups does become embedded in general public attitudes. Research indicated that many people believe that psychiatry overprescribes medication for what they believe are mere behavioural problems, and such professional action results in delays in dealing with the underlying issues (Pescosolido et al., 2007). Problematically, the stigma associated with medication also has an impact on parents. Research has shown that parents do experience anxiety about giving their children pharmacological treatments as they worry about the long-term effects, and the degree of stigma attached (Bussing & Gary, 2001). Stigma had a real impact on the adherence to medication prescribed. Indeed, research showed that those who saw mental health treatment as stigmatizing opposed the use of medication more strongly than those who place more trust in doctors, who subsequently viewed medication more favourably (Pescosolido et al., 2007).

Despite the stigma, overall, parents are still generally willing to give their children medication where needed. Parents tended to hold positive views of medication, although some were initially hesitant because of negative or stigmatizing media reports, but ultimately believed in the science and trusted the doctor (dosReis et al., 2003). Furthermore, in providing medication for their children, parents reported that there were improvements in their child's behaviour and functioning, which resulted in a reduction of parental stress (Hansen & Hansen, 2006). Not all parents reported positive views as some avoided medication because of fear and stigma, although most parents did give their children prescribed treatments, even where they held mixed views (Blum, 2007).

Mother-Blaming, Stigma, and Autism

Parents of autistic children tend to be highly stigmatized, especially mothers. Parents of autistic children face considerable enacted stigma because of their association with the child, and while they can resist the stigmatizing discourse through medicalization, they nonetheless are impacted by societal attitudes and discrimination (Farrugia, 2009a, b). Much of this being due to the behaviours displayed by the child (Mitter et al., 2019). Problematically therefore, the stress and impact of the courtesy stigma felt by parents of autistic children can negatively influence their mental health, and thus require help to build coping strategies and resist the stigma (Lodder et al., 2019), especially that associated with the societal ideals of good mothering.

The traditional ideology of the good mother is one that fulfils domestic aspirations (Boris, 1994), and those who fail to comply with such a view of motherhood can become subject to stigma. Notably, this was reinforced through behavioural trends in the work on attachment, from leading theorists such as Bowlby (Chess & Thomas, 1980). Such early work posed the idea that mothers are responsible for the behaviour, health, and wellbeing of their children, and in so doing carry the burden of public and professional disapproval if they fail to fit the social idealized view of motherhood (Jackson & Mannix, 2004). Indeed, by the 1950s good mothering was argued to be dependent on the relationship with normalcy (Singh, 2002). In the context of mental health, therefore, such blaming of mothers represents a clear gender bias as mothers are seen to contribute to their child's maladjustment while ignoring any contribution from fathers (Phares, 1992), and while fathers are becoming more visible in public advocacy in the context of autism at least, it remains mothers who are in the spotlight and mothers who undertake most of the caring labour (Silverman, 2012). Indeed, parenting practices continue to be gendered, and while things are changing, mothers remain high for parental contribution and involvement (Fox, 2009).

Mother Blaming, Mental Health and Disabilities

In western culture, women are afforded multiple and contradictory positions in terms of motherhood (McKeever & Miller, 2004). These mothering discourses and positions occur from the moment of conception, through pregnancy and throughout the child's life (Jackson & Mannix, 2004). Such positioning of responsibility with the mother, therefore, has led to a general attitude of mothers being blamed for many different childhood conditions, including schizophrenia and autism (Singh, 2004). This positioning led to a greater stigmatization as such problems were attributed to moral flaws and poor parenting (Heflinger & Hinshaw, 2010) which has led to negative public responses resulting in a preference for social distance from the child and family, as well as blaming the mother for the child's problems (Pescosolido et al., 2007). Consequently, this tendency to blame children's difficulties on poor parenting, and stigmatizing their role in help-seeking, means that such families are in negative stigmatized contexts (Brannen et al., 2003; Mukolo et al., 2010).

Such stigmatized perspectives about mothers and motherhood, are intrinsically tied to the idea of a universal mothering, one grounded in biology. Indeed, the cultural rhetoric around mothering is a dominant one (Austin & Carpenter, 2008). It is one that extends a level of homogenization to mothers who are the primary caregivers to children with disabilities (Tabatabai, 2020), despite motherhood being textured and influenced by a range of social positions and multiple identities (Collins, 2000). Yet, mothers are constructed as responsible for protecting their children and promoting growth, within the parameters of social standards (Ruddick, 1989), creating a burden for mothers for managing the perfect childhood, that is the 'normalcy project' (Frederick, 2017). Thus, we need more work on the process of 'doing mothering' and the personal and lived experiences of motherhood (Frantis, 2011; Warnes & Daiches, 2011), because cultural ideals of motherhood influence the way in which those women are perceived by others, but also how they perceive themselves (Tabatabai, 2020). In other words, women are influenced by cultural expectations of what it means to be a mother, but particularly what it means to be a good mother (Collett, 2005).

As we noted earlier in the book, a neoliberal ideology is highly important in the context of disability, and this too connects to mothering and disability. Under a neoliberal ideology, a good mother is one that promotes self-sufficiency, independence, and personal responsibility for her children, as people are required to care for themselves and be autonomous (Tabatabai, 2020). Thus, the notions of sufficiency and independence have been rhetorically imbued within discourses of good mothering. In other words, good mothering is not merely about selflessness and care, but for those with a disabled child, it is about advocating for including and doing their best for that child (Tabatabai, 2020). In a neoliberal society, mothers are required to take responsibility for compensating for their children's disability (Lareau, 2003), and have been described by some as 'vigilantes' in a battle for resources for their children (Blum, 2007). Despite this fight, mothers of disabled children may be in a position to accept that their child may never be a contributor to the economy (Dupras

& Dionne, 2014) and this can create a tension with the market-driven society (Luxton, 2015).

While mother blaming for is a well-known and highly perpetuated myth in society, there is little known about how women experience this phenomenon, and whether this stigmatizing practice influences their help-seeking, service engagement, and parenting practices (Jackson & Mannix, 2004). Research has shown that mothers of children with mental health difficulties had regularly experienced critical remarks, with some arguing that even clinical experts had targeted them as the cause of their child's difficulty (Blum, 2007; Sommerfeld, 1989). Mothers frequently reported that their identity as a good mother was being scrutinized by clinical professionals (Todd & Jones, 2003), and often parents worked hard discursively to present a view of themselves as good parents during therapeutic interactions (O'Reilly & Lester, 2016; O'Reilly & Kiyimba, in press).

