Discourses in Autism Assessment and Diagnosis

Thesis

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KAREN DONNA PATRICIA HAGAN

DISCOURSES IN AUTISM
ASSESSMENT AND DIAGNOSIS

Thesis submitted to the Open University
School of Psychology, for the award of
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ABSTRACT

This thesis explores the range of discourses in which parents and professionals engage when a child is assessed and diagnosed with autism. The main focus is on the parents’ meaning-making in recognition of the investment parents have in the topic. It also takes an anti-discriminatory and emancipatory standpoint in recognition of the relative lack of voice parents are awarded in research and in the development of autism services.

A team of professionals in an autism assessment centre were recruited along with parents of four families referred to them to receive an autism assessment for their child. Data were collected during routine assessment centre meetings between parents and professionals and in pre-assessment and post-diagnosis research interviews with parents.

A critical discursive psychological approach was taken to analyse data. This synthetic approach, merging a macro-level and micro-level analysis, was used to explore the application of diagnostic criteria, policies and protocols as discursive resources alongside analysis of talk-in-action.

The findings of the research programme produced three themes for the thesis: knowledge, power and possibilities. In relation to the first theme, parents talk and the practices of autism assessment and diagnosis, produced a distinction between expert ‘knowledge’ and parents’ ways of ‘knowing’. The two forms of knowledge were not of equal value in the assessment process, varying in the situated power and influence they could wield. In relation to the second theme, the thesis examined both how parents were subjectified by the processes and discourses of diagnosis and how professionals were subjectified as agents of policy and protocol. Analysis of exchanges between parents and professionals exposed further practices of self-subjection, but also identified some strategies of resistance.

Prevalence rates of autism diagnosis and the challenges faced by parents and service providers mean this is currently an area of research of considerable applied significance. This thesis aims to contribute specifically to knowledge about how assessment and diagnostic practice might be improved, ultimately proposing a shift in the approach to autism diagnosis. As such, the third theme, possibilities, examined both the constraints on parents’, and professionals’, discourses in the diagnosis of a child and the opportunities to transcend those constraints. It highlighted the benefits of learning from approaches to diagnostic practices based around open dialogue. Future research could develop the work here to focus on professional meaning-making. It might also consider the complex situation of parents of children referred with autistic characteristics who do not receive a diagnosis.
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I wish to dedicate the thesis to my mother who was so proud when I started PhD study but, unfortunately, didn’t live to see it finished. She always believed that I would succeed and I know she hoped it would make a positive contribution.

To Mary Ann Lyttle Hagan
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INTRODUCTION

‘When I first had Kim he was my son. A year later he was epileptic and developmentally delayed. At eighteen months he had special needs and he was a special child. He had a mild to moderate learning difficulty. He was mentally handicapped. I was told not to think about his future. I struggled with all this. By the time he was four he had special educational needs. He was a statemented child. He was dyspraxic, epileptic, developmentally delayed and had complex communication problems. Two years later, aged six, he was severely epileptic (EP), cerebral palsied (CP) and had complex learning difficulties. At eight he had severe intractable epilepsy with associated communication problems. He was showing a marked developmental regression. He had severe learning difficulties. At nine he came out of segregated schooling and he slowly became my son again. Never again will he be anything else but Kim – a son, a brother, a friend, a pupil, a teacher, a person.’ (Murray and Penman, 1996, p11 talking about Kim, their autistic son)

Autism is not a new topic for psychological research and, arguably, there have been enormous developments in understanding autism and a proliferation of strategies for supporting people and their families. However, the experience of autistic people and their families continues to be challenging and relatively negative. The quote above from Murray and Penman (1996) movingly articulates some of the distress experienced by families as a result of diagnostic practices and their implications. It highlights how the ‘problem’ of autism begins with the process of accessing, from professionals charged to assess a child presenting with behavioural traits typically associated with autism, a beneficial assessment of their child’s situation. Some parents claim that working with services is the most difficult thing they have to deal with (Hodge and Runswick-Cole, 2008; Runswick-Cole, 2007).

This thesis reports on a social psychological study of the interaction between professionals and parents when a child is assessed and diagnosed with autism. At the heart of the work is the proposition that what we understand by ‘autism’ is a discursive construction. Indeed, the very fact that the criteria for autism spectrum disorders has shifted over time in the Diagnostic and Statistical Manual of Mental Disorders, and has recently seen significant changes in the emergence of DSM 5 (American Psychiatric Association, 2013), makes the case for autism to be understood as a construct which is highly unstable and contingent (Lester 2014). The focus of the research was to examine a key part of the discursive construction - the co-construction between parents and professionals when parents receive a diagnosis for their child.

The thesis makes no claims over the authenticity of autism as a thing outside of discourse. Historically and contemporarily, autism is viewed as a neurodevelopmental disorder but, like many mental health issues, there is a growing awareness that the construct and the practices (social, medical, educational, political and even economic) that surround it are socially
constructed. The thesis does not debate whether or not autism, as a ‘real’ thing, exists. Indeed, the clinical symptomology and diagnosis is not directly an issue that the research can address. What the thesis addresses is how this construct and the diagnostic practices around it are accomplished in discourse and with what consequences.

**Autism defined**

Autism is a challenge to define. The aim of this section is to do some brief background and definition work, albeit fairly open ended. It is not intended to produce a guide to autism. Rather, it offers sufficient contextualising to make sense of the use of the term and its common understandings employed by both parents and professionals.

The prevalence of autism has been on the increase in the last 10 years with a current estimate of around 1 in 100 of the UK population being diagnosed with autism ([http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx](http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx), 2018). It has become much more widely known and support, and services have grown exponentially over the last couple of decades. Such developments may have had a significant impact on the rates of diagnosis but, inarguably, the term 'autism' is now a part of most people’s vocabulary. The concept of autism is much contested, however. In a commonly accessed definition, Wikipedia states that:

‘Autism is a disorder of neural development characterized by impaired social interaction and communication, and by restricted and repetitive behaviour’ ([http://en.wikipedia.org/wiki/Autism#cite_note-DSM-IV-TR-299.00-0](http://en.wikipedia.org/wiki/Autism#cite_note-DSM-IV-TR-299.00-0), 2010).

Although not originating from an academic or validated source, this is an important definition as it is a key source for many modern parents who search for answers to the questions they have about their child’s behaviour and the labels they are given.

Another important source of information for parents is the National Autistic Society, whose website states that:

‘Autism is a lifelong developmental disability. It is part of the autism spectrum and is sometimes referred to as an autism spectrum disorder, or an ASD. The word 'spectrum' is used because, while all people with autism share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'everyday' lives; others will require a lifetime of specialist support. The three main areas of difficulty which all people with autism share are sometimes known as the 'triad of impairments'. They are: difficulty with social communication, difficulty with social interaction, difficulty with social imagination.’
As will be demonstrated in chapters one and two, professionals rely on two main systems of classification: the Diagnostic and Statistical Manual (DSM) and the International Statistical Classification of Diseases and Related Health Problems (ICD). Professional and medical guidelines such as these base the definitions of autism largely on Lorna Wing’s (1997) triad of impairment (she identified three areas of impaired functioning: social interaction, communication and activities/interests) as do the two widely available online definitions above. So, there is consistency to some extent in the resources available to parents and professionals. This consistency anchors on the triad in a rather generalised way, however, while there is a huge amount of professional literature covering, in depth, features and causes of autism. Wing also recommended that diagnosis should include individual (medical and life) history and observation to ensure a comprehensive clinical overview. These are embedded in the NICE guidelines and most autism service procedural documents.

### i.i. Terminology

One ongoing debate, relevant to the application of particular ‘autism-related’ language in the thesis, concerns whether it is most appropriate to use ‘people with autism’ or the phrase ‘autistic people’ – the argument for the former was that it put the person first and the Autism second (Government White Paper: People First). However, the Aspie and neurodiversity movements and others argue that they do not want to put autism in second place as it is an integral part of who they are (Cascio, 2012). A creative person would not usually be described as a ‘person with creativity’. ‘Creative person’ is a descriptive term and treats creativity as part of the person’s character and essential to who they are. To use the term ‘people with autism’ is to suggest there is a reason to separate out the person from the autism and that autism is something undesirable. In essence, it may reinforce the understanding of autism as a disease, syndrome, medical condition or disorder like a ‘person with cancer’, ‘a person with measles’. This thesis adopts the term ‘autistic people’ as a response to that argument.

In addition, the term ‘autism’ is utilised throughout the thesis in recognition of, and to make space for, the available range of constructions of autism: paradoxically, ‘autism’ is restrictive yet it means many things to many people. Adopting more specific language steers understanding into particular categories and networks of meaning from neurodiversity to disorder. The use of this broadest (albeit powerful) form of wording embraces such variability in language and position. It
encompasses all positions except one – that which denies the very existence of autism itself – and assuming this position is beyond the remit of the current study.

**Assessment and diagnostic criteria and tools**

In the studies reported in this thesis, professionals used specific standardised tools and procedures. However, the research project’s focus was on the discourses between parents and professionals during the process of a child’s assessment and diagnosis. Therefore, it is not necessary to examine the tools per se but it is important to briefly outline what these are. This section provides basic description to appreciate the implementation of professional documentation and the discussion of their consequences in the analysis of the data.

**Diagnostic criteria**

Professionals work to a prescribed set of diagnostic criteria laid down in the Diagnostic and Statistical Manual of Mental Disorders: DSM IV (1994)/DSM 5 (2013). During the data collection DSM IV was the active version used by professionals so, although DSM 5 has succeeded it and is the active version at time of writing thesis, the thesis will refer to DSM IV. For a diagnosis of autism an individual must meet three conditions: the first is a minimum combination of six items from a list of 12 behaviours and aspects of communication, the second covers at least one social, linguistic or creative developmental delay and the third stipulates that the behaviours and developmental delays identified must not be better attributed to another diagnosis.

The following is a summary of the diagnostic criteria for autism from the Diagnostic and Statistical Manual of Mental Disorders: DSM IV whereby an individual must meet three conditions:
These criteria are wide-reaching, relatively imprecise and provide a great degree of flexibility - which is evidenced by the fact that the exclusion of other diagnoses must be used to support a diagnosis of autism. The recent term ‘Autism Spectrum Disorder’ in common usage was shortened to ASD and then changed to ASC, Autism Spectrum Condition lately by many
organisations and government agencies, e.g. Autism Initiatives, in an attempt to move away from the negative meanings associated with ‘disorder’:

‘Due to the different focus and philosophy that we have as an organisation we prefer to use the term autism spectrum condition as opposed to autism spectrum disorder. We feel that this fits with our core values, and although we are aware that there is much current debate on this subject, we agree with the reasoning of Simon Baron-Cohen et al (2009)’


However, little discernible difference seems to exist between ‘disorder’ and ‘condition’ while accepting that ‘condition’ is part of the medical narrative of assessment and diagnosis, for example, ‘The condition (autism) was one of a group of disorders brought together under a new term’ (Tidmarsh and Volkmar, 2003, p.518).

The DSM 5 has been criticised for drawing upon more medicalisation in its approach to autism and this as a result of the US national Institute of Mental Health concern that the criteria is the DSM IV was ‘insufficiently scientific’ (Strong, 2014, p106). A major debate raised about DSM, both IV and now V, is around the promotion of diagnosing. DSM appears to embolden professionals, policy makers and institutions to disorder greater numbers of people, in particular children, yet without due consideration of the ontological premises and consequences of the practice. One recent key argument is that DSM 5 continues on a path to lower the thresholds for diagnosis, thus meeting the neoliberal and economic concerns of separating out individuals with needs that are different to the optimal social level or who pose a threat to economic security and prosperity (Frances 2013). This is not a straightforward issue though as others are concerned the DSM 5 excludes people who identify as autistic, particularly Aspie, from a formal diagnosis (McPartland, Reichow and Volkmar, 2012). The disordering of human diversity is a significant debate with which the thesis engages throughout.

**Assessment Tools**

The main assessment tools used in assessment in the research site were the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview- Revised (ADI-R). However, there were also additional processes such as physical examinations. The assessment tool used with parents in the assessment meetings, the ADI-R, and the protocols for gathering life and medical histories are relevant here as the study applied to the parents and professionals. The ADOS is not directly relevant because the study did not focus on the child or professional
observation of the child. The final document of particular significance to the study was the
diagnostic report, given verbally at a meeting between the professional and parents six weeks or
so after the assessment (this meeting will be referred to as the diagnostic meeting hereafter), and
then sent to the parents and relevant agencies or professionals. Other materials such as reports
and team deliberations over scoring ADOS are referred to in the thesis as they contribute to the
assessment and diagnosis, but these are not so core to the talk between parents and
professionals.

i.ii. Synergy – a personal, professional and academic rationale

My interest in autism began in the early 1980’s and was one of the reasons I applied for a
psychology degree in early 1980. I was intrigued by autism, schizophrenia and other forms of
human experience that were ‘different’, trying to imagine their experience of the world and what
that might mean about human ontology. Theory, intervention and connotations of autism have
changed considerably since then, in some ways radically. I worked in social care work for 14
years and engaged a little with autistic people and their families. There I found such variation in
the autistic people I met, my clinical knowledge of symptoms, causes or interventions failed to
attend to the crux of understanding such diversity. It was not cognisant of subjectivity and
meaning.

I questioned the concept of autism, the spectrum disorder, because I found it unhelpful and
limiting. At the same time, parents told me how difficult a journey they had with their autistic
child and how they felt professionals and social services did not care and would not help. As a
professional at the time, I was distressed by this account and also somewhat perplexed as it
wasn’t the impression I had in general of other professionals or of my own work. Perspectives of
parents and professionals are very different. There have been escalating concerns about the
levels of dissatisfaction and that the dominant medical model on which autism services are based
do not adequately meet the needs of autistic people and their families (Andreasen et al. 2003;

The knowledge base of diagnosing professionals draws directly upon medical, developmental,
neurological and psychological discourses of autism and on diagnostic criteria from DSM. Parents
draw upon a different topography of knowledge and essentially use their child and comparison to
others as their point of reference to assemble flexible and rather less certain or powerful
meanings. The relationship with professionals has often been viewed by parents as stressful and
conflicting (Hodge and Runswick-Cole, 2008). At the initial stages, parents describe receiving the
diagnosis as ‘horrible and empowering’ because the diagnostic label provides a hook for gathering information and help (Schall, 2000, p.414). Thus they become committed to a stressful process awash with conflict.

The parents’ investment is in their child, in contrast to the professional investment in their subject, institution or career and this contrast can also feed into the nature and force of the conflict. Assessment and diagnostic meetings have been described as a ‘site of micro-political struggle… contest between the physician and patient to define the nature of the patient’s disorder’ (Banks and Prior, 2001, p.12). This is a wider issue than the autism diagnosis as it carries additional implications and connotations. In seeking help for autism during this micro-struggle the parent-professional discourse can also to be used to define fundamental category memberships – good parent, good child, worthy help-seeker (Holt, 2010; Higashi et al., 2013; Sointu 2017). Similar to other contested diagnoses, such as MS or CFS, autism assessment is so prescriptively and effectively constructed in diagnostic criteria and practices (ADOS, ADI-R) that the contest is rather one-sided. The aim of this thesis is to give voice to alternative discourses of autism, drawing on a unique data set.

Anthologies of parents’ accounts frequently criticise professionals and services for diagnosis. With the blurring of knowledge lines, professional knowledge claims are contested (Banks and Prior 2001). Professional knowledge is now partially available through the internet, although the expert claims special authority, through training, to assess the knowledge of variable quality now so openly available. Knowledge claims and criticisms are the discursive instruments of power negotiations. Given the rise of the internet as the information tool used by the majority of the population on so many matters, this flawed but encompassing information and support resource is now part of the parental armoury in confronting the professionals.

The opportunity for opening up possibilities, for acceptance and celebration of diversity, appears to be closing but it is argued that this is in the name of protecting and supporting autistic people and their families. This can be seen directly in the research and funding. A key report commissioned by the UK charity Research Autism, identified a need for more research and funding along with an increased focus on the agendas and experiences of autistic people and their families. It reviewed all research and funding in the UK into autism and found that research into autism focuses on neuropsychology (see diagram 1), 56% biology, brain and cognition, 18% intervention, 15% causes, 05% diagnosis, 06% others (Pellicano, Dinsmore and Charman, 2013). Little of this work is ever made available or accessible to autistic adults and their families. It has, arguably, made little impact on their lives, and much of it is inconclusive and highly contested.
(Timimi, Gardner and McCabe, 2011). The percentage of qualitative research into the experiences of autistic people and their families is comparatively sparse. The direction of funding is core to setting the research agenda, of course. It is no surprise that the allocation of funding is directed to neuropsychological interests, and embraces epistemological goals aligned to the medical model, when much of it is generated through pharmaceutical companies and medical institutions. For example, Medical Research Council funding accounted for 42% of all spending on autism research (Pellicano, Dinsmore and Charman, 2013).

Diagram 1 (from Pellicano, Dinsmore and Charman, 2013)

i.iii. Epistemological choices in autism research: An ethical standpoint and the interrogation of power

Psychology in the 21st Century continues to develop along multiple lines of enquiry. Critical discursive psychology developed in response to limitations in traditional positivist approaches to complex concepts. However, positivist ontological investments and epistemological ambitions continue to be the dominant directions for psychology, for example, with an increase in technologies and theories in neuropsychology and psychometrics. Simultaneously, the 21st Century has seen a prioritising of subjectivity. More recently, writers espousing a ‘psychosocial’ perspective argue against a sole focus on the discursive subject in favour of a ‘psychosocial’ appreciation of human experience (Blackman et al 2008). My focus on discourse is not a statement that discourse is all that there is, but rather that it is the most significant and useful ontological investment for the purpose of exposing the problems inherent in diagnostic practice.
What I want to focus on in the thesis is not the subject as such but subjectification and subjection. This takes form in the language of diagnostic procedures. These are interactions of knowledge production and power that facilitate or necessitate subjection and subjectification (Butler, 1997; Foucault, 1966; 1969). This requires some conceptualising of the subject and particularly the discursive subject, but such focus is not meant to undermine the contributions of others around the psychosocial subject nor does it argue that there is no psychic life behind discourse. I follow a more structuralist view along the lines of Foucault:

‘Foucault’s work on power/knowledge understood subject positions as formed within the apparatuses of power/knowledge, the discursive practices and technologies of the social through which subjectification occurred’ (Blackman, L., Cromby, J., Hook, D., Papadopoulos, D. & Walkerdine, V. 2008, p6).

I argue that my focus on the discursive productions between professional and parent are a negotiation of knowledge and power. Ideology provides only a discursive resource in this struggle, while the internalisation of meaning is beyond the scope of both the study and my interrogative skills. Although, I will admit that the force and commitments to such negotiations must indeed reflect internal drives and investments. For example, I do not claim that a parent’s love for their child is simply a discursive construct.

A further interest for the thesis is the expedition of new ‘possibilities’ in discourses of autism and approaches to diagnosis. Foucault may be criticised for paying scant attention to agency in his writing and this seems justified to a large extent. However, Foucault’s focus on power/knowledge as the mode of negotiating all positions does not quite erase the possibility of an individual with other aspects to their being. Blackman et al (2008) take up one of the concerns of parents in autism diagnosis by asking if the subject is constituted by power alone then how can they, as an individual, find a source for resistance or be open to new possibilities. There are two alternative answers to this. Firstly, we can interrogate whether Foucault really intended to suggest that the subject is constituted by power alone, i.e. the negligent treatment of agency does not equate to Foucault claiming there is no embodied subjectivity, no unconscious entity nor biologically driven source. Secondly, if entirely constituted by discourse then, surely with such a dynamic and flexible means such as interlocution, a source for resistance would be as likely as a source of compliance, albeit not as easily evolved. Subjects are always subjected to a range of discourses and some of these will be resistant and adaptable.

This thesis is concerned with the development of anti-discriminatory and emancipatory practices (Thompson, 2001; Dominelli, 1998). I do not claim to be an activist for autism causes or the causes
of the autistic. However, I accept that the voices of autistic people and their families have been largely ignored by institutions of government and service providers.

The latest developments in collaboration and inclusion, e.g. NHS Patient/Personal and Public Involvement initiatives, produce very sophisticated strategies for engagement. However, discussion of the 'latest developments in collaboration and inclusion' could be framed both as an advance in patient care and as a potential discursive limitation in terms of parents’ voice (Arnstein, 1969, Autism NI 2016). For the most part parent engagement by institutions of professionals has been conceptualised as solutions to technical problems (Orsini and Smith, 2010). I aim to take a discursive and emancipatory approach to excavate below the level of technologies of autism and analyse the values and meaning-making. I have focused on the parent perspective both in the data collection – which includes interviews at either end of the process with the parents, i.e. pre-assessment and post-diagnosis – and in the analysis of the implications of talk and power relations specifically in terms of the parents’ experiences. The research topic and approach to it are ‘applied’ in the strongest sense and it is intended to contribute to both clinical and parent practice.

i.iii.i. The aims and contribution of the research

'The formation of a pathological identity is a recursive process, which involves a narrowing of the repertoire of available narratives and the dominance of problem-saturated meanings, which are typically associated with the medical discourse' (Avdi 2005 p.495).

This pathological identity begins to take a particular form during the autism diagnosis. The process of diagnosis pathologises not just the child but also the parents. Research has already suggested that parents and autistic children benefit when parents can be engaged positively in the process of assessment and support development (Broadhurst, 2003). It is clear from the statements of parents, however, that positive engagement is not always achieved. In common with most traditional research into autism and families, Carinci (p.4813, 2008) identifies this lack of positive engagement as a problem owned by the family, and specifically the mother: ‘not all families display the characteristics that allow them to take an active role regarding their child’s education and training’. However, he found that ‘a critical aspect ... was the way in which she (the mother) reacted to and digested the initial diagnosis’ and that this impacted on the parent’s perspective and ability to adjust. The contribution of research into family experience tends to deliberate on family stress and evaluations of intervention through explanations of family’s abilities to cope and competencies in parenting.
The powerful and dominant medical discourse - evident in journals, assessment strategies and reports and drawn on in diagnosis - places parents in unequal subject positions, defining essential criteria such as normality and the validity of particular forms of knowledge. In McHoul and Rapley’s (2005) analysis of a diagnostic interview with parents of a child displaying possible ADHD symptoms they claim the doctor takes control discursively, setting the agenda and placing themselves as decision-maker. Even when the parents offer their own theory the doctor ‘trumps the parents with the invocation of a set of specific numbers’ (McHoul and Rapley, 2005, p428) leaving only ADHD on the agenda. Professionals use their encounters with parents to reinforce their pre-conceived ideas and limit the range of talk with medical discourse and its dominant, science-based status.

As a consequence of the pattern of research and the lack of voice, parents and autistic people are allowed in the assessment and diagnostic process and in the wider policy context, a gap exists in the understanding of what is constructed when a child is diagnosed with autism. The empowered parent requires a mutual reconstruction or repositioning in discourse which can only emerge out of open, fruitful and flexible ways of negotiating the diagnosis and concept of autism. The thesis aims to explore the contributions of both professionals and parents in constructing these experiences and characteristics, arguing that such characteristics are interactional constructions through discourse which are initiated at the first point of contact and opening diagnosis.

i.iv. The Research Programme

The research reported on in this thesis consisted of a research programme that investigated the interactions between parents and professionals when a child is diagnosed with autism. It focused primarily on the meaning-making of parents, arising during their talk with professionals and their positioning in relation to this process. The fieldwork was carried out in an urban area of Northern Ireland and the core data was collected from four families (mainly mothers) and one professional. Research interviews were carried out before and after the assessment and diagnostic meetings but the most novel contributions were the recordings of parents and professionals in the assessment meetings and the meetings where professionals read the diagnostic report to the parent. The recordings were transcribed and a Critical Discursive Psychological (CDP) analysis conducted on the transcriptions. The initial stages of analysis involved identifying themes in the data but the final stages of analysis focused on applying CDP concepts to the themes and data, identifying interpretative repertoires or common pattern of talking, the negotiation of subject positioning, and variability or dilemmas emerging in the talk.
i.iv.i. Research questions

The research project was essentially about positions and meaning-making of parents during the process of autism assessment and diagnosis, not about what autism is in any realist sense. It is not concerned with aetiology or prognosis or in interventions per se but is concerned only with the emerging range of constructions. Constructions of meaning takes place in the linguistic space between the professional and the parent and draw essentially on the discursive resources each party has to hand from their social and cultural backgrounds. The salient issues for parents are the ways they understand their child, and how others react to them, how their issues are constructed and how society, professionals and those close to them contribute to the available discursive resources and environment.

The main research question for the project was:

What range of discourses do parents and professionals engage in when a child is assessed for and diagnosed with autism?

