

# **Drawing a line in the sand: Autism diagnosis as social process**

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## **Abstract**

This PhD explored how clinicians make diagnostic decisions about autism in secondary care. Symptoms of autism are considered to be widely heterogeneous, meaning that decisions about where the diagnostic threshold lies can be challenging. Diagnosis in the UK is usually undertaken by multi-disciplinary teams (MDTs) and can involve numerous stages of decision-making in different contexts across an extended time period. The process of diagnosis is complex and multi-faceted, and can be particularly challenging when cases are considered 'borderline' or where there are coexisting conditions.

A qualitative approach was used in four studies. A narrative review of twenty-one clinical guidelines was conducted (study one); observation of eighteen assessment team meetings on four sites was undertaken (studies two and three); and sixteen interviews were conducted with clinicians engaged in autism diagnosis (study four). The narrative review found that guidelines varied in recommendations for assessment procedures and provided no guidance as to how MDT meetings should be facilitated. Guidelines highlighted utilising clinical judgement, valuing experience and dealing with contradiction and uncertainty. A thematic analysis of observation data found that clinicians produce objective accounts through their situated practices and perform diagnosis as an act of interpretation, affect and evaluation to meet the institutional demands of the diagnostic setting. A discursive psychology analysis explored interaction in the team meetings and found a four-part narrative structure utilised to account for and explain potential contradictory evidence and manage uncertainty. A preliminary thematic analysis of the interview study found that clinicians value working collectively to enable them to feel confident about difficult decisions. Clinicians appear to be engaged in a 'push/pull relationship' with diagnostic decision-making which involves resisting or accepting patient and family wishes; working within time and resource constraints; and consideration of the potential positive and negative consequences of the diagnosis.

This PhD offers an empirical contribution to the nature of practical uncertainty work in healthcare. Diagnosticians are charged with the burden of uncertainty in

autism diagnosis, and find strategies to manage this dilemma to find the best outcomes for their patients. Uncertainty is readily displayed in inter-clinician discussion, however, clinicians are compelled to deliver a clear and certain diagnostic outcome for patients, families and other professionals. The result of this translation from uncertainty to certainty is the construction of a condition whereby it is possible to be both part of a spectrum as well as categorically defined. Overall, this PhD contributes to a growing field of scholarship on autism diagnosis and provides insight into our understanding of diagnosis as a social process.

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## Definitions and Abbreviations

3di	Developmental, Dimensional and Diagnostic Interview
ADHD	Attention Deficit Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview Revised
ADOS	Autism Diagnostic Observation Schedule
APA	American Psychiatric Association
AS	Asperger's Syndrome
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
ASD-DC	Autism Spectrum Disorder-Diagnostic for Children
BAP	Broad Autism Phenotype
BMJ	British Medical Journal
BPS	British Psychological Society
C&YP	Children and Young People
CAMHS	Child and Adolescent Mental Health Services
CCG	Clinical Commissioning Group
CPG	Clinical Practice Guideline
CF	Cystic Fibrosis
CMHT	Community Mental Health Team
CRM	Case Review Meeting
DID	Dissociative identity disorder
DISCO	The Diagnostic Interview for Social and Communication Disorders
DSM	Diagnostic and Statistical Manual of Mental Disorders
DZ	Dizygotic
EBM	Evidence Based Medicine
FSD	Female Sexual Dysfunction
GP	General Practitioner
HCP	Healthcare Professionals
HD	Huntingdon's Disease
HMIC	The Healthcare Management Information Consortium
HRA	Health Research Authority
ICD	International Classification of Diseases
ICIDH	International Classification of Functioning, Disability and Health
ID	Intellectual Disability
IQ	Intelligence Quotient
LD	Learning Disability

MDT	Multi-Disciplinary Team
MMR	Measles, Mumps and Rubella Vaccine
MR	Mental Retardation
MZ	Monozygotic
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
OT	Occupational Therapist
PDD-NOS	Pervasive Development Disorder – Not Otherwise Specified
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PTM	Power, Threat, Meaning Framework
PTSD	Post Traumatic Stress Disorder
RAADS	Ritvo Autism Asperger Diagnostic Scale – Revised
RASDN	Regional Autistic Spectrum Disorder Network
RCPsych	Royal College of Psychiatrists
RCSLT	Royal College of Speech and Language Therapists
RRBI	Restricted, repetitive patterns of behaviour, interests or activities
SES	Socioeconomic Status
SIGN	The Scottish Intercollegiate Guidelines Network
SLT	Speech and Language Therapist
STS	Science and Technology Studies
TAR	Tape-Assisted Recall
UEMC	University of Exeter Medical School
UK	United Kingdom
US(A)	United States of America
WHO	World Health Organisation



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## Introduction and Overview of Thesis

*'if we think about it diagnostically  
... somewhere there is a line drawn in the sand  
... and where that line is ... changes really, historically'.*

Consultant Clinical Psychiatrist



## Introduction

Autism is diagnosed when there are persistent patterns of difficulty in social communication and social interaction, combined with restricted and repetitive patterns of behaviour, interests or activities (APA, 2013a). Diagnosis in the UK is usually undertaken by multi-disciplinary teams (MDTs) and can involve numerous stages of decision-making in different contexts across an extended time period. The process of diagnosis may involve the use of clinical guidelines and can incorporate questionnaires, observations and rating scales, as well as clinical interviews about the history of difficulties and the impact of associated impairment on the individual and/or the family.

Prevalence rates for autism have increased dramatically in recent years from just over 1 in 2000 in 1966 (Lotter, 1966) to about 1.1% to 1.2% of the population (Brugha et al., 2012; Sadler et al., 2017) although some estimates are as high as 3.3% (Waugh, 2019). Whilst it is understood that the apparent increase in diagnosis must in part be related to broadening the diagnostic concept of autism (Russell et al., 2015; Rutter, 2005), other factors may include increased awareness of the condition alongside the development of available services (Fombonne, 2009) as well as the decreasing age of diagnosis (Leonard et al., 2010).

Both lay and clinical understandings of autism inform and are informed by an influential neurodiversity movement, increased public prominence of parent advocates and lobbying charities, and a proliferation of representations of autistic people in television, film and fiction. To meet demand and as the result of lobbying, legislation has been passed to ensure the existence of assessment and support pathways for adults (Northern Ireland Assembly 2011; Scottish Parliament 2010; UK Parliament 2009). This range of factors both create and respond to demand for support and assessment needs of autistic people and shape our understanding of what it means to be autistic.

Research has shown that, with other conditions such as suspected heart failure, social factors can influence clinicians' decisions (Fuat et al., 2003) which may

also impact on diagnostic rates. In psychiatric diagnosis, psychiatrists can employ diagnostic 'workarounds' offering a more benign diagnosis to reduce the possibility of stigma, or fudging to meet insurance requirements (Whooley, 2010). Studies examining clinicians' views of autism diagnosis have shown that they may diagnose even when uncertain - for pragmatic reasons - to secure best outcomes for patients (Skellern et al., 2005). Further studies suggest that diagnostic rates can be affected by contextual and social drivers, such as diagnostic resources (Mazumdar et al., 2013) or diffusion of information about autism through social networks (Liu et al., 2010a). Where there is diagnostic uncertainty, clinicians may 'upgrade' to an autism diagnosis if it would be in the best interests of the patient, trigger appropriate services, or counteract the limitations of diagnostic tools (Rogers et al., 2016; Skellern et al., 2005). Furthermore, a more positive societal view of autism achieved through a growing neurodiversity movement and increased positive cultural representations of autistic people, may determine who comes forward for diagnosis and why, shaping the context within which clinicians consider the impact of diagnosis for an individual.

Deciding where the diagnostic threshold for autism lies can be problematic as symptoms are heterogeneous and are distributed as a continuum extending into the general population (Constantino, 2011; Constantino and Charman, 2016). Despite neuroscientific advances and significant genetic research, autism is not yet diagnosed by biomarkers or any test considered to provide other kinds of objective measures (Klin et al., 2000; Vllasaliu et al., 2016). The subject of assessment, human behaviour, is in itself interactive, interpretive and contextual, providing an additional layer of complexity. The process of diagnosis, therefore, is complex and multi-faceted, and can be particularly challenging when cases are considered 'borderline' or where there are coexisting conditions.

## The PhD Study

The pathway for diagnosis (noticing a difficulty, referral, screening, assessment, testing, feedback etc.) takes the form of a series of judgements framed and sanctioned by society and implemented primarily by clinicians. It is a classification process that frames behaviour, particularly in a psychiatric context, as normal or pathological. Diagnosis provides a framework which enables someone to fit or not fit, to explain, to seek treatment and support within, to excuse, to give meaning to those things in society that seem different and can be distressing, and to label.

Whilst clinicians are, for the most part, responsible for diagnosis and for the labelling of a condition as one thing or another, the process of diagnosis itself is an interaction. It evolves with every utterance and engages a wide range of actors: patients, educationalists, families, health professionals in other sectors such as GPs and patients, as well as a range of diagnostic tools and types of evidence. People coming for diagnosis are experts in their own behaviours; cultural and medical understandings of autism merge as lay people shape how autism is seen in the popular imagination and clinicians find ways to categorise behaviours one way or another.

There has been very little research undertaken on how clinicians make a diagnosis of autism in practice in the UK and in particular how clinicians deal with the uncertainties inherent to diagnosis of the condition. With a condition such as autism, with its breadth of behavioural symptoms and lack of biomarkers, resolving uncertainty may be particularly relevant in clinicians' discussions about autism. Controversies about the efficacy of current treatments, the benefits or otherwise of early intervention in childhood diagnosis, the availability (or not) of local resources and support, and the difficulties of accurately predicting prognosis, add to the complex context of autism assessment.

There are some exceptions to this research gap (for example, Hollin and Pilnick, 2018; Parish, 2019) which are discussed later in this thesis. An

extensive body of work examining assessment data from the US is also discussed and built upon (for example, Maynard and Turowetz, 2017; Turowetz and Maynard, 2016). This PhD study extends the research on this topic by exploring specific mechanisms by which clinicians make a decision together in the context of specialist assessment team meetings in England; exploring their beliefs and practices through interview; and siting the study in the context of a review of clinical guidelines which outlines the procedures by which diagnosis should be delivered. Together these contribute to building a picture of autism diagnosis in the UK in the early 21<sup>st</sup> century and highlights some of the challenges and ambiguities present in this social process.

### **Overarching Aims**

The PhD aimed to explore social factors in autism diagnosis in secondary care; and to understand how clinicians collaboratively make diagnostic decisions in autism assessment. The thesis had the following objectives:

- a) To undertake a review of clinical guidelines in use in the UK and consider where, within those guidelines, social factors and influences are taken into account (study one)
- b) To document and analyse discussions made in MDT meetings (or local equivalent) to identify social and interactional processes (studies two and three)
- c) To gather views and experiences of clinicians involved in the diagnostic process via interviews (study four)
- d) To contribute to a social understanding of diagnosis



## Research Questions

The study asked the questions:

1. What **diagnostic guidelines** are available for clinicians assessing children and adults for autism in the UK; and how does guidance reflect social factors and influences?
2. How do healthcare professionals **make diagnostic decisions** in specialist autism assessment team meetings?
3. How do clinicians **understand autism and diagnosis** in secondary care?

Specifically, the project comprised four inter-related studies:

- Review of clinical guidelines, existing diagnostic classifications and assessment processes to map the social and institutional context of diagnosis and identify potential social influences (study one)
- Observation of specialist autism assessment team meetings where diagnostic decisions are made to identify themes (study two) and interactional processes (study three)
- Interviews with clinicians involved in the diagnostic process (study four)

The review of clinical guidelines covered the whole of the UK, however the remainder of the studies pertain to practice in England only, as responsibility for healthcare is devolved to each of England, Scotland, Wales and Northern Ireland.

## Theoretical Approach

The study draws on sociology of diagnosis, which argues that diagnosis cannot be separated from wider influences of human agency and deliberation (Jutel, 2011). A sociology of diagnosis approach challenges the taken-for-granted fit of diagnostic categories to their conditions and instead considers them as socially framed and shaped by wider social forces and interaction (Brown, 1995).

Clinical judgements, for example, may be seen as products of social processes influenced and shaped by context, discourses, human interaction and the particular classification framework pertinent at the time of working (White and Stancombe, 2003). By exploring clinician interaction in meetings this thesis provides insight into how clinicians 'do diagnosis' together. Understanding how clinicians draw the line between what is considered 'typical' behaviour and a pathology has far reaching consequences for individuals being diagnosed and their families. Furthermore, because of these consequences, we are compelled, as a society, to consider who we label as having a medical condition and why.

The thesis takes a cross-disciplinary approach combining sociological theory and discursive psychological methods. Discursive psychology is an appropriate approach to analysing interaction in that it focusses on how talk creates action. Interaction in this case is considered a 'social factor' in its own right, in that the way in which interaction between people unfolds is inseparable from the diagnostic outcome and the broader context. In other words, how clinicians talk together about diagnosis, creates what diagnosis is. This, in turn, contributes to the creation of autism as a condition.

### **Overview of thesis chapters**

The thesis is organised as follows. Chapters One to Four comprise the literature review for the PhD study. Chapter One reviews the medical model of autism and of diagnosis, including examining classification systems and the diagnostic pathway in England. This chapter also discusses diagnostic tools, symptoms, aetiology and differences in the diagnostic pathway for adults and children. Chapter Two explores the social model of diagnosis and outlines the implications of taking a sociology of diagnosis perspective. This chapter explores the diagnosis of autism as a category, as a process and the consequences of diagnosis.

Chapter Three considers how our understanding of autism as a condition has changed over time and examines research which considers the cultural, political

and historical conditions that shape how we understand health and illness in society. This chapter draws particularly on theorists who have examined how conditions are created and how knowledge around those conditions are constructed through the clinic. It discusses how we decide as a society where 'normal' behaviour begins and ends and how the influences of medicalisation shape our understandings.

Chapter Four outlines the literature on narrative in medical case construction, the specialist knowledge of the clinician, and diagnostic uncertainty. This review goes on to examine research to date on clinician interaction in multi-disciplinary team (MDT) meetings and how this shapes decision-making.

Chapter Five outlines the methodological approach to the PhD, including the rationale, research question, overall study design, details of recruitment and ethics. This chapter describes the epistemic perspective and the rationale for examining the observation data discursively. Finally, it outlines details of the observed sites, and provides a reminder of the diagnostic pathway, tools and technical terms in the data. This final section provides the context for the articles to follow.

Chapters Six to Nine comprise the central original research component of the PhD thesis and includes three articles for publication and one preliminary analysis. These articles are drawn from the four inter-related studies and incorporate a review of clinical guidelines as published in *BMC Psychiatry*; a thematic analytic overview of the observation data (under review); a detailed discursive analysis of the narrative structure of the assessment team discussion (under review); and a preliminary thematic analysis of the interview study.

Finally, Chapter Ten draws together key findings and conclusions from the studies. The thesis concludes by outlining the strengths and limitations of the study and considering implications for theory and practice. Taken together, the studies which comprise the original research in this thesis contribute to theory around the sociology of diagnosis and provide insight into diagnostic practices for a particular condition, that of autism. The final discussion considers whether

these findings might be transferable to other conditions and makes suggestions for further study.

## **A Note on Terminology**

### ***Autism as a disorder or condition***

Autism is categorised as Autism Spectrum Disorder (ASD) in DSM-5 and ICD-11. However, there is significant debate about classifying autism as a ‘disorder’, with many preferring to use the term ‘condition’ (NICE 2012). I use the term ‘autism’ throughout to embrace the spectrum of conditions as currently defined in the DSM-5 (APA, 2013a) and International Classification of Diseases (ICD-10, ICD-11) (WHO, 2018, 1993). There are also critiques of the terms ‘high’ and ‘low’ functioning autistic people; the former dismissing a person’s needs or struggles, and the latter undervaluing a person’s individual strengths (Iland, 2018). Kapp (2018) argues that ‘functioning’ is a product of an individual’s support network, not an inherent aspect of an individual. Therefore these are terms that I avoid except where I report on studies which utilise this term, either to critique it, or to define their participant selection.

### ***Patients, clients and people***

I have considered what term to use to discuss those coming for diagnosis. People attending autism assessments, and discussed by clinicians in my study, are not the *subject* of my PhD study, but clearly are central to the discussion of diagnosis. In a medical sense they are ‘patients’; in mental health settings, people are often considered to be ‘clients’ or ‘service users’. I began by wanting to retain the human-ness of this person (who I never met) as a person, rather than as a patient or client, but the repetitive ‘person coming for assessment’ was clumsy. Finally I decided that the term ‘patient’ was a necessary compromise, as I struggled to conceive of an eight-year old as a ‘client’ and required a term that embraced all ages. I understand the limitations and medical nature of this terminology and can only justify it by noting that we might all consider ourselves patients whilst we sit, for whatever reason, within the clinic

(as do the patients in this study). On leaving we can aim to re-assert our identities as more rounded human beings, labelled as something else, or not.

### ***Autistic people and people with autism***

There is a great deal of variation in the way that different stakeholders choose to describe autism. There has been a movement within disability activism towards 'person-first language', for example, using terminology such as 'person with a disability' in preference to 'disabled person', which has also been adopted by many health professionals (Kenny et al., 2016). However, many members of the autism community prefer 'identity-first' language, such as 'autistic person', on the basis that a person cannot be separated from their autism (Kenny et al., 2016; Sinclair, 2013, 1993) and that foregrounding autistic identity recognises the value and worth of that person as autistic (Brown, 2011). Whilst acknowledging that there are different ways of talking about autism, in this thesis I use identity-first language throughout.

### ***Clinicians and healthcare professionals***

I use the term 'clinician' to encompass all healthcare participants in this PhD study. Whilst strictly and historically, a clinician is usually considered to be a medical doctor, here I define clinician as a member of a registered health profession involved in direct patient care, as each of these participants has, to some extent, a key role in diagnosis. I also use the term diagnostician interchangeably when discussing the participants in my PhD studies. The exception to this is in Chapter Six, a published article reviewing clinical guidelines for autism diagnosis, in which I use the more general term, healthcare professional (HCP).

All references included in this chapter, and all other chapters, have been collated in one list for the thesis. The reference list can be found on page 419.



## **CHAPTER ONE: Medical framing of diagnosis**

*A classification is a way of seeing the world at a point in time.*

Norman Sartorius, World Health Organisation





## **1.1 Introduction and overview of chapter**

In this chapter I will outline the current clinical understanding of autism as a medical condition. This means, to some extent, putting aside some of the questions I later ask about the ways in which clusters of symptoms are grouped together or pulled apart to create conditions, as well as broader issues of social factors which shape diagnosis.

I begin by discussing what diagnosis is in a medical context, and then go on to outline the symptoms of autism and related issues of prevalence and aetiology. The chapter continues by looking at changes in diagnostic criteria since the beginning of the classification of autism, and pathways to diagnosis for both children and adults in England.

Here and throughout this thesis I draw on both diagnosis generally as a medical concept, and also specifically within conditions classified as 'mental and behavioural disorders' (WHO, 1993). Whilst there are overlapping issues in the diagnosis of somatic and mental disorders, there are also specific diagnostic issues related to mental disorders as defined in classification manuals, which will be addressed during the thesis.

## **1.2 What is diagnosis?**

Diagnosis is defined as the 'process of identifying a disorder by examining its signs and symptoms' (Colman, 2009). This commonly understood definition, however, fails to illuminate the complexity of functions of diagnosis which extend beyond an apparent linear process of identifying disorders. To be effective, diagnosis requires cut-off points, or thresholds, whereby individuals can be identified as ill or well, diseased or healthy, disabled or not. Diagnosis facilitates a culturally shared understanding of a disorder between clinicians, and one that can be communicated more broadly with patients, families and the wider public.

Diagnosis has a necessary function as a mechanism for delivering treatment and estimating a prognosis. Modern medicine requires a system whereby patients can be assured that the treatment they receive is appropriate to the condition; that the best available research associated with the condition is used as a basis for clinical decision-making; and that predictions about disease progression are based on evidence and experience. Society also uses classification for understanding aetiology and specific problems associated with any particular condition (Goodman and Scott, 2012). It could be argued that without naming the condition, there is no shared understanding. Without classification, illness becomes no more than a messy description of symptoms which may or may not mean one thing or another. Diagnosis itself, therefore, creates meaning around disease and disorder, as well as providing a mechanism for managing that disorder.

To be useful, therefore, diagnosis must separate out difference: individuals with a diagnosis must have different symptoms from those who have different diagnoses, or none at all (Goodman and Scott, 2012). For the classification system of diagnosis to work, therefore, cut-offs should not be arbitrary, but based on clearly observable symptom differences. However, in psychopathology, as well as in some physical conditions, a threshold for a particular condition can be difficult to locate. Furthermore, in autism, 'symptoms' are behavioural – or, conversely, behaviours are, in themselves, interpreted as symptoms – thereby necessitating a judgement around when a behaviour becomes a symptom and in what circumstances. Our classification system, designed to be categorical, becomes problematised by symptoms (or behaviours) which operate on a dimension. Symptoms can be coded on a spectrum of severity (from 'normal' to severe) but imposing a threshold along that dimension can be a complicated and contradictory matter, involving a negotiation based on clinical judgement rather than the objective discovering of a fixed entity (Goodman and Scott, 2012). Clinical judgement, therefore, is considered to be crucial to the diagnostic assessment process (Falkmer et al., 2013; NICE, 2012, 2011; Westman Andersson et al., 2013).

### **1.2.1 Diagnosis and biomarkers**

In somatic or physical health practices, examination of tissue, blood or urine at a molecular level is used to predict the presence of some specific conditions, for example, cardiovascular disease and hepatic (liver) disease (Kobeissy et al., 2013). As patients, we generally have an understanding of some commonly used biomarkers, considered to be objective, measurable indicators of a condition, which are utilised in primary care or at home. For example, we understand that a high temperature is related to fever, and that blood pressure measurement is used to determine the risk of stroke. We have also become accustomed to imaging technologies such as x-ray, CT-scans and MRI (magnetic resonance imaging) as ways to evidence the link between bodily activity and particular conditions.

The development of sophisticated screening technologies such as mass spectrometry, cell and tissue based DNA microarrays, high-throughput screening and combinatorial chemistry (Biomarkers Definitions Working Group, 2001) are considered to have enhanced the ability of clinicians and researchers to identify and utilise biomarkers. The development of accurate biomarkers is seen as key to the future of modern precision medicine as a way to enhance the efficacy of drug development, clinical care and regulatory decision-making (Biomarkers Consortium, 2017).

However, in psychiatric conditions, there are no diagnostic tests utilising biomarkers currently in clinical practice (Kobeissy et al., 2013). In some psychiatric conditions, there are the beginnings of molecular or genetic patterns which may form the basis for future biomarker-based diagnostic tests. For example, there is some evidence to show distinct molecular and genetic patterns in people with schizophrenia, which may lead towards the creation of a blood-based schizophrenia biomarker (Lai et al., 2016). However, this has been critiqued by Hedgecoe (2001) who argues that the construction of genetic explanations for schizophrenia undermines non-genetic factors such as environmental influence. In dementia, whilst there are currently no blood or urine based biomarkers in use, structural brain imaging (CT or MRI) is recommended and widely used across clinical settings to rule out other causes

of cognitive impairment and to identify patterns of neuronal loss, which has positive predictive value for dementia (Ahmed et al., 2014). The use of biomarkers in psychopathology, therefore, is less established than in physical health.

In autism, despite a great deal of research exploring the underlying genetic, neurobiological, chemical and cognitive factors that may, in the future, provide biomarkers in autism diagnosis, no research currently has enough evidence to support routine clinical use (Goldani et al., 2014; Vllasaliu et al., 2016). Some argue that available biomarker tests would do more harm than good, given their poor positive predictive value. This means that typically developing children may be identified as at risk, and a large number of children who go on to develop autism would be missed (Anderson, 2015; Anderson and Stahl, 2014).

Recent research in autism has identified changes in brain growth (hyperextension of the cortical surface area) in pre-symptomatic children (between 6 and 12 months) who have a high familial risk of autism (Hazlett et al., 2017). The authors suggest this finding may offer a 'proof of principle' basis on which to develop potential biomarkers as predictor tools for autism in clinical practice (Hazlett et al., 2017). One study examined a range of potential biomarkers in autism including biochemical (blood serotonin, urine melatonin sulfate excretion) and clinical tests (head circumference, dysmorphology exam, digit ratio, cognitive and behavioural function) (Bridgemohan et al., 2019). The authors propose that an integrative approach to biomarker development might be fruitful in the future (Bridgemohan et al., 2019). It could be argued, however, that a 'scattergun' approach to tests with the aim of triangulating towards 'something' called autism, may suggest that this 'something' called autism is simply too complex to describe as one entity.

### **1.2.2 Critiques of biomarker development**

The use of biomarkers to identify disease has also been problematised, with some arguing that the belief that a condition is a 'specific entity defined by a unique pathophysiology' (Rose, 2013, p. 13) is one that should be challenged. More broadly, in relation to genetic biomarkers, scholars in Science and

Technology Studies (STS) have developed a critique of what has been termed 'geneticisation' which aims to define differences between people – disorders, behaviours and physiological variations – primarily in terms of genetic explanations (Lippman, 1998).

Biomarkers, particularly when used in screening, can create a new medicalised status of 'potentially ill' (Conrad, 2007, p. 138) or 'pre-symptomatically ill' (Rose, 2010, p. 73) which can contribute to the expansion of the medical gaze and of diagnostic categories, with the resulting impact on identity, social status and insurability, for example (Armstrong, 1995). This in itself reinforces the idea that there is a person who can be defined as 'normal' via their genetic make-up which, as Rose (2010) argues, is at best elusive.

Other work identifies how scientists and clinicians are not passive in their use of categories of genetic classification but, in their clinical practice, actively generate, debate and evaluate genetic classifications (Latimer, 2013; Timmermans and Buchbinder, 2014). The process in the clinic, therefore, generates knowledge about the condition, and about genetics, rather than engaging in a straightforward application of externally produced knowledge (Timmermans and Buchbinder, 2012). Whilst the promise of a genetic biomarker for autism, therefore, is sometimes considered to be the 'holy grail' required to solve the difficulties of diagnosing an uncertain condition, geneticisation does not necessarily solve these problems of categorisation. The process of geneticisation fails to challenge how we construct disease categories, rather it provides another mechanism for doing so. I will explore the question of biomarkers in the context of medicalisation in Chapter Three.

### ***1.2.3 Diagnosing psychiatric conditions***

The remainder of this chapter will consider diagnosis in the context of mental disorders, because, as a neurodevelopmental condition, autism is classified within the mental disorder categorisation structure. Whilst some of the issues discussed will be pertinent to physical conditions, and I acknowledge that physical and mental conditions cannot be artificially separated, I will confine discussion to mental or psychiatric conditions.

The diagnosis of mental and behavioural disorders is framed by the use of two main classification manuals, the Diagnostic and Statistical Manual of Mental Disorders (DSM) (APA, 2013a) and the International Classification of Mental and Behavioural Disorders (ICD) (WHO, 1993). The DSM is considered to be the main reference source for psychopathology worldwide; the ICD, although rarely used in the US, is considered important for clinical practice (Taylor and Vaidya, 2009) and is most commonly used in the UK (National Autistic Society, 2016a). Both manuals provide operationalised diagnostic criteria (Goodman and Scott, 2012) for many conditions including psychiatric, behavioural and neurodevelopmental disorders. The diagnostic manuals, therefore, provide a tool for diagnosis as well as the basis for clinical guidelines and diagnostic measures. However, within clinical practice, diagnostic boundaries are not necessarily as clear cut as the manuals might suggest, with dividing lines between groupings of disorders potentially unhelpful and leading to patients meeting criteria for several closely related disorders (Goodman and Scott, 2012). Goodman and Scott (2012) argue that there are both advantages and disadvantages to diagnostic classification as represented by ICD and DSM. The advantages include that labelling a condition ensures that there is a greater likelihood that clinicians and researchers across disciplines and settings are discussing similar conditions. The disadvantage is that the criteria can be interpreted rigidly 'making it easy to forget that the criteria are often built on very shaky foundations' (Goodman and Scott, 2012, p. 27).

Psychiatric conditions too are intertwined with environmental and social conditions which impact on behaviour, distress and mental wellbeing, although it is argued that this is common to physical conditions too. In psychiatric diagnosis, clinicians adopt a holistic 'bio-psycho-social' model (Engel, 2012) meaning that this broader range of environmental, biological and social contexts are taken into account. The identification of a single cause for a psychiatric disorder is rarely possible and therefore 'risk factors' might include adverse life events such as abuse or neglect at home, or bullying at school (Goodman and Scott, 2012). In psychiatric health practices, therefore, diagnosis is further complicated by the interaction of biological and environmental factors. We know, therefore, that the reality of psychiatric diagnosis is more nuanced and

richer in consideration of a range of relevant factors than diagnostic criteria suggest.

### **1.3 What is autism?**

Diagnostic criteria for autism and other neurodevelopmental conditions are outlined in the ICD-10 (WHO, 1993) and DSM-5 (APA, 2013a). Whilst there are differences in the way in which autism is conceptualised between these two versions of ICD and DSM, I will focus in this section on the current commonly understood notion of autism as a 'spectrum' as outlined in current DSM-5 criteria. A revision of ICD-10 has been published and will come into use in 2022 (WHO, 2018). This eleventh revision has been aligned with DSM-5 in conceptualising autism as a spectrum (see Section 1.4.1).

Autism Spectrum Disorder (ASD) is diagnosed when there are “persistent deficits in social communication and social interaction across multiple contexts” and “restricted, repetitive patterns of behaviour, interests or activities” (APA, 2013, p. 50). The first domain of social communication and interaction includes deficits in social-emotional reciprocity such as difficulties in turn-taking in conversation and responding to or initiating social interactions. It also includes impairments in what might be considered 'normal' expectations of body language, eye contact and facial expression in communication. In addition, individuals have difficulties developing and maintaining social relationships. In children, for example, this may manifest itself in an inability to engage in imaginative play or make friends.

The second domain of restricted, repetitive patterns of behaviour, interests or activities (RRBI) can include repetitive movements or speech, inflexible adherence to routine or unusually intense interest in specific objects or topics. It also includes hyper/hypo-sensitivity to sensory stimuli in the environment, such as sound, light, texture or smell. An individual coming to the clinic for diagnosis is required to meet criteria in the domain of social communication and interaction, as well as the domain of repetitive behaviours.

In addition to the above, diagnostic criteria state that symptoms must be present in early development and must cause clinically significant impairment in social, occupational or other important areas of functioning (APA, 2013a). Symptoms should not be better explained by an intellectual disability or global developmental delay (APA, 2013a). However, autism and intellectual disability frequently co-occur, and for a co-morbid diagnosis, social communication should be below that expected for general developmental level.

ASD is defined by diagnostic criteria as a lifelong condition, although research shows that some individuals with an early diagnosis of autism do not meet criteria for the diagnosis later in life (Fein et al., 2013; Shulman et al., 2019). One review identifies that this may affect between 3% and 25% of diagnosed children (Helt et al., 2008). Symptoms are typically seen during the second year of life but can be recognised earlier or later depending on severity (APA, 2013a). Individuals can present for diagnosis in later childhood, when symptoms can become problematic if 'social demands exceed limited capacities' (WHO, 2018). This can take place due to changes in circumstances, such as moving school (Baird et al., 2011); or as adults, triggered by changes in environment such as leaving home. However, it is also believed that some adults seek assessment due to diagnosis of a relative, particularly a child, which then triggers a re-interpretation of their own retrospective behaviour as autistic (Lister, 2019).

As a spectrum, ASD is heterogeneous and therefore manifestations of the condition can vary widely (APA, 2013a). In DSM-5, severity specifiers with varying levels differentiate between those 'requiring very substantial support' to those 'requiring support' (APA, 2013a). Impairments in social interaction and communication are considered to be pervasive and sustained, and assessment is therefore seen as being most reliable when there are multiple sources of information from caregivers, clinicians and patients where possible (APA, 2013a). There is no clearly identifiable threshold for diagnosis and some children, whilst demonstrating autistic symptoms, fall short of the full diagnostic criteria. In both DSM-IV and ICD-10 there was a diagnosis of 'pervasive



development disorder, not otherwise specified' (PDD-NOS) which helped to classify this near-threshold group (Goodman and Scott, 2012).

There are multiple clinical guidelines and protocols in use in the UK that cover diagnosis of ASD for both children and adults. Clinical guidelines draw from diagnostic criteria to support practitioners and patients in the identification and treatment for specific conditions (Field and Lohr, 1992). These include national guidelines (NICE, 2012, 2011; RASDN, 2013, 2011; SIGN, 2016) and those aimed at different professional interests such as clinical psychologists (British Psychological Society, 2016) and psychiatrists (Royal College of Psychiatrists, 2014). The breadth of guidelines suggest that there may be differences in recommendations for autism diagnosis, particularly in relation to specific disciplines. A review of guidelines in use in the UK can be found in Chapter Six.

### ***1.3.1 The meaning of autism to different actors***

Autism has gained increased public prominence and awareness in recent years. One large-scale general population study in Northern Ireland demonstrated that over 80% of people are aware of autism with over 60% knowing someone with the condition (Dillenburger et al., 2013). This may be due to a number of factors, including a broadening of the diagnostic classification of autism; increased political activism by the neurodiversity movement; charitable advocacy work by organisations such as the National Autistic Society (NAS); controversies around causality; as well as popular representations in media, literature and film. This means that a wide range of actors have an interest in defining and shaping the meaning of the condition. Sontag (1978) argued that every era has its own illness which tells us as much about the decade as the illness: Hacking suggests that autism may be 'the pathology of our decade' (Hacking, 2010, p. 633).

Some of the actors with an interest in the meaning of autism include parents with a severely impaired autistic child, for whom autism can mean learning to live with and negotiating family relationships around a child that can seem, at times, to lack the very skills required to maintain those relationships. The meaning of autism for those families is accompanied by a struggle for

recognition, support and resources (Crane et al., 2018, 2016). For other actors, such as clinicians working in the field of diagnosis, autism can mean managing distress, questioning the validity of diagnostic tools in 'atypical' presentations, dealing with the pressure of providing timely assessments (Rogers et al., 2016) and finding strategic ways to respond to diagnostic uncertainty (Skellern et al., 2005). Other actors active in establishing the meaning of autism include some adults with a diagnosis, who argue that autism is part of the 'normal' human range of diversity rather than a disorder or a deficit (Jaarsma and Welin, 2012). Autism can represent pride in an identity of difference, an explanation for difficulties experienced over many years, or a route to support and validation (Crane et al., 2018). Alternatively, autism can be considered a 'profound disability' requiring support and understanding, rather than an identity label (Clements, 2019). To other actors, autism can represent the potential medicalisation of a range of behaviours that might not only be considered 'normal' but are valuable to society (Lorenz and Heinitz, 2014). Autism, therefore, can mean different things to different actors depending on their experience, the severity of symptoms or, as I will examine later, the family, social, cultural and historical context.

Society perpetuates a view of disease and illness as classifiable and static, but autism defies diagnostic boundaries by being broad, fluid, changing and defined only through and by the development of what is considered a condition at any particular time. In this sense, our knowledge of autism is situated – by our experience, our environmental context, our training and education and our conversations. From this perspective, there is no one homogeneous definition of what autism is or what a diagnosis means, even amongst those who have first-hand experience of diagnosis.

### **1.3.2 Prevalence**

Current estimated prevalence of autism in children and young people in the UK is reported at 1.2% of the population (Sadler et al., 2017) although one estimate in Northern Ireland is as high as 3.3% (Waugh, 2019). A study of diagnosed children across the spectrum in the south Thames area reported a prevalence of children with autism at 116 children in 10,000 (1.16%) (Baird et al., 2006). A

study estimating the prevalence in adults in the UK suggests a similar ratio in the adult population, estimated at 1.1% (Brugha et al., 2012). Autism diagnosis has a male to female ratio of approximately 4:1 (Green et al., 2004).

Research studies suggest that prevalence figures are similar in other countries. A study of fourteen US sites, for example, monitoring reported behaviours rather than diagnosed patients, suggests prevalence is around 11.3 children per 1,000 (1.13%), although this varies geographically between states (Centers for Disease Control & Prevention, 2012). Some studies show rates as high as 2.6% in South Korea (Kim et al., 2011) and as low as 0.39% in China (Wang et al., 2018). A worldwide systematic review of epidemiological studies suggests a median prevalence of 62 in 10,000 (0.62%), and no ethnic or geographical differences, but with the caution that further research is needed in low and middle income countries (Elsabbagh et al., 2012). Different methods of collecting data, use of different diagnostic or screening tools and cultural definitions of autism may vary between or within different countries, meaning that the prevalence rates across studies may not be comparable.

What is certain is that the numbers of those being diagnosed have increased greatly. The first epidemiological study of autism took place in Middlesex in 1966 and found that 4.5 in 10,000 children (0.045%) displayed autistic symptoms (Lotter, 1966). This study included examining case and medical histories from those children who attended special schools and were already deemed 'handicapped' as well as all other children aged between eight and ten, described as the 'normal' school population. Four decades later, a study of children on the Special Educational Needs (SEN) register in Cambridgeshire, alongside parental screening of non-diagnosed school children, estimated the prevalence at 157 per 10,000 (1.57%) (Baron-Cohen et al., 2009). A visual representation of the increase in diagnostic rates is at Figure 1.

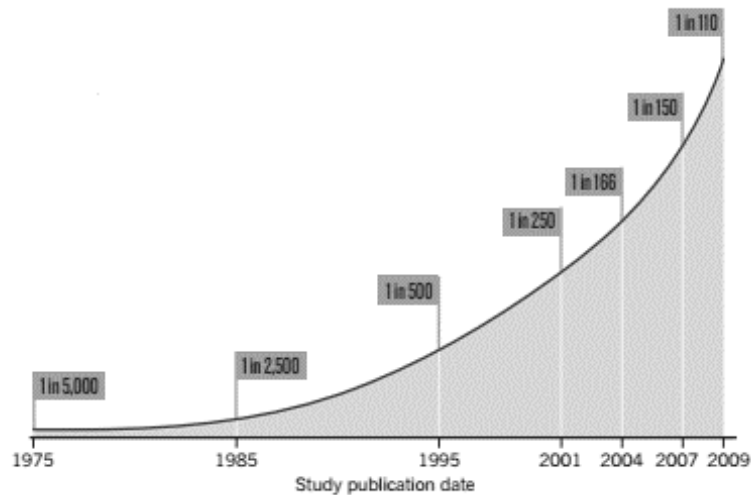


Figure 1: Rise in diagnostic rates between 1975 and 2009 (Weintraub, 2011)

Whilst it is acknowledged that the apparent increase in diagnosis may in part be related to broadening the diagnostic concept of autism (Russell et al., 2015; Rutter, 2005), other factors may include increased awareness of the condition alongside the development of available services (Fombonne, 2009). For example, differences in prevalence estimates are marked in Northern Ireland (3.3% in 2019), where the Autism Act was introduced in 2011, as opposed to the Republic of Ireland where prevalence estimates sit at around 1% - 1.5% where there was no such provision made (Government of Ireland, 2018). Other factors may include the decreasing age of diagnosis (Leonard et al., 2010; Prior, 2003; Wing and Potter, 2002); and multiple or more specific methods of prevalence data collection, such as gathering both educational and medical records (Christensen et al., 2016). Others argue that there has been a reconceptualization of what might be considered 'normal' psychological development in children (Evans, 2013), leading to an apparent, but not actual, increase in prevalence. A study comparing diagnosis and behavioural traits within two cohorts from 1998/1999 and 2007/2008 identified an increase in diagnostic rates (from 1.09% to 1.68%) and also showed an increase in behavioural traits associated with autism amongst non-diagnosed children (Russell et al., 2015). Whilst this might suggest an increase in the condition, it may be due to other factors, such as greater teacher and parent recognition of potential autism symptoms in the later cohort, for example. It should be noted,

therefore, that although diagnostic rates have increased, this may not be a true reflection of an increase in autism as a condition (Fombonne, 2001).

### ***1.3.3 Co-occurrence with other conditions***

Many people with symptoms of autism also have an intellectual disability (ID), with about 40% having an IQ under 50, classed as 'severe', and a further 30% with an IQ between 50 and 69, classed as 'mild' (Goodman and Scott, 2012). In addition, many children and adolescents with autism also experience behavioural difficulties such as Attention Deficit Hyperactivity Disorder (ADHD) and approximately 70% of people who are diagnosed are considered to meet criteria for at least one other psychiatric condition (NICE, 2011). Because a majority of people diagnosed with autism have other conditions too, it is difficult to be certain about what specific presenting behaviours constitute autism.

Additionally, some symptoms are perceived to be similar to those of other conditions, such as social anxiety disorder, attachment disorder or obsessional personality disorder, for example (Timimi and McCabe, 2016a). Therefore, 'diagnostic overshadowing' can take place with autism assessment, whereby the attribution of one diagnosis overshadows another (Rosen et al., 2018). For example, due to perceived overlapping symptoms, a proportion of young people receive a diagnosis of emotional or behavioural disorder before receiving an autism diagnosis (Mazefsky et al., 2012). Conversely, ADHD symptoms can overshadow those of autism, or vice versa (Rosen et al., 2018). However, some argue that the lack of understanding of the aetiology of autism and the crossover of patterns of behaviours with conditions such as attachment disorder make the diagnosis of autism a subjective question of semantics (Timimi and McCabe, 2016a). Nevertheless, these factors contribute to the complexities of diagnosing autism in day-to-day clinical practice.

### ***1.3.4 Aetiology and heritability***

Autism has no clearly understood aetiology - identifiable cause - although there are a number of risk factors which it is thought may be associated with the condition. Evidence for these risk factors, however, is mixed. About 10% of children with autism have specific genetic, neurologic or metabolic disorders

which may be considered to be aetiologic (Newschaffer et al., 2007), although those who also have an intellectual disability are more likely to show this association (Goodman and Scott, 2012). Other risk factors which have been explored include parental immigration (Keen et al., 2010; Magnusson et al., 2012) and maternal age (Bolton et al., 1997; Glasson et al., 2004). In contrast one study based on parental reports found no link between maternal age and diagnosis (Russell et al., 2014).

A meta-analysis of environmental risk factors found that advanced parental age, some birth complications and, to a lesser extent, maternal obesity or diabetes, and caesarian section were linked to autism diagnosis (Modabbernia et al., 2017). The same meta-analysis also found limited studies on toxic elements such as inorganic mercury and lead, that might warrant further investigation (Modabbernia et al., 2017). One further study identified increased maternal and paternal age at birth; birth order, with being first born the greatest association; and having a mother born abroad as risk factors (Gardener et al., 2009). Lower maternal age, however, may be an access barrier rather than a risk factor (Russell et al., 2011), in that the age of the mother may determine whether the family access assessment, rather than a link with autism as a condition. I discuss this further in Chapter Two.

Contentious debates around aetiology related to environmental changes due to changing lifestyles or modern technologies are still embedded in the lay conceptualisation of autism (Russell et al., 2010b) but are generally not considered to have enough scientific evidence to be considered seriously. Evidence linking the measles, mumps and rubella vaccine (MMR) with the onset of autism symptoms in the UK, whilst contributing greatly to public interest in autism, has been the subject of epidemiological studies which demonstrate no evidence of a link (Modabbernia et al., 2017; Rutter, 2005). Similarly, claims that autism is linked with thimerosal, a vaccine preservative, have no supporting evidence (Modabbernia et al., 2017; Rutter, 2005).

It is generally understood that autism has a genetic base, evidenced through twin and family studies. Folstein and Rutter, for example, studied twins where

one of the pair exhibited autism symptoms (Folstein and Rutter, 1977). The researchers found that there was a 36% concordance rate for autism in monozygotic (MZ) (identical) twins compared with 0% concordance in dizygotic (DZ) (non-identical) twins. The researchers concluded that there was strong heritability, although not one that was restricted to autism. A further study suggested that 60% of MZ twins were concordant for autism versus 0% of DZ pairs (Le Couteur et al., 1995). Folstein and Rutter also noted that 'milder' versions of autism symptoms were often present in non-autistic relatives of those diagnosed with autism, suggesting an underlying genetic liability for autism which has become known as the Broad Autism Phenotype (BAP) (Hurley et al., 2007; Piven et al., 1997). Overall it is considered that the results of twin studies indicate a very high heritability of genetic determination, rather than environmental factors or biological damage at birth, for instance (Folstein and Rutter, 1977). There is, therefore, a general medical consensus that genetics plays a strong part in autism, despite the lack of a discovery of an 'autism gene'.

However, others challenge both the methodology and findings of twin studies, citing the problems of generalising from a twin to non-twin population and asserting that the environmental influences on MZ twins and DZ twins cannot be assumed to be the same (Joseph, 2006). One study examining social demographic change argues that the estimated heritability of autism has been dramatically overstated, suggesting that twin studies rely on small convenience samples that cannot be inferred from more broadly (Liu et al., 2010b). Furthermore Liu and colleagues (2010b) argue that social demographic change – increased parental age – can yield genetic changes that, at population level, combine to contribute to increased prevalence of autism.

### **1.3.5 Refrigerator mothers**

As I have outlined above, there have been continued debates about causation and risk factors for autism, including vaccination, family risk factors such as parental age, maternal obesity or mental health and broader environmental factors such as exposure to toxins. However, the debate about aetiology would

be incomplete without mentioning a long-standing debate about the impact of poor parenting.

Kanner was first to make a link between autism and bad parenting, as he noted that the parents of the children he was treating were cold and distant (Hacking, 2006a, 1995). However, the main drive towards the connection between parenting and autism was from Bettelheim who, in 1967, termed the phrase 'refrigerator mothers' (Bettelheim, 1967). Hacking describes this as a moral shift from Kanner's 'feeble-minded' children to a re-conceptualisation of autistic children as young people liberated by parent-blaming (Hacking, 1995). This neat pathologising of mothers was hard to shake off: although the thesis is discredited today, blaming mothers as entirely responsible for their child's behaviours is a common trope. It is reflective of the move towards psychiatry at the time, and the expansion of the field, that social actions or behaviours began to be explained in medical terms. For example, Bettelheim also pathologised anti-war student protestors as 'acting out an unresolved Oedipal conflict' rather than considering that they might have a legitimate claim to political protest (Brown, 1990, p. 388).

#### **1.4 From childhood schizophrenia to an autism spectrum**

The term 'autism', drawing on the Greek work 'autos', meaning 'self', was first used in 1911 by psychiatrist Bleuler to describe the self-absorbed behaviour of some of his schizophrenic patients (Bleuler, 1911). It was later described almost simultaneously in the 1940s by Kanner as a distinct psychiatric disorder which he termed 'early infantile autism' (Kanner, 1943); and by Asperger as 'autistic psychopathy' (Asperger, 1944). Despite the fact that Kanner did not consider the condition to be associated with childhood schizophrenia (Nadesan, 2005), early infantile autism was classified under 'schizophrenia, childhood type' in DSM-I and DSM-II (APA, 1968, 1952; Manolova and Achkova, 2014).

In 1972 Rutter posited that the term of 'childhood schizophrenia' had outlived its usefulness, describing the range of diagnoses this covered as 'chaotic' (Rutter,



1972, p. 315). Instead Rutter delineated childhood schizophrenia as a separate condition, and described autism as having ‘three cardinal features’: (Rutter, 1972, p. 327) a failure of social development, delayed language development and ritualistic activities (Rutter, 1972). Autism was redefined under a category of ‘Pervasive Developmental Disorders in DSM-III (APA, 1980) creating it as a separate entity from childhood schizophrenia. The redefinition also heralded autism’s first appearance as a distinct diagnostic classification, ‘infantile autism’, in 1980 in DSM-III, within a new class of disorder, pervasive development disorder (APA, 1980; Volkmar and McPartland, 2014). Evans argues that this constitutes the exact opposite of the way in which autism had been understood in the 1950s – as a condition with excess of hallucinations and fantasy (Bleuler, 1911) – to one where the child has a lack of an unconscious symbolic life (Evans, 2013). The condition of autism now became one of behaviour, cognition and communication (Evans, 2013).

In 1979, Asperger differentiated his concept of autism from that of Kanner’s by describing his four young patients as ‘very intelligent with extraordinary originality of thought’, whereas Kanner’s described his eleven child patients as ‘near psychotic’ (Nadesan, 2005, p. 12). Although Kanner’s work was initially better known, and framed the early concept of autism, Asperger was later to have his name associated with a sub-section of autism through the work of Wing who introduced his work to a wider English-speaking audience (Wing, 1981).

Wing and Gould (1979) found that there were a group of children other than those that might have been identified by Kanner, with higher IQ but similar social impairments, and forwarded the idea that these children encompassed deficits which were on a ‘continuum of severity’ rather than ‘discrete entities’ (Wing and Gould, 1979, p. 26). In this way their influential work constructed a new ‘high-functioning’ category of autistic people – people with ‘normal’ intellect but with social impairments – those with Asperger’s Syndrome (AS). This was subsequently included as a sub-classification in DSM-IV (APA, 1994) alongside other sub-categories of Autistic Disorder, Childhood Disintegrative Disorder (CDD), Rett’s Disorder and Pervasive Development Disorder – not otherwise

specified (PDD-NOS). This development shaped the continuum between those with AS and the broader spectrum of autistic people (Grinker, 2015). Wing and Gould outlined the three features of autism as impairments in social interaction, impairment of verbal or non-verbal language, and repetitive or stereotyped activities (Wing and Gould, 1979), focussing on observable behaviour and creating the well-known 'triad' of behaviours (Evans, 2013).

Rutter, Wing and Gould, therefore, were key to repositioning autism as a disorder of social development, shifting a focus to language development and considering the groups of symptoms as a 'triad'. In doing so they re-conceptualised childhood autism, childhood schizophrenia and childhood psychosis as problems of social behaviour and management (Evans, 2013). An outline of changes in classification of autism is at Table 1.

#### **1.4.1 Current classification of autism**

As outlined above, the classification systems in use during the course of this PhD were DSM-5 and ICD-10. As ICD-11 is now aligned with DSM-5, I will discuss two important changes that took place with the publication of DSM-5 in 2013, which are now incorporated into the newly published ICD-11.

First, although autism had been understood as a spectrum for some time, the umbrella term 'Autism Spectrum Disorders' (ASD) was first used in DSM-5 (APA, 2013a). This new classification of ASD brought together the DSM-IV classifications of Autistic Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and PDD-NOS (APA, 2013a; Vllasaliu et al., 2016). The DSM-IV category of Rett's Disorder was omitted (Harker and Stone, 2014) as it is now considered to have a distinct genetic profile identifiable through a blood test showing the presence of a MECP2 gene mutation (Neul et al., 2010). It was argued that the changes towards one overarching condition, rather than several sub-classifications, reflected a scientific consensus and had a clear empirical basis (e.g. Ozonoff 2012). Autism became a single condition with different levels of severity rather than separate disorders as outlined in DSM-IV (APA, 1994). Today, therefore, within this spectrum, people who qualify for ASD diagnosis range from those who are severely affected, who may have an

DSM	Classification	Subtypes	ICD	Classification	Subtypes
<b>DSM-I (1952); DSM-II (1968)</b>	Schizophrenia	Childhood type	<b>ICD-8 (1967)</b>	Schizophrenia	Infantile autism
<b>DSM-III (1980)</b>	Pervasive Development Disorders (PDD)	Infantile autism; Childhood onset PDD	<b>ICD-9 (1977)</b>	Psychoses with origins specific to childhood	Infantile autism; Disintegrative psychosis; Other; Unspecified
<b>DSM-III-R (1987)</b>	Pervasive Development Disorders	Autistic disorder; PDD-Not otherwise specified (NOS)	<b>ICD-10 (1993)</b>	Pervasive Development Disorders	Childhood autism; Atypical autism; Rett Syndrome; Other childhood disintegrative disorder; Overactive disorder associated with mental retardation and stereotyped movements; Asperger syndrome; Other PDD: PDD - unspecified
<b>DSM-IV (1994)</b>	Pervasive Development Disorders	Autistic Disorder; Childhood Disintegrative Disorder; Asperger's Disorder; PDD-NOS; Rett's Disorder	<b>ICD-11 (2018)</b>	Neurodevelopmental disorders	Autism spectrum disorder.
<b>DSM-5 (2013)</b>	Neurodevelopmental disorders	Autism spectrum disorder			

Table 1: Evolution of diagnostic criteria and subtypes for autism  
adapted from (Ousley and Cermak, 2014) with information from (Manolova and Achkova, 2014)

intellectual disability, and meet DSM-5 specifiers of 'requiring very substantial support', to those who require less support, are cognitively able, and are often diagnosed in adulthood.

In the change to DSM-5, the removal of Asperger's Syndrome (AS) – considered to be differentiated from autism by there being no delay in language or cognitive development (WHO, 1993) – was hugely controversial. Autism advocates argue that the removal of AS as a discrete diagnosis was a challenge to the identity of many people for whom the label is positively embraced (Giles, 2014; Singh, 2011).

Furthermore, the efficacy of the move to 'lump' rather than 'split' has been questioned, particularly when the heterogeneity of autism symptoms are a key challenge to diagnosis (Ozonoff, 2012). There is a diagnostic presumption that the cluster of symptoms identified for autism have a common aetiology and therefore are inevitably intertwined. Some argue that there should be a separation of the triadic behavioural symptoms – taking a 'fractionable autism triad' approach – because, cognitively and genetically, there is no satisfactory account that explains the diversity of symptoms in autism (Happé and Ronald, 2008). Although a diagnostic category of autism may still be useful, it may be more helpful, for research purposes, to consider the condition across three dimensions of social interaction, communication and repetitive behaviours, rather than one overarching spectrum (Happé and Ronald, 2008). The authors argue that a fractionable approach would mean that genetic studies may have more success finding genes associated with specific behaviours rather than a whole spectrum.

The second key shift in DSM-5 was a move from classifying autism as having three symptom domains (communication; social interaction; and restricted and repetitive patterns of behaviour) to two (social communication and interaction; restricted, repetitive patterns of behaviour, interests or activities) (Wing et al., 2011). This reduction to two symptom domains was a change from the then accepted notion of a symptomatic 'triad' which, at the time of writing is still core to ICD-10 diagnostic criteria. In DSM-5, symptoms from both domains are

required for an ASD diagnosis, although a new classification of Social Communication Disorder can be diagnosed if there are no restricted repetitive behaviours present (APA, 2013b). ICD-11 will follow suit and collapse the ICD-10 categories of Childhood Autism, Atypical Autism, (defined by atypicality in age of onset or symptomatology) and Asperger's Syndrome (WHO, 1993) into an overarching category of Autism Spectrum Disorder. A table of differences between key criteria in DSM-IV, DSM-5, ICD-10 and ICD 11 can be found in Table 2.

Changes in diagnostic classification demonstrate how definitions of autism have changed. It is argued that changes have been made based on developing clinical experience and research (Mahjouri and Lord, 2012; Vivanti et al., 2013; Yaylaci and Miral, 2017). However, given its heterogeneity and the lack of conclusive and singular evidence of aetiology, some have argued that diagnostic definitions may be shaped as much by economic, social, political and cultural practices of our time than in scientific developments in autism research (Nadesan, 2005) including conceptualisations of child development, psychiatry and wider cultural and social factors.

#### ***1.4.2 Diagnosis in England***

The purpose of the autism diagnostic assessment is to confirm a diagnosis, to assess the needs of the family (or adult seeking diagnosis), to seek a cause where possible, to assess strengths and weaknesses of the patient and possible co-conditions as well as to identify necessary resources for support (Baird et al., 2003). In England the main diagnostic guideline in use is that produced by the National Institute for Health and Care Excellence (NICE). There are separate versions for children and young people (National Collaborating Centre for Women's and Children's Health, 2011; NICE, 2011) and adults (National Collaborating Centre for Mental Health, 2012; NICE, 2012).

	<b>ICD-10 (1993)</b>	<b>ICD-11 (2018)</b>	<b>DSM-IV (1994)</b>	<b>DSM-5 (2013)</b>
<b>Classification</b>	Pervasive Developmental Disorders	Neurodevelopmental Disorders	Pervasive Developmental Disorders	Neurodevelopmental Disorders
<b>Sub-types</b>	Sub-classifications of: Childhood autism; Atypical autism; Rett Syndrome; Other childhood disintegrative disorder; Overactive disorder associated with mental retardation and stereotyped movements; Asperger syndrome; Other PDD: PDD – unspecified	A single diagnosis: Autism spectrum disorder.  Differentiates autism with and without intellectual disability	Sub-classifications of: Autistic Disorder; Childhood Disintegrative Disorder; Asperger’s Disorder; Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS); Rett’s Disorder	A single diagnosis: Autism spectrum disorder.
<b>Symptom domains</b>	Three symptom domains: Problems in: Communication Social interaction Restrictive, repetitive activities and interests (RRBIs).	Two symptom domains: Persistent deficits in: Reciprocal social interaction and social communication Restricted, repetitive, and inflexible patterns of behaviour and interests.	Three symptom domains of: Qualitative impairment in social interaction Qualitative impairments in communication Restricted repetitive and stereotyped patterns of behaviour	Two symptom domains: Persistent deficits in: Social communication and social interaction Restrictive, repetitive patterns of behaviour, interests or activities; sensory difficulties
<b>Age of onset</b>	For childhood autism (but not for Asperger syndrome) ‘functional impairment’ in social interaction, or in language use for communication, must have appeared by age 3 years.	Onset occurs during development, typically in early childhood, but symptoms may manifest later.	Symptoms must be present in early developmental period (although may not fully manifest till later).	Must have been present in early development period; however, symptoms may not be apparent till later.
<b>Sensory difficulties</b>	Not included	Not included	Not included	DSM-5 includes sensory hyper/hypo-sensitivities

Table 2: Key differences between diagnostic criteria in DSM-IV, DSM-5, ICD-10 and ICD-11

Adapted from (Harker and Stone, 2014; Ozonoff, 2012)

Best practice for autism assessment is considered to be that which involves clinical consensus combining information from standard instruments of direct observation of the patient, screening and diagnostic instruments, parent/patient interview and additional independent information from other professionals and/or family members (Baird et al., 2006; Vllasaliu et al., 2016).

To reach a clinical consensus for both child and adult diagnosis, guidelines recommend that a multi-agency team should be set up to deliver the autism assessment (Lai et al., 2014; National Institute for Health and Care Excellence, 2014; NICE, 2011). In both adult and child diagnosis, the 'gold standard' of diagnostic decision-making, therefore, is considered to be consensus agreement within a multi-agency team utilising appropriate diagnostic tools and other related assessments (Falkmer et al., 2013; Woolfenden et al., 2011). Studies suggest that a multi-disciplinary assessment is important for valid clinical diagnosis (Huerta and Lord, 2012; Westman Andersson et al., 2013). In practice, there are occasions when a decision is made primarily by an experienced single clinician. However, a multi-disciplinary approach is required to develop a profile of the person and an understanding of a person's strengths and weaknesses for a complete diagnostic assessment (National Collaborating Centre for Women's and Children's Health, 2011). The different elements considered within an autism diagnostic assessment are given in Table 3.

Multi-disciplinary approach	<ul style="list-style-type: none"> <li>• Diagnosis decisions should take place through clinical consensus</li> <li>• Professionals involved should be trained and competent</li> <li>• The process should be team-based and draw on a range of professions and skills</li> </ul>
Parent/caregiver interview, ideally using standard tool such as the ADI-R or DISCO.	<p>To include:</p> <ul style="list-style-type: none"> <li>• Prenatal, perinatal, birth, developmental and health history, family medical and psychiatric history</li> <li>• Focus on the development of social, emotional, language and communication, cognitive, motor and self-help skills, the sensory profile and unusual behaviour and interests (core autism symptoms)</li> <li>• Behavioural presentation across different contexts</li> <li>• Functioning at home, in education or employment</li> <li>• Adaptive skills</li> <li>• Parent-child interaction and parent coping strategies (in child diagnosis)</li> <li>• Hyper and/or hypo sensory sensitivities and attention to detail</li> </ul>
Interaction with individual through interview (adult), ideally using standard tool such as the ADI-R or DISCO.  Additionally, self-report questionnaires can be used where appropriate e.g. RAADS-R	<ul style="list-style-type: none"> <li>• Interviews to be interactive and engaging</li> <li>• Assessment of social-communication characteristics in structured and unstructured contexts</li> <li>• Assessment of coping in peer environment</li> </ul>
Observation, ideally using observation tool such as ADOS	<ul style="list-style-type: none"> <li>• Of core autism signs and symptoms especially in social situations</li> </ul>
Documentation of behaviour in community settings	<ul style="list-style-type: none"> <li>• School reports and job performance records can indicate an individual's strengths and difficulties in real-life settings</li> </ul>
Cognitive assessment, using standardised tools	<ul style="list-style-type: none"> <li>• Assessment of language and intelligence; verbal and non-verbal ability</li> </ul>
Medical examination	<ul style="list-style-type: none"> <li>• Physical and neurological examinations (eg head circumference, motor function)</li> <li>• Consider genetic analysis (not as routine) (FMRI testing, chromosomal microarray analysis), hearing or sight tests, electroencephalography (for epilepsy)</li> <li>• (in children) look for signs of self-harm or maltreatment; congenital anomalies and dysmorphic features; skin stigmata</li> </ul>
Screening for co-occurring conditions	<ul style="list-style-type: none"> <li>• Through medical and genetic analysis</li> <li>• Take into account other neurodevelopmental conditions, mental disorders, neurological disorders, physical disorders, communication difficulties</li> </ul>
Consider differential diagnosis (children)	<ul style="list-style-type: none"> <li>• May include other neurodevelopmental disorders e.g. developmental coordination disorder; mental and behavioural disorders e.g. ADHD; conditions in which there is developmental regression such as Rett syndrome; other conditions (eg hearing or visual impairment)</li> </ul>
Assess challenging behaviour (adults)	<ul style="list-style-type: none"> <li>• Functional analysis, including identifying potential triggers or maintaining factors</li> </ul>
Assess risks (adults)	<ul style="list-style-type: none"> <li>• For self-harm, rapid escalation of problems, harm to others, self-neglect, breakdown of family/residential support, exploitation or abuse by others</li> </ul>

Table 3: Elements in a clinical assessment of autism  
from (M.-C. Lai et al., 2014; NICE, 2011, 2012)



## **1.5 Pathways to autism diagnosis**

The clinical pathway for autism diagnosis in the UK differs for children and adults and also across health systems and trusts (Villasaliu et al., 2016). Individuals can be referred directly to specialist autism assessment services in secondary care via their GP or health professional in secondary care (e.g. Community Mental Health Team); and, in children and young people's assessment, the process can be triggered via a school or other professional involved in education or health (National Collaborating Centre for Women's and Children's Health, 2011). Initial screening, sometimes utilising screening tools (See Section 1.5.3), determines whether individual cases are considered for full comprehensive assessment. This full assessment usually involves the use of diagnostic tools as well as developmental history-taking and information from other professionals. Assessment information will usually be discussed and considered by a range of clinicians, coming to a consensus at a multi-disciplinary team (MDT) meeting. MDTs are made up of a number of health professionals relevant to the case including consultant psychiatrists, consultant psychologists, nurse practitioners (who are often specialists in autism), speech and language therapists and paediatricians. At these meetings all assessment data will be considered and a diagnosis made, although some cases may require further assessment or advice.

Rather than diagnosis being a single decision-making opportunity for classification, therefore, there are multiple opportunities for diagnostic assessment within the extended process, often in consultation with patients, parents/carers and other clinicians. A wide range of information is taken into account. Further discussion about decision-making in multi-disciplinary teams is in Chapter Four.

### ***1.5.1 Autism diagnostic pathway for children***

Many different pathways for diagnosing autism in children are in place (Baird et al., 2011) depending on local trusts and priorities. Karim and colleagues' (2014) interview study shows that, across services, diagnosis for children and young people can take place in different settings, may involve different kinds of

observations, and can involve different health professionals depending on time or availability. Although some settings do not have specialist autism clinics (Karim et al., 2014) there is a requirement for there to be a diagnostic pathway across local agencies. Assessment is generally located within the wider provision for children and young people with emotional and psychological difficulties provided for by Child and Adolescent Mental Health Services (CAMHS) (NHS Choices, 2016). CAMHS provision includes services in early years and primary care (Tier 1 services) through to highly specialist services such as in-patient and specialised assessment and treatment services (Tier 4) (NHS England, 2015). Specialist multi-disciplinary teams (Tier 3) will provide autism assessment via an out-patient service, and where necessary, there is a highly specialist Tier 4 assessment process for children who may be deemed to be at particular risk or require intensive input. This process will take place over a number of days, involving a wider range of professionals, often including teachers and art therapists (S. Howson, personal communication, 2016). The NICE recommended pathway for assessment of children and young people is at Figure 2.

In practice, many health trusts have specialist autism assessment teams and others channel assessment through CAMHS or a paediatric team. Different processes can come into play depending on the complexity of the case or whether, for example, a child has had primary contact with another specialist team such as Learning Disabilities (LD). Guidelines suggest that whilst different geographical areas may have different referral policies, in general younger children are more likely to be referred to paediatricians at a child development centre or to speech and language therapists, whilst older children are more likely to be referred to a paediatrician or CAMHS (National Collaborating Centre for Women's and Children's Health, 2011). Policy and practice guidelines suggest that early diagnosis is important as it enables early intervention strategies, leading to better long-term outcomes (Filipek et al., 2000; Lai et al., 2014). 'Earlier is better', however, has been challenged by some researchers on the basis that the evidence for efficacy of treatment interventions is inconclusive and that there are potentially adverse effects for the child in receiving a diagnostic label (Russell, 2016).

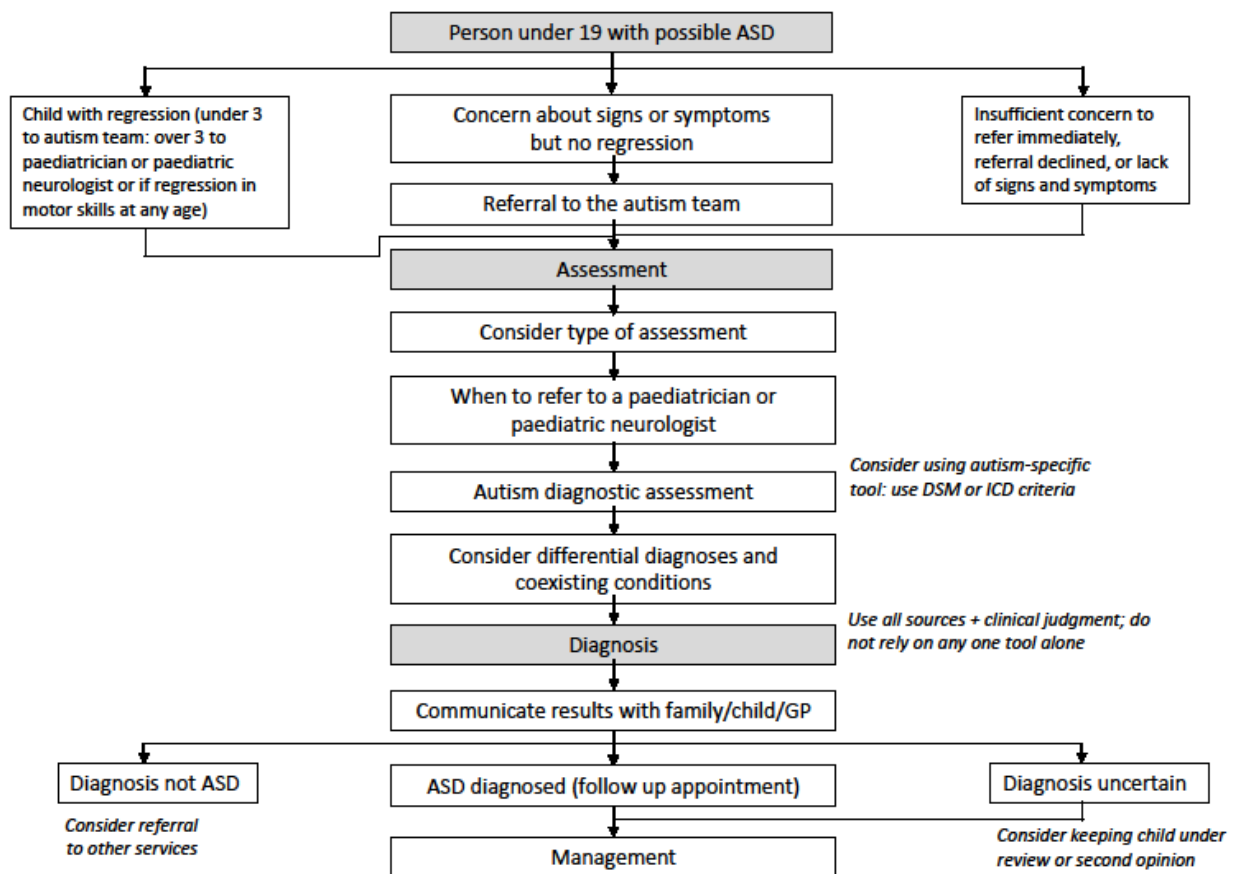


Figure 2: NICE pathway for autism diagnosis for children and young people

As outlined above, symptoms are related to social interaction, reciprocal communication and repetitive and restrictive behaviours or interests (NICE, 2011). In addition, a key aspect in the diagnosis of autism in children and young people is that behavioural signs and symptoms are examined against what is considered typical development in relation to the child’s age or developmental level (Huerta and Lord, 2012; Lord et al., 1997). A diagnostic framework which takes into account what might be considered ‘typical’ child development also makes assumptions about what this might mean in relation to the nature of typicality. I consider questions around what might be considered typical or normal behaviour in Chapter Three.

When considering the possibility of referring a child to a specialist autism assessment team, there are a number of interacting factors which may make even an initial referral difficult. Many of these contextual factors relate not

simply to the child's overall development, but also take into account whether symptoms can be accounted for by disruptive home experiences. This can include parental illness, cultural variations and the possibility that the child may have found strategies for coping which 'mask' symptoms, for example (NICE, 2011). Diagnosis of autism in children can be further problematised by interaction with non-autistic factors such as cognitive functioning (Huerta and Lord, 2012). One study shows that different diagnoses can be given by different clinicians even within the same case (Russell et al., 2012c), leading to questions about the validity of the model of a discrete underlying condition being measured.

NICE recommends that the diagnostic assessment process should commence within three months of an individual's referral to the autism team and, after diagnosis, plans for any support or intervention should involve the family. A 2014 self-assessment exercise found that only 33 (22%) of local authorities reported meeting the NICE recommended waiting times in both children and adult services (Glover et al., 2014).

Guidelines recommend that there should be a single point of contact, a case coordinator, through which the parent or family can communicate with the wider assessment team (NICE, 2011).

### ***1.5.2 Autism diagnostic pathway for adults***

The Autism Act 2009 was passed in order to make provision to meet the needs of adults with autism in England and Wales (UK Parliament, 2009). The resulting Autism Strategy acknowledged that services for adults were inconsistent and that obtaining a diagnosis could be difficult, time-consuming and frustrating (Department of Health, 2010). The Autism Act laid a duty on government to produce an autism strategy for adults, alongside guidelines for local authorities about the identification of those with autism and provision of services for the purpose of diagnosing autism in adults (UK Parliament, 2009). A similar process has taken place in Scotland (Scottish Parliament, 2010) and Northern Ireland (Northern Ireland Assembly, 2011). Local authorities, therefore, have a statutory duty to ensure that there is a clear pathway for

adults seeking diagnosis. A key aim of the Autism Strategy was to increase capacity around diagnosis throughout the country, and to ensure that relevant information is provided to patients at the point of diagnosis to help them understand the condition and access local support (Department of Health, 2010). The resulting NICE guidelines include a model care pathway to inform the development of referral and care pathways in local health authorities (NICE, 2012). An outline of the NICE pathway for adults is at Figure 3.

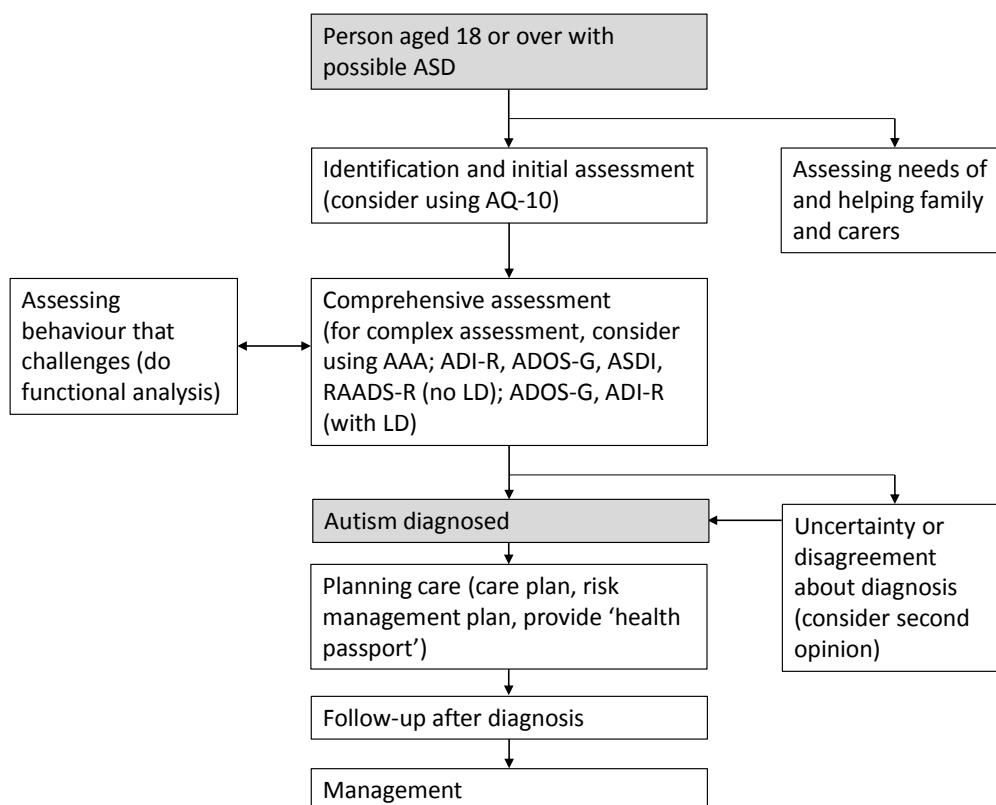


Figure 3: NICE pathway for autism diagnosis for adults

Referral routes to diagnosis for adults tend to come from GPs or mental health teams in secondary care and some teams accept self-referrals (National Autistic Society, 2016b). Diagnosis is based on the same symptom domains as children. In addition, individuals should present with one or more of the following: problems in obtaining or sustaining employment or education; difficulties in initiating or sustaining social relationships; previous or current contact with mental health or learning disability services; a history of a

neurodevelopmental condition (including learning disabilities and Attention Deficit Hyperactivity Disorder) or mental disorder (NICE, 2012).

Guidelines recommend a second opinion if there is uncertainty about the diagnosis. This might be caused by disagreement within the assessment team or between the person/family and the assessment team; lack of local expertise; or presence of a complex coexisting condition (NICE, 2012).

The NICE recommended diagnostic pathway incorporates a process by which an adult, in any part of England and Wales, presenting for diagnosis has the opportunity for a full assessment. The assessment should be undertaken with specialist and highly trained clinicians working within a multi-disciplinary team, using diagnostic tools based on agreed criteria where appropriate, with the support of a family member or other informant. The assessment process should commence within three months of an individuals' referral to the autism team. Factors from developmental history, details of past and current conditions and relevant documentary evidence should all be taken into account. Importantly, all adults receiving a formal diagnosis of autism should be offered a follow-up appointment to discuss their support needs and implications of the diagnosis (NICE, 2012).