In our own work on family therapy, we have explored how parents seek aetiological explanations that are consistent with the scientific paradigm and in such way distance their parenting identity from the dispositional aspects of the child's problems (O'Reilly & Lester, 2016). Constructing the child's behaviours and difficulties as dispositional and medical, and orienting to the discourse of genetics or science, was important within a family therapeutic environment. This is because the nature of family therapy is to focus on systems and could be perceived to allocate blame (Patrika & Tseliou, 2016), whereby the move away from individualism to multiparty risks perceptions of accusation because of the parent blaming rhetoric within society (Stratton, 2003). Parents therefore are motivated to present themselves as 'responsible good parents', as they work to align with the therapist (Stancombe & White, 2005) and to use language consistent with medical explanations of the child. This is something that we observed in our data (with reference to mental health generally, rather than autism specifically).

Mother Blaming and Autism

Both Kanner's and Asperger's work laid a foundation for how the central characteristics of autism came to be understood, but also in terms of the role of parenting and potential aetiologies. The attribution of such behaviours was relatively complicated. Kanner, for instance, argued that some of the aspects of autism could be attributed to the condition, but noted that this single factor was insufficient in explaining it. During the twentieth century there was a strong promotion of psychodynamic causes (Karim, 2017). Indeed, the influence of parents on children's development and their influence in the development of psychiatric conditions has been heavily discussed in the literature. For example, even Kanner (1943/1985, p.50) wrote of this, noting:

> In the whole group, there are very few really warm-hearted fathers and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in

> people. Even some of the happiest marriages are rather cold and formal affairs. Three of the marriages were dismal failures. The question arises whether or to what extent this fact has contributed to the condition of the children.

With Kanner's descriptions of the 11 children and their parents it was the case that an official discourse surrounding autism started to evolve. Kanner's descriptions of autism implicitly and explicitly linked autism to certain social and economic norms and parenting styles. Further, the claims of autism as innate to the individual captured the public and professional imagination, driving much of the research that ensued. Yet even with the term "infantile autism"[1] entering the psychiatric nomenclature by 1944, for many years to come, much to Kanner's dismay, the new disorder's official name remained "schizophrenia childhood type" (Grinker, 2007).

In 1967, Bettleheim picked up on Kanner's claim about parenting styles and argued that it was a specific style of parenting that led to autism; that is, a cold and unavailable mother, that caused the child to shut down emotionally. This parenting type he coined as the 'refrigerator mother', leaving an entire generation of mothers feeling blamed for the onset of their child's problems (see Simpson & Quinn, 2006, *PBS* documentary "Refrigerator Mothers" for an exploration of the effects). In his famous book, *The Empty Fortress* (1967), he claimed that "...the precipitating factor in infantile autism is the parent's wish that his child should not exist" (p. 125). As a holocaust survivor himself, Bettelheim also suggested that the world of the autistic child was analogous to a Nazi concentration camp. With the popularity of the book, the notion that "refrigerator mothers" cause autism became widely accepted in popular culture and to some extent within academic circles. In current times, this mother-blaming rhetoric has been heavily challenged, predominantly with the discourse of science (Blum, 2007; Phelan, 2005), but the mother-blaming rhetoric has not fully disappeared (O'Reilly & Lester, 2016).

Importantly, the idea of a 'refrigerator mother' has been disregarded. The old-fashioned psychoanalytic idea of the mother causing the child's autism, or indeed any mental health condition because of their cold nurturing style is now completely discredited. However, despite this, mothers still tell stories where they report professionals have told them that they need to love their children more (before a diagnosis is made). Consider the following extract from the UK-based mental health assessment dataset described in Chap. 1, where a child is being assessed by the mental health practitioner (MHP) for the possible presence or absence of a mental health problem.

Example: Family 18

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Mum: I did take him to the doctors a couple of times during
     that period
MHP: um
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[1] "Infantile autism" was also referred to as "Kanner's Syndrome."

```
Mum: (0.70) to be told that (0.41) it was me (1.72) um: (0.22)
     and that it was my parenting skills (.) the doctor said
     that he just needs love and I was like well he gets that
MHP: Um
Mum: You know an and I was just (0.54) erm (.) fobbed off really
```

In the above extract, it is clear that mother felt that being blamed was a considerable burden and some women internalized these societal attitudes and began to blame themselves for things out of their control (Jackson & Mannix, 2004). Indeed, mothers felt public judgement and sometimes avoided public places to avoid public comment, criticisms that are reflective of a culture of mother-blaming (Singh, 2004). Such blame and intolerance are, therefore, based on stereotypes and misinformation, as well as political and policy discourse which can provide narrow perspectives on the issue (Duvnjak, 2013). Yet, the modern mother of the autistic child is now expected to be a 'child-saving hero', in that they are encouraged to pursue normalcy by implementing special diets and special educations, using modern medicine to improve quality of life and play a central role in utilizing behavioural interventions (Waltz, 2015). Thus, where the child grows into an autistic adult, the mother is still blamed for failing to do sufficient work to 'save him or her' (ibid.). The consequences for mothers of autistic children are therefore profound. As Waltz (2015, p.356) argued:

> The costs of continued mother blaming are high, and not only financially. Encouragement to heroics can cause direct physical harm to autistic people. Psychological damage may also occur, both to wrongfully guilt-ridden parents and to people with autism, who get the message that they are "sick" or even, since some extreme therapies carry fatal risks, that having autism is a fate worse than death. The extreme focus on child saving also contributes to a lack of services for autistic adults: if you believe your child can and should be cured, that becomes the goal rather than fighting for inclusion, services, and support in partnership with disabled adults. For the sake of people with autism and their families, we need to do better.

