What's in a label? An exploration of how people acquire the label 'autistic' in adulthood and the consequences of doing so

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I certify that all material in this dissertation which is not my own work has been identified and that any material that has previously been submitted and approved for the award of a degree by this or any other University has been acknowledged

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Abstract

Background. Since the 1960s the estimated prevalence of autism has increased. This has been accompanied with greater public awareness of the condition and a growing demand for diagnosis, particularly in adulthood. For sociologists, diagnoses such as autism play a fundamental role in modern social life. As well as organising the clinical picture for patients – determining their prognosis and treatment options – diagnoses also have the capacity to change how a person thinks about themselves and other people. Previous research has shown that obtaining an autism diagnosis in adulthood comes with significant benefits (greater self-awareness and access to support services) as well as some undesirable drawbacks (shame and a sense of helplessness). Yet a medical diagnosis is not the only way of acquiring the label. An individual can also label themselves – that is, self-identify – as autistic, and they can be labelled as such by other autistic people. To date, little has been done to investigate these other ways of acquiring the label, and more broadly the implications of being labelled autistic, by any means, have yet to be clearly theorised by sociologists. I aim to address these gaps in this study.

Methods. I conducted a qualitative study in order to answer the question: "How do people come to be labelled, or to label themselves, as autistic in adulthood, and what are the consequences of doing so?" Using snowball and theoretical sampling, I recruited twenty-one autistic adults, eleven with a medical diagnosis and ten who self-identified as such, to take part in two loosely structured qualitative interviews (forty-two interviews in total). These accounts were analysed using a method called situational analysis, a form of constructivist grounded theory.

Findings. I present three theoretical concepts that illustrate how people go about acquiring the label autistic and what it means to live with it. The first is the concept of the 'sticky-slippy' label, which is a figurative expression used to illustrate some of the properties of the label autistic. Once acquired, the label has an inherent 'stickiness' to it (a sense of permanence) whilst at the same time exhibiting more 'slippery' qualities (a fluid and shifting prominence in a person's identity). The second concept relates specifically to people self-identifying as autistic and their reasons for doing so, which are conceptualised as four different ways: (1) somebody who self-identifies as autistic as a *precursor* to seeking a medical diagnosis, (2) somebody who self-identifies as autistic *despite* a negative diagnosis, (3) somebody who self-identifies as autistic as an *alternative* to a diagnosis, and (4) somebody who self-identifies as only having *autistic traits*. The third concept relates to the practice of autistic lay people labelling other lay people as autistic (which I call a 'lay diagnosis'). Within this, I distinguish between 'passively spotting' and 'actively seeking' autism in others.

Discussion. The ambition of this study is to provide a conceptual vocabulary for thinking about the nature of the label autistic, the different ways in which people can acquire it, and the implications of doing so. The concepts presented here may be applicable to other physical and psychiatric categories, of which autism serves as an illustrative example. The concept of the sticky-slippy label offers a means of understanding and reporting the consequences of being labelled autistic, something that is markedly absent in the current literature. The four ways of self-identification represent a sustained engagement with the growing phenomenon of people labelling themselves as autistic, which may be of interest to those researching the self-identification or self-diagnosis of other psychiatric conditions. Finally, I open the door on a potentially interesting research agenda: the act of lay people diagnosing other lay people with physical and psychological afflictions – lay diagnosis – which could sit alongside current research endeavours within the sociology of diagnosis.

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List of abbreviations

ADHD:	Attention Deficit Hyperactivity Disorder
ADOS:	Autism Diagnostic Observation Schedule
APA:	American Psychiatric Association
APPGA:	All Party Parliamentary Group on Autism
DSM:	Diagnostic and Statistical Manual of Mental Disorders
DVLA:	Driver and Vehicle Licensing Agency
GDPR:	General Data Protection Regulation
GP:	General Practitioner
GT:	Grounded Theory
ICD:	International Classification of Diseases
IPA:	Interpretive Phenomenological Analysis
LDX:	Lay diagnosis
MDX:	Medical Diagnosis
NHS:	National Health Service
NICE	National Institute for Health and Care Excellence
OCD:	Obsessive Compulsive Disorder
PHE:	Public Health England
PIP:	Personal Independent Payments
PMDD:	Premenstrual Dysphoric Disorder
PPI:	Patient and Public Involvement
SA:	Situational Analysis
SID:	Self-Identification
UK:	United Kingdom
US:	United States
WHO:	World Health Organisation

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Whilst a PhD is first and foremost an independent piece of work, there are many people who have lent a helping hand. Whilst it would take the length of a dissertation to name and thank all of those who have been there over the last three (and a bit) years, there are a few people that I wish to give a special thanks to.

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Chapter One: Introduction

“It sounds kind of melodramatic, but it put my life into a very different context. It was a huge relief. All the things that I thought were negative aspects about myself and failures and flaws, things that I couldn’t control, were suddenly put into a context where they made sense, where I could deal with them, where I could research about them, where I could turn them into positives. It was very transformative.”

That was Jane, a woman in her thirties, recounting the moment she was diagnosed with autism spectrum disorder. As she explained in the BBC documentary, *D is for Diagnosis* (2019), Jane had grown up thinking that the reason she struggled to understand and relate to other people was because she was “a little bit odd” and “a bit of a weirdo,” though she was unable to explain why this was the case. Prior to her diagnosis, Jane did not know much about autism and mostly associated it with young children, particularly young boys. It was only after a friend had mentioned it to her that she started to consider autism as something that might explain the way she felt about herself. And so, after giving it some thought and speaking about it with her doctor, Jane finally received a medical diagnosis of autism, the results of which fundamentally changed her life.

Although there are many competing explanations as to what exactly autism is, it is widely regarded as a neurodevelopmental condition that affects the way people perceive the world around them (Runswick-Cole, 2016). This generally relates to persistent difficulties in typical forms of social communication and interaction, as well as restrictive and repetitive patterns of behaviour (APA, 2013). Autism is known as a spectrum condition because it can affect different people in different ways, but often includes avoiding eye contact with other people, repetitive bodily movements (e.g.

rocking, shaking, jerking), and regular difficulties reading and managing social situations (Lai, Lombardo, & Baron-Cohen, 2014).

Whether these behaviours are seen as symptomatic of an underlying disorder depends on your view of autism as a psychological state. For the most part, autism is viewed through the lens of the medical model which sees it as a deficit-based psychiatric disorder (e.g. Serur et al., 2019).[1] The alternative view, mostly associated with the neurodiversity movement and the social model of disability (see Kapp, 2020), sees autism as nothing more than a natural part of human neurological variation, that is different rather than pathological, adaptive rather than typical (Armstrong, 2010; Singer, 1999). There are some who even question the validity of the term as a clinical and scientific construct, arguing that there is no 'real' biological evidence for the disorder, and that it is just a set of cultural beliefs and practices – albeit highly influential ones – that problematises and medicalises people's behaviour (Timimi, Gardner, & McCabe, 2010). Whatever perspective is taken (see p. 29 for my own views), it is widely acknowledged that there are some people who require regular and specialist support (e.g. assisted living arrangements), and there are others who need assistance now and then, if at all, depending on the situations they find themselves in (Kapp et al., 2013).

Like other neurodevelopmental conditions (e.g. attention deficit hyperactivity disorder, ADHD), autism is formally identified using a medical diagnosis. Ever since the

[1] That said, the aetiology of the condition is unknown, its symptoms are somewhat ambiguous, and rather than it being a single discrete condition, it is generally considered an umbrella term that includes a diverse group of other mental states (e.g. rett syndrome; Nadesan, 2005).

inception of the condition in the 1940s (see Kanner, 1943), the estimated prevalence of autism has increased. Whilst it is difficult to pin down an exact figure, estimations have increased from one in every two thousand in the 1960s (Lotter, 1966), to between one and three percent of the population in the last decade (Brugha et al., 2012; Waugh, 2019). Whether there are actually more people living with the condition remains unknown, but the increase has been accompanied with a broadening of the formal diagnostic criteria (Russell et al., 2015) and a growing demand for a diagnosis (King & Bearman, 2009; Smiley, Gerstein, & Nelson, 2018).

A sizeable chunk of this increase has likely come from people seeking a medical diagnosis in adulthood. Previously seen as a condition of infancy and early childhood (see Silberman, 2017), the behavioural and psychological characteristics associated with autism are now understood to be lifelong, with similar prevalence rates across all parts of the lifespan (Brugha et al., 2012). This has led to a growing acknowledgement that there may well be a 'lost generation' of autistic adults, those who meet the diagnostic criteria for the condition but grew up without an official diagnosis (Lai & Baron-Cohen, 2015). This idea has been fostered by, and has contributed to, an explosion in the media's interest in autism in adulthood (e.g. BBC, 2018; Channel 4, 2018), and in recent years, policy makers and medical professionals have placed greater emphasis on identifying and diagnosing the condition in those over the age of eighteen (All Party Parliamentary Group on Autism, APPGA, 2019).

Academic researchers have also taken more of an interest in the topic. Historically, most of the studies on autism focussed on children and teenagers, with research into older adulthood comparatively limited (Hickey, Crabtree, & Stott, 2018). Given the

progressively ageing populations in Western countries, the increasing rates in diagnosis, and the reportedly high costs associated with the condition (Knapp, Romeo, & Beecham, 2009), more and more studies are now being undertaken to investigate the experience and impact of autism in older people.[2]

Previous studies have shown that receiving a medical diagnosis of autism in adulthood can be a transformational moment (Wylie, 2014). What was previously an inexplicable series of challenges and difficulties suddenly becomes a collection of 'symptoms' associated with an underlying neurodevelopmental condition, the meaning of which can help explain and potentially excuse an individual's socially deviant behaviour (Punshon, Skirrow, & Murphy, 2009).[3] Receiving an autism diagnosis can also fundamentally shift how a person thinks about themselves, leading them to re-evaluate their identity in light of their newly acquired 'autism lenses' (Lewis, 2016a). Not only that, but on a more practical level, an official diagnosis also grants an individual access to a variety of social, therapeutic, and financial services that can help improve their quality of life (Powell & Acker, 2016).

But there are also some drawbacks to a diagnosis, with some adults reporting a sense of shame and stigma following their positive autism assessment (Milner et al., 2019). Others have expressed to researchers concern about their future prospects (both in terms of their work and social lives) after being officially marked as different, the worry being that other people will treat them less favourably after they discover that they are

[2] The findings of which can now be read about in newly dedicated research journals, such as the aptly named *Autism in Adulthood* publication.

[3] I say symptoms, here, in inverted commas, to acknowledge the contested nature of the term in relation to autism.

autistic (Bargiela, Steward, & Mandy, 2016). There also appears to be a disconnect between the promise of a diagnosis and the reality of having one, particularly in relation to the limited number of services that are available to support people with the condition (Camm-Crosbie et al., 2019).

Although a medical diagnosis is the official means of acquiring the label, there are alternative ways that somebody can come to be labelled as autistic. One of these is by labelling oneself – that is, self-identifying or self-diagnosing – as autistic, which an increasing number of adults are choosing to do (Lewis, 2018).[4] This is in part a response to the growing demand for diagnostic services. In the UK, the National Institute for Health and Care Excellence (NICE, 2016) states that the wait between the initial referral for an autism assessment and the appointment itself should be no longer than thirteen weeks, yet a report by Public Health England (2019) found that only eighteen percent of National Health Service (NHS) trusts were meeting this target, with some referrals lasting as long as three years. This stretched capacity means that some people are unable to obtain a formal diagnosis, as one individual told a recent parliamentary inquiry (APPGA, 2019, p. 23):

> "I asked my GP [general practitioner] for [a] proper diagnosis as she and other professionals have agreed that I am extremely likely to be autistic and I have children who have all been diagnosed as on [the] spectrum. My GP said, 'no point in getting [a] diagnosis and [the] waiting lists were closed.'"

Because of this, some adults forgo a medical diagnosis and instead self-identify as autistic, either out of choice or necessity. With a vast amount of information now

[4] I discuss my use of the terms self-identification and self-diagnosis on p. 29, 'notes on terminology.' In the meantime, I use both terms to refer to people labelling themselves as autistic.

available on the internet – from scientific sources to charitable and user-generated content – it has never been easier for people to judge whether they meet the diagnostic criteria for a medical condition (Lupton & Jutel, 2015; Nettleton, 2004). There are a whole host of social media sites dedicated to autism that enable people who suspect that they have the condition to talk it through with other autistic people (self-identified or with a medical diagnosis), drawing on their collective expertise and lived experience to arrive at their own conclusions (Brownlow & O'Dell, 2006).[5] This is aided by the vast array of do-it-yourself diagnostic tests that are available online, including more recently on the smartphones in people's pockets (see Lupton & Jutel, 2015).[6] Even though many recognise the 'unofficial-ness' of these tests, and there is evidence to suggest that users *do* cast a critical eye over these resources (Lupton, 2013), these tests can at least give an individual a sense of whether autism is a condition that applies to themselves, which can then be used as evidence to bolster their own self-diagnosis (Kivits, 2013).

For those who have studied the act of labelling oneself autistic, a self-diagnosis can often feel like a double-edged sword. Whilst the self-assigned label can offer just as much relief and self-awareness as a medical diagnosis, the fact that it has not been officially confirmed by a clinician raises the potential for doubt and uncertainty, particularly amongst other autistic people with a medical diagnosis (Lewis, 2016b). That said, for those who do not see autism as a medical matter and therefore a

[5] For example, www.wrongplanet.net, is a popular site for discussing all things autism, including self-diagnosis and self-identification (see https://wrongplanet.net/forums/viewtopic.php?t=274725).
[6] See https://psychcentral.com/quizzes/autism-test/

diagnosable psychiatric condition, self-identifying as autistic is by far the preferred option when compared to acquiring an official diagnosis (Sarrett, 2016).

A final way that somebody could acquire the label autistic in adulthood is to be labelled as such by another autistic person. In this instance, somebody with a medical diagnosis draws on their experiential knowledge of the condition to identify the symptoms of autism in somebody else, which is something that I later refer to as a 'lay diagnosis.' To date, little has been said about this form of labelling and identification, but there are examples in the sociological literature of lay people being able to identify the symptoms of mental illness in other people (e.g. Olafsdottir & Pescosolido, 2011) and issue their own diagnoses on behalf of them (see Giles & Newbold, 2011).

The purpose of this study

Thinking about the different ways of acquiring the label, there are two overarching concerns directing this study. The first is that little is known about the alternative, non-medical ways that somebody comes to be labelled as autistic in adulthood. There is some fascinating work on how somebody obtains a medical diagnosis in adulthood and what happens during the clinical encounter (e.g. Hayes et al., 2020; Maynard & Turowetz, 2019), but little has been done to investigate how somebody *labels themselves* or *other people* with the condition and their reasons for doing so. The second is the more general observation that the implications of acquiring the label, by any means, has yet to be clearly theorised by sociologists and others working within the field. What is needed in order to advance the current, mostly descriptive, work in this area, is a conceptual vocabulary for thinking about the nature of the label and the consequences that it has on a person's life (i.e. how the label 'works' to change things

for its recipient; Bowker & Star, 1999). Therefore, my aim in this study is to *develop a theoretical account of how people acquire and experience the label 'autistic' in adulthood.*[7]

Empirical work

In order to achieve this aim, I conducted an empirical study in which I attempted to answer the question: "How do people come to be labelled, or to label themselves, as 'autistic' in adulthood, and what are the consequences of doing so?" I carried out forty-two qualitative interviews with twenty-one autistic adults between January 2018 and November 2019 (each participant was interviewed twice). Eleven of the twenty-one participants had a medical diagnosis of autism (which included autism spectrum disorder and Asperger syndrome) and ten self-identified as such. The interviews were loosely structured and covered a range of topics, including when participants became aware that they might be autistic, how they acquired the label, and the impact that it had on their day-to-day life. The duration of these interviews were between three-quarters of an hour and an hour-and-a-half, with most lasting just over sixty minutes. The majority of interviews were conducted in the South West of England, with some occurring elsewhere in the UK, and others using online video platforms. I employed a snowballing strategy during the earlier stages of the study (Spreen, 1992), seeking referrals for interview participants from social acquaintances, and later combined this with a more targeted form of theoretical sampling, selecting new participants according to developing analytical concerns (Morse, 2007). I analysed these accounts using a method called situational analysis (Clarke, 2005; Clarke, Friese, & Washburn, 2018),

[7] By theoretical account, I mean an abstract and generalised description of a person's experience.

which is a type of constructivist grounded theory (Charmaz, 2014), as well as more generic qualitative tasks, such as data familiarisation and group analysis (Braun & Clarke, 2013; Strauss, 1987). The whole process was overseen by an advisory group of six autistic adults (four with a medical diagnosis and two without) who throughout the duration of the project were given the opportunity to share their views on the design, implementation, and findings of the study (see p. 102 for more details on the advisory group).

The work presented in this dissertation is part of a wider research project at the University of Exeter called *Exploring Diagnosis: Autism and the Neurodiversity Movement* (funded by The Wellcome Trust). The remit of the project, led by Ginny Russell (my second supervisor), is to explore the role diagnosis plays in society and medicine using autism as a case study.[8] This includes, amongst other things, investigations into the prevalence of the condition and rates of diagnosis (Russell et al., 2015); factors that determine clinicians' diagnostic decision-making (Hayes et al., 2020); the use and misuse of pharmaceutical interventions (Russell et al., 2018); and more broadly the first-hand experience of autism (Kapp et al., 2019; Russell et al., 2019; White et al., 2019).

Structure of subsequent chapters

The content of the subsequent chapters are as follows. In Chapter Two, I will situate this study within the existing work on the topic, which will take the form of a narrative review of the sociology of diagnosis and autism research literatures. This will be

[8] Project webpage: https://blogs.exeter.ac.uk/exploringdiagnosis/

followed by the methods chapter, where I delve into the methodological detail of the study. In the next three chapters I will present the main findings of my research. Here, I will introduce three new theoretical concepts that will help researchers better understand the process of acquiring the label autistic in adulthood and the consequences of doing so. The first of these, outlined in Chapter Four, is something called the 'sticky-slippy' label, which is a figurative expression used to illustrate some of the properties of the diagnostic category. Here, autism is framed as a label that has an inherent 'stickiness' to it (a sense of permanence that is difficult to remove or shake off socially) whilst at the same time exhibiting more 'slippery' qualities (a fluid definition and shifting prominence in a person's sense of self). The second concept, which will be discussed in Chapter Five, relates specifically to the act of adults labelling themselves (i.e. self-identifying) as autistic. In this chapter I present four empirically observed ways, or reasons, for doing so. The third and final concept relates to what I described earlier as a 'lay diagnosis' (i.e. autistic lay people labelling other lay people as autistic), and in Chapter Six, I will explore this idea in more detail by making the distinction between people 'passively spotting' and 'actively seeking' autism in others. In Chapter Seven I will discuss these concepts in relation to some of the major themes already identified in the existing literature, as well as position them alongside broader sociological concerns and future research agendas. You will find a full reference list and appendices on p. 291 and p. 317.

Notes on terminology

Before moving on, I would like to clarify what I mean by some of the terms used throughout this work. First, I use the words autism, autistic, and phrases denoting the autism spectrum, to refer to the widely held assumption that some members of the

population see the world differently and experience a diverse range of cognitive sensations, some of which are a virtue to an individual, some of which are inhibiting.[9] As noted earlier, what it actually means to be autistic is not particularly well known or even agreed upon (Timimi & McCabe, 2016). Consequently, I hold what could be described as an agnostic view of autism: we do not know what it is – we do not know if it is even an *it*, something to be had – but we do know that it is a meaningful construct for clinicians, patients, and the wider public that has solidified over the last half a century. The 'true' meaning of the word autism is not pertinent to my aims in this study. I am not in the business of trying to find out whether people 'really' are autistic. I am instead interested in why people think they are and how they go about acquiring the label. Whether the category is itself on shaky ground does not detract from this aim.

On a related point, I tend to use identity-first language (i.e. an autistic person) to describe the people in this study. Although there are alternative ways of talking about those with the condition, such as person-first language (i.e. somebody with autism; see Kenny et al., 2016), the majority of the people that I interviewed, when given the choice, preferred identity-first phrases, and so that is how I will describe them.

The other frequently used terms are self-diagnosis and self-identification. Self-diagnosis, as you may expect, refers to a person identifying themselves as having a particular set of physical and/or psychological symptoms and labelling them with what they see as the appropriate diagnosis. It is a phrase commonly used by those

[9] In line with the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (APA, 2013), and the International Classification of Diseases, 11th edition (WHO, 2019), I also include the category of Asperger syndrome in this definition, which is widely acknowledged to be a related cognitive state.

researching such matters (e.g. Jutel & Banister, 2013; Sarrett, 2016). But as I found during the planning stages of this study, when it comes to autism some people (like my advisory group, see p. 102) believe that it is more appropriate to talk about self-identifying as autistic, rather than self-diagnosing the condition.[10] In part, this has something to do with people *not* viewing autism as a psychiatric disorder, and therefore something that can be diagnosed by a clinician or an individual person (Armstrong, 2010). Indeed, when asked, most of my interview participants (both those with and without a medical diagnosis) preferred the phrase self-identification, with some seeing self-*diagnosis* as a dirty word. There were others, though, who felt that self-identification sounded flimsy and less rigorous than self-diagnosis, as it gave the impression that identifying as autistic was simply a matter of choice, in the same way that somebody would identify as a Manchester United supporter. It may be that there is an important conceptual difference between the two terms, and it might be something that warrants further consideration elsewhere. However, for my purposes, I will be using the term self-identification, as this broadly reflects the views of my advisory group and study participants. When reporting on a study where the author(s) uses the phrase self-diagnosis, I will do the same, but when it comes to talking about my own work, I will use the alternative.

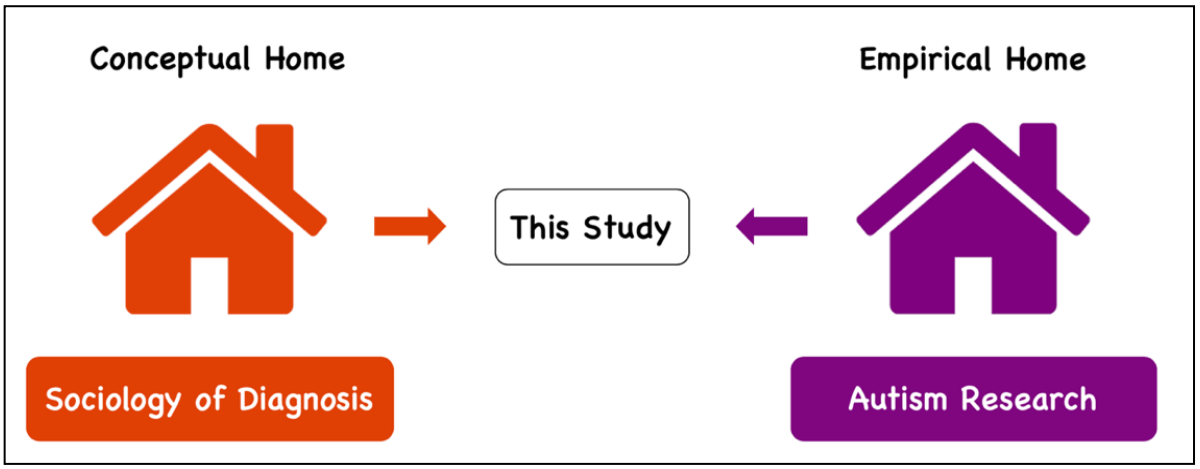
[10] It is worth noting that some autism researchers (e.g. Angulo-Jiménez & DeThorne, 2019; Linton et al., 2014) use the term self-identification to refer to people who self-report their medical diagnosis (i.e. they self-identify as having a medical diagnosis). This is not my use of the word.

Chapter Two: Literature review

In this chapter I will turn my attention to the work of other researchers. There are two fields of inquiry that I will focus on. The first is the sociology of diagnosis (e.g. Jutel, 2009) – a subfield within the sociology of health and illness – that considers how medical diagnoses are defined, implemented, and the role they play in society. This is a relatively new area of study, but one that is particularly pertinent to our understanding of autism as a diagnostic and social label. The sociology of diagnosis can be seen as the conceptual home of this study (see Figure 2.1).

The second body of work is the empirical research into the impact of a medical and self-diagnosis of autism in adulthood.[11] This is a relatively small body of work that has mostly been conducted by clinicians, psychologists, and health service researchers. This work provides an insight into what it is like to be labelled, or to label oneself as autistic in adulthood, and can be seen as the empirical home of this study.[12]

Figure 2.1: The conceptual and empirical homes of this study



[11] As noted in the previous chapter, I use the term self-diagnosis as and when other researchers use it.
[12] The distinction between the conceptual and empirical homes is a little misleading as the sociology of diagnosis includes many empirical studies. I use the phrase conceptual, in this instance, to refer to the intellectual heritage of this study – the field that has informed many of the ideas in this project.

This chapter will take the form of a narrative review (Jesson, Matheson, & Lacey, 2011). It will *not* be a comprehensive appraisal of these two literatures, but rather a tour of their most relevant ideas and findings. As Bryman (2008) points out, a literature review can either be a *means* to something (a springboard for a researcher's investigation), or it can be an *end* in its own right (a way of examining and scrutinising what is already known). This review is the former – a means of positioning my work in relation to others before delving into my research findings. Here, the literature review:

> "[is a] means of gaining an initial impression of the topic area that [one] intends to understand through their research […] narrative reviews therefore tend to be less focussed and more wide-ranging in scope" (Bryman, 2008, pp. 92–93).

The books and articles to be discussed were identified through a systematic search of research databases (see Appendix 1 for sources and search terms used), forward and backward citation searches, and by drawing on my own knowledge of the field after twelve years of study (returning to key texts used in previous dissertations and taught classes).[13] Like other narrative reviews (see Glasby & Lester, 2005), I used some procedures associated with systematic reviewing (e.g. database searches) in order to find studies that could help me make better sense of my own work. This was particularly the case for the adult autism literature which, as I will demonstrate shortly, had limited published studies. This again was used as a means to an end, and not as a way of comprehensively mapping and evaluating the existing work in this field.

I will start this review by examining some of the key themes to come from the sociology of diagnosis, before exploring some of the major findings published in the adult autism

[13] Thank you to the team at the University of Exeter Library for assisting me with my systematic search (see Appendix 2 for my search strategy).

literature. The two sections will be organised around different types of diagnosis (see p. 38), and at the end of each I will offer a few remarks about what is missing in these literatures and what this study will do to remedy it.

Conceptual home: The sociology of diagnosis

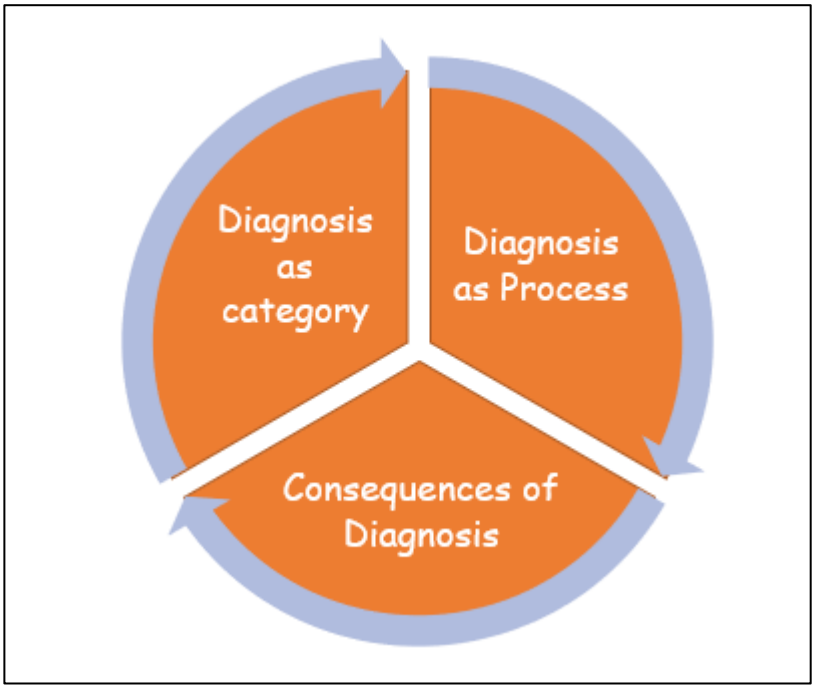
The sociology of diagnosis is a recent addition to the broader sociological study of health and illness. Diagnosis, that is the categorisation and labelling of medical disorders, has previously been studied by sociologists looking at the history of medicine (e.g. Collyer, 2015), illness narratives (e.g. Bury, 1982; Charmaz, 1991), and the formation and drivers of various types of medicalisation (e.g. Conrad, 2005). But as Jutel and Nettleton pointed out, "diagnosis has had an *absent presence*" in these studies (2011, p. 793; emphasis added). Similar remarks were made by Blaxter in the 1970s, who noted that "the activity known as 'diagnosis' is central to the practice of medicine but is studied less than its importance warrants" (1978, p. 9). Since then, specific calls for a sociology *of* diagnosis have been made (see Brown, 1990; Jutel, 2009), and in 2011 *Social Science & Medicine* published a special issue on the topic – edited by Jutel and Nettleton (2011) – marking the formal establishment of the discipline.[14]

A diagnosis is both a category – a name given to a collection of physical and psychological symptoms – and a process – something that is assigned to an individual by a doctor using a variety of methods and techniques (Blaxter, 1978). Once a

[14] It is worth noting that the sociological study of diagnosis has always been there, *absently present*, and since the formation of the sociology of diagnosis these studies have been retrospectively identified and added to the discipline's portfolio. Much like a diagnosis, sociologists have identified the traces of this research and put a name to it.

diagnosis is made, it can have a profound impact on an individual's life. Seeing a diagnosis as a category, a process, and something with lasting consequences is the foundational framework of the sociology of diagnosis (see Figure 2.2; Jutel, 2011). It acts as an analytic tool, a focal point "where numerous interests, anxieties, values, knowledges, practices and other factors merge and converge" (Jutel & Nettleton, 2011, p. 798). Conceptualising diagnosis in this way offers a gateway into the subject and a suggested course of travel. Whilst in practice diagnostic categories, processes, and consequences are inseparable, distinguishing between them "serves as a prism that reflects and casts light on a multiplicity of issues in health, illness and medicine." (Ibid., p. 799).

Figure 2.2: An adapted version of Jutel's (2011) model of diagnosis



In this review I am going to focus on the third part of the model: the consequences of diagnosis. It would be too large a task to outline the contents of the whole framework, which would take me into the realm of disease classification and the patient-doctor

relationship (amongst other things), which is beyond the remit of this study. Instead, I aim to display a range of works focussing on what exactly diagnoses do to and for the people who have them. This will include a whole range of physical and psychological diagnoses. I will consider the specific consequences of an autism diagnosis in the next section. It is worth noting that the first part of my research question ("how do people come to be labelled, or to label themselves, as 'autistic' in adulthood"), also relates to the process of acquiring a diagnostic label, albeit alternatives to a medical diagnosis. I will consider this more in Chapter Seven.

Throughout this review, and for the remainder of the dissertation, I want to make the distinction between three different types of diagnosis. This distinction is based on my reading of the two literatures to be reviewed and my own empirical work. The first is a *medical diagnosis*, the conventional means of identifying and labelling a medical disorder. This is usually performed by a doctor or other health professional, and is generally recognised as the official means of obtaining a clinical diagnosis (Langlois, 2002). The second type is a *self-diagnosis*, where an individual identifies themselves as having a particular set of symptoms and labels them with what they see as the appropriate diagnosis (something I refer to as self-identification in relation to my own work). This may be done with or without consulting a doctor, but it is the individual who carries out the diagnosis and not a medical professional (Giles & Newbold, 2011). The third type is a *lay diagnosis.* There has been some confusion about what exactly this term means, with some (e.g. Prior, 2014) using it to describe a lay person diagnosing themselves – in other words, somebody who is not a doctor carrying out a self-diagnosis. I believe there is a better use for the term and that it should be clearly distinguished from self-diagnosis. As defined from here onwards, a lay diagnosis

refers to *the act of lay people* (i.e. non-medically trained persons) *diagnosing other lay people with medical conditions, which may be done with or without the knowledge of that person*. There are two reasons for prising self- and lay diagnosis apart. The first is that there is some evidence in the literature of people doing both types of diagnosis (i.e. labelling *themselves* and *other people* with medical conditions). The second is that I have observed this distinction in my own work and therefore feel that I am in a position to offer some clarity on the topic. The distinction between these three types of diagnosis will play a prominent part in this dissertation, particularly when I present my findings in Chapters Four, Five, and Six.

The consequences of a medical diagnosis

Fundamentally, a medical diagnosis constitutes the naming of a disease or disorder through the recognition of signs and symptoms located in the body and psyche (Langlois, 2002). Diagnoses do what Bowker and Star (1999) refer to as 'work:' they bring order to what was previously disordered, enabling us to differentiate between bodily states, and in the process valorise some and disregard others (Jutel, 2009). It is through this work that diagnoses are able to organise a disparate set of symptoms into an organised illness (Balint, 1963).

Thinking about a medical diagnosis as something that orders things is a good way of framing the sociological significance of them. By turning random symptoms into a named and recognisable disorder, a diagnosis organises the clinical picture for patients, determining who has access to what resources and under whose jurisdiction they may fall (Mol, 2002). Without one, most pharmaceutical, therapeutic, and surgical interventions are unavailable to people. A diagnosis determines what is available to a

person outside the clinic. In the UK, for example, eligibility for Personal Independent Payments (PIP) – a financial benefit for people who need assistance with mobility or care costs, amongst other things – requires proof of disability, which is often verified using a medical diagnosis. A diagnosis can also help structure and assist people in their working environment. A letter from the doctor detailing a recent diagnosis provides what Parsons (1951) referred to as a 'claim of exemption,' kick-starting an organisational process that enables formal provisions to be made to assist an afflicted individual in their day-to-day practice (e.g. flexible work arrangements).

As highlighted by Nicholas Rose (2013), the social functions of a diagnosis are far-reaching. For epidemiologists (those who study the incidence and distribution of illness and disease), diagnostic categories are the fundamental units on which they carry out their work – the very things that they seek estimate and to predict. This is influenced by, and contributes to, the directions taken in medical and public health research, in which diagnoses are used to identify problems and concerns worthy of further investigation. For those who provide health services – hospitals, clinics, independent providers – diagnoses inform and provide justification for funding and resource allocation, not to mention the timber from which virtually all patient records and databases are constructed from. For commercial entities, like large pharmaceutical enterprises, new diagnoses earmark and enable the development and production of disease-specific drugs and other medical remedies. Even the availability of special educational resources in schools are allocated on the basis of diagnostic categories. In effect, Rose (1999) argues that medical diagnoses are well and truly entrenched in the infrastructure and functioning of wider society. What seems to be a personal

matter, something intimately located inside one's body or psyche, is in fact a social artefact constructed, regulated, and shaped by wider structures and interested parties.

Once acquired, a diagnosis organises how we think about ourselves (Balint, 1963). It offers a framework from which to interpret bodily and psychological experiences, providing a "structure to a narrative of dysfunction […] sorting out the real from the imagined, the valid from the feigned, the significant from the insignificant" (Jutel, 2009, p. 279). For some, a diagnosis can initiate what Bury (1982) called 'biographical disruption,' whereby the news of a chronic or terminal disorder pulls the rug from under a person's feet and forces them to fundamentally change how they think about themselves in relation to previously held notions of health and selfhood. For other people, certain diagnoses such as stroke or cardiovascular disease (e.g. Lister, 2015), are seen as part-and-parcel of their lives and not something to be considered too disruptive when situated within the 'biographical flow' of their life (Faircloth et al., 2004). How somebody interprets their diagnosis may depend on how much they know about the condition. Some diagnoses (e.g. autism) are contested classifications that are shrouded in confusion and uncertainty, and so individuals may search for 'e-scaped' information to learn about their condition and what it means for them in the long term (Nettleton, 2004). In some cases, this information-seeking may result in the rejection of the assigned medical diagnosis and the acceptance of a new self-assigned classification (more on that shortly). Although a diagnosis has the power to structure how we think about ourselves, the meaning we ascribe to it is not a one-off event, but rather a process of discovery, which unfolds over time and is based on a variety of social contingencies, for example age and previous health status (Adamson, 1997).

A diagnosis also has the capacity to organise a person's everyday activities. It gives an individual permission to be ill (Gerhardt, 1989). What was previously a complaint or a worry is now a disease or a disorder. With a diagnosis, an individual can legitimately claim to be sick; without one "an individual is in a socially invidious position – claiming to be ill but not socially defined as such" (Madden & Sim, 2006, p. 2963). Receiving a diagnosis can legitimate a person's complaints and thrust them into the 'sick role' (Parsons, 1951), where they find themselves treated rather than blamed for any abnormalities they are experiencing. A diagnosis can afford the afflicted individual certain rights, but also certain obligations. The sick person may be exempt from carrying out some, or all, of their normal duties (e.g. going to work, family responsibilities), but only if they are seen to be making an effort to get well, something that is not always possible with chronic disorders and neurodevelopmental conditions (Williams, 2005). A diagnosis also allows for the social incorporation of afflicted individuals, with certain tools and allowances put in place to accommodate and explain the things that are troubling people (Jutel, 2009).

More broadly, medical diagnoses organise how society thinks about normality and abnormality. The measures taken to define (diagnosis-as-a-category) and assign (diagnosis-as-a-process) diagnostic labels provide a cultural expression of what society is prepared to accept as a normal part of the human condition, and what, ultimately, it feels should be identified and treated (Jutel, 2009). What comes to be defined as pathological has changed over time and is determined by a whole host of social, cultural, and historical factors (Aronowitz, 2001). For example, witchcraft, homosexuality, and the tendency for slaves to try and escape from the persecution of their owners – also known as drapetomania – have all previously been categorised as

medical disorders, before being declassified at a later date (Cartwright, 1981; Gevitz, 2000; Mendelson, 2003). In more contemporary times, things that were previously seen as normal for older men – reduced levels of testosterone, baldness, and erectile dysfunction – are now assigned diagnostic categories that trigger a raft of medical and pharmaceutical therapies that aim to treat and alleviate the defined problem (Leo, 2004; Randall, 2000; Rothman & Rothman, 2003). Capturing undesirable states and behaviours in a diagnostic label is known as medicalisation; that is, where "a problem is defined in medical terms, described using medical language, understood through the adoption of a medical framework, or 'treated' with a medical intervention" (Conrad, 2007, p. 5). The engines or drivers of medicalisation can come from the top-down – medical professionals, research groups, pharmaceutical companies – as well as from grassroot sources – patients, charities, pressure groups (see Conrad, 2005). What eventually comes to be seen as different or pathological configures and re-shapes the practice of diagnosis, which has a dramatic impact on the health status of citizens, treatment regimes, and research into new medical disorders (Horwitz, 2011).

Some have argued that the increased medicalisation of various aspects of our personal and social lives has more recently morphed into the broader *bio*medical transformation of human existence (Clarke et al., 2003). Here, the processes and consequences of medicalisation are seen to be evolving and intensifying in uniquely biological and technoscientifically enmeshed ways – that is, the incorporation and prioritisation of biomedicine and information technologies in the healthcare arena, and more broadly 'life itself' (Clarke et al., 2010; Foucault, 1988). The *biomedicalisation* of health and illness has been marked, according to Clarke and colleagues (2003; 2010; 2021), in five inter-related ways: (1) The emergence of a new biopolitical economy of

medicine, health, illness, living, and dying (what is colloquially known as the 'medical industry' (Ehrenreich & Ehrenreich, 1971), or what Clarke et al. (2003) term the 'Biomedical TechnoService Complex, Inc'); (2) A new and intensifying focus on health, risk, surveillance, and optimisation (see below); (3) The technoscientisation of medical and biomedical practices where interventions are progressively reliant on information science and other digital technologies (e.g. big data medicine; Ristevski & Chen, 2018); (4) The transformation of biomedical knowledge production and consumption in ways that make it a fundamental feature of mass and popular culture (see Bauer, 1998); and (5) The transformation of bodies and identities that are imagined, created, and regulated using biomedical discourses and technologies (see Clarke, 1995).[15]

The second transformation noted by Clarke et al. (2003) – a new and intensifying focus on health, risk, surveillance, and optimisation – incorporates many interesting themes in relation to the consequences of (and for) a medical diagnosis. In the biomedicalised era (which, according to Clarke et al., started in the mid-1980s), health itself becomes a prized and monetised commodity, a state of embodiment that is "an individual goal, a social and moral responsibility, and a site for routine biomedical intervention" (Clarke et al., 2003, p. 171). As the authors note, in a biomedicalised world, the focus is not just on overcoming and recovering from illness, but on viewing health and wellbeing (physically and mentally) as "a matter of ongoing moral self-transformation" (Clarke et al., 2003, p. 172). To be a healthy person is to be a good person, and in this biomedical state the pursuit and prioritisation of health, which includes the familiarisation and use

[15] Note, that Clarke et al. (2010) do not see biomedicalisation as replacing or surpassing the concept of medicalisation (see Conrad, 2007; Zola, 1972). Rather, they see biomedicalisation as a framework in which they capture the evolving and intensifying nature of medicalisation and the transformations that it brings.

of medical expertise and diagnostic practices, becomes an ongoing project that is continually and reflexively made (Giddens, 1991). Within biomedicalisation, "there is a shift in the general cultural expectations of whole populations" (Clarke et al., 2003, p. 172) whereby people actively pursue biomedical knowledge to obtain and maintain an image of health.

The notion of disease risk and various self-surveillance practices have emerged as important ways in achieving and preserving health. We, the public, are increasingly aware of a plethora of risk factors associated with different diseases and disorders, and what we should do in order to avoid or mitigate their outcomes. We routinely monitor our health and wellbeing using smartphones and the internet (Lupton & Jutel, 2015), as well as many other at-home devices and technologies (e.g. blood pressure monitors). As Clarke et al. (2003) neatly put it:

> "Risk and surveillance are aspects of the medical gaze that is *disciplining* bodies. They are aspects of biomedicalization that […] are no longer contained in the hospital, clinic, or even within the doctor-patient relationship […]. Rather they implicate each of us and whole populations through constructions of risk factors, elaborated daily techniques of self-surveillance, and the management of complicated regimens around risk and chronic conditions" (p. 172, emphasis added).

In what others have termed our 'diagnostic culture' (Brinkman, 2016), we are invited, if not encouraged, to see ourselves and others through the lens of biomedicalisation, and the concepts, disorders, and categories that it cultivates. 'Surveillance medicine' and the increasing 'problematisation of the normal' (Armstrong, 1995, p. 393) implicates virtually everybody in what Petersen (1997) described as the process of *eventually* becoming ill. Here, the 'worried well' find themselves thinking about and embracing notions of sickness, risk factors, and possible medical explanations for their fears and concerns (Verhoeff, 2012; Williams and Calnan, 1994). "Both individually

and collectively," Clarke et al. (2003, p. 172) note, "we inhabit [a] tenuous and liminal space between illness and health […] *rendering us ready subjects* for health-related discourses, commodities, services, procedures, and technologies" (emphasis added). Authors such as Frances (2013) have expressed many concerns about where these kinds of trends have led, particularly in relation to what he sees as the 'diagnostic inflation' of certain disorders (i.e. the unnecessary or inaccurate diagnosis of physical and psychiatric conditions, whether by a trained clinician or a lay person upon themselves). I will return to some of these ideas later in this work.

The changes bought about through the biomedicalisation of human existence, and the widespread adoption of medical knowledge and diagnostic categories in everyday life, can be seen as a driver for what Ian Hacking (1995) describes as the 'making up' of people and the 'looping effects' that follow them. Simply put, the making up of people refers to the ways in which new scientific classifications, such as medical diagnoses, bring into being new 'kinds' of people that are conceived of and experienced as different from other 'kinds' of classified people (an idea particularly relevant to psychiatric diagnoses). The looping effect, in turn, refers to the ways in which classifications interact with the people being classified; such as how the knowledge generated about a particular kind of person is ultimately used to shape and make possible that particular kind of person (2007).[16] For instance, our knowledge of somebody with a personality disorder (a so-called 'human kind') directly feeds into our image of who that kind of person is, which alters the way one may experience such a disorder, which consequently changes our understanding of the disorder and the

[16] An idea not too dissimilar to the notion of 'reflexivity' (Giddens, 1984), which I will discuss in the coming chapters.

people to whom the category is applied (the 'looping,' here, referring to what Hacking sees as the iterative and continuous sequence of 'making up' people).

Hacking (1995; 2000) points to five key elements that enable this process to happen: (1) the *classification* itself; (2) the *people* that the classifications are applied to; (3) the *institutions* that are involved in the management and distribution of points *(1)* and *(2)*; (4) the *knowledge* generated about *(1)* and *(2)*; and (5) the *experts* and *authorities* who aim to advance our understanding of the aforementioned elements.

Hacking uses this framework to illustrate what he describes as the "conceptual evolution of the high-functioning autist [i.e. autistic people]" (2007, p. 304). The main thrust of his argument goes as such.[17] The generation of a new classification (in this case, autism) allows for the possibility of a new kind of person. According to Hacking, prior to the establishment of autism as a psychiatric condition, it was not possible for somebody to experience themselves as an autistic individual – it was simply not a way to be a person prior to the inception of the category (see 2007, p. 303).[18] Once labelled with the classification (often via medical diagnosis), groups of people begin to change how they see themselves as they are recognised by others as a different kind of person (i.e. an autistic person, should they choose not to resist the label). This is possible because there are institutions – schools, research centres, medical and social services – that act upon, disseminate, and revise our current knowledge of autism

[17] The following is paraphrased from Hacking (2007, p. 304), and can be applied to other types of diagnostic categories, as Hacking demonstrates with dissociative identity disorder (see 2007, p. 298).
[18] In saying this, Hacking does not mean that there were no autistic people prior to the 'discovery' of the condition. Instead, he is suggesting that the advent of the classification made it possible for somebody to *be* an autistic person – to experience and associate oneself, and others, with the condition – and to live in a society as such.

(which may be associated with different schools of thought, who might be contested or at odds with each other). Then there are the experts, be they scientific, clinical, or self-described, who are bolstered by and give credence to the institutions and knowledges for whom they are associated with. As Hacking notes, it is the interaction between these five elements that creates the conditions to make up a "high-functioning autist," or other kinds of people associated with a diagnostic classification.

At its heart, the making up of people is rooted in the ways in which the names we assign to people interact with the very people we have named, causing categories to shift and change based on the people and practices that they have become a part of (Mol, 2002). When thought about in this way, not only do medical diagnoses bring about a series of diverse consequences for those in receipt of one, but those individuals (and society's view of others like them) also feedback into, and have consequences for, the diagnostic labels themselves. I will talk more about this, and the related concept of 'reflexivity' (Giddens, 1984; 1991) in Chapter Seven.

Making a self-diagnosis

With an abundance of medical information now available on the internet, it has never been easier for people to check the potential cause of their symptoms and make a self-diagnosis. While patients have always contributed to the diagnostic process – by instigating the medical consultation (Zola, 1973), and presenting and narrating symptoms for consideration (Balint, 1963) – today, with the help of information technology, a patient "might seek out the doctor not for the purposes of *deciding* a diagnosis, but rather for *endorsing* a diagnosis" (Lupton & Jutel, 2015, p. 129; emphasis added). After all, we can all pull up the diagnostic criteria on our

smartphones and match a particular set of symptoms to a syndrome identified in the text (Giles & Newbold, 2011).

Lay people can draw on different types of knowledge to identify and label the things afflicting them. From old wives' tales and folklore (Blaxter & Paterson, 1982) to 'hybridised' models of illness (Dew et al., 2014) that incorporate lived experiences, medical knowledge, and 'lay epidemiologies' (Davison, Smith, & Frankel, 1991) – thoughts and opinions ordinary people have about disease risks – non-medically trained individuals can call upon these ideas to diagnose themselves, or other people, with a medical disorder (more on other people shortly). For example, Prior and colleagues (2011) examined how older people spoke about, and subsequently self-diagnosed, the common cold and the flu. Aside from the obvious observation that lay and professional knowledge of colds and flu diverge significantly – the former mostly drawing on self-reported symptoms (e.g. runny nose, lethargy, and feeling down), the latter using those as well as laboratory-based evidence (e.g. the detection of different types of virus) – the elderly people studied used what Prior et al. referred to as a 'lay surveillance system' to diagnose themselves: "anecdotal evidence anchored in knowledge of small worlds – worlds composed of near neighbours, friends, and close relatives" (2011, p. 927). Whilst this 'lay surveillance' may be utilised in the self-diagnosis of relatively minor conditions, people generally look to medical professionals as the adjudicators in more serious or contested diagnoses (Dumit, 2006).

As loath as doctors may be to see people self-diagnose, there are examples where this is encouraged. Infectious diseases such as influenza can pose a real threat to the health of a community, and public health messages often encourage people to identify

signs of the condition – i.e. self-diagnose – as early as possible in order to reduce the spread of the disease and lessen its impact (Jutel & Banister, 2013). Indeed, this is what happened in the UK during the Covid-19 pandemic. If an individual suspected that they had the virus based on an increased temperature, persistent cough, and/or change in their sense of taste and smell, they were advised to stay at home and only seek medical assistance if they experienced complications or belong to an at-risk group.[19] Whereas the majority of public health messages are about early detection and subsequent presentation to a medical expert – for example, if somebody is suspected to have the measles (Ghebrehewet et al., 2016) – with influenza and Covid-19 medical intervention is frequently discouraged, leaving people to self-diagnose and manage the conditions themselves (Jutel & Banister, 2013).

Information technology has had a profound impact on an individual's ability to take control of their healthcare. As Andreassen and Trondsen (2010) described, this started with the idea of the consumerist patient in the 1970s, where patients were encouraged to be empowered and engaged in their healthcare, and to view the medical encounter as a partnership in which they participate in their own self-management practices (Bury & Taylor, 2008). Now, the notion of the digitally engaged patient sees lay people championing the use of new technologies to exchange experiences of diagnosis and treatment, and even challenge conventional medical thinking (Lupton & Jutel, 2015).

Online self-help networks, particularly those related to mental health issues have flourished over the last two decades (Charland, 2004; Stapleton, Evans, & Rhys, 2019;

[19] See NHS guidance at the time of writing, retrieved on 6th July 2020 (https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms/).

Vayreda & Antaki, 2009). As Giles and Newbold (2011) explained, these platforms provide a place for people to participate in an informal medical consultation by pitching their symptoms to others and using their collective experience to arrive at a possible diagnosis. This sees users empathising with each other's concerns – *"you're not alone, me too"* – and translating them into diagnostic talk – symptoms, indicators, risk factors – thereby legitimising them (Ibid.). For those seeking a medical diagnosis, these online consultations can form the bedrock of their own self-diagnosis. Yet as Giles and Newbold point out, these online forums represent an uncomfortable counterculture where members often reject the conventional diagnostic process, encouraging people to self-diagnose conditions, whilst at the same time using their own formal diagnostic category to validate their claims of expertise – *"as somebody with a diagnosis, I know what it is like."* Even in these online spaces, it seems a medical diagnosis still reigns as king.

Technologies that assist people in self-diagnosis are part of a lucrative commercial market promoting the interests of manufacturers who sell these technologies and pharmaceutical companies whose products they recommend (Lupton & Jutel, 2015). As noted by Ebeling (2011), the marketing appeal to self-diagnose is not new: "as long as mass marketing has existed patients have been encouraged to self-treat and to determine the physiological meaning of their symptoms" (Ibid., p. 828). Ebeling investigated how pharmaceutical companies used online marketing and symptom checklists to encourage women to self-diagnose Premenstrual Dysphoric Disorder (PMDD) – a condition in which women experience mood swings, tiredness, and headaches in the weeks before their period. The checklist Ebling analysed – which came from the website of the pharmaceutical giant, Bayer Healthcare – was "both

vague in its description of symptoms and rigidly clear in the intent of its purpose: the checklist must lead the user to self-diagnose the DSM-IV category for PMDD" (Ibid., p. 829), and most importantly, suggest the best course of treatment: a medication known as 'YAZ,' which happens to be sold by Bayer Healthcare. Ebling described how the intent of these tools is to shift the diagnostic determination from the doctor to the patient, empowering patients to make their own healthcare decisions (with the help, it should be noted, of some very powerful corporations). Here, self-diagnosis is transformed from a "threatening enactment of patient agency" to a "conveyance of pharmaceutical ideology in the guise of patient self-knowledge and empowerment to take action" (Ibid., p. 829).

Similar observations have been made of the self-diagnosis of digestive disorders using direct-to-consumer laboratory testing. Conditions such as coeliac disease and gluten intolerance can be difficult to identify as the tests used to confirm a medical diagnosis are often invasive, lengthy, and involve a certain degree of interpretation by clinicians (Green & Jones, 2007). In lieu of or despite a negative diagnosis, those who suspect that they have a digestive disorder may choose to self-diagnose, which involves identifying and linking symptoms with the diagnostic criteria and adopting a gluten-free diet to test how their symptoms respond (Copelton & Valle, 2009). This can often work for people, with the pain and discomfort that comes with eating gluten vanishing within a matter of days. However, continuing to self-diagnose without medical confirmation risks other people questioning the legitimacy of the self-diagnosis, making it difficult to convince doubting family members and friends of the necessity of the diet and the negative implications of consuming *"just a little bit"* of gluten. In addition to this, if an individual decides to resume the consumption of gluten and attempts medical testing

– which requires the patient to eat at least two portions of gluten a day for six weeks (NICE, 2015) – they risk their symptoms returning with no guarantee of a positive diagnosis (Copelton & Valle, 2009).

Self-diagnosis is therefore the only option available to some people. And yet, the lack of recognition and support available to those who self-diagnose compels many to seek additional and more authoritative forms of evidence. One of these comes from a direct-to-consumer test carried out by a company called EnteroLab in the US, a laboratory specialising in food sensitivities and digestive disorders. Customers are able to send a stool sample to the company's research laboratory, where an antibody test is carried out (secretory IGA antibodies to gliadin (sIgA-AGA)), which EnteroLab claims offers a valid measure of coeliac pathology.[20] Customers find that with this measure they test positive for coeliac disease, which validates their initial self-diagnosis. Copelton and Valle call this a 'scientific self-diagnosis,' which "grants individuals greater legitimacy for their claims of an illness identity than self-diagnosis alone, but less legitimacy than a medical diagnosis" (2009, p. 623). A scientific self-diagnosis builds on a self-diagnosis by including pseudo-medical testing, allowing people to circumvent the doctor and issue their own 'scientifically approved' label. As Copelton and Valle point out, this type of diagnosis reflects both a rejection and acceptance of biomedical constructions of disease and standards of diagnosis; it reflects the general acceptance of the importance of biomarkers in the diagnosis of these disorders, but rejects the standards of proof required for a clinical diagnosis.