Employing the conceptual tools of critical discursive psychology facilitated more in-depth exploration of specific questions:

• What interpretative repertoires were evident?
• How were parents’ and professionals’ positions negotiated?
• How did parents and professionals negotiate power/agency?
• What ideological dilemmas were evident and how were they managed?

i.iv.ii. Limitations of the thesis

Some significant issues will be glaringly omitted or neglected in the thesis because the richness of the topic and the data demanded a ruthless prioritising of material and argument. I want to acknowledge that the following issues were ubiquitous through the research process but will not be expounded in any detail in the thesis:

• Socio-economic issues - ‘The younger the children were when they received an ASD diagnosis, the higher the parents’ level of education, the greater their family income, and the more satisfied parents were with the process of getting a diagnosis’ (Goin-Kochel et al, 2006, p444). The typical assumption is that families from lower socio-economic backgrounds ‘may have fewer resources from which to draw support and information and
may, in turn, put forth less of a “push” toward clarifying their children’s issues and needs’ (Goin-Kochel et al, 2006, p447). Inequitable socio-economic levels between parents and professionals were evident informally through a number of indicators such as home, work and even accent, however, these indicators were not measured in the study. Certain assumptions work to blame families for not having the ‘push’ to obtain a diagnosis. However, families in lower socio-economic classes do not have access to information, services and the range of discourses to obtain and exercise power in contrast to professionals and even to families in higher socio-economic groups. Alternative explanations were not explored in the research, such as the possibility that professionals do not interact in the same way with families from different socio-economic backgrounds. The language and cultural/societal values and resources in the lower socio-economic class can be sufficiently different or alien to those of the higher economic professional classes to impact on communication patterns and understanding and vice versa. This may be where the discourses of professionals and parents have the highest risk of being incommensurate.

- The information age, autism and parents – Online resources and parent organisations’ websites appropriate expert knowledge while attempting to advocate and support parents. Their accounts blur knowledge forms by at once trying to uphold the value of parents experience while giving precedence to expert knowledge. The appropriation and association with expert knowledge works to add power to the organisation and its work and aims, whether this is working with parents or lobbying government or influencing policy and practice. However, it simultaneously serves to undermine the value of the parent voice. Pseudo-professionalisation ‘lay accounts that have been filtered through medical or other professional health rationality’ (Shaw, 2009, p.289) usurps the layperson’s accounts as the organisation adopts the stances and concepts/constructs of the professional. Expert knowledge trickles into the popular culture (Farr and Moscovici, 1984) informed by information technology, and online media constructions (Shaw, 2009).

- Gender – Though it does provide some discussion of this through adopting the feminist arguments of ‘women’s’ ways of knowing (Elby, 2009; Hofer and Pintrich, 1997). There are clear gender issues as the majority of parents in the study and in parent-related research are mothers.
• Liminality and transition – Parents engaging with autism assessment are arguably in a liminal space, transitioning from one state of having an undiagnosed child to another state with a diagnosed child. This is a complex experience which, to study, would require much more exploration of identity, lived experiences and personal meaning-making. This is not the aim or focus of the research or the thesis, yet at times liminality would be a useful tool for exploring talk or experiences of thresholds for diagnosis and service provision and affect such as fear, hope and uncertainty (Rattray, 2016).

i.v. Synopsis of chapters

Three consistent threads, which could be considered as ‘themes’ of the thesis, run through the thesis: knowledge, power and possibilities. These concepts will be used to both interrogate the literature and analysis but also to construct a coherent argument. Each chapter will attempt to unravel the construction of knowledges, identify how power is accessed and negotiated, and explore what this means for closing down or opening up the possibilities for alternative ways of talking, practising and collaborating in autism diagnosis.

Chapter 1 - ‘The trouble with autism diagnosis’ provides an account of the topic and focus of the thesis, autism diagnosis and parent-professional discourses, and their relevance to various stakeholders: parents, professionals and the public. In order to account for the topic the chapter employs specific conceptual tools. It uses problematisation to question current approaches to autism diagnosis and open up the possibility of formulating new questions and directions. A basic historical account of autism is advanced by considering it as part of an episteme (Foucault, 1966). Considering autism as part of an episteme appreciates that it is situated within particular discourses and meaning-making. It accounts for some of the limitations and directions taken in autism diagnosis and further employs Foucauldian tools: archaeology to expose the content of the epistemes and genealogy to explore the paths of knowledge production contained within the operations of power.

The final conceptual tool for the literature review is the psychological complex – psy complex (Rose, 1979). The psy complex encourages the consideration of autism as a consequence of the technologies of diagnosis, but also the consideration of its implications and consequences. Using these conceptual tools the chapter begins to unpick the construction of autism in the diagnostic clinic and demonstrate how this is positioned within a wider set of institutionally constructed structures, processes and divisions. It reviews perspectives of stakeholders in autism: media, ‘experts’ and parents, excluding autistic people themselves.
Chapter 2 - ‘Power and Possibilities’, moves beyond the stakeholder accounts to explore the wider social, cultural and political context of autism diagnosis. It explores the contemporary episteme of neoliberal values, economic worth, and individualism (Beck, 1992 and Giddens, 1991) and what this has meant for the discourses and practices of autism diagnosis. These wider values and regimes of knowledge are embedded in the practices of institutional policies and professional practice but this is not an entirely coherent state of affairs. Contradictory discourses of care and control emerge and debates begin to open up about institutional discriminatory practices and power.

The chapter also examines the notion of the post-modern parent and how parenting competency is understood. Parenting an autistic child also reveals contradictions and conflicting positions, especially when parents enter the diagnostic system. The thrust of this chapter becomes the subjection of parents and the restrictions or limitations in diagnostic procedures, for example, in the range of discourses available when using prescribed documentation. The final section of the chapter attempts to open a variety box of alternative approaches which have potential to disrupt the hegemonic notions of autism, service delivery and the agency of parents and professionals.

The argument developed through chapter 1 and 2 is that autism diagnosis is distressing and frustrating to parents. Rather than supporting parents, it creates tensions between professionals and parents specifically as a result of their disparate subject positions in relation to knowledge and power. These positions are embedded and acted out in institutionalised discourses, culture and professional practices. Therefore, the final proposition presented is to consider alternative ways of engaging with parents when they are referred for autism assessment.

Chapter 3 - 'Theoretical and Methodological Perspective', I describe, explain and justify the approach I have taken to the project, the Critical Discursive Psychological (CDP) approach. It provides an outline of the influences on CDP from Chomsky to Potter and Wetherell. Bakhtin and Foucault were of particular relevance to the research. Foucault because of the focus on the relationship between knowledge and power relations in the analysis, and Bakhtin because his ideas elucidate the struggle between authoritative professional discourses and the subjectified voices of parents. CDP is a synthetic approach to discourse analysis which takes more account of the psychosocial nature of discourse and meaning-making. It explains that micro-level talk in action (the meetings between parents and professionals or parents and researcher) should be analysed in conjunction with macro-level discourses (doctrine embedded in policy and public narratives) as these wider settings provide individuals and groups with discursive resources and
situate the talk within a particular context. In fact, this is not a one-way relationship but more fluid, akin to the meanderings workings of power according to Foucault. The chapter also includes a brief description of the conceptual tools for the CDP approach: interpretative repertoires, subject positions and ideological dilemmas.

**Chapter 4** details the Method employed in the study. Recruitment was carried out in a National Health Service (NHS) Trust Autism Assessment Centre from their referrals over a period of 6 months. The substantive data was collected from 4 families with children of 6 years old or under attending for autism assessment. The chapter explains the recruitment process, describes participants and explores the ethical considerations. It also raises discussion around discourse as data and collection of discourse data. The steps of analysis are described in detail to present a transparent account of how themes, repertoires, subject positions and dilemmas were identified. Two particular sections are of note in CDP. Firstly, it is relevant to include the researcher as a co-producer of data and secondly to discuss, as relevant for its absence, what is not included in the data. Finally, the chapter ends by explaining the criteria for validation and evaluation of CDP work as this contrasts significantly with other forms of research in psychology such as experiments and surveys.

**Chapter 5** - ‘Knowledge and knowing’ presents the first analysis of the data. It argues that parents construct the discourses of professionals and discourses of parents as incommensurate with each other, emerging from incongruent discursive genres and from distinctly separate positions. There is plenty of evidence in the data between parents and professionals (displayed in word clouds to illustrate the point) but this chapter focuses on the meaning-making of parents during the research interviews rather than the assessment and diagnostic meetings. The analysis is worked up into a conceptual contrast of ‘knowledge and knowing’ whereby parents confer on the professional expert knowledge, power and even moral capital. However, they also heavily criticise professionals for their failure to dispense this knowledge and resource. Tensions of knowledge and power emerge in accusations of gatekeeping resources.

A further focus in this chapter is affect. Parents talk was rich with emotion about their child in particular but also about services, professionals and the public. This talk was part of their descriptions rather than offered as points in themselves but it was recurrent and powerful. Affect was often used for particular purposes, e.g. to highlight damage by service lack or to manage potential criticism of them as parents. Finally, parents’ talk exposed the significance of the diagnosis as validation and a passport to service provision. This is the pay-off for engaging in a ‘battle’ with professionals.
Chapter 6 - ‘Documenting an autism diagnosis’ focuses on the meetings between professionals and parents and, particularly, use of documentation in the process of assessment and diagnosis. Drawing upon the assessment meeting data, the chapter exposes a number of uncomfortable consequences of using the ADI-R: quick fire questions of a sensitive nature some with unclear relevance and abrupt changes of sensitive topics as a result of working through the questions. This was a memory test which produced a vulnerable parent position. Likewise the data from the diagnostic meeting uncovered some fundamental issues for parents around hearing upsetting and complex information in a clinical manner. Since parents own words were used throughout the report, parents received the diagnosis justified by their own claims thus preventing them from challenging the detail or findings of the report. In both meetings parents were trapped into a pattern of confirming and conforming, discouraged from asking questions and prohibited, by the procedure and use of documents, to disagree. Knowledge at both meetings changed hands but in one direction in the main, from parents to professionals. There was little flow of knowledge from the professional to the parent in terms of the professional view of the child, their expert knowledge of autism or a compound account of what autism meant specifically to their child.

Chapter 7 - ‘Trouble and dilemmas in autism diagnosis’, explores autism as a troubled concept in parent and professional discourses. It draws on all data collected during the research interviews and the assessment and diagnostic interviews. Autism carries many negative connotations and so the chapter begins by analysing the level of commitment parents demonstrate to obtaining a diagnosis. The illogicality of seeking an undesirable label is warranted by the diagnosis acting as a passport to services, validating their voices and vindicating their claims. Two ideological dilemmas are picked up in this chapter. Firstly, for the professionals there is a dilemma between the values and subject positions of the caring professional and the clinical expert. Secondly, for the parent; they have to discursively manage discourses for help-seeking which compromise their positions and status as unconditional nurturers. In help-seeking they must present conditions of norms for their children and own to them not achieving. They present extreme-case formulations of their child’s behaviour to stress ‘need’ but do a lot of discursive work to manage potential criticism of their parenting and their child’s character, and to maintain their worthiness to access services and support.

The final chapter, Conclusions, is in two parts. Part one draws together the issues and arguments from the three data chapters and, amalgamating the literature, it considers a range of possibilities for potential directions in autism diagnosis. Part two provides a reflection of the research process, methods, strengths, limitations and future research suggestions.
Chapter 1

The trouble with autism diagnosis

This first chapter of the thesis aims to conceptualise the topic under investigation and flag up some pertinent meta-issues by means of problematizing autism diagnosis and critically interrogating the antecedents of the current state of affairs. It will review literature of autism diagnosis but with an orientation specific to the ontological and epistemological standpoint of the research. In other words, it does not intend to review diagnostic criteria or evaluate diagnostic practice but it will expose some of the troubled conceptions in autism-related discourses and the performance of the clinical diagnosis of autism. The account will be relational and indexical, looking first at public media social constructions (what the papers say), professional formulations (what the experts say) and familial voices (what the parents say), to expose underlying ontological perspectives, functions and epistemological consequences of talk from different perspectives or standpoints.

1.1. Conceptual tools

Certain objects of social discourse need to be problematized to: illuminate dominant structures and functions and our relationships to them, to question established networks of meanings, and to explore alternative ways of understanding and performing social life (Foucault, 1985). In problematizing autism assessment and diagnosis it is possible to examine claims that the biomedical management of autism pathologises the child and the family (Avdi, 2005). We can examine the consequential way autism diagnosis reduces their experience, aspirations and relationships to the measures/benchmark-driven networks of meanings guided by a formula of around 16 criteria in the DSM (appendix A). It constrains possibilities for appreciating the variability and richness of autistic life and experience but also severely restricts family possibilities. Problematizing allows for a refocusing outside of the accepted regimes of truth (Foucault, 1979). Yet, ‘the simultaneous constitution of a problem, of its explanation, of its solution, and of the means by which this solution is to be effected... appears to threaten the well-being of an ordered and regulated social body’ (Rose, 1979, p.13) and so the thesis must consider meta-issues and the politics of autism diagnosis.
1.1.1. Foucault and the episteme

In order to achieve a deeper appreciation of where autism is positioned in the early 21st Century, it is necessary to understand how it got here and why. However, a chronological account of autism is not sufficient to expose the relationships between knowledge regimes, functions of the diagnosis and power that can be wielded in its name. Instead, the epistemological aim of this chapter and the next is to critically examine the situated account of autism diagnosis, the concept and function. Appreciation of the situated constraints can then be used to encourage or liberate alternative ways of conceptualising autism and the procedures and processes surrounding it. The account below will be more a genealogy than historical chronology i.e. Foucault’s notions of episteme, archaeology and genealogy will be drawn upon in this chapter to justify and provide the conceptual basis for such prominence awarded to context (Foucault, 1966; 1969). According to Foucault, an episteme denotes a time and place that embraces particular discourses through which society accepts particular understandings or truths. Such truth conditions pervade the professionals knowledge but also the common understanding in that society. Autism, the concept, has been subject to the episteme of each time. Although there may be distinguishable genres to the discourses of discrete groupings there will be commonality drawn from the episteme. The episteme and thus discourses determine not just what is acceptable or the norm but actually constrain what is possible to understand or hold as true within the each episteme.

Of course, epistemes are always subject to change and this is significant for the analysis of autism diagnosis and the thesis. One of the themes of the thesis is possibilities, specifically in recognition of the parents’, autistic people’s and even professionals’ vocalisations of dissatisfaction of the diagnostic process. In the midst of increasing acknowledgements of their constraints and augmentations in diagnosis, particularly in view of DSM 5, the thesis is concerned with possibilities for a change in episteme or paradigm shift (Kuhn, 1962). There is a similarity of treatment between Foucault’s concept of episteme and Kuhn’s concept of paradigm. However, Foucault’s focus on the relationships between discourse, knowledge, power and context is more specifically relevant and useful here. For Foucault, episteme change refers to change over eras. He offers us an archaeological approach to uncover the epistemes or forms of knowledge and truths about autism in various periods of history. I restrict this to the US, Europe and UK as these are the most relevant to the current DSM dominated understanding of autism as it is experienced in the UK. The archaeological approach allows the academic excavation of the epistemes, the discovery of discursive traces of forms of knowledge and reification of autism criteria and diagnostic procedures. In answer to the limitation of archaeology to expose how and why
particular formulations of knowledge and truth flourish, Foucault also offers ‘genealogy’, a tool to discover the systems by which knowledge obtains the power to operate. Genealogical investigations expose operations beneath the level of individual consciousness. This is not so much a psychodynamic unconsciousness but rather that our ways of knowing and what we know are already given and constrained within the framework of the episteme. In the case of autism, scientific and medical mechanisms over the years and the technology of the diagnostic criteria in the DSM creates a genealogy.

1.1.2. Psychological Complex

The concept of the psychological complex (psy complex) will be drawn on to explore the relationship between the technologies of autism diagnosis and their social and cultural impact, specifically in relation to parents and professionals. Rose (1979) proposed the concept of the psy complex ‘a heterogeneous but regulated domain of agents of practices, of discourses and apparatuses which has definite conditions of existence and specific effects’ (p. 6). Autism diagnosis has emerged from particular psychological assumptions that have had a profound impact on understanding of autistic people and their place in the world. The possibilities for autistic people, their families and for anyone involved with them are contingent on such assumptions. The thesis will examine the particular conception of autism through its history and in relation to the administration of its conceptualisation and technologies of diagnosis. At the end of the 19th century the predominant method in psychology was observation and measurement. Psychological theory also developed a preoccupation with individuals and individual differences (Richards, 2002; Gergen, 1973). Autism diagnosis uses and produces a mobilisation of specific explanations. For example, it armed professionals and society with the notion of individual pathology and directed research questions to be limited to the use of observation and measurement which were then set against established rated norms (Nadesan, 2005).

The accounts of autism and values of psychology have been both in line with and informed political investment and debate. On the one hand, the establishment have positioned autism as a degeneration and form of deviance that needs to be monitored and controlled. On the other hand, socialist and disability critiques have highlighted the limitations and failings of the technology of mental measurement (Rose, 1979). The latter view extends to arguing that psychological positioning of autism speaks to the economic interests of the capitalist elite and thus is also a class issue. What this chapter hopes to unearth is not a truth about autism but, in Foucault’s terms, a ‘regime’ of truths or established knowledges and available possibilities in
autism discourses. In fact, a multiplicity of ‘regimes’ of truths is evident, each serving a different function and action depending on context.

The dominant discourse about autism simultaneously presents it as a problem, provides some explanation, and proposes the interventions necessary to solve the problem. Furthermore, it attempts to accomplish the concept and diagnosis of autism as incontestable through the establishment of agreed criteria in DSM IV and 5 and through established protocols in policy and practice. Autism is constructed as a particular kind of object through such psychological conceptualisations and practices. It has moved from the domain of the family and social group to the domain of science, psychology and medicine/psychiatry. More recently, as witness to the ability of the psy complex to change, autism research and explanatory discourses have located to the domain of neuropsychology and neurodevelopmental science with the development of technology for brain scanning (Ortega, 2011).

The chapter will develop the argument that autism diagnosis, owned by professionals as a problem to solve, is fashioned to be reliant on medical knowledge and scientific moral authority. This is a direction of travel which has ultimately led to a mismeasurement and appropriation of the autistic experience to the dominant medical discourse (Chown, 2013). The journey of autism is reminiscent of Rose’s reflection of the plight of degenerates ‘born of a ‘double movement… in both a moralisation and medicalisation… the conception of character which is implicated from an ethical to a scientific domain… as a category of science, of psychology, becomes inextricably linked to a threat to civilised existence’ (Rose, 1979, p13).

1.2 Disentangling autism: Diagnosis and causes

This section will be brief as the history of autism has been the subject of numerous, accessible books and papers (Timimi, Gardner and McCabe, 2011; Nadesan, 2005). Autism diagnosis has taken the form of different types of narratives over the years but the early forms can mainly be categorised as medical or developmental. In 1943 Leo Kanner coined the term ‘early infantile autism’, distinguishing a particular group of children who had previously been treated as part of a homogenous group thought to be displaying symptoms of childhood schizophrenia. Autism, meaning ‘an absorption in the self’, was ‘characterised by developmental deficits in communication, unusual cognitive abilities and behaviour problems such as obsessions, repetitive actions and unimaginative play’ (Bursztyn 2007, p7). In 1944 Hans Asperger published a paper detailing 4 children with similar characteristics and later the term Aspergers syndrome came to mean ‘the shutting off of relation between self and the outside world’ (Bursztyn 2007, p7).
During the 1950s and 1960’s the medical profession and others framed autism as a psychological condition resulting from poor mothering – ‘the refrigerator mom’ (Bettelheim, 1967) theory claimed that mothers of autistic children were apathetic and did not provide warmth and care. In 1964 Bernard Rimland suggested that autism had a basis in the biological make-up of the child and thus went some way to absolving mothers of the blame of their child’s condition. However, the concept of the ‘refrigerator mom’ is one that has endured to the present day in the public and at times in the professional view – often perceived as such (and therefore real) by mothers of autistic children.

The 1970s brought ‘scientific’ evidence for a genetic link through twin studies and during the 1980 and 90s ‘Autistic Disorder’ was categorised as one of a group of Pervasive Developmental Disorders with 16 diagnostic criteria outlined in the DSM III, DSM IV and in DSM 5. This terminology gave rise to the expressions of autistic people as ‘sufferers’ and continued the stigma which was epitomised in the labels ‘mentally handicapped’ or ‘retarded’. These are terms which continue to be used today but are contentious. ‘The Diagnostic Interview’ was a tool for assessment designed by Lord, Rutter and Le Couteur in 1991 and revised in 1994 in order to standardise the procedures for assessment and diagnosis, to provide better differentiation between autism and other diagnoses and ensure professional objectivity. The ‘Diagnostic Interview – Revised’ is the version used by professionals in the research site.

Biomedical research and funding has increased exponentially since, in 1998, a link was made between autism and chromosomes 15q and 7q (Schanen, 2006). Subsequently researchers have claimed to find links to specific genes. However, a massive amount of research has resulted in weak links being made to a number of other factors including virus infections, diet, vaccines and brain injury. While causes and cures for autism continue to elude researchers and families, there is still a great consensus that cure and improvement is the desired outcome and that early diagnosis and intervention is vital (Nadesan, 2013; Timimi, Gardener and McCabe, 2011). The medicalisation of autism is reproduced through the practices of psychiatrists, health care professionals, psychologists and many researchers, who embrace the expert knowledge of the clinical team within the process of diagnosis. Terminology of diagnosis in the ADI-R is based on the DSM IV criteria and each is understood across the world, applied relatively consistently in the developed countries. However, diversity is developing within the discourses of medical and other professions as they merge with a growing richness from voices of autistic people themselves and advocates. Discourses of advocacy and empowerment have been mobilised, however, these social activities or practices also work to stress the lack of autonomy, authority and power autistic people have in society. It is patronage by society that supports advocacy and empowerment and
so some claim it continues to put autistic people into lower status positions while elevating society and professionals who support advocacy to a new contextual power (Bumiller, 2013). A more recent narrative has emerged, however, which does not rely so much on patronage - the neurodiversity movement has asserted a positive positioning of autistic groups in relation to ‘neurotypical’ status (Brownlow, 2007).

Accounting for terminology around autism highlights the limitations and range of understanding and meaning as does attempting a shift in perspective. Autistic people and those around them have ‘conversations of possibility’, opening up the possible alternative conceptual foundations and networks of meanings that parents and others can construct around autism. However, the position of parents caught between the professional ownership of diagnosis and neurodiversity reclamation of autism is troubled (Cascio, 2012). It is not my intention to explore, in depth, these complex set of arguments but to highlight that this raises a further challenge for parents to negotiate.

Two genealogical threads have emerged within this debate with regard to parents. On the one hand parents are inculpated along with professionals for the deficit/disorder model of autism because they ‘collude’ with professional diagnoses and operate the technologies of intervention - many of the therapeutic interventions, e.g. ABA, are incompatible with the philosophy of neurodiversity and so parents who espouse this approach are assumed to have values and ideological positions incompatible with neurodiversity. On the other hand parents have also been advocates and ‘have used autism therapies to create a technical infrastructure to support autistic personhood’ (Hart, 2014, p284).

The debate is important, but what it suggests for this study is that parents have difficult decisions to make about their standpoint to autism when approaching professionals for a diagnosis and they need some space in which to voice and work through troubled positions. To provide support for this requires a level of ‘discursive competence’ with the ability to open up and access a number of different discourses not only for oneself but for others, to listen to the parents voices and to enable reflection and contemplation (Strong 2002). It can be immensely difficult to embrace unfamiliar discourses and to integrate them into existing discourses (or move between them) as they may not complement the other discourses in one’s repertoire or may challenge practice and ability. It requires a breaking out of restrictions of the episteme, the technologies of diagnosis. ‘Le differend occurs when there are two forms of discourse that are incommensurate with each other’ (Strong 2002, p229). The philosopher Lyotard, wrote about ‘le differend’, highlighting the challenges of taking a polyocular stance. Le differend refers to ‘a case of conflict,
between (at least) two parties, that cannot be equitably resolved for lack of a rule of judgement applicable to both parties. One side’s legitimacy does not imply the other’s lack of legitimacy’ (Lyotard, 1989, p.xi).

The meeting of professionals and parents may be one such example of incommensurate discourses coming together. Each has a different genre of discourse with different purposes and evaluated by different criteria (Lyotard, 1989). I will develop this later in the thesis specifically in relation to their form of knowledge and subject positions. However, there is an inequity in the struggle for one voice to be heard over the other which relates more to the power of institutional discourses, hence it is important to explore these discourses through relevant policy and strategy. This broader context frames the empirical work introduced later in the thesis, which explores some of tensions in the relationships between parents and professionals and some of the complexities in the process of diagnosis.

1.3. Perspectives on autism

This section explores some of the context for the groups in the study. The first section on media representations of autism provides the backdrop for the shared experience of parents and professionals, the foundations that are common to each. Section 1.3.2 then focuses on the professional voice, interests and viewpoints while section 1.3.3. develops the parent voice, the main focus of the study and the thesis.