### ***1.5.3 Diagnostic tools***

Classification criteria in DSM-5 and ICD-10 form the basis for the creation of screening and diagnostic tools to be used in clinical practice and research.

Diagnostic tools primarily take the form of structured or semi-structured clinician-administered observational frameworks, interviews with parents/caregivers or adults seeking diagnosis, or a combination of the two. In addition, questionnaires or rating scales are used as screening tools (and can also be used in assessment), either administered by or with a clinician, or by the parent/caregiver/patient. Screening and diagnostic instruments vary for target sample and purpose so it is recommended the most appropriate tool should be selected (Lai et al., 2014).

Because autism is defined as a developmental disorder, assessment instruments take into account developmentally-caused behaviour changes (Vllasaliu et al., 2016). According to best practice guidelines, diagnostic tools should assess social functioning in a developmental context and take into account behaviour across a range of settings (Lord and McGee, 2001). Diagnostic tools utilise ratings scales based on behavioural symptoms and endeavour to make the diagnostic process less subjective in the absence of any equivalent definitive biological scales such as those used to measure physical conditions, such as blood pressure or temperature. There are a wide range of diagnostic tools available and an initial (not comprehensive) search identified 31 tools specifically designed for autism diagnosis and screening (See *Appendix 1: Selected Diagnostic and Screening Tools for Autism*).

It is recommended that diagnostic tools are not used in isolation and that the results of scales should be considered a guide rather than a definitive decision-making framework (Woolfenden et al., 2011). Indeed, guidelines suggest that although tools are useful in gathering information in a structured way, they are not essential and should not be used to make or rule out a diagnosis (NICE, 2011).

Furthermore, tools which utilise parent ratings of behaviour may show different results than those administered by a clinician. For example, a study examining the use of multiple diagnostic tools found that parents of preschool children with good verbal skills were likely to perceive their child's symptoms, using the ADI-R, as less severe than clinicians utilising ADOS (Kim and Lord, 2012). This suggests that understanding the source of the information assessed, in this case, parental assessment, as well as contextual factors such as age, stage of development and language level, are extremely important (Huerta and Lord, 2012). It is therefore considered that the use of multiple tools, especially with complex cases, may be particularly useful to increase the possibility of diagnostic accuracy (Kim and Lord, 2012).

It is argued that diagnostic tests utilising tools should demonstrate high sensitivity and specificity, be simple and brief, ideally be available at no charge,

be accurate, and appropriate for all ages and ranges within the spectrum (Mayes et al., 2009). A high level of sensitivity means that the test will correctly identify patients with the condition (high true positive rate); a high level of specificity will enable an ability to correctly detect patients without the condition (true negative rate) (Greenhalgh, 1997). Diagnostic tests, even in physical health, are rarely 100% accurate (Greenhalgh, 1997). In addition, diagnostic tests should demonstrate high validity, meaning that the test should measure what it is intended to measure. Diagnostic tests should also be reliable, meaning that, over time, they should be able to deliver the same outcome, to an acceptable level, on a subject whose condition has not changed (Greenhalgh, 1997).

A review of diagnostic tools found that the ADOS (Autism Diagnostic Observation Schedule), and the ADI-R (Autism Diagnostic Interview - Revised) demonstrated the highest levels of sensitivity and specificity with the largest evidence base (Falkmer et al., 2013). The NICE review found that only ADOS and ADI-R met pre-defined levels of accuracy (compared to using criteria in DSM-IV and ICD-10) and that evidence for use of tools generally was of low quality (National Collaborating Centre for Women's and Children's Health, 2011). This informs the generally accepted notion that the ADOS and ADI-R represent the 'gold standard' for autism diagnostic tools (Ozonoff et al., 2005). Other tools, such as the 3Di, a computer-aided assessment tool which endeavours to produce quantified symptom profiles (Skuse et al., 2004), showed high specificity and sensitivity but this was based on only one study and is therefore not yet considered the best tool available (Falkmer et al., 2013). In addition, some clinicians are uncomfortable with using a computer generated tool, even alongside clinical judgement (Clinical Psychiatrist, personal communication). Overall, however, evidence for the accuracy and consistency of diagnostic tests for autism is low, with either a lack of a wide independent evidence base for tools which are currently used in practice (e.g. ASD-DC and RAADS) (Falkmer et al., 2013); or the studies available being of low quality (National Collaborating Centre for Women's and Children's Health, 2011).



Use of diagnostic and screening tools requires highly specialised training (Lord et al., 1997) and the ADOS kit (includes test materials and 50 protocol booklets) costs more than £2000 including VAT (Hogrefe catalogue 2017). ADOS training is available only to clinicians or authorised researchers. This means that utilising ‘gold standard’ tools demands both training and financial investment making them inaccessible to lay people and, as argued by Milton in a commentary on ADOS training, not designed to be operated by autistic people (Timimi et al., 2019). The attempt to consolidate clinical judgement via diagnostic tools – to create an objective, measurable scale equivalent to a biological diagnostic test – seems currently to lack evidence of clinical accuracy which is likely to be due to the problem of assessing behavioural symptoms in a way that avoids subjectivity and interpretive bias (Falkmer et al., 2013).

### ***The Autism Diagnostic Observation Schedule***

The ADOS is commonly used as the core assessment tool in autism diagnosis and therefore is outlined in more detail here. The ADOS is an activity-based semi-structured standardised observation tool whereby the person being assessed performs a number of communication and interaction tasks, involving interactive stimulus materials, for example, using objects to build a story. The person is then scored on a range of behaviours such as emphatic or emotional gestures and overall quality of rapport. There are five modules in ADOS-2 which are used in assessment for different ages and abilities, from toddlers to adults. As an example of the range of tasks, I have outlined the tasks in ADOS Module 4 (adult and adolescent) in Table 4.

#### **Observation tasks**

- |                                      |   |
|--------------------------------------|---|
| 1. Construction task*                | 9. Cartoons*                            |
| 2. Telling a story from a book:      | 10. Break (observed)                    |
| 3. Description of a picture*         | 11. Daily living*                       |
| 4. Conversation and reporting        | 12. Friends, relationships and marriage |
| 5. Current work or school*           | 13. Loneliness                          |
| 6. Social difficulties and annoyance | 14. Plans and hopes                     |
| 7. Emotions                          | 15. Creating a story                    |
| 8. Demonstration task                |   |

\*optional

Table 4: ADOS observation tasks in Module 4 (adult and adolescent)

ADOS facilitates the coding of behaviours related to language and communication, reciprocal social interaction, imagination, stereotyped behaviours and restricted interests as well as ‘other abnormal behaviours’. These are rated between 0 (no evidence of abnormality related to autism) and 3 (definite evidence) (Vllasaliu et al., 2016). Assessment takes between 40 and 60 minutes to administer although in practice this can take longer. The coding groups for Module 4 are outlined at Table 5.

Coding groupings		
<p><b>A. Language &amp; Communication</b></p> <p>A1 Overall level of non-echoed spoken language</p> <p>A2 Speech abnormalities associated with autism</p> <p>A3 Immediate echolalia</p> <p>A4 Stereotyped/idiosyncratic use of words or phrases</p> <p>A5 Offers information</p> <p>A6 Asks for information</p> <p>A7 Reporting of events</p> <p>A8 Conversation</p> <p>A9 Descriptive, conventional, instrumental or informational gestures</p> <p>A10 Emphatic or emotional gestures</p>	<p><b>B. Reciprocal social interaction</b></p> <p>B1 Unusual eye contact</p> <p>B2 Facial expression directed to examiner</p> <p>B3 Language production and linked nonverbal communication</p> <p>B4 Shared enjoyment in interaction</p> <p>B5 Communication of own affect</p> <p>B6 Comments on others’ emotions/empathy</p> <p>B7 Insight into typical social situations and relationships</p> <p>B8 Responsibility</p> <p>B9 Quality of social overtures</p> <p>B10 Amount of social overtures/maintenance of attention</p> <p>B11 Quality of social response</p> <p>B12 Amount of reciprocal social communication</p> <p>B13 Overall quality of rapport</p>	<p><b>C. Imagination</b></p> <p>C1 Imagination/creativity</p> <p><b>D. Stereotyped behaviours and restricted interests</b></p> <p>D1 Unusual sensory interest in play material/person</p> <p>D2 Hand and finger and other complex mannerisms</p> <p>D3 Self-injurious behaviour</p> <p>D4 Excessive interest in or references to unusual or highly specific topics or repetitive behaviours</p> <p>D5 Compulsions or rituals</p> <p><b>E. Other abnormal behaviours</b></p> <p>E1 Overactivity/agitation</p> <p>E2 Anxiety</p> <p>E3 Tantrums, aggression, negative or disruptive behaviour</p>

Table 5: Coding groups for ADOS module 4 (adult and adolescent)

Whilst the ADOS is considered to be a gold standard tool in research and clinical practice, some scholars have criticised it, arguing that the tool lacks transparency, and observing that context, emotion, and differences in interpretation and power imbalances play an unidentified role in the assessment process (Timimi et al., 2019).

## 1.6 Concluding comments

To conclude, autism is defined by behaviours, reinterpreted as symptoms, and is therefore particularly interesting for considering as a case study to explore diagnosis. As I have outlined above, there are a number of ongoing debates around aetiology, heritability and the usefulness of the diagnostic classification.

A symptom is generally regarded as an indicator of a disease or disorder and one that is reported by the individual coming for diagnosis. However, in autism, behaviour itself constitutes the symptom of the condition. And yet behaviour is something we all engage in every day: the boundaries between typical and atypical behaviour is subject to a wide range of social factors embedded in context, culture, setting, interaction, interpretations and relationships. As I shall explore, interpretation of behaviours as symptoms (i.e. as pathological) is core to diagnosis of autism. This chapter has demonstrated both our contemporary understanding of *what autism is* – our ontological understanding – as well as how we know it through identification and classification – its epistemological framework. Ontological and epistemological understandings inform each other and are of their time in that we can only ‘know’ and reflect on knowing through our contemporary understandings. Looking at psychiatric diagnoses more broadly, Whooley (2019) argues that a general inability of the psychiatric profession to pin down the essence of mental distress – what psychiatric disorders *really are* – means that ontological assumptions are only temporary. Shifts in knowledge and understanding can be seen through changing labels and classifications. Ontological and epistemological elements are self-reinforcing in that how one conceives a disorder shapes how we investigate it; and how we investigate a disorder shapes the object itself (Whooley, 2019). I will explore how clinicians deal with ontological uncertainty in Chapter Eight.



## **CHAPTER TWO: Social Framing of Diagnosis**

*...diagnoses have become part of how we make sense of ourselves,  
each other, and the world*

McGann, 2011, p. 343



## **2.1 Introduction and overview of chapter**

This chapter sets out the conceptual framework for the thesis which is sited within a sociology of diagnosis framework. I introduce a social model of diagnosis as outlined by Jutel (2011) incorporating diagnosis as process, category and the consequences of diagnosis. I will consider three studies in conditions other than autism to explore diagnosis as categorisation. I then consider one aspect of diagnosis-as-process: socio-demographic factors in diagnosis, which impact on who comes to the clinic for assessment. I will also consider the consequences of diagnosis specifically in relation to stigma. The chapter then goes to consider the three aspects of diagnosis as they relate to autism.

## **2.2 Sociology of diagnosis**

In 1978 Blaxter asserted that diagnosis, as a subject for sociological interest, was not studied as much as it might be, despite its centrality to the practice of medicine (Blaxter, 1978). She discussed the concept of diagnosis as a category, a way in which collections of symptoms are collected into diseases and used for classification; and also as a process, the act of diagnosing undertaken by clinicians and all that entails. She described these two factors as inextricably linked: diagnosis-as-process being dependent on the categories created within which the process happens; but categorisation being the result of the process of diagnosis itself (Blaxter, 1978).

Building on this work, and the work of Brown (1995, 1990), Jutel and Nettleton called for a sociology of diagnosis (Jutel, 2009; Jutel and Nettleton, 2011) which pushed for acknowledgement and development of this sub-disciplinary field within the wider discipline of medical sociology. This call, which was extended in further work undertaken by Jutel (see, for example, Jutel, 2011, 2015, 2016, 2019), revisited diagnosis as a powerful social tool, considering its social framing, its place in the institution of medicine and, ultimately, the way in which it confers authority to medicine (Jutel, 2009). Jutel and Nettleton added a third

rubric to Blaxter's process and category: that of 'consequences of diagnosis', acknowledging that diagnosis has consequences for those to whom it is applied, including stigmatisation and blame, vindication and legitimisation, facilitation of access to resources as well as limitations in opportunity (Jutel and Nettleton, 2011).

Jutel describes the ways in which diagnosis shapes, and is shaped by, society. She argues that diagnosis creates social order by organising illness, enabling access to support and resources, and by bestowing permission on the individual to be ill and to assume a sick role (Jutel, 2009). Importantly, diagnosis provides, through classification, the framework in society which judges what is normal and what is pathological and triggers the process by which that behaviour is treated. It confers authority to the medical profession and 'sets the doctor apart' (Jutel, 2009, p. 279) from lay people. It has been argued that the patient-doctor relationship has shifted with greater lay knowledge available through technology, increased information and greater patient-doctor consultation leading to individuals becoming highly knowledgeable lay experts (see Epstein, 1995; Hardey, 1999). However, the final judgement remains with the doctor alone (Jutel, 2011).

In Chapter One I asked the question 'what is diagnosis?' which, in medical terms, can appear to be a linear process of identifying signs and symptoms. This medical model for understanding, diagnosing, managing and treating disease and disorder, is dominant in Western society (Latimer, 2013). Examining psychiatric diagnosis, Rose (2013) outlines at least ten functions of diagnosis which broaden this definition and incorporate a number of social factors which are meaningful for different actors. For patients, diagnosis can have the function of eligibility for treatment, insurability, legitimising absence from work, or allocation of educational support or funding, for example. For lawyers, diagnosis can be a condition for involuntary detention and treatment. For epidemiologists, diagnostic categories provide the basis of estimates of prevalence and predictions for the future. For funders of research, diagnosis can serve to highlight a problem that is worthy of research. For commercial entities, diagnosis enables the production and development of disease-specific



drugs. Diagnosis can also be the basis for social mobilisation with charities, support groups and activists lobbying for services and research based on a specific diagnosis (Rose, 2013). In summary, therefore, diagnosis is entrenched in the infrastructure and functioning of wider society. Rather than relying on diagnostic categories which, he argues, are arbitrary and constructed (Rosenberg, 2006), Rose argues that research and treatment should begin with the experience and difficulties of the individual and what types of support would mitigate them (Rose, 2013). I shall consider this idea further in Chapter Ten.

### 2.3 Jutel's social model of diagnosis

Jutel's (2011) social model of diagnosis demonstrates the interaction between how disease is categorised (social framing), the social consequences of diagnosis and the process of diagnosis represented by the clinician-doctor relationship (see Figure 4). Jutel draws from Aronowitz's (2008) definition of 'social framing' of diagnosis, as the way that societies generally 'recognise, define, name and categorise disease states' (Aronowitz, 2008, p. 2; Jutel, 2011).

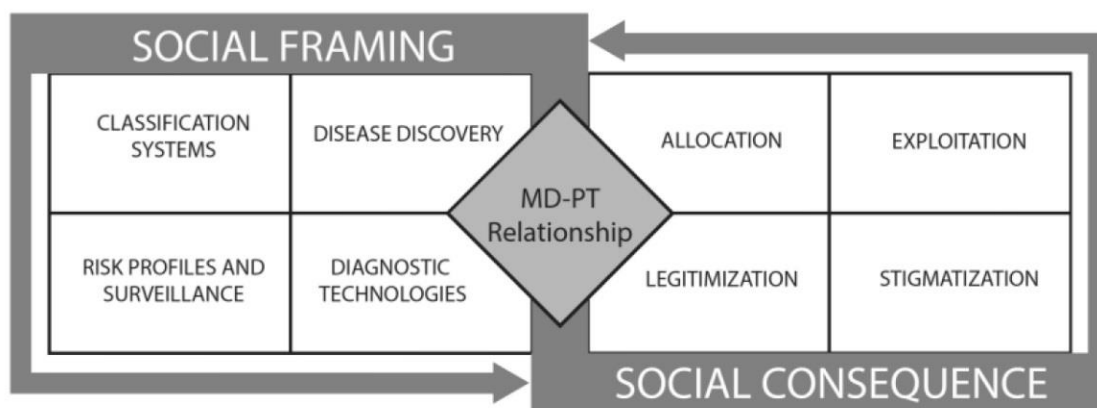


Figure 4: Jutel's social model of diagnosis (Jutel, 2011)

Jutel's model frames diagnosis as an integrated social system whereby each of these three concepts - category, consequence and process – serve to frame and shift the meaning, impact and conception of disease categories over time.

As Jutel describes, there is a circular relationship between the two parts of her original model, with ‘diagnostic categories shaped by the consequences they entail, and the consequences shaped by the categories imposed’ (Jutel, 2019, p. 3621). The social framing of diagnosis – how the category of a disease or disorder is created, shaped and revised – is rooted in contemporary versions of utilised classification systems and the historical, cultural and social events that inform them (Jutel, 2011). Social framing includes the way in which we carve up understanding of ‘symptoms’ or behaviours to construct one disease category or another (Jutel, 2019). The category (or social framing) of diagnosis also encompasses how risk profiles and surveillance systems contribute to blurring the boundaries between ‘normal’ and pathological (Armstrong, 1995), as well as the development of diagnostic technologies and their contribution to redefining conditions (Jutel, 2019).

Social consequences include legitimisation of the patient’s distress, stigmatization as the result of a diagnostic label, exploitation by commercial interests such as drug companies, or allocation of resources or support. These consequences inform how we understand a condition and how it is diagnosed, thereby contributing to the iterative and developing understanding of disease categories (Jutel, 2011). Diagnosis is particular to the value and technologies of its time, and, in the clinic, is subject to practices and processes of debate and adjudication between different forms of evidence (Latimer, 2013). It is, however, presented as a reflection of the natural, as if it is ‘validating a reality’ (Jutel, 2009).

At the centre of Jutel’s model is the relationship between the clinician (MD) and the patient (PT) – the process of diagnosis. I use a simplified version of this three-part model in Section 2.8 to review autism separately as a category, process and as a consequence. The ‘diagnosis as process’ aspect of the model is explored further in Chapter Four where I examine clinician interaction in team meetings. I return to the model in the light of my own findings in Chapter Ten.

## 2.4 Lumping and splitting

Jutel's vision of a sociology of diagnosis builds on Blaxter's notion of diagnosis as a category and a process; both the way that a collection of symptoms becomes a disease or disorder but also a method, the judgement by which individuals are labelled with the designated category (Jutel, 2009). Considering how symptoms are lumped together or split apart (Zerubavel, 1996) and how this changes over time, enables an examination of the way in which disease and disorder are 'of our time': some classifications no longer exist as medical entities and others are likely to change again in the future (Jutel, 2009). Jutel uses examples of witchcraft, homosexuality and drapetomania – the tendency of slaves to try to escape – to illustrate the former; and surmises that conditions such as erectile dysfunction and excited delirium may well follow suit in the future (Jutel, 2009). She argues that 'disease entities' are framed by and then, in turn, frame social and cultural values around our understanding of health, illness, normal and pathological behaviour and symptoms (Jutel, 2009).

There is a great deal at stake in the construction of disease entities and the decisions around which ones are validated as disease entities through the medical gaze. As diagnosis can both validate and offer practical support post-diagnosis, the struggle for legitimisation through diagnostic labelling can be fraught and contentious. This is reflected, for example, in the battle to retain the diagnosis of Asperger's Syndrome (AS), by those who have the label (Giles, 2014; Singh, 2011) and in the struggle for acknowledgment of stigmatised conditions such as HIV/Aids (Parker and Aggleton, 2003). It is also an ongoing dispute in the emergence of contested or medically-unexplained illnesses (see, for example, Armentor, 2017; Dumit, 2006; Shriver and Waskul, 2006). The impact of a label on an individual can be life-changing.

Blaxter argues that diagnostic categories can be viewed as a 'museum of past and present concepts of the nature of disease' (Blaxter, 1978, p. 10). Categorisations emerge from, in different eras, the conflation of the symptom and the disease, the site of the disease, and, in the twentieth century, the contributions of new scientific techniques, for example, naming Down's

Syndrome as a 'chromosome abnormality' (Blaxter, 1978). This does not change the 'nature' of the condition, but can contribute to a conceptual shift in how we understand a condition, or how we configure a number of symptoms into a disease entity, and therefore how we approach its diagnosis, treatment and prognosis.

To understand this better, it is necessary to look further at some specific conditions in relation to diagnosis as a category, process and consequence.

## **2.5 Diagnosis in practice: classification (diagnosis-as-category)**

Standard medical texts tend to present the diagnostic process as a way to identify underlying pathology from signs and symptoms located in the body (e.g. Langlois, 2002), however there are a growing number of studies which challenge this assumption (e.g. Gardner et al., 2011; Jutel, 2013; North, 2015; Willig, 2011). There is some overlap between a general sociology of health and illness which has not specifically excluded the matter of diagnosis, however, here I focus on three studies in conditions other than autism, which make specific relevant points about diagnosis. I will go on to discuss the concept of diagnosis-as-category as it relates to autism in Section 2.8.2.

Halpin's study of Huntingdon's Disease (HD) demonstrates how classifications are not just theory-based or as Bowker and Star suggest 'properties of mind'; rather they have a 'material force in the world', with consequences (Bowker and Star, 1999, p. 39). Halpin undertook interviews with people diagnosed with HD, recognised as a neurological condition but which has frequently been misdiagnosed as a psychiatric illness (Halpin, 2011). Halpin argues that the conceptualisation of HD within a diagnostic schema designed around psychiatric illness highlights ambiguities between neurology and psychiatry which has consequences for those who might be misdiagnosed. Misdiagnosis because of these 'interdisciplinary ambiguities' based on 'epistemological divides' has led to incorrect treatment, confusion and grief for those diagnosed, as well as the application of further misdiagnoses to family members (Halpin,

2011, pp. 859, 864). Halpin's study illustrates the construction of diagnostic schemas which may differ between disciplines, and provides an important analysis, tied to Jutel's focus on consequence, of the impact of allocating individuals to diagnostic categories that do not accurately reflect their condition. He notes how each gaze (neurological and psychiatric) looks deeply but partially: the former focusing on structural damage, the latter on changes in mood or personality. Halpin concludes by suggesting a more comprehensive diagnostic tool may alleviate the real distress caused by misdiagnosis (Halpin, 2011).

Whilst Halpin's analysis is a powerful illustration of Jutel's argument around the consequences of diagnosis when classifications are considered from different disciplines, it does little to challenge the reality of the diagnostic categories themselves. Other studies examine conditions within which genetic explanations play a role in classification. Focussing on how classification systems are represented in medical and scientific texts, Hedgecoe examined the way in which the boundaries of the disease Cystic Fibrosis (CF) have expanded to include previously neighbouring, but separate, conditions (Hedgecoe, 2003). Importantly, he argues that the use of genetic explanations does not alleviate uncertainty in diagnosis, indeed it can increase diagnostic uncertainty in some cases because of a conflict with the diagnostic practice of clinicians (Hedgecoe, 2003). Through this example Hedgecoe claims, in contrast to Halpin's argument, that tests which are intended to provide more definitive evidence do not absolve us from social decision-making in diagnosis. He argues that the introduction of genetic testing in this field highlighted, rather than removed, social decisions from the process of classification (Hedgecoe, 2003). Hedgecoe's argument concurs with other views that a reliance on genetic markers as objective proof of disease is inappropriate, rather, the meaning and relevance of biomedical entities must be addressed (Rabeharisoa and Bourret, 2009). Hedgecoe's study, in contrast to Halpin's, does not consider the development of more accurate tools as the answer to diagnostic uncertainty, or misdiagnosis. Rather, it challenges the construction of categories in the first place by demonstrating that they are socially constructed and therefore open to expansion, contraction or overlap.

If disease categories are constructed, what are some of the drivers of change? It is argued that particular sets of historical and social circumstances shape the creation and development of diagnostic categories (Eyal et al., 2010; Latimer, 2013; Mol, 2002; Nadesan, 2013) which can involve an interaction between, for example, changes in legislation (for example, see Eyal, 2013; UK Parliament, 2009); the work of advocacy and activist groups (for example, see Epstein, 1995; Singh, 2011); increased access to specific genetic technologies (Latimer, 2013; Navon and Eyal, 2016; Rabeharisoa and Bourret, 2009); and changes in institutional structures and understandings (Nadesan, 2013). In particular there is a strong argument for the influence of commercial and political concerns which may produce 'technological catalysts' such as the development of population screening programmes (Timmermans and Buchbinder, 2014), for example. Commercial concerns can also drive the promotion of self-diagnostic 'tools' (Ebeling, 2011) and, most strikingly, the creation of 'new' disease entities for commercial gain (Moynihan et al., 2002). Some researchers argue that as a condition becomes a 'discrete ontological entity', that is, becomes a 'thing', it is open to commodification (Mallett and Runswick-Cole, 2016). Mallett and Runswick-Cole (2016) argue, for example, that the marketing and sale of diagnostic tools contributes further to the reification of the condition by fulfilling the need for differentiation, training and treatment programmes, scientific and academic conferences and published research.

The condition of 'female sexual dysfunction' (FSD), it is argued, is entirely constructed to enable drug companies to profit from its treatment (Moynihan, 2003). Moynihan and others argue that, in order to build a market for a medication, a disease entity has to be established. The marketisation of illness is extremely lucrative: the prescription of Viagra for the condition of erectile dysfunction provided the main drug companies with reported sales of upwards of \$1bn each (Moynihan, 2003). The drive to construct a 'new category of illness' of FSD involved meetings of selected attendees primarily funded by pharmaceutical companies who therefore had a financial or reputational stake in the development of a new disease entity (Moynihan, 2003). This marketisation was based on a study which concluded that 43% of women experienced FSD (Laumann et al., 1999) although Moynihan argues that the methods and

conclusions were inadequate. Nevertheless, this figure is widely quoted in articles about the newly-termed condition (for example see, Allahdadi et al., 2009; Berman et al., 1999) thereby iteratively contributing to cementing an understanding of what 'FSD' 'is'.

These examples illustrate just three important debates that challenge diagnostic classification. The examples illustrate how the creation of conditions can be driven, not by biomedical advances but by commercial interests. In addition, these examples reveal how different medical disciplines can project a different kind of gaze and therefore interpretation of symptoms, which can impact on the diagnostic category allocated. The examples above also demonstrate how technological developments such as in the development of diagnostic tools or genetic testing does not increase the certainty of diagnosis, rather it can raise further questions around meaning and relevance. Diagnostic categories, therefore, are transformed by social forces and in turn transform society.

## **2.6 Diagnosis in practice: who gets assessed? (diagnosis-as-process)**

One element of the process of diagnosis is the question of who is able to present to the clinic in the first instance, and be available for assessment. Across the world, social factors such as employment conditions, social exclusion, gender inequality, poverty and unequal health systems are at the root of gross inequalities in health (Marmot, 2005; WHO, 2017). Between countries there are huge differences in life expectancy, for example: in Sierra Leone life expectancy at birth is 34, in Japan it is 81.9 (WHO, 2004). Within the USA, there is a 20 year life expectancy gap between the most and least disadvantaged people (Murray et al., 1998). There is a large literature on social inequality in health which space does not permit me to discuss in detail. However, the concept of the 'inverse care law' (Tudor Hart, 1971) is a useful one for considering social demographic factors in diagnosis.

The inverse care law proposes that the availability of effective medical care varies inversely with the need for it in the population served. The inverse care

concept, therefore, suggests that those people who live in socio-economically deprived environments are less likely to be able to access the health provision they require. The inverse care law is reflected in lower levels of resources and provision in such areas and may even influence how clinicians perceive the relationship of the symptoms to the environment. This may lead to a sense that the condition (or the behaviours attached to the condition) is insoluble, as found in the case of depression in an interview study in north-west England (Chew-Graham et al., 2002). One study examining data from the US and Puerto Rico found that lack of access to mental healthcare resources despite evidence of psychopathology, was linked with economic disadvantage (including not being covered by health insurance) and parent psychopathology (Flisher et al., 1997). The authors conclude that access could be improved by better information for parents about accessing mental health services as well enabling access for children and young people independent of their families (Flisher et al., 1997).

Research exploring ADHD diagnosis using a 'pathways to care' model (Goldberg and Huxley, 1980; Huxley, 1996) found that parents were the main 'gatekeepers' to accessing specialist services for their children with ADHD (Sayal et al., 2002). Goldberg and Huxley's model suggests a framework through which patients pass from primary care to access specialist mental health care providers (Goldberg, 1995), with patients traversing four 'filters' in order to access treatment (See Figure 5).

The first of those filters is whether the patient presents at a GP surgery in the first instance. The second filter concerns GP recognition and referral through the pathway, which is reliant both on local resources and clinician expertise. By examining data for children who had passed through filter one and two with those who had not, researchers found that parental perception of the child's behaviour as problematic determined whether they attended primary care in the first instance, providing the most important access barrier (filter 1). Child conduct, however, was important in clinician identification, and GP non-recognition (filter 2) was the main barrier to accessing specialist services (filter 3). (Sayal et al., 2002). This suggests that an interaction of parent, child and GP factors all contribute to the progression (or not) of a child through a pathway to



care for ADHD. There are therefore a number of 'gatekeepers' related to access which can include parents, health and education professionals as well as access to local resources. I will consider socio-economic factors in relation to autism in Section 2.8.3.

Filter 1: The decision to consult (illness behaviour)

Filter 2: GP recognition (ability to detect disorder)

Filter 3: The decision to refer (referral to mental health services)

Filter 4: Admission to psychiatric hospital/services

Figure 5: Goldberg and Huxley's pathways to psychiatric care  
(Goldberg, 1995)

## **2.7 Diagnosis in practice: stigmatisation (consequence of diagnosis)**

The social context of a disorder can shape the way in which individuals labelled with a condition live their lives. This section takes one aspect of this – stigmatisation – and considers it as a consequence of diagnosis. The consequences of diagnosis can be both positive and negative and I consider this in relation to autism in Section 2.8.4. Being seen as someone who is associated with mental ill health is to hold a stigmatised identity, with implications for our relationships, experience of work, education, medical treatment and other fundamental aspects of daily life. Goffman's classic work on stigma suggests that the presence of a stigmatised identity can provoke others ('normal' people) to turn away from the stigmatised individual with the impact that the person feels devalued and rejected. This reaction from others contributes to the 'spoiling' of 'normal' identity (Goffman, 1963).

Whilst responses to stigma vary, possession of this spoiled identity can impact negatively on an individual's behaviour and health. For example, when an individual perceives that their identity is socially devalued or tainted because of their attributes related to a particular stigmatised group, their responses to this identity threat can cause reactions that are both voluntary (e.g. coping

mechanisms) and involuntary (e.g. anxiety, increased vigilance). Individual responses can impact on health, academic achievement and self-esteem (Major and O'Brien, 2005). This complex relationship to one's personal and social identity, therefore, can determine how and whether one seeks diagnosis in the first place; and how one copes with diagnosis of a stigmatised condition if it is given.

Being stigmatised, therefore, contributes to how our identities are shaped and understood, and this impacts both on how clinicians see a condition and the social implications of diagnosis – clinicians do not sit outside society's shared understanding of the world – as well as how individuals, parents and families perceive the value or otherwise of seeking and receiving a diagnosis. What seems personal, located in the body and intimate is actually regulated, shaped and informed by society's creation of the science of psychology and the meaning it brings (Rose, 1999). This impacts on what diagnosis means in different times for different conditions, how we value and devalue these different diagnoses and why we might substitute one for another over time.

## **2.8 The social framing of autism diagnosis**

### ***2.8.1 Introduction***

This section will consider how the sociology of diagnosis framework can be applied to autism diagnosis in particular. As above it will use an organising framework comprising the three rubrics of process, category and consequence. However, as will be seen, these three concepts cannot be separated as each iteratively impact on the others.

Nadesan's (2005) social study on the identification, interpretation and treatment of autism explores how autism as an 'interactive kind' (Hacking, 2000) is produced in relation to historical conditions and interpretative frameworks. Nadesan argues that there was a particular set of historical conditions which enabled the identification of autism in the 1940s. These conditions related to a 'matrix of social institutions and practices' that included increased forms of

social surveillance of children and the emergence of 'childhood' as a research focus resulting from nineteenth century social, political and cultural developments (Nadesan, 2005: 27). Nadesan argues that a particular culturally and historically situated set of understandings have developed from the institutional frameworks of 'knowledge, practice and identities' (Nadesan, 2005, p. 210) as well as the appropriation of and resistance to these identities and dominant discourses, by those who identify as autistic. These include the development of social conditions to enable children to be monitored, identified and labelled, such as mass public schooling and the growth of child psychiatry and psychology. She argues that changes in the built environment might have contributed to what we conceptualise as autism symptoms and that the emerging fields of psychoanalysis and medical models of disease have produced a framework for understanding behaviours which 'render intelligible' autistic symptoms (Nadesan, 2005, p. 184). These emerging fields have enabled the production of a set of knowledges to understand particular behaviours in specific (medicalised) ways.

Drawing from Hacking, she argues that these particular conditions led to the development of a 'niche disorder' (Nadesan, 2005, p. 184) of autism, that is, one that is only possible due to specific historical, economic, cultural and social developments of the time. This enabled the construction of autism as a condition and as a social construct for defining the normal and the pathological. Nadesan argues that this does not negate the possibility that the biomedical conditions that gave rise to autism did not exist prior to this, but that the 'conditions of possibility' (Nadesan, 2005, p. 184) for naming and framing the condition were socially and historically specific to this time. In summary, Nadesan argues that no fixed, conclusive or universal 'truth' about autism as a biological or psychological entity can be located, rather autism is produced through a particular set of historically specific social conditions and practices. Nadesan's work illustrates the interaction of process, category and consequence in diagnosis, not as a linear or static relationship, but one in which active agents, both social and individual, shape and are shaped by the developing conceptualisation of autism.

I will discuss how different understandings of the condition of autism are understood in Chapter Three. However, it is important to mention here the influential and important body of work that is termed ‘critical autism studies’ (see Kapp, 2019; O’Dell et al., 2016; Orsini and Davidson, 2013). A critical approach to what constitutes autism is driven by a neurodiversity movement which aims to develop new analytical frameworks for studying both the nature and culture of autism, to challenge power relations that shape the field of autism and support enabling narratives of autism that challenge existing deficit-focussed constructions (Orsini and Davidson, 2013). These newly emerging activist-focussed definitions of autism are in turn influencing contemporary understandings of the condition.

### ***2.8.2 Autism: Diagnosis-as-category***

In the previous chapter, I discussed the heterogeneous nature of autism symptoms. People who qualify for diagnosis range from those who are severely affected, may have an intellectual disability, and meet DSM (APA, 2013a) specifiers of ‘requiring very substantial support’; to those who require less support and are often diagnosed in adulthood. Aetiology is uncertain and approximately 70% of people who are diagnosed are considered to meet criteria for at least one other psychiatric condition (NICE, 2011). All of these factors problematise the practice of fitting people within a diagnostic box. Importantly, as I have outlined, diagnostic rates for autism have increased greatly and it has been argued that a key contributor to this increase has been a result of the reclassification of autism as a spectrum in DSM-5 (APA, 2013a) and the broadening of diagnostic criteria (Russell et al., 2015; Rutter, 2005). Russell (2014) argues that this reclassification has resulted in the inclusion of less severe cases in the category of autism, thereby increasing diagnostic rates.

Some researchers go further and argue that it is precisely the expansion of the category of autism, without corresponding evidence, that has created a ‘false epidemic’ of autism (Frances, 2010). Others argue that autism as a category is neither scientifically accurate nor clinically useful with its heterogeneity, in particular, having no prognostic value (Timimi and McCabe, 2016a). The category, therefore, is one of ideology rather than science in that the

classification is about how autism is constructed and conceptualised rather than through scientific knowledge (Timimi and McCabe, 2016a). There is also a challenge to the presumed standardisation of tools such as the ADOS, given the interactional nature of the assessment: the assessor cannot help but influence behaviour by the actions they take, or do not take (Timimi and McCabe, 2016b).

### ***Diagnostic substitution***

Shattuck argues that the expansion of the category of autism can be identified in prevalence estimates (Shattuck, 2006). His study of data on the prevalence of disabilities among children in US special schools found that the growing apparent prevalence in autism (from 0.6 to 3.1 per 1000 from 1994 to 2003) increased with corresponding declines in categories for 'mental retardation' (MR) and learning disabilities (LD) (declining by 2.8 and 8.3 per 1000 respectively in the same period) (Shattuck, 2006). Higher autism prevalence was therefore significantly associated with corresponding declines in prevalence of LD and MR. Shattuck argues that this represents a process of 'diagnostic substitution', which can skew prevalence figures (Shattuck, 2006). Other studies have identified that people who are currently diagnosed with autism would, in the past, have been diagnosed with MR, now intellectual disability (ID) (Coo et al., 2008; King and Bearman, 2009). For example, a Canadian study examining special education codes suggested that diagnostic substitution accounted for over a third of the increase in autism diagnosis in British Columbia between 1996 and 2004 (Coo et al., 2008).

One study identified that more than one quarter of those diagnosed with autism in California between 1992 and 2005 would previously have been diagnosed with MR (King and Bearman, 2009). Researchers note that the majority of the increased diagnoses can be seen at the 'tail' ends of the spectrum of autism symptoms – what is considered 'low' and 'high' functioning (Liu et al., 2010a). According to this research, increasing heterogeneity of symptoms and diagnostic expansion to include 'milder' symptoms has increased diagnosis, and at the most severe end the shift has been at the expense of a diagnosis of

MR/ID. At the less severe end of the spectrum, diagnostic symptoms overlap with other learning disorders, leading to diagnostic ambiguity (Liu et al., 2010a).

The change in how we name these conditions does, in itself, tell a story of how social processes interact – including those of social activism – to produce a category label deemed appropriate to contemporary thinking around value, stigma and personhood. It is unacceptable now to talk about ‘retardation’ – indeed, it is generally considered offensive. The assertion of the disability rights movement and other social activist movements to the right to define their own identities has changed both the label and the stigma attached to it and, consequently, the social implications of diagnosis. I consider autism in relation to stigmatisation further in Section 2.8.4.

### ***2.8.3 Autism: Diagnosis-as-process***

#### ***Accessing autism assessment***

There are barriers to accessing healthcare support in autism. For example, parents or families may not perceive their difficulties as problematic or health related (Sayal et al., 2002). It may be that certain groups have poorer access to information about the condition or fewer opportunities to seek diagnosis.

Studies show that children from socially disadvantaged groups are diagnosed later than more socially advantaged groups (Baird et al., 2006). In the US, black children tend to be identified with autism later than white children (Mandell and Palmer, 2005). Alternatively, there may be different perceptions of the stigma attached to the label or perceived necessity for diagnosis, leading to a greater reluctance to enter into the diagnostic process. Popular archetypes attached to the condition of autism (such as it being a male condition, and one linked with particular types of male interests) also shape how families and clinicians may perceive the behaviours of an individual. Such social and demographic factors, therefore, may wield an influence at every stage of diagnosis.

Prior to diagnosis, therefore, social factors can determine who comes forward for diagnosis and who is referred for further assessment. In autism, Russell and colleagues (2011) explored social and demographic factors that may provide

barriers to assessment. The authors outline how identifying differences between access barriers (socially determined factors) and risk factors, which may predispose individuals to develop a condition, is necessary to understand access barriers. Working with a longitudinal UK cohort study, therefore, the authors differentiated children with a diagnosis, from those who had clinical traits at diagnostic level, but had not been formally diagnosed. Russell and colleagues found that, with the severity of autistic traits held constant, younger mothers and mothers of first-born children were significantly less likely to have children diagnosed with autism (Russell et al., 2011). This may be due to older mothers being better at identifying their child's difficulties. Lack of diagnosis was linked with maternal depression, which may mean that a depressed mother is unable to seek help for their child, or that a GP attributes her concerns to depression (Russell et al., 2011). Young motherhood and depression in motherhood may, therefore, be access barriers to seeking support for a child with difficulties. In other conditions, similar social factors can be observed, for example, a study examining late stage diagnosis of breast and cervical cancer found that age, class and cultural background were factors in late stage diagnosis (Mandelblatt et al., 1991).

Finally Russell et al's (2011) study found that boys were more likely to receive a diagnosis than girls (Russell et al., 2011). Whilst it is generally understood that more boys are considered autistic than girls (Rutter, 2005), with severity of autistic traits held constant, Russell and colleagues found that there is an additional bias towards male identification. This study suggests that social as well as biological factors can influence whether children are brought to the clinic (Russell et al., 2011).

### ***Socio-demographic factors and autism***

There is a strong positive association between socioeconomic status (SES) and autism diagnosis in the US, with higher SES and parental education linked to increased likelihood of diagnosis (King and Bearman, 2011; Liu et al., 2010a). However, it has been shown that in the UK and in Denmark, the reverse is found, with lower SES associated with increased diagnosis (Russell et al., 2014). This may be related to different health systems: in the US where health

insurance is required to access services, there may be a barrier to access for poorer families, but wealthier parents have resources and the education to pursue an assessment. In the UK where healthcare is free at the point of entry, poorer families can access services when required. A French study also found that autism with ID is more likely to be diagnosed in areas of high levels of deprivation (Delobel-Ayoub et al., 2015). These contrary findings suggest both cultural and economic differences in the social framework for autism diagnosis.

King and Bearman explored why autism prevalence is uneven across different communities by looking at socially salient community characteristics (King and Bearman, 2011). Working with California birth cohorts from 1992 through to 2000, they found that communities have different effects on different individuals at different times in relation to levels of diagnosis (King and Bearman, 2011). Importantly, they found that higher levels of education and SES were consistently linked with higher levels of diagnosis, reasoning that this is driven by knowledge or information diffusion in wealthier and highly educated communities (King and Bearman, 2011).

A further study on California data found that there was a strong link between clusters of diagnosed children and the availability of diagnostic resources, measured as SES (as a proxy for good local resources and health related information), paediatrician density, government spending and advocacy organisation density (Mazumdar et al., 2013). This included the finding that children moving into a neighbourhood with more diagnostic resources than their previous neighbourhood were then more likely to receive a diagnosis than children whose neighbourhood does not change (Mazumdar et al., 2013). These findings highlight the important role of resources in autism diagnosis, demonstrating that diagnostic resources in a neighbourhood have an independent effect on autism incidence, although the study does not reject outright the potential role of toxicants, for example, in additionally driving prevalence (Mazumdar et al., 2013). Furthermore, it might also be argued that knowledge obtained via social clustering may enable a parent who desires diagnosis for their child to prepare an 'expert' case in how their child fits the diagnostic criteria, which might influence diagnosis. In this case, the ability to



'perform' the condition, which has no biomarkers, could be a significant factor in the diagnostic decision.

### ***Awareness of autism, access to resources and information diffusion***

Leonard and colleagues (2010) reviewed a number of socio-cultural factors – related to infrastructure, relationships, local services and socioeconomic disparities – which are linked with autism diagnosis. The authors suggest that increased awareness of autism has led to shorter pathways and diagnosis at a younger age (Prior, 2003; Wing and Potter, 2002). Other studies have shown that rates of diagnosis are linked with the number of paediatricians in a geographical area in both the US (Mandell and Palmer, 2005) and the UK (Howlin and Asgharian, 1999) although this may also be related to socio-economic factors (local resources).

Diagnosis of autism in children can lead to access to services and funding which may not be available to children with other types of disabilities, including intellectual disabilities (Caronna, 2003). In some countries or regions, for example, some US states, access to support is dependent on diagnosis (Barbarese et al., 2005; Leonard et al., 2010; Ruble et al., 2005). One study from Australia showed that, in borderline cases, clinicians may 'upgrade' to a diagnosis of autism if they believed it would enable access to appropriate support (Skellern et al., 2005) (See Section 2.8.4).

Liu and colleagues (2010a) identified that geographical proximity to others with a diagnosis can increase diagnosis rates through 'information diffusion'. The authors used a longitudinal data set from California and examined geographical information of children between the ages of two and six over five years from 2000 to 2005. They then matched this with data of every child diagnosed with autism over that period to examine whether proximity to a child with autism affected the likelihood of being subsequently diagnosed with autism (Liu et al., 2010a). The researchers ruled out other possible factors such as toxicants in the local environment, virus diffusion and the results being a by-product of neighbourhood selection i.e. parents choosing to live in a particular area who have a child with a greater risk of autism. Liu and colleagues concluded that the

availability of knowledgeable parents – because they had a child with a diagnosis – created ‘clusters’ of diagnosed children through information about autism flowing through interpersonal networks. Parents require both the resources to seek diagnosis, and the knowledge in how to deploy these resources, and this becomes available through social proximity. This was found to be the case particularly in younger children, where parental resources are more important, and in ‘high-functioning’ cases, where a parent might not pursue a diagnosis without a knowledge base provided by other parents. Notably, it was found that children who were diagnosed with autism had a similar mode of referral to their nearest neighbour with autism (Liu et al., 2010a).

The evidence of ‘clusters’ of diagnosed children, (King and Bearman, 2011; Liu et al., 2010a; Mazumdar et al., 2013) therefore, highlights the role of social influence and resources in diagnosis. Health professionals use standard diagnostic criteria, but the numbers of those diagnosed are dependent on whether a parent brings a child to the clinic and whether that parent has the resources, desire and knowledge to pursue a diagnosis when meeting barriers or disputes, as well as whether there are local diagnostic resources. This might also provide a mechanism to support families when the diagnostic process becomes difficult or lengthy. Liu and colleagues note that most accounts of the diagnostic process suggest that it can be very difficult to obtain a diagnosis, which may be an access barrier, although this might be, in part, accounted for by selection bias, as those with straightforward accounts of the process might be less inclined to tell them (Liu et al., 2010a).

### ***During assessment***

Once an individual has reached the clinic, diagnosis of autism (as well as other conditions) is dependent upon interaction between patients, families and clinicians, as well as between clinicians themselves, and between clinicians and other professionals. What is particular to autism, however, is that assessment is based on observation of behaviours and patient and family reporting of behaviours outside the clinic. Diagnostic activity in autism assessment, therefore, is dependent on interaction (between the clinician and the

patient/parent); on context (the site of behaviour shapes its interpretation); and on clinicians working together to consider and make collaborative judgements about their interpretations of behaviours and reported behaviours.

The diagnosis of autism, therefore, is open to shaping by social, environmental and psychological factors and is the result of the interaction of a number of actors involving clinical interpretation and interaction as well as patient presentation and interaction, both of which are time and setting sensitive. I explore the specific interaction of diagnostic decision-making in teams in Chapter Four. However, here I introduce the concept of diagnosis as process by exploring an important body of work undertaken by Maynard and Turowetz, which examines interaction at several stages of autism assessment. Whilst there has been a significant amount of research exploring interaction between doctors and patients, including diagnostic delivery (for example, Heritage and Maynard, 2006; Peräkylä, 1997), there has been little examination of the way in which clinicians accomplish autism diagnosis through talking about their patients together. One exception to this gap in research is an influential body of empirical work undertaken by Maynard and Turowetz (Maynard and Turowetz, 2019, 2017; Turowetz, 2015a, 2015b; Turowetz and Maynard, 2019, 2017, 2016).

### ***Maynard and Turowetz and the diagnostic process***

Maynard and Turowetz have undertaken extensive conversation-analytic studies of observations of autism assessments of children over two time spans (1984-5 and 2011-15) in the US. These studies include analysis of autism assessments during facilitation of the ADOS; during 'pre-staffing' meetings which take place without the patient/family present and are most akin to specialist assessment team meetings in the UK, the subject of this PhD study; and during 'staffing' meetings, where clinicians present findings to caregivers (Maynard and Turowetz, 2019, 2017; Turowetz, 2015a, 2015b; Turowetz and Maynard, 2019, 2017, 2016). Their detailed analysis of the diagnostic process for autism in children considers how clinicians 'assemble' a diagnosis, constituting the facts of a case, and ultimately build a narrative which supports a diagnostic decision or otherwise. They demonstrate how diagnostic stories are

methodically produced through interaction between clinicians and between the child and clinicians. I outline some of Maynard and Turowetz' findings here, although I attend to other aspects of their work throughout this thesis, particularly in Chapter Four in relation to the construction of diagnostic narratives. Important to this thesis is the concept that the very process of diagnosis itself, and how clinicians interact to make diagnosis happen, impacts not only on diagnosis as an outcome, but on the creation of autism as a condition.

Turowetz followed the case of one child, Tony, aged ten, through assessment, case discussion and delivery of diagnosis, to track how a narrative about Tony's mental functioning developed interactionally through the assessment process to materialise as a clinical fact at the point of diagnostic delivery to parents (Turowetz, 2015a). Turowetz claimed that clinicians identify and select diagnostically salient (story-worthy) symptoms to recount to colleagues who will, together, build consensus around their importance to a potential diagnosis. Clinicians orient to story-worthy events, therefore, to create diagnostic consensus.

Turowetz draws parallels with Gibson's (2011) analysis of deliberations between politicians about how to respond to the Cuban Missile Crisis, suggesting that in both cases participants use storytelling to formulate a problem, consider and evaluate different interpretations, steer discussions down a particular path and finally come to consensus. Through exploring the interpretation of Tony's understanding of a picture of a cup, Turowetz examined how interpretations of Tony's ambiguous actions were revised and developed, and served to emphasise certain (abstract) interpretive frames over others (concrete). Ultimately Turowetz claimed that story-telling through interaction is a mechanism by which local situated events (behaviours in assessment) are transferred into a warrantable diagnostic conclusion – as a clinical event or fact (Turowetz, 2015b).

Drawing on the same dataset, Turowetz argued that while behaviour in assessments is 'interactionally-occasioned', clinicians cite practices in such a

way that the assessing clinician is presented as a neutral facilitator and diagnostic tools as largely passive recording measures (Turowetz, 2015b). Whilst focussing on the actions of the child fits with the institutional objectives of the clinic (Drew and Heritage, 1992), muting or minimising the influence of other actants present in assessment (clinician and clinical tools) renders the child solely responsible for behaviour, individualising his or her symptoms. This is particularly relevant in a condition which is assessed primarily by observing behaviour, as it serves to interpret the presence of symptoms as embedded within the child rather than as an interaction between child and environment (Turowetz, 2015b). Furthermore it can be argued that the act of being social is dependent upon the 'interactional ecology' of the situation – the nature of the specific kind of social interaction taking place rather than an essentialist embodied quality of the individual (Solomon, 2015). Behaviours are contextual, social and interactional.

Turowetz argues that the foregrounding of clinically relevant behaviour is done through citing conduct via reported speech and persistence markers which allows clinicians to incrementally build a diagnostic case. Clinicians quote the speech of the child being assessed which then vividly demonstrates (rather than just reports) a particular action, reinforcing an emerging diagnosis of autism. Persistence markers (such as 'always', 'still', 'a lot') mark behaviour as persistent, pervasive and stable (Turowetz, 2015b).

Turowetz' work is extended in partnership with Maynard with further studies related to interaction in autism assessment (Maynard and Turowetz, 2017; Turowetz and Maynard, 2017, 2016). They argue that clinicians use a device called 'category attribution' which provides a narrative about the child presenting for assessment alongside a claim about members of a category - children with autism or typically developing children (Turowetz and Maynard, 2016). These category attributions have a moral dimension because they assess discrepancies between where the child is and where they 'ought' to be. They reflect normative expectations of child development and therefore a child is considered typical or atypical in respect of social and clinical norms. This categorisation has to be robust enough for a convincing argument to be

delivered to parents and translates general understandings of child development to specific claims about particular children (Turowetz and Maynard, 2016). Ultimately the authors argue that, as symptoms never fit perfectly into one diagnostic category, the process of category attribution 'bridges the gap' between the diagnostic category and the individual child (Turowetz and Maynard, 2016).

To summarise this body of work, the researchers have identified that clinicians' practices do not simply organise and document symptoms, but play an active part in fitting symptoms within diagnostic categories (Turowetz and Maynard, 2017). Strategies such as foregrounding clinically relevant behaviour, building a case from story-worthy events, presenting the clinician as neutral facilitator and presenting the child as solely responsible for behaviour, enable clinicians to construct a warrantable case for diagnosis.

### ***Empirical studies in interaction in autism diagnosis***

Other than this extensive work by Turowetz and Maynard, I identified several further studies examining interaction in autism diagnosis. One study observed triage assessments in CAMHS in the UK to examine how parents build a case for diagnosis (O'Reilly et al., 2017). O'Reilly and colleagues examined the interaction between parents and clinicians in this initial assessment and found that parents generally raised the possibility of autism first, before the clinician, in a manner that served to build a case for autism (O'Reilly et al., 2017). The speculative presentation by the parent of what is termed a 'candidate diagnosis', suggests that the parent is seeking confirmation of their assessment whilst both respecting the expertise of the doctor and raising the diagnosis as a possibility (Stivers, 2002). Clinicians are then positioned to either refute or agree with the parental assessment. The authors demonstrate how distinctive patterns of social interaction shape the diagnostic process and illustrate the role of the invested, well-informed and experienced parent in diagnosis (O'Reilly et al., 2017). Here the non-linear (though interactionally patterned) nature of diagnosis is demonstrated.

One further study observed meetings of two multi-disciplinary autism assessment teams in the UK where children who had recently been assessed for autism were discussed (Parish, 2019). The study found that clinicians presented information in an uncertain manner, interjected in a discussion to present relevant information, and indicated the noteworthiness of information through their response (Parish, 2019). These interactional strategies enabled clinicians to discuss different candidate suggestions for diagnosis and elicit information as required. Parish argues that the multi-disciplinary context, therefore, can help to reduce cognitive bias which might be more likely with a clinician working alone (Parish, 2019). However, other research demonstrates that the assessment team can foreground diagnostically relevant behaviours whilst discounting those that do not fit (Turowetz and Maynard, 2017), thereby challenging this finding. Nevertheless, Parish's work contributes to a body of work which examines how clinician interaction can shape diagnostic decision-making.

Hollin and Pilnick (2018) studied assessment of young adults (late teens to mid-twenties) who had already been diagnosed with autism. In ADOS assessment sessions facilitated by ADOS-trained researchers, Hollin and Pilnick demonstrated how judgements are made about which kinds of behaviour are consequential for diagnosis. Whilst the authors are cautious about generalising their findings due to the particular settings of the assessments (as a research project involving people who were already diagnosed) they were able to conclude that the interpretation of behaviour in ADOS sessions can be challenging. Hollin and Pilnick examined whether resistance on the part of the patient would be interpreted as a diagnostic indicator or as an appropriate choice from a number of possibilities (Hollin and Pilnick, 2018). The researchers found that some forms of resistance, for example, resisting a particular task as inappropriate, were deemed acceptable; whereas other forms of resistance, for example, resistance to a particular line of conversation, were considered a diagnostic indicator of autism. The study demonstrated both how clinicians continually make judgements about which kinds of behaviour are consequential for diagnosis, as well as identifying the significant level of interpretation of

behaviours required to identify and separate these kinds of behaviours with consistency (Hollin and Pilnick, 2018).

Muskett and colleagues also explored the interpretation of one symptom of autism, inflexibility, by observing play between an adult and an eight-year-old diagnosed child (Muskett et al., 2010). They concluded that this behaviour, rather than a direct reflection of an underlying deficit, was the product of a child's attempts to gain control over the situation. Muskett et al (2010) argue that the adult (assessor) initiated actions which triggered inflexible behaviour, thereby leading to the allocation of certain behaviours as residing within the child, when in reality they were interactionally-produced. One further study examined interaction in the ADOS and found that the way in which clinicians formulated questions for the child being assessed, either created difficulty for the child or facilitated the production of a 'valid response' (Stickle et al., 2017).

Finally, Rossi, in her ethnographic study of an autism assessment clinic in the US, found that all but two children undergoing assessment over the course of fourteen months received a diagnosis of autism (Rossi, 2012). Rossi argues that we need to have an institutional understanding of diagnosis, with examination of how a network of agencies and organisations eventually lead to the diagnostic label. The diagnosis of autism is a product of the institutional matrix within which it is embedded: the institutional routines of the clinic favour one outcome over another and therefore contribute to the 'epidemic'. Rossi argues that diagnosis is achieved through 'translation' – a parent/clinician interaction that enables the clinician to shift narratives to align with parent responses; and the calibration of diagnostic tools can modify the diagnostic process and category (Rossi, 2012).

This section has briefly considered some interactional practices in the process of diagnosis. I extend this examination of the process of diagnosis in Chapter Four where I examine narrative and uncertainty in diagnostic decision-making.



## **2.8.4 Autism: Consequence of diagnosis**

### ***Benefits of diagnosis***

Clinical guidelines suggest that diagnosis of autism can offer a number of helpful consequences for the individual and for families. In diagnosis of children and young people, it is considered that autism diagnosis can offer families a framework for understanding their child and an opportunity to make informed decisions about interventions and management strategies (National Collaborating Centre for Women's and Children's Health, 2011). Furthermore, diagnosis can be a relief for a young person, and enable access to resources and support, emotional benefits, appropriate support from education, healthcare and social care services and recognition of existing conditions (National Collaborating Centre for Women's and Children's Health, 2011). Early recognition is considered important for accessing targeted treatments and appropriate support services, and improving outcomes by 'maximising opportunities for skills development and adaptive learning, and reduce the risk of abnormal non-adaptive behaviours becoming entrenched and the development of secondary behavioural problems' (National Collaborating Centre for Women's and Children's Health, 2011, p. 67).

For adults, the benefits may be less clear given the apparently lost opportunity for impacting on developmental changes, therefore, treatment interventions are unlikely to be recommended. Clinical guidelines, however, suggest that a number of interventions (such as access to leisure programmes or supported employment) might offer improved quality of life in diagnosed adults (National Collaborating Centre for Mental Health, 2012). NICE (2012) also recommends that diagnosis should trigger an assessment for social care services. Additionally, research suggests that it can be a relief for those diagnosed to be able to meet other autistic people in support groups, for example (National Collaborating Centre for Mental Health, 2012). However, interviews and surveys with autistic adults, parents and professionals have found a dissatisfaction with the quality and availability of post-diagnostic support (Crane et al., 2018, 2016; Jones et al., 2014; Rogers et al., 2016).

I have explored earlier in this chapter how Hacking (2006b) and Nadesan (2005) consider that individuals may be transformed by their diagnostic categorisation. Those diagnosed become a 'moving target' (Hacking, 2007): a person for whom the diagnostic label changes through their interaction, with the result that they become a different 'type' of person, a process Hacking calls 'making up people' (Hacking, 2007, 2006b). I discuss this further in Chapter Three. Several empirical studies have considered the consequences of an autism diagnosis.

### ***Identity and legitimisation as a consequence of diagnosis***

One survey of 'high-functioning' autistic adults found that a majority (71.9%) experienced relief on receiving a diagnosis, suggesting that the diagnosis may provide an understanding of their life experiences to date and offer a way to reframe their understanding of their own behaviour (Jones et al., 2014). However, a significant proportion also felt angry (12.5%), upset (17.2%), anxious (25%) or confused (24.2%) and unsure about the future given the lack of formal support, post-diagnosis (Jones et al., 2014). Another study found that diagnosis can act as a 'sense-making narrative' (Molloy and Vasil, 2004). One study, utilising a focus group and interview design, found that diagnosis provided a way for individuals to obtain an explanation for their previous experiences, including exonerating them from blame. Diagnosis enabled access to support and services, and the opportunity to meet others with a diagnosis enabled them to find a place to 'fit' (Punshon et al., 2009). Punshon and colleagues (2009, p. 265) liken this to having a 'not guilty verdict'. Here diagnosis provides both legitimization and potential allocation of resources.

Diagnosis can represent pride in an identity of difference, an explanation for difficulties experienced over many years, or a route to support and validation (Crane et al., 2018). An acknowledgment of the 'autistic advantage' such as hyperfocus, attention to detail, good memory, and creativity as experienced by autistic adults (Russell et al., 2019a), can be applied to foster a positive self-identity (Hurlbutt and Chalmers, 2002; Russell et al., 2019a).

It should be emphasised that some of the above studies (e.g. Jones et al., 2014; Molloy and Vasil, 2004; Punshon et al., 2009) were conducted with people diagnosed with Asperger's Syndrome (AS) or 'high-functioning' adults. Russell and colleagues found a selection bias against inclusion of participants with an intellectual disability (ID) across all fields of autism research (Russell et al., 2019b), thereby suggesting that the views of more severely impacted autistic people do not adequately inform our understanding of the impact or experience of diagnosis of autism.

Molloy and Vasil (2004) acknowledge that their survey participants, who had received a DSM-IV diagnosis of AS, may have felt differently, and perhaps more negatively, if they had received a DSM-5 diagnosis of ASD. The type of label can affect the initial impact of the diagnosis and, potentially, an individual's future relationship with an autistic identity. For example, in advance of changes to DSM-IV, Singh conducted an interview survey of adults diagnosed with AS (Singh, 2011). In DSM-5, autism was re-conceptualised as a 'spectrum' disorder with the consequent disappearance of the classification of AS. Singh (2011) found that the potential consequences of this disappearing diagnostic category threatened the identity of those with the diagnosis or those self-identifying with AS. The majority of her participants distinguished themselves from the broader category of autism, as people who were 'verbal, smart and 'high-functioning' (Singh, 2011, p. 253). Participants expressed concern that there would be implications to their sense of identity, particularly in relation to having a label (autism) they considered to be more stigmatised than AS.

### ***Resource access as a consequence of diagnosis***

Service provision, in the form of support in school or work, treatment options, signposting or support groups, has been found to diminish dramatically as individuals grow past adolescence (Howlin, 2008). The likelihood of helpful, practical outcomes after autism diagnosis, therefore, is questionable for adults receiving a diagnosis. Both Howlin's (2008) study and Russell et al's (2012) study outlined above, suggest that the perception that individuals and families might have hopeful outcomes after diagnosis is one that may encourage the pursuit of diagnosis but, in reality, offers less than having the label might

suggest. For example, Russell and colleagues' (2012b) study examined a longitudinal birth cohort study based in South West England, and found no difference in the development of prosocial (as opposed to antisocial) behaviours in children who were diagnosed and those who were not. These findings suggest that social behaviours are not impacted adversely or otherwise by diagnosis (Russell et al., 2012b). This study examines one aspect of a consequence of diagnosis – social behaviours – and suggests that post-diagnostic treatment is not effective in improving prosocial skills, thereby questioning the promise of effective treatment as a result of diagnosis (Russell et al., 2012b).

One study found that parents were able to access a range of resources after diagnosis, including educational, social, and health resources, and access to information and financial support (Russell and Norwich, 2012). In this interview study, parents were positive about the resources and opportunities an autism diagnosis for their child would offer, while still weighing up the balance of these benefits against the stigma that their child might experience with the diagnostic label (Russell and Norwich, 2012). Benefits for parents included a way to come to terms with their child's behaviour and understand it, as well as being able to draw on a biomedical understanding of autism which served to alleviate blame (Russell and Norwich, 2012).

A survey study examining Queensland-based paediatrician and child psychiatrist decision-making, found that clinicians may diagnose when uncertain – for pragmatic reasons – to secure best outcomes for the child (Skellern et al., 2005). Of a total of 105 respondents, 58% indicated that they had exaggerated (or upgraded) a child's symptoms in order to enable access to additional educational resources; and 36% to allow access to a carer's allowance when the diagnostic process had not met requirements to do so (Skellern et al., 2005). The authors argue that clinicians therefore use diagnosis as a strategy to enable appropriate support for patients and families, in a system which demands categorical diagnoses despite the complexities of diagnosing within a 'spectrum'. In the UK, an online survey of 116 healthcare professionals involved in autism assessment found that 67% of respondents acknowledged that they

had 'upgraded' a diagnosis to autism when faced with unclear presentation or patients failing to meet criteria on diagnostic tools (Rogers et al., 2016). This was attributed to a combination of factors: enabling access to support, differing opinions within the diagnostic team or pressure to meet targets (1%). 32% of respondents reported that they would never upgrade. These practices challenge both the consistency and efficacy of diagnostic labels. Skellern et al (2005) argue that provision of services would be better measured by functional need rather than diagnostic label.

These survey studies rely on clinicians' interpretation and reporting of questions which may differ across individuals and services. However, the results present a potential challenge to the category of autism in that individuals may be diagnosed with the condition due to pragmatic or functional reasons rather than strict diagnostic classification. The studies offer a useful perspective on the potential consequences of diagnosis, in this case positive, at least in the short-term, as the diagnosis provides access to services. Rogers et al's (2016) and Skellern et al's (2005) studies also offer insight into the process of diagnosis, in that it demonstrates how diagnosis is embedded in disciplinary practices within which there resides a set of beliefs around the function of diagnosis which, in turn, affects the category.

### ***Autism and stigma reversal***

At the same time as the diagnosis of autism has expanded, stigma around autism in the US has decreased, whilst stigma related to MR has increased (Liu et al., 2010a). Liu et al (2010a) attribute this to a reclassification of autism from an emotional to a developmental disability, informed by the shift away from the idea of autism being caused by inadequate parenting, a highly stigmatising position, as first suggested by Kanner and later promoted by Bettelheim (1967). De-stigmatisation of autism may also be related to increased resources being attached to autism research alongside the expansion of advocacy through activist groups. Additionally, because of de-stigmatisation, more people are likely to be seeking diagnosis which would contribute to a feedback effect (Hacking, 1995) and further drive de-stigmatisation. Parents of autistic children also perceive that talking about autism publicly reduces its potential stigma,

thereby further contributing to a social model by which autistic people and parents seek to destigmatise the condition (Russell and Norwich, 2012). This process of advocacy serves to reframe the condition within a different narrative which might better serve their children (Russell and Norwich, 2012).

Some research has shown that, for parents, the attachment of a label of autism to their child can reduce the way in which parents experience stigma when their child has been diagnosed, as it enables parents to resist stigmatisation by applying their medical knowledge to perform their family identity as one which is unspoiled *and* autistic (Farrugia, 2009). This assertion, however, rests on the continued categorisation of the child as 'other' – not normal – whilst attempting to locate the family identity as a different kind of 'normal' (Farrugia, 2009). The tensions inherent in these conflicting identity positions are likely to impact on the whole family and may, indeed, contribute to highlighting or categorising behaviours as deviant or 'autistic' when they might otherwise have been considered normal or 'lively', 'different', 'eccentric' or similar. The diagnosis itself is not neutral – in this case, the label provides a coping strategy for families at the same time as creating a medicalised category for the child, with lifelong implications for understanding that child's development, and for that child's own understanding of his/her social and personal identity. The social framing of diagnosis, therefore, shapes the condition as the condition is shaped by diagnostic criteria.

Different diagnostic labels are associated with different levels of stigma and this can also differ in different geographical or cultural contexts. In Silicon Valley, for example, autism is increasingly less stigmatised as employers recognise the particular skills in technological innovation that autistic people bring to the workplace (Grinker, 2015). In contrast, children with autism in Kenya are so stigmatised that children are hidden or abused (Grinker, 2007). The experience of stigma, therefore, is not universal or static.

## 2.9 Concluding comments

Increasingly, our ailments and difficulties are understood as medical, including all kinds of mental health conditions such as depression, personality disorder and schizophrenia, as well as what Blaxter termed 'social' diseases such as alcoholism, obesity and hypertension (Blaxter, 1978). Whilst this offers an avenue for potential treatment and resources, this chapter has shown how diagnosis, in particular autism diagnosis, is a thoroughly social process. The focus on the medical shifts attention away from the social. In an attempt to alleviate symptoms, it is possible to overlook how disease categories come about. In a practical sense, a focus on the medical can detract from important social issues that impact on health. These include, for example, alleviation of poverty, investment in education, improvements in housing and employment opportunities as well as generally challenging systems and structures that fail to deal with social issues that undermine individual attempts to keep healthy. Focussing on the medical may also obscure the social decision-making mechanisms concerned with how we categorise disease, who decides and how, and what the consequences are for people who are diagnosed.

This chapter has outlined the challenge to a medical model of diagnosis and offered some examples of empirical studies which support a social perspective. It has also begun to provide a background as to how autism can be viewed as an entity that can be socially framed. The next chapter will consider the social framing of autism diagnosis further by looking at how the concept of medicalisation and social notions of normality shape how we see autism now, and how this has developed historically.





## **CHAPTER THREE: The Construction of Autism**

*Every era imposes its own normative values on the human body, and contemporary Western medicine takes biology as the cause, and behaviours as the emerging effect.*

Annemarie Jutel, 2019



### **3.1 Introduction and overview of chapter**

This chapter extends the argument in Chapter Two by exploring further the construction of autism as a category. I consider how society separates the 'normal' from the pathological in the context of medicalisation, technological advances and how this conception changes over time. Although I draw from a range of conditions, my focus is particularly framed within concepts of acceptable human behaviour in relation to psychological, behavioural or neurological conditions. This is partly because this is the framework within which autism is located. Additionally, it could be argued that considering psychological, behavioural or neurological conditions forces attendance to issues different from (some) physical illness, related, for example, to aetiology and how society deals with entities that are beyond our understanding.

### **3.2 Defining normal**

According to standard diagnostic classification, we either suffer from mental illness or we do not: we are either ill or not, sane or insane, normal or abnormal, ordered or disordered. However, this has been challenged. Bentall, for example, suggests that mental illness is arbitrary rather than scientific and that psychiatric illness should be seen as part of human variation in behaviours, rather than as a disease or disorder (Bentall, 2003). In forwarding this argument, Bentall proposes, contrary to medical classification systems, that the boundaries between mental ill health and wellness are indistinct and permeable, and that normal and abnormal symptoms reside on a continuum which he describes as a 'principle of continuity' (Bentall, 2003, p. 115). Bentall's argument proposes that the division between symptoms and behaviours related to psychiatric illness only differ from what is currently considered 'normal' behaviour and experiences, by frequency, severity and phenomenology. He argues that comparable experiences and behaviours can be identified in non-clinical populations as part of everyday normal life (Bentall, 2003).

This challenge to the medical model of madness sits within a long history of debate around the meaning and existence of mental illness. The controversial 'anti-psychiatry' movement, associated with R.D. Laing (1970) is only one movement in the challenge to psychiatric diagnosis. Laing argued that mental illness, rather than being medical, was meaningful and caused by oppressive family systems (Bentall, 2003). Szasz, whilst denying an anti-psychiatry alignment with Laing (Szasz, 1960) proposed that mental illness is a 'myth' as no underlying pathology can be found. Bentall rejects this stance, however, but argues that our current understandings of mental illness are flawed (Bentall, 2003). Bentall advocates for an understanding of mental illness based on the idea that 'abnormal behaviours and experiences exist on a continuum with normal behaviours and experiences' (Bentall, 2003, p. 155). Bentall also suggests that whether someone is 'mad' or 'sane' depends on the perspective taken. Bentall illustrates his 'principle of continuum' and idea of perspective by examining the differences in understandings of mental illness across cultures and geographies. For example, black British people of African Caribbean origin are more likely to be diagnosed with schizophrenia, or be admitted to psychiatric hospital, than the British white population. But studies in the Caribbean show lower incidence rates than in the UK. There is no evidence that demonstrates any underlying sensitivity to madness in this group (Bentall, 2003). It is likely, therefore, that there are environmental determinants of madness (or different cultural understandings of madness) which challenge the concept of the existence of underlying biological or medical determinants alone. Bentall's research underpins the argument that, at the very least, psychiatric symptoms should be viewed from multiple perspectives, as no one framework provides a sufficient explanation (Bentall, 2003).

Other theorists and practitioners propose a pragmatic approach to supporting individuals through mental distress. As I discussed in Chapter Two, Rose (2013) argues that research and treatment should be rooted in the needs of each individual and the support they require as opposed to arbitrary diagnostic categories. Bentall's pragmatic conclusion to the challenge of the medical model is that distress should be the defining criteria in seeking and bestowing both diagnosis and treatment (Bentall, 2003). More specifically, researchers and

clinicians have developed conceptual alternatives to psychiatric classification. Johnstone and colleagues (2018) propose an alternative perspective conceptualised as the 'Power, Threat, Meaning (PTM) Framework'. This framework focusses on people's lived experiences and social, material and cultural contexts which the authors believe have been marginalised in current theoretical frameworks which inform psychiatric classification and diagnosis. The framework proposes a radical non-diagnostic system which aims to 're-integrate many behaviours and reactions currently diagnosed as symptoms of mental disorder back into the range of universal human experience' (Johnstone et al., 2018). Rose (2013), Johnstone et al (2018) and Bentall's (2003) conclusions, therefore, appear, to varying degrees, to be attempts to erase artificial boundaries between conditions, whilst acknowledging that people in mental distress require specific support and treatment. Considering mental distress as part of normal human functioning, therefore, may be a way to reconsider diagnosis in practice. But does this relate to autism too?

### ***3.2.1 Autism and normality***

Autism Spectrum Disorder is classified in DSM-5 (APA, 2013a) as a neurodevelopmental disorder, located within a categorisation system for 'mental disorders'. Although there is an argument about whether a neurodevelopmental disorder should be classified as a mental disorder at all, it can be argued that, as with other 'mental disorders', its existence as non-arbitrary and self-contained can be challenged. This is illustrated by the shifting definitions of behavioural criteria and resulting classifications that determine its existence that I outlined in Chapter One.

Bentall argues that the line between normal and abnormal is socially constructed. This may apply to autism, where symptoms are behavioural, broad and wide ranging and extend into what is considered a sub-clinical or 'normal' range of behaviours distributed as a continuum extending into the general population (Constantino, 2011; Constantino and Charman, 2016; Russell et al., 2012a, 2010a). Diagnosis demands a threshold and therefore a 'cut-off' between those who are autistic and those who are not. Russell argues that where we choose to draw the line for diagnosis of autism has changed, is

historically and culturally determined and is a reflection of values prominent in society at the time (Russell, 2014). This phenomenon can be witnessed in the historical changes in classifications from childhood schizophrenia to pervasive developmental disorder, for example (See Chapter One).

One study examining online discussion forums examined the apparent 'natural' trajectory of child development and how children with particular behaviours are produced as deficient and 'abnormal' (O'Dell and Brownlow, 2015). O'Dell and Brownlow (2015) argue that dominant discourses of normal child development limit the ability of autistic people to create positive self-identities. Focus groups with professionals, parents and autistic people demonstrated how the boundaries between 'normal' and 'autistic' are fluid and negotiated (Lester et al., 2014). The negotiation incorporates whether autism is considered a disability (in which case constructed as abnormal) or an 'ability'. This rhetoric was further 'couched within a repertoire of severity, by which participants negotiated different meanings of normality/abnormality against the benchmark of the severity of the condition' (Lester et al., 2014, p. 149). The authors suggest that different positions and differences *within* the condition, therefore, may be central to the perceptions of normality or abnormality in autism (Lester et al., 2014). The authors argue that without a singular understanding of what autism is, negotiating these boundaries is problematic. Both studies challenge the clinical discourse within constructions of autism and normality.

Culturally determined understandings of how to behave shape all our interactions. Societies have social expectations – to smile in the right place and at the right time, to greet people in particular ways and to interact in a way that seems appropriate to the setting. When individuals do not conform to these norms of behaviour, it may not in itself cause distress, but society's expectations of normal behaviour might impact on the individual in ways that are practical (e.g. failing a job interview) as well as emotional (e.g. feeling pressure to conform). It may cause no distress to the individual to be non-verbal; but in a society that values verbal communication above all others, it is likely that before long, an individual who does not speak is made to feel of less value than those who do, or even feel a challenge to personhood itself (Baggs,

2007). Mental distress in social contexts, therefore, may be to do with an individual's ability to relate and function in a world that does not accept social difference. Whether underlying biological differences exist or not, one solution to mental distress, therefore, is for society to better accept different kinds of social behaviour thereby lessening the difficulties individuals may have in functioning in a social world.