[20] This test, according to Copelton and Valle, has fallen into disrepute in the medical profession because of its low specificity for coeliac disease (see 2009, pp. 628-629).

Lay diagnosis: Labelling other people with a medical disorder

As I mentioned earlier, the term lay diagnosis is not without its ambiguities. Most researchers tend to use the term to mean self-diagnosis, that is, lay people diagnosing their own medical ailments. In 2001, the journal *Text & Talk* published a special issue on lay diagnosis (edited by Sarangi & Wilson, 2001), which mostly focussed on the interactional nature of the doctor-patient relationship and the role lay people played in the diagnostic process (e.g. what patients say to doctors and how they respond to decisions). Offering readers some preliminary thoughts on the topic, Beach (2001) recalled an email he received from a doctor responding to an earlier draft of his article '*Diagnosing 'lay diagnosis."* It read:

> "The title [lay diagnosis] is misleading in that *it is not about diagnosis by non-physicians*, but about how medical diagnosis is understood by non-medical persons" (2001, p. 15; emphasis added).

I would agree. Beach's use of the term (as well as other authors in the special issue) is primarily about lay people researching, advocating for, and issuing their own diagnoses (i.e. self-diagnosis). The point that the doctor was making was that diagnosis *can also be done by a non-physician to another person*. Although I am not aware of anybody making this distinction between self- and lay diagnosis, there are a few examples in the medical and social scientific literatures of lay people diagnosing other lay people with physical and psychiatric disorders.

One of these comes from Giles and Newbold (2011) – the researchers who examined how people self-diagnosed mental health issues using internet forums. At the end of their paper, they briefly report on instances where people "move away from self-diagnosis toward working up informal diagnoses of other individuals" (2011, p. 425).

Although Giles and Newbold do not use the term lay diagnosis – they instead use the phrase 'other-diagnosis' – they present data from an online chatroom where one user announces: "I'm convinced my relative is mentally ill" (2011, p. 425).[21] In their analysis of the comments that followed, Giles and Newbold observed a particular sequence to the act of lay people diagnosing other people with medical disorders. It started with a disclaimer, such as *"I'm not a psychologist"* or *"I'm no expert,"* before a potential diagnosis was delivered. The suggested diagnoses are discussed and debated amongst forum users, who then arrive at a likely or probable diagnosis. Recommendations are then made about useful remedies and supporting services that the afflicted individual could access. As Giles and Newbold noted, although the majority of forum users were happy to issue their own lay diagnoses, these assessments were often made with extreme caution and caveated with the message: seek medical confirmation.

In a separate investigation, Olafsdottir and Pescosolido (2011) analysed data from a world-wide survey (Stigma in Global Context – Mental Health Survey) on "the nature and correlates of lay diagnosis" (2011, p. 929). Amongst other concerns, they were interested in whether people from eight different countries would be able to identify somebody who demonstrated the clinical symptoms of schizophrenia. To do this, survey respondents were presented with a vignette of a man named John. As the vignette described, John had started to feel uneasy about himself. He was worried that people were spying on him and that they could hear what he was thinking. The vignette also described how John had become so preoccupied with this that he started skipping

[21] I considered using the term other diagnosis but opted for lay diagnosis as the term is already in use within the sociological literature.

meals, that he stopped bathing, and that at night he would pace around his room because he was hearing voices. Olafsdottir and Pescosolido wanted to see whether participants first thought that John was experiencing a mental illness, and second if so, what condition it was. Amongst the many reported findings, the most relevant was that participants who knew somebody with a mental health diagnosis were more likely to recognise John as experiencing a mental illness than participants who did not report such affiliations (this only applied to participants in the UK and USA). Although Olafsdottir and Pescosolido did not offer an explanation as to why this was the case, it could be suggested that participants recognised in John behaviours similar to those observed in people they knew who had a mental health disorder. They were able to see and correctly identify those same issues in the vignette.

Similar observations have been made in psychiatric and epidemiological research. In a study into the delayed treatment for psychosis, Norman and colleagues (2007) found that patients with a family history of the disorder were more likely to be diagnosed and treated sooner than patients without this familial link. This was because “families with a history of psychotic illness were more likely to recognise the need for help for the ill person prior to the onset of psychotic symptoms” (2007, p. 507) – they could see the signs of psychosis developing before they were actually present, which led to them seeking medical consultation sooner. Hambrecht (1995) suggests that familial experience of such disorders leads to a more rapid response because relatives are increasingly sensitised to the signs of illness and the need for treatment. They are able to draw on their own knowledge and experiences of a disorder to correctly identify it in their loved ones, which they then act upon.

A lay diagnosis, either by a family member or a friend, can be accompanied by a suggestion or a plea to go and see a doctor. Freidson (1960) described this as a 'lay referral.' A lay referral can be made by various non-clinically trained persons who talk through symptoms with the afflicted individual, offer advice about remedies and treatments, as well as reassurance that a medical consultation is necessary – *"that sounds like something you should talk to your doctor about".* As Cornford and Cornford (1999) found in their interviews with patients who recently sought medical advice, roughly seventy percent had decided to go to the doctor because a friend or relative had encouraged them to do so. It was through passing conversations with those people that participants disclosed the things that were troubling them, with these conversations concluding with a lay referral to the doctor. Although Cornford and Cornford were unable to identify an extensive network of lay people that participants passed through before arriving at the clinic doors (something that Freidson theorised as a 'lay referral network'), they did acknowledge that the conversations and encouragement from lay people did form an important step in seeking a professional diagnosis. It might be the case that a lay diagnosis – *"I think you have x"* – is a precursory step in a friend or relative making a lay referral to the doctor – *"you should check that out."* (I will talk more about this in Chapters Six and Seven)

What is missing from the sociology of diagnosis?

Much has already been done in this flourishing area of research. Using diagnosis as a lens through which to study matters concerning health and illness has greatly advanced medical sociology as a whole. In thinking about how to push this work forward, the following bullet points outline what I believe is missing in this area of inquiry and how I can go about addressing it.

- The first is a substantive point and that is that *there is limited sociological research on the consequences of an autism diagnosis in adulthood.* There are examples of sociologists studying the classification of the condition (e.g. Singh, 2011) and how clinicians arrive at their diagnostic decisions (e.g. Hayes et al., 2020), but as I will demonstrate in the next section (my empirical home), the consequences of a diagnosis have mostly been studied from a psychological or health-service perspective. This needs remedying as the existing work in this area is overwhelmingly description-heavy and theory-light. A sociological perspective would add more depth to this field.
- On a related point, thinking about the sociological significance of a medical diagnosis (of any condition), I think there is space for a *more sustained conceptualisation of what exactly these labels do to the people who acquire them*. What is it about a diagnosis, be it a medical, self-, or lay diagnosis, that fundamentally changes how we think about ourselves and other people? How, in the words of Bowker and Star (1999), do these labels work? Also, what exactly do we mean by the term self-diagnosis (or self-identification)? Is self-diagnosis the same for everybody, or are there different ways and reasons for doing it? Similar questions could be asked of lay diagnosis. A more conceptually driven account of these three types of diagnosis would add to the already theoretically-rich portfolio of the sociology of diagnosis. This is the overarching aim of this work.
- Finally, I think adding lay diagnosis to sociologists' research agendas would be empirically and analytically fruitful. As I demonstrated in the last section, there is already some evidence of lay people labelling other lay people with medical disorders, and this certainly warrants further investigation. How does one identify

a medical condition in another person? Why do people do this, and what do they do once a lay diagnosis has been made? This will be my topic of discussion in Chapter Six.

And now to the second body of work: the research into autism in adulthood.

Empirical home: Autism research

In this part of the review I consider the empirical work into the medical and self-diagnosis of autism in adulthood. As I mentioned earlier, this is a relatively small body of work that has mostly been conducted by medical practitioners (nurses and psychiatrists), psychologists, and health-service researchers. The focus of these studies is generally on the impact of a medical diagnosis in adulthood. Self-diagnosis is considered in some of these studies, but it is usually framed as a secondary concern, a bolt-on, to the official psychiatric label. There are a few exceptions to this – studies that explicitly study the phenomenon of self-diagnosis – but even then, it tends to be viewed as a precursory step in obtaining a formal medical diagnosis, and not an end in itself.

Figure 2.3 (overleaf) offers an overview of the studies reviewed in this section. I included studies that were empirical investigations (not theoretical or commentary pieces) published in peer-reviewed journals. The focus of these studies were the experiences of acquiring, and the impact of living with, a medical or self-diagnosis of autism in adulthood (some studies included teenagers and parents of autistic adults in their sample). As mentioned at the beginning of the chapter, this does *not* represent an extensive review of all the studies published in this area, either because I was

unable to locate a study using my search criteria (see Appendix 1) or because I was unable to access the publication using my '@exeter.ac.uk' account, or other university subscriptions.[22]

Figure 2.3 is organised in chronological order (from 2001-2020). It outlines the focus of the study (as stated in the article), the method of data collection and analysis (some authors provided more details than others), and the studies most notable findings. As I will argue shortly (see 'what is missing,' p. 72), many of these authors report the same, mostly descriptive findings around the experience of acquiring the label autistic (usually reported as a series of analytical themes). I have tried to avoid this repetition in Figure 2.3 by noting what I saw as the most novel findings from these studies, which is inevitably based on my own judgement.

[22] For example, Lewis (2018) was excluded from this review because it was published behind a pay wall. I requested a copy from the author but unfortunately got no reply.

Figure 2.3: Overview of autism studies (continues overleaf)

Authors (*n*=15)	Focus of Study	Data Collection & Analysis	Key Findings
Jones et al. (2001)	The emotional experience of autism	Analysis of internet blogs written by 5 autistic adults; thematic analysis	Predominantly negative emotions (e.g. alienation, fear, frustration, and other mental health difficulties)
Portway & Johnson (2005)	The everyday and long-term "risks" of Asperger's syndrome	Interviews with 18 young adults (18-35 years) and their parents; constant comparative analysis	Everyday risks: misunderstanding others and being misunderstood; being bullied Long-term risks: underachievement at school and work; prolonged dependency on parents
Punshon et al. (2009)	Psychological reactions to medical diagnosis of Asperger's syndrome	Semi-structured interviews with 10 adults (22-45 years); interpretive phenomenological analysis	A sense of "finally fitting in" and being exonerated for previous difficulties: "not guilty verdict"
Singh (2011)	The removal of Asperger's syndrome from the DSM-5 and the implication for people with a medical diagnosis	Semi-structured interviews with 19 adults (18-55 years) who had a medical diagnosis or self-diagnosed Asperger's; grounded theory	'Diagnosis-identity fusion:' an Asperger's diagnosis is incorporated into an individual's identity and their sense of self
Jones et al. (2014)	Experience of obtaining an autism medical diagnosis and post-diagnostic support.	Survey of 128 adults with a medical diagnosis; statistical analysis (correlations and multiple regressions)	Routes to diagnosis were varied with regards to waiting time and number of referrals. Satisfaction with the process was mixed. More support post-diagnosis requested
Bargiela et al. (2016)	Experience of women with an autism medical diagnosis	Semi-structured interviews with 14 women (22-30 years) plus quantitative measures of autistic traits; framework analysis	"Camouflaging" and "pretending to be normal"
Lewis (2016a)	Experience of "realising" a self-diagnosis of autism	Survey of 37 adults who self-diagnosed autism; "Colaizzi's seven-step method"	Feeling othered; managing self-doubt; questioning the need for a medical diagnosis
Lewis (2016b)	Experience of "realising" a medical diagnosis of autism	Survey of 77 adults with a medical diagnosis; "Colaizzi's seven-step method"	Feeling different from others; riding an emotional rollercoaster; striving to accept oneself; creating strategies to improve quality of life

Powell & Acker (2016)	Emotional response to, and impact of, autism medical diagnosis	Survey of 74 adults (50 with a medical diagnosis and 20 “sub-threshold”); thematic content analysis	Emotional response: relief; gratitude; validation; confusion; shock Impact: diagnosis as explanation and exoneration; lack of official support; little clarity
Sarrett (2016)	Arguments for and against self-diagnosis	Analysis of comments made on the website WrongPlanet.net; no reported method of analysis	Arguments for: suspicion of medical intervention; diagnosis inaccessible; fears of stigma. Arguments against: lack of accuracy; self-confirmation bias; “scammers” and “fakers” seeking secondary gains
Kanfiszer et al. (2017)	Experience of women with an autism medical diagnosis	Semi-structured interviews with 7 women (20-59 years); narrative analysis	Battling stereotypes and gendered expectations
Lewis (2017)	The barriers to acquiring a medical diagnosis of autism	Secondary analysis of Lewis, 2016a & 2016b survey data; content analysis and descriptive statistics	Financial cost; anxiety; mistrust of doctors; fear of not being believed
Hickey et al. (2018)	Experience of older people with an autism medical diagnosis	Semi-structured interviews with 13 adults (50+ years); thematic analysis	Diagnosis offers a framework for understanding past and future experiences
Milner et al. (2019)	Female experience of autism spectrum disorder	Individual and group “discussions” with 18 women (16 with a medical diagnosis, 2 self-diagnosed); thematic analysis	Fitting in with the norm; difficulties getting a medical diagnosis; “girls can be autistic too;” benefits of autism
Leedham et al. (2020)	Experience of women receiving a medical diagnosis in late adulthood (40+)	Semi-structured interviews with 11 adults (43-64 years); interpretive phenomenological analysis	Pretending to be normal; the process of self-acceptance; stereotypical assumptions from others; forging a new autistic identity

As with the previous section, I have split the following discussion into different types of diagnosis – in this instance, a medical diagnosis and self-diagnosis (I have yet to come across any studies investigating the lay diagnosis of autism). At times I will draw on authors not cited in the above table as they offer ideas related to the current discussion, but their work falls outside the loose inclusion criteria outlined above.

The impact of a medical diagnosis of autism

Everybody who has investigated the impact of an autism diagnosis has described it as a positive thing in a person's life. For the most part, getting a diagnosis brings with it a sense of relief and gratitude as it enlightens people about the troubles and symptoms they have experienced over the years (Powell & Acker, 2016). Often described as "the missing piece of the jigsaw," a formal diagnosis offers an explanation as to why people behave and see the world the way they do (Punshon et al., 2009, p. 227). It legitimises any concerns that an individual may have had and exonerates them from being blamed for previous difficulties and deviances (Lewis, 2016a). As one person told Punshon and colleagues, "[getting] the letter saying that I had Asperger syndrome […] was a bit like standing up in court and hearing the jury say: 'not guilty'" (2009, p. 227). A positive diagnosis can also act as a source of confirmation for those who have always suspected that they were different from others, and having that suspicion rubber stamped by a doctor can be immensely empowering for an individual (Leedham et al., 2020).

Beyond these initial reactions, an autism diagnosis has the power to profoundly change an individual's sense of self, even when a positive diagnosis is anticipated. Those who have acquired one talk about a process of self-discovery, or re-discovery,

in light of this new information (Kanfiszer, Davies, & Collins, 2017). This is especially true for those later in life, as Hickey and colleagues (2018) found in those diagnosed after the age of fifty:

> "Experiences such as bullying, academic underachievement, employment difficulties, persistent anxiety, and problems making and maintaining friendships and romantic relationships could be understood in a new light on the basis of [an autism] diagnosis" (p. 361).

Here, obtaining the diagnosis initiates an intense period of biographical reflection in which an individual looks back on their life and starts to re-evaluate it using their newly acquired autism lenses (Lewis, 2016a) For some people, reaching some sort of self-acceptance is a big part of this journey, in particular recognising autism as a major part of their identity (Leedham et al., 2020; Rossiter, 2016). Singh (2011) described this process as a 'diagnosis-identity fusion,' where characteristics or traits associated with a diagnosis are used to affirm who a person is – *"I am fidgety. I am quirky. I am obsessive. I am autistic."* The way some people refer to themselves as 'Aspies' or 'Autists' can be seen as an example of this diagnostic-identity fusion (Muggleton, 2012).

One of the major consequences of acquiring a medical diagnosis is that it grants its recipient access to a variety of services that can be used to manage the condition and improve one's quality of life (Powell & Acker, 2016). This may include welfare support, financial benefits, as well as specialist autism services such as out-patient meetings and patient-led community groups (Collins, 2016). These benefits can also extend beyond the person with the diagnosis, with spouses and parents of adult children also accessing social and financial services to help with care and other important arrangements (Calzada, Pistrang, & Mandy, 2012). Furthermore, in the case of those

who feel that they need more help and support (Jones et al., 2014), an official diagnosis can be used as a symbolic weapon to pressurise gatekeepers (doctors, social workers) into granting access to additional services (Calzada et al., 2012).

And yet, the arrival of a diagnosis can also be accompanied with some unpleasant and upsetting emotions. Adults recently diagnosed have reported feeling "shocked," "daunted," and "confused" at the prospect of being autistic, whilst others have found themselves "angry" and "upset" about being officially labelled a "weirdo" (Lewis 2016a; Powell & Acker, 2016). The diagnosis, which in its current classification is an indefinite one, can also engender a sense of hopelessness as the label comes to symbolise the final "nail in the coffin," as one person explained to Punshon and colleagues (2009):

> "There was this dip [after the diagnosis] […] I was feeling a bit hopeless, you know that maybe this wasn't something I could overcome … I am never going to be like one of these 'normal' people and you know … and I thought '*I am stuck being like this now*' (p. 278; emphasis added).

This sense of unease can also extend to the way an individual feels in the presence of other people. Those who have obtained a medical diagnosis in adulthood have reported being "shunned," "shamed," and "othered" by those who have recently discovered their new psychiatric label (Jones, Zahl, & Huws, 2001; Portway & Johnson, 2005). This has a lot to do with the way autism is generally perceived by the public, as one autistic adult explained to Singh (2011, p. 245): "A lot of people […] when they hear 'autistic spectrum' think 'mentally handicapped' and 'sort of slow' and they'll be like, 'oh no, a retard.'" The common misconceptions surrounding autism, particularly the way people conflate autism with a learning disorder, often results in people lowering their expectations of autistic people because they believe them to be less capable and cognitively astute than 'normal people' (see O'Brien & Pearson,

2004). Another popular belief, despite attempts to change public opinion (e.g. BBC, 2018b), is the view that autism is something that only affects young boys and men. As a result, women (and girls) with a diagnosis often attract additional stigma and discrimination for not adhering to normative gendered expectations, particularly if their appearance and interests align with their autistic male peers (Bargiela et al., 2016; Kanfiszer et al., 2017).

Such experiences can leave people feeling disillusioned with their diagnosis. As well as the perceived stigma associated with the label, the promise of help and support following a successful diagnosis is not always realised (Jones et al., 2014). In the UK, for example, adult autism services are often in short supply – in part due to staff shortages and limited funding (Knapp et al., 2009) – and many newly diagnosed adults can find themselves without any professional support or care (Calzada et al., 2012). When support is accessed, some have reported healthcare professionals being "uninterested" and having "little or no knowledge" about autism, rendering the service "useless" (Powell & Acker, 2016). This disappointment also extends to the diagnosis itself, with some suggesting that the assessment "failed to provide the clarity needed" (Ibid., p. 77). This may be particularly true for those who do not obtain a full diagnosis as they are 'sub-threshold' – they are not *not* autistic, but they do not meet enough of the criteria to obtain a diagnosis, leaving them in a state of 'diagnostic disappointment' (Ibid.). What people do following a negative autism assessment has yet to be examined. Perhaps some people choose to self-diagnose the condition despite the negative result, as has been observed in other conditions such as gluten intolerance (Copelton & Valle, 2009). I will consider this question in Chapter Five.

Self-diagnosing autism

When compared to the research on a medical diagnosis, relatively little has been written on the subject of people self-diagnosing autism. At the time of writing (July 2020), there are only two studies that have explicitly investigated the self-diagnosis of autism and the consequences of doing so.[23] The first of these was an online survey carried out by Lewis (2016b) in which she asked respondents "[to] describe [their] experience of coming to a self-diagnosis of autism spectrum disorder. Please share any thoughts, feelings, and specific experiences." The second was carried out by Sarrett (2016), who analysed comments made on an internet forum to a post entitled: "Why is there a lot of hatred towards people who self-diagnosis [sic] themselves with Asperger's or autism?" It should be noted that Sarrett does not report whether the comments she analysed came from people who self-diagnosed autism, had a medical diagnosis, or were non-autistic users of the site. Although, as the website (WrongPlanet.net) is a popular forum for discussing all things autism, including self-diagnosis, it could be assumed that at least some of the respondents to the post had self-diagnosed autism, but there is no way of telling. The point is that there are few studies looking at self-diagnosis in any detail. There are other publications that have considered the topic, but as I mentioned at the start of this section, self-diagnosis is usually framed as a secondary concern to the primary focus of obtaining and living with a medical diagnosis (e.g. Wylie, Lawson, & Beardon, 2016). Nevertheless, there is much we can learn from these studies, including how people arrive at a self-diagnosis in adulthood.

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[23] As noted on p. 31 (footnote 10), some authors report that they are studying the experience of those who self-identify as autistic (e.g. Angulo-Jiménez & DeThorne, 2019; Linton et al., 2014), but these authors use the term to refer to people who self-report their medical diagnosis, and not those who have labelled themselves as autistic.

One way is by basing it on their children's medical diagnosis. As Singh (2011) found in her interviews with autistic adults, prior to their children's diagnosis none of the adults who self-diagnosed saw themselves as autistic – it was simply not something that applied to them. However, it was only after reading the diagnostic criteria on behalf of their children and talking about it with clinicians did they start to join the dots and identify their own autistic traits (see Zener, 2019). For some of the people Singh interviewed, this resulted in them self-diagnosing autism and reconstituting their identities in light of this discovery – fully embracing the notion that they, and their children, belonged to the autistic community.

Something similar was noted by Conrad and Potter (2000), who traced the emergence of ADHD in adults. Like Singh, they described how one of the paths to a self-diagnosis of adult ADHD came following parents' encounters with their children's medical diagnosis of the condition. Using their children as a point of reference, parents were able to recognise the difficulties and symptoms they had experienced when they were growing up, and, using their knowledge of their child's diagnosis come to the conclusion that they too had ADHD, albeit undiagnosed. Conrad and Potter described how some parents, armed with this knowledge, went on to pursue a formal diagnosis, whilst others preferred to leave matters as they were and continue to self-identify as 'adult hyperactives.'

Like a medical diagnosis, making a self-diagnosis of autism can bring an individual immense relief. It can offer an explanation for a person's difficulties and woes, it can instigate a new-found sense of understanding, and mark an individual as belonging to

a collective community of people (see Brownlow & O'Dell, 2006). Although a self-diagnosis does not bring with it the tangible gains of a medical diagnosis (e.g. access to services and state welfare), for some people simply knowing that they might have the condition is enough to help them manage their symptoms and identify their strengths (Milner et al., 2019; Russell et al., 2019), leading to more positive outcomes, such as securing steady employment or establishing better relations with loved ones (Calzada et al., 2012).

For those who self-diagnose autism, the very absence of a medical diagnosis can be seen as a good thing. For instance, Lewis (2016b) found that fear of being discriminated against on the basis of a formal diagnosis was a significant concern for many people without one, and that this was a major reason for not pursuing one in the first place. Similar concerns have also been raised about bullying and stigma in the workplace, with the perception being that having an official diagnosis puts a metaphorical target on your back for others to exploit (Hendricks, 2010).

In some cases, the lack of a medical diagnosis is not only viewed as a social necessity, but an actual preference. This is particularly true for those who question the assumption that autism is a neurodevelopmental *disorder* that must be diagnosed and treated under the auspices of psychiatry (see Kapp et al., 2013). As Sarrett (2016) noted, many people who self-diagnose autism have a strong suspicion of medical and scientific expertise. They believed that the notion that autism is a deficit-based medical disorder is incorrect – instead viewing it as a neurological *difference* – and that clinicians are no better at identifying autism than autistic people. As one respondent

in her study said: “I don’t exactly trust that the ‘experts’ have it all together,” and that professional diagnoses are “just guesses most of the time” (Ibid., p. 30).

The suspicion with which a medical diagnosis is regarded ties into the notion of an autistic self-expert (see Gillespie-Lynch et al., 2017). This is the view that autistic people know more about the condition through their lived experience than mental health professionals, who are only able to observe predetermined symptoms and compare them with certain diagnostic criteria. Whether this is a fair assessment of clinicians is up for debate, but at its heart is the assumption that experiential knowledge trumps the professional knowledge of the doctor (see Brown, 1992). Those who hold such views believe that autism is simply too complex a thing to be identified by a stranger in a clinical setting, and that a more credible option is for people to identify it themselves, with the help of other autistic people if needed (Sarrett, 2016).

That said, the absence of a medical diagnosis can also cause issues for people. As Lewis (2016b) found in her survey of self-diagnosed adults, the lack of professional confirmation made some respondents doubt whether they were ‘truly’ autistic, and for those who had this concern, “researching ASD [autism spectrum disorder] became an obsession in an attempt to confirm or refute their self-diagnosis” (p. 576). This sense of doubt can also be compounded by other people questioning the validity of one’s self-diagnosis. In Sarrett’s (2016) research, many people took the view that it was not possible to accurately identify autism without the input of a medical professional, directly contradicting the view of others in the study. Many argued that until a professional diagnosis was obtained, “the [self-assigned] label is just a guess, similar to how people often guess that they have the flu or a migraine” (Ibid., p. 28). In addition

to this, people who self-diagnosed were also seen as biased and untrustworthy – “scammers” and “fakers” – merely seeking to confirm what they already believed in the hope that they could access certain benefits and services.

Some of these concerns may encourage people to pursue a formal diagnosis. However, transitioning from a self-diagnosis to a medical diagnosis is not always possible, or even desirable. As documented by Lewis (2017), there are various barriers that prevent adults from obtaining a formal assessment. These include anxiety about the evaluation itself, a perceived inability to communicate symptoms clearly, a fear of not being believed by clinicians, or a general mistrust of medical professionals due to negative experiences in the past (e.g. being ‘misdiagnosed’ with a different condition). Overperforming or camouflaging during the diagnostic assessment may also prevent clinicians from recording the vital evidence needed to make a positive diagnosis (I will talk more about this in Chapter Five; Milner et al., 2019). Because of these concerns, those who have self-diagnosed but would like a medical diagnosis may feel that they are unable, or that it is too difficult, to obtain one. Whereas those who are neutral or indifferent about a diagnosis may feel that it is just not worth the effort to overcome these issues, particularly if they question the value of a medical diagnosis in the first place (see Lewis, 2017, p. 2418). In order to remove these barriers, Lewis – a practising clinician herself – argues that healthcare professionals must do more to build trust with autistic people, and that they must understand the motivations behind self-diagnosis so that they can ultimately help people transition to a formal diagnosis.

Even though there are many barriers that prevent people from seeking a formal assessment, self-diagnosis is seen by many as an important precursory step to obtaining an official diagnosis (Wylie et al., 2016). This was the case for Wylie (2014), an autistic researcher and author, who self-identified as autistic before receiving a medical diagnosis of Asperger's syndrome later in adulthood. This is not uncommon. It can take years to get an autism diagnosis – an average of 3.25 years from the initial consultation to the final assessment, according to data collected in the US by Lewis (2016a) – and during that time many people find themselves self-identifying with the label they hope to eventually obtain. For Moore (2016) this makes a lot of sense, as it stands to reason that if an individual seeks an autism diagnosis in adulthood, then they must at least suspect that they are autistic, otherwise why would they pursue the matter in the first place? Eventually, they may become so assured in their self-diagnosis that they see the clinical assessment as nothing more than a confirmatory test, telling them what they have already suspected for years (Sarrett, 2016).

What is missing from the autism research?

As with the sociology of diagnosis, I want to close this section with a few remarks about what is missing from this body of work and how I aim to contribute to it. This can be summarised as the following:

- On the back of the previous section on self-diagnosis, *much more work needs to be done to understand how and why people label themselves as autistic in adulthood*. With the exceptions of Lewis (2016b) and Sarrett (2016), the self-diagnosis of autism has received little attention empirically speaking. When it is studied, it is usually framed as a precursory step in obtaining the formal medical

label. However, this is not the only reason somebody may choose to self-identify as autistic – they may do it as an alternative to a medical diagnosis or in response to a negative diagnostic assessment. So rather than seeing self-diagnosis as the 'warm up' act to the official label, more attention needs to be paid to the alternative reasons people have for labelling themselves as autistic (see Chapter Five). The desire to self-diagnose autism (and other medical conditions) is an interesting and complex phenomenon, and researchers are only just scratching the surface of why people are doing it and what it means in the context of a medical diagnosis and professional expertise. Also, there has yet to be an investigation into the lay diagnosis of autism – that is, autistic people labelling other people as autistic. As I mentioned in the first half of the chapter, adding this to our research agendas would add a new dimension to the study of diagnosis and lay people's involvement in it.

- The next is the general observation that *there is a distinct lack of conceptual depth displayed in the current literature* (which is in part the result of a lack of *empirical depth* when it comes to data collection, see the next bullet point). For the most part, the findings surrounding the medical and self-diagnosis of autism are overwhelmingly descriptive in nature. Findings are usually presented as a series of major themes that lay out the positives and negatives associated with the label, with little or no attempt to analyse these ideas in any more detail. Speaking candidly, if you have read one of these studies you have read *most* of them, as they often describe the same reported experiences and analytical themes (e.g. the label brings with it negative emotions whilst also providing a framework for

understanding past experiences).[24] Indeed, as Hickey and colleagues (2018) conclude in one of the more recent publications:

> "This study confirms, in a new sample [people over fifty], *what individuals with autism have previously spoken about in [other] qualitative research*, and therefore suggests that earlier research can be used to understand the experiences of people with autism in older age [the unique angle in this study] (p. 364; emphasis added).

Whilst such work has been important in mapping the general experience of an autism diagnosis and self-diagnosis, there now needs to be an explicit and more sustained attempt to conceptualise and explain what autistic people are telling researchers. This is where a sociological analysis will be of benefit. What exactly does a diagnostic label such as autism do to, and for, the people who have acquired it? How does the label work to change things for a person and those around them? And from a broader sociological perspective, what does seeking a label for cognitive and behavioural concerns say, as well as tell us, about our current state of social existence in this era of 'late modernity' (Giddens, 1990). More needs to be done, in other words, to take these kinds of data and abstract them up and out so that they speak to something larger than autism (see p. 272 for a detailed discussion on such matters).

- One way to achieve this is to *put greater emphasis on collecting richer and more detailed sources of data*. Whilst half of the studies in Figure 2.3 used semi-structured interviews to collect their data – with some using verbally administered questionnaires as part of the interview – much of the empirical material to come from other studies came from somewhat limited sources of information: surveys

[24] It was actually difficult to not repeat myself when writing the content for Figure 2.3, as the majority of the studies cited report variations of the same findings.

and comments made on the internet. Whilst these forms of data collection capture the thoughts and opinions of huge swathes of people, there is limited opportunity for researchers to really dig into what people are saying in order to find out what the label and their diagnosis means to them. More detailed qualitative interviewing would be a good way of addressing this issue and would capture far more information than a few lines of text in a survey. Better still, repeated data collection from the same people would allow for even greater depth and detail, giving researchers the opportunity to test ideas, pursue new lines of inquiry as their analysis progressed, and thus build more rigorous sociological theory. At present, I am not aware of any studies that have conducted repeated qualitative interviews with autistic people (I will talk more about this, and other methodological considerations, in Chapters Three and Eight).

Chapter conclusion

In this narrative review I have delved into the research heritage of this study. Conceptually speaking, this study sits within the sociology of diagnosis and spans three different types of diagnosis: medical, self-, and lay diagnoses. Empirically speaking, this study speaks to the social scientific research into the diagnosis and self-diagnosis of autism in adulthood. These two sources of work form the bedrock of my research, and I hope to expand on and contribute to both literatures in an analytically exciting way.

In bringing this review to an end, I want to reiterate the key points that this study aims to address. As both groups of scholars have pointed out, diagnoses can have a profound impact on a person's life. We know that diagnoses have the capacity to order

and organise things, but the question is *why* do they do this? How can we explain the impactful and lasting consequences of a medical or self-diagnosis? Here, we are missing a conceptual account of a diagnosis as a type of social label. What is it about a diagnosis as a label that makes it so important, so enduring? I believe there is room in the literature for this kind of thinking, and I will use my work around autism as my entry into this type of theoretical work. Similar remarks can be made about self-diagnosis, but the need for robust theorising is even greater as there is limited work in this area. What does it even mean to self-diagnose a physical and psychiatric ailment? How do people go about doing it and what are their reasons for doing so? These questions have been all but overlooked in the autism literature, and a sustained attempt at analysing this phenomenon would really advance this area of research. Finally, whilst others have yet to make the distinction between a self- and lay diagnosis, I think separating the two will make for an analytically exciting area of inquiry. Lay people do issue their own diagnoses of other people and learning how this is done will add a new feature to the sociology of diagnosis. The three concepts that I will present in my findings chapters (listed below) are my attempt at addressing these gaps:

- The label autistic, when aquired through any means, can be envisioned as a label that is both ‘sticky’ and ‘slippery’ (Chapter Four)
- There are different reasons for labelling oneself autistic, and these can be conceptualised as four different ways of self-identification (Chapter Five)
- A lay diagnosis of autism involves autistic people ‘passively spotting’ and ‘actively seeking’ the condition in others (Chapter Six)

Chapter Three: Methodology

In this chapter I will delve into the methodological detail of this study: what I did and why I did it. This will include information about my study design, the advisory group that I recruited, various sampling strategies employed, data collection and analysis techniques used, and some of the ethical issues raised in this work. A large part of this discussion surrounds my study design, situational analysis. As situational analysis is one of the lesser-known qualitative approaches, I have devoted more space to introducing the method and spelling out exactly how I used it in this study.

Study design

Before explaining why I took a particular approach in this study it is worth reflecting on what I see as my key foundational assumptions: the ideas and beliefs I have about this particular topic of inquiry and the most appropriate means of researching it. As I mentioned at the end of Chapter One (see 'notes on terminology,' p. 29), I took what could be described as an agnostic view of autism. I do not know what it 'truly' means to be autistic. I cannot point to an image of a person's brain or an observable set of behaviours and say that *that* is autism. Autism is, at least from my perspective and that of other researchers (Timimi & McCabe, 2016), a medical construct – a reified and highly influential construct – that has morphed and changed since its inception to mean different things to different people at different times. Because of that, I am not in the business of categorically determining whether somebody 'really' is autistic, in part because I do not necessarily see that as a productive research endeavour (what it means to be autistic is ultimately open to interpretation). But what I am interested in is why people think that they are autistic, how they go about acquiring the label, and what are the consequences of doing so.

This starting assumption informed my approach to this study. Essentially, my inquiry revolved around the thoughts and beliefs of other people. I wanted to understand what it was that participants understood about the positions they found themselves in – namely, their thoughts on acquiring the label autistic. On a practical level, this meant adopting a method of data collection that allowed for people to reflect on their experiences and talk about them in sufficient detail so as to allow me, the researcher, to get a sense of how they have interpreted the events in their life. But by asking somebody to describe their thinking to me, I am not, in the words of Holstein and Gubrium (2016), initiating an uninhibited flow of information from a passive vessel of knowledge (the study participant) to an eagerly awaiting receptacle (me). As Pool (1957, p. 192) points out, "the milieu in which communication takes place modifies not only what a person dares to say, but even what he [sic] thinks he chooses to say." In other words, the type of inquiry that I had in mind was interactional, a site of, and occasion for, producing reportable knowledge about the world (Gubrium & Holstein, 1997).

This left me with a research topic that is open to interpretation, and a source of information about that topic which is itself the product of an interpretive encounter. What about my analysis of those data? As others have pointed out (see Denzin, 2016), *it too is an interpretive act*, an interactional process between the researcher – the ideas, beliefs, and experiences they inevitably bring to a study – and the data co-created with research participants. It is another layer of meaning making: *my* interpretation of *participants'* interpretation of a *construct* that is itself frequently re-interpreted. Therefore, my analysis of such data should not be seen as an objective statement about the world. It is instead a characterisation or expression of a world that

is multiple, processual, and constructed. “An *interpretive* portrayal of a studied world, not an exact picture of it” (Charmaz, 2014, p. 17; emphasis in original). These basic or foundational assumptions about my subject matter naturally pushed me towards qualitative inquiry, particularly the type that emerged towards the end of the twentieth century following the ‘constructivist’ or ‘interpretivist’ turns in social science (Morse, 2009).[25]

With that in mind, when it came to designing this study (with the support of my supervisors and the plans they had put together as part of the original Wellcome Trust bid) there were two overarching considerations that needed to be addressed in whatever methodological approach I chose. The first was that *I wanted the analytical products of this research to be theoretical in nature*. As noted at the end of Chapter Two (p. 72, much of the existing research into the medical and self-diagnosis of autism in adulthood is heavy on description and light on interpretation. I wanted this study to go into far more conceptual depth than had been done in previous studies. The second consideration was something my supervisors and I noticed when discussing the phenomena of diagnosis and self-identification more broadly: how somebody acquires the label autistic is a complex process that draws on different types of knowledge, experiences, and encounters with other people. What it means to be autistic and how professionals, individuals, and the public go about identifying and labelling the condition is an incredibly messy and elaborate fusion of ideas, actions, and perspectives, and an individual must navigate all of these (and more) when acquiring

[25] These turns refer to the theoretical and methodological dissatisfactions some researchers had with twentieth century positivism, especially in some of the earlier forms of grounded theory and cultural studies. The approaches that followed, mostly informed by postmodern and narrative critiques of modernist objective epistemologies, emphasised researchers’ perspective and positionality in the research process, and the interpretive and constructed nature of their subject matter (see Denzin, 2007).

the label for themselves. *I was therefore looking for a methodological approach that could help me manage the complexity of the topic* whilst at the same time offering the tools to help realise my theoretical ambitions. I decided upon situational analysis.

Introducing situational analysis

Situational analysis (SA) is a method of qualitative analysis that has evolved from the grounded theory (GT) tradition. It was developed by Adele Clarke – a former student of Anselm Strauss, one of the original developers of GT – who outlined the use and purpose of the method in the 2005 book *Situational Analysis: Grounded theory after the Postmodern Turn.*[26] Considered to be part of the second generation of GT methods, which includes Kathy Charmaz's (2014) popular constructivist GT, SA has been positively received amongst the GT community (see Mathar, 2008; Whisker, 2018), and is widely used amongst a variety of social science and humanities disciplines.[27]

At its heart, SA is about situating social phenomena within what symbolic interactionists call 'the big picture' (Park, 1952). Historically, qualitative inquiry has tended to focus on the small things, on micro-level interactions, at the expense of the wider social scene within which they take place (Denzin & Lincoln, 2018). For example, qualitative researchers have concentrated their analyses on the actions of individual people and particular social processes (such as in GT; e.g. Charmaz, 1991); on inner selves and personhood (such as autoethnographic research; e.g. Frank, 2013); on

[26] A second edition of the book was published in 2018, with Carrie Friese and Rachel Washburn joining as co-authors.

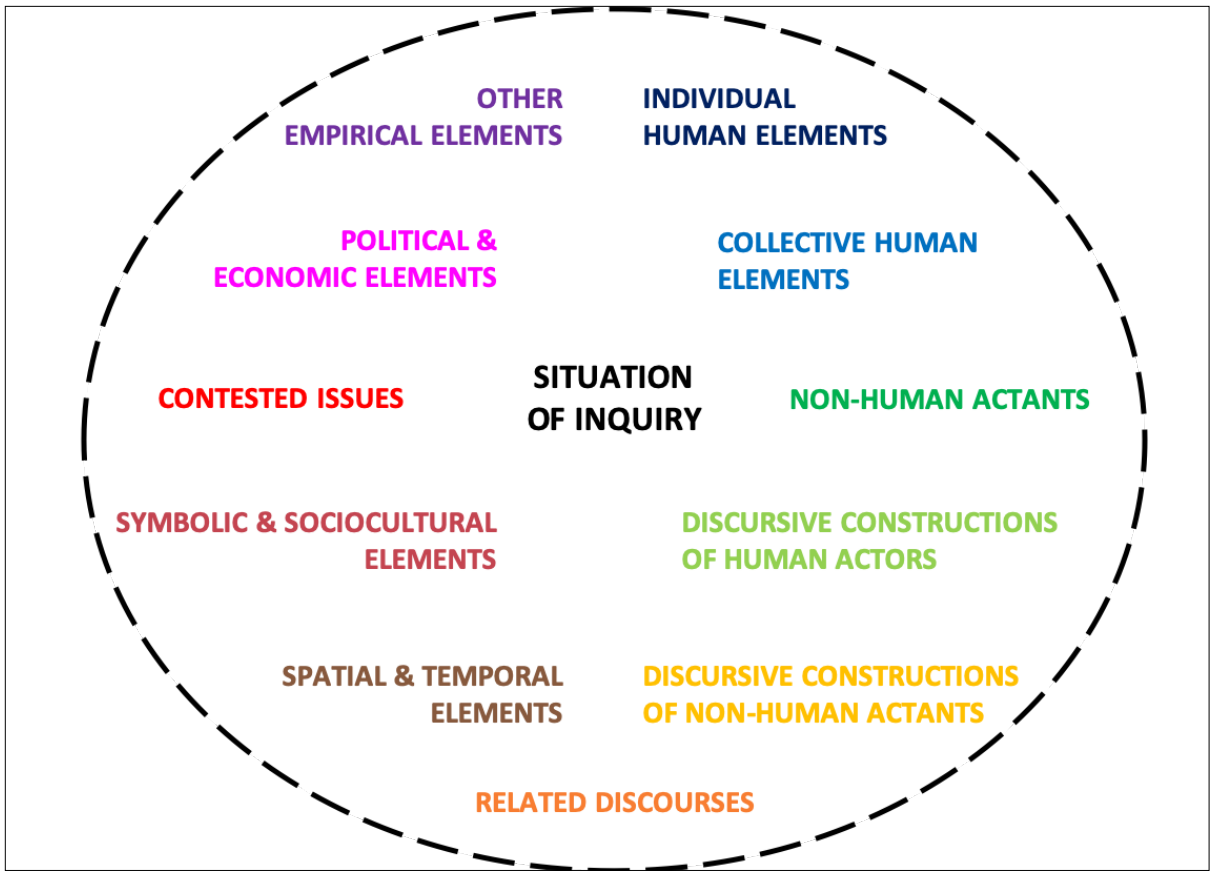
[27] See https://study.sagepub.com/clarke2e/student-resources/exemplars-of-situational-analysis-projects for a list of published studies that have used the method.

specific groups of people, their affiliations and social cultures (such as in ethnography and anthropology; e.g. Willis, 1981); or on individual accounts, experiences, and ideas they speak of (such as in narrative and discourse analysis; e.g. Riessman, 1990).

In an attempt to move away from this tendency, the emphasis of SA is to broaden the researcher's field of vision to include these micro-level elements as well as larger structural and material concerns. One way that SA tries to do this is by replacing the action-centred 'basic social process' that is the focus of GT research (see Glaser & Strauss, 1967) with the more inclusive concept of 'the situation.' Instead of focusing one's analysis on one or two particular elements that make up social phenomena (e.g. the things that people say or do), SA is about analysing, if not at least considering, *all the pertinent issues and facets that surround the thing that one is studying and locating it within the broader situation*. Similar methodological calls have been made elsewhere. For example, the pragmatist philosopher John Dewey (1938), and the sociologists Erving Goffman (1964) and C. Wright Mills (1940) have all written about the importance of social situations and how they warrant sociological analysis in their own right. SA is an attempt at doing this.

But what does it mean to talk about the situation in SA? It can be a tricky concept to pin down, and one that is best illustrated visually. The figure below demonstrates the kind of big picture elements that qualitative researchers should consider when collecting and analysing their data using SA (model adapted from Clarke et al., 2018, p. 45).

Figure 3.1: Common elements found in the situation



In SA, the situation is a sensitising concept (Blumer, 1969). It is a suggestion of where to look, "a general sense of reference and guidance in approaching empirical instances" (Ibid., p. 147). Here, the situation is meant to represent *the contextual whole in which a person, object, or event is situated* (depicted in Figure 8.1 as the 'situation of inquiry'). It can include other people (both individual persons and collective organisations), non-human and material objects (e.g. technologies and infrastructure), as well as various ideas, concepts, discourses, debates, and other cultural, political, and economic 'stuff.' As the situation is intended to be a sensitising concept, it should not be seen as a single event, encounter, or moment in time. It is instead an imaginative entity used for the purpose of qualitative analysis. Depicted in Figure 8.1 using a dashed line rather than a concrete circle, the situation of inquiry is an emergent

and loosely bounded entity that is to be empirically grasped over the course of a project, and not something that is constructed or hypothesised *a priori* (Clarke et al., 2018).[28] In this study the situation is understood to be the growing interest, both clinically and within wider society, in identifying autism in adulthood. It is the current trend, for want of a better word, in which people in the UK (i.e. doctors, journalists, members of the public) are increasingly labelling certain behaviours and characteristics as 'autistic.'

In order to make sense of the situation, the primary analytical work in SA involves the creation and analysis of three different kinds of maps:

1. **Situational maps,** which lay out the major human, non-human, discursive, and other elements found in the situation of inquiry and are used to analyse the relations among them (see Clarke et al., 2018, Chapter Five).
2. **Social worlds and arenas maps,** which lay out the major collective groups (e.g. organisations, institutions, social worlds) and the arena(s) of commitment (Strauss, 1978) with which they are engaged in (Ibid., Chapter Six).
3. **Positional maps,** which lay out the major positions taken and not taken in the discussions and debates on the topic of analysis (Ibid., Chapter Seven).

All three maps are intended "as analytic exercises, fresh ways into empirical social science data that attend to its complexities, relationalities, and ecologies" (Ibid., p. xxv). The content of each map is made using qualitative data, which can come from

[28] An idea not too dissimilar to Pierre Bourdieu's (1975) 'field' or the analytical strategy of 'radical contextualisation' in cultural studies (Grossberg, 2006).

primary and/or secondary sources. The maps are created as soon as data collection begins and are revised and updated until the study ends. Drastically different from other methods of qualitative analysis, the making and re-making of these three maps is where most of the analytical work is done in SA.

Situational maps

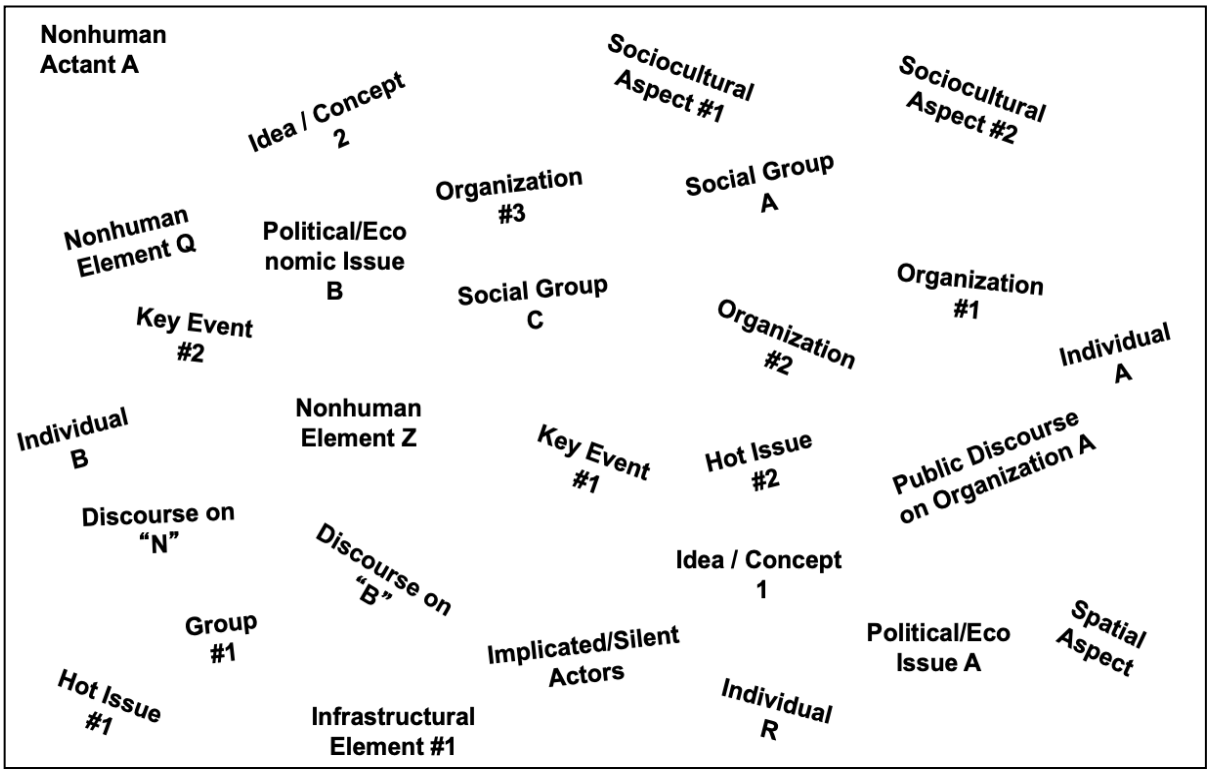
Situational maps are the first map created when doing SA. They are a visual representation of the situation of inquiry as framed by the analyst and their empirical data (the elements outlined in Figure 8.1 represent the kinds of things one should look out for). When making these maps the researcher asks themselves: "Who and what is in the situation? Who and what makes a difference here? And who and what really matters to the thing that I am studying?" (Ibid., p. 127). With reference to the data collected, everything that might be analytically important is put on the map. Not everything included will remain of interest as the study progresses – in fact, it is likely that only a fraction of it will make up the final analysis – but all potentially important elements should be specified at this point. As Clarke et al. (Ibid., p. 128) explain, "their ultimate analytical importance cannot be known for some time [but] having the elements on the map works as a reminder to return to them analytically as the project unfolds."

Figure 3.2 (overleaf) is a template of a situational map and the kinds of elements usually presented on it (Ibid., p.128). Figure 3.3 (p. 88) is a situational map created using my own interview data.[29] As you can see, the template version is unorganised

[29] I have included maps based on my empirical data for illustrative purposes only. I will not dwell on the content of these maps, but rather discuss their application and methodological uses.

(known as a 'messy map'), with various elements scattered randomly throughout the map. In my own version, I have organised my data around some of the headings outlined in the model above.

Figure 3.2: Situational map template (messy version)



There are no concrete instructions for producing situational maps, "what appears in your situational map is based on what is in your empirical situation of inquiry – your project" (Ibid., p. 130). What I have presented in Figure 8.3 (overleaf) is a zoomed-out version, a bird's eye view, of the empirical landscape that I entered – the 'general orders' (Strauss, 1993, p. 252) that my participants discussed in relation to acquiring the label autistic (the content of Figure 3.3 came from my interview transcripts, see pp. 115 for more details). There are the key human actors that participants were engaged with either on a sustained or passing basis (e.g. doctors and autism charities); the diverse political, symbolic and sociocultural conditions that framed their

understanding and views of the condition (e.g. stereotypical images); the hot topics that surrounded autism (e.g. the right to self-define as autistic); various discourses called upon to describe autistic people (e.g. autistic people as savants); changing spatial and temporal elements associated with autism (e.g. the rate of diagnosis in the UK); and important non-human items utilised by people seeking to obtain the label for themselves (e.g. the internet).

Figure 3.3: Situational map based on my interview data

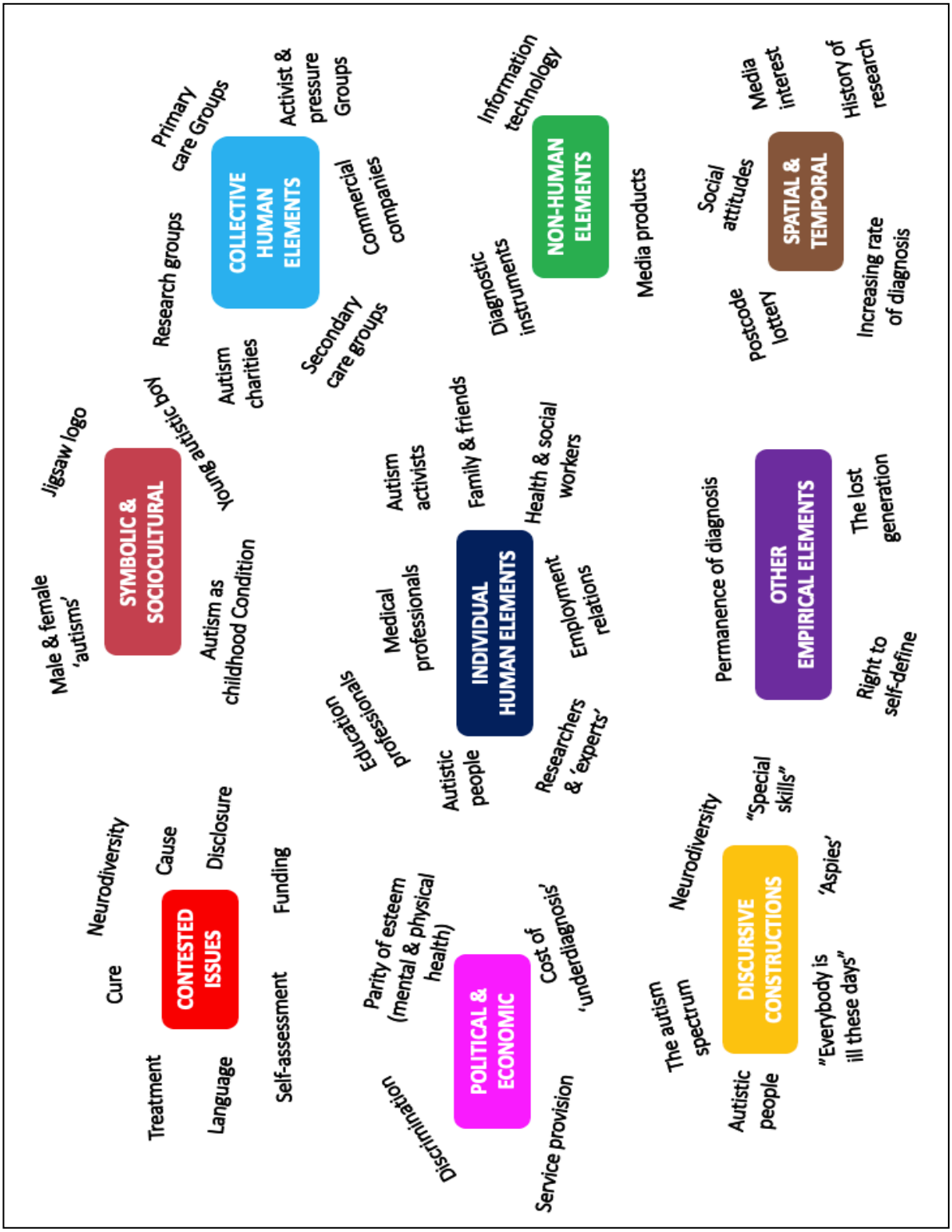


Figure 3.3 is one of fifty-plus situational maps created over the duration of this study (most of them created using pen and paper). I have created modified versions of this map where I have zoomed in on each of the labelled headings to outline in more detail

who and what participants talked about in the interviews (see Appendices 3 and 4 for some examples). I also created specific situational maps that focussed on data gathered from self-identifying participants and compared them with maps about the medically diagnosed group (see p. 112 for details about my study sample).