1.3.1 What the papers say: A social pariah

A relative glut of papers now exist that critique the negative representations of autism in the media and in social discourses in general. It is also notable with some irony that many of the papers themselves carry negative meanings of autism. For example, Jones and Harwood (2009) found in the media a profusion of negative terms attached to autism but categorised them broadly into a dichotomy between autism as dangerous/damaged/lacking and autism as a pitiable affliction. The affliction of autism was then linked to costly medical and educational needs, placing the person firmly into the professional domain whether it be medical, educational or developmental; ‘needing full-time care... $60,000 a year for therapy they say can work miracles’ (Jones and Harwood, 2009 p.9). Once identified as having needs the person was then made a drain on resources and in such dire conditions that it would take a ‘miracle’ to improve the situation, an almost irresolvable problem. The only time positive language was used was in relation to obtaining funding, where funding and subsequent improvements were cited in order to justify the expenditure and to facilitate future bids.
It is debatable whether this was actually a positive construction of autism, however, since it simply reinforces the position that people with autism should be changed, normalised or managed with the right resources. Diagnosis, as a process, was found to be unquestionably essential for a person with autism and importance was placed on early diagnosis and intervention (Jones and Harwood, 2009). The medical and educational professionals alone had the power to make diagnoses and develop interventions so their relation to the person being diagnosed was inherently unequal. The autistic person was positioned as powerless and devalued in his or her own right as they had an unequivocal need for the professional.

Autism and autistic people have been repeatedly represented as harmful to society and a drain on social resources. Shaked in 2005 even noted how mechanisms were brought to bear to exclude autistic people from community activities. Her study in Israel found the status of the autistic child in the ultra-Orthodox community was inextricably linked to religion and as such their status was lowered by being excluded from taking part in the religious customs which are so imperative to community membership. In a more private domain, negative representations of the impact on the family prevail. Having a child with autism was presented by media, professionals and academics as damaging to marriage, to siblings and to the daily routines of the family with stresses particularly voiced in terms of ‘mother at breaking point’ (Jones and Harwood, 2009, p.12). Bumiller (2005) highlights the negative starkly by saying that researchers devalue people with autism by holding demeaning beliefs and she cites one researcher’s comment, ‘autistic children as a destructive force, really, really aggressive kids... They attack everybody... They bit their mothers... No human can look at them’ (Bumiller, 2005, p.971).

The finger has been pointed at the media for maintaining a one-dimensional view of autistic people through the ‘cumulative effect’ and ‘drenching’ of negative reports of autism (Farnall and Smith, 1999, cited in Jones and Harwood, 2009). As a result, autistic people have been constructed over the long-term in negative stereotypes and this has been further reinforced by strong images in film, television and news media. The entire row over the link between the MMR vaccination and autism further expounds on the negativity of the media construction of autism. O’Dell and Brownlow (2005) identified much negative language employed by the media in relation to autism and the question of its link to MMR. In discussing the dangerousness of the vaccine, autism was constructed as something to be feared and avoided. Its meaning ranged from ‘damaged’, ‘faulty’ to just a plain ‘problem’ (p.198). It is important to realise that not only was the general society exposed to these messages but autistic people and their families have been continuously bombarded by such negative formulations and have found themselves positioned,
without autonomy or power, as burdens on medical, educational and care resources as well as on the people closest to them.

The impact on identity for people with autism hasn’t really been examined, but it can be supposed that the negative social constructions must inform identity construction and relations with others – negative connotations will often be the only ones that parents have as they await diagnosis. This language produces action which debilitates and devalues the person with autism. Bagatell (2007) wrote about Ben, an autistic man, who experienced deep disturbance about his identity and her paper demonstrated how disparity between multiple identities for autistic people can develop through multiple, mainly negative, constructions and the disintegration of the individual’s esteem.

Bagatell (2007) reframed the idea of power into understanding it as the force or strength of the person’s voice, drawing on Bahktinian theory. Bagatell revealed that Ben’s own inner speech, his own identity was constructed in a context of discourses that orchestrated multiple present and past other voices. These other voices held varying levels of power but most of the voices he experienced through his life constructed him negatively and marginalised him. The voices with great authority (medical and educational) also urged him to conform and so put additional pressure on him and left him powerless. After attending an Aspie conference Ben’s identity was reconstituted with the new, positive, understandings he developed there - he had experienced different voices. He used the voices to reconstruct his earlier understanding of the world around him and what autism, and he, meant to himself and others. Unfortunately, these voices were not the ones he returned to after the conference and they conflicted dramatically with the more dominant previous voices to leave him in dilemma.

O’Dell and Brownlow (2005) also used the Bahktinian concept of ‘voice’ when they reported on media reports of parents’ voices in the MMR-autism link debate. The language used by parents comparing their child before and after vaccination was uniformly negative, contrasting the ‘normal child’, ‘normal happy boy and ‘normal development’ with the ‘damaged’ child who had ‘lost language’, ‘went downhill very rapidly’ and ‘was about to lose the ability to even identify himself in the mirror’ (O’Dell and Brownlow, 2005, p.197).

O’Dell and Brownlow identified ‘safety and dangerousness’ as a thematic dichotomy within the MMR-autism discourse. The debate around MMR has highlighted and enhanced the fear people have of having an autistic child. The language of autism in the media over this period centred around autism as a ‘dangerous risk’, concerning ‘safety’ over the vaccine and ‘dangerousness’ of
the ‘risk’ of autism (O’Dell and Brownlow, 2005, p.196). Autism was something to be avoided even at significant cost, such as at the risk of contracting rubella or causing a rubella outbreak. ‘Brain damage’ and ‘vaccine damaged’ terminology suggest the autistic person is broken, not acceptable or right, but the authors note that this is ‘in contrast to the more positive views of autism held by people labelled’ (O’Dell and Brownlow, 2005, p.195).

1.3.2. What the experts say: Blame and the neurobiodevelopmental model

While research includes work on attitudes to autism, cultural representations and a little qualitative work on parents’ experiences, the majority of work around autism is clinical and is focused around causes and treatment (Pellicano et al, 2013). Avdi (2005) acknowledges that the impact of diagnosis is profound and that the networks of meanings and the ways they are ‘used by parents in their interactions with professionals are complex and variable’ but claimed this was beyond the remit of their own study. In an earlier paper by Avdi, Griffin and Brough (2000) parents’ constructions of the ‘problem’ during assessment and diagnosis were explored along with their constructions of professional knowledge and authority. The data from interviews with parents demonstrates how negative meanings were attached to the medical process and professionals. A discourse of disability emerged in juxtaposition with a concurrent construction of ‘normal’ development which served to highlight the deficit aspect of disability. However, parents found an alternative, more positive, way of understanding their child and their achievements rather than relying on generalized norms. ‘Parents described their “acceptance” of their child’s differentness as marked by a discursive shift towards holding personalized “norms”’ (Avdi et al 2000, p.246).

Avdi’s studies did not examine the interactional constructions that took place during the assessment and diagnosis process between parents and professionals but they did highlight the cultural contradictory positions of parents when a child is regarded as not conforming to the norm: the parents are simultaneously seen by themselves (and by professionals) as experts on the one hand and as lacking in knowledge and understanding on the other. Parents constructed the professional position as contradictory but also as having privileged access to and control over information; a framing which created and constrained meanings and behaviour associated with assessment and diagnosis and resulted in frustration and resentment. (Avdi, 2005). This research highlighted the complexity and importance of the interactions between parents and professionals and provided the foundations for the rationale for the focus of the research. The thesis specifically makes a contribution to understanding better the parents constructions and parents’
and professionals’ positioning. The next section begins to examine the genealogy of the dominant professional discourse and position, the medical model.

**Medicalisation of autism**

The hegemonic discourse of the medical model owns autism as a medical condition, requiring medically trained professionals to make ‘formal diagnoses’ and provide treatment or intervention: ‘Hegemonic ideologies preserve, legitimate and naturalise the interests of the powerful-marginalising and subordinating the claims of other groups. Hegemony is not automatic but involves contest and constant struggle’ (Wetherell and Edley, 1999, p.336).

The dominance of the medical ideology is pervasive throughout the review of research and literature provided for parents. Often, while recognising the issues of medicalising autism, it is still discussed in terms of a medical condition which must be diagnosed by a medical expert, symptoms outlined and treatment or intervention recommended as early as possible. While no cause or treatment is uniformly accepted by the medical profession this does not stop academics and practitioners continuing to formulate autism as a neurobiological disorder. The language used tends toward the clinical and diagnosis, it is claimed, has to be precise because, as Goin-Kochel et al argue, ‘a wrong diagnosis could cause unnecessary anxiety... it is a necessary tension between sensitivity and specificity’ (Goin-Kochel et al, 2006, p.440). The use of phrases such as ‘symptom appearance’, ‘developmental screening tools’ and ‘eligibility for early intervention’ reinforce the construction of autism as an illness which affects development and needs to be fixed or treated. Clarke and Van Amerom (2007) found that organisations set up to support families with an autistic member advocated early diagnosis and treatment in order to have increased success at school and an independent life. Furthermore, the organisations warned of the negative outcomes if ‘left untreated’ (Clarke and Van Amerom, 2007, p.767) and encouraged parents to persevere with the diagnostic process beyond initial diagnosis in case of co-morbidity, i.e. for fear of missing the autistic person’s ‘tendency toward anxiety, depressive illness and suicide’ (Clarke and Van Amerom, 2007, p.768).

This creates a sort of moral panic about autism that is more specific to the families of people with autism on top of the generalised fear and moral panic in society about such people as being aggressive, unresponsive and erratic. Families who do not follow the advice are implicated in their child’s certain later negative behaviours and experiences - if they do not ensure early and ongoing diagnosis and a strategy of intervention and treatment their child will do poorly at school, will be isolated, bullied, may suffer from undiagnosed mental health problems, will not be able to
live independently and they may even be responsible for their child taking his or her own life (Clarke and Van Amerom, 2007).

A recent development to the medicalisation of autism (and it could be said to be a possible reaction to the reducing regard and power assigned to medics and other professions and their attempt to regain control and status by increasing the levels of fear and uncertainty) is the notion that there is an increase in autism diagnoses, along with other developmental conditions, to ‘epidemic proportions’ (Clarke and Amerom 2007 p.766). The epic figures lend weight and urgency to the call to remedy the situation, to get diagnoses and treatment to quell the tide of ‘disease’ and ‘disorder’ and gives further credence to the pathologising of autism, pathologising the differences.

Clarke and Van Amerom (2007) go on to demonstrate, through blogs of ‘Aspies’ (groups identifying as having Asperger characteristics), the experience of being medicalised, as bloggers illustrate the impact felt and meanings they constructed through this process. Bloggers can serve to demystify medicalisation and refute the position assigned to them by society, medics and their families. They aim to promote a positive view of Aspies and contend the diagnosis of autism. However, ‘the experts position themselves as “experts”’ (O’Dell and Brownlow, 2005, p.196) by claiming the general public have a lack of knowledge and understanding of scientific procedures and means of evaluation. In one report cited, the public’s views held on the link between the MMR vaccine and autism were compared to a religious belief against which was pitted medical ‘objective data’(O’Dell and Brownlow, 2005).

And certainly there does seem to be some evidence that scientific research has been used strategically. Service users claim professionals ‘don’t have a clue what it’s like, experimenting’ (Bagatell 2007, p.423) with medication to control the symptoms. Bumiller (2008) takes a historical view of medicine’s interest in autism and claims this led to the definition of autism as a medical condition. This medical hegemonic construction of autism is now a requirement to earn eligibility for services but without such labelling there is no other system or process that is open to parents and people with autism. In developing a critique of the medical profession Baumiller cites the deaf community and reviews the implications of the moral panic over the reported ‘autism epidemic’ (Bumiller, 2008, p.970). This way of framing the ‘truth’ of autism builds upon a deep-seated, historical ‘regime of knowledge’ in the Foucauldian sense.

The neurodiversity movement have positioned themselves in resistance to medicalisation and the negative language used with regard to autism, e.g. ‘epidemic’ suggests that others can be
contaminated and made ill also. This movement, constructing and enforcing its own voice may be seen as a culturally distinct group. However, the hazard is that a positive distinct neurodiverse group is an ideal state that may not now or ever exist. It does not take account of the other worlds in which people with autism live. Some families and people with autism have not embraced this construction and will be excluded. It is essentially an all-embracing philosophical position but difficult to enact while functioning in the wider society with its preconceptions and ideological prejudices (Bumiller, 2008).

1.3.3. What the parents say: Negotiating pathologised and disabled parent positions

While research into the causes and treatment of autism is prolific, relatively little research has focused on the impact on family life and support (Pellicano, 2013). Within the literature the voice of parents has been constrained into predetermined categories and restrictive measures for wide-scale surveys, typically focused on gathering information e.g. regarding stresses and services (Hodge and Runswick-Cole 2008). Through the discourses and relationships between parents and professionals the meaning of having a child with autism is mutually constructed. One of the most enduring themes in anthologies of parents’ experiences is that of the frustration involved in dealing with what they see as transient, unsympathetic or unhelpful professionals and failing systems. Many note that when diagnosis was given they felt they were alone and floundering: ‘We seemed to be left totally alone to cope with an increasingly distraught child’ (Brown, 1998 p.22).

The professionals involved with the parents and diagnosis were typically medical staff whose expertise lay in using the diagnostic criteria to assess and providing the label, but their relationship to what happened after diagnosis was less clear. At best, the parents felt the diagnostic team did not have access to services nor could they deal with the issues or their needs, in fact:

‘Most of the doctors just gave us a diagnosis without any thought to intervention’ (Richman, 2001 p.155).

‘As soon as the experts surmised Jamey’s level of care was out of their league, they wrote their reports and split’ (Oakley, 2008 p.77).

At worst, the parents suspected that the medical and support services and staff were indifferent or were actually working against them:

‘The cursory brush-off we received when we tried to interest different physicians… a uniform and amazing lack of curiosity on the part of the professionals’ (Schulze, 1998 p.224).
'For me, the hardest part of our experience has not been John himself, but rather the difficulty of obtaining and keeping services' (Swezey, 2008 p.104).

This indifference developed for some parents into a suspicion that information was being kept from them to save professionals time, efforts and money even to the point where they claimed they were penalised if they did not conform to the agendas and decisions of professionals. Penalisation can take many forms but one all-or-nothing example is where specialist education services are denied because a parent decides it is better for their child to attend mainstream school (Woodcock and Tregaski, 2008). Parent accounts situate the professionals within ‘the system’, a wider network of professional health, social care or educational facilities and the state; the system is a distant big brother-style gatekeeper for knowledge and services: ‘Schools and state agencies often don’t really want parents to know what is available... an elaborate, often secretive system’ (Oakley, 2008 p.77).

1.4. Avoiding affect and effectiveness through policy

While consultation with parents is included and even used at times to provide a rationale for strategic directions (e.g. a one stop shop for parents’ enquiries) researchers and service providers do not engage with intrinsic concepts and issues. In the anthologies, and as will emerge in the later empirical chapters, parents use affect talk frequently and to striking effect. Therefore, I will use here the concept of affect as one demonstration, applying it to the Autism Strategy and Action Plan for Northern Ireland and drawing on parents’ response to its implementation, Broken Promises (Autism NI, 2016). Anthologies by parents, critical autism papers and some policy documents e.g. the Autism Strategy for Northern Ireland are awash with affect talk in parent accounts. By this I mean they use emotion talk but their talk also reflects an intensity and sense of urgency or force beyond a simple expression of feeling e.g. in expressing their frustration it is enhanced by talk of struggles. This section explores, a little, why this is a continuing gloomy theme in parents’ experiences and talk, and links it to restricted policy development and implementation.

Parents use language of affect and emotive talk, about professionals, which pivots around axes of interest and empathy (Woodcock and Tegaski, 2008). Yet, what tends to get acknowledged and incorporated into research and policy are parent stresses, their coping strategies and the technologies of support (Orsini and Smith 2010; Blackman et al, 2008). Initial consultations for the Autism Strategy and Action Plan NI (2013), the key strategy documents for autism in Northern Ireland, included parents talk of love for their child, exclusion, confusion, distress and ‘battles’.
These expressions provided a rationale for the strategy and proposed actions. This should have meant that parents’ voices, strategy, practice and experience would be lined up. Yet after a period of 2 or 3 years parents, through parent organisations, railed against the discrepancy between what these policy documents proposed and instructed and their experiences of failing supports (Autism NI, 2016). Their voices, strategy, practice and experiences did not line up. The strategy contains eleven key themes containing sixteen strategic priorities overall:

| Awareness                        | 1. Deliver an autism awareness programme within government departments for frontline staff; and  
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<th>2. Promote opportunities to raise awareness about autism generally.</th>
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| Accessibility                    | 1. Improve accessibility to travel and transport for people with autism;  
|                                  | 2. Ensure that communications and signposting information is available and accessible by people with autism; and  
|                                  | 3. Ensure that a range of advocacy services are available across the various sectors for people and families living with autism. |
| Children, Young People and Family| 1. Provide timely joined up support services for families living with autism;  
|                                  | 2. Promote awareness regarding the availability of support services available to families in their area; and  
|                                  | 3. Ensure that support and interventions is provided for carers of people with autism. |
| Health and Wellbeing             | 1. Enhance access to health and wellbeing programmes for people with autism;  
|                                  | 2. Enhance and promote early recognition and early intervention for people with autism; and  
| Education                        | 1. Continue to build capacity in schools to effectively meet the needs of children and young people with autism;  
|                                  | 2. Provide effective support to parents and carers of children and young people with autism to ensure they are involved and informed regarding their child or children’s education;  
|                                  | 3. Formalise collaboration between health and social care and education sector to help improve support, including specialist support; and  
|                                  | 4. Expand trans-disciplinary assessments, interventions and support for children and young people with complex needs. |
| Transitions                                      | 1. Ensure that transition planning takes account of the needs of people with autism; and  
|                                                | 2. Deliver co-ordinated and integrated seamless care across transition stages for people with autism throughout their lives. |
| Employability                                   | 1. Increase awareness about the support available to people with autism to help access opportunities for employment, training, and life-long learning; and  
|                                                | 2. Promote opportunities to access and attain employment, training and life-long learning for people with autism. |
| Independence, Choice and Control                | 1. Provide supported independent living options for people with autism;  
|                                                | 2. Provide advice and support on the impact of Welfare Reform for people with autism their families and carers;  
|                                                | 3. Increase the use of self directed support within health and social care for people with autism; and  
|                                                | 4. Commission and establish a multi-agency autism service pilot for people and families living with autism in NI. |
| Access to Justice                               | 1. Provide protection, support and information for people with autism who come into contact with the criminal justice system;  
|                                                | 2. Improve services for victims and witness in the criminal justice system encompassing the needs of people with autism;  
|                                                | 3. Review and revise guidance for practitioners within the criminal justice system to take account of the needs of people with autism; and  
|                                                | 4. Promote autism awareness across criminal justice organisations. |
| Being Part of the Community                     | 1. Establish and raise awareness about community social activity for people with autism, their families and carers. |
| Participation and Active Citizenship            | 1. Involve people with autism in the design, development and review of relevant policy across government departments. |

This policy, typical of its type, prescribes preferred cultural values, identities and social systems while simultaneously producing space for relations of power that contradict these features. Policy does this via the ways it is established and transmitted and the ambiguity built in which allows for interpretation (Yanow, 1993). The themes in the table and their priorities indeed leave room for institutions and professionals to continue to mobilise their powerful positions and resources as they wish. Policy, according to parents in their Broken Promises (Autism NI, 2016) paper, has not translated into action and has not addressed their needs.
‘We have found some great examples of autistic people being supported because of an individual service, charity or person. But in too many cases, people are struggling to get services and are being forced to fight for support, leading them to feel isolated, frustrated and alienated from the services they need and the communities they want to be part of…. But it’s not just support that has been lacking. So has oversight and accountability. Since the publication of the Strategy and Action Plan, parents, carers, autistic adults and the autism sector have not been involved in the oversight of its implementation. This has led to frustration, disillusionment and the feeling that there is a lack of accountability’ (Autism NI, 2016).

The parent organisation points to a fundamental issue of involvement and what this means. Arnstein (1969) argued that consultation, without citizen control or delegated power, amounts to tokenism on her scale of citizen participation. Parents seem to agree. They accuse professionals and government of producing sophisticated strategies which, in practice, distract and rebuff meaningful dialogue or agency to them while providing apparent forums, opportunities and encouragement for participation and collaboration (Autism NI 2016).

For the most part parent ‘engagement’ by institutions of professionals has been conceptualised as solutions to technical problems (Orsini and Smith, 2010). The proposals are ambiguous so it is unclear what level of involvement autistic people and their families should have or what this means. Certainly it does not provide for them to have agency. The focus on awareness is praiseworthy but awareness of what aspect is unclear. What about a movement to ‘acceptance’ as much as awareness and what would that mean? The strategy does not address the fact that the concept is variable and contested; it is fully reified in legislation and policy. There is no mechanism for addressing affect and no apparent appreciation of the actual workings of affect. Generating autism legislation, a strategy and an action plan was a huge project but it seems to miss some fundamental debates and points because in creation and consultation it relied on traditional structures, procedures and divisions and even conceptualisations. Autism, knowledge and power were treated as unproblematic thus any possibilities emerging from the project were maintained within traditional constraints. In reviewing the table the policy was, arguably, constructed not to address the needs of autistic people and their families but to address the statutory, institutional and cultural/social obligations to construct a strategy.

Parents complain that progress is not being made, that nothing is being learnt from parents’ experiences and that good practice and practical knowledge is not being shared. They struggle to have a voice that is taken seriously or used constructively but they are powerless to effectively
challenge professionals’ procedures or conclusions (Woodcock and Tregaskis, 2008). However, they use a form of discursive manipulation, resistance by controlled conforming (Firestone, 2008): ‘When talking to professionals, particularly medical professionals... we found it helpful to do our homework first... at appointments, we obtained the best results by staying calm and paying due respect to the expertise of the professional, but we remained firm about our desires when necessary’ (Ferris and Ferris, 1998 p 188).

The above quote highlights how parents managed their position of powerlessness by apparently giving the professionals the respect their position in society demanded, while equipping themselves with tools for assertiveness and empowerment: clarity, resolution and knowledge. The final point to note, however, is that the anthologies by parents were authored by well-educated and professionally-employed parents, and there is virtually no voice in the literature for parents from lower socio-economic backgrounds.

1.5. Diverging Trends

Already in the chapter there is evidence of a polarising of positions in autism interests and I could call them establishment and anti-establishment because these terms seem to sit as comfortably over the range of issues and sub-positions as any other. This polarisation pervades a number of areas such as autistic people’s forums, diagnostic practice, interventions, parent organisations and research. This section will use one debate, the empathy and humanity debate, to demonstrate the seriousness of the politicising and ideological context of autism diagnosis. A position on either side of this debate means a world of difference to how a professional may approach diagnosis and to the claim of worth made by a parent for their child.

Being human and autistic: Constructing the empathy criterion

This disturbing debate centres on a narrowing language of ‘humanity’ which questions the autistic person’s claim to humanity on the grounds of lack of empathy. The leading proponent of this development in framing autism is the eminent Cambridge Professor Simon Baron-Cohen, but he is not alone (McDonagh, 2013). Baron-Cohen has focused, for some time, on providing evidence of a lack of empathy in autistic people (Baron-Cohen 2011; 2003). More recently he has initiated a discussion around evaluative criteria for ‘humanity’ mainly based on the concept of autism. The concept of autism, as embedded in the diagnostic criteria, has been accused of being so reductionist that it severely limits our understanding of the autistic person, in particular their variability as the purpose of such an approach to autism is to produce standard, homogenised
markers for prediction. It relies on categorising to the extent that the idea of personhood is actually reconstructed without appreciation of a diverse range of experience and being (Murray, 2017). Baron-Cohen excludes autistic people from the concept of humanity through the criterion of empathy; by constructing particular principles of empathy which, by definition of the diagnosis autistic people are unable to meet, and arguing that empathy is core to humanity Baron-Cohen (2011) excludes autistic people from being fully human. Baron-Cohen and others position autism as outside human norms by formulating the concept for ‘human’ in increasingly restrictive terms (McDonagh, 2013).

The wording of autism diagnostic criteria is reminiscent of Galton and Guy’s eugenics discourses (Rose, 1979). Translating terminology from eugenics to autism discourses, ‘deficiency’ becomes ‘deficit’ in the DSM. Avdi (2005) and others claim autistic people and their families are pathologised in neoliberal and individualistic narratives of autism, similarly to eugenics discourses. ‘All this misery is the result of personal defects and vices’ (Guy, 1873, cited in Rose, 1979, p.22). The Eugenics movement also embraced measurement and thresholds to define normal. ‘Intelligence tests will bring tens of thousands of these high-grade defectives under the surveillance and protection of society’ (Galton, cited in Rose, 1979, p.13). In effect this is not much different to the ideology and aims of the DSM which uses various psychological assessments to diagnose autistic individuals in society. As Galton notes, part of the justification for a register and services is to protect either the individual and or society but as Camus is credited with noting, ‘the welfare of the people in particular has always been the alibi of tyrants, and it provides the further advantage of giving the servants of tyranny a good conscience’. As such it should be incumbent on all decision-makers and welders of power in autism strategy to consider whether indeed their actions are truly acting in the interests of autistic people and their families or if they are simply attempting to manage a socio-economic irritant, mediating this by apparent benevolence.