### ***Normality, autism and DSM revisions***

Sweet and Decoteau analysed debates around revisions to DSM-IV and argue that a definition of normal depends on the condition being discussed, and therefore our rules for normality can shift and contradict each other (Sweet and Decoteau, 2018). They argue that there exists 'lumpiness and inconsistencies in biomedicalisation and in the neo-liberal mandate to self-optimize' (Sweet and Decoteau, 2018, p. 115). In other words, in a society which values the free market state and focuses on individualisation, we shape normality around what benefits society best. The researchers take the conditions of autism and of depression to illustrate this. They argue that the category of autism was defended in debates around DSM revisions, as normality is about having and keeping the label in order to access services that improve functioning. This biomedical construction of normal rests on a concept that behavioural intervention and support (made available through keeping the diagnostic label) is necessary for future achievement (normality), which they call 'normalisation via optimisation' (Sweet and Decoteau, 2018, p. 115). In contrast, the category for depression was attacked, mainly by therapists and healthcare professionals, as being too expansive. This, they argue, was because achieving normality in this condition is about losing the label and instead, working towards a kind of natural innate 'human-ness' by rejecting psychiatric intervention and drawing on our own inner resilience. Depression as a condition, therefore, is represented as a loss of normality; normality in autism is instead an 'end goal of a set of interventions' (Sweet and Decoteau, 2018, p. 117). Therefore ideas of 'normal' in these two conditions are shaped by contemporary debates, different ideas of normal and potential future achievement.

The protection of the autism boundary became fraught during the revisions of DSM-IV, particularly in relation to the loss of the AS sub-category. I would argue that the picture painted by Sweet and Decoteau is also 'of its time'. Revisions to the next version of DSM may begin to critique autism boundaries, given the ongoing debates around the difficulties of the practical aspects of diagnosis when symptoms are considered widely heterogeneous. However, this is likely to be set against continuing 'diagnostic domain defence' debates (Barker and Galardi, 2015) around identity and Asperger's Syndrome (Giles, 2014; Singh, 2011).

### **3.2.2 Technological advances**

Advances in genetics, neuroimaging and medical technologies appear to have done little to help define the boundaries between normal and abnormal. I outlined genetic biomarker developments in autism and a critique of these in Chapter One. Rose suggests that, given advances in technology and brain imaging, we might by now have expected to know what a 'normal' brain looks like (Rose, 2010). However, even with Alzheimer's Disease, which is considered to have a distinct neurological basis, there is no simple relationship between the visual representation of the brain and the way in which someone behaves or other kinds of symptoms (Rose, 2010). For example, Rose explains that although plaques and tangles in the brain are likely to be linked to Alzheimer's, it is still the case that visualisation of the brain cannot predict the development of the disease. Advances in medical genomics take us no further into this, as there is no 'normal' – single standard or reference – genome (Rose, 2010).

Latimer and Thomas (2015) undertook an observational study of a dysmorphology genetics service and a Down's Syndrome prenatal screening clinic. They demonstrated that, although diagnosis is associated with chromosomal abnormalities and genetic mutations, the pathway from genetic mutation to specific conditions is still unclear. Latimer's extended ethnography of dysmorphology explores how certain forms of life become constituted as malformations or abnormalities and, consequently, contribute to the 'shrinking normal': the way in which difference is no longer simply difference but



pathological and problematic (Latimer, 2013). Latimer argues that society's preoccupation with the genetic story illustrates how much 'difference' bothers us as a society and outlines how genetics is concerned with mapping minute deviations in growth and form to describe congenital abnormality. She argues that this search for congenital abnormality connects to how genetics plays its part in defining normal human development, and through this work of division, medical authority is exercised (Latimer, 2013).

### **3.2.3 Defining normal in 'physical' conditions**

There are many studies which explore the idea of 'normality' outside the discipline of psychiatry and psychology, for example, in short stature (Morrison, 2019), female sexual dysfunction (Moynihan, 2003) and osteoporosis screening (Salter et al., 2011).

Drawing from Rose's work, Timmermans and Buchbinder's influential study of the genetic screening of babies explores the way in which the clinic uses measures of 'normal' child development to develop categories of normal or abnormal children in their discussion with parents (Timmermans and Buchbinder, 2012). The authors argue that clinicians use normalisation techniques – regulating babies according to statistical norms (e.g. see Bellman, Byrne, and Sege 2013) – to foster a sense of 'objective normality' (Timmermans and Buchbinder, 2012, p. 123). The process of normalisation incorporates a moral assessment about the kind of life a child might be expected to lead. As with other studies (see Barker and Galardi 2015; Latimer and Thomas 2015), judgements of 'normality' are linked with future expectations related to that specific condition. Timmermans and Buchbinder argue that it was the growth of child surveillance that enabled the privileging of child health and the establishment of a set of standards for child development (Timmermans and Buchbinder, 2012).

To conclude this section with Rose, ideas of norms are socially and historically variable and indeed there has never been a 'normal' or natural human (Rose, 2010). Rose argues that it appears that a lifetime *without* mental illness now would be considered abnormal, such is the 'epidemic' of disorders (Rose,

2010). And yet, these divisions between the normal and the pathological shape our understandings of society and help us make moral judgements about groups and individuals. Key to understanding the context within which definitions of normal are constructed is the idea of medicalisation, which will be the subject of the next section.

### **3.3 Medicalisation**

Medicalisation is a sociological concept which describes a process by which non-medical problems become viewed and treated as medical (Conrad, 1992). Some commentators consider medicalisation as illuminating how medicine functions as a method of social control (e.g. Zola 1972). However, Conrad, in tracing its conceptual roots since the 1970s, asserts that it is simply a neutral way to describe something that has become medical (Conrad, 1992). Freidson argues that medicine has obtained exclusive jurisdiction over deciding what illness is and therefore how people must behave in order to be treated as ill (Freidson, 1970). Freidson argues that this jurisdiction can lead to a society which prioritises its version of health and wellbeing over civil liberties and moral integrity (Freidson, 1970). According to Conrad, however, medicalisation must include all problems defined in medical terms, not just non-medical problems considered to be inappropriately medicalised (Conrad, 1992). Notwithstanding, he acknowledges that a key concern is medicalisation of so-called deviant behaviours (madness, alcoholism) and 'natural' life events (childbirth, menopause) (Conrad, 1992).

#### ***3.3.1 Shifting concepts of medicalisation***

Zola considers the process of medicalisation as an insidious process which is the result of an 'increasingly complex technological and bureaucratic system' (Zola, 1972, p. 487) which has led us to rely on the 'expert'. Zola argues that these experts are presented as morally neutral and yet are part of a system which, for example, prioritises the diseases of the rich (cancer, stroke) over the diseases of the poor (malnutrition, infant mortality) and thereby are embedded

in moral social practices. Zola argues, therefore, that clinicians are guided not by technical knowledge but by values (Zola, 1972).

Zola argues that medicine is involved in the management of the state and works hand-in-hand with institutions with legal powers to change social aspects of life. These social aspects can include, for example, imposing quarantines or vaccinations to achieve social ends (Zola, 1972) or introducing fluoridisation into water systems (Freidson, 1970). Psychiatry, in particular, has served the state in actively dealing with deviance and determining, for example, when individuals should be involuntarily deprived of their liberty (Zola, 1972). Zola argues that the role of medicine has expanded to include broader issues than those related to individual health and illness, for example, the absolute right to control over technical and 'specialist' procedures such as surgery and prescribing medication. It is this 'omnipresence of disorder' (Zola, 1972, p. 498) that enables, for example, a Californian judge to order the sterilisation of an unwed mother as a condition of probation (Zola, 1972).

### ***3.3.2 Medicalisation as interactional***

Arguing against narrower concepts of medicalisation such as those that equate with 'medical imperialism' (Strong 1979), Conrad and Schneider explicate their definition of medicalisation by describing it as having three levels: conceptual (for example, defining illness through research journals or diagnostic manuals); institutional (the adoption of a medical approach to treat a problem); and interactional (doctor-patient interaction, for example, in diagnosis and treatment) (Conrad and Schneider, 1980). This can be mapped on to macro, meso and micro levels (Gabe, 2013) and relocates the site of medicalisation from being the responsibility of the medical practitioner alone, to a broad and inter-related set of practices and values that, at a micro level, can include non-clinical actors such as teachers and employers (Halfmann, 2012) (See Figure 6).

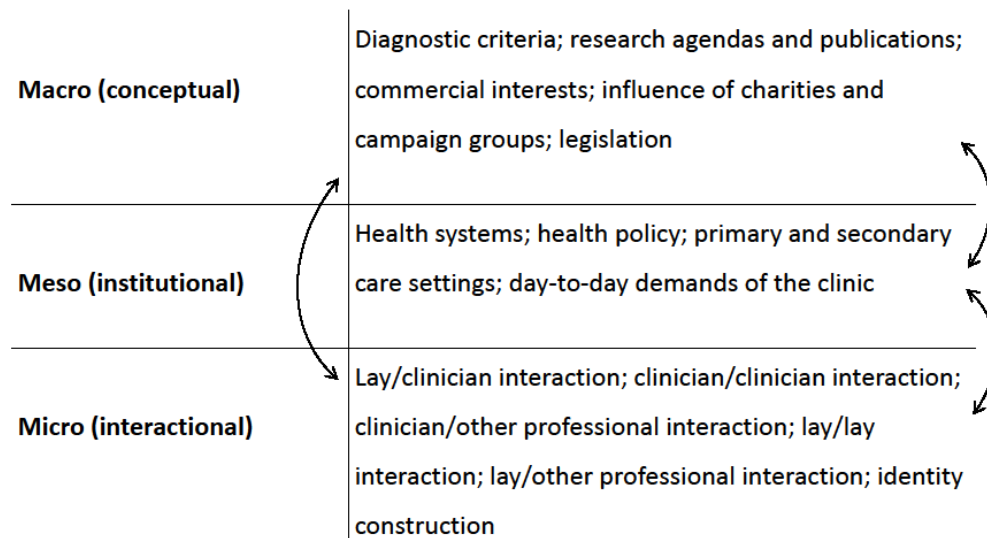


Figure 6: Macro, meso and micro medicalisation in autism based on Halfmann (2012) and Conrad and Schneider (1980)

In his study of two periods of US abortion history, Halfmann (2012) illustrates the operation of medicalisation at these three levels and acknowledges multiple dimensions of medicalisation which include discourses, practices and identities. Halfmann argues that the conceptualisation of medicalisation as this fluid and interactive state enables attention to be paid to detailed changes in medicalisation as well as instances when medicalisation and de-medicalisation occur simultaneously (Halfmann, 2012). Medicalisation, then, is neither static nor absolute and can be driven by a number of intersecting factors.

### **3.3.3 Drivers of medicalisation**

There are a number of arguments to explain the way in which medicalisation occurs. For example, one argument suggests that the medical profession expands concepts of health and illness in order to extend its professional dominance (Gabe, 2013). Studies of paediatrics consider how medicine has extended its role to one which encompasses the psycho-social and behavioural difficulties of children, for example. Pawluch (2012) argues that paediatricians expanded their role when there were fewer sick children to treat due to improved standards of living. Paediatricians, therefore, met the challenge of

their declining status by extending their territory to include behavioural difficulties, thereby medicalising the behaviour of children (Pawluch, 2012). Alternatively, Halpern argues that this focus on psychosocial disorders came about because of 'routinisation' – the paediatric profession extending their remit into an area more stimulating than routine outpatient care (Halpern, 1990).

Others argue that medicalisation is the result of broader social processes to which clinicians and other medics respond (Gabe, 2013), including increasing bureaucratisation and professionalism as a result of industrialisation (Illich, 1976). Some argue that lay interests can drive medicalisation (e.g. Ballard and Elston, 2005; Gabe and Calnan, 1989; Riessman, 1983). Some examples of lay influence of diagnosis include the case of Vietnam veterans helping to define Post Traumatic Stress Disorder (PTSD) (Scott, 1990); people with chronic fatigue fighting for recognition and advocating for the benefits of diagnosis (Woodward et al., 1995); or charity activists and families campaigning to support a private members bill to provide autism diagnostic services for adults (National Autistic Society, 2019).

Medicalisation can also be driven by the lowering of treatment thresholds, such as in hypertension (Pereira Gray et al., 2016) resulting in an expansion of the category and medical jurisdiction of it. In contrast there are few examples of domain contraction, leading to de-medicalisation, except where the diagnostic criteria have been removed altogether, for example, with homosexuality (Barker and Galardi, 2015; Conrad and Schneider, 1980). Domain expansion, leading to increased medicalisation, has been argued to be the case in autism classification, with the introduction of the 'spectrum' in DSM-5. However, it is also argued that lay people perceived domain contraction to take place as DSM-5 changes were seen to exclude some individuals who were already diagnosed (Barker and Galardi, 2015). This perception led to 'diagnostic domain defense' (Barker and Galardi, 2015, p. 121) whereby people who had 'experience-based' expertise argued against de-medicalisation, instead advocating for the importance of the existing diagnosis.

Some research has focussed on the way in which pharmaceutical and technology companies are driving medicalisation in order to promote products (Conrad, 2007; Moynihan, 2003; Moynihan et al., 2002). This aggressive promotion of pharmaceuticals, Conrad (2007) argues, leads to a society where drugs seem to be the answer for a range of conditions previously un-noted (the potentially ill) and the lay public are transformed into consumers rather than patients (Gabe, 2013). Critics however, suggest that these scenarios paint a picture of the lay public as passive rather than, at times, active in the process of medicalisation (Riessman, 1983).

Some argue that a 'top-down' view of medicalisation as a 'sinister agent of social control' (Pereira Gray et al., 2016, p. 8), as represented by the work of Zola and Illich, is now outdated. Rather, medicalisation consists of an interaction between a range of active agents, individual, institutional and conceptual. In addition, others argue that the focus now should be on biomedicalisation, incorporating major transformations in techno-scientific biomedicine such as scientific innovation in geneticisation (Clarke et al., 2003). Featherstone and Atkinson argue that it would be a mistake to supplant one kind of medicalisation with another, as the newer developments in medical knowledge do not entirely supplant those of a previous age (Featherstone and Atkinson, 2012). Rather, medical knowledge becomes a 'palimpsest of knowledge forms, techniques and practices' (Featherstone and Atkinson, 2012, p. 188) in that visible traces of the earlier form can be seen through the new. Others argue that, despite its critics, medicalisation as a concept is still current and relevant (Busfield, 2017).

For the purposes of this PhD study, I would align with the argument against 'medical imperialism' as a concept which suggests that individuals within the medical professions have an agenda of intent to control and dominate (Conrad and Schneider, 1980). This is in line with Blaxter's comment that a contemporary view of medicalisation encompasses influences not just from the medical profession, but from commercial interests, social movements and the lay public (Blaxter, 2010). However, medical authority remains a factor in the medicalisation picture. Drawing from Featherstone and Atkinson's palimpsest

metaphor (Featherstone and Atkinson, 2012), some argue that the authority of the clinician has been diminished with advances in technology, access to information and critiques of the 'expert'. However, medical authority remains a part of the palimpsest of medical knowledge and its traces might still be seen in macro, meso and micro contexts. In any case, others argue that medicine continues to find ways to reassert its dominance, in part through the clinic (Latimer, 2013). My position is that the concept of medical authority being wielded through the actions of individual clinicians is mostly outdated and reductionist. Medical authority resides at structural and societal levels and operates in a complex interaction between different institutions (including education, research bodies, the criminal justice system, commercial interests as well as the medical establishment). Neither should the concept of medicalisation be used as a general attack on the medical profession (Busfield, 2017) but rather as a mechanism to explore structures, knowledge and authority.

This PhD study engages primarily with the way in which healthcare professionals talk together (micro), and this is viewed in the context of the institutional demands of the clinic (meso) which is in turn dictated by macro structures such as diagnostic criteria and research agendas (See Figure 6). It may be possible to observe how medicalisation is operated in the specialist autism team, but this does not happen in a vacuum, rather it is part of a belief system and value base that is pervasive throughout society and supported by our institutional structures. As outlined by Mann (2016) in her study of the medicalisation of ADHD, expertise is no longer the 'possession of the powerful' (Mann, 2016, p. 4) but is distributed across a range of actors including medical professionals, patients and families, pharmaceutical companies, educational institutions and researchers. Although power may be distributed unevenly between them, medicalisation becomes an interaction between these, and other, different parties.

#### ***3.3.4 Consequences of medicalisation***

The consequences of over-medicalisation are potentially grave. Frances argues that, with the expansion of diagnostic boundaries as seen in DSM-5, a new cohort of patients are brought into play, leading to the potential for unnecessary

drug treatment, over-medicating, stigma, problems with insurance, and a reduced sense of personal responsibility (Frances, 2010). Frances (2013, p. 77) expresses concern about what he calls 'diagnostic inflation' i.e. the unnecessary diagnosis of the worried well, which turns the healthy into the sick (Verhoeff, 2012). According to Frances, diagnostic inflation can cause the creation of false epidemics such as those of childhood bipolar disorder, ADHD and autism (Frances, 2010). With this 'shrinking normal' Frances argues that there is more pressure on resources in health, education and in broader services, leading to a displacement of services from those who really need them (Frances, 2010).

The consequences of medicalisation have been particularly examined in relation to 'natural' life processes in women's lives. Normal events such as menopause, childbirth, menstruation and pregnancy are reinterpreted as pathological and therefore automatically require medical attention (Purdy, 2001). The result of subjection to the medical gaze is the removal of responsibility and control from individuals and communities (Jutel, 2009; Sawicki, 1991; Stanworth, 1987). Riessman (1983) argues that the challenge in women's health is to separate out where medical intervention is necessary from those normal and healthy processes in a woman's life cycle.

There can be positive benefits to medicalisation. For example, before 1980, when the classification for ADHD first appeared in DSM, children now diagnosed with ADHD may have been considered bad or naughty, with the resultant parent-blaming and challenges to their educational progress (Grinker, 2015). Now children with ADHD are more likely to be supported and treated rather than stigmatised as naughty.

As well as clinical benefits related to treatment, support and prognosis, there can be symbolic benefits for the individual and family (Gabe, 2013) as I outlined in Chapter Two in relation to autism. For example, research shows that diagnosis can offer a sense of relief in that it can give meaning to difficulties individuals may have experienced throughout their lives, as well as legitimising their condition and potentially reducing stigma (e.g. Woodward et al. 1995). Gabe outlines the advantages of medicalisation of those with a 'drinking



problem' in that it can counteract accusations of moral weakness and counteract blame (Gabe, 2013).

Perhaps, therefore, as first suggested by Conrad, medicalisation is neither a good nor a bad thing: the reframing of behaviour as medical provides both benefits (treatment, support, de-stigmatisation) as well as difficulties (stigmatisation, over-medication, commercialisation).

### **3.4 Shifting concepts of autism**

Drawing from broader studies of medicalisation, and from our understanding of how autism has developed as a condition, it can be seen how autism has emerged as a product of shifting diagnostic boundaries, parental and patient activism, the rise of lobby and political groups such as the neurodiversity movement and increased visibility through cultural and media representations of autism. Eyal and colleagues argue that visibility of autism is higher than ever. However, rather than autism being an epidemic that has 'made autism visible', the visibility of autism has 'made the epidemic' (Eyal et al., 2010). This construction of autism does not render as 'unreal' the very present experiences of those diagnosed with the condition. Indeed Eyal et al argue that this polarisation between whether autism is a 'true' condition, or a social construction misses the main point of the complexity of the development of autism as we know today (Eyal et al., 2010). Autism (or any other condition) can be both 'real' and constructed.

Some social theorists have explored the conceptualisation of autism in relation to changes in classification (e.g. Evans, 2013; Eyal et al., 2010; Nadesan, 2005). Evans (2013) argues that the work of Wing and Rutter in particular was highly influential in expanding the category of autism and linking it to other childhood disorders (Evans, 2013). With this expansion, increasing numbers of children could now be classified by this behavioural criteria (Evans, 2013) and the inclusion of those with even the 'mildest' symptoms served to pathologise difference (Nadesan, 2005, p. 216). By considering shifts in classification in

DSM, Eyal et al claim that psychiatry has retrospectively modified diagnostic criteria to suit current notions of the condition, thereby leading to an increase in diagnostic rates (Eyal et al., 2010).

According to critical autism theorists Timimi and McCabe (2016a), the psychiatric and psychology professions developed new theories of autism to help forward research into the biological basis of autism. This included developing ideas of Theory of Mind as a central deficit (Baron-Cohen, 1995; Baron-Cohen et al., 1985) and the extreme male brain theory (Baron-Cohen, 2003). Other psychological theories developed around autism included a lack of executive function (Hughes and Russell, 1993) and deficits in central coherence (Frith, 1989; Frith and Happé, 1994). Timimi and McCabe argue that the expansion of the category of autism has no scientific basis and that instead of focussing on individual deficit we should challenge medical models that define disorder and consider the political and social reform that will eradicate inequality and discrimination (Timimi and McCabe, 2016a).

In Chapter Two I discussed Nadesan's argument that autism has emerged out of a particular set of niche conditions, including shifts in standards of parenting, a focus on the psychological, and measurements of child development (Nadesan, 2005). Her thesis argues that the medicalisation of childhood behaviour was in part because concerned parents were encouraged both to monitor their children against developmental norms and to seek expert advice from those increasingly available to offer it (Nadesan, 2005; also see Hacking 2006b).

Rather than contributing to a discussion about whether autism is 'really' on the increase, or whether the condition is socially constructed, Eyal et al instead argue that the rise in autism diagnosis is the result of the deinstitutionalisation of mental disorders from the 1960s, which led to a redistribution of expertise and the rise of parental activism (Eyal et al., 2010). This shift included both physical and structural change (the closure of large institutions for example) and symbolical change with 'categories' of people emerging which reflected the changes of the institution. A new institutional matrix was born, that which

included community services, special education and early intervention rather than incarceration and containment. This change gave rise to a redistribution of expertise, so that a range of people from parents to special educators now claimed a right to specialist knowledge and began to reshape the landscape of our understandings of conditions (Eyal et al., 2010).

The campaigning and lobbying sector can also influence how a condition is considered legally and conceptually. This can be seen in the work of the patient/parent lobby who argued for the establishment of the Autism Act 2019 in England (National Autistic Society, 2019) as well as in the challenges to category changes in DSM-5 (Barker and Galardi, 2015). Similarly, intensive lobbying by parent activists in Brazil led to the formation of a federal law which recognised autism as a disability, in a political manoeuvre to take control of treatment of autistic people away from the mental health profession (Rios and Costa Andrada, 2015). Silverman has tracked the development of autism in the United States, including how parents have contributed to the development of the condition through funding specific kinds of research and advocating new therapies (C. Silverman, 2013).

#### ***3.4.1 The autism epidemic and call for action***

Verhoeff argues that society's development of 'autism' has much to do with how modern society deals with distress and suffering, and is based on prevailing values and implicit norms which impact on our (children's) lives (Verhoeff, 2012). Verhoeff argues that autism cannot be a 'natural' phenomenon because such a thing demands shared underlying structure, but autism has a large diversity of classified traits. Furthermore, the history of autism classification demonstrates the constructed nature of the diagnostic boundary. And yet, it is argued, these factors are considered relatively unimportant in the call for action that is the search for 'autism's natural boundaries at neurobiological levels' (Verhoeff, 2012, p. 429). Verhoeff considers this search to be driven by society's desire to locate suffering as a natural phenomenon rather than as embedded in the social world. Rather than the boundaries of autism being natural they are constructed as a way to explain uncertainty, to shape a body of deviance into a treatable entity and to 'frame discontent' (Verhoeff, 2012, p.

428) about people who relate to their environment in a way that is troublesome (Verhoeff, 2012).

Ebben, in a study analysing texts about autism, found that metaphors of danger and contagion are widely present (Ebben, 2018). Ebben argues that the notion of autism as an epidemic represents an urgent call to action to regain control over normalcy (Ebben, 2018). Reality is produced through cultural encounters and these encounters are shaping how we see autism as an epidemic. More than simply being a linguistic framing, it structures our thinking and action about what autism is and how we need to deal with it. This in turn 'creates the social reality we live in' (Ebben, 2018, p. 143). This cultural framing of autism as an epidemic, I would argue, positions autism as a medical entity that we should urgently work hard to do something about abating. This message is not just for autism researchers and scientists: it impacts how parents might interpret their own child's behaviours, how charities shape their own understanding of autism and how society looks upon autistic behaviours as undesirable and deviant. This 'epidemic' message is one that is challenged by the neurodiversity counter-narrative (Kapp, 2019).

### ***3.4.2 The Neurodiversity movement***

Drawing from a social model of disability, the neurodiversity movement argues that forms of 'neurodivergence', rather than being abnormal or deviant, are inherent and valuable variations of human development (Exploring Diagnosis, 2018). Activists within this movement seek to provide mutual support and self-advocacy and to develop a sense of positive self-identity (Kapp et al., 2013). This movement, led by autistic people, seeks to re-position autism as an inseparable aspect of a person's identity rather than as a condition which requires a cure (Ortega, 2009). However, although neurodiversity proponents would generally support a social model of disability, many argue that autism is essentially biological and part of normal neurological difference, rather than seeking to reframe autism as socially constructed (Kapp et al., 2013). Some argue that there has been a shift in the way we see Asperger's Syndrome or so-called 'high-functioning' autism to the extent that 'genius' has been medicalised (Shepard, 2010). The shift towards genius is bolstered by speculation about

retrospective diagnoses of renowned figures such as Newton and Einstein (Shepard, 2010). These new models of autism, whilst apparently positive, are associated with particular norms around gender, race and class (male, white and middle/upper class) which can then lead to stigmatisation towards those that may be more impaired by their condition (Shepard, 2010).

The neurodiversity movement tends to be opposed to parent groups who demand a 'cure' and professional groups working towards this end (Ortega, 2009). These two views are characterised by Hart as 'autism-as-difference' (self-advocates) – where the autistic person is 'differently connected' to the world (Hart, 2014, p. 289); and 'autism-as-disorder' (parents) – where the autistic person is cut off from the world (Hart, 2014). These opposing tensions are likely to continue to shape our shifting understanding of autism in contemporary debates and into the future.

Overall, however, the neurodiversity movement is contributing to a realigning of autism as a positive identity, albeit one in which difficulties have, at times, to be overcome (Kapp, 2019). Along with others in the disability rights movement, autistic advocates argue that society, rather than disabled individuals, needs to change to enable the successful functioning of disabled people in society. The work of the neurodiversity movement, therefore, reframes autism as a positive self-identity and in turn this contributes to how we might consider (some aspects of) autism in the future.

### **3.5 Hacking's Looping and 'Making up people'**

I discussed in Chapter Two, Jutel's observation that the process and category of diagnosis frame and are framed by social and cultural values (Jutel, 2011). Here I explore the construction of autism in relation to Hacking's concept of 'looping', defined as how we choose to classify people to enable systematic and generalizable knowledge of a particular 'kind' of human which then, in turn, shapes and makes happen that particular 'kind' of human (Hacking, 1995). Hacking takes the example of multiple personality disorder, now classified as

Dissociative Identity Disorder (DID), arguing that whilst people diagnosed with DID were once rare, there has been an 'epidemic' in north America. The epidemic, Hacking argues, is not based on a 'real' increase in incidence, rather is caused primarily by a particular set of discourses that grew around multiple personalities. This discourse was fed by the psychiatric profession, the media, political movements such as feminism, growing concern about child sexual abuse, and a growing number of professional conferences and journals around the condition (Hacking, 1995).

The condition of DID has become, in Hacking's words, a 'human kind': a 'kind' of people that are studied and categorised, for whom we would like to have systematic and accurate knowledge. These 'kind' of people constitute a group that we come to understand in relation to a particular accepted set of knowledges, specialist and general, including the cause of their condition, the potential prognosis and range of behaviours (Hacking, 1995). Whilst the beginnings of the condition start within the remit of the medical profession, it becomes general and owned by those with the condition and the broader public. This set of knowledges then feeds into our understanding of the 'kind' of human this person is: according to Hacking, 'the kind and the knowledge grow together' (Hacking, 1995, p. 361). This 'feedback effect' changes those within this 'kind', changes how they think of themselves and changes how wider society thinks about them. This in turn forces the classification-makers to reconsider how they are classified (Hacking, 1995).

It is worth expanding on this by briefly exploring Hacking's five-part framework in relation to DID. Hacking's framework describes the interaction of a number of entities: the classification; the people assigned a diagnosis who, prior to classification, are 'unhappy people'; institutions (medical and lay); knowledge (expert and popular); and experts who generate knowledge, judge its validity, and use it in their practice (Hacking, 2006b). Knowledge includes conjecture, presumptions and 'so-called' facts about the now named disorder. For example, psychiatrists declared that multiple personality disorder was caused by early sexual abuse and repressed memories. Hacking argues that this knowledge then caused people to report early sexual abuse within the context of their

understanding of multiple personalities. Early sexual abuse then became part of both lay and medical knowledge of multiple personality (Hacking, 2006b). Hacking argues that when a classification is created and assigned to a person, they then become a 'moving target' – a way that this particular condition 'changes its contours and its lived experience' through the way of life of diagnosed people (Hacking, 2006b, para. 33). Remarkably too, more and more 'unhappy people' then begin to manifest symptoms of multiple personality (Hacking, 2006b). Experts work within institutions that provide legitimacy and assures their status as experts. People assigned a diagnosis are now classified as a 'given kind' (Hacking, 2006b). In 1985, therefore, multiple personality was a way to be a person; it had not been in 1955.

For autism, Hacking argues a different case: autism clearly did exist in the 1950s, say, but it was still not experienced, for 'high-functioning' autistic people, as a way to be a person (Hacking, 2006b). Once the term of autism has been assigned, it is through people experiencing themselves in that way (of being autistic) that a looping effect occurs. The category of 'high-functioning autistic' therefore is expanded as it became understood that it was possible to be autistic and have strengths and acquire skills to overcome difficulties. Therefore a new group of people were encompassed within the category – those who may not have had such difficulties in childhood and who have managed their difficulties into adulthood (Hacking, 2006b). More and more people, then identify as autistic.

As we assess behaviour and label the individual with a condition, then, the category shifts along with the shift in behaviour. Diseases are not stable but shift and change based on the practices of which they become a part (Mol, 2002). 'Making up people', Hacking argues, is rooted in the way in which 'names interact with the named' (Hacking, 2006b, para. 4). The process of diagnosis relates to a particular set of criteria relevant to a particular time but we know this can change (e.g. from multiple personality disorder to dissociative identity disorder), grow (e.g. ADHD and autism) or become obsolete as a (medical) classification (e.g. homosexuality). These shifts in conceptualisation matter because of the actions that diagnosis precipitates: how we treat, care for,

cure or consider prognosis (Timmermans and Buchbinder, 2012). How we understand a condition, what we call it, who gets diagnosed with it and how this impacts on our future understanding of the condition is inextricably linked.

### **3.6 Concluding comments**

Combining a broadening of diagnostic criteria, the re-presentation of autism in all aspects of the media and, in the UK, the establishment of a route to diagnosis for adults, we can see how the idea of autism has changed and shifted and therefore can be argued as socially constructed. At the same time, it is acknowledged that there can be real distress for those who may have behaviours considered to be autistic, and further distress caused by society's view towards those behaviours. The development of the category of autism has been shaped by developments in how we understand behaviour (as psychological, as cognitive, as behavioural), how we want to manage that as a society and how we decide what the future of a person with particular behaviours should look like. Autism is the medicalisation of certain types of behaviours, the definitions of which have also changed over time.

We have a new idea of autism that is far removed from Kanner and Asperger's initial definitions. This now includes the possibility of adults (as well as children) being diagnosed, challenging the idea of autism being a condition identified in childhood. These new definitions require the medical profession to assess a much broader range of people than they did in the past with the challenges that brings. The next chapter will go on to consider how clinicians make diagnostic decisions together before introducing the studies that form the empirical element of this PhD thesis.



## **CHAPTER FOUR: Making diagnostic decisions**

*The clinic is not simply a place in which people are fitted into existing diagnostic categories. Rather, the categories themselves are fashioned and refashioned. The clinical encounter involves not merely the assembly of an individual diagnosis. The diagnostic category... itself is being actively shaped and negotiated amongst experts.*

Featherstone and Atkinson, 2012, p. 10



## **4.1 Introduction and overview of chapter**

The clinical setting is a site of knowledge production (see, for example, Featherstone and Atkinson, 2012; Latimer, 2013) in that decisions made in this context inform and shape our understandings of disease and disorder, their aetiology, symptomatology and capacity for treatment. Diagnostic decision-making is informed by its institutional setting and interactional context. This includes the potential for competing opinions, different disciplinary frameworks and varying levels of experience. Given the potential for uncertainty in autism (and perhaps other) diagnoses, how do clinicians both draw on and produce knowledge in this context? This section explores diagnostic uncertainty, narrative case-building, and how clinicians utilise different types of knowledge to come to assessment decisions. In particular it explores the role of experience within diagnostic decision-making in medicine and draws on ideas of objectivity and disciplinary knowledge.

## **4.2 Knowledge and uncertainty**

### ***4.2.1 The scientific method***

The medical profession seeks certainty: we rarely hear about society's desire for diagnosis to become broader or less specific. Instead, it seems that there is a perpetual pursuit of precision, a striving for increased accuracy in diagnostic tests and the biomarkers that will remove uncertainty, alongside revisions of tools to enable clinicians to make 'objective' and robust decisions.

It has been argued that the most effective form of decision-making in diagnosis should take the form of scientific hypothetico-deductive reasoning (see Elstein et al., 1978). This type of reasoning comprises a rigorous search for disconfirming evidence and enables decisions to be made between alternative hypotheses (White and Stancombe, 2003, p. 5). The development of evidence-based medicine (EBM) stresses that medical decisions should be made with only the most current, highest quality, methodologically rigorous, scientific evidence (Engebretsen et al., 2015). The EBM approach downplays the role of

expert opinion and clinical reasoning (Engebretsen et al., 2015). Some argue that it must be possible to extract medical 'truth' from the clinical encounter without recourse to the individual views or knowledge of the clinician (critiqued, for example, by Greenhalgh, 2011; Timmermans and Berg, 2003).

EBM translates to the clinic via clinical practice guidelines, based on current scientific evidence (Timmermans and Berg, 2003). As I will demonstrate later in Chapter Six, clinical guidelines for autism (and other conditions) include recommendations for the use of clinical judgement in decision-making. In practice, therefore, decision-making may deviate from this positivist model, because real-world decision-making is located, contextual and a human process, with all the difficulties and benefits this involves. Clinicians themselves value experience, specialist knowledge and an ability to incorporate patient preferences into their assessment, thereby immersing interpretation, experience, opinion and interaction at the core of the decision-making process.

#### ***4.2.2 Critiques of the scientific method***

Despite the introduction of guidelines, gold standard diagnostic tests and other 'scientific' procedures, Featherstone and others argue that attempts at standardisation do not succeed in determining clinical practice (Featherstone and Atkinson, 2012). The hypothetico-deductive method has been critiqued within the domain of the bio-psycho-social model where it is understood and acknowledged that, for example, patient experience should be valued and considered. Researchers also argue that the method of hypothetico-deductive reasoning, or information processing model, may have some merit in some situations, but this method of reasoning does not cope well with ambiguity, uncertainty or complexity (White and Stancombe, 2003). Encounters between patients and clinicians, and between clinicians, are conducted through language and therefore have potential for misunderstandings, inaccuracies and 'false trails' (White and Stancombe, 2003). Models such as pattern recognition ('I know this is autism because I've seen it before'), intuitive reasoning and multi-disciplinary consultations may be more appropriate and productive (Higgs and Jones, 2000).

Similarly, others argue that EBM must integrate scientific evidence with clinical experience, patient values and preferences (Sackett et al., 1996). Recent critiques of EBM argue that interpretation should be central to the EBM process (Engebretsen et al., 2015; Greenhalgh, 2011). Greenhalgh argues that rather than attempting to rely on evidence alone, clinicians must, therefore, incorporate a 'narrative-interpretive paradigm' (Greenhalgh, 2011, p. 323) in their consultations. This narrative-interpretive approach should take into account experience, the patient's culture and perspectives, and the results of scientific research (Greenhalgh, 2011). However, Engebretsen and colleagues argue that there is little guidance about how to apply these different knowledge components to decision-making (Engebretsen et al., 2015).

#### ***4.2.3 Uncertainty in medical practice***

It is argued that uncertainty is central to medical practice (e.g. Beresford, 2006; Bursztajn et al., 1986) because diagnosis is an act of interpretation and involves transposing clinical research to the idiosyncrasies of the individual patient (Tanenbaum, 1993). Beresford suggests that uncertainty in diagnosis can be caused by inadequate scientific data, not knowing patients' wishes or the problem of applying abstract criteria to concrete situations (Beresford, 2006).

Medical sociologists have sought to challenge ideas of certainty in diagnosis more fundamentally, by raising questions about the nature of objectivity, challenging the concept of standardisation, and problematising the creation and recreation of medical knowledge as a certain entity. Studies have explored, for example, pharmaceuticals and neuroscience (e.g. Fitzgerald, 2014; McGoey, 2009; Pickersgill, 2011); medical training (e.g. Atkinson, 1984; Fox, 1957; Timmermans and Angell, 2001); classification, patient/doctor interaction and diagnostic decision-making (e.g. Bowker and Star, 1999; Bursztajn et al., 1986; Hedgecoe, 2003; Star, 1989; Zayts et al., 2016); uncertainty as a resource for clinicians (Pilnick and Zayts, 2014; Timmermans and Buchbinder, 2012); and uncertainty in medically unexplained or contested diagnoses (e.g. Armentor, 2017; Jutel, 2011; Marks et al., 2016).

I do not offer a full review of this body of scholarship here but instead include a small number of studies which provide a context for my PhD project. For example, early work by Fox (1957) examines the theme of uncertainty in her exploration of how medical students acquire knowledge. Fox proposes that there are different meanings of uncertainty in the way in which students develop their knowledge base. Firstly, there are the inherent limitations of medical knowledge generally. Secondly, the understanding of medical students is imperfect in that they cannot master all available knowledge. Thirdly, there are challenges for clinicians in distinguishing between the two (Fox, 1957). Uncertainty, therefore, may have different sources and implications for practice.

Bursztajn and colleagues argue that medical culture denies uncertainty in the pursuit of the 'objectively correct decision' (Bursztajn et al., 1986, p. xi), which they term a 'mechanistic paradigm' (Bursztajn et al., 1986, p. xxvi). This mechanistic paradigm seeks certainty and can lead to over-diagnosis as clinicians make every effort to cover all bases and alleviate risk. Bursztajn and colleagues argue, instead, for a 'probabilistic paradigm' which accepts uncertainty as an inherent part of reality and questions whether subjective and objective knowledge can be separated. This approach, they argue, would bring medicine up-to-date with developments in physics, would recognise values and feelings as a core aspect of science and become a science of action and practice rather than of the laboratory (Bursztajn et al., 1986). Further, they argue that an acceptance of uncertainty enables shared risk-taking, mutual support and the possibility of trust-building between clinicians, patients and families. The probabilistic paradigm incorporates a capacity to doubt (Bursztajn et al., 1986). This approach would return to a 'many-sidedness of reality' that was lost in the over-simplification of medical science in the 19<sup>th</sup> century (Bursztajn et al., 1986, p. 63).

#### ***4.2.4 Practical reasoning and experience***

Both Bursztajn and Fox's studies have been critiqued as being too reductionist, with Atkinson, for example, suggesting that a general sociological focus on uncertainty as conventional wisdom lacks rigour (Atkinson, 1995). Atkinson argues that rather than assuming uncertainty as a 'taken-for-granted'

concept within medical sociology, certainty and uncertainty reflect different attitudes which may co-exist together (Atkinson, 1984). The 'moral certainty' (Atkinson, 1995, p. 116) of practical reasoning resides alongside the uncertainty of theoretical discourse. These are different sorts of knowledge, reflecting (at least) two different orientations towards knowledge and practice, and, according to Atkinson, are adopted in different settings. The moral certainty of practical reasoning, experience or routine, is adopted in day-to-day clinical practice; and the uncertainty of theoretical discourse is the knowledge of the laboratory (Atkinson, 1995). Paradoxically, Atkinson argues that it is personal knowledge – what might be termed clinical judgement or intuition – that is given the privileged place of certainty within medical decision-making. However, clinical judgements themselves are the products of social processes influenced and shaped by context, discourses, human interaction and the particular classification framework pertinent at the time of working (White and Stancombe, 2003).

The framing of medical decision-making as practical reasoning, or as pragmatic, positions the clinician as one who, rather than engaging in information-processing, can respond to the complexities of diagnosis by justifiably drawing on personal experience and judgement. Experience and personal opinion cannot necessarily be validated by scientific knowledge, but Atkinson argues that this is 'not normally treated by practitioners as reflections of uncertainty but as warrants for certainty' (Atkinson, 1995, pp. 114–115). In other words, clinical judgement is not considered by clinicians as a source of uncertainty but as a way to be sure, especially in the light of ambiguity or consideration of co-conditions.

Atkinson argues that Bursztajn and colleagues' vivid examples of practice serve to illustrate that, contrary to their argument, the process of diagnosis is, in practice, far more complex than their argument of a mechanistic paradigm suggests. Atkinson suggests that there are changing local definitions of knowledge and action therefore uncertainty encompasses a complex set of attitudes towards knowledge and practical activity (Atkinson, 1995). Different orientations to uncertainty are reflected in different circumstances, for example, delivery of diagnosis to the patient and (private) discussion between clinicians

of different disciplines. How certainty or uncertainty is conveyed in these different settings, therefore, is key to what knowledge is drawn on and what kind of warrant that knowledge has (Atkinson, 1995).

Freidson's classic text on the profession of medicine also considers the role of experience and reasoning in diagnosis, suggesting that clinicians have a particular perspective of their professional role which values pragmatic action and practical reasoning over theoretical approaches or acquisition of knowledge for its own sake (Freidson, 1970). He argues that clinicians must believe in the efficacy of her or his actions rather than attend to research that identifies the unreliability of diagnosis, or is rooted in uncertain findings, for example. These factors lead the clinician to be a pragmatist focussed on results and with an emphasis on emotional experience, rather than general concepts or probabilities. In this way the clinician comes to rely on the 'authority of his (*sic*) own senses' (Freidson, 1970, p. 170). The clinician therefore depends on a clinical mentality which is primarily individualistic and reliant on a personal bank of experience and knowledge (Freidson, 1970).

It could be argued, therefore, that the science of medicine is filtered through the hands of the experienced clinician, which can outweigh any research-based evidence (Timmermans and Berg, 2003). Experience places the clinician as 'one who knows', and allows a space for interpretation and judgement. Reliance on experience might meet the challenge put forward by White and Stancombe (2003) in relation to the limitations of the hypothetico-deductive method: experience and specialist personal knowledge can navigate some of the uncertainties and interactional difficulties in making the diagnostic decision. A focus on experience may enable the clinician to find moral or pragmatic certainty within a context of conflicting evidence and inconclusive tests. For example, in psychiatric diagnosis, an interview study identified that psychiatrists deal with the institutionally-induced competing demands of diagnosis by engaging in 'psychiatric workarounds' such as negotiating diagnoses with patients or fudging codes on paperwork (Whooley, 2010). A workaround approach relies not only on clinical judgement in interpretation of symptoms, but



depends on the clinician making 'moral sense' (Leydon, 2018) of the diagnostic decision by taking into account the consequences for the patient.

Timmermans and Buchbinder's study of the genetic screening of babies considers how experience and judgement can be considered as a different type of 'objectivity' which is utilised to foster a sense of objective normality (Timmermans and Buchbinder, 2012). The authors describe three types of objectivity: narrative objectivity (e.g. parental report); mechanical objectivity (e.g. growth chart); and disciplinary objectivity in the form of the physical examination (Timmermans and Buchbinder, 2012). However, the authors argue that medical authority – disciplinary objectivity – is privileged and therefore plays a 'pre-eminent role' in assessment (Timmermans and Buchbinder, 2012). The ability to foreground disciplinary objectivity, or trained judgement (Daston and Galison, 2007) is particularly important, not simply to interpret test results when the results of diagnostic tests may be ambiguous, but as a strategy to make sense of uncertainty (Timmermans and Buchbinder, 2012). The warrant to make this judgement is rooted in a cultural framework that privileges the health professional with 'the disciplinary eye' (Daston and Galison 2007). This expert medical gaze (Featherstone and Atkinson, 2012) positions the clinician as one who 'knows', and who can therefore categorise and collate in a way that lay people cannot. As I will explore further in Chapter Eight, clinical expert judgement can take epistemic precedence over standardised tests, making the clinic a place where clinicians shape diagnostic categories through their practice.

I would argue that diagnostic uncertainty is not necessarily problematic or a failure of medicine or individual medics, rather it is inherent to the interaction and social process of diagnosis (Malterud et al., 2017). It serves to illustrate the nature of scientific knowledge as partial, situated (Haraway, 1988) and socially created. An acceptance of the partial and constructed nature of our disease classification system may help us consider what diagnosis 'does' for people, not just individually, but for society and how we come to understand behaviour as 'normal' or pathological.

#### **4.2.5 Autism as an uncertain entity**

Atkinson argues for a detailed analysis of how clinicians locate the sources and nature of doubt, and how they express them discursively, within case discussions (Atkinson, 1995). Social science scholars have explored the 'practical uncertainty work' undertaken by clinicians in practice (see Hollin, 2017a; Moreira et al., 2009; Pickersgill, 2014, 2011). This work involves the implementation of strategies to overcome diagnostic uncertainty enabling diagnosis to take place. Above, I have explored uncertainty in diagnosis generally; this section considers uncertainty in the case of autism.

Some scholars have explored the concept of uncertainty specifically in relation to autism as a condition (e.g. Fitzgerald, 2014; Hollin, 2017a, 2017b; Turowetz and Maynard, 2019). Hollin (2017b) has explored how the cognitive work of key autism researchers in the 1980s and 1990s, such as Frith, Happe and Baron-Cohen, shifted autism into the cognitive domain as an explanatory framework. In doing so, the work of these researchers embedded the concept of heterogeneity as core to the definition of autism (Hollin, 2017a). Hollin considers how the belief that autism is a heterogeneous condition can be conceived as an 'agential cut' – a point at which autism became one thing to the exclusion of others – which was a result of this early work of these autism researchers (Hollin, 2017a). Hollin argues that this incorporation of difference into one category has ethical considerations as it locates differences in behaviour *within* the condition of autism, rather than perceiving it as 'dynamic, contextually dependent and co-produced' (Hollin, 2017a, p. 628).

Specifically, Hollin introduces the term 'ontological indeterminacy' into his concept of autism as a condition (Hollin, 2017a, 2017b). Rather than seeking to erase uncertainty, Hollin argues, researchers have effectively centralised it within the meaning of the condition itself. The result of this is that autism, in its heterogeneity, has become 'determined by its indeterminacy' (Hollin, 2017a, p. 611). By definition, therefore, 'no two individuals with autism are the same and an individual's symptoms cannot be explained with reference to a single causative factor' (Hollin, 2017a, p. 617). Heterogeneity, therefore, delivers the

concept of autism as an 'uncertain entity' (Hollin, 2017b, p. 209), with the resulting implications for clinical and research practice.

The concepts of practical uncertainty work and, in particular, Hollin's ideas around ontological indeterminacy, are explored more fully later in relation to data collected as part of the PhD study (Chapters Seven and Eight). This section has explored how diagnosis is imbued with uncertainty (of different kinds and shifting across disciplines, settings and times), and how clinicians draw on what Freidson (1970, p. 172) calls 'self-validating and self-confirming' individualistic experience-laden understandings of different conditions to make decisions. Those experience-based understandings contribute to constructing a condition in the image of that experience, with the circular and re-affirming consequences that brings. As Atkinson argues, we must look at how this happens in practice, and the following sections will look at the use of narrative in diagnostic decision-making and how clinicians diagnose in collaborative teams.

### **4.3 Narrative case-building**

One way of reducing uncertainty, it is argued, is for clinicians to work together to create a coherent diagnostic narrative before relaying information back to the patient (Messer et al., 2018). If there are divergent conclusions, clinicians should give priority to those aspects they deem most important and be sure to come to a 'firm conviction' (Messer et al., 2018, p. 268). A lay person or patient might be intrigued by this ability to fit evidence into a classification despite divergent information. The development of 'conviction' from 'uncertainty' then is something that may happen in narrative case-building, which is explored in this section.

#### **4.3.1 Narrative and medicine**

There is a body of work which examines narrative in medical settings. For example, Hunter examined doctors' case presentations and suggests the narrative produced is a 'doubled narrative' in that the patient's story is

encapsulated within the doctor's narrative (Hunter, 1991, p. 51). Other work includes Silverman's examination of medical decision-making (Silverman, 1987); clinical reasoning in occupational therapy (Mattingly, 1998, 1991); how clinical experience is invoked to ground diagnostic claims (Mischler, 1984); genetic counselling in paediatrics (Bosk, 1992); and how clinicians talk to patients (Ainsworth-Vaughn, 1998; Byrne and Long, 1976) including extensive conversation-analytic studies into patient-doctor communication (see, for example, Heritage and Maynard, 2011, 2006; Maynard and Heritage, 2005; Pilnick et al., 2009).

There is also a large body of work, not dealt with here, related to the narratives of patients and individuals experiencing different conditions and diseases (for example see Charmaz, 1999; Frank, 2013; Kleinman, 1988; Riessman, 1990). Narratives can help to produce shared experiential meanings around particular conditions and have also increasingly been used as part of what is termed 'narrative based medicine' whereby the meaning of patient experiences are used, particularly in general practice, to help decision-making (Greenhalgh, 2011). Some argue that there is a shift from the dominant medical narrative being that of the clinician, to that of the patient and, indeed, that clinicians are increasingly incorporating patient narratives into their own case narratives (Kalitzkus and Matthiessen, 2009; Morris, 2006).

#### **4.3.2 What is a narrative?**

At its simplest, narrative is defined by a sequence of utterances which are organised in such a way as to be consequential for later action and to convey the meaning a speaker wants to communicate to their audience (Riessman, 2008). Although there are various detailed accounts of what constitutes a narrative, Riessman argues that narrative must include a 'sequenced storyline, specific characters and the particulars of a setting', therefore, not every form of talk is framed by narrative structure (Riessman, 2008, p. 5). There are patterns in communication between people and, as I will discuss in Chapter Five, talk is designed to meet particular aims: to persuade, to account for, to position oneself or to manage investment in the story, for example. The structure of a

narrative matters, then, because only in certain forms does it become rhetorically persuasive (Riessman, 2008).

Classic studies of narrative by Labov and Waletzky (Labov, 1972; Labov and Waletzky, 1967) are influential and important despite later developments which challenge or develop their strict structural approach (Riessman, 2008). At its most basic, they argue, a narrative takes the form of ‘a sequence of two clauses which are temporally ordered: that is, a change in their order will result in a change in the temporal sequence of the original semantic interpretation’ (Labov, 1972, p. 360). In Labov’s study of the language of young black people in inner-city US, he found that narrative story-telling formed a basic six-part structure: abstract, orientation, complicating action, evaluation, resolution and coda (Labov, 1972) (see Figure 7). Each of these elements describes the function of a clause in the overall narrative and can be repeated to generate complex structures. Not all features need to be present. Labov and Waletzky argued that an important element to driving narrative forward was the temporal aspect of the story: certain elements have to be told in a particular order otherwise they will not make sense, although not all researchers agree with the importance of this element (e.g. Gee 1991).

Clause description	Underlying question	Purpose
<b>Abstract</b>	What was this about?	Summarises the whole story
<b>Orientation</b>	Who, when, what, where?	Identifies important contextual features
<b>Complicating Action</b>	Then what happened?	Introduces event sequence or plot, usually a turning point
<b>Evaluation</b>	So what?	Identifies the point of the narrative – comment on meaning for speaker and communicates emotions
<b>Resolution</b>	What finally happened?	States outcome of the plot
<b>Coda</b>	Questions are no longer relevant	Signals the narrative is finished

Figure 7: Narrative structure (Labov 1972 and Riessman 2008)

### **4.3.3 Atkinson and case presentation**

Atkinson's study of a haematology clinic observed how case presentation takes a narrative form which includes a common pattern of presentation of highly selected and compressed information; introductory statement, recent history, outline of physical examination, results of lab and other tests, and initiation of treatment (Atkinson, 1995). Atkinson argues that the rhetorical ability to tell appropriate stories is a tacit competency requirement of clinicians (Atkinson, 1995). Medical practitioners, he argues, must effectively turn the results of tests and investigations into a plausible and persuasive story which serves to 'justify past actions, current understandings and future plans' (Atkinson, 1995, p. 90). These oral narratives are shaped in both formal (e.g. the ward round) and informal (e.g. passing conversations between colleagues) occasions and can be places where social control and status are enacted (Atkinson, 1995). Atkinson argues that this talk does not just reflect the work of the medical setting, but is in itself medical work, in that the case is produced by the talk about it (Atkinson, 1995). Turowetz and Maynard also argue that being a competent clinician includes the ability to foreground diagnostically relevant 'storyable' episodes in order later to recount to colleagues, patients and families (Turowetz and Maynard, 2017).

Atkinson argues that recounting the case in a medical context does more than communicating the facts of the case. As with other kinds of talk, individuals do things with words and, in case construction, clinicians may be giving good accounts of themselves (for example, in seeking particular actions in a timely fashion) or questioning the credibility or moral status of the patient or family (Atkinson, 1995). For example, White's (2003) analysis of professional narratives in paediatrics and child health found that clinical talk is often underpinned with moral judgements about the family, including culpability. White argues that these characterisations provide a warrant for diagnosis and suggests that judgements about the adequacy of parental love are key to the clinical discussion (White and Stancombe, 2003).

Goffman argues that some types of interaction develop an institutionalised form and when this occurs, situated and differentiated roles can appear which meet

the purpose of the setting (Goffman, 1961). These interactions are constrained by particular 'ground rules' whereby each speaker conforms to their mutual obligation to those rules (Goffman, 1983). Strong developed this concept through an analysis of interaction between clinicians, patients and parents in two paediatric clinics in Scotland and the US to demonstrate what he terms the 'ceremonial order' of the clinic (P.M. Strong, 1979, p. 12). Strong suggested that these roles, whilst structured, are not singular and specific to individuals, but can be seen repeatedly across encounters and settings (P.M. Strong, 1979).

Atkinson's analysis extends Strong's notion of the ceremonial order of the clinic to explicate a highly formalised set of procedures through talk, which he terms a 'liturgy' or sacred quality of case-talk (Atkinson, 1995, p. 94). Atkinson argues that clinicians assemble stories which produce and reproduce medical knowledge about particular medical conditions. It is through this recounting of stories that clinicians 'reproduce the orthodoxies of medical thought, knowledge and talk' (Atkinson, 1995, p. 5). Through recounting narratives, knowledge is produced by clinicians via the clinical setting, shaping how conditions are understood and communicated back to patients.

Anspach examined the case presentation of clinicians in training and suggested that there are four key elements that are core to their presentational rhetoric (Anspach, 1988). Firstly, clinicians separate biological processes from the person, which she terms de-personalisation; secondly, clinicians use the passive voice which separates the speaker from the action, emphasising what was done rather than who did it; thirdly, clinicians treat technology, e.g. CT Scans or EEG's, as an active agent; and finally they treat patients' accounts as subjective (Anspach, 1988). Anspach highlights linguistic features, which demonstrate how clinicians achieve these actions, arguing that they serve to enact functions such as enhancing credibility, mitigating responsibility and downplaying patient accounts (Anspach, 1988). Atkinson argues that, although there are important features to note and analyse, Anspach fails to demonstrate how clinicians pull these features together to produce a case account which is plausible and persuasive (Atkinson, 1995). For example, in Atkinson's own study he demonstrates that, within the case narrative, some evidence is marked

as more credible than others and includes threads of responsibility, judgement and culpability (Atkinson, 1995).

Atkinson proposes that the temporal order of the narrative is key to managing uncertainty and the establishment of credibility (Atkinson, 1995). For example, the chronological narrative of temporally-located facts and events serves to 'scaffold' uncertainty within a framework of uncontested assertions (Atkinson, 1995). The difference in how these events contribute to the diagnostic narrative can be found in how they are uttered as unproblematic and unmarked by hesitancy. In contrast, there are more complex statements about the patient, which are marked as tentative or uncertain, using, for example, hedging statements and approximations. Atkinson suggests that these case presentations, along with many others, follow the Labovian pattern as outlined above with the evaluative aspect of narrative used to communicate the moral of a story to peers (Atkinson, 1995). Overall, the narrative frame constricts the case as subject for medical talk and establishes the boundaries of what is important.

Atkinson, therefore, demonstrates through data analysis how clinicians orient to the knowledge presented in different ways and argues that this orientation can mark each piece of information as more or less credible. These orientations to knowledge cannot be defined as simply being either certain or uncertain, rather degrees of certainty may be expressed and are embedded in talk. Contrastive rhetoric can apply blame or judgement and inscribe aspects of power between different medical disciplines and roles (Atkinson, 1995).

#### ***4.3.4 Narrative in autism diagnosis***

An important body of work in the use of narrative in the diagnosis of autism has been undertaken by Turowetz and Maynard. I provided a brief overview of their research in Chapter Two: here I discuss specifically their examination of narrative structure in autism diagnosis across two time spans (1985 and 2014). The authors undertook a conversation analysis of meetings where clinicians discuss a case of a child's diagnosis both with and without parents present (Maynard and Turowetz, 2017; Turowetz and Maynard, 2017).



A conversation-analytic approach to storytelling tends to examine the way in which turns of talk are structured interactively (see Sacks et al., 1974; Sacks, 1992) and considers how interaction functions to make things happen and what clinicians produce through this interaction (Turowetz, 2015a). Turowetz and Maynard show how narrative works as a 'mechanism for translating local, situated events into warrantable findings' (Turowetz, 2015a, p. 73). With the conversation-analytic approach, narratives are shaped by a process of interpretation and interaction: how people respond to storied assessments contributes to the success, or otherwise, of diagnosis (Maynard and Turowetz, 2019).

The authors argue that diagnostic practices are narratively constructed whereby clinicians engage in storytelling to rule in, or out, a diagnosis of autism (Maynard and Turowetz, 2017). The authors argue that these systematic narrative practices of diagnosis are generic and cut across differences in time and social environments (Maynard and Turowetz, 2017). Narrative practices are shaped by an interactive process between tellers and recipients in real-time which involves assembling story components and types towards collaborative production of a narrative. The authors draw on Goffman's (1983) concept of the 'interaction order', briefly mentioned above, in the way that 'ground rules' are established for social interactional norms. Maynard and Turowetz describe how the microanalysis of face-to-face social interaction can contribute to understanding how clinicians 'do diagnosis' – as an active, inter-active, interpretive process rather than as a static classificatory exercise (Maynard and Turowetz, 2017). In particular, they argue that by examining this social interaction during diagnosis we can better understand the social organisation involved in *all* diagnosis, not only in the diagnosis of autism (Maynard and Turowetz, 2017).

Maynard and Turowetz's studies demonstrate how the diagnostic process takes a narrative form in four parts: preface (an introductory narrative); possible stories (either tendency or instantiation); typifications (categorical assertions which include diagnostic upshots); and story reciprocity (how the story is received, supported or facilitated by others in the room) (Maynard and

Turowetz, 2017) (see Figure 8). This narrative structure is used to gradually build an evidential case for diagnosis. Tendency stories, or ‘habitual stories’ (Riessman, 1990), differ from instantiation stories (anecdotal instances of particular behaviour) in that they extend behaviour beyond the individual behavioural act (Turowetz and Maynard, 2017). Tendency stories serve to present the behaviour as habitual or recurrently atypical and therefore are implied to be more inherent or core to the child’s being rather than a one-off and perhaps situational occurrence. The authors assert, therefore, that narrative is part of ‘the practical epistemology of clinical work’ through which clinicians assign and adapt classification to specific individuals (Turowetz and Maynard, 2017, p. 4).

<b>Preface</b>	Setting up the stories to follow
<b>Stories</b>	Either instantiation (single episode, reference to a single instance): or tendency (propensity to behave in a certain way)
<b>Typifications</b>	Relatively static, categorical assertions and assessments including diagnostic upshots
<b>Story reciprocity</b>	Responses by others affecting how narrative is assembled

Figure 8: Narrative structure for diagnosis in interaction (Turowetz and Maynard, 2017)

Clinicians use what Maynard and Turowetz call ‘contrastive elements’ of both positive (away from diagnostic symptoms) and negative (associated with diagnostic symptoms) to enable ‘interactional progressivity’ towards diagnosis (Maynard and Turowetz, 2017, p. 265). This culminates in the creation of a coherent diagnostic narrative in preparation for communication of the assessment to parents and families. Particularly relevant to this thesis is the claim that this recurring narrative of instantiation, tendency and typification can be seen as a method for resolving uncertainty even with tentative diagnoses.

More recent work from Maynard and Turowetz consolidates previous studies by exploring how narratives shift over time to accommodate different historical periods and incorporate contemporary classifications and understandings of the condition (Maynard and Turowetz, 2019). The delivery of diagnosis can include contemporary references to, for example, access to services, resources or

cultural phenomena not previously available (Maynard and Turowetz, 2019). Maynard and Turowetz argue that diagnosis is not just interpretive and interactive but interactional in that the success of the diagnostic narrative is dependent on how it is received and responded to by other clinicians and families (Maynard and Turowetz, 2019). The authors argue that 'narrative discourse is dynamic – assembled in real time through ongoing talk and embodied conduct' (Maynard and Turowetz, 2019, p. 91). Drawing from Hacking, the researchers show how parents are complicit in 'making up people' in their response to the diagnostic narrative (Maynard and Turowetz, 2019). For example, in one case, parents resisted and refused the categorisation of both autism and MR for their son, despite 'artful deployment of narrative practices' by the clinician, thereby shifting the diagnostic narrative (Maynard and Turowetz, 2019, p. 98). Maynard and Turowetz describe this as an 'interactional accomplishment' (Maynard and Turowetz, 2019, p. 98) which has long-term consequences both for the child and for the diagnosis.

Finally, these researchers found that clinicians use narrative as a method for differentiating autism from a possible co-condition. They demonstrate that narrative is a pervasive and endogenous practice for producing diagnostic decisions (Turowetz and Maynard, 2017) which involves foregrounding symptomatic behaviours and incrementally building a case to rule in or rule out, a diagnosis. They also argue that lay-actors, such as parents and caregivers, can 'harness narrative structure' by using stories that align with or challenge the findings of clinicians (Turowetz and Maynard, 2017, p. 21).

In this section I have shown how the use of narrative can be a means to alleviate uncertainty and to shape contradiction into coherence. Narrative is created through interaction and this interaction shapes the narrative told. Narratives of diagnosis change and shift over time and, as we can see in the work of Maynard and Turowetz, are constructed in interaction and are shaped by contemporary understandings of a condition. The next section will look at how clinicians work together in meetings to make diagnostic decisions.

#### 4.4 Decision-making in teams

Messer and colleagues (2018) argue that, in the field of rheumatology, where clinicians can often find themselves working alone, one strategy to help resolve uncertainty is to ensure consultation with colleagues. Consultation can include asking for advice, or working within multi-disciplinary teams (MDTs) (Messer et al., 2018). The authors argue that this is crucial to 'shape opinion into a consensus' (Messer et al., 2018, p. 268) prior to communicating with the patient. However, as I will argue, working with others may serve to alleviate uncertainty but also involves a further and complex layer of social interaction which impacts on decision-making. Furthermore, consulting between disciplines and with those with differing experience may introduce an element of competing medical authority. I will argue that it is the process itself that resolves uncertainty (through the dynamics of interaction), as consensus offers a way for clinicians to feel more confident in their diagnostic decisions. This section explores research which has examined discourse and interaction in team meetings.

Most healthcare practitioners work in collaboration with others and it is considered especially important due to the growing complexity of healthcare and when dealing with complex or chronic health conditions (Croker et al., 2000). In autism assessment, involvement of the MDT is generally recommended for both children and adults (NICE, 2012, 2011; RASDN, 2013, 2011; SIGN, 2016). However, the team working context can vary between settings and practices. Teams may make decisions collaboratively, or separately and then report back to the team, work with patients as part of the team or use meetings to refer on or receive advice (Higgs and Jones, 2000). In MDTs, skills in communication, experience, understanding of roles and team dynamics can all play a part in team effectiveness (Croker et al., 2000).

There have been many studies which broadly examine the effectiveness of collaborative decision-making in multi-disciplinary healthcare settings and which assess performance and outcomes of such meetings (e.g. Blazeby et al., 2006; Lamb et al., 2011; Pullon et al., 2016; Raine et al., 2014; Strong et al., 2012).

However, for the purposes of this PhD I am particularly interested in studies which examine the collaborative and discursive elements of diagnostic decision-making.

#### **4.4.1 Interaction in teams**

It is argued that the social complexities of medical work problematise attempts at standardisation, including the use of statistical and computerised models (Måseide, 2006). Evidence itself has no meaning without interaction and discourse to make it practically useful (Måseide, 2006). In his study exploring collaborative decision-making in a thoracic ward, Måseide found that evidence is a discursively generated, interactional product, suggesting that although 'aspects of nature' (Måseide, 2006, p. 53) may not change, the meaning of facts and evidence change with their use in discourse. These discourses are made up of voices present and not-present: voices include those of the institution, voices of representation (i.e. of the diagnostic tool) as well as the mediated voices of patients and other professionals. Måseide argues that evidence is grounded in local interaction and 'moral and situational considerations' (Måseide, 2006, p. 53) which are made useful locally, rather than systematic scripts rooted in evidence-based medicine.

Research within a gynaecological cancer MDT identified that clinicians prioritised disease-centred information over patient-centred factors, such as patient choice. The process of diagnosis was affected by the complexity of the case, the make-up of the team, and the extent of participants' agreement (Kidger et al. 2009). Further work in a head and neck cancer clinic identified that the absence of the patient in MDT meetings led to the creation of an 'evidential patient' in discussions which focussed on clinical information, rather than patient-centred information, selectively-reported to steer the discussion one way or another (Hamilton et al. 2016).

Where patients are not present in the meeting, they can be considered as 'implicated actors' (Clarke and Star, 2008): actors who are silent or not present in an action which nonetheless has an impact on their lives. At this stage the patient and family are not actively involved in the negotiation, rather, are re-

represented, re-constructed and 'talked into being' (Nikander, 2003) by the team. In the course of this reconstruction of the patient, diagnosticians may assess the information given on the perceived credibility of the source (Cicourel, 1990) thereby asserting a moral judgement. Hughes and Griffiths (1997) examined how moral and social discourses in a cardiology clinic contributed to ruling in (as deserving) or ruling out (as unsuitable) potential access to resources in the form of surgery or admission to a specialist neurological rehabilitation centre. Subsequent work by Griffiths found that resource pressures also came into play in referrals to Community Mental Health Teams (CMHTs) (Griffiths, 2001). Through a process of implicit as well as explicit categorisation, patients fall in or outside availability for services, which effectively defines the category of mental illness and enacts rationing of services through interaction (Griffiths, 2001).

#### ***4.4.2 Power and epistemic authority***

Some researchers have explored power and epistemic authority (rights to particular knowledges) in MDTs. Smart and colleagues (2018b) consider power both in terms of the privileged power of the psychiatrist in the mental health setting as well as what they term the 'expert power' of the disciplinary specialist. Smart et al (2018b) argue that clinicians have ways of exerting 'power over' those without, either because of traditional hierarchies which place the medical doctor at the 'top', or because of the ability to draw on their own specialist disciplinary knowledge. Epistemic order (focus on specialist disciplinary knowledge) rather than a traditional hierarchy (doctor at the top) provides opportunities for those with the most appropriate knowledge to be heard, and greater equality in discussions (Smart et al., 2018b). In addition, the disciplinary specialist may be able to assert 'encountered authority' (Dew et al., 2015) through having had more personal knowledge of the patient. Considering power in this way shapes it as interactional and fluid; traditional hierarchies can be trumped by domain specific expert power, and, the authors argue, need not be inherently problematic (Smart et al., 2018b).

One study explored hierarchies and potential conflict in a ward round in a teaching hospital. Graham (2009) found that clinicians who might be perceived

as low on an institutional hierarchy, but high on a social/experience hierarchy, such as registered nurses and social workers, engaged in 'mitigating strategies' to deal with potential disagreement. These strategies included deferential strategies (politeness) as well as empowering strategies (claiming authority through social hierarchy as care-giver) in order to disagree with clinicians with perceived higher status in the institutional hierarchy, for example, attending physicians (Graham, 2009). A study on teams in palliative care also found that questioning was used as an interactional device to save face and manage potential tensions (Arber, 2008).

Housley's work on role as an interactional device and resource in team meetings suggests that role is a mechanism by which different types of knowledge are inserted into the decision-making process (Housley, 1999). Examining interaction in social work meetings, Housley argued that membership categories are deployed as decision-making strategies. Team members negotiate and contest role, and, rather than being imposed from above, role is an 'emergent property' of participants' work within meetings (Housley, 1999, p. 10.1). Roles, therefore, are interactively achieved and are contested and dynamic. Housley's later work examines how knowledge is produced through interaction and conversation (Housley, 2000). Rather than occupying clearly defined and static positions, team members work together locally through structured and methodical interaction and discourse to achieve the interactional accomplishment of knowledge (Housley, 2000).

#### ***4.4.3 Clinician interaction in autism assessment***

There is a smaller body of work examining how clinicians assess autism in MDTs by examining interaction. One recent study (Parish, 2019), briefly mentioned in Chapter Two, observed two autism assessment teams in the UK. Parish found that clinicians presented information in an uncertain manner and used strategies to encourage participants to elaborate on information. This study asserts that team decision-making can reduce cognitive bias, as 'conversational cues' that encourage elaboration may make clinicians more attentive to relevant information (Parish, 2019).

The extended body of work by Maynard and Turowetz, which includes discussions without the patient present (termed 'backstage'), has been discussed in Chapter Two and in this chapter in Section 4.3.4. One particular aspect of these backstage discussions noted by the authors, is that the lack of presence of the patient or family enables preparation for later diagnostic delivery to the family. The clinicians are then able to present themselves with a unified and 'jointly determined' response in terms of both the content and style of delivery (Maynard and Turowetz, 2017).

Studies examining discourse, therefore, have the potential to examine how decision-making is socially and interactionally bounded (Halvorsen, 2015) and how decisions are woven with temporal, spatial, sequential and interactional aspects. Examining interaction in decision-making can render problematic the notion of straightforward, context-free decision-making processes (Boden, 1994). Rather, interaction within MDTs are 'occasioned, locally ordered, situated, interactionally achieved resources for getting the day's work done' (Housley, 1999, p. 1.4).

#### **4.5 Concluding comments**

To conclude, studies have shown that, despite best efforts at standardisation, decisions in teams are made through interaction and discourse and therefore are not just *complicated* by social and contextual factors but are, *in themselves*, social products.

The next section outlines the methodological framework for this PhD study and describes in detail the study design of each of the three empirical studies which explore these issues further.



## CHAPTER FIVE: Methods and Approach

*Academic study, but in fact all aspects of experience, are based on acts of classification, and the building of knowledge and interpretations is very largely a process of defining boundaries between conceptual classes, and of labelling those classes and the relationships between them...Seen this way, language ceases to be a neutral medium for the transmission and reception of pre-existing knowledge. It is the key ingredient in the very constitution of knowledge.*

Jaworksi and Coupland, 1999, p. 4



## **5.1 Introduction and overview of chapter**

This chapter describes the methodological and theoretical approach to the PhD as a whole, and then outlines the research question, method and analytic approach for each study.

### **5.1.1 Rationale for PhD**

Diagnosis is traditionally thought of as a way to identify underlying biological problems that cause disease. Scholars working in the field of sociology have problematised that, claiming diagnosis is a social process that involves multiple actors and is context specific (see Blaxter 1978; Brown 1995; Jutel 2009, 2013; Jutel and Nettleton 2011).

The condition of autism is a powerful case study for exploring diagnosis and its meaning: autism has uncertain aetiology, there are no biomarkers in regular clinical use, diagnostic classifications have shifted and expanded and symptoms are considered to be widely heterogeneous. In addition, approximately 70% of people who are diagnosed are considered to meet criteria for at least one other psychiatric condition (NICE, 2011). Furthermore, autism assessment is based primarily on the observation of behaviours which can be ambiguous and dependent on context, and are therefore open to interpretation. I was interested in how diagnosticians manage to be clear and *unambiguous* about the borderlines between classifications.

Autism is considered to be a lifelong condition, and therefore it is important to understand how we assign the label to a person. This has implications not only for the individual and their family, but also for a wider society and how we understand 'normal' or typical behaviour, what we do about it, and how that contributes to the values we have and the judgements we make about people in daily life.

### ***Empirical work in autism diagnostic team interaction***

Previous studies, as outlined in Chapters Two to Four, have explored uncertainty in autism diagnosis, have rendered problematic the concept of

medical classification and examined the construction of conditions in ethnographic work and in patient-doctor interaction. There remains, however, very little empirical work undertaken on how clinicians make a diagnosis of autism together by observing clinical practice in situ. In particular there is little research on how clinicians work together in team meetings to resolve uncertainties inherent to diagnosis of the condition. I have found three exceptions to this. Firstly the extensive work of Maynard and Turowetz explores the process of autism assessment of children across two time spans, including multi-disciplinary 'pre-staffing' meetings – case conferences where the patient and diagnosis is discussed. This body of work examines the way in which a clinical category of autism is constructed by, and for, diagnosticians in the clinic, through talk. However, this work is entirely within a US context and with diagnosis of children. Further work by Rossi (2012) represents an important contribution to the field and again examines diagnosis of children in a US context. Finally, Parish (2019) observed MDT meetings in children's services in the UK where diagnosis of autism was discussed. However, this work, whilst an important insight into working practices, does not consider the findings in relation to wider debates around medical uncertainty or the construction of disease categories.

I was keen to include adult assessment in this PhD study as this is a particular gap in the literature. The increased trend towards diagnosis of adults in the UK suggests that, as an institution, medicine has a warrant to retrospectively explain a person's behaviour within a contemporary understanding of autism. By this I mean that someone who might not have been considered autistic in the past, or have had access to an autism assessment, can now have their historical behaviour assessed in the light of contemporary understandings of the condition, rather than the understanding that might have been commonplace in their childhood. This has implications for the assessment process. There is less likelihood of accessing a well-documented developmental history for an adult, for example, therefore there is an increased reliance on a patient or family's version of historical events.

### ***Social factors in diagnosis***

I was interested in the social factors, or social framing, embedded in the diagnostic process of autism. My understanding of social factors was initially influenced by a study of the barriers to accurate diagnosis of heart failure in primary care settings (Fuat et al., 2003). This study informed an understanding of 'social factors' which included time constraints on clinicians, lack of availability of tests, patient preference and training limitations. However, as the project progressed, the concept of social factors broadened to include, for example, the interaction between clinicians and other agents such as the diagnostic tool, or non-present patient (for discussion of this conceptual shift, see Section 5.8).

From the literature review, I became interested in how clinicians negotiate ambiguity and uncertainty in assessment, and felt that this would give some insight into the contemporary meaning of autism and its social framing.