Situational maps are used for doing something called relational analysis (see Clarke et al., 2018, pp. 138–143). This involves identifying, describing, and explaining the relationships between various elements on the map. This starts by drawing a line between two units on the map and specifying the nature of that relationship in a research memo (see p. 129). The focus of these reflections "should not be on the elements per se, but rather on the relations between them" (Ibid., p. 138). How and why do they matter, if they matter at all? Does a change in one element provoke a change in the other? This is done systematically, one at a time, from every element on the map to every other element. Doing relational analyses is not particularly exotic, but it does "provide a systematic, coherent, and potentially provocative way to enter and memo the considerable complexities of a project laid out on a situational map" (Ibid., p. 140). This type of work draws deeply on the GT emphasis of being systematic about data analysis. In GT and other coding-based approaches, coding is done word by word, line by line, chunk by chunk. In SA, the analytical focus "is on relationality, mapping and examining relations among the elements one at a time, in a systematic way similar to GT coding" (Ibid., p. 140). Doing relational analyses helps the analyst decide what empirical stories – which relations – to pursue. Some relations may be considered irrelevant, but working through them one after another can spark creative thinking, which is the primary goal of SA (I will discuss how I used these techniques to arrive at my own findings shortly).

Situational maps are very messy (especially compared to the other two kinds of map) and this is intentionally so. Their very messiness makes them accessible to researchers and easy to manipulate. Qualitative research can involve an extensive amount of data processing, and situational maps act as excellent holding devices for data and ongoing lines of inquiry. It is important that these maps are made and re-made throughout the duration of a study. During the latter stages of a project, they can help to open up things and see data in a new light. Seeing data afresh can prevent analytical foreclosure, a particular hazard that GT research tries to forestall through 'constant comparison' (see Charmaz, 2014, p. 132). "It is far too easy to become analytically caught up in a few stories and lose sight of the big picture, which needs to be bought back into view regularly" (Clarke et al., 2018, p. 134). Creating situational maps also forces the analyst to think through their data systematically, particularly in relation to the wider situational elements outlined in Figure 8.1. Looking through a situational map can prompt ideas for further theoretical sampling (see p. 106). If certain elements are missing on a situational map, or some areas are particularly light on detail, they can be easily identified, and a strategy can be put in place to sample the relevant data. A situational map will not have everything on it, but it should at least err on the side of inclusion.

Despite their appearance of fixity, situational maps are not static, at least not in the way we think of street maps representing more or less fixed entities. Situational maps are snapshots, which are themselves situated in a particular time and place. There is considerable fluidity in situational maps, especially as the researcher revises,

expands, and collapses elements over time. Eventually, one must make some sort of analytical commitment (however provisional) and move on. And so:

> "Having a big piece of paper or an electronic document with most everything that you can identify in the situation of inquiry can be extraordinarily powerful and empowering of the analyst. It allows you to get a grip on your research, which, in turn allows analysis to proceed" (Clarke et al., 2018, p. 130).

Social worlds and arenas maps

Social worlds and arenas maps, the second type of map created in SA, draw on the symbolic interactionist concepts of social worlds and arenas (Becker, 1960; Shibutani, 1955; Strauss, 1959). Social worlds are collective groups of varying sizes that generate a life of their own (e.g. a recreational group, an occupation, a school of thought, or an academic discipline). "They generate shared perspectives that form the basis for both individual and collective identities and for commitment to collective action" (Clarke et al., 2018, p. 71). People typically participate in multiple social worlds, and their participation usually remains highly fluid.

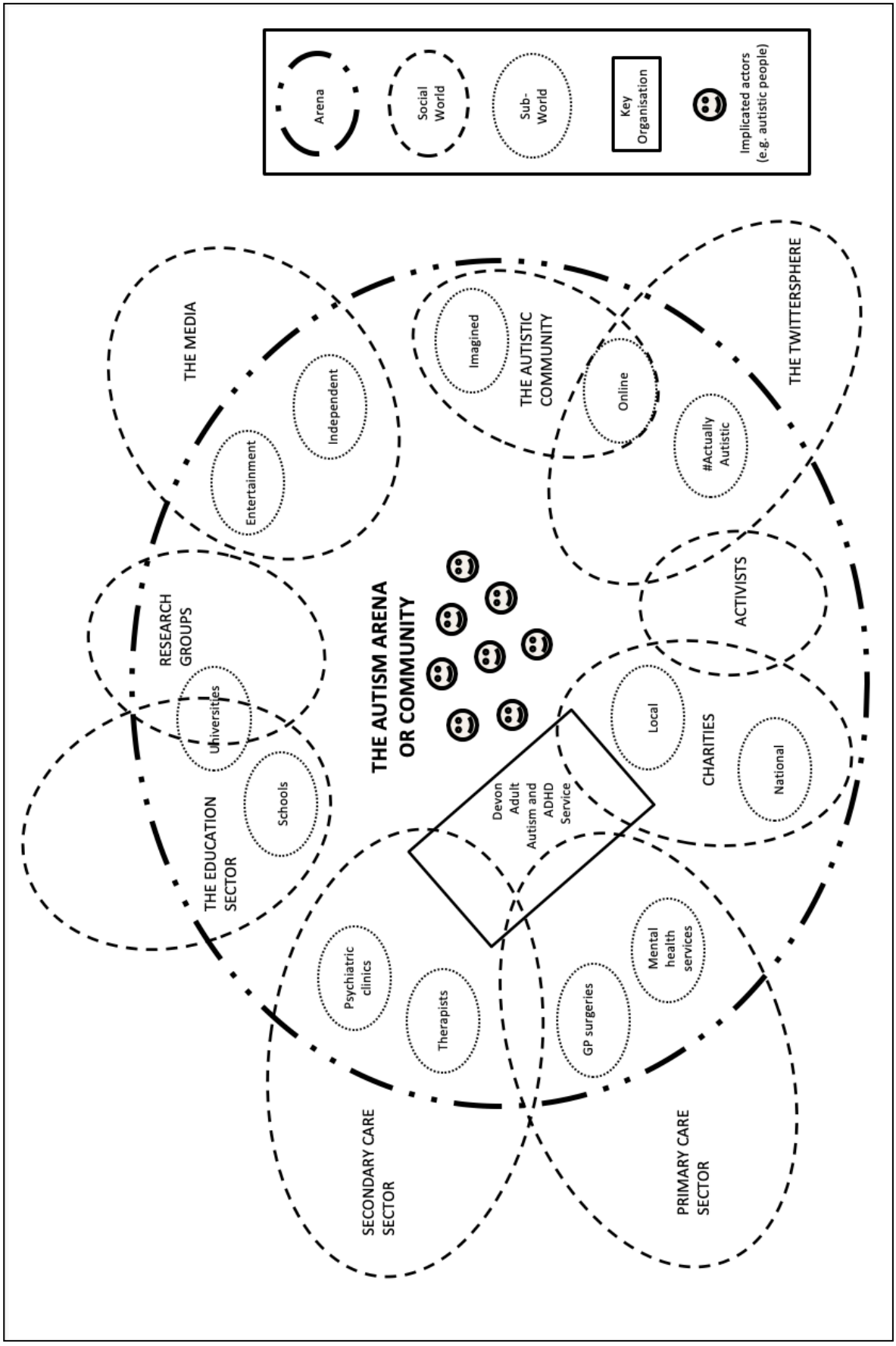
Social worlds are situated within a particular arena of concern (Strauss, 1978). An arena is a broader field within which multiple social worlds are committed to particular issues and prepared to act in some way (Clarke et al., 2018). In arenas, "various issues are debated, discussed, fought out, forced and manipulated by representatives" of the participating worlds (Strauss, 1978, p. 124). According to symbolic interactionists, social worlds and arenas are the principle affiliations through which people organise social life. Society as a whole, then, can be conceptualised as consisting of layered "mosaics of social worlds" in arenas of shared concerns (Wirth, 1928, p. 15).

In SA, social worlds and arenas maps are a distinctive interactionist approach to analysing the collective structure of the situation of inquiry. As Colapietro (2011, p. 32) argues:

> "Situations must themselves be situated in a field, or more accurately a multiplicity of fields, so that a critical understanding of the power, limits, and mutability of these situations become (at least) an imminent possibility and (at best) a transformative power."

Social worlds and arenas maps are an attempt at getting a grip on the bigger picture, something that is rarely done in qualitative analysis. Overleaf is an example of this kind of map using my own data.

Figure 3.4: Social worlds and arenas map



When creating a social worlds and arenas map the aim is to make collective sense of the data gathered – what participants told me about *their* social worlds. As illustrated in Figure 8.4, the dotted lines indicate the porous nature of the boundaries of social worlds and the arenas they are located in. The arena identified in my data was the autism community. As reported by many of my participants, the *autism* community is different from the *autistic* community, with the latter "only encompassing those who are actually autistic, whereas the autism community encompasses professionals, family members and so on."[30] Those other groups are depicted here as social worlds. Some social worlds are larger than others. Some are exclusively inside the autism community (e.g. autism charities), whereas others straddle additional arenas (e.g. the primary and secondary care sectors, which could also be seen as part of the 'mental health' and broader 'healthcare' arenas). Some social worlds overlap and engage with key organisations that have similar interests (e.g. The Devon Adult Autism and ADHD service). Within social worlds there exist specific sub-worlds, such as the online and imagined autistic communities (i.e. those in the minds of participants: *"us autistic people"* and *"people like me"*). The size, position, and extent to which social worlds overlap is something that the analyst has to work out with reference to the data collected. At the centre of these maps are the implicated actors – in this case, my participants – who come into contact with these worlds. This is the picture they find themselves in, the 'conditions of possibility' (Foucault, 1988) within which they can self-identify and/or be medically diagnosed as autistic.

[30] This quote came from a participant called G-mdx. I will introduce my study sample on p. 112.

Like situational maps, social worlds and arenas maps are only ever a snapshot of a particular moment in time. Whilst based on empirical investigation, the social worlds depicted in them are always prone to change. That said, their purpose in SA is to make the broader picture clear and legible to those who do not know about it, and to provoke further analytical thinking. As I found for myself, these maps became the conceptual infrastructure for the study at large, undergirding the analytical stories told in Chapters Four through Six.

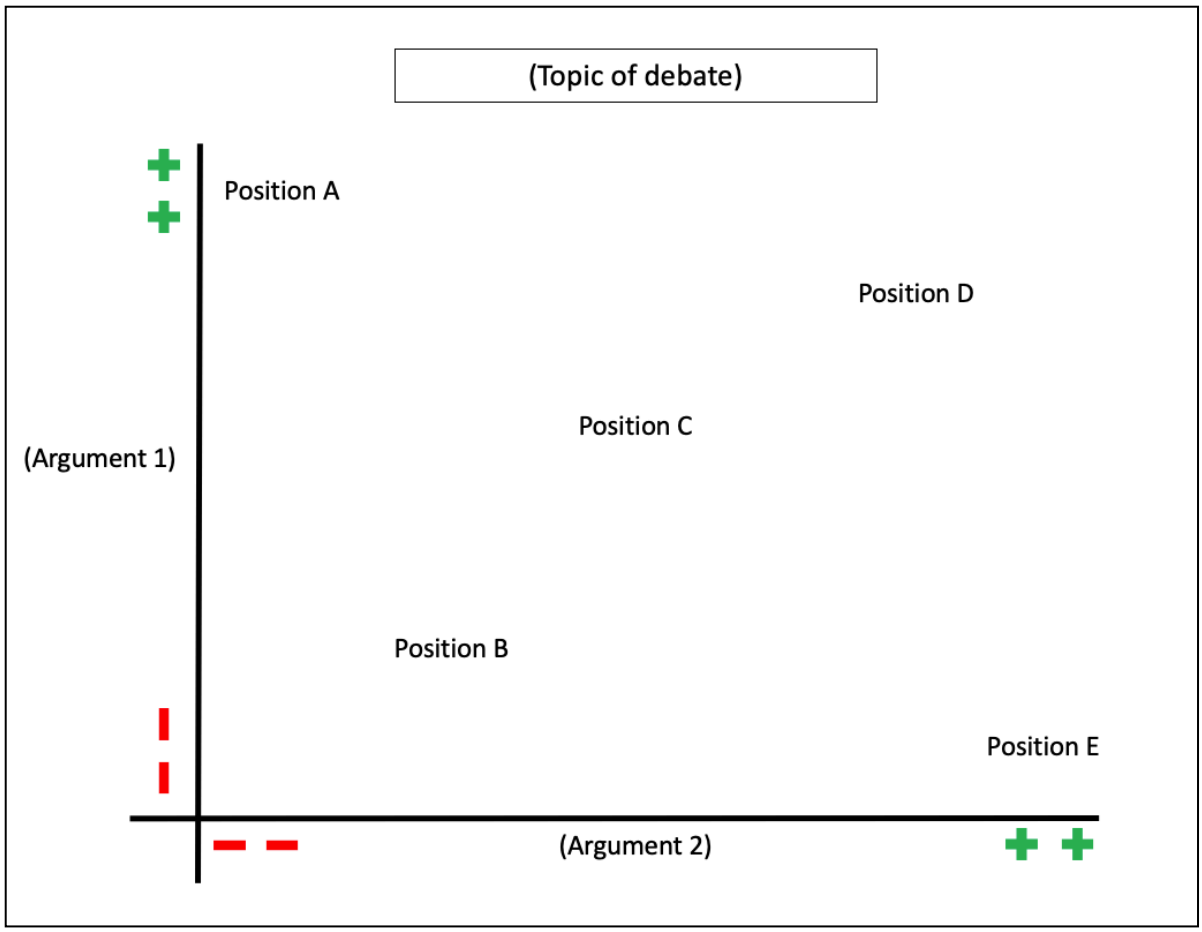
Once I started collecting data and producing these maps, it was important to stay engaged with them, to keep improving them, so that they better represented my interpretation of what participants had told me. Like the situational maps, I created dozens of social worlds and arenas maps over the duration of the study – the aim being to make them as good and as accurate as possible, and not to zoom in or zoom out on the data (the purpose being to depict the big picture). Whilst the macro emphasis of these maps may be better suited to a study whose focus is more institutional (e.g. the diagnostic practices of a hospital; Bone, 2002) they nevertheless sensitised me to the broader picture in which participants found themselves in when acquiring the label for themselves.

Positional maps

Positional maps are the third and final type of map created in SA. They are the analytical tools applied to the ideas (i.e. positions) found in the data. Positional maps are used to do a very different kind of analytical work from that of situational or social worlds maps. The core goal of positional maps is to “lay out the major positions taken [and not taken] on issues in the situation – topics of focus, concern, and often but not

always contestation" (Clarke et al., 2018, p. 165). For interview data, this would involve laying out the major views expressed by participants on topics where there are differing and competing opinions. Whilst Clarke and colleagues describe them as maps, it is perhaps best to think of them as grids, as the template in Figure 8.5 illustrates:

Figure 3.5: Positional map template



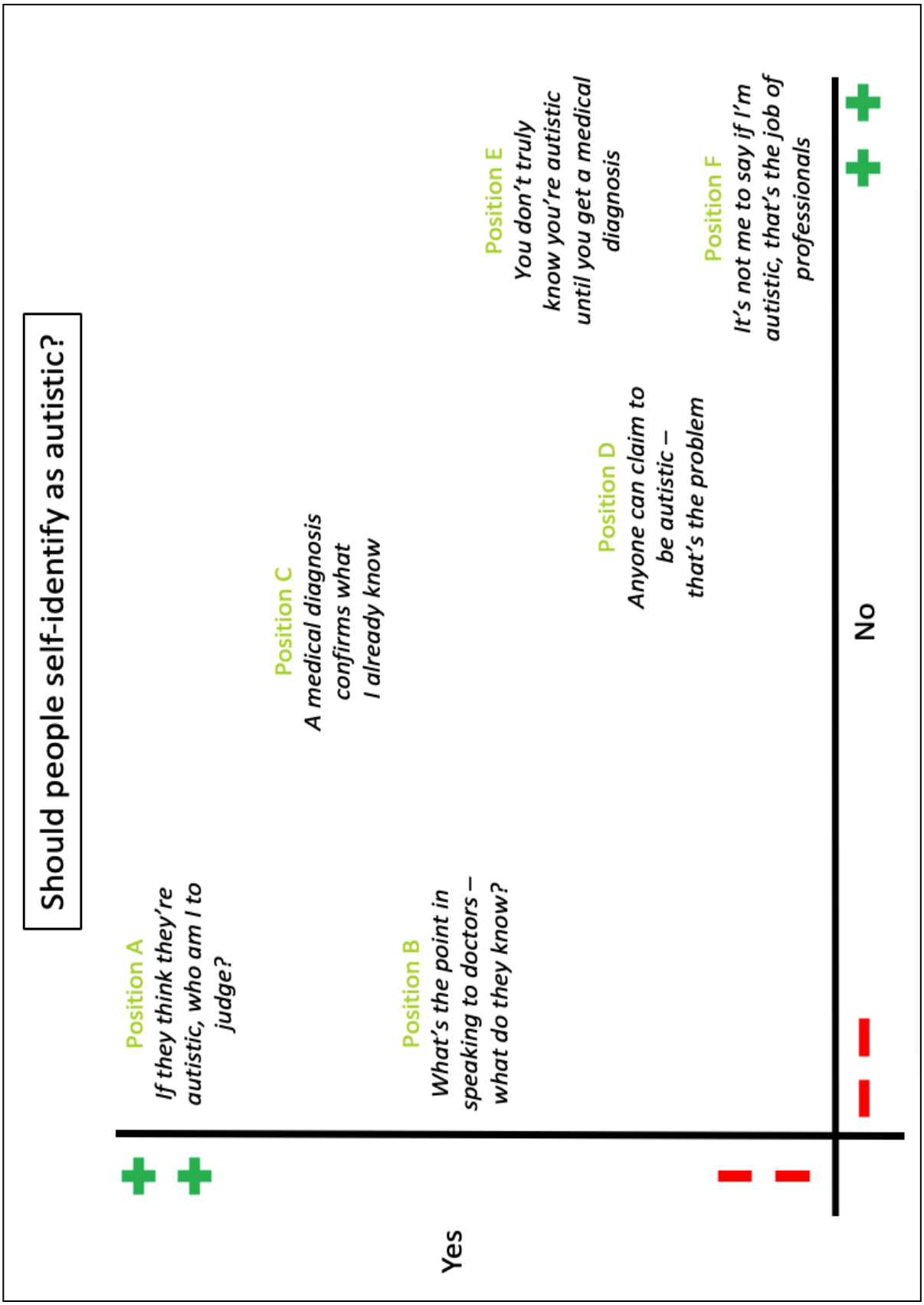
To create a positional map, you first need to identify the key issues being discussed in the data. What are the big things people are talking about? What are the sites of controversy? Looking at the contested issues identified in the situational maps (see Figure 8.3) is usually a good place to start. Each debate forms the content of a positional map (topic of debate), so there will be different versions looking at a variety

of contested issues. Next, you need to establish the major lines of argument as found in the data. These are normally opposing opinions held by participants (e.g. “global warming is an existential threat to humanity” vs. “global warming is a hoax”), which are usually easy to identify after a period of data familiarisation (see p. 125). These opposing arguments form the axes of a positional map (arguments 1 and 2). Then you need to populate the map, or grid, with the various positions taken by participants in relation to these arguments, which are laid out in terms of more or less agreement along the two axes. Some positions in the data will be extremely supportive of one argument (e.g. global warming *is* a hoax) and would sit along the supportive end of the corresponding axis (e.g. position A or E). Other positions will be more nuanced, embracing aspects of both arguments (e.g. position C). The task of the researcher is to work out where such positions would sit in relation to both axes. Overleaf is an example of a positional map based on my own data. It highlights some of the positions participants’ took on the question of self-identifying as autistic (a hotly debated topic within the autistic community).

For the purpose of this discussion, I have framed the positional map in Figure 8.6 as a question (should people self-identify as autistic?) with a simple yes/no answer on the axes. You could, as I have done in other versions of this map, present a statement with corresponding arguments. As with the other two SA maps, finding the best way to represent your data is all part of the analytical process. In Figure 8.6, there are some positions that are very much supportive of self-identification (e.g. “If they think they’re autistic, who am I to judge?”), some that are not (e.g. “It’s not for me to say if I’m autistic, that’s the job of professionals”), and others that are somewhere in the middle (e.g. “A medical diagnosis confirms what I already know). The purpose here is to

represent as best as one can a range of positions taken on various topics of discussion in the data.

Figure 3.6: Positions taken on self-identifying as autistic



The data on a positional map should be direct or paraphrased quotes from participants (or other sources of data) for clarity and simplicity. In terms of the number of positions plotted, the aim is to illustrate the major points of view taken in the data, not every single refinement of a particular argument. Some maps can have as little as two or three positions on them (e.g. Alonso-Yanez & Davidsen, 2014), whereas others can have up to eight or nine (e.g. Washburn, 2013). Deciding how many positions to put on the map is an empirical and analytical question. How many positions are found in the data? Is it analytically meaningful to include all of them? Playing around with the map, sliding positions up and down the axes, adding and removing points of view is all part of the analytical exercise (alongside regular and detailed memoing). Like the other maps, you should anticipate "doing multiple versions of each positional map, showing multiple ways of representing a particular issue and positions taken on it" (Clarke et al., 2018, p.168).

You will notice that the positions in Figure 8.6 are not referenced alongside the participants who made such statements. This is for good reason. Individuals and social groups can often take competing and sometimes contradictory positions on certain topics. For example, the views taken in positions A and E were expressed by the same participant in the space of twenty minutes during our first interview (as were many of the other positions noted). The positions laid out on the map are therefore disassociated from the people holding them to accommodate the heterogeneity and complexity of views taken. It is not about illustrating who said what, but rather outlining what positions and perspectives are available to people.

One of the most interesting aspects of doing positional maps is that they encourage you to see the positions *not* taken in the data – the things that are not said or not yet articulated. They "allow the silences to 'speak' […] helping the researcher to notice such things" (Ibid., p. 172). As you can see in Figure 8.6, there were certain positions that I was unable to identify in my data. This may be because such points of view were untenable (disagreeing with both self-identification and professional diagnoses) or, in the case of more controversial research topics (e.g. birth control and abortion; Clarke & Montini, 1993), people simply do not talk about those things, or least not to a sociologist.

Finding missing positions on a map should trigger several research strategies. The first is that these absences should be carefully noted in a research memo. Perhaps it is possible to speculate as to the potential cause of these missing positions. What is the elephant in the room and why is nobody talking about it? The second is that these missing positions should prompt theoretical sampling – further data collection specifically focused on learning more about that issue. This was a good reason for conducting repeat interviews. If I identified missing positions on my positional maps, I was able to return to participants to ask them about it (if it was relevant to my ongoing analysis).

Once no new issues or hot topics are identified in the data it is possible to say that the maps are good enough – that they are 'analytically sufficient' (Dey, 2007).[31] Once created, they are particularly useful tools for constructing a narrative about your

[31] The same could be said about situational and social worlds and arenas maps.

analysis. In fact, whole publications have been based on the exploration of a single positional map (e.g. Nutter-pridgen, 2015). I have also used these maps to refine my thinking around the concepts developed in this study, for example plotting data relating to sticky-slippy labels (positioning data along the 'sticky' and 'slippery' axes). Representing ideas in this way can help rupture normal ways of thinking and help us to see things afresh (Suchman, 2007). These maps are also excellent representational devices for showing others the complexities of qualitative material (see p. 128 for a description of how I implemented each of them in my analysis).

Study advisory group

It has become increasingly common in health service and social science research to involve members of the public (i.e. non-academics) in the design, implementation, and dissemination of research. Members of the public can enhance the quality of research by offering a perspective that can make it more appropriate, relevant, and accessible to study participants and the wider public (INVOLVE, 2012). There are many ways that members of the public can get involved in research, from acting as co-applicants on research grants and undertaking empirical work (see Gillard et al., 2012; Walker & Pandya-Wood, 2015), to supporting researchers and offering advice as part of a formal steering committee. In this study, I recruited autistic members of the public to take part in an advisory group that would comment and make recommendations on various aspects of the research process. The group was recruited because my supervisors and I felt that the study would benefit from some input from the autistic community, particularly as we ourselves do not identify as autistic. Inviting autistic people to join the group was a good way to hear what they had to say about the study, providing them with a space to contribute to the research as well as critique it.

The advisory group was made up of six autistic adults (three men and three women) aged between eighteen and fifty-five. Four of the six members had obtained a medical diagnosis in adulthood (eighteen years and over), whilst two of the members self-identified as autistic. All members lived in Devon, and four of the six were either in full-time or part-time employment. They were a highly educated group of people, with all but one having a degree.

The advisory group was recruited from the University of Exeter via the University's weekly news bulletin, which is sent to all staff with an '@exeter.ac.uk' email address. In the bulletin, under the header 'Research News,' I placed a small advert inviting autistic people to contact me if they were interested in joining a study advisory group (see Appendix 5 for a screenshot of the advert). The criteria for participation was that members must either have a medical diagnosis of autism (obtained in adulthood) or self-identify as autistic. The response to the advert was surprisingly high, with eighteen people putting themselves forward within one week of the advert being placed. Most of the respondents were not members of the University, but people who had been sent the advert by a member of staff who had encouraged them to apply.

I contacted the first three men and three women who responded to the advert and arranged to meet with them to discuss the purpose of the study and the role of the advisory group, which was detailed in an information sheet (see Appendix 6). After a face-to-face meeting, one of the six declined to take part, citing a lack of availability. A further member was recruited from the remaining email respondents. Those who were not recruited were thanked for their interest and asked whether they would be willing

to take part in the study as a research participant at a later date. Of the six members recruited, three had no affiliation with the University, two were full-time employees (one was an academic and the other worked in professional services), and the other worked at a university-affiliated company on campus.

Over the course of the study, the advisory group were invited to contribute to the following research tasks:

- *The design and content of the study information sheet and consent form*. The group assisted me in developing study materials that were accessible, appropriate, and sensitive to the needs of potential research participants. They made suggestions on what to include in these documents based on what they, as members of the target population, would want to see if they were reading the information for themselves. They also helped me phrase important information in an autism-friendly way.
- *The design and piloting of the interview topic guide*. The group played an important role in the development of the interview topic guide. Thinking about what I wanted to learn from participants, we discussed potential themes to bring up at interview, what language to use, how to phrase particular questions, and what to do if participants struggled to engage in conversation, and how a secondary, more structured guide, might be used as a back-up in those situations. I also conducted two of four pilot interviews with two members of the advisory group (see p. 115).
- *The research ethics application*. When I applied for ethical approval (which came from the University of Exeter Medical School Research Ethics Committee, see Appendix 7), there was a matter raised by the committee that directly related to the

advisory group and the participants I sought to interview: should they be considered a vulnerable group of people? I wished to challenge the Committee's presumption that adults with an autism diagnosis were vulnerable precisely because they had a medical diagnosis – a point that illustrated the transformative power of the diagnostic label (either given to somebody by a doctor or self-assigned). The advisory group were invited to share their thoughts on the matter over two separate meetings at the University (the meetings were audio recorded with the group's consent), where we discussed how I would navigate this concern and pre-empt any ethical challenges raised by the Committee. Listening to what the group had to say directly informed my position on the matter and challenged my own preconceptions about how people with autism and other mental health diagnoses were viewed by researchers and ethics committees (see my written response to the Committee in Appendix 8).

- *Discussing research findings*. Drawing on the group's experience of autism, I shared a selection of anonymised interview transcripts with them (with the consent of participants) and asked them to comment on notable ideas and features within the data. I also shared my ongoing analysis with the group and encouraged members to pull apart and critique my lines of thinking. This was part of a wider shared analysis strategy (see p. 130).

These matters were discussed during four group workshops hosted at the University, several one-on-one meetings with specific members of the group, and a series of email exchanges throughout the duration of the study. The advisory group were also invited to comment on the written findings presented in Chapters Four, Five, and Six.

Study sample and recruitment

The participants in this study were recruited using a combination of snowball and theoretical sampling. Snowball sampling is a type of purposive recruitment where the aim is to sample cases or participants in a strategic way so that those identified are relevant to the research question being asked (Bryman, 2008). In qualitative inquiry, this involves identifying particular individuals or groups (also known as 'sources') who meet the study's inclusion criteria and using their social networks to recruit similar participants in a multi-stage process (Sadler et al., 2010). For example, in an interview study, once the initial source (participant 1) has been interviewed, they are then asked to nominate another person like them (participant 2) to be interviewed by the researcher (the likeness may be based on demographic features, group affiliation, or other important credentials determined by the research question). Once that individual has been interviewed, they too are invited to suggest another person (participant 3) who might be interested in taking part in the study, and so it continues, starting a process analogous to a snowball rolling down a hill. As more and more participants are interviewed, the referral process between one member of the target population and another allows the sample, or snowball, to gradually expand (Spreen, 1992).

Theoretical sampling is another form of purposive recruitment that is used to collect data that are specifically relevant to the researcher's ongoing analysis (Morse, 2007). Say a researcher has conducted six of their planned twelve interviews and has begun to analyse the data, they may begin to develop an analytical hunch or have a tentative theoretical idea that they are working on. In order to refine this idea, the researcher may recruit specific participants who have had particular experiences which may help to shed light on aspects of the researcher's thinking. (Charmaz, 2014). The process

of recruitment is therefore controlled by the analyst's emerging ideas, with an emphasis on "finding new data sources (persons or things, not theories) that can best explicitly address specific, theoretically interesting facets of the emergent analysis" (Clarke et al., 2018, p. 5). Theoretical sampling is first and foremost concerned with the refinement of ideas, which is an ongoing process rather than a distinct single stage that can be achieved with a pre-defined sample (Butler, Copnell, & Hall, 2018).

It is common for qualitative researchers to use both types of sampling in tandem with one another, each offering unique benefits when compared to random or probability sampling (Coyne, 1997). Snowball sampling is particularly useful when attempting to recruit hard to reach populations, such as those involved in criminal activities or members of elite social groups (Faugier & Sargeant, 1997). In my own area of research, it was recognised that seeking an autism diagnosis or self-identifying as such may be a relatively private matter, with many people preferring not to disclose this to those outside their immediate friends and family (Huws & Jones, 2008). Therefore, in order to reach these individuals, one must go through a network of people who are able to identify and refer members of the target population to the researcher (Biernacki & Waldorf, 1981). In relation to those who self-identify as autistic, because they do not have a medical diagnosis their names are not listed on any patient records or service-user groups. Consequently, a source of recruitment is not readily available and must be generated through alternative means. In addition to this, there is a certain amount of mistrust amongst the autistic community about scientific research being conducted by non-autistic people (see Pellicano, Dinsmore, & Charman, 2014). This may be particularly true for those who reject medical diagnoses because of what they see as the pathologization of individual difference. One of the benefits of a snowballing strategy is the potential trust that it engenders

amongst research participants (Faugier & Sargeant, 1997). A potential participant may be more likely to talk to a researcher and take part in a study if they have been referred to them by a trusted friend or acquaintance who has also taken part in the research.

With regards to using theoretical sampling there were two major benefits. As this study was primarily an exploratory investigation that aimed to develop a theoretical account of acquiring the label autistic, this strategy allowed me to purposefully recruit participants as and when they were needed as I moved through my analysis. Because I did not know what direction this work was going to take until after I had started collecting and analysing some of the early interviews, recruiting participants as the analysis unfolded allowed me to seek out those who were particularly relevant to the concepts being developed (I will provide an example of this shortly). Secondly, because there were few existing studies looking at the self-identification of autism in adulthood, and no studies that recruited such individuals to participate in qualitative interviews, there was no tried and tested sampling strategy to apply to my own work. Therefore, how I sampled participants and the recruitment criteria used needed to stay open and flexible in order to respond to what I learnt in the field.

Below are the general inclusion and exclusion criteria used in this study. I say general because as we will see shortly, the use of theoretical sampling meant that the criteria were changed and refined as the analysis progressed:

Inclusion criteria:

- Male or female aged 18 years and above
- Fit one of the following two groups:

1. Those who have received a medical diagnosis of any autism spectrum disorder in adulthood (i.e. 18 years and older)[32]
2. Those who have labelled themselves as autistic in adulthood and do not have a medical diagnosis

Exclusion criteria:

- Those who received a medical diagnosis of any autism spectrum disorder in childhood (i.e. under 18 years)
- Those who labelled themselves as autistic in childhood
- Those without the capacity to give informed consent[33]
- Those who do not have a firm grasp of English

Having discussed the matter at length with my supervisors and advisory group, it was agreed that around forty interviews would be enough to reach what Dey (1999) described as 'theoretical sufficiency.' Rather than employing the common measure of 'theoretical saturation,' a metaphor that implies that a certain completeness in one's conceptual understanding has been reached, we felt that it was more appropriate to determine my sample size according to something like conceptual density or conceptual depth (Nelson, 2017, p.556; emphasis added):

> "To reach conceptual density is not to reach a final limit, beyond which it is impossible to achieve new insights, but it is to reach a *sufficient depth* of understanding that can allow the researcher to build a theory."

[32] Participants' medical diagnosis and age at which they obtained it was self-reported.
[33] If I suspected that an individual's capacity to consent was impaired, I planned to ask them to complete a modified Standard Participant Question Response Survey developed by the National Autism Project, which would help me determine whether participants understood what was expected of them and the possible risks of taking part in the study. This measure was not needed.

Forty interviews were therefore deemed a sufficient number from which to base my analysis off. As I planned to conduct repeat interviews with participants (see below), a total of twenty-one participants were recruited; eleven with a medical diagnosis and ten without.

Recruitment started with snowball sampling. I initiated multiple snowballs at two autism charities in the South West of England, an autism support group in Devon, the University of Exeter, and on Twitter. For the autism charities and support group, this involved me contacting the relevant personnel and asking them if I could place a study information sheet on their notice boards (see Appendix 9). I also visited each venue to introduce myself and answer any questions people had about the study. When it came to recruiting participants at the University and on Twitter, I posted a digital advert on various mailing lists and shared it using my personal Twitter account. Following the interview itself, participants were asked to refer me to somebody like them who might be interested in taking part in the study. When participants made a referral, my contact details and an information sheet were passed to the nominated person, who was free to contact me in their own time. The snowballs continued to grow from these initial sources, incorporating those who were not part of the venues from which the recruitment was initiated.

Once I started analysing some of the data collected and got a better idea of the direction of travel, I started to recruit participants that related specifically to the theoretical concepts being developed. A good example of this relates to the data which informed the development of the four different ways of self-identifying as autistic, which I discuss in Chapter Five. Without going into too much detail at this stage, as I was

analysing the accounts of participants who self-identified as autistic, it became clear that the original inclusion criteria outlined above excluded other analytically interesting scenarios. What about those who do not label themselves as autistic per se, who perhaps believe that they are autistic but feel that they are not in a position to claim the label for themselves? I thought that it would be interesting to talk to people like that to see how that impacts my findings. As is the case with theoretical sampling, the criteria were changed so that I could recruit those sorts of people. Further into my analysis, I started to consider how somebody might avoid embracing the label autistic altogether, instead claiming that they had autistic traits (see p. 188). Again, I needed to collect data that would help me develop the idea further, so I expanded the criteria to include those who thought they had autistic traits. There have been three iterations of my recruitment criteria that have enabled me to theoretically sample participants who were relevant to this part of my analysis. They were:

1. Those who have labelled themselves as autistic in adulthood and do not have a medical diagnosis [the original criterion]
2. Those who have come to believe, in adulthood, that they are autistic but do not have a medical diagnosis [i.e. those who have *not* categorically labelled themselves as autistic]
3. Those who have come to believe, in adulthood, that they have autistic traits but do not have a medical diagnosis

Knowing that I wanted to interview particular kinds of people (in this case, people who identified as having autistic traits), I would then ask my snowball sources to point me

in the direction of people who met my new theoretical sampling needs. Using the two methods of recruitment in conjunction with one another worked very well.

Study participants

I recruited twenty-one adults to take part in this study. Eleven of the twenty-one participants had received a medical diagnosis of an autism spectrum disorder in adulthood (i.e. eighteen years and over), whilst the remaining ten self-identified as autistic. Fifteen of the twenty-one participants came from the South West of England. Four came from elsewhere in the UK, and two were recruited from overseas. The majority of participants were in their thirties. The youngest was in their early-twenties and the eldest was in their seventies. The gender split was eight males to thirteen females. For those with a medical diagnosis the split was five males and six females. For those who self-identified as autistic the divide was more uneven, with three males recruited compared to seven females.[34] Figure 3.1 (overleaf) provides an overview of my sample.

[34] Note that it was surprisingly easy to recruit females who self-identified as autistic and surprisingly difficult to find males who had done the same. I will consider the potential reasons for this on p. 243

Figure 3.7: Sample overview

Participant Identifier	Age	Gender	Diagnostic status*	Yrs. since diagnosis	Mos. between interviews
A	60s	Male	MDX	7	8
B	30s	Female	SID	4	9
C	50s	Female	MDX	3	20
D	50s	Female	SID	20	11
E	30s	Male	MDX	2	9
F	30s	Male	SID	19	8
G	20s	Female	MDX	10	13
H	50s	Female	SID	5	6
I	30s	Male	MDX	5	13
J	50s	Female	SID	4	8
K	50s	Female	MDX	2	11
L**	30s	Male	SID	3	8
M	30s	Male	MDX	5	10
N	40s	Female	SID	4	8
O	30s	Female	MDX	5	13
P**	30s	Male	SID & MDX	4	18
Q	30s	Female	MDX	2	11
R**	30s	Female	SID	11	10
S	20s	Male	MDX	10	16
T	70s	Female	SID	20	14
U	20s	Female	MDX	4	12

*MDX = Medical diagnosis; SID = Self-Identify
**Participants resided in the same household

A brief word on Figure 3.1. As is noted with the double asterisks in column one, participants L, P, and R all lived with each other. L and R were in a relationship and P was their housemate. My use of a snowballing strategy meant that my sample was built around social acquaintances. I first recruited participant R, who then suggested that I interview her boyfriend (L) and housemate (P), both of whom recently started to self-identify as autistic. I will talk more about this and why I decided to interview all three housemates in Chapter Six. You will also notice that the diagnostic status of participant P is both self-identified (SID) and medically diagnosed (MDX). This is because in the eighteen months between our first and second interviews (see data collection below), participant P had gone from self-identifying as autistic to having a formal medical diagnosis. Although P had made this transition, I continued to classify him as one of the ten self-identified participants, as this was his diagnostic status when I recruited him. Although I knew that he was awaiting an autism assessment, I did not anticipate him obtaining a medical diagnosis during the course of the study.

In regard to column five, yrs. since diagnosis, I have included this number to give a sense of when participants acquired the label autistic. For those with a medical diagnosis, this was a straightforward calculation from when they had their diagnosis confirmed by their doctor. For those who self-identified as autistic, things were a little more complicated. As I will show in Chapter Five, for some participants there was no definitive start date to self-identifying as autistic. They may have identified as having autistic traits without embracing the label wholeheartedly, or they may have identified with the label on an on/off basis for many years (identifying as autistic at the time of interview). The point is that self-identifying as autistic is an emergent process that does not just happen in a single moment. There is a lot of to-ing and fro-ing as people get

a better sense of themselves and what it means to be autistic. Nevertheless, I asked those participants to report approximately the number of years that they had self-identified for, but these figures are purely for comparative purposes and should be treated with some caution. Also, as I will demonstrate in Chapter Five, some of the medically diagnosed participants had also self-identified prior to obtaining their official diagnosis, but this is not reflected in the figure.

Data collection: Repeat qualitative interviews

I collected the data in this study using repeat loosely structured qualitative interviews (Kvale & Brinkmann, 2008). The decision to interview people was simple, as "it seems to make intuitive sense that if you want to find out about something you should go and ask some people about their experience of it" (Seal, 2004, p. 253). In this instance, I wanted to find out how people acquired the label autistic in adulthood, and the impact the label had on their lives. The type of interviewing that I conducted was described by Jones (1985) as depth interviewing. Depth interviewing is not a particular research technique, it is instead an emphasis, an underlying focus that drives the researcher's line of inquiry. Here, richness and detail are the aims of the interview, not breadth and concision as is the case in structured interviews.

One way of achieving this is by taking a loosely structured approach to interviewing, that is, a conversation with a purpose (Kahn & Cannell, 1957). I wanted to encourage participants to talk openly and freely about their lives, which would be difficult to do if I had a long list of questions to ask. I instead used a topic guide to steer the conversations, which was developed and piloted with the help of the advisory group

(see Appendix 10). The content of the first interviews revolved primarily around the following themes:

1. When did participants become *aware* that they might be autistic?
2. What *action* did they take?
3. What *impact* did the label have on their life?
4. How did they *use* the label in day-to-day encounters?

As I progressed through the first round of interviews, some additional themes were added which reflected my developing ideas and interests. These included specific things that participants had talked about, such as the representation of autism in the media, and thoughts relating to my ongoing analysis, such as the idea that participants could see autism in other people. The themes in the topic guide were used as prompts in what was intended to be a fairly natural two-way conversation (Charmaz, 2014).

I conducted four pilot interviews to test the suitability of the topic guide. Two of them were what I called ‘annotated rehearsals’ where participants (two members of my advisory group) and I would discuss the content of the guide and the likely sequence of the interview, each with a guide to hand to make notes and changes. The second two interviews were ‘normal runs’ of the guide, where I interviewed two participants selected from the declined respondents who applied to join the advisory group in a normal fashion, with them responding to the questions that I asked. Minor changes were made to the guide following piloting.

Questions were initially raised (by one of my supervisors and the Ethics Committee) about the suitability of using a loosely structured topic guide with autistic people, the concern being that autistic participants might find it difficult to converse in a way that would achieve the desired depth of qualitative interviews (see Benford & Standen, 2011). This potential issue was also noted in the autism literature reviewed in Chapter Two:

> "Given the array of social communication differences experienced by individuals with autism, there are inherent challenges to using a research methodology that relies on interviews, especially the semi-structured, open-ended and conversational approach[es]" (Hickey et al., 2018, p. 365).

I strongly believe that this is an outdated stereotype that researchers have about autistic people, particularly those with relatively low support needs. As I hope to demonstrate in the data excerpts used in the forthcoming chapters, autistic people can and do hold very detailed and nuanced conversations with interviewers, providing the questioning is done well. My advisory group and pilot interview participants (four autistic adults) did not see my use of qualitative interviewing as an issue, and overall, the use of a loosely structured topic guide proved to be no hinderance to my research participants.

Prior to taking part in the first interview, participants were asked to read a participant information sheet. This offered an overview of the study, what would be expected of them, and outlined some of the potential risks of taking part. If participants decided to go ahead with the study, they were asked to provide their written consent using a participant consent form (see Appendix 11). We then arranged a time and place to conduct the interview. Where possible, I tried to interview participants face-to-face and in a quiet setting. This was not always possible as some participants lived far away or

outside the United Kingdom. Fourteen of the twenty-one participants were interviewed in their homes, two were interviewed in an office at their place of work, and five were interviewed on Skype or using Facebook Messenger.

Online video calling proved to be an interesting way of interviewing participants. Because of the reduced visual cues that come with webcam conversations, it was more difficult to initiate the back-and-forth chatter that comes with face-to-face interviews, particularly because it was difficult to see when to pick up on comments made by participants.[35] Instead, the video interviews felt more like a series of speeches where participants held the floor for lengthy periods of time before inviting me to probe or ask a different question. I do not believe this impacted the quality of the data collected, but it did demonstrate how the setting and medium of qualitative interviews can change the nature and flow of the conversation. At the time of interviewing, I was not aware of any data or ethical issues relating to the European Union's General Data Protection Regulations (GDPR).

Participants were interviewed alone, although there were occasions where there were family members in a nearby room, some of whom made passing or interrupting remarks. When this occurred, participants asked those people to leave the room until the interview was over. Having family members in earshot of the interview did not appear to hinder what participants had to say, particularly as I had some very candid conversations with participants about the very people who were in the house.

[35] Something many people are now acutely aware of because of the new working arrangements following the Covid-19 pandemic. All of my interviews were conducted prior to the UK going into 'lockdown.'

The interviews lasted between forty-one and one hundred and two minutes, depending on how much participants had to say and their other commitments that day. I used the topic guide to write down field notes during the interview. These notes often consisted of prompts, notes-to-self, and analytical themes to explore after the discussion. I also made more detailed notes immediately after each interview. These were often knee-jerk reactions dictated to my voice recorder or ideas written down on the topic guide.

With the permission of participants, all interviews were recorded using a digital voice recorder and transcribed verbatim by a freelance transcriber who worked at the University of Exeter (adhering to a strict confidentiality agreement). All identifiable information related to participants (e.g. names, dates, places) were anonymised. Participants were invited to review the anonymised transcripts and make suggestions for alterations. This included further anonymisation or requests to remove certain segments of text. There was only one request to remove a portion of an interview transcript, and the text that was removed did not relate to my research question.

After each interview, participants were asked if they would be willing to take part in a second interview. All agreed. There were four reasons for conducting repeat interviews.[36] First, it was inevitable that as I moved through the first round of interviews the content of the conversations became more diverse and wide-reaching. In the early interviews, I talked to participants about the four broad themes outlined above. As the interviews progressed, new and equally interesting themes were added to the discussion; themes that I never got to discuss with those already interviewed. In a

[36] Thanks to my upgrade examiners, Nicky Britton and Hannah Farrimond, for suggesting a repeat interview strategy for this study.

way, these early interviews felt like the ‘guinea pigs’ for the later, more detailed interviews. I therefore felt a sense of responsibility to go back to those early participants and have those rich and diverse conversations. In order to minimise the same issue when re-visiting participants, I tried, where possible, to reverse the order in which I interviewed people.

Second, not only were the contents of the interviews evolving, but so too was my thinking. As the study progressed, I became sensitised to the concerns of autistic people, rapidly learning more about autism, diagnosis, and self-identification. I was also refining my interviewing technique (knowing when to probe and when to stay quiet). Again, I felt encouraged to re-visit participants and continue the discussion in light of the things that I had learnt, which takes me on to the third reason. A second interview gave me the opportunity to test my analysis with the people who had informed it. I therefore set aside some time to talk to participants about my findings and the ideas that I wanted to write about, taking note of what they liked and what they had reservations about. This proved particularly useful, as I was able to draw on their lived experience to refine my thinking on certain aspects of my analysis. As noted by Barbour (2013), when given the chance research participants can prove rather adept and insightful around matters of theorising and analytical thinking. Barbour argues that we – social scientists – should share our analyses with participants and give them the time and space to contribute to our developing theories. Airing my analysis in this way felt like the ethically responsible thing to do, particularly as some strands of my thinking at the time were a little contentious and may have caused offense. In an effort to follow the slogan “nothing about us without us” (Charlton, 1998), this was seen as a democratising move that allowed participants to contribute to the ongoing analysis and

voice any concerns. Naturally, this was only possible after a sustained effort to analyse the first round of interviews, enabling me to return to participants with some analytical ideas to mind.

The fourth and final reason for conducting repeat interviews was a substantive one: it gave me the opportunity to capture some of the transitions between different ways of self-identifying as autistic (as discussed in Chapter Five). In fact, one participant actually received the result of his diagnostic assessment over the phone during our second interview. The result was negative, and in that moment his reasons for self-identifying as autistic transitioned drastically, as I will demonstrate later. Repeat interviewing also allowed me to learn more about the transition from self-identification to a formal diagnosis, as was the case for participant P, who acquired his medical diagnosis between the first and second interview. As Vincent (2013) points out, conducting repeat interviews allows researchers to glimpse the "multiple identities and shifting realities" that people experience, which was something participants were able to reflect on during my second visit.

A few thoughts on my use of repeated interviews. Not only did multiple visits to participants provide the opportunity to discuss new lines of inquiry, present and debate my ongoing analysis, as well as capture some of the labelling transitions that I was interested in, but repeated interviewing simply allowed me to go into far more empirical depth than I would have otherwise done had I only interviewed participants once. As is often the case when conducting qualitative interviews, we can always think of additional things to say, questions to ask, or strands of thinking to follow-up *after* a discussion has taken place. Going back to participants a second time, therefore, gave

me the chance to dig a little deeper and pick up on any ideas that came to mind following my first discussion with participants.

The second interviews also enabled me to observe what I later suspected was the 'softening' of views and opinions expressed by participants. What I mean by this is that in the first interviews it was not uncommon for participants to make some sort of definitive statement about a particular topic of discussion (for instance, holding the view that people should definitely *not* self-identify as autistic, but should instead seek medical opinion). On such occasions, participants would often explain their reasoning for holding such points of view, and this may be something that I reflected on and wrote about in some form or another. But what was interesting was that on my second visit, when asked about such opinions or prompted for further comment, participants who held such clear and decisive views appeared to soften, or perhaps moderate, their initial judgement. Instead of taking the view, for example, that an individual should *never* self-identify as autistic, participants would recognise, on reflection, some of the reasons why somebody might choose (or has no other choice but) to self-identify as autistic, and concede that their initial thoughts on the matter had changed since the first interview. Like my own thinking which had evolved throughout the duration of the study, so too did my participants' between the first and second interviews. It was as if the time between these two discussions had encouraged participants to reflect – and in some cases reconsider – some of the things they had previously said, the outcome of which, I felt, led to participants taking their more hardened beliefs and softening them somewhat.

This observation was neatly illustrated when plotting some of these shifting opinions on a positional map (see p. 95). Quite simply, if you imagine a blank positional map with the two axes labelled for a particular topic of discussion, some of the views expressed in the first round of interviews might be plotted towards the more extreme ends of the axes (something overwhelmingly supportive of, or opposed to, the idea being analysed). But in the second interviews, as participants began to soften their earlier points of view, it was possible to move some of these positions away from the outer edges of the map, instead plotting them more towards the middle. It certainly was not the case that all positions mapped from the first interviews found themselves coalescing around the centre of the map after the second interview, but it was noticeable that some of the more definitive views expressed by participants earlier in the study softened during our second discussion; becoming less categorical and absolute, and more nuanced and considerate of the opposing argument.

This was one of the unexpected benefits of using both a repeat interview strategy and the positional mapping techniques of SA. By conducting a second interview, I was able to record (or perhaps more accurately, invite), these softening opinions, which I would have never known about had I only conducted stand-alone qualitative interviews. Instead of merely capturing a snapshot of participants' thoughts, I was able to observe some of the transitions and passages that characterised not only my own thinking, but that of the people who took part in this study (a transition, no doubt, that would have continued to manifest had I interviewed participants a third or fourth time, or perhaps following a longer gap between my first and second visit). By analysing these accounts using positional maps, I was clearly able to observe, and demonstrate to others, how my participants' points of view changed from one interview to the next – something I

later saw as one of the unique strengths of positional mapping. Whilst I raise the softening of opinions here as a methodological and empirical reflection, I also see these ideas tying in with some of the conceptual products to be discussed in the coming chapters. Just as the experience of a diagnostic (or self-assigned) label changes and morphs (see Chapter Four), so too do the things that participants express to researchers in an interview scenario; their thoughts and ideas reforming and evolving from one discussion to the next. By choosing to conduct repeated interviews in this study, I got just a small glimpse of this process in action.

Finally, a brief word on the structure of the topic guides during the second interviews. Whilst the first-round guide was essentially a generic template used on all participants, albeit with a few additions later on, the second-round guides were much more personalised to each participant. There were three parts to the second guide: (1) things I wanted to clarify from the first interview, (2) topics that had emerged in subsequent interviews and, (3) a discussion about the three strands of my analysis (sticky-slippy label, ways of self-identifying, and spotting & seeking autism). The questions that I asked, and the emphasis placed on each part of the guide, varied between participants. For example, if they self-identified as autistic or had done so previously, we would talk more about the four ways of identifying as such, whereas if they had a lot to say about spotting autism in the first interview, I would ask them to elaborate on that in the second interview. This strategy was also used to ask participants about topics that they did not have much to say on in the first interview. As a result, I created twenty-one separate guides, each specifically tailored to each of the twenty-one participants (see Appendix 12 for some examples). This helped make the second interviews more targeted and purposeful (Vincent, 2013).

Data analysis

There were a variety of tasks that made up my analytical process. Some of them were specific techniques related to SA, others were common analytical tasks carried out by researchers using other qualitative methods. In this section I want to describe what I actually did with the data I collected, why I made the decisions that I did, and how they ultimately informed the analysis presented in earlier chapters.

Mulling over the data

With each interview there was an audio recording of the conversation, a verbatim transcript, and my own field notes taken during and after the discussion. Multiply that by forty-two and there was a lot of material to get to grips with. One of the ways I did this was by "mulling over the data informally" (Wood & Welch, 2010, p. 67) in order to familiarise myself with what participants said and how I reacted to it at the time. Braun and Clarke (2013) refer to this as a process of immersion, whereby the researcher starts to notice things of interest and generate preliminary impressions about the data. I would regularly listen to the audio recordings of the conversations and would read and re-read the transcripts until I became intimately familiar with them. Any ideas that came to mind would be noted on the transcript itself, and I would reflect on some of these in more detail in a dedicated research memo.

Lifting data from transcripts

Within the transcripts, any comments, sentences, or paragraphs that related to my research question, or anything that struck me as particularly relevant, were identified

and highlighted as such. I used different coloured highlights to differentiate between different ideas or topics, all of which were noted in a research journal. These segments of data were then transferred or 'lifted' to a separate document where they were organised under descriptive headings for ease of access. For example, early in the study I was interested in the way participants talked about autism as a concept and diagnostic construct. What did autism mean to them and how did they talk about it? I collated all instances relating to this under one heading and moved them to a separate computer or printed file. Over the course of the study I created dozens of these files, each focussing on a specific aspect of the data. The material in these files would later form the content of the three SA maps described above.