The parent attending the diagnostic assessment may be viewed, not as a parent of a child whose diversity is worthy of acceptance and support, but as a parent of a ‘non-human’. Such a difference in framing can make a huge difference to a parent’s experience and their ability to negotiate with professionals, the public and even their child. If the autistic child is ‘non-human’ or disordered then they become the property of the experts and are taken out of the realm of typical, normal parenting practices.

Baron-Cohen has framed autistic people as lacking empathy and then argued that empathy is the key to the concept of humanity. This could be developed to suggest that autistic people by
definition cannot achieve full human status. Aside from the obvious horror that the logical
conclusion to this may be a new eugenics, the evidence suggesting other interpretations carry
some weight of evidence must call into question this position. Indeed much of the argument
against this comes from autistic people themselves who accuse Baron-Cohen as lacking empathy
in regard to neurodiversity and complain that they suffer from the problem of ‘Double Empathy’

‘The ‘double empathy problem’: a disjuncture in reciprocity between two differently disposed
social actors which becomes more marked the wider the disjuncture in dispositional perceptions
of the lifeworld – perceived as a breach in the ‘natural attitude’ of what constitutes ‘social reality’
for ‘non-autistic spectrum’ people and yet an everyday and often traumatic experience for
‘autistic people’ (Milton 2012, p884)

Agosta (2010) debates the availability of an uncontested definition of empathy or stability of the
concept. Bielsky (2010, cited in McDonagh 2013) found that his sample of 21st Century American
students were 40% less empathetic than similar samples in the 1980s – and were rather more
narcissistic. Empathy, it appears, is a socially constructed production and the concept itself is
culturally defined. Historically, there is no evidence of empathy being linked so centrally to
human identity, it is now recognised that it is not a uniquely human trait, and only trace mentions
appear in prominent autism research. The empathy link to autism was only constructed in 1990
and was not in the original expositions by Kanner and Asperger (McDonagh, 2015). It was
tentative even then by Baron-Cohen, Frith and other ‘experts’ until Baron-Cohen connected firmly
via his controversial notion of the extreme male brain conceptualising of autism (Baron-Cohen,
2003).

Milton (2012) disputes the validity of the construction of the empathy criterion as a result of a
double empathy problem on the basis of the following premises:

1. Traditional understanding states that empathy is the ability to understand the nuances or
   ‘subtext’ of a social situation and autistic people do not have this ability.

2. ‘Social subtext is never fully given as a set of a priori circumstances, but is actively constructed
   by social agents engaged in material and mental production’ (p.884).

3. Traditional approaches, e.g. cognitive psychology, developmental and medical approaches,
   assume that there are rules for social behaviour. There is evidence that people follow patterns
   but these are then reified into fixed notions of norms.
4. If, in fact we take into account that empathy is co-constructed by social agents then this must include autistic people [N.B. Baron-Cohen could argue that it must not if autistic people are less than human, but that means he is using his conclusion as part of his argument thus working up a fallacious argument, begging the question]. Including autistic people as co-constructors can change our understanding of the concept of empathy. What has happened is that the concept has been formed in the absence of including a significant group of the population, since 1 in 100 now may be diagnosed autistic.

5. The final main point is that Baron-Cohen’s argument is a demonstration of lack of empathy in itself by neurotypical theorists. Autistic people must empathise with neurotypical people or they are disordered, but neurotypicals do not have to empathise with autistics because they are difficult to understand.

I include this because the argument works to help explain the incommensurate nature of communication between parents and professionals in the diagnostic process. The empathy gap between the establishment and autistic movements can be exaggerated because the clinical process provides a distancing from the autistic person and their family. Parents’ subjectivity and affect is overlooked by the use of schedules of set and standard questions; the lack of context for empathy presents an obstacle to empathising with the parent and the autistic person. In addition, if professionals do not empathise with the autistic child they do not get to the level of understanding or engagement that might be useful to help parents understand their child better. Othering occurs and the consequences are profound in relation to the position of the autistic person and their family. The ‘natural attitude’ (Garfinkel, 1967) assumes certain norms of behaviour and functioning to which autistic people do not fit and so they are ‘other’. When this occurs and there is a problem of empathising, or having space to be a different way, the position of those who assume a natural attitude (i.e. norms defined by the ‘normal’ population) is that blame rests on those outside the norms. They are pathologised and must be ‘worked’ by experts (Said 1987, Milton 2012). Milton suggests, and Butler takes this a step further, that this othering, pathologising and natural attitude are internalised by families and autistic people so that they become the proponents and subjects of their own oppression.

We must be clear in the thesis that this is about the parents and professionals rather than the autistic person. There is an inherent issue with this in that autistic people may now see parents as complicit or colluding in the positioning of autism and autistic people as ‘the problem’ and the object to be fixed. Indeed, it is clear why this may be so as parents are engaged in all the
processes around diagnosis, interventions and care. However, parents are doing so in an environment of existing dominant discourses, strict procedures for accessing support and are challenged in understanding and using the traditional approaches to parenting. They do not have the open possibilities and are constrained themselves but they have more voice than the autistic person, even Milton.

**Conclusion to the chapter**

This chapter has provided an overview of some of the issues raised by current practices in autism diagnosis. It specifically focused on different perspectives on autism: the public, professionals and parents. The core argument is that parents’ and professionals’ ways of talking about and understanding autism are, despite exposure to a common public discourse, sometimes incommensurate. Rather than coming together openly to explore the child’s needs, there are different stakeholder investments, category memberships, discursive genres and practices which result in manipulation at best and conflict at worst. Unfortunately, the empathy debate demonstrates that positions appear to be polarising rather than converging. The next chapter will explore the social context of autism diagnosis, particularly neoliberalism. Neoliberalism is a pervasive ideological system which has been accused of widening the socio-economic gaps in general but I argue that it has a particularly pejorative impact on (neuro)diversity.
Chapter 2

Power and Possibilities

In Chapter 1 distinct stakeholder positions were outlined and the relationship between parents and professionals was characterised as problematic, as indeed was the very concept of an autism diagnosis. One key issue raised, which will be developed here, is how professional power and status is achieved and maintained while parents’ frustration with their inability to negotiate services grows.

Power is understood, by parents, to be held by professionals in a number of ways: through access to information, knowledge, qualifications, access to other professionals and services, resources and even as a result of their socio-economic backgrounds or alliances to other dominant groups in society. The individual parent subjected to professional scrutiny in autism assessment ‘can be seen as both object, target and instrument in a complex but describable relation of knowledge and power’ (Rose, 1979, p.15). Parents’ rhetorical work to persuade doctors that their child was ‘worthy’ of assessment demonstrates a number of issues to do with expert knowledge (Goin-Kochel, Mackintosh and Myers, 2006). Parents do not, in research, locate themselves as experts and claim knowledge and their access to it is restricted. This is somewhat redressed in the parents’ anthologies where experiential knowledge is given some status but ‘physicians often minimise or dismiss parents’ concerns’ (Goin-Kochel et al, 2006, p440).

Chapter 2 explores some of the macro-level context and meta-issues surrounding parents and professionals, progressing on from their viewpoints toward considering the relationship between them during autism assessments. It exposes detail of the assessment protocols and gatekeeping and the ‘significant struggle during the process of obtaining an autism diagnosis’ which may result in some parents waiting 5 years before diagnosis is confirmed or services are denied or restricted (Goin-Kochel et al, 2006, p440). The final section of the chapter considers debates and alternative approaches to diagnostic practices, included to initiate debate about potential change in the current episteme. Each offers innovative ontologies and methodologies for diagnostic practices which embed more emancipatory and anti-discriminatory values and practices.
2.1. Neoliberal society, individualism and policing values

This section sets autism diagnostic procedures and the positioning of institutions and individuals within a socio-cultural context. As a UK based research site I draw on sociological affirmations to make an assumption that ideological context can be understood as neoliberalist and individualist (Beck, 1992 and Giddens 1991). The concepts of individual freedom and individual responsibility are ones which emerge most predominantly at the twentieth century. The neoliberal dual concept of ‘individual freedom and equality’ is an oxymoron - when people attempt to exercise their individual freedom they are inevitably unequal in terms of their abilities to do so. Althusser identified the implicit notion of agency embedded in the concept of individual freedom and equality as fraudulent, ‘arguing that bourgeois institutions attribute agency to individuals only to hide the determining effect of social structures on behaviour’ (Arribas-Ayllon and Walkerdine, 2008, p.112). ‘Individual freedom and equality’ is a phrase commonly associated with neoliberal propaganda but Beck argues that in this revised world:

‘Inequalities by no means disappear. They merely become redefined in terms of an individualisation of social risks. The result is that social problems are increasingly perceived in terms of psychological dispositions: as personal inadequacies, guilt feelings, anxieties, conflicts and neuroses... Social crises appear as individual crises, which no longer (or are only very indirectly) perceived in terms of their rootedness in the social realm. This is one of the explanations for the current revival of interest in psychology’ (Beck 1992, p. 100).

I embrace Beck’s statement to provide explanations for the current rise in status of related professions, including those involved in autism assessment and diagnosis and for its contribution to explaining the rise in diagnosis itself. To cope with social problems, now foisted on individuals to bear the burden of responsibility, people are often forced to negotiate and even form ambiguous, unpalatable and conflicting alliances (Beck, 1992). Hence, the autistic advocacy movements accuse parents of colluding with professionals while parents are often at odds with professionals and dispute services provision. These more enduring conflicts are connected to ascribed characteristics such as autism or other topographies of diversity/differentness. The autistic person, and their families, are made individually responsible, accountable and the inequality justified by their deficit characterisation and the panic over their economic and social impact on those who are viewed as more individually successful and responsible or dependable (Eyal et al, 2010).

The current neoliberal climate of individual responsibility supports only those that can claim worthiness are seen as deserving of services, especially if the service is state/tax funded as in the
UK (Orsini and Davidson, 2013). There is a catch 22 scenario forming therein since help-seeking or even referral for help, such as autism services, implicitly suggests that the individual is not worthy because they are individually at fault; they (and their autistic child) are pathologised (Avdi, 2005). The medical model does not operate successfully in autism sufficiently to support autistic people and their families to be released from such a fate. It seeks to find causes and cures and in doing so it manages the responsibility for medical patients. Causes are biological and thus beyond individual responsibility and medicine cures so they are grateful to the medics and worthy of the investment. The narrative for autism is entirely different although the medical model attempts to address it in the same way. Despite significant funding, causes are elusive and cures have, at best, erratic success and not sufficiently explicitly so to counter the suspicions of bad management by parents or to alleviate blame for the autistic individual.

2.2. Institutional discourses and practices of power

Acknowledging professionals as agents of institutions (parents are also agents of the institution of ‘family’), this brief section will highlight how discourses of power are embedded and transmitted through institutional discourses and practices, in policies, protocols, ideologies and values. It relates specifically to the action of assessment and diagnosing autism in the institutional setting through professionals’ employment of assessment tools such as the Autism Diagnostic Interview-Revised (ADI-R) and scheduled meetings with parents.

The ‘institution’ is a hierarchical organisation of discursive relations both textual and in talk in action but with a special relationship between these media. In autism diagnosis there is a clear allocation of agency to the professional via the institution and its practices. The circulation of texts, of documents is part of this transfer and key to understanding the control wielded over and by members and clients of the institution. They constitute and regulate agency, specifying ‘capacities to control and mobilise the work of others’ (Smith, 2005, p.183). For example, professionals in autism assessment can command reports from other professionals such as teachers and therapists. This control extends to the parent. The process of transposing the parents’ experience and meaning-making about their child and their situation into the institutional category of a diagnosis begins with an interrogation/consultation: “Needs” are thus “objectively” determined; patients do not participate; their desires and concerns are not to be confused with formalised and standardised interrogation built into the (report)’ (Smith, 2005 p.189).
This is all carried out in the spirit of what I would call neoliberal ‘benevolent othering’. To position professionals and the institutions as benevolent they construct the ‘needy other’ whom they can help. However, the relationship is not reciprocal, and institutional and professional benevolence is contingent on conforming to their value-laden practices (Grey, 2016).

As a direct consequence of the procedures practiced by the professionals and colluded in by the parents, the procedures themselves can be viewed as systemic barriers to parent, and even professional, autonomy. Procedures are often constructed by institutions and professionals in a way that meet the needs of the service provider, especially in a high demand area and autism diagnosis has grown to challenge services to meet demand. Standardisation and norms of the agency result in professional evasion of diverse or individualised needs by way of a focus on a homogenised group needs approach (Woodcock and Tregaski, 2008).

2.2.1. Autism services – policy and protocols

Autism assessment services in Northern Ireland are directed by a number of documented macro-level devices for diagnosis which should ideally be reviewed as instruments of benevolent othering:


- **Trust level**: Six Steps of Autism Care Regional Autistic Spectrum Disorder Network for Northern Ireland (For Children and Young People in Northern Ireland) (2011) and more generic Trust Vision, Mission and Principles. For example, the Six Trust ‘Guiding Principles’ include the commitment to provide safe, person-centered and compassionate care and advocacy; to promote wellbeing and early intervention, partnership working, appropriate knowledge, skills and attributes, achieve efficiency, effectiveness and equity across all our resources. Its values include respect and dignity but they must ‘make the most of the financial and other resources we have through effective and efficient service
planning, delivery and evaluation’ which would potentially put them at odds with being person-centred.

- Family level: There are numerous documents for parents distributed by Trusts and the voluntary sector but I will prioritise one here which directly relates to the guidance to professionals and is conceived from the genealogy of the macro-level legislation and policy: Six steps of autism care; Autism: A guide for families (2011) ‘How does the ‘Six Steps of Autism Care’ start? (http://www.belfasttrust.hscni.net/AutismAssessmentandInterventionService.htm accessed 03-01-17)

Since the focus of the thesis is on the experience, meaning-making and subjectification of parents this section will briefly discuss the ‘Six steps of autism care; Autism: A guide for families’ (2011). Within the guide is evidence locally of the psy complex in operation, using psychological concepts to regulate family and social life and relationships. There are clear indications of both surveillance and control, for example, over services, family practice (through ‘training’) and constraining opportunities or possibilities:

The team provides a range of services including:

- assessments that will diagnose if a child or young person has Autism Spectrum Disorder (ASD)
- help and support for children, young people and their families who are being assessed for ASD
- a range of interventions for children, young people and their families who have been diagnosed with ASD
- training to families whose child has been diagnosed with ASD...

This is simply a snippet of information but even in this overview the focus on standardised procedures and instruments is signposted. The effect of this is to erect boundaries and set the agenda off on particular directions. For example, ‘assessments’ will determine the label assigned to the child, rather than the parents and professionals. The process is reified and not negotiable because the formalised assessments contain the power of scientific knowledge and measures (Rose, 1979). The status and position of parents also begins to be moulded in statements of surveillance and control. As well as assessments as a form of surveillance, parents will obtain institutionally decreed support and interventions. These will be deployed from a predetermined ‘range of interventions’, including ‘training’ which suggests parents are, as yet, incompetent. ‘Training’ is a rather clinical or work-based approach to family relations.
2.2.2. Institutionalising the experts

Service providers on the frontline, i.e. professionals, are ‘situated agents’ (Prior and Barnes, 2011). They act, interpret and have a set of discourses and practices within a range of possibilities that are shaped by the organisational contexts in which they work. This includes the culture, strategies and policies/procedures of the organisation even when these are conflicted or troubled themselves, and contradictions are immediately evident in the institutional statements above. The aim of the various guidelines is to provide benchmarked, consistent and standardised practices. These would be in contradiction to the person-centred values espoused since this would require a flexible approach to diverse needs - unless, of course, these persons were a homogeneous group. Given the neurodiversity of autism homogeneity would be a hard claim to make (Timimi, Gardner and McCabe, 2011). Professionals are situated, or situate themselves, in this context. They may have their own limited agency to draw upon subjective and alternative meaning making, e.g. their own empathy or moral compasses. However, the development of services along the managerial governances of services means that the context of the institution has taken on an enhanced strength and ubiquity (Prior and Barnes 2011; Newman, 2007).

Furthermore, the language of the elite, the professionals or politics is not the language of the people (Bakhtin 1984). Professionals continue to hold an exclusive and elite position (Foucault, 1961; 1969). This is observable in inter-agency co-operation. Professionals have in common ‘expert habitus’ (Mackenzie and Leach Scully, 2007) and can command knowledge from other experts. Professionals in education, child care, speech and language therapy, psychology and paediatrics collaborate as experts, sharing reports and programmes of intervention. However, parents’ scope for co-operation at the institutional level lies mainly in parent and advocacy organisations and these have a rather troubled identity (see below). The discourses of professionals appears to favour neoliberal values rather than care values despite some written guidance directing practice to be client-focused: ‘although the legislation adopts the language of the social model, professionals continue to apply individual model based interventionist strategies, aimed at changing the child and the family, rather than identifying and dismantling external barriers to achievement’ (Hodge and Runswick-Cole 2008).

Conflicts of interest and of ideological positions arise for professionals on a societal and institutional level. As a result of neoliberal values and focus on individualism, the achievements of particular individuals earns more recognition and reward than before (Beck 1992). Thus professionals are encouraged to be competitive and produce the outcomes that are not just self-
sustaining but elevating – activities which can be promoted in far-reaching manners and which in turn promote their creators/architects. When considering the design and implementation of the diagnostic criteria and protocols such individual justifications should be considered as part of the architecture (Eyal et al, 2010).

**Linear development and linear service protocols**

In psychology Piaget’s stage theory of childhood development helped to establish norms and measurements and established criteria which could be used to categorise the ‘abnormal’. Such measurement facilitated the surveillance of child development as parents, and more significantly professionals, had benchmarks for assessment. The stage theory also speaks to a linear notion of development and in general of life which has developed in more recent times in contrast to pre-industrial personal ontologies of a cyclical, variable and unstable quality of life and nature (Bakhtin, 1984). This notion of a linear progression is one that puts pressure on autistic individuals, families and even professionals to adhere to programmes of linear development and practice typified by flowcharts:

THIS DIAGRAM HAS BEEN REMOVED FROM THE ACCESS VERSION OF THE E-THESIS ON ADVICE OF THE OPEN UNIVERSITY RIGHTS TEAM
In addition, the neoliberal child grows out of the notions of individualism, individual freedom and individual responsibility. Conviction to such ideals produces a ‘natural’ understanding of self-government, self-regulation and self-discipline which must be nurtured through childhood. Play is scrutinised and mobilised as a mechanism for development of regulatory behaviour and experience and abhorrent behaviour becomes more broadly defined because of the narrow scope of ‘normalisation’ of behaviours associated with stage models, measurement and the concern over productivity and contributions of members of society. Childhood becomes an object for scientific knowledge, expertise and management and a focus for Government policy. The role of the parent is to act as the primary executor of management for policy, an agent of the state via the institution of the family (Ayllon-Arribas and Walkerdine, 2008). When the child fails to meet institutional, scientific, or social thresholds for norms then both child and parent are blamed collectively. The parent is judged to have failed their child, the society and state institutional standards (Holt, 2010).
2.3. Parenting: ideologies, parent organisations and parenting competence

In this section, the neoliberal parent will be discussed in relation to their help-seeking for an autism diagnosis for their child. Parents in society in general and in dealing with service providers can risk a position of being unworthy by association:

‘If there's something wrong with the bitch, there'll be something wrong with the pup’ – J.K. Rowling (Prisoner of Azkaban).

The parent is, of course, inevitably and inextricably linked to the neoliberal concept of the child. J.K Rowling characterises criticism by association, whereby criticism for deviance from the acceptable norms can move between parent and child such that they share space as receptacles of social, and professional, judgement. However, the parent’s position in relation to the child and deviance inevitably carries particular connotations of accountability. It could be argued that this is a three way game – the state, parent and child – where the state holds all the cards. The child was seen, in the last century, as the carrier of genetic material and a primary concern for the moral fibre of society, and a moral blank slate. As such the state and society had a moral imperative to monitor, control or regulate and constrain deviance (Ayllon-Arribas and Walkerdine, 2008). More recently, the child is a focus of policy but with an inclusivity agenda: it is brought into being as an autistic child by diagnosis and invited to participate in its own subjectification by processes of involvement, such as children’s service user groups (Goodley and Runswick-Cole, 2012). In another twist of state management, responsibility for control has become devolved to the parent and deviance can be measured against norms and linear stages (Ayllon-Arribas and Walkerdine, 2008).

2.3.1. Ideological double jeopardy or catch 22

In the modern western neoliberal, risk-aware and risk-averse society (Beck, 1992) parents are simultaneously held responsible for appropriate child care and regarded as potentially incompetent to make informed decisions (Johnson and Capdevila, 2014). They walk a thin line in help-seeking, negotiating potential positions between being worthy of help and being disparaged. A range of research on NHS professional views of patients found patients categorised as ‘good’ and ‘bad’ (Dingwall and Murray 1983; Sointu 2017) or even ‘rubbish’ (Jeffrey 1979). Sointu relates this sort of talk as ‘entrenching inequality’ as bad patients are those that question professional knowledge, and perhaps therefore status, whether rightly or wrongly. ‘Good’ patients typically
went along with the medical procedures and knowledge but also tended to have similar skills and values sets, i.e. belong to a similar socio-economic group or at least conform to similar attributes. In the ‘moral economy’ of the NHS some people are understood institutionally and subjectively as more or less worthy and thus can access services and help more readily from professionals. This can be assessed by determining the amount of time and effort professionals are willing to invest in them or even how convinced they will be by their claims (Higashi et al 2013; Fineman 1991). Grey (2016) argues that provider’s construct status claims through ‘benevolent othering’ – i.e. professional gets status from helping worthy parents and families and thus the construct persists, serving multiple functions.

Institutionally constructed discourses of autism constitute the parent as a bad parent, in need of state assessment and interventions. Parents are compelled to participate in compulsory parenting or training programmes which produce experiences of ‘spoil identities’ (Holt, 2010). Burman (2008) highlights that such ‘parenting expertise’ is constructed from neoliberal values of what is appropriate in parenting. It is based on a neurotypical, middle-class reading of developmental psychology where parents are responsible for ensuring their child conforms to the dominant norms in society and looks forward to playing a contributory role. When this aim is not achieved or is at risk of not being achieved, then the state is entitled to take control, make demands and ‘train’ the parents by means of ‘expert’ interventions. Parents are expected to help-seek actively and be responsible for researching and accessing information and ‘training’ yet there is an ‘increasing insertion of the expert voice’ into parenting practices (Johnson and Capdevila, 2014, p.861). Parents are expected essentially to actively instigate and maintain their own subjection or attract criticism:

‘In fact, if the parents have not become autism experts, the family therapist is advised to wonder what keeps them from learning more about autism. Learning about autism helps parents cope, select and coordinate appropriate treatments, and advocate effectively on their child’s behalf.’ (Solomon and Chung, 2012, P251).

The practice of assessment, involving significant case histories, reports from other professionals, observation and interviews, also occasions a process of ongoing and extensive assessment of the parents, their family life, values and parenting practice (Singh, 2004: Berman and Wilson, 2009). Such practice to diagnose and treat children can proceed to blaming the parent (typically the mother) and this can have a detrimental impact on the parent-identity as well as restrict their time, movement and opportunities (Frigerio, Montali and Fine, 2013).
Essentially the parent experiences a ‘disabling’ of their own identity both by the demands of parenting but also by the practices of professionals, the clinical and educational interventions and finally by the society as a whole. In such a devaluing process the parents ability to negotiate ‘what must be done but also by whom, allocating rights, duties and obligations in ways that (re)produce power relationships and efforts to resistance’ are gravely diminished (Frigerio et al, 2013, p.599).

Activist mothers ‘of disabled children negotiate, manage and approach their daily lives, operating within what are described by feminist scholars as oppressive mothering ideologies and disabling environments’ (Runswick-Cole, 2008p.199). The activist mother turning to parent organisations may not experience the resistance to oppression they may expect or desire.

2.3.2. Parent organisations

Debate already rages about the role of parent organisation. The thesis will not engage with this in any detail but it is important to appreciate the role of such organisations as parents often turn to them for information and advocacy. Their role is ambiguous and many parents also do not engage with them beyond reading websites.

Many parent organisations mobilise discourses and practices of pseudo or para professional knowledge in order to gain the status and power to have a voice in policy (Runswick-Cole, 2007; Eyal 2010). Information from the main parent organisation in Northern Ireland, Autism NI, strongly constructs the authoring organisation as the ‘expert’, taking language from the discourse of the medical expert or professional and citing lists of research studies and training/educational material for parents and professionals. Shaw (2002) argues that lay people, parents and organisations such as Autism NI appropriate expert knowledge, by ‘a process of training so that they [the patients] know “what to look for” and the “legitimate ways” in which they can contribute’ (p.293). In this way parents and parent organisations endow experts with righteousness and power and they invest into this by adopting the expert stances, categories and knowledge. They then can only assess on the expert-establish agenda and meanings rather than questioning it on a fundamental level.

This presents dilemmas in positioning and ideology. On the one hand, it constructs the organisation as an expert player on the highest level and, on the other as being of and for ordinary families. The organisation has been caught between two posts in its role as autism and family advocate. On the one hand it has to access power and influence for people with autistic spectrum disorder and their families and also convince parents that it is a force to join to help them access
services and support available, but on the other hand it must be accessible and approachable to people with autism, parents, families and carers. These two goals are not particularly commensurate as the accessing of power and status requires a framing that often excludes many families, particularly those who actually require such specific support and whose usual discourse does not have a voice at the macro level of autism policy.