'Good mothers' therefore police themselves through fear, guilt and response to mother-blaming as they experience being judged as inadequate (Blum, 2007). Arguably mothers have the most to gain from medical absolution and solutions. In the context of mother-blaming, medical and rehabilitation discourse dominant in clinical practice and policy is often embraced by parents as an official label has the potential to protect them against a charge of incompetence (Ryan & Runswick-Cole, 2008). However, blame is not simply eradicated through diagnoses and treatments, and mother-blame can be reconstituted through biomedical understandings, rather than eradicated (Singh, 2004). Thus, the era of genetics and neuroscientific explanations of autism have not managed to eliminate mother-blaming, but instead have simply shifted the rhetoric and polemic around how mothers are responsible for their child's autism. This is because they experience secondary stigma as mothers contributed genetic material to the child and because mothers are still held accountable for the ways in which their children behave and respond to their social and educational environments (Blum, 2007).

Genetic Essentialism, Stigma, and Blame

As noted then, in more recent years the mother-blaming rhetoric has shifted somewhat, moving away from nurturing or parenting skills to genetics and biology. Discourses of motherhood and maternal blaming as related to autism are now more subtly managed through the discourse of science, whereby a genetic revolution has been reconstructed as explaining the onset of certain conditions (Phelan, 2005). Interestingly, this discourse of science and genetics places parents in a less accountable position, as it is their child's 'genes' that are argued to be at fault rather than their behaviours; yet, still implied within this argument is found some level of parental blaming. Problematically, such genetic aetiology also positions the autistic individual as beyond fixing. In other words, such genetic attributions simply strengthen the undesirable characteristics in the individual making the label attributed even more difficult to move past and the possibility of 'recovery' even more reduced (Phelan, 2005). In other words, the genetic basis, and in the case of autism the neurodevelopmental basis, means that the individual is 'legitimately' and biologically positioned as 'impaired'. The boundary between science, genes, and biology against parenting, the environment, and social factors is a challenge for parents and one that is frequently deployed as they grapple to understand their child's behaviour.

The rise of genetic explanations has meant that those with conditions that can be attributed to biological aetiology are seen as less blameworthy than those considered more psychological or environmental in nature (Mehta & Farina, 1997). People are less likely to endorse social avoidance or anger toward those diagnosed when they believe that there is a genetic or biological basis (Corrigan, 2007). Such a genetic essentialist position argues that genetic characteristics are attached to an individual and the family members who share genes, and characteristics that are viewed positively are not inherently stigmatizing (Phelan, 2005). In most branches of medicine, diagnosing an illness depends on biological markers, and yet in psychiatry the underpinning neurobiology of a condition has not been fully established, meaning that diagnoses typically rest on subjective reports of symptoms or characteristics and measuring the person against a standardized manual (Borgelt et al., 2011). For autism, research has not yet determined a genetic cause, and the diagnostic process can take considerable time. Although there are useful tools to aid diagnosis, ultimately professionals rely on individual or parental reports, school reports and observations.

However, despite the uncertainty that still reflects autism and genetics, the notion that there are underpinning biological aspects of psychiatry does mean a paradigmatic shift in terms of how we think of mental health conditions. While this has had some positive impact, the issue of stigma has arguably not lessened, it has just shifted. Research suggests that the new discourse of brain and behaviour in mental health has left the public with an impression that recovery or improvements are not possible and individuals with mental health conditions will not be capable of living productive lives (Corrigan et al., 1999). In this way genetic essentialism exacerbates stigma. What a genetic position leads to is a belief that the individual with a mental health condition is fundamentally different from others, that the problem is serious, and that family members may also be at risk of the problem (Phelan, 2005). Phelan argued that because genetics are a basis of personal identity, the stigmatized person then becomes fundamentally different from others, and this has potential to increase social distance. This is further problematized with the general critique targeted at the reductionist ideology of psychiatry. While neurobiological factors may play a role in mental health conditions, this arguably over-simplifies our understanding and ignores the impact of the individual and their relationship with others.

The Role of the Media in Perpetuating Stigma

The media has played an important role in presenting family discourses and has also had some responsibility for maintaining the blaming rhetoric historically associated with mothers of autistic children. Many of the stigmatizing practices we outlined in the previous section regarding how mothers were spotlighted as responsible for autism have been spread by various forms of media. Certain arguments have been presented through print and social media, that can misrepresent the role of the mother in autism and has implication for the good mothering role (see for example, Yochim & Silva, 2013). However, the role of the media in understanding autism transcends the role of mothers and has focused on a wide range of areas in this field.

The role of the media in ‘educating’ the public about mental health is well established. Historically, newspapers were considered the main conduit through which the public came in contact with issues of mental health (Wahl, 2003), and in a contemporary society, digital media connects people of all ages to information, both accurate, misleading and false, in this area (Livingstone et al., 2014; O’Reilly et al., 2018a, b). Problematically, mostly media reports of mental health conditions tend to be presented in especially biased ways that misrepresent links between mental health conditions and violence, tend to report stories in sensationalist ways, and perpetuate the stigma associated with the misconception that those individuals are unpredictable and dangerous (Corrigan, 2007). This is because media reports capitalize on sensationalist angles and dehumanize individuals diagnosed with mental health conditions (Chen & Lawrie, 2017). Unfortunately, the media strongly influences public stigma and reinforces negative stereotypes and promotes fear, although it does have the power to challenge the myths shrouding mental health conditions (Mukolo et al., 2010).

In autism especially, the media has played a pivotal role in shaping and reconstructing public perceptions of the condition. For example, there was an increased social interest in autism during the late 1980s with the release of the film Rain Man (Murray, 2012). Since then, autism has continued to create media presence with sensationalist stories such as that of the vaccinations as a possible etiological explanation (Singh et al., 2007), along with stories of despair, funding, and research campaigns (Jones & Harwood, 2009). Thus, the media has continued to represent autism in various ways through news media and film narratives that speculate about the causes and effects of autism (Garner et al., 2016). In such ways the media influences what is worthy of exploration as its representations form public images of what autism means (Jones & Harwood, 2009). Furthermore, the media plays a central role in raising the profile of autism, and it is through such social artefacts like the media, that the public is presented with notions of what it means to be labelled as autistic (Garner et al., 2016). These of course can be both positive and negative, empowering and stigmatizing, but importantly, and of concern, not always accurate.