Some people would describe this as a form of qualitative coding, but I hesitate to use the term here. For one, the terms coding and codes have come to mean different things depending on your methodological approach (Denzin & Lincoln, 2018). It has become a tacit assumption in many qualitative methods that one must code one's data in order to analyse it, or that the act of coding is itself the analysis (an exception to this being an approach like narrative analysis). This is something that has been debated within the SA literature (see Whisker, 2018). Do you need to code your data before creating SA maps? According to Clarke et al. (2018, p. 132, emphasis in original), the short answer is no:

> "Let us say a few things about *what situational maps are not* […] They are *not* intended to be […] based on GT codes. In fact, analytic codes should not even be on these maps unless they are 'in vivo' codes used by participants in your situation."

Although Clarke et al. reiterate this point throughout their texts on the method, there is still a difference of opinion amongst those using SA in their research. Some do not

report having done any form of qualitative coding prior to producing their SA maps (at least not in the conventional sense). Instead, they describe how they selected interesting segments from their data and applied them to their maps (Message, 2016). Other researchers have referred to doing a type of codification where they extracted 'situational elements' from their data using a coding framework (Hart, 2018). If, like Saldana (2009), you take the view that extracting or organizing any information from raw data is a form of qualitative coding, then the process I have described above would be considered a type of coding (although not the same as the coding you would find in a thematic analysis or discursive psychological analysis, or the type you would do using a software package such as NVivo). The point I am trying to make is that there are many competing explanations as to what coding is and how one should go about doing it. As SA comes from the GT tradition, which has a long and distinguished history of qualitative coding (most of which has formed the basis of more recent analytical approaches), a more descriptive or basic form of coding would not constitute GT coding (e.g. line-by-line, focused, axial, theoretical coding etc., Charmaz, 2014). GT coding and SA mapping are considered "*two different kinds of analysis pursued separately*. They are to be done one at a time, not blended together" (Clarke et al., 2018, p. 109, emphasis in original). Acknowledging that this is an area of continuing debate, I do not wish to claim that I have done any form of qualitative coding. Like Potter and Wetherell (1987, p. 42), I would instead describe what I have done as a "selective reading" of my data, where I have identified and highlighted interesting segments of text based on my research question, my initial mulling over the data, the things that I have read and the conversations that I have had with my supervisors and peers.

Mapping the data using situational analysis

As soon as I started interviewing participants I was able to produce the three types of SA maps described above. They were mostly made using A3 pieces of paper and a selection of coloured pens. Each mapping session was always accompanied with a research memo. The early maps mostly took the form of 'brain dumps' (Zuber-Skerritt & Fletcher, 2007) where I included anything and everything that might be relevant to my subsequent thinking. Over time they became more refined and focussed as I got a better grip on the data collected and the SA techniques used.

The first map, situational maps, were created most frequently. I would create one for each participant interviewed, outlining *their* situation as described to me. This would be edited or remade following our second interview. I also created some big picture maps which included the most common features found amongst the study sample. These were the zoomed out, bird's eye view of the situation (as seen in Figure 3.3, p. 88). As the study progressed, I also created situational maps that compared the situations of the medically diagnosed and self-identified participants. These were all made using data lifted from the transcripts.

Social worlds and arenas maps (the second type of map), were made less often as they were primarily used to frame the overall picture of my research. After completing the majority of first-round interviews, I felt I was in a position to start plotting the collective groups and organisations that my participants either belonged to or engaged with (as referenced in the transcripts). Creating these maps involved constant edits and revisions – changing the size, spacing, and overlapping of the worlds – so that they best represented my interpretation of the data collected.

Positional maps, the final SA map, were often created when I came across a hot topic within the data or the existing literature. I would draw up the blueprints of a potential positional map – the topic of debate, the axes of the argument, and the possible positions taken – and would then look for instances of it throughout the transcripts. This may be something already noted in my initial mulling over and lifting of the data – in which case there was a file with the relevant segments of data already available – but if not, I would review all of the interviews at that point in search of positions held by participants that could populate a positional map.

Although the three SA maps form a key part of my analysis strategy (along with the other techniques used), you will see in my findings chapters that I decided not to report my findings using these maps. Like others using the approach (Gagnon, Jacob & Holmes, 2010), I chose to background my use of SA maps in order to focus on the substantive content of my findings. I will explain why I took this decision, and reflect more critically on my use of SA, later in the thesis (see p. 247).

Writing research memos

Research memos were informal analytical notes (written and/or recorded) where I attempted to converse with myself about the data and my ideas relating to them. Memo writing was first and foremost an exercise in conceptualisation (Charmaz, 2014). Rather than noting or describing particular things in the data (as I would when mulling over the transcripts), it was an opportunity to "formulate ideas, to play with them, to reconfigure them, to expand them, to explore them, and ultimately to distil them for publication and participation in conversation with others" (Lempert, 2007, p. 247). In

these memos (which were mostly written using pen and paper), I tried to think about how the things participants told me and the SA maps that I had created related to more theoretical and sociological concerns. It was a chance to take my data and abstract up and out, and some of the memos formed the conceptual bridge between the data and the concepts presented in my findings chapters. These memos also acted as analytic bookmarks when I was between research tasks.

Sharing data with others

During the first year of my PhD, I co-founded a qualitative analysis network (made up of graduate students and early career researchers) that would meet fortnightly to discuss members' qualitative data and ongoing analyses.[37] Over the course of the study, I presented anonymised interview recordings and transcripts to the group, as well as some of the SA maps and concepts that I was developing. The group gave me the space to air my analysis whilst offering a multitude of different readings of the data. Presenting my work to others helped me decide which strands of analysis to preserve, which ones to drop, and which to pursue further through additional theoretical sampling (Strauss, 1987). The group setting also kept my own ideas in check and acted as a form of quality control, as I was pushed to defend and evidence my abstractions from the data (Silverman, 2015). I also shared my findings with members of the advisory group, either in a face-to-face or email discussion.

[37] The group is called the Data Bee (Twitter handle: @DataBee2).

Refining ideas through repeat interviews

Part of the rationale for returning to participants for a second interview was to present, discuss, and test the various parts of my analysis. Known by some as member checking (Lincoln & Guba, 1985), sharing my analysis with participants presented another opportunity to add more data to the concepts being developed, as well as listen to feedback given by those who inspired the analysis. During my return visits, a portion of the interview was dedicated to reviewing the three strands of my analysis. This took the form of a two-way conversation where participants were able to critique the concepts I was pitching, and I could respond to their feedback by explaining my reasoning and how it related to the comments made in earlier interviews. Like sharing my data with my PhD peers, this was another chance to refine, enhance, and elaborate my analysis.

Clarifying through writing

Contrary to what many believe, we do not simply report our analysis when we write up our research articles, book chapters, and dissertations. It is not transferred from our brains to a blank Word document. It is through the very process of writing, of narrating our ideas to a future reader that the contours of our arguments start to take shape (Glaser, 2012). As Stern notes (2007, pp. 121–122), “researchers fail to realise how much analysis goes on in the writing; it’s only when you see it on paper that the final integrated theory is clear.” Transforming the ideas distilled in my research memos into a coherent and compelling narrative was the hardest part of the analytical journey (something I hope I achieved); an arduous and at times frustrating process that required lots of drafting, re-drafting, tinkering and clarification. Whilst I was able to

generate the content of my analysis using the aforementioned tasks and techniques, it was the process of telling the story that gave it its structure and form.

Ethical considerations

Like all research with human participants there are a number of ethical issues to reflect on. Some of these were anticipated at the outset of the study, whereas others came to light during the course of the project. The first of these relates to the emotional wellbeing of participants. Talking about health and illness and medical diagnoses can be an upsetting subject for people. Participants were made aware of the potentially distressing nature of the study in the information sheet and at the beginning of each interview. On the occasions when participants found the topic of conversation upsetting, I invited them to take a short break, reminded them that they were under no obligation to answer any of the questions asked, and changed the topic of discussion if deemed appropriate. That said, every participant answered every question that I asked them, no matter how upsetting the topic. As a researcher, there were also instances where I found the conversations troubling or distressing. I too found it difficult to talk about participants' woes and difficulties, especially as these were people that I had got to know fairly well over the course of the study. When this occurred, I felt that displaying some of these emotions (e.g. welling eyes, offering participants a comforting hand) furthered my rapport with participants and often led to more open and frank discussions.

The second consideration revolved around managing the expectations of participants, particularly those who self-identified as autistic. As my advisory group anticipated, there was the potential risk that participants who wanted a medical diagnosis, but did

not have one, would see their participation in this study as a vehicle for acquiring one. This turned out to be the case for two participants, who asked whether I would be able to help them obtain a diagnostic referral. My affiliation with a medical school, which is associated with a hospital that carries out these assessments, was seen by these participants as their way in. At times it felt that all I could do was empathise with their concerns and offer the somewhat empty comment of “talk to your doctor about it.” I got the impression that some participants saw me as an advocate for their claims for a medical diagnosis, and that I could use my relative power and authority as a researcher at a respected university to lobby clinicians for a diagnosis. From the outset I made it clear that this was a social scientific study into how people acquired the label, both self-assigned and given to somebody by a doctor, and that I was not in the position to offer participants a diagnostic assessment or make recommendations on how to obtain one. That said, it felt as though some of my sample were disappointed with the observer status that I took in this study, and perhaps hoped that I would take on more of an activist role.

Halfway through the study I joined an advisory committee for a local clinical commissioning group, in which I mostly shared what I had learnt in this project as an academic advisor. I had the opportunity to talk with clinicians, policy makers, and other stakeholders about some of the difficulties participants faced when it came to seeking an autism assessment or a second opinion following a negative result. I felt these discussions were constructive and the commissioning group took these issues seriously. I then explained to participants that I was able to use this forum to share their concerns and experiences of the diagnostic process, as well as some of the other relevant research findings. I felt that this enabled me to balance my responsibilities as

a social scientist investigating participants' lives without too much interference, with the desire to help them and promote their interests where appropriate. Personally, this seemed to ease some of the ethical concerns that I had about some participants wanting more from the study. Plus, joining the advisory committee provided an outlet for disseminating some of the more practical applications of this study (see p. 267 for more details).

Ethical approval for this study was granted by the University of Exeter Medical School on the 17th November 2017 (reference: Nov17/B/136). All matters relating to information governance was informed by the University of Exeter's data management policy.[38]

Notes on reporting data

Before moving on to the findings chapters I want to explain how I will be reporting the data. You will see that each extract, whether presented in the main text or in a separate paragraph, is followed by a bracket detailing: (1) participants' anonymous identifier (as listed in Figure 3.1), (2) the number of the interview, and (3) the line in the transcript from which the quote was taken. I will also put the diagnostic status of each participant alongside their anonymous ID so as to identify whether they have a medical diagnosis or self-identify as autistic, for example: (A-mdx, 1, 100), (B-sid, 2, 200).[39]

[38] See www.exeter.ac.uk/ig/

[39] Please note that participant P's diagnostic status will reflect his transition from self-identification to a medical diagnosis. His first interviews are reported as P-sid, whereas his second interviews are P-mdx.

I should also note that because I shared my analysis with participants there were often times when they used my words and concepts to relay their experiences back to me. For example, participants sometimes referred to their medical diagnosis as a ‘sticky’ or a ‘slippery’ label (see Chapter Four). These were phrases that I had introduced to them during our second interview, and participants would often use them when applying my ideas to the situations they found themselves in. There are therefore occasions where I cite participants using my own theoretical terms, and I will endeavour to highlight when this is the case.

Finally, as the content of the following chapters has a specific focus, you will find that some participants are quoted more often than others (for example, the self-identified group make up most of the data presented in Chapter Six). Where appropriate, though, I try to present data from as many participants as possible.

Let us now turn to the first findings chapter: autism as a ‘sticky-slippy’ label.

Chapter Four: Autism as a sticky-slippy label

In this chapter, the first of three findings chapters, I will introduce the concept of the 'sticky-slippy' label.[40] The concept, or rather image, that I aim to provoke, is the notion that autism can be envisaged as a label that is 'sticky' – something that is lasting, holding, gripping – and at the same time 'slippery' – fluid, morphing, and constantly changing. In the following pages I will describe exactly what I mean by this, and how the sticky-slippy image provides a useful conceptual basis from which to analyse the consequences of acquiring the label autistic.

Introducing the sticky-slippy image

Terms like autism and autistic are complex social labels that have a life of their own. What it means to be autistic, how somebody comes to possess such a label, and ultimately what it is like to live with, are questions that medical sociologists have been grappling with for decades (Cockerham, 2017). But as is sometimes the case in this area of inquiry, there are often a series of unquestioned assumptions about the nature of the entity being studied; specifically, the fixed and enduring nature of psychiatric categories (Pickersgill, 2014).

Michel Foucault (1978) made similar remarks about our historical and contemporary understanding of sexuality. He astutely observed that the way sexuality has been narrated, particularly in Western Europe, assumes a certain stability to the concept – what it is and its variations, mainly homo and hetero sexuality (see Butler, 1999). This narrative was understood by Foucault as merely a way of *talking* about sexuality, and it was a narrative, most importantly, that cast sexuality (and its associated labels and

[40] A special thank you to Professor Anthony Giddens for assisting me with earlier drafts of this chapter.

identities) as an unchanging and ever-present constant (Bell, 1993). Foucault wanted to argue something different. He asserted that these biological and social categories have been in a state of flux throughout history. They are not as fixed as we are led to believe – they evolve and shift (see Weeks, 2017).

It is this line of thinking, albeit applied to a specific psychiatric category, that has inspired my analysis of sticky-slippy labels. Like a person's sexual identity, it is assumed that autism is a fixed entity that is applied to an individual who meets the criteria for the condition, and once the label is applied it remains with them forever; a permanent fixture of their identity. But as I discovered from my conversations with participants, being told or deciding that you are autistic is not necessarily a final state of being. For some people, in certain moments, the label may symbolise a fixed and enduring status – *"I am autistic, and this is what it means"* – whereas in other moments the label can become much more fluid, adaptable, and in some cases, unstable. It is the duality of this reported experience – what I refer to as the label's sticky-slipperiness – that I want to explore in this chapter.

But what exactly does this term mean? Before delving into specific empirical examples, here is a general overview of the idea. We start by likening the label autistic to one of those sticky name tags you get at academic conferences and social events. Once somebody acquires the label, either from a doctor or by assigning it to themselves, we can imagine the word autistic (or words to that effect) being written in block capitals across the front of the name tag, which is then metaphorically stuck to the person's clothing for others to see. Whilst this does not literally happen, for the people that I interviewed, this is what it can feel like when acquiring the label. They

find themselves metaphorically stuck with the label autistic, which becomes difficult to remove or shake off socially, giving the label a sense of permanence and everlastingness. Although imagined, once the label is disclosed to other people (friends, colleagues, acquaintances), it has the capacity to lodge itself in their minds and stick with them so that it colours their opinion of the person before them. Once they have seen the autism tag, they cannot unsee it. This can be of consequence to the person with the label. There are many ideas and images associated with the condition – some positive, others less so – and these associations can, over time, find themselves sticking to the label to the point that they become synonymous with the condition itself. Because of this, we can imagine our sticky name tag as having double-sided adhesive, with one side sticking to the person who has acquired it, and the other having various ideas and affiliations applied to it – a series of smaller labels attached to a bigger one. This is what I have in mind when I say that autism is a sticky label.

However, leave a name tag on an item of clothing for too long and the adhesive starts to run out. The label can start to peel at the edges, becoming frayed, and eventually falling off. We can envisage an autism diagnosis or self-assigned label doing the same thing. For some people, having applied the label years if not decades ago, the importance and prominence of the category can lessen over time to the point that it too wears out and metaphorically 'slips off' them – its significance no longer recognised. Thinking to when the label is initially acquired, when the adhesive of the autism tag takes hold, its application can cause other previously assigned labels (other mental health diagnoses, preconceptions, and social stigmas) to 'slide off' a person – the new autism name tag 'explaining away' those other labels. The apparent slipperiness of the autism label also extends to the meaning of the word itself. Although

different ideas and images can find themselves figuratively sticking to the label, these associations can morph and change over time. Even the official definition of the psychiatric category has evolved since its inception, with different symptoms, categories, and ways of talking about the condition slipping in and out of usage. And so it is in a figurative sense that autism can be described as a sticky-slippy label. It exhibits *both* of these qualities, neither one nor the other.

The notion that diagnostic and social labels have the capacity to stick to people is an idea very much associated with symbolic interactionism and labelling theory (Becker, 1963). One only has to glance at the findings of the now infamous 'Rosenhan experiment' to see the sticking power that certain psychiatric labels have in particular institutional settings (Rosenhan, 1973).[41] As Rosenhan described, the stickiness of the diagnostic labels applied to the pseudo patients in his experiment meant that:

> "Having once been labelled schizophrenic, there is nothing the pseudo patient can do to overcome the tag. The tag profoundly colours others' perceptions of him [sic] and his behaviour" (1973, p. 253).

My use of the term follows on from this description, but it is also a little broader than that used in the classic labelling studies (e.g. Scheff, 1966). As well as the stickiness of a label in an institutional setting, there is also an 'imagined stickiness' felt by people in possession of certain kinds of labels. By employing the phrase here, I aim to offer a new take on a classic sociological concept, whilst supplementing it with a contrasting yet complementary idea: the capacity for labels to exhibit somewhat slippery qualities. Taken together, the image of the sticky-slippy label captures many of the essential

[41] I say infamous, because it has been reported that Rosenhan's experiment was almost entirely fabricated by the author himself (see Cahalan, 2019).

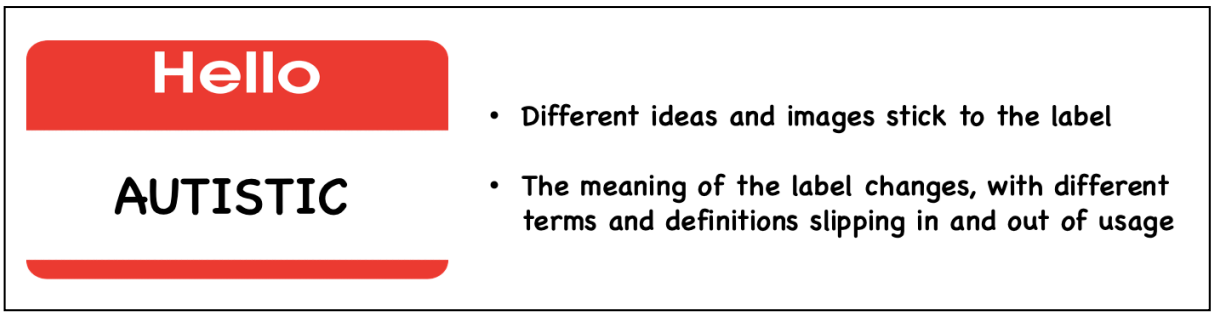
features found in my interview data, and provides a conceptual lens through which to view much of the descriptive findings reported in the existing autism literature.

The content of this chapter has been split into three parts. In the first part I will look at the label itself and explain how it can be imagined in sticky-slippy terms. Then I will consider what happens when an individual acquires the label and how this image captures some of its major implications. To end, I will discuss the label in relation to other people and the impact that it has on their perceptions of those in receipt of it. Each section will be accompanied with an illustrative figure which summarises the main thrust of the argument. The sticky-slippy image is woven throughout these discussions and expanded on using empirical examples from my interviews (for a reminder of my participants, see Figure 3.7, p. 113).

The label itself

Starting with the label itself, there are two notable features that make it sticky-slippy (as illustrated in Figure 4.1).

Figure 4.1: Autism as a sticky-slippy label



Let me take each of these points in turn.

Ideas and images stick to the label

As with other psychiatric diagnoses, such as bipolar disorder and schizophrenia, there are a whole host of ideas and images associated with the category autistic. Although some of these may be seen in a positive light – like the view that autistic people have exceptional cognitive capabilities (Russell et al., 2019) – the majority are felt to be less favourable – such as the view that autistic people cannot feel empathy (see Milton, 2012). As F-sid (1, 129) noted in our first interview, "there is a lot of stigma attached to an autism diagnosis," with phrases such as mad, lazy, or stupid often used to describe autistic people (see Davies, 2016). These associations, and others like them, can find themselves metaphorically sticking to the autism label. According to G-mdx (1, 314), these associations are part of a broader societal narrative about autism and the people who have acquired the label:

> "I find it so infuriating and insulting, because the prevailing narrative is very much…it's inherently [and] exclusively negative: 'autistics are a burden, they're a drain on society, they're a drain on your family […] they can't do this, they can't do that' […] all the focus is on difficulties with this, difficulties with that, and our strengths tend to be overlooked."

Many of the people that I spoke to felt that this narrative was often propagated through popular culture (Murray, 2010). For example, participants routinely pointed to Dustin Hoffman's portrayal of an autistic adult in the 1988 film *Rain Man* as a major source of the publics' perception of autism:

> "…[once] *Rain Man* got out there, everyone [starts to] think that *Rain Man* is what an autistic person looks like. We don't all walk, talk, and act like that" (N-sid, 2, 435).

> "…it's that *Rain Man* thing, so autism is *Rain Man*. So to most people I think autism is that communication difficulty" (K-mdx, 2, 188).

As noted by the historian, Martin Norden (1994), the portrayal of disabled people in film and television goes a long way in shaping the publics' beliefs around matters of

health and illness. Not only that, Norden argues that these representations also feed into how disabled people – or people with neurodevelopmental conditions, in this study – actually come to think about themselves:

> "The movie industry has perpetuated or initiated a number of stereotypes over the years […] stereotypes so durable and pervasive that they have become mainstream society's perception of disabled people and have *obscured if not outright supplanted disabled people's perception of themselves*" (1994, p. 3; emphasis added).

This was something that particularly concerned one of my participants. Although L-sid self-identified as autistic, he was reluctant to associate himself with what he saw as the 'extreme end' of the autism spectrum (i.e. those with high-support needs) that was often shown in the media:

> "When I first came across autism as a concept it was specifically presented in the media […] as an extreme thing, as an illness […] and they had a very extreme sufferer, a person who was actually having severe trouble being … coping, being helped, and that was how [autism] was presented, and I think that might have skewed how I thought about it initially" (1, 398).

Because of this particular portrayal of autism, a depiction that L-sid felt was all-encompassing of people with the condition, he was particularly keen to keep his distance from the label as "the stereotype that everybody knows about is the extreme, and I am *not* identifying as being the extreme" (1, 101). He did not, in other words, want to associate himself with what he saw as the negative images affiliated with the condition (I will talk more about this in relation to self-identification in Chapter Five).

Although the public's perception of autistic people has improved greatly over the years, particularly since the release of films such as *Rain Man*, there is still a tendency to view autism as a pathologized deficit-based condition (Runswick-Cole, 2014). Because of this, different prejudices and misconceptions can find themselves sticking

to the label to the point that these associations fuse with the label so as to become synonymous with the condition itself – becoming a permanent fixture on our imaginary autism name tag.

The meaning of the label changes

Wading through these sticky associations, peeling them off one after another, we may find ourselves asking the question: what does it actually mean to be autistic? Many of my participants asked the same question and found it difficult to arrive at a satisfactory answer. As N-sid (2, 379) noted, "there's probably lots of things that could be called autism because our understanding of [the condition] is in a constant state of flux." J-sid (2, 610) felt the same way, telling me that "[autism] is a very difficult concept to pin down […] because it is so changeable."

I would agree. What it means to be autistic and the criteria for diagnosing an individual as such is constantly adjusting and evolving. The label itself and the meaning we attach to it is never completely in a solid state: it is fluid, fluctuating, slippery.[42] As J-sid (2, 717) explained, our understanding of autism is:

> "Like a lens that society is using to try and understand differences between people, and the lens is changing all the time. It's like going to the optician's and […] getting a new prescription to try and focus in better and understand it more."

In clinical circles the term autism has had a contested past, and over the years the very definition of what it means to be autistic has been recast and reformulated (see Frith, 2003; Latif, 2016). Certain defining features or symptoms of the condition have

[42] Granted, the label takes on a solid form when codified in the latest diagnostics manuals, but it is only a representation of an idea at a particular point in time, which is always open to revision at a later date.

slipped in and out of usage as diagnostic guidelines have been updated. For example, autism was previously codified as a 'triad of impairments' relating to difficulties with social interaction, communication, and imagination (Baron-Cohen, Leslie, & Frith, 1985). But with the publication of the DSM-5 (APA, 2013) – the latest and most frequently used psychiatric classification system – this triad was reduced to a dyad, with impairments relating to communication subsumed under the rubric of social interaction (Wing, Gould, & Gillberg, 2011). Even entire conditions such as Asperger syndrome have fallen out of classification manuals, engulfed under the larger category of autism spectrum disorder (Parsloe & Babrow, 2016). Whilst Asperger's has officially slipped out of diagnostic manuals, it continues to stick in the minds of many people who still see it as a valid and conceptually different neurological state (Huynh, McCrimmon, & Strong, 2020). The condition even has some sticking power in the minds of doctors who, it is reported, continue to diagnose people with Asperger's even though it is no longer in the major diagnostic manuals (Fasulo, 2014).

The apparent slipperiness of the label also extends to the language people use to describe the condition. Person-first identifiers (i.e. a person with autism) was previously seen to be the preferred means of describing somebody with the condition. Over the last few years, however, that has slipped out of usage, with identity-first descriptors (i.e. an autistic person) now the preferred language (Callahan, 2018):

> "I guess currently I tend to say on […] the autism spectrum, because that seems to like rub along with people on both sides of the argument at the moment. You know how much language has changed about it, by this time next year that might not get me out of trouble either" (O-mdx, 1, 42).

It is perhaps unsurprising that the very meaning of the word autism is in a constant state of flux given the reflexive nature of medical expertise (Giddens, 1991). At its

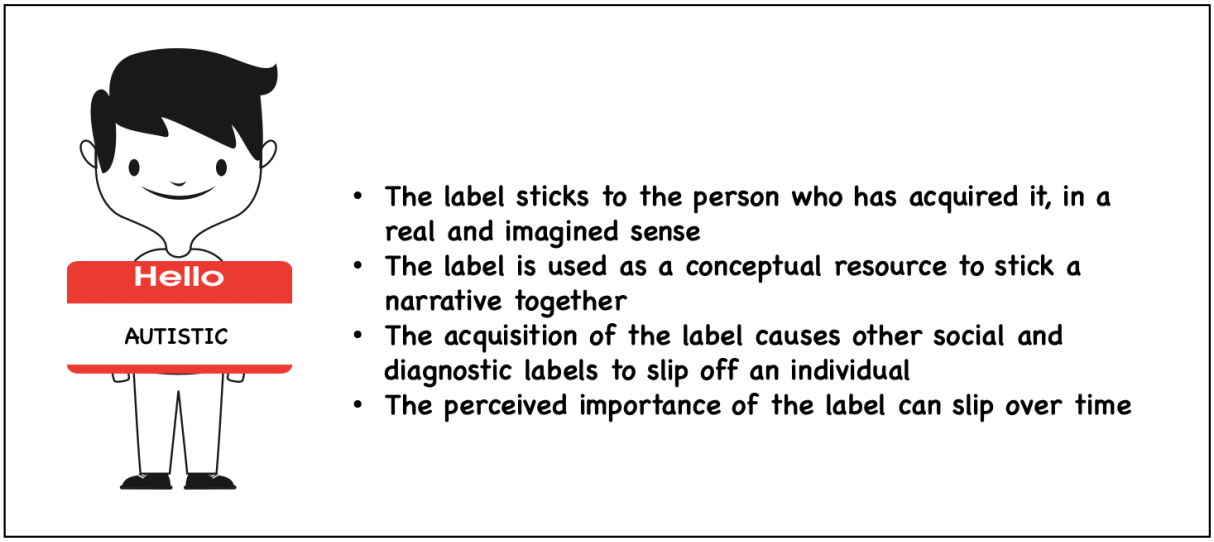
heart, scientific and medical knowledge is based on the principle of doubt. From this perspective all knowledge, including the 'discovery' and codification of diagnostic categories, take on the form of hypotheses: "claims which may very well be true, but which are in principle always open to revision and may have at some point to be abandoned" (Ibid., p. 3). The former psychiatric diagnoses of drapetomania – the tendency for slaves to try and escape their owners – and female hysteria are a case in point (Jutel, 2011). Systems of accumulated expertise, such as those in the medical profession, can often find themselves in disagreement with one another. This can lead to internally contested debates about the nature of known diseases and their accompanying diagnostic categories. In light of new knowledge and information about particular disorders, diagnostic classifications are routinely revised and updated, and it is this chronic revision of medical knowledge – its reflexivity – that ultimately undermines the apparent certainties of psychiatric categories (Giddens, 1991).[43] Categories such as autism are hotly debated, both within psychiatric medicine and public discourse. Whilst the classification of autism in the most up-to-date psychiatric manuals tends to be seen as the definitive statement on the condition (Hassall, 2016), "even the most cherished beliefs underlying expert systems [such as psychiatric medicine] are open to revision, and quite commonly they are regularly altered" (Giddens, 1991, p. 141).

[43] I will talk more about reflexivity and how this idea applies to my work in Chapter Seven.

The label as applied to an individual

Once applied to an individual, the label has the capacity to significantly alter how a person feels about themselves. The most notable changes in regard to the sticky-slippy image are outlined in Figure 4.2.

Figure 4.2: The sticky-slipperiness of the label when applied to an individual



The label sticks to a person

Autism is a label that has the capacity to stick to the person who has acquired it. Whilst the label does not literally bind itself to a person's flesh, it does in a figurative sense become attached to a person's identity and their sense of self (Singh, 2011). Part of this stickiness comes from the way people perceive the label. In the case of obtaining a medical diagnosis, it can feel like a deliberate attempt to brand an individual with an unwelcomed tag:

> "So I went to see this guy [a psychiatrist] and he just saw that I was autistic from the moment I walked in, and he was trying to pin that label on me […] It felt like it was stuck to me – it's on my forehead – and no matter what I said [the psychiatrist] was fitting what I'm saying into the picture [he] already decided" (N-sid, 2, 530-538).

For some participants, the perceived permanence of the label was enough to prevent them from seeking a medical diagnosis, because “once you’ve been given that label […] that’s the camp you’re in, it’s the diagnosed camp” (B-sid, 2, 445). For those that had a medical diagnosis, this sense of finality caused them concern as they were worried about how other people would respond to them:

> “And I thought, ‘well, I am finally about to go to university, why should I then at the age of nearly twenty-one, arrive at university with a label plastered across my forehead saying ‘antisocial?’ Because that’s what a diagnosis would do” (I-mdx, 1, 24).

But as E-mdx (2, 17) explained, the perceived stickiness of the label, particularly a medical diagnosis, is not just imagined: a person can, in a very real sense, be stuck with the label for the rest of their lives:

> “It can't be undone once it's been done, and really once the diagnosis is there it's in all of my medical records for everybody to see, and I guess in a medical sense it applies forever.”

Once somebody is diagnosed as autistic, they cannot go into remission or have the diagnosis revoked at a later date (although I consider the possible reasons for rescinding a medical diagnosis in Chapter Seven, p. 268). This is the case even though there is evidence to suggest that people who meet the diagnostic criteria in childhood can fall below the same threshold later in life (Seltzer et al., 2003). This probably has something to do with people getting progressively better at managing their symptoms as they get older, and that as the diagnostic criteria is updated those who were just over the cusp of a diagnosis at one time may fall out of the category following its update (Howlin et al., 2000; Volkmar et al., 1992). That being so, there may be people living with the diagnosis who no longer meet the criteria for the condition and wish to have it removed, particularly if the diagnosis was pursued by a

parent when they were younger (Huws & Jones, 2008). One of my participants, O-mdx (1, 263), felt a similar sort of regret after obtaining her diagnosis in her twenties:

> TL: "I mean, I get the feeling…do you regret getting the diagnosis?
>
> O-mdx: Oh yes, absolutely! I mean, it's only brought me distress. It has never done anything for me."

Although the diagnosis had helped O-mdx manage her work situation at the time, for the most part she felt "short-changed" by the presumption that getting a medical diagnosis would lead to a newfound sense of self:

> "I'm really, really, angry about the very public sort of 'diagnosis as self-discovery' narrative that gets very heavily promoted, especially by the #ActuallyAutistic Twitter mob who are really shoving it down people's throats like, 'oh, I've got a diagnosis and then I understood myself and then I could accept myself and then I found this community.' I just don't understand where people are getting this crap!" (1, 270).

This, combined with the perceived permanence of the label, left O-mdx feeling very uneasy about her decision to pursue a medical diagnosis:

> "I was quite floored. […] I felt like I'd gotten a death sentence. […] You know, 'congratulations, you are a freak forever!' […] So I was stuck like this" (1, 270; 381).

Alongside this imagined stickiness, the label can also find itself sticking to things in official circles. Keeping with a medical diagnosis, it is possible for the label to be recorded and held indefinitely on various databases organised by the state and other public bodies. A recently quashed policy announcement by the Driver and Vehicle Licensing Agency (DVLA) is a good example of this. Under proposed plans, autistic drivers would be asked to inform the DVLA about their medical diagnosis, even if their condition did not affect their ability to drive. Failure to do so would result in a £1000 fine (Moore, 2018). Following intense scrutiny in the days after the announcement, it

was reported that drivers who were on the waiting list for an autism assessment were cancelling their appointments for fear of being prejudiced against by the DVLA (Hill, 2019a). One woman told a newspaper:

> "Some of us, driving safely for 30 years or more, had to fight to get on a waiting list for an autism diagnosis […] [and that] thanks to the DVLA, we've felt threatened into deleting our names and refusing a diagnosis and support" (Hill, 2019b).

Although we will never know if people actually cancelled their assessments because of this announcement, it was clear that people did *not* want their diagnosis recorded by the DVLA. For some people, sticking the label on a motorist's driving record, for no obvious reason – particularly as those in question had already passed their driving test and had therefore been deemed safe to drive – was seen as a breach of privacy and trust. After the public backlash that followed the announcement, the policy was dropped.

Although the DVLA announcement was met with a certain amount of hostility, the 'bureaucratic stickiness' of the label is not always a bad thing. On the contrary, the fact that the label has a reasonable sticking power in official circles is seen as one of the major benefits of an autism diagnosis, as R-sid (1, 405), a participant who sought one, explained:

> "People talk about labels as if they're bad, but they're not entirely bad. When it comes to getting help with things, if you don't have a label, they [clinicians, social service providers] won't help you."

A diagnosis of any kind often has a tremendous amount of traction in areas of social and financial welfare. Having the official label rubber-stamped by a doctor grants the recipient access to a variety of (albeit limited) resources and services available to autistic people (Runswick-Cole, 2016). This can include financial support in the form

of Personal Independence Payments (PIP), help with accommodation or full-time specialist residency, and access to social support groups in the local area. A diagnosis does not automatically grant somebody access to these services, but for many of them it remains the main barrier to entry (Jutel, 2009). What makes the diagnosis sticky in these circles is the fact that once it is on record, once it is registered that a person is autistic, it is relatively easy to continue accessing the resources needed, as S-mdx (2, 131) explained:

> "And I think if I didn't have a label, I couldn't make a case for [certain services]. In terms of getting things like Personal Independence Payments, which help me because I'm not able to work full-time or would really struggle to work full-time. So having a bit of support income from that helps a lot and wouldn't be achievable without the official diagnosis. So that's, I guess, kind of a bit like what you were saying, the sticky end of things."[44]

Accounts like these illustrate how the stickiness of the diagnostic label offers what Davidhizar (1994) called the 'secondary gains' of a diagnosis – advantages and benefits not directly associated with the label (most notably treatment) that nevertheless help people to manage their illness or condition. S-mdx saw his medical diagnosis in precisely these terms, likening his diagnosis to the provisional driving license he carried around in his wallet. As he explained, he applied for a driving license not because he wanted to learn how to drive (in Davidhizar's terms, the primary gain), but because he wanted to use the license as an official form of identification (the secondary gain). As for his autism diagnosis, he does not use it to access clinical services and therapies – the primary gain – but rather, as evidence of entitlement when applying for welfare services – the secondary gain:

[44] Here is an example of participants in the second interviews using my own terminology to describe their experiences to me.

> "But for the purposes of getting PIP, yes […] it was a nightmare to get, it took me over a year from filling in the initial forms, and if I hadn't had a formal diagnosis then I doubt I would have got it at all, and I think I probably deserve it. So, I think I would pursue a diagnosis [if I didn't currently have one] for official purposes, but not for personal or medical reasons" (S-mdx, 1, 500).

The label is used to stick a narrative together

Acquiring the label helps people make sense of their lives by helping them stick an ordered and coherent narrative together. As sense-making beings, we strive to understand who we are and the events that make up our lives. In a way, we are all psychoanalysts, constantly analysing and interpreting psychological processes in light of new events and past experiences. New information in the form of social and diagnostic categories play a vital role in the reflexive formation of the self (Giddens, 1991). Labels such as autism can be used by an individual as a conceptual resource to make sense of who they are and how they want to think about themselves. The label, and the newfound knowledge that it brings, can be used to stitch disparate events, feelings, and questions together in a way that makes sense to an individual (Jutel & Nettleton, 2011). We can see examples in previous work of autistic adults trying to understand why they struggled in social situations when they were younger, or why they think and act the way they do, and how they are different from other people (Hickey et al., 2018; Punshon et al., 2009). What we learn from these studies is that for those adults, learning about autism and acquiring the label (either as a medical diagnosis or by self-identifying as such) provides the conceptual glue to stick these reflections together and give them meaning – *"I am like this because I am autistic."* This was something noted by U-mdx (2, 48), who felt that her diagnosis gave her the means to better understand herself:

> "The part that sort of hit home for me […] was that kind of making sense of things that have happened in your life under a new perspective. Because I think that has very much happened to me since I got my diagnosis. Sometimes when I … if I have moments when I doubt my diagnosis because I don't seem to have any problems or I don't care about it, or something like that, I will think back to things that have happened in childhood and think, 'oh no, I definitely am autistic because this happened and that happened,' you know, it makes so much more sense now. Yeah, it's like you said, I'm able to stick that story together."[45]

As was clear talking to other participants, this sticking together of life events often started with early memories of childhood. "I've thought about this a lot," D-sid (1, 6) said, "I don't think I would ever have got a diagnosis as a child, but I recognise in myself traits of … autistic traits, probably." D-sid started to think this way after her son was medically diagnosed as autistic, which was when she started noticing similarities between his behaviour and that of her younger self (I will talk more about identifying similarities in family members in Chapter Six, p. 215):

> "I can see in myself a lot of things that were probably … probably more obvious as a child […] a lot of anxiety, very, very, very withdrawn. Uncertain. I tried very hard as a child to be normal. And I see my son doing that now, but from a slightly more extreme position" (1, 18).

This introspection was even more profound for G-mdx, who received her diagnosis when she was in her twenties. Upon discovering autism, she recalled how "everything fell into place" when she read the diagnostic criteria. "I was like, yeah, yeah, yeah, yeah, yeah, okay, this is me!" (1, 11). Autism gave her the conceptual tools to dive back into her childhood and create a narrative that helped her explain certain inexplicable events:

> "Like one of the classic signs of autism in small children is a tendency to line up toys, and, looking back, it was like 'I did that! I did that constantly!' […] One of the other big things, when I was about two […] we were in Woolworth's [a department store] and all of

[45] Another example of participants responding to my analysis.

> a sudden I just lay down on the floor and started kicking and screaming for no apparent reason […] and suddenly it made sense: I wasn't having a tantrum, I was having an autistic meltdown, because I couldn't cope with the sensory input from the music being played, and probably also the fluorescent lights" (1, 199).

G-mdx described other sensory sensitivities as a child, such as not having different food textures on her plate because "it's too loud visually" (1, 162). Prior to her diagnosis, these memories (the toys, Woolworth's, food textures) were unexplained oddities about herself. But when she learnt about autism and acquired the diagnosis, these events made sense. "Looking back, it was actually because I was autistic" (1, 80).

Obtaining a medical diagnosis of any kind, but perhaps even more so for a psychiatric diagnosis, initiates a series of biographical reflections that have a profound impact on a person's sense of self, for better or for worse (Bury, 1982; Faircloth et al., 2004). The biographical work that an individual undertakes is in part *this sticking together of past events and experiences so as to transform them into an understandable and meaningful narrative*. Of course, this is not something that is unique to autism or any other psychiatric category. All diagnoses are, and can be, transformed into conceptual resources that help people stick elements of their life history and biography together (Jutel, 2011). Creating this narrative helps an individual make sense of themselves and communicate their struggles and experiences to other people. But as we will see shortly, divulging these concerns (and their associated labels) to other people can have a sticking quality of their own (see p. 159).

Acquiring the label causes other labels to slip

As was noted by many of the people that I spoke to, it is not uncommon for autistic people to find themselves tarnished with other undesirable labels, such as weird, strange, or special (Davies, 2016). It is also the case that many autistic individuals have additional psychiatric diagnoses (or 'comorbidities'), such as anxiety disorder or ADHD (Simonoff et al., 2008). Like autism, these social and diagnostic labels have a sticking power of their own, but they do not exist in isolation of one another. The various labels that people carry with them are understood and narrated in relation to each other – "*the reason I am this is because of that"* – and the presence of one label can change the nature of another. Acquiring the label autistic, it seems, can cause other potentially harmful labels to disintegrate and slide away.

Like other autistic people, I-mdx found it difficult to secure long-term employment, in part because of the perceived discrimination he felt from employers and recruitment agencies. Out of work and facing the expectation that somebody his age can and should be working, I-mdx (1, 418) was made to "feel guilty about being a chronically unemployed person." The label unemployed and the various connotations associated with it (e.g. idleness, freeloading), was something I-mdx tried to shrug off for many years prior to being diagnosed as autistic. However, when he finally obtained his medical diagnosis, he felt he was able to explain to himself, and most importantly, to other people, why he was unable to secure and hold down a full-time job. "If I didn't have my diagnosis", I-mdx (1, 453) told me, "I would [still] be known as an unemployed person and I would be feeling guilty for not being able to secure work." In this instance, the stickiness of his autism diagnosis provided the social lubricant to dislodge another less favourable label. I-mdx was out of work before he received his diagnosis, but as

he acquired one label (autistic) the other label (unemployed) fell away. The same thing can occur with other descriptions and associations, such as phrases used to describe an individual's character:

> "I was just thinking that for me my autism diagnosis helped my shy label slip away […] over the years people [have] perceived me as shy and I guess that label no longer applies […] as my autism diagnosis explains […] why I struggle to initiate conversations with people" (Q-mdx, 2, 69).[46]

It is also the case that other diagnostic categories previously assigned to an individual can find themselves metaphorically sliding off them and their medical record. Prior to his diagnosis, E-mdx had been diagnosed with dissocial personality disorder and borderline personality disorder (amongst other conditions). These two labels were later removed by the psychiatrist who carried out his autism assessment:

> "First of all, she said, there's no indication of dissocial personality disorder, so that one's out the window. Next, there's no indication of borderline personality disorder, so that one is out too" (1, 304).

E-mdx believed that he would have retained these diagnoses had he not met the threshold for autism, but because he did, they were subsequently removed as they could be explained away by his new diagnosis. Here, autism acts as a kind of 'master status' (Hughes, 1968), or perhaps more accurately, a 'master diagnosis,' whereby the condition becomes the primary label which other labels constellate around. Of the diagnoses assigned to E-mdx, autism was the stickiest and became the principle means of explaining his behaviour, both for him personally and the psychiatrist assessing him. By acquiring this label, it caused his other diagnostic labels to slip off him.

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[46] Again, this is a participant incorporating my analysis into their response.

The importance of the label can slip over time

For many people, being told or coming to the conclusion that they are autistic is a life changing moment. It can change the trajectory of a person's life and form the basis of a newfound identity (Wylie et al., 2016). And yet, the perceived importance of the label can lose its prominence over time. Like a name tag stuck to an individual's lapel, leave it long enough and the adhesive will start to fade and eventually it will fall off. Sticky labels like autism can fade in a similar way. Take S-mdx for example. When I interviewed him, he had been living with his diagnosis for just over ten years. In the early days, whilst at university and later at work, the label served many emotional and practical functions: "it helped me understand myself a lot better […] [and] it meant the possibility of more support" (1, 97). But as time moved on, the perceived importance of the label had started to slip:

> TL: "So what kind of impact has the diagnosis had on your life? On you?
>
> S-mdx: I don't know, it's hard to say. To be honest, and I know we are talking a lot about the diagnosis, but in recent years I've been feeling more that [the diagnosis] doesn't matter as much" (1, 247).

A big part of this change was how S-mdx thought about himself. When he was first diagnosed, he used to think of himself predominantly in terms of autism – how it made him think, feel, and behave – but as time went on, it later became something that he chose to background, as it was no longer, in his eyes, the defining feature of who he was. "Now," he told me, "I don't feel the need to say that I'm autistic anymore" (2, 201). P-sid (1, 233) felt a similar way:

> "It's useful to know [that you are autistic] at the time, it's useful to have that knowledge. [I] generally wasn't expecting there to be much, but as time has passed it's become, hmm … it's just a thing that is there. I don't give it much thought."

When the label is first applied – when the name tag is stuck to the person's chest – it has the capacity to become their master status – their primary identifying feature. But this can change, and for some people, the label can soon become part of an eclectic mix of other characteristics and descriptions which they associate with themselves:

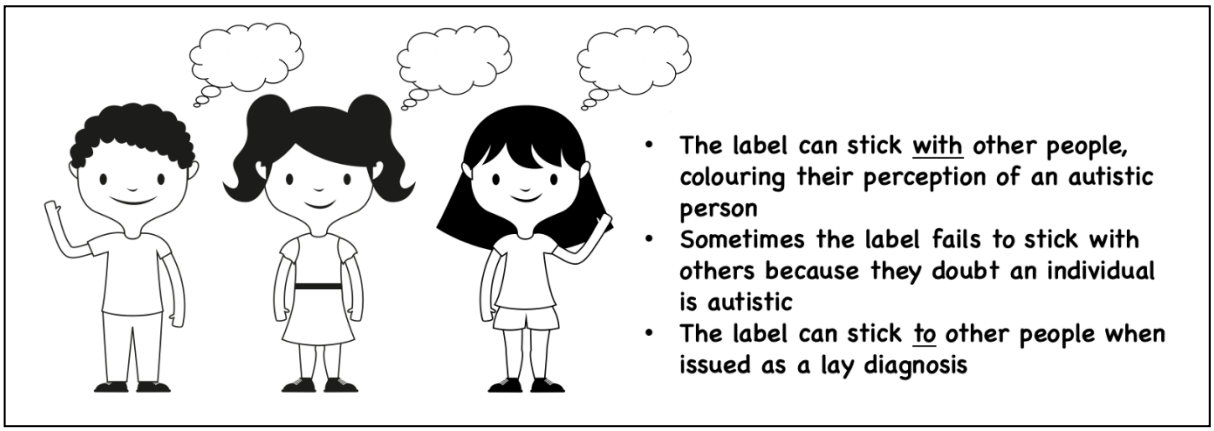
> "I used to think of myself primarily as an out-and-out autistic person, but over time that has changed […] and I'm less focused on that now […] autism is one of many things about me [and I] feel that it has become a less important feature in my life" (A-mdx, 1, 73).

The apparent redundancy of the label may even get to the point that an individual starts to doubt whether they are actually autistic, as was quoted by U-mdx (2, 50) on p. 151: "I have moments when I doubt my diagnosis because I don't seem to have any problems or I don't care about it." The label may become so insignificant that a person questions whether they need the diagnosis or whether it accurately describes who they are. It seems that in the first instance, autism can be an all-encompassing label that sticks to an individual and changes their sense of self. But over time, the perceived importance (the stickiness) of the label can start to fade, slowly becoming something less noteworthy, less fundamental.

The label in relation to other people

Finally, the sticky-slipperiness of the label also extends to how other people respond to somebody who has acquired the label, and on occasion, how they think about themselves. The final part of this discussion is summarised in Figure 4.3 (overleaf).

Figure 4.3: The sticky-slipperiness of the label in relation to other people



The label sticking (and not sticking) with other people

As we saw earlier, the label autistic has the power to stick – in a metaphorical and official sense – to the person who has acquired it. But its stickiness is also felt, knowingly or unknowingly, by other people. Once somebody discloses that they are autistic, the label has the capacity to lodge itself in the minds of other people to the point that it colours their perception of the person before them (Wylie et al., 2016). The label can, in other words, stick *with* other people.

Most of my interview participants were acutely aware of the sticking power of the label and its ability to change another person's opinion of them. It was for this reason that O-mdx (1, 449) decided not to tell other people about her diagnosis:

> "I suppose part of the reason that I do not tell people is that, yes, I think it would be damaging […] because it would change people's perception of you […] [and] anything that changes people's perception of you like that can have an enormously negative impact."

As noted in Chapter Two, diagnoses provide a cultural expression of what society is prepared to accept as 'normal' and what it feels is 'abnormal' and should therefore be treated (Zola, 1972). If an individual acquires a label signalling an apparent

abnormality then the label has the power to change people's perceptions of that person (Jutel, 2009). With a label comes a reinterpretation of an individual's behaviour: "what once would just be a little odd or cultural difference or whatever, is, well, now you have a label on it: now it's a condition or a disorder" (J-sid, 1, 307). The disclosure of a psychiatric label like autism can lead others to think less of an individual:

> "In general, you see people […] assuming a lack of competence as a default, or being patronising, or assuming that people might not want to be involved in social things as a default […] No matter what I say or do, people just can't get this sort of stuff out of their head" (O-mdx, 1, 463).

However, the fact that the label sticks with other people was not always seen as a bad thing. For G-mdx, she was able to use this stickiness to her advantage. When she was looking for work, she always found that she struggled to secure a job offer. Her interview feedback provided a clue:

> "Every time in the feedback after the interview, every single time they said, 'we didn't like that you didn't make eye contact.' Now for me, making eye contact is physically painful and I hate it because it's just uncomfortable. But I've since found out that interviewers don't like it when you don't make eye contact […] because it might be that you're hiding something. It might be a lack of confidence. It might be a lack of knowledge" (1, 90).

As G-mdx reasoned, the people interviewing her did not know that she was autistic and were therefore applying the "neurotypical standard" of maintaining eye contact to her, which was something that she struggled to do. At that time, G-mdx self-identified as autistic, and was concerned that if she disclosed this in future interviews she would not be believed, "because anyone can rock up to an interview and claim to be autistic, whether or not they are" (1, 103). The sticking power of the formal label was the main reason she decided to pursue a medical diagnosis:

> "So if I had a diagnosis I could say to them in advance, 'look, I'm autistic, because of that it makes eye contact very uncomfortable for me, so I want to warn you now, in advance,

> that I will not be making eye contact at the interview, and that is because I'm autistic, not because of any other reason'" (1, 98).

After disclosing her medical diagnosis, G-mdx received a job offer. As well as providing another illustration of the secondary gains of a diagnosis, G-mdx's account also demonstrates how, once disclosed to other people, the label can stick with them and change their expectations of the person in front of them, in this case for the better. Indeed, for many of the people that I spoke to, expectation management was one of the major reasons for disclosing and not disclosing their autism label.

But it is also the case that other people may choose not to believe that an individual is autistic, even if that person has a medical diagnosis. This was the case for K-mdx (2, 60), whose parents had difficulty acknowledging that she was autistic: "I don't think my parents have really accepted that I'm autistic. They can't or won't accept it for whatever reason." It may be that the mostly negative images affiliated with autism were something that K-mdx's parents did not wish to associate with their daughter, as noted elsewhere (Chamak et al., 2011). Furthermore, this revelation may have even prompted K-mdx's parents to conclude that they too were autistic; that the condition is hereditary and that it must have come from them. This was something C-mdx (1, 300) found when she disclosed her diagnosis to her family: "you don't have autism", her mother said to her, "because that would mean that I've got it." Aside from the way some family members attempt to rationalise the genetic basis of autism (something I will return to in Chapters Five and Six), this sort of response also demonstrates how the label can fail to stick with other people – that it can be met with scepticism or resistance. This is often embodied in phrases such as "you don't look autistic," which implies a sense of uncertainty or disbelief that the person disclosing the label is

actually autistic. In some cases, this might flourish into the outright denial of an individual's autistic status:

> "There are quite a few people who deny it, that actually shut it down, they just don't give a hoot about your feelings. They're like, 'no, you're not autistic, so stop making this crap up'" (A-mdx, 1, 266).

> "People are denied access to their own community and people who are like them, because the gatekeepers [doctors, other autistic people] aren't allowing it, because they don't believe that they are autistic" (J-sid, 1, 326).

In these exchanges, the label is not sticking, it is slipping. If envisioned in these terms, for the label to stick with other people it not only requires some sort of social adhesive – often provided by an official diagnosis – but it also requires some receptiveness on the part of other people, some willingness to recognise and accept an individual's claim that they are autistic. If this is not the case, then the label does not stick with other people. Whilst we might anticipate that a self-assigned label does not have the sticking power of a medical diagnosis because, as G-mdx (1, 103) noted, "anyone can rock up […] and claim to be autistic," the diagnosis itself can sometimes fail to find traction with other people. The symbolic backing of a medical diagnosis can be called into question by critical others who do not believe that an individual is 'truly' autistic. In these moments, both the medical and self-assigned labels can feel rather slippery.

The label sticking to other people

Clinicians are not the only people who judge whether or not somebody has autism. Autistic people do it too. Based on their knowledge and experience of the condition, they are able to make a lay assessment as to whether a family member or a friend is autistic. Like a ball being thrown from one person to another, it can be 'thrown out there' by an autistic person (person A) that a friend or relative (person B) – somebody

who has struck them as having certain characteristics or unusual traits – is in fact autistic. Here, person A sticks the same sticky name tag that they have on the lapel of person B – *"I think you are autistic too. Here, have one of these."* Although put in quite crude terms, this is how we can imagine a lay diagnosis being issued; a lay person labelling another lay person with a diagnostic category (in this case, autism).

I have devoted the whole of Chapter Six to exploring this idea, but I mention it here because the label issued in a lay diagnosis can find itself sticking *to* the person in question to the point that it is internalised as part of their identity. After being told by person A that they are autistic, person B may genuinely believe that they are, which may instigate the process of self-identification and perhaps the pursuit of a medical diagnosis. This is particularly true if the person doing the labelling (person A) is seen by the recipient (person B) as somebody that I call a 'knowledgeable other' (Vygotsky, 1962); somebody who knows what they are talking about and who is seen as an authority on autism. I will talk more about the role knowledgeable others play in the acquisition of the label in subsequent chapters.

Chapter conclusion

In this chapter I outlined the first part of my analysis into how people acquire the label autistic in adulthood and the consequences of doing so. Using the imagery of a sticky-slippy label, I have tried to conceptualise the nature of the label and the implications of living with it based on the accounts of the participants in this study.