Clarke and Van Amerom (2007) argued that it was actually in the organisations’ interests to construct a negative, deficit-focused and need-led model. The organisation would not exist if it did not construct such an understanding nor would it be able to attract funding and develop mechanisms to ‘suppress and subordinate those whom they serve’ (p772). In fact they use a combination of stances simultaneously to progress their cause: philanthropic, positioning the organisation as helping and working toward treatment; heroic, emphasising autism links to outstanding role models and highlighting high moral character; and compensatory, finding redeeming qualities to compensate for the predominantly presented negative features.

2.4. Partnerships? The relational positioning of power

This section looks specifically at the relational positioning for the neoliberal expert and parent and the consequences, mainly for parents, of such positioning in terms of knowledge and power. Much is made in all levels of institutional policy of ‘partnership’ working (for example, The Autism Strategy for NI, the NICE guidelines and NHS and Trust policy documents). Each raises expectations that parents should be ‘involved, informed, consulted and agreements’ formed between professionals and parents. However, in reality, partnership between parents and professionals are fraught with challenges, tensions and even conflict because the culture, values, methods and processes do not always align to these ambitious aims (Hodge and Runswick-Cole, 2008). Indeed the Autism NI paper, Broken Promises (2016) argues these points at the local level. The Autism Strategy for Northern Ireland was one of the few documents which acknowledged tensions and powerful negative emotions in the relationship between professionals and parents. In acknowledging these it raised expectations yet did not provide appropriate strategies or carry enough force to produce the actions it prescribed. There was insufficient provision within the document for policing the strategy so parents produced their own, damning, evaluation conceptualising their disappointment as ‘Broken Promises’. The Autism Strategy was a brave attempt in policy to address the incommensurate interlocutions between the professional and service seeker but it failed to address the core issues within parents talk, taking at face value statements about the battles to get services. It did not sufficiently acknowledge, or address, affect or autonomy. The next section takes knowledge and knowing as a way of addressing affect and
autonomy through knowledge, which Foucault (1969) identified as core to retrieving the agenda and negotiating power.

2.4.1. **Knowledge and knowing: Dialoguing differentiation**

Within these polarised and conflicting relations parents experience feelings of vulnerability; a misplaced word could jeopardise their opportunity to access a service or even a diagnosis (Murray, 2017). They face pressure to conform to professional expectations and risk being categorised as difficult (Azzopardi, 2000). At the core of this divergent position and incommensurate discourses is the relationship of parent and professional to autism as a disability, and to knowledge about that disability. Parents of autistic children experience their own disabling and criticisms of their parenting (Bumiller, 2013). As such their lived experience is very different to that of the professional; parents are positioned in the habitus of disability while professionals are positioned in the habitus of experts (Mackenzie and Leach Scully 2007; Hodge and Runswick-Cole, 2008).

Parents are urged to be prepared and show respect in their dealings with professionals (Ferris and Ferris, 1998) but this can be challenging (Hodge and Runswick-Cole, 2008). One area of challenge is the sharing of knowledge. This area creates frustrations because parents feel, firstly, they are unable to adequately share knowledge of their child, secondly, professionals withhold knowledge rather than freely share and finally, professionals demonstrate reluctance to discuss emotions or complexities. Affect has been used as a disabling strategy against parents almost since autism was conceptualised. Parents have been unfairly accused of causing autism by being unemotional and detached yet now their voices are dismissed on the grounds that they are too emotionally involved with their child. A second challenge to parent and professional partnerships, despite access to online information blurring the boundaries of knowledge and its access, are ‘hierarchies of knowledge’ (Hodge and Runswick-Cole, 2008, p.639). Parents in the process of diagnosis are positioned as ‘informants’ and their capacity for autonomy is thus compromised. Decision-making is institutional and deferred to professionals.

I have separated out 2 forms of erudition, one is priori and propositional while the other is experiential. Knowing connotes experiencing, connecting, being aware, empathising, sharing, affecting and being affected by. Thus knowing includes affect. In contrast, knowledge cannot access this depth, complexity and richness of relating to intersubjective epistemological systems of beliefs (Hofer and Pintrich 1997). Formal knowledge of the professionals is privileged over experiential knowledge and this can create obstacles, inequity and may result in deterioration in decision-making (Woodcock and Tregaski, 2008).
This hierarchy of knowledge resonates with feminism research on the social devaluing of experiential knowledge of women, including mothers specifically (Clinchy, 2002). Women’s ways of knowing amounts to a received knowledge. Women can receive and even pass on knowledge but do not value or have valued their own knowing as ‘knowledge’ or consider themselves or are considered, competent to generate new knowledge (Belenky 1986). However, the intention here is not to specifically adopt a feminist standpoint or develop a feminist critique (this is already owned as a limitation of the thesis, albeit the similarity is stark) but to establish compounded devaluing for mothers. In addition to distinguishing between professional/parent knowledge and knowing, the devaluing of women’s ways of knowing presents a double obstacle for the mothers in the study. They are not simply demoted in the knowledge hierarchy by being parents but doubly by being women and parents.

Collins and Evans (2008) also indicate that involvement of the non-expert parent can take the professional into a ‘problem of extension’ (p.10). Is it right or helpful to give over knowledge and upset the boundaries of expert and non-expert? The right of the professional to have privileged knowledge over parents is based on many assumptions around autism, ability, roles (expert and parent), protocols, ethics, resource management, parenting etc and these need to be interrogated and reflected upon. The expert status of parents is a complex issue too and Collins and Evans distinction between lay expertise and expertise without qualifications is an interesting conjecture on which to ponder and debate on another occasion.

2.4.2. Subjection and subjectification

The above sections highlight numerous constraints for parents in projecting a voice and accessing power. This section explores the subjection of parents and varying processes of subjectifications relevant to their participation in autism diagnosis. The foundational premise is that the ‘parent of an autistic child’ is brought into existence as a subject through the machinations of power in the process of autism assessment and diagnosis (Butler, 1997; Foucault, 1975), e.g. as the concept of crime brings about a criminal class for incarceration. If there were no property or rules about how to behave then the criminal subject would not exist. In terms of autism there is a clear topology between the diagnosis and subjectification of the autistic person, the parent and, to a lesser explored degree, the professional.

‘When talking to professionals, particularly medical professionals... we found it helpful to do our homework first... at appointments, we obtained the best results by staying calm and paying due
respect to the expertise of the professional, but we remained firm about our desires when necessary’ (Ferris and Ferris, 1998 p 188).

The above signifies a recommended identity position for parents (from an experienced parent) but it is a complex and ambiguous one. The subjective identity of parents is constructed through positioning by others and the situational constraints on active self-positioning imposed externally, especially in a prescribed context such as autism assessment and diagnosis, ‘where existence is always conferred from elsewhere, it marks a primary vulnerability to the Other in order to be’ (Butler, 1997, p21).

Subjectification relates to the process of an individual becoming a subject, for example from Althusser’s interpellation if the parent is hailed as a mother then they become a parenting/mothering subject or in the case of the participants in this study, a parent of a disabled child becomes such a subject in the process of being treated as one i.e. being subjectified as a parent of a disabled child and this may be different to being subjectified as the parent of a special child or a parent of, simply, a child. Subjection is being under the dominance of another, an institution, a system or an individual. Butler (1997) identifies this as a paradox when we consider individuals actually collude in their own subjection. Parents have and exercise power, but within the constraints of their subjectification, this is directed in a particular way and with particular consequences that only can partially achieve something of benefit to their desires. To access any power in the process they must give up autonomy to subjectification, or be further excluded by way of losing worth and entitlement to services. This would be too high a cost for the parent.

However, it is not a comfortable position nor does it entirely mobilise autonomy so parents resist their subjectification – this becomes an iterative process of negotiation. There is a troubled relationship between agency, power and the possibilities that power produces as their assemblages can be moved, changed, loosened. Agency, in fact, is a logical conclusion to subjectification and subordination and has been acted out this way in all liberation movements whether slight or grand (Butler, 1997). Parents and professionals appropriate power in multiple ways and with multiple consequences. The diagnosis of the child brings about the subjectification of the parent and the establishment and protocols bring about the subjectification of the professional so both are subjected by the protocols, by the diagnostic criteria, by the institutionalisation of ‘autism’. Yet professionals are given power through these institutionalised relations, then they enact further power so they are doubly endowed, ‘the subject eclipses the conditions of its own emerging; it eclipses power with power. The conditions not only make possible the subject but enter into the subjects’ formulations’ (Butler, 1997, p14). From this I
would propose that professionals in particular lose awareness and fail to resist their own 
subjectification. However, both parents and professionals are caught up in a restrictive practice 
which obstructs reflexivity, obscures harm and constrains possibilities, ‘the subject emerges both 
as the effect of a prior power and as the condition of possibility for a radically conditioned form of 
agency’ (Butler, 1997, p15).

2.5. **Possibilities: Shifting the episteme toward new knowledge regimes**

To move beyond such subjectified positioning I find Dan Goodley’s work (e.g. Goodley and Roets 
2008, based on Deleuze and Guttari), on rhizomes, nomads and multiplicity particularly useful. 
The sense of possibilities emerging from numerous points and in multiple directions is freeing and 
inspiring. Butler also talks about a ‘vassilation between the already-there and the yet-to-come’ 
(Butler, 1997, p18) which is akin to the idea of emerging possibilities and the rhizome. The 
relationship between subjectification and agency means that people move in and out of multiple 
positions, they utilise and embrace the tools of subjectification in multiple different ways and this 
emerges out of context, needs, competence etc and has multiple consequences, some of which 
are agency and subordination. So, we see a vassilation between these but we must not miss the 
fact that there are infinite positions between and around these – more like a rhizome event.

How can a parent open up the possibilities and widen their range of ways of talking about their 
child and perform alternative and more active/direct agency? The constraints and punishments 
are severe and difficult to resist. Parents in anthologies identify subordination as the only way to 
have voice accepted and heard, albeit only if the voice is presented in a particular way and limited 
to particular issues (Ferris and Ferris, 1998). This is a choice but within a very constrained set of 
discursive practices. This section aims to explore what possibilities are already emerging through 
discourses and practices that provide alternative directions to the DSM and medical hegemony.

2.5.1. **Ideological shifts**

Much of the thrust of recent government (the Autism Strategy for NI, for example) and 
professional practice (see PPI, for example) promote a more inclusive approach to working with 
autistic people and their families and this spills over into modern research models. However, the 
above discussions raise concern that participation and partnership, and its benefits, can be 
compromised by parents joining forces with professionals and academics on the professionals’ 
terms e.g. taking the ‘professional’ stance in their research approaches or surveys with theory-
driven constraints on knowledge production.
Many researchers advocate for participants to be ‘full members of the research team’ (Raymaker and Nicolaidis, 2015, p169) but I make the case that participants can never be ‘full members’. For full membership to occur there are many obstacles to overcome:

- Set the agenda and make decisions about research question and methodology.
- Appropriate theoretical knowledge.
- Access to relevant material, recruitment, funding, processes such as ethics etc.

Given the discussion above on knowledge and knowing, let’s take the example of ‘appropriate theoretical knowledge’. This looks fairly contentious as it could be argued that academic researchers or practitioner researchers also do not have ‘appropriate knowledge’ as they lack the experiential knowledge of the participants. This is indeed so but, given the value and power associated with experiential knowledge as opposed to expert knowledge integrating participant and ‘expert’ knowledge into a discreet piece of work inevitably means that there is inequality of status and agency i.e. the expert will have the knowledge and position to drive their own agenda and ideas much more forcefully than the participant member. Often participants engage with academics or professionals to ensure their voices are heard at all, as this offers legitimacy and weight otherwise impossible to achieve – see Autism NI for examples. This is entirely understandable and indeed has provided some beneficial insights. However, the cost of using this approach to vocalise participants is that their voices are changed somewhat, sanitised or intellectualised to be more acceptable. In essence, what this often means is that the power of their feelings are diluted or the range or depth of their issues is masked.

Raymaker and Nicolaidis (2015) expose the systemic approach to knowledge production, highlighting how knowledge circulates and changes as it moves between professionals, the public and specific minority populations. The circulation of knowledge production is dynamic and generative but it is ultimately dominated by ‘expert’ power and thus expert knowledge, ‘stigmatisation can also be cloaked in the academic language of academic discourse’ (p172). One group that have been put forward as a possibly uber researcher in autism is the autistic academic or the parent academic. These people offer a depth of insight that is exceptionally helpful but again making assumptions that this is the way forward excludes particular perspectives, it could be assumed that the intellectual, eloquent and middle class assertive parent provides the ‘voice’ of all parents again masking issues around citizenship, access, multiple discriminations and so on. Also, the assumption that the most able autistic person can talk for such a heterogeneous group as autistic individuals is fallacious. Participant researchers often do not have the skills to critically
evaluate research or to present critiques in customarily acceptable ways and so their views can be further dismissed even at the end point, batted back with the assertion that professionals do ‘sciences’ and so produce facts (Raymaker and Nicolaidis, 2015).

However, the autistic community themselves have produced a plethora of research which seem to fulfil many purposes from tendering some form of validation in itself to providing insightful critiques into the ontological and methodological directions of academics and professionals (Chamak et al, 2008).

2.5.2. Positive positioning

There are now movements to present autism in a much more positive manner to the world. However, one of the most assertive activities has been the formation of, mainly online, groups of ‘Aspies’, people on the autism spectrum who use ICT to construct a social world. In contrast to the organisations which are intended to help autistic people and their families, Aspie blogs reject the ‘disabling environment’ that creates uncertainty about autism and carries much conflicting and incomplete or simply inaccurate information with the effect of confusing parents to the point that they assign blame to themselves, each other or the child when life becomes difficult. They pick out ‘judgemental neighbours, financial pressures, an environment that is often stressful and dangerous to children, and the what’s-in-it-for-me attitude of the modern world’ but recognise it is a wider structural issue in society (Clarke and Van Amerom 1997, p 771). Bagatell (2007) identified Aspie space as as a ‘figured world’:

‘Skinner et al. (2001) defined figured worlds as ‘historical and social phenomena into which individuals enter or are recruited and which are reproduced and developed by and through the practices of their participants... In a figured world discourses, activities and artefacts come to have unique meanings. Figured worlds are social worlds, with certain actors (people) and actions valued over others. Identities, according to Holland and co-workers, are constructed in these figured worlds, worlds mediated by relationships of power. Identities are crafted through participation in activities and by discourses becoming part of one’s consciousness or inner speech.’ (Bagatell, 2007 p419)

The figured world of Aspies is an exclusive world itself, inaccessible to anyone on the autism spectrum who is not ‘high functioning’ but it is arguably one of the only places that uncompromisingly presents people with Aspergers and autism positively, to be accepted and respected inclusive of this aspect of themselves. I have drawn on the Aspie figured world as an
example for parent possibilities and to maintain coherence with directions of autistic people themselves. Aspies mobilised discourses and practices to co-construct their own identity and experiences without having them invented, constructed or interpreted by others (Bagatell 2007).

However, there are complications with this isolated sub-system of networks and meanings and it is not without costs. Figured worlds cannot be completely isolated from the ancestry of their discourses, all utterances have a past and can arguably never be truly unique. Nor can the figured world be truly in splendid isolation, nor especially so their members. Each individual’s identity is multirelationally constructed and as much as there needs to exist some continuity or there must be ways of dealing with the disparity between worlds of meaning, orchestrating the voices ‘that are part of one’s inner speech’ (Bagatell 2007, p422) to produce a harmonic experience.

There are some notable issues for Aspies and the neurodiversity movement which mark it as different to all the other autism advocacy organisations. For one thing the movement opposes ‘those who advocate for a cure’ (Bumiller, 2005, p.968). An assertion of a positive identity does not permit the search for a cure since ‘cure’ constructs autism as a sickness and supports a negative identity. The resistance to sympathisers and those who think they are supporting autistic people may increase the levels of isolation for people with autism. Such a side-effect may not be a problem to the neurodiversity movement but may be to parents of young autistic children for multiple reasons. Restructuring of roles, contexts and social constructions apparently is a painful process.

Two sets of dilemmas have arisen for parents already, though these were constructed in the literature mainly in terms of the mother. The first was the concept of the professional – whether professionals were trusted experts or secretive and unsympathetic gatekeepers. The second was the parent’s understanding of their autistic child – whether to accept the child unconditionally or to problematise the child and surround them in negative meanings. If they accept the child then they cannot ask for help, treatment or intervention as the asking for this inevitably reformulates the meaning of the autistic child as faulty and difficult and contradicts the unconditional acceptance.

Shaked (2005) however, showed that women can also help to reframe autism to earn acceptance for autistic children. In the ultra-Orthodox community in Israel the children in Shaked’s study were reconstructed as highly spiritual individuals, ‘based on the notion of the transmigration of souls’ (Shaked, 2005, p2194). In the face of social formulation of autism as retribution for their own or
others’ sins, mothers taught autistic children the religious rituals from which they were excluded and so mothers became mediators:

‘Mothers can either perceive the child through the eyes of social norms or examine the norms through the child’s viewpoint in ways that may either reaffirm the norms or challenge them’ (Shaked, 2005, p2196).

These are powerful identities for both the child and the mother (within that particular study), enabled by religious beliefs and diverse understandings of the autistic child, in contrast to the social positions constructed for women in other settings. The mothers drew on the existing beliefs and networks to integrate with and anchor new understandings, to ‘seek to amend the child’s status by... culturally accepted terms, so that he is viewed as a legitimate member of society’ (Shaked, 2005, p2198).

2.5.3. Critical autism studies: Critical cogitations on autism diagnosis

The multiple yet limited positions ascribed to autistic people and their parents, have serious consequences foremost at diagnosis, since the connotations established at that point have a regulatory power to anchor subsequent claims and views of the experiences of autistic individuals and their families (Orsini and Davidson, 2015). The literature demonstrates how particular networks of meanings are predominantly negative and disabling or restrictive. It is the role of critical autism studies to challenge the restrictive meanings and stimulate a rethinking of the understandings, relationships and practices associated with autism through closer examination of these meanings and their consequences. As such it has a primacy for the current thesis and I, as researcher and writer, align my work most closely with this movement. The themes of the thesis - power, knowledge and possibilities - contain much of the interests of the movement and it shares a common value of acceptance of diversity.

Milton (2012), an autistic academic writes, ‘such cognitive-behavioural discourses abstain from acknowledging the universal issue of relationality and interaction in the formation of a contested and constantly reconstructed social reality, produced through the agency of its ‘actors’’. This expresses what is usually implicit in the discourses of parents when they complain that professionals or services don’t give them resources or make them wait for far too long. The implication is that this is a deliberate act of gatekeeping knowledge or resources or of holding power. The concept of intentionality alongside agency raises questions around the calculation or deliberateness of professional actions which are beyond the scope of this thesis but it must be...
acknowledged as inherent, albeit implicitly so, in parents talk. Intentionality talk is caught up in stake management and is an inherent part of how people have a stake in their intentionality, and in the other person’s intentionality (Potter 1996).

Mallet and Runswick-Cole (2016) argue that ‘autism has become a commodity; it is produced, exchanged, traded and consumed.’ (p110). As such we look at all the stakeholder’s interests and levels of investment, their risks and returns.

2.5.4. Institutional shifts

According to Rose (1979) knowledge may be used to achieve ‘social closure’. In such a practice knowledge is used to exert power over another to the extent to exclude others from opportunities and options and close off possibilities. Indeed, autism diagnostic criteria and the prescribed processes of assessment and diagnosing present a form of closure. Diagnosis is a liminal space of meaning-making and affect where multiple understandings, positions and possibilities are constrained by the macro and micro-level discourses and practices of the neoliberal episteme. We have problematized the episteme but there are emerging institutional shifts which expose alternative constructions of diagnosis and intervention. This section will briefly identify 3: Parent and Patient Involvement, the British Psychological Society Clinical Division and Open Dialogue.

Personal and Public Involvement (PPI)

Across the UK health and social care providers, a range of similar movements have gathered pace around the concept of service user participation as a result of the Health and Social Care Board Strategy (2012) Valuing People, Valuing Their Participation; A Strategy for Personal and Public Involvement’. The strategy aims to promote inclusion and in the paper PPI ‘…Means discussing with those who use our services and the public: their ideas, your plans; their experiences, your experiences; why services need to change; what people want from services; how to make the best use of resources; and how to improve the quality and safety of services’ (p.8).

The paper also includes reference to Arnstein’s (1969) ladder of citizen participation so I would use this ladder to account for the limitations of PPI.
<table>
<thead>
<tr>
<th>Degree of Participation</th>
<th>Description</th>
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<tbody>
<tr>
<td>8 Citizen control</td>
<td>HIGH Users have authority to take decisions</td>
</tr>
<tr>
<td>7 Delegated power</td>
<td>Users have authority to take selected decisions</td>
</tr>
<tr>
<td>6 Partnership</td>
<td>User’s views are sought before decisions are finalised</td>
</tr>
<tr>
<td>5 Placation</td>
<td>Users may take the initiative to influence decisions</td>
</tr>
<tr>
<td>4 Consultation</td>
<td>Decisions are publicised and explained before implementation</td>
</tr>
<tr>
<td>3 Informing</td>
<td>LOW Information is given about decisions made</td>
</tr>
<tr>
<td>2 Therapy</td>
<td></td>
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<td>1 Manipulation</td>
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<tr>
<td>Non-participation</td>
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Figure 2.2 Arnstein’s ladder of citizen participation (Arnstein, 1969, p217)

With regard to ‘informing’ and ‘consultation’ categories, under which assessment and diagnostic meetings may fall, Arnstein argues, ‘citizens may indeed hear and be heard. But under these conditions they lack the power to insure that their views will be heeded by the powerful. When participation is restricted to these levels, there is no follow through, no “muscle,” hence no assurance of changing the status quo’ (p217).

Arnstein does acknowledge that neither the service users nor decision-makers such as professionals are homogeneous groups but she justifies the simplified structure because in many cases, ‘the have-nots really do perceive the powerful as a monolithic “system,” and powerholders actually do view the have-nots as a sea of “those people.”
At best we can look at this ladder and how the elements operate within it as providing opportunities to give power at different levels. At worst ‘powerholders can hire poor people to co-opt them, to placate them, or to utilize the have-nots’ special skills and insights’ (p218). The PPI strategy produces a framework which looks ideologically emancipatory but in practice allows institutions and professionals to maintain the system for the status quo, subjugating the masses by the disempowering practices of consultations, assessments, pathologising, placating and so on.

There is strong consensus for the concept of participation and even partnerships with service users but ‘when the have-nots define participation as redistribution of power’ (Arnstein p216) this agreement is tested beyond limits most professionals and organisations are willing to tolerate. The premise that professionals are the experts in autism and parents are the experts in their child is not effectively disrupted in this approach.

For Arnstein, the various levels of involvement are understood in terms of their access to power and decision-making but the Board asserts that ‘meaningful involvement’ will be at the level of seeking users views only rather than delegating any authority or decision-making power to users. The claim that it facilitates users to challenge, influence and advise is highly dubious for this is only possible at the bequest of the decision-makers and is not in the users gift to guarantee. Basically, it is tokenism because it puts in place a mechanism for users’ views to be offered but no mechanism to ensure these views are actually influential or carry any power at all. In the process of consultation the professional retains all right to use or ignore parents views and the professional maintains all power to diagnose and release services and support.

BPS Position Statement

In 2007 John Cromby, Dave Harper and Paula Reavey advocated ‘Moving Beyond Diagnosis’ in a special edition of the British Psychological Society (BPS) publication ‘The Psychologist’. It marked a shift for the association and initiated a transparent questioning of diagnostic criteria, protocols and practices. The result of the ensuing debates was a statement paper, Division of Clinical Psychology Position Statement on the ‘Classification of Behaviour and Experience in Relation to Functional Psychiatric Diagnoses: Time for a Paradigm Shift’ (BPS, 2013). This marked a significant development both in practice but also in status for the old medical knowledge regimes:

‘The DCP is of the view that it is timely and appropriate to affirm publicly that the current classification system as outlined in DSM and ICD, in respect of the functional psychiatric diagnoses, has significant conceptual and empirical limitations. Consequently, there is a need for a paradigm
shift in relation to the experiences that these diagnoses refer to, towards a conceptual system which is no longer based on a ‘disease’ model’ (BPS, 2013, p.1).

The two main points of the paper were; firstly, that the system of criteria was restrictive and reductionist and secondly that the medical model on which diagnostic criteria are based is fundamentally inappropriate. The application of the ‘disease’ model leads practitioners to approach mental health and neurodiversity in a manner as unsuitable as interviewing a molecule.