A Critical Appraisal of the Notion of Vulnerability

Despite the spectrum nature of autism, variations of ability and capabilities, this group is frequently positioned as homogenous. In terms of the inclusion of autistic people in society, at work, at school, and in research, the status of autism brings with it certain assumptions, and one that stands out is that of vulnerability, a term you may have noticed us using in some places within the book. This is especially the case if the autistic person is deemed to not have capacity to make decisions for themselves. All psychiatric patients are constructed as vulnerable and have impaired decision-making (Oeye et al., 2007) and while this may be the case for some autistic persons, this does not mean they cannot be involved in decision making and neither does it mean that they should be excluded. Instead, additional safeguards may be needed, consultation with family members or staff who are responsible for protecting their best interests, and care should be taken. However, protectionist positions often govern, with little effort or attention to how this automatic exclusion is discriminatory and underestimates the abilities and rights of those persons. This is especially true in the research context, where researchers seek ways to improve the lives of autistic people and their families, but often face barriers because of an assumed vulnerability of the diagnosed individuals. What this means is that these groups are further stigmatized as they are not provided with the same opportunities as other groups (Oeye et al., 2007). A good example of this is the study of autistic inpatients and communication conducted by Drewett, where initially the ethics committee were concerned that those autistic individuals who lacked capacity should not be included (Drewett & O'Reilly, in press). However, after some carers complained that their relatives ought to have a voice, the decision was changed and careful safeguards are in place to include them in the work (ibid).

We therefore offer some critique of the notion of vulnerability. This is not to say that autistic individuals who are not able to safeguard their own interests do not need others to do this for them, but instead critiques the idea that all autistic people are vulnerable because of their autism status, and to critique the automated protectionist ideology that is imposed on them. For example, children are considered to not have full capacity to make decisions due to their chronological and developmental age, and historically they were excluded from certain activities such as research (O'Reilly et al., 2013). However, with the rise of the UN Convention of Children's Rights (UNCRC, 1989), a change in attitude has occurred and now children are included in many areas of decision making, including healthcare and research. Therefore, while potentially well-meaning, this protectionist position can simply reinforce an already pervasive stigma for those with autism (especially those without capacity) and lead to them being excluded from important decisions, and also from research which has potential to improve their lives or the field.

Vulnerable groups are argued to be those who are disadvantaged in some way and therefore warrant additional protections (WMA Declaration of Helsinki, 2008). Typically, these are groups with limited autonomy and lack the skills to protect themselves from risk (Shivayogi, 2013). The notion of vulnerability is indexical (Nordentoft & Kappel, 2011) and definitions of vulnerability are varied and contested. Arguably there are different types of vulnerability and Nickel (2006) proposed two core types:

- First, was consent-based vulnerability, whereby the individual has challenges expressing their autonomy.
- Second, is fairness-based vulnerability, whereby the individual lacks opportunity of freedom and thus are susceptible to coercion or pressure.

Importantly, this argument was extended with the argument that all humans are vulnerable, and the extent and impact of the vulnerability is what should be assessed. Thus, three types of vulnerability were offered by Rogers et al. (2012) who claimed that these vary according to context:

- First, was inherent vulnerability, which impacts all people as everyone is vulnerable to illness, injury, and disease.
- Second, was situational vulnerability, which notes that humans are all part of a social, economic and political context and these factors influence vulnerability of individuals in different ways.
- Third, is pathogenic vulnerability, whereby individuals have different situational vulnerabilities due to adverse social circumstances, for example a vulnerability to stigma.

Concluding Thoughts

While parents and families often work hard to resist stigma and cope with the negative effects that it imposes on their lives, governments and wider communities have also made an effort to combat the stigma associated with mental health conditions and disability more broadly. This is because it has been shown that education is a crucial way to combat stigma (Bolton, 2012). Educating society and certain populations is important for replacing stereotypes and facts, and can protest against the negative and prevailing views that are often associated with mental health conditions (Betton et al., 2015), especially autism (Botha et al., 2020). This is crucial, as Botha et al. indicated that autistic stereotypes tend to associate those with the condition with being male, being infantile and being dangerous, typically white and minimally verbal and thus completely misrepresents the condition and the person. Furthermore, autistic individuals have described how they feel trapped by the stereotypes that are held about them by neurotypical groups (Treweek et al., 2019).

Research has shown that those individuals who better understand mental health conditions are less likely to endorse stigma or discrimination (Link & Cullen, 1983), and educating children about disability is shown to have a similar effect (Campbell, 2006). Yet, despite significant effort and investment in anti-stigma campaigns, there has been limited long-term impact in practice. While we have pointed to the positive side of being diagnosed autistic, showing that parents can strategically employ labels within a medical framing to actively resist stigma by articulating subjectivities that are positioned as a world of autism (Farrugia, 2009a, b), there is a negative side, whereby individuals and family members have their quality of life diminished by the stigma they are subjected to from their communities (Broady et al., 2017). Nonetheless, autistic advocates and autistic individuals continue to push against the negative framings of autism and seek recognition for a multifaceted condition with a range of ability and competences (Hacking, 2009).

Chapter 8
Summarizing Core Issues

Evidence is showing that across the globe, autism is being increasingly diagnosed and as we have shown throughout the book, much of the public discourse surrounding autism presents a discourse of deficit and disability (Lester, 2014; Lester & Paulus, 2012; Lester & Paulus, 2014). Consistent with medical responsibility, diagnosis, and medicalization, metaphors of "medical intervention" and "cure" are typically evoked when talking about autism (Broderick & Ne'eman, 2008, p. 469), which serve to locate autism as something that rests outside of culture (Nadesan, 2005) and the neurodevelopmental profile of the condition contributes to this narrative. Thus, in many ways, the growing debates and conflicting discourses that surround autism that we have drawn attention to throughout this book, highlight in explicit ways, arguments concerning the boundaries between normality and abnormality, between ability and disability, and between mental health and mental 'illness.'

Introduction

The ideas and arguments presented in this book are positioned at the intersection of critical disability studies and discourse studies, contributing to the growing polemic about the very meaning(s) of autism and what it means to be autistic. Our positioning throughout has been that of social constructionism and thus we have sought to illustrate the social and cultural construction of autism as being made visible in everyday, institutional, and historical discourses, alongside a careful consideration of the bodily and material realities of embodied differences (Oliver, 1996). The arguments we have presented across the chapters have sought to offer differing viewpoints, research, and ideas, to encourage readers to make their own critical decisions; yet, for transparency, our positionalities have been reiterated throughout.

By presenting several core issues at stake that are interrelated and intrinsically connected, we have provided an appraisal of a contemporary understanding of autism.