I started by looking at the label itself, and how various ideas and images come to stick to the label autistic (becoming synonymous with the condition itself). I also

demonstrated how the meaning of the word, in both general and diagnostic terms, is fluid and ever-changing, with different ways of thinking and talking about the condition constantly slipping in and out of usage.

I then explained how the stickiness of the label extends to the way autism is experienced as a social and diagnostic category. Autism can feel like a label that an individual is stuck with for life, and in some official channels it *is* something that marks an individual forever. I also considered how the label is used as a conceptual resource to stick an ordered and coherent narrative together, transforming memories and experiences from something inexplicable to something understood. Next, I examined how the acquisition of such a label can cause other social and diagnostic labels to fade away. Being autistic can dislodge other unwanted personality disorders or social badges, such as lazy or unemployed. These labels no longer have traction when affiliated with autism and subsequently find themselves sliding off an individual. Whilst acquiring the label can be a life-changing moment, the label also has a fluid and shifting prominence in a person's identity. Where it might once have been an individual's master status – *the* defining feature of their personhood – it can, over time, become less important, less noteworthy, slipping in status to one of many defining characteristics and features of an individual.

Finally, I discussed how the stickiness of the label can be felt by other people. Not only can the label colour another person's perception of an autistic individual (i.e. sticking *with* other people), but in some instances the label can find itself sticking *to* other people in the form of a lay diagnosis (see Chapter Six).

This analysis, and the image that I have presented, is intended to be a means of making sense of the data collected. It is a conceptual device, a way of imagining and describing what it is like to live with the label autistic. Whilst I hope the sticky-slippy image will have some conceptual utility elsewhere, this analysis was not just a case of theorising for theory's sake. It was encouraging to see participants recognise the sticky-slipperiness of their label when I discussed the idea with them during our second interview. In some instances, I was merely describing what they already knew and were able to tell me about their label. In other moments, my attempts to interpret what they had told me using this imagery, and sharing it with them, gave them the conceptual resources to understand and explain their own experiences. In other words, participants were able to apply the notion of the sticky-slippy label to their own life in a way that made sense to them. This was one of the many benefits of returning to participants for a second interview, and it illustrates a fundamental methodological point about conducting social scientific inquiry on subjects (i.e. people) that are able to engage with and interpret sociological findings (Giddens, 1984).

Whilst the sticky-slippy label is just one part of my overall thesis, it does underpin many aspects of my subsequent analysis. The sticky-slippy image will make further appearances throughout the remainder of this dissertation, albeit in a more focused way. I will also elaborate on the concept in parts, introducing additional elements that have not been covered here. In the next chapter, I will turn my attention to the phenomenon of people self-identifying as autistic and their reasons for doing so. As with this chapter, I will introduce a new theoretical concept that attempts to illustrate how people acquire the label and the implications that it has on their lives.

Chapter Five: Four ways of self-identifying as autistic

In this, my second findings chapter, I will focus on the act of self-identifying as autistic and introduce four ways of doing so. These are (1) identifying as autistic as a *precursor* to seeking a medical diagnosis, (2) identifying as autistic *despite* a negative diagnosis, (3) identifying as autistic as an *alternative* to a medical diagnosis, and (4) identifying as only having autistic *traits*. Drawing on examples from my interview data, I will demonstrate how these represent four different reasons for self-identifying as autistic, and how they also mark four empirically observed states that a person can transition between.

Focussing on self-identification

One of the unique features of this study is the attention paid to people self-identifying as autistic, a phenomenon that has largely been ignored in the existing autism literature (see 'what is missing,' p. 72). For those that do study self-identification (or self-diagnosis, as it is referred to in those studies; e.g. Lewis, 2016b; Sarrett, 2016) it is usually framed as something people do prior to obtaining a formal medical diagnosis. Whilst this is undoubtedly true for some, it is not the only reason people label themselves as autistic, as I will demonstrate shortly. In developing this analysis, I therefore aim to offer a sustained engagement with the act of self-identification that goes far beyond the taken-for-granted assumptions found in the existing literature.

By amalgamating the key facets of self-identification as found in my interview data, there are four ways in which people can come to label themselves as autistic: as a *precursor* to a medical diagnosis, as an *alternative* to or *despite* a medical diagnosis, or by self-identifying as having autistic *traits*, rather than the label itself. The purpose of this chapter is to explore these reasons in order to better understand how and why

somebody would label themselves as autistic. But before doing so I would like to issue the following provisos.

The first is that the four suggested ways of self-identifying as autistic do not represent a like-for-like account of the people interviewed as part of this study. They are not descriptions of my participants organised under a general set of headings (i.e. *B-sid self-identifies as a precursor to a medical diagnosis, whereas D-sid self-identifies as an alternative to one*). They are instead a group of categories, developed by me, that best represent some of the key features of self-identification as found in my data. Whilst some participants may recognise themselves as engaging in a particular way – as I discovered when sharing this analysis with them during the second interviews – it is not my intention to sort participants into one of the four groups.

On a related note, although there are clear and obvious distinctions between the four ways to be discussed, they should not be seen as discrete categories in which a person could only be described as *this* or *that* kind of self-identifier. Unlike a typology, which aims to classify phenomena into distinct non-overlapping groups, a person's experience of self-identification can be associated with more than one of the ways to be presented in this chapter. Therefore, it may be best to think of these groups as idealised representations of a person's motive for self-identifying as autistic, whose boundaries are open and porous. Because of this, there is an interesting temporal element underlying these ways that allows for some transitioning in, out, and between these groups. In other words, it is possible to envisage people moving from one type of self-identifier to another. I will talk more about this later.

Self-identifying as a precursor to a medical diagnosis

The first category of self-identification is somebody who believes that they are autistic and self-identifies as such prior to seeking, and hopefully obtaining, a medical diagnosis. These individuals self-identify as autistic because they believe that they display the characteristics associated with the condition and have therefore initiated the formal diagnostic process.

Although most people have heard of autism and have some understanding of what it is (whether based on scientific knowledge or social stereotypes), the majority of people do not see it as a condition that applies to themselves. Those in this group are different. There came a time in their life (at some point in adulthood) where they started to recognise and identify the features of autism in themselves. This might have been bought about after watching a film or documentary on the subject, or perhaps as a consequence of reading a book on autism:

> "I did get a book recommended by [a friend], '*The Complete Guide to Asperger's*,' I think, by [Tony] Attwood. […] And I read through that one and pretty much most of it was things I could relate to in some way … or a lot of it was, in fact. So it was kind of a case of thinking, 'well, there seems to be something here'" (P-sid, 1, 107).

The recognition that "there seems to be something here" – that it is plausible that they might be autistic – can instigate a more concerted effort to learn about the condition:

> "I sort of compiled all of this [information] together and highlighted the things that I thought applied to me […] I suppose I was just trying to find out more about […] [the] symptoms […] [and] what kind of issues people had, particularly women" (J-sid, 1, 124).

For somebody in this position, this involves delving into the scientific literature to access the most up-to-date information on the condition: "I've downloaded all the scientific papers and stuff, I know what they say about autism […] I've read all of that"

(H-sid, 1, 65). This information is then used to make what seems to be a reasonably informed judgement about whether or not they are autistic:

> "Look, I've done my reading, I've read the latest articles coming out of journals like *Nature* and *The Lancet*, I've read the [diagnostic] guidelines, I've got a pretty good idea of what [autism] is and whether I meet the criteria for a diagnosis" (A-mdx, 1, 656).

As an individual learns more about the condition and becomes increasingly assured that it is a category that applies to themselves, they may start to talk about it with other autistic people – those I referred to in the previous chapter as knowledgeable others – in the hope that they might confirm their suspicions:

> "I just asked [my autistic friend], 'do you think that I am autistic?' […] [and] there have been times when he's said to me, 'yes, [B-sid], you definitely have traits and you probably are autistic'" (B-sid, 1, 73).

> "[A friend] said to me, 'I have 'aspiedar' and I think you're on it' […] and I've since had a couple of other people who have got a diagnosis saying similar things about me […] And they know more about it than I do" (L-sid, 1, 179).[47]

The 'autistic approval' that comes from knowledgeable others can act as a springboard to instigate an initial diagnostic inquiry.

Seeking a medical diagnosis

The journey to a medical diagnosis starts with a decision to seek professional assessment: "One day you think, 'I've been [...] really thinking about the traits I have', and I think, 'yeah, maybe now it is time to get a medical diagnosis" (B-sid, 2, 386). If one pursues a diagnosis through the NHS, it will start with a visit to a GP who will

[47] An 'aspiedar,' or an 'autism radar' as other participants have referred to it, is the Asperger/autism equivalent of what is colloquially known as 'gaydar' – the reported ability to determine a person's sexuality by identifying individual and social cues (see Rule & Alaei, 2016). I will talk more about this in relation to autistic people identifying other people with the condition in Chapter Six.

determine whether an additional diagnostic assessment is required. If a GP thinks that an individual might meet the threshold for a diagnosis, and would benefit from obtaining one, a referral will be made to a specialist psychiatric service that will carry out the evaluation. The wait for a referral varies between NHS Trusts and depends on the resources and personnel available, but it is not uncommon for the wait to be 2-3 years (APPGA, 2019).[48] Once a referral is made, the client (the term used in mental health to describe a patient) can expect multiple visits to a psychiatrist or other affiliated professional (e.g. a speech and language therapist or a clinical psychologist) who will conduct a series of interviews and diagnostic tests (e.g. the Autism Diagnostic Observation Schedule, ADOS) to determine whether or not they meet the criteria for autism. Although the exact details of this process can vary between different regions (and different countries and healthcare systems), an individual may find themselves in the system and going through various procedures for a considerable amount of time, which will conclude with either a positive or a negative diagnosis (see Rossi, 2012).

For somebody who self-identifies as autistic as a precursor to a medical diagnosis, the referral made by their GP is in part confirmation of their self-assessment: "As the GP recommended going for a diagnosis, there must be some truth in me being autistic" (I-mdx, 2, 885). During the wait for the referral, they continue to think about autism, reading new material on the condition and talking with knowledgeable others about what to expect from the diagnostic process: "I'm not taking any chances with this […] I've spent the last four months researching it obsessively – obsessively!" (N-sid, 1, 330). As noted in Chapter Two, the long wait for an autism assessment can see people

[48] As one participant was told by their GP: "'A diagnosis can take ages and the service isn't very good for getting seen by anyone. I'm not even sure we can refer you anywhere'" (N-sid, 1, 158).

gradually start to self-identify with the label they hope to eventually obtain (Moore, 2016). For those self-identifying as a precursor, they may start to construct a picture of themselves as an autistic person:

> "It explains a lot of things […] it gives a lot of answers [and] there is a clear view in my mind that this is the case [that I am autistic] and that I am going to get a diagnosis" (P-sid, 1, 179).

> "I was 99.9% sure that I was [autistic]. I just knew it, and when you know, you know" (C-mdx, 1, 237).

For somebody in this position, the diagnostic process can start to feel like a box ticking exercise. It is a formality that they must go through in order to obtain an official diagnosis. Going to see a psychiatrist is not going to tell them anything that they do not already know. A positive diagnosis will not present them with a moment of diagnostic clarity, where a disjointed and confusing set of symptoms suddenly becomes an organised illness (Balint, 1963).[49] These individuals believe they already know what condition they have, and they are merely seeking formal confirmation from a doctor:

> TL: "And are you confident you'll get the diagnosis? There's no doubt in your mind?

> F-sid: I'd be extremely surprised if I don't […] it's one of those ones where [I will] wait over a year to get a piece of paper which tells me something I've suspected for the best part of two decades now" (1, 243; 489).

[49] It is worth noting that this was not the case for everybody that I interviewed. Some participants did not self-identify prior to obtaining a medical diagnosis because they were unsure whether they were autistic. I will talk more about this on p. 195.

Why seek a medical diagnosis?

If somebody is convinced that they are autistic, why do they need a medical diagnosis? One reason is so they can access the various social and financial services available to people with a diagnosis (Powell & Acker, 2016). An individual may find themselves struggling to live independently or might find it difficult to secure a consistent form of income. As a medical diagnosis is often the only means of accessing certain welfare resources, an individual may pursue a diagnosis purely on pragmatic grounds: "If I'm ever going to get any support with housing and money then I may need an official diagnosis anyway" (F-sid, 1, 36). It can be with an air of reluctance that somebody in this position pursues a medical diagnosis, "but unfortunately that is the way the world works, you need a diagnosis to get help with stuff" (A-mdx, 1, 222).[50]

Another reason for seeking a medical diagnosis is that it provides an official form of recognition (Jutel, 2011). What was previously a self-assessment, or to those a little more critical, "nothing more than a guess" (Sarrett, 2016, p. 30), becomes a professionally recognised rubber-stamped neurodevelopmental condition. The 'autistic authenticity' that comes with the official label can be particularly important for those without one, especially if they have previously been "nit-picked by others for not having an official diagnosis" (F-sid, 1, 364). Although the status of self-identifying adults has improved greatly because of organisations such as the Autistic Self Advocacy Network,[51] people are still generally suspicious of those who circumvent the doctor and diagnose their own medical conditions, particularly as it is seen to trivialise

[50] An example of what I described earlier as the label's 'bureaucratic stickiness.'
[51] See www.autisticadvocacy.org

physical and mental health problems.[52] A diagnosis is widely regarded as the best way to determine whether somebody is autistic, and as a result the official label takes on the form of a symbolic marker; proof that an individual has a right to call themselves autistic.

But whilst one is awaiting their official autism assessment a question might be floating in the back of their mind: *"Am I autistic enough?"* Specifically, am I autistic enough to reach the clinical threshold for a diagnosis? People in this position might believe that they *are* autistic, and this is bolstered by the fact that a GP has referred them to an autism specialist. But what if the result comes back as negative?

> TL: "If it turned out that you didn't get a diagnosis, do you think you would continue to self-identify [as autistic]?
>
> F-sid: Err … I don't know […] because at this point it would be such a shock and I've no idea how I would respond […] I mean, [being] autistic [has] become a massive part of my self-identity, and if I'm not autistic [then] what the hell am I?" (1, 254).

For people like F-sid, they are invested in the idea that they are autistic. They have tried on the label and it fits, they have embraced it as part of their identity because "autism makes so much sense" (P-sid, 1, 110). Using the imagery of the previous chapter, F-sid has stuck the label on himself and likes the way it feels. What he requires now is the glue that the official diagnosis provides to make his self-assigned label more permanent, more sticky. But "what would happen if my attempt to get a diagnosis failed? Do I work something else out?" (F-sid, 2, 544). The second way of self-identifying as autistic, doing so *despite* a medical diagnosis, may shed some light on this.

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[52] See www.mentalhealthtoday.co.uk/blog/teach-me-well/self-diagnosis-trivialises-severe-mental-disorders

Self-identifying despite a negative medical diagnosis

If somebody were to self-identify as autistic prior to anticipating a positive medical diagnosis, then this next reason could be seen as the successor to that motive had the diagnosis come back as negative. In this instance, an individual has gone to see their GP, who referred them on to an autism specialist, and according to the specialist's assessment they do *not* meet the diagnostic criteria for autism. Here, the client may be experiencing what Trevor Powell and Louise Acker (2016) described as 'diagnostic disappointment:' anger and frustration at the fact that they were unable to obtain an official autism diagnosis. However, despite the negative result, this individual continues to self-identify as autistic, albeit in a more socially precarious way. In a way, we can imagine the claim that they are autistic preceding a small asterisk which says "not approved by doctors," which may undermine their credibility when identifying as such.

Why was the diagnostic assessment negative?

There are many reasons why an individual may have failed to meet the criteria for a diagnosis. Some of these relate to the diagnostic decisions of clinicians, while others relate to the things a client says and the symptoms they present during the clinical encounter.[53] Looking at the judgement of clinicians, it may be that they missed important information during the diagnostic assessment (Aggarwal & Angus, 2015), or that they interpreted certain symptoms as evidence of a condition other than autism,

[53] Although outside the remit of this chapter, it is important to note that whilst the act of diagnosis is seen to be a definitive and clear-cut decision, researchers have shown that there are a whole host of social factors – knowledges, practices, values, judgements – that inform whether or not somebody comes to be diagnosed with a condition such as autism (see Hayes et al., 2020).

such as schizophrenia or Tourette's syndrome (Zafeiriou, Ververi, & Vargiami, 2007). As some have argued, it may be that the assessing clinicians lacked the specialist expertise to identify and diagnose autism in adulthood (see Gillespie-Lynch et al., 2017), and that they hold out-dated and perhaps even stereotypical views of the condition, which makes it difficult for them to identify symptoms in traditionally 'underdiagnosed' segments of the population (e.g. girls and women; Gould & Ashton-Smith, 2011).

From the client's point of view (that with which my data are about), it may be that they were unable to sufficiently demonstrate the symptoms associated with autism, or that the symptoms that they did demonstrate were insufficient to warrant a medical diagnosis. In either case, no matter how convinced somebody is about their autistic status, without enough supporting evidence from the various diagnostic measures taken, those conducting the assessment will be unable to issue a medical diagnosis:

> "Basically I didn't fit [the doctor's] checkboxes. Because what I said didn't match up with the list in front of him, he said, 'no, you don't meet the criteria so I can't offer you the diagnosis.' Basically I didn't give him enough" (N-sid, 1, 166).

> "After all those tests no matter what I said […] [the doctors] were trying to say that I couldn't be autistic because this and that thing said so. They weren't interested in how I felt" (R-sid, 1, 276).

In thinking about the diagnostic assessment as a social encounter between two (or more) people, it is clear that there is an element of performativity on behalf of the doctor and the patient seeking a diagnosis (Butler, 1999). In the case of autism, self-reported history is an important part of the diagnostic process as there are no biomarkers for the condition (Lai et al., 2014). After a long wait for a diagnostic referral, and given the relatively short amount of time patients have to talk with clinicians

(APPGA, 2019), patients may find themselves in the position where they need to present the 'right' kind of evidence, in sufficient quantities, in order to convince clinicians that they meet the threshold for a diagnosis. In Svend Brinkman's words (2016), they need to be able to 'do' autism by 'performing' the specific norms relating to the diagnostic category. The performative aspects of the diagnostic process have been noted elsewhere, such as in the case of bipolar disorder, where people are "able to perform 'mania' in a situationally appropriate way, commenting through meta-action on the condition itself" (Martin, 2007, p. 86). As Agnes Ringer (2013) argues, patients learn to perform conditions in ways that are deemed appropriate by medical professionals for diagnosis and treatment: act too well and you risk being discharged and sent home, act too ill and you risk being accused of fabricating illness. "One must learn how to perform one's suffering properly," Brinkman (2016, p.32) notes, "and [a] diagnosis provides a significant 'script' in this regard." By pointing to the performative aspects of the clinical encounter, I am not suggesting that people fake symptoms in order to get a medical diagnosis. But what I am suggesting, as does Brinkman (Ibid., p. 32), is that the complex and idiosyncratic symptoms that people experience must become "aligned with the authoritative models such as those made explicit in the diagnostic manuals," and that this is realised by doing and saying the right thing at the right time during the diagnostic encounter.

As has been pointed out by others (Wylie, 2014), undergoing an autism assessment can be an extremely stressful experience. For somebody in this position, it can feel like an invasive process where they are put under a spotlight and questioned about various aspects of their life:

> "I mean, it's a stranger asking you loads of personal questions, like there's never not going to be something not distressing about that" (O-mdx, 1, 320).

The pressure felt during a diagnostic encounter – that is, behaving appropriately and answering questions 'correctly' – can lead to an overwhelming sense of unease and confusion that can inhibit how an individual responds to the doctor's inquiries:

> "It's horrible. It's like being in an exam, you can revise all you like and then you get in there, you start talking to [the doctors] and your head goes blank" (P-mdx, 2, 623).

> "I think because I was very unhappy when at the diagnosis […] a lot of things I simply forgot or I just wasn't thinking about […] and so [the doctors] couldn't get a clear enough picture from me" (R-sid, 1, 372; 324).

For somebody seeking an autism diagnosis, part of the performance is about demonstrating one's 'true autistic self' – the thoughts, behaviours, and emotions that have been supressed or hidden away due to social norms or fear of attracting stigma. This can be difficult to do after years, if not decades, of learned behaviour, and it may not be something that people seeking a medical diagnosis feel that they can do, or feel comfortable doing, in the presence of a clinician during a short consultation:

> "It's very hard […] actually letting [doctors] see the extent of what is wrong with you, especially when you are trying to kind of go, 'but I'm alright really,' because that's your instinct, that's what you've been doing for years […] so I was sort of consciously masking [during the assessment] […] I [was] trying to appear okay, I [was] trying to play down things that really are an issue, which seems stupid afterwards" (N-sid, 2, 85).

By "playing things down," an individual may feel as though they impede their chances of obtaining a positive diagnosis "because basically I shot myself in the foot" (N-sid, 2, 82). But it may also be the case that the client appears to be trying too hard to secure a diagnosis, to the point that clinicians start to question the authenticity of the account provided. As was observed by my colleague, Jennie Hayes (2019), when clinicians discuss a patient's case during a multidisciplinary meeting – one of the methods used

to arrive at a diagnostic decision – they often talk about the plausibility of an individual's reported history and their motivation (or that of family members) for seeking a diagnosis. Coming across as too keen or too eager for a diagnosis was often noted by clinicians and used as evidence against issuing one (for other factors that contributed to clinicians' decisions, see Hayes et al., 2020). This is something that some of my participants – those on the receiving end of the assessment – were acutely aware of:

> "[The doctors] knew that I was coming into [the diagnosis] believing that I was autistic […] and they believed that I wanted to believe it, as opposed to having researched it properly […] it felt like they dismissed my research and knowledge […] and didn't take me very seriously (R-sid, 1, 346).

Identifying as autistic prior to a diagnostic assessment (as described above) is a double-edged sword. Whilst learning about and embracing autism can bring with it a greater sense of awareness and self-understanding, there is a danger that it can backfire during the assessment if it looks like an individual is trying too hard to get a diagnosis:

> "[The doctors] treat you as if you have to be one of those sorts of people who are just looking for a diagnosis, any diagnosis, that you are after something, and starting from that assumption it can be difficult for them to see past all your enthusiasm and knowledge about autism" (C-mdx, 2, 222).

Whether a client fails to provide sufficient evidence for a diagnosis, or perhaps tries too hard to obtain one, the assessment inevitably concludes with a negative result – they do not meet the clinical threshold for a diagnosis – and yet, as I will now discuss, the client may ignore this result and choose to continue self-identifying as autistic anyway.

Why continue to self-identify as autistic?

One reason for continuing to self-identify is that the client believes that the clinician's assessment was incorrect and that he or she made the wrong decision:

> "I wrote to the head of the [autism] service, like an 8-page letter, detailing why I thought I had autism [and] why I thought [the doctor's] assessment was wrong" (N-sid, 1, 183)

Here, an individual may take the view, like others (see Kapp et al., 2013), that the clinician who carried out the assessment "had a very fixed and concrete understanding […] about what autism is" (N-sid, 2, 45), particularly in relation to those outside the typical demographics associated with the condition (e.g. young boys). This may stem from a broader critique of the diagnostic criteria:

> "…which were developed based on young white males […] [so] the diagnostic kind of process is kind of biased against [others] because they're maybe black or maybe they're female and the criteria and the doctors just don't pick them up" (U-mdx, 2, 372).

Having now been through the process, the client may even start to question the apparent objectivity of clinicians' decision-making in the context of stretched services and limited resources:

> "The reality is for most autistic people there are no resources [available for them], so what is the issue that [the doctors] are gatekeeping this diagnosis, what is it that they're preserving? They're very conscious of the public purse […] that is what it is, and they don't want to give out a diagnosis willy-nilly (J-sid, 1, 397).

Aside from challenging the decision made by the doctor, somebody in this position may also find themselves heavily invested in the idea that they are autistic. They might have integrated the concept into their sense of self. Autism makes sense to them. It explains why they feel and act the way they do. What is missing now is the corroboration that comes from the formal diagnosis:

> "I very much need things to make sense […] I need a framework […] [and] I have what I think is one, but I can't get anyone who is supposed to know about this stuff, any professional, to verify that I am autistic" (R-sid 1, 427).

Part of this commitment to autism, and the belief that the doctor must have got the assessment wrong, comes from the fact that other autistic people – knowledgeable others – might also believe that the person in question is autistic. They recognise in them the characteristics and behaviours that they associate with themselves and others with a medical diagnosis (see Chapter Six). Following a negative diagnosis, these knowledgeable others are able to reassure the client, at least from their experience, that they *are* autistic and that the doctors must have missed something:

> "My friends have said, 'of course [you] are autistic […] you are definitely on the spectrum, as if there was ever a question about it. I can't believe the doc didn't see it!'" (F-sid, 2, 214).

Gaining the autistic approval of knowledgeable others is important for somebody in these circumstances as it is easy to see how their credibility regarding their self-referral is undermined following a negative assessment. Not only do these knowledgeable others, at least in the client's eyes, have some lived experience and therefore a better sense of what it means to be autistic, but they also have the autistic authenticity that comes with a medical diagnosis which, ironically, is often used by those people to discredit the very clinicians who issued it (see Giles and Newbold, 2011):

> "The people I know who I consider more to be the experts, autistic people, […] they have a lot more credibility than [doctors] do because they actually know what they're on about. They've lived autism, they know what it's like to have the condition and what to look out for" (A-mdx, 2, 751).

It is the welcomed approval of knowledgeable others that enables some to confidently self-identify as autistic despite a negative medical diagnosis, and take solace from those who have obtained a diagnosis who have said "that in their experience people

who self-diagnose are very rarely wrong" (N-sid, 1, 249). I will consider what options (if any) are available for somebody like this later in the chapter.

Self-identifying as an alternative to a medical diagnosis

Compared to the two previous reasons, the next way of self-identifying as autistic is fundamentally different. Here, an individual does so because they do *not* want a medical diagnosis. They do so as an *alternative* to seeking, and possibly obtaining, the official medical label. They may be just as confident that they *are* autistic – they have done their research and spoken to knowledgeable others about it – but unlike others in this position, they disagree on the course of action to be taken regarding a diagnosis. There are two major reasons for this. The first is that they might not see autism as a psychiatric disorder that requires a medical diagnosis, and the second is that they question the value and utility of a diagnosis at this point in their life. They do not believe that they need the approval of a doctor to self-identify as autistic and have no plans to seek a diagnosis any time soon.

"I don't believe autism is a medical issue"

The dominant narrative when it comes to matters of health and illness is that if you suspect that there is something wrong with you, or that something does not feel as it should, you should go and talk to a doctor (Cockerham, 2017). By speaking with a doctor, they can attempt to make a diagnosis and suggest a course of treatment (if at all possible). Although there are some significant differences with neurodevelopmental conditions such as autism – namely, whether there are any effective treatments for autism and whether it is even a suitable target for treatment (Kapp et al., 2013) – the same logic still applies. Adults (and parents of children) who suspect that they have

autism are advised to seek medical opinion and are encouraged to pursue a formal diagnosis. Somebody who self-identifies as an alternative to a diagnosis does not take this view, partly because they do not see autism (and the broader autistic spectrum) as a medical condition that requires diagnostic intervention:

> "Well, diagnosis puts it firmly into a medical issue to me, and I don't believe autism is a medical issue" (J-sid, 1, 165).

> "I don't like the concept of diagnosis because of its implication of pathology" (T-sid, 1, 5).

Like others (Armstrong, 2010), somebody taking this view may see autism as a natural part of human variation – part of its 'neurodiversity' (Singer, 1999) – and feel that they themselves are "positioned somewhere on the autistic end of the human condition" (T-sid, 1, 7). If autism is seen not as a pathology, but as part of the natural diversity exhibited in the human gene pool, then it would not, from this perspective, warrant a medical diagnosis:

> "I am autistic just as much as I'm somebody with brown hair […] and you wouldn't diagnose me with that, would you?" (J-sid, 1, 173).

The concern, at least from this perspective, is that the medicalisation of autism – viewing various characteristics exhibited by certain parts of the population as symptoms of a deficit-based neurological condition – means "that the bits of weirdness that lots of [people] do become signals to others that they're objects of special concern" (T-sid, 1, 98) – things that are 'wrong' with them. This is what is most troubling for some:

> "I [would] find it very offensive to hand over the core of my being to be stamped with a pathology [by] a doctor. I mean, why should a doctor have anything to do with saying who I am. It makes me want to curse and swear!" (T-sid, 1, 291).

Not only that, but as noted in the previous chapter, the lack of specificity surrounding autism as a medical construct – what I called the label's 'slipperiness' – leads some people to doubt the diagnostic application of the label:

> "I've learnt that through the psychological testing that I've been put under, there are no definitives […] it's all very much a guess game with [doctors] following tick lists […] and I think there is so much that isn't known about so many conditions, including autism, that I don't see why I need a specialist to sit down and go […] 'Hmm, yes, I think you are [autistic]'" (N-sid, 2, 381).

"I'm not sure what I would gain from a diagnosis"

As well as questioning the validity of autism as a psychiatric concept, an individual may also question the need for a formal diagnosis: "Wow, [a doctor] gave me a piece of paper saying, 'oh, you're autistic.' It's just like, so what?!?" (J-sid, 1, 312). Part of this has something to do with the practical utility of a diagnosis:

> "I'm not sure what I would gain from having a diagnosis. If it had existed […] when I was a kid, I think maybe it would have been helpful, but I don't think it would be so helpful now" (D-sid, 2, 295).

> "I just don't see what the point is, because I've got a good job, I'm very high functioning […] and I have a much higher standard of living than […] the majority of people […] so I don't see the point" (H-sid, 1, 405).

As we saw in the previous chapter, the official autism label is often required to access certain welfare resources (e.g. social support, housing, financial assistance) – the secondary gains of the diagnosis (Davidhizar, 1994). If, however, somebody finds themselves in a position where they do not require those resources, then the secondary gains that may have persuaded others to pursue a medical diagnosis will not persuade them:

> "I'm not staking claim to a high moral ground […] because I chose not to have a diagnosis, I'm just saying that if you happen to be a lucky and privileged person who is being supported by a fairly good earner […] then why would you need to go and get

> yourself stamped with this thing which says you've got everything wrong [with you]" (T-sid, 1, 331).

As we saw when self-identifying as autistic as a precursor to a medical diagnosis, seeking a diagnosis can be a long and potentially complicated process. For somebody considering an autism diagnosis, it may simply be too much effort, "too much of an inconvenience" (C-mdx, 2, 65) to pursue one, especially if they have already been through the process with a child of theirs who has recently been diagnosed (I will talk more about this in Chapter Six):

> "The nearest place I've found for adults is […] a 2-hour drive [away], then you have a 2 to 3-hour session and another 2-hour drive home. I don't have time to do that. I suppose I would if I could choose the time and the day, but you get some random [appointment]. What happens if I'm [working]? It's stupid!" (H-sid, 1, 294).

Notwithstanding the apparent inconvenience of the assessment, somebody like H-sid may have also arrived at the conclusion that it is better not to pursue a diagnosis after all, particularly because of some of the negative connotations associated with the condition. As noted on p. 160, autism is a label that has the capacity to stick *with* other people to the point that it changes their expectations of the person before them. Some of the people that I spoke to were aware of this and may avoid a medical diagnosis because:

> "People are very intolerant of people who are different […] [so] if you can get away with it, you're better off masking and not telling people that you're autistic and functioning better […] because nobody knows then" (N-sid, 2, 339).

Of course, if N-sid had a medical diagnosis then she may choose not to disclose it, but she may feel a pressure or expectation to do so, if not informally then at least to her employer:

> "It would change people's perception of me at work and they'd always be treading on eggshells around me […] you're essentially losing social capital" (H-sid, 1, 383; 420).

This apprehension about getting an autism diagnosis may also extend to concerns about future healthcare treatment, particularly if one has already been diagnosed with another psychiatric condition:

> "I am worried about getting a formal diagnosis because of what seems to be implied that autistic people can be sectioned in ways that other people can't, and I'm not comfortable with that" (J-sid, 1, 759).[54]

The perceived drawbacks of a diagnosis, therefore, appear to outweigh the apparent benefits of obtaining one. Even if one took the view that autism is not a medical condition, for them there may still be no obvious reason for 'upgrading' their self-assigned label to the formal medical category, even if on pragmatic grounds (see Figure 5.1,' p. 193). That said, for somebody self-identifying as an alternative to a diagnosis, they may find themselves lacking the autistic authenticity that comes with the official medical label. Self-identifying as having what is predominantly seen as a psychiatric condition can often be met with varying degrees of scepticism (as I found with some of my medically diagnosed participants). Although some may not care for medical approval, particularly if they do not see autism as a psychiatric condition, they might find that their claim to being autistic somewhat tenuous with those who *do* value the judgement of medical professionals. And yet, had the diagnosis been available prior to the 1980s (the diagnostic category did not enter the DSM until 1980), some adults today might have been formally diagnosed with the condition, but now feel that

[54] I am not aware of any policies or codes of practice which state that it is more (or less) likely that somebody with an autism diagnosis can be detained in hospital under the Mental Health Act (https://www.legislation.gov.uk/ukpga/1983/20/contents). But even if this quote by J-sid is incorrect, such beliefs illustrate another reason why somebody like her may avoid getting a medical diagnosis.

it is too late, or not worth the effort, to pursue one. Those who find themselves in this position are collectively known as the 'lost generation' (Lai & Baron-Cohen, 2015); those children, who are now adults, who were never diagnosed with autism because of medicine's previous ignorance of the condition. Knowing that there are a generation of people who are probably autistic but have slipped through the system without a diagnosis, some have no qualms in self-identifying as autistic, even if others are sceptical of them or doubt their intentions.

Self-identifying as having autistic traits only

The final way of self-identifying is somewhat different from the previous three. Unlike those, it is possible for somebody to take the view that they are *not* autistic (and thereby do not self-identify as autistic), but instead recognise in themselves certain features associated with the condition which could be described as their autistic traits. These may be particular feelings, mannerisms, or behaviours that they have identified in themselves (perhaps with the help of knowledgeable others), but, most importantly, they stop short of saying that together these traits constitute autism itself. This might be because they do not feel 'autistic enough' to claim the label for themselves – that the observable traits are not severe enough to warrant the label – or perhaps because they want to avoid the stigma associated with the condition.

You may be wondering why somebody like this is included in a discussion on self-identifying as autistic when they clearly do *not* self-identify as autistic. There are two reasons. The first is that this sort of thinking has been observed in my empirical data. I interviewed participants who believed that they had autistic traits but felt that they did not meet the diagnostic criteria for the condition. They saw themselves as having

characteristics associated with the condition, but not the condition itself. As B-sid (1, 189) pointed out, "you can definitely have autistic traits without being what people would say is autistic." The second reason, and this is something that I will talk more about at the end of the chapter, is that this kind of self-identification (one associated with traits, not the label itself) could be seen as a precursory step to the other ways of self-identifying as autistic, particularly when doing so as a precursor or an alternative to a medical diagnosis. Before somebody self-identifies as autistic, they may go through a phase of identifying with particular traits or characteristics associated with the condition, slowly building up a store of evidence that eventually convinces them (and other autistic people) that they *are* autistic and should self-identify as such. This might therefore represent the first tentative steps towards the fully-fledged self-identification as seen in the previous sections. I will return to this idea shortly.

Why identify with traits and not the label itself?

What constitutes an autistic trait generally has something to do with the way an individual perceives the world and the people around them. For instance, they may recognise what they describe as their intense hobbies and specialist interests as possible autistic traits. It is not that the content of these activities are particularly autistic, but rather the intensity and voraciousness of them:

> "I'm really passionate about music and I spend a lot of my time thinking about it, or listening to it or critiquing it … it forms a large part of me which I think, looking at it, could be considered obsessive […] like the tendency to obsess over it in infinite minutiae and kind of ignoring more pressing things like work, or chores, or family […] it could definitely fall into the category of traits that people seem to associate with autism" (B-sid, 2, 27).

Some of these traits might be viewed in a negative light, problematic aspects of a person's behaviour, whereas others (perhaps less intrusive behaviours) can be seen much more positively:

> "There's lots of weird benefits [in having autistic traits], it's like being able to … err … cooking, I can hear flavours, so I can put [ingredients] together because I can hear how they go together […] Yeah, it's a skill I have. Well, actually, it's not even a skill, it's just a weirdness (laughs) […] It's very strange. I just didn't realise other people couldn't do that" (D-sid, 1, 303).

It is these idiosyncrasies that somebody can come to view as evidence of autism. These skills or obsessions are not, in their eyes, considered 'normal' behaviours that non-autistic people experience. They are something different. *They are autistic traits*. Yet an individual may hesitate to call themselves autistic:

> TL: "Are you an autistic person?
>
> D-sid: No
>
> TL: What then would you describe yourself as?
>
> D-sid: (Long pause) I was going to say that the obvious thing would be to say neurotypical, but I think that's wrong too […] I don't think I would ever have got a diagnosis as a child, but … I recognise in myself traits of … autistic traits probably" (1, 2).

There are a few reasons why somebody might stop short of identifying as autistic, instead preferring to identify as having autistic traits. The first is that any form of self-identification, from fully embracing the diagnostic label to only associating with certain features of it, is an emergent process that can happen over the span of many weeks, months, or years. Unlike receiving a medical diagnosis, which marks a clear and decisive categorisation (at least that is how the act of diagnosis is generally perceived), labelling oneself as autistic is a much more iterative process where one may consider

the idea for a while, 'trying on' the label and 'taking it off' in order to determine whether the category fits – taking the sticky name tag on a trial run, so to speak. Autistic traits, whether defined as psychiatric symptoms or broader psychological characteristics, are generally the first thing people associate with the condition (Hassell, 2016). Therefore, if somebody were to consider whether autism is something that might apply to them, they might start by looking for autistic traits. This is what some of my participants were doing. They were attempting to explain certain aspects of themselves – certain skills or obsessions – using the language of autism, and it appeared, at least in their eyes, to make some sense, to be sticking. "And so over time I've just gradually kind of osmosed the concept of autistic traits into me, and some of them seem to fit" (L-sid, 1, 123). Identifying with autistic traits may be the beginning of a more comprehensive form of self-identification, where the entire category, not just elements of it, are embraced by an individual.

If an individual finds themselves in this position, gradually identifying with aspects of the label, then they may avoid categorically identifying as autistic because they do not feel 'autistic enough' to do so, at least for the moment. This might be because they do not see their autistic traits as problematic or detrimental in their day-to-day life, at least not when compared to those with a medical diagnosis:

> "I wouldn't use [the label] because for me whatever traits I have do not impact on my life as an obstacle like [a friend with a medical diagnosis]" (B-sid, 1, 144).

> "I am looking at myself and going, I may be autistic in terms of […] having particular traits, but I don't think I'm autistic enough in terms of it being a disability" (L-sid, 1, 726).

Therefore, it may feel inappropriate, or perhaps disingenuous, to fully embrace the label as their own, and that it is better to stick with autistic traits:

> "I use [the term] traits as I think that's more genuine, whereas if I use the term autistic, I think that it takes away from people who … who are genuinely, 100%, without a doubt [autistic]" (B-sid, 1, 152).

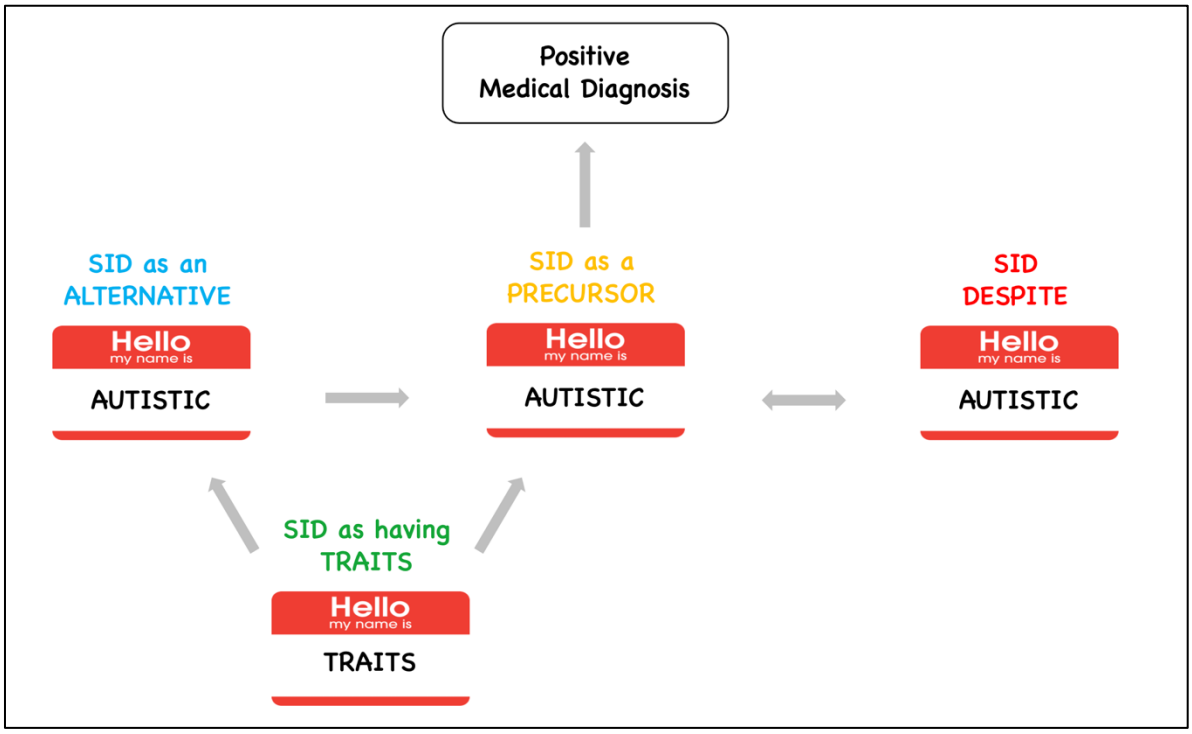
Another reason why one may avoid self-identifying as autistic is to avoid the stigma associated with the condition – the negative ideas and images that find themselves sticking to the label and those wearing it. "It is the extreme representations of autism found in parts of the media that put's me off identifying as autistic" (L-sid, 1, 356). The desire to eschew the negative connotations associated with autism can be likened to a political phenomenon that psephologists call 'shy Torie voters' (Berthezéne & Gottlieb, 2018; Whiteley, 2016). These are members of the public who generally hold conservative or right-wing values, would vote for the Conservative Party (colloquially known as the Tories) in local and general elections, but would *not* identify themselves as a Conservative supporter when asked by a friend or a polling company. These people keep their conservative values to themselves, perhaps because within their social circle it is an unpopular political position to have, hence the name *shy* Tories. Considering the stigma associated with autism and the possible apprehension one may feel toward the label, it might be possible to describe people in this position as 'shy self-identifiers,' for want of a better phrase. They do not wish to affiliate themselves with the negative images associated with autism, and that may prevent them from fully identifying with the label in the way that other people do. Although, as I will demonstrate in the following section, that opinion might change.

Transitioning between ways of self-identifying as autistic

As noted earlier, there is a temporal element to these ways of self-identifying and it is possible, if not likely, that people who self-identify as autistic transition between these

reasons at different points in their life. I want to end this chapter by considering some of these transitions (as found in my data), which are illustrated in Figure 5.1.

Figure 5.1: Transitions between ways of self-identifying



Self-identifying as a precursor to a diagnosis: A state of transition?

If one self-identifies as autistic whilst seeking a medical diagnosis, they inevitably find themselves in a state of transition where the label they have assigned to themselves is likely to change following their official assessment. There are three possible outcomes. The first is that they receive a positive medical diagnosis (upward facing arrow in Figure 5.1). They have met the clinical criteria for the condition and the doctor has formally diagnosed them with autism spectrum disorder.[55] Here, the 'upgraded' medical diagnosis overwrites the self-assigned label. Of course, it is still possible to self-identify as autistic with a medical diagnosis, but as I found talking to people who

[55] As was the case for participant P, who received his medical diagnosis between our first and second interviews.

used to be in this position, the medical diagnosis becomes the primary and preferred means of thinking about and communicating the label: "I *used* to self-identify as autistic before getting a diagnosis" (C-mdx, 2, 279, emphasis added).

The second outcome is that the assessment comes back as negative – the client does not meet the criteria for a diagnosis – yet they continue to self-identify as autistic, transitioning to somebody who self-identifies despite a medical diagnosis (the right facing arrow). The third outcome, not depicted above, is that the result comes back as negative and the individual ceases to identify with the condition. The doctor has said "no" to autism and the client revokes their self-assigned label. Here, they become somebody who *used* to self-identify as autistic but no longer does.[56] This transition raises an interesting methodological question surrounding my sampling strategy, which I will talk more about in Chapter Seven (p. 246).

In any of these outcomes an individual's transition is dependent on the results of a clinical assessment, which is why it may be best to see this type of self-identification as a transitory phase. How long an individual finds themselves in this position depends on the diagnostic process. As my colleague, Jennie Hayes (2019) and others (Rossi, 2012) have found, those seeking an autism diagnosis may find themselves in a diagnostic or institutional loop for some time, particularly if their assessment comes back as inconclusive or there is disagreement amongst the assessing clinicians. Indeed, one of my participants, F-sid, was awaiting his fourth diagnostic assessment after three indecisive results. For him, this transitory phase was starting to feel more

[56] It is worth noting that although Figure 5.1 illustrates the possible transitions *between* the ways of self-identifying as autistic, all four groups could stop identifying as autistic at any time.

like a permanent state of limbo, with each inconclusive assessment resulting in another lengthy referral for a new evaluation.

Self-identifying despite a diagnosis: Stuck here?

As the successor to the above way – that is, if one were to continue self-identifying as autistic following a negative result – those who self-identify as autistic despite a negative diagnosis find themselves with limited options. The medical diagnosis they so badly sought is no longer within their grasp and they are stuck with their self-assigned label. If inclined, an individual in this position could pursue a second opinion and a new assessment – transitioning back to self-identifying as a precursor (left facing arrow) – but whether that option is available to them depends on the availability of autism services within their healthcare region.[57] They could pay for a private diagnostic assessment, as one of my participants (E-mdx) did, but this is often an expense that is out of reach for many people. Officially, there seems to be limited guidance available for those who wish to contest the outcome of their autism assessment, and even less information about how to request a second opinion (APPGA, 2019). But putting these issues to one side, even if the option of a second opinion was available to an individual they may feel as though they are not entitled to it:

> "It feels like I've been blacklisted […] the weight of that first negative result has blown any chance of me having another go at this […] it feels like I have no recourse now, it feels like I have nowhere to go from here in terms of actually being able to do anything about it" (R-sid, 2, 149).

Because of this, those who find themselves in this position may feel as though they are at a terminal state, that they are stuck self-identifying as autistic and cannot get

[57] There were no instances of this transition in my data.

referred for another diagnostic assessment. They may eventually accept the outcome of their previous evaluation, but having spent months if not years identifying as autistic it is unlikely that they will change their mind, at least according to those that I interviewed in a similar position.

Self-identifying as an alternative to a diagnosis: Happy here?

As those who self-identify as an alternative to a diagnosis do not see autism as a medical condition and/or see no benefit in obtaining an official diagnosis, it is likely that they will continue to self-identify as autistic indefinitely. If, however, something were to change their mind – perhaps they started to see the potential benefits of a medical diagnosis (e.g. greater accommodations at work) – then they might pursue one and in doing so transition to somebody who self-identifies as a precursor to a medical diagnosis (right facing arrow). This might be done, it is worth noting, with an air of reluctance, particularly if they disagree with autism being classified as a psychiatric disorder. But it is still possible to hold this view whilst seeking a medical diagnosis purely on pragmatic grounds, especially if one feels that they would benefit from some of the secondary gains of the label. Yet whilst an individual feels that there are no overall benefits to obtaining a formal diagnosis, they are likely to continue self-identifying as autistic.

Self-identifying as having autistic traits: Potential to change?

As I mentioned earlier, it is possible for somebody to identify with certain features of a psychiatric condition without fully embracing the category for themselves. For those who do this, recognising that they have certain autistic traits may mark a transitory phase that eventually leads to them fully self-identifying as autistic. However, in order

to do this, one would have to move from identifying as having only autistic traits to actually being autistic, which would involve embracing the diagnostic category to a greater extent. If one were to come to this conclusion and wanted to have this confirmed through an official diagnosis, then they would have made the transition to somebody who self-identifies as a precursor to a diagnosis (right upward arrow). Alternatively, if they decided that they did not want a diagnosis – at least for now – then they would be self-identifying as an alternative to a medical diagnosis (left upward arrow). Either way, an individual would have to start seeing themselves as autistic rather than somebody with autistic characteristics, which they may never do because of the perceived stigma associated with the condition.

Never self-identifying as autistic

It is important to note that not everybody who obtains a medical diagnosis self-identifies beforehand. An individual may suspect that they have autism, or that there is something 'wrong' with them and that what they are experiencing is a medical matter, but they may not choose, like some of my participants, to actively and definitively identify it as autism:

> TL: "Did you go into the referral thinking, 'I'm going to get the diagnosis?'
>
> E-mdx: No.
>
> TL: Why not?
>
> E-mdx: (Long pause) Because it wasn't for me to make that judgement. That is why I never self-identified. It wasn't for me to make that judgement. That's for somebody else.
>
> TL: Who?

> E-mdx: It's going to be the psychologist, the psychiatrist. That is their assessment. That is their criteria. It is not for me to presume that I'm going to get something" (1, 349).

As such, these four ways of self-identifying represent a certain type of person who is willing, or who has no other choice, but to self-identify as autistic. Some of the participants that I interviewed had been through some of the above transitions before obtaining their official diagnosis, whereas others, like E-mdx, went straight to a medical diagnosis without self-identifying first. The point is that not everybody with a medical diagnosis previously self-identified as autistic, and not everybody who self-identifies as autistic wants a formal diagnosis.

Chapter conclusion

In this chapter, I have outlined the second part of my analysis into how people acquire the label autistic in adulthood and the consequences of doing so. Here, I have focussed specifically on how people go about labelling themselves as autistic and their reasons for doing so, which have been categorised as the following: (1) identifying as autistic as a precursor to seeking a medical diagnosis, (2) identifying as autistic despite a negative diagnosis, (3) identifying as autistic as an alternative to a medical diagnosis, and (4) identifying as only having autistic traits.

As well as offering a useful description of my own empirical data, it is my intention that these four ways are used as 'sensitising concepts' (Blumer, 1969) when others are investigating the self-identification or self-diagnosis of other conditions. As noted earlier, when self-identification is discussed in the existing autism literature it is usually framed as a precursory step to obtaining a medical diagnosis (Lewis, 2016b; Sarrett, 2016). As I have demonstrated this is not the only reason somebody would label

themselves as autistic. The process of self-identification is far more nuanced than previously thought, and these four ways sensitise researchers to some of the possible reasons people may have for doing so. Autism is just one example of these motivations, which may apply equally to other physical and mental health diagnoses. I will consider the wider application of these ideas in Chapter Seven, but for now let us turn to the final findings chapter: spotting and seeking autism in others.

Chapter Six: Spotting and seeking autism in others

In this, the third and final findings chapter, I focus on what I described earlier as one of the alternative ways that somebody can be labelled as autistic in adulthood: being labelled as such by another autistic person. As I discovered, many of the people that I interviewed had both labelled other people with the condition and had been on the receiving end of this labelling, which I refer to as a lay diagnosis. In order to explore this phenomenon in more detail, I make the distinction between 'passively spotting' and 'actively seeking' autism in others, and consider the reasons somebody may have for labelling another person with the condition.

An interesting observation

One of the great advantages of doing qualitative research is that it provides the opportunity to explore unanticipated lines of inquiry. For instance, during the design of this study I knew that I wanted to investigate how people went about labelling themselves as autistic (see Chapter Five) and the implications of acquiring the label, whether self-assigned or given by a doctor (see Chapter Four). Something that I did not anticipate studying, however, was the act of autistic people (that is, my participants) labelling other people as autistic. This idea came to my attention during one of my early interviews with E-mdx (see p. 113 for a reminder of the participants interviewed). We were coming towards the end of the conversation when E-mdx made the following, unprompted remark:

> "I did once meet somebody with autism in the [organised group] that I was in. He had an IQ, he said, of 198. I mean, he could maintain three different thought processes at once … but at the same time you could see he had some obvious failings in other areas, especially in his personal interactions with his wife and children" (1, 778).

I was particularly interested in the idea that E-mdx could "see" that this man had "some obvious failings" of his own – a phrase, I suspected, E-mdx was using as a euphemism for autistic traits. I inquired further:

> TL: "When you met this guy, did you see any similarities between you and him?
>
> E-mdx: Yeah, I immediately knew he had … from the research I'd done I was like, yeah, I know.
>
> TL: Before he told you, you knew [that he was autistic]?
>
> E-mdx: I knew immediately, I picked it up, I knew it […] I'm like, no, there's something about this guy, there's something there, and I was not surprised when he said that he was [autistic]. I'm like, yeah, I can see it in you" (1, 785).

It was that last comment, "I can see it in you," that stuck with me. I came across a similar idea in the book *Re-Thinking Autism*, in which the author, Katherine Runswick-Cole, whose child has a medical diagnosis of autism, described how she was able to "spot [autism] in [her] husband," and how she would "look for autistic pathology in [other] family members" after discovering what the condition was (2016, p. 23). It struck me that Runswick-Cole and E-mdx were describing a similar experience, which was that after learning about autism and, in the case of E-mdx, acquiring the label for himself, both believed that they were able to identify the signs of the condition in other people. *They could see autism in them*. This was a fascinating idea, and one that I explored in subsequent interviews with participants.

All of the twenty-one participants that I interviewed reported that they were able to identify the signs of autism in other people (at least to some extent), and there were two ways that they did so. The first was when participants *passively recognised* the signs of the condition in others, like the encounter E-mdx had with the man in the

group, where certain characteristics or features jumped out as being typically autistic. This type of identification is what I call ‘passively spotting’ autism (i.e. to see, notice, or become aware of it in others). The second way is a much more deliberate form of identification, which saw participants *actively search* for evidence of autism in other people, much like the way Runswick-Cole described in relation to her family. When an individual purposefully looks for the condition in others, I call this ‘actively seeking’ autism (i.e. to search, inquire, or cast around for signs of the condition).

Recognising that I might be in danger of oversimplifying things, the difference between the two types of identification can be thought of in the following way: spotting autism involves an *individual seeing autistic people around them*, whereas seeking autism involves an *individual seeing the people around them as autistic*. As I will demonstrate shortly, the people that I interviewed reported doing both types of identification. In some moments they may spot autistic traits in an individual they have just met, and in other moments they may be on the lookout for signs of the condition, particularly in relation to family members and friends. It is the distinction between the two that I aim to tease apart in this chapter.