**Figure 2.3 Open Dialogue as an alternative to assessment and diagnostic practices**

Open dialogue is an approach to psychosis that has yet to be applied in autism service delivery. At its core are values that resonate strongly with the caring principles of the NHS and most professionals, yet its practice looks very different to NICE guidelines and Trust practices. Open dialogue is not concerned with diagnosis but responds to calls for help when a person has a psychotic episode. At least two therapists together meet with the person and person/people close to them within 12 hours. The practice involves talking together openly. The therapists discuss their understanding and any suggestions (including debating these between therapists) with the person and they do this over a number of sessions. Open dialogue professionals have reported very positive results with a reduction in psychotic episodes and a decrease in the use of medications (Seikkula, Alakare & Aaltonen 2011). The purpose of meeting is dialogue and so ‘change’ is a consequence rather than first purpose. The approach actually changes the concept of ‘psychosis’ for both practitioners and in a wider sense – this could have profound implications and could provide a way to explore a better meaning making around autism.
So what are the issues around using open dialogue in autism services and how willing may professionals and policy makers, directors of services and other stakeholders be in adopting such practice? Razzaque and Wood reported on one survey of NHS users and professionals in the UK in 2015 which, unsurprisingly, concluded that although the principles of open dialogue were viewed positively (unsurprising since they are essentially embedded in care policy and training e.g. person-centred) NHS staff identified a number of challenges or obstacles to adopting the approach. One of the key debates raised was whether the principals actually existed in NHS practice, despite awareness that these were embedded in care values. The key principals of open dialogue were summarised as:

- The provision of immediate help: Access to services in the first 24 hours with the aim of integrating treatment as soon as possible within the patient’s everyday life. ‘Open Dialogue is client focused and likely to provide a much better and much more helpful experience for the client’ (Staff participant, p.934).

- A social network perspective: Central involvement of patient’s key networks in care e.g. family, friends, employers, other care agencies, neighbours, who are all seen as partners or potential partners in the process. ‘I like the idea of dealing with the space around the individual, i.e. if an individual is mentally disturbed by abuse. To treat them long-term is harmful. To treat the issue and circumstances and to train them in life skills is a more useful approach and prevents a revolving door situation’ (service user participant, p935). ‘Able to give power and self-knowledge to the client with the support and kindness of mental health worker rather than imbalance of power’ (staff participant, p935).

- Flexibility and mobility: Adapting the therapeutic response to change in needs using the therapeutic models which best suit each case.

- Responsibility: The first staff contacted are to take charge of arranging first meetings and the initial team coordinates the entire treatment process.

- Psychological continuity: The same team in engaged with the social network throughout, and for as long as necessary.

- Tolerance of uncertainty: An active attitude among the therapists to stand together with the network, and allow for tolerance of uncertainty around the presentation and treatment that is
provided. Hodge and Runswick-Cole (2008) theorised that professionals withhold knowledge and their considerations out of concern that complexity, uncertainty and inconsistency may confuse or disturb. This is further evidenced in the policy and guidelines focus on providing clear and simple information.

- **Dialogism:** The focus is primarily on promoting dialogue, and secondarily on promoting change in the patient or in the family, thus fostering a sense of agency in service users and their family.

In terms of adopting or adapting this approach for autism services there is a clear overlap in principles in terms of the core care values i.e. with the Strategy for NI and NICE guidelines. Razzaque and Wood (2015) note also that ‘NHS mental health services have been developed in the context of medical based Victorian institutions which used extensive medical interventions to treat mental health patients in isolation from their social networks’ (p.932). This focuses on alleviating symptoms and rehabilitation in contrast to the open dialogue focus on the psychosocial experience and meaning making that people use to continually reconstruct life. It relates more closely to a social constructionist perspective to human understanding, and thus to a critical discursive psychological approach. However, the implementation of these takes very different routes and the extent to which these principles are adhered demonstrate huge discrepancies. These discrepancies are highlighted specifically and extensively by parents although they are variably acknowledged by policy makers and professionals. For example, in terms of immediate help a duty professional may indeed take a call and so there can be immediate contact with NHS staff but this would not equate to ‘immediate help’ and parents describe lengthy waits or obstacles to referral to autism services. A second example is the expert culture around assessment and diagnosis to which the families are referred. In this expert culture there is little tolerance of uncertainty by the service or the families as the professional is viewed as the ‘expert’ and there are expectations along with that concept around knowing and having certainty.

In fact, in the face of uncertainty families and others demonstrate dissatisfaction and lack of confidence because of the expectation that is already established – as a wider western culture, and as a specific NHS/service culture, we are essentially intolerant of uncertainty. This is probably enhanced with autism services and families, as the expectations around knowing and parenting a child are that parents should understand, have control over their children and be able to meet their needs so there are multiple levels of meanings that are intolerant of uncertainty.
Conclusion

Avdi’s (2000, 2005) work was one of the major initial influences on this research project, orienting research toward the parent’s understanding of autism and their relationship with professionals. But a range of literature, albeit still rather slim in volume, demonstrates the importance of the discursive resources brought to the table by parents and by professionals. For example, O’Dell and Brownlow’s 2005 study raised the issue of common knowledge and media dissemination of meanings around autism and these are as much a part of parent’s discursive resources as any internet search or NHS document – though perhaps not as much as their own interactions with their child. Professionals, on the other hand, can rely on powerful medical and expert discursive resources as Goin-Kochel et al (2006) highlight. A gap exists in autism research specifically in relation to the interactional process of autism assessment and diagnostic meetings when these two worlds collide. During this time parents construct a key framework to understand a child’s diagnosis of autism and the research aims to address this gap by analysing what is constructed in this discursive space between parents and professionals.
Chapter 3

The Theoretical and methodological Approach

As evident in the previous chapter, autism is a phenomenon researched prolifically for the last 5 decades, yet parenting an autistic child itself has attracted a limited level of interest and funding. The critical discursive psychological approach taken in this work is also less typical of the traditional approaches to examining the experience of families. In order to fully engage with this analytic approach it is expedient to forefront the methodological and theoretical perspective taken in the research, dislocating it from the next ‘method’ chapter. The purpose of this is to provide the theoretical frame for the thesis and to outline the epistemological tools.

Section 3.1 will provide a broad overview of discourse analysis, the turn to language in the social sciences and social constructionism as these provide the general foundations of the approach. Section 3.2 focuses in on some specific theoretical fields which influenced critical discursive psychology directly. The psychosocial discursive subject is briefly discussed in section 3.3 before section 3.4 outlines the premises of critical discursive psychology itself. Finally, section 3.5 outlines the conceptual tools used in critical discursive psychological analysis.

3.1. Introduction to discourse analysis

The research project employed the synthetic strategy of Critical Discursive Psychology (CDP), integrating the broader macro-level discursive practices in society and micro-level talk in action. The ontological position and epistemological aims, theory and methodology of CDP are intricately tangled – hence the title of the chapter. However, this approach needs to be set in the wider context of the rise of discourse analysis in social sciences and psychology to vindicate its related ontological position and the rationale for language as the most consistent epistemological focus for analysis. The theory of discourse analysis is drawn from social constructionism, which is concerned with how people construct their social worlds, but discourse analysis focuses specifically on the use of language in constructing meanings and practices. It developed alongside the wider cultural turn in social sciences which saw the emergence of cultural studies, with more emphasis on meaning within social activities and processes, and the turn to languages in sociology in the 1960s (McDonagh, 2013). This period has seen a movement toward cultural relativity and new epistemological theorising in social sciences. ‘Discourse analysis’ can be applied to any research involving language from the minutiae of language rules and specific patterns to how it is
used in a social context and cognitively processed. For a more apposite understanding of the term discourse it is necessary to sift through the ways it is used by academics. Potter and Wetherell (1987) highlight how:

‘Some continental discourse analysts such as Foucault take “discourse” to refer to much broader, historically developing, linguistic practices’ (Foucault, 1972). Some workers make a contrast between discourse analysts and conversation analysts on the basis of different theoretical and methodological strategies (Levinson, 1983), while others want to make a very different contrast between discourse analysis and text structures from actual linguistic performance (Halliday, 1978)’ (Potter and Wetherell 1987 p 6-7).

Discursive analysis covers a broad range of related approaches and so it is important to be specific in the approach taken in this thesis and its relation to the gamut. Language is an action and performs a function whether it is implicit or direct. It is used, though not intentionally so for the most part, to construct particular understandings, and language will diversify in response to what action it is performing, what its function is at any given moment.

‘The principle tenet of discourse analysis is that function... is demonstrated by language variation. The term construction is apposite for three reasons. First, it reminds us that accounts of events are built out of a variety of pre-existing linguistic resources, almost as a house is constructed from bricks, beams and so on. Second, construction implies active selection: some resources are included, some omitted. Finally, the notion of construction emphasises the potent, consequential nature of accounts... In a profound sense, accounts ‘construct’ reality’ (Potter and Wetherell, 1987, p.33-34).

It is imperative that the changing nature of accounts be emphasised and the implications of such dynamic constructions explored. Accounts can be adapted over context and time, and this impacts on how discursive psychologists study and use their data. Such data cannot be held as representative of larger sets of data or generalised in the same way as experimental psychologists’ tend to use their data, nor can it be replicated or tested necessarily. The data itself is the focus of the study, it is the subject rather than what it represents or symbolises.

‘The general problem for researchers such as Harré, who wish to explain behaviour through the control of rules, is that there can be no neutral, disinterested statements of rules and how they are applied’ (Potter and Wetherell, 1987, p. 73).
Discursive psychology emerged as part of the turn to languages in social psychology so is relatively new. It has been developed since the mid 1980’s as a response to limitations of the, traditionally dominant, cognitive experimental approaches to complex social issues. Psychologists, wanting to explore deeper understanding of attitudes and emotions than surveys allowed, exposed alternative ways to think about these issues through the work of linguistics and philosophers such as Michael Foucault. Discourse comprises of any language or utterance. However, the definition requires opening up from the usual conceptualising. It is not just about language used to communicate but about utterances which carry meaning of their own, that are actions in themselves. Discursive approaches to psychology do not just challenge the traditional approaches to psychological research, they also defy common-sense understanding of language as representative and communicative. Wetherell (2001) identifies discourse as: constitutive of social life in that it builds the social world; functional, as it actively does something; co-productional, because it is a product of more than one individual; relational, as words are given meaning through their relationship to other words; and indexical, for the action of language depends on their context of use. As Jonathon Potter and Margaret Wetherell’s 1987 book, ‘Discourse and Social Psychology: Beyond Attitudes and Behaviour’ introduced discourse analysis as a paradigm shift away from the traditional or mainstream approaches to social psychology, it is discussed here as a theoretical approach as well as simply a methodological approach.

There are a number of different forms of Discourse Analysis in social psychology but for the purposes of this research a critical discursive psychological approach will be adopted (Wetherell, 1998). This synthesises top-down and bottom up discursive approaches, permitting micro and macro level analyses. It is argued that this integrative approach, encompassing talk in action and how people draw on discursive resources, will produce a comprehensive picture of the social practices, positions and understandings constructed during autism assessment and diagnosis. The following sections erect the building blocks for CDP, its underlying philosophical and ontological assumptions and its epistemological aims, culminating in the theorising of specific analytical tools which are drawn upon in the data analysis chapter.

3.2. Three fields of influence

The following sub-sections will outline the most pertinent contributions from these theorists and approaches before proceeding to detail the additional influences, such as Foucault, on critical discursive psychology and describe the conceptual tools of the critical discursive psychological approach. Discursive psychology responded to critiques of Chomsky and drew on the work of Bakhtin, Austin, ethnomethodologists and, conversational analysts (Wetherell, 2007). Each of
these theorists and approaches brings something relevant to the thesis aim to critically analyse the practices of discourses in autism diagnosis. They will be used to address meta-issues of power and position and explore the gaps in the literature around parents meaning-making and its construction during diagnosis.

3.2.1. Creativity, rules and patterns: Chomsky to Bakhtin

Chomsky, in the first half of the 20th Century, was a leading theorist who established sets of grammatical rules which were very detailed but it is the circularity of Chomsky’s arguments and methodology that has influenced discourse analysis/psychology in their attempts to address these flaws. Chomsky chose to use specific types of language and sentences to form his theory thus essentially only using evidence which met the criteria of his theory. He also stressed “the importance of speakers’ intuitions” (Potter and Wetherell, 1987, p11) and further compounded the circularity of his argument by assuming that he could define what was grammatical or non-grammatical from his own experience of language. As actual speech does not follow such idealised and grammatical patterns and is not uniform or static, these are serious weaknesses which discursive analysts sought to overcome by drawing examples from actual, naturally-occurring talk. The final difficulty for discursive analysis was that if Chomsky’s view of speakers having limitless creativity in language were true then looking at naturally-occurring talk would be impossibly difficult in terms of examining performance data i.e. what the talk actually is and does. And, in fact, in examining ordinary conversations it became evident that creativity and originality in language was not so commonplace. A theoretical approach to language which could not take account of language as it actually happens naturally and does not include the rich performance data, while elegant, was severely limiting. Discursive analysts needed to develop underlying principals which facilitated a more encompassing approach to language.

Structuralists suggested that language was a system, and that meaning and understanding could be broken down into rules and relations:
‘The meaning of an element in the system arises by virtue of its opposition to the other elements’ (Kress, 2001 p31).

Structural linguists such as Saussure (1857 –1913) broke language systems down into characteristics and relations of form rather than meaning, assuming form and meaning can be established by convention. Semiology, championed by Saussure in the late 19th Century, focused on language as ‘sign’ with two rules: a syntagmatic rule relating to order of language and a paradigmatic rule relating to how options may be substituted. Applying these two rules allows the
utterance to be understood more than the actual words themselves as a consequence of the arbitrariness of words, the signs. The arbitrariness of the sign means that there is no concrete relationship between a word or signifier and that which is represented or the signified and that concepts or the signified are in themselves arbitrary as they are only understood in terms of the signifier and language can create different concepts depending on how it is applied. Ultimately, therefore, there are no absolute signifiers, they are all arbitrary. This leaves the analysis of language more reliant on the rules and systems than on the actual words themselves as they are arbitrary. Barthe, developing these ideas in the mid-20th Century, added a further level of meaning, the second level termed ‘myth’. At this new level an existing signifier can become the signified and another level of signifier can be culturally constructed. For example, a ‘building’ can be the signified with ‘house’ as a signifier but when the term ‘dream home’ is added at the second level it constructs a cultural artefact in language to which specific meanings are also attached. These meanings are culturally dependent and the application of them is dependent on the user’s competence with the complex system of social conventions around language and social action. Harré (1974) argues that this competence is developed through the user’s ‘knowledge of sets of social rules’ which regulate and allow us to interpret events and behaviour; discursive psychologists should investigate these contextual social rules (P&W 1987 p 58). Ultimately, ‘tendency to privilege linguistic constants, its failure to theorize conflict and its general disregard for context offered little challenge to the humanist notion of timeless human nature’ (Arribas-Ayllon & Walkerdine 2008, p92).

Labov (1972) claimed that the role of the ‘social’ is to establish the environment through language but the role of the individual is to ‘implement and substantiate’ (in Kress, 2001 p33). How we do that may also be determined by our communication competence. Critical linguistics assumed a social view of language and argued that language was a much more dynamic process. Wittgenstein regarded language as a toolkit (Potter, 2001). Meanings of words were as diverse as the applications of tools in the toolkit, making different forms of sense in different contexts and with reference to other words. It was Wittgenstein who first proposed the idea that words perform actions. For example, descriptions are practices in themselves, doing something more than merely reflecting. He also wrote about cultural practice as a ‘form of life’ within which knowledge is grounded, and argued that meaning within language could only be understood within the context in which it existed or was uttered i.e. within its ‘form of life’. This proposes an ‘insider perspective’ for researchers or at least that a much greater degree of appreciation and reflection would have to be embedded in any investigation of knowledge in discourse.
This idea of language doing something active was taken up further by Austin who produced a general theory of speech acts, claiming that ‘utterances both state and do things’ (Potter and Wetherell 1987, p.17). The distinction between stating and doing however, becomes merged as Austin recognised that in stating or describing anything the speech act also always does something; it creates or constructs a particular understanding of the thing it states or describes.

In the middle of the 20th Century, Austin presented an argument against the logical positivist view that the value of statements, ‘constantatives’, resided in their truth status. From this traditional position, sentences were only meaningful if their truthfulness could be established. Austin postulated that other sentences were important and called them ‘performatives’; they are not truth statements but are statements that do things and produce action. For the performatives to be accomplished successfully they must meet ‘felicity conditions’. These conditions state how recognised conventions must be fully and correctly followed (including intentions and thoughts), by appropriate persons and in appropriate circumstances. He came to realise that performative sentences also had truth elements in them and constantative statements also do something, and he joined the two elements into his compound ‘general theory of speech acts’. In this Austin claimed that a sentence has a meaning, a force and an effect and he adopted a social view of language as ‘human practice’ which is extremely relevant and useful to social psychologists’ efforts to appreciate how language is used in natural contexts. Although Austin’s theory was weak in exposition when applied to natural talk (as it was a philosophical approach rather than an applied theory), and it cannot deal with indirect or imprecise speech, nor take account of speech that serves multiple purposes or carries multiple meanings, the general theory of speech acts has still contributed some foundational ideas for critical discursive psychology.

Bahktin’s ideas are highly significant for the current research in exploring the precise ways that speech genres are constructed within communities and how these are complex and mobile to some extent. He came from a very different place to many of the other theorists and philosophers, applying Marxist ideas to language. He claimed, firstly, that language derives from struggle within social interaction and, secondly, that language is reciprocal. This gives language an ‘evaluative accent’ (Maybin 2001 p65) so that the term ‘autism’ for example may carry a negative meaning while ‘professional’ a positive meaning. This is rather a simplistic example, of course, because these terms can be regarded in multiple ways. However, with regard to gaining status, power and authority these evaluations often hold up rather well under closer examining.

Furthermore, Bahkin clarified the struggle as a pulling apart of two forces: an authoritative Centripetal force of dominant dogma such as that held by professionals, against a more diversified Centrifugal force with multiple and stratified language communities such as parents, autistic people and family or voluntary organisations. These conceptualisations are similar in notion to
that of the Foucauldian ‘centre’ and ‘margins’, whereby the margins can act to decentre the dominant discourses, but these have to struggle with the embeddedness of the ‘centre’ dominant narratives in the cultural context (Avdi, 2005). Bahktin also presents conceptual tools for understanding the ‘speech genres’ created by each group employing particular themes, constructions and styles. These are contextual and specific for the social purpose and can vary in stability and flexibility. In terms of the current research it will be helpful to regard the speech genres within the discourses between parents and professionals as very specific to the context, but spilling out to the wider context the sense of context can be flexible and fairly permeable. Another important contribution from Bahktin is the idea of ‘heteroglossia’. This takes the notion of language and populates it with ‘voices’ of others.

‘The word in language is always half someone else’s. It becomes one’s own only when the speaker populates it with their own intentions, their own accent, when they appropriate the word, adapting it to their own semantic and expressive intention... Language is not an abstract system of normative forms but rather a concrete heteroglot conception of the world... Each word tastes of the context and contexts in which it has lived its socially charged life’ (Bahktin 1981, p293-294).

To fully appreciate the meanings that language carries and constructs, language cannot, therefore be studied in isolation as attended by conversational analysts but any analysis must appreciate the history, diversity and context of the speech. In this research, parents and professionals appropriate different speech genres from the particular voices to which they have access. The relevance of Bahktin’s ideas to the approach taken in the current research is that it lays the foundation for integrating a top-down approach, exploring the discursive resources, the heteroglossia of voices, that participants bring to any discourse, to the bottom-up analysis of the talk as it happens. To ignore the history, genres and heteroglossic nature of talk and thus privilege talk as it happens would only expose part of the picture, as if people talk in vacuums of experience. Such a negligent view would overly emphasise the creative and agentic (Chomsky’s failing and a criticism aimed partially at CA and ethnomethodology) over the reliance on existing constraints and opportunities offered by discursive histories, context and resources.

3.2.2. Ethnomethodology and conversational analysis

‘Ethnomethodology – was to study how socially shared methods of practical reasoning are used to analyse, understand, and to act in the common-sense world of everyday life... Every aspect of shared understandings of the social world depends on a multiplicity of tacit reasoning. These
methods are socially shared and they are ceaselessly used during every waking moment to recognize ordinary social objects and events’ (Heritage 2001 p 50).

Ethnomethodology is the study of the ordinary practices of peoples and of how language is used in those practices to produce meaning and action. It is a highly descriptive method of approaching communities’ accounts of social practice and order. It emerged (though has transformed somewhat) specifically through Garfinkel’s approach to understanding *shared practices and understandings* in the everyday life and cultures that are an inherent part of society, and has fed directly into conversational analysis. The diagnosis of autism is a co-constructed activity in the talk between parent and professional but it relies on a range of socially shared practices and meanings at a range of levels as indicated in the above quote by Heritage. Chapter 1 briefly outlined the shared meanings of different groups which interact together also: the public and media, the professionals and institutions, and parents themselves.

Ethnomethodologists also point to a reflexive aspect of language, building in some level of autonomy for the speaker and some flexibility over how language is used. They make an assumption that language users actively chose language to do certain things which is in some contrast to a more social constructionist view of language as imposing meaning on the user. The ‘etcetera clause’ expounded by ethnomethodologists claims that language can be used in varying ways so is not limited to tight rules of application – indeed, anyone listening to a teenager using language should immediately be struck by the flexibility in meaning of words and phrases. The final claim by ethnomethodologists that has been taken up by discursive psychology is of ‘indexicality’, asserting that statements’ ‘meaning alters with their context of use’ (Potter and Wetherell, 1987, p23). This alteration is with regard to what is being referred to, or indexed. This led the way to greater focus on the context of language and the person using language in order to fully appreciate what utterances were doing. There has, however, been a heavy reliance on the researcher’s interpretation of what the language is doing and this often involves drawing on the researcher’s own assumptions and culturally-specific and idiosyncratic linguistic resources. Significantly, language is the principal frame of reference for understanding a community. Ethnomethodologists focus on social norms of a speech community rather than a logical relationship between language and the world i.e. they do not assume language represents a ‘reality’ out there. The approach, however, raises an issue over containment in the concept of the ‘community’. Research on the shared practices and discursive resources of a community must include a reflective discussion of whether a researcher is part of the community and involve a definition of the ‘community’ and its size. As a researcher, and co-constructor, I am or was part of: the Northern Ireland public community, a professional community, an academic community and
parent community. Therefore, I will include, in the final conclusion to the thesis, a reflective discussion that takes into account my affiliation in each speech community.

The main proponents in the early development of another form of discursive analysis, conversational analysis (CA), drew on the work of ethnomethodologists. They included Harvey Sacks, Emmanuel Schegloff and Gail Jefferson and focused on the natural and mundane talk that ‘has an essential part to play in the creation and maintenance of our social worlds’ (Potter and Wetherell, 1987, p 81). For CA, talk has to be examined within the context of its sequence and set in order to observe the rules and patterns as they naturally occur e.g. ‘adjacent pairs’ and ‘preference structure’ (Potter and Wetherell, 1987, p 81). ‘Conversational analysts study the way in which social organisation is accomplished in talk... Flexibly applied situated social practices rather than prescriptive, all-or-nothing, rules’ (Wetherell, 1998, p391). The focus for CA is on how people construct social order through interactional talk.

Sacks and other CA theorists argued that as social interaction is essentially orderly, follows rules and has patterns, these can be identified and used as data in psychology. Rules and patterns occur in ordinary discourse and should be explored in naturally occurring situations in order to reflect the talk as it happens and establish ecological validity. Talk is composed of sequences and taken out of sequence and context talk can change thus the validity of conducting research on naturally occurring talk revolves around the notion that to take it out of the natural occurrence changes it and interferes with these sequences and contexts. The procedures within talk are normative i.e. each part creates the next and so on and speakers should not depart from the procedures as doing so creates a confusing rule break. While CA initially focused on ‘ordinary talk’, more recent researchers in this vein have investigated institutional patterns of turn taking, sequential organisation, structure, repair of difficulties in speaking, hearing and understanding, story telling, word selection and so on (Heritage 2001). This is particular interest to the study of autism diagnosis as an institutionalised and clinical practice.

CA, however, is not so concerned about where language comes from and how or why it produces such complex and dynamic understandings in the wider sense. ‘For CA it is the members world, the world of the particular members in a particular occasion, a world that is embodied and displayed in their conduct with one another, which is the grounds and the object of the entire enterprise’ (Schegloff, 1998, p 416). However, my research was concerned with the origins and developments of autism diagnosis, understanding these as the discursive resources of professionals in the sense of formal knowledge regimes. Parents also brought a range of socially shared prior understanding to the talk in assessment and diagnosis and used these as their own
Discursive resources. Conversational analysts does not enter into a discussion of such resources because they regard theorising or applying ‘a priori’ knowledge to the talk as infringement, meddling and violation, and less than entirely or validly empirical (Wetherell, 1998).

**Categorisation** is a concept which spans ethnomethodology and conversational analysis and is relevant in terms of autism, parents and professionals being part of specific categories. Consideration of categorisation allows analysis of how language orientates to them and positions them in autism assessment and diagnosis:

‘Workers in the more linguistic orientated traditions of ethnomethodology and discourse analysis have been interested in how categories are constituted in everyday discourse and the various functions they satisfy… It is regarded as a social accomplishment… This work emphasises the action orientation of categorisation in discourse. It asks how categories are flexibly articulated in the course of certain sorts of talk and writing to accomplish particular goals, such as blaming or justifications.’ (Potter and Wetherell, 1987, p116).