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In so doing, we discussed the economic consequences of a disabling culture, and explored how autism fits within broader arguments related to normality, abnormality, and stigma. To do this, we provided a theoretically and historically grounded discussion of autism—one designed to layer and complicate the discussions that surround autism and disability in schools, health clinics, and society writ large. To facilitate our arguments and discussion, we have presented our own work that has taken place across two contexts – the US and the UK – and drew upon empirical examples to illustrate our key points. Utilizing both discursive psychology and conversation analysis, we positioned our analytical and methodological focus within a particular approach to discourse analysis, which attends to the micro-details of interactions.

Our Arguments and Positionality Under the Spotlight

In this book, we presented a range of different perspectives, views, ideologies, positions, models, and research evidence. We ourselves are two academics who have undertaken numerous research studies with autistic children and adults, and have combined that academic research profile with our professional work that we engage with in different fields. This has been juxtaposed with our personal experience having family members diagnosed autism and at times, our professional, academic, and personal ideas and experiences have been at odds, creating a tension as we examine the evidence and reflect on our own beliefs. As such, this book has presented a whole combination of different scholarly perspectives, ideologies, and theoretical positions around autism, as the literature has sought to shape, reshape, and reconfigure the very concept of what autism means, how it presents, how it is diagnosed, and how it is experienced.

In this book, we have tried particularly hard not to advocate too strongly in favour of any given argument presented in the wider literature, but instead have sought to take a reflective, and more personal and experiential understanding of where we sit in relation to research in autism and the lived experiences showcasing autistic voices. In so doing, we have been keen to recognize that there are many different ways in which autism is thought of in the academic literature and provide our audience with an overview of these. We have therefore tried through our chapters to assess, appraise, and critically understand these different ways of exploring autism by considering the spectrum of views that exist around this condition; from very specific medical and psychiatrized ideas around autism as a psychiatric disability and disorder to more politically motivated neurodiverse voices that challenge and actively disagree with the notion. Our own position is somewhat more tempered as we sit somewhere in the middle of these two ideologies and try to reconcile the very fact that autism is so heterogeneous that one explanation, one viewpoint, one argument, is unlikely to offer a satisfactory overview or understanding of such a complex issue.

We have tried to be clear that our own theoretically view is that of social constructionism to the extent that conditions, understanding of those conditions, and lived experiences are co-constructed, co-created, and given meaning through social interaction by the very people who matter within these arguments; that is, by the autistic individual, their families, the policy makers, professionals, and researchers, among many others. These groups, together through a dialectical pluralism (see Johnson, 2017), somehow create this web of intricate, exciting, and different ways of thinking about a condition that has become increasingly highlighted in the modern world.

Issues at Stake

At times through this book, it may have felt a little fragmented as we shifted through an iterative cycle of reflection and transition between the different ways in which the literature has discussed and argued around the meaning(s) of autism and matters related to it. Each of the areas we have covered has a large evidence base, as well as a wider set of discussion and dialogue. Indeed, each chapter could easily be a whole book given how much has been written about these issues from a diverse set of disciplines, including psychology, psychiatry, sociology, criminology, and history. There is therefore no way to escape the fact that each of our chapters is a distilled and somewhat selected overview of the issues and evidence, and merely serves as a platform for the reader to start engaging in the debates. Indeed, we do not offer a comprehensive discussion of each issue at stake for autism. In this way, we see this book as the beginning of a learning journey, and not a complete resource for its reader; instead, we view this book as one that provides an interdisciplinary basis for thought, encourages critical thinking, promotes reflection in the reader, and provides a good basis for identifying further areas to read around the matters we highlighted. Our very comprehensive references list provides an excellent source of further reading for the interested audience.

A central theme throughout this book has been our focus on the notion of disability. When we examine the wider health and illness literature, mental health conditions are generally cast in the shadow of physical disability, and while there has been a drive for parity of esteem to put mental health on an equal footing with physical health for resources, services, and research (see Morton & O'Reilly, 2019), this has not been achieved (Patel, 2014). This is complicated further with critical questions about the extent to which mental health conditions are disabling or can be classified as a disability. While medical practice positions mental health conditions, and thus also autism, in the category of psychiatric disability, there has been some resistance to this reasoning. This is predominantly because of the deficit-laden language of mental health conditions encouraged by medicalization (Walker, 2006).

To better understand this configuration of ability versus disability, we provided a brief historical account of how mental health conditions were classified and the rise of the responsibility of psychiatry (and psychology) to manage and treat those diagnosed and labelled. The evolution and shifts in thinking about the conceptualization of mental health conditions and the ways in which individuals have been viewed and treated by society have been important indicators in how we now consider autism today. The twentieth century was especially significant for autism and saw changes in the discourses of autism, diagnosis of autism, and classification of autism (O'Reilly et al., 2019a, b), with significant changes including conceptualizing autism on a spectrum (Wing, 1996), and the removal of Asperger's Syndrome from DSM-5 (American Psychiatric Association, 2013).

The diagnosis of autism therefore is a crucial aspect of our understanding of the condition. We highlighted in the book that some have argued that the diagnostic process itself is a powerful social tool (Jutel, 2009), and is the mechanism by which normality is defined, and pathology constructed (Canguilhem, 1989). Thus, the diagnostic practices of psychiatry and psychology, the manuals used to provide a foundation for labelling, and the mobilization of treatment pathways based on those decisions, are grounded in medical ways of thinking about psychiatric disabilities. It is this language that has come under sharp focus in the literature, with varying perspectives emerging from disability studies, sociology, and critical psychology, along with other interesting works. In this book, we have sought to present these different ideas and illustrate how there is consequential language use within the field of autism.

We have argued that a focus on language is crucial for any reconfiguration of autism, as well as a way both to make visible and potentially resist deficit focused perspectives. We have noted that this focus on language and mental health conditions reflects a critical turn to language, and our own work using discursive approaches provided evidence and examples for those ideas. Drawing upon our work, we sought to illustrate our understanding of mental health conditions, and the conceptualization of autism more specifically, recognizing that our responses to mental health are always already socially determined within historical and cultural contexts (Thomas et al., 2018). Thus, in alignment with social constructionism, we view health and illness, and the various categories within them, as social constructs, rather than discoveries (Bury, 1986). Thus, throughout the book, we have advocated the position that autism is reified, defined, constructed, and accepted through language and shared meanings.