Whilst both forms of identification are mostly a private affair – something that one thinks about on one’s own – there are occasions when an individual may choose to disclose their suspicions to the person in question (that is, tell another person that they are autistic, or that they might be, based on the signs that they have displayed). As noted in Chapter Two, the act of a lay person diagnosing another lay person with a medical condition can be described as a lay diagnosis (not to be confused with self-diagnosis or self-identification, which refers to a lay person labelling *themselves* with

a medical disorder). As I discovered talking to participants, it was not uncommon for them to issue their own lay diagnosis on those who they suspected had autism. When this occurred, being on the receiving end of this lay assessment acted as a catalyst for others to self-identify as autistic and/or pursue an official diagnosis, as was the case for some of my participants. This giving and receiving of a lay diagnosis, as I will demonstrate, works in a cyclical fashion, whereby being told that you are autistic prompts an individual to acquire the label for themselves, and once they have done so, use that newly acquired knowledge to label other people as having the condition. This process cycles from one person to another, and the distinction between spotting and seeking autism illustrates the empirically observed mechanics of this process.

Before moving on, I want to be absolutely clear about my use of the term lay diagnosis. Here, a lay diagnosis refers to *both* the assessment made by an individual and the disclosure of that assessment. It is perfectly possible for an individual to make a lay diagnosis without telling the person in question, just like a medical doctor can, and, as I will demonstrate shortly, there are a variety of reasons for not telling someone that they might be autistic. The first half of this chapter therefore focuses on the assessment side of a lay diagnosis, whereas the second half considers why somebody would disclose their lay assessment and what happens when they do.

Spotting autism

Spotting autism involves an individual passively identifying the features and mannerisms that they associate with the condition in other people. For many participants, like M-mdx, this was seen as an inevitable consequence of knowing what autism is and how it displays in people like himself:

> "… whilst I wouldn't go so far as to say that I'm going around diagnosing anybody […] I'll see little foibles that people have and think, 'oh yes, that's a sign,' because that's what you do, you pick up on these things" (2, 24).

These signs, M-mdx explained, were often related to the way an individual presented themselves or the way they behaved in certain situations:

> "Eye contact, obviously, is often a marker. Excessive or insufficient physical contact and, erm, non-conformance to social norms, either because you don't care about them or because you don't notice them" (1, 413).

Sensitive to the signs of autism, most participants were able to recall a particular moment when they first realised that a stranger or a recent acquaintance displayed what they saw as the hallmarks of autism. A good example came from Q-mdx, who told me about a time she spotted a young, apparently autistic girl at an event that she worked at:

> "I was volunteering at a camp for girls, ages eight through to seventeen, for a week this summer, and I'm not around children very often so it was fun to see what little girls typically behave like again. But in a group of fifty girls there was … I could pick them out! There was one that I would give my life, like, she was on the spectrum! It was just the way she moved, the way she interacted. […] she was so autistic!" (1, 437).

I asked Q-mdx why she thought that girl was "so autistic." What was it that she saw in her? Q-mdx told me that she saw *herself* in the girl, that the girl looked and behaved in the same way she did when she was younger:

> "Like I said, she moved differently. I don't watch myself move that often, but I know that in school I [took part in sporting events] […] and at one point we had to [perform] then be filmed and watch ourselves in the replay […] and there was always something a little robotic and maybe a little awkward to my movements. And this girl, she moved differently, she was really hunched in on herself, like she was almost protecting herself from all the sensory things around her […] like, it was crazy how alike me and this girl were!" (1, 451).

This tendency to "spot the things autistic people typically do" (I-mdx, 2, 470) included identifying particular features in those outside participants' physical presence. For instance, participants routinely gave examples of people they saw on television who they felt jumped out as being "clearly autistic:"

> "You know on the news when they interview an expert on something and they're really, really passionate about whatever the subject is, but they're not particularly making eye contact or [any] kind of social chit-chat with the interviewer […] sometimes I think, 'ah, that person is clearly autistic,' it is just so obvious that they are" (S-mdx, 1, 223).

This also extended to fictitious characters in books and television programmes. Some of the characters participants identified as autistic included Sherlock Holmes (both in the original short stories and in the BBC's 2010 adaptation of him in the series *Sherlock*); Sheldon Cooper in the American sitcom *The Big Bang Theory*; Luna Lovegood from the *Harry Potter* books and movie franchise; Will Graham, the FBI agent from the *Hannibal Lecter* stories; and the detective Elise Wassermann from the Danish drama spinoff, *The Tunnel*. I relayed some of these examples to U-mdx during our first interview, at which point she described a recent spot she had made in the BBC drama *Casualty*:

> "They recently introduced a character called Ruby, and by the end of the first episode I was like, 'she's autistic!' […] 100 percent, 100 percent!" (1, 493).

I asked U-mdx to explain why she thought Ruby was autistic:

> "Because I was like, I've never related to a character so hard in my life. I really, really felt like I could relate to her 100 percent – which kind of made me sure she was autistic. […] Plus there was this scene where Ruby closed the curtains round a hospital bed and she sat down and said to [a patient], 'look, I know what it's like to be different,' and when she said that I was like, you're definitely autistic! Why would she say that if not?" (1, 506; 528).

Once again, seeing oneself in another person and experiencing a sense of similarity or relatability prompted participants to see these characters as autistic.[58] This was not always the case, however. Some participants described how prior to obtaining their diagnosis, or self-identifying as autistic, they had been unable to recognise the apparently autistic characters in works of fiction, and that they did not understand why some people in the autistic community claimed certain characters as their own:

> "[Sherlock] Holmes is claimed as being on the [autism] spectrum by a lot of people, and prior to my diagnosis I'd always thought, 'why are people doing that? They [characters like Holmes] seem perfectly normal to me, they've got these slight odd things about them but there's nothing particularly odd about them.' In retrospect, ha!" (M-mdx, 1, 61).

In retrospect, knowing what he now knows, M-mdx felt that he was able to distinguish between those "odd little things" and the behaviours and mannerisms that he associated with autism. In other words, *he could now see things that he could not previously see*. Prior to acquiring his label, M-mdx, like many other participants, knew very little about autism, aside from some of the stereotypical images associated with the condition. Since acquiring the label, however, M-mdx had inevitably become more aware of the condition, and it is this raised awareness that enabled him to spot the signs of autism in other people.

This experience can be likened to what psychologists call frequency illusion, that is, our tendency to notice things that we have recently become aware of, giving us the sensation that they are more common than previously thought (Griffin & Buehler, 1999).[59] A common example of this phenomenon is the feeling you get when you buy

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[58] I should note that just because participants believed that an individual or fictitious character was autistic does not mean that they are according to official diagnostic guidelines. What I am talking about here is the apparent presumption that participants could identify autism in others. I will say more about this at the end of the chapter.
[59] Otherwise known as The Baader-Meinhof phenomenon (Aust, 2008).

a new car and suddenly notice more people driving the exact same vehicle. This is the brain consciously identifying that which we have recently become aware of. Something similar may be happening with my participants. Once they become aware of autism, acquiring the label for themselves and learning more about the features associated with the condition, they begin to spot those exact features in the people they come into contact with. Some participants were aware of this propensity and had a name for it, calling it their autistic 'sixth sense' or their 'autidar.'

"I see autistic people"

Like the young boy who was able to see and communicate with the dead in the 1999 film *The Sixth Sense*, one of my participants, C-mdx, believed that her ability to identify other autistic people resembled a similar intuition:

> "To coin a phrase from *The Sixth Sense:* I see autistic people! Because you do, suddenly they're everywhere and you can point them out like that [clicks fingers]. I've worked in schools where I've been, 'he's autistic, she's autistic, I'm sure he's on the spectrum if he's not been diagnosed already. Aspie, Aspie, Aspie! [pointing]' And you can even point them out on trains and other public places" (1, 239).

Another participant, G-mdx, likened this predisposition to the way an individual identifies another person's sexual orientation:

> G-mdx: "You know how some people have something called gaydar, where they can spot other gay people? I have the autistic equivalent of that. I can usually go into a room and spot an autistic [person] immediately.
>
> TL: Do you have a name for it?
>
> G-mdx: Autidar, I tend to call it. I suspect some of it's *subconscious cues* that my brain picks up on that I don't necessarily notice" (1, 238, emphasis added).

The gaydar comparison is an interesting one.[60] According to Rule and Alaei (2016), Canadian psychologists who have investigated the purported ability of those who can identify the sexual orientation of others using their so-called gaydar, there are four broad physical and social domains that people make their assessment on. The first of these is how people *adorn* themselves (e.g. the clothes people wear and their grooming habits; Hennen, 2008). The second relates to a person's *physique*, such as their body shape or the presence of unusual physical features (Conron et al., 2010; Re & Rule, 2015). The third is about how an individual *moves* and *interacts* with other people (e.g. hip sway and shoulder swagger; Johnson et al., 2007). And the fourth relates to how a person *sounds* when they talk to others, such as their pitch and tone of voice (Munson, 2009). The supposed accuracy of an individual's sexuality assessment has been tested under experimental conditions. In one such investigation, Rule and Ambady (2008) showed participants of different sexual orientations photos of gay and straight men and asked them to categorise the images based on their gut feeling. Participants were exposed to the images for between one-tenth of a second and ten seconds. In all but the subliminal conditions (i.e. those below the threshold of consciousness, one-thirteenth of a second), the homosexual participants were statistically more likely to correctly identify the sexual orientation of the people in the images than their heterosexual counterparts ($P < .001$).

Looking at my own data, there was some evidence of participants drawing on similar cues to identify other autistic people. Whilst adornment may relate more specifically to

[60] 'Gaydar' is a colloquial term used to refer to an individual's apparent ability to determine the sexual orientation of other people. My use of the term in the following pages reflects its usage in the psychological studies that claim to investigate this phenomenon.

the presentation of one's sexual orientation (e.g. wearing a gay pride t-shirt or using facial cosmetics), some of the people that I interviewed routinely wore autistic pride badges or t-shirts promoting a positive autistic identity (see Parsloe, 2015), and frequently identified others doing the same. One participant, D-sid, offered a particularly good example of how somebody may spot an autistic individual based on their physical appearance:

> "I took my son to [university] last year. And a friend from [home] has an autistic brother and he was going to meet us at the railway station in [university city]. And we'd never met him before, and so in all this mass of people we had to find him. […] And we knew [when we arrived] who he was, it was plain as a pikestaff which one he was. […] The way he held himself, the way he looked. […] I don't even know how to describe it, but there is a way of … err … almost holding your face, I think." (1, 332).

F-sid made a similar remark, noting that "you can actually look autistic […] maybe because of slightly different posture [or] eye gaze" (2, 665). Q-mdx's earlier description of the young girl at summer camp offers another example of this ("she moved differently"). Other participants felt that it was easier to detect the signs of autism by listening to the way other people spoke:

> "There are certain cadences, like I didn't actually know about these till I read my [diagnostic] report, and apparently I have a very typical autistic voice. […] you can tell in others because they start going off on a monotone […] and don't have the ability to put in inflections and intonations and so on" (G-mdx, 1, 299).

Unlike the above psychological experiments, I am unable to comment on the accuracy of participants' autistic hunches – that would require a different and more focused form of data collection (see p. 264 for suggested research studies). That said, some participants thought that their initial impressions about somebody's autistic tendencies were fairly reliable:

> "If the way I behave and the way I think has been deemed autistic, and I see those same things in other people, then presumably … I mean, I'm no expert here … presumably

> they're autistic too? Surely, right? Whether or not they know it is a different question" (A-mdx, 2, 980).

> "My autidar is normally pretty much infallible, but if someone is really heavily masking, they may slip under it, but that doesn't happen often. I can usually tell who's autistic" (G-mdx, 2, 141).

Whilst everybody that I interviewed recognised that they were able to identify the signs of autism in other people, not all took the view that this equated to an autistic instinct or sixth sense:

> "I don't have an autism radar or anything like that, but you know what I mean, you can … I do get a feel for when somebody is displaying certain, erm, autistic signs … I did see it in [a former work colleague] and I do worry that my boss has it" (E-mdx, 1, 822).

Whether or not participants put a name to their intuitions, the feeling that E-mdx described is the essence of what I mean by spotting autism – the passive, sometimes unconscious recognition people experience when they identify (who they believe to be) another autistic person. This is different from the second form of identification described by participants: when they seek autism in others.

Seeking Autism

Seeking autism refers to the direct and sustained attempts made by an individual to determine whether or not somebody is autistic. It is a much more active process that involves a person drawing on their experiential knowledge of the condition in order to identify the signs of autism in others. The distinction between this and spotting autism – a passive form of identification – did not occur to me until after the first round of interviews and following a prolonged period of data analysis. Although participants did not express it in the same terms that I am using, there was evidence of this difference in the way participants came to see certain individuals as autistic: sometimes it hit

them in a passing encounter (i.e. they spotted it), and other times it became clear following more thoughtful consideration (i.e. they sought evidence of it). Armed with this idea and sensitised to the distinction, I returned to participants for a second interview in the hope of learning more about it.

Much like a clinician who draws upon formal psychiatric criteria to determine whether a patient meets the threshold for a medical diagnosis, so too do autistic people draw upon their own ways of knowing to determine whether or not somebody is autistic. In this instance, participants utilised a form of experiential knowledge to create a framework of what autism looked like in people like them (i.e. adults with relatively low support needs):

> "When looking at other people I'm putting the pieces of evidence together, but I don't think I've built that framework quite up enough for myself that I'm starting to [think], 'okay, let's go look for this feeling and this type of person,' because I'm still building that … yeah, just building that framework and kind of clues in my head. It's getting there though" (Q-mdx, 2, 562).

This framework evolves and becomes more refined as an individual acquires more knowledge about the condition, utilising the same physical and social cues discussed earlier (e.g. how another person moves or talks). As I-mdx explained, this mental scheme was something that he "built up over time as [he] understood more about autism" (2, 733). The problem now, I-mdx acknowledged, was that it was all too easy to go around looking for autistic traits in other people:

> "I do rein myself in [especially] when I'm interacting with people and think, 'oh, there's something there.' In the back of my head I'm always like 'hmm,' you know? I could spend all day looking for little bits and pieces in individuals, you know? I know what to look out for and I see it everywhere" (2, 706).

Another participant, F-sid, reported doing something similar: “I know enough autistic people to know, to have a reasonable idea, what is [and] isn’t plausible for an autistic [person], and I’m constantly on the lookout for it” (1, 375). Interestingly, F-sid also believed that he was able to discern the difference between people *falsely claiming* to be autistic and those *falsely denying* that they had the condition. In the case of the former:

> “… you might have someone who self-identifies as autistic but I’m thinking, ‘hang on, I’ve had a broad enough range of experience [with other autistic people]’ that very rarely you’ll find someone who self-identifies as autistic and I think, ‘hmm, maybe not, their symptoms don’t ring a bell’” (1, 381).

And for those falsely denying that they are autistic:

> “I’ve had a couple of occasions where I’ve dealt with … well, the phrase they used to say was ‘denaspies’ – Aspies in denial. I’ve had at least a couple of those over the years. […] You sort of see a pattern in their behaviour, yes, maybe they’re autistic, probably and yeah, they’re often in denial about it” (1, 408).

The idea of a ‘denaspie’ is a fascinating one and something worth unpacking, if only briefly. F-sid felt that part of the reason people were in denial about being autistic (or having Asperger syndrome) was because of the perceived stigma associated with the condition: “the term autistic [can be] referred to in a derogatory sense in the same way as gay was in the 90s” (1, 453). As I demonstrated in Chapter Four, various ideas and images (often negative ones) can find themselves metaphorically sticking to the label autistic, and when the label is applied to an individual – either through self-referral or a medical diagnosis – it too has the capacity to stick indefinitely (see p. 148). F-sid believed that the continued stigma associated with the condition dissuaded those who suspected that they might be autistic from identifying with the label or pursuing a medical diagnosis. It could be, as I suggested in Chapter Five, that some people prefer not to identify as autistic because they feel that they are not autistic enough to do so

when compared to other people, especially those with a medical diagnosis. They may prefer to identify as having autistic traits, rather than embrace the autism label wholesale. Perhaps these people can be thought of as 'shy self-identifiers' (see p. 192), rather than the provocatively named 'denaspies?' Even so, using the term 'denaspie' offers an insight into the kind of knowledge claims made by people like F-sid. In the context of this chapter, F-sid claims to be able to see something that other people cannot: *he can differentiate between who is and who is not autistic*. Drawing on an experiential framework created over many years, he believes he is able to identify an individual's true autistic self, even if the person in question does not see it for themselves.

Looking for autism in family members, living or deceased

As we saw with the author, Katherine Runswick-Cole, once somebody discovers what autism is (either because they or somebody they know acquires the label) they may find themselves looking for signs of the condition in other people. For many of my participants, a common place to look was their family, as K-mdx explained:

> "As an autistic person you are more likely to have family members with autistic traits […] that's just what happens … you've got to have some level at which you can communicate with people. So you're going to have a bit of a cluster of people with autistic traits around you" (2, 357).

For participants in long-term relationships, it was often their partners who were a source of comparison. For example, N-sid felt that her husband's tendency to continuously hum was a possible sign that he was stimming (a form of repetitive self-stimulant behaviour that is prevalent in autistic people, Kapp et al., 2019):

> "He hums continuously, like as in if he's awake and he's not speaking […] he's literally humming the entire time […] sometimes he'll hum instead of responding to your

> question. That's not normal, and I said, 'that's stimming, that's what that is, you're stimming!'" (1, 428).

Recognising, as other participants had, that it is "possible that people simply interpret some things as autistic that actually aren't" (K-mdx, 2, 362), I later asked N-sid if she truly thought that her husband was autistic because of his proneness to hum:

> "I think he's autistic. I'm quite clear, I think he's autistic. He has meltdowns, he hums if he's awake and not speaking, he has to regulate his environment quite carefully, and he is very technically minded […] to the point that he gets focussed on one thing and one thing only" (2, 599).

N-sid also believed that her father-in-law (her husband's father) was autistic, citing similar reasons, and that this would explain why she thought her husband had the condition. I will return to this familial kind of thinking shortly.

Other participants sought more scientific forms of evidence. Prompted by the Channel 4 (2018) documentary *Are You Autistic?* H-sid downloaded a version of the Autism Spectrum Quotient – a questionnaire used by clinicians to determine whether an adult of average intelligence exhibits the symptoms of autism spectrum disorder (Baron-Cohen et al., 2001) – and asked her husband and children to complete it. There are fifty questions in the survey, and studies have shown that people with a clinical diagnosis of autism tend to score thirty-two and above (out of a maximum score of fifty; Hoekstra et al., 2011). H-sid did not have a medical diagnosis, instead choosing to self-identify as autistic as an alternative. She had two daughters, one of whom had received a formal autism diagnosis when she was younger. H-sid suspected that she and her daughter would score over the thirty-two threshold – which they did, scoring forty-two and forty-six respectively – but her interest was in her husband's score:

> "So, I downloaded this [questionnaire] and tested the family, but I kept the answers to myself. And my husband bloody cheated! Because the first [question] says, 'do you prefer the company of other people compared to yourself?' and he put, 'yes, he did prefer it' … no he bloody doesn't! It isn't true, so he cheated" (1, 84).

Her husband scored twenty-one out of fifty, eleven points below the typical score for respondents with a medical diagnosis. "I don't believe him," H-sid told me, "he swears blind that his score was twenty-one, but he didn't answer the questions honestly. I reckon it's probably much higher than that" (1, 90).

Partners were not the only family members that participants set their sights on, with most suspecting that their parents and grandparents also had the condition. "After all," as A-mdx (1, 624) noted, "it would explain why I am autistic. I must have got it from them!" After C-mdx and her son were diagnosed in quick succession, C-mdx started to believe that her mother was also autistic. She observed the way her mum behaved and the way she talked to other people, the rigidity in her actions and the uncompromising tone she took when plans suddenly changed. "We've had some quite lively arguments about it," C-mdx explained, and "looking at the criteria and how my mum behaves, I do think that she is autistic … actually, I'm certain of it" (1, 300). C-mdx described how her mum had questioned the validity of her (C-mdx's) diagnosis, mostly because of what may be inferred by having a child and grandchild with autism: "'[You] can't have autism' she would say, 'because that would mean that I have got it!'" (1, 302). C-mdx insisted that her mother was autistic and that she was in denial about it.

I relayed this story to another participant. Like C-mdx, since M-mdx had acquired his medical diagnosis, he increasingly found himself turning to his parents in search of identifiable autistic features:

> "Rather like the person you mentioned who found their [son] was [autistic] and they found out that they were and suspected that their mother was, since my diagnosis I've certainly been looking round the house and thinking, 'gosh, dad does have an awful lot of books about Bob Dylan'" (1, 293).

According to M-mdx, the sheer number of Bob Dylan books his father had accumulated "made [him] raise an eyebrow [as] that's clearly one of those so-called autistic obsessions" (1, 308). He saw this as an autistic trait because his own interest in battleships and the American civil war were used as evidence of autistic tendencies in his own diagnostic assessment three years prior. The Bob Dylan books were not the only thing M-mdx pointed to. His father's dress sense and the way he interacted with other people were also things he noted as likely signs of autism (he had also come to the same conclusion about his mother). That said, M-mdx acknowledged that neither of his parents "are interested in getting themselves a diagnosis, so I just have my own little pet theories" (1, 327). As his parents were not interested in pursuing a medical diagnosis, M-mdx kept his observations to himself (I will consider what happens when people disclose their suspicions shortly).

Seeking the signs of autism in other people, be they family members or a complete stranger, is not just something that occurs in a face-to-face interaction, it is also something that is retrospectively done. Having discovered what autism is and observed evidence of it in family and friends, participants routinely found themselves reflecting on previous encounters with other people and recognising now what they did not know then: that certain individuals were apparently autistic. As the following extracts demonstrate, part of this retrospective re-assessment is about viewing an individual's oddities and idiosyncrasies through the newfound lens of autism:

> "Some people in the past, you pick up and think, 'oh, they [came] across as a bit unusual, a bit odd, a bit eccentric, a bit weird' etcetera, but at the time you don't necessarily know that they're autistic – *they* might not even know. But yes, then you look back and go, 'oh, actually now I've found out that I'm autistic, I've learned about it, actually, I think that person might have been" (G-mdx, 2, 116).

> "There's this guy who's an artist and, yeah, he's got a bit of a funny way of communicating. And my partner actually said, 'I think he's autistic' and I thought, 'yeah, it's quite likely.' Yeah, I would previously have just thought that's just the way that person is and now, okay, that is the way he is, but quite possibly because of autism" (K-mdx, 2, 364).

Some of the people that I interviewed applied their understanding of autism to deceased family members in the hope of tracing the lineage of the condition back through previous generations:

> "So I think a lot of people do this, but I've looked at both my family trees very carefully, and there's neurodiversity of what sort I can't pin down on my father's side, and that comes through my paternal grandfather. […] I've read that sometimes a lot of people in your family might display certain traits, but until it got down to you none of it would have been enough, like, 'okay, you're autistic, you're kind of autistic but not diagnosable,' and I see that on both sides of the family" (Q-mdx, 1, 538).

As the next exchange illustrates, one of the reasons people looked for evidence of autism in previous generations was that it offered a possible explanation as to why they were autistic – there is a family history of it – which in turn acted as a form of genetic confirmation for their own self-assessment or medical diagnosis:

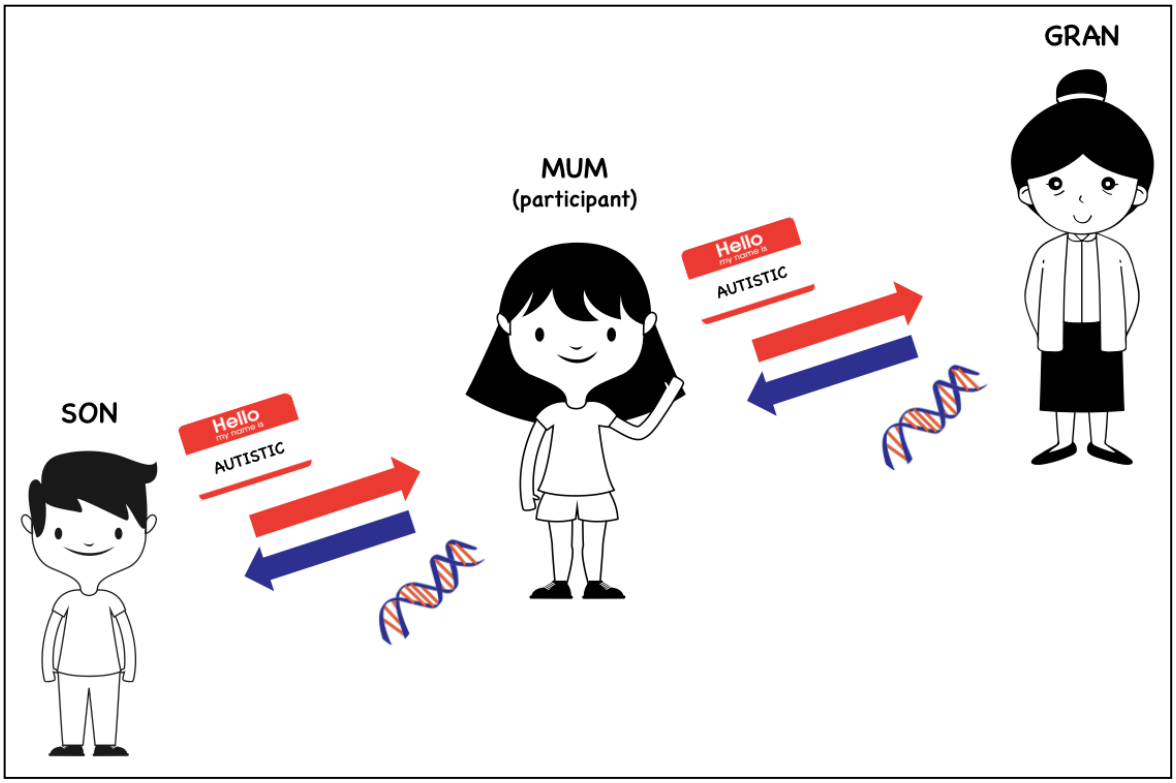
> G-mdx: "The more I think about it, the more I'm convinced that my [paternal grandmother] was autistic, and also I suspect at least one of her sisters was, from what I remember of them and what my parents have told me.
>
> TL: So thinking about these family ties, does this give you kind of an explanation for things?
>
> G-mdx: Yeah, very much so, it just explains so much about my family. They've always been a bit different and now I know why.

TL: I guess there's no doubt on your part about being autistic then?

G-mdx: Ha-ha, absolutely not. It's in my genes!" (1, 243).

Many participants believed that there is a genetic component to autism, that it was in some way passed on to them by their parents. This in turn explained why they were autistic and why they could see autistic traits in their parents. It is worth pausing and looking at this reasoning in a little more detail. Below is a figure of three generations of the same family. The characters depicted in this example are based on my interviews with C-mdx, but the ideas represented apply equally to the other participants (with the genders of different family members switched). In this example, we have son, mum (i.e. C-mdx), and gran.

Figure 6.1: The upward identification and downward explanation of autism across three generations



There are two processes that I want to draw your attention to. The first is the red set of arrows moving left to right, from son, to mum, to gran. This depicts the order in which each member of the family acquired the label autistic. In this example, the son was the first to be medically diagnosed as autistic after his schoolteachers raised some issues with his behaviour, a common occurrence when identifying autism in childhood (Russel, 2016). Going through the diagnostic process with her son bought mum to the realisation that it was likely that she was also autistic, and after a brief period of self-identification also acquired a medical diagnosis. From here, mum started to look for identifiable autistic features in other family members (i.e. actively seeking autism) and came to the conclusion that gran was probably autistic too, labelling her as such.[61]

When mum attempts to explain why she and (in this case) her son are autistic, she draws on a genetic explanation of autism: there must be a hereditary component at play. Mum's reasoning is represented by the purple arrows moving in the opposite direction, from right to left, from gran, to mum, to son. The explanation goes as such: if gran is autistic (as identified by mum), then that would explain why mum is autistic, which would in turn explain why son is also autistic – there is a genetic link between them that is related to autism. Participants were hesitant to claim that there was an autism gene (or sets of genes), but many did take the view, like the majority of scientists and clinicians working in this area (see Yuen, Szatmari, & Vorstman, 2019), that there is a high degree of hereditability of autistic traits across families and the general population. The outcome of both processes (the upward identification of autism through the generations and the downward genetic explanation) is the creation

[61] In the case of C-mdx, gran did not believe that she was autistic, as quoted on p. 215, but there were other participants whose parents acknowledged that they might be on the autism spectrum.

of a circular argument: the autistic traits found in son and mum are applied to the behaviour of gran, and once they are identified in her it is assumed that gran passed on these traits through her genes, which confirms their presence in son and mum. The processes depicted in Figure 6.1 offers an insight into why participants might have gone looking for autistic traits in other family members – it provides an explanation for their own medical diagnosis or self-assigned label.

Giving and receiving a lay diagnosis of autism

Spotting and seeking autism – two observed ways of identifying the condition in other people – is, for the most part, a private affair, something that occurs in the confines of one's own thoughts. An individual may discuss their suspicions with another person, who may or may not agree with them, but the person in question – the individual who has registered on the 'autidar' – is not privy to the assessment that has been carried out on them. That is until somebody tells them about it.

As noted in Chapter Two, the term lay diagnosis is often used to mean self-diagnosis: an individual *labelling themselves* with a medical disorder. My use of the term relates to lay people *labelling other lay people* with a medical condition, which many of my participants reported doing. I must acknowledge that I hesitate to use the term diagnosis in this context, in part for the same reason that I do not use the term in relation to people labelling themselves as autistic. As the process that I am referring to does not involve trained clinicians, formal classification systems, and standardised diagnostic tests, my use of the term diagnosis may appear a little misleading. On the other hand, lay people are capable of identifying physical and psychological conditions in other people and labelling them with the appropriate clinical label, which could be

seen as a type of diagnosis.[62] My main reason for using the term here, though, is that the phrase lay diagnosis is already in use in the sociological literature (e.g. Prior, 2014), and I want to appropriate it for my own use in order to distinguish it from self-diagnosis (or self-identification). And so, the remainder of this chapter is about what happens when an autistic person discloses their lay diagnosis to another individual.

Giving a lay diagnosis: Telling somebody that they are autistic

Informing another person that they display the hallmarks of autism and that they might be autistic could be seen as downright offensive and untoward, or seen as a moment of clarity and enlightenment, depending on how the other person feels about it. Whilst it may be volunteered in the sincerest of terms, rather than made as a throwaway comment meant to cause offense, telling another person that they are autistic presented a fine line that participants were careful to toe:

> "Some people really kick off if you tell them that they're [autistic], and I understand as it can be difficult news to hear. Others are like, 'oh, I never thought of that, do you really think I am? Thanks for letting me know.' […] It's a fine line to walk and you never know how somebody's going to react […] so it's sometimes best just to keep schtum! I don't always though. Sometimes I have to say something" (B-sid, 2, 1141).

If participants chose to disclose their suspicions they often did so with good intentions. As everybody that I spoke to discovered that they were autistic in adulthood, many of them had spent years, if not decades, battling with themselves and the world around them, and often trying, unsuccessfully, to find an answer to their concerns. It was only

[62] Some authors believe that the term diagnosis should be reserved only for the classification of disease by doctors (e.g. Gill, Pomerantz, & Denvir, 2010), whereas others believe that it is suitable to use the term in the context of lay people identifying ailments and illnesses (Prior et al., 2011). I tend to agree with the latter stance, particularly as it is possible to talk about diagnosis outside of a clinical setting, for example a mechanic diagnosing an electrical or mechanical fault in a car.

when they "learnt about autism did things finally start to fall into place" (I-mdx, 1, 267). Therefore, if participants suspected that somebody was autistic, they might be inclined to tell that person in the hope that it would help them better understand themselves and prompt them to seek the appropriate help and support:

> "If it might seem to do them good […] if it would be very beneficial to them in some way, help them get a better grip on things […] [then] I would tell someone that I thought [autism] applied to them … like, in the hope that they could get help" (Q-mdx, 1, 491).

> "After all, if you know that you are autistic then that's better than not knowing. Doesn't matter who breaks the news to you" (F-sid, 1, 435).

Other participants, however, were a little more reluctant to do so. For example, L-sid felt that "it would be harsh to call people out and tell them that they're autistic [as] it's not for me to say … you know … that they look a bit … you know [autistic]" (2, 515). For E-mdx, he was less worried about causing undue offense, and more concerned about encroaching into the territory of the doctor:

> "And the thing is, yes, it is down to somebody else to diagnose it. I can spot it in other people… like with [a recent acquaintance], but I would never have said anything to him if he hadn't have mentioned it himself […] It is for the … (big sigh) experts to decide. I hate using that word, but it is for the people that fully appreciate and understand autism" (1, 832).

Balancing the desire to help and inform people whilst at the same time trying to avoid undue insult, many of the participants that I spoke to were selective about who they shared their lay diagnosis with. For example, J-sid felt that she could broach the subject with family members – even if they disagreed with her – but not with people she did not know:

> "I mean, obviously, with family members I can say, 'I think you're autistic,' and they'll say, 'get lost,' even though I know they're wrong. But I can't do that to Joe Bloggs on the street, can I? They'd be a bit upset having me come up to them and tell them that they're an Aspie. So you can say it to some people and not others" (1, 704).

As we saw earlier with M-mdx and his father's Bob Dylan books, some participants felt that it was not worth telling their parents about their autistic suspicions because it was "too late in the day to do anything about it" (A-mdx, 1, 934). Although participants often noted particular autistic traits in elderly family members – normally the result of actively looking for them after acquiring the label for themselves – they believed it best not to tell them because "there [would] be a lot of regret that comes with learning about autism and potentially getting a diagnosis later in life," as Q-mdx explained:

> "Why does my grandpa need to know? Why does my grandma need to know? […] like, 'what if I'd known sooner, I could have lived my whole life differently.' My grandparents don't need that stress at their age. They have lived their life thinking they are one thing when actually they are something else. I don't think they need to know that now" (1, 532).

The idea that knowing about autism might profoundly change how a person feels about themselves and their life up to that point can be likened to a form of biographical disruption: a fundamental shift in how a person thinks and behaves following the onset of major illness (Bury, 1982). The development of such conditions, it is argued, instigates "profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved" (1982, p. 169). Although the concept originally derived from an analysis of how people managed long-term physical disorders, such as rheumatoid arthritis or multiple sclerosis, it has also been used to better understand how people respond to psychiatric conditions such as schizophrenia (Perry & Pescosolido, 2012).

The biographically disruptive elements of an autism diagnosis were poignantly illustrated in a 2018 BBC Radio 4 interview with a 50-year-old man who had recently been diagnosed with Asperger Syndrome. He described how he had managed to live

a relatively normal life prior to his diagnosis, but since being told that the reason he "always felt like an alien" was because he was autistic, he found himself at a crossroad: did he continue to try and pass as a 'normal person,' undertaking, with much stress and difficulty, the social niceties that were expected of him, or did he embrace a kind of autistic identity (see Lester, Karim, & O'Reilly, 2014) and behave in a way that came naturally to him?

> "Maybe I have the opportunity to do that now, maybe I can unlearn some of those ['normal'] things? I could just say [to people], 'there you go, that's me, that's Asperger's, so see ya!' Or I could endeavour to set myself on a path where actually now I understand these impulses. I should be able to mitigate them to a certain extent. […] Yeah, I think it might be all too easy to throw the baby out with the bath water" (BBC, 2018a, 17:31-18:29).

Here, the Asperger's diagnosis initiated a profound biographical shift in which the interviewee started to question who he was and how he wanted to live his life from that point forward. It was a difficult and confusing process that caused much internal conflict with himself and also with his wife and children. My participants, it seems, were aware of the biographical shift that came with the realisation that they were autistic, and it was with that in mind that people like M-mdx and Q-mdx decided not to tell their elderly relatives, as it may have caused them more harm than good.

Receiving a lay diagnosis: Being told that you are autistic

As well as issuing their own diagnoses, most of my participants had been on the receiving end of somebody else's lay diagnosis. In fact, this was how many participants first became aware that they might be autistic – another autistic person told them so:

> "As soon as he saw me, he thought that I was on the spectrum. I remember there was […] a party at [a friend's] place, and one of the other autistic people I had never seen

> before, as soon as they saw me the first thing they said was, 'you're totally an Aspie' […] They were dead certain of it." (P-sid, 1, 102).

Other participants, like G-mdx, started to consider the possibility after somebody had asked them about it:

> "Someone […] who was diagnosed as autistic at a young age […] went, 'hope you don't mind me asking this, but there is something about you and the way you phrase [things] […] that makes me think you might be autistic. Are you?'" (G-mdx, 1, 5).

In this instance, the signs and signals participants drew upon to identify autism in other people were being used by other autistic people to identify the condition in themselves, whether in-person or on the internet:

> M-mdx: "[Somebody] suggested to me that it might be a possibility on Facebook.
>
> TL: And what did [they] say?
>
> M-mdx: [They] suggested that [autism] might be a possibility. I think it was in relation to something I'd failed to understand about something that somebody had said.
>
> TL: Online?
>
> M-mdx: Yeah, […] they weren't suggesting it in a negative way, but he had observed something that I had written and an expression that I'd made, I think about being frustrated at an inability to comprehend things, and he suggested – he himself having been diagnosed and familiar with such difficulties – that it might be something I should look in to. Apparently the language I was using and the excessive editing of comments came across as very autistic" (1, 5).

Interestingly, being on the receiving end of this lay diagnosis prompted many participants to self-identify as autistic or pursue a medical diagnosis of their own. Here, having another autistic person tell them that they were autistic acted as the catalyst for acquiring the label for themselves. This was especially true if the person issuing the lay diagnosis already had an official diagnosis:

> TL: "If you were to suggest to someone that they might be autistic, do you think they are more likely to buy it or accept it coming from you because you have a diagnosis?
>
> A-mdx: Yeah, yeah, that's the power of the label isn't it? That's the power of the diagnostic label. Absolutely. I suppose it has more clout coming from me because I've been through the [diagnostic] process so I have a decent idea what autism is. […] I suppose if I was still a self-identifier and told people what I thought they probably wouldn't believe me. But with a diagnosis, they listen" (2, 478).

A medical diagnosis, by the very fact that it is an official form of identification, carries with it a sense of authenticity and legitimacy on the part of its recipient. An individual with a diagnosis has been professionally verified as autistic, and the diagnosis itself can be seen as a form of symbolic capital: a social credential that is perceived and recognised by other people as legitimate (Bourdieu, 1989). It is the professional and cultural recognition of a medical diagnosis that provides a type of symbolic currency when it comes to identifying and labelling other people as autistic. In the language of the sticky-slippy label, a lay diagnosis that comes from somebody with a medical diagnosis is more likely to stick *to* a person than one that comes from somebody who self-identifies as such.

As well as prompting participants to inquire into the label for themselves, being on the receiving end of this lay assessment also gave them permission to disclose their own autistic suspicions to other people, in a kind of passing of the knowledge from one autistic person to another. Like passing a label from A to B to C, participants frequently shared their own autistic assessments with other people (from A to B), who then issued their own lay diagnoses to other people (from B to C):

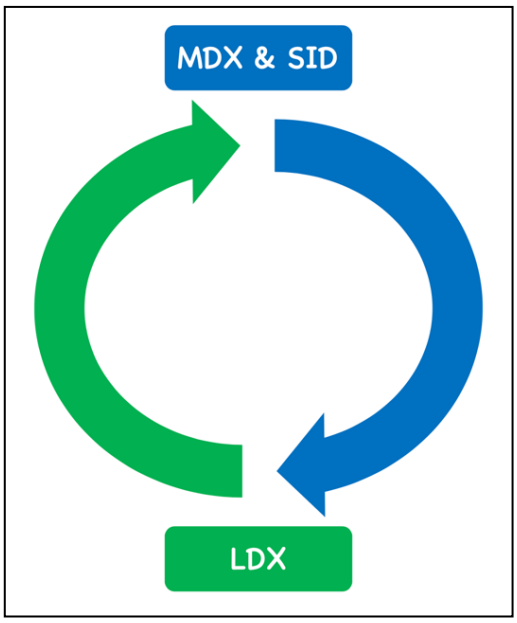
> "There was this one woman […] who said that since I'd mentioned that she was autistic, she recognises it in herself and has been thinking about it in relation to her brother and […] her mum" (J-sid, 1, 708).

> "I thought one of my friends was autistic, and he and I actually had a chance to speak between now and [the first interview] […] and he is absolutely autistic and he [now] identifies [as having] autistic traits, and interestingly he has started to notice those same traits in one of his family members" (Q-mdx, 1, 533).

Something similar was noted by Liu and colleagues (2010), albeit in relation to parents of autistic children. "Meeting children with autism and having discussions with parents of children with autism," the authors wrote, "could lead parents (of children not diagnosed with autism) to observe behavioural symptoms consistent with autism" in their own children (2010, p. 1389). In other words, parents of autistic children could convince parents of non-autistic children (intentionally or unintentionally) that their kids are displaying the hallmarks of the condition because they are doing and saying the same things as their own children with a medical diagnosis. This sharing of information between parents – at the school gate, during a play date – can lead to what Mazumdar et al. (2013) refer to as 'diagnostic clusters' of adults and children seeking a formal diagnosis, with individual's referring each other for an autism assessment.

As illustrated in Figure 6.2 (overleaf), the interaction between acquiring the label autistic – either as a medical diagnosis (MDX) or by self-identifying (SID) as such – and making a lay diagnosis (LDX) is cyclical, in that being told that you are autistic can initiate the acquisition of the label, which is then used to issue further lay diagnoses of the condition, in a process that cycles from one person to another.

Figure 6.2: The interaction between acquiring the label autistic and lay diagnosis



The sequence of *receiving* a lay diagnosis, *acquiring* the label for oneself, before *telling* other people that they might be autistic, was a series of events that most of my participants had experienced. As G-mdx explained, this passing of the label could almost be seen as an inevitable consequence of being on the receiving end of a lay diagnosis:

> "I find particularly those of us who've been identified as adults, *particularly if we've had someone say to us, 'I think you might be autistic,*' we tend not to have too many qualms about *saying it to someone [else]*" (1, 309, emphasis added).

Like Freidson's (1960) notion of a lay referral, the lay diagnosis of autism represents a precursory step in a person acquiring a medical diagnosis or self-identifying as autistic. Here, the lay assessment precedes that of the doctor or the individual in question, and once the label is acquired, this lay assessment is then used to issue additional lay diagnoses on other people. I will talk more about the relationship between these two concepts in Chapter Seven (p. 260).

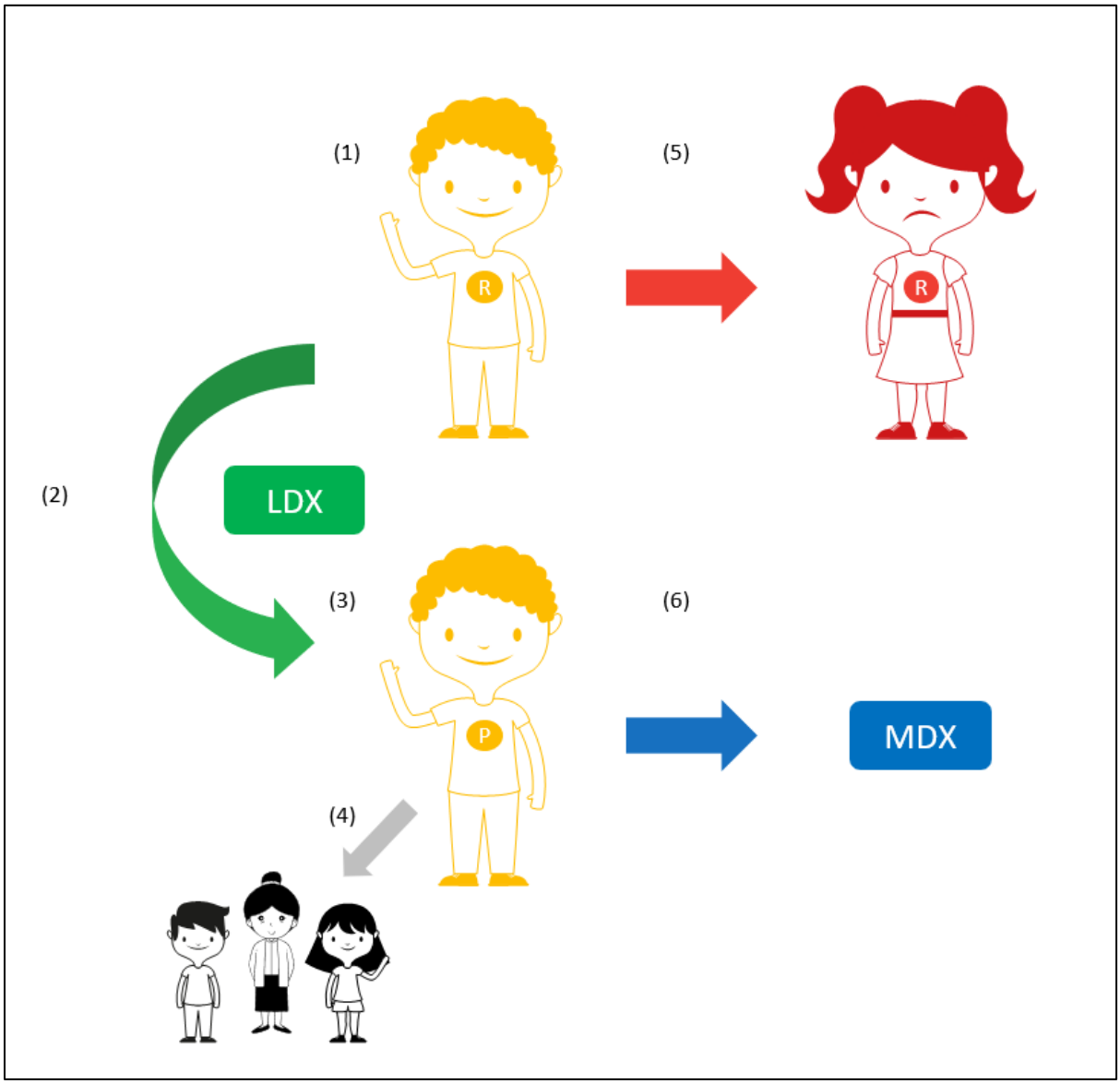
The risks of disclosing a lay diagnosis

Before bringing the chapter to a close, I want to take a moment to consider the potential risks of disclosing a lay diagnosis.[63] As I have already noted, some of the people that I interviewed chose not to disclose their lay diagnosis with the person in question, either because they were worried about causing offense or because they did not see any benefit in doing so (e.g. M-mdx and his father's Bob Dylan books). There was however one participant who discovered that there are some unintended consequences when it comes to disclosing a lay diagnosis. Figure 6.3. (overleaf) details what happened when participant R lay diagnosed her housemate, participant P (as noted on p. 113, both participants lived in the same shared house).[64]

[63] I am not sure whether 'risk' is the right word in this instance, but as I will demonstrate, there are some potentially negative consequences when sharing a lay diagnosis with someone.

[64] To make the following discussion easier to follow, I have removed participants' diagnostic designations.

Figure 6.3: Risks of disclosing a lay diagnosis



There is a lot to discuss here, so I have numbered the sequence of events from 1-6. The top row of characters are participant R, and the bottom row is participant P (as noted on the badges on the characters' chests). Starting at (1) R self-identifies as autistic and decides to pursue a medical diagnosis. (2) Whilst waiting for her diagnostic assessment, R starts to notice autistic traits in her housemate, P, and makes a lay diagnosis. R shares this with P and encourages him to seek a diagnostic assessment. (3) P agrees with R's assessment and begins to self-identify as autistic. (4) P consults

with other autistic people – knowledgeable others – who confirm R's lay diagnosis and encourage him to seek a medical diagnosis (and in doing so issue a lay referral).[65] (5) The instigator, R, eventually visits an autism specialist who carries out a diagnostic assessment. The result comes back as negative, she does not meet the threshold for a medical diagnosis. R, nevertheless, continues to self-identify as autistic, despite the doctor's assessment. (5) The housemate, P, later takes part in an autism assessment and the result is positive. P receives a formal medical diagnosis, whilst R is left without one.

This was doubly disappointing for R. Not only did her attempt to obtain a medical diagnosis end with a negative result, but then her housemate, P, went on to acquire one. As noted in the previous chapter (p. 177), R believed that her autism assessment was negative because she masked her true autistic self during the diagnostic interview. She suspected that P had not done the same – that he clearly and unambiguously demonstrated the symptoms of autism during his assessment – and that was why his result was positive:

> "It's been difficult. I don't resent P for it, but I do resent [the doctors], because it kind of feels like ... why did P get all this actual attention and validation and why did they actually listen to him? […] I do begrudge that they did it for him when they didn't for me […] I kind of feel like because I've had all these decades of having to not be weird, the fact that I've done a better job of not being weird kind of feels like, like I said, that that's screwed me over. And it feels like ... I'm not angry at P, but I'm angry at [the doctors] because it kind of feels like they're the sort of people who are supposed to know this, why weren't they looking for masking, why weren't they recognising it for what it is. So, yeah, it was upsetting. I'm not begrudging to P and I'm glad that they've done this for him, but I'm still angry that they didn't for me."[66]

[65] R consulted her own knowledgeable others when she started self-identifying as autistic, but this is not depicted here.

[66] R made these remarks in an interview with P (2, 371).

R's disappointment was compounded by P. R presumed that she was going to get a medical diagnosis, hence self-identifying prior to the assessment. By disclosing her lay diagnosis to her housemate, she also believed that she was doing P a favour, offering him an explanation for why he was feeling the way he was (his unusual traits, his troubling symptoms). By acquiring a medical diagnosis, P's concerns, as well as R's assessment of them, were validated and professionally verified by a doctor. But now P has got the one thing that R desperately wanted: a formal diagnosis and the benefits that come with one. "I do feel bad about it," P explained:

> TL: "Why's that? I mean, I can kind of see why…
>
> P: Well, R really wanted one […] I knew how much the diagnosis meant to her, and it's sad that I got one and she didn't […] I mean there's a group, a support group, and I said I'll check with them to see if R needs a specific diagnosis to join" (2, 427).

P sensed the unease that his autism diagnosis caused and tried to use the symbolic capital that came with it to grant R access to the support group that he attended. Unfortunately, this request was denied as R did not have an official diagnosis, as is often the case with these services. What this account illustrates, above all else, is the potential risk of sharing a lay diagnosis, especially when the person issuing the diagnosis is awaiting a formal assessment themselves. Disclosing a lay diagnosis, in this example, resulted in the unwelcome consequence of feeling frustrated and empty-handed. Not only did R fail to acquire the diagnosis for herself, but she was instrumental in helping somebody else obtain one. Although the disclosure of her lay diagnosis did not hinder R's chances of acquiring a medical diagnosis, it eventually led to some resentment between the two housemates.

Chapter conclusion

This chapter has focussed on the third and final part of my analysis into how people acquire the label autistic in adulthood and the consequences of doing so. The focus of this discussion has been on how autistic lay people identify and label other lay people as autistic. In regard to my research question, the findings discussed above are both a means of acquiring the label (i.e. being told that you are autistic) and a subsequent consequence of being diagnosed or self-identifying as autistic (i.e. the perceived ability, and possible authority, to identify other people with the condition).

In this chapter, I made the distinction between an individual 'passively spotting' and 'actively seeking' autism in others: two terms which capture the empirically observed mechanics of lay people identifying the condition in other people. Both the making and disclosure of an autism assessment illustrates what I have called a 'lay diagnosis,' and being on the receiving end of one can act as an important precursory step in acquiring the label, either as a medical diagnosis or by self-identifying as autistic.

Just as with the previous findings chapters, the ideas discussed here are in no way unique to autism. It is likely, as has been demonstrated in the case of identifying another person's sexual orientation (Rule & Alaei, 2016), that those with other psychiatric diagnoses may be able to spot and seek evidence of the condition in other people. The purpose of this chapter has been to demonstrate and conceptualise this process, which has yet to be done by sociologists and other autism researchers.

Finally, a word on the apparent accuracy of participants' 'autistic sixth sense' and 'autidars.' Just because the people in this study claimed that they could identify the

signs of autism in other people does not mean that they were actually able to do so, at least according to the criteria outlined in the DSM-5 (APA, 2013) and ICD-11 (WHO, 2019). I have no evidence to determine the validity of participants' claims, and I am unable to say whether they were correctly identifying the symptoms of autism or simply interpreting people's behaviour as such. This is an interesting empirical question, and one that I will consider in relation to future studies in the next chapter, but it is not mine in this study. The point is that participants *believed* that they could do this, and they explained their reasons for thinking so. My task was to conceptualise what they said, the products of which will inevitably require further empirical investigation by myself and others in the field.

Chapter Seven: Discussion

In this final chapter I aim to situate this PhD within the bigger picture. I will start by offering a quick summary of the study and the findings presented, before reflecting more broadly on empirical process itself. From there, I will outline the different ways in which this work has contributed to the existing research in this area, before offering some suggestions for future research studies. I will then position this study within the wider sociological canon, drawing on the ideas of theorists beyond autism and the sociology of diagnosis.

Study summary

Ever since the inception or 'discovery' of autism, the estimated prevalence of the condition has increased (Kanner, 1943; Waugh, 2019). This has been accompanied with a greater demand for a diagnosis, particularly in adulthood (Smiley et al., 2018). Although there are no known treatments or cures for the condition, and there is much debate about whether autism is even something that needs treating or curing (Armstrong, 2010; Timimi et al., 2010), there are many people who welcome a medical diagnosis in order to put a name to their concerns and difficulties (see Jutel, 2011). Having a formal diagnosis can bring an individual an immense sense of relief as it can offer an explanation for why they behave and see the world as they do (Jones et al., 2014; Punshon, Skirrow, & Murphy, 2009).

But a medical diagnosis is not the only way of acquiring the label. Like with other psychiatric conditions (e.g. anorexia; Stapleton et al., 2019) there are an increasing number of people labelling themselves as autistic (Sarrett, 2016). With an abundance of medical information now available on the internet, including social media sites and self-help groups devoted to sharing content about specific medical disorders, it has

never been easier for people to learn about different conditions in order to make a self-diagnosis (see Vayreda & Antaki, 2009). For some people, self-identifying as autistic is preferable to being formally diagnosed with the condition, either because it is too difficult to get a diagnosis or because they do not see autism as a medical matter (Lewis, 2016b; Wylie, 2014).

Another way of acquiring the label is to be labelled as autistic by somebody else with the condition. Here, an autistic lay person identifies the symptoms or traits of autism in another lay person and labels them as such. In the same way that people use the internet and the collective experience of self-help groups to make a self-diagnosis, these platforms can also be used by lay people to issue their own diagnoses of other people (Giles & Newbold, 2011).