Traditional psychological approaches to categorisation have focused on the cognitive processes (structure and organisation) and outcome categories and consequences rather than on how categorisation is constructed and the content of categories, the meanings. This is a very fixed notion of categories, where they are rigidly anchored into some preformed structures and ideas. For example, Wilder (1978) found that seeing people as part of a group, participants of an experiment judged the views of people as more similar when they were framed by the experimenter as being in a group. In other words, we homogenise groups and produce prototypes when we categorise people. The concern then is that leads inevitably and naturally to bias as an adaptive strategy, stereotyping and ultimately discrimination in some circumstances. This approach is limiting and rather negative in this sense, discursive psychologists call on a greater depth of understanding about what is being constructed within these processes and how flexible such categories may be. Potter and Wetherell, in exploring discourses of the white New Zealanders about Maoris have found that such prototypes are more variable than cognitive approaches would suggest or can reasonably accommodate (Potter and Wetherell, 1987).

Categories are formed but also policed i.e. maintained and secured through discourse. Sacks (1974 in Potter and Wetherell, 1987) also explored categories in ordinary talk and developed the idea of a ‘membership categorisation device’, grouping concepts together into higher order categories. These are active membership categorisations which work to put groups together, but they are also flexible and multiple in the sense that these groups can be placed into a range of membership categories and the meanings attached to them can alter depending on the
membership category to which they are associated within a particular discourse. These membership categories allow people to make sense of groups and ideas and to develop inferences about them and social actions. Comparing this approach to that of the concept of genres (Bakhtin) or a genealogical approach (Foucault) highlights that a categorical understanding of language is too formal to allow for the variability that often emerges in talk, and fails to stimulate analysis of meaning.

3.2.3. Post structuralism and Foucauldian discourse analysis

The work of French philosopher, Michel Foucault, offers ideas for critical discursive psychology around three main concepts of interest in this thesis: discourse, power and the subject. Foucault shifted the focus of analysis from the structuralist view of ‘language’ to a more post-structural concept of ‘discourse’. Discourse became, for post-structuralists, the wider social system of language and social practices, all of which carry meanings and produce knowledge. Discourse is not simply language. Foucault opened up the concept of data to consist of social actions, practices and language. He was concerned primarily with the production of meaning, knowledge and power (rather than the detail of language, its rules and patterns) and how these are embedded within their particular context or ‘episteme’ - meaning a ‘statement of knowledge at any one time’ (Hall, 2001, p73). According to this view knowledge is situated and relative, changing and continually reconstructed. Foucault developed a historicised concept of discourse in his theory of ‘genealogy’, relating the discourse of the subject to its history or genealogy. In this way he used the history of practices and language, to explain their current form, and he ‘emphasised discontinuities’ in the apparent logicality of established discourses, for example of psychiatry (Donnelly, 1982).

Knowledge as produced by this wider discourse was inevitably connected to power so social structures and divisions which produced systems of knowledge were all embedded in language and social practices.

‘Similarly, a power whose aim is to normalise or discipline produces and utilises systems of knowledge which are useful in attaining this objective. There is a constant, reciprocal articulation “of power on knowledge and of knowledge on power” (Foucault, 1989, p51)’ (Yates and Hiles, 2010, p56).
Foucault further linked power and discourse to the actual make-up of the subject in the sense that people are positioned by discourse in relation to power. Ideologies, as productions, are instrumental in social control (Town and Adams, 2009).

‘The use of a particular discourse which contains a particular organisation of the self not only allows one to warrant and justify one’s actions in Gergen’s sense, it also maintains power relations and patterns of domination and subordination. In constructing the self in one way, other constructions are excluded’ (Potter and Wetherell, 1987, p109).

This thesis draws significantly from Foucauldian discourse analysis as it focuses specifically on the production of power relations in the talk between professionals and parents. So what does Foucauldian Discourse Analysis bring to this project? “Firstly, the analysis of discourse entails historical inquiry, otherwise known as ‘genealogy’. Secondly, analysis attends to mechanisms of power and offers a description of their functioning. And lastly, analysis is directed to subjectification – the material/signifying practices in which subjects are made up.” (Arribas-Ayllon and Walkerdine, 2008, p91). Foucault facilitated a new understanding of the relationship between theory and practice which was more assimilated and complex rather than the simpler versions of theory informing practice. Such theorising lends itself to this research it critiques and explore issues otherwise hidden or avoided by traditional psychological and neurobiological/developmental approaches. From a Foucauldian discourse approach it is possible, through the genealogical excavation of the evolution of ideas and practices in autism, to turn a microscope on the government/policy interventions and explore wider social trends and patterns of disability talk and neoliberalism as well as medical and social discourses work together in a whirlpool of mixed meanings and possibilities.

Foucault (1969) argued that people engage in self-constituting discourses and practices, but that these were constrained by governmentality. Governmentality and institutionalism was regarded by Foucault as the context and method of control both politically and socially, whereby subjectivities were formed and constrained (Ayo 2012). Autism diagnostic practice is awash with legislation, policy and prescribed structures and practices which work as tools of governmentality. Social control of autism is both overt through the practices of governmentality, often via institutions but is also covert as ‘autonomous individuals wilfully regulating themselves in the best interests of the state’ (Ayo, 2012, p.100). This is why we need to expose the genealogical foundations of autism as a concept and position in the social context as well as in individual exchanges. Such treatment of psychological enquiry takes us away from the Cartesian dualism
and positivist simplifications and underestimations dominant in the discipline (Rose, 1985) and allows us to understand the psychosocial subject.

Foucault’s genealogical approach to topics is also of relevance because the claims made by autism diagnostic procedures and by ‘experts’ are contextual, historically and culturally constructed, and so these must be and will be examined more thoroughly in the analysis. The analysis will partially take a genealogical approach to exposing the assumptions/drivers and implications/consequences of conceptualising autism with DSM criteria and in policy. Foucault’s analytic procedure takes the object of focus on a different level to the other discursive analysts in the sense that it relates to wider discourses and also draws fundamentally on the genealogical aspects e.g. biohistory. Foucauldian analysis anchors discursive and social practice firmly in historical context, arguing that tracing the history of meanings provides the genealogical trail which explains meaning and usage. Autism and its diagnostic practices and materials emerged out of a particular time and place, and is contextual. When set in this genealogical context it can be unravelled to illuminate particular practices and implications/consequences.

A Foucauldian approach does not relate to talk in action significantly, and thus it does not enter into the synthetic ground of CDP, but argues these are deferent to the grand narratives of hegemonic regimes of knowledge e.g. medicine, neurodevelopmental, science, moral panics, economics and ultimately the socially dominant neoliberal individualism and regulatory discourses that pervade western culture (see chapter 4). As well as providing guidance of what can be counted as criteria for being a discursive object, Foucauldian analysis directs research to explore what the range of possibilities might be for a discursive object. This is one of the themes of this research, along with knowledge and power, i.e. to explore the possibilities for autism discourses and the possible implications and opportunities that may be opened up. Furthermore, Foucauldian analysis also allows an uncovering of how and why we understand autism historically. One of the most important functions of taking a Foucauldian approach is that it advocates a visible ‘problematisation’ (Foucault, 1985) of autism:

‘Problematisations serve an epistemological and methodological purpose: they allow the analyst to take up a critical position in relation to research; and they allow the analyst to trace how discursive objects are constituted and governed’ (Arribas-Ayllon, and Walkerdine, 2008, p.10).

Power and the self are ‘technologies’ according to Foucault (1985) which serve to regulate social practice and behaviour and are key to understanding autism and parenting an autistic child and this is a key objective of the current research – exploring discourses of power between parent and
professional and the discourses that constrain, monitor and direct parents to self-regulate within 
the available repertoires or practices/technologies.

Foucault also refers to subject positions which allow people to locate themselves in multiple ways 
including morally or in terms of power/knowledge. Given the conflicting positions and parents’ 
criticism and claims, this is a key issue for parents and professionals in their negotiation of the 
diagnosis. The next section briefly examines the production of the psychosocial discursive subject 
and particularly in relation to autonomy and the enactment of ‘possibilities’.

3.3. Psychosocial discursive subject

The initial motivation for undertaking this research project was to understand the dissatisfaction 
parents have with the process voiced by parents in anthologies. This is a dissatisfaction identified 
in the NI Strategy (2013-2020) as well as by the lead professional in the assessment site. More 
recently Autism NI and The National Autism Society NI have reiterated the issues, claiming that 
most families feel services have not improved or have deteriorated. In examining many of the 
complaints and tales of ‘struggle’ and not being heard there is a strong need to understand how 
parents and autistic people are positioned in accessing services. This begins pre-referral and the 
period of accessing assessment services and a diagnosis provides the anchor point moment on 
which to hang future meanings, positions and actions. How are parents mobilised as subjects and 
what happens to their subjectivities and identities in the assessment?

Some take issue with Foucault’s treatment of the ‘subject’ arguing that Foucault’s subject is 
partially negated (as with the structuralists like Saussure) and ‘subjected to discourse’ too much. 
Indeed the subject is no longer a thing or entity as such but, rather, is a discursive position. 
According to Foucault, the subject is essentially constructed through mechanisms of discursive 
practice and he was able to relate these to specific groups of subjects such as prisoners, the 
mentally ill and homosexuals. (Foucault 1961, 1975, 1985). There is too little contribution from the 
subjects in how they choose and the options they have within discourse. For Foucault, early in his 
theorising, ‘the “subject” was produced within discourse’ (Hall, 2001, p79) and must acquiesce to 
the discourses, rules and practices to which they were subjected. This does not seem to take 
account of the diversity of discourses, rules and practices within which ‘subjects’ exist and of the 
subsequent dilemmas and decisions within a subject’s social world. It would be impossible to 
acquiesce to all discourses, rules and practices in this case and some choices and positioning must 
occur to manage them, as evidenced even within the pilot study of this research (see analysis 
section). Foucault’s position on agency has been debated but his later consideration of
subjectivity and agency seemed to point toward a more sympathetic and synthetic understanding of agency in relation to his version of social discourse. ‘As Dreyfus (2004) points out, the absence of any notion of the agentive subject in Foucault’s earlier works, and his reduction of subjectivity to a function of discourse, was something he later came to regret and moved to correct’ (Yates and Hiles, 2010, p53).

However, Foucault did not simply argue that the subject was suppressed by power in discourse but that it was constructed in discourse. ‘Side-step the society–individual dualism by first dismantling the monolithic, unitary character of power’ (Arribas-Ayllon and Walkerdine, 2008, p4).

The ontological underpinnings of the discursive subject is psychosocial as the subject is constituted in social being. To be clear, the standpoint I take within my critical discursive psychology approach is that this is primarily a discursive construction albeit accepting that the individual is also neurobiologically constructed and embodied – constrained from within and without, or endowed with opportunities from within and without in an infinite interaction. I want to understand what is done to the parent as subject in the autism discourses and discursive practices currently carried out in our society. The parent is positioned by relations of power or force within the professional-parent relationship as well as within all other relationships and discursive and social practices of relating (Foucault 1979; Arribas-Ayllon and Walkerdine, 2008). These positions are emergent, flexible, multiple. This view of the emerging subject in relational positions can access different positions with new knowledge, mobilising new mechanisms of power. This in turn also reflects back on Foucault’s claim that subjects are not determined by power, but that there is always some element of choice or chance and so the psychosocial discursive subject is indeed more than their discursive syndrome.

This work focuses on the empirical/observed discursive subject constructed and positioned in the external linguistic space between the parents and professionals. However, there is a need to highlight and explain the dramatic change this is away from subject of the traditional psychologist i.e. as rational, biologically determined, predictable, rule-bound, individual and measurable/observable and driven by universal (cognitive) processes. A Foucauldian reading of such traditional approaches offers an opportunity to deny their mechanisms and practices of power, including the status of ‘scientific’ knowledge and the construction and status of truth and evidence. Foucault’s subject does not inherently contain power but rather is constituted by practices of power and these are dynamic and multiple. They are also often contradictory or conflictual (Foucault, 1975). One of the key issues raised by Foucault is agency and determinism; ‘there is a sense of affirmation with which the subject manages to escape a pure determination’ (Arribas-Ayllon and Walkerdine, 2008, p93). However, even the range of possibilities comes under
constraining power of wider discourses and practices so that these can be variable and each subject may have more or less choice. This position is a challenging one for Foucault. He did not engage in discussions of the internal but others have drawn upon psychoanalytic theory to rationalise the internal in this socially deterministic position (e.g. Hollway, 1989, Parker 2002).

Such a framing relates most precisely to Rose’s psy complex as Rose defines this as a ‘regulated domain of agents, of practices, of discourse and apparatuses which has definite conditions and specific effects’ on the subject (Rose, 1979, p6). Rose considered mainly the formulation of the concept of mental defection alongside the rise and dynamics of the practice of medicalisation and administration (Rose, 1979). Both Foucault and Rose (along with many other such as Butler, Strong, Goodley and recent critical disability scholars) interpreted the connotations that followed mental difference in the subject – criminality, drain on society, needy, damaged and so on – as a means to justify state control. This control came in two main forms: medicalisation and moralisation. Both means of control will need to be explored in their macro and micro levels and relationship to each other. Psychology and psychiatry became the means to justifying discrimination between the normal and the abnormal and to access methods of surveillance and control, a space that had been vacated by regimes of punishment and discipline. The cult of individual freedom supported this positioning, as those classified as abnormal thus lost their right to freedom as a discourse of moral and natural justification prevailed. To explore the assessment and diagnosis without taking account of this genealogy and backdrop would be to miss the consequences, and perhaps very purpose, of the classification in its most pervasive sense. A Foucauldian discursive analysis, alongside Rose’s concept of a psy complex allows the macro-level scrutiny necessary to unpick the resources deployed against the discursive subject and manipulated during talk in action.

3.4. Critical discursive psychology

Essentially the whole of this section on methodology expounds the different aspects of what makes up critical discursive psychology. The purpose of this sub-section is to draw together the pertinent points from the preceding sections and move them toward the conceptual tools that are utilised in critical discursive psychology and specifically in this research project. The limitations of Chomsky shifted discourse analysis toward an interest in naturally-occurring talk and questioned the assumed originality of utterances. Structural linguistics theorised on the flexibility of language to construct different concepts and noted how language use relies on culturally shared understandings. They first developed the idea that words perform action and this was taken up
further by Austin in his general speech acts theory, asserting that language both states and does something, and utterances have meaning, force and effects.

Structural linguists also first queried how people’s competence in using language varied and this, when linked to Bakhtin’s concept of ‘heteroglossia,’ raises some questions about the abilities of professionals and parents, for example, to draw on a range of discourses. Bakhtin argued that speech genres are created in communities and that struggle can exist between authoritative centripetal forces and diversified centrifugal forces. As utterances do not emerge from a vacuum, it is imperative to scrutinize the history, diversity and context of talk. This provides a foundation for some of the later ideas around language and power and can usefully be related to the discussion of hegemonic discourses in the literature review in this thesis. Foucault argues that the person, or subject, and knowledge are produced within discourse and that discourse positions the subject thus in relation to power. Exploiting the Foucauldian influence in critical discursive psychology, this research will be able to explore the positioning in discourse of professionals and parents in relation to knowledge and power.

So far this summary expedition into language has veered off toward macro-level analysis – justifiably so as CDP’s distinction from discursive psychology arises from its emphasis on pervasive uses of existing discursive resources drawn upon for everyday talk (Wiggins and Potter, 2010) - and leaves little room for personal autonomy over meaning and understanding. The influence from ethnomethodology and conversational analysis, however, facilitates micro-level analysis. Critical discursive psychology is also concerned with the patterns and rules of interactional construction and how speakers apply reflexivity, flexibility and membership categorisation to make sense of their own social worlds.

It is possible to distinguish between a discursive psychology offering a fine grain analysis of the action orientation of talk (e.g. Edwards, 1997; Edwards and Potter, 1992) and investigations concerned with the imbrication of discourse, power and subjectification which take their lead from the work of Foucault’ (Wetherell, 1998 p388). Wetherell remarks on this divide as being between critical and non-critical stances toward discourse analysis and argues for a ‘synthetic approach’, fusing analysis of the talk as it happens as a form of social action with the context of cultural patterns of talk that reveal shared understanding and networks of meanings from the broader discursive environment (Wetherell, 1998). However, ‘some mobilisations of discourse become more stable and pervasive than others’ (Edley and Wetherell, 1999, p 182) and the most ubiquitous and persistent dominant version of autism is the medicalised neurodevelopmental translation.
Critical discursive psychology involves examining the discursive resources available culturally to form explanatory frameworks and identifying interpretative repertoires, subject positions and ideological dilemmas. It will focus on the flexibility and multiplicity of discourses, identifying the discourses from which participants draw their resources, the constructions of reality they produce and where they locate themselves and others in relation to this reality (Edwards and Potter 1992).

Therefore, it seems most productive, though challenging, to adopt Wetherell’s two pronged approach, bringing together analysis based on the CA and ethnomethodology traditions with those from Foucauldian and post-structuralist camps. The challenges lie in dealing with the inevitable complexity and ontological or epistemological conflicts that can emerge at flashpoints such as around the debate over the extent of subjective agency. However, the synthesis of these two aspects of language ‘best captures the paradoxical relationship that exists between discourse and the speaking subject’ (Wetherell and Edley, 1999, 182).

3.5. Analytical tools of the critical discursive psychologist

The diverse foundation stones for critical discursive psychology as a theoretical approach establish a strong rationale for its ontological assumptions, including the synthesis of macro and micro level discourses. However, how to capture such synthesis is the resulting problem. Epistemologically, this requires the collation of a multiplicity of entangled discourses essentially in a simultaneous analysis. The challenges are numerous but include the management of: different levels of data (micro to macro); large amounts of data for detailed analysis; and almost eternal iteration in recognition of the relational and indexical nature discourse. The process of analysis must move beyond the stages of thematic coding to appreciate the relationship between the wider cultural discourses and talk as it happens and what action discourse performs. The tools of the critical discursive psychologist provide the means by which people’s talk, drawing on culturally available discursive resources, can be identified and their functions understood, particularly in terms of how power is exercised and circulated and how participants position themselves and are positioned by others.

3.5.1. Interpretative repertoires

‘The interpretative repertoire is basically a lexicon or register of terms and metaphors drawn upon to characterise and evaluate actions and events’ (Potter and Wetherell, 1987, p138).
Interpretative repertoires are explanatory frameworks by which people form an understanding of aspects of their social worlds, ‘structured discursive resources that underlie and sustain interaction’ (Wiggins and Potter, 2010, p.3). Potter and Wetherell first applied this concept to allow them to understand what traditional psychology studied as attribution and attitude. They found that people’s talk tended to contain particular stylistic features, grammatical structures, fitting metaphors and ways of talking which would be recognisably linked to a particular group or situation – interpretative repertoires. There is no set size or form but each interpretative repertoire has its own set of terms and resources and these can range between discrete and concrete interpretative repertoires and those which are much more complex and convoluted. Repertoires can be contradictory and can cause difficulties themselves but they allow us to look in detail at how these contradictions are managed, e.g. through contingent repertoires. People are not necessarily conscious of their use of interpretative repertoires but they do orientate themselves toward their own interpretative repertoires. A repertoire is not the belonging of any particular group but can instead be an available resource to be drawn on as appropriate. This opens up repertoires and even group memberships to much greater flexibility than previous approaches could manage.

3.5.2. Subject Positions

Subject positions refer to where a person locates themselves discursively within talk. Aspects of the social uptake of a person’s talk depends on the positioning of the speaker, such as in the interlocution. Although the critical discursive approach views language as constitutive there is also a notion of choice which allows the person some autonomy, albeit limited and dependent on resources, over which position they assume. The person becomes the subject in this scenario, but actively locates themselves within a particular category which has associated implications and consequences: the language used will contain connotations and metaphors which carry particular meanings. They do this reflectively to some extent and are instrumental in placing themselves in their chosen categories while excluding themselves from others. This does not mean that they are aware fully of the impact and concept of position but simply that the particular way of talking is appropriate according to the cultural expectations and discursive resources of which they have knowledge. Position is a fluid process, fragmented and cumulative, with ambiguous positions taken up to allow shifts dependent on the changing values and meanings emergent and creatively embedded within the categories and discursive positions.

‘A subject position incorporates both a conceptual repertoire and a location for persons within the structure of rights for those that use that repertoire. Once, having taken up a particular position as
one's own, a person inevitably sees the world from the vantage point of that position and in terms of the particular images, metaphors, story lines and concepts which are made relevant within the particular discursive practice in which they are positioned. At least a possibility of notional choice is inevitably involved because there are many and contradictory discursive practices that each person could engage in’ (Davies and Harré, 2001, p262).

Positions are often multiple and may be made troubled or untroubled, according to Wetherell (1987). Examining variability between and within accounts may throw up explanations for different positions. Interactive positioning is possible through speakers positioning themselves and others during conversation particularly. These become joint intersubjective constructions.

3.5.3. Ideological dilemmas

Billig, Condor, Edwards, Gane, Middleton and Radley (1988) developed the idea that ideological dilemmas would inevitably arise from lived ideology. Ideology, they claimed, is a social practice, historically and contextually constructed through language, comprising of beliefs, ways of thinking and values. In each society or culture there exist multiple and often contradictory ways of thinking about the world, there are inconsistent values and these dynamically interact. As a result of dealing with such varying lived ideologies, conflict and fragmentation can arise in ways of thinking about the world around us and our place in it. The dilemmas that people are faced with in their social lives are evident in the variability of their interpretative repertoires as these are the vehicles of understanding, meaning, beliefs and values. Our explanatory frameworks are rarely entirely coherent. Critical discursive psychologists explore ideological dilemmas as a natural part of discourse and social life. Typically, ideologies of discrimination, racial, sexual etc, are popular topics among discursive psychologists (Edley and Wetherell 2001, Wetherell and Potter, 1992, Towns and Adams 2009 etc).

Conclusion

The relevance and benefits of applying CDP to examine autism assessment and diagnosis emerge specifically from the fact that the concept of autism is contested and the criteria and procedures for diagnosis are institutionalised and top-down. The various elements of critical discourse analysis outlined in the chapter attend to the complexity of the construction of networks of meanings in autism diagnosis. CDP can draw up parents and professional discursive resources and demonstrate how they are part and parcel of their relations of power. The practice of diagnosis is institutional and CDP provides a unique opportunity to understand better the relationship
between institutional discourses and the conversations of assessment and diagnosis between parents and professionals. The next chapter outlines the methods used to collect data for the research programme and the steps of CDP analysis applied to the data.
Chapter 4

Method

This chapter sets out the method for investigating interactions between professionals and parents during autism assessment and diagnosis as problematised objects of enquiry (Foucault, 1979). It should be stressed that this is particularly unique fieldwork as no previous research has examined ‘discussions’ during autism assessment from a critical discursive psychology perspective. Given the tensions between services and users, pressures on time and resources, and the sensitive and challenging nature of the encounters, allowing a researcher access to such meetings and to personal narratives was a remarkable act of courage, reflection and generosity on the part of all the professionals and families involved.

Section 4.1 will outline the process used for accessing participants, from finding a suitable research site to producing a viable protocol and valid criteria. It will end with a description of the actual participants. After section 4.2 clarifies why discourse is valid data, section 4.3 will explain how and what data was collected. Sections 4.4 and 4.5 will briefly discuss data management and ethical approval and section 4.6 will outline the steps of data analysis. Unusually, the CDP approach allows researchers to take into consideration what is not in the data so this is explained in section 4.7. The final sections focus on criteria for evaluating qualitative research; section 4.9 examines the range of different criteria that can be applied but focuses on reflexivity, while section 4.10 provides an outline of my own credentials and what they meant for the research.

The following table provides a summary of the research activities that will be outlined in the chapter.

Table 1: Summary of procedure

<table>
<thead>
<tr>
<th>Stages of procedure</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Acquiring research site</td>
<td>An agreement was made with one Assessment Site to provide access to participants, both professionals and parents.</td>
</tr>
<tr>
<td>Design, informed consent documents</td>
<td>The protocol was firmed up and checked with the research site. Documents (appendix A) were produced to inform participants and obtain ‘informed consent’.</td>
</tr>
<tr>
<td>Ethical approvals</td>
<td>Approval was obtained from The Open University, NHS REC and Trust Research and Development.</td>
</tr>
<tr>
<td>Recruitment</td>
<td>Participants were recruited, both professional and parents.</td>
</tr>
</tbody>
</table>
Stage one of data collection
Unstructured interviews were conducted, and recorded, by the researcher with parents in the family home to discuss parents’ understanding of their child and autism as well as their experiences around the referral.

Stage two of data collection
Each assessment meeting (i.e. where the parents were asked for the information which would be used to assess their child) between the parents and professional was recorded by the professional without the researcher present.

Stage three of data collection
Each diagnostic meeting (i.e. when the diagnosis was given) between the parents and the professional was recorded without the researcher present. N.B. One of these meetings was with a professional whose data is not included in the study.