I chose to observe team meetings where diagnostic decisions were made. Although partly pragmatic, in that observing the whole assessment process would not have been possible within the scope of the PhD, the team assessment meeting is one that typically takes place 'backstage' (Goffman, 1959; Maynard and Turowetz, 2017) without patients present. Therefore, this meeting is a place where clinicians can talk about the patient and the condition without recourse to shaping the discourse in a way that is acceptable or understandable to the patient. Consequently it is a place where I considered it would be possible to gain some insight into how clinicians draw on, and shape, meaning in the diagnostic process and autism, collectively. Here is where we see diagnosis 'in the making' (Maynard and Turowetz, 2017).

The core of the PhD, therefore, was designed as an observational study, with supporting studies to include a review of clinical guidelines and a set of interviews. The research questions were kept deliberately broad to enable an exploratory approach.

### **5.1.2 Study Design**

#### ***PhD Aims and Objectives***

The aims of the PhD were to explore social factors in autism diagnosis in secondary care; and to understand how clinicians collaboratively make diagnostic decisions in autism assessment. The thesis had the following objectives:

- a) To undertake a review of clinical guidelines in use in the UK and consider where, within those guidelines, social factors and influences are taken into account (study one)
- b) To document and analyse discussions made in MDT meetings (or local equivalent) to identify social and interactional processes (studies two and three)
- c) To gather views and experiences of clinicians involved in the diagnostic process via interviews (study four)
- d) To contribute to a social understanding of diagnosis

#### ***Research Questions***

The PhD asked the questions:

1. What **diagnostic guidelines** are available for clinicians assessing children and adults for autism in the UK; and how does guidance reflect social factors and influences?
2. How do healthcare professionals **make diagnostic decisions** in specialist autism assessment team meetings?
3. How do clinicians **understand autism and diagnosis** in secondary care?

The PhD project comprised four inter-related studies:

- a) Review of clinical guidelines, existing diagnostic classifications and assessment processes to map the social process of diagnosis and identify potential social influences (study one)

- b) Observation of specialist autism assessment team meetings where diagnostic decisions are made to identify themes (study two) and interactional processes (study three)
- c) Interviews with clinicians involved in the diagnostic process to explore understandings around autism and diagnosis (study four)

The four inter-related studies were designed to inform each other. The clinical guidelines review provided a context for the other studies, in that it produced a potential reference point and also enabled an informed approach when interviewing clinicians and observing meetings. The interviews and team meetings observation happened concurrently, with data collection taking place between October 2017 and October 2018. A visual representation of the PhD can be found at Figure 9, although it should be noted that there was some time overlap between data collection and analysis.

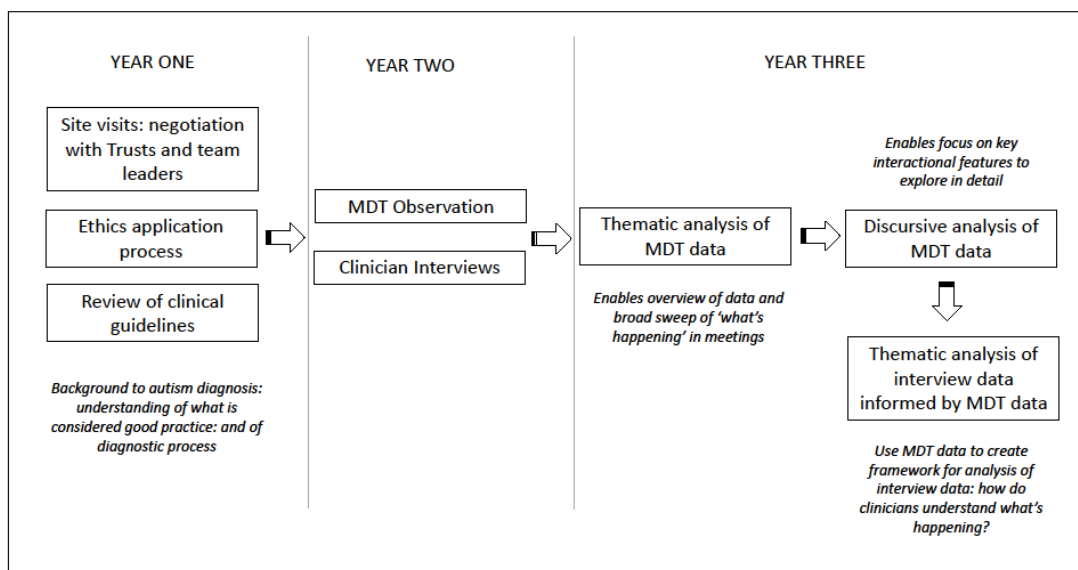


Figure 9: Overview of PhD study

## 5.2 Recruitment and selection of assessment services

### 5.2.1 Recruitment

Autism diagnosis is generally undertaken by multi-disciplinary teams (MDTs) in secondary care, comprising a range of health professionals including, for example, psychologists, psychiatrists, occupational therapists and specialist

nurse practitioners. I therefore recruited to include specialist autism assessment teams in secondary care. I purposively sampled to ensure both adult and child settings to include a range of sites in the study.

Ten sites in total were considered for inclusion after promoting the study through a list of contacts drawn together by the wider *Exploring Diagnosis* project and through the NIHR Clinical Research Network. Two sites were excluded due to the absence of regular diagnostic decision-making meetings and one site decided they were unable to be part of the study due to other commitments. Three further sites expressed interest in the study but were excluded for reasons of geography.

Four sites (teams) took part in the study, two of which were adult autism assessment services, two of which were children and young people's (C&YP) assessment services. One of the C&YP sites specialised in adolescent assessment (14+). All sites were in the south of England and were NHS providers within NHS Health Trusts. Although I had initially assumed all teams would be multi-disciplinary, one team was single-disciplinary. However, I decided to include this team in the study as the setting met the inclusion criteria outlined in Section 5.2.2. I consider some of the implications of the 'single-disciplinary' approach in Chapter Ten.

A limitation of the study was that sites were primarily self-selecting, and further selected by myself on the basis of locality for practical reasons of access. Details about sites and settings are given in Section 5.2.4.

### **5.2.2 Inclusion criteria**

To take part, teams had to be engaged in autism assessment and be made up of healthcare professionals actively engaged in autism assessment in secondary care. Participants took part in both the interview and observation study.



### **5.2.3 Sampling, saturation and information power**

The qualitative concept of 'saturation' is generally used to decide when data collection should cease. Data saturation is based on the point at which additional data fails to generate new information (Morse, 1995). However, this term makes the positivist assumption that it is possible to reach definitive and truthful conclusions from more data (and a specific amount of it) rather than less data (Braun and Clarke, 2013) making it more problematic to apply to a study with constructionist roots (Malterud et al., 2016). (See section 5.4 for discussion of my theoretical perspective). Furthermore, the concept of saturation is drawn from a particular methodology (grounded theory) and is therefore not always applicable to other qualitative methods or consistently applied (Malterud et al., 2016).

Instead I used Malterud et al's concept of 'information power', which is a way in which researchers can more clearly specify the sampling strategy to demonstrate how it might meet the aims of the study (Malterud et al., 2016). This concept suggests that with data that are very rich (with greater information power), fewer participants are required. How much data are required depends on the aim of the study, sample specificity, use of established theory, quality of dialogue and analysis strategy. Malterud et al (2016) propose, therefore, that the focus for sampling should be on the potential for acquisition of new knowledge rather than number of participants.

In this study, although my research aim was broad (how clinicians make collaborative diagnostic decisions), my sample specificity was narrow and specialist (clinicians involved in diagnosis) and I was able to involve a range of clinical disciplines within a smaller number of meetings/participants. My aim was exploratory, but the theoretical framework within the sociology of diagnosis field meant that the focus was highly specific. My data were to be analysed in detail on a case by case basis, with a discursive analytic strategy, meaning that fewer participants would be required.

Nevertheless, an anticipated number of participants and meetings was required for planning purposes, therefore I planned for twenty meetings across four

teams on the basis that this would give me the data required to undertake a productive analysis and be manageable within the scope of a PhD study. However, after eighteen meetings I felt the data was adequate to meet the aims of the study on the basis that this is an exploratory study with the aim of offering new insights within the sociology of diagnosis framework. The number of interviews (sixteen) was restricted to participants in the observation study.

#### **5.2.4 Site details**

A summary of each of the four teams can be found in Table 6.

##### **Adult Site 1**

Adult Site 1 is a specialist Adult Autism and ADHD (Attention Deficit Hyperactivity Disorder) Assessment team. The team is commissioned to provide adult assessment services across two NHS Clinical Commissioning Groups (CCGs) with a total population of approximately 1.17 million served by 146 GP practices. The team provides screening, assessment and diagnostic services, training and support for other trust staff, signposting to other services and a support group for those diagnosed.

Unusually for this study, the team is a (primarily) single-disciplinary team made up of Clinical Psychologists. There is an occasional attendance from other professionals (Peer Support Worker, Police Officer) primarily for observation purposes. Cases are brought to a weekly Case Review Meeting (CRM) for discussion with team members. Five CRM meetings were observed.

##### **Adult Site 2**

Adult Site 2 is a specialist Adult Autism Assessment team established in 2015. The service offers diagnosis to adults who have no previous diagnosis of learning disability, as well as brief interventions and advice. The team is commissioned by the local CCG to provide adult autism assessment services across an area made up of 42 GP practices with 322,616 registered patients. The population is diverse and highly transient with approximately 37% of children in the Borough affected by poverty.

Site	Team make-up (not all team members at every meeting: visitors in italics)	Rural or Urban	Frequency of meetings	Purpose of meetings	Average number of cases discussed at each meeting	Criteria for referral	Main diagnostic tools and diagnostician
Adult Team 1	Clinical Team Manager; Clinical Psychologists (CPo) (x4), Assistant Clinical Psychologists (ACP) (x3); <i>Peer Support Worker</i> . (Occasional input sought from other professionals outside the team).	Rural	Weekly	To discuss selected cases for assessment (referrals dealt with separately)	2.2 (assessments)	Over 18; registered with GP in area; Include LD if able to manage assessment process; must not have been previously assessed.	ADOS (ACPo); Adi (CPo)
Adult Team 2	Team Manager (TM); Consultant Psychiatrists (CPi) (x2); Occupational Therapist (OT); Medical Secretary; <i>Social Worker; Speciality Doctor; STS Psychiatrist</i> .	Urban	Weekly	To discuss all cases for assessment and decide on referrals	4 (assessments); 6 (referrals and administrative discussions)	Over 18; registered with GP in area.	ADOS (OT or TM); ADi-R or 3Di (CPi)
C&YP Team 1	Clinical Team Manager (CTM); Consultant Psychiatrists (CPi) (x2); Clinical Psychologist; (CPo) Senior Manager (SM); Speech & Language Therapist (SLT); Educational Psychologist (EP); Autism Practitioner (AP) (x2); Senior Administrator.	Rural	Monthly with further 'mini' meetings as required	To discuss selected cases for assessment	4 (assessments); 2.6 (referrals and administrative discussions)	Children and young people up to 18	ADOS (CTM or SLT or AP); 3di or other interview (CPi or CPo)
C&YP Team 2 (14+)	Consultant Psychiatrist (CPi); Clinical Psychologist (CPo) (x2); <i>Clinical Psychologist; Senior Nurse; Foundation Doctor</i> .	Urban	Weekly	To discuss current case for assessment (referrals dealt with separately)	1 (assessment)	Young People aged 14 and over; must be registered with GP in area	ADOS (CPo); 3Di (CPi)

Table 6: Site details

*(Adult site 2 continued)* The team is multi-disciplinary and made up of part-time staff who also work in other services such as the Learning Disability team. Four meetings were observed.

### ***C&YP Site 1***

C&YP Site 1 is a specialist children and young people's Autism Spectrum Assessment Service. The multi-disciplinary assessment service was established in 2012, with diagnosticians drawn together from different services. The dedicated specialist autism assessment team as currently constituted, however, was formed more recently and since 2017 has been part of CAMHS. A lead clinician undertakes preparatory work which determines the type of assessment required (complex or straightforward, for example). The assessment outcome can happen through discussion on the day of assessment, or, for more complex cases, at an MDT meeting.

The team is part of a wider assessment service which comprises 128 GP services across a population of 1.2 million. Since inclusion in this study, the service has undergone changes due to a new alliance of NHS Trusts which may have impacted on working practices. Five meetings were observed.

### ***C&YP Site 2 (14+)***

C&YP Site 2 is an adolescent autism assessment clinic which sits within specialist CAMHS in a large city and was established in 2014. The specialist team is separate from the under-14 multi-agency children's service to ensure that adolescents who are likely to have additional mental health difficulties or other co-conditions benefit from this specialist team. The service covers a geographical area which comprises 42 GP practices with 322,616 registered patients. The team provides assessment and a psychoeducation group for parents. Four meetings were observed.

### ***Assessment pathway in participating sites***

There were some differences in the diagnostic pathway within different teams, for example, in children's services, referrals could come from a paediatrician. However, the pathway was broadly similar for all teams and tended to differ

within teams depending on the complexity of the case (See Figure 10). For example, further tests or information were sought if there was a lack of clarity, complicating co-conditions or difficulty conducting the assessment. All teams had a core assessment which utilised a form of clinical interview and an ADOS assessment and, wherever possible utilised further developmental information or reports. One team (Adult Team 1) regularly used other tests such as ‘Reading the mind in the eyes’ test (Baron-Cohen et al., 2001a) for more complex or uncertain cases.

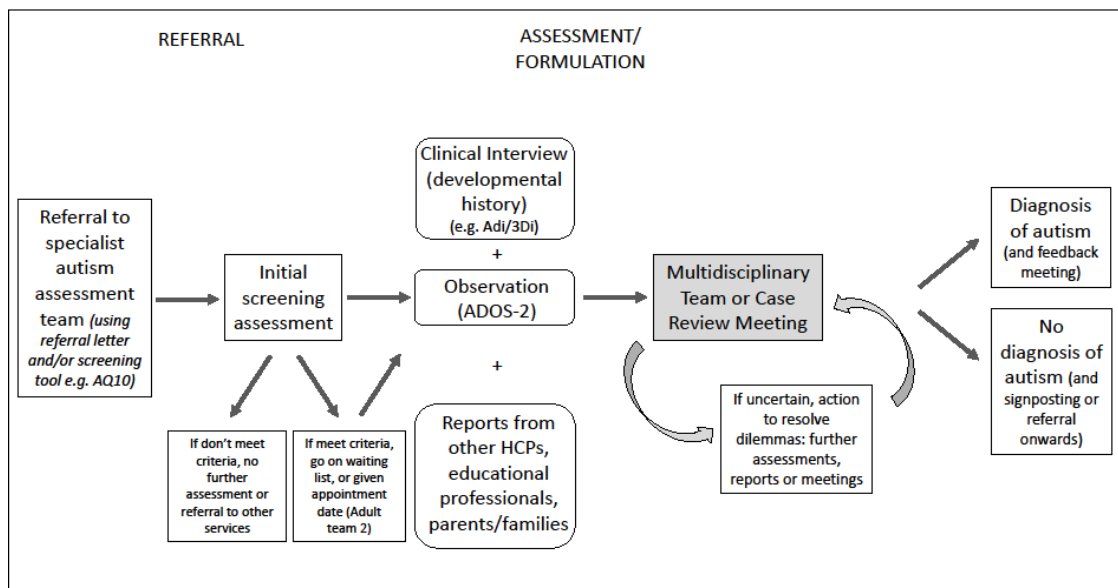


Figure 10: Autism assessment pathway in participating sites

### 5.3 Ethics and consent

Ethical approval was granted by the University of Exeter Medical School (UEMC) ethics committee in March 2017 (Ref: Mar17/B/114) and by the Health Research Authority (HRA) (Ref: 220180) in July 2017 for the observation and interview studies (see *Appendix 2: Ethical Approval*). The review of clinical guidelines was not subject to ethical approval.

An application to be included in the NIHR (National Institute of Health Research) portfolio was granted in August 2017. Approval for further sites was applied for and granted by HRA in April 2018. Local agreements and reporting

mechanisms were established on an individual basis with all Trusts involved in the project.

### **5.3.1 Participant Consent**

For both the observation and interview study, sites were sent an information pack prior to participation which included participant information sheets (*Appendix 3: Participant Information Sheets*) and consent forms (*Appendix 4: Participant Consent Forms*). I made visits to teams, or had detailed phone conversations prior to recording to ensure that everyone understood the consent and confidentiality procedures. Agreement was made about dates and the number of times I would attend to record meetings and conduct interviews. All participants were able to contact me directly with any queries or concerns.

For the observation study, consent form and information sheets were available at every meeting in the event of new participants attending. Full consent was obtained prior to recording. In addition, a meeting attendance sheet was distributed and completed (*Appendix 5: Meeting Attendance Sheet*).

### **5.3.2 Patient Consent**

The study was focussed on how staff work together and I had no direct contact with patients. It was therefore agreed by both UEMC and HRA Ethics Committees that we should observe strict patient confidentiality and anonymity procedures, but that individual patient consent was not necessary for this study. In another study examining healthcare meetings where the patient is absent, it was considered to be unethical to seek patient consent as it may increase pressure on the patient (Smart et al., 2018a). Each site managed its own consent procedure for patients discussed in meetings.

### **5.3.3 Anonymity and Confidentiality**

Steps were taken to ensure patient anonymity. No identifying information about patients (name, NHS number, date of birth, address, postcode or GP registration) were recorded as part of this study and access to patient records was not required. Data were anonymised with patient ID numbers replacing names (where identified) on data collection (see pro forma at *Appendix 6:*

*Patient Data Form*). Names and identifying information of patients were 'bleeped out' from the audio recording. Any non-anonymised audio (e.g. on video recordings) was stored on an encrypted secure drive accessible only at the University site. Data (audio and transcriptions) were stored on a secure drive accessible only to myself for the course of the PhD study. The video and audio data files and accompanying transcriptions were identified by a meeting ID number. Pseudonyms for participants and patients were used in all transcriptions, data analysis, and reporting.

It is a condition of funding that the data be made available for open access. To protect patient and clinician confidentiality the data was further anonymised before archiving with the UK Data Service (<http://reshare.ukdataservice.ac.uk/>). An additional security measure was put in place which necessitates a request for data access prior to use.

## **5.4 Theoretical perspective**

### **5.4.1 Social constructionism**

The study took a social constructionist approach within a sociology of diagnosis framework. The sociology of diagnosis framework assumes that diagnosis cannot be separated from wider influences of human agency and deliberation (Jutel, 2011). This approach challenges the taken-for-granted fit of diagnostic categories to their conditions and instead considers them as socially framed and shaped by wider social forces and interaction (Brown, 1995). This approach is discussed in detail in Chapter Two.

Epistemologically, I worked from a position which assumes that meaning is socially produced and reproduced rather than being primarily located within the individual (Burr 1995). This social constructionist approach makes the epistemological assumption that we create meaning collectively through our interactions and experiences of the world, whilst at the same time acknowledging that we experience the world as 'real'. In this sense, the project recognises the experiences of autistic people and families and friends, as well

as healthcare practitioners. However, it also interrogates the meaning we create around the experience of 'being autistic', the societal judgements and assumptions we make about those with the condition as well as the process of diagnosis. As articulated by Hacking, one definition of social construction is that an entity (such as mental health and how we understand it) could be constructed differently (Hacking, 2000). It is possible, therefore (as can be seen through the history of our understanding of autism), to take different positions on what autism means and how behaviours are interpreted. My constructionist approach, therefore, means that I approached the PhD project by exploring how autism is constructed through the work of clinicians, rather than examining how clinicians identify autism as a condition.

#### **5.4.2 Social constructionism and relativism**

One difficulty with social constructionism is that it considers that there is no one 'truth', rather there are different constructions of reality which depend on specific cultural and historic factors (Burr, 1995). This relativist approach is problematic for critical approaches to examining data: it renders all viewpoints as equally valid or invalid. But as researchers, by asserting our own analysis as valid, we render others less valid. However, social constructionism is concerned with how knowledge is produced by and through culture, language and discourse, therefore is an important core 'value' for examining how language both constructs and is shaped by institutions and social conditions.

Therefore, unlike more radical approaches to social construction, I also borrow from the work of Elder-Vass (Elder-Vass, 2012a, 2012b) who advocates for a socially constructionist realism (or realist social construction). Although this approach comes from a critical realist position, it embraces the notion of social construction and asserts that it is possible for (some versions of) critical realism and social constructionism to be compatible. The critical realist approach argues that all events are caused by 'multiple interacting causal powers' which includes individuals and institutions (Elder-Vass, 2012a). The combination of 'powers' is always contingent and therefore critical realism is anti-positivist in that happenings or entities cannot be regular or entirely predictable (Elder-Vass, 2012a). However, I refrain from taking a fully realist approach to the extent that I



consider that entities cannot easily exist independently of how we think or speak about them. This is not to say that, for example, pain isn't 'real' for the person experiencing it; rather pain and our understanding of pain differs according to culture, environment and historical period. My interest is not in whether autism exists or not as an independent biological entity, but in how we understand autism as a condition and its diagnosis, and what that means for those experiencing both autism and diagnosis, as well as for wider society.

The way in which we come to 'know' some entities over others is rooted in power relationships and histories, therefore, we can challenge the orthodoxy of what is known and how it is known by taking a critical and constructionist approach to research. This approach does not privilege one view over another; however, it does seek to consider those views that might not otherwise be privileged or foregrounded.

## **5.5 Discursive Psychology Analysis and Social Construction**

### ***5.5.1 Discursive psychology***

A social constructionist approach to the study aligns with the method of analysis of study three, discursive psychology, and, to a lesser extent, study two.

Discursive psychology is concerned with how particular versions of reality are constructed, negotiated and deployed in conversation (Willig, 2008). This approach moves away from an interest in cognition or underlying mental states and instead seeks to understand how knowledge is 'talked into being' through discursive devices (Willig, 2008).

Discursive psychology takes a relativist position, in that there is no one 'truth' about the world, rather there are different discursive constructions of the world that are enacted through language specific to particular settings and conversational contexts (Willig, 2008). Our objects of study cannot be separated from our representations of them (Wiggins, 2017). Importantly, the researcher plays an active role in the construction of knowledge and acknowledges that their analysis is only one way to consider the phenomena in question. The

version of discursive analysis utilised in this PhD is one in which discourse is examined to understand how participants use language to achieve particular social actions and objectives, such as blame or accountability.

At its simplest, discourse can be considered to be any form of spoken or written language (Wiggins, 2017). Burr extends this to define discourse as ‘a set of meanings, metaphors, representation, images, stories, statements...that in some way together produce a particular version of events’ (Burr, 1995, p. 48). Discourse analysts emphasise that exploring language *in use* helps us to understand how the language we use is embedded within social, political and cultural frames, and how it both reflects and shapes social order (Jaworski and Coupland, 1999). Exploring discourse in the specific context of diagnostic assessment meetings therefore, enables us to examine how language is used to shape the diagnostic process, to make day-to-day decisions and, as Jaworski and Coupland would argue, to constitute knowledge of the medical category of autism (Jaworski and Coupland, 1999).

Discourse is both constructed and constructive of reality, is situated in a particular context (Wiggins, 2017) and expressed through cultural resources such as words, gestures and ‘culturally available phrases and expressions’ (Wiggins, 2017, p. 10). This relativist approach means that we question how we know what we know about the world and how that understanding is shaped by social practices (Wiggins, 2017).

### **5.5.2 Discourse in medical settings**

In relation to health and wellbeing, as a society we have constructed (and continue to shape and construct) a sense of what it means to be healthy and, in contrast, what it means to be unwell. This construct is only in part related to people’s symptoms of disease; whilst diagnostic classification systems could be considered to be objective measures of physical and mental illness, they have themselves already been shaped, or constructed, by society and are dependent on human interpretation in each moment of diagnosis or assessment. In this way, discourse (how we name and talk about entities) shapes reality, and our ongoing engagement with those entities continues to mould and shape their

meaning depending on the contemporary political, economic, health and social context.

In diagnosis, the clinician comes to the diagnostic moment with a history of specialist training and experience, and their ability to diagnose is specifically framed by this experience. Their process of diagnosis – from the moment of reading medical notes, meeting the patient, assessing the patient, discussing assessment with co-clinicians, through to diagnostic delivery, use of particular diagnostic tools, and recommendations for treatment – is only possible by drawing on meanings and understandings that are currently culturally available to allow this process.

The medical condition, therefore, is constructed through the sense-making practices of particular groups of people, at particular times, in particular contexts. In autism, one aspect of how clinicians jointly create the category of autism is through how they discuss the condition together in assessment meetings. Lay people can only speculate about diagnosis (and frequently do) but, no matter how knowledgeable, they lack the recognised framework of expertise to definitively diagnose (because that is exclusively linked to training and role) as well as society's permission to hold the privileged position of being able to bestow diagnostic labels on individuals. Ultimately only clinicians have the warrant to diagnose because society has framed diagnostic power within a context of health provision, attached to specific specialist health practitioners and tied to a specific classification framework.

### ***5.5.3 Key concepts in discursive psychology***

Wiggins argues that discourse is situated within specific interactional contexts, a rhetorical framework, and the turn-taking sequence of interaction (Wiggins, 2017). I will briefly explore all three aspects here and their relevance to this study.

#### ***Context***

The context of talk frames the talk itself. Each setting for talk has its own rules, allowances and prohibitions which we learn to adopt and adhere to. So a

conversation between friends has its own, perhaps informal, rules and, in addition, each participant may have a specific role. In institutional contexts, such as in the clinic, rules and roles are more explicitly framed and delineated. There are expectations of the clinician in this role which are different from those of the patient which, in turn, differ from those of the administrator, and these in themselves differ inside and outside the clinic. Within each of those categories too, individuals performing different roles will have within that role different expectations at different times. What each individual says in that context is not only produced by the context but shapes it (Wiggins, 2017). This creates a set of social practices which become the 'norm' for interaction in that context and create meaning which is jointly understood.

For example, in the assessment meeting, the way in which a clinician describes the behaviour of a patient is both shaped by the setting and shapes how the rest of the team, in context, consider the assessment of that person. Even allowing for individual differences of presentation, experience, enthusiasm or knowledge, a pattern of discursive interaction is present which is framed by, and frames, the social action of the meeting: the assessment decision.

### ***Rhetorical framework***

Discourse constructs one version of events over and above others and, although it can appear that there can be only one version and therefore one outcome, by constructing that one path, other, alternative versions are undermined (Wiggins, 2017). If discourse in context, therefore, shapes our understanding of reality, then it can be assumed there are potential different understandings of that reality that could have been utilised (Wiggins, 2017). The assessment process for diagnosis of autism constructs the choice available to clinicians as 'this person has autism' or 'this person does not have autism'. Rhetorically, the choice for clinicians in this context is a binary one. The diagnostic moment does not allow for a diagnostic outcome to be 'a little bit autistic', or 'almost autistic but not quite', or 'not autistic now but perhaps in the future': these outcomes, although possible, fall under 'not diagnosed'. Simultaneously, and perhaps paradoxically, however, the complexity of clinicians' discussions, their experience and their clinical understanding allow

for all these options. So whilst there may be discussion of autistic 'traits', or of 'nearly meeting the threshold' in assessment meetings, an individual emerges from this process with a diagnosis of autism or not: traits, uncertainty or 'watch and wait' are not, diagnostically, autism, even although they may be available as outcomes.

The rhetorical 'allowance' in the clinic, therefore, is for one thing or another (having autism or not). This production context of rhetorical allowances is key to diagnostic decision-making based, as it is, in one version of reality which defines the process: this person can only be one thing or another and here are the criteria by which we need to assess this. Clinicians construct one version of reality, one coherent narrative, which then becomes reality. However, in the assessment meeting, it is also part of this rhetorical framework (if not the rhetorical allowance for diagnosis of autism) to allow for uncertainty, dispute, disagreement, co-conditions (i.e. more than one thing) and a range of other complexities. In assessment meetings, the social practice of diagnosis allows clinicians to deal with the paradox (and impossibility) of the binary choice by using the discursive device of narrative construction.

### ***Turn-taking***

Examination of the way in which people take turns in talk and what they say – the 'indexicality of utterances' (Wiggins, 2017) – is situated in relation to what is said before and after each utterance. What we say and how we say it is created in response to what goes before and in anticipation of what might come next. Through this we can support (affirm) another's preference or assertion or disagree with it. This process is key to reaching consensus in groups and is a social psychological process by which we negotiate and assert our preferences, our relationships, our roles and needs or requirements. Consensus and how this comes about is made through turn-taking in discourse.

To conclude, this PhD study takes the position that how we name and talk about entities (in this case, a patient or a condition for example) is not a passive process through which we objectively report a self-contained piece of information; it's a context-bound social interactive process through which

actions such as consensus, decision-making and disagreement are accomplished via talk and which, in turn, confirms the meaning of the entity itself (Wiggins, 2017). By taking a discursive approach I was able to examine how the particular rhetorical context of the diagnostic assessment meeting frames the diagnostic process and gives it meaning. Furthermore, this approach helped me to understand the particular and time-specific understanding of the condition of autism and what it has come to mean.

## **5.6 Introduction to PhD Studies**

I adopted a qualitative methodology throughout this PhD as I was interested in both the meaning of diagnosis and autism, as well as the everyday practice of autism diagnosis. Examining qualitative data allows for ‘thick description’ (Geertz, 1973) of rich data and utilising naturally occurring data alongside interviews allows the opportunity both to explore the meaning of diagnosis and of autism; and to examine issues of language and the construction of meaning through discourse (Silverman, 2004).

Study one comprised a narrative review of clinical guidelines and was the first study undertaken whilst applying for ethical approval, recruiting teams and building relationships with NHS Health Trusts. Studies two and three are drawn from observational data in autism assessment teams and comprise two different analyses (one thematic, one discursive), with discrete write-ups (Chapters Seven and Eight). However, as analysis took place concurrently and iteratively, and the thematic analysis was informed by a discursive approach, the methodological detail of these studies are described together below (Section 5.9). Study four comprised an interview study.

## **5.7 Study One: Review of Clinical Guidelines for Autism Diagnosis**

### ***5.7.1 Purpose of study and methodological approach***

Prior to undertaking my main study, the observation of assessment teams, I undertook a review of diagnostic guidelines. The review aimed to enable understanding of what is considered to be good practice in autism diagnosis, what the process of diagnosis involves, and how guidelines deal with what I define as 'social factors'. This helped me to understand the diagnostic context for autism assessment in the UK and (later) to consider actual practice in relation to these guidelines.

A scoping search and qualitative narrative analysis with a systematic search strategy was chosen for this study as I wanted to tell the 'story' of diagnostic guidelines as a set of texts which shape diagnosis. A full methods outline is in the published article in Chapter Six.

### ***5.7.2 Research Question***

*What diagnostic guidelines are available for clinicians assessing children and adults for autism in the UK; and how does guidance reflect social factors and influences?*

### ***5.7.3 Data Collection***

Data collection details, search strategy and inclusion/exclusion criteria are outlined in the published article, Chapter Six.

### ***5.7.4 Analysis and definition of social factors***

A detailed outline of my data extraction framework and analysis is outlined in the published article as above. A process of inductive analysis was undertaken based on social factors and influences and a narrative review was written. Social factors were defined, for the purpose of this review, as socially related phenomena that influenced diagnosis, and drew from three areas as outlined by Jutel and Nettleton (2011): diagnosis as a process, as a category and the consequences of diagnosis. I included factors that were relevant to multi-disciplinary working or parental/family influence (the process of diagnosis); the potential outcomes of diagnosis for the

patient and how clinicians may take this into account (the consequences of diagnosis); and how issues around classification shape the diagnostic process such as how borderline cases are dealt with (diagnosis as a category).

The write-up of Study One can be found in the published article at Chapter Six.

## **5.8 Social factors in diagnosis: a conceptual shift**

As outlined in Section 5.1.1, the PhD study began with a concept of ‘social factors’ that was primarily influenced by a study of the barriers to accurate diagnosis of heart failure in primary care settings (Fuat et al., 2003). This study found that there were three categories of difficulties experienced by clinicians: uncertainty about clinical practice; lack of awareness of relevant research evidence; and influence of individual preference and local organisational factors (Fuat et al., 2003). This study informed my understanding of ‘social factors’ which included time constraints for clinicians, lack of availability of tests, patient preference and training limitations.

My operational definition of social factors, therefore, was defined as socially related phenomena that influence or contribute to the diagnostic decision-making process. I used the term ‘social factors’ to consider those aspects of interaction in meetings which seemed to sit *beyond* discussion of clinical symptoms, or to blur the boundaries of diagnostic categories.

The first study, the guidelines review, suggested that there were a number of areas of uncertainty in autism diagnosis where social factors might come into play. I found that diagnosis, despite how it is overtly presented in guidelines as a largely mechanistic process involving a series of tests and assessments, is a social process that is underpinned with uncertainty resolved by clinical judgement (Hayes et al., 2018).

During the analysis of study two, a conceptual and methodological shift developed as a result of reading around sociological concepts of diagnosis,



medicalisation and interaction, as well as helpful feedback from reviewers of an early version of article two. This brought the project more in line with a social constructionist perspective.

First, to consider social factors as 'beyond' clinical symptoms became conceptually flawed within the context of relevant literature to the study. As an anonymous peer reviewer noted:

*Healthcare professionals don't just report or narrate symptoms, but actively constitute them through their deliberative work. It is not that symptoms aren't 'real' but rather that they're inseparable from the methods used to discover them, including storytelling. (Peer reviewer, article two submission, April 2019)*

To consider social and clinical factors as separate entities then became problematic because this conceptual shift determined that what I was previously considering as clinical 'symptoms' are entirely dependent on how society chooses to collect them together to create a condition. For example, 'repetitive interests', both a behaviour and a clinical symptom, is dependent on how we tell the story about someone's interests. An 'intense' interest in model railways or insects in the context of a clinical discussion may be considered as disordered autistic behaviour; but an athlete with an intense focus on training to win a race might be interpreted, in a different context, as competitive and determined, although their behaviour, in reality, may also be repetitive.

Second, I took an inductive approach to analysis. I wanted to see what was happening in the data without squeezing out factors that did not fit with my operationalisation. If I limited myself to looking at factors that I considered to be 'above and beyond' clinical symptoms as outlined in criteria and guidelines, I would be both ignoring how those symptoms are in themselves socially created and narrowing my gaze on the data.

Finally, it became apparent that taken-for-granted clinical concepts and processes such as 'clinical judgement' or 'clinical intuition', are clearly and simultaneously a 'social' factor, making a separation of 'clinical' and 'social' meaningless.

As social factors are inseparable from the wider context of diagnosis (in that diagnosis *is* a social process, informed and shaped by culture, society, history and the institution of medicine; and contributing to it), an ‘operationalisation’ of social factors became problematic. My working concept of social factors became more fluid and rooted particularly in concepts of interaction and how meaning is made through that interaction. I adopted an alertness to a social process of interaction in which the condition of autism and the process of diagnosis are inseparable from the way in which it is talked about. Later articles (Chapters Seven, Eight and Nine) reflect this change in thinking.

## **5.9 Studies Two and Three: Team Meeting Observation**

### ***5.9.1 Purpose of study and methodological approach***

I wanted to examine how diagnostic decision-making happened in practice and to explore the interactional processes within the decision-making process. I chose to utilise naturally occurring data as this enables exploration of real-world practices underpinning healthcare (Kiyimba et al. 2019). It provides data which is ‘context-rich’ and minimises the active role of the researcher in shaping the data (Kiyimba et al. 2019; Potter 2002). Using naturally occurring data to examine interaction enables analysis of both the ‘how’ (interactional sequences) and the ‘what’ of talk, enabling then an exploration of ‘why’ (Silverman, 2013).

I chose to examine clinician interaction (without the patient present) as this involved an aspect of diagnostic decision-making that is rarely observed and allowed exploration of how clinicians work together to come to a consensus. Given the literature review and findings in study one, I also became interested in how clinicians resolve potential uncertainty and ambiguity in autism assessment.

A hybrid qualitative discursive/thematic methodology was chosen for this study. I was interested in both the content of discussion and the way in which diagnosis was discussed and agreed on collaboratively.

Details of data collection and method of analysis are outlined in two articles which are at Chapters Seven and Eight. Here I give a more detailed account.

### **5.9.2 Research Question**

*How do healthcare professionals make diagnostic decisions in specialist autism assessment team meetings?*

I should note here that, prior to the conceptual shift outlined in Section 5.8, I had been working with a broad research question which included the term 'social factors' (*How do social factors play a role in diagnosis in specialist assessment team meetings?*). I decided that the term 'social factors' suggested the possibility of a separation of clinical and social factors, which had become problematic, so removed the term at this stage.

### **5.9.3 Data Collection**

Data collection took place over a period of ten months across four sites during 2017-18. Assessment team meetings were observed, audio-recorded and field notes made. Where possible meetings were also video-recorded although this was primarily used to aid accuracy in identifying individual voices in group discussions, especially in situations where multiple voices interrupted each other, rather than for analysis. An observation strategy was developed (See *Appendix 7: Observation Strategy for Meetings*).

The number of participants at each meeting ranged from 2 to 6. The number of cases discussed at each meeting ranged from 1 to 9, and in total the observations provided data related to 88 cases, documenting over 19 hours of meeting time. 13 cases discussed were at the referral stage and 24 were classified as administrative discussions, primarily relating to booking dates for assessments or action other than assessment. These two groups were excluded from analysis as they did not involve direct decision-making about diagnosis. The final analysis included a total of 51 cases - 24 children and young people and 27 adults (See *Appendix 8: Characteristics of All Patient Cases*).

#### **5.9.4 Analytic Overview**

The study took an inductive approach to observational data, with analysis beginning during data collection. This enabled a 'dialectical interaction' between data collection and ideas (Hammersley and Atkinson, 1995). For example, early in the observation it was noted that the way in which clinicians discussed the wishes of the patient or family appeared to contribute to the trajectory of the discussion. This observation enabled a memo to be written about this potential area of interest, and to consider whether or where this discussion appeared in future meetings. This allowed for expansion of the memo as the data was analysed, including reflections on where this did not arise and what difference this might make. Ultimately some early ideas were dismissed because they seemed less important as data were collected, or they were developed further as a major analytic concept. Initial ideas and hypotheses from early data collection and analysis were continually refined and reformulated as the study progressed, iteratively informing later data collection and analysis.

In addition, early analysis allowed for the development of the interview framework from themes drawn from the observational data. For example, a concept such as 'patient and family as active agent' developed and this theme was used, alongside data extracts, to present to clinicians for further discussion when they were interviewed.

As outlined above, study three took a discursive psychology approach (Wiggins, 2017; Wiggins and Potter, 2013) and study two drew from aspects of constructionist thematic analysis (Braun and Clarke, 2013, 2006a). Discursive psychology is considered to be sited within a critical epistemology, with constructivist roots, which views language as productive rather than reflective (Braun and Clarke, 2013). It is particularly suited to the analysis of naturally occurring data, and can provide detailed insight into how discourse is situated in interaction and bound up with social action (Wiggins and Potter, 2013).

This approach, therefore, enabled an investigation into how clinicians create a case for, or against, diagnosis by shaping a particular version of events designed to counter a potential alternative version (Edwards and Potter, 1992).

My interest was in how participants in the MDT meeting (or Case Review Meeting<sup>1</sup>) accomplish the social action of diagnosis interactionally by aligning or orienting to particular kinds of reports that support a specific version of events and, conversely, dismissing or distancing themselves from others. The analysis began, however, with a constructionist thematic overview (study three) which enabled an overarching engagement with the data prior to discursive analysis.

An iterative series of analytic steps was developed which drew from these two traditions (thematic and discursive) and enabled the analysis of both the content and process of the meetings (see Figure 11) (Braun and Clarke, 2013; Potter and Wetherell, 1987; Wiggins, 2017; Wiggins and Potter, 2013).

This method enabled the potential for exploration of:

- How clinicians both draw on, and create, categories of the condition of 'autism' through their talk
- The everyday and medical discourses drawn on by clinicians in team meetings
- How social relations (agreement, disagreement, persuasion etc.) between clinicians contribute to diagnostic decision-making

### **5.9.5 Analytic Steps**

#### ***Step one: transcription***

An orthographic (words only) transcription of all audio data was created in the first instance. In Discursive Psychology (DP) it is important to understand the way in which utterances are produced and how talk is delivered and received, as well as the content. A Jefferson transcription of selected extracts was used, therefore (Jefferson, 2004), alongside repeated listening to the audio recordings. Jefferson transcriptions enable the representation of talk to include some of the messiness that is obscured in orthographic transcription. For example, people rarely say things in a straightforward way. They hedge their

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<sup>1</sup> As noted in the site details, three of the teams studied were multi-disciplinary; one team held Case Review Meetings (CRMs) which were single-disciplinary, being made up of clinical psychologists.

statements (e.g. using ‘em’, ‘huh’ or ‘sort of’, for example); they include gaps and pauses, overlaps of talk; voices are raised; words are emphasised or talk is speeded up or slowed down. These details can help to understand what is going on in interaction. Is there disagreement or tension? Is someone struggling to speak? Are they finishing sentences and, if not, what is stopping them? Jefferson transcription, therefore, helps us to understand the social interaction and context of talk – the discourse (Wiggins, 2017).

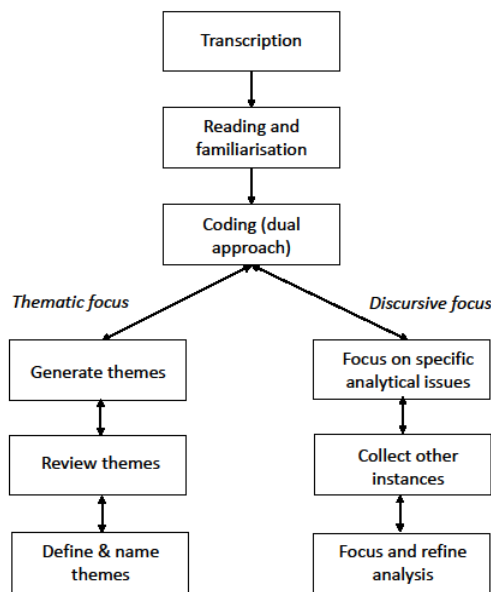


Figure 11: Analysis plan

**Step two: reading and familiarisation**

I listened to audio recordings and read transcriptions several times for familiarisation purposes. I made margin notes to begin to consider relevant themes, the use of language and the interaction between clinicians and as a way to describe the data focussing on the what, how and when of different parts of the interaction (Wiggins, 2017). I decided at this point to consider the clinical ‘case’ discussion as my unit of analysis as this enabled me to explore the trajectory of the discussion which led to a diagnostic decision. Familiarisation notes included a description of the case, reflections from field notes, general observations of the make-up of the meeting and early thoughts about the content.

### ***Step three: generating codes and identifying social actions across the dataset***

I entered transcripts into Nvivo for data management and coding. The coding process took a dual approach and drew from both thematic analysis (study two) (Braun and Clarke, 2013) and discursive psychology (study three) (Wiggins, 2017). This included coding chunks of data (thematic) as well as searching for particular discursive features to be analysed.

*Thematic coding:* I developed codes inductively from the data, noting content (e.g. where there was a discussion about practical elements such as 'school' or 'work' or where particular types of tools/evidence were used (e.g. ADOS2 or SLT report)). As I coded additional data, new codes were added, existing codes were refined and some codes were grouped together or split apart depending on the data. Initial coding descriptions were devised by producing a framework of early groupings of data. Codes and groupings were refined iteratively as coding progressed.

*Discursive coding:* As the research question relates to diagnostic decision-making, I focussed discursively on social actions related to the diagnostic narrative structure; dilemmas or disagreement; and consensus. Sequences of text were maintained to ensure the preservation of narrative construction (Atkinson, 1995). I allocated codes when something interesting was happening interactively or related to a sequence of talk. For example, a broad category of 'diagnostic dilemma' was developed when there was a sequence when clinicians were faced with conflicting evidence to discuss, such as a below-threshold score on ADOS, alongside a developmental interview that suggested a positive diagnosis.

### ***Step four: generating themes and focussing on discursive issues***

Analysis focussed on two key areas. For study two, I explored the 'whats' – such as discussions about the consequences of diagnosis and support available, and the way in which clinicians come to consensus particularly when the decision seems uncertain. For study three, I explored the 'hows' – focussing on clinician interaction and social actions. Whilst these are described separately

(and reflect both the thematic and discursive approach) in reality they were undertaken at the same time. This was achieved by undertaking a general approach of 'analytic bracketing', whereby I 'shifted back and forth' between the 'hows' and 'whats' of the text (Gubrium and Holstein, 2009). This strategy for moving between analytic perspectives was applied throughout the research process in order to explore the interplay between narrative work and its environments (Gubrium and Holstein, 2009). This meant that I was able to explore the interaction between the kinds of matters that were discussed and the way that they were discussed, and how this, interactively, led to the production of a diagnostic narrative that, in turn, enabled a decision, diagnostic or otherwise. For example, an analytic category of 'diagnostic resources' was created (*'what'*), and a note was made of how clinicians discussed, for example, those diagnostic resources in relation to the diagnostic decision (*'how'*). These entities are inter-related with 'what' being a potential theme, and 'how' being a potential social action of interest (for example, how do clinicians ask questions of each other, complain, make decisions or support another's view) (Wiggins, 2017). These features of discourse were identified by using 'discursive devices' such as hedging, corroboration and category entitlements as outlined by Wiggins (2017), which enables a discursive 'lens' to be shone on the data.

I wrote memos to establish clarity about analytic categories and explore decisions around overlapping codes and code boundaries. I grouped and re-grouped codes using mind-maps and frameworks as visual aids. This helped to establish connections between cases, negative cases, absent phenomena, common themes and processes and enabled a gradual development of insights, examining how discourses were constructed and situated in interaction (Wiggins and Potter, 2013).

#### ***Step five: reviewing themes and actions***

I devised an initial conceptual framework based on early collection of data. I revised and developed this framework throughout analysis and drew from data maps developed in step four. The development and revision of themes (study two) and social actions (study three) throughout the study enabled an ongoing



graphic representation of the key factors and concepts being studied, as well as the relationships between them (Miles et al., 1994).

At this stage it was necessary to focus on a specific analytical issue related to the research question concerning social action (of decision-making) (study three). For the purposes of exploring the interaction element of the analysis, I excluded instances if they were no longer relevant to the key question. I then collected further instances of the analytic issue of interest. At this stage specific data was revisited selectively and more detailed transcription and coding made where necessary. The overall analysis, therefore, combines both complete (thematic) and selective (discursive) coding (Braun and Clarke, 2013, p. 218).

#### ***Step six: defining and naming themes and refining analysis***

Finally, I returned to the complete data set and checked for instances across the data, further refining the analysis. For study two (thematic) I grouped codes together towards defining and naming themes. For study three (discursive) I undertook a systematic sweep of the data to check that the provisional discursive model identified held across the data.

#### ***Reflexivity***

I held discussions with other researchers on a regular basis to consider additional viewpoints and interpretations (Josselson and Lieblich, 2003). This was facilitated through a data analysis sharing group and data swaps between researchers. Data were discussed in at least six data-sharing meetings with a range of researchers present. These meetings were made up primarily of PhD students and post-doctoral researchers with occasional attendance from senior researchers. In addition, four further data-sharing sessions took place with two of the co-authors and regular discussions about the data with one other co-author. Data were discussed on one occasion with a wider mental health research group which included researchers with both qualitative and quantitative expertise as well as clinical experience. Anonymised data were also analysed with specialists in discursive psychology and conversation analysis outside the research team on at least three occasions. All of these sessions took the form of listening to and reading transcripts of short sections of data,

discussing preliminary themes and ideas and, on occasion, supporting with coding. Numerous presentations of work in progress at meetings and conferences contributed towards the analysis.

The write-up of Studies Two and Three can be found in Chapters Seven and Eight.

## **5.10 Study Four: Interview Study**

### ***5.10.1 Purpose of study and methodological approach***

The interview study was designed to provide insight into how clinicians understand autism and diagnosis. I was interested both in how clinicians perceived the process of diagnosis, and also their views on the social context of diagnosis. A qualitative thematic approach was undertaken for this study as I was interested in themes across the data that might reflect those understandings.

### ***5.10.2 Research Question***

*How do clinicians **understand autism and diagnosis** in secondary care?*

### ***5.10.3 Data Collection***

I devised a semi-structured interview framework and topic guide which allowed for variation in interview depending on the individual interviewee's experiences. The topic guide had two parts: some general questions around the diagnostic process; and a section where specific cases were discussed and, where possible, sound extracts from meetings were played for clinician reflection (Tape-Assisted Recall). (See *Appendix 9: Interview Topic Guide*). In Tape-Assisted Recall (TAR), recordings are used to prompt relevant discussion about the topic in question (Elliott, 1986). Although commonly used in studying therapeutic relationships and patient/clinician consultations (Baker et al., 2019; Cape et al., 2010; Elliott, 1986; Elliott and Shapiro, 1988) it was anticipated that this method, utilising recordings from the assessment meetings, would provide a relevant and useful prompt to discuss specific cases.

Embedding the interviews into the observation study meant that I was able to utilise different methods of data collection within the same settings. This approach also had the pragmatic effect of determining sample size and participant selection as only clinicians involved in observation could be included.

A total of sixteen interviews were conducted across four specialist autism assessment teams over a period of eleven months during 2017-18.

### ***Using Tape-Assisted Recall***

Audio files of team meetings were imported into Audacity sound editing software, listened to, and labels applied to sections which could then easily be located in interview for playback. In addition, transcripts of the relevant cases were produced and copies available for both the interviewee and interviewer, highlighted in the areas that were available to be played.

The specific extract of sound material to be played was informed by an early conceptualisation of emerging 'social factors' taken from the assessment meeting data. This included factors such as the desires of the parent or patient driving the process; a focus on the needs of the patient or a functionalist approach to diagnosis; discussion of masking of symptoms or performing autism. An audio extract was played and I would ask for a response. This was generally effective in eliciting rich discussion.

In some cases it was not possible to play sound files; in one case the Audacity file was corrupted and therefore not accessible. In three cases, the interview took place before there had been time to upload and select extracts from the recording. In these cases my detailed notes or a transcription were used as the basis for discussion.

I am aware that the selection of sound material for discussion shapes the nature of the discussion that ensued. However, I would argue that it is a valid method for stimulating discussion, with more flexibility and scope than a straightforward question which serves to define its answer in the question itself. Nevertheless, I am aware of the researcher's active role in creating knowledge through

research and this is something that is taken into account in the write up and analysis of this study.

#### **5.10.4 Analysis**

Interviews were audiotaped and transcribed. A thematic analysis approach was used to identify patterns and themes within the data (Braun and Clarke, 2006a). I took an inductive approach to the analysis to enable the identification of themes that are of particular concern to participants. I also analysed the data deductively to explore specific themes that arose in the observation data. In line with my overall theoretical approach, I took a constructionist approach to analysis which enabled me to think about the interview as discursively produced (between interviewee and interviewer) rather than constructing the views of clinicians as context-less and neutrally produced.

Inductive analysis followed Braun and Clarke's (2006a) framework for thematic analysis: transcription and familiarisation; generating initial codes; collating codes into potential themes; reviewing themes; defining and naming themes; refining analysis through writing up. Codes and themes were identified on paper using colour-coded highlighters; exploration of groupings of codes was undertaken with mapping and index cards. The analysis is currently being refined and a preliminary explorative write-up is at Chapter Nine.

Initial deductive analysis involved identifying key areas of interest from the observation data (feeling autism, pragmatism, the role of the family/patient) and colour-coding these themes in each interview. The purpose of this deductive process was to examine clinicians' understandings of these themes. Extracts were then collated in an excel document for further exploration.

As with the observation data, ongoing analysis was informed by sharing data at data analysis sessions and with co-authors.

## 5.11 Personal Reflection and Position

As a non-clinician, I had to learn and understand a culture and institutional structure I was unfamiliar with. This meant having to learn about 'taken-for-granted' concepts in frequent use during meetings and interviews, as well as questioning my own assumptions about hierarchies of knowledge and the privileged role of the clinician.

I was conscious of being over critical of hard-working NHS staff trying to do a difficult job under pressure, and who, furthermore, had given their time to support my research project. I considered the difficulties of diagnosis as an institutional and socially-created problem, not as difficulties created by individual clinicians. The responsibility for our diagnostic system and any 'workarounds' clinicians employ to make the assessment process work in day-to-day practice, sits with society as a whole. We demand diagnostic decisions from our healthcare practitioners, no matter how ambiguous or uncertain the boundaries between conditions may be. It remains the case that the subject of this PhD is the detailed analysis of how individual healthcare practitioners talk to each other. However, they do so to meet the needs of the service organisation within which they practice, as well as the wider medical institution.



## **Introduction to Analytic Chapters**

### **Overview and introduction**

This section (Chapters Six to Nine) represents the empirical work of the thesis. Studies one to three are written up as articles for publication. Study four is written up as a preliminary analysis. Linking statements introduce each article, outlining the way in which the article extends the previous empirical study and noting its status in the publication process (published, in press or under review).

### **Understanding the data**

#### ***Diagnostic tools***

Key tools referred to in meetings are the ADOS (Autism Diagnostic Observation Schedule) and a clinical interview, usually an ADI (Adult Diagnostic Interview) or a 3Di (Developmental, Dimensional and Diagnostic Interview) or a more in-depth clinical interview. The two assessments are undertaken by different assessors and then are brought together to discuss amongst the wider team.

#### ***Diagnostic criteria***

Autism is diagnosed when there are persistent patterns of difficulty in social communication and social interaction, combined with restricted and repetitive patterns of behaviour, interests or activities (APA, 2013a). There were two diagnostic systems in use at the time of the study: DSM-5 and ICD-10. Although these systems are conceptually different (see Chapter One) clinicians in meetings generally referred to a broad understanding of criteria related to the definition outlined here. There was very little reference to diagnostic guidelines in meetings, however, in interview, clinicians generally expressed their practical use of guidelines to be linked to either DSM or ICD, or an understanding of both, in addition to current NICE guidelines (NICE, 2012, 2011).

## **Statement of candidate's contribution to co-authored papers**

All empirical studies were undertaken by the PhD candidate including conception, research design, ethics applications, recruitment, data collection (including systematic search in article 1), analysis, reporting, draft writing and revision. Co-author's contributions are outlined in each linking statement.



## Introduction to Chapter Six

### Overview

This chapter consists of a narrative review of clinical practice guidelines for autism in the UK. The narrative review aimed to consider how the content of clinical guidelines shapes practice. The review findings helped to inform the focus for later studies, including the potential range of factors that might be relevant in an exploration of social framing of diagnosis.

All aspects of the study were undertaken by the PhD candidate. Co-authors contributions were as follows:

GR: pilot extraction framework; review data selection; revision for intellectual content

TF: research design; review data selection; revision suggestions

HR: support with data extraction and initial coding

The rest of this chapter presents the published manuscript of the narrative review of clinical guidelines. It was published in *BMC Psychiatry* in July 2018 (Hayes et al., 2018).



**CHAPTER SIX: Clinical practice guidelines for diagnosis of  
Autism Spectrum Disorder in adults and children in the UK: a  
narrative review**



## **Abstract**

**Background:** Research suggests that diagnostic procedures for Autism Spectrum Disorder are not consistent across practice and that diagnostic rates can be affected by contextual and social drivers. The purpose of this review was to consider how the content of clinical practice guidelines shapes diagnoses of Autism Spectrum Disorder in the UK; and investigate where, within those guidelines, social factors and influences are considered.

**Methods:** We electronically searched multiple databases (NICE Evidence Base; TRIP; Social Policy and Practice; US National Guidelines Clearinghouse; HMIIC; The Cochrane Library; Embase; Global health; Ovid; PsychARTICLES; PsychINFO) and relevant web sources (government, professional and regional NHS websites) for clinical practice guidelines. We extracted details of key diagnostic elements such as assessment process and diagnostic tools. A qualitative narrative analysis was conducted to identify social factors and influences.

**Results:** Twenty-one documents were found and analysed. Guidelines varied in recommendations for use of diagnostic tools and assessment procedures. Although multi-disciplinary assessment was identified as the 'ideal' assessment, some guidelines suggested in practice one experienced healthcare professional was sufficient. Social factors in operational, interactional and contextual areas added complexity to guidelines but there were few concrete recommendations as to how these factors should be operationalised for best diagnostic outcomes.

**Conclusion:** Although individual guidelines appeared to present a coherent and systematic assessment process, they varied enough in their recommendations to make the choices available to healthcare professionals particularly complex and confusing. We recommend a more explicit acknowledgement of social factors in clinical practice guidelines with advice about how they should be managed and operationalised to enable more consistency of practice and transparency for those coming for diagnosis.



## 6.1 Introduction

The diagnosis of autism poses particular challenges for healthcare professionals (HCPs) as, in common with other neurodevelopmental disorders and most psychiatric disorders, there are no biomarkers utilised in clinical practice (Klin et al., 2000; Kobeissy et al., 2013; Vllasaliu et al., 2016). In addition, the condition is heterogeneous, with wide ranging levels of severity and symptom expression and characteristics common to autism may occur in people with other conditions (Huerta and Lord, 2012). Those coming for diagnosis may also have symptoms of other conditions such as epilepsy, learning disability or sleep disorders, for example, complicating diagnosis further, with some arguing for a de-compartmentalisation of these conditions in younger children (Gillberg, 2010). The 'gold standard' of diagnosis is considered to be consensus agreement within a multi-agency team (Falkmer et al., 2013; Woolfenden et al., 2011). However, negotiating consensus between HCPs with different training, professional roles, experience and knowledge can be challenging and time consuming. Finally, a review of the accuracy, reliability, validity and utility of reported diagnostic tools and assessments found that many diagnostic instruments for autism lack a high-quality independent evidence base (Falkmer et al., 2013). For example, only three instruments - the Autism Diagnostic Observation Schedule (ADOS), Autism Diagnostic Interview Revised (ADI-R) and the Childhood Autism Rating Scale (CARS) - had a strong supporting evidence base (Falkmer et al., 2013).

Given the potential challenges, clinical practice guidelines (CPGs) perform an important role in informing HCPs of best practice. CPGs are 'systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances' (Field and Lohr, 1992, p. 2). National CPGs in the UK help to provide evidence-based recommendations to support Autism Strategies and Action Plans (NICE, 2012) and form the guidance framework for HCPs undertaking assessment and diagnosis of autism in the UK. In addition to CPGs produced by specialist, government supported healthcare associations, for example, the Scottish Intercollegiate Guidelines Network (SIGN) (SIGN, 2016), professional clinical bodies also publish discipline-specific practice parameters or

position papers, for example, the Royal College of Psychiatrists (RCPsych) (Royal College of Psychiatrists, 2014).

## **6.2 Social factors**

Although CPGs aim to inform diagnostic practice, research suggests that diagnostic and assessment procedures vary in practice (NICE, 2012). Diagnosis is dependent on observing socially-based behaviours that are arguably not necessarily characteristic of the person under assessment but arise from two-way social relationships and social context. Assessment mechanisms include drawing information from a range of sources, including clinician observation, reporting from family members and wider contexts such as school or workplace. This means that assessments are contextual and inter-relational and symptoms may change according to context or interpersonal relationship, making different assessment sources potentially contradictory.

Some studies show that social factors such as individual patient preference, availability of resources or local organisational factors can shape diagnostic practice, in, for example, heart disease (Fuat et al., 2003). Studies in autism have also shown how diagnostic rates can be affected by contextual and social drivers, such as diagnostic resources (Mazumdar et al., 2013) or diffusion of information about autism through social networks (Liu et al., 2010a). Where there is diagnostic uncertainty clinicians may 'upgrade' to a diagnosis of autism if they believe it would be in the best interests of the patient; if the diagnosis would trigger appropriate services and funding; or counteract the limitations of diagnostic tools, particularly in atypical presentations (Rogers et al., 2016; Skellern et al., 2005). It seems, in practice, clinicians may adopt a pragmatic, practical or functional approach.

## **6.3 Socio-economic and cultural factors**

Research has shown that lower socioeconomic status (SES) is associated with increased parent-reported prevalence (Russell et al., 2014), contrasting with the



US where higher SES and parental education is linked to increased likelihood of diagnosis (King and Bearman, 2011; Liu et al., 2010a). Research also suggests that people with autism from Black, Asian and Minority Ethnic (BAME) communities are less likely to be diagnosed with autism or access appropriate services (National Autistic Society, 2014) despite research which shows that behaviours associated with autism are likely to be consistent across cultures and countries (Norbury and Sparks, 2013).

Prior to diagnosis, social factors can also determine who comes forward for diagnosis and who is referred for further assessment. Research examining a longitudinal UK cohort study identified that with the severity of autistic traits held constant, younger mothers and mothers of first-born children were significantly less likely to have children diagnosed with autism (Russell et al., 2011). In addition, boys were more likely to receive a diagnosis than girls, and maternal depression was linked with a lack of diagnosis (Russell et al., 2011). These findings suggest both cultural and economic influences impact the diagnostic pathway.

#### **6.4 Biomarkers in autism diagnosis**

There is a great deal of research that explores the underlying neurobiological, genetic, chemical and cognitive factors that may, in future, provide biomarkers which could be utilised in autism diagnosis (see Goldani et al., 2014 for a review of genetic, metabolic and brain focused biomarkers). For example, a recent research study has identified a link between damage to proteins in blood plasma and autism symptoms (Anwar et al., 2018); while another found shared brain activity between boys diagnosed with autism and those with obsessive-compulsive disorder (OCD) which in turn differed from a non-diagnosed control group (Carlisi et al., 2017). However, it has been argued that the heterogeneous and interactive nature of autism symptoms makes the identification of clinically useful biomarker tests problematic (Anderson, 2015). Furthermore, findings from biomarker research have yet to be integrated with clinical practice and none currently have enough evidence to support routine clinical use (Goldani et

al., 2014). For the foreseeable future, therefore, these developments are unlikely to change diagnostic practice (NHS Choices, 2018).

## **6.5 Purpose of the review**

Although a few studies have begun to explore health professionals' views of autism diagnosis (Imran et al., 2011; Rogers et al., 2016; Taylor et al., 2016) to our knowledge there are few studies that examine how clinical guidelines may inform assessment. One exception is a recent systematic review of English speaking guidelines undertaken by Penner et al (2017) which reported that guidelines varied considerably in quality, content and recommendations but included guidelines working across incomparable health systems in different countries. We therefore carried out a focussed narrative review of guidelines that impact on UK-based practice. Penner et al suggest that in the face of disparate clinical guidance clinicians should 'be mindful of local resources and wait times, eligibility requirements for ASD services...and the wishes of families when deciding on how best to assess for ASD' (Penner et al., 2017, p. 10). Our narrative review responds to this call for a pragmatic approach by investigating where, within guidelines, social factors and influences such as those suggested are considered.

## **6.6 Method**

### ***6.6.1 Scoping search***

A scoping search was undertaken to check there was no similar review published. A search was made in the following databases; PsychARTICLES; Embase; Global health; HMIC; Ovid (books; medline; journals); PsychINFO; Social policy and practice. One relevant article was retrieved (Penner et al., 2017), as discussed above.

### ***6.6.2 Inclusion and exclusion criteria***

Full inclusion and exclusion criteria are in Table 7. Whilst we took a broad approach to CPGs, including, for example, journal articles summarising national CPGs and

the diagnostic process, as well as national CPGs, the researchers acknowledge that each of these type of guidelines have different purposes (see Table 8). However, we argue that each may have an impact on HCP's process of diagnosis to a greater or lesser extent and for the purposes of this study all were included under the term clinical practice guidelines.

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**Inclusion Criteria**

Documents with guidance-based status for HCPs working in secondary care in the UK; or were published papers, aimed at HCPs, with the aim of reviewing CPGs

Documents related to autism diagnosis and assessment for either children, adults or both

Documents produced either by or through government or professional clinical bodies or published in a journal aimed at HCPs

Documents related to diagnosis and assessment in UK (England, Scotland, Wales and N Ireland)

Documents dated from 2009 (reflecting publication of the first UK specific Autism Act) or were the most recent CPG published by a key professional body

**Exclusion Criteria**

Documents related solely to referral, treatment, prognosis or support services

Reviews of diagnostic criteria and other academic papers

Guidelines related to primary care as we were interested in diagnosis rather than referral

Narrative reviews, editorials and opinions

Documents related to parliament or legislature; national or regional strategies as they are not the primary source for clinicians

Local guidance

Guidance provided by private providers of diagnostic services

International professional body guidelines (other than ICD/DSM)

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Table 7: Inclusion and exclusion criteria (guidelines review)

Type of guideline	General purpose of type of guideline
Diagnostic Criteria	To assist clinicians in the diagnosis of mental conditions by providing descriptions of the main clinical features in each category
National Clinical Guidelines	To offer best practice advice and guidance for professionals and service users and their families
Guidelines from Professional Bodies	To offer profession specific advice to clinicians and healthcare professionals in their specialist area
Journal Articles	To summarise clinical guidelines in clinician-facing publications to keep clinicians up to date and/or alert them to changes in good practice

Table 8: Purpose of diagnostic guidelines

### 6.6.3 Identification of CPGs

We did not set out to undertake a comprehensive systematic review, as it was not a requirement of our study that we consider risk of bias either within or across studies (Moher et al., 2009). However, we took a PRISMA approach to our search strategy, borrowing from systematic review methodology in terms of screening titles and abstracts and data extraction techniques (Liberati et al., 2009). A systematic search was conducted in June 2017 using the following databases: NICE Evidence Base; TRIP; Social Policy and Practice; US National Guidelines Clearinghouse; HMIC; The Cochrane Library. In addition, searches were made of government related websites and relevant professional bodies as well as NICE and SIGN. We used the following search terms to search all databases and websites: ‘autism’, ‘diagnosis’, ‘guidance’, ‘statutory’, ‘clinical’, ‘practice’, ‘guideline’, ‘protocol’, ‘strategy’, ‘policy’, ‘bill’, ‘act’, and ‘parameter’. A full search strategy is in Figure 12.

**Scoping search:**

- PsychARTICLES; Embase; Global health; HMIC; Ovid (books; medline; journals; PsychINFO; Social policy and practice

**Main Review Search Strategy:**

- Organic **web searching** starting from Government Health and Professional Bodies sites: The Scottish Government; Gov.UK; The Welsh government; The Northern Ireland Executive; NHS Scotland; NHS England; NHS Northern Ireland; NHS Wales; National Institute for Health and Care Excellence (NICE); Scottish Intercollegiate Guidelines Network (SIGN); British Psychological Society; American Academy of Child and Adult Psychiatry (AACAP); American Academy of Paediatrics (AAP); American Academy of Neurology (AAN); Royal College of Child Health Practitioners (RCCHP); Royal College of Psychiatrists (RCP); Royal College of Paediatrics and Child Health; Royal College of Nursing; British Medical Journal; Royal College of General Practitioners; Royal College of Physicians
- **Databases:** NICE Evidence Base; TRIP; Social Policy and Practice; US National Guidelines Clearinghouse; HMIC; The Cochrane Library

**Search terms:**

1. autism\*
2. strateg\*
3. statutory
4. policy
5. protocol
6. diagnos\*
7. bill
8. act
9. guideline
10. 1 and 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11. parameter
12. 1 and clinical and 9
13. 1 and practice and 11

Figure 12: Search strategy (guidelines review)

#### 6.6.4 Study selection

The first reviewer (JH) removed duplicates and screened titles for relevance. Full text copies of the potentially relevant documents were downloaded for screening. The first reviewer screened full text documents and excluded those not relevant. The remaining titles were independently checked by the clinical specialist (TF) using pre-specified inclusion/exclusion criteria (outlined in Table 7). Discrepancies were resolved by discussion, with involvement of a third reviewer (GR). Twenty-eight documents were considered for analysis, with seven being withdrawn at full analysis stage. See Figure 13 for full details.

Guidelines from the International Classification of Mental and Behavioural Disorders (Tenth edition) (ICD-10) (WHO, 1993) and the Diagnostic and Statistical Manual of Mental Disorders (Fifth edition) (DSM-5) (APA, 2013a) were considered alongside UK relevant guidelines as they are considered authoritative sources for the definition of symptoms utilised in autism diagnosis, as well as other neurological conditions.

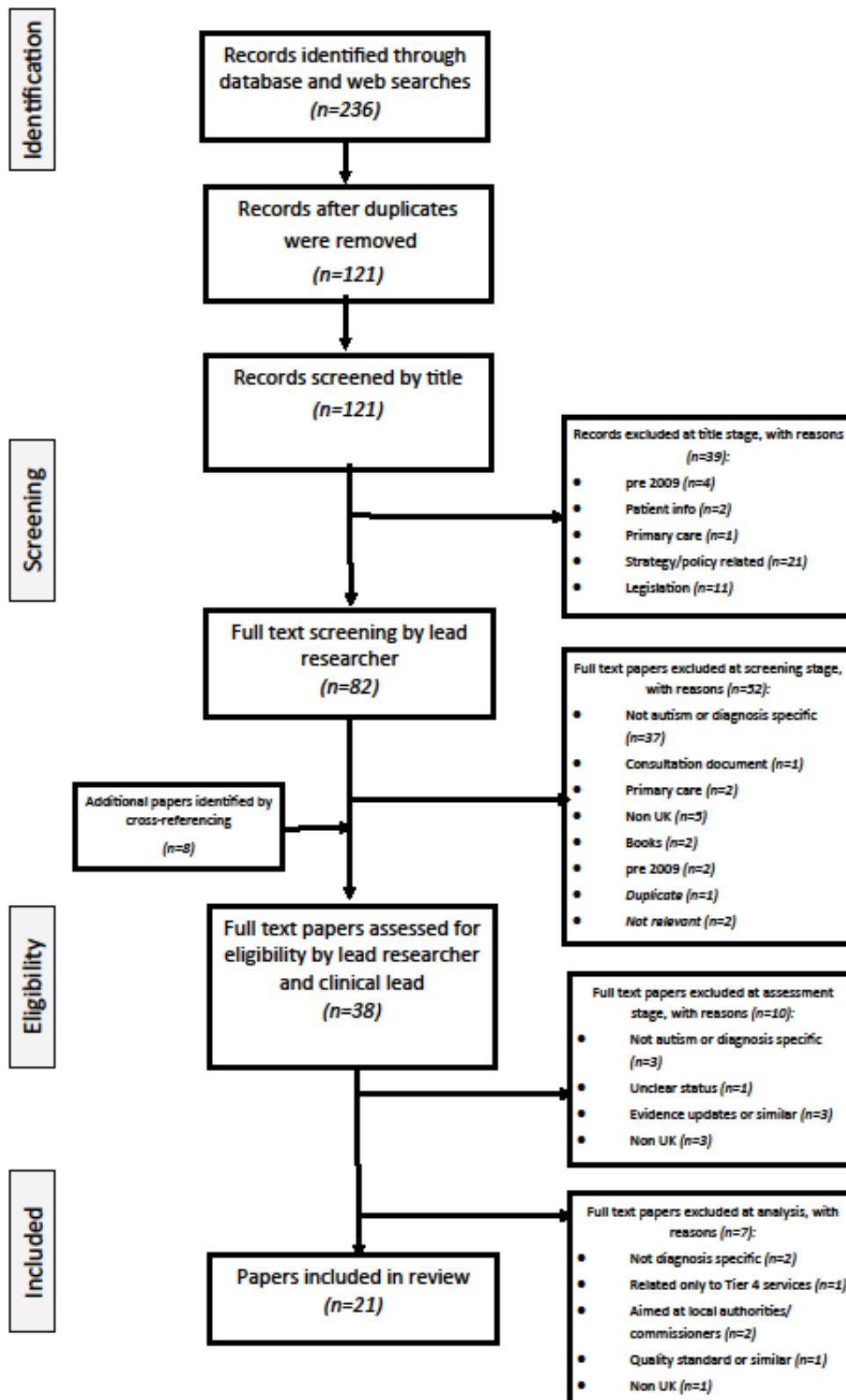


Figure 13: Study selection flow diagram (guidelines review)

### **6.6.5 Data extraction**

A data extraction framework was created to draw key characteristics from the guidelines (year, author, geographical remit, target audience, age range, range of diagnoses covered, age at which symptoms are recognised, diagnostic criteria referred to); as well as key elements in the diagnostic process (recommended tools, role and composition of the multi-disciplinary team (MDT), who can diagnose, assessment targets and key features of assessment). This framework was piloted with four reviewers (JH, GR, RW and DE) in a comparison of analysis of three guidelines. The framework was amended accordingly and is included in *Appendix 10: Guidelines Review Data Extraction Framework*. Data were independently extracted by two reviewers (JH and HR) from 21 CPGs and disagreements were resolved by discussion and further checks. Data were tabulated and analysed.

### **6.6.6 Analysis of social factors**

A modified form of narrative review, as described by Popay et al. (2006) and Ferrari (2015), was adopted whereby data extraction enabled synthesis of key data, whilst also allowing rich narrative description (Ferrari, 2015). Narrative review was selected as it enabled the telling of the 'story' of CPGs, and consideration of how guidelines, as a set of texts, shape diagnosis (Popay et al., 2006).

A process of inductive analysis was undertaken based on social factors and influences. These were defined, for the purpose of this review, as contextual factors that influence diagnosis but are not based on symptoms of autism. We drew from the concept of a social model of diagnosis as developed by Jutel and Nettleton (2011). This model considers how diagnostic classifications and medical diagnoses are socially created and how social forces – including technological, professional, cultural and economic forces – contribute to shaping aspects of the diagnostic process including those related to classification, the consequences of diagnosis and the process of diagnosis itself (Jutel and Nettleton, 2011). Overall, a social model challenges the idea of diagnosis as 'a moment of clinical purity' (Latimer, 2013, p. 196) or as a way simply to identify underlying biological problems. We included factors that were relevant to multi-disciplinary working or parental/family influence (the process of diagnosis); the potential outcomes of diagnosis for the patient and how HCPs may take this into account (the consequences of diagnosis);

and how issues around classification shape the diagnostic process such as how borderline cases are dealt with (diagnosis as a category). This was a dynamic process whereby data extracts were considered in relation to each other via conceptual mapping and clustering (Popay et al., 2006).

### **6.6.7 Terminology**

For the purposes of this review and in line with the Autism Strategy (Department of Health, 2010) we use the term 'autism' throughout.

## **6.7 Results**

### **6.7.1 Characteristics of guidelines**

A total of 236 documents were retrieved, and 21 were included in the final narrative review (see *Appendix 11: Clinical Guideline Characteristics* for full list of included documents). The documents studied are grouped into four types: a) International Diagnostic Criteria (n=2); b) National Clinical Guidelines (n=5); c) Journal articles that summarise National Clinical Guidelines and the diagnostic process, published in key clinical journals (n = 10); d) Guidelines from professional bodies (n=4). It should be noted that journal articles, in some cases, are designed to give an update rather than a full guideline therefore the lack of detail in some areas should not necessarily be seen as a weakness.

Of the 21 guidelines considered, six dealt with diagnosis of adults, seven with children and eight with all ages. Of those, two guidelines were international but key to diagnostic practice in the UK (ICD-10 and DSM-5), five related to the UK as a whole, five to England and Wales, one to Scotland, two to Northern Ireland and one to outside the US and Canada (and therefore included the UK). Five guidelines did not specify a geographical remit but were published in the UK in clinician-facing journals. All guidelines were aimed at HCPs, with six aimed at particular specialist roles that included psychiatrists, psychologists, speech and language therapists, community practitioners and paediatricians.



Guidelines acknowledged that there is variation in rates of identification, assessment criteria and practice (NICE, 2012); that there is increasing demand for diagnostic services (NICE, 2011); and that increased awareness of autism is likely to lead to a rise in people presenting for assessment (British Psychological Society, 2016).