Thinking about the three different ways of acquiring the label – either through a medical diagnosis, by self-identifying as such, or by being labelled by somebody else – it was clear from the outset of this study that there was still more to learn about the alternative, non-medical ways that people come to be labelled as autistic. And as a more general observation, it seemed that the wider implications of acquiring the label, through any means, were yet to be explicitly theorised by sociologists and others working within the field. I set out to address these gaps.

In the preceding chapters, I presented three theoretical concepts that illustrated how people go about acquiring the label and what it means to live with it. The first was the concept of the sticky-slippy label (see Chapter Four), which is a figurative expression

used to illustrate some of the properties of the label autistic and the consequences of being labelled as such. The stickier attributes of the label were as follows:

- Different ideas and images (associations and stereotypes) can find themselves sticking to the label to the point that they become synonymous with the condition itself.
- Once acquired, particularly in the form of a medical diagnosis, the label has a certain stickiness to it, a sense of permanence, that is both imagined (*I'm stuck like this forever*) and realised in an official capacity (i.e. its bureaucratic stickiness).
- The label acts as a conceptual resource in which a person can stick an ordered and coherent narrative together, initiating an intense period of biographical work where an individual reimagines themselves in light of the label.
- Once disclosed, the label has the capacity to stick in the minds of other people, colouring their opinions and expectations of the person before them. The label can also stick *to* other people when issued as a lay diagnosis (see below).

The label's slippery qualities included:

- The historical and cultural meaning of the label changes over time, with different concepts, symptoms, and ways of talking about the condition slipping in and out of usage
- Autism can act as a master status that explains away other diagnostic and social labels, causing them to slide off an individual.
- The label has a fluid and shifting prominence in a person's identity. Whilst it may have previously been *the* defining feature of an individual's sense of self, it too can

become less important, less noteworthy, to the point that the label is perceived as redundant.

- The label can struggle to find traction with those who do not believe that an individual is autistic. The label sometimes lacks the social adhesive to stick *with* some people in the way that it does with others.

Although it is possible to talk about these ideas separately, it is my intention that they are seen as a dualism – a label that is *both* sticky and slippy – as this better represents the shifting experiences as described by my participants.

The second concept related specifically to people self-identifying as autistic and their reasons for doing so, which was illustrated as four different ways (see Chapter Five):

1. Somebody who self-identifies as autistic as a *precursor* to seeking a medical diagnosis.
2. Somebody who self-identifies as autistic *despite* a negative diagnosis.
3. Somebody who self-identifies as autistic as an *alternative* to a diagnosis.
4. Somebody who only self-identifies as having *autistic traits*.

These different ways also marked four empirically observed states that a person can transition between when self-identifying as autistic (i.e. moving from one reason to another).

The third concept related to a practice observed in this study of autistic people labelling other people as autistic, something I refer to as a lay diagnosis (see Chapter Six).

Within this, I made the distinction between passively spotting and actively seeking autism in others. The first of these involves an individual recognising the signs of autism in other people – that is, having certain characteristics or features jump out as typically autistic. The second is a much more deliberate form of identification which involves an individual purposefully searching for autistic traits in other people. In either case, disclosing a lay diagnosis to the person in question can initiate their own process of acquiring the label, either by self-identifying as such or pursuing a medical diagnosis.

Empirical reflections

Study strengths and limitations

One of the major strengths of this study has been the inclusion of an active and supportive advisory group. The advisory group played a vital role in the design of this study and helped me get a better grip on the data by offering their insight on what participants said to me. Drawing on the groups first-hand experience of acquiring the label sensitised me to some of the common themes identified in the data. More broadly, the advisory group (both collectively in group meetings and individually in one-on-one discussions) gave me the time and space to work through any methodological and substantive concerns, adding their autistic perspective to the matter – something not always prioritised in similar research studies (see Chown et al., 2017).

Another strength was the commitment to collecting rich and detailed data using repeat qualitative interviews. As noted at the end of Chapter Two, there is a lot of research in the autism literature that relies on limited sources of information (e.g. surveys, online

forum data) when investigating the impact of a medical or self-diagnosis of autism. This is in part due to the presumption that autistic people can be difficult to interview because of social and communication difficulties. As a researcher in my department once told me, “autistic people can’t tell narratives” [apparently!] And yet, with the help of the advisory group, I was able to develop a series of topic guides that enabled me to conduct the type of depth interviewing that Jones (1985) recommended for those looking to collect extensive data on their subject matter. Autistic people can be incredibly detailed and articulate when taking part in qualitative interviews, providing researchers are able to plan, prepare, be flexible, take their time when questioning (perhaps over multiple interviews, if needed), and not just list off a load of standardised questions, with limited input, in the hope that participants will be able to understand what is expected of them. With sensitive and diligent conduct, researchers can make greater use of qualitative interviews in this area of research, and move beyond the limited sources of data frequently relied upon in this field (see Smith & Jones, 2020, p. 594).

On a related point, the sample size and number of interviews conducted in this study is substantially larger than much of the comparable research in this area. In some instances, my sample was two (Leedham et al., 2020) and four (Jones et al., 2001) times larger than those recruited in similar qualitative studies, with significantly more data collected because of repeated interviewing. Of course, the merit of qualitative research should not be judged on the quantity of data collected, but by carrying out this research over the length of a PhD, I have collected much more empirical material than other researchers in the field (and, as noted above, the quality of those data is much richer).

Additional strengths of this study include my use of member checking – as carried out during my second interviews and interactions with the advisory group – and discussions with critical friends during the group analysis sessions (Smith & McGannon, 2017). Sharing my analysis with participants gave them the opportunity to comment on my work and assess whether it fairly represented the positions they found themselves in, ensuring at least some element of real-world applicability. Regularly discussing my analysis with other researchers was also a good way of keeping myself grounded to the data and ensuring that I was not making too many conceptual leaps from the empirical evidence. Because of the theoretical nature of this study, it was not appropriate to carry out any form of inter-rater reliability checks, as is often done in qualitative studies, as I was not attempting to assess the 'accuracy' of my analysis. It was important, however, to critically engage with the products of this research and to invite dialogue about them, from colleagues, the advisory group, and study participants.

The most notable limitations of this study relate to sampling. As noted in Chapter Three (footnote 34, p. 112), I found it particularly difficult to recruit men who self-identified as autistic, whereas I found it relatively easy to find women who had done the same (I recruited three males and seven females in this group). Based on their encounters with other autistic people, my advisory group speculated that this would be the case – that I would find more women self-identifying as autistic because it is harder for them to get an official diagnosis. There is some support for this argument in the literature, with some suggesting that women and girls on the autism spectrum present differently to men and boys – due in part to gender norms and social camouflaging (Dean,

Harwood, & Kasari, 2017) – and that the procedures used to assess autism have historically been geared towards male symptom patterns (Haney, 2016).[67] Because of this, it is argued that women routinely fail to meet the diagnostic criteria for autism and are often misdiagnosed with a different psychiatric condition (Gould & Ashton-Smith, 2011). Although I am in no position to add any insight to these claims, I was genuinely surprised by how many self-identifying women came forward during my recruitment calls (six or seven women for every one man, although I did not keep a record of these figures). And for the women that I did interview (both those with a medical diagnosis and those who self-identified), they often talked about the challenges of obtaining an official diagnosis and how difficult it was to convince a clinician to review their case. This may go some way towards explaining the gender skew in my self-identifying sample. Nevertheless, it would have been good to recruit an even number of men and women in that group.

Another sampling issue worth noting was that my participants were a highly educated group, with all but one educated to at least degree level. This level of educational attainment confirms that my sample was a group of highly functional autistic adults. This could be explained by the fact that some participants were recruited from the University of Exeter, but as only three of the twenty-one participants came from this venue, I think this educational bias may be telling of something more interesting. Self-identifying with, or self-diagnosing, a condition such as autism, requires a reasonable amount of knowledge in order to read about the condition and identify the appropriate

[67] In a recent publication, Russell (2020) described how women on the autism spectrum often attempted (with much effort and anxiety) to conform to typical gendered norms and expectations by 'masking' their 'true' autistic behaviour so as to pass as 'womanly'. Russell also noted how obtaining a medical diagnosis excused some women from the apparent social obligation to behave and act in a feminine way (e.g. being sociable and caring).

symptoms so as to make an informed decision about whether it is a category that applies to oneself (the same could be said about pursuing a medical diagnosis). Of course, an individual could just wake up one day and decide that they are autistic, but as I found in my discussions with participants, this is often a long and considered decision that requires a lot of thinking and research. Participants routinely told me how they delved into the medical and scientific literature on the topic, reading the latest research on identifying and diagnosing autism in adulthood.[68] Knowing where to find this literature, as well as having the intellectual capacity to understand it, is something university graduates are likely to possess. As one of my supervisors said, my participants could be described as a 'group of reflectives:' individuals who have the capacity to think seriously about their cognitive state and apply a diagnostic category to it, which may lead them to self-identify with a condition or pursue a medical diagnosis. Again, I have no evidence to make such a claim, but I wonder whether there is a relationship between one's educational attainment and the desire and ability to diagnose one's own medical categories. Perhaps this is a question that can be explored elsewhere.

This next point is not necessarily a limitation per se, but rather something that is of methodological interest. Thinking back to the four ways of self-identifying as autistic, you will remember that one of those ways was self-identifying *despite* a negative diagnosis (p. 176). In this instance, a doctor has concluded that an individual does not meet the diagnostic criteria for the condition, but that person continues to self-identify as autistic anyway. Now it is likely that there will be some people who, having been

[68] Some participants had even read some of the studies reviewed in Chapter Two, which we talked about during our second interview.

told that they are not autistic or that they do not meet the threshold for a diagnosis, cease to identify with the label – *I thought I was autistic, but the doctor said 'no.'* They may have previously self-identified as autistic, prior to their diagnostic assessment, *but stopped doing so in light of their negative result*. The sampling criteria I used in this study meant that I never reached those kinds of people. When recruiting self-identifiers, I sought people who "self-identified as autistic" and later "believed that they were autistic but did not have a diagnosis." These criteria imply that people are self-identifying as autistic *at this moment, right now.* What about the people who used to self-identify but no longer do so? It would have been interesting to speak to those people and find out why they never stuck with their self-assigned label. Why, unlike some that I interviewed, did they accept the doctor's assessment that they were not autistic? Unfortunately, this consideration came to mind after data collection came to an end, but this is again something that could be explored in future research (i.e. why do people *stop* self-identifying as autistic?).

Critical reflections on situational analysis and qualitative research

I think that it is important to spend some time reflecting on my use of SA. On the face of it, it may be hard to see how my chosen analytical approach has informed the analysis presented in the preceding chapters, and this is something that I have been grappling with throughout my studies. I have written about this elsewhere (see Lister, 2019) and think that it would be beneficial to reflect on some of those ideas here.[69]

[69] I have reproduced portions of Lister (2019) on pp. 246-252.

It is generally accepted that qualitative research is an active process carried out by an active researcher (Gubrium & Holstein, 1997). This relates to the idea that we, as researchers, contribute to the analytical process in important ways by drawing on our own knowledge and experiences to make sense of the things that we are studying (Holstein & Gubrium, 2016). As sense-making beings, we cannot help but draw on what we already know to shape the analytical products of our research. That is why there is a growing consensus in the qualitative literature that researchers actively formulate and construct their analyses, rather than 'find' or 'discover' something that is already 'out there' (Bryant & Charmaz, 2007). Phrases like "themes do not emerge" help us resist the temptation to see qualitative analysis as something that naturally unfolds during the analytical process, but rather to view it as a product of the researcher's own engagement with their data.[70] We do not hit upon our analysis, but create and craft it through detailed and scrupulous interactions with our empirical material.

In trying to make sense of the role researchers play in the analytical process, it seems, from my experience in this study, that the ideas surrounding the activeness of the researcher are very subtly bound to the assumption that our analysis is determined by the methods we use. What I mean by this is that there is the view in institutions like mine, a medical school, that researchers should be able to demonstrate how their analyses – their findings, theories, models – are the direct result of the analytical approach that they used. This is also the case in the methods literature. Take GT as an example. There are different versions of the method, the main ones being the

[70] "Themes do not emerge" is an increasingly popular phrase used by Virginia Braun and Victoria Clarke that applies equally to other methods of analysis, not just their version of thematic analysis (Braun & Clarke, 2006).

‘Glaserian,’ ‘Straussian,’ ‘Charmazian,’ and ‘Clarkeian’ approaches (see Apramian et al., 2017). The authors and proponents of each of these methods suggest that if you use the Glaserian or Charmazian versions, you will produce an analysis that focuses on different social processes that are either objectively present in the world (Glaser, 1978) or socially constructed (Charmaz, 2014). If you use Clarke’s (2005) version of the method, SA, you will develop an analysis that centres on the relational ecologies of situations and social worlds. There are other versions of GT, for example dimensional GT (Schatzman, 1991), that have been created to help researchers analyse the plethora of actions and interactions between individuals and social groups, rather than their underlying social processes. Each of these approaches is presented as a method that, if implemented correctly, will *ultimately produce a different type of analysis*. The same could be said when making comparisons between other analytical approaches. A thematic analysis (Braun & Clarke, 2006) will produce something entirely different from a discourse analysis (Gee, 2014), and depending on what type of thematic analysis you use, your reading of the data will be more inductive (Patton, 1990) or theoretical (Hayes, 1997) in nature.

In reflecting on my own practice over the last three years, I believe there exists a tension between the notion of an active researcher, who is constantly and unashamedly trying to make sense of their data, and the idea that different methods produce different types of analysis. Whilst many methods authors are acutely aware of the agency of the researcher, there is still the tendency for even the most reflexive of them to give the impression (probably unintentionally) that a particular method of analysis, *their* method of analysis, will provide a certain analytical product, *as if it is the method itself, not the researcher’s use of it, that produces the final analysis*.

Thinking about this in terms of social theory, this is a very structuralist way of thinking about qualitative analysis. It implies that whilst the researcher actively constructs the analysis through their engagement with their data, they do so within the structural confines of the method they are using. From this point of view, the researcher is active, but only to a point. As a consequence of this kind of thinking, we arrive at the expectation that researchers should be able to explain how their analysis is the result of the method they are using. I do not think this is always possible, as the development of our analyses is much more nuanced than simply following the procedures laid out in a particular method. We – the active researchers – use our methods in different ways, and I think that it is important that we reflect on this when reporting our analytical process.

Looking at my own findings, it is clear that there is a distinction between the ideas that have been *applied to* my method of analysis, and those that are more the *product of* them. The ideas that I apply to SA are those that I have about the topic precisely because I have immersed myself in a particular area of research; collecting data, reading books, making notes and talking it through with others. This is me actively making sense of things and gradually becoming more sensitised to my research topic. We all generate ideas like this, and when it comes to formally analysing our data, we filter these ideas through analytical tasks in a top-down fashion. Some ideas will continue to stick around and evolve, others will not. For those parts of my analysis that are more the product of my method, they have come about because I am using a particular approach with an assortment of analytical techniques. My use of SA has opened up my data in new and unexpected ways, which has mobilised my analytical

thinking as a result. These ideas have come from the ground up, through the method itself.[71]

Applying this distinction to specific parts of my work, the basis for passively spotting and actively seeking autism in others (as well as other parts of Chapter Six) came from one of my early interviews with E-mdx. As already quoted on p. 202, E-mdx believed that he could *see* autism in a guy he had just met. For me, this idea was a profound one and one that I mulled over for some time, looking for articles on similar behaviours, talking it through with my colleagues and supervisors, and writing detailed research memos about it. Spotting autism then became a focus of my data collection, and as I gathered more data on the topic I was able to apply these ideas to the techniques of SA (and the other analytical tasks used in this study), using the three kinds of maps in order to flesh it out in more detail. Thinking about how this idea was conceived, it was something that came from my interview with E-mdx, which I pondered on long before conducting any formal SA mapping. Spotting autism was something I was thinking about prior to data analysis, but through the analytical process (and subsequent data collection), the idea gained more substance and depth (including seeking autism and the ideas around lay diagnosis). If I were using a different method of analysis, say conversation analysis (Boden & Zimmerman, 1993), the emphasis of my analysis would undoubtedly be different – I might focus on how people talk about spotting autistic people by examining the structure and content of what they say – but the

[71] To clarify, I mean top-down as in I took what the data were 'saying' and applied them to the mapping techniques of SA – *my* thinking, based on the data collected, directed the formal analysis. Whereas ground-up refers to the ideas that came to my attention *after* analysing the data using SA. These ideas were not on my radar prior to implementing the three mapping techniques – they surfaced through the method itself.

substance of the analysis, the take home message, I would argue, would undoubtedly be the same.

In contrast, the analytical work that went into the development of the four different ways of self-identifying, particularly the various reasons participants had for labelling themselves as autistic (or their reasons for not doing so), was very much initiated and bolstered by my use of the third SA map: positional maps. Initially, I was sceptical about these maps. They seemed counter intuitive and a little formulaic in their process. But I quickly realised that they helped me open up my data in distinct and important ways. One of these were the various positions participants held around a person's right to self-identify as autistic, which ranged from supportive to outright dismissed (as illustrated in Figure 3.6, p. 99). Plotting these views on a positional map bought these ideas to my attention, and through subsequent map-making and analysis helped me formulate the four different ways. Would I have developed these groups using a different qualitative method, for example a basic thematic analysis? It is hard to say. But in this instance, these findings came about and took shape precisely because I was analysing my data using positional maps.

By recognising the distinction between the parts of my analysis that are applied to my method, and those that are more the product of them, I see the analytical process as a dynamic interplay between the thinking and musing of an active researcher and the use of the tools and techniques available to them. Analytical methods can help us organise and refine our thinking (as in the case of spotting and seeking autism), but they can also be used to provoke and construct new ideas (like the four ways of self-

identifying). *Our analysis is not exclusively the product of our methods, nor is it accomplished without them*.

So what does this all mean in terms of the methodological decisions taken in this study? As you may have noticed, I have chosen to background my use of SA when reporting my research findings. Some researchers put the method at the forefront of their analysis, narrating their findings in terms of their SA maps (see Alrich & Rudman, 2016). Others, however, choose to focus more on the substantive content of their work, placing less emphasis on their use of the method (see Gagnon et al., 2010). I took the latter approach. Part of my reasoning was that, on reflection, SA may have been better suited to a study that had a more institutional focus (e.g. a study examining the provision of autism diagnostic services in a particular country or region, as my colleague Jennie Hayes (2019) did). That is not to say that SA was inappropriate for a study like mine. As noted earlier, my ambition from the outset of this work was theoretical in nature, which inevitably pushed be toward a GT approach (indeed, that was the original design for this study in the Wellcome bid). I ruled out other approaches used in similar studies (e.g. thematic analysis, Hickey et al., 2018; interpretive phenomenological analysis, Punshon et al., 2009) precisely because I wanted to develop new theoretical concepts (not that theory generation is exclusive to certain analytical approaches). It was during my reading of the GT literature that I came across SA. I was attracted to the method because of its emphasis on managing the messiness of qualitative research (see Mathar, 2008), its focus on developing sociological theory, and its unique cartographic approach to analysing qualitative material (alongside the other analytical techniques outlined in Chapter Three). Furthermore, I have always

taken a keen interest in research methods, so if there was ever an opportunity to delve into a new methodological approach, it was during a PhD.

Was SA a suitable method for this study? I think so, although as I have tried to explain in the previous pages, I do not see our choice of method as solely determining the type of analysis that we produce. As Scambler (2018) notes, “methodology is very important, but nothing like as important as we think it is.” I would agree. My aim in this study was to develop a theoretical account of how people acquired the label autistic in adulthood, and my implementation of SA helped me achieve that aim. According to that simple criteria, I would say that SA was a suitable method for this study.

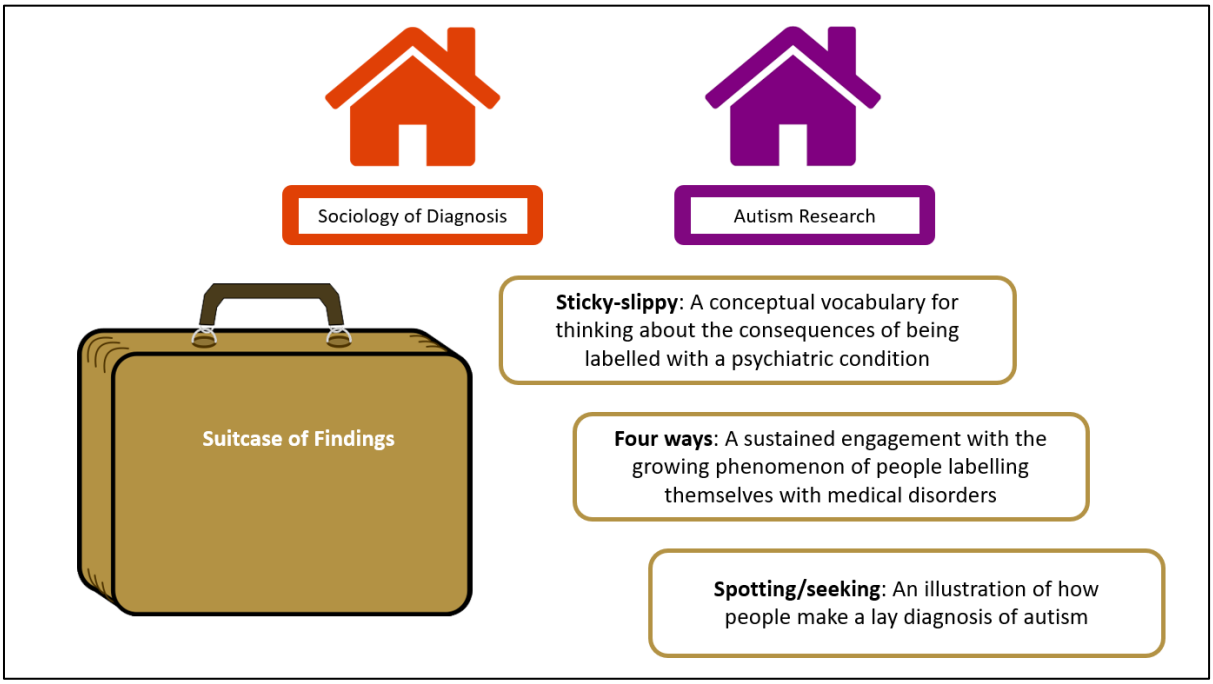
Study contribution and suggestions for future research

I have split the contributions of this study into research and wider contributions, with my suggestions for future studies sandwiched between the two.

Research contribution

At the beginning of Chapter Two, I depicted what I described as the conceptual and empirical homes of this study: the sociology of diagnosis and the autism research literature. Keeping with this image, I want to frame the contributions of this work in terms of what I have returned home with following my research endeavours (outlined in Figure 7.1 overleaf).

Figure 7.1: Returning home from the field

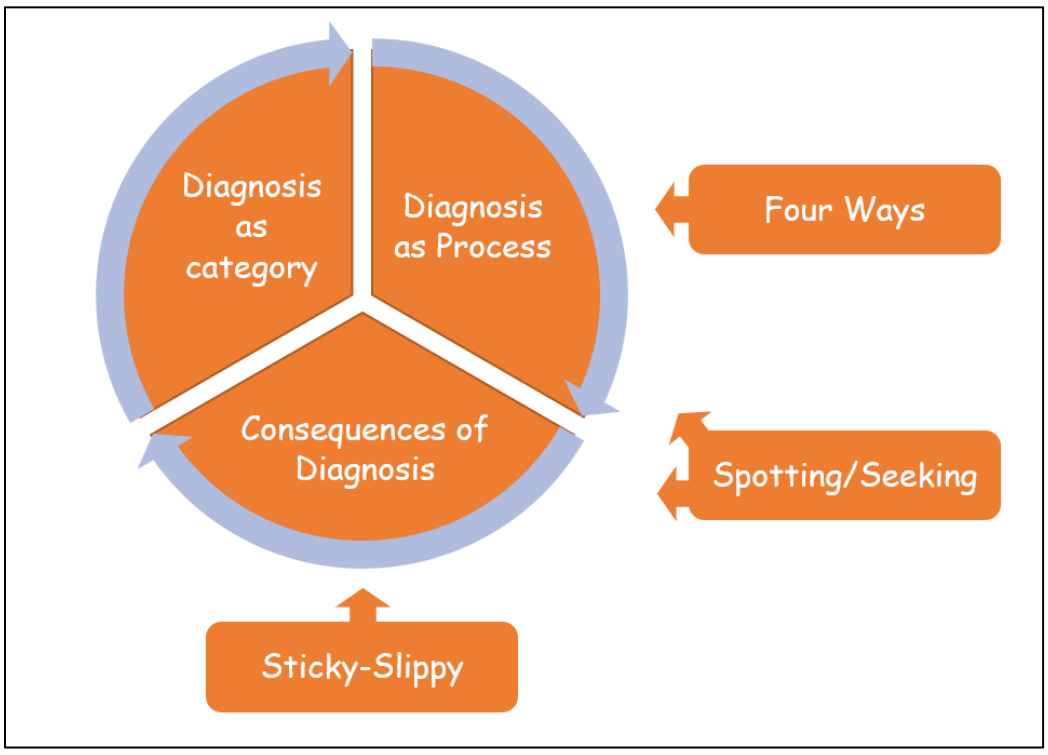


Starting with the sticky-slippy label, this idea offers both literatures a conceptual vocabulary for thinking about and reporting the consequences of acquiring a diagnostic label such as autism. As noted in Chapter Two, sociologists have demonstrated how diagnoses 'work' to organise things for people (Bowker & Star, 1999). They organise the clinical and social picture for patients (Mol, 2002; Parsons, 1951), they have the capacity to transform how a person thinks about themselves (Balint, 1963; Bury, 1982) and how society, in turn, comes to think about them (Aronowitz, 2001; Jutel, 2009). The concept of the sticky-slippy label provides a means of explaining some of these observations.

In regard to Jutel's (2011) model of diagnosis (see Figure 7.2 overleaf), the sticky-slippy label offers a generalised account of some of the fundamental consequences of acquiring a diagnostic label (my other contributions to the model are also noted in the figure). It is a concept that can be used by sociologists to better understand the

nature and implications of a diagnostic category, and an idea that might also apply to labels outside the realm of medical classifications (e.g. those associated with criminality and social deviance, such as thief or smoker). As noted at the beginning of Chapter Four (p. 138), the sticky-slippy label is in part an extension of the classic interactionist work around the sticking power of undesirable social categories (e.g. Becker, 1963; Rosenhan, 1973). My ambition has been to revive and expand upon this kind of theoretical thinking by incorporating contrasting images of malleability and fluidity – labels that are multiple, processual, and prone to change (see 'liquid modernity,' p. 277). By bringing these ideas together, the sticky-slippy label attempts to explain how different social labels 'work' once they are acquired.

Figure 7.2: My contribution to Jutel's (2011) model of diagnosis



In regard to the autism literature, the idea of the sticky-slippy label puts a name to, and expands upon, some of the findings already discussed by researchers. You can see traces of the idea (particularly the stickiness of the label) when authors talk about the

sense of permanence and helplessness that people feel when they acquire a medical diagnosis (Lewis, 2016a), or the way the label appears to 'fuse' with a person's social identity after acquiring it (Singh, 2011). In fact, one research participant actually alluded to the perceived stickiness of the label in an interview with Punshon and colleagues (2009, p. 278; emphasis added):

> "There was this dip [after the medical diagnosis] […] I was feeling a bit hopeless, you know that maybe this wasn't something I could overcome … I am never going to be like one of these 'normal' people and you know … and I thought '*I am stuck being like this now.*'[72]

There are other examples of the autism label changing how a person feels about their previously assigned diagnoses (e.g. Smith & Jones, 2020), and how, once the label is disclosed, it sticks with other people and changes how they behave towards an individual:

> "Many participants described how the diagnosis had changed how other people reacted to them. […] One person said, 'It limited the expectations of others, who watch me more closely or assume I will never be able to do things at work or socially that I think I can do'" (Powell & Acker, 2016, p. 77).

As many of the studies in this area tend to be descriptive in nature, little has been done to conceptualise these findings in more abstract terms. The sticky-slippy label provides a means of doing so, offering a theoretical frame from which to interpret the existing work. Indeed, it is possible to look at many of the published articles in this area and map this concept 'on top' of these studies, noting where researchers are alluding to the sticky and more slippery aspects of the label, albeit in more descriptive terms.

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[72] As already cited on p. 65.

The second finding in my suitcase, the four ways of self-identifying, represents a sustained engagement with the growing phenomenon of people labelling themselves as autistic. In terms of Jutel's model, this fits into the diagnosis-as-process segment (see Figure 7.2). Incorporating these groups into the framework demonstrates the utility and adaptability of Jutel's model, pushing it beyond a traditional medical diagnosis which, from my understanding, was its original focus (personal communication with Jutel, 28th October 2018). In both the sociological and autism literatures, researchers tend to refer to self-identification (or self-diagnosis) as the act of lay people making their own medical diagnoses. The elaboration of these different ways deconstructs this phenomenon into four different stages or states, which can be identified in previous studies of conditions other than autism.

Take Copelton and Valle's (2009) study of the 'scientific self-diagnosis' of human digestive disorders as an example. In their analysis, Copelton and Valle report on some of the reasons their participants had for self-diagnosing and/or seeking a medical diagnosis of coeliac disease (see 2009, pp. 626-629). Looking at some of the data they presented, it is possible to point to evidence of the four ways introduced in my own work. For example, Copelton and Valle's commentary of the following participant could be seen as an example of somebody who self-identifies as a *precursor* to a medical diagnosis (the following extracts are all quoted from their 2009 article):

> "[Participant 1] asked her physician for the [diagnostic test] after reading a list of symptoms online […] 'It was really convincing to see all my symptoms listed there all together.' Though her physician thought coeliac [disease] unlikely, she agreed to testing, and about four weeks later *a medical diagnosis followed [Participant 1's] preliminary self-diagnosis*" (p. 627, emphasis added).

The next could be seen as an example of somebody self-identifying *despite* a negative diagnosis:

> "*Negative test results are likely to produce distress if a patient has already adopted a coeliac illness identity*. This was especially true for [study participants] for whom self-diagnosis prior to medical confirmation was common. [Participant 2] described her negative [diagnostic test] as 'an immediate let down,' as she believed a positive result 'would have been an answer to all this awful pain'" (p. 626, emphasis added).[73]

Self-identifying as an *alternative* to a medical diagnosis:

> "The inaccuracies of medical testing […] were further fuel for *discounting medical testing entirely and supporting self-diagnosis*. [Participant 3] offered this advice to someone considering [pursuing a diagnosis]: 'It might not even be worth doing. There is always a chance that […] the [test] comes back as negative'" (p. 628, emphasis added).

And finally, identifying with autistic *traits*:

> [Participant 4:] "'I did some reading on the internet and *the symptoms kept ringing true to my situation* […] so then I said, well maybe there is something to this'" (p. 627, emphasis added).

Each of these accounts was reported by Copelton and Valle as examples of self-diagnosis. If viewed using my four different ways we start to see the reasons participants had for self-identifying with, or in this case self-diagnosing, coeliac disease, and thereby opening up the analysis in a little more detail. It is difficult to find similar examples in the autism literature as there are few studies investigating self-identification, and those that do (e.g. Sarrett, 2016) do not report the relevant data. That said, there are brief hints of the *precursor* and *alternative* reasons in Lewis (2016b, p. 578, emphasis added):

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[73] Copelton and Valle do not report whether Participant 2 continued to embrace her coeliac illness identity following her negative result.

> "…self-identification [is] an *important precursor* to [a] formal diagnosis."

> "Many individuals reported facing barriers that made formal diagnosis impossible or at least very unlikely […] *they did not perceive that there would be any benefits to being diagnosed*."

Finally, my findings concerning people passively spotting and actively seeking autism in others not only demonstrates an alternative means of acquiring the label (something yet to be discussed in the autism literature), but it goes some way in opening the door on a potentially interesting research agenda: the act of lay people diagnosing other lay people with medical disorders. This again slots into the diagnosis-as-process part of Jutel's model, as well as illustrating one of the potential consequences of a medical or self-diagnosis: the apparent capacity to identify the same condition in other people (see Figure 7.2).

Although I have yet to come across any studies explicitly investigating this phenomenon, there is a general sense that lay people can and do diagnose other people with medical conditions, be that unintentionally through the increased use of diagnostic language to understand and explain another person's problems (see 'diagnostic cultures,' p. 275), or as a more deliberate form of identification – *it sounds like you might be suffering from x.* [74] The latter of these ties into the existing sociological research on help-seeking behaviour, particularly lay consultations and lay referrals (Cornford & Cornford, 1999; Freidson, 1960).

[74] Indeed, when I talk to clinicians about this idea (on an informal basis) they often point to instances where patients attempt to diagnose family members and friends with the same condition that they were recently diagnosed with.

As others have pointed out, friends, family, and other social acquaintances are often the “principle mechanism through which individuals recognise health problems, contact health facilities, and comply with medical advice” (Pescosolido et al., 1998, p. 1057). If an individual (person A) is experiencing troubling symptoms and suspects that there is something wrong with them, they may choose to consult a friend or relative (person B) who can advise them on the potential cause of their problem and possible treatment solutions (e.g. a home remedy or over-the-counter medication). These lay consultations can happen many times with different people with varying degrees of medical and experiential knowledge (e.g. a spouse, a parent, or somebody known to have a similar health issue; Strain, 1990). As has been noted elsewhere, these lay consultants (person B) not only advise on the symptoms person A is experiencing, but also make recommendations on the next person (lay or medical) that they could consult (Furstenberg & Davis, 1984). This is where a lay consultation turns into a lay referral – a plea or request to seek the opinion of a doctor (Edwardson, Dean, & Brauer, 1995; Freidson, 1960). Here, person B believes that whatever is troubling person A requires medical attention and advises them to seek it. Over the years, sociologists have had a lot to say about the role lay people play in advising, encouraging, and in some cases dissuading somebody from seeing a doctor, as well as the role these lay consultations play after a visit to a health professional (see Edwardson et al., 1995; Stoller & Wisniewski, 2003). As I see it, my contribution to this area relates to the role a lay diagnosis plays in the initiation of a lay consultation and lay referral.

In the case of a lay consultation, person A *asks* person B for their advice – they feel that something is wrong with them and seek the advice of others (which might

culminate in a lay referral). This is slightly different from a lay diagnosis, where person A is *spontaneously told* by person B that they have a particular medical condition, that in person B's opinion person A is suffering from *x*. Person B could issue a lay diagnosis following a consultation with person A, which could again conclude with a lay referral, but as I found in my interviews with participants, a lay diagnosis often *precedes* any form of lay consultation (i.e. person A is simply told that they are autistic by person B, without prompting or encouragement). Therefore, a simple way of distinguishing the two concepts is to think about who initiates the conversation: is it the person who suspects there is something wrong (person A) or is it somebody else (person B)? It is a very subtle difference, but one that was clearly observed in my empirical data.

As demonstrated in the previous chapter (p. 231), participant P was on the receiving end of a lay diagnosis that was issued by participant R. P did not request this assessment from R; he did not consult her and ask for her opinion. Unprompted, R told P that he was autistic because (in R's opinion) he exhibited the characteristics and features associated with the condition. Receiving this lay diagnosis then initiated a series of lay consultations in which P asked other autistic people (knowledgeable others) about (1) whether R's assessment was, in their opinion, correct, and (2) whether he should talk to a doctor about it (which he eventually did). In this instance, *a lay diagnosis preceded the lay consultations that culminated in a lay referral to see the doctor*. In Zola's (1973) terms, the lay diagnosis 'triggered' P's help-seeking behaviour, which eventually led to him acquiring a medical diagnosis.

But this might not always be the case. After P received his lay diagnosis, he could have chosen not to talk about it with other people and immediately consulted a doctor

– the lay diagnosis prompting him to seek medical opinion but not the views of other lay people. Alternatively, there may have been a scenario where P never received a lay diagnosis from R, but decided to visit the doctor on his own accord. After the medical consultation, P might have then initiated a lay consultation with R in which he discusses what the doctor said to him. During this conversation R might have then issued her own lay diagnosis, perhaps an alternative diagnosis to the doctor, which P then acts upon in the same way outlined in Figure 6.3 (p. 232). The point that I am trying to make is that whilst it may be the case that there is a close relationship between a lay diagnosis, a lay consultation, and a lay referral, it is not necessarily the case that one always precedes the other two. In this study, I have observed a lay diagnosis initiating a lay consultation and referral, but it is entirely plausible for this process to unfold in a different order.

One final point about lay diagnosis. The act of lay people labelling other lay people with medical disorders may also tell us something about lay people challenging and usurping the clinical authority of the doctor. In an era of the informed patient (Henwood et al., 2003), lay people have the opportunity to learn about medical classifications and diagnose themselves, and other people, with what they see as the appropriate diagnosis, pre-empting and in some cases bypassing the professional judgement of the doctor. As Giles and Newbold (2011) found in their analysis of online forum data, when lay individuals diagnose other people it is often tentatively done and accompanied with a referral to see a doctor. But as demonstrated in the previous chapter, a lay diagnosis can also be issued with apparent authority and certainty, especially if the person doing the diagnosing has a formal diagnosis themselves. In the autistic community there is the view that those with the condition (i.e. those with a

medical diagnosis or those who self-identify as such) are the *true* experts on autism, and it is this lay expertise, some would argue, that best places autistic people to identify and judge whether somebody else has the condition (see Milton, 2014; Prior, 2003).[75] I will consider a possible implication of this line of thinking shortly (see p. 270).

Based on the data collected in this study, I am unable to say whether autistic people are better at identifying the condition than non-autistic individuals (see 'suggestions for future research'), but I have demonstrated that people *are* making their own lay diagnoses and that this warrants further investigation. For sociologists, this could join existing research into the categorisation, implementation, and consequences of a medical and self-diagnosis. And for autism researchers, the lay diagnosis of the condition could be further explored in relation to autistic people's self-expertise (Gillespie-Lynch et al., 2017) and alternative means of sharing and acquiring the label, particularly online (Angulo-Jiménez & DeThorne, 2019).

Suggestions for future research

As the products of this research are intended to apply to diagnostic categories besides autism, the first and most obvious recommendation for future work would be to see whether these ideas have conceptual utility within the context of other physical and psychiatric conditions. My own ambition is to apply these concepts to human digestive disorders such as gluten intolerance and coeliac disease, two conditions that people are increasingly seeking a diagnosis of, or self-diagnosing, in this era of healthy eating

[75] Although as Sarrett (2016) found, some with a medical diagnosis debate whether those who self-identify as autistic are 'truly' autistic and therefore in a position to judge whether somebody else has the condition.

and dietary modification (Reilly, 2016). This would add some conceptual depth to the work already conducted in this area (see Copelton & Valle, 2009).

Taking each of the three concepts in turn, more empirical work needs to be done to chart and measure the conditions in which a diagnostic label such as autism is experienced as something that is more or less sticky-slippy. For example, when does somebody perceive the label to be at its stickiest, and under what circumstances does the label start to lose its prominence in an individual's sense of self (i.e. when does the label start to become slippery)? These are empirical questions that could be addressed in future research. Although this study focussed on developing this idea, as well as the other two concepts, I did get a sense from participants that those who had recently acquired the label felt that it was more sticky (more pervasive and all-encompassing) than those who had acquired the label many years ago, who experienced more of its slippery qualities. Perhaps there is a relationship between the duration since acquiring the label and its perceived sticky-slipperiness? I do not have any data to support this analytical hunch, but it does point to a possible avenue for further research which would add greater depth to the concept.

Next, the four ways of self-identifying are by no means exhaustive, and further empirical work into other conditions might reveal additional reasons that could be added to those presented here (the same goes for the observed transitions between them). It is my intention that these ways come to represent a sensitising concept (Blumer, 1969), a suggestion of where to look, and I would encourage others to pull them apart and reconfigure them in ways that make sense according to their own data. These ways are, and will always be, on probation, and should be changed and

removed when they become analytically redundant. If they were to be used in future studies, however, I would caution against trying to associate demographic groups (e.g. genders or age groups, etc.) with particular types, as their analytical utility comes from the fact that they loosely illustrate particular forms and features of self-identification, which may be observed in all kinds of people.

Finally, as I alluded to at the end of Chapter Six, more research is needed to establish the accuracy of an autistic person's lay diagnosis of autism. Taking inspiration from those who have investigated the intuitive assessments people make of others' sexual orientation (e.g. Johnson et al., 2007; Rule & Alaei, 2016), which has demonstrated under experimental conditions that homosexual people are statistically more likely than their heterosexual counterparts to correctly identify the sexual orientation of other people, a similar study could be conducted in order to investigate whether autistic individuals are better able to identify other people with the condition than non-autistic individuals. As an example, if one were to replicate Rule and Ambady's (2008) experiment, two groups of participants (autistic and non-autistic) could be shown images or videos of people with and without a medical diagnosis, and be asked to identify those that displayed autistic people.[76] Like Rule and Ambady's investigation, participants could be exposed to these images for various lengths of time (e.g. 0.5 of a second, 1 second, 2 seconds, etc.) and under different experimental conditions. Such a study would help substantiate or refute claims made by some of the participants in this study that they can accurately identify other autistic people by briefly

[76] The autistic group could also be split into those with and without a medical diagnosis in order to determine whether there is a difference between those who self-identify as autistic and those with the formal label.

observing their behaviour, mannerisms, and physical appearance (which may have practical applications in the diagnostic process, see p. 270).

Wider contribution

One of the great pleasures of doing sociological research, and thereby thinking sociologically, is that it encourages you to question why people – individuals, groups, even whole societies – do the particular things that they do. It is about challenging the taken-for-granted assumptions in the world and pointing to the different possibilities that are available to us. "What you want sociology for," as Laurie Taylor (2015b) artfully explains:

> "is to ask the questions that nobody else is asking – wider, bigger, broader, more subversive, irritating, awkward, devilish, difficult, unanswerable in some cases – to keep poking away at the ice that constantly freezes over the contemporary world, in which people say, 'well it's only natural,' 'it's only common sense,' 'that's the way we do it,' 'we've always done it that way.' This is where sociologists come along and say, 'ah, but you could think in this way,' 'you could have that thought' […] 'might we do [things] this [way]?'"

And so thinking about the broader and more awkward implications of my research, there are two questions that I want to pose that go beyond mere academic considerations. The first relates to the permanence and irrevocability of an autism diagnosis after it has been issued by a doctor, and the second relates to the role that lay autistic people *could* play in the formal diagnostic process. I will take each question in turn, and offer a suggestion about how, on a practical level, the things that "we've always done" might be done differently.

Should people be allowed to have their medical diagnoses of autism revoked?

First, I believe there is merit in having a serious conversation about the permanence of a medical diagnosis of autism. As it currently stands, once a diagnosis has been issued it remains in place for life – an individual will forever be diagnosed as autistic. This is also the case for other mental health diagnoses (e.g. schizophrenia) as well as some chronic physical conditions, such as type 2 diabetes. In the case of diabetes, a doctor would diagnose the condition when the pancreas struggles to produce enough insulin or the cells in the body no longer respond to the hormone in a normal fashion. Although the disease can be treated through medication and sustained lifestyle changes, the fact that an individual has shown these hormonal deficiencies – which could reoccur if measures taken to treat the condition are halted – means that they will forever be classified, and therefore diagnosed, as a diabetic. In contrast, this is not the case for certain types of cancer. An individual can contract and be diagnosed with prostate cancer, for example, but after a spell of successful treatment go into a period of remission and then, following no new evidence of the disease, outside the parameters of a formal diagnosis. Here, an individual *had* cancer, or a *history* of cancer (WHO, 2019), but they no longer have a formal diagnosis.

I think something similar could be implemented for an autism diagnosis. Whilst it may sound controversial, there is some evidence that those who meet the diagnostic criteria for the condition earlier in life no longer meet it at a later date, yet their diagnosis remains in place (Seltzer et al., 2003). As I alluded to in Chapter Four, this may have something to do with the diagnostic criteria shifting, or with an individual getting progressively better at managing their symptoms so as to fall below the threshold for a diagnosis (Howlin et al., 2000). If that were the case, then perhaps

people with a diagnosis could be given the option to have their diagnostic status reviewed at a later date (say, ten or fifteen years after their initial diagnosis) with the possibility of having it revoked if the appropriate evidence is available. I suggest this as some of my self-identified participants believed that they would have benefited from a medical diagnosis, but they did not pursue one because they were concerned about the permanence or the stickiness of the official label. For those people, the perceived drawbacks outweigh the possible benefits of a diagnosis. If, however, an autism diagnosis was not automatically set as a permanent categorisation, but one that could be reviewed and possibly removed at a later date, then I do believe more people would pursue a diagnosis in the hope that they could get the help that they need today, *at this moment*, and not have to worry about the lifelong and enduring consequences of the label. Autism would then become a diagnosis that is situationally specific, based on clinical evidence (much like a prostate cancer diagnosis), and not a blanket category that is applied indefinitely. Such changes might encourage those who were initially hesitant about pursuing a diagnosis to do so, and it might reassure those currently living with one, but feel that it is no longer applicable or that it is becoming a burden in their life, to reassess their status with their doctor.

In offering this suggestion I am not, to be absolutely clear, implying that autism should be viewed as something that a person *had* and that it has somehow gone because they have been successfully cured. This is purely a conversation about the application and longevity of the diagnostic label, not about the person to whom it is applied. Mental health diagnoses are more than just simple classifications of psychological ailments. They are also statements about a person's core being, who they are, and how they should be treated by society (Rogers & Pilgrim, 2014). Diagnoses such as autism have

far reaching implications beyond the doctor's clinic. They have the potential to fundamentally change how a person sees themselves, and how others, in turn, come to see them. Thinking about this in terms of the sticky-slippy label, perhaps we should be questioning why some diagnostic categories stick forever whilst others are able to slide off an individual's medical record? What is the scientific basis for the permanence of certain diagnostic categories and the revocability of others? And how do we know, with any degree of confidence, that certain symptoms are lifelong without routine assessments and re-evaluations, particularly following the publication of new editions of the diagnostic criteria? There is also an ethical question about a diagnostic label that sticks for life. Are we, the broader public, happy to have clinicians assess our psychological state at a particular moment in time (with great care and diligence, no doubt) and issue us with a psychiatric category that will remain with us indefinitely, especially when such labels often take on a life of their own, bringing with them (in some cases) great prejudice and stigma? Knowing that some labels stick and others do not, should we at least be asking why this is the case and on what basis? The definitions of different diagnoses are routinely changed in light of new evidence about particular conditions; perhaps something similar should occur regarding the application of those labels?

Should autistic people be included in the diagnostic process?

As I found in my interviews with participants, some autistic people firmly believe that they are able to identify the signs of the condition in other people (be that through passive or active forms of identification). Based on the assumption that it might be possible to empirically demonstrate that autistic people can identify others with the condition and that they are better at doing so than their non-autistic counterparts,

perhaps it might be possible to envisage a role for autistic people in the formal diagnostic process. Although patients and members of the public are increasingly seen as having a role to play in scientific and medical activity (e.g. sitting on advisory groups for research projects), lay knowledge is still, for the most part, barred from diagnostic decision-making, which remains firmly under the purview of doctors and clinicians.

But what if lay ways of knowing – the intuitive, first-hand perceptions of autism as described earlier – were put to use by clinicians in order to aid their diagnostic assessments? Perhaps autistic people and their apparent 'autidars' could be used as an additional means of identifying autistic adults who come for a medical diagnosis? For example, alongside the normal clinical interviews and assessments, prospective clients (the term used in mental health to describe patients) could also have informal talks with other medically diagnosed autistic adults, who could offer an opinion on whether or not the client is autistic. This could take the form of a one-to-one meeting (like the diagnostic encounter), or a group session with multiple clients and autistic adults socialising in an out-patient setting. The autistic assessors could then feedback (verbally or via writing) their lay assessment to the clinician in charge of the diagnostic evaluation, which could then be used as evidence when making the final decision. Alternatively, autistic assessors could attend the multi-disciplinary team meetings where diagnostic decisions are arrived at (see Hayes et al., 2020), offering their thoughts on the client's behaviour and symptoms. As one member of my advisory group humorously put it, autistic involvement in the diagnostic process could be likened to a police sniffer dog, whose role is to assist clinicians in identifying suspected cases of autism, rather than illicit objects and narcotics.

Having autistic people involved in the diagnostic process might sound like a far-fetched suggestion, but if (and it is a big if) there is empirical evidence to support the notion of an accurate lay diagnosis, then this might be a plausible application of the idea. Perhaps this lay way of knowing could finally be admitted into the diagnostic process, not only improving the accuracy of clinicians' assessments, but also democratising the overall procedure. Perhaps the formal, less tokenistic (Milton, 2019), involvement of autistic people in such decision-making may actively encourage those already sceptical of clinicians to come forward for a diagnosis in the knowledge that they will also be assessed by what might be called their autistic peers.

Going further: Abstracting up and out

In Chapter Two, I talked about the need for researchers to take their research findings and abstract them up and out – to apply them to issues *beyond* their original focus. As others have pointed out (Taylor, 2015a), over the years sociologists have been gradually losing touch with the theoretical foundations of the discipline. There have been constant moves towards the specialisation and compartmentalisation of sociology – capsules of thinking and research that have gradually moved away from the historical edifice of the subject: the nature of society and people's place within it. Not that this is a bad thing. Moves by forward thinking scholars to call for and develop specialisms such as the sociology of diagnosis (Blaxter, 1978; Brown, 1990; Jutel, 2009), for example, have gone a long way in extending the reach of the discipline and confirming its purpose and utility within the broader social sciences. And this, to be absolutely clear, is one of the great strengths of sociological thinking. But whilst sociologists have been hard at work in their specialist fields, less attention has been

paid to some of the broader sociological concerns. Annemarie Jutel talks about "hooking up to the sociological mothership," whereby researchers translate their specific findings into something broader and more applicable to others working within the wider discipline (personal communication, 28th October 2018). It is this docking with the mothership that I want to attempt here.

But before I do let me issue this disclaimer. The following discussion should be read as a tentative pitch about how the findings in this study might relate to something beyond autism. Doing a PhD gives you the time and space to read beyond your immediate subject, and the following is something that I have been thinking about in relation to this study for the last three years. However partial this discussion may be (and I do not wish to claim that this is a comprehensive analysis), I do see a clear connection between the ideas to be discussed and the findings presented in Chapters Four, Five, and Six. In offering a quick summary of what is to come, I want to try and trace how the emergence of modernity and some of its defining features has created the conditions in which people seek psychiatric labels to explain their concerns and afflictions. I shall do this by drawing on three interrelated social theories – (1) reflexive modernisation (e.g. Beck, Giddens, & Lash, 1994), (2) diagnostic cultures (Brinkmann, 2016), and (3) liquid modernity (Bauman, 2000) – in addition to some of the concepts already discussed in Chapter Two.[77] I will outline the premise of each theory before hooking them up to my own work, and in doing so, attempt to push it beyond the sociology of diagnosis.

[77] Again, a special thank you to Professor Anthony Giddens for helping me tie these ideas to my own work.

Reflexive modernisation

We start by looking at how sociologists have attempted to make sense of our current state of social existence, which has come to be known as modernity. Modernity, in a general sense, "refers to modes of social life or organisation which emerged in Europe from about the seventeenth century onwards and which subsequently became more or less worldwide in their influence" (Giddens, 1990, p. 1). These modes of social life are often understood to be the creation of the nation state (Weber, 1978/1922), the formation of a capitalist economic order (Marx, 2009/1867), and the expansion of an industrial mode of production (Durkheim, 2013/1893). Some have argued that we stand at the opening of a new social era, that the preceding state of affairs is drawing to a close and that we are moving into a post-modern, post-industrial, post-capitalist society (Lyotard, 1984). I will leave it to others to make this case, partly because whether we live in a modern or post-modern society does not change what I am trying to do here. That said, the authors who have informed the following discussion (e.g. Beck et al., 1994) argue that we have *not* transitioned into an era of post-modernity, but rather a phase of 'late modernity.'

One of the key features of modernity that is most relevant to this discussion is what sociologists have referred to as its 'reflexivity' (Archer, 2012).[78] Tied to the foundational assumptions of the Enlightenment and the idea that we can generate knowledge about the world through empirical inquiry (Isreal, 2011), reflexivity refers to the application of scientific knowledge – particularly knowledge of the social world and human behaviour – to inform and ultimately change its practice (Beck, 1992). Some

[78] A term frequently used in the context of research methods. As you will notice, its use in social theory is not too dissimilar to that used to describe a researcher's reflections on their empirical work.

see reflexivity as a fundamental characteristic of all human action – the never-to-be-relaxed monitoring of our behaviour and its contexts (Goffman, 1966). As Giddens (1990, p. 36) notes, “all human beings routinely ‘keep in touch’ with the grounds of what they do as an integral element of doing it.” *The point is that with the emergence of modernity this becomes a chronic feature of social life*. Its reflexivity “consists in the fact that social practices are constantly examined and reformed in light of incoming information about those very practices, thus constitutively altering their character” (Giddens, 1990, p. 38). Here, knowledge ceases to be knowledge that is independent of reality, in part because it *constitutes* that reality (Williams & Calnan, 1996).

The study of social life plays a part in this. Take the collection of official statistics concerning various features of social life. On the face of it, they provide demographers with a means of studying social activity with a reasonable amount of rigor and precision. But as Giddens (1990) points out, official statistics are not just analytical tools used by researchers as the contents of these statistics *reflexively enter into the social universe from which they were taken*. He uses marriage as an example. The majority of people who embark upon marriage today know something about the state of this union, in particular the increasing rate of divorce, as documented by official statistics. Knowledge about the percentage of marriages that dissolve can affect the very decision to marry in the first place, as well as other important decisions regarding the allocation of wealth, property, and other assets. Awareness of the levels of divorce, Giddens (1990, p. 43) argues, is “theorised by the lay agent in ways pervaded by sociological [and demographic] thinking. Thus, everyone contemplating marriage has some idea of how family institutions have been changing […] all of which enter into processes of further change which they reflexively inform.” Put another way, the

information generated by social scientists continually “circulate[s] in and out” of the worlds that they refer to, and in doing so “reflexively restructure[s] their subject matter” (Giddens, 1990, p. 40). This reflexive application of knowledge, which theorists argue is one of the fundamental features of modernity, also applies to the medical sciences, in particular psychiatry (see p. 279 for how these ideas apply to my own work).