Throughout our writing, we have acknowledged that there are different aspects to the debates about autism, and, through our reflective and inclusive approach, we have sought to provide different forms of evidence. For those individuals engaging with various systems, or parents raising concerns about their child, they must navigate the boundaries between medicalized ways of thinking with neurodiversity arguments (Cascio, 2012). Thus, for parents seeking support and wanting an explanation for the difference they observe in their child, they actively build a case to illustrate to medical professionals that there is a legitimate reason for their help-seeking (O'Reilly et al., 2020b). In that way, they collude with the medical explanations for their children's behaviour, and potentially reify the deficit ideology of autism (Hagan, 2018). Yet, parents and autistic individuals themselves may feel that they want some supports, interventions, or financial help that a label may bring. It is therefore arguably unhelpful to dichotomize medicalization and neurodiversity. It is important that neurological difference can be celebrated, social competence recognized, but support and benefits provided where needed (Orsini, 2012). It is critical to remember that some autistic individuals, and some parents of autistic children believe the autism is a positive aspect of their identity, while others experience challenges and sadness, requiring support (Kenny et al., 2016). These different positions and emotional reactions mean that we do need some balance in our views and treatment of autism as it is crucial to respect the beliefs, emotions and reactions of the whole autistic community and their families.

One core feature of the presentation in this book has been the performative aspects of autism, and we included with some examples from our own research to illustrate these ideas. Through this narrative, we illustrated the social, political, and economic constraints that have shaped the performative aspects of autism and highlighted how autism labels shape and create different versions of autism (Nadesan, 2005). In our own research, professionals and parents oriented to the diagnosis of autism as subjective, as they navigated and negotiated the child's normality and competence against their presumed pathology and incompetence. Such a navigation of normality underscores the social and political contexts that privilege the functioning person who behaves in normative ways and points to the experiences of stigma, prejudice, and discrimination. Challenges are bound up and tied to health inequalities and societal perspectives that favour those people who are seen to contribute to society in meaningful and productive ways.

These societal level challenges have contributed to the way in which autism is constructed and perceived by those affected by the label and diagnosis. While ultimately legitimizing the thinking and concerns about difference, such conceptualizing can be highly problematic as families face a range of adversities to fit in with society. While autistic individuals and families often work against the stigmatizing views of society, such views nonetheless have a negative impact. Throughout this book, we have argued that we need to change our thinking about autism and move away from deficit focused language and do more to recognize the social competencies of all autistic persons across the spectrum. Society needs to change its attitudes toward autism and celebrate the differences and create opportunities for all individuals to be well placed within society.

Future Directions for Research

It has not been our intention to offer solutions to the disagreements that currently exist in the field, but rather to recognize and to some extent celebrate the interdisciplinarity that shrouds autism. Research in autism is so wholly necessary so that different views, ideas, and styles of research can help inform our understanding and take us forward into the future. It is essential that we manage to find peace with the different ways of thinking about this spectrum condition and recognize the heterogeneity and diversity that exists within this population. Most importantly, as we go forward, it is absolutely crucial that we do more research that focuses on quality of life, communication experiences, lived experiences, and autistic voices. We have frequently pointed to the lack of research in various areas as we have worked our way through the range of important issues in each chapter. We argue that qualitative research is an important way to navigate and progress these important areas of autism research. This is not to dismiss the quantitative research and randomized controlled trials that have focused on epidemiology, aetiology, and treatment pathways, as this has proven valuable in advancing our understanding of many issues related to autism. Indeed, that work complements the qualitative work that promotes autistic individuals' rights and voices and creates new waves of knowledge that are important in the field.

Qualitative Research

Advances in the field require much more work that showcases experience and voice, whereby autistic people are empowered to contribute to research regardless of where they are on the spectrum, and that those in power have opportunities to listen, hear, and act on those ideas and perspectives. We argue that it is time that funding bodies, medical councils, policy makers, practitioners, researchers, key stakeholders, and others start to value qualitative research as a form of evidence and stop implicitly or explicitly reifying the idea that research evidence is hierarchical (Lester & O'Reilly, 2016). It is through qualitative research that autistic voices and experiences can be illuminated, and autistic rights demonstrated.

It is likely to obvious to readers, then, that we advocate the need for more qualitative research in autism. We have consistently and repeatedly argued the need to include autistic voices in practice, decision-making, policy development, and academia. Qualitative approaches provide a mechanism to showcase those voices and to explore and explain issues related to autism from the perspectives of those who are important. Qualitative research has gained popularity over the last couple of decades and has become an important part of the suite of expertise for many practitioners working in mental health (O'Reilly & Parker, 2014).

Historically, research in the field of mental health was dominated by quantitative research, and this resonates with medical practice training where the natural sciences have dominated (Peters, 2010). While this research is highly valuable, we have noted throughout this book some of the critical issues and challenges with relying too heavily on medical ideologies for the field of autism. Quantitative approaches are not always appropriate and cannot address all areas of autism that are highly important. At this moment in time, qualitative research is crucial as it can build theories, generate ideas, and foreground the perspectives of those who have lived or have personal experiences of autism. This is becoming increasingly acknowledged in a wide range of fields as qualitative research to study autism is now more accepted (Bőlte, 2014), and there is emerging a hugely important volume of qualitative research in autism using autism-themed interviews, focus groups and open-ended questionnaires (e.g., Ludlow et al., 2011), along with a growing body of evidence using naturally occurring data in autism, and approaches like discourse and conversation analysis approaches (Lester et al., 2017). This research using naturally occurring data makes a unique and important contribution to the evidence base in the field of autism, which can augment, triangulate, complement, or in some cases challenge existing knowledge and theory (O'Reilly et al., 2016).