### **6.7.2 Definitions of autism**

Definitions of autism in ICD-10 and DSM-5 differed. ICD-10 took a categorical approach with a definition of Pervasive Development Disorders that included sub-diagnoses within it; whilst DSM-5 used the overarching dimensional concept of Autism Spectrum Disorder. Some inconsistencies were present related to the differences in classification in ICD-10 and DSM-5, therefore, for example, Rett's Syndrome and Asperger's Syndrome were sub-diagnoses of Pervasive Development Disorders in ICD-10, but were encompassed in the overarching diagnosis of Autism Spectrum Disorder in DSM-5 (APA, 2013a; WHO, 1993). Definitions of autism in all other guidelines considered in this study were broadly consistent with the idea of a 'spectrum'.

Most guidelines (n=14) referred to symptom criteria from both ICD-10 and the (then) current version of DSM (DSM-IV up to 2012 and DSM-5 from 2013), with eight guidelines recommending that HCPs should use the current version of DSM or ICD criteria for diagnosis. Exceptions were NICE CG142, which was based on ICD-10, (NICE, 2012); Royal College of Speech and Language Therapists (RCSLT) (RCSLT, 2005), which drew on the International Classification of Functioning, Disability and Health (ICIDH-2) for general clinical assessment (WHO, 2001); and journal articles describing NICE guidelines which made no mention of DSM/ICD (n=3).

Overall, therefore, the guidelines were mixed in their recommended sources for symptom criteria due to the current differences in the two classification systems.

## 6.8 Narrative review of social factors

We used three inter-related elements as an organising framework to describe the social factors identified in clinical guidelines: operational, interactional and contextual. These factors do not stand alone from each other, indeed, they appear to have a dynamic and inter-dependent relationship, however, organising them provides a way to map their range and scope (see Figure 14).

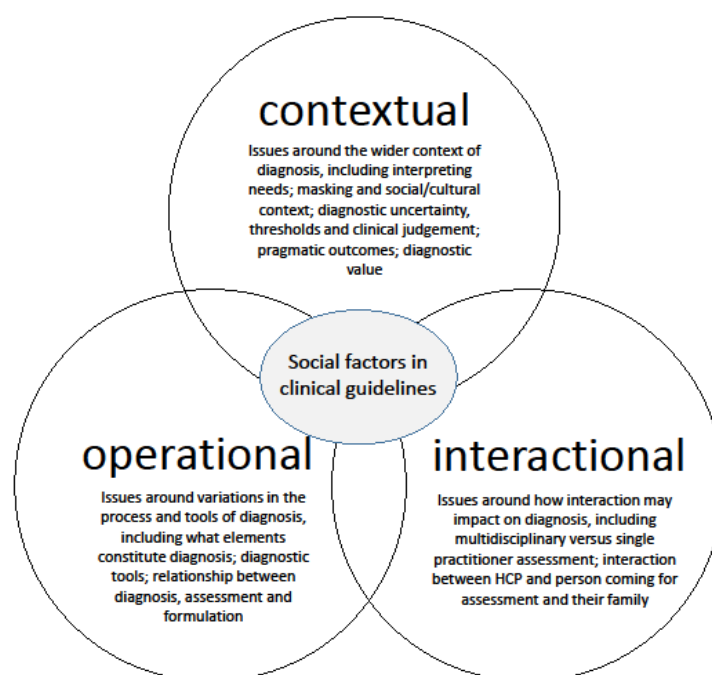


Figure 14: Social factors in clinical guidelines

### 6.8.1 Operational factors

Operational factors included how different assessment processes impact on the diagnostic decision, such as which tools and processes are engaged and when; what constitutes an assessment; and whether the decisions take place as part of diagnosis or formulation. *Appendix 12: Key Recommendations of Clinical Guidelines* outlines some of these operational factors.

#### ***The assessment process***

One guideline suggested that clinical practice varies greatly (Parr and Woodbury-Smith, 2017) and we found this to be mirrored in CPGs with a wide

range of potential assessment processes included. DSM-5 recommended that a diagnostic assessment should include gathering multiple sources of information from clinician's observations, caregiver history and self-report (where possible). National guidelines, although providing far greater detail, tended to include these areas and additionally suggested various other detailed assessments such as gathering wider functional/assessment information (SIGN, 2016); using documentary evidence, assessing risks, and assessment of challenging behaviour (NICE, 2012); assessing for co-conditions (NICE, 2012, 2011); physical examination (NICE, 2011); comprehensive educational assessment (RASDN, 2011); assessment of communication, neuropsychological functioning, motor and sensory skills, and adaptive functioning (SIGN, 2016). Professional guidelines added other factors such as comprehensive cognitive assessment (British Psychological Society, 2016) and impact of individual's mental health (RCSLT, 2005), accounts of relationships in different settings (RASDN, 2011) and observation in school or another setting (Parr and Woodbury-Smith, 2017). Journal articles tended to reflect national guidelines and varied in the level of detail outlined for assessment factors. Two articles gave little detail of assessment processes but one referred readers directly to NICE guidelines for further detail (Howlett and Richman, 2011) and the other was aimed at community practitioners who would be more likely to be involved in referral than diagnosis (Reynolds, 2011). Articles also included assessment of co-occurring conditions (e.g. Blenner et al., 2011; Carpenter, 2012; Garland et al., 2013; Lai et al., 2014; Levy et al., 2009; Wilson et al., 2014) and a physical or medical examination (e.g. Blenner et al., 2011; Lai et al., 2014). Additional assessment areas included assessment of specific domains such as family stressors and coping abilities (Garland et al., 2013). In one guideline (Carpenter, 2012) it was suggested that some clinicians bypass ICD/DSM criteria and instead undertake:

*...testing for specific underlying difficulties such as lack of theory of mind or lack of central coherence and then using these to decide the presence of the behavioural criteria (Carpenter, 2012, p. 125).*

The RCSLT guideline (RCSLT, 2005) differed from most by suggesting consideration of theories relating to the triad of social impairments, such as

executive functioning deficits, motivation, memory and central coherence, as well as social interaction and communication. However, some (e.g. British Psychological Society, 2016) suggested cognitive or neuropsychological testing whilst SIGN guidelines stated that such assessments are 'useful for individual profiling but are not diagnostic instruments' (SIGN, 2016, p. 16). This anomaly may reflect the specialist role of SLTs in the diagnostic process.

Overall, we would concur with a reflection in one guideline, which noted how the HCP may be faced with 'possible uncertainty as to where to go next in their investigation framework as this could be potentially enormous' (O'Hare, 2009, p. 164).

### ***Diagnostic tools***

Recommendations about the use of diagnostic tools were mixed. One third of the guidelines (n=7) did not specify any particular tool for diagnostic assessment. Other CPGs tended to suggest the consideration of a range of tools without specifically recommending any particular instrument(s), although regular references were made to ADOS (n=13), ADI-R (n=11), DISCO (n=9) and 3di (n=6). The NICE guideline for children and young people emphasised use of DSM/ICD criteria rather than tools; the NICE guideline for adults did the opposite (NICE, 2012, 2011). Overall, findings concurred with Penner et al. in that guidelines varied substantially in their recommendations for use of diagnostic tools (Penner et al., 2017).

### ***Diagnosis and formulation***

There were differences in the way guidelines described the relationship between, or referred to, diagnosis, assessment, profiling, needs assessment and wider formulation. All guidelines encompassed the concept of a wider (needs related) assessment but few explicitly separated out these processes or discussed how this related to a diagnostic assessment. One exception to this was the Regional Autistic Spectrum Disorder Network (RASDN) children's guideline, which separated the diagnostic from the formulation process, describing the latter as including examination of the person's wider environment:

*The outcome of the formulation should be to understand an individual in a more global holistic way rather than merely in terms of signs and symptoms, as in the case of diagnosis (RASDN, 2011, p. 18).*

The RCPsych guideline suggested that diagnosis is only one component of the wider multi-disciplinary exercise (Royal College of Psychiatrists, 2014). Some guidelines did not mention formulation but suggested a profile of strengths, abilities and weaknesses should be carried out alongside a diagnostic assessment (e.g. NICE, 2011; SIGN, 2016). Adult guidelines from RASDN separated out a diagnostic assessment from a full needs assessment (RASDN, 2013); NICE guidelines for adults considered comprehensive assessment to include diagnostic, needs and risk assessment (NICE, 2012); whilst the full children's guidelines similarly brought together the diagnostic and needs elements under 'autism diagnostic assessment', explaining that:

*..the label of autism does not constitute a complete diagnostic assessment and a profile of the child or young person's strengths and weaknesses is also essential. This requires a multi-disciplinary team which has the skills to undertake the assessments necessary for profiling (National Collaborating Centre for Women's and Children's Health, 2011, p. 108).*

Operationally, therefore, there were contradictions between guidelines about what constitutes the diagnostic process, how it should be structured and which diagnostic tools should be used.

### **6.8.2 Interactional factors**

Interactional factors related to how the dialogue between HCPs and between HCPs and families impacts on the assessment process. These include how consensus is reached, how disagreement is resolved and how the views of the person and family are integrated into the decision-making process.

#### ***Multi-disciplinary assessment versus single practitioner assessment***

Where specified, all guidelines advocated for diagnosis to take place within a multi-disciplinary setting with various guidelines suggesting this was 'necessary' (RASDN, 2011), the 'optimum approach' (SIGN, 2016) or 'ideal' (Parr and Woodbury-Smith, 2017) (See Appendix 12). Some suggested (n=4) that an

appropriately trained and experienced single professional is sufficient to diagnose in particular cases, but to be alert for indications for a more specialist assessment (Royal College of Psychiatrists, 2014) and with access to multi-disciplinary support if required (Carpenter, 2012).

Despite this almost universal recommendation, the extended version of NICE children's guidelines (and cited by SIGN (SIGN, 2016) and Carpenter (Carpenter, 2012)) questioned the evidence base for multi-disciplinary assessment reporting a study (Mahoney et al., 1998) that showed moderate agreement between an individual HCP and an MDT in making a diagnosis, but stating that it was a low quality study (National Collaborating Centre for Women's and Children's Health, 2011). These guidelines also suggested in practice that a diagnosis can be made by a single experienced HCP but that a comprehensive profile of the patient requires a multi-disciplinary approach (National Collaborating Centre for Women's and Children's Health, 2011). SIGN guidelines also cited research (Moore et al., 1998) which demonstrates that parents value a multi-disciplinary assessment (SIGN, 2016).

None of the guidelines in this review dealt with how HCPs come to a consensus within a multi-disciplinary context, although Northern Ireland guidelines recommended that training should include the promotion of collaborative and innovative working (RASDN, 2011) and that clinicians must understand the profession specific roles and responsibilities of the overall team (RASDN, 2013, 2011).

Therefore, most guidelines referred to MDTs as best practice, but lacked recommendations about how roles within MDTs are negotiated, how disagreement is resolved (other than second opinion outside the team); or how teams should work together, a factor that is acknowledged by NICE adults guideline (NICE, 2012).

### ***Interaction with the person and their family***

Many guidelines (n=9) outlined the importance of keeping the person/family informed and involved throughout the process or recommended a person-

centred approach. Some described the relationship with the person coming for diagnosis and their family as a partnership (e.g. NICE adult guideline (NICE, 2012) or as person-centred (e.g. RASDN adult guideline (RASDN, 2013)). Some guidelines (n=6) acknowledged that the person or family may disagree with or be reluctant to accept a diagnosis or, alternatively desire one (Reynolds, 2011) and be determined on a particular outcome, which can lead to misleading results (Royal College of Psychiatrists, 2014). Carpenter asserted that some people may begin to see diagnosis as a desirable outcome and pre-prepare answers based on structured interviews published on the internet (Carpenter, 2012). The potential for disagreement or desire for diagnosis, therefore, may impact on the interaction with the person or their family. So, although the relationship with the patient/family is considered within CPGs, there is little guidance as to how HCPs might deal with patient/family desire or disagreement.

### **6.8.3 Contextual factors**

There were factors related to the way in which HCPs interpret symptoms in different settings, how diagnostic thresholds are judged against criteria and included considerations around the impact and consequences of a diagnosis.

#### ***Interpreting needs***

All national guidelines (n=5) outlined the requirement to consider the needs, preferences and values of the individual and their family and/or support them to communicate their needs and concerns. Most guidelines (n=17) described elements of diagnosis that relate to either family environment, family needs and concerns, circumstances, relationships, functioning, experiences in different settings, contextual information or level of support needs. Many guidelines reflected the need to consider assessment of support required. Enquiries should be made about how symptoms impact on function within the family, at home, school or work (Blenner et al., 2011; NICE, 2012, 2011; Pilling et al., 2012; RASDN, 2013). Overall, therefore, there was a focus not only on the assessment of symptoms, and the way in which these affect the daily life of the person and their family, but the wider environmental and social context of the person and the way in which they are supported, or not, by that context.

### ***Masking, and social context***

Some guidelines (n=6) reported the difficulties of diagnosing autism when compensation strategies may 'mask' difficulties in some contexts, particularly as an adult (APA, 2013a), and in girls (Lai et al., 2011) where autism may go unrecognised. Some suggested that individuals may come forward for diagnosis when their circumstances change and/or stressors increase (e.g. Howlett and Richman, 2011; RASDN, 2013; SIGN, 2016). Some guidelines (n=5) noted that cultural differences will exist in norms for social interaction or that cultural variations can deliver misleading signs and symptoms. DSM-5 suggested that the boundaries between normality and pathology differ between cultures and the level at which experience may become problematic may differ (APA, 2013a).

SIGN suggested that those with autism may not have met 'normal' adult milestones in work, relationships or independence and contained extensive information on how females can present with a different symptom profile (SIGN, 2016). Others warned that behaviours might be the result of disruptive home experiences, carer illness (NICE, 2011) or complex psychosocial or child protection backgrounds (O'Hare, 2009).

Despite research showing links between diagnostic rates and SES, there was very little mention of the impact of SES in CPGs. DSM-5 stated that cultural and socioeconomic factors may affect age at recognition or diagnosis (APA, 2013a) but generally guidelines failed to consider how this might be considered in practice, other than to be aware that 'cultural variations can deliver misleading signs and symptoms' (Howlett and Richman, 2011, p. 48) or that autism is 'not restricted to particular ethnic or economic backgrounds' (British Psychological Society, 2016, p. 4). RCSLT guidelines considered assessment of bilingual individuals (RCSLT, 2005) and some suggested that ethnicity may delay engagement in the diagnostic process (Royal College of Psychiatrists, 2014) or may increase difficulty in accessing services (RASDN, 2013).



Overall, guidelines suggested it was the responsibility of the HCP to make a judgement about which behaviours appear to be 'normal' in complex social and family circumstances, as well as against norms for behaviour.

### ***Diagnostic uncertainty, thresholds and the role of clinical judgement***

Overall the general focus of guidelines was to outline a framework to find the best way to decide whether autism is present or not around a threshold of symptom severity. However, many guidelines problematised this, for example, one guideline discussed how definitions of autism have changed with DMS-5 (Royal College of Psychiatrists, 2014) and others suggested that social factors, such as an upbringing characterised by lack of boundaries (Howlett and Richman, 2011) or symptoms amplified by distress (Royal College of Psychiatrists, 2014) may cause diagnostic difficulties.

All national guidelines considered uncertainties around diagnosis, particularly with very young children or those with co-existing disorders (NICE, 2011); when there may be disagreement within the diagnosing team or between the team and the patient or family, or when there is a lack of local expertise (NICE, 2012). Many warned of diagnostic difficulties, or 'obscuring' (O'Hare, 2009; Royal College of Psychiatrists, 2014) that can take place if there is an intellectual disability or other complex coexisting condition and several considered the difficulties of overlapping diagnostic criteria (APA, 2013a; Lai et al., 2014; Levy et al., 2009; O'Hare, 2009). Further uncertainty was outlined when individuals may not reach the diagnostic threshold (NICE, 2011) or when children with autism score below the cut-off as determined by the diagnostic instrument (Parr and Woodbury-Smith, 2017).

Despite this uncertainty, CPGs generally proposed a systematic approach to diagnosis and, in some cases, asserted that progress has been achieved in establishing consensus around a behavioural definition and established systematic clinical assessments (e.g. Lai et al., 2014) even whilst recognising that the 'boundaries between disorders are more porous than originally perceived' (APA, 2013a, p. 6).

Eight guidelines stressed the key role of clinical judgement in the diagnostic process. DSM-5 outlined that the use of diagnostic criteria should be informed by clinical judgement (APA, 2013a) and ICD-10 suggested that guidelines should be used flexibly in clinical work (WHO, 1993). The full version of NICE children's guideline recommended: 'Use information from all sources, together with clinical judgement, to diagnose autism based on ICD-10 or DSM-IV criteria' (National Collaborating Centre for Women's and Children's Health, 2011, p. 113). One guideline suggested that clinicians may depend on the 'feel' of the interaction with the patient for diagnosis (Carpenter, 2012). The RCPsych guideline stated that: '...much will depend on the extent of the clinician's experience, their rigour in applying standard criteria and their ability to recognise alternative diagnoses' (Royal College of Psychiatrists, 2014, p. 15). Uncertainty, clinical judgement and clinician experience, therefore, were all identified as important factors in the diagnostic process.

### ***Pragmatic outcomes and diagnostic value***

Most guidelines (n=17) discussed the need for HCPs to have knowledge of local support and resources available to deliver appropriate advice when required. The value of the diagnosis was generally described as a way to provide appropriate support, intervention and resources. NICE guidelines for children and young people clarified this:

*'Diagnosis and the assessment of needs ...can open doors to support and services...all of these can improve the lives of the child or young person and their family'* (NICE, 2011, p. 5).

However, NICE guidelines for adults acknowledged that adults who are diagnosed may receive no support due to lack of services (NICE, 2012) and Pilling et al stated that whilst care for children and young people is generally well coordinated, this is not always the case for adult services (Pilling et al., 2012).

Although some guidelines acknowledged that people may not want a diagnosis and the label it brings with it (e.g. RASDN, 2013, 2011) or that it can be stigmatising or damaging to career plans (Royal College of Psychiatrists, 2014),

generally guidelines described the benefits of a diagnosis primarily as relating to improved quality of life, creating an opportunity to have needs met, greater understanding and reassurance about one's own situation and access to interventions and services. Some guidelines considered that diagnosis can provide relief, understanding or an opportunity to move on with increased support (Howlett and Richman, 2011; NICE, 2011; Royal College of Psychiatrists, 2014).

Many guidelines stressed the importance of early diagnosis as this enables early intervention which leads to improved health outcomes (e.g Blenner et al., 2011; Lai et al., 2014; RASDN, 2011; RCSLT, 2005). However, the BMJ guideline asserted that the, '...efficacy of early intervention varies from child to child' (Parr and Woodbury-Smith, 2017, p. 7), and that 'consideration of the direct financial costs, indirect costs... and the impact on relationships within the family... must be balanced against likely and possible improvements in outcome for the person with ASD' (Parr and Woodbury-Smith, 2017, p. 21), bringing uncertainty into the benefits of diagnosis. Furthermore, O'Hare asserted that it is difficult to prove that earlier intervention is more effective (O'Hare, 2009).

Overall, guidelines reflected a concern about the potential impact or benefits on the child or adult receiving a diagnosis and considered positive factors such as access to support and intervention, increased understanding or relief; as well as potential negative impacts such as stigma. Carpenter, however, questioned the relationship between need and diagnosis, by asking whether diagnosis is influenced by what intervention the person needs or '...explicitly determined by the person's need to have the label to access a service... rather than their fitting strict diagnostic criteria?' (Carpenter, 2012, p. 124).

To conclude, whilst CPGs appeared to frame a methodical and clinical diagnostic process, they also rehearsed a number of subjective dilemmas that HCPs have to negotiate along the way. Some CPGs themselves drew attention to social issues that muddle the process: the difficulties of establishing a clear threshold in a condition where symptoms are impacted by the stressors of environment (Royal College of Psychiatrists, 2014); the problem of relying on

mechanistic assessments or algorithms (Carpenter, 2012; Royal College of Psychiatrists, 2014); the crucial role of clinical judgement (RASDN, 2013); the possibility of diagnostic uncertainty through disagreement, lack of local expertise or when a complex coexisting condition is present (NICE, 2012); the complexity caused by interaction with co-occurring conditions; masking of autism by comorbid conditions in secondary care (Pilling et al., 2012); the impact of good (or poor) social support and coping strategies on how symptoms present (APA, 2013a), to name a few.

## **6.9 Discussion**

We found that CPGs varied in how they described the diagnostic process in relation to use of diagnostic tools, key elements and structure of the diagnostic process (for example how diagnosis related to wider needs assessment) and how autism was classified, defined either by current versions of DSM or ICD. In addition, whilst some recommendations were clear and universal, for example, recommendations for multi-disciplinary working, there was little guidance as to how this should work in practice.

In addition, we found that uncertainty was central to many diagnostic decisions, placing a great emphasis on clinical judgement. This uncertainty included questions around the benefits of early intervention, the shifting nature of the diagnostic threshold, the difficulties of interpreting needs in different social contexts, the problems of interpreting 'masking' or coping strategies, the differences in presentation across age and breadth of symptoms, the inter-relationship with co-conditions and sharing of symptoms, the impact of stressors on symptoms as well as interpretation of symptoms and needs in different cultural contexts.

Overall, therefore, our narrative review found that although individual guidelines appeared to present a coherent and systematic assessment process, they varied enough in their recommendations to make the choices available to healthcare professionals particularly complex and confusing; and presented a

context of uncertainty which appeared to be central to the diagnosis of autism. We argue that clinical guidelines for autism diagnosis illuminate the process of diagnosis as social rather than straightforwardly clinical, and that judgement is required to consider a number of sometimes contradictory and complex social factors.

### **6.9.1 Social factors in CPGs**

Organising the narrative review findings in relation to operational, interactional and contextual factors enabled consideration of the influence of social factors throughout the diagnostic process.

In the wide range of inter-related assessment processes that HCPs negotiate in order to make the diagnostic decision, the factors considered appear to be both social and medical. Social factors include: how the category of 'autism' is defined and bounded; operational and interactional factors present in the process of diagnosis; to the consequences of diagnosis including how diagnosis is valued (see Figure 14). Each of these factors had a place in clinical guidelines to a greater or lesser extent but in many cases they were not operationalised to enable a clear and transparent framework. For example, although there were many references to individuals masking symptoms, family 'scaffolding' of social impairment and coping strategies, there was little guidance about how HCPs can judge the impact of these on need, behavioural symptoms or functioning.

CPGs, therefore, tended to mask (whilst paradoxically acknowledging) the existence of social factors in the diagnostic process. A more explicit acknowledgement of social factors and how to manage them might problematise the nature of autism diagnosis altogether: if all these factors have a place in diagnosis, how do they relate to clinical factors and what does it mean for descriptions of symptoms? Whilst it is not our intention to undermine the utility of diagnostic categories in relation to access to resources or support, there appears to be a need for balance in CPGs between a clinical approach which both recognises and acknowledges the uncertainty of the diagnostic

threshold; and a pragmatic or functional approach which responds to individual and wider needs and takes account of social factors.

### **6.9.2 Diagnostic tools and process**

Clinical guidelines for autism varied in aspects of their key recommendations in operational factors. Ambiguities around which tools to use, the key elements in the diagnostic process and the relationship between diagnosis, assessment and formulation suggest that local practice may be shaped by other factors, such as available resources, experience and professional roles. Which tools are used, whether different elements of the process are considered together, sequentially or inconsistently, and the specific aims of each part of the assessment process may have an impact on diagnostic outcomes. A clearer framework would help HCPs to consider which elements of the process are relevant and when.

### **6.9.3 MDT working and views of the family**

Guidance about how HCPs can reach a consensus with others in a multi-disciplinary context or deal with patient/family disagreement or desire was lacking, leaving interactional factors as key to the process but largely unexplained. Whilst it might not appear to be in the remit of CPGs to make specific recommendations about how teams are organised and configured, particularly across different health systems, we argue that team functioning as a key shaping factor in diagnosis requires more attention in CPGs, to ensure clarity of roles and transparency for those coming for diagnosis. Similarly, as acknowledged by some CPGs, desire of the patient/family can influence the diagnostic process, therefore CPGs should offer guidance about how that might be managed.

### **6.9.4 Diagnostic uncertainty and judgement**

Uncertainty about diagnostic thresholds and differences in diagnostic criteria make clinical judgement key to the diagnostic process and yet how this comes about was not clearly defined. The extent to which diagnosis should be based on underlying symptoms versus contextual factors such as wider needs or circumstances of the individual was unclear. In addition, how HCPs consider the consequences of the diagnosis for the patient and their family was unclear,

although there was a strong link described between diagnosis and access to support.

Ambiguities in CPGs suggest that guidelines have limitations in how far they are able to promote consistency across practice especially given the lack of a biomarker for autism, the reliance on observed behaviour and family narratives for diagnosis, and the differences across health systems. However, adults, children and families coming for diagnosis might expect a consistent process of assessment in keeping with a framework outlined in CPGs, as CPGs become a fixed reference point both for HCPs and the lay public. There is, therefore, a tension between potential expectations of those coming for diagnosis that there should be a uniform process; and the flexibility HCPs require to respond to individual need.

Given the social nature of diagnosis as argued in this article, biomarker use in clinical practice, if and when it is successfully developed, is likely to remain only one aspect of an interactive diagnostic process, and therefore may not necessarily alleviate some of the difficulties and complexities of diagnosis that we describe. However, as biomarker research develops, it is likely that it will produce important evidence to be considered in the development of future CPGs.

#### ***6.9.5 Building on previous work***

Whilst our narrative review differed in purpose to the systematic review undertaken by Penner et al (Penner et al., 2017), there were some similar findings across the two studies. We found, as did the authors of this previous review, that guidelines were inconsistent in their recommendations around diagnostic assessment. For example, whilst guidelines generally recommended MDT assessment, some suggested that a single experienced clinician could diagnose (Carpenter, 2012; NICE, 2011; Royal College of Psychiatrists, 2014) and there was little cited evidence for the efficacy of MDT assessment. In addition, CPGs did not provide guidance as to how waiting times (where specified) would be achieved and we would add that they provided little operational guidance as to how MDT decision-making should operate to be

most effective. We found, as did Penner et al, that guidelines varied substantially in recommended tools and personnel; and that none of the professional guidelines provided target waiting times for assessment (See Appendix 12). Whilst we did not assess guidelines for quality, we agree that there are multiple guidelines that HCPs might access, and that they vary in their level of detail and their recommendations.

We built on Penner et al's findings in a number of ways. Our review of the range of assessment processes that HCPs involved in autism diagnosis may undertake (See Appendix 12) suggested a wide range of choices in assessment processes. We also found that using different classification criteria (ICD-10 and DSM-5) further increases complexity in CPGs. Finally, we found that consideration of factors such as interaction with the patient and family, how needs might be defined and assessed, and issues of masking, social context, uncertainty and clinical judgement highlighted the way in which social processes and factors might impact on diagnostic decision-making. We also found that, despite the CPGs in our study operating within comparable health systems across the UK, CPGs did not make consistent recommendations around how diagnosis might release post-diagnostic resources, and what that means for the process of diagnosis itself.

Overall we agree with Penner et al's findings that CPGs should incorporate flexibility to ensure that individual needs are met. Additionally, we suggest that guidelines should acknowledge more explicitly the social framing of diagnosis and support clinicians with a framework which enables them to act pragmatically in the best interests of the patient. We would argue that inconsistencies and lack of operational guidance around social factors in CPGs suggests that local factors such as access to resources and HCP expertise are likely to shape diagnosis more than is explicitly outlined in CPGs.

Unlike Penner et al, we do not think that a formal approach to decision-making such as the Delphi method would help HCPs in the assessment process; rather it might simply add another layer of complexity to a process which is already challenging. Our experience is that HCPs already struggle to find time to meet



together in the context of an ever-increasing workload; an extra administrative burden may make this even more difficult.

Finally, unlike Penner et al, we included in our review CPGs for adult diagnosis and children over six years old, which enabled us to consider factors common across age groups. Whilst we did not specifically look for differences between children's and adult's CPGs we are aware that the different pathways for children's and adult's assessment (Baird et al., 2011; Vllasaliu et al., 2016), may well impact on an individual's ability to access diagnostic services, the process of assessment itself as well as potential support post-diagnosis. We would consider these differences as social organisational factors that may impact the assessment process and merit further consideration in the development of future CPGs.

Guidelines, therefore, appear to offer a relatively linear and straightforward pathway towards a diagnostic decision in their presentation, with DSM-5 asserting that criteria facilitate an objective assessment of symptom presentations in a variety of settings (Norbury and Sparks, 2013). However, comparing individual guidelines suggests inconsistencies in this framework and close analysis reveals a more fluid process, disrupting the apparent clinical purity of diagnosis (Latimer, 2013).

## **6.10 Conclusion**

Overall, there was a bewildering range of options for HCPs in the assessment process, and a number of different emphases in guidelines which might lead a clinical team one way or another. Navigating this framework in practice is, therefore, likely to be less systematic than the guidelines might suggest, allowing for, as it must, social and contextual influences. In reality, the clinical pathway for autism diagnosis differs across health systems and trusts across the UK (Vllasaliu et al., 2016) leading to the potential for a great deal of variation in diagnostic decision-making.

### **6.10.1 Strengths and limitations**

Although there has been a recent systematic review of clinical guidelines (Penner et al., 2017), we consider our narrative approach to be helpful to understand the complex and sometimes contradictory nature of the diagnostic process. Methodologically, we undertook a systematic search and included a transparent but pragmatic selection of documents. This is, to our knowledge, the first review which strives to consider where social factors are considered in clinical guidelines for autism diagnosis. One limit was that as it was a review of current guidelines, changes through time were not exposed. Our review was limited to the UK context because health care settings vary widely in international contexts. In addition, we only examined the content of guidelines rather than how they are used. Whilst CPGs are intended to assist clinical decision-making by improving effectiveness and decreasing variations in clinical practice (Kredo et al., 2016), one review of guidelines for psychiatric diagnoses suggested that CPGs are not implemented enough in clinical practice due to either lack of agreement or ambiguity between guidelines (Saddichha and Chaturvedi, 2014). It is likely that there is wide variation in how CPGs are used in practice in autism diagnosis and we plan further studies to consider this.

### **6.10.2 Implications and recommendations for future research**

Social factors were not only explicit in guidelines, but were central to them. However, an observer might be forgiven for assuming these are subsidiary factors in diagnosis, with the more 'medical' 'symptom checklist' at its core. HCPs are expected, as outlined in DSM-5, to integrate the social, psychological and biological in case formulation, however, greater clarity about how this should operate would be helpful. Our findings suggest that more detail about how clinical judgement should consider social factors in diagnosis would provide a more transparent guideline for HCPs.

We would not recommend greater rigidity within CPGs when evidence for best diagnostic practice is inconsistent (e.g. use of diagnostic tools), and which may restrict HCPs in making decisions that are in the best interest of the person coming for diagnosis. Rather we recommend a more explicit acknowledgement of social factors in CPGs with advice about how they should be managed and

operationalised to enable more consistency of practice and transparency for those coming for diagnosis.

Specifically, greater clarification is required related to the sequence and timing of the diagnostic, assessment and formulation processes. The recognition and assessment of needs is both part of the assessment process and inextricably linked to the consequences of diagnosis; guidelines might attempt to consider how these might be reconciled. A greater acknowledgement of the active role of the patient, client or patient's family in the diagnostic process would help to place potentially competing narratives into context. It would be useful to consider whether guidelines are culturally specific to health services and setting and we would recommend that further narrative reviews should be conducted to examine CPGs in other countries. In addition, greater clarity is required around how multi-disciplinary interaction might operate to support consensus decision-making. Further research creating an evidence base on best practice for multi-disciplinary decision-making and the use of different diagnostic tools in practice is required, taking into account the complexity of social factors in diagnosis.



## Introduction to Chapter Seven

### Overview

The narrative review in Chapter Six demonstrated that clinical guidelines varied in their recommendations for diagnostic practice. I identified a number of ‘social factors’ which complicate the straightforward notion of diagnosis as a way to identify underlying conditions. There appeared to be potential for ambiguity and significant scope for the use of clinical judgement, a term that was ill-defined. Building on these findings, the aim of the assessment team observation study was to examine how autism diagnosticians make diagnostic decisions in practice, given the complexity of factors as outlined in guidelines.

I have talked in detail in Chapter Five: Methods and Approach about the conceptual shift in the project in relation to social factors. The initial concept of ‘social factors’ as defined in Chapter Six was based on a positivist concept that implied that the social was a ‘thing apart’ from the clinical or medical: and that there could be a divide between the two so that what we considered ‘social’ could be measured. Just as with medical classification, I struggled to see where these things – the clinical and the social – could be separated.

In retrospect, the review of clinical guidelines demonstrates how guidelines themselves are constructed from social concepts of categorisation and classification. The study perhaps illustrates the struggle that medicine has to hold on to authority in classification. If there are human judgements made about what should and should not be in clinical guidelines (and how can there not be) which leads to discrepancies between them, then it illustrates how subjectivity is inherent in our classification systems.

The following articles were written after a conceptual shift, and consider social ‘factors’ to be inseparable from the wider context of diagnosis (in that diagnosis *is* a social process, informed and shaped by culture, society, history and the institution of medicine; and contributing to it).

Eighteen assessment meetings were attended across four teams. The data was analysed with a hybrid thematic/discursive method (Braun and Clarke, 2013; Wiggins, 2017) (see Chapter Five: Methods and Approach). This chapter represents the thematic study.

All aspects of the study were undertaken by the PhD candidate. Co-authors contributions were as follows:

GR: research design; revision for intellectual content

RM: revision for intellectual content

TF: revision for intellectual content

The rest of this chapter presents the published manuscript of the thematic analysis of clinical guidelines. It was published in *Sociology of Health and Illness* (Hayes et al., 2020) in February 2020.

**CHAPTER SEVEN: Drawing a line in the sand: affect and  
testimony in autism assessment teams in the UK**





## **Abstract**

Diagnosis of autism in the UK is generally made within a multi-disciplinary team (MDT) setting and is primarily based on observation and clinical interview. We examined how clinicians diagnose autism in practice by observing post-assessment meetings in specialist autism teams. Eighteen meetings across four teams based in the south of England and covering 88 cases were audio-recorded, transcribed and analysed using thematic analysis.

We drew out two themes, related to the way in which clinicians expressed their specialist disciplinary knowledge to come to diagnostic consensus: *Feeling Autism in the Encounter*; and *Evaluating Testimonies of Non-present Actors*. We show how clinicians produce objective accounts through their situated practices and perform diagnosis as an act of interpretation, affect and evaluation to meet the institutional demands of the diagnostic setting. Our study contributes to our understanding of how diagnosis is accomplished in practice.



## 7.1 Introduction

*If we think about it diagnostically, somewhere there is a line drawn in the sand ... and where that line is, changes really, historically.*

Consultant Clinical Psychiatrist

Autism Spectrum Disorder (ASD) is diagnosed when there are persistent patterns of difficulty in social communication and social interaction, combined with restricted, repetitive patterns of behaviour, interests or activities (APA, 2013a). In a context of increasing prevalence rates, neurodiversity activism, parent advocacy, and debates around aetiology of autism, sociologists have considered how the category of autism has shifted and changed, examining the role of parent activists, genetic and genomic developments, and the broader issues of psychological and child development that shape the category (Evans, 2017; Eyal et al., 2010; Fitzgerald, 2017; Hollin, 2017a; Hollin and Pilnick, 2015; Nadesan, 2005; C. Silverman, 2013; Singh, 2016).

The condition of autism is particularly interesting for a study of diagnosis because it has uncertain aetiology, symptoms can be inherently ambiguous, and rather than being a single condition, autism is considered to comprise a group of heterogeneous disorders which vary widely. Furthermore, approximately 70% of people who are diagnosed are considered to meet criteria for at least one other psychiatric condition (NICE, 2011). Core symptoms are considered to be present in early childhood but many people are now diagnosed in adulthood. Diagnostic rates have increased greatly, now estimated at about 1.1% - 1.2% of the population (Brugha et al., 2012; Sadler et al., 2017), leading to debates around the broadening of diagnostic criteria (Russell et al., 2015; Rutter, 2005); the decreasing age of diagnosis (Leonard et al., 2010); the conceptualisation of autism as an 'epidemic' (Ebben, 2018) and ultimately the medicalisation of behaviour through domain expansion (Conrad, 2007).

Whilst there are many screening and assessment tools for autism, the most commonly used tool in both adults and children is the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000), alongside a clinical interview

such as the Developmental, Dimensional and Diagnostic Interview (3di) (Skuse et al., 2004) or Autism Diagnostic Interview-Revised (ADI-R) (Le Couteur et al., 2003). The ADOS is an activity-based standardised observation tool and the clinical interview is a set of standardised interview questions for caregivers designed to elicit developmental and behavioural information to assess the presence of autistic symptoms (Skuse et al., 2004). Diagnosis, therefore, is determined primarily through observation of behaviours and the accounts of informants: patients<sup>2</sup>, family members, friends or colleagues. The ‘gold standard’ of diagnostic decision-making is considered to be consensus agreement within a multi-agency team utilising appropriate diagnostic tools and other related assessments (Falkmer et al., 2013; Woolfenden et al., 2011). As a case study, therefore, there is an opportunity to consider the interaction of different agents within the diagnostic process: clinicians<sup>3</sup>, patients and family testimonies, and diagnostic tools, in the institutional context of the assessment meeting.

There has been little direct observational work examining how clinicians accomplish autism diagnosis through talking about their patients together; and no studies to our knowledge that do so in adult assessment. This article explores the question of how clinicians utilise and interpret evidence together, to create an accountable diagnostic narrative.

### **7.1.1 Constructing autism**

Our study is sited within a ‘sociology of diagnosis’ framework (Brown, 1995; Jutel, 2009) which considers the place of diagnosis in the institution of medicine, the social framing of disease definitions and how diagnosis confers authority to medicine (Jutel, 2009). Considering diagnosis as a social process rather than a ‘moment of clinical purity’ (Latimer, 2013) allows investigation into the social forces that may shape diagnosis, the cultural discourses drawn upon,

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<sup>2</sup> There is significant debate about classifying autism as a ‘disorder’, with many preferring to use the term ‘condition’ (NICE, 2012). We use the term ‘autism’ to embrace the spectrum of conditions as currently defined in the DSM-5 and International Classification of Diseases (ICD-11) (WHO, 2018).

<sup>3</sup> We use the term ‘clinician’ to encompass all healthcare participants in this study, defined as members of a registered health profession involved in direct patient care.

the ways in which human problems and experiences become viewed and treated as medical – a process known as medicalisation (Conrad, 1992) – as well as the practices clinicians use together to resolve the challenge set by wider society. In this context, the category of autism can be viewed as a conceptual framework that proscribes varying contemporary versions of acceptable societal behaviour, understandings of psychiatry, as well as technological and genetic developments.

Conrad and Schneider's (1980) approach to medicalisation embraces interaction, shifting the site of medicalisation from being the responsibility of the medical practitioner alone, to a broad and inter-related set of practices and values. At micro-level, this can include non-clinical actors such as teachers and employers (Halfmann, 2012). The intersection of different actors (including commercial interests, advocacy groups, genetic technologies and institutions) can shift a collection of behaviours into a 'thing': a concrete entity which becomes a disease category. For autism, this process of reification transforms what is sometimes an inconsistent or intangible set of social behaviours into a concrete condition, perceived as an inherent attribute of an individual. Examining clinician interaction can help us to understand how social behaviours become medicalised through the social process of diagnosis.

Social and institutional practices, therefore, enable the framing of autism as a condition and as a social construct for defining the normal and the pathological. Scholars have illustrated how social practices have reconceptualised autism. For example, increased forms of social surveillance of children and the emergence of 'childhood' as a research focus enabled the reframing of autism as a condition in the 1940s (Nadesan, 2005). Others argue that deinstitutionalisation from the 1960s led to a redistribution of expertise, a rise in parental activism, and a change in how we understand 'mental retardation', contributing to extending autism into a broader spectrum (Eyal et al., 2010). Evans argues that the development of autism in the UK must be seen in the light of major institutional transformations from the 1960s including the growth of new statistical and epidemiological methods for measuring childhood behaviour and prevalence (Evans, 2017, 2013). These methods served to reconceptualise

psychological development: 'autism' shifted from a category related to the inaccessible inner life of a child, to a problem of social impairment (Evans, 2013).

The reclassification of autism as a 'spectrum', Autistic Spectrum Disorder, in DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, fifth edition) (APA, 2013a), simultaneously, and controversially, removed Asperger's Syndrome (AS) as a discrete and separate sub-group. This conceptual change to a heterogeneous 'continuity of severity' rather than 'discrete entities' (Wing and Gould, 1979, p. 26) determined that autism became a single condition with different levels of severity rather than four separate types of pervasive developmental disorders as outlined in DSM-IV (APA, 1994).

Some scholars argue that the development of the category of autism as broadly heterogeneous can be conceived as an 'agential cut' – a point at which autism became one thing to the exclusion of others (Hollin, 2017a). Hollin argues that the work of key cognitive researchers such Frith, Happe and Baron-Cohen in the 1980s and 90s shifted autism into the cognitive domain as an explanatory framework. Moreover it led to a stable definition of autism 'determined by its indeterminacy' (Hollin, 2017a, p. 617) as a heterogeneous condition with no two people being the same, and with no single cause. Whilst there has been extensive work undertaken on medical uncertainty (for example, see Atkinson, 1984; Bursztajn et al., 1986; Campbell, 1985; Fox, 1957; Greenhalgh, 2013; Hedgecoe, 2003; McGoey, 2009; Pickersgill, 2011; Pinch, 2012; Timmermans et al., 2018), which we discuss elsewhere (see Hayes et al., 2019, under review), here we consider Hollin's concept of ontological indeterminacy to be particularly relevant for this study. Hollin argues that autism's inherent heterogeneity lends it an ontological indeterminacy, meaning that exactly what autism is can never be known (Hollin, 2017a). Nevertheless, it still defends the status of object as a reified category.

Finally, critical diagnostic work has explored how parent advocates and adult self-advocates have helped to shift public awareness of what autism is and how it is represented (Eyal et al., 2010; C. Silverman, 2013; Singh, 2016). Eyal et al

(2010) argue that a redistribution of expertise provided a new network whereby parents moved from being the 'least credible' of witnesses, for example being blamed as 'refrigerator mothers' (Bettelheim, 1967), to experts on their children. Parents became core to a network of expertise whereby there was a 'hybridisation of identities' between medical experts and lay people (Eyal et al., 2010, p. 8). This, they argue, means that the production of autism takes place relationally and outside the traditional medical field of psychiatry, instead in a 'space between fields' where boundaries between lay and medical expertise are blurred (Eyal, 2010; Eyal et al., 2010). Combining this concept with an interactional approach to medicalisation, raises the question of how these networks of expertise work in practice, and how this might contribute towards defining the condition.

### ***7.1.2 Talk between healthcare professionals about diagnosis***

There has been some observational research examining autism assessment, for example, observation of initial assessment meetings (O'Reilly et al., 2017) and of multi-disciplinary team meetings (Parish, 2019). The empirical body of work most relevant to our study is that undertaken in the US by Turowetz and Maynard (Maynard and Turowetz, 2019, 2017; Turowetz, 2015a, 2015b; Turowetz and Maynard, 2019, 2017, 2016). In their analysis of talk-in-interaction in autism assessments, case conferences and diagnostic feedback meetings, Maynard and Turowetz demonstrate how diagnostic stories are methodically produced through interaction between clinicians themselves and between the child and clinicians. This article builds on two inter-related findings from their work related to how clinicians 'attend to' different factors in the diagnostic process: foregrounding diagnostically salient behaviours; and disattending to interactional agents within the assessment.

On the first point, Turowetz claim that clinicians identify and select diagnostically salient (story-worthy) behaviours to recount to colleagues who will, together, build consensus around their importance to a potential diagnosis (Turowetz, 2015a). Turowetz examined how interpretations of a child's ambiguous actions were revised and developed, and served to emphasise

certain interpretive frames over others. Clinicians orient to story-worthy events, therefore, to create diagnostic consensus (Turowetz, 2015a).

Second, and with reference to Actor Network Theory (see Latour, 2005), Turowetz argues that whilst behaviour in assessments is 'interactionally-occasioned', clinicians cite practices in such a way that presents the assessing clinician as a neutral facilitator and diagnostic tools as largely passive recording measures (Turowetz, 2015b). This finding is extended in later work where Turowetz and Maynard argue that although diagnosis is an embodied, interactional process, clinicians 'disattend' to interactional agents – the clinician and the diagnostic tool - within assessment (Turowetz and Maynard, 2019). This is a necessity born of the institutional pressure for standardisation, and results in the behaviours being reported as an inherent feature of the child, rather than as an interaction between clinician, tool and child.

However, a UK study by Hollin and Pilnick (2018) found that the diagnostic decision can shift depending on how similar types of behaviour are interpreted. In ADOS assessment sessions, facilitated by ADOS-trained researchers, they demonstrate how judgments are made about which kinds of behaviour are consequential for diagnosis. The authors discuss the significant level of interpretation required to identify and separate these kinds of behaviours with consistency (Hollin and Pilnick, 2018). This suggests that despite attempts at standardisation, interaction and interpretation play a significant part in assessment.

Whilst Turowetz and Maynard argue that autism diagnosticians routinely 'gloss over' embodied interaction in assessment (Turowetz and Maynard, 2019, p. 1023), other researchers have shown how affect, emotion and the expert 'gaze' are woven into the social actions of different stakeholders in the world of autism (e.g. Fitzgerald, 2017, 2013; Hollin and Giraud, 2017).

Silverman (2013) argues that autism as a condition is characterised by expert knowledge, through standardised systems of measurement and description with their associated screening and diagnostic tools. And yet, for parents and



families these standardisations fail to represent the emotional consequences of these diagnostic practices, or the messiness of real life experience (C. Silverman, 2013). Silverman argues that, rather than being a liability, emotion can be a source of committed and reliable knowledge. Fitzgerald extends this argument to suggest that autism neuroscientists engage in their work not simply as an intellectual or technical task but as an act of affective and emotional labour (Fitzgerald, 2017, 2013). In his interviews with neuroscientists he finds that they express a 'feel' of autism, as something distinct and knowable, as something we 'recognise when we see it' (Fitzgerald, 2017, p. 48). He argues that, where specificity in testing is less important than the level of impairment, 'epistemological space' is given to whether autism is 'felt' by the clinician during the interaction' (Fitzgerald, 2017, p. 50).

These empirical studies serve to illustrate how clinicians may navigate the complex process of diagnosis when heterogeneity is considered to be core to the condition. In this article, we focus on the way in which clinicians talk about diagnosis together in specialist autism assessment meetings in the UK. We were particularly interested in how diagnosis of autism is constructed as an interactive event within meetings and how this might contribute to the reification of autism as a condition.

## **7.2 Methods**

As part of a larger study exploring autism diagnosis, this study collected naturally occurring data by observing how clinicians talk together in specialist autism assessment teams. Using naturally occurring approaches in healthcare settings enables exploration of real-world practices underpinning healthcare (Kiyimba et al., 2019). It provides data which is local and contextually focussed and therefore 'context-rich'; and minimises the active role of the researcher in shaping the data (Kiyimba et al., 2019; Potter, 2002).

We purposively sampled teams that specialised in autism assessment and who held regular assessment meetings. Four teams took part in the study: two adult

and two children and young people (C&YP) assessment teams. Patients and families were not present at any meetings.

Sites were recruited from an open call to a list of clinical contacts drawn from the internet and via the Institute for Health Research (NIHR) Clinical Research Network. All sites were National Health Service (NHS) providers. Seven teams were approached: two were excluded as they did not hold formal meetings, and one withdrew. Table 9 gives characteristics and description of each team by role and setting.

A process of ethical approval and research governance was undertaken in line with NIHR Good Clinical Practice guidelines. This included full informed consent from participants, rights to withdraw from the study, secure storage and data management. Names and identifying details were changed throughout to protect the identity of participants and patients. Ethical approval was granted by University of Exeter Medical School (UEMC) ethics committee (Ref: Mar17/B/114) and the Health Research Authority (HRA) (Ref: 220180).

### **7.2.1 Data collection**

Observations of meetings were carried out by the first author who audio-recorded eighteen autism specialist team meetings in four different sites (nine meetings in two adult and nine in two C&YP settings). We used Malterud et al's (2016) concept of 'information power' to assess when we had adequate data to meet the aims of the study. This involved consideration of quality of dialogue, analysis strategy, use of established theory and sample specificity.

The number of cases discussed at each meeting ranged from 1 to 9, and in total the observations provided data related to 88 cases and documented over 19 hours of meeting time. Thirteen cases discussed were at referral stage and 24 were classified as administrative discussions, primarily related to booking dates for assessments or related actions. These two groups were excluded from analysis as they did not involve decision-making about diagnosis. The final analysis included a total of 51 cases – 24 children and young people and 27

Team details (a)	Meeting Number	Attendees per meeting	Total case discussions	Diagnosed with autism	Diagnosed not autism	Deferred (b)	Referrals & Admin discussions (c)
<b>Adult Team 1 (d)</b>	1	6	3	1	0	2	0
	2	6	2	0	0	2	0
Clinical Team Manager; Clinical Psychologists (x4), Assistant Clinical Psychologists (x3); <i>Peer Support Worker</i> . Meets weekly (Case Review Meetings) Predominantly rural area	3	5	1	0	0	1	0
	4	6	2	0	0	2	0
	5	5	3	0	0	3	0
			<b>11</b>	<b>1</b>	<b>0</b>	<b>10</b>	<b>0</b>
<b>Adult Team 2</b>	1	5	3	2	1	0	8
Team Manager; Consultant Psychiatrists (x2); Occupational Therapist; Medical Secretary; <i>Social Worker; Speciality Doctor; STS Psychiatrist</i> . Meets weekly; Predominantly urban area	2	4	6	2	1	3	6
	3	5	5	1	2	2	5
	4	4	2	1	0	1	5
			<b>16</b>	<b>6</b>	<b>4</b>	<b>6</b>	<b>24</b>
<b>CYP Team 1 (d)</b>	1	6	9	3	3	3	4
Clinical Team Manager; Consultant Psychiatrists (x2); Clinical Psychologist; Senior Manager; Speech & Language Therapist; Educational Psychologist; Autism Practitioner (x2); Senior Administrator. Meets monthly with 'mini' meetings as required; Predominantly rural area	2	5	2	2	0	0	4
	3	4	1	0	0	1	2
	4	4	6	4	0	2	1
	5	3	2	1	0	1	2
			<b>20</b>	<b>10</b>	<b>3</b>	<b>7</b>	<b>13</b>
<b>CYP Team 2 (14+)</b>	1	2	1	1	0	0	0
Consultant Psychiatrist; Clinical Psychologist (x2); <i>Clinical Psychologist; Senior Nurse; Foundation Doctor</i> . Meets weekly; Predominantly urban area	2	3	1	1	0	0	0
	3	4	1	1	0	0	0
	4	4	1	1	0	0	0
			<b>4</b>	<b>4</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>TOTALS</b>			<b>51</b>	<b>21</b>	<b>7</b>	<b>23</b>	<b>37</b>

Notes: a): Not all team members present in every meeting; *visitors in italics*; b): Cases were generally deferred due to team requiring further tests or information; c): Cases which came in as referrals and were allocated for assessment: or were subject to admin discussion; d) In these teams only selected cases were brought for presentation

Table 9: Team Characteristics and Diagnostic Outcome

adults. The first author's field notes, short case summaries written after fieldwork and the transcribed, anonymised audio data comprised the dataset.

### **7.2.2 Method of analysis**

We undertook a thematic analysis which enabled identification of patterns across the dataset (Braun and Clarke, 2013, 2006a). Thematic analysis is theoretically flexible (Braun and Clarke, 2013) and we took a social constructionist approach which acknowledges that meaning is socially produced and reproduced rather than being located within the individual (Burr, 1995). This social constructionist approach makes the epistemological assumption that we create meaning collectively through our interactions and experiences of the world, and that our constructions of reality depend on specific cultural and historic factors (Burr, 1995). Knowledge is produced, therefore, by and through culture, language and discourse. Discourse is considered to be a social practice with consequences (Edwards and Potter, 1992) and by examining clinicians' talk, we can examine how 'facts' and meaning are socially produced.

Our analysis was based on a data-driven, inductive, organic approach (Clarke and Braun, 2018) prioritising depth of engagement. We followed Braun and Clarke's six-stage process: familiarisation, coding, generating, reviewing and defining/naming themes, and writing up (Braun and Clarke, 2013). Throughout, we focussed on discursive issues as outlined by Wiggins (2017), which allowed the authors to consider how, through interaction, the social action of diagnosis is accomplished.

Data were transcribed orthographically, in line with thematic analysis, and initial coding was undertaken by the first author across the complete dataset using Nvivo software. The developing analysis was conducted by the first author, presented at qualitative data sessions and discussed with co-authors throughout to develop and challenge emerging ideas and to develop consensus.

### 7.3 Analysis

Clinicians considered a range of assessment material in their meetings that included the results of diagnostic tests, primarily the ADOS and a clinical or developmental interview such as the 3di. The team discussion led either to a diagnostic decision – autism or not; or a deferred decision dependent on further testing or information (Table 9). In the process of analysis, two inter-related themes were identified in relation to the way in which clinicians expressed their specialist disciplinary knowledge in order to come to diagnostic consensus: Feeling Autism in the Encounter; and Evaluating Testimonies of Non-Present Actors.

#### ***'Feeling' Autism in the Encounter***

We found that clinicians routinely expressed an idea that they could feel or sense when a person they were assessing was autistic.

Cameron is a nine-year old boy. The Speech and Language Therapist (SLT) has undertaken the ADOS assessment and has '*scored*' Cameron as within the clinical range suggesting autism. However, there is concern there may be other factors that might explain his score, due to a complex family history. There is an impasse in the discussion and the Clinical Team Manager (CTM) prompts a shift in direction.

#### **CYP Team 1: Cameron, age 9**

CTM: You've got a feeling that it felt ASD?

SLT: Oh yeah.

CTM: Yes, which you can tell by the way you're reporting it

The question, framed as a statement, offers SLT an opportunity to underpin the ADOS report with a subjective impression. There is a shared understanding that this subjective account has weight in this setting; it makes the clinician doubly accountable for assessment, both 'objectively' through the diagnostic tool, and 'subjectively'. Our interest is not whether or how SLT 'feels ASD': rather what the expression of 'feel' might be doing discursively. There is invocation of two types of feeling here. The clinician has a feeling; and in addition 'it' felt ASD.

The use of 'it' rather than 'he' is ambiguous in relation to the location of this aspect of 'feeling'; the way in which this is framed sites the feeling not in the child, but somewhere else, in the space between.

This can be seen further in discussion about Gail, where the location of the feeling is *'in the room'*. Gail *'didn't quite reach threshold'* on the ADOS, suggesting not autism, but the Clinical Psychologist (CP) and an Assistant Psychologist (AP) are pursuing further tests.

**Adult Team 1: Gail, age 44**

AP: I think though we're just going to do some more with her aren't we? I don't feel like there's nothing in it.

CP: Absolutely. I think there is something in there and I think it's that having to remember what it was like being in the room with her because... and I think particularly I'm finding it quite helpful to talk about her and actually, because I'm quite cynical about certain aspects

Here clinicians recall the experience of being *'in the room'* with Gail and this appears to be a motivator for pursuing *'some more'* (tests). The participants agree there is *'something'* and this is driven by feeling and *'what it was like'*. Here we do not assume a cognitivist position which asserts that either AP or CP are *experiencing* emotion during this process of assessment. Neither do we claim that these things are *not* being experienced. Rather, we consider this expression of affect as a social action rather than a reflection of inner states. Here clinicians are accounting for their continued pursuit of diagnosis, despite a score on the ADOS that does not indicate autism, and some cynicism about the narrative being told by Gail and her informant. Like the *'affective space'* (Fitzgerald, 2014, p. 245) within which autism scientists work, here *'feeling'* circulates dynamically and expansively between actors, its transitioning presence enabling discursive flexibility and warranting future action.

'Feeling' can be seen to drive forward assessment. Brian is a 58-year-old man who was assessed by a Clinical Psychologist (CP) and was scored *'under-threshold'* on the ADOS, outside the clinical range for autism. However, the clinicians in assessment considered the case further.

**Adult Team 1: Brian, age 58**

CP: It's just reminding me a little bit of who we saw today in that we both feel there's something in it but we don't feel we've quite got to it yet and it's something around sometimes how you get there and how you ask these questions. It's uncovering it, isn't it? It sometimes takes a little while to get there as well

CP suggests that there is '*something*' inherent to Brian that requires a particular kind of approach to 'uncover'. This locates the source of the condition, autism, as embedded within Brian and asserts the special knowledge of the clinician to discover it. Clinicians' stated ability to 'know' there is something there, a clinical intuition, is a kind of 'disciplinary objectivity' (Timmermans and Buchbinder, 2012) – a specialised evaluative knowledge or trained judgement (Daston and Galison, 2007) - which can drive clinicians to seek further evidence towards a diagnosis or support a particular diagnostic trajectory. However, as with Cameron and Gail, the location 'it' assumes there is a 'thing' that has to be found. The CP's analysis suggests corroboration with the second assessor with the use of 'we', thereby strengthening the account and their accountability. Here we can see what Fitzgerald (2014, p. 235) calls a 'particular dynamic of ambiguity and presence' in that there is a certainty and commitment embedded in the expression of the feel of autism, and yet the expression of it emerges from ambiguity in assessment. Finally:

CP: And essentially that was kind of driven by the fact that ultimately we kind of feel that there's something there actually but he's not necessarily playing ball and reporting it or its not necessarily coming up in the way we'd expect

Brian's lack of co-operation or insight (*'not necessarily playing ball'*) is invoked as a reason why autism may not be apparent when the clinicians believe there is '*something there*'. The process leads to a 'firm conviction' (Messer et al., 2018, p. 268) as the final guide to diagnosis which allays any uncertainty previously experienced when Brian demonstrates insight into his own difficulties in a feedback meeting. Brian was diagnosed with autism.

CP: I felt that he met criteria and, what's more, I felt for the first time I felt actually that there was sort of clinical grounds for the diagnosis

Unlike some other instances where clinicians cited various forms of evidence, here the clinician describes their own judgement or 'feel' for autism. In the space of the team meeting, expressions of feeling serve to drive or inhibit progress towards a diagnostic decision, makes diagnosis doubly accountable, and allows the expression of dilemmas and contradiction. It becomes a warrant for further exploration. Whilst the *feeling* resides between assessor and assessed, the *behaviour* is located in the individual being assessed. And yet, as noted by Hollin and Giraud (2017), affective responses are not entirely determined by the organism (patient) but by the 'whole ecological setting within which that organism is immersed and perceived' (Hollin and Giraud, 2017, p. 2). Clinicians are *part of* the ecology of diagnosis, not separate to it. The discursive accomplishment of expressing affect is to signal a shared understanding of what autism 'feels like' to clinicians who are also part of that ecology and who, in accepting this affective assessment, jointly make 'feeling' relevant to the task in hand. The expression of affect, therefore, enables collective 'interactional progressivity' (Maynard and Turowetz, 2017, p. 265) towards a decision.

### ***Evaluating Testimonies of Non-Present Actors***

Throughout the meetings clinicians cited instances of behaviour reported by non-present patients, their parents, partners or other informant, frequently drawn from a clinical interview such as ADI-R, which tacitly or explicitly linked to diagnostic criteria for autism.

Elisha is a 15-year-old girl who has been assessed by clinical interview (3di) and ADOS. Elisha has '*scored up across all domains*' on the 3di, suggesting that she is within the range for an autism diagnosis. The Clinical Psychologist suggests that she is also likely to '*score up*' on the ADOS, which has not yet been scored. Here CPi recounts a story told by Elisha's parents.

#### **CYP Team 2: Elisha, age 15**

CPi: The other unusual thing she started doing at that time was when she left her home to visit her friends, she would insist on bringing all of her clothes with her on the bus, which I think the parents went along with, although it was such hard work bringing these clothes back and forth



Firstly, CPi primes listeners to hear the upcoming talk in the context of abnormality by prefacing the story with '*the other unusual thing*'. '*She would insist*' suggests that Elisha's actions were undertaken in the face of opposition, presenting her as unreasonable. The parents then have to engage in '*hard work*' which indicates significant effort required to meet Elisha's needs. Together, the elements of this narrative suggest a young person whose behaviour is troublesome, with the speaker inviting listeners to locate symptoms of autism - restrictive, repetitive behaviours, interests or activities - in Elisha's behaviour. Here CPi is actively constituting parental reports about Elisha's behaviour as evidence of autism and drawing on 'the importance of parents' caring as a source of insights' into their own children (C. Silverman, 2013, p. 229). Parent testimonies are valued and reinforced by clinicians in their retelling, with the parents' commitment to their child ('*went along with*', '*hard work*') and parental understanding of the difficulties of Elisha's behaviour invoked. Alongside the reporting of many such instances, observations made during the ADOS, test scores and discussion of potential complicating co-conditions, the clinicians agree a diagnosis of autism for Elisha, on condition that the ADOS scores as expected.

With Hayley, who is 16, the ADOS assessor, Senior Manager (SM), does not undertake a full scored ADOS stating, '*I wasn't quite sure how she [Hayley] was going to react*' and instead used the ADOS guidelines for a conversation with Hayley. SM recounts a number of descriptive incidences, both 'tendencies' and 'instantiations' of autistic behaviours, as defined by Maynard and Turowetz (2017), to support the assessment.

#### **CYP Team 1: Hayley, age 16**

SM: Mum said that she used to twirl when she was younger...Em, always been obsessed with various things ... and this is come from Hayley: Only Fools and Horses, Finding Nemo, em Monsters Inc, The Simpsons, Ghostbusters

SM presents this as mum's narrative, with the term '*she used to*' suggesting a behaviour in the past (and no longer observable, although here cited as developmental information towards a diagnosis); and '*always been obsessed*' as a recurring and ongoing difficulty. Presenting interests as an obsession

constitutes Hayley's behaviour as problematic and unusual rather than as constituting normal childhood interests. Listing a large number of interests reinforces, through illustrative detail, the repetitive behaviour and adds rhetorical strength to the argument (Wiggins, 2017). Here SM has recounted stories told by both Hayley and her mum. Although the two stories seem apparently disconnected, they combine to enable SM to present Hayley's behaviour as aligned with autism symptoms – restricted and repetitive behaviours - and constitute her behaviours, both past and present, from two different sources, as evidence, actively constituting Hayley's behaviour as evidence of autism. Together, the elements of this narrative suggest a young person whose behaviour is unusual, with the speaker inviting listeners to locate symptoms of autism in Hayley's behaviour. Hayley is diagnosed with autism.

In both Elisha and Hayley's cases, clinicians construct the accounts of patients and families as warranted and plausible evidence of autism. Clinicians can be seen to 'narrate objectivity', that is, to construct the behavioural accounts of patients and families as objective evidence (Timmermans and Buchbinder, 2012) and use their disciplinary expertise to build those accounts as evidence of autism. Therefore, behaviours which might be unusual are embraced within a category of autism, and reproduced through talk as what autistic behaviour looks like.

Here lay and professional expertise interact: from a lay perspective, patients and families understand what constitutes autistic behaviour and utilise it within the assessment process, whilst clinicians use their specialist disciplinary perspective to weight the value of this parent/patient testimony. However, in the process of corralling lay testimonies in the team meeting, there is a blurring of boundaries (Eyal, 2010) between the source and nature of that expertise. Whilst, as Eyal argues, the expertise of parents was once interpreted as 'parental coldness', or evidence of the cause of the condition, the 'credit-worthiness' (Eyal, 2010, p. 4) of that expertise now has been upgraded to be almost indiscernible from clinicians' own accounts. However, as we illustrate here, clinicians also distance themselves from patient and family accounts as evidence, when they are considered un-creditworthy.

In some cases patients were considered by clinicians to have researched or rehearsed relevant behaviours, leading to them 'perform' autism. We return to Gail, who has come to assessment with a friend who has been interviewed as Gail's 'informant'. The team is worried that Gail is too invested in receiving a diagnosis.

#### **Adult Team 1: Gail, age 44**

CP: This sounds also like I mean we've talked about this quite a lot haven't we, but in those situations where someone comes and they are quite invested, there is a sort of like slight, if they feel, that sort of slight recoil don't you and kind of like and that I think is what I'm struggling with. It gives you a sort of even more sceptical edge I think sometimes doesn't it?

CP acknowledges that a perception that a patient is 'invested' in diagnosis can impact on how they, as clinicians, 'feel' about the patient and their diagnosis. This is further developed when the interview leads to a conclusion that the friend is keen for Gail to be diagnosed too and '*sees herself as a bit more of an expert in autism*'. The team question how much Gail and her friend have planned the assessment together.

AP: It's hard to not get a word in edgeways, but kind of get to the bottom of actually how rehearsed is this? How much have you spoke about this? How much have you researched this? It felt very much like none of the questions I asked were a surprise in any way

AP expresses mistrust of the patient/informant account, casting doubt on its veracity. A consideration of motivation and 'investment' contributes to judgement of the credibility of the patient's position and consequently the weight clinicians give to those reported behaviours. Patient accounts that are too coherent (or too chaotic in other cases) raise suspicion. In Gail's case, the lead clinician also felt there was '*something*' there and the case was deferred pending further observation and interviewing a second informant.

Finally, Nadia is a 29-year-old woman who has been assessed by the Team Manager (TM) whilst in hospital. TM is concerned that, despite scoring 'quite high' on the ADOS, suggesting autism, the result may be invalid as Nadia was

dosed on heavy medication and this '*affects a lot of your interaction with her*'. TM then also expresses concern to the Consultant Psychiatrist (CPI) that Nadia may be invested in diagnosis:

**Adult Team 2: Nadia, age 29**

- TM: And then she said at one point, she said to me, cos she wants the diagnosis, ... 'oh what would an autistic person say?'
- CPI: That's really interesting. What would she gain from an autism diagnosis? Like why would she want it?
- TM: They've told her unhelpfully ... that we're going to see her and we're going to find her a great new house.

TM introduces this incident as an interjection in a number of problematising factors about the assessment. TM prefaces this story with '*cos she wants a diagnosis*' which alerts the listener to hearing the story as someone motivated to manipulate the assessment. '*They've told her unhelpfully*' suggests that TM thinks that the assessment has been compromised, because a clinician has misinformed Nadia who then has misconceptions about the potential benefits of a diagnosis, leading to her attempting, albeit unsuccessfully, to 'perform' as autistic in assessment.

In this case a patient was perceived to be attempting to manipulate the assessment for secondary gain thereby alerting clinicians to question the credibility of the patient. Here Nadia's account is used to construct a case against an autism diagnosis, constituting Nadia's behaviour as manipulative rather than autistic. The result for Nadia was left open as she was still to be assessed through a clinical interview with the Consultant Psychiatrist.

To summarise, in the cases of Hayley and Elisha, the ADOS is downplayed in favour of parent and patient narratives which support autistic behaviours. Parental accounts align with the anticipated outcome and are constituted as autistic behaviours both by parents and by clinicians. With Gail and Nadia, the ADOS is compromised or questioned due to the testimony or behaviour of the patient in assessment that suggests that they might be trying to subvert the assessment.

In these cases, clinicians use their disciplinary expertise to assess the veracity and value of lay expertise. Their collective knowledge determines that patients can manipulate assessment for secondary gain; that they can perform or rehearse autism if invested in diagnosis; and that lay knowledge of autism can help or hinder, depending on its credibility. Clinicians decide the value of different accounts to offer a warrant for diagnosis or not.

The discursive accomplishment of co-opting patient and family accounts is to enhance (or diminish) the trajectory towards diagnosis. Reported speech in particular can serve to enhance the factuality of the account (Wiggins, 2017) and the extent to which the patient is presented as agentic (e.g. Elisha cannot help her troublesome behaviour but Nadia is motivated to adapt her behaviour for secondary gain) works discursively to present the patient/family as credible or not.

#### **7.4 Discussion**

Our study builds on Turowetz and Maynard's (2019) work examining autism diagnostic practices in situ. We have found, in line with these researchers, that clinicians foreground discussion of behaviours that are 'story-worthy' and these include both their own observations as well as harnessing informant testimony that contribute to the diagnostic account. We also found, in line with Hollin and Pilnick's (2018) study, that, in the process of retelling the behavioural story, clinicians interpret that behaviour in the light of known autistic behaviours.

We found that clinicians attended to the embodied impact of 'being in the room' with the patient. Like Fitzgerald (2017) and his neuroscientists, clinicians routinely invoked the qualitative description of 'feeling' an interaction as autistic. Clinicians directly referred, therefore, to their own interaction with the patient, although this was not apparently reflective of their role as an active agent impacting on the patient's behaviour, rather it served to reiterate the location of autistic behaviours within the patient. The behaviour of the patient, however, can affect the clinician's approach to standardisation, for example, when the

assessor changes the assessment to allow for anticipated patient behaviour (Hayley); or when there is a recognition that other factors (e.g. medication) can impact on assessment. We have not found clinicians to be naïve to the social complexities of their job, indeed, they appear to be acutely aware of the difficulties, ambiguities and social consequences of their task.

In this context, clinicians are permitted to draw on their disciplinary expertise (unlike 'lay experts' whose sense of 'feel' can only ever be opinion; or beyond this diagnostic space, where clinicians, socially, would not be warranted to 'diagnose'). It is not, therefore, that the clinician always takes for granted (and therefore renders invisible) their own role in the assessment process as argued by Turowetz and Maynard (2019). Rather, by institutional necessity, and due to indeterminacy, they stake their own expertise on what happens in the social space between patient and clinician. This serves to enable dissent from the 'objective' evidence of the diagnostic tool, to bring colleagues on board with this dissent, and to re-align the evidence in this new embodied context. It presents clinicians, not as unknowing slaves to criteria, but as active agents in the diagnosis; as one human being in relation to another. In the space of indeterminacy, clinicians draw, not just on references to where symptoms can be seen in the patient, but on affect; to how the patient in this room, at this time, makes them feel.

When clinicians invoke feeling they are staking out their territory. Feeling here is not presented as either a lack of neutrality or a call to subjectivity: it is presented and received as objectively important, as a different kind of objectivity. This assertion of an autistic presence is received as concrete and objective knowledge by colleagues. The specialist disciplinary understanding, or expert gaze (Featherstone et al., 2005) determines that there is 'something there' and is therefore treated as a source of committed and reliable knowledge. It asserts credibility on the part of the clinician, as the only way they can feel autism is through having experienced it many times.

Drawing on Eyal's exploration of networks of expertise, we found that clinicians interact with different types of expertise in an applied and pragmatic way to

achieve the function of the institution: diagnosis. In team meetings, clinicians draw on both their own disciplinary expertise, and that of patient and family actors, who are absent but discursively present (Clarke and Star, 2008), to both understand and shape concepts about autism. Patients and families (informants) are considered by clinicians to 'know' autism, not just from experience, but as 'well-informed citizens' (Schutz, 1946), or active agents, able to understand and construct a body of 'story-worthy' evidence for presentation. Informants, in their desire for diagnosis, retell their testimony knowingly. This form of lay expertise lies not in their experience of particular behaviours alone, but in the contemporary meaning society prescribes to those behaviours, and their access to diagnostically relevant information and cultural frames.

Our study shows that in the absence of the body of the patient, the clinician recalls story-worthy events in their stead, their presence retold through descriptive instances of pertinent behaviours that can be seen as troublesome. Testimonies (motivated, mediated, partial, variously-informed, invested, interpreted and bodily absent), and how clinicians feel about them, are core to assessment. Here diagnosis is happening relationally, with the absent voices of patients and families being interpreted by the clinician. As argued by Eyal (2010) we can see how medical and lay expertise is blurred in the discussions between experts: the knowing patient narrative is re-constructed through the medical lens of autism. However, clinicians acknowledge together that informants have stake and interest, and the veracity and value of their testimony is judged according to the clinician's expert understanding. Although this might be indicative of Eyal's (2010) 'space between fields', the way in which expertise is drawn on is, inevitably, asymmetrical (Pilnick and Dingwall, 2011).

The process of diagnosis is 'institutionally determined' (Gill and Maynard, 2012) in that the rhetorical 'allowance' in the clinic is, by necessity, for a diagnosis of autism or not: the delivery of this ultimately binary decision is the institutional imperative and must be the key task of the team. But diagnosis is socially framed in the clinic, and is subject to practices and processes of debate and adjudication between different forms of evidence (Latimer, 2013). Clinicians accomplish diagnosis by necessity, constructing objectivity from indeterminacy

via discursive resources, through affective, interpretive and evaluative labour. Testimonies of patients and families are co-opted as evidence; diagnostic tools are interpreted in the light of disciplinary objectivity (and also narrated in this way); and disciplinary objectivity in the form of expressions of affect can serve to support or disrupt the diagnostic momentum.

The institutional imperative across the institution of medicine is to diagnosis. We argue that the findings here related to autism diagnosis have broader relevance to understanding diagnosis more generally. As an act of affect we have explored the way in which clinicians translate inter-subjective feeling into a diagnostic outcome. A recent review of literature suggested that a 'Praecox Feeling' of 'bizareness' is a determinant in medical decision-making in schizophrenia (Gozé et al., 2019). Despite attempts at standardisation, therefore, affect can be seen an active presence in diagnostic deliberations - a signal for reflection, further exploration or testing. As an act of interpretation and evaluation we have considered the role of patient and family testimonies in diagnostic practice. This indicates how parental and family knowledge has been formalised and incorporated into medical knowledge through the adoption of the clinical interview as a standardised test. Lay expertise and the role of the family as 'credible witnesses' are central in diagnostic deliberation. Acknowledging and examining inter-subjectivity in diagnostic practice, therefore, seems extremely pertinent across conditions and medical practices, as, rather than constituting a linear clinical practice, it illuminates the process of diagnosis as relational and interactively constructed between patient, family, clinician and diagnostic measure.

## **7.5 Strengths and Limitations**

This study is one of few to directly observe clinician interaction in diagnostic decision-making, particularly in closed team meetings. This makes the data rich and relevant to contemporary understandings of diagnosis. Our current analysis represents a broad brush-stroke of our data: interaction in assessment meetings is complex and the content of discussion wide-ranging. Here we



endeavour to consider key threads through the data, each of which might be expanded on further. There is a need to examine all stages of assessment, particularly those that take place in informal interactions and in the presence of patients and families.

## 7.6 Concluding comments

Our study adds to the growing literature on sociology of diagnosis by furthering our understanding of how diagnosis is accomplished in practice. We argue that autism as a condition is, in part, shaped through this clinical interaction, through the interpretation of behaviours as framed by patients and families; and through a sense of autism as a 'thing' that can be experienced by clinicians. Schrader (2010) argues that what we know cannot be separated from the way that we know it. Autism is an object of knowledge: it is what we know, but it is an object delineated by the process of knowing it. In clinicians' talk, autism is rendered an object *through the process of* its identification by healthcare practitioners. Uncertainty inherent in autism's heterogeneity of presentation and aetiological variation (what Hollin (2017a) refers to as autism's 'ontological indeterminacy') is dismissed and re-interpreted in diagnosis in order to reify autism, as fixed, real and knowable.

Reification is the institutional requirement for these diagnostic services. Clinicians understand that autism is a pragmatic psychiatric construct, underpinned by best evidence but still somewhat indeterminate, but nevertheless they must act to reify, as their role necessitates the assignation (or not) of a diagnosis. They actively constitute informant stories as evidence of autism and constitute symptoms through and in their deliberations. The net effect is to present autism as an ontologically 'natural kind' (Hacking, 2007; Verhoeff, 2012), with autism diagnosis 'validating a reality' (Jutel 2009). This confirms a particular kind of person as autistic and the category becomes reified (Hacking, 2000). Objectivity is produced through these situated practices.