Diagnostic cultures

Today, many people living in the West are able to freely use diagnostic terms like anxiety, depression, and OCD (obsessive compulsive disorder) when talking about their problems or those of their family and friends. Many read books and articles about how to manage various psychological afflictions that could be formally diagnosed, and consume films and television shows where the characters are suffering from identifiable psychiatric disorders (Atanasova et al., 2019). When reading the news we are routinely confronted with frightening accounts and statistics about the state of the population’s mental health. At the present time, psychiatric terminology and the knowledge that it represents has “been democratised and has travelled from the clinics and medical textbooks into popular culture” (Brinkmann, 2016, p. 8).

According to Svend Brinkmann we are now living in a ‘diagnostic culture.’ The term is meant to “point to the spread of diagnostic vocabulary and associated practices to new areas of social life” (Ibid., p. 11).[79] More specifically, Brinkmann uses the term to capture “the numerous ways that psychiatric categories are used by people – patients, professionals, and almost everybody else – to interpret, regulate, and mediate various

[79] Brinkmann talks of cultures, plural, to acknowledge the different ways that this can occur.

forms of self-understanding and activity" (Ibid., p. 1). In previous eras, particularly pre-modern times, we may have turned to religious concepts to make sense of the experiences that caused us suffering, such as the Will of God or demonic possession (Williams, 2005). But now, it is "more often psychiatry and its diagnoses that are invoked to account for the problems that people experience" (Brinkmann, 2016, p. 2). What was formerly a sin is now a sickness (Taylor, 2007). Because of the prominence of psychiatric knowledge, it has become increasingly difficult to think and talk about a person's mental state outside what is made possible by psychiatric categories, to the point that this diagnostic discourse has become hegemonic (Lakeman & Cutcliffe, 2016). The widespread and pervasive nature of diagnostic cultures means that there are an increasing number of people living under the description of a diagnosis (Martin, 2007), which may be the result of 'medicalisation from above' (e.g. doctors and pharmaceutical companies creating new diagnostic categories) or patients and activists pushing for 'pathologization from below' (Brown, 1995; Conrad, 2007; Dumit, 2006; McGann, 2011). In this state of affairs, *we are invited to think about ourselves in diagnostic terms and are given the tools and knowledge to do so* (see p. 279).

Liquid modernity

But why are people doing this? Why are individuals and society at large applying psychiatric concepts to their concerns, knowingly or unknowingly? A possible answer comes from the way sociologists have come to think about modernity and the role diagnostic categories play in it. According to Zygmunt Bauman (2000), the vast and drastic changes ushered in by modernity have fundamentally destabilised the apparent order in the world. For Bauman, words like 'fluidity' and 'liquidity' are useful metaphors for grasping our current state of existence. Prior to the emergence of

modernity, we lived in what Bauman called 'solid times.'[80] There were traditions, structures, and ways of being that went back centuries. However, with the dawn of the Enlightenment, science and rationalism promised radical change. Doing away with previous modes of thinking (e.g. religious beliefs), the application of empiricist reasoning would offer a new and exciting world; a world built on order and predictability, where the structures of old could be dismantled and rebuilt, where the previous solids would be melted down into something new.

The arrival of the modern age literally saw the melting of solids. The industrial revolution liquified metals to create new materials. "All that is solid," Marx (1996/1848, p. 1) once proclaimed, "melts into air." Figuratively speaking, modernity thawed traditional hierarchies before reshaping them into new forms of social organisation. And whilst the world became more fluid and dynamic at an institutional level, this transition also occurred at an individual level (Bauman, 2005). No longer was a person's identity solely determined by the structures of old – the church, one's family, their social class – as they too found themselves thrown into the melting pot of modernity. Individuals were left to forge their identity on their own terms (with the help, Bauman notes, of modern consumerism). In solid times, the world and our place within it was narrated for us, usually in relation to God and traditional practice. In liquid times, there are no readily available narratives to tell us what to think and how to behave, or at least these narratives are less prominent than they used to be (Bauman, 2013). We are free to choose who we want to be. We can create different images for ourselves.

[80] Note, that Bauman does not see the pre-modern era as solely a solid time and the modern era as one that is fluid. There were elements of fluidity in earlier eras, but it is the *degree of fluidity* that he points to as the defining feature of modernity. Giddens makes a similar argument with regards to reflexivity.

We can hold multiple identities. *The very contours of our individuality are mobile and free forming*. With few anchors tying us to the solid regimes of the past, the self, Bauman argues, has also become fluid and shifting. Modernity's consistent and systematic assault on the settled has invaded our thinking of ourselves, which can lead us to feeling chaotic, disorganised, and dislodged from one another (see MacLaughlin, 1999).

Applying these theories (and those of others) to the current study

So how do these three theories relate to my own work? To start with, for many of the people that I interviewed there came a point in their life when they started to see themselves as unusual, different, or odd. This may have occurred recently or much earlier in their life. Seeking an answer to why they feel the way they do, the knowledge readily available to them in this diagnostic culture meant that they started to see their concerns as psychiatric in nature (and specifically related to autism). Participants may have arrived at this conclusion on their own or, as demonstrated in Chapter Six, somebody else might have pointed this out to them. Some then sought the opinion of a doctor to confirm whether or not this was the case, whereas others chose to apply the category to themselves and self-identify as autistic. In either case, *the knowledge and concepts of psychiatric medicine, which have become the dominant way of understanding human behaviour in this era of modernity, are being reflexively applied* to *and* by *more and more people in adulthood*. The latest scientific thinking around autism, which is filtered through cultural resources such as newspaper articles and television shows, is circulating in and out of the social world and thereby fundamentally changing how people think about themselves. We are "awash in a sea of biomedicalising discourses," Clarke et al. (2003, p. 184) note, that encourages us to

see ourselves and others through the lens of twenty-first century biomedicine. Our bodies and behaviours are constantly examined within the context of biomedicalised knowledge and practices (the major components of which can be found on p. 43). The growing imperative to "know and take care of thyself" (ibid., p. 184) has flourished alongside notions of disease risk and health surveillance techniques (epidemiologically, genetically, and individually speaking; Armstrong, 1995), which has transformed matters of health and wellbeing into an ongoing project of self-transformation, for which autism and many other psychiatric labels, I suspect, play an important part.

Like marriage statistics, the upward trends in diagnosis (Waugh, 2019) mean that more people are becoming aware of the condition. Greater awareness of the condition means that clinicians and members of the public are more likely to think about psychological concerns in these terms, viewing autism as a likely explanation for why they feel the way they do. The increased application of the label feeds back into the research and official statistics on autism, which prompts further categorisations of autism in the future. As a result, our knowledge of autism alters how we see ourselves, which subsequently alters our knowledge of autism. This is exactly what Ian Hacking (2007) had in mind when he talked about the 'looping effects' that feed into the 'making up' of different 'kinds' of people (see p. 46). The conception and application of new diagnostic categories, such as autism, leads to the creation and examination of new kinds of classified people. Knowledge about these people, and the classifications assigned to them, reflexively shape and restructure both the labels and the people to whom they are applied, which ultimately changes our understanding of both. It is this reflexive application of knowledge, which loops in and out of the social world, that

creates the conditions in which new kinds of people are conceived of, and experienced, as different from other kinds of people (Giddens, 1991; Hacking, 1995). As I see it, this fundamental feature of modernity is crucial to understanding the state of affairs in which people like my participants find themselves in. They have found themselves, either through their own doing or otherwise, implicated in a continuous sequence of knowledge generation, whereby the autism label they have acquired has transformed their understanding of themselves and other people, which has reflexively looped back into our broader knowledge of autism and the people who are classified as such. Their acquiring of the label autistic is both a product and a consequence of this reflexive looping of diagnostic knowledge.

Putting a name to our concerns using the language of psychiatry not only illustrates the reflexive application of this knowledge, it can also be seen as a response to the liquidising pressures of modernity. We – the public, clinicians, researchers – are increasingly trying to make sense of who we are and how we behave. In the context of an era that is fluid, where we no longer have the social anchors of the church, the state, or our tribe to tell us what to think and how to act (at least not to the same extent as in previous eras), psychiatric diagnoses can be seen as a means of marking and solidifying the social world, settling the confusion and chaos that surrounds the human cognitive experience. For people like my participants, diagnostic categories offer a narrative for understanding themselves: *I am like this – awkward and anxious – because of that – autism.* It answers some of their concerns. It stabilises the fluid. It is a narrative that sticks.

But we can go one step further than this. As noted at the beginning of Chapter Four, there are certain social and biological categories, like sexuality, that are understood in ways that cast them as natural, permanent, and ever-present constants (e.g. the assumption that humans are naturally monogamous and heterosexual, Bell, 1993; Foucault, 1978). The same could be said for gender, which in the West has been denoted as a simple binary division between male and female identities (man and woman when categorised as biological sex, Butler, 1999). These categories are narrated as if they are solid entities: things that are real and unchanging. But in this era of liquid modernity, these concepts, like an individual's identity and sense of self, have also started to become permeable and malleable, cast and reshaped in ways previously unimaginable.

For example, it is now possible to talk about gender fluidity, which assumes that the gender that a person identifies with and expresses (which are two separate processes) is not a fixed category, as previously thought, but one that can shift and change over time (Linstead & Brewis, 2004). This transition may occur between the traditional male/female binary (i.e. *trans*gender), between a whole multitude of alternative gender identities (e.g. cis, demi, queer identities; collectively known as *pan*gender), or outside all preconceived gender assignments (i.e. *a*gender). Here, a person's gender identity has become mobile and adaptable, transformed into something that can be played and experimented with. The traditional binary of male/female – categories that have been essential to our basic understanding of ourselves over the centuries – have succumbed to the melting pressures of modernity, enabling them to be moulded and reshaped in ways previously at odds with conventional thinking.

Psychiatric diagnoses, I would argue, are undergoing a similar transformation. Once diagnostic categories are out in the public domain, published in psychiatric manuals that are filtered through the media and popular culture, lay people are free to interpret and apply these categories to themselves, and other people, in a manner of their choosing – such is the temptation in this diagnostic culture. In seeking a narrative to which to anchor one's identity to, an individual is free to choose aspects of different conditions to stick together a hybridised account of who they are using the language and concepts of psychiatric medicine. Some psychiatric categories, such as autism, have also morphed into cultural references, labels that people choose to associate themselves with because they feel an affinity to the collective identity that the category represents (see Davidson, 2008). In this liquid life, not only can an individual play with their gender and sexuality, but they can also experiment with their 'psychological identity' using diagnostic categories. As a consequence of biomedicalisation, the body and psyche are no longer viewed as relatively static and immutable – as was, to an extent, traditionally the case – but rather as things that are flexible and capable of being reconfigured and transformed. The opportunities for biomedicalisation, as Clarke et al. note, extend beyond merely regulating and controlling what bodies and psyches can (and cannot) do, "to also focus on *assessing, shifting, reshaping, reconstituting, and ultimately transforming* bodies [and psyches] for varying purposes, including new [social and psychological] identities" (2003, p. 181, emphasis added).

The slipperiness of psychiatric categories, in particular their constantly revised and shifting definitions (Hassall, 2016), has seen lay people appropriate and redefine them in ways that sometimes bear little resemblance to the original classification. And why not? Who is to stop somebody reading the diagnostic criteria for autism and saying,

hey, that sounds like me? The point is that it does not matter whether somebody who self-identifies as autistic 'truly' has the condition – it does not matter what the clinicians or the experts say – because *people are free to apply and use these categories in any way imaginable*. In a way, this is the ultimate (or perhaps unintended) achievement of the neo-liberal individualist ideology that has dominated Western modernity (Smith & Moorse, 2015). Psychiatric categories, like other markers of our identity, are just one of the many resources available when building and shaping our individuality.

At the crux of this discussion, however provisional it may be, is the assumption that modernity – its reflexivity, its liquidity, and the prominence of its diagnostic discourse – has fundamentally changed how we think about ourselves. In this era of modernity, the self has become a biographical project that is reflexively made (Giddens, 1991), and psychiatric categories are just one of the many readily available resources that are used in this process. The three theories described above (and their links with the ideas of authors such as Ian Hacking and Clarke et al.) help to contextualise the findings of this study, offering a possible explanation as to why people label themselves, or are labelled, as autistic in adulthood. Broader social theories such as these offer an overview of the current state of play, sociologically speaking, and my three concepts – the sticky-slippy label, four ways of self-identifying, and spotting and seeking autism – offer a means of tying them to particular empirical instances. In attempting to hook up to the sociological mothership, I see the above discussion as an ongoing endeavour that will become clearer and more refined as I progress through my academic career, perhaps becoming a topic that I investigate more thoroughly in the future.

Epilogue

In bringing this dissertation to a close, I want to reflect on a few of the ideas presented in the preceding chapters. I started this work by quoting a woman called Jane. Jane was diagnosed with autism when she was in her thirties and, as she recounted in a BBC (2019) documentary, the diagnosis had had a profound impact on her life:

> "It sounds kind of melodramatic, but it put my life into a very different context. It was a huge relief. All the things that I thought were negative aspects about myself and failures and flaws, things that I couldn't control, were suddenly put into a context where they made sense, where I could deal with them, where I could research about them, where I could turn them into positives. It was very transformative."

For me, it is the final part of this quote that is the most important: the diagnostic label was *transformative*. Based on my conversations with the people in this study, I am in no doubt of the transformations the diagnostic label initiates, and in a way, the products of this research (particularly the concept of the sticky-slippy label) are an attempt at capturing and explaining some of these changes.

At its heart this has been a study about labels, and I cannot help but notice some similarities between the things that I have written about in relation to my participants and my own attempts at securing a different kind of label: the title Doctor of Philosophy. In undertaking this degree, I suspected that I had some of the characteristics associated with an independent academic researcher, and over the course of this dissertation I have attempted to demonstrate that I meet the required standard for a PhD. This could be likened to seeking a medical diagnosis of autism. In this instance, my examiners, who could be thought of as my assessing clinicians, are trying to make an evaluation, an academic diagnosis: does this candidate, on the evidence he has

presented here, meet the threshold to be awarded a PhD and the title Doctor of Philosophy?

Like the label autistic, if successfully acquired, the title Doctor has the capacity to stick to me should I choose to disclose it. Barring any disciplinary action that sees the qualification withdrawn, I will retain the title indefinitely, with the prefix ‘Dr’ attached to my name in both an official and informal capacity. Like a medical diagnosis, the label can be used to construct a newfound sense of self, in which a new narrative is stuck together to describe my apparent knowledge and expertise in a particular field of inquiry. Like a psychiatric label, the PhD title comes with its own associations and stereotypes (smart, nerdy, highbrow, posh), which can find themselves sticking in the minds of other people so as to change their perception of the newly minted academic. If awarded, the title Doctor may become my master status, causing other social labels, associations, and expectations to lose their traction and slide off me. After a while, the PhD label may also lose its prominence and notability, surpassed by another equally sticky label (with any luck, Professor, or perhaps less desirably, a psychiatric diagnosis of my own), or made redundant after decades outside of academia, becoming part of a varied set of attributes and features used to describe myself.

Although I hope to be awarded the qualification and corresponding title, perhaps my examiners will judge my work to be sub-threshold, more like the quality associated with a master’s dissertation. Regrettably, I might find myself transitioning from a ‘PhD precursor’ – somebody anticipating a successful viva – to somebody experiencing the academic equivalent of ‘diagnostic disappointment’ (Powell & Acker, 2016), with the examiners concluding that my work is of insufficient quality based on their experience

of examining other candidates and the assessment criteria outlined in the University guidelines. They may award the dissertation a failure, preventing me from advancing any further. Alternatively, they might allow me to resubmit pending revisions. Here, I get another shot at the qualification, another chance to acquire the academic label I so hope to secure.

If the examiners award me a PhD, maybe one day I will be asked to recruit, tutor, and examine other PhD candidates. Having successfully been through the process myself, I should hopefully have the ability to judge whether future students meet the required standards for the qualification. Like the tutors and supervisors who previously encouraged me to undertake doctoral studies, I may be able to spot potentially successful candidates in the future, recognising in them the characteristics I saw in myself when I was a postgraduate student. Like those tutors, I too will become instrumental in identifying future sociologists who go on to achieve a PhD, in a cycle that moves from one generation of researchers to another.

The somewhat humorous but serious point that I am trying to make is that the ideas in this study apply to other non-medical labels and categories. In thinking about my own attempts to acquire an academic qualification, I feel that I can empathise with a lot of the things that the people in this study said about their autism label. That is not to trivialise the diagnostic label and the impact that it has had on their lives. Rather, it is to do what all good sociologists do and that is apply their findings and thinking to other related phenomena. All social labels, whether diagnostic categories or awarded titles, have a potentially transformative impact on their recipient. That is why it is worth

studying them and trying to understand their sociological significance. This work is a small but hopefully informative attempt at doing just that.

Conclusion

The aim of this study was to develop a theoretical account of how people acquire and experience the label autistic in adulthood. In order to achieve this aim, I conducted a qualitative investigation where I attempted to answer the question: "How do people come to be labelled, or to label themselves, as 'autistic' in adulthood, and what are the consequences of doing so?" Relaying the findings of my research back to this question involves breaking it down into two parts: *how* do people acquire the label, and what are the *consequences* of doing so? I address the how part of this question with the four ways of self-identification (somebody labelling themselves as autistic) and the notion of a lay diagnosis (being labelled as autistic by somebody else). These represent two different methods of acquiring the label other than a traditional medical diagnosis, which has already been well documented in the research literature. The consequence part of the question is answered using the concept of the sticky-slippy label, which illustrates some of the fundamental aspects of the label and the implications of living with it. My findings around the lay diagnosis of autism also demonstrates an additional consequence of acquiring the label: the perceived ability and authority to identify other people as autistic. Taken together, these ideas advance the sociological knowledge of diagnosis by providing a conceptual vocabulary for thinking about the nature of the label autistic and some of the alternative, non-medical, ways in which people acquire it. These findings not only further sociologists' understanding of how people acquire labels such as autism, but also act as an

illustrative example of themes and topics that might be applicable to other physical and psychological conditions.

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Appendices

Appendix 1: Systematic search terms (autism literature)

Criteria	Details
Search terms	Diagnos* AND autis* AND adult* Impact AND diagnos* AND autis* AND adult* “Self-diagnos*” AND autis* “Self-identi* AND autis*
Databases	Google Scholar, International Bibliography of the Social Sciences, JSTOR, Scopus, Web of Science
Timeframe	All dates
Sources	Peer-reviewed articles from sociology, psychology, and health science journals
Inclusion criteria	Empirical investigations into the process and consequences of self-identifying, self-diagnosing, or acquiring a medical diagnosis of autism in adulthood

Appendix 2: Literature search strategy (provided by the University of Exeter Library; continues overleaf)

Sociology/Medicine and Psychology resources / search support
Thomas Lister – Postgraduate researcher, Exeter Medical School

Research Question: "How do people come to be labelled, or label themselves, as autistic? What are the consequences?"

Initial ideas:

- Group similar keywords together so that a complex search can be carried out in one go
- Group your results into themes
- Use ASD (autistic spectrum disorder) as another keyword when searching, in addition to autism etc.
- Choose to search multiple databases simultaneously if they are on the same platform i.e.
    - Proquest Applied Social Sciences Abstracts and Index
    - Proquest International Bibliography of Social Sciences
    - Proquest Dissertations and Thesis Global
    - Proquest Sociology Collection
- Web of Science/Scopus – allow you to run a number of previous searches together
- Use related references or journal keyword searches etc to lead onto other relevant journal articles
- A lot of databases search for self-diagnosis as two distinct words (self and diagnosis). To avoid this use speech marks to ensure it is searched for as a phrase: "self-diagnosis".
- Keep a record of the search combinations and keywords you have used and where you have searched
- Always keep hold of anything useful looking, either citations or the full-text article so you can easily find it again if required

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Key concepts to draw upon in literature review (not all will be relevant):

- Medicalization
- Sick role
- Surveillance medicine; Medical gaze
- Stigma; Diagnostic lens; Master status; Illness career
- Illness identity; Illness narrative
- Epistemic authority; Ways of knowing; Explanatory models
- Reflexive project
- Disease/illness dichotomy
- Self-advocate
- Enactment
- Path to diagnosis; Path to doctor; Lay referral networks
- Doctor-patient relationship
- Diagnostic disappointment
- Self-diagnosis*; Self-identification
- Boundary objects; Social worlds
- Scientific discourse (re: autism)

*Key theme (self-diagnosing autism)

Background

- Research topic
- Prior knowledge/experience
- Help and guidance available on Libguides for:
    - Sociology http://libguides.exeter.ac.uk/sociology
    - medicine http://libguides.exeter.ac.uk/medicine
    - psychology http://libguides.exeter.ac.uk/psychology

- Key databases for each subject can be found on the Resources tab of each libguide

1. **Finding/accessing databases**

   - Accessing resources through Library catalogue (http://as.exeter.ac.uk/library/)
   - Database A-Z and 'best bets'

2. **Potential keywords:**

   Keyword search: **self-diag* AND (autism OR ASD)**

   Will find self- diagnosed, self-diagnostic, self-diagnosis etc

   ("self-diag*" OR "self-identif*") AND (autis* OR ASD)

   Will find all variants of words in combination with other variants

   Journal article found using these keywords in Proquest:

   A Mixed Methods Study of Barriers to Formal Diagnosis of Autism Spectrum Disorder in Adults –

   Keywords at end of abstract: Autism spectrum disorder, Adult, Mixed method, Diagnosis, Self-diagnosis, Barriers

3. **Key databases for Sociology/Medicine/Psychology**

   Proquest Sociology

   Proquest Sociology is a key resource for finding research literature. It searches both Sociological Abstracts and ASSIA databases, covering literature in sociology, social services and related fields. It provides access to a range of full text resources including journal articles, book chapters, working papers and more.

   International Bibliography of Social Sciences

   IBSS is a large bibliographic database covering the social sciences. It's content spans the social science subjects of anthropology, economics, politics, and sociology.

   PsycINFO

   PsycINFO is an extensive bibliographic database covering psychology and related disciplines. Can choose a number of database collections to search in one go.

   Keywords: (**"self-diagnosis" OR "self-diagnosed") AND (autism or autistic) – don't think truncation works on this**

   Look at: **Exploring the Experience of Self-Diagnosis of Autism Spectrum Disorder in Adults.**

   PsycARTICLES

   PsycARTICLES is a full text database covering psychology and related disciplines. If you are short on time and need to find articles that are available immediately for you to read, use this option.

   SCOPUS

   SCOPUS provides an index to scholarly literature across the life sciences, medicine, social sciences and humanities.

Some every relevant looking journal articles

Web of Science
This is a multi-disciplinary database that covers a wide range of subjects including psychology.**Create account to save searches and results**

4. **Planning your search strategy**

Identify keywords and phrases

Consider:

- subject-specific terminology; technical terms
- acronyms and abbreviations
- synonyms and related terms
- broader and narrower term
- spelling and terminology variations (e.g. UK and US)
- changes in terminology over time

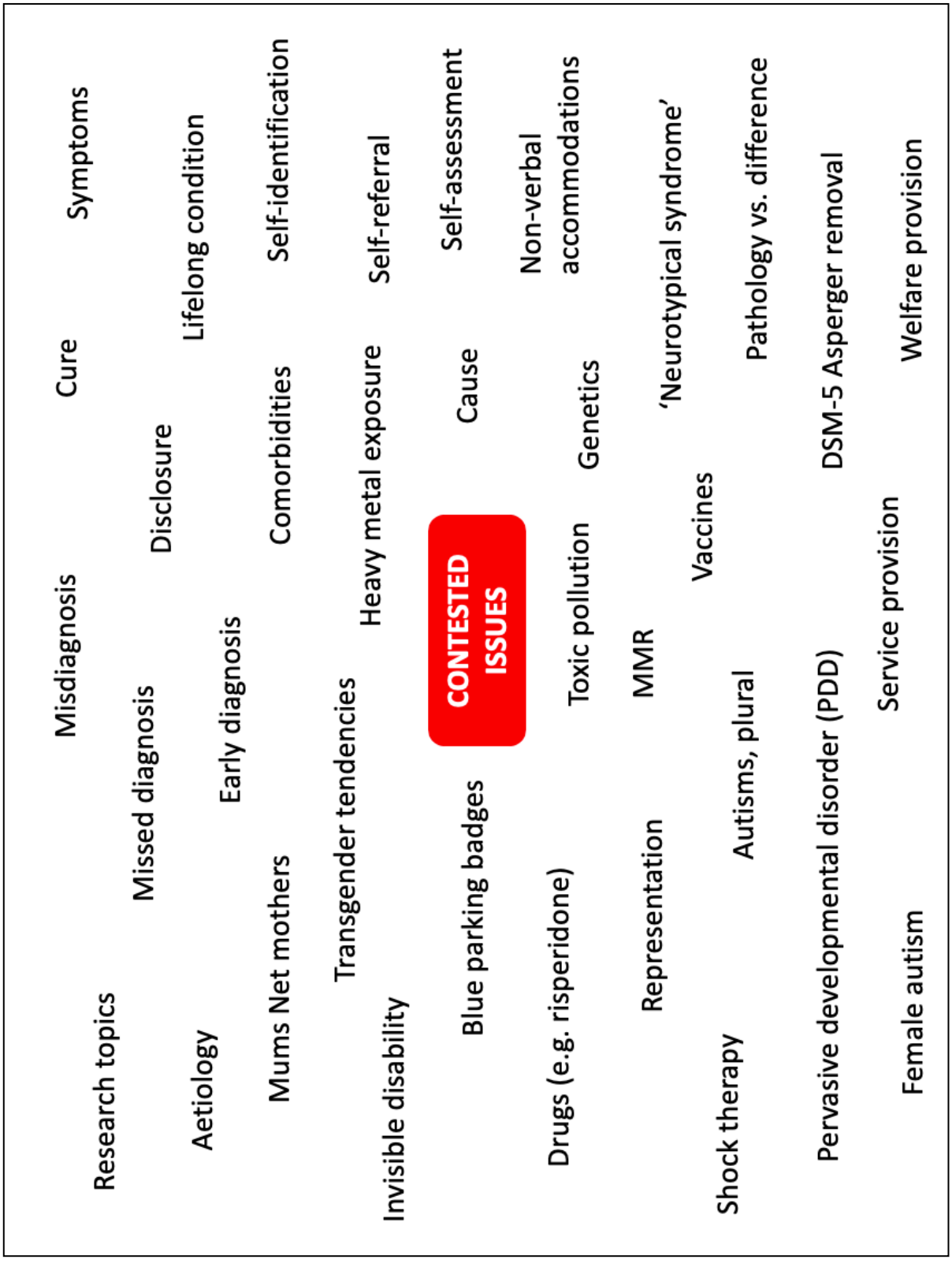
5. **Database advanced searching**

- **Boolean operators:** AND, OR, NOT
  autism AND self-diagnosis = both keywords will appear on results
  autism NOT aspergers = no results with the word aspergers in will be returned
- **Truncation:** autis* = would retrieve autism, autistic, self-diag* =would retrieve self-diagnosis, self-diagnosed etc.
- **Wildcards:** wom?n (would retrieve woman and women)
- **Phrases:** "Autistic Spectrum Disorder"
- **Parentheses:** depression AND (autism OR ASD) = groups words together

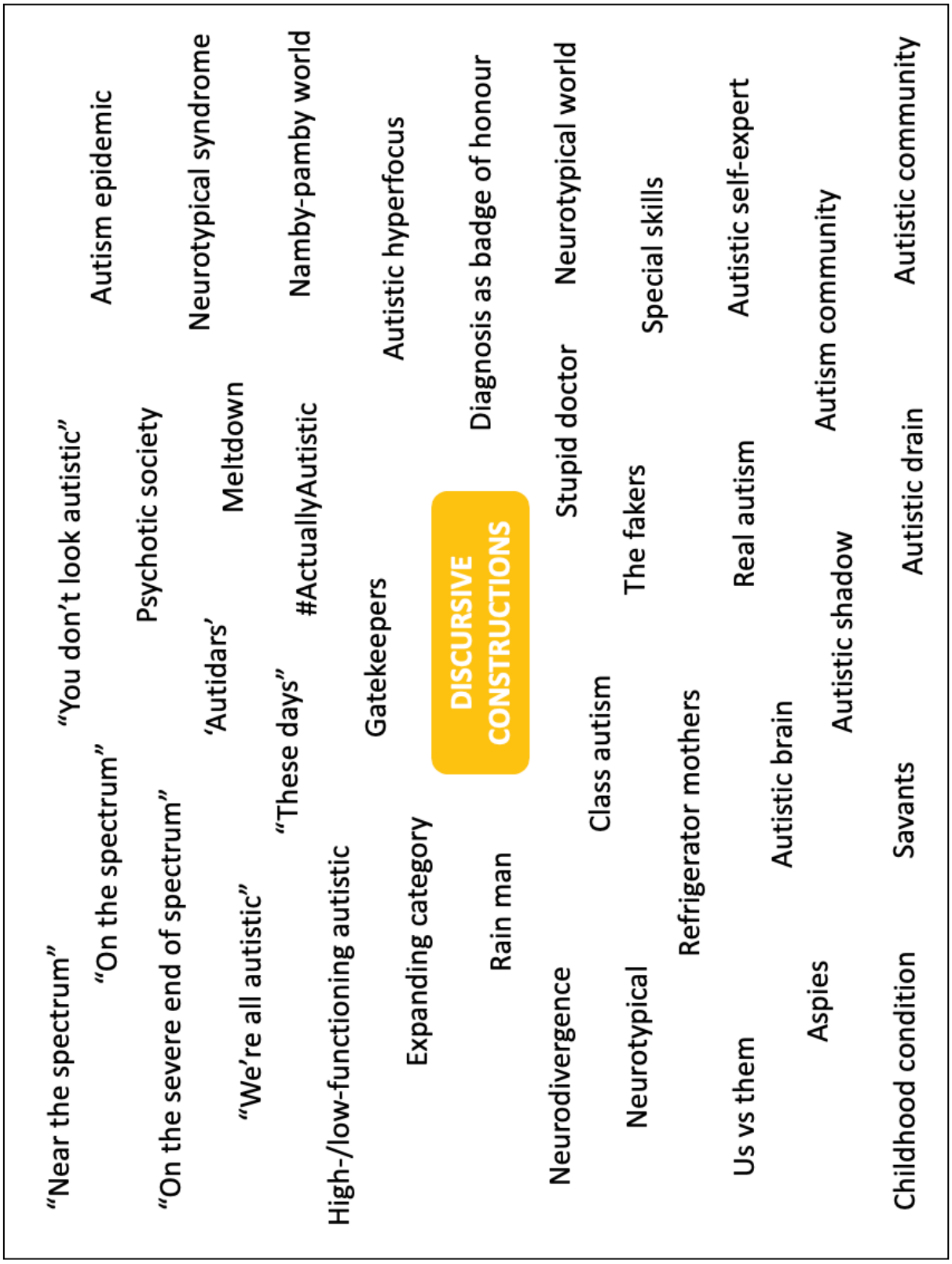
From the **Psychology libguide** under **Search Techniques**:

Selecting Search terms	Define your research topic. Identify search terms and alternative words /phrases
Boolean Operators	Combine search terms for online processing
Truncation & Wildcards	For variant word spellings and endings
Phrase & Proximity searching	To specify the proximity of multiple search terms
Field Searching	To search particular fields such as author/title etc. for focused searching
Database Facets	For refining your search by one or more facet/category. e.g. language/date
Reviewing your search	To evaluate and tweak your search, as and when needed

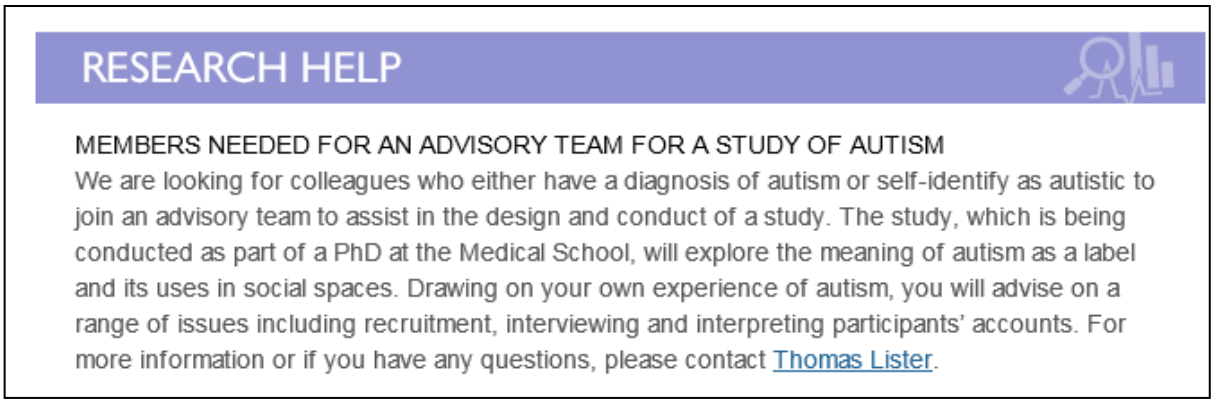
Appendix 3: Zoomed in situational map: Contested issues



Appendix 4: Zoomed in situational map: Discursive constructions



Appendix 5: Advisory group advert (screenshot)



Appendix 6: Advisory group information sheet

What's in a label? The functions and consequences of identifying and diagnosing autism in adulthood: A grounded theory study

Thank you for showing an interest in this study. Below is some information about the role of the advisory team and how you will be able to contribute to the study. If you have any questions or want to know more, feel free to drop me or my supervisor an email.

What is the study about?

This study aims to understand (1) why people self-identify as autistic and/or seek a medical diagnosis of autism in adulthood, and (2) the functions and consequences of the label in everyday life.

Why are you recruiting an advisory team?

Following the motto "Nothing about us without us!", we believe it is important that members of the autistic community are able to contribute to the design, conduct and implementation of scientific research. Recruiting an advisory team ensures that the views of autistic people are represented throughout the research process and that the quality of research is enhanced by working with those who have a first-hand experience of autism.

How will I contribute to the team?

You will be invited to review and comment on any of the research materials used in this study. This will include providing feedback on information leaflets, consent forms, interview question guides, and any additional information given to participants. The advisory team will also be given the opportunity to share their own ideas on the research topic and will be invited to contribute to the interpretation of research findings.

How much time will I need to commit to the role?

The team will meet every six to nine months to discuss ongoing tasks. I will contact the group via email to arrange a time and location. From time-to-time the group will also be invited to share their thoughts on a particular issue or topic of debate. Attending team meetings and responding to messages is not compulsory. If you're unable to attend a meeting but would like to share your thoughts on a topic you can do so via email.

Will I be able to get my travel costs refunded?

Yes, the University is able to reimburse any travel expenses you incur. Information about how to claim expenses will be given at the end of every meeting.

Contact details

Thomas Lister (lead researcher)
Email: tl418@exeter.ac.uk, Tel: 01392 726013

Professor Christabel Owens (lead supervisor)
Email: c.v.owens@exeter.ac.uk, Tel: 01392 726006

Appendix 7: Certificate of ethical approval

UNIVERSITY OF EXETER | MEDICAL SCHOOL

University of Exeter Medical School
Research Ethics Committee

Certificate of Ethical Approval

Research Institute/Centre: Institute of Health Research

Title of Project: What's in a label? The functions and consequences of diagnosing and labelling autism in adulthood: A grounded theory study

Name(s) of Project Research Team member(s): Thomas Lister
Professor Christabel Owens
Dr Ginny Russell
Professor Susan Kelly

Project Contact Point: Thomas Lister

This project has been approved for the period

From: 13 November 2017

To: 31 January 2020

University of Exeter Medical School
Research Ethics Committee approval reference: Nov17/B/136

Signature: RGarside

Date: 13 November 2017

Name of Chair:
Ruth Garside, PhD

Your attention is drawn of the attached paper "Guidance for Researchers when Ethics Committee approval is given", which reminds the researcher of information that needs to be observed when Ethics Committee approval is given.

Application Reference Number 17/09/136

Appendix 8: Response to Ethics Committee

"Care will need to be taken to formulate inclusion/exclusion criteria that clearly justify why certain individuals are to be excluded, to avoid giving the impression of unnecessary discrimination. On the other hand, the need to conduct research in 'special' or 'vulnerable' groups should be justified and it needs generally to be shown that the data required could not be obtained from any other class of participant."

20.1 Other vulnerable groups

The question of 'vulnerability' is something that we have considered at great length, both as a research team and in consultation with the [advisory] group. We believe that it is potentially unethical to label *all* participants as 'vulnerable' by virtue of being labelled, or labelling themselves, as autistic. Defining participants as a 'vulnerable group' is problematic because people with autism are not a homogeneous group. Autism is a spectrum condition, associated with a wide variety of symptoms, skills, and individual support needs. It impacts on different people in different ways, so to refer to all autistic people as a vulnerable group would be inappropriate. Furthermore, the population of interest is made up of those who have either received a medical diagnosis or have labelled themselves as autistic, *in adulthood*. The fact that they reached adulthood without a diagnosis or specialist care means that they are likely to have developed effective coping strategies.

The vulnerabilities experienced by an individual (be they autistic or 'neurotypical') are situational, and not intrinsic to the person. Autistic adults are not necessarily vulnerable at all times. They can find themselves in situations that make them vulnerable, as can anyone, but they are not vulnerable by virtue of being autistic. We cannot see on what grounds somebody who labels themselves as autistic should be considered *more* vulnerable, or at greater risk of experiencing feelings of vulnerability, than somebody who does not self-identify as autistic. This is a key point that illustrates the transformative power of a diagnostic label (either medically assigned or self-assigned) and therefore relates directly to the focus of this study. It suggests that by assuming the label 'autistic' one is automatically also assuming the label 'vulnerable' and is forced to be categorised as such, which disregards the potentially empowering nature of the diagnosis or self-assigned label. We intend to explore participants' views on this issue as one of the potential consequences of being labelled as autistic.

For the above reasons, we believe a dichotomous classification of vulnerability is unhelpful and that a more nuanced approach is needed. We propose that within the study population there may be some vulnerable individuals, and that situations may arise that trigger particular responses [page signpost], but to label the whole target population as vulnerable is inappropriate. This position has been recommended by the [advisory] group, who are themselves members of the target population. For details about how we plan to manage and minimise any potential risks to participants, please see [page signpost].

Appendix 9: Participant information sheet (continues overleaf)

UNIVERSITY OF EXETER

Autism and Neurodiversity Exploring Diagnosis

STUDY INFORMATION SHEET

What's in a label? The functions and consequences of an autism label in adulthood

Thank you for showing an interest in this study. Please read this information sheet carefully before deciding whether or not to participate.

What is the aim of the study?

In the UK, there are around 700,000 people on the autism spectrum – that's around 1 in 100. Some people grow up without a medical diagnosis, sometimes through choice. In this study, we want to explore why some people seek a medical diagnosis of autism in adulthood, and why others choose to self-identify as autistic. We want to find out what people hope to gain from the label, and what it does for them in their day-to-day life.

Who is conducting the study?

This study is being carried out by Thomas Lister, a Ph.D. student from the University of Exeter. He is being supervised by Professor Christabel Owens, and assisted by an advisory group made up of adults who have either been diagnosed, or self-identify, as autistic.

Who can take part in the study?

Thomas would like to hear from you if you are **aged 18 or over** and fit into one of the following groups:

- You received a **medical diagnosis** of autism in **adulthood**
- You believe that you are autistic but **do not** have a medical diagnosis

If you are in doubt about whether you fit into one of these groups, please get in touch (details below). Thomas will be happy to talk it through with you and tell you whether you can be included in the study.

What will I be asked to do?

You will be contacted by Thomas, who will talk you through the study in more detail. If you decide that you would like to participate, Thomas will send you a participant consent form, which will highlight any important information that you should be aware of. You will need to read and sign the consent form before participating in the study.

Thomas will then arrange a time to meet you and conduct an interview. The interview will be at a mutually agreed location at a time that is convenient for you. The interview will likely take between 1 and 2 hours, depending on your experiences. You are welcome to bring along somebody you know for support. Whilst they can sit with you during the interview, they should not expect to participate

in the discussion, and we kindly ask that they refrain from answering any questions on your behalf. A Skype interview can be arranged if a face-to-face meeting is not possible.

During the interview, you will be asked some questions about your experience of being diagnosed/identifying as autistic. The questions are not all set in advance and will depend on the way the interview develops, so it will feel like a conversation. Consequently, although a Research Ethics Committee is aware of the general topics to be explored in the interview, the Committee has not been able to review the precise questions to be used. You will be allowed to talk at your own pace and you will not be made to disclose anything you don't want to. You will be free to stop the interview and leave at any time without giving a reason. Thomas may invite you to participate in a second interview if he is unable to ask all of the questions he has planned, or if he would like to ask any follow-up questions after the interview. You do not have to participate in a second interview if you do not want to.

If you have to travel to the interview, please obtain a receipt for any tickets you buy and we will reimburse your expenses in line with the University of Exeter guidelines.

What will happen to the information I provide?

With your consent, Thomas will use a digital voice recorder to record the interview so that he can give you his full attention while you are talking. Afterwards, the recording will be typed up in full, but Thomas will be careful to remove or change the names of people, places, and any other details that might enable you to be identified. You will be invited to read the typed-up interview and make any changes if you wish. Any quotations we use when writing up the results of the study will be anonymous. All the information we collect will be stored securely at the University of Exeter. **The only person who will know your identity is Thomas Lister.** Neither Christabel Owens, the advisory group, nor anybody else will know your name or any other personal information.

When Thomas has completed all the interviews and analysed the findings, the results will be written up as part of a Ph.D. and published in academic journals. We will send you a summary of the findings if you wish. The typed-up interviews will be made available to other researchers via an anonymous online data depository (as requested by the research funders). **No identifiable information will be stored in the depository**. If you do not want the anonymous interview text to be stored in the data depository, you can choose to opt-out using the participant consent form.

What are the risks involved in taking part?

Whilst Thomas will try to make the interview a comfortable and enjoyable experience, we recognise that it can sometimes to be difficult to talk about a personal experience of autism. Talking about past events may cause unhappy memories which some of you might find upsetting. If you become upset during the course of an interview, Thomas will offer you the chance to pause the discussion to take a moment to gather your thoughts. If you choose to bring somebody along to the interview, you are welcome to take a break with them at any time. At no point are you under any obligation to answer any of the questions asked, and you are free to end the interview at any time.

Are there any benefits?
We hope that you will find being interviewed a rewarding experience. By drawing on your own experiences, it will be a chance for you to tell us what it is like to be diagnosed, or identify, as an adult with autism. This is something that has been generally overlooked in the research community, and something that we are really interested in learning more about. By contributing to this study, we hope to shift the focus surrounding autism, and illustrate some of the reasons why someone may seek a diagnosis, or an alternative label, in adulthood. Your insights and experiences will help us achieve this aim.

Please note that Thomas is unable to offer any medical advice about autism or diagnosis. If you require any information relating to a medical matter, please go and see your doctor.

What if I wish to make a complaint?
If you have any complaints about the way in which this study is being conducted, please contact the Chair of the University of Exeter Medical School Ethics Committee, Dr Ruth Garside, via email: uemsethics@exeter.ac.uk

Who do I contact if I want more information or if I wish to take part?
Please email or call either of the following researchers:

Thomas Lister (lead researcher)
University of Exeter Medical School
Email: tl418@exeter.ac.uk
Tel: 01392 726013

Professor Christabel Owens (project supervisor)
University of Exeter Medical School
Email: c.v.owens@exeter.ac.uk
Tel: 01392 726006

This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee.
UEMS REC REFERENCE NUMBER: Nov17/B/136

Thank you for taking the time to read this information

Appendix 10: Frist round interview topic guide (example)

Interview Topic Guide

Introduction and review of research documents (e.g. information sheet, consent form, data depository)

Theme 1: How do people come to be labelled, or to label themselves, as autistic?

Realisation: "Tell me how you became aware that you might be autistic/have autism?"

- Was there a particular moment that you realised that you might be autistic/have autism, or did you think about it over a period of time?

Action: "What did you do when you realised that you might be autistic/have autism?"

- Did you seek any information about autism? Where did you get it from?
- Who, if anyone, did you talk about it to?
- Why did/didn't you seek a medical diagnosis?
- What did you *think* a diagnosis would do? (perceived consequences)

Theme 2: What are the consequences?

Consequences: "What *has* the diagnosis/label done for you?" (actual consequences)

- How do you think it has benefitted you?
- What do you think are the drawbacks?

Uses: "How do you use the diagnosis/label?"

- When do you tell people that you are autistic? Why do you tell them?
- Does the diagnosis/label do what you want it to do?

Concluding questions and comments

Appendix 11: Participant consent form

PARTICIPANT CONSENT FORM

What's in a label? The functions and consequences of an autism label in adulthood

If you would like to take part in the above study please read the following information carefully. The information you provide will be used for research purposes and your personal data will be processed in accordance with current data protection legislation and the University's notification lodged at the Information Commissioner's Office. Your personal data will be treated in the strictest confidence and will not be disclosed to any unauthorised third parties. The results of the research will be published in anonymised form.

Please provide your initials in the space provided then sign and date below.

		Initial Box
1	I confirm that I have read and understand the information sheet dated 08.01.2018, and have had the opportunity to ask questions	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason	
3	I agree to the interview(s) being audio recorded	
4	I understand that this study involves an open-questioning technique where the precise nature of some of the questions asked have not been determined in advance, but will depend on the way in which the interview develops	
5	I understand that all identifiable information will be anonymised and that Thomas Lister will be the only person who knows my identity	
6	I give my permission for verbatim quotation or short extracts of the interview(s) to be used in research reports, presentations, and training materials	
7	I understand that audio recordings will be securely stored for 5 years in accordance with the University of Exeter Data Protection Policy	
8	I give my permission for anonymised interview transcripts to be made available to other researchers via an anonymous online data depository	
9	I understand that the University of Exeter Medical School Research Ethics Committee has reviewed and approved this study	
10	I would like to receive a summary of the final research report	
11	I agree to take part in this study	

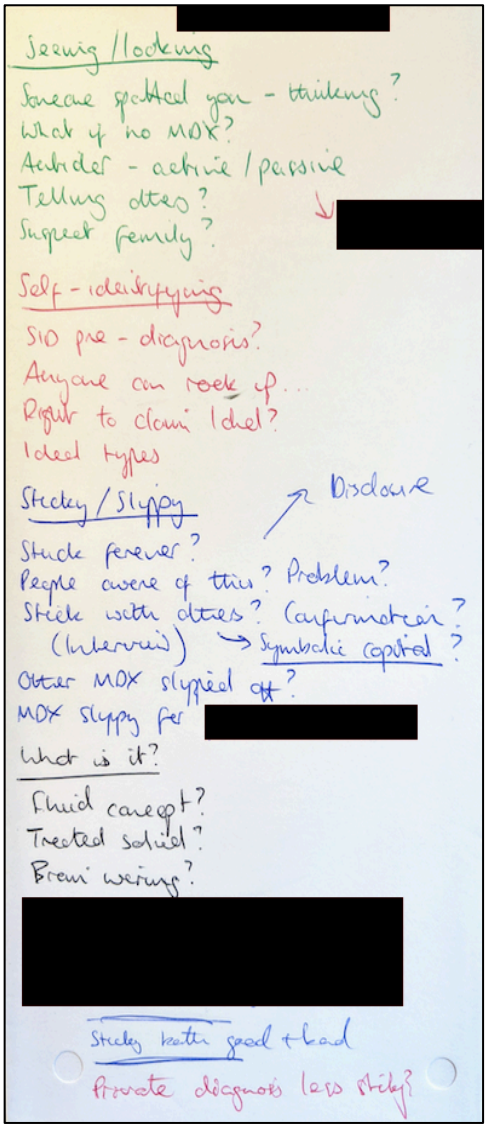
Participant name _____ Date _____ Signature _____

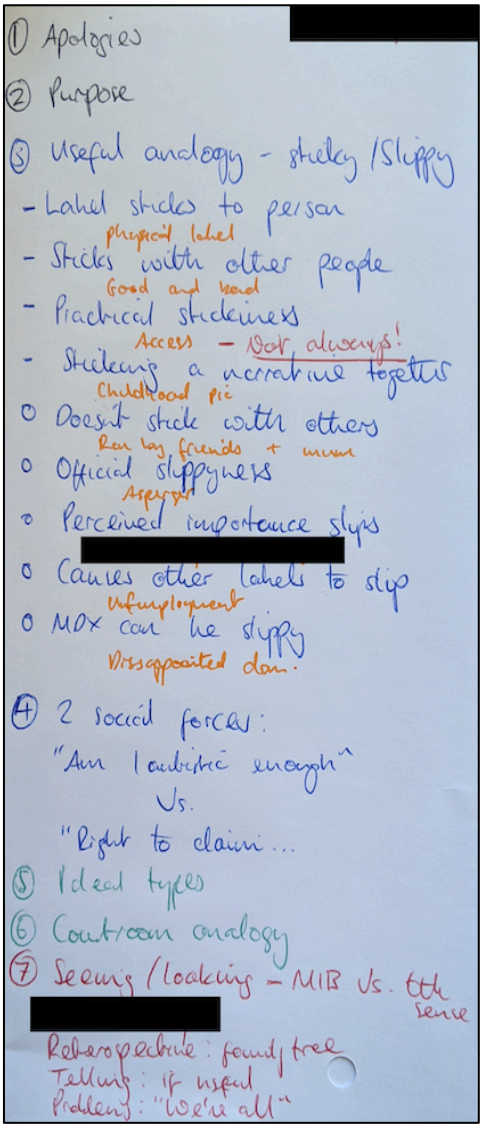
Researcher name _____ Date _____ Signature _____

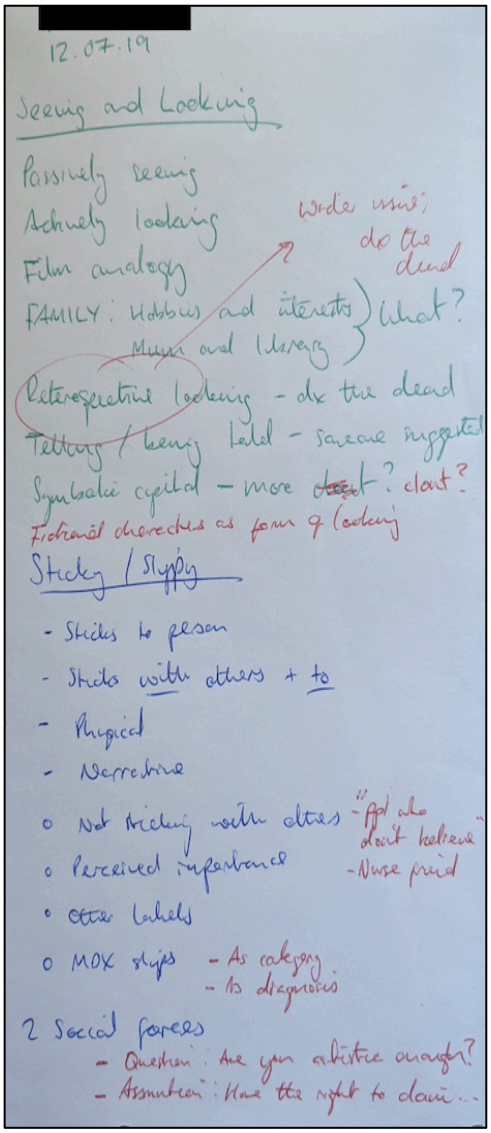
Consent Form V.3 (08.01.2018)

Appendix 12: Second round interview topic guides (continues overleaf)

Here are four second round interview topic guides tailored to particular participants (all identifying information has been redacted). Each guide emphasises a different part of my then working analysis (i.e. sticky-slippy, ways of self-identifying, spotting & seeking autism) depending on the content of the first interview. For convenience and discreetness, I switched to short form handwritten guides for the second round of interviews.







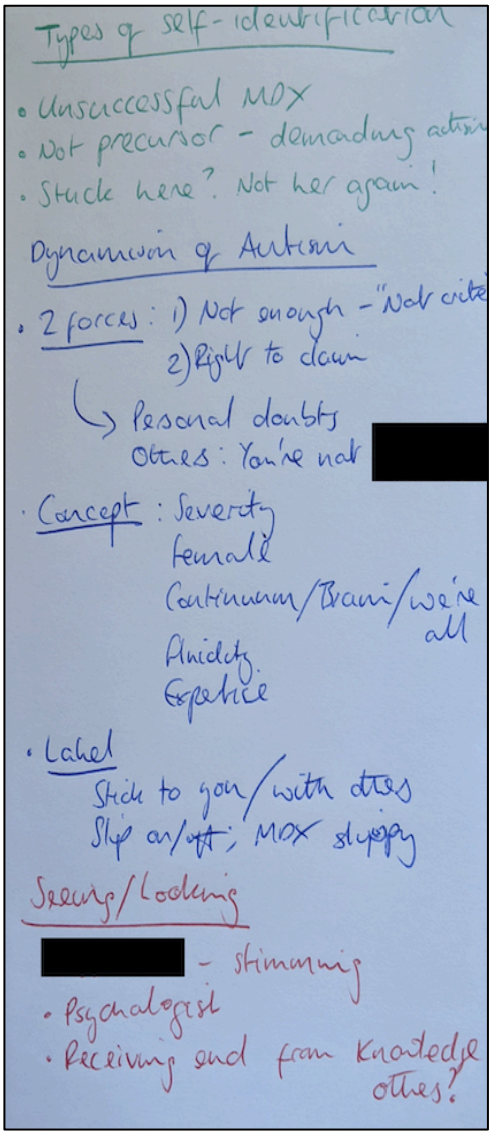
[redacted]

12.07.19

Seeing and Looking

Passively seeing
Actively looking
Film analogy
FAMILY: Hobbies and interests } What?
Mum and literacy }
Retrospective looking - do the dead
Tattoos / being Label - because suggested
Symbolic capital - more ~~cheat~~? clout?
Fictional characters as form of looking
Sticky / Slippy
- Sticks to person
- Sticks with others + to
- Physical
- Narrative
  - Not sticking with others - "ppl who don't believe"
  - Perceived importance - Nurse priest
  - Other Labels
  - MOX slips - As category
    - As diagnosis
2 Social forces
- Question: Are you autistic enough?
- Assumption: Have the right to claim...

Wider issue; do the dead



Types of self-identification

- Unsuccessful MOX
- Not precursor - demanding action
- Stuck here? Not her again!

Dynamism of Autism

- 2 forces: 1) Not enough - "Not autistic"
  2) Right to claim
  ↳ Personal doubts
  Others: You're not [redacted]
- Concept: Severity
  Female
  Continuum/Brain/we're all
  Fluidity
  Expertise
- Label
  Stick to you/with others
  Slip on/off; MOX slippy

Seeing/Looking

[redacted] - stimming
- Psychologist
- Receiving end from knowledge others?

The end