Qualitative approaches are so valuable because they help to stimulate debate through their gathering of rich and in-depth data, using a diverse set of tools and techniques. This is often much more meaningful to those living with and working with mental health conditions and can usefully inform clinical practices (Peters, 2010). We argue therefore that it is unacceptable that qualitative approaches are often positioned lower down the evidence base hierarchy, and tend to be seen as less robust, or less useful than their quantitative counterparts (Lester & O'Reilly, 2016). Qualitative research does have a robust and clear set of quality indicators, and these differ across perspectives and methodologies (Lester & O'Reilly, 2021), with discourse analysis (O'Reilly et al., in press), conversation analysis (Janusz & Peräkylä, 2021), and Video-Reflexive Ethnography (Iedema, in press) (amongst others - see the special issue edited by Lester & O'Reilly) all being recently spotlighted to show how to assess the quality of those studies. Thus, despite the hierarchical organization of evidence that tends to dominate healthcare fields (Rishel, 2007), qualitative research has a strong scientific and quality framework to produce important and valuable knowledge and understanding of autism that critically questions some of the taken-for-granted ideas and policies in the area.

By using qualitative methods to explore autism, we can complement, challenge, and better understand some of the claims made from quantitative research. Furthermore, we can learn more about the lived experiences, and what it is like from the perspective of autistic individuals to operate in society with a complex condition. This provides important insights into their experiences and means that we can communicate those experiences to those with the power to enact change.

Discourse Analysis

We recommend that there needs to be more discursive research in the field of autism; that is, work that focuses on autistic voices in real world settings. Discourse analysis is a valuable method for exploring autism. Discourse analysis includes within it a range of approaches that study language (Wetherell, 2001) and is often thought to be an umbrella term to bring together certain theoretical, methodological, and analytic assumptions (Lester et al., 2018). Collectively, discourse approaches study talk and text as used in social practice (Potter, 1997a, b). In that sense, discourse analysts view language as performative; that is, as doing things. In other words, language is not a neutral reflection of social life, but it is through language that actions are accomplished (like invitations, complaints, or excuses). This is important in the context of autism, as discourse analysis can explore how the autistic identity is accomplished, how complaints about services are negotiated and constructed, how disability is positioned or resisted, and so on.

Discourse analysis is a contemporary qualitative approach to research as it was not until the 1980s that different approaches became more mainstream. Notably, the different types of discourse analysis, such as Foucauldian, critical, discursive psychology, do analysis in slightly different ways with different theoretical foundations, they nonetheless are important for the field of autism. Some approaches take a micro and fine-grained approach to analysis, whereas others attend to broader cultural, social, and institutional concerns (Avdi & Georgaca, 2007). Our preferred approach that we have frequently used in our own work is that of discursive psychology as pioneered by Edwards and Potter (1992) as this is grounded epistemologically in social constructionism. The focus of discursive psychology is on the study of psychological concepts through language as traditional, cognitive ways of making sense of psychological processes were deemed dissatisfactory (Edwards, 1997).

This social constructionist, discursive way of conceptualizing mental states and psychological processes, evidently has implications for the way we study autism. Psychology (and indeed, psychiatry) typically explains mental health in terms of dispositional properties, but social constructionist work, as we have shown in this book, seeks to reframe psychological constructs, like memory, personality, psychopathology, as socially constructed (Burr, 1999). Thus, it is appropriate, and preferable, to examine discourse in its own right rather than attempt to use discourse as a vehicle to access underlying mental processes. Thus, discursive psychology is driven by three central aims as outlined by Wetherell (2001):

1. Discursive psychology seeks to study psychological topics with a focus on language, and this includes representations, social categories, attribution, rules, identity, gender, emotions, memory.
2. Discursive psychology seeks to promote an interest in new ways of theorizing and studying psychological constructs, like emotion, memory, attention, as it is made evident in talk and text, seeing language as performing social actions.
3. Early discursive psychologists sought to advance qualitative methods across the social scientists, promoting techniques for exploring social interaction.

These core aims reflect the ways in which further research in autism could highlight autistic voices, by examining autism as performative, as we highlighted in Chap. 6.

For autism then, discursive psychology provides a platform to view the condition as a social construct. When applying discursive psychology to the study of mental health conditions generally, and autism specifically, we can see how the social positioning of these groups is accomplished. We can examine in more depth how autistic individuals socially interact with those around them, and how those around them interact in return.

Conversation Analysis

Aligned with the discourse analysis approaches is that of conversation analysis and this is an excellent approach for the study of autism. We have often used conversation analysis to undertake our research in mental health, and in autism. Indeed, we edited a special issue to showcase the value of this methodology to the study of autism (see O'Reilly et al., 2016) and we host an international group of academic scholars and clinical practitioners interested in promoting language focused research, called Conversation Analysis Research in Autism (CARA).

Like discourse analysis, it was during the 1980s that conversation analysis became popular among the social sciences. Of particular interest was one focus of conversation analysis on applied settings and institutional talk. In this way, conversation analysis researchers began to undertake work that could be used to inform practice (Lester & O'Reilly, 2016). In recent times, conversation analysis has earned respect in a range of disciplines and is increasingly being used by practitioners as academics forge important partnerships. We do note, however, that conversation analysts do not necessarily intentionally position themselves as applied researchers. While applied conversation analysis tends to focus on institutional talk, this is not always the case (Antaki, 2011; Lester & O'Reilly, 2019). Conversation analysis is frequently used to explore how the institutional business of practice unfolds, and how institutional agendas are made relevant via working activities (Drew & Heritage, 1992).

We argue that using applied conversation analysis for the study of autism is highly valuable. One area where conversation analysis has advanced our knowledge and understanding of autism is in relation to communication in practice settings. It is recognized that clinical professionals require competencies in the art of good communication and in managing and maintaining therapeutic relationships (Priebe & McCabe, 2008) and this is especially important for autism where communication may require some modification or attention. By using conversation analysis to explore these communication practices, researchers can make recommendations by identifying examples of good practices, and identifying areas where communication broke down (Lester & O'Reilly, 2016) and can help us understand how mental health professionals and those with mental health conditions make sense of the therapeutic process and how that interaction unfolds (Kiyimba & O'Reilly, 2016).

Conversation analysis has the benefit of a micro-attention to how social interaction works, to language, to meaning and the performance of social actions. Conversation analysis relies on the analysis of naturally occurring data (Kiyimba et al., 2019) and therefore is concerned with autistic individuals in their natural settings, engaged in naturally occurring events. Conversation analysis can inform our understanding of areas of practice because it is based directly observable properties of conversational data (Drew et al., 2001) and are grounded in real-world events. In this way, conversation analysis provides an important form of evidence, which can be situated within the modern rhetoric of evidence-based practice. However, conversation analysis is not concerned with outcomes and effectiveness, but instead explores process and interaction, and reveals how interactions operate in the real world (Streeck, 2010).