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## **Data Statement**

Access to the data that support these findings will be granted on request to the corresponding author via UK Data Service at <http://reshare.ukdataservice.ac.uk/>.

## Introduction to Chapter Eight

### Overview

The thematic analysis in Chapter Seven constituted a broad sweep of the data and identified several themes, two of which were explored in Chapter Seven. The thematic analysis identified several other aspects that might have been explored (including belief systems about diagnosis and autism, interpreting ambiguity, team working). However, what was striking in the data (although perhaps not unsurprisingly given the variation in clinical guidelines) was the level of contradiction and expressions of uncertainty in diagnosticians' talk. I decided to make this a focus of the discursive psychology analysis. Interaction between diagnosticians, in this article, is taken as a 'social factor' in itself, in that I explored how the narrative structure of interaction enabled the resolution of seemingly contradictory accounts. Data were regularly presented at data sessions and with a smaller supervisor-led data group.

All aspects of the study were undertaken by the PhD candidate. Co-authors contributions were as follows:

GR: research design; revision for intellectual content

RM: revision suggestions; support with analysis

TM: revision suggestions

DP: support with analysis; revision suggestions

A guide to Jefferson Transcription is at *Appendix 13: Selected Jefferson Transcription Symbols*.

This chapter consists of a manuscript that is currently under review with *Social Science and Medicine* (Hayes et al., 2019, under review).



**CHAPTER EIGHT: Setting aside contradiction: creating  
narrative coherence in autism assessment teams**



## **Abstract**

Social science literature has documented how the concept of diagnosis can be seen as an interactive process, imbued with uncertainty and contradiction, which undermines a straightforward notion of diagnosis as a way to identify underlying biological problems that cause disease. We contribute to this body of work by examining the process of resolving uncertainty in autism diagnosis for adults and adolescents. Autism is a useful case study as diagnosis can be a complex and protracted process due to the heterogeneity of symptoms and the necessity to interpret behaviours that may be ambiguous. We audio-recorded and transcribed 18 specialist clinical assessment meetings in four teams in England, covering 88 cases in two adult, one child and one adolescent (14+) setting. We undertook a qualitative analysis of discursive processes and narrative case-building structure utilised by clinicians to counteract contradiction.

This paper contributes to our understanding of practical uncertainty work in medicine. We identified a four-part discursive structure which allows clinicians to forward evidence for and against a diagnosis, facilitates their collaborative decision-making process and enables them to build a plausible narrative which accounts for the diagnostic decision. Pragmatism was found to operate as a strategy to help assign diagnosis within a condition which, diagnostically, is permeated by uncertainty and contradiction. Resolution of contradiction from different aspects of the assessment serves to create a narratively-coherent, intelligible clinical entity that is autism. We discuss the transferability of the findings in the context of utilising a diagnosis as a pragmatic construct, thus contributing to the sociology of diagnosis literature.

Keywords: diagnosis; uncertainty; autism; sociology of diagnosis; discourse; narrative; UK





## 8.1 Introduction

Diagnosis is traditionally thought of as a way to identify underlying biological problems that cause disease. Scholars working in the field of sociology have problematised this, claiming diagnosis is a social process that involves multiple actors and is context specific (see Blaxter, 1978; Brown, 1995; Jutel, 2013, 2009; Jutel and Nettleton, 2011). Some argue that uncertainty is central to medical practice (e.g. Beresford, 2006; Bursztajn et al., 1986) because diagnosis is an act of interpretation and involves transposing clinical research to the idiosyncrasies of the individual patient (Tanenbaum, 1993). Atkinson (1995) argues for a detailed analysis of how clinicians locate the sources and nature of doubt, and express them discursively, arguing that that this approach will further understanding about how medical knowledge is organised socially and produced through discourse (Atkinson, 1995). Studies of interaction can examine how decision-making is socially and interactionally bounded (Halvorsen, 2015) and woven with temporal, spatial, sequential and interactional aspects that challenge the concept of straightforward context-free cognitive decision-making processes (Boden, 1994).

There is a surge of interest in the conceptualisation of Autism Spectrum Disorder, henceforth 'autism', as a diagnostic category (e.g. Evans, 2013; Eyal et al., 2010; Fitzgerald, 2017; Nadesan, 2005; Silverman, 2013). Despite this, there remain few empirical studies which examine in detail how autism diagnosis actually comes about in practice, given autism's widely heterogeneous symptoms and largely unknown aetiology. In previous work we examined how clinicians diagnosing autism produce objective accounts through their situated practices, and perform diagnosis as an act of interpretation, affect and evaluation (Hayes et al., 2020). This article contributes further to the sociology of diagnosis literature by using a discursive approach to examine narrative case-building in clinical assessment teams. Autism diagnosis for both adults and children can be a complex and protracted process due to heterogeneity of symptoms, the necessity of interpreting behaviours that may be ambiguous, and the lack of clinical biomarkers (Klin et al., 2000; Vllasaliu et

al., 2016). It is therefore an ideal case study to explore how clinicians, in their role as diagnosticians, manage uncertainty.

## **8.2 Background**

### ***8.2.1 Diagnostic uncertainty***

Uncertainty and contradiction have long been important topics for medical sociology in relation to clinical training (e.g. Atkinson, 1984; Fox, 1957; Timmermans and Angell, 2001); pharmaceuticals and neuroscience (e.g. Fitzgerald, 2014; McGoey, 2009; Pickersgill, 2011); classification, patient/doctor interaction and diagnostic decision-making (e.g. Bowker and Star, 1999; Bursztajn et al., 1986; Hedgecoe, 2003; Star, 1989; Zayts et al., 2016); medically unexplained or contested diagnoses (e.g. Armentor, 2017; Dumit, 2006; Jutel, 2011; Marks et al., 2016); as well as in science more broadly (e.g. Campbell, 1985; Edwards, 1999; Fochler and Sigl, 2018; Pinch, 2012; Shackley and Wynne, 1996; Star, 2009).

Particularly relevant for this study is how clinicians engage in what has been termed 'practical uncertainty work', that is, the implementation of strategies to overcome diagnostic uncertainty and to make scientific research or, in our case, diagnosis, 'doable' (Hollin, 2017a; Moreira et al., 2009; Pickersgill, 2014, 2011). From a series of interviews with neuroscientists working in the field of personality disorder and antisociality, Pickersgill (2011) argues that neuroscientists engage in practical uncertainty work to allow uncertainty and ambiguity to be eliminated by the mutual and reciprocal constitution of the concept and categorisation of a condition. Each uncertainty can be 'set aside through recourse to the assumed certainty of the other' (Pickersgill, 2011, p. 84). In this way, conceptual concerns about ontological/taxonomic uncertainty (what a disorder 'really is'); and classification concerns about epistemological/diagnostic uncertainty (how it can be identified) are sidestepped, with the effect of standardising medical discourse and practice, as well as sustaining and producing the 'disordered' subject.

Drawing on Atkinson's (1985) call for analysis of how uncertainty is expressed discursively, we can consider the expression of uncertainty as both a social action and an interactional resource. For example, Timmermans and Buchbinder (2012) demonstrate that uncertainty is a resource for both parents and clinicians in newborn genetic screening. For parents, uncertainty enables them to maintain hope in the future of their child's health; whilst for clinicians uncertainty works, in part, as a resource to alert families to possible unpredictable difficulties (Timmermans and Buchbinder, 2012). One study examining antenatal screening considers uncertainty as an interactional resource to support different interpretations of high risk results (Pilnick and Zayts, 2014). The expression of uncertainty, in this setting, becomes a demonstration of clinicians' professionalism, in that they understand the limits of medical knowledge and, therefore, are best placed to express doubt about what sounds like a precise measurement (Pilnick and Zayts, 2014). Uncertainty then can be a strategic opportunity to enact professional judgement and assert the authority of the clinician (Timmermans et al., 2018).

On the other hand, the resolution of contradictory evidence is explored in Gardner et al (2011) who examined how clinicians seek to make sense of potential contradiction in diagnosis of chest pain. Drawing from the work of Mol (2002), the authors argue that ontology is not fixed but fluid and transitory, and assembled through interaction between entities in the clinic. By following the trajectory of one patient from GP to cardiologist, they demonstrate how particular practices assemble information such as family background, the impact of exercise and the results of an ECG, that then enables the patient's chest pain to become intelligible as a clinical entity (Gardner et al., 2011). Different (and potentially contradictory) accounts from these interactions are consolidated through discrediting one source of information (the ECG test) enabling the clinician to reframe the condition with a sense of coherence. The effect of this 'patching together' (Gardner et al., 2011, p. 849) of multiple accounts is to reify the notion into a 'singular coherent body' (Gardner et al., 2011, p. 848). As with Latimer's (2013) ethnographic study of dysmorphology, clinical judgement within the wider picture is privileged over any single test.

### **8.2.2 Diagnosis of autism**

Autism is diagnosed when persistent patterns of difficulty in social communication and interaction, combined with restricted and repetitive patterns of behaviour, interests or activities are judged to cause significant impairment in functioning (APA, 2013a). The most commonly used assessment measure for both adults and children is the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000), alongside a clinical interview such as the Autism Diagnostic Interview-Revised (ADI-R) (Le Couteur et al., 2003). The ADOS is an activity-based semi-structured standardised observation tool whereby the person performs a number of communication and interaction tasks, and is then scored on a range of behaviours such as emphatic or emotional gestures and overall quality of rapport. Clinicians may also utilise other tools such as questionnaires, clinical guidelines, rating scales or specialist tests alongside reports from other health professionals and educational reports. First-hand reports from the patient, and their informants (usually a family member) are utilised, and the impact of associated impairment on the individual and the family is considered. Diagnosis is undertaken, therefore, primarily on the basis of observation and informant accounts.

Deciding where the diagnostic threshold lies can be problematic as autism symptoms are distributed as a continuum extending into the general population (Constantino, 2011; Constantino and Charman, 2016). Hollin (2017b, 2017a) argues that the embedded heterogeneity of autism means that the condition is characterised by its very uncertainty, or ontological indeterminacy. Further complications in assigning diagnosis arise for people considered to be near the threshold for diagnosis according to standardised tests; where there are co-existing conditions; or where there are complicating environmental factors, for example, childhood neglect. Despite these potential ambiguities and contradictions, clinicians in diagnostic assessment services are compelled to work within a system that requires a categorical diagnosis and therefore assumes that clear definitions between conditions exist (Pickersgill, 2011).

### **8.2.3 Working in multi-disciplinary teams**

Messer and colleagues argue that one strategy to help resolve uncertainty is to ensure consultation with colleagues, including working within multi-disciplinary teams (Messer et al., 2018). Most healthcare professionals work in collaboration with others and it is considered especially important when dealing with complex or chronic health conditions (Croker et al., 2000). In autism assessment, the involvement of a multi-disciplinary team is generally recommended for both children and adults (NICE, 2012, 2011; RASDN, 2013, 2011; SIGN, 2016). There are, however, interactional complexities in locating decision-making within teams, which may problematise its potential as a way to counteract uncertainty.

### **8.2.4 Narrative and autism diagnosis**

Scholars have explored narrative case-building as a mechanism by which clinicians deal with uncertainty (Atkinson, 1995). There is a significant body of work which demonstrates how narrative is shaped and purposed in medical settings (see Ainsworth-Vaughn, 1998; Bosk, 1992; Byrne and Long, 1976; Hunter, 1991; Mattingly, 1998, 1991; Mischler, 1984; Silverman, 1987) including conversation-analytic studies into patient-doctor communication (e.g. Heritage and Maynard, 2011, 2006; Maynard and Heritage, 2005; Pilnick et al., 2009).

Classic studies of narrative by Labov and Waletzky (Labov, 1972; Labov and Waletzky, 1967) argue that, at its most basic, a narrative takes the form of two clauses, 'temporally ordered' (Labov, 1972, p. 360). Labov found that narrative story-telling formed a basic six-part structure: abstract, orientation, complicating action, evaluation, resolution and coda (Labov, 1972). Atkinson (1995) demonstrates how, in a haematology clinic, clinicians follow a similar narrative case-building process to establish a diagnostic outcome, drawing on the temporal facts of a case which can serve to 'scaffold' uncertainty within a framework of uncontested assertions (Atkinson, 1995).

Particularly relevant is a body of work exploring autism assessment in the US (see Maynard and Turowetz, 2019; Turowetz, 2015a, 2015b; Turowetz and Maynard, 2019, 2016). Maynard and Turowetz claim that there is a universality

to the narrative of diagnostic practice across social settings and historical periods and this takes a structural form in four parts: preface (an introductory narrative); possible stories (either tendency – reporting a general propensity towards particular patient behaviour; or instantiation – reporting a single instance); typifications (categorical assertions which include diagnostic upshots); and story reciprocity (how the story is received, supported or facilitated by others in the room) (Maynard and Turowetz, 2017; Turowetz and Maynard, 2017).

The researchers demonstrate how clinicians collaborate in assessment to build a narrative case together, which enables ‘interactional progressivity’ (Maynard and Turowetz, 2017, p. 265) towards diagnosis. They assert that narrative is a ‘practical epistemological method’ (Turowetz and Maynard, 2017, p. 21) through which clinicians assign and adapt classification to specific individuals to rule diagnosis in or out and to differentiate from possible co-conditions. Rather than simply organising and documenting evidence, these narrative practices ‘play a constitutive part’ (Turowetz and Maynard, 2017, p. 20) in aligning symptoms to disease categories, in this case, shaping autism as they diagnose it in practice.

### **8.3 The current study**

Other than Maynard and Turowetz’s study, there remains very little work observing how clinicians discuss autism diagnosis together and none that we know of related specifically to uncertainty in adolescent and adult diagnosis of autism. The current study takes a narrative focus to examine how clinicians in diagnostic teams make diagnostic decisions together in the light of ambiguity or contradiction. It builds on the work of Maynard and Turowetz by including analysis of diagnosis of adults and young people over the age of 14; siting the study in a UK context where an adult diagnostic pathway has become more accessible since the passing of legislation between 2009 and 2011; and specifically looking at how clinicians deal with contradiction in their narrative accounts. We are interested in the question: how do clinicians navigate the

difficulties of autism diagnosis in the face of uncertainty, ambiguity and, in particular, contradiction?

## **8.4 Data and Method**

### **8.4.1 Sample and Recruitment**

We purposively sampled teams that specialised in autism assessment and who held regular assessment meetings (two in adult assessment; one with children; and one with adolescents (14+)). Recruitment was undertaken from an open call to a list of clinical contacts drawn from the internet and via the National Institute for Health Research (NIHR) Clinical Research Network. All teams were located in England and were National Health Service (NHS) providers. Three teams were multi-disciplinary with specialists from different disciplines (including psychiatry, clinical and educational psychology, speech and language therapy, nursing, social work, and occupational therapy). One team (adults) was single disciplinary and primarily included clinical psychologists and assistant psychologists. Written informed consent was obtained from all participants, and ethical approval was granted by the University of Exeter ethics committee and by the Health Research Authority (HRA). Patients and families were not present at any meeting.

### **8.4.2 Data collection**

We observed and audio-recorded over 19 hours of data from 18 autism assessment team meetings, covering discussion of 88 cases. The purpose of the meetings was to discuss specific cases after assessment or referral. Audio data were transcribed, anonymised and entered into Nvivo for data management and initial coding. We used Malterud et al's (2016) concept of 'information power' to assess when we had adequate data to meet the aims of the study. This involved consideration of quality of dialogue, analysis strategy, use of established theory and sample specificity.

### **8.4.3 Analysis**

We took a discursive psychology approach to enable an investigation of how participants' talk created a case for or against diagnosis. With this approach we can examine how the particular rhetorical context of the diagnostic assessment meeting frames the diagnostic process and gives it meaning.

The process of analysis followed guidance as outlined by Wiggins (2017). As our research question relates to diagnostic decision-making, we identified 'social actions' – things we do in talk and interaction (Wiggins, 2017) - related to diagnostic decision-making; for example, disagreement or consensus. These features of discourse were identified by using 'discursive devices' (e.g. hedging, corroboration and category entitlements) which enabled a discursive 'lens' to be shone on the data (Wiggins, 2017). Sequences of text were maintained to preserve narrative construction (Atkinson, 1995). Detailed transcripts were made using Jefferson transcription to enable analysis of how talk is delivered (Jefferson, 2004) (See *Appendix 13: Selected Jefferson Transcription Symbols*). Finally we returned to the complete data set and checked for instances across the data, further refining the analysis. The developing analysis was conducted by the first author, presented regularly at data analysis sessions, and discussed with co-authors throughout to develop and challenge emerging ideas and to develop consensus.

### **8.4.4 Note on terminology**

We use the term 'clinician' to encompass all healthcare participants in this study, defined as members of a registered health profession involved in direct patient care.

## **8.5 Analysis and Results**

Of the 88 cases recorded, 51 were diagnosis specific. Of these 51 cases, 43 included discussion of potential or diagnosed co-conditions; 24 were child or adolescent cases and 27 were adults. Twenty-five cases were female, 25 were male and one was transgender. There were 27 cases with a diagnostic outcome



(15 female, 12 male; 11 adults, 16 children or adolescents) where it was possible to track when evidence discussed was contrary to the final diagnostic decision. For the purposes of this study, we only included those cases with a diagnostic outcome. Of these 27 cases, 21 case discussions included contradictory accounts (from a range of sources) and six were presented as largely straightforward and certain. In four cases the diagnostic decision made was in contradiction to the ADOS result (three cases were under-threshold on ADOS and diagnosed with autism: one was over-threshold and not diagnosed). Two of those cases – one adult and one adolescent (from 14+ team) – are discussed in detail here. A table at Appendix 14 gives further characteristics of cases by setting, including evidence discussed and diagnostic outcome (*Appendix 14: Characteristics of Patient Cases with a Diagnostic Outcome*).

#### ***Four-part narrative structure***

Whilst specific details of team discussions varied according to the purpose of the case discussion and the participants attending, we found a four-part discursive structure – constraining preface, contradictory account (evidence not in alignment with the diagnostic decision), re-alignment, and helpfulness – utilised to account for and explain contradictory evidence, illustrated in Figure 15. Within this structure, clinicians managed contradiction together through the use of evaluative statements to reframe and align complicating factors within a coherent diagnostic narrative. The re-aligning element of the discursive structure (Figure 15, Part 3) enabled team participants to be collaboratively accountable for a decision that incorporates contradictory accounts.

The four-part narrative structure is discussed in detail in the analysed cases below. In cases where diagnosis was assigned, contradictory evidence was most commonly explained (Figure 15, Part 3) by 'masking' (n=13): it was thought that patients had developed strategies to compensate socially thereby making observation of autistic behaviours in assessment problematic. This was frequently tacitly or explicitly linked to the inadequacy of the ADOS tool to 'pick up' autistic behaviours (when masking was present), and occurred most often in the assessment of women and girls. The masking re-alignment was sometimes combined with a judgement that patients and families were under-reporting

symptoms (n=2) or reference to a high ADOS score (n=1). For those patients who did not receive a diagnosis, the explanations for contradictory accounts were primarily that the behaviours could be better explained by a different condition (n=5), or that the patient/family was over-reporting (n=1). (See *Appendix 14: Characteristics of Patient Cases with a Diagnostic Outcome*).

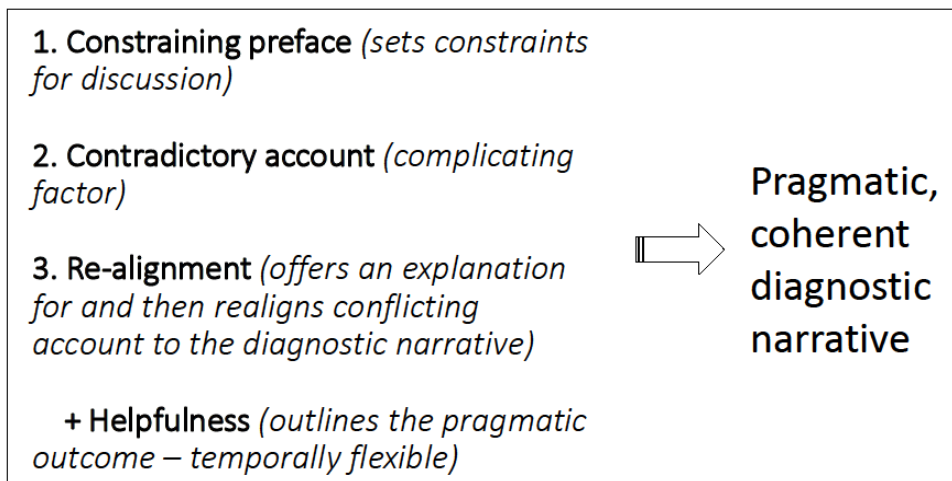


Figure 15: Four-part narrative structure in autism diagnostic discussions

### **Case 13: Teresa, age 45**

Teresa, a 45-year-old woman, is discussed by a Consultant Psychiatrist, Catherine, and the Team Manager, Jo, who is an Approved Mental Health Practitioner and experienced diagnostician. Catherine has conducted a clinical interview with Teresa, and Jo an ADOS. The case discussion begins with a brief orienting section which proceeds to Catherine’s overview of the case and prefacing statement.

## 1. *Constraining Preface*

1 Cath: >I think I think< I probably thought she did have autism  
2 Jo: .hh yeah [so...  
3 Cath: [And she's probably not going to score on the  
4 ADOS=  
5 Jo: =No [that's what you said to me]  
6 Cath: [Yeah there we go]  
7 Both: .hhh .hhh  
8 Jo: [And she didn't] .hhh  
9 Cath: [There we go]  
10 Both: .hhh .hhh  
11 Cath: So >there we go< [but...  
12 Jo: [I think she got two. Off [the top of my  
13 head] (0.3)  
14 Cath: [Yeah] fine

Catherine immediately formulates the case (lines 1-4) and announces the potential outcome. Catherine's formulation sets the agenda: the patient has autism but this will not be apparent on the ADOS result. Catherine presents this potential contradiction as normative: not scoring and being autistic is not an unlikely outcome. Whilst hedging ('probably', 'I think') might represent uncertainty, it allows space for disagreement without conflict and can be withdrawn or amended depending on Jo's response (Wiggins, 2017). Jo's response to Catherine's assertion is to agree, both with the statement that that is what Catherine thought, and, then, with the ADOS result. This interaction therefore strengthens Catherine's prefacing statement as it corroborates her predicted assessment, and her receipt of this is one that serves to reinforce the accuracy of her view ('there we go') and express her certainty.

During the following exchange the ADOS score is introduced, which aligns with Catherine's formulation, in that a score of two would be considered to be consistent with 'not scoring', i.e. under-threshold for diagnosis. The lack of precision around the score ('I think she got two') and the apparent lack of preparation to report the score ('off the top of my head') inoculates against any potential claims that Jo might be invested in the ADOS score (Wiggins, 2017) and serves to downplay its importance in the discussion. Together these actions serve to foreground other types of evidence that, later on, are more clearly or definitively expressed (Dubois, 1987), for example, in lines 34-36. Jo's

minimisation of the ADOS score, therefore, aligns with Catherine's initial declarative statement.

The constraining preface can be compared to the preface described by Turowetz and Maynard, in that it sets up the stories that follow (Turowetz and Maynard, 2017), flags pertinent issues and allows the teller to project the forthcoming story (Jefferson, 1978). Here, the preface often includes either an implicit or explicit prediction or judgement about the outcome; or a suggestion of the problematising factor. The preface therefore sets the rhetorical framework for the resulting discussion, and potentially undermines alternative versions or topics. We do not mean by this that there is intention by the opening speaker to constrain, rather, interactionally, it serves a 'shaping' role as it takes the form of a statement against which other evidence must align or contradict: contradicting is generally more difficult in interaction. The resulting interactional sequence is informed by this preface: in this case Jo's alignment serves to further reinforce the prefacing judgement.

#### **+ Helpfulness (temporally flexible)**

During the discussion Jo provides a tendency story – a general propensity to a type of behaviour (Maynard and Turowetz, 2017) ('she did tend to do that going off on a tangent on something but she was a bit sort of quite rigid too') which she checks with Catherine ('did you find that with her?'); but this is not supported by specific instances of autistic-like behaviours. Jo then goes on to describe a particular issue for Teresa.

34 Jo: Em (.) she really struggles on the friendship bit.  
35 Cath: °Yeah°  
36 Jo: So that's been a massive issue and she was crying and  
37 upset [and]  
38 Cath: [°Yeah°]  
39 Jo: (1.0) .hh em yeah there's ↑definitely some definite  
40 tra:its.  
41 Cath: Yeah  
42 Jo: And I think it would help (.) it would help her=  
43 Cath: =Yep [ok

Jo uses maximising quantifiers ('really', 'massive') which serves to upgrade an earlier assessment of Jo's ('a bit sort of') from minimised and tentative to significant. The objective description of difficult emotions (line 36) further upgrades Jo's assessment by illustrating Teresa's distress about her difficulties as genuine. Jo's statement that Teresa has 'traits' has the effect of more definitively supporting Catherine's diagnostic statement, particularly with the repeated use of 'definite', which serves to dispel uncertainty.

Jo completes her turn by introducing a functional element to the potential diagnosis ('it would help her'): combining a description of Teresa's distress with the view that diagnosis would be helpful, which makes a pragmatic argument in support of diagnosis. Whilst there is no detailed discussion about how the diagnosis might be helpful, the suggestion provides a function for the diagnosis which enables the decision to 'make moral sense' (Leydon, 2018). In this case the idea of diagnosis being helpful can be seen as an account towards diagnosis and enables 'interactional progressivity' (Maynard and Turowetz, 2017): not evidence as such but a meaningful way to create justification for a decision.

However, in the next turn, Jo introduces a contradictory account, or complicating action. Labov (1972) defines a complicating action as a sequence of events; here it is an actual potential complication that impedes a straightforward conclusion to the case discussion.

## **2. Contradictory account**

44 Jo:                    [↑THOUGH I didn't get an overwhelming (1.8) .hh  
45                    she's actually got very good social interaction actually  
46                    on the whole (.) except for this thing she was quite  
47                    rigid. (1.0)

'Though' suggests a forthcoming contrastive element (Maynard and Turowetz, 2017, p. 265) – a statement against diagnosis in contrast to the trajectory of the meeting, whilst enabling Jo to give an implicit explanation for the low ADOS score. Jo embodies her own experience of meeting Teresa through her first-

person declaration of how this felt ('not overwhelming'). A significant pause here suggests some difficulty in expressing this turn, perhaps due to disaffiliation with the general narrative towards diagnosis. Good social interaction would, generally, be an argument against diagnosis, as diagnosis requires 'persistent impairment in reciprocal social communication and social interaction' (APA, 2013a). This utterance, therefore, should problematise a diagnosis of autism, however, Teresa's behaviour has already been accounted for as autistic (from line 1) and therefore, this statement is couched within a context of evidence towards rather than evidence against. Jo immediately counters her 'good social interaction' assessment with a contrast term ('except that') and then introduces a behaviour that would support a diagnosis – rigidity - thereby diminishing the initial assessment. The close sequential order also highlights the contrast between the two assessments (Wiggins, 2017).

### 3. *Re-alignment*

Catherine responds.

48 Cath: So-o I'll have to look at the report (.) and see what  
 49 I've described in terms of (0.5) you know (0.6) I-I'm  
 50 sure I will have asked questions about adaptations <that  
 51 (.) she's (.) [ma:de>  
 52 Jo: [Yeah  
 53 Cath: socially=  
 54 Jo: =Yeah  
 55 Cath: (0.4) Em-m (0.4) But I ↑think I (0.2)  
 56 Jo: But I think you [thought-you had to:ld me that you (.)  
 57 felt]  
 58 Cath: [I think I sa:id (.) I think I said]  
 59 >that I think she does<↑  
 60 Jo: Yeah

Catherine's so-prefaced response attends to Jo's problematising factor – good social interaction - with a potential explanation. With reference to her report and assessment, Catherine implies that Teresa's behaviour could 'look like' good social interaction but is in fact adapted behaviour (masking) (line 50). Catherine appears to prepare to provide a further contrastive element ('but') (line 55); Jo, however, continues this utterance (line 56) which is completed by Catherine.

Here Catherine (with Jo's corroboration) has again drawn a line under contradiction, not by reporting different evidence, but by re-asserting her clinical judgement ('I think she does'). There is a complex interplay of epistemic deference (deferring to Catherine's view) from Jo (lines 5 and 56-7) and epistemic entitlement (claiming the warrant to make the judgement call) from Catherine (lines 6, 9, 11 and 58-59). Whilst there is no apparent conflict in the discussion, there appears to be a hierarchy of knowledge whereby the psychiatrist's judgement provides the baseline around which the discussion revolves and prompts displays of accountability and sense-making.

This sequence serves to fit Teresa into a category of autism despite some behaviours that would not align with this diagnosis. Catherine and Jo successfully realign Teresa's 'non-autistic' behaviour within a category of autism by suggesting she has adapted her social difficulties to the extent that her social interaction appears to be very good, even though she still has underlying autism.

Further supporting accounts are cited which included tendency stories (specialist interests, difficulties with relationships) and one instantiation story (rigid behaviour in assessment) (Maynard and Turowetz, 2017) and then finally there is a diagnostic upshot or resolution.

163 Cath: Yeah ok so we agree. (0.8) Yep↑ ok Asperger's diagnosis=  
164 Jo: =Yes  
165 Cath: Great  
166 Jo: [So]  
167 Cath: >[We] need to book her in↑<

To summarise this case, clinicians can be seen to engage in a number of interactional devices to create a coherent diagnostic narrative for Teresa: setting the rhetorical framework for the discussion through a constraining opening preface; realigning contradictory accounts by discrediting one account (ADOS score) and invoking specialist understandings of autistic behaviours (adaptations); and making sense of the diagnosis by invoking the helpfulness of a potential diagnosis. In this way the potential uncertainty that might have been

indicated by Teresa's good social interaction is managed by a realigned narrative around masking, adaptation and utility of a diagnosis.

### **Case 50: Gabrielle, age 15**

Gabrielle is a 15-year-old girl who has been assessed by two Clinical Psychologists, Fatima and Carol; and a Consultant Psychiatrist, Maria. The psychologists, who have undertaken the ADOS, identify her behaviours as relating primarily to anxiety, and score Gabrielle as under-threshold (suggests not-autistic). The psychiatrist conducted a clinical interview and has assessed Gabrielle as autistic. Bob is a visiting student doctor.

#### **1. Constraining Preface**

1 Maria: So how did you get on, with the (.)↑scoring? (1.0)  
2 Fatima: Not-not even ↑close ((shakes head))  
3 Maria: You are [jo:k:ing me  
4 Bob: [Ye:a:h that's what I thought heheheh  
5 Fatima: But (.) we said >she's very different<=  
6 Carol: Yeah  
7 Maria: That's really [interesting. [The ADOS isn't  
8 picking her up  
9 Fatima: [=But (.) [hand gestures (.)  
10 Carol: [highly  
11 Fatima: Huh?  
12 Maria: The ADOS isn't pick:i:ng (0.5)[((inaudible))  
13 Fatima: [No, no it's not picking  
14 (.) yeah  
15 Carol: Mmm

Maria begins the discussion with an apparently neutral question (line 1) but her surprised response to Fatima's negative score (lines 2-3) becomes a constraining statement, as it signals her difference of view. The responses to line 3 illustrate that this statement is not received passively. Bob aligns with Maria's surprise; and Fatima's typifying response ('she's very different') enables interactional progressivity towards diagnosing by downgrading the stark reality of the ADOS score ('not even close') and re-aligning with a potential diagnosis. Through overlapping talk, as Fatima and Carol attempt to describe the reasoning behind the low score, Maria evaluates the contradiction by suggesting the ADOS isn't 'picking her up', which is repeated by Fatima (lines



7-12). This opening sequence contains three aspects of our proposed structure, thereby serving a comprehensive constraining function: preface, contradictory account (low ADOS score) and initial evaluation leading to re-alignment (inadequacy of ADOS tool). As with Teresa, it is striking that, even without any detailed narrative content (either instantiation or tendency stories), there is already an interactional 'pull' towards diagnosis at this early stage. It can also be seen that this narrative structure provides a social function in maintaining a collegiate atmosphere whilst there are differences of opinion (Turowetz and Maynard, 2017). Maria's expression of the ADOS as an active agent in 'not picking her up', serves to distance the psychologists from the ADOS result.

The psychologists go on to provide justification for the low ADOS score by outlining factors which would conflict with an autism diagnosis:

## **2. Contradictory account**

17 Carol: [Cos:s]  
18 Fatima: [=r-really] great gestures, really good rapport, great  
19 [eye contact,  
20 Maria: [↑mmm  
21 Carol: °yeah°  
22 Fatima: good facial expressions, ↑some diffi[culties  
23 Maria: [mmm  
24 Fatima: with (1.0) understanding relationships and emotions↑=  
25 Carol: yeah  
26 Fatima: =but  
27 Carol: <Highly socially anxious>  
28 Fatima: Yep [>incredibly so<  
29 Maria: [mmm  
30 Carol: And I wonder if that prevents exposure to social  
31 relationships which (.) is [where (0.5) she'll learn↑  
32 these things.  
33 Fatima: [mmm  
34 Maria: mmm (1.5)  
35 Carol: But yeah highly socially anxious, >and that's what we  
36 said< from the (.) when we finished the assessment,  
37 that we weren't sure whether or not it was (0.9)  
38 [autistic or socially anxious or both.  
39 Fatima:[no

Fatima uses maximising quantifiers ('really great') to describe behaviours (lines 18-22) not considered to be aligned with autism. These contradictory accounts are then contrasted with a minimised assessment ('some') of difficulties with understanding relationships and emotions (lines 22-24). On balance this utterance foregrounds non-autistic behaviours, and accounts for Fatima's role in the ADOS assessment, whilst allowing some opportunity for discussion of autistic-like behaviours. The contrast term ('but') is introduced and the turn is completed by Carol who interjects with their key finding: that Gabrielle is 'highly socially anxious', upgraded and corroborated by Fatima with, 'yeah, incredibly so'. Carol's consequent explanation suggests that Gabrielle's anxiety may be impacting her socially. Her repetition of the anxiety assessment strengthens the weight of this view by invoking a corroborative agreement with her colleague ('that's what we said'). Carol expresses uncertainty ('we weren't sure') which sidesteps a direct disagreement with Maria's assessment and instead, utilises uncertainty as an interactional resource (Pilnick and Zayts, 2014) by allowing space for renegotiation of the outcome. Whilst hedging and expressions of uncertainty may be used in part because Carol actually *is* uncertain, uncertainty markers also work to keep discussion open and flowing whilst potentially challenging clinicians who may have more experience or higher status roles.

There follows a series of questions from Maria (e.g. 'what about her quality of insight into relationships?') and an overview of the clinical interview with Gabrielle's mother, which includes a series of reported stories (both instantiation and tendency) from Gabrielle's childhood, including typifying components towards an autism assessment (e.g. 'she's not socially curious').

### **+ *Helpfulness***

During the case discussion, the team considers Gabrielle's preference for a diagnosis and how it might help her:

295 Carol: And I guess (1.0) >from what you were saying< about  
 296 she's hoping to have a diagnosis I guess if she gets a  
 297 diagnosis <that explains> (0.2) to her (0.3) that gives  
 298 her a reason why she finds it difficult and (0.8) why  
 299 (1.4) like she is the way she is whereas (0.2) >if you  
 300 don't get a diagnosis< then (.) it's more well it's  
 301 just (0.7) it's me

Here Carol tentatively speculates on the benefit for Gabrielle of receiving a diagnostic label, as an explanation for why she finds 'it' difficult. This interjection, prior to a diagnostic decision, provides further justification for a potential positive outcome, in that the diagnosis would make meaning for the patient and offer her an explanation for her difficulties. Carol draws on Maria's assessment (line 295) to make 'moral sense' of a potential diagnosis in relation to benefit for the patient.

### 3. *Re-alignment*

After further discussion about the source and manifestation of Gabrielle's anxiety, Carol offers a formulation:

408 Carol: Well (.) I kind of (.) I guess m:y (.) my >kind of  
 409 perspective is< that (0.3) like with the (0.8) the  
 410 autism spectrum she's kind of [0.3] >she's definitely  
 411 on it<  
 412 Fatima: [yeah]  
 413 Carol: [but] she's not far enough along it to get a diagnosis↑  
 414 (1.3) from f-from in the A- f-for the (0.4) ADOS=  
 415 Fatima: =From the [ADOS yeah yeah absolutely  
 416 Carol: [For the ADOS she's on it but she's (0.7) n-  
 417 **not** at the [diagnosis point  
 418 Maria: [Or the ADOS isn't picking up her  
 419 difficulties=  
 420 Fatima: [yeah yeah  
 421 Carol: [yeah yeah

Carol accounts for her assessment by categorising Gabrielle as 'on the spectrum' - and therefore presumably diagnosable - and immediately contrasts this by suggesting instead that Gabrielle may be sub-threshold ('but...not far enough along it') (line 413). This contradictory account is then clarified, with a footing shift from 'my kind of perspective' to 'from the ADOS', which serves

again to lay the difficulty with the ADOS. The frequent pauses and hesitations suggest trouble (Jefferson, 1989) or the management of psychological business (Wiggins, 2017). Carol is attempting to summarise a diagnostic narrative inherent with conflict and contradiction at the same time as holding her turn to enable a full and nuanced account. Carol's complex account is again translated by Maria (line 418) as an inadequacy of the ADOS ('isn't picking up on her difficulties') thereby countering the suggestion that Gabrielle is not at 'diagnosis point' (line 417). The psychologists concur with this analysis (lines 435-6). Here the first part of the re-alignment consolidates the inadequacy of the ADOS tool. Maria goes on to explain how this has happened:

422 Maria: =[I think that's >and we've seen that< [haven't we=  
423 Carol: [yeah  
424 Fatima: [yeah  
425 Maria: = with kind of [intelligent [females in particular who=  
426 Carol: [high functioning  
427 Fatima: [yeah yeah  
428 Maria: =beautifully mimic and [kind of=  
429 Carol: [yeah  
430 Maria: =one to [one can mirror and (0.5)=  
431 Fatima: [That's it she's learned enough yeah  
432 Maria: =em (0.4) she knows what she's [doing]  
433 Carol: [yeah]  
434 Fatima: yeah (1.3)  
435 Carol: But yeah there is a social (0.5) difference.  
436 Fatima: °yeah°

The second and explanatory part of the re-alignment compares Gabrielle to other (intelligent, high-functioning, female) patients who are able to mask symptoms of autism by mirroring and mimicking. Maria draws both psychologists into this concept of shared understanding ('we've seen that haven't we'). Both recipients immediately demonstrate understanding (lines 423-4) and finally Carol suggests that despite Gabrielle's ability to mask symptoms, there is still a 'social difference' which would therefore contribute to an autism diagnosis (line 435).

This repeated upshot of 'difference' becomes the key typification around which the psychologists make sense of the diagnostic narrative. Here the possibility of learned behaviour becomes a criteria for diagnosis and draws on a collective

understanding that the ADOS has limitations when assessing women and girls as it is considered that women may have 'subtler' manifestations of social and communication difficulties (APA, 2013a) which may not then show on the ADOS assessment.

## **8.6 Discussion**

Whilst individual clinician's views on the validity of autism as a diagnostic category may vary, diagnostic services, i.e. the institution, considers autism as an ontological reality: it is a thing that exists, and can therefore be diagnosed. However, within this ontological certainty, we found that clinicians expressed uncertainty around its identification, what Pickersgill (2011) would call epistemological uncertainty, in a number of ways.

First, and as expected, we found that uncertainty was expressed primarily when a case was considered to be near threshold. This included when evidence was contradictory (for example, when the ADOS result did not match other evidence), or when diagnostic criteria were only partially met.

Second, we found that clinicians expressed uncertainty during discussions in relation to interpretation of symptoms, for example, when symptoms were perceived to be overlapping with different conditions (e.g. attachment difficulties or anxiety); or when patient behaviour changed across settings (e.g. between different assessments or between school and clinic); or when environmental factors might have influenced behaviours (e.g. neglect).

Finally, we found that uncertainty was expressed when interaction between clinicians or between clinicians and the patient or their family had caused uncertainty. This included disagreement between clinicians; when pre-information, external professional views or previous diagnoses complicated the assessment; when a patient or family member was thought to be performing (under-reporting) or over-invested (over-reporting) in diagnosis, leading to a

mistrust of the patient narrative; and when new information or different perspectives were introduced into the discussion.

The study shows how clinicians bring together potential contradictory accounts to create a coherent narrative which then explains particular behaviours as autistic. We can see that contradiction caused by factors that might disrupt the idea of a 'typical picture' (Star, 1989, p. 73), such as strengths in social interaction; or the absence of others, such as repetitive behaviours or interests, are resolved by drawing on clinicians' assumed knowledge. These suppositions are embedded in their clinical, practical understanding of what autism does (or does not) look like, and are collectively drawn on and understood, virtually unnoticed (Pickersgill, 2011). The resolution of epistemological uncertainty (commonly expressed and accepted) is possible due to the assumed ontological certainty that there is a 'thing' called autism despite ongoing uncertainties about aetiology, shifting definitions and lack of specificity about its neurobiology (Fitzgerald, 2014).

If there are uncertainties related to ontology (what autism *really* is) then these uncertainties are absent in the collective context of the diagnostic team, whose task is to 'find' autism. The assumption of autism as an ontological entity (even an indeterminate one) must be certain despite some clinicians' ambivalence towards the category and the consequences of diagnosis (see forthcoming article related to interviews with clinicians). Our proposed narrative framework (Figure 15) demonstrates how the interpretation of behaviours that 'look like' autism (or not) are managed epistemologically, enabling allocation to the appropriate disease category. These strategies circumvent the messiness of diagnosing a condition defined by indeterminacy and ambiguity, to meet the institutional purpose of categorising behaviours in order to 'do diagnosis'. In reality, this practical uncertainty work delivers autism as an ontological certainty, sidestepping, by necessity, whether the term 'autism' can indeed denote a 'homogenous discrete population' (Hollin, 2017b, p. 219).

As with Maynard and Turowetz (Maynard and Turowetz, 2017; Turowetz and Maynard, 2017) we found that the narrative frame enables an evidential case

for diagnosis to be built and constricts the case as a subject for medical talk, establishing the boundaries of what is important. We note, as do these scholars, that clinicians use different story-types (e.g. instantiation and tendency stories) to build a case for diagnosis, however, we also have shown that the detail of these stories can be minimal and tacit. It is possible for team members to discuss the conflicting nature of 'good social interaction' without explicit detail of how this manifests in behaviours.

We consider our proposed narrative structure as a potential 'micro-insertion' into Maynard and Turowetz's model: it offers a specific detailed co-produced narrative framework by which contradictory accounts are managed and as a mechanism by which an 'impasse' can be resolved in interaction. Evidence becomes an interactional product, in that the meaning of facts and evidence change with their use in discourse (Måseide, 2006), through the negotiation and evaluation of contradictory accounts towards a coherent diagnostic narrative.

Our work further adds to the sociology of diagnosis by demonstrating that clinicians consider an autism diagnosis, in some cases, as a pragmatic construct which enables them to offer patients and families a label which may provide understanding and (sometimes) access to support. Managing uncertainty and contradiction in this way enables the clinicians to 'make moral sense' (Leydon, 2018) of their decision.

Further drawing from Gardner (2011), our analysis demonstrates that clinical entities are made intelligible by discrediting diagnostic accounts (e.g. the ADOS result) which enables the clinician not only to reframe the condition coherently but to provide an explanation for its dismissal that serves to contribute to the diagnostic narrative. Studies suggest that autistic women and girls may present better in social interaction than do boys and men because they are better able to mask their autistic behaviours (Attwood, 2007; Hull et al., 2019; Lai et al., 2015; Schuck et al., 2019). Contradictory accounts (a woman with good social skills but other autistic-type difficulties) are explained via masking, for example, which become incorporated into the diagnostic narrative as a clinical unified whole. Some scholars challenge assumptions about what might be considered

typical or autistic gendered behaviour (e.g. Cheslack-Postava and Jordan-Young, 2012). Here in the clinical settings under study, ambiguities about social behaviour can be explained without recourse to debates about gendered social behaviour more broadly, or specific quantifiers about how 'masking' can be separated from general socialised behaviours of any gender.

In the autism assessment team, clinicians do not avoid or disregard uncertainty (Katz, 1984); the expression of doubt about the ADOS reinforces clinicians' professionalism as those who understand the limitations of the tool (Pilnick and Zayts, 2014). We would suggest that expression of uncertainty in this setting is a means to deal interactionally with the inherent indeterminacy of the condition; to enable less experienced clinicians to raise conflicting issues; and ultimately achieve interactive progression towards collective accountability for the decision whilst maintaining a collegiate atmosphere. The structure of the assessment meeting, and the narrative structure within it we have identified, facilitates this perfectly as it provides the architecture for different clinical perspectives, examination of different assessments and resolution of differences.

## **8.7 Conclusion**

The rhetorical framework of the assessment meeting allows for uncertainty, dispute, disagreement, co-existing conditions and a range of other complexities. This is a place where shared specialist knowledge and narrative structure provides 'scaffolding' for diagnostic deliberations, enabling progression towards diagnosis despite contradiction and uncertainty. We would argue that the 'narrative scaffolding' utilised in this context is centred on shared knowledge of the contradictory and indeterminate nature of autism diagnosis, rather than temporal and uncontested events and decisions (Atkinson, 1995).

In the process of assessment, therefore, clinicians contribute to the construction of autism as a biological entity rooted in the individual, and yet, at the same time, as a condition with symptoms that can be socially concealed (via masking, gender, under-reporting or co-conditions) or exaggerated (through over-



reporting or rehearsing for assessment). This study examining autism as a case study may provide insights into the production of clinical entities more broadly. It would be interesting to explore, in other conditions, whether the discursive structure that allows for the dismissal of contradiction to take place is replicated in diagnostic decision-making; as well as to observe the types of specialist knowledge that are invoked to enable realignment to the diagnostic trajectory.

An individual, diagnostically, can only be autistic or not (Russell, 2014): we find that the achievement of this diagnostic binary is made possible through 'practical uncertainty work' (Hollin, 2017a; Moreira et al., 2009; Pickersgill, 2014, 2011) undertaken by clinicians together. We have shown how this work serves to counteract uncertainty, and utilises contemporary medical understandings of how autism can be 'seen' (and not seen) behaviourally within the clinic, and via patient and family reporting. Potential uncertainty caused by contradictory narratives is resolved through understanding that autism can be present but not seen (due to compensating or masking); seen but not present (due to behaviours that 'look like' autism, such as anxiety); or seen by some and not others (when patient and family member accounts conflict, for example). This resolution of contradiction from different aspects of the assessment then serves to create a narratively-coherent, intelligible clinical entity that is autism.



## Introduction to Chapter Nine

### Overview

Chapters Seven and Eight explored how diagnosticians deal with contradictory accounts, how clinical judgement (expressed in terms of affect) helps to move towards diagnostic progressivity, and how patient and family testimonies are subsumed into the diagnostic (clinical) narrative.

I was interested in how diagnosticians themselves considered some of these issues and undertook an interview study alongside the meeting observations. I used sound extracts and transcripts from the assessment meetings to prompt a response from clinicians within those teams. Time has not permitted a full analysis of this interview data therefore the analysis that is presented here is a preliminary thematic analysis (Braun and Clarke, 2013). Data were presented at data sessions.

All aspects of the study were undertaken by the PhD candidate. Co-authors contributions (to date) were as follows:

GR: research design; revision for intellectual content

TF/RM: revisions

Although I had hoped to observe how diagnostic guidelines were used in practice, in reality the guidelines were 'invisible' in practice, in that there was rarely a time when guidelines were explicitly referred to. It may be that because these were specialist teams there was no need to refer directly to guidelines or, generally, to have written criteria present, as diagnosticians were extremely familiar with their content. There was, however, frequent reference to 'evidence in all areas' (including RRBs, social communication and interaction, language development, sensory difficulties).

This chapter consists of preliminary notes towards an article for submission to *Autism Journal*.



**CHAPTER NINE: 'Not a precise art': clinicians' perspectives on  
the diagnosis of autism**



## 9.1 Introduction

During the course of this PhD study, I undertook interviews with sixteen clinicians involved in the observation study. The interview study enabled me to gain an understanding of how healthcare professionals' perceive the diagnostic process I had observed. Time has not permitted full analysis and submission to a journal prior to thesis submission. This chapter represents a preliminary analysis of this data, which will be developed towards an article for publication.

## 9.2 Background

Key literature for this study has been included in Chapters One to Four and includes a number of survey and interview studies examining the perspectives of autistic adults, parents of autistic children and professionals involved in autism diagnosis (Crane et al., 2018, 2016; Imran et al., 2011; Jones et al., 2014; Rogers et al., 2016; Rutherford et al., 2016; Skellern et al., 2005; Taylor et al., 2016). A further body of work examining the views of autistic adults and parents of autistic children is relevant (Kapp, 2018; Kapp et al., 2019; Russell et al., 2019a; Russell and Norwich, 2012). I wish to draw on studies which discuss the views of autistic adults and parents as well as professionals, and include some discussion about '**who is the expert**' in relation to lay and medical expertise (Crane et al., 2018).

Theoretically, the analysis, as with the earlier studies (Chapters Seven and Eight) will be sited with a sociology of diagnosis framework and draw on concepts of **ontological and epistemological uncertainty** (Hollin, 2017b), and questions of **emotion and affect** in diagnosis, science and the autism world ('feeling' autism) (Fitzgerald, 2017; C. Silverman, 2013). Finally, the underlying question around how we decide **who is 'normal'** will be returned to in the light of affect, ambiguity and uncertainty.

### 9.3 Method and analysis

Interviews were conducted with sixteen clinicians drawn from the observation study. Interviews were conducted using Tape-Assisted Recall (TAR) which enabled direct discussion about cases discussed in meetings through re-listening to audio recordings. A list of clinicians, their role, sex and age range is at Table 10.

Participant Characteristics		
Role	Psychiatrists	4
	Psychologists	6
	Educational Psychologists	1
	Speech and Language Therapists	1
	Occupational Therapists	1
	Team managers	3
Team	Adult assessment	7
	Child and adolescent assessment	6
	Adolescent assessment (14+)	3
Demographics	Age range	30 - 60
	Years practiced as a clinician	2 - 30
	Years practiced in autism diagnosis	1 - 12
	Female	13
	Male	3

*Note: team managers all had a clinical background*

Table 10: Characteristics of interview participants

A thematic analysis approach was used to identify patterns and themes within the data (Braun and Clarke, 2006a). I took both an inductive and deductive approach to the analysis to enable the identification of themes that are of particular concern to participants. I also drew from themes arising from the observation data. A full outline of methods of data collection and analysis is in Chapter Five, Section 5.10.

The study was designed to provide an explanation for some of the decisions that were made in meetings, as well as collect more general views on the



assessment process, particularly the team meeting<sup>4</sup>. Because I selected audio extracts to play in the interviews<sup>5</sup>, I expected particular issues would arise in interview based on those extracts. As well as pulling out themes inductively from the data, I have also aimed to explore, through the views of clinicians, some of the specific themes that have arisen during the observation study. The interviews, therefore, enabled me to gather clinicians' perspectives on these themes. For example, issues of 'feeling autism' arise in meetings (see Chapter Seven), and therefore one aspect of this paper is to explore what clinician participants might mean by 'feel'. The preliminary analysis explores the data under two themes drawn inductively from the data:

- Diagnosis is a collective effort
- Diagnosis is tricky

I then consider the interview data related to 'social factors' already identified in observation data, and explore:

- Who is the expert?
- Diagnosis as a pragmatic construct
- Feeling autism

## 9.4 Analysis

### ***Diagnosis is a collective effort***

Clinicians expressed the importance of the role of the team meetings in their diagnostic decision-making. The main strength of the team meeting was considered to be its value as a place to bring together different specialist roles and experience to jointly discuss a case. This process was seen as a crucial mechanism for 'teasing out' or 'unpicking' what was happening for the patient

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<sup>4</sup> These were multi-disciplinary team meetings in three teams; one team was single-disciplinary, made up of clinical psychologists.

<sup>5</sup> Audio extracts were played in most meetings: in some meetings we discussed cases without audio, either due to lack of audio being available due to timescale between meeting and interview; or (on one occasion) technical difficulties.

and to bring together the results of different assessments from practitioners with different roles. This combined narrative then enabled the team to feel that they had achieved a good assessment:

I think we all bring something, a bit of difference, and just a different perspective... like no one's wed to this particular outcome, you know, everything is discussed and considered and that's what feels nice for me, so I kind of go away thinking yeah, I feel like we've done a good assessment.

*Participant 5: 8 years in practice, 3 in autism diagnosis*

When the assessment was uncertain, or there was contradictory evidence, the meeting served to resolve this:

...it was a bit of a tricky one because the ADOS didn't score up, but the 3DI did, and I think what the MDT helps with is to pull that nicely into a formulation, like a strengths-based formulation.

*Participant 5: 8 years in practice, 3 in autism diagnosis*

Further, the meetings helped the team to consider whether, collectively, there was enough evidence to diagnose:

So by the end, us thinking collectively, we're able to say, 'yes there's enough information in there'. But I think it needs all of us to do that process.

*Participant 6: 12 years in practice, 3 in autism diagnosis*

Importantly, clinicians valued the meetings to ensure shared responsibility for the decision, and to feel confident about the diagnostic outcome:

Actually the conversation then can be quite short, but we do still like to go through the process of sharing kind of the examples and the experience, I guess that's to assure ourselves that yeah, it's a shared experience, and a shared understanding, so that we can formulate that and put that back to the young person.

*Participant 9: 19 years in practice, 12 in autism diagnosis*

Clinicians also described how opinions can change in a meeting, and how different views were reconciled:

So there was one two or three weeks ago, when [clinician A] felt quite strongly that they didn't have a diagnosis, and then [clinician B] did, and then [clinician B] went through her report and then she kind of convinced [clinician A] and he was actually satisfied after he'd read ... some of the information.

*Participant 7: 18 years in practice, 3 in autism diagnosis*

Having a good rapport, and equality of view in the meeting was considered important.

We've got a culture in the team that everyone's opinion is important and valid.

*Participant 7: 18 years in practice, 3 in autism diagnosis*

Although clinicians generally felt that the team allowed expression of all views, some clinicians expressed difficulties in challenging the diagnostic trajectory:

My two colleagues were like 'this presents yes', and he was saying no, so ok what about this, this, and this? Have we thought about these factors? How do we explain... given you're saying this where does that fit in or can that be explained by attachment or is there something else? Which takes a good level of rapport to try and challenge that, at times, and that wasn't the easiest thing from my perspective, I think I had to be gentle.

*Participant 11: 5 years in practice, 5 in autism diagnosis*

Even though I'm [senior] ... the membership of the team does sometimes reflect or impacts how comfortable or safe you feel to be challenging ...

*Participant 1: 10 years in practice, 7 in autism diagnosis*

Overall, whilst the meeting format was considered to be extremely important in the assessment process, clinicians acknowledged that decision-making could still sometimes be problematic. Generally, the meeting discussion was important as a way to ensure both personal and collective responsibility for a decision.

### ***Diagnosis is tricky***

Many of the meetings I observed were those where more complex or 'borderline' cases were discussed. Some decisions were considered straightforward, particularly '*at either end of the spectrum*'. Clinicians expressed difficulty with making diagnostic decisions in cases which might be considered borderline or near threshold, or where symptoms were perceived to overlap with other conditions.

We do have these tricky ones... some that present with maybe a lot of sort of personality traits as well, and they might have some autistic traits, and then we think 'is that going to help them?', and in some cases it might not help them, they may be far more PD [personality disorder] and they need to work on that. I don't know it's very difficult... it's tricky isn't it?

*Participant 7: 18 years in practice, 3 in autism diagnosis*

In particular, clinicians voiced difficulties at finding a clear line between those who meet the diagnostic threshold and those who do not:

We have to give a binary outcome in this clinic, but in reality, as we know, you know autism can be viewed as more of a spectrum.

*Participant 6: 12 years in practice, 3 in autism diagnosis*

And whilst clinicians considered the process of diagnosis as standardised and objective, they, at the same time, acknowledged its subjectivity:

...which is not a precise art, it's a difficult thing, it can be quite subjective at times, and it's... that's why I think having that team discussion is crucial, you know, you could never do it on your own because trying to manage all those thoughts and make sense of it is just too much

*Participant 11: 5 years in practice, 5 in autism diagnosis*

One clinician felt that subjectivity and interpretation of behaviours could be shaped by the experience or 'passion' of clinicians in a particular area, which could lead to some perspectives being weighted over others:

It's hard to think about alternative psychological formations, or even if we do, perhaps because the team don't have a passion or an experience in that area that wouldn't necessarily be given the same kind of weight... this very similar set of symptoms could be understood in a slightly different way.

*Participant 1: 10 years in practice, 7 in autism diagnosis*

Generally, clinicians were deeply aware of the challenges of interpreting ambiguous behaviours. Because of the context of the assessment process, some clinicians considered it possible to look for autism to the exclusion of other 'normal' behaviours:

I just saw him as a... you know from his history we're reading all the school reports, a belligerent teenager who didn't quite fit into school, wasn't comfortable, didn't want to be there, but he was in the pathway because someone said 'well is he autistic?'... often they get the tick because they do some minor little... but anxious children do kind of start to... but that's a tick for autism.

*Participant 14: 30 years in practice, 5 in autism diagnosis*

Many clinicians expressed a worry about pressure on services and waiting lists. Some considered that this pressure could compromise what they considered to be the best assessment, either through lack of time for deep discussion, or a reduction in the number of observations in different settings that were possible:

I mean there's still a waiting list of a year for even... well a minimum of a year for people, so... whereas that commissioner pressure to get people through the system, which is obviously important, I think sometimes has watered down the time for good team discussion.

*Participant 1: 10 years in practice, 7 in autism diagnosis*

But interestingly, because I guess pressures of time, the school observation is not done as much now, you know, if it's felt there's enough evidence from the developmental and the ADOS then the diagnosis is given. But I feel less comfortable with that. And that might help partly explain why the sheer number getting the diagnosis has gone up, because we don't have that observational context of the... where the child will be behaving in as much of a normal way as they will.

*Participant 14: 30 years in practice, 5 in autism diagnosis*

Reporting back to the family with a negative outcome, after months (or years) of waiting can also be challenging:

Well to be honest it's easier to say you've got a diagnosis than not. They're the harder ones. I think because they've kind of waited for a while so they're expecting the diagnosis, and when you say actually no it's not explained by that, they go 'eurgh' because that's not... and yet actually it ought to be good news that it isn't but it's not the way it's received usually, it's much harder to give a no.

*Participant 12: 2 years in practice, 2 in autism diagnosis*

Difficulties with the process of diagnosis, therefore, included the interpretation of ambiguous behaviours, pressure on services, the heterogeneity of symptoms and the concept that a particular focus on looking for autism leads clinicians to look at behaviours a particular way. Finally, this might be summed up by one response, which seems to suggest a core difficulty with autism diagnosis:

The confidence that we think we should have as clinicians is perhaps sometimes ahead of the science that backs it up.

*Participant 1: 10 years in practice, 7 in autism diagnosis*

### ***Who is the expert?***

Clinicians acknowledged the potential difficulties of interacting with patients or parents who were actively seeking a diagnosis, or for whom the outcome was likely to be in opposition to their hopes. Clinicians expressed a view that patients or parents would foreground relevant information to support a potential diagnosis:

If you then think of the developmental history, I'm not saying all parents, but there will be some parents who will skew that because they want the diagnosis, and information is out there, they could go on the internet and read the sorts of criteria that are there and what behaviours we need to tick the boxes for, so they will say the right things, but it doesn't mean to say it's real.

*Participant 14: 30 years in practice, 5 in autism diagnosis*

We all kind of look to make a coherent narrative of how we see things and how we see the world, so it's the same if a parent was actively not wanting a diagnosis, they'd discount things that didn't fit with the idea of... well I guess you've got a view of how things are so you discount the things that go against that, and count the... and notice the things...

*Participant 3: 2 years in practice, 1 in autism diagnosis*

In some cases, the resistant behaviour of an individual, ironically, provided an argument *for* an autism diagnosis.

I mean the patient was very helpful in a way, because she sent me a four page email once a week for several weeks which was kind of diagnostically indicative, listing all the reasons why she couldn't be autistic, but kind of confirming why she was.

*Participant 15: 17 years in practice, 1 in autism diagnosis*

In some cases, the clinician felt that the clinical team had given too much weight to a parent's view:

Mum was happy but I felt perhaps in the end the weight of mum's emotiveness... we'd given that too much weight actually, and it's painful to say to a parent actually... we struggle sometimes to say no.

*Participant 1: 10 years in practice, 7 in autism diagnosis*

There were differences in views as to how much to take an individual's opinion and desires into account. Some clinicians were very aware of the potential long-term impact of a diagnostic label on the identity of the individual. Others were more 'hardline' about not taking this into account. Although individual clinician views varied, there was a strong sense of the patients' and families' views, values and desires having to be managed through the process:

I understand that desire, that need, to have an identity, but as a clinician it doesn't really overly impact my decision, to be honest, because it's probably a bit mean, but actually it's the diagnostic criteria... and I've seen a number of people online say, oh well, of course I'm autistic, but we need to change the autistic criteria - well, you're not then, I'm sorry.

*Participant 2: 17 years in practice, 2 in autism diagnosis*

There would be quite an incentive to say yes to certain people, certainly because actually the implications can be really difficult. But that's something that we sort of manage and we are kind of used to that, and we also know that that's an experience that other people working in other teams certainly have as well, and they face those challenges on a regular basis. So we support each other around that. But it is tough.

*Participant 13: 7 years in practice, 7 in autism diagnosis*

Clinicians appeared to be engaged in a 'resistance/acceptance' relationship with (some) patients and families: resisting and accepting the family testimonies as credible or not, and finding ways to assert the right to make the final decision. Clinicians conceptualised patients and families as active agents who are motivated to seek or discourage a diagnosis. This motivation is something that required resistance and management.

### ***Diagnosis as a pragmatic construct***

In team meetings, clinicians often discussed how helpful a diagnosis may be for the individual, through enabling access to support or resources, or greater understanding of their own difficulties. In interview, clinicians varied in how much the pragmatic outcome of a diagnosis might help shape a decision in borderline cases:

What's important is actually making sure that we're correct and that we're accurate, because the whole point of diagnosis is understanding, understanding how to support someone and understanding where to go next.

*Participant 2: 17 years in practice, 2 in autism diagnosis*

Many clinicians questioned how they could tell that a diagnosis might, or might not, be helpful for an individual, especially long-term:

So it can be really hard to think about if they are ticking all those boxes and there's functional impact and nothing else explains it, it can be quite an interesting discussion around 'but should we give them a diagnosis?' if they're meeting the criteria, and I think that's something that's developing... it can be really hard to know whether having a diagnosis could do harm in the future, and that's quite tricky.

*Participant 8: 12 years in practice, 3 in autism diagnosis*



Others suggested there were times when the outcome would vary depending on the utility or not of a diagnosis for the individual, or on patient preference:

So especially with people that are sort of borderline ... we think is that going to help them? ...but that is an arbitrary thing as well isn't it?... we do think about that, is it going to help them. Yeah. ..Only for people that are kind of borderline

*Participant 7: 18 years in practice, 3 in autism diagnosis*

Given diagnosis does have that subjective social value judgment element to it, but if people don't wish to identify with a diagnosis I think I do take a position that I don't think they should have to, we shouldn't force it upon them.

*Participant 1: 10 years in practice, 7 in autism diagnosis*

Some clinicians considered the impact of diagnosis on the patient, and how this might affect the decision. At the same time, however, there was concern about a conflict with clinical training:

Actually I think its comes back a lot to what's going to benefit the individual in those kinds of borderline cases ...you can really see that giving the diagnosis is going to help them access additional support or resources or strategies which will have a benefit, then I almost feel it easier to give a diagnosis, whereas actually if I think the opposite, potentially someone is at risk of being stigmatised or struggling because of it, and they really don't identify with it and don't want it, then in these very grey areas it might disincline me from making a diagnosis. But that upsets me as a clinician because it doesn't sit naturally with my preference to have an evidence-base.

*Participant 6: 12 years in practice, 3 in autism diagnosis*

The functional outcome of a potential diagnosis, therefore, was expressed as always being a consideration, but with some concerns about being able to predict the benefits of a diagnosis, longer term, as set against meeting criteria and shorter term benefits.

## ***Feeling autism***

I explored the question of 'intuition' and 'feel' with participants in interview. Many recognised this 'feeling' and, whilst describing it as subjective, related the feeling to experience.

An experienced clinician brings that they've done this so many times... So I think that's what I mean by 'in the room', it's not necessarily a... I wouldn't say it's like a psychoanalytic kind of how they make you feel, I don't think it's that level, I think it's more about the kind of the... yeah that kind of social understanding of what you'd expect the young person to manage.

*Participant 9: 19 years in practice, 12 in autism diagnosis*

Getting the balance right between 'gut instinct' and meeting diagnostic criteria was expressed as another dilemma in diagnosis:

There's also a certain amount of stuff that probably isn't recorded by clinicians, and I don't know if it's an omission or not, but it's often how you felt, it's a subjective opinion, but based on subjective opinion of someone who's worked in an area for a number of years who's developed an instinct or a... yeah your gut instinct about how someone makes you feel, and that's often... you can't always articulate that... I think it's valid as long as it's done within kind of constraints and we're not just wildly speculating about things.

*Participant 15: 17 years in practice, 1 in autism diagnosis*

'Feel' suggests an expression of many years of inculturation in clinics which becomes experienced as instinct or 'clinical intuition'. Sometimes instinct or 'feeling' was acknowledged, and the meeting was utilised as a mechanism for resolving those dilemmas:

But yeah, try not to be biased by the fact that I've got a feeling, and I think what we try and do in MDT... we'd often talk about the fact that just because that young person has strengths in x, y, z, areas, doesn't mean that they're not meeting criteria if they've also got difficulties in those areas, so it's just trying to pull that apart really, rather than just going just by gut.

*Participant 8: 12 years in practice, 3 in autism diagnosis*

Many clinicians considered feeling in relation to the interaction with the individual in assessment:

Sometimes with the diagnosis, it's not just the factual and the kind of criteria that you're looking at but it's also a feeling that you get with people ... It's just a feeling. It's the way people make you feel I think. I don't know. It's really hard to describe, but you do get it, like I do feel now when I see people that I usually know within five minutes, most people, with autism, like I can kind of tell already. So there is subtle things in their interaction, the way they come into the room, the initial contact. You can just kind of tell actually.

*Participant 7: 18 years in practice, 3 in autism diagnosis*

Many clinicians were understandably cautious about over-estimating the emphasis on clinical intuition. Alongside assertions of meeting criteria, striving for accuracy and standardisation, and the benefits (or otherwise) of diagnosis, the way in which clinicians can 'just kind of tell', is a strong feature of the process of autism assessment. The ability to feel or recognise autism was considered as a factor that either had to be managed, or might provide an opening to further enquiry.

## **9.5 Preliminary Discussion**

### **9.5.1 Overview**

To summarise the preliminary findings, clinicians expressed diagnosis as tricky in borderline cases, with difficulties in interpretation of behaviours, knowing where the threshold lies, and a pressure on services, making the diagnostic process time-limited and potentially restricted. Whilst clinicians expressed that the decision-making process was challenging at times, particularly in 'borderline' cases, they also felt it was more straightforward at '*either end*' of the spectrum (i.e. for those very straightforwardly not-autistic, and for those very severely affected). The team meeting was valued as a way to explore uncertainty and ambiguity, examine different accounts together, and take shared responsibility for making a collaborative decision. The collective work of the team meeting, therefore, could be considered as a way in which clinicians can be relieved from uncertainty as well as individual responsibility for the decision.

Clinicians were aware of having to manage the expectations, desires and motivation of patients and pay attention to how researched or prepared individuals may be in order either to avoid or gain a diagnosis of autism. Clinicians varied in how much they would take into account the desires of the patient and the impact of diagnosis on the patient. This ranged from those who considered it irrelevant, to those who believed it could shape the diagnostic decision. Factors considered here included issues of practical support and access to resources, as well as issues of identity and long-term impact of labelling. Overall, however, there was a strong focus on 'personalising' the patient to include discussion, not only of their behaviours, but their desires and motivations. There appears to be an epistemic tussle, with parents, and with adults coming for diagnosis, about who has the right to define autism and therefore 'be' autistic.

Clinicians were deeply aware of the ambiguities and difficulties of diagnosing autism and took great personal responsibility in managing this process for the benefit of the patient and family. Concern was expressed about the long-term impact of diagnosis, which means that decision-making is threaded through with a concern for the consequences of diagnosis for the patient. Some interview participants expressed concern about pressure on services which they believe is constraining the diagnostic process and restricting time available for observations in 'natural settings' and longer, deeper assessments, for example. 'Feeling' autism was described as an intuitive process based on experience and knowledge rather than speculation or uninformed emotion. The positioning of the clinician as one who has this ability through 'day-in, day-out' experience, enables them to assert epistemic authority over the knowledgeable lay person, as a specialist who 'knows autism when they see it'.

### **9.5.2 Beliefs about diagnosis**

The interview data suggests that clinicians hold contradictory beliefs about diagnosis, which they slip between, in order to perform the function of assessment. Those beliefs are that:

- a) autism is a clinical entity that can be found through the diagnostic process, which is objective, standardised and evidence-based
- b) diagnosis of autism can be difficult as evidence can be ambiguous, decisions are not always clear cut, patients are motivated and decisions have a subjective element

As with Russell et al's (2016) study of educational practitioners' views of ADHD, these views seem polarised but they are not considered to be mutually exclusive. They appear to comprise an objective medical understanding of autism and of diagnosis (a); but this is framed within a social understanding of the challenges of classification (b). The dilemma of diagnosis, therefore, is rooted in the ontological certainty of autism as a condition, i.e. there is a thing called autism. However, as suggested in previous studies, there is epistemological uncertainty (how to classify it), which is related to ambiguity of behaviours, motivation and insight of patients and families, and differences of view in assessment. I have shown (Chapters Seven and Eight) how these dilemmas are resolved through drawing on specialist knowledge, judging the credibility of patient and family testimonies, drawing on pragmatism, and building a diagnostic narrative to construct a coherent diagnostic picture.

This set of interviews builds on my previous studies by demonstrating the importance of the collaborative decision-making process in the face of uncertainty. Assessments are troubled by the conflicting views of patients and families and questions about whether diagnosis will be helpful. Interpretations of clinicians' own instinct about the person can trouble the diagnostic trajectory (if the feel of autism is in contradiction to test scores); but also help move towards a diagnostic outcome (when feel and test scores are in alignment).

### ***9.5.3 Push/pull social factors in diagnosis***

The dilemmas faced by clinicians in autism assessment can be conceptualised as a balancing act with pressure on both sides. The working model, represented in Figure 16, is based on a study by Russell and Norwich (2012) drawn from a set of interviews about parental decisions for pursuing or avoiding a diagnosis of autism for their child. The authors found a 'tipping point', with parents juggling

between resisting diagnosis (due to potential stigma), or accepting diagnosis (because of the potential for support).

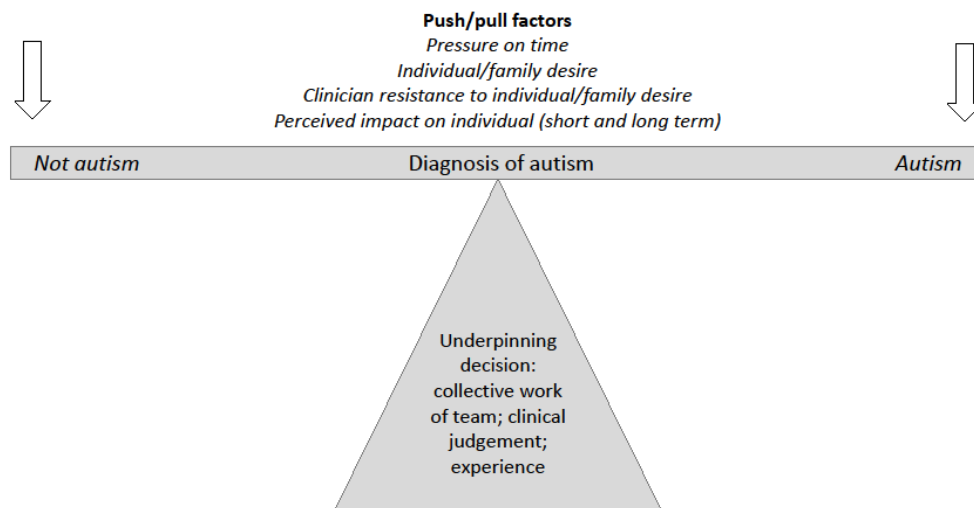


Figure 16: Working model of push/pull social factors in diagnosis

In my study, there appears to be a 'tipping point' related to a number of social factors. Pressure on time is expressed as potentially restricting a full assessment process; individual and family desire is taken into account with clinicians engaging in a process of resisting or accepting the credibility of patient and family accounts. Clinicians suggest that it is easier to diagnose than not, if the individual desires a diagnosis, or if parents are desperate and have been waiting for a long time for an outcome. In this working model, these factors, as illustrated above, all have weight in the consideration of diagnosis.

Clinicians, therefore, are engaged in a 'push/pull' relationship with the diagnostic decision. 'Pull' factors (pulling towards a diagnostic decision) may be stronger than 'push' factors (away from diagnosis). This may be because by the time patients reach the team, they are already in an 'institutional funnel' (Rossi, 2012) leading towards diagnosis.

Further analysis will explore the push/pull factors (pushing away from or pulling towards a diagnostic decision) as discussed by clinicians. In the context of these social interactional factors, clinicians value working collectively to enable

them to feel confident about decisions that have been troublesome, and to strive for standardisation. The meeting itself is considered part of the 'standardisation' procedure, as it includes a range of perspectives and assessments. However, as I have shown in Chapters Seven and Eight, interaction between different agents in meetings can shape the outcome of the meeting itself.

#### ***9.5.4 Reflection and future plans***

I am aware from reviewing the interview transcripts how some voices resonate with what I have observed in meetings, and others describe the process in a more straightforward way. As I analyse the data further I plan to ensure the inductive element of the analysis is stronger, to ensure that clinicians' views are represented. Further analysis of the interview data and write-up will take place in 2020.





## CHAPTER TEN: Discussion

*I never see medicine as as simply one thing rather than another. Rather it is bio one moment and social the next... Critically we need to understand more how medicine shifts between its hybrid associations to moments of clinical purity.*

Latimer, 2013, p. 196



## 10.1 Overview of chapter

The chapter includes a summary of the background, aims and objectives of the thesis and of each of the empirical studies. This is followed by a discussion of strengths and limitations and a summary of key findings. The chapter then goes on to discuss the findings and what they mean taken together as a whole, the contribution this thesis makes to current literature and the implications for theory and practice. The chapter concludes with a brief reflection on the process, discussion about future research and a concluding summary.

## 10.2 Summary of background

### 10.2.1 Introduction

A child's drawing of children on swings (Röttger and Klante, 1964) has been with me throughout my PhD (see Figure 17). The child on the second swing (I call him Jessie) behaves differently to the others: he faces in a different direction. In this context his behaviour is not out of place. But if Jessie were to turn his back in class when being spoken to, his behaviour might be considered problematic. If done repeatedly, it might be termed disruptive or resistant. But when does this behaviour shift from being 'difficult' to being 'pathological'? When do we decide Jessie needs a label to describe his behaviour? And why?

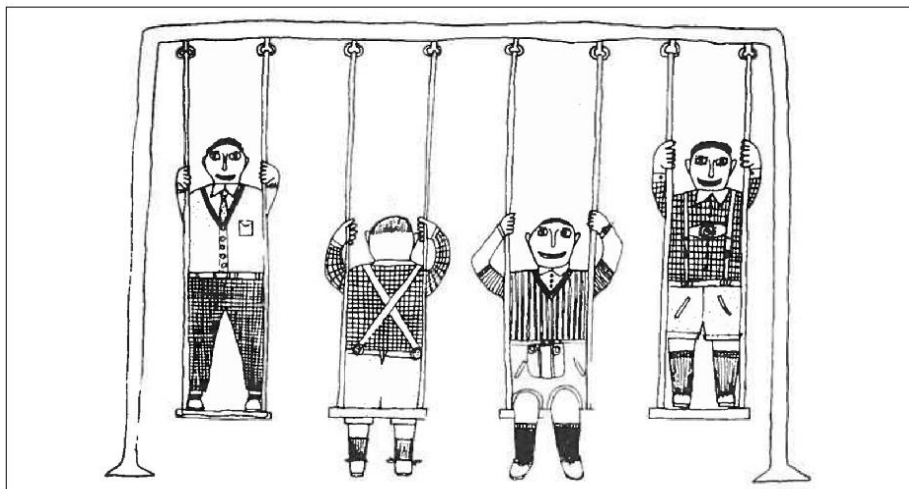


Figure 17: Drawing by un-named boy, age 12

Exploring the concept of acceptable social behaviour has been a thread throughout my PhD. A passing conversation with a mentor introduced me to the expression 'Normal for Fife' (NFF); medical slang, alongside Funny Looking Kid (FLK) and Normal for Norfolk (NFN) which, thankfully, seems to be going out of favour (Fox et al., 2003)<sup>6</sup>. This conversation was particularly striking for me, not just because I am from Fife, or because it seemed such an unacceptable shorthand for a child's situation, but because it said so much about what we expect normality to be. And it placed normal in context, in that, normal is one thing in some contexts, and apparently quite another in Fife (or Norfolk).

The framework to diagnose (to consider diagnosis, to send Jessie for diagnosis, to make the referral, to make the assessment, to give the feedback etc.) is a judgement that is framed and sanctioned by society and implemented by clinicians. It is a classification process that frames behaviour as normal or pathological. It is a framework which enables someone to fit or not fit, to explain, to seek treatment and support within, to excuse, to give meaning to those things in society that seem different and can be distressing, painful or difficult. It helps people without the label to support those with the label, and to understand and to find ways to alleviate real distress and difficulty.

Whilst clinicians are, generally, responsible for the diagnostic moment, for the labelling of a condition as one thing or another, the process of diagnosis itself is a social interaction and societal construct which begins long before the moment of referral. The shape of normal behaviour is decided before entering the assessment room; and although diagnosticians may have specialist expertise in making judgements about what those social norms of behaviour may look like, that expertise is based on how society defines it. As I discussed in Chapter Three, diseases and medical conditions have different meanings, understandings of aetiology and consequences depending on the historical period, culture, geography and environmental circumstance. As Bentall points out, investigators studying cross-cultural differences in depression across the world find that, in developing countries, depression is considered to consist of

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<sup>6</sup> And it should be noted that I did not, ever, hear any of the healthcare practitioners in this study using anything resembling these terms.

somatic factors such as fatigue or dizziness; whereas in Western countries the focus is on cognitive symptoms such as low self-esteem (Bentall, 2003). Context does not only change behaviour, but the meaning we ascribe to it. This thesis has explored how clinicians navigate the borderline between 'normal' and 'pathological' behaviours in their diagnostic deliberations.

### **10.2.2 Background literature**

As I have described throughout this thesis, diagnosis of autism poses particular challenges for healthcare practitioners. There are no biomarkers regularly utilised in diagnostic tests (Vllasaliu et al., 2016) and the condition represents a heterogeneous group of disorders, with wide ranging levels of severity and symptom expression. Symptoms that are common to autism may occur with other conditions (Huerta and Lord, 2012), leading to potential ambiguity; and research also suggests that diagnostic procedures are not consistent across practice (NICE, 2012).

Some studies show that social factors such as individual patient preference, availability of resources, or local organisational factors can shape diagnostic practice in, for example, heart disease (Fuat et al., 2003). Studies in autism have shown the existence of 'diagnostic clusters', where autism diagnosis is high, especially where there is greater availability of assessment resources (Liu et al., 2010a; Mazumdar et al., 2013).

Whilst environmental causes for an increase in prevalence cannot be ruled out (for example, see Liu et al. 2010a), given the current lack of evidence of any organic increase in symptoms, there is significant debate about the reason for the increase in prevalence of autism. Research has considered the broadening of diagnostic criteria (Russell et al. 2015; Rutter 2005); diagnostic substitution (Bishop et al., 2008; Shattuck, 2006); the decreasing age of diagnosis (Leonard et al., 2010); information diffusion (Liu et al., 2010a); the conceptualisation of autism as an 'epidemic' (Ebben, 2018); clinicians 'upgrading' to autism diagnosis if they consider it might offer the patient access to appropriate support (Rogers et al., 2016; Skellern et al., 2005); and the medicalisation of behaviour through domain expansion (Conrad, 2007).

This qualitative study was not intended to offer evidence for any direct relationship between clinicians' practice and increased diagnostic rates. However, given the potential for inconsistencies in practice and ambiguity around symptoms, this phenomenon of increased diagnosis makes autism a particularly interesting study for examining the social framing of diagnosis.

The above literature informed the design of the PhD which was intended to explore social factors in diagnosis within a sociology of diagnosis framework (see Blaxter 1978; Brown 1995; Jutel 2009, 2013; Jutel and Nettleton 2011). I was interested in the social framing of autism diagnosis as defined by Aronowitz (2008) and Jutel (2011) as the way that societies generally 'recognise, define, name and categorise disease states' (Aronowitz, 2008, p. 2). As Jutel (2011) notes, the delivery of diagnosis from the clinician to the lay person is not simply one of linear conveyance, which implies passivity and conceals the intricate web of relational possibilities and societal pressures inherent in the process. Similarly, the receipt of diagnosis need not constitute 'passive re-identification' (Jutel, 2011, p. 140), as those seeking diagnosis (or their families on their behalf) may drive for diagnosis, resist it, withdraw from the process or choose not to seek it at all. Diagnosis, rather, is relational and dynamic with the potential for shifting roles, responsibilities, stakes and interests.

I undertook a further review of the literature and found a significant body of work related to uncertainty in medicine generally (e.g. Atkinson 1984; Fox 1957; Freidson 1970; Hedgecoe 2003; McGoey 2009; Pickersgill 2014) and in autism specifically (e.g. Hollin 2017a, 2017b; Hollin and Pilnick 2015, 2018; O'Reilly et al. 2017). I became particularly interested in how clinicians engage in 'practical uncertainty work' (Hollin, 2017b; Moreira et al., 2009; Pickersgill, 2011) which enables diagnosticians a means of counteracting diagnostic uncertainty to enable the 'doing' of diagnosis.

I then explored further work examining the conceptualisation of autism as a clinical entity in both the UK and US (Evans, 2013; Eyal et al., 2010; Fitzgerald, 2017; Nadesan, 2005; C. Silverman, 2013). This body of work traces how autism as a classification has shifted in relation to our conceptualisation of

psychological development, the emergence of 'childhood' as a research focus and the deinstitutionalisation of 'mental retardation'.

There remain few empirical studies, however, which examine in detail how autism diagnosis comes about in situ, given the way it might be understood as an 'uncertain entity' (Hollin, 2017b). Some exceptions include an ethnographic study of an autism clinic (Rossi, 2012) and an exploration of multi-disciplinary team meetings considering autism diagnosis (Parish, 2019).

I considered the work of Maynard and Turowetz to be particularly relevant for this PhD (Maynard and Turowetz, 2019, 2017; Turowetz, 2015b, 2015a; Turowetz and Maynard, 2019, 2017, 2016). In a number of conversation-analytic articles examining autism diagnosis of children in the US over two time spans, the authors consider how clinicians build a narrative case for diagnosis, including implementing strategies to enable differential diagnosis and foregrounding clinically relevant behaviours. They demonstrate how interaction in assessment serves to present assessors as neutral facilitators and diagnostic tools as passive recording measures.

The PhD project then became framed by three intersecting bodies of work. First the overall framework of sociology of diagnosis which considers the process of diagnosis as relational and dynamic. Second, the concept of uncertainty in medical practice which is particularly interesting given the history of autism classification and the heterogeneity of autism symptoms. And finally, the body of empirical work by Maynard and Turowetz which examines in detail how clinicians work together in assessment to make a diagnosis. These three works of scholarship helped to frame the project as one which would directly observe and analyse the talk of clinicians, in order to examine how interaction contributes to the diagnostic process.

I set out, therefore, to explore how clinicians make collaborative diagnostic decisions given the complexity of autism diagnosis and what this means for our understanding both of the condition and of diagnosis generally. I was interested broadly in what I termed 'social factors', although I came to consider 'social

factors' as integrated within the clinical and found the definition of 'social framing' as outlined above more useful. My object of study, therefore, became more complex but arguably more interesting. Broadly, I was interested in the social framing of autism as a condition, and how beliefs, practices and histories, as well as lay/medical practices, might contribute to our understanding of autism. Specifically, I became interested in considering how the complexity of interactional and diagnostic factors led to a conclusion of 'autism'.

### **10.2.3 Exploring Diagnosis**

My broader understanding of autism and diagnosis has also been informed by being part of the wider research project, *Exploring Diagnosis*, a Wellcome Trust funded research project led by Dr Ginny Russell. *Exploring Diagnosis* examines the role that diagnosis plays in society and in medicine, using diagnosis of autism as a case study. *Exploring Diagnosis* also aims to celebrate and value the abilities and attributes of the neurodiverse community. My PhD study has both contributed to, and learnt from, this wider project in a number of ways.

*Exploring Diagnosis* was informed by a series of research studies in autism, in particular examining time trends in the diagnosis of autism (Russell et al., 2015). This broader context of diagnostic rates, social and demographic factors, and issues around aetiology and prevalence, shaped the project and outlined the social and epidemiological context within which autism as a condition could be examined as a case study (for example, see G. Russell et al., 2016; Russell, 2014; Russell et al., 2014, 2012b, 2012c, 2010b, 2010a).

The *Exploring Diagnosis* team comprises a number of researchers working on related projects concerned with, for example, the first-hand experiences of autistic people (Kapp et al., 2019; Russell et al., 2019a), first-person accounts of social action and autism rights in the neurodiversity movement (Kapp, 2019), labelling and stigmatisation (White et al., 2019), psychiatric classification, self-diagnosis and self-identification as autistic (Lister, 2019; Sarrett and Kapp, 2018), quality of life (Kapp, 2018), patient and public involvement in pharmaceutical interventions (Russell et al., 2018) and a critique of the diagnostic observation tool, the ADOS (Timimi et al., 2019). The depth and



breadth of these studies has provided me with an understanding of wider issues related to cultural and epidemiological factors in autism diagnosis which were not directly part of my study.

One significant strand of *Exploring Diagnosis* includes a number of studies that actively seek the views and experiences of people with a diagnosis of autism. Whilst my own PhD study has not involved autistic people, I have learned from being part of a wider team for which this has been the main focus. The wider study has included a 'sister' PhD project led by Thomas Lister (Lister, 2019) that explores how and why people come to be labelled, or label themselves, as autistic in adulthood, and the consequences of doing so. This involves interviewing people who have been diagnosed or who self-identify as autistic in adulthood. Tom's work has been a constant 'mirror' to my process of examining diagnosis from the 'other side' and we have had many discussions which have helped us both to focus on particular aspects of relevance for our individual studies. For example, whilst I have found that clinicians are deeply conscious of patients' motivations in coming for assessment, Tom has been able to explore how and why people do or do not choose to go for assessment, their experiences of assessment and the impact on their identity as autistic.

Further work from the *Exploring Diagnosis* team has explored aspects of autistic experience and behaviour which are generally regarded as 'deficits' but may be understood from an autistic perspective as advantageous. This has included an interview study examining strengths in autistic adults (Russell et al., 2019a) where participants described key strengths such as good memory and attention to detail, but also included strengths related to social interaction such as honesty and loyalty. The findings suggest that traits associated with autism could be experienced as either negative or positive depending on social context. A further study highlighted the importance of stimming (stereotyped or repetitive motor movements) to autistic adults as a self-soothing mechanism, or as a way to communicate intense emotions or thoughts (Kapp et al., 2019). This study reframes a behaviour generally considered to be a disadvantageous trait of autism, medicalised as 'motor stereotypies' such as 'hand or finger flapping' in DSM-5 (APA, 2013a), to one which can be considered helpful in some

situations. Considering so-called 'deficits' from the perspective of those who experience them offers an expert reframing of how we understand behaviours that we medicalise as problematic. The authors conclude that stimming, because of its potential helpfulness to some autistic people, should not automatically be the subject of interventions which seek to eliminate it.

The above outline does not do justice to the depth and breadth of the work of *Exploring Diagnosis* or reveal the continual and iterative process of knowledge sharing that we have enjoyed through the life of the project. This has included fortnightly team meetings where we presented work in progress for discussion and feedback, planned joint presentations and events and welcomed scholars and autistic advocates to present and discuss their work and ideas. At my instigation we regularly discussed topics in the news or media of relevance to diagnosis or to autism, including reports about whether computers can diagnose, incidents of violence against disabled people, debates about autism and gender, vaccination controversies, autistic representations on TV and in fiction, as well as reactions to challenges to diagnosis such as the Power, Threat, Meaning Framework (Johnstone et al., 2018) (see *Appendix 15: Selected In The News Items*). These discussions reminded me to consider my work in the wider arena of disability rights, changes in legislation and current cultural representations of autistic people.

A Patient and Public Involvement (PPI) project supporting autistic artists to create short animated films (*Exploring Diagnosis*, 2019) managed by Dr Jean Harrington, demonstrated how creative practices can provide insight into autistic experiences of diagnosis and of the condition. On a practical note, the *Exploring Diagnosis* team provided support for each other in areas of expertise. For example, Daisy Elliott researched and supported on anonymisation of my data for data archiving, as well as piloting my framework for study one, along with Rhianna White and Ginny Russell. I also supported Rhianna on her study examining labelling and stigma, by helping to facilitate her experimental study in schools. I was also involved in early discussions around 'diagnosing the dead', which has culminated in a forthcoming article being developed by Ginny.

The *Exploring Diagnosis* advisory board, made up of experts in the field (*Appendix 16: Exploring Diagnosis Advisory Board*), provided an opportunity for specialist discussions around particular areas of interest. Visiting scholars such as Chloe Silverman and Annemarie Jutel enriched our understanding and provided critical debate. I have been involved in an autism reading group, convened by Dr Steven Kapp, which has extended the breadth of my reading into articles advocating for a neurodiversity approach as well as examining biological and cognitive perspectives. I have also been a regular attender at a 'sociology of diagnosis' reading group convened by PhD student Elena Sheratt where I have been introduced to articles which discuss social issues beyond the condition of autism, including dementia and chronic pain.

#### **10.2.4 Conferences, peer reviewers and Data Bee**

I have also benefitted from attending and presenting at conferences. Of particular value was a presentation with Ginny Russell at the Critical Autism Network (Russell and Hayes, 2017) where I learned a great deal about the neurodiversity movement and disability politics in relation to autism and diagnosis. In addition, feedback from a presentation at the British Sociological Association Medical Sociology Conference (Hayes, 2018) helped me to shape my study at a key stage in developing my analysis. Annual presentations at the University of Exeter College of Medicine and Health as part of an Annual Research Event to showcase student work, and a presentation at CACE (Conversation Analysis in Clinical Encounters) (Hayes, 2019) significantly helped my confidence in analysis as well as connecting me to a wider scholarship in healthcare services research. I have also benefitted significantly from anonymous peer reviewers who have taken time and trouble to help me reframe my second article (Hayes et al., 2020) in a way that was more 'sociological' and embedded in relevant literature.

Finally, with a small group of PhD colleagues, I initiated and set up 'Data Bee', a qualitative data-sharing and analysis group based in the College of Medicine and Health. This peer-led group has met fortnightly and been invaluable in supporting my own data analysis, and learning from others. In particular, sharing data with Tom enabled us to find connections across our work and

sparked discussion which has contributed to our thinking. Data sharing with Daisy Parker, who is examining doctor-patient communication when dealing with psychological distress, has been particularly helpful in examining the structure of interaction in healthcare settings (Parker, 2019). In collaboration with Tom and Daisy, and the fourth member of our team, PhD student Catherine Talbot, I organised a day event for PhD students and early career researchers throughout the south-west of England, which enabled us to share our experiences of sharing data with others.

To conclude this section, my specific interest during this PhD has been a focus on diagnostic decision-making by clinicians. However, my approach was grounded in wider understandings of autism research, sociology of diagnosis, exploration of methods, and current debates playing out in the fields of autism and of diagnosis more broadly.

### **10.3 Aims and objectives of PhD**

The aims of the PhD were to explore social factors in autism diagnosis in secondary care; and to understand how clinicians collaboratively make diagnostic decisions in autism assessment. The thesis had the following objectives:

- a) To undertake a review of clinical guidelines in use in the UK and consider where, within those guidelines, social factors and influences are taken into account (study one)
- b) To document and analyse discussions made in MDT meetings (or local equivalent) to identify social and interactional processes (studies two and three)
- c) To gather views and experiences of clinicians involved in the diagnostic process via interviews (study four)
- d) To contribute to a social understanding of diagnosis

I designed and implemented four inter-related studies: a review of clinical guidelines, a thematic analysis of observation data, a discursive analysis of observation data and an interview study. These are briefly summarised below.

## **10.4 Summary of studies and findings**

### ***10.4.1 Review of clinical guidelines (study one)***

#### ***Overview of study***

The preliminary study was a qualitative narrative review of clinical guidelines for autism diagnosis in the UK. I undertook a scoping search for similar studies and a systematic search of multiple databases and relevant web sources to identify relevant guidelines. Twenty-one documents were found and analysed. A process of data extraction synthesised key diagnostic elements such as assessment process and diagnostic tools.

I found that guidelines varied in recommendations for use of diagnostic tools and assessment procedures. Although multi-disciplinary assessment was identified as the 'ideal' assessment, there was no guidance as to how that should take place. Social factors in operational, interactional and contextual areas added complexity to guidelines but there was little guidance as to how these factors impacted on assessment, or recommendations as to how they might be managed in day-to-day practice. Clinical practice guidelines varied in their recommendations, making the choices available to healthcare practitioners particularly complex and confusing.

#### ***Strengths and limitations of study***

The strengths of this study were that a narrative approach was helpful to understand the complex and sometimes contradictory nature of the diagnostic process. Methodologically, I undertook a systematic search and included a transparent but pragmatic selection of documents. This is, to my knowledge, the only review which strives to consider how the process of autism diagnosis may be socially framed.

One limitation of the study was that as it was a review of current guidelines, changes through time were not exposed. My review was limited to the UK context because healthcare settings vary widely in international contexts. Although in this study I could only examine the content of guidelines rather than how they are used, it was expected that this might become possible in subsequent studies.

### ***How study addresses aim of PhD***

This study aimed to understand the broad context of autism diagnosis in the UK and, in line with the aims of the PhD, to begin the exploration of social factors in autism diagnosis. This study enabled me to understand that, despite clinical guidelines which attempt to standardise assessment, the process of diagnosis for autism remains ambiguous, potentially contradictory, and complex. I found that clinical guidelines for autism diagnosis illuminate the process of diagnosis as social rather than straightforwardly clinical.

A focus on clinical judgement in guidelines seemed to offer a way in which clinicians might negotiate ambiguity and contradiction, but a lack of guidance about how the multi-disciplinary aspect of diagnosis should work leaves that process open to local forces. The study constituted an initial scoping review which set the context for examining social factors in situ. Uncertainty and ambiguity became a key concept as a result of this study which was then further explored in subsequent studies.

### ***10.4.2 Observation of assessment team meetings (studies two and three)***

#### ***Overview of studies***

The core study of this PhD was an observation of specialist autism assessment team meetings on four sites in the south of England. Eighteen meetings were observed in two adult and two C&YP teams. In over 19 hours of meeting time, a total of 88 cases were discussed, with 51 directly related to diagnosis. These 51 cases form the cohort for this study. Meetings were audio-recorded and a dual thematic/discursive process of analysis was undertaken. The study was written

up as two articles to reflect this dual approach. This enabled me both to take a broad overview of the themes within the data in study two (thematic analysis) whilst also capturing the detail of interaction on selected cases in study three (discursive psychology analysis). A full outline of the method is in Chapter Five.

Through thematic analysis (study two) I found that, within these settings, expressions of uncertainty and ambiguity were common. However, diagnosticians employed a number of strategies based on their specialist disciplinary knowledge to overcome this difficulty. This included invoking the 'feel' of autism in their encounter with patients; and drawing on instances of behaviour reported by non-present patients and their families, especially parents, which tacitly or explicitly linked to diagnostic criteria for autism.

A discursive analysis (study three) identified a four-part structure to diagnosticians' talk which was utilised to account for and explain potential contradictory evidence. This structure enabled diagnosticians to forward evidence for and against a diagnosis, facilitated a collaborative decision-making process and enabled them to build a plausible narrative which accounted for the diagnostic decision. I also found that uncertainty was used as an interactional resource within meetings to enable the introduction of contradictory views or evidence whilst retaining a collegiate atmosphere.

I found that healthcare practitioners frequently vocalised the potential benefits or harm for the patient and family as a result of the consequences of diagnosis. Diagnosis in this setting can, at least in part, be considered as a pragmatic construct within a condition which, diagnostically, is permeated by uncertainty and contradiction. This resolution of contradiction from different aspects of the assessment then served to reify a narratively-coherent, intelligible clinical entity that is autism.

### ***Strengths and limitations of studies***

The main strength of these studies is the rich quality of the observational data. The data offers an insight into an area of diagnosis rarely seen: a 'backstage' moment which is a fundamental part of the diagnostic process. I found that this

social arena is a crucial one for shaping the diagnostic decision and, therefore, for shaping autism. Gaining access, building trust with clinicians and developing working relationships with Health Trusts to enable this access was a long process, with each Trust having different governance mechanisms to navigate. This in itself makes the data rare and valuable. To my knowledge, this is the first data of its kind recorded in adult autism assessment; and one of only three collections internationally in children's assessment (along with Turowetz and Maynard, and Parish).

My studies represent only one aspect of the diagnostic process, that of the post-assessment team meeting where the diagnostic decision is made. There is, therefore, a need to examine all stages of assessment, particularly those that take place in informal interactions and in the presence of patients and families. As recording equipment and the researcher was present during meetings, it is possible that discussion was inhibited through this observation. However, it is likely that a requirement to focus on the task in hand (diagnosis) would alleviate some of this potential observer effect.

### ***Limitations of the data***

It was my intention to include data from the assessment of both adults and children within the observation sample for the PhD studies. As described in Section 5.2.1, I recruited four specialist assessment teams across C&YP and adult services, to facilitate a sample which included a range of ages. However, during the course of the observation period, the majority of cases discussed by the teams were adults, or young people over 14. The final sample of 51 cases, therefore, included only 13 children under the age of 14 (25.49%). I was particularly interested in exploring 'borderline' cases - cases considered to be near the diagnostic threshold - so the questions in my studies further determined the sample for detailed analysis.

As previously noted, the disciplinary field in which my studies are located – interaction in autism assessment - has mainly been concerned with examining the diagnosis of children (e.g. Turowetz and Maynard 2017; Parish 2019). In this sub-field, therefore, my studies have identified and addressed a gap in



research. Nevertheless it is important to note that the sample overall is skewed towards adults and young people. This has two main implications.

Firstly, I acknowledge, that, however unintentionally, my studies may contribute to the bias in research identified by Russell and colleagues towards under-inclusion of populations with Intellectual Disability (ID) in autism research (Russell et al., 2019b) as these individuals are more likely to be identified in childhood. Secondly, and more broadly, the sample is likely to be skewed towards individuals who are less severely affected (requiring less support) both because I have focussed on cases that might be considered near threshold, and because they were again not identified in childhood. A longer term study, focussing only on children's teams, and specifically sampled for children with severe symptoms, would provide a sample more inclusive of children who are currently frequently excluded from autism research.

### ***How studies address aim of PhD***

These studies meet the aim of the PhD by directly examining how clinicians make collaborative decisions in autism assessment as well as considering how interaction, clinical judgement and pragmatism can operate as social factors in autism diagnosis. I show how clinicians produce objective accounts through their situated practices and perform diagnosis as an act of interpretation, affect and evaluation to meet the institutional demands of the diagnostic setting. I demonstrate that autism is rendered an object through the process of its identification by healthcare practitioners. Uncertainty inherent in autism's heterogeneity of presentation and aetiological variation is ultimately dismissed and re-interpreted in diagnosis in order to reify autism, as required by the institution, as fixed, real and knowable. The interactive talk of diagnosticians is, in itself, a social factor in that *how* clinicians talk about diagnosis shapes the diagnostic decision.

### **10.4.3 Interview study (study four)**

#### **Overview of study**

Sixteen clinicians involved in autism assessment meetings were interviewed in this study. Interviews were conducted with participants drawn from the observation study, using Tape-Assisted Recall (TAR), which enabled direct discussion about cases discussed in meetings through re-listening to audio recordings. Interviews were transcribed and analysed with thematic analysis. Findings are at a preliminary stage.

I found that clinicians were deeply aware of the ambiguities and difficulties of diagnosing autism and took great personal responsibility in managing this process for the benefit of the patient and family. They expressed doubt at times about their decision-making, but valued the forum of the team meeting to explore this uncertainty, examine different accounts together, and make a collaborative decision. Concern was expressed about the long-term impact of diagnosis, and decision-making was threaded through with a sense of personal responsibility and concern for the consequences of diagnosis for the patient. Clinicians were aware of having to manage the expectations, desires and motivation of patients and pay attention to how researched or prepared individuals may be in order either to avoid or gain a diagnosis of autism. There is a suggestion of an epistemic tussle, with parents, and with adults coming for diagnosis, about who has the right to define autism and therefore 'be' autistic. Some interview participants expressed concern about pressure on services which they believe is constraining the diagnostic process and restricting time available for, for example, observations in 'natural settings' and longer, deeper assessments.

#### **Strengths and limitations of study**

The method chosen enabled direct discussion about cases discussed in meetings, allowing a rich and free-flowing discussion in interview. The interviews offer an insight into how clinicians see the process witnessed by the researcher, allowing an insider's perspective of the diagnostic process.

As participation was limited to those involved in the observation study, there was no opportunity to ensure a breadth of professional roles or ages. In addition, there was a danger of over-directing the discussion through the selection of cases to discuss. However, this probably represented a more open approach than direct questioning about social factors might have allowed.

### ***How study addresses aim of PhD***

The interview study enabled me to explore how clinicians' perceive the diagnostic process. Clinicians' views reflected my observations of team meetings, in that they described the process of diagnosis as challenging, particularly in borderline cases. Clinicians valued working collectively to feel confident about decisions that have been troublesome. I found that clinicians are engaged in a 'push/pull' relationship with the diagnostic decision and that 'pull' factors (pulling towards a diagnostic decision) may be stronger than 'push' factors (away from diagnosis). This may be because by the time patients reach the team, they are already in an 'institutional funnel' (Rossi, 2012) leading towards diagnosis.

## **10.5 Overall contribution of thesis**

### ***10.5.1 Introduction***

Specific findings from each study have been summarised in Section 10.4. In this section I consider the contribution of the PhD as a whole. I discuss the contribution in the context of diagnosis as an interactional product, with particular attendance to pragmatism and diagnostic uncertainty. I then go on to discuss the transferability of my findings to other settings, and my contribution to the sociology of diagnosis, methods and clinical practice.

### ***10.5.2 Diagnosis as an interactional product***

Findings from all four empirical studies demonstrate the importance of the multi-disciplinary (or case review) meeting for autism diagnosis. A review of clinical guidelines demonstrated that guidelines consider multi-disciplinary assessment for autism as 'ideal': in interview, clinicians expressed the importance of the

team meeting in order to look at evidence together, gather perspectives from a range of disciplines and consider these in the light of diagnostic criteria. Observation of team meetings found that interaction within the meeting served to manage uncertainty, dispel contradiction and enable individual clinicians within the team to feel confident about the diagnostic outcome. The team meeting enabled collective accountability for the decision which produces an outcome that shapes both the future life of an individual, and the nature of autism itself.

Autism is an object of knowledge: it is what we know, but it is an object defined by the process of knowing it. I found that clinicians' interactive practices serve to deliver autism as an ontological certainty, despite a tacit acceptance of the inherent uncertainty and contradiction present in (some) diagnostic discussions. In the act of resolving contradiction and uncertainty (through the feel of autism, through corraling patient accounts, through narrative) clinicians reify the notion of autism itself as a contradictory condition, that is, one where it is possible, for example, both to have good social skills and also to be autistic. This contradictory condition is one where lack of 'insight' can be registered as a 'symptom' but also utilised to downplay a patient narrative; where 'performing autism' is possible and yet not 'be' autism. This contradictory condition is defined as being pervasive across settings, and yet, behaviour can be seen to change across settings and timespans. This contradictory condition is one in which it becomes possible to be both part of a spectrum into the general population, as well as categorically defined.

I would argue that clinicians 'hold' these inherent contradictions in their deliberations and yet produce ontological certainty through their diagnostic delivery. Clinicians, as active agents in diagnosis, translate feel, testimony, contradiction and ambiguity into objective knowledge. Conflicting accounts are incorporated into the diagnostic narrative and reified into autism as a condition. This contradictory condition of autism, therefore, is one which is held by clinicians as uncertain and indeterminate, and simultaneously is produced as certain and determinate, by necessity of the institution of medicine. These various factors (affect, testimony, interpretation and narrative) enable the team

to shine a specialist lens on autism and give the team a warrant to set aside lay testimonies, ADOS scores and the views of other professionals, when required. This specialist lens privileges the search for autism which is produced and reproduced in its own image.

I found that pragmatism – the practical consequences of a diagnosis (Phillips et al., 2012) – is woven into the diagnostic narrative. Pragmatism represents a concern by clinicians that the outcome is the right one for the patient and family in terms of accessing appropriate support. However pragmatism also represents a way to alleviate an impasse in the diagnostic narrative. If a diagnosis can be seen to have a functional outcome, then that is one more good reason for assigning it. To look at this another way, there appears to be little to be gained in assigning a diagnosis if there can be no sense that it will, in some form, be helpful for the patient, at some point. The narrative case-building process, therefore, includes dances around epistemic authority (between clinicians, and between clinicians and lay accounts), the authority (or not) of tools such as the ADOS, and how helpful a diagnosis may or may not be.

Clinician credibility and authority is asserted through expressions of uncertainty (knowing when the ADOS score is to be accepted and when it is to be set aside); through expressions of affect (utilising the feel of autism in the room, made possible through the experience of assessing others with similar behaviours); and through the ability to assess the credibility of patient and family testimonies. I observed that uncertainty is transformed, therefore, in the team discussion into something that reinforces professionalism as it demonstrates that the clinician is the one who knows, through experience. As Featherstone states, ‘personal knowledge and professional status coincide in the synthesis of clinical experience’ (Featherstone and Atkinson, 2012, p. 116). We can see in practice how the individual clinician’s reliance on ‘feel,’ or the ‘authority of his (*sic*) own senses’ (Freidson, 1970, p. 170), is jointly ratified through shared understanding and experience within the team.

This thesis has demonstrated how the push away from and pull towards diagnosis is a dynamic process visible through clinician interaction. Deeply held

beliefs based on clinical training and a desire to make an accurate diagnosis, sit alongside the inherent ambiguity and heterogeneity of autism. Diagnostic criteria sit alongside subjective interpretations of behaviours. Credible patient narratives contradict test scores. Standardisation in the form of the clinical interview and the ADOS sit alongside inconsistent testimonies from families, educationalists and colleagues. Through this tangle of accounts, clinicians weave a story of diagnosis: picking apart, teasing out and unravelling. Some argue that an over-simplistic understanding of mental illness is foisted upon clinicians (Whooley, 2010) and it could also be argued that the burden of uncertainty (Dwyer-Hemmings, 2018) (or ambiguity) of the diagnostic category of autism is laid at the door of the diagnostician. In my studies I observed the day-to-day practice of clinicians managing this ambiguity in situ. The meeting serves to reinforce and underpin the conventions of what we consider autistic behaviours to be and, importantly, what autism might become in the future.

I have responded to Atkinson's (1995) call to examine the detailed interaction of clinicians' talk in order to understand the meaning and consequences of uncertainty. This PhD study supports other studies which find that uncertainty is used as an interactional resource (Pilnick and Zayts, 2014) in this case to smooth over potential conflict, as well as signalling doubt about the causes of behaviour (e.g. autism or anxiety) in practice. I therefore offer an empirical contribution to the nature of practical uncertainty work in healthcare.

Diagnosticians are charged with the burden of indeterminacy and heterogeneity, and find ways to manage this dilemma to find the best outcomes for their patients. And whilst clinicians may readily display uncertainty in the privacy and relative security of the inter-clinician discussion, they are compelled to produce from that discussion a translation which delivers a clear and certain diagnostic outcome for patients, families and other professionals. The result of this translation from the clinic to the patient is the construction of a condition whereby it is possible to be both part of a spectrum as well as categorically defined, leading to the conceptualisation of a condition as one which is heterogeneous and broad-ranging.

I would argue that the dialogic space of the assessment meeting embraces indeterminacy; but this in itself does not facilitate the necessary institutionally-determined accountable diagnostic clarity. The meeting is the space in which the messy indeterminacy of autism assessment is shaped to fit the function of diagnosis. In this process of translation, diagnosticians are simultaneously able to work-around and to satisfy the institutional necessities of standardisation.

Dealing with the indeterminacy of autism in practice, through joint working in assessment meetings, demonstrates how one aspect of knowledge around autism is produced – through clinical interaction. Highly valued experience in these meetings serves to replicate autism in its image, forming an experience ‘looping’ effect. At the same time, new concepts are embraced that develop over time, such as the way in which women might present autistic behaviours differently to men. The clinic produces the image of that person through its assessment process. Beliefs about the efficacy of diagnosis, and conventions around social behaviour, frame the decision-making context and serve to resolve uncertainty. What is socially framed becomes objective reality in that it contributes to a collectively endorsed understanding of this particular condition.

I return to Jessie, the boy on the swing introduced at the beginning of this chapter, whose behaviour, forty years ago, might have been considered eccentric or odd. With the expansion of diagnostic criteria, it is far more likely today that the behaviour of a child like Jessie might be interpreted as autistic and assigned a diagnostic label.

### **10.5.3 Beyond autism**

This PhD study has focussed on the diagnosis of one condition – autism. Utilising autism as a case study for diagnosis is particularly interesting because of factors already outlined. I also argue that these findings may have transferability to other settings, both in other autism diagnostic teams as well as other conditions, and inferential and theoretical generalisation (Lewis and Ritchie, 2003). Theoretical generalisation in relation to sociology of diagnosis is discussed in Section 10.5.6.

Inferential generalisation concerns the question of whether the findings can be assumed to apply in other settings. Inferential generalisation requires 'congruence' between the different research contexts which necessitates knowledge of both contexts (Lewis and Ritchie, 2003). I am therefore limited in how much I can assert this kind of transferability given my knowledge is sited in this specific context of autism diagnosis. However, it is worth considering where these findings might be transferable or appropriate to consider as a potential 'working hypothesis' of extrapolation for further research (Cronbach, 1975). I will therefore briefly consider the potential transferability to different settings, and of different concepts.

### ***Settings***

Although I found that each team worked differently in response to local contexts, organisational structures and resources, the findings I have described in this thesis were common to all three multi-disciplinary teams. The fourth, single-disciplinary team, also had findings in common, however, because this team did not, for the most part, come to diagnostic conclusions in their meetings, it was not possible to judge, for example, how they dealt with contradictory evidence (See Chapter Eight). I would propose that it is likely that these findings could be transferable to other autism assessment teams in the UK.

The findings may also be transferable to other clinical settings where clinicians hold meetings without the patient present, to discuss assessment. Whilst some of my findings appear to be specific to autism, for example because of autism's heterogeneity of symptoms, research has explored the role of narrative in other kinds of clinical settings, suggesting that developing a narrative structure as a discursive device to manage particularly complex conditions is not uncommon. The particular way that clinicians deal with contradiction and uncertainty together, therefore, may be transferable to other multi-disciplinary team settings. Exploration of discursive practices in these settings may find similar strategies for managing these dilemmas.



The particular case of autism is also interesting due to the potential overlap of symptoms with other conditions, particularly psychiatric conditions and learning disabilities. This provides a particularly challenging task for clinicians in clearly deciding where one diagnostic classification begins and another ends.

However, this is not just the case for autism, indeed, it is likely to be the case for a wide range of psychiatric conditions. It can be argued that psychiatric symptoms, as with autism, exist on a continuum into the general population (Phillips et al., 2012) with the resulting difficulties in separating normality from pathology, thereby suggesting possibilities of transferability. Therefore, it may be possible to extrapolate the findings to psychiatric settings where the threshold between conditions may be uncertain. Observation of community mental health teams, for example, may identify similar dilemmas and solutions. Mental health teams in the UK are also under pressure in terms of access to resources and workload, therefore, there are similarities across contexts in relation to a pressure on services which may impact on diagnosis. However, I have found that clinicians perceive in autism diagnosis that there is a strong desire for patients and families to receive a diagnosis, which is strongly linked to clinicians' judgement of the credibility of patient and family stories. This may transfer across some settings but not others.

I have considered the transferability of these findings to settings for which there is a more 'definitive' biological test for a condition, such as cancer or heart disease. The roots of my study are in psychiatric, behavioural and neurological conditions. There are particular issues attached to this range of conditions rooted in mental distress, social difficulty and challenging behaviours which may not transfer to some other physical conditions. Some of those issues include, for example, moral judgements around behaviours, stigmatisation and significant emotional distress. Psychiatric conditions are subject to continual reinvention dependent on how society judges acceptable behaviours at any particular time (Whooley, 2019). Managing this uncertainty and interpreting ambiguity is core to the work of clinicians in psychiatric settings. However, to return to the study which initially framed my PhD, it has been found that social factors such as individual patient preference and availability of resources may impact on diagnosis of heart disease in primary care (Fuat et al., 2003). Whilst I would be

cautious about advocating for transferability of my findings to settings in physical health, it would be interesting to explore how clinician interaction may be similar in the multi-disciplinary context of heart disease, for example, or how context specific my findings may be in secondary care.

### **Concepts**

I have explored several key concepts as part of this PhD study, including uncertainty, 'feeling autism', the role of the (non-present) patients, the way in which the condition of autism is created and reified through day-to-day clinical practice, and diagnosis as a pragmatic construct.

Other research previously discussed shows that uncertainty in diagnosis is not particular to autism or to psychiatric conditions. The way in which clinicians in autism diagnosis *deal with* uncertainty and contradiction, therefore, may also not be particular to autism diagnosis. As I have discussed earlier, both 'feeling' that someone has a condition, and the way in which the patient narrative is incorporated into the clinical narrative have been explored in other conditions. These concepts may be transferable, therefore, particularly to other clinical mental health settings in secondary care. Similarly, considering diagnosis as a pragmatic construct may be a relevant concept for a range of conditions, particularly those which challenge the boundaries of classification or where categorisation may be uncertain. For example, my recent visit to the GP resulted in an uncertain diagnosis accompanied by a prescription for a steroid nasal spray, a pragmatic outcome in an attempt to alleviate symptoms of unknown aetiology. Pragmatism, therefore, may not be confined to autism or to psychiatric conditions or to secondary care.

I have argued that autism as a clinical entity is produced and reproduced through day-to-day clinical practice. Clinicians' understanding of autism through repeated experiences of diagnosing autism, serves to determine what autism is. Clinicians turn judgement into objective knowledge, which, in turn, shapes how wider society sees the condition (for example as something that can be masked). I would argue that clinicians, through their talk, enact this process of

reification throughout the medical profession and, therefore, is transferable as a concept that is core to diagnostic practice.

#### **10.5.4 Contribution to Sociology of Diagnosis**

As stated by Jutel, diagnosis is both a ‘pivotal tool’ for the work of medicine, and a ‘profoundly social act’ (Jutel, 2019, p. 3619) in the way society recognises, defines and names a disease and attributes it to a cause (Aronowitz, 2008; Jutel, 2011). Aronowitz argues that how we frame disease influences health and illness beliefs, perceptions of what interventions work and, important for this study, clinical and health practices. Whilst we must of course understand the reality of living with disease and disability (and not negate its impact on people’s lives) we can, simultaneously attempt to understand social practices that shape our understanding of health and illness (Brown, 1995). It is social framing that considers some diseases stigmatising and others noble: and it is social framing that interprets some behaviours as ‘disease’ and others as ‘normal’.

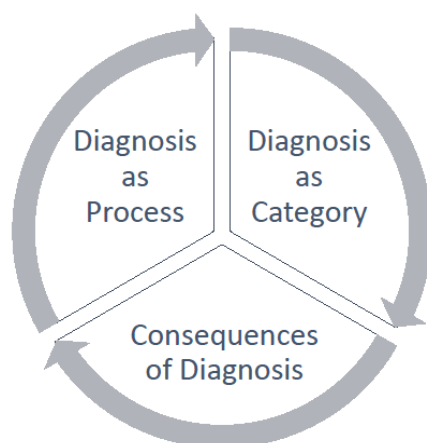


Figure 18: Jutel's social model of diagnosis (revised) (Jutel, 2019)

In her influential book, *Putting a Name To It: Diagnosis in Contemporary Society* (Jutel, 2011), Jutel proposed a model for the social framing of diagnosis which she also discussed more recently when reframing her work for the ‘genomic era’ (Jutel, 2019). I was interested in how my findings might contribute to this model. I reproduced Jutel’s model in Chapter 2, Section 2.3 (Figure 4). Here I offer a simplified and circular social model of diagnosis based on Jutel’s earlier model (Figure 18).

This model extracts the three core components of Jutel's model, placing the elements in a circular and iterative ongoing relationship (A. Jutel, personal communication<sup>7</sup>). Here each element – category, consequence and process – is given equal weight. At the centre of Jutel's original model (Figure 4) is the relationship between the clinician (MD) and the patient (PT) – the process of diagnosis. In this revised model (Figure 18) the process of diagnosis is embedded in this relationship more prominently to explicitly demonstrate a three-way inter-dependent process.

Having encountered Jutel's model early on in my PhD study, I now return to it to explore where my particular findings might fit. In my study the patient is absent, and yet of course, still central to this part of the process of diagnosis, that of assessment discussions between clinicians. The patient is present as an 'implicated actor' (Clarke and Star, 2008): absent and yet not only central to the discussion, but the actor for whom the outcome is most significant. Even in the absence of the patient, the patient-clinician relationship is core to the discussion, which is demonstrated, for example, in how clinicians incorporate patient testimonies in their diagnostic narrative. Patient testimonies and interpretation of them replace the patient and become the concrete objects of medical work (Måseide, 2006). I have demonstrated that the process of diagnosis includes interaction between clinicians and non-present patients: implicated or invisible actors.

However, my study also demonstrates that equally important to the process of diagnosis is the relationship *between* clinicians. If the diagnostic moment itself is relational (Jutel, 2011) then this interactional, behavioural and relational moment extends beyond the instance where the patient is in the presence of the clinician. The complex network of actors extends to include case notes, diagnostic tools, educational, mental health and paediatric professionals, families and friends, to name a few. The actors in the process of diagnosis weave a complex story between them during which, in the case of autism, the patient is present only some of the time. Clinician interaction in this context,

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<sup>7</sup> The concept of the model as circular came from Annemarie Jutel whilst attending an Exploring Diagnosis team meeting during the course of my PhD.

therefore, becomes part of a broader system of diagnosis (as a category, a process, an intervention, and with consequences) which helps to shift a collection of behaviours into a clinical entity. My study demonstrates that the 'process' element of diagnosis is not restricted to the relationship between doctor and patient, but can encompass interaction between clinicians, diagnostic tools and other actors, both visible and invisible.

My study, therefore, contributes a micro-analysis of that central concept of 'process' in Jutel's model. Drawing from my findings and working with Jutel's social model above (Figure 18) I have mapped social actions in the process of diagnosis which contribute to the social framing of diagnosis of autism (Figure 19). My findings show that social factors are not just deeply embedded within clinical practices but inseparable from them, elucidating diagnosis as a social practice.

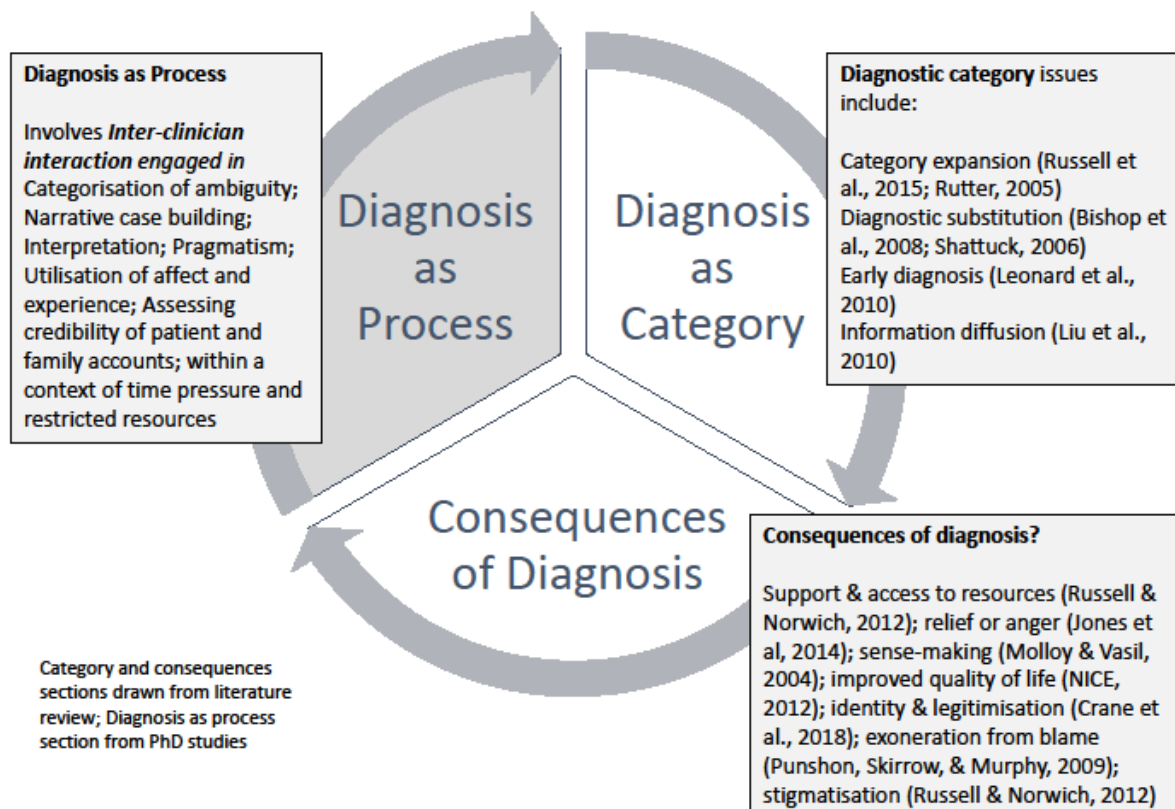


Figure 19: Building on an understanding of the social model of diagnosis

As can be seen from Figure 19, my PhD study demonstrates that the 'process' of diagnosis connects both to the category and consequences of diagnosis. The process of clinician interaction is intimately entwined with issues of categorisation (where is the threshold? where do symptoms begin and end? is there 'enough' to diagnose?); and simultaneously with issues of consequences (relief, understanding, validation, support, legitimisation).

In the context of diagnostic ambiguity (Charman et al., 2009; Liu et al., 2010a), the process of diagnosis in the shape of the specialist team discussion is socially framed and influenced by a number of interactional agents including patients and families, diagnostic tools and stretched resources. With the specialist team comes a particular focus on looking for autism; and the team creation itself both feeds and generates demand. Pragmatism, interpretations of ambiguous behaviours, and recourse to experience and 'feel', shape both the interaction and the outcome. My contribution to the sociology of diagnosis concept therefore is to demonstrate how the social framing of autism and autism diagnosis shapes the diagnostic process and produces autism not simply as a clinical entity but as the result of a complex interaction of factors.

Together these factors present a picture where the 'push and pull' of diagnostic decision-making does not rely purely on objectively assessing behaviour against clinical symptoms. Factors such as team make-up, experience, pressure of targets, interpretation of diagnostic measures and the perceived attitudes of patients and families are all players in the assessment process. The institutional demand to diagnose or not – to draw a line – in a condition which is generally accepted to have no clear threshold, shapes the process and the consequences. These different pressures and social interactional issues are brought together in the shape of the autism assessment meeting.

My contribution to the social model of diagnosis is to show how the process and consequences of diagnosis cannot be separated and are firmly sited within the institution of medicine. The perceived consequences are part of the deliberation process; and the process itself has consequences due to its involvement of many actors and the length of time it takes. There are consequences for the

patient, for the clinician (personal and clinical responsibility, time pressures, impact on working relationships) and for the category of autism. Process, category and consequences, therefore, are highly interdependent.

#### **10.5.5 Contribution to method**

I have taken a novel approach to methods in the PhD, striving to ensure that the methods meet the research questions. For example, although a narrative approach to qualitative synthesis is relatively unusual (and the only one I know of related to clinical guidelines) it enabled the telling of a story of how diagnosis is framed, and allowed both a deductive and inductive approach.

The dual analysis approach to analysing interaction in assessment meetings was designed as a staged process which allowed a thematic overview of the data, whilst at the same time identifying social actions for further examination with a discursive psychology approach. Whilst time-consuming, this approach resulted in a deep and rich exploration of the data. Thematic analysis is theoretically flexible (Braun and Clarke, 2013) therefore it is possible to combine this method of analysis with a social constructionist discursive approach.

In other studies, analysis of clinical interaction has been primarily related to doctor-patient interaction and much less to the 'backstage' elements of the diagnostic process. This study, therefore, offers a detailed insight into a rarely seen aspect of diagnosis. The method of analysis elucidates the complexity of interaction in diagnostic decision-making that might have been lost in a purely thematic or content-type analysis, for example.

Finally, I used Tape-Assisted Recall (TAR) for the approach to interviews, a method which has been used primarily in therapeutic settings (Baker et al., 2019; Cape et al., 2010; Elliott, 1986; Elliott and Shapiro, 1988). As a mechanism for prompting responses to meeting interaction, it proved effective and is one that could be developed further in a broader range of settings.

#### **10.5.6 Clinical implications**

This thesis has demonstrated some of the constraints within which diagnosticians work. Interviews, informal conversations with clinicians and

observations demonstrate that clinicians work within a context of significant time and resource constraints, increasing referral rates and an institutional system which is stretched. Furthermore clinicians work in a context where it appears difficult to share information, expertise and experiences across services (clinical psychiatrist, personal communication). The development of 'assessment only' services, whilst supporting specialist approaches, potentially disrupt the transition between assessment and post-diagnostic services with research showing that post-diagnostic services are the area of least satisfaction for parents (Crane et al., 2016). This study contributes to understanding this institutional pressure through illustrating the complexity of diagnosis and the challenge of diagnostic decision-making in autism.

Overall the data suggest that:

- Clinicians value the multi-disciplinary team context to enable them to draw from a range of disciplines and experiences to ensure the team comes to a conclusion that everyone feels confident in. However, each service devises their own team structure and operation, based on local resources and knowledge. This process is both time-consuming and leads to the effectiveness of teams being dependent on local expertise and resources.
- Assessment is a lengthy process with multiple assessments to enable triangulation across different types of evidence, meaning that waiting times for assessment are lengthy and assessment can be stressful for patients and families.
- Evidence for and against diagnosis is frequently contradictory, therefore, clinicians manage diagnosis in a context of uncertainty and ambiguity.
- Clinicians frequently refer to the limitations and difficulties of diagnostic tests for autism (especially for girls).
- Diagnosis is frequently complicated by the presence of (potential) co-conditions (e.g. anxiety) or adverse environmental factors (e.g. history of abuse).



- Ambiguity of symptoms can lead to the expression of uncertainty in assessment team meetings which can lead to extended discussions about diagnosis, and the implementation of further tests.
- Clinicians build a diagnostic narrative from their own observations and assessments, patient and family testimonies and how the patient 'feels' in relation to social interaction, in the context of considering how helpful a diagnosis may be for patient and family.

### ***Multi-disciplinary team working***

As discussed in Chapter Six, clinical guidance for autism diagnosis gives little detail about how the multi-disciplinary aspect of specialist autism assessment teams should operate. This PhD study has identified that each team has carved a method of working from what is possible within their own diagnostic service. The positive aspect of this is that teams are fit for purpose locally: they draw from resources and personnel that are locally available and design their working practices to suit their local needs. This can be seen in the range of different disciplines available (or not) to each team, frequency of meeting, selection of cases for discussion and roles in meeting, for example.

However, this lack of guidance also leaves space for variability in working practices, and therefore in outcomes and services for the patient. The team as formed and the way it works is only as rigorous as local resources and operational management allow. Even more importantly, lack of access to some disciplines as part of the recommended multi-disciplinary approach seems defined by local availability and funding rather than ideal make-up of the team. Each team strives both for rigour and efficiency: but in a stretched and under-resourced NHS, allocating enough time to ensure best organisational systems for joint working may not be possible.

With regard to interaction in team meetings, my analysis was not intended to provide a template for how healthcare professionals might communicate more effectively in team meetings or be the basis for training, as in much conversation-analytic research on clinical interaction (for example, Smart and

Auburn 2018). However, I suggest that some of the outcomes might be useful for reflective practice.

Teams strive for equality of role and contribution, although team members have varying experience and role status. More junior or less experienced members of the teams feel they are listened to and their views valued. This is essential for good team working and decision-making. Clinical psychiatrists, in particular, feel they were 'looked to' for the lead on a diagnostic decision, and in some cases there was a sense that a senior member of staff (usually a psychiatrist) would make the 'final call' in the case of uncertainty or ambiguity. In interview, some participants expressed difficulty in challenging the decision-making process even if they were a senior member of the team. This may be because time pressure does not allow for fullness of debate, or because of concern about being collegiate, for example. This was also observed in team meetings where challenges were often accompanied by hesitation or expressions of uncertainty.

Observation of teams suggests there is a complex interplay of epistemic authority which can be linked to discipline and role, but also to experience. The balance of power and hierarchy in autism assessment teams, therefore, is not a straightforward institutional hierarchy (Graham, 2009) but may also be shaped by beliefs about diagnosis and its benefits or harms, the perceived function of the assessment team and its targets, or the perceived limitations of the assessment process itself. An awareness of the difficulty of challenging the diagnostic trajectory (i.e. disagreeing with the prospective decision) even in well-established teams may help teams to develop methods for supporting conflicting views and debate.

In relation to team make-up, some teams particularly valued the contribution of healthcare professionals who were not involved in the assessment (and therefore had not met the patient) as they could take a questioning role. In meetings it could be observed that this role tended to facilitate a different perspective on the discussion. One diagnostician however found it difficult to fully contribute to discussion without having had a role in assessment themselves as the team meeting provided only a 'snapshot' which then had to

be brought to a conclusion. This notion of the assessment as a 'snapshot' was mentioned by several diagnosticians in interview: and yet this contrasts with concern about 'getting the diagnosis right' because of the lifelong impact of having the label of 'autism'.

I would argue that the team meeting offers a mechanism for clinicians to feel supported in their decision-making and comfortable with decisions made. However, I would caution against assumptions that the team meeting process inevitably aids a rigorous decision-making process. For healthy team working, trust-building and mutual respect between individuals of different levels of role and experience is essential. Good chairing of meetings, easy access to clinical information during the meetings, and detailed preparation is necessary. Disagreeing with a decision in a meeting is challenging even, at times, for senior clinicians. Without time dedicated to reflective practice, including ongoing review of practice and procedures, team meetings cannot work effectively. Unfortunately in a resource-restricted NHS system, time to invest in reflective practice is extremely limited.

### ***Pragmatism***

A key finding of this study is that diagnosticians are acutely aware of the complexity and ambiguity of autism diagnosis, but work in a system that is pressured and demands a level of output that many feel uncomfortable with in day-to-day practice. I have discussed in Chapter Eight the way in which diagnosis is considered, in part, to be a pragmatic construct to enable access to short-term support. There is, however, a lack of research and information on the long-term impact of a diagnostic label of autism. Diagnosticians are able to assess the short-term impact in relation to school support for example, but are not able to predict the outcome for someone whose developing identity formation will be shaped by a diagnostic label of autism. This presents a dilemma for clinicians whose aim is to achieve best outcomes for the patient.

An important factor, therefore, is the tension between alleviating distress and the usefulness of the diagnosis. Clinicians can only assess on their experience in real time: however, there is general acknowledgement that with a change in

situation, symptoms can become better or worse to the extent that someone might not appear to be autistic at all. This conflict between behaviours being situational, relational and changing, and the duty to confer a lifelong label, is a problematic one.

What might be helpful or not, therefore, is problematised by the notion of 'helpfulness' of diagnosis being subjective, relational and impossible to predict in the longer term. There are 'ethical tradeoffs' (Phillips et al., 2012, p. 13) in considering the utility of the diagnosis for the clinician. Diagnosis may trigger appropriate support in school but there is no mechanism for assessing the impact of a lifelong label. Diagnosis may be a problematic concept for someone who does not desire the label, but longer term may benefit from understanding their own behaviours within a diagnostic biography. The impact is not confined to the individual but also to parents and families, and to wider society, in relation to the potential for overall diagnostic rates for example, and, whilst linked to a label, an increasing expansion of the domain of medical disorders (Phillips et al., 2012).

I would argue that there are difficulties attached to the concept of autism diagnosis conferring a 'lifelong' label, given the problem of predicting long-term outcomes for any one individual. This difficulty could be alleviated by the removal of this concept of lifelong-ness from diagnostic criteria and integrating a review process for those diagnosed. As with anxiety, therefore, autism may come to be seen as a difficulty which manifests in response to certain social environments. For some this will be a lifelong difficulty requiring support: for others a temporary period of difficulty after which the label can be removed. Importantly, for clinicians, this would offer a safety buffer, particularly when diagnosing children and young people without the benefits of understanding prognosis or long-term impact. There are, of course, resource implications to reviewing an individual's diagnosis but one which may have benefits in terms of support required longer term.

I would also argue that (overtly) focussing diagnostic decisions around pragmatism in borderline cases might be an effective mechanism to manage

assessment in autism, given its heterogeneity and ambiguity. Scholars and clinicians have advocated for this position in psychiatric diagnosis, stressing the importance of focussing on distress and alleviating it, rather than diagnostic labelling (e.g. Bentall, 2003). However, when we become patients we have a desire to know 'what it is', so that we can understand and manage it (my prescription of a steroid nasal spray is unsettlingly dissatisfying – and under-used - whilst I do not know what is causing my symptoms). The diagnostic label, then, is not simply a *clinical* construct but one that patients desire and, occasionally, fight for. As Rose (2013) suggests, diagnosis is deeply embedded in our system of medical care and is therefore difficult to abandon. Therefore, in the current medical institution, pragmatism remains only one factor in the diagnostic process, but crucial to the diagnostic narrative and an important moral and ethical guide for clinicians in the context of ambiguity or uncertainty.

### ***Adults and children***

The study did not set out to make a comparison between child and adult diagnosis of autism, rather I aimed to include a range of settings. In the data, there were few differences in how clinicians discussed adult or child diagnosis. The findings outlined in this thesis – utilising patient and family testimonies, constructing diagnostic narratives, assessing ambiguous behaviours, drawing on 'feel' and experience as well as discussions of masking, insight and under-reporting – all appeared in discussions within both adult and C&YP assessment.

The developmental history was considered important in both adult and C&YP settings, however, it was frequently either unavailable or equivocal with adults. With the expansion of adult diagnosis, therefore, diagnosticians work out in daily practice how to retrospectively diagnose autism for (some) people for whom there is no reliable developmental information. In these adult cases, an increased reliance on self-report brings with it those difficulties of interpretation of mediated accounts and judgements around insight, memory, motivation, apparent compensation and perceived developmental gains.

Both sets of clinicians considered the consequences and utility of a diagnosis, however, in C&YP assessment there was often more detailed discussion about

school provision or specific interventions, for example. This was often connected, in both teams, to the meaning of an autism diagnosis to the patient (or family). Across the study, consideration of consequences involved questions around the perceived benefits of an autism diagnosis to those concerned, as well as explorations of the motivations of patients and families.

As previously discussed, there were some differences within teams (not specific to age of patient), for example, length of discussion, personnel, regularity of meetings, number of cases discussed and whether all or selected cases came to the meeting.

## **10.6 Future Research**

### ***10.6.1 The assessment process***

By necessity, within the limitations of a PhD, this study was able to observe only one aspect of the diagnostic process for autism. Throughout this PhD I have been curious about other stages of assessment – referral, assessing the patient, and delivering feedback in particular – and how they might interact to produce the diagnostic outcome. Observation of how these particular assessment conversations translate into feedback to patients and families would have been fascinating, particularly in relation to uncertainty and contradiction. Inclusion of interviews with those in receipt of diagnosis to enable an understanding of some of those factors raised by clinicians (motivation, insight, masking etc.) would provide another layer of understanding of the complexity and the social framing of the broader assessment process. Similarly, views and observations of referrers would enable an exploration of the earlier part of the process.

I have been particularly struck by the lack of specific guidance about how MDT autism assessment meetings should work, and the assumptions made both about their effectiveness and their capacity to deliver. There is a great deal of scope to build on my PhD study through examining the micro-interaction of autism assessment teams. This research could be designed to specifically

shape training materials to support clinicians in practice. Training materials could include recommendations on frequency of meetings, structure and organisation and how/when to review cases. Further research could develop a protocol for managing borderline or uncertain cases in particular<sup>8</sup>.

### **10.6.2 Adult assessment**

The PhD study has worked broadly across both children and adult services, however, there is a pressing necessity to examine adult diagnosis more closely, given the expansion of services and the difficulties of adult diagnosis as outlined in this thesis. There are a number of possibilities: not simply for observing and analysing the diagnostic process, but to explore commonly held understandings of lifespan development in autism ('losing' a diagnosis, gaining a diagnosis in later life and issues of camouflaging, for example). Some clinicians suggested that tools which have been transferred from children's diagnosis do not necessarily transfer effectively, and, in some cases, adults and young people object to using them because they appear childish. Furthermore, is autism the 'same thing' in children who are diagnosed and in adults who are diagnosed in adulthood?

### **10.6.3 Supporting clinicians in practice**

Diagnosticians noted the difficulties of predicting the long-term outcomes for people they had diagnosed, particularly young people and their relationship with identity when living with a label of autism. Whilst a diagnosis might meet the short-term needs of children who might be struggling at school, clinicians cannot predict the long-term impact. A study which examines short-term and long-term impact of diagnosis would help diagnosticians to understand the real-life consequences of a lifelong diagnosis.

Conversations and interviews with clinicians have raised several potential areas for future research which seem urgent for clinical practice. For example, there appears to be no comprehensive study which examines geographical or time differences in referral rates across the UK, and the relationship (if any) between

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<sup>8</sup> Suggestion by a clinician in conversation with Ginny Russell.

referral rates and diagnostic rates. This might also be compared with the timing of awareness-raising of the assessment pathway within different areas (and its relationship to referral rates), referral routes and quality of referrals. Some clinicians consider less structured and rule-based school environments may disadvantage children and young people who struggle with social interaction. A study examining the nature and location of children's difficulties would help to understand to what extent children would or would not present with serious psychiatric difficulties other than in school.

## **10.7 Strengths and limitations of PhD**

### ***10.7.1 Strengths***

A strength of the PhD is the range of empirical data (review of guidelines, observation and interview) and of analysis (narrative, thematic and discursive) which enables a rich exploration of the 'hows' as well as the 'whats' of autism assessment. Much of the debate around the social framing of autism diagnosis is not rooted in empirical study. I believe the data and analysis make a strong contribution to the field of sociology of diagnosis as well as offer insight into the construction of autism as a condition.

The PhD study aims to develop a contribution to the field of sociology of diagnosis, whilst also attending to the difficulties of real-world practice of diagnosis. The data and analysis provide material which may be useful for reflection by clinicians and there are clinical implications which are discussed in Section 10.5.8. A strength of the study is that the data were collected across settings with a diversity of geography (urban and rural) and patient age (child and adult diagnosis).

It would be inappropriate to discuss the concept of generalisability in a qualitative study as this concept does not fit with the ontological and epistemological assumptions of qualitative research (Smith, 2018). As I have argued above (Section 10.5.5) the study has analytical generalisation, as the findings can be applied to an established concept (sociology of diagnosis)



contributing new understandings to this body of literature (Lewis and Ritchie, 2003; Smith, 2018). I would also argue that the PhD as a whole has 'transferability' (Smith, 2018; Tracy, 2010) or inferential generalisation (Lewis and Ritchie, 2003) in that the cases discussed here will overlap with settings elsewhere and therefore can be applied and reflected upon and intuitively transferred to other clinical settings or diagnostic processes in other conditions where appropriate (Smith, 2018) (see Section 10.5.5).

### **10.7.2 Limitations**

I have discussed above the commonality of findings across teams. One difference between settings was in the way that teams selected patients to bring for case discussion at meetings, with two teams bringing selected cases, and two teams bringing all cases. This meant that case discussions were based on a different set of patients (for example, those that selected cases generally brought more complex cases to discuss). To capture case discussions about all patients would have meant taking a more ethnographic approach to the whole PhD, to include attending clinic days to capture the discussion and outcome of straightforward cases as well as capturing less formal occasions for case discussion such as desk discussions and phone calls. Therefore a limitation of the study was that I was unable to observe decision-making within the wider context of the clinic: however, a focus on the particular interaction of one aspect of the clinic enabled an in-depth analysis that would not have been possible with a broader ethnographic study.

Two teams who had initially been involved in the study (and I had been granted ethical approval to work with) were excluded from the study as they did not hold meetings where decisions were made. Inclusion of these teams would have offered a different insight into the assessment process which would have been valuable but only possible with an ethnographic-type approach. Furthermore, a focus on adult teams only might have strengthened my arguments about autism diagnosis in adults in the context of increased demand. There are, therefore, both limitations and strengths related to the diversity of my team selection, which was determined, at least in part, by issues of geography and time available during the course of a PhD.

## 10.8 Reflection

Alongside a critique of how clinicians create a story to make a diagnostic decision, I have been constructing a story too about how clinicians construct that story. Just as clinicians work within a socially constructed institution, with expectations, limitations and objectivities carved out of apparently objective tools (diagnostic tools in the case of diagnosis; rigorous methods in the case of research), academics, qualitative or quantitative, work within a set of 'knowns' which are created too by society. The story told is not fiction: but it is only possible here and now, due to particular sets of circumstances and frameworks available.

My own story in this PhD is one of a non-clinical researcher finding out about a set of practices previously alien to me. As a social psychologist I'm interested in how people interact, how groups work and how together we make things happen through language. Prior to this PhD I've mostly experienced interaction in a learning or education setting. In a medical setting, relatively short interactions have significant consequences for the patient and family in a way that the outcome of other sorts of interaction might not. I do not imply that educational interaction cannot be equally influential, only, for the most part this influence happens over a longer period of time. I might have looked at other social factors within the diagnostic process had I not had this interest – economics or environmental factors or aetiology or treatment for example.

As someone who has often felt they do not 'fit', I am intrigued by how we, as a society, decide what is acceptable behaviour and what is not; what we choose to label as a disorder and why; and why we are so drawn, as a society, to make judgements about those who might be different from ourselves, whether through behaviours, skin colour, gender, age, disability or race. Typologies are fundamental to so many aspects of our social world: I can understand and be reassured by a system which relies on diagnosis to ensure I get the treatment I require as a patient. At the same time it remains important to be alert to the consequences and shifts in diagnostic classifications so that we can understand

the wider social and cultural implications of those changes, how diagnoses are conferred, and how, once made, they become 'real' knowledge about a person.

It is important to question how we make judgements, moral in nature, about individual lives so that we can understand that the consequences of these judgements are human-made and not inevitable. How we classify and categorise human pain, suffering and distress has consequences. I am grateful to those invisible actors (patients, families and other participants) who have been a part of my study. It is easy to remain removed from the day-to-day difficulties of living with a disability or impairment if that is not your experience. It is easy to offend those who experience disability and who are rightly protective of those boundaries that guard their identity status, human rights and potential access to support. We live in an unequal world, and battles have been fought for good reason. Examining diagnosis does and should not undermine the lived experiences of those with disabilities or seek to replace the fight for equality and de-stigmatisation that can come with or without a diagnostic label.

I am grateful to the healthcare professionals who have both given me their time and trusted me to observe their interaction within a complex and 'tricky' process. Healthcare professionals are human and doing a difficult job, with enormous personal responsibility. I hope that my observations are recognisable to my participants, and that my research might contribute further to reflective practice. I also hope my analysis reflects the complexity of the job they do, and the challenging decisions they make every day, in attempting both to alleviate distress for some of the most vulnerable members of our society and to maintain 'accuracy' of diagnosis for a condition that slips between and around categorical definition.

## **10.9 Concluding comments**

I began this thesis with an idea of a 'line in the sand': a line that represents the threshold of diagnosis which, once crossed, is permanent and lifelong. However, as noted in an assessment meeting by a clinician participant, it is a

line which has changed historically. Autism is no longer what it was. I have attempted to demonstrate how diagnosticians in contemporary autism diagnosis both navigate and contribute to this shifting line. The interaction of clinicians represents just one aspect of the long journey of assessment for each and every child, young person or adult. If diagnosis, as I have shown, is an interactional product, this entity that is autism is one shaped and framed by social forces, contemporary understandings and society's deeply held beliefs about medicine and its consequences. The narrative of autism diagnosis is part of a belief system in diagnosis that we all share and contribute to in seeking answers for our distress, and in looking to medicine to provide them.

My overall contribution to the sociology of diagnosis field is to demonstrate how one aspect of the process of diagnosis is managed by clinicians to meet the needs of the clinic, even when uncertain. I demonstrate how the process of diagnosis is intimately integrated with both category and consequence through interactional practices. My contribution to autism research is to demonstrate how challenging diagnosis of autism can be in threshold cases, and how clinicians develop strategies to manage those troubling cases. The role of pragmatism, resistance (or acceptance) of patient and family narratives and the reliance on clinical intuition are key to diagnosis in borderline cases.

As Russell (2014) points out, current criteria define research, and research defines the revision to criteria, leading to a circular and reciprocal underpinning of the meaning of autism. Circulating within the worlds of diagnostic criteria and society's research-based understandings of autism, is the work of the diagnostic team. Diagnosticians draw on both existing criteria and research, and by producing the autistic subject through the clinic, frame and shape a contemporary version of autistic behaviour.