We argue that interventionist conversation analysis is particularly helpful (especially, reflective interventionist conversation analysis, see O'Reilly et al., 2020a) as this form of applied conversation analysis is highly practice focused. This type of applied conversation analysis involves participants in partnership and considers the implications of the findings for those participants (Wilkinson, 2014). Thus, researchers can identify good practice, and where relevant areas for change and training need (Barnes, 2019).

Video Reflexive Ethnography

Congruent with our preference for discourse analysis and conversation analysis approaches, we argue that a further framework for future directions in autism research is that of Video Reflexive Ethnography (VRE). While theoretically different to conversation analysis, VRE also favours the use of naturally occurring data which consist of video recordings of natural events. However, where this approach differs is in it combining that data with other qualitative methods of data collection, such as interviews or focus groups and the promotion of active reflection between the researcher and the participants.

VRE is a valuable approach for investigating how interactional work is accomplished so that change, ideas, and reflections can be built with practitioners and individuals with mental health conditions (Iedema et al., 2019). Thus, the data collection via video-recordings of real-world interactions prioritizes the complexity of work as done, as opposed to work as imagined (Hollnagel et al., 2015). In other words, it focuses on what happens naturally in practice, rather than on what people believe or think has happened in practice.

The reflexivity aspect of VRE is a useful aspect of the design, as the researcher, practitioner and individual with the mental health condition can work together to reflect and engage with what they see in the video material. The ethnographic aspect of the approach allows the researcher to understand the issues from the perspectives of those involved in that naturally occurring event. VRE is often used by practitioner-researchers, those who occupy a dual role of working in the field but also doing research. In that way, the 'clynalist' (clinician-analyst) capitalizes on their insider status and epistemic position (Carroll & Mesman, 2018). This could therefore be an especially useful for the autistic researcher as they seek to reconcile their epistemic positions as an autistic individual and a researcher.

What is especially useful about VRE approaches to research, is that it shines a spotlight on activities that have become invisible to the members of the interaction (Iedema et al., 2019), the autistic person and those working with them. The reflexive aspect of the approach means that researchers can work collectively with those involved to reassess and reshape the aspects of the behaviour and communication that are highlighted by exploring the video (Iedema et al., 2013). Furthermore, using a VRE approach allows the researcher to work closely with all participants, professionals and autistic individuals, empowering them to have a say and to identify areas that warrant further attention. Using this reflective framework, examining video-recordings, and working with all involved in the naturally occurring event, provides a mechanism for pursuing further what is important to the key stakeholders from the interaction (Drewett & O'Reilly, in press). Drewett and O'Reilly illustrated that for those autistic individuals who are frequently disempowered and disadvantaged by society, such as those residing in inpatient care, this kind of research can really showcase their perspectives and what life is truly like from their perspective.

Concluding Thoughts

We conclude by arguing for the continued need to seek and invite alternative narratives of autism; that is, narratives that stand in contrast to the historical and present-day descriptions of disabled voices, bodies, and minds. Rather, there remains a need to counter deficit-models that serve to sustain inequitable access to education, health services, communities, and society writ large. Health inequalities, stigma, and discrimination have long been a problem for those with disabilities, and for those with autism who sit on the fringe of what it means to be disabled with such varied and different discourses associated with it, these inequalities are even sharper.

The COVID-19 pandemic has likely changed the landscape of autism, as narratives of mental health, disabilities, health inequalities, and economic challenges dominate the rhetoric of health. While there is resistance to categorising autism as a disability or mental health condition, and various new discourses of autism circulate society, the medicalization of autism, the psychiatric classification of the condition still dominates, and while this is a double-edged sword creating opportunities for support, change, treatment, and care, and simultaneously stigmatising and negatively impacting autistic communities, it nonetheless remains highly influential in societal thinking and action. We have presented a wide range of views and evidence throughout this book and have included where possible the autistic voice, and representatives of that voice. We have shown that there are diverse arguments, heterogeneity in thinking and challenges associated with the very meaning of autism. We have also set out our positionality and language-focused frameworks and have advocated for more research that centres autistic voices, autistic priorities, and autistic language through qualitative methods.

Now, we leave it to the reader to consider, reflect, and digest the broader autism polemic to draw their own conclusions on the matter. We encourage proactive engagement with the literature we have presented throughout the chapters, critical thinking on the arguments we have navigated, and inquisitive questioning on the ways in which we have prioritised certain subjects and ideas throughout. Our voices are one set of academic, professional, and personal voices as we have a mixed epistemic position and epistemic rights to talk on the matter. Yet, we are not autistic, and while autism has touched our lives in so many ways, we cannot and do not speak for the autistic community in any direct manner. Rather, we advocate for their rights, for the competence paradigm, and for equality; and, the reader must decide for themselves where they sit in relation to these complex considerations.

Appendix A: Jeffersonian Transcription Symbols (Jefferson, 2004)

Symbol	Meaning
(.)	A period inside of a parentheses represents a micro-pause that is hearable but not measurable or significant enough to measure.
(0.2)	A number inside parentheses denotes the length of a pause.
[]	Square brackets represents speech that is overlapping.
> <	Text encased with 'greater than' and 'less than' symbols represents a pace of talk that is hearable as faster than the surrounding talk.
< >	Text encased with 'less than' and 'greater than' symbols represents a pace of talk that is hearable as slower than the surrounding talk.
()	A space between parentheses represents that the words spoken were unclear and thus impossible to transcribe.
(())	Double parentheses with a description inserted provides contextual information when no symbol of representation is available.
Under	Underlining a word or a part of a word represents a rise in the volume or emphasis of the talk.
↑	An upward arrow represents an upwards shift (i.e., rise) in intonation.
↓	A downward arrow represents a downward shift (i.e., drop) in intonation.
⟶	An arrow highlights a particular aspect of the interactions or sentence that is of interest to the analyst.
CAPITALS	Capital letters represent something being said loudly or shouted.
Hum(h)our	A bracketed 'h' represents laughter in the interaction.
=	An equal sign represents speech that is latched; that is, a continuation of talk.
:::	Multiple colons represent elongated speech; that is, a stretched sound.

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