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## Appendices



## Appendix 1: Selected Diagnostic and Screening Tools for Autism

Tool	Type	Age range	Number of items and ratings	Reference	Details and notes
<b>DIAGNOSIS BY DIRECT BEHAVIOURAL OBSERVATION</b>					
<b>ADOS, ADOS-2, ADOS-G (Generic), ADOS-T (Toddler Module)</b> Autism Diagnostic Observation Schedule	Clinician administered direct observation tool (observation via interaction)	Children and adults (≥ 12 months)	Five modules of between 29 and 34 items each, tailored to individual language and cognitive development (Toddler module 11 items).  Ratings between 0 (no evidence of abnormality related to autism) and 3 (definite evidence)	(Lord et al., 2000)	ADOS-G included in NICE guidelines as a tool for adults who do or do not have a learning disability; and for adults for whom a more complex assessment is required.  Considered the 'gold standard' of ASD assessment but training is not free.  Standardised play and communication sessions are administered and observed.
<b>ASD-OC</b> The Autism Spectrum Disorder – Observation for Children	Clinician administered direct observation tool	1 – 15 years	45 items	(Neal et al., 2012)	
<b>BOS</b> The Behaviour Observation Scale for Autism	Clinician administered direct observation tool	23 – 65 months	67 items	(Freeman et al., 1978)	
<b>DIAGNOSTIC INTERVIEW WITH PARENT OR CARER</b>					
<b>3Di, 3Di-sv (short version)</b> The Developmental, Dimensional, and Diagnostic Interview	Computer operated clinician administered parent/caregiver interview	>2 years through to adulthood	740 items (183 on demography, family background, developmental history, motor skills; 266 on autistic disorders; 291 on mental states relevant to other diagnoses)	(Skuse et al., 2004)	Produces computer-generated report containing detailed quantified symptom profiles (Skuse, 2004)

			53 item computer assisted interview		
<b>ABI</b> The Autistic Behaviour Interview	Clinician administered interview with parent/carer	Parent/carer	18 subscales each with 168 items	(Cohen et al., 1993)	
<b>ADI-R</b> The Autism Diagnostic Interview - Revised	Clinician administered parent/caregiver semi-structured interview	≥2 years (mental age)  Children and adults	93 items, two-three hours to complete	(Le Couteur et al., 2003)	Included in NICE guidelines as a tool for adults who do or do not have a learning disability; and for adults for whom a more complex assessment is required
<b>ASD-DA</b> The Autism Spectrum Disorder - Diagnosis Scale for Intellectually Disabled Adults	Clinician administered structured interview with care staff working with individual for ≥6 months	≥16 years	31 items	(Matson et al., 2008)	
<b>ASDI</b> The Asperger Syndrome Diagnostic Interview	Clinician administered semi-structured interview with parent/carer	6 – 55 years	20 items	(Gillberg et al., 2001)	Included in NICE guidelines a tool for adults who do not have a learning disability  Asperger syndrome specific (Falkmer et al, 2013)
<b>DISCO, DISCO-II</b> The Diagnostic Interview for Social and Communication Disorders	Clinician administered semi-structured parent/carer interview	All ages	362 items	(Leekam, 2012; Wing et al., 2002)	Included in NICE guidelines as a tool for more complex assessment for adults.  Dimensional scale
<b>DIAGNOSTIC INTERVIEW FOR ADULTS</b>					
<b>AAA</b> The Adult Asperger Assessment (includes the Autism-Spectrum	Clinician operated semi-structured interview with patient and a	≥16 years	18 plus 5 prerequisites	(Baron-Cohen et al., 2005)	Included in NICE guidelines a tool for adults who do not have a learning disability  Asperger syndrome specific

Quotient (AQ) and the Empathy Quotient (EQ)	relative or informant				
<b>TOOLS USING COMBINATION OF INTERVIEW AND OBSERVATION</b>					
<b>CARS, CARS-2</b> The Childhood Autism Rating Scale – 1 <sup>st</sup> or 2 <sup>nd</sup> edition	Clinician operated rating scale (observation) plus parent interview	≥2 years old	15 items rating scale plus parent/carer interview	(Schopler et al., 1980)	
<b>OTHER</b>					
<b>Reading the Mind in the Eyes</b>	‘Theory of mind’ test	Adult	25 photographs of eyes	(Baron-Cohen et al., 1997)	To identify subtle impairments in social intelligence in otherwise normally intelligent adults (Baron-Cohen et al., 2001a)
<b>SCREENING TOOLS</b>					
<b>Autism Behaviour Checklist (ABC)</b>	Parent/caregiver/teacher	3-14 years	57 items in yes/no format	(Krug et al., 2008)	
<b>ASDS</b> Asperger Syndrome Diagnostic Scale	Parent/caregiver/teacher	5-18 years	50 items (10-15 minutes)	(Myles et al., 2000)	Asperger syndrome specific
<b>ASD-DC</b> Autism Spectrum Disorder – Diagnosis for Child	Caregiver	2-16 years	40 items	(Matson et al., 2009)	
<b>ASSQ-parent (teacher)</b> Autism Assessment Screening Questionnaire	Parent/carer questionnaire	7 – 16 years	27 items	(Ehlers et al., 1999)	Can also be completed by teacher
<b>AQ</b> Autism-Spectrum Quotient (child and adolescent versions)	Parent/carer questionnaire	4-11 years; 10 -16 years	50 items  Short version – 10 items	(Auyeung et al., 2008)	
<b>AQ, AQ-10</b> Autism-Spectrum Quotient	Self-report questionnaire for adults	>16 years (with average or above average intelligence)	50 items  10 items (AQ-10)	(Allison et al., 2012; Baron-Cohen et al., 2001b)	Included in NICE guidelines as a potential screening tool for adults who do not have a learning disability, prior to a comprehensive assessment (if person scores above 6; or if autism is suspected based on clinical judgement)

<b>CAST</b> Childhood autism screening test	Parent/carer questionnaire	4 – 11 years	37 items (5-10 minutes)	(Scott et al., 2002)	
<b>CHAT</b> checklist for autism in toddlers	Parent/carer questionnaire plus primary health care provider questionnaire	18 months	14 item (parent/carer) 5 item (health care provider)	(Baron-Cohen et al., 1992)	
<b>DBC-ES</b> Developmental Checklist- Early Screen	Caregiver tool	14-18 months	17 items (10 minutes)	(Gray et al., 2008)	
<b>ESAT</b> Early screening of autistic traits	Health care provider questionnaire	14 months	14 items	(Dietz et al., 2006)	Completed after parent interview
<b>ITC</b> Infant Toddler Checklist	Parent/carer questionnaire	6 – 24 months	24 items	(Wetherby et al., 2008)	
<b>GADS</b> Gilliam Asperger's disorder scale	Asperger Syndrome specific	3 – 22 years	32 items with 8 additional items for parents	(Gilliam, 2001)	For professionals and parents; to discriminate those with AS from those with autism
<b>GARS-3</b> Gilliam Autism Rating Scale	Screening tool	3-22 years	56 items	(Gilliam, 1995)	For teachers, parents and clinicians, based on DSM-5 criteria
<b>M-CHAT</b> Modified checklist for autism in toddlers	Parent/carer questionnaire	16-30 months	23 items	(Robins et al., 2014, 2001)	
<b>Q-CHAT</b> Quantitative checklist for autism in toddlers		18 – 24 months	25 items 10 items (short version)	(Allison et al., 2008)	
<b>RAADS, RAADS-R</b> The Ritvo Autism Asperger Diagnostic Scale - Revised	Self-report questionnaire for adults, completed with a clinician	>18 years (with average or above average intelligence)	80 items	(Ritvo et al., 2011)	Included in NICE guidelines as a tool for adults who do not have a learning disability

<b>SCQ</b> Social Communication Questionnaire	Parent/carer questionnaire	>4 years (and mental age >2 years)	40 items	(Rutter et al., 2003)	
<b>SRS, SRS-2</b> Social Responsiveness Scale	Parent/carer report questionnaire Or self-report version for adults	>2-5 years (plus adult version)	65 items	(Constantino and Gruber, 2012)	Can also be completed by teacher, relative or friend.
<b>STAT</b> Screening tool for autism in 2 year olds	Clinician administered level two screening tool	24 – 36 months	12 items and activities involve child interaction (20 minutes)	(Stone et al., 2008)	Level two screening measure

\*Studies including children with all ages and abilities, for diagnosis/identification of autism or ASD, from NICE Guidelines (2011)

**Source:** Vllasaliu et al., 2016; Lai, Lombardo, & Baron-Cohen, 2014; Falkmer, Anderson, Falkmer, & Horlin, 2013; NICE, 2011; NICE, 2012; Maljaars, Noens, Scholte, & Berckelaer-Onnes, 2011

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With additional information from:

<http://www.autism.org.uk/about/diagnosis/criteria-changes.aspx>

<http://researchautism.net/glossary/832/diagnostic-tools;>

<https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildAutisticSpectrumDisorders/gars3/gilliam-autism-rating-scale-third-edition.aspx>

[https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildAutisticSpectrumDisorders/GilliamAspergersDisorderScale\(GADS\)/GilliamAspergersDisorderScale\(GADS\).aspx](https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildAutisticSpectrumDisorders/GilliamAspergersDisorderScale(GADS)/GilliamAspergersDisorderScale(GADS).aspx)





## Appendix 2: Ethical Approval



### University of Exeter Medical School Research Ethics Committee

### Certificate of Ethical Approval

**Research Institute/Centre:** Institute of Health Services

**Title of Project:** Autism diagnosis as social process: an exploration of clinicians' diagnostic decision-making

**Name(s) of Project Research Team member(s):** Jonnie Hayes, Dr Ginny Russell, Prof Rose McCabe and Prof Tamsin Ford

**Project Contact Point:** Jennie Hayes

**This project has been approved for the period**

**From:** March 2017

**To:** October 2019

**University of Exeter Medical School**

**Research Ethics Committee approval reference:** Mar17/B/114

**Signature:**

A handwritten signature in black ink that reads "R Garside".

**Date:** 24 March 2017

**Name of Chair**

**Ruth Garside, PhD**

Your attention is drawn to 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 17-02114



## Health Research Authority

Ms Jennie Hayes  
PhD Student  
University of Exeter  
Room 1.23, College House  
St Luke's Campus, University of Exeter  
Magdalen Road, Exeter  
EX1 2LU

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

19 July 2017

Dear Ms Hayes,

### Letter of HRA Approval

**Study title:** Autism diagnosis as social process: an exploration of clinicians' diagnostic decision-making  
**IRAS project ID:** 220180  
**Protocol number:** 1617/19  
**Sponsor:** University of Exeter

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

## Appendix 3: Participant Information Sheets



### **AUTISM DIAGNOSIS AS SOCIAL PROCESS: AN EXPLORATION OF CLINICIANS' DIAGNOSTIC DECISION-MAKING**

#### **INFORMATION SHEET FOR PARTICIPANTS: INTERVIEWS**

**VERSION NUMBER 2 (14/03/2017)**

We would like to invite you to take part in a research study. Please read this information sheet which tells you about the study and take time to decide whether or not to take part.

#### **What is the aim of the project?**

The aim of the project is to explore the key issues for healthcare professionals in diagnostic decision-making around Autism Spectrum Disorders (ASD). We are interested in healthcare professionals' beliefs, practices and decision-making processes when undertaking ASD assessments in secondary care. We would like to conduct interviews so that we can consider how healthcare professionals work in practice to pragmatically achieve best end results for children and adults on the autism spectrum with a view to offering our findings regarding best practice to be considered as part of a NICE guidelines review.

#### **Description of participants required**

We are interested in interviewing healthcare professionals who are involved in contributing to diagnosis of autism spectrum disorders, with either children or adults, in any way, in secondary care, throughout the UK. We are seeking to gather the views of people with different roles in ASD diagnosis, and want to make sure we have a range of perspectives.

#### **What will participants be asked to do?**

Should you agree to take part in this project you will be asked to attend an interview with the lead researcher or, depending on your location, be interviewed by telephone. The interview can take place in your place of work if you have somewhere quiet we can meet, and at a time convenient to you. The interview will take no longer than one hour.

#### **What data will be collected and what use will be made of it?**

This study involves an open-questioning technique where the precise nature of the questions asked have not been determined in advance, but will depend on the way in which the interview develops. Consequently, although the Medical School 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.

In the event that the line of questioning does develop in such a way that you feel uncomfortable, you may decline to answer any particular question(s). You can also withdraw from the study at any stage for any reason, without any disadvantage to yourself of any kind.

Interviews will be audio recorded, transcribed and analysed for themes.

#### **Will the data collected be confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential and be held in accordance with the Data Protection Act 1998. Your name and personal details will be removed from the data so that you cannot be recognised from it. If you discuss any patient cases in interview this information will also be anonymised.

All electronic data including audio recordings and transcripts will be stored on a password protected University of Exeter laptop with access to the files restricted to the research team. All personal information will be stored separately from the interview data. Files will be backed up on a secure, encrypted server and a password protected external hard drive. After the project is finished, in accordance with the University of Exeter recommendations, the anonymised data will be held and stored in an electronic database. The anonymised data may be analysed by other researchers as required by the funder.

Results of this project may be published but any data included will not be individually identifiable. If you wish, you will be sent copies of any publications resulting from research.

#### **What are the possible disadvantages and benefits of taking part?**

You will not be exposed to any hazards or risks by taking part in this study. By taking part in interview you will have the opportunity to reflect on your own beliefs, practices and experiences as an expert clinician, share your views with others through publication and ultimately contribute to best end-results for children and adults on the autism spectrum.

#### **What will happen to the results of the research study?**

The results of the study will form part of a broader PhD project. The resulting thesis will be openly available upon completion. The results of this study will be written up in an academic paper and submitted to a journal as well as presented at conferences and other research events. If you wish you will be provided with copies of any publications resulting from the research. Please be assured that you, or any patient cases you discuss in interview, will not be identified in any report or publication.

#### **Who is organising and funding this research?**

The research is coordinated at the Mental Health Research Group at the University of Exeter. Jennie Hayes, who is a PhD student at the University of Exeter, will be leading the study. Dr Ginny Russell, Senior Research Fellow in Mental Health and Developmental Disorders has overall responsibility for the study. The project is supervised by Dr Russell, Professor Rose McCabe, Professor of Clinical Communication and Professor Tamsin Ford, Professor of Child and Adolescent Psychiatry.

The project is being undertaken as part of the requirements for a PhD in Medical Studies at the University of Exeter. The study is funded by the Wellcome Trust.

#### **What happens if you would like more information about the study?**

If you have any questions, either now or in the future, please contact either:

**Jennie Hayes:** [Jennie.Hayes@exeter.ac.uk](mailto:Jennie.Hayes@exeter.ac.uk); 01392 726013

**Dr Ginny Russell:** [G.Russell@exeter.ac.uk](mailto:G.Russell@exeter.ac.uk); 01392 726015

#### **Complaints**

If you have any complaints about the way in which this study has been carried out please contact the Chair of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD  
Chair of the UEMS Research Ethics Committee  
Email: [uemsethics@exeter.ac.uk](mailto:uemsethics@exeter.ac.uk)

**This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee**

**UEMS REC REFERENCE NUMBER:** Mar17/B/114  
**IRAS Project ID:** 220180

**AUTISM DIAGNOSIS AS SOCIAL PROCESS:  
AN EXPLORATION OF CLINICIANS' DIAGNOSTIC DECISION-MAKING**

**INFORMATION SHEET FOR PARTICIPANTS: OBSERVATION OF MDT MEETINGS**

VERSION NUMBER 2 (14/03/2017)

We would like to invite you to take part in a research study. Please read this information sheet which tells you about the study and take time to decide whether or not to take part.

**What is the aim of the project?**

The aim of the project is to explore decision-making processes in diagnosing Autism Spectrum Disorders (ASD) in secondary care by observing the decision-making process in MDT meetings. It will enable exploration of how healthcare professionals work together to come to a consensus; to what extent institutional, social or psychological factors influence diagnosis and what they are; and how different voices, processes or influences are 'weighted' in decision-making. The observation will also enable an exploration of how guidelines and diagnostic tools are used in practice as a framework for diagnosis.

**Description of participants required**

We are interested in observing MDT meetings involved in the diagnosis of autism spectrum disorders, with either children or adults, in England.

**What will participants be asked to do?**

Should you agree to take part in this project we will require permission to video record up to five consecutive MDT meetings. Meeting attendees will be required to give demographic information (name, job title, role, number of years in practice and gender). We will not require access to patients or patient information and all references to identifying information of patients discussed in the meetings will be removed. We will require basic non-identifying demographic information of patients who are discussed at the MDT meeting (age, ethnic group, gender).

**What data will be collected and what use will be made of it?**

The meetings will be video recorded, uploaded to computer and transcribed by the lead researcher. Video recording equipment will be unobtrusive. The recordings will be analysed to explore decision-making processes of healthcare professionals within the teams.

**Will the data collected be confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential and be held in accordance with the Data Protection Act 1998. Your name and personal details will be removed from the data so that you cannot be recognised from it. Data related to the discussion of patients within the meeting will be anonymised. If video material is presented at conferences or seminars, data will be anonymised by blurring faces, distorting voices and deleting identifying patient data. Only short extracts will be used.

All electronic data including audio recordings and transcripts will be stored on a password protected University of Exeter laptop with access to the files restricted to the research team. All personal information will be stored separately from the data. Files will be backed up on a secure, encrypted server and a password protected external hard drive. After the project is finished, in accordance with the University of

Exeter recommendations, the anonymised data will be held and stored in an electronic database. The anonymised data may be analysed by other researchers as required by the funder.

Results of this project may be published but any data included will not be individually identifiable. If you wish, you will be sent copies of any publications resulting from research.

### **What are the possible disadvantages and benefits of taking part?**

You will not be exposed to any hazards or risks by taking part in this study. By taking part in the project you will have the opportunity to reflect on your own beliefs, practices and experiences as an expert clinician, share your views with others through publication and ultimately contribute to best end-results for children and adults on the autism spectrum.

### **What will happen to the results of the research study?**

The results of the study will form part of a broader PhD project. The resulting thesis will be openly available upon completion. The results of this study will be written up in an academic paper and submitted to a journal as well as presented at conferences and other research events. Please be assured that you, or any patient cases you discuss in the meeting, will not be identified in any report or publication.

### **Who is organising and funding this research?**

The research is coordinated at the Mental Health Research Group at the University of Exeter. Jennie Hayes, who is a PhD student at the University of Exeter, will be leading the study. Dr Ginny Russell, Senior Research Fellow in Mental Health and Developmental Disorders has overall responsibility for the study. The project is supervised by Dr Russell, Professor Rose McCabe, Professor of Clinical Communication and Professor Tamsin Ford, Professor of Child and Adolescent Psychiatry

The project is being undertaken as part of the requirements for a PhD in Medical Studies at the University of Exeter and is funded by the Wellcome Trust and the University of Exeter.

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Dr Ginny Russell: [G.Russell@exeter.ac.uk](mailto:G.Russell@exeter.ac.uk); 01392 726015

### **Complaints**

If you have any complaints about the way in which this study has been carried out please contact the Chair of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD  
Chair of the UEMS Research Ethics Committee  
Email: [uemsethics@exeter.ac.uk](mailto:uemsethics@exeter.ac.uk)

**This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee**

**UEMS REC REFERENCE NUMBER:** Mar17/B/114  
**IRAS Project ID:** 220180

## Appendix 4: Participant Consent Forms



### PARTICIPANT CONSENT FORM (Clinician Interviews)

#### AUTISM DIAGNOSIS AS SOCIAL PROCESS: AN EXPLORATION OF CLINICIANS' DIAGNOSTIC DECISION-MAKING

#### CONSENT FORM VERSION NUMBER 2 (14/03/2017)

I have read the Information Sheet Version Number \_\_\_\_ dated \_\_\_\_ concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

**I know that:**

*please circle*

- |  |          |
|--|----------|
| 1. My participation in the project is entirely voluntary   | Yes / No |
| 2. I am free to withdraw from the project at any time without disadvantage   | Yes / No |
| 3. The interview will be audio recorded and extracts from the transcripts of the audio recording may be published. My anonymity will be preserved. | Yes / No |
| 4. Data (audio recordings) will be retained in secure storage for 5 years in accordance with University of Exeter Data Protection Policy           | Yes / No |
| 5. The interview will take the form of an open questioning technique   | Yes / No |
| 6. After the project is finished, the anonymised data will be stored in a repository and may be analysed by other researchers                      | Yes / No |

**I agree to take part in this project.**

\_\_\_\_\_  
Name of Participant (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee**

**UEMS REC REFERENCE NUMBER:** Mar17/B/114

**IRAS Project ID:** 220180

**PARTICIPANT CONSENT FORM (Meeting Observation)**

**AUTISM DIAGNOSIS AS SOCIAL PROCESS: AN EXPLORATION OF CLINICIANS' DIAGNOSTIC DECISION-MAKING**

**CONSENT FORM**

VERSION NUMBER 2 (14/03/2017)

I have read the Information Sheet Version Number \_\_\_ dated \_\_\_ concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

**I know that:**

*please circle*

- |  |          |
|--|----------|
| 1. My participation in the project is entirely voluntary   | Yes / No |
| 2. I am free to withdraw from the project at any time without disadvantage   | Yes / No |
| 3. The MDT meetings I take part in will be video-recorded and extracts from the resulting transcripts of the video recording may be published. | Yes / No |
| 4. My anonymity and that of my patients will be preserved  | Yes / No |
| 5. Data (video recordings) will be retained in secure storage for 5 years in accordance with University of Exeter Data Protection Policy       | Yes / No |
| 6. After the project is finished, the anonymised data will be stored in a repository and may be analysed by other researchers                  | Yes / No |

**I agree to take part in this project.**

\_\_\_\_\_  
Name of Participant (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher (printed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee.**

UEMS REC REFERENCE NUMBER: Mar17/B/114

IRAS Project ID: 220180



**Appendix 5: Meeting Attendance Sheet**

**AUTISM DIAGNOSIS AS SOCIAL PROCESS:  
AN EXPLORATION OF CLINICIANS' DIAGNOSTIC DECISION-MAKING**

**ATTENDANCE SHEET**

IRAS Project ID: 220180

*Please complete for researcher records, thank you.*

Name

Job title

---

Meeting date:

Meeting venue:

Meeting ID Number:



**Appendix 6: Patient Data Form**

**AUTISM DIAGNOSIS AS SOCIAL PROCESS:  
AN EXPLORATION OF CLINICIANS' DIAGNOSTIC DECISION-MAKING**

**PATIENT DEMOGRAPHIC SHEET**

VERSION NUMBER 1 (23/03/2017)

IRAS Project ID: 220180

Meeting date:

Meeting venue:

Meeting ID Number:

(for researcher use only)

Patient ID Number		Age of patient	Sex	Pseudonym (if given)

REFERENCE NUMBER: Mar17/B/114

IRAS Project ID:



## Appendix 7: Observation Strategy for Meetings

### Observation Strategy for MDT Assessment Meetings

VERSION NUMBER 1 (23/03/2017)

**Purpose:** Observation of MDT meetings will provide data on how a diagnosis is formulated and inter-clinician decision-making processes. It will record the narrative that is created and built upon during meetings leading towards the diagnostic decision. It will enable exploration of how clinicians work together to come to a consensus; to what extent they draw on social factors and what they are; and how different voices, processes or influences are 'weighted' in relation to decision-making. The observation will enable a comparison to be made between what happens in clinical practice in relation to guidelines and policy frameworks explored in study one.

**Method:** observe at least 20 MDT autism assessment meetings in at least four different settings (up to five consecutive meetings in at least two adult and two children's assessment settings). The number of patients discussed at each meeting varies, but this number should allow data related to at least 50 patients. Meetings will be recorded on video, or on audio recorders if consent is declined, and the resulting audio will be transcribed and analysed using conversation analysis, enabling subtle and detailed exploration of how diagnostic discussion evolves through interaction and taking account of both verbal and non-verbal communication. Follow up discussions with clinicians involved will, where possible, explore the trajectory of particular cases raised in MDT meetings and elicit clinicians' perspectives around the social/psychological and institutional influences on decision-making, enabling detailed exploration of the mechanisms behind decision-making with those taking part.

**Outcome:** The study will be written up as a paper for publication.

1. **Pre-recording:** contact will be made and a main contact established. Consent will be sought. Researcher will provide information sheet explaining right to withdraw, confidentiality and video recording. Main contact will seek agreement from MDT.
2. **Introductory meeting:** prior to the study beginning, the researcher will attend an MDT meeting to introduce herself and the study and allow members to raise concerns and ask questions before the observations begin. Information sheets will be provided and consent forms signed.
3. **Subsequent meetings:** a laminated information sheet will be left when video recorders are set up to explain that the session is being recorded and why. An attendance sheet will be passed round for completion to aid transcription. Demographics sheet (name, job title, clinical role in meeting, other role in meeting, number of years in practice and gender) and consent forms will be available in advance of subsequent meetings for any participating health professionals who did not attend introductory meeting. The researcher will be present at some meetings, with consent, to enable a richer understanding of the resulting data.
4. **Transcription and analysis:** transcription with Jeffersonian notation (Heritage and Frankel, 2005) and analysed using conversation analysis
5. **Particular observations** will be noted around: use of diagnostic tools and guidelines; how consensus is reached; what determines resolution; discussion of social factors and influences; views of the patient/parent/carer; weight of different voices/roles; meeting structure; points of agreement/disagreement.



## Appendix 8: Characteristics of All Patient Cases

Case No	Age	Sex	Referred by	Informant	Patient/family desire	Tests done	ADOS result	Outcome	Next steps
<b>Adult Team 1</b>									
1	36-50	Male	GP	Informant to be sought (mother)	Ambivalent	Screeners, ADOS, Reading the mind with the eyes	Under threshold	In process	Get informant (mum)
2	51-60	Male	GP	Father; Wife	Ambivalent	ADOS, dev interview, plus others	Under threshold	Diagnosed ASC	Feedback meeting
3	61-70	Male	GP	No informant	Yes (patient)	ADOS, dev interview, plus others	Meets threshold	In process	Get informant and do second assessment
4	61-70	Female	Community mental health team	No informant but will talk to Support Worker	Yes (patient)	ADOS plus dev interview	Too difficult to score	In process	Extended clinician interview, info from mental health team/social worker
5	36-50	Male	Liaison and Diversion Team	Carer	Not discussed	ADOS plus dev interview	Meets threshold	In process	Further appointment and talk to social worker
6	26-35	Male	GP	Wife	Patient ambivalent, wife wants dx	ADOS, dev interview, plus others	Under threshold	In process	Further tests
7	36-50	Female	GP	Friend	Yes	ADOS plus 3DI	Under threshold	In process	Get informant/tests
8	26-35	Female	GP	Mother	Ambivalent	ADOS, dev interview, plus others	Meets threshold	In process	Further tests
9	51-60	Male	GP	Informant to be sought (parents)	Knows he is autistic and ambivalent about dx	ADOS	Under threshold	In process	Get informant/tests (extended interview, further test, talk to parents)

10	61-70	Male	GP	Wife	Yes, knows he is autistic. Be disappointed if not diagnosed	None yet	Not Applicable	In process	Further tests (ADOS next) plus talk further to informant
11	18-25	Female	GP	Mother	Mother does, patient wants answers	ADOS plus ADI	Under threshold	In process	Get information from other professionals (CAMHS and GP)
<b>Adult Team 2</b>									
12	26-35	Female	Not discussed	Not discussed	Yes	ADOS plus dev interview	Meets threshold (assumed - not discussed)	Diagnosed ASC	Feedback meeting
13	36-50	Female	Not discussed	Not discussed	Patient will agree with diagnosis, thinks she has autism	ADOS plus dev interview	Under threshold	Diagnosed ASC	Feedback meeting and post diagnostic group
14	18-25	Male	Not discussed	Father	Father driving diagnosis due to patient's problem behaviour	Screeners, ADOS plus clinical interview	Too difficult to score	Not diagnosed	Refer onwards
15	51-60	Female	Not discussed	Not discussed	Not discussed	ADOS plus dev interview (assumed)	Meets threshold (assumed - not discussed)	Diagnosed ASC	Feedback meeting
16	18-25	Female	Not discussed	Parents	Not discussed	ADOS plus 3DI	Meets threshold	Diagnosed ASC	Feedback meeting and post diagnostic group
17	26-35	Male	Mental Health Professional	No informant but brother involved in referral	Not discussed	ADOS	Under threshold	In process	See doctor (for clinical interview)
18	26-35	Male	Primary Care Liaison	Not discussed	Not discussed	Other dev interview	ADOS not completed	Psychotic can't assess	Refer back to Primary Care Liaison



19	26-35	Female	Not discussed	Not known	Ambivalent	ADOS plus 3DI	Under threshold	Not diagnosed	Feedback meeting
20	36-50	Female	Not discussed	Not discussed	Wants to come for assessment	Other developmental interview	Not yet done	In process	Further tests (ADOS next)
21	36-50	Female	ADHD team	No informant	Ambivalent	Screeners, ADOS plus clinical interview	Under threshold	Not diagnosed	Refer onwards
22	36-50	Female	GP	Daughter	Ambivalent	ADOS plus dev interview	Meets threshold	Diagnosed ASC	Outcome and offer group and reasonable adjustments
23	26-35	Female	Not discussed	Father	Yes	ADOS	Meets threshold	In process	Further tests (psychiatrist to see)
24	36-50	Female	Not discussed	Not discussed	Not discussed	Other dev interview	Not yet done	In process	Further tests (ADOS next)
25	26-35	Male	Not discussed	Not discussed	Not discussed	Screeener	Under threshold	Not diagnosed	Refer onwards (ADHD assessment)
26	26-35	Male	Not discussed	Not discussed	Not discussed	ADOS plus dev interview	Meets threshold	Diagnosed ASC	Feedback and reasonable adjustments
27	18-25	Female	Not discussed	Not discussed	Not discussed	Other dev interview	Not yet done	In process	Further tests (ADOS next)
<b>C&amp;YP Team 1</b>									
28	5-10	Female	Not discussed	Mum	Yes	ADOS, 3DI plus others	Under threshold	Not diagnosed	Specialist tests then parental support
29	14-18	Transgender	Not discussed	Not discussed	Yes	ADOS plus dev interview	Meets threshold	In process	Review potential diagnosis with doctor
30	14-18	Male	Other agency	Mum	Not discussed	Other dev interview	Not yet done	In process	Check consent, safeguarding and then 3di
31	14-18	Female	Not discussed	Not discussed	Not discussed	ADOS	Meets threshold	Watch and wait	CAMHS
32	14-18	Male	Not discussed	Not discussed	Doesn't want language disorder	Not discussed	Under threshold	Not diagnosed	Negotiate outcome with family

33	5-10	Male	Paediatrics	Mother	Yes, mother pushing for assessment	Other dev interview	ADOS not completed	In process	Further tests (ADOS next)
34	14-18	Female	GP	Parents	Patient implied (keen to see us)	ADOS plus dev interview	Not discussed	Diagnosed ASC	Feedback meeting
35	5-10	Male	Not discussed	Not discussed	Not discussed	Other dev interview	Not yet done	In process	Further tests (ADOS next)
36	14-18	Male	Not discussed	Parents	Patient relates to autism and wants to know	ADOS plus dev interview	Meets threshold	Diagnosed ASC	Feedback and offer patient choice
37	11-13	Male	Parent adviser	Mother	Mum thinks autism, dad does not	ADOS plus dev interview	Meets threshold	Diagnosed ASC	Feedback and consider educational support
38	5-10	Male	Not discussed	Parents	Not discussed	ADOS plus 3DI	Meets threshold	Diagnosed ASC	Feedback
39	5-10	Female	Not discussed	Not discussed	Not discussed	ADOS, 3DI plus others	Meets threshold	In process	Get tests/info (awaiting paed report)
40	5-10	Female	Not discussed	Mother	Not discussed (mother under-reports)	ADOS plus 3DI	Meets threshold	Diagnosed ASC	Complete
41	11-13	Female	Not discussed	Parents	Not discussed	ADOS plus 3DI	Meets threshold	Diagnosed ASC	Complete
42	5-10	Male	Not discussed	Mother	Not discussed	ADOS plus 3DI	Meets threshold	Diagnosed ASC	Not discussed
43	5-10	Male	Not discussed	Mother	Not discussed	Screeener, ADOS, paediatric and educational reports	Meets threshold	In process autism and/or attachment	Take to bigger MDT
44	5-10	Male	Not discussed	Parents	Not discussed (parents underplay difficulties)	Screeener, ADOS, 3di	Meets threshold	Diagnosed ASC	Report + enhanced transition
45	14-18	Male	Not discussed	Mother	Yes	ADOS plus dev interview	Not discussed	In process	Take to wider MDT
46	14-18	Female	Not discussed	Parents	Yes, implied both mother and child	Screeener	Not Applicable	In process	Book for assessment

47	5-10	Male	Special Educational Needs Coordinator	Parents	Not discussed	ADOS, 3DI plus others	Meets threshold	Diagnosed ASC	Feedback
<b>C&amp;YP Team 2 (primarily 14+)</b>									
48	14-18	Female	Mental Health Professional	Mother	Not discussed	Screeener, ADOS, 3di	Meets threshold (assumed - not yet scored up)	Diagnosed ASC	Feedback + psychiatric review + talk to school
49	5-10	Male	CAMHS worker	Mum	Not discussed	ADOS plus 3DI	Meets threshold (assumed - not yet scored up)	Diagnosed ASC	Feedback and post diagnostic group
50	14-18	Female	Eating disorder clinic	Parents	Yes, all think she is autistic	ADOS plus 3DI	Under threshold	Diagnosed ASC	Feedback and post diagnostic group
51	14-18	Female	Adolescent mental health team	Mum	Not discussed	ADOS plus dev interview	Meets threshold	Diagnosed ASC	Feedback plus formulation (also diagnosed anxiety & LD)

Code: ASC (Autism Spectrum Condition); CAMHS (Child and Adolescent Mental Health Services); LD (Learning Disability); ADOS (Autism Diagnostic Observation Schedule); 3Di (The Developmental, Dimensional and Diagnostic Interview); MDT (Multi-Disciplinary); Screeener (any screening tool)



## Appendix 9: Interview Topic Guide

### Interview strategy and Topic Guide

Version number 3 (10/07/2018)

**Research Question:** What are the social factors that drive diagnostic practice?

**Overview:** follow up interviews with clinicians involved in MDT meetings will, where possible, explore the trajectory of particular cases raised in MDT meetings and elicit clinicians' perspectives around specific influences on decision-making, drawn from the MDT data, enabling detailed exploration of the mechanisms behind decision-making with those taking part.

**Sampling:** interviews will be conducted with HCPs involved in the MDTs observed, between 15 and 20 interviews.

**Method:** A semi-structured approach will be used and the order of questions may vary depending on the progress of the interview. The first two parts of the interview comprise a series of questions. Part three of the interview will draw from a case which has been discussed at a team meeting (tape assisted recall). Where possible, a transcript of the meeting will be available, along with the audio recording. This case will be selected on the basis of an emerging social factor drawn from the data (e.g. parental/informant/patient desire driving process; need/functionalist approach or clinical approach; masking of symptoms/insight or performing autism). Where possible, extracts from the audio recording and/or transcript will be used as prompts during the interview. Where this is not possible, cases will be discussed as examples without prompts.

**Analysis:** Interviews will be audiotaped, transcribed and analysed with thematic analysis. This will enable broad themes to be summarized from the data suited to informing policy development (Braun and Clarke, 2006b). The questions below will function as prompts for interview. Follow up questions and discussion will arise from the individual interview and may vary or develop in different directions.

**Outcome:** The study will be written up as a paper for submission to publication.

**Proposed structure of interview** (see table below for prompts)

- Introduction and consent
- Part one: the diagnostic process.
- Part two: diagnostic tools and guidelines
- Part three: case discussion
- Thank you and debrief

## **Interview schedule**

**Background and administrative items:** interviewer explains purpose and context of interview, length and structure, right to withdraw, confidentiality and audio recording. Participant completes consent form and demographic info.

### **Part one: the diagnostic process (10 mins approx)**

1. To start with, can you talk about the different things you take into account during diagnosis?
2. How does the MDT meeting contribute to dx process?
3. How do different roles in meetings contribute to negotiating the diagnostic decision?
4. How do factors outside your control impact on dx: EG SES, clinician availability, resources, govt spending etc, waiting lists?
5. How do you deal with that intersection between the social/environmental/biological/behavioural aspects of autism?

### **Part two: using diagnostic tools and guidelines (5 mins approx)**

1. How do you use clinical guidelines? (and which ones) ICD/DSM etc and or NICE etc.
2. How do you use diagnostic instruments (and which ones?)
3. How do they contribute to dx process?

### **Part three: case discussion drawing from MDT data – tape/transcription assisted recall (20 mins approx)**

1. Can you tell me a bit about NAME?
2. Can you tell me where they were referred from?
3. Do you know the background to them seeking a diagnosis?
4. Specific questions to prompt based on the data extract
5. Is there anything you'd like to add?

**Debrief:** Interviewer will bring the interview to a close, thank participants for their involvement, describe next steps for research project and how they can keep in touch.

UEMS REC REFERENCE NUMBER: Mar17/B/114

IRAS Project ID: 220180

## **Appendix 10: Guidelines Review Data Extraction Framework**

### **SECTION A: document characteristics**

- A1 Name of document
- A2 Author
- A3 Year of publication
- A4 Journal title/publisher
- A5 Geographical remit
- A6 Type of document (practice parameter, clinical guideline etc.)
- A7 Status of document (statutory/guidance only etc.)
- A8 Who is the guidelines target audience?
- A9 What age range (of patients) does the document encompass?
- A10 Range of diagnoses covered by document
- A11 Legal Framework on which guidance is based?

### **SECTION B: Pre-diagnosis and context for diagnosis**

#### **DO THE GUIDELINES OFFER RECOMMENDATIONS RELATED TO THE FOLLOWING?**

- B1 Who can refer to autism team?
- B2 Which professionals can provide a diagnosis?
- B3 What training or experience of clinicians is required to diagnose?
- B6 Is there a stated or recommended age at which symptoms can be assessed/recognised?
- B4 Is there a targeted waiting time from referral to diagnosis?
- B5 Is there guidance about how to achieve any targeted waiting times?
- B6 Is there additional guidance about how to deal with numbers of patients waiting and throughput?





## Appendix 11: Clinical Guidelines Characteristics

Title	Year	Author	Publisher/ Journal	Geographical remit	Target audience	Age range	Range of diagnoses covered	Diagnostic criteria referred to	Age at which symptoms are recognised
<b>DIAGNOSTIC CRITERIA</b>									
<b>The ICD-10 Classification of Mental and Behavioural Disorders: clinical descriptions and diagnostic guidelines</b>	1993	N/A	World Health Organisation	International	Clinical, educational and service use	All ages	Pervasive development disorders	N/A	Before age of 3 years (childhood autism); after age 3 (atypical autism).
<b>Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition)</b>	2013	N/A	American Psychiatric Association	International	Clinicians, students, practitioners, researchers	All ages	Autism Spectrum Disorder	N/A	During 2nd year of life (12-24 months) or earlier than 12 months if developmental delays are severe
<b>NATIONAL CLINICAL GUIDELINES</b>									
<b>NICE Autism in under 19s: recognition, referral and diagnosis (NICE CG128)</b>	2011	National Collaborating Centre for Women's and Children's Health	National Institute for Health and Care Excellence (NICE)	England and Wales	Healthcare professionals	From birth up to 19 years	Pervasive developmental disorder (PDD)	ICD-10 or DSM-IV	May be uncertainty before 24 months, or with developmental age of less than 18 months
<b>Six Steps of Autism Care for children and young people in</b>	2011	Regional Autistic Disorder	Health and Social Care Board	Northern Ireland	Health care and education professionals,	Up to the age of 18 years	Autism spectrum disorder	ICD-10, DSM-IV, NICE, SIGN, NZ Guidelines, NHS	Pre-school. Language delay by the age of two years.

<b>Northern Ireland (RASDN)</b>		Network for Northern Ireland			parents, carers, service users and providers.			Map of Medicine	
<b>Autism Spectrum Disorder in adults: diagnosis and management (NICE CG142)</b>	2012	National Collaborating Centre for Mental Health	National Institute for Health and Care Excellence (NICE)	England and Wales	Health and social care providers and commissioners	Adults aged 18 and over	Autism spectrum disorders	N/S *ICD-10 specified in full version of CG142	N/A
<b>Autism Adult Care Pathway (RASDN)</b>	2013	Regional Autistic Spectrum Disorder Network	Health and Social Care Board	Northern Ireland	Professionals, adults and families	Adults from age 18	Autism spectrum disorders	DSM-5 and ICD-10, NICE guidance CG142.	N/S
<b>Assessment, diagnosis and interventions for autism spectrum disorders: A national clinical guideline (SIGN 145)</b>	2016	N/A	Scottish Intercollegiate Guidelines Network	Scotland	Healthcare professionals	Whole age range	Autism spectrum disorder	ICD-10 and DSM-5	Autism can be reliably diagnosed between the ages of 2–3.
<b>GUIDELINES FROM PROFESSIONAL BODIES</b>									
<b>RCSLT (Royal College of Speech and Language Therapists Clinical Guidelines (autism))</b>	2005	N/A	Royal College of Speech and Language Therapists	UK	Speech and language therapists	Children and adults	Autism spectrum disorder	ICIDH-2 ( <i>for general clinical assessment</i> )	N/S

<b>Good practice in the management of autism (including Asperger syndrome) in adults (RCPsych CR191)</b>	2014	Royal College of Psychiatrists	Royal College of Psychiatrists	UK	Psychiatrists working with adults of at least normal intellectual ability	Adults from age 18	Autism	ICD-10, DSM-5, NICE, 2012.	N/S
<b>Autism Spectrum Disorders: Guidance for Psychologists (BPS)</b>	2016	Stuart-Hamilton, Dillenburger, Hood & Austin	British Psychological Society	UK	Psychologists	All ages	Autism Spectrum Disorder	ICD-10 and DSM-5, NICE, 2011.	Both diagnostic manuals consider ASD indicators to be present by the age of 36 months although some children can be identified under the age of 24 months.
<b>BMJ Best Practice online resource</b>	2017	Parr & Woodbury-Smith	British Medical Journal	Outside US and Canada	Medical Practitioners	All ages	Autism Spectrum Disorder	DSM-IV, DSM-5 & ICD-10. NICE, SIGN, AACAP, AAP, NZ ASD guideline, AAN	More than 80% of children with ASD show clear behavioural signs by the age of 24 months, some indicators in 12-18 months
<b>JOURNAL ARTICLES</b>									
<b>Diagnosis and management of autism in childhood</b>	2011	Blenner, Reddy & Augustyn	British Medical Journal	N/S	General clinicians	Children	Autism Spectrum Disorder	DSM-IV TR or ICD-10	N/S
<b>Diagnosis and assessment in autism spectrum disorders</b>	2012	Carpenter	Advances in Mental Health and Intellectual disabilities	N/S	Those designing and providing diagnostic services	All ages	Autism Spectrum Disorder	DSM-IV TR or ICD-10. Gillberg's for AS.	N/S

<b>Autism spectrum disorder in adults: clinical features and the role of the psychiatrist</b>	2013	Garland, O'Rourke & Robertson	Advances in Psychiatric Treatment	UK	Psychiatrists	Adults	Autism Spectrum Disorders	ICD-10 and DSM-5, NICE	To satisfy ICD-10 criteria for childhood autism, impairments must manifest before the age of 3 years
<b>Recognising, referring and diagnosing autism</b>	2012	Howlett & Richman	Every Child Journal	England and Wales	Professionals working with children and young people	Children and young people	Autism	NICE	The core autism behaviours are typically present in early childhood; but features can appear different with age or change with circumstances
<b>Autism</b>	2013	Lai, Lombardo & Baron-Cohen	The Lancet	N/S	N/S	All ages	Autism or the autism spectrum	DSM-5, ICD-10	N/S
<b>Autism</b>	2009	Levy, Mandell & Schultz	The Lancet	N/S	N/S	N/S but primarily talks about children	Autism Spectrum Disorder	DSM-IV and ICD-10	Parents often aware from age 18 months, a diagnosis is often not made until 2 years after the initial expression of parental concern.
<b>Autism spectrum disorder: diagnosis and management</b>	2009	O'Hare	Archives of Disease in Childhood: Education and Practice Edition	N/S but relates primarily to SIGN guidelines	Paediatricians	Children and young people	Autism Spectrum Disorder	ICD-10 and DSM-IV, SIGN	N/S
<b>Recognition, referral, diagnosis, and management of</b>	2012	Pilling, Baron-Cohen, Megnin-	British Medical Journal	England and Wales	N/S	Adults	Autism	N/S	N/S

<b>adults with autism: summary of NICE guidance</b>		Viggars, Lee & Taylor							
<b>Autism Spectrum Disorders in childhood: a clinical update</b>	2011	Reynolds	Community Practitioner	UK	Community practitioners	Children	Autism Spectrum Disorder	ICD-10, DSM-IV	N/S
<b>The NICE guideline on recognition, referral, diagnosis and management of adults on the autism spectrum</b>	2014	Wilson, Roberts, Gillan, Ohlsen, Robertson & Zinkstok	Advances in Mental Health and Intellectual Disabilities	England and Wales	Health care professionals, service managers, service users, practitioners	All adults	Autism spectrum disorder	N/S	N/S



## Appendix 12: Key Recommendations of Clinical Guidelines

CPG	Recommended tools	MDT recommended	MDT membership	Assessment targets	Key features of assessment
<b>DIAGNOSTIC CRITERIA</b>					
<b>ICD-10</b> (1993)	N/S	N/S	N/S	N/S	Diagnose on the basis of behavioural features
<b>DSM-5</b> (2013)	No specific tool	N/S	N/S	N/S	Careful clinical history & summary of social, psychological & biological factors. Multiple sources of information: <ul style="list-style-type: none"> <li>• clinician's observations</li> <li>• caregiver history</li> <li>• self-report (where possible)</li> </ul> Clinical judgement
<b>NATIONAL CLINICAL GUIDELINES</b>					
<b>NICE CG128</b> (2011)	No specific tool recommended	Autism team members should carry out assessment (short version). A diagnosis can be made by a single experienced HCP; profile of strengths & weaknesses is essential, and requires MDT [55] (full version).	Autism team made up of Paediatrician &/or Child & Adolescent Psychiatrist, SLT, Clinical &/or Educational Psychologist & access to paediatrician/paediatric neurologist, Child & Adolescent Psychiatrist, Educational Psychologist, Clinical Psychologist, OT, if not in team. Also consider specialist health visitor	Start the autism diagnostic assessment within 3 months of referral. Follow up appointment within 6 weeks of assessment.	Seek report from the pre-school or school; gather additional health or social care information. Include in every autism diagnostic assessment: <ul style="list-style-type: none"> <li>• questions about parent/carer/child's concerns</li> <li>• details of the child's experiences of home life, education and social care</li> <li>• developmental history, focusing on developmental and behavioural features</li> <li>• assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours</li> <li>• medical history, including prenatal, perinatal and family history, and past and current health conditions</li> <li>• physical examination</li> </ul>

			or nurse, specialist teacher or social worker.		<ul style="list-style-type: none"> <li>• consideration of the differential diagnosis</li> <li>• systematic assessment for conditions that may coexist with autism</li> <li>• development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context</li> <li>• communication of assessment findings to the parent/carer/child</li> </ul>
<b>RASDN (2011)</b>	No specific tool	The use of MDT approach is necessary	Involving at least two disciplines: paediatrician; child psychiatrist; SLT, OT, clinical psychologist; specialist health visitor; mental health practitioner (CAMHS); social worker; nurse; ed. psych. teacher; other trained professionals	Referral screened within 5 days. Info provided within 4 weeks. 13 weeks to first appointment. Feedback within 4 weeks, report within 6 weeks of formulation.	<p>Step one: Initial directed conversation.</p> <p>Step two: Integrated multidisciplinary team assessment (leads to diagnosis/non-diagnosis) includes:</p> <ul style="list-style-type: none"> <li>• medical history inc: birth history, family history, &amp; general medical concerns</li> <li>• developmental history focusing on developmental &amp; behavioural concerns</li> <li>• observational assessment of the child/young person</li> <li>• further assessment/observations in another setting (school/home)</li> <li>• physical exam in some groups</li> <li>• specific assessments may be required, e.g. SLT assessment</li> <li>• educational assessment</li> </ul> <p>Step three: Integrated MDT formulation (leads to wider understanding of difficulties)</p> <p>Step four: family feedback and care planning</p>
<b>NICE CG142 (2012)</b>	<u>Identification:</u> Consider AQ-10 (without LD); Brief assessment (with LD). <u>Diagnosis and assessment:</u> AAA including AQ and EQ; ADI-R; ADOS-G; ASDI;	Comprehensive assessment should be team based (short version). At a minimum by a qualified clinician	Specialist autism team made up of: Clinical Psychologists, Nurses, OTs, Psychiatrists, Social Workers, SLTs, Support Staff	N/S	<p>During a comprehensive assessment, enquire about and assess the following:</p> <ul style="list-style-type: none"> <li>• core autism signs and symptoms that have been present in childhood and continuing into adulthood</li> <li>• early developmental history, where possible</li> <li>• behavioural problems</li> </ul>



	RAADS-R (without LD). ADOS-G; ADI-R (with LD); DISCO, ADOS-G, ADI-R	usually a clinical psychologist, psychiatrist or neurologist [62] (full version).			<ul style="list-style-type: none"> <li>• functioning at home, in education or in employment</li> <li>• past and current physical and mental disorders</li> <li>• other neurodevelopmental conditions</li> <li>• hyper- and/or hypo-sensory sensitivities and attention to detail.</li> </ul> <p>Direct observation of core autism signs and symptoms especially in social situations. Assess for possible differential diagnoses and coexisting disorders Assess risks; Develop care plan, provide health passport, consider 24 hour crisis management plan; Assess challenging behaviour Consider further investigations on individual basis</p>
<b>RASDN</b> (2013)	<p><u>Screening:</u> GADS, GARS-2, AASQ, ASAS, NAS, AQ-10</p> <p><u>History:</u> ADI-R, DISCO, ASDI, RAADS-R;</p> <p><u>Direct assessment:</u> ASIT, HSST, SSQ, <u>Observation:</u> ADOS-G</p>	Diagnosis must be team based & draw on a range of professionals.	At least two of: clinical psychology (core), psychiatry, SLT, LD/MH nursing; OT, other appropriately trained professionals.	Final report to be provided within 6 weeks of assessment.	<p>As an absolute minimum, elements 2, 3 &amp; 4 <i>must</i> be included in the assessment.</p> <ol style="list-style-type: none"> <li>1. Neurodevelopmental history, corroborated via relative/family;</li> <li>2. Direct autism specific assessment with individual;</li> <li>3. Observational recording of assessment sessions;</li> <li>4. Clinical judgement.</li> </ol> <p>May also include; standardized measure of adaptive functioning; assessment of language &amp; communication skills; functional assessment of problematic behaviour; full needs assessment</p>
<b>SIGN 145</b> (2016)	<p><u>Identification:</u> AQ-10</p> <p><u>Diagnosis and Assessment:</u> E.g. ADI-R, DISCO, 3di, CARS, CARS-2, ADOS-G. NAPC and RCPsych guides.</p>	MDT ... should be considered as the optimum approach	Experienced professionals	N/S	<ul style="list-style-type: none"> <li>• History taking (informant interview): prenatal, perinatal &amp; developmental history; description of the current problems experienced; family history; description of who is in family; coexisting conditions and differential diagnoses</li> <li>• Clinical observation/assessment (individual assessment/interview): directly observe &amp; assess the individual's social &amp; communication skills and behaviour</li> </ul>

					<ul style="list-style-type: none"> <li>• Contextual and functional information from a variety of settings and people</li> <li>• Profile of the individual's strengths and difficulties: communication, cognitive, neuropsychological and adaptive functioning; motor and sensory skills</li> <li>• Biomedical investigations on an individual basis when clinically relevant</li> <li>• Assessment of mental health needs, wellbeing and risk should be considered</li> </ul>
<b>GUIDELINES FROM PROFESSIONAL BODIES</b>					
<b>RCSLT (2005)</b>	N/S	Should always be multidisciplinary & multi-agency to achieve optimum benefit.	This may include SLT, child psychology, child psychiatry, clinical psychology, paediatrician, EdPsych., OT & teacher	N/S	<p>During assessment, consideration must be given to the triad of social impairments, as well as theories relating to the triad, for example sensory sensitivity and integration; intersubjectivity; executive functioning deficits; motivation; memory and central coherence.</p> <ul style="list-style-type: none"> <li>• Joint attention</li> <li>• Readiness &amp; ability to focus &amp; shift attention</li> <li>• Social interaction</li> <li>• Use of communicative strategies</li> <li>• Evaluation of child's play</li> <li>• Info about learning potential</li> <li>• Impact of individual's mental health</li> </ul>
<b>RCPsych (2014)</b>	<p><u>Identification:</u> AQ, RAADS-R. RPsych Guide.</p> <p><u>Questionnaires:</u> ASAS, GARS, GARS-2, SCQ, SRS-2, AQ, AQ-10, RAADS-R, SCDS, ABC. <u>Diagnostic interviews:</u> ADI-R, ADOS-2, DISCO, 3Di, AAA, RPsych Guide, PDD-MRS, ASDI, CARS-2, HBS, WADIC <u>Assessment for associated dev disabilities:</u></p>	NICE advocates multidisciplinary exercise, but psychiatrists might be expected to diagnose straightforward cases & be alert to indications for a more specialist assessment.	MDT usually includes psychology & nursing as core membership	N/S	<ul style="list-style-type: none"> <li>• Speak with informant</li> <li>• Take neurodevelopmental history</li> <li>• Consider obtaining early health records</li> </ul> <p>Might include assessment for; cognitive ability, functional ability, coexistent neurodevelopmental disabilities, coexistent psychiatric disorders, mental capacity, risk of harm/offending, medical problems</p> <p>Wherever possible, it is essential that the clinician gets accurate accounts of relationships in different settings (e.g.</p>

	AQ, EQ, SQ, Faces test, eyes test, Faux Pas Recognition Test, SSQ, Dewey's Social Stories, Adult/Adolescent sensory profile				at work & at home), particularly where they might be more demanding for that individual.
<b>BPS (2016)</b>	e.g. ADOS, ADI, DISCO, ADI-R	It is recommended that assessment is multidisciplinary.	At least one psychologist, in addition to other relevant personnel, such as OTs, mental health workers etc.	It is recommended that assessment is timely.	The taking of a developmental history with carers as well as observation across different settings. Information from a range of sources. Psychologists contribution to identification and assessment may include: <ul style="list-style-type: none"> <li>• Assessment of protective factors, strengths and abilities</li> <li>• Assessment of associated mental health issues</li> <li>• Comprehensive developmental and family history</li> <li>• Assessment of learning styles</li> <li>• Assessment of strengths and of barriers to learning</li> <li>• Assessment of environmental conditions for learning</li> <li>• Functional behavioural assessment</li> <li>• Assessment of social communication style</li> <li>• Assessment of the needs of families.</li> <li>• Comprehensive cognitive assessment, which may include psychometrics if deemed necessary</li> </ul>
<b>BMJ (2017)</b>	<u>Screening:</u> CHAT, M-CHAT <u>Parental questionnaires:</u> SCQ, CAST, CARS; for adults, the SRS, ASQ. <u>Diagnosis and Assessment:</u> eg ADOS-G, ADI-R; 3di; DISCO	Diagnosis should be confirmed or made by an appropriately trained professional, ideally working as part of MDT	Paediatricians, child psychiatrists, adult psychiatrists or psychologists, & other professionals	N/S	A combination of: <ul style="list-style-type: none"> <li>• neurodevelopmental history</li> <li>• standardised interview, &amp;</li> <li>• observational assessment</li> </ul> Gather information about functioning in more than one environment; A full neurological examination including measurement of head circumference is routinely performed in all children.

JOURNAL ARTICLES					
<b>Blenner et al (2011)</b>	<p><u>Screening</u>: CHAT, PDDST, STAT, CHAT-23, M-CHAT, ITC, SCQ.</p> <p><u>Diagnosis</u>: ADOS.</p>	Paediatric neurologists, developmental & behavioural paediatricians, child psychiatrists or psychologists, or, ideally, MDT.	N/S	N/S	<p>Comprehensive evaluation that includes</p> <ul style="list-style-type: none"> <li>• lifetime &amp; family history</li> <li>• review of medical &amp; educational records</li> <li>• behavioural observation</li> <li>• physical examination</li> <li>• administration of standardised instruments such as the autism diagnostic observation schedule</li> <li>• cognitive &amp; adaptive assessment</li> <li>• review of established DSM or ICD diagnostic criteria</li> <li>• Assessment of specific domains, such as communication skills, sensory and motor problems, and family stressors and coping abilities</li> <li>• Look for causes &amp; co-occurring conditions (further tests)</li> </ul>
<b>Carpenter (2012)</b>	<p><u>Screening</u>: ASDASQ, AQ and EQ, AAA, AQ-10, RAADS-R. RCPsych guide.</p> <p><u>Observation</u>: PDD-MRS (with ID); ADOS-G.</p> <p><u>Interview</u>: ADI-R, DISCO, 3Di.</p> <p>AAA to provide structure.</p>	Diagnosis can be made by one clinician. Wider assessment requires a team. A variety of professionals can diagnose.	N/S	Labour intensive - up to 8 hours to make & document diagnosis.	<p>Three elements (judged against criteria of ICD-10 or DSM-4):</p> <ul style="list-style-type: none"> <li>• interview with person</li> <li>• observation</li> <li>• interview with an informant</li> </ul> <p>Some clinicians bypass the criteria &amp; test, for example, theory of mind, central coherence.</p> <p>Consider possible co-morbidities</p> <p>Holistic assessments needs to be structured around:</p> <ul style="list-style-type: none"> <li>• Need for social support and for help with employment</li> <li>• Sensory and processing difficulties</li> <li>• Medical issues</li> <li>• Neuro-psychiatric conditions</li> <li>• Practical skills, including motor difficulties</li> <li>• Social interaction skills</li> <li>• Emotional understanding (of self and others) and personal coping strategies</li> <li>• Interests and preoccupations</li> </ul>

					<ul style="list-style-type: none"> <li>• Sexual interests and future desires</li> <li>• Insight and future desires and motivation</li> <li>• Psychiatric concerns</li> <li>• Other behaviours that may get person into contact with the law</li> <li>• Support for carers</li> </ul>
<b>Garland et al (2013)</b>	<p><u>Screening:</u> AQ-50, AQ-10</p> <p><u>Diagnosis:</u> ADI-R, ADOS=G, RCPsych Diagnostic Interview Guide</p>	When mental health difficulties also exist, the expertise of the wider MDT is likely to be engaged.	Outlines psychiatrist's role.	Enough time should be set aside	<ul style="list-style-type: none"> <li>• History of presenting complaint</li> <li>• Psychiatric history</li> <li>• Family history</li> <li>• Medical history</li> <li>• Developmental history</li> <li>• Personal &amp; social history</li> <li>• Mental state examination</li> <li>• Assess for comorbid disorders inc. neurodevelopment disorders</li> <li>• Physical assessment</li> <li>• Functional level assessment</li> <li>• Assess risk</li> <li>• Assessment of care &amp; support needs</li> <li>• Consideration of need in areas of education &amp; employment</li> </ul>
<b>Howlett &amp; Richman (2011)</b>	No specific tool	If the local autism team does not have the skills to assess these children themselves, they should liaise with professionals who are able to do so	Minimum, paediatrician &/or child & adolescent psychiatrist, SLT & clinical &/or Ed.Psych. Other professionals ... specialist health visitor, nurse, specialist teacher, social worker	Timely & appropriate. Follow up appointment within six weeks of assessment	Should provide detailed developmental profile. Based on NICE guidance.

<b>Lai et al</b> (2013)	<u>Screening:</u> CHAT, ESAT, M-CHAT, ITC, Q-CHAT, STAT (for young children); SCQ, SRS, SRS-2, CAST, ASSQ, AQ (for older children and adolescents); AQ, RAADS-R (FOR ADULTS). <u>Diagnosis and assessment:</u> ADI-R, DISCO, 3Di (for structured interview); ADOS, ADOS-2, CARS, CARS-2 (observational measure).	Assessment needs to be multidisciplinary	N/S	N/S	<ul style="list-style-type: none"> <li>• Interview with the parent or caregiver</li> <li>• Interaction with the individual</li> <li>• Collection of information about behaviour in community settings</li> <li>• Cognitive assessments</li> <li>• Medical examination</li> <li>• Co-occurring conditions</li> </ul>
<b>Levy et al</b> (2009)	<u>SCREENING:</u> Q-CHAT, M-CHAT, FYI, ECI-4, CSI-4, SCQ, ASDS, KADI, AQ-Child, A (AUTISM) ABC (autism), PDDRS, PDD-MRS, DBC, DBC-ES, PDDBI, ABC (aberrant), CCC, SRS, RBS-R, SCDC. <u>Diagnosis and assessment:</u> PIA-CV, DISCO, ADI-R, 3Di. CHAT, STAT, AOSI, ADOS, CARS	These assessments should be multidisciplinary	The MDT should include clinicians skilled in speech & language therapy, occupational therapy, education, psychology, & social work.		<ul style="list-style-type: none"> <li>• Use ICD or DSM criteria</li> <li>• Core and comorbid symptoms, cognition, language, &amp; adaptive, sensory, &amp; motor skills.</li> <li>• Review of caregiver concerns, descriptions of behaviour, medical history, &amp; questionnaires.</li> <li>• Include stage 1 data.</li> <li>• Observations across settings</li> <li>• Cognitive, communication, &amp; ASD-specific assessment</li> <li>• Medical assessment</li> <li>• Differential diagnosis</li> </ul>
<b>O'Hare</b> (2009)	<u>Screening:</u> M-CHAT, NAPC Checklist <u>Diagnosis:</u> ADOS-G, SRS	A multidisciplinary diagnostic approach is recommended	Paediatricians are essential members.	N/S	<ul style="list-style-type: none"> <li>• Direct clinical structured observations</li> <li>• Critical that information is gathered from different settings, outwith the clinic – there are structured questionnaires for parents/teachers</li> <li>• Physical exam and other specialist tests as required</li> </ul>
<b>Pilling et al</b> (2012)	<u>Identification:</u> AQ-10.	N/S	N/S	N/S	<p>Inquire about &amp; assess the following:</p> <ul style="list-style-type: none"> <li>• Core autism signs &amp; symptoms</li> <li>• Early developmental history</li> </ul>

					<ul style="list-style-type: none"> <li>• Behavioural problems</li> <li>• Functioning at home, education, employment</li> <li>• Past &amp; current physical &amp; mental disorders</li> <li>• Other neurodevelopmental conditions</li> <li>• Neurological disorders (for example, epilepsy)</li> <li>• Communication difficulties</li> <li>• Hypersensory &amp;/or hyposensory sensitivities &amp; attention to detail</li> <li>• Carry out direct observation of core autism signs &amp; symptoms especially in social situations</li> <li>• Functional analysis</li> </ul>
<b>Reynolds (2011)</b>	No specific tool	N/S	N/S	N/S	Observed behaviours with patient presenting symptoms from 'Triad of Impairments': social interaction, social communication, social imagination
<b>Wilson et al (2013)</b>	<u>Identification:</u> AQ-10 <u>Diagnosis and assessment:</u> ADI-R; ADOS-G. AAA, ADI-R, ADOS-G, ASDI, RAADS-R (without ID). ADI-R and ADOS-G (with ID). DISCO, ADI-R, or ADOS-G.	Should be carried out by MDT consisting of professionals who have experience in diagnosing autism (from NICE).	N/S	N/S	<p>A comprehensive assessment of autism should involve an assessment of</p> <ul style="list-style-type: none"> <li>• core autism signs and symptoms</li> <li>• early developmental history, where possible, and in the absence of an informant written information, such as school reports may be used</li> <li>• behavioural problems</li> <li>• functioning at home, in education, or in employment</li> <li>• past and current physical and mental disorders</li> <li>• other neurodevelopmental conditions</li> <li>• neurological disorders (e.g. epilepsy)</li> <li>• sensory processing and sensory sensitivity issues</li> </ul> <p>Assess coexisting mental health disorders. Risk assessment. Functional analysis for challenging behaviour</p>





## Appendix 13: Selected Jefferson Transcription Symbols

[ ]	Overlapping talk
,	Upward intonation
.	Falling intonation
↑	Marked pitch rise
::	Lengthening of preceding sound
£	Smiley voice
(.)	Micro pause
(0.2)	Timed pause (tenths of second)
> <	Speeded up talk
< >	Slowed down talk
<u>So</u>	Emphasis
=	'Latching' of successive talk
.hhh	In-breath
Bu-u-	Cut off of previous sound
°so°	Quieter speech
But	Consonant produced more sharply than normal

Adapted from Hepburn and Bolden, 2013; Jefferson, 2004



## Appendix 14: Characteristics of Patient Cases with a Diagnostic Outcome

Case no	Age	Sex	ADOS result	Pattern	FOUR-PART NARRATIVE STRUCTURE				Co-conditions	Outcome
					1. Preface	2. Contradictory evidence	3. Re-alignment	Helpfulness		
<b>Adult team 1 (11 cases discussed in total, 1 with outcome)</b>										
2	51-60	Male	Under threshold (4)	Four part	Constraining	Under threshold on ADOS	Compensating*; under-reporting	Yes	Yes	Diagnosed ASC
<b>Adult team 2 (16 cases discussed in total, 10 with outcome)</b>										
12	26-35	Female	ADOS score not mentioned	No (straightforward)	Constraining	n/a	No contradictory evidence	No	Yes	Diagnosed ASC
13	36-50	Female	Under threshold (2)	Four part	Constraining	Under threshold on ADOS	Compensating	Yes	None mentioned	Diagnosed ASC
14	18-25	Male	Too difficult to score	Four part	Constraining	Traits; social difficulties; variable eye contact; delayed language development	BEDC** (schizoid personality disorder)	Yes	Yes	Not diagnosed
15	51-60	Female	ADOS not mentioned	No (straightforward)	Constraining	n/a	No contradictory evidence	Yes	Yes	Diagnosed ASC
16	18-25	Female	Meets threshold (7)	No (straightforward)	Constraining	n/a	No contradictory evidence	Yes	None mentioned	Diagnosed ASC
19	26-35	Female	Under threshold (2)	No (straightforward)	Constraining	n/a	No contradictory evidence	No	None mentioned	Not diagnosed
21	36-50	Female	Under threshold (2)	Four part	Constraining	History and AQ10/RQ suggestive of ASC; repetitive behaviours	BEDC (OCD/ADHD/attachment)	Yes	Yes	Not diagnosed
22	36-50	Female	Meets threshold (9)	Four part	Constraining	Social interaction ok; lot of gesture	Compensating	Yes	Yes	Diagnosed ASC
25	26-35	Male	Under threshold (4)	Four part	Constraining	Special interests	BEDC (anxiety)	Yes	Yes	Not diagnosed

26	26-35	Male	Meets threshold (11)	No (straightforward)	Constraining	n/a	No contradictory evidence	Yes	None mentioned	Diagnosed ASC
<b>C&amp;YP Team 1 (20 cases discussed in total, 12 with outcome)</b>										
28	5-10	Female	Under threshold	Four part	Neutral	Parental report	Over-reporting	Yes	Yes	Not diagnosed
31	14-18	Female	Meets threshold	Four part	Constraining	Over threshold on ADOS; history and symptoms suggestive of ASC	BEDC (depression/neglect)	Yes	Yes	Not diagnosed
32	14-18	Male	Under threshold	Four part	Constraining	Language difficulties; traits; repetitive behaviours	BEDC (neglect/language difficulties)	Yes	Yes	Not diagnosed
34	14-18	Female	Not discussed (didn't do full ADOS)	Four part	Neutral	Good eye contact, insight, facial expression; no language difficulties	Compensating (gender)	Yes	Yes	Diagnosed ASC
36	14-18	Male	Meets threshold	Four part	Constraining	Good social manner, eye contact, social play	Compensating	Yes	Yes	Diagnosed ASC
37	11-13	Male	Meets threshold (9)	Four part	Constraining	Other prof and one parent believes not-ASC	ADOS is clearly above threshold; some compensating	Yes	Yes	Diagnosed ASC
38	5-10	Male	Meets threshold	No (straightforward)	Constraining	n/a	No contradictory evidence	Yes	Yes	Diagnosed ASC
40	5-10	Female	Meets threshold	Four part	Constraining	Non verbals under threshold on 3di; some gesture	Compensating; under-reporting	Yes	Yes	Diagnosed ASC
41	11-13	Female	Meets threshold	Three part	Constraining	Absence of observed repetitive behaviours	Subsequent report of repetitive behaviours; no other explanation	No	Yes	Diagnosed ASC
42	5-10	Male	Meets threshold (9)	Four part	Constraining	Eye contact, non-verbals, emotion recognition OK; other profs believe not-ASC	Compensating	Yes	Yes	Diagnosed ASC

44	5-10	Male	Meets threshold	Four part	Constraining	Gets on well socially, lots of friends; language within normal limits	Parents under reporting; compensating	Yes	Yes	Diagnosed ASC
47	5-10	Male	Meets threshold	Four part	Constraining	Good non-verbals, eye contact, language, pretend play/conversation; no echolalia	Compensating	Yes	Yes	Diagnosed ASC
<b>C&amp;YP Team 2 (4 cases discussed, all outcomed)</b>										
48	14-18	Female	Meets threshold (not yet scored up)	Four part	Constraining	Early to talk; no mannerisms; uncertain about stereotypical/repetitive language	High 3di scores; 'enough there'	Yes	Yes	Diagnosed ASC
49	5-10	Male	Meets threshold (not yet scored up)	Four part	Constraining	Good at recognising emotion, social/creative play; some gesture; socially motivated	Compensating	Yes	Yes	Diagnosed ASC
50	14-18	Female	Under threshold	Four part	Constraining	Under threshold on ADOS; good gestures, rapport, eye contact, facial expressions, imagination, building conversation	Compensating (gender); complicated by anxiety	Yes	Yes	Diagnosed ASC
51	14-18	Female	Meets threshold (not yet scored up)	Three part	Constraining	Good insight, gesture; some emotion recognition, roleplay/creativity	Compensating	No	Yes	Diagnosed ASC

\*Compensating includes: learned behaviours, taught strategies, training (eg in presentation skills), masking and camouflaging; putting on a show

\*\*BEDC Better explained by different condition



## Appendix 15: Selected In The News Items

- BBC article on Paddy McGuinness responding to his children 'not looking disabled' (despite having autism): <https://www.bbc.co.uk/news/entertainment-arts-50289637>
- A Thinking Person's Guide to Autism post 'Neurodiversity FAQ': <http://www.thinkingautismguide.com/p/so-youre-doing-story-about.html>
- A Guardian letter to 'our friends who share autism success stories': <https://www.theguardian.com/lifeandstyle/2019/sep/28/a-letter-to-our-friends-who-share-autism-success-stories>
- The Guardian article by Simon Baron-Cohen about Neurodiversity and autism: <https://twitter.com/GdnSocialCare/status/1179331882565156864>
- NBC news article: Why the focus of autism research is shifting away from a search for a 'cure': more attention is on identifying children as early as possible and support for the health and well-being of autistic adults  
<https://www.nbcnews.com/health/kids-health/cure-autism-not-so-fast-n1055921>
- Transcribed radio discussion debating the Neurodiversity movement: [http://www.thinkingautismguide.com/2019/09/countering-neurodiversity.html?fbclid=IwAR040JdlzBO-4cv9h8bOdp72aivFdQQQsHa\\_zl3RcSJT1NzslwNFNmfCwzs](http://www.thinkingautismguide.com/2019/09/countering-neurodiversity.html?fbclid=IwAR040JdlzBO-4cv9h8bOdp72aivFdQQQsHa_zl3RcSJT1NzslwNFNmfCwzs)
- Guardian article 'women 'better than men' in disguising autism symptoms': <https://www.theguardian.com/society/2019/sep/13/women-better-than-men-at-disguising-autism-symptoms>
- What is Autism? How the term became too broad to have meaning any more. Guardian article: <https://www.theguardian.com/commentisfree/2019/aug/26/autism-neurodiversity-severe>
- The Telegraph article, 'Autism now so over diagnosed it will be a meaningless condition in 10 years' <https://www.telegraph.co.uk/science/2019/08/21/autism-now-over-diagnosed-will-meaningless-condition-within/>
  - NAS response: <https://www.autism.org.uk/get-involved/media-centre/news/2019-08-22-new-research-on-diagnosis.aspx>
  - Paper it is based on: <https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2747847>
- BPS *Psychologist* article, 'Me and Monotropism: A Unified Theory of Autism': <https://thepsychologist.bps.org.uk/volume-32/august-2019/me-and-monotropism-unified-theory-autism>
- Dispatches programme 29th July 2017, 9pm – Young, British and Depressed (trailer): <https://twitter.com/C4Dispatches/status/1155523311725699072?s=20>
- Study finds psychiatric diagnosis to be 'scientifically meaningless': <https://neurosciencenews.com/meaningless-psychiatric-diagnosis-14434/>
- Spectrum Article 'Stimming, therapeutic for autistic people, deserves acceptance': <https://www.spectrumnews.org/opinion/viewpoint/stimming-therapeutic-autistic-people-deserves-acceptance/>
- Spectrum Article 'Autistic people with intellectual disability often excluded in studies': <https://www.spectrumnews.org/opinion/viewpoint/autistic-people-intellectual-disability-often-excluded-studies/>
- Blog post 'Autistic communication differences and how to adjust for them': <https://theaspergian.com/2019/06/09/autism-autistic-communication-differences/>
- *Scientific American* article 'Cleaning Up Some Misconceptions about Neurodiversity': <https://blogs.scientificamerican.com/observations/clearing-up-some-misconceptions-about-neurodiversity/>

- Article from *The Washington Post* about an employee helping an autistic boy having a meltdown: [https://www.washingtonpost.com/lifestyle/2019/06/07/theme-park-employee-lay-down-ground-next-an-autistic-boy-having-meltdown-her-act-solidarity-went-viral/?utm\\_term=.6b366bb2ec5d](https://www.washingtonpost.com/lifestyle/2019/06/07/theme-park-employee-lay-down-ground-next-an-autistic-boy-having-meltdown-her-act-solidarity-went-viral/?utm_term=.6b366bb2ec5d)
- How Asperger's helped Greta Thunberg realise there was a climate crisis: <https://www.thetimes.co.uk/article/greta-thunberg-on-how-aspergers-helped-her-realise-there-was-a-climate-crisis-53qhhknj0>
- Spectrum article on the divisions in and between the Autistic Community and Neurodiversity Movement: [https://www.spectrumnews.org/features/deep-dive/search-truce-autism-wars/?fbclid=IwAR15ZD-ujj\\_UIO9wLJ\\_7QvmHxY4gCle-pYUjvcBMd7WhL5S4lg6qpC4vTE](https://www.spectrumnews.org/features/deep-dive/search-truce-autism-wars/?fbclid=IwAR15ZD-ujj_UIO9wLJ_7QvmHxY4gCle-pYUjvcBMd7WhL5S4lg6qpC4vTE)
- A review suggesting the DSM-5 narrowed eligibility for autism diagnoses, while the new social communication disorder diagnosis is barely used: [https://www.disabilitycoop.com/2019/03/20/study-autism-definition-drop-diagnoses/26227/?fbclid=IwAR2\\_TDRver6mtDND3rnNDzCCfa6ia3Tt7ti52hEpnNHKEGwXj-kVF0H29MA](https://www.disabilitycoop.com/2019/03/20/study-autism-definition-drop-diagnoses/26227/?fbclid=IwAR2_TDRver6mtDND3rnNDzCCfa6ia3Tt7ti52hEpnNHKEGwXj-kVF0H29MA)
- 'The good thing about ADHD: It's my superpower' – BBC video: <https://www.bbc.co.uk/news/av/stories-47630021/the-good-things-about-adhd-it-s-my-superpower>
- Autism Ireland closing down: [https://www.irishtimes.com/news/social-affairs/autism-charity-collapses-after-years-of-financial-struggles-1.3826365?mode=amp&fbclid=IwAR2QgjcZHNCLHI\\_8uSdQn1asnF4VLFtSETxEsIT7IbCmRFwWvV1YISVull4](https://www.irishtimes.com/news/social-affairs/autism-charity-collapses-after-years-of-financial-struggles-1.3826365?mode=amp&fbclid=IwAR2QgjcZHNCLHI_8uSdQn1asnF4VLFtSETxEsIT7IbCmRFwWvV1YISVull4)
- Care Quality Commission rebuked for failure to prosecute National Autistic Society over care home abuse: <https://www.theguardian.com/society/2019/mar/10/cqc-rebuked-for-failure-to-prosecute-national-autistic-society-over-mendip-house-care-home-abuse>
- A study by researchers at the University of Surrey led by an autistic adult from November 2018 that found social stigma accounted for 72% of the distress reported by autistic adults: <https://consumer.healthday.com/cognitive-health-information-26/autism-news-51/stigma-of-autism-can-take-toll-on-psyche-739089.html>
- West End play 'All in a Row' receiving criticism over use of puppet to portray boy with autism: [https://www.chroniclive.co.uk/news/north-east-news/all-in-row-alex-oates-15823286?fbclid=IwAR1IOSgE9SGwA9f26AKQ\\_4eHMApXq41Shh\\_fd3eshGa6BZdQcJnSSS1ceg](https://www.chroniclive.co.uk/news/north-east-news/all-in-row-alex-oates-15823286?fbclid=IwAR1IOSgE9SGwA9f26AKQ_4eHMApXq41Shh_fd3eshGa6BZdQcJnSSS1ceg)
- London Evening Standard report on a drop in vaccination rates across Europe, particularly in London: <https://www.standard.co.uk/news/health/antivaxxers-behind-alarming-drop-in-number-of-children-having-mmr-a4060001.html>
- The dangers of 'Neurodiversity': <https://www.spectator.co.uk/2019/01/the-dangers-of-neurodiversity-why-do-people-want-to-stop-a-cure-for-autism-being-found/>
- Spectrum article 'Can computers diagnose autism?': <https://www.spectrumnews.org/features/deep-dive/can-computer-diagnose-autism/>
- What the neurodiversity movement does and doesn't offer: <http://www.thinkingautismguide.com/2018/02/what-neurodiversity-movement-doesand.html>
- Puzzle Piece Controversy for Autism: <https://www.disabilitycoop.com/2018/02/02/autism-journal-abandons-puzzle/24668/>
- The Power Threat Meaning Framework: <https://www.bps.org.uk/news-and-policy/introducing-power-threat-meaning-framework>



## Appendix 16: Exploring Diagnosis Advisory Board

Liz Pellicano	Professor and director of Centre for Research in Autism and Education
Irina Singh	Professor of Sociology known for her work on 'ADHD voices' project.
Katherine Runswick-Cole	Disability activist, scholar and parent. Founder of critical autism network.
Stuart Murray	Professor at Leeds, and parent, known for book 'Representing Autism'.
Chloe Silverman	STS scholar based at Penn State University, Philadelphia, author of 'Understanding Autism'.
Annemarie Jutel	Professor of Sociology of Diagnosis
Denis Pereira-Gray	Retired GP and former president of Royal College of GPs
Tom Pittwood	Intervention researcher (Brain in hand). First person perspective on ASD
Sami Timimi	Child and adolescent psychiatrist who has argued for socially constructed nature of ASD, ADHD
Kabie Brook	Founder of Autism Rights Highland Group
Adam Feinstein	Author, translator and Journalist: Has written a book about autism: 'A History of Autism: Conversations with Pioneers'.
Jan Slaby	Berlin: Critical Neuroscience Movement: Social and cultural context of neuroscience
Tim Webb	Award winning animator who made 'A is for Autism'
Virginia Bovell	Ethicist and Activist



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