Stage four of data collection
Post-diagnosis unstructured interviews were conducted, and recorded, by the researcher with parents in the family home to discuss their experience of the process of assessment and diagnosis and what it meant to them.

Analysis
The data from the 16 meetings (4 meetings each for 4 families) produced 241 pages of transcript and 130,000 words for analysis. The steps of analysis are detailed in section 4.6.

4.1. Participants and recruitment

Obtaining a suitable research site

Looking at discourse independently from the context or practice of clinical diagnosis is not sufficient (Potter, 1998), so my method treated diagnoses as a range of discourses emerging from, and impacting on, prescribed practices of autism diagnosis. The nature of the topic and the approach determined the procedure adopted since researching autism assessment and diagnosis required a journey into the discursive interactions between professionals and parents. To access these at the earliest point of contact, parents needed to be identified through the referral processes. To explain further, ‘parents of children who would subsequently receive a diagnosis of autism’ are not a defined membership category or group and thus are inaccessible for contact. As they could only be known retrospectively, it was necessary to work backwards in the process of diagnosis to isolate the earliest opportunity to identify and access appropriate parents. This transpired, after some informal investigation with service providers and known parents, to be the ‘referral’ leg of their journey, i.e. when the referral was made to the autism assessment team. So the challenge then was to acquire a referral partner from the service providers. Several statutory providers in Trusts in Northern Ireland were approached informally and three assessment teams expressed interest. However, one chiefly stood out as having a particularly reflective stance and
more formal agreements were struck with the assessment lead there to access participants, both professionals and parents.

**Professional**

A single research site was used and the Autism Assessment Team at the research site agreed to participate. The team is a permeable concept in this instance as contributors to the team change depending on the referral and other factors. However, it generally consists of a team leader (paediatrician), speech and language therapists, clinical psychologists, educational psychologists and social workers. Each participating team member was required to give consent (appendix B). General consent was given by the team, and two team members agreed to participate by consenting to have their data collected and analysed. Although the wider team of professionals formally gave consent, in practice data were collected from two professionals at the single research site, an inner city assessment centre. This occurred because, of the 8 families initially recruited, data from only 4 families contributed to the study and only two professionals conducted meetings with these families. One of the two professionals withdrew her consent after the research had commenced, and so the data from only one professional were included in the analysis. In fact, the withdrawal of this professional’s consent affected the data from one meeting only. The remaining participating professional (professional C) was the team leader who conducted the majority of the assessment and diagnostic meetings with parents. The team used the Autism Diagnostic Interview – Revised (ADI-R) questionnaire and diagnostic report recommended by NICE guidelines. The professional was a paediatrician with a substantial number of years’ experience in the medical profession and in assessing autism and she was a mother herself - a fact she shared with participating parents.

**Parents**

**Criteria for parent recruitment**

The principal inclusion criteria for parents were: they should be referred through the research site, i.e. NHS assessment centre; the participating parents should have a playgroup or school aged child referred with a potential autism diagnosis; and the parents were willing to participate. The rationale for recruiting parents of playgroup or school aged children was that, according to the team leader in the assessment centre, school aged children were more likely to have a clearer prognosis than younger children, thus reducing the number of families involved who will not meet criteria as a final outcome. The families of this group of children are also more likely to have been told that there is a possibility that their child is autistic and thus the research focus will raise fewer
new issues for them. The principal exclusion criteria were: if the referral excludes the possibility of an autism diagnosis, and where the child was below school age.

Eight families were recruited initially to participate in the research but the final number for the project was 4 families due to the application of the study criterion that the child must subsequently be given a diagnosis. Diagnosis is made later in the process, i.e. some of the families recruited were offered alternative diagnoses, postponement (e.g. one was told a diagnosis could not be offered at this stage but would be reviewed in a year when it may be possible to offer a diagnosis), or no diagnoses and their data was then removed from the research and destroyed before analysis.

Recruitment was carried out via the assessment centre; as referrals came in, administrators at the centre sent information to parents about the research along with a request to consent to being involved. Only when parents contacted the assessment centre to offer to participate were their details added to the study. I then contacted them and made arrangements to obtain written consent and conduct the first interview in their homes. Parents needed to give written consent after reading the information provided. Some parents consented but did not engage in research fully, e.g. two fathers consented but only one of these was involved, and this was only partially. Two families did not have fathers involved in the assessment centre, the research or consent.

During the data collection a disclosure was made incidentally during an informal conversation - the assessment centre had actually screened out any families they felt had ‘issues’ (word used by the team leader i.e. professional participant) by not sending them the introductory information about the research. The situation was revealed when the professional handing over one recording said it (the diagnostic meeting between the parent and professional) was a difficult one because that parent had ‘issues’. The professional then remarked that many of the families had ‘issues’ and some of them hadn’t been contacted about the research because of their ‘issues’. There was little expansion about this but the term ‘difficult’ was also used by the professional to describe them.

Parents and families

Real names were replaced by randomly allocated initials to maintain confidentiality and neutrality. Names can be associated with ethnic groups, social class and so on but the location of the research site raised more specific sensitivities; since the research was carried out in Northern Ireland names carry connotations of religious and political affiliations and these can be
confounded with stereotypical and prejudiced associations and assumptions (Feenan, 2002). The table below carries details of the family as this is relevant information relating to the parents who contributed to the study.

Table 2: Families in the research

<table>
<thead>
<tr>
<th>Family</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family One</strong></td>
<td>Mother (TT) and Father (QT) were both unemployed. Their child (RT) was a boy, 3 years 11 months old at time of assessment. They had one other child together, an older sister to Child R, and Father Q had children from a previous relationship. They had concerns about Child R since he was two and half (so for almost a year and a half). Both parents were present during the assessment meeting, and part of the pre-assessment research meeting but only T was present during the other meetings.</td>
</tr>
<tr>
<td><strong>Family Two</strong></td>
<td>Mother (NN) and Father (LN) were divorced. Mother N was living with partner (F). Partner F was employed, Mother N was unemployed, and no information was available on Father L's employment. Their child (DN) is a boy, ten years eight months at assessment. Child D lived with Mother N but sees Father L a couple of times a week and stays one night every three weeks. Child D has one older brother (also being assessed for autism), one older sister and a younger sister. Mother N had concerns since Child D was 6 months. This was his second assessment for autism with the last one being several years before. He had been given diagnoses of developmental coordination disorder, hypotonia and dyspraxia and being referred for ADHD. Professional C conducted the assessment meeting with Mother N but a different professional conducted the diagnostic meeting. This other professional had agreed to take part in the research but subsequently withdrew consent for their data to be used. Mother N wanted her data to be used. Father L and Partner F did not attend any of the meetings.</td>
</tr>
<tr>
<td><strong>Family Three</strong></td>
<td>Mother (KM) was unemployed and Father (EC) was employed. Their child (UM) was 4</td>
</tr>
</tbody>
</table>
years old at assessment, and had one older half-sister from Mother K’s previous relationship. Mother K’s previous partner committed suicide (W) and KM found him so suffered some depression and also had some family turmoil, e.g. younger brother killed in car accident and all within a year. They have had to move house because of threats to their safety. Mother K didn’t consider Child U may be autistic though did feel there was some speech and language delay. However, concerns had been raised at nursery in previous year and Mother K readily acknowledged Child U may be autistic

| Family Four | Mother (QJ) and Father (S) were both employed with Mother Q working part-time. Their child (TJ) was a boy, six years and five months at assessment. He has an older brother. Parents had concerns from when he was a year old. |

4.2. Discourse as data

Discourse analysis involves an in-depth study of talk. It is about the language and what it does rather than who is saying it or the processes involved i.e. the talk is the topic or focus rather than a means to reveal the topic or focus. Arribas-Ayllon and Walkerdine (2008) claim there are 5 valid sources of data for Foucauldian Discourse Analysis and these are relevant to CDP: ‘spatiality and social practice; political discourse, expert discourse, social interaction and autobiographical accounts’ (p.11). This study incorporates all of these to some extent but the focus - on analysis of talk in action in the interactions between parents and professionals and in the autobiographical accounts provided during researcher interviews - positions the data collection and analysis more in line with CDP. The wider discourses such as political policy, legislation and institutional practices were treated as constituting discursive resources and situating the context of the talk rather than as the primary focus on my empirical analysis. That is, the epistemological focus was on how wider discourses were drawn upon in talk and what functions they performed, particularly in relation to negotiating power in parent-professional relations.

In view of managing the amount of data and the fact that this was not about providing regular laws of behaviour to allow prediction, testability or even validity and reliability in the same way as
experimental research, discursive analysis does not require a large sample size. Instead the sample must be relevant and appropriate to the research question – in fact I would argue that we should move away from using the term ‘sample’ at all as the participants in what is, in fact, an idiographic approach are not being treated purely as samples of larger populations. The general contribution of CDP research is a more complex and nuanced one, as Potter and Wetherell (1987) highlight:

‘Because one is interested in language use rather than the people generating the language and because a large number of linguistic patterns are likely to emerge from a few people, small samples or a few interviews are generally quite adequate... The value or generalisability of results depends on the reader assessing the importance and interest of the effect described and deciding whether it has vital consequences for the area of social life in which it emerges and possibly for other diverse areas’ (Potter and Wetherell, 1987, p161).

The study did not observe conventions of sample saturation. Guest et al (2006) has accused qualitative literature of making ‘a poor job of operationalizing the concept of saturation, providing no description of how saturation might be determined and no practical guidelines for estimating sample sizes for purposively sampled interviews’ (p.60). They argued that the notion of saturation was a ‘gold standard’. However, in qualitative idiographic research it is typical to rely on and analyse small data samples. The decision on sample size in this study was determined by the research question (Marshall, 1996), the ontological position of CDP and the epistemological aims of the study; it addressed the appropriateness of the sample size rather than a generic concept of a gold standard notion (O’Reilly and Parker, 2012).

The research question focuses on rich and complex data in the form of discourse. The analysis aimed to explore a range of repertoires and the negotiation of positions which can also give rise to trouble and dilemmas in talk. In order to explore such depth of meaning making, discursive resources and talk in action the size of the data set requires containment in order to be manageable. However, more significantly, the rationale for accessing data to saturation point is untenable, given the ontological position of CDP. CDP claims that each interaction is unique and situated in the particular time and place, that variability in talk is typical, and that this is where meaning and positioning are dynamically constructed (Potter and Wetherell, 1987). In this study this was within an institutionalised framework of discourses, instruments and practices and so the analysis aimed to explore the commonality and the variability of the individual encounters. Each new sample would bring new discoveries and so saturation could never be achieved. The study could not aim to achieve a saturation of either data or interpretation as each instance of
discursively constructed diagnosis is situated in that particular time and place and the researcher, as a co-constructor, brings to it their own discursive resources and competences.

Instead, the sample size respected the participants by not drawing upon more than could be utilised – between 4-8 families was the basis for ethical approval – but included a sufficient scope to reveal commonalities or patterns. This is not in the sense that the quest was for generalisable rules or laws, but that the knowledge of patterns and idiosyncrasies can contribute to understanding the negotiations between parent and professionals in general ways (Bowen, 2008).

Discourse analysts can work with a language from a range of sources: transcriptions from interviews; meetings or everyday conversation; speeches or reports; letters; official papers and other documents. Data from a range of these sources provides greater depth and variation to work from, however, and allows the researcher to develop a fuller picture of a participant’s talk. For the discursive researcher the ideal is to capture discourse that is valid: unfettered and pure, naturally occurring discourse from ordinary conversation or documents that already exist. However, it is also valid to conduct interviews, e.g. where natural talk is not accessible or where ethical considerations prevent the collection of other data. As the talk itself is the focus of the analysis, in the case of an interview, the construction under examination is between the participant and the interviewer and the data is taken up with this proviso, ‘the researcher’s questions become just as much a topic of analysis as the interviewee’s answers’ (Potter and Wetherell, 1987, p165). My questions were constructed to be open and to respond spontaneously to the participant’s direction, and to be provoking; they were intended to generate the sort of detailed and meaningful data that can be obtained in more natural settings rather than the restricted responses typical of questionnaires and structured interviews.

4.3. Data collection method: Semi-structured interviews and recording assessment/diagnostic meetings

Data for this project was collected from two source events: (1) research interviews with parents and (2) naturally-occurring talk in the assessment and diagnostic meetings that would typically be held between professionals and parents in the event of a referral. Each approach brought its own advantages and challenges but both offered valuable contributions to our knowledge and understanding of the complex meanings and associations constructed in the parents’ accounts.
4.3.1. The research interviews: semi-structured and open-ended

Two sets of research interviews were conducted. The first set of research interviews involved meeting with each parent (or in one case parents plural as one father was present for part of one of these interviews) before the assessment meeting – ‘pre-assessment research interviews’. The second set of research interviews involved meeting with each parent after the diagnosis had been given to the parents – ‘post-diagnostic research interviews’.

The schedule of questions was very thin for each set of interviews, veering more toward the unstructured end of the semi-structure continuum. Open-ended questions were prepared, to elicit as freely as possible the parents’ own understandings and their networks of mean-making around autism. I used a form of responding to the participants akin to what Potter and Hepburn (2005) called ‘conversational’ interviews in qualitative research. In line with the emancipatory standpoint of the research this approach was adopted as empathetic and respectful, responding as it did directly to the participants’ contributions (Brunero et al., 2010).

Willig (2013) distinguishes between an empathetic and suspicious approach whereby the first focuses on eliciting a descriptive, ‘insider’ narrative of experience to ‘explicate meaning’ (p. 43), while the second produces an interrogation style of interviewing, questioning and challenging. The approach used in the research here was very much in line with the empathetic approach. Instead, follow-up questions were free to assume the direction provided by the parent, probing for more rather than questioning what was given. When necessary, my own answers to their questions or emotional responses were offered, e.g. if asked if I was involved in diagnoses or had an autistic child I could explain I wasn’t and didn’t and I also did at times offer comments such as, ‘she’s very bright’.

Table 3: Questions used in research interviews

<table>
<thead>
<tr>
<th>Pre-assessment interviews</th>
<th>Post-diagnosis interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-prepared schedule of questions:</td>
<td>Pre-prepared schedule of questions:</td>
</tr>
<tr>
<td>1. Please tell me about child’s name</td>
<td>1. I wanted to ask today about the assessment meeting in date and the meeting on date where you were told of child’s name’s diagnosis. How has this all been for you?</td>
</tr>
<tr>
<td>2. Let’s go back to the beginning, before this referral. Can you tell me how this situation started with child’s name?</td>
<td>2. Can I ask you to tell me a bit about the assessment meeting?</td>
</tr>
<tr>
<td>3. Who referred child’s name? How did that happen?</td>
<td></td>
</tr>
</tbody>
</table>
4. How have you found the process up to now?
5. What do you understand by the term ‘autism’, what does that mean to you?
6. How did you find out about autism?

3. How was the meeting when you got the diagnosis? What happened there?
4. Did you feel that you were able to tell them everything you wanted to?
5. What does it mean to you to get the assessment and diagnosis?
6. Were you able to get what you wanted?

Elaborations used in response to the parents’ talk:

1. How did you deal with that?
2. Who are they?
3. How did they get involved?
4. Why did that happen?
5. Was that part of the decision?
6. What did that mean to you?

Elaboration questions used in response to the parents’ talk:

1. What does the information do for you? Why is it so important?
2. Is it a different type of information from parents and professionals? Which do need at each time?
3. What sort of thoughts did you have through that?
4. Will the school explain the diagnosis to the other children?
5. Would you want that?
6. What difference would that make to you?
7. How does that affect you?
8. How have you felt with the professionals?

4.3.2. Talk-in-action: Utilising naturally-occurring assessment and diagnostic meetings

My research used not only interview data but also data on interaction within assessment and diagnostic meetings. According to Wiggins and Potter (2010, p.7-8), such naturalistic data has several advantages:

- ‘It avoids imposing the researchers’ own categories or assumptions onto the data.
- It situates research within the seemingly ‘messy’ settings of everyday life; people are not separated from the sorts of agentic and accountability issues that arise in social interaction.
- It provides a directly practical way of doing research. Rather than trying to ‘apply’ findings from one setting (e.g. interviews) to another (e.g. workplaces), it studies peoples’ practices in situ.
- It allows the research to be guided by issues that may not have been anticipated by the researcher; this is often how novel and unexpected topics arise.
• It captures life as it happens, in sufficient detail to be able to analyse the complexity of seemingly ‘mundane’ situations.

The data gathered in the naturalistic contexts of assessment and diagnosis is the core part of the research as I see it. This was the most original part of the research and provided an almost unique opportunity to examine the events referred to in such different ways by the written procedures of practice and the parents’ accounts of their experiences.

The ‘talk-in-action’ data refers only to data collected during the meetings between parents and professionals. The first meeting held with each parent was an assessment meeting, using the ADI-R, while the child was being assessed in an adjoining room, visible through a one-way mirror, using the ADOS. These meetings lasted on average 1 hour 45 minutes. The parent was then invited back approximately 5-6 weeks later to receive a verbal report of the diagnosis with the written report to follow in the post – although in one case the parent received it directly after the meeting. These meetings lasted around one hour. These were meetings that would have happened irrespective of the research. There was no need for the researcher to be present and I felt my presence would have had an unnecessarily disruptive impact. Therefore, the professional recorded the sessions and passed on the recordings to me after the meetings.

4.3.3. Data collection stages

The research involved data collected from research interviews with parents and the meetings between the parents and professionals as outlined below. I had intended to collect textual data such as reports and letters but this proved impractical as parents and professionals did not produce the documents on request for the most part. In retrospect, it was immaterial to the analysis of the interactions based on the use of documentation, i.e. it was more meaningful to analyse their use in the assessment and diagnostic meetings and I may have been distracted by the documents themselves. It would also have been unmanageable due to the amount of data generated. The content of the assessment materials and reports is somewhat clear from the transcripts of the interactions and their use carries their audio recordings of scheduled meetings between parents and professionals. A research diary was kept throughout the process and an interview guide was used to provide appropriate focus though was not prescriptive. The stages and methods of data collection were as follows:

Stages One: Pre-assessment research interviews. I met with the parents who agreed to take part in the research prior to them attending the autism assessment clinic. As an ongoing briefing, they
were offered the opportunity to ask questions and consent was confirmed. The parents were interviewed about their understanding of their child and autism as well as their experiences around the referral. The interview was recorded and was largely unstructured beyond identifying the focus areas with the parents (see Table 2 for interview questions).

**Stage Two:** Assessment meeting. Post-referral, a letter by the clinic prompted parents to ring to arrange a time for the assessment meeting and they rang to agree at time and date to meet for assessment at the clinic. This is what typically would occur on referral, and thus comprised the ‘naturally-occurring data’ along with stage three. The researcher did not attend these meetings so as to reduce the level of intrusion in the process and be sensitive to both parents and the work of the professionals. The professional completed documentation which included the ADI-R and family history with the parent, in adherence to the NICE guidelines. This meeting between the parent and professional was recorded by the professional and the recording only, was given over for purposes of the research.

**Stage Three:** Diagnosis meeting. A meeting was held with parents 5-6 weeks after the assessment meeting. Again, this meeting between parents and professionals was recorded by the professional without my presence. The purpose of the meeting, according to protocols, was for the professional to give a verbal report of the diagnosis to the parent.

**Stage Four:** Post-diagnostic research interviews. I conducted these interviews with each parent after they had received the diagnosis for their child. The questions focused on their experience of the process and on their meetings with the professionals. It was also considered a debriefing as it consisted of a discussion of the parents experience and meanings around the assessment and diagnosis (see Table 2 for interview questions).

Originally, it was intended that information about autism and support groups in the area could be provided but this did not seem appropriate in terms of the researcher’s role (i.e. it may have confused my attempts at a neutral stance and drawn me into inappropriate positions but this was at risk of being aloof) and the information was provided to parents by the clinic. It was important that findings should be disseminated to families and professionals and a report was completed for this purpose within one year of the conclusion of the final stage of data collection. As the ethical approval included a provision that I should destroy names and addresses at the end of transcription the report was given to the clinic to be disseminated to the four families. The interview was recorded and was largely unstructured beyond identifying the focus areas with the parents (see Table 2 for interview questions).
4.4. Data management and security

Raw and transcribed data were stored as encrypted data on a password protected memory stick. The data was anonymous from the point of transcription. The data holdings were registered with the Open University data protection officer for the Social Sciences Faculty. Data was destroyed immediately when consent for use was withdrawn or participants failed to meet any recruitment criteria i.e. when the assessment team informed me the child was not to be given a diagnosis of autism. Names and addresses were destroyed at the end of transcription. All recordings were destroyed by 2013, as agreed for ethical approval and according to the Social Sciences Faculty Disposal Policy.

4.5. Ethical approvals

Research into autism is arguably always sensitive but carrying out sensitive research can be beneficial to participants and other stakeholders (Corbin and Morse, 2003). The fieldwork adhered to the ethical guidance provided by the British Psychological Society (BPS, 2009). These included key principals of informed consent (see appendix A), anonymity and confidentiality, debriefing and values of respect, acceptance and dignity.

Approvals were obtained from:

- The Open University Ethical Committee Approval granted in June 2010
- NHS Regional Ethics Committee (REC 2). This involved using the IRAS system and attending the REC 2 meeting.
- Trust Research and Development Team. Agreement was established for the Trust to be the Care Organisation with the Open University as sponsor. I received an Honorary Contract from the Trust, and attended a short course to be awarded a Certificate of Clinical Practice. I also received a Certificate of Enhanced Criminal Records Bureau (CRB) Check.

As this array of approvals are evidence of adhering to strict ethical guidance and procedures the details will not be described here but further discussion of ethical considerations is developed in part 2 of chapter 8.

4.6. Data analysis

The aim of this analysis is to examine what the diagnostic criteria and diagnostic protocols are doing. This interest arises from the problematizing (Foucault, 1985) of the biomedical genealogy of autism diagnosis. At this point it may be useful to have a reminder of how Wetherell (2001)
identifies discourse as: constitutive of social life in that it builds the social world; functional, as it actively does something; co-productional, because it is a product of more than one individual; relational, as words are given meaning through their relationship to other words; and indexical, for the action of language depends on their context of use. The analysis must explore what is performed in the talk, what relationality is exposed, how indexical meanings are created in line with diagnostic formulas and practices. All of these can be analysed in the talk-in-action but understanding of this talk is enhanced by setting these in the contexts from which both parents and professionals derive their discursive resources. Therefore, the analysis was also mindful of the genres of parent and professional discourses, their relative positions in the practice of medical consultation and the genealogical foundations and variation in such practices and discourses.

4.6.1. Steps of analysis

**Repeated listening to the recordings:** Discursive approaches to research all require a significant familiarisation with the talk which is the subject of the analysis (carried out prior to transcribing) but also alongside and following transcribing. Repeated listening facilitated an immersion in the data and developed a strong familiarisation with the talk, emphases, rhythm and tones (Potter and Wetherell, 1995).

**Transcribing**

Full transcription of all recordings was required to allow for the process of detailed and iterative analysis and, indeed, transcription is part of the process of familiarisation. I transcribed all recordings myself, checking and rechecking for accuracy and recording my thoughts and reflections in my research diary as I proceeded. This ensured a greater familiarity through purposeful and persistent focus on the audio (Potter and Wetherell, 1987).

Clearly, transcription is not a neutral process. The approach I took was to provide sufficient detail specifically and only to meet the requirements of the theoretical and methodological perspective adopted for the research (Taylor, 2001; 2013). Basic language, therefore, was at the core of the transcription but it was also important occasionally to include details of pauses, gaps or hesitations, intonations, overlapping talk, laughing, crying or interruptions (Atkinson and Heritage, 2006). The transcription detailed occasional, significant pauses or laughs etc. The significance of these was decided based on whether they seemed to indicate something relevant, e.g. where they had an impact on the talk; a laugh can reduce the harshness of critical language or indicate irony or sarcasm.
Other approaches to transcription entail minute detail of pauses, intonation, overlaps and any of features of the talk that are possible to represent in text (Potter, 1996). The detailed transcription is appropriate for the fine-grained analysis of conversation analysts but to meet the needs of the CDP approach and in recognition of the agenda of the synthetic analysis of both micro and macro-level features it was more relevant to gather and consider a range of data, talk-in-action plus research interviews, which would not have been practical or useful to transcribe in minute detail.

This less specific transcription does not mean it is less accurate and criticism of the lack of detail can be defended in terms of utility. Unnecessarily complex and busy transcription may really simply be buying into positivist ideas of objectivity, measurement and reductionism (Parker, 2004). An advantage for CDP in not including fine detail is that it allows the networks of meanings, negotiations and positioning to be more transparent; the minute detail which is not the focus of CDP can, in fact, mask or obscure the pertinent data so that it would have to be mined out. Hence, I justified the less detailed approach to transcription not just in terms of practicalities and essentialism but rather as beneficial visibility for the process of analysis.

In discursive analysis the transcription is itself a construction with the researcher or transcriber making judgements about what to put in and deciphering muffled or unclear talk. Some reflections on this process are included in part 2 of chapter 8. The time taken to produce transcripts can be considerable and needed to be built into the research schedule. As advised by Ochs (2006), it took approximately 8-10 hours for each hour of recorded talk and there was approximately 26 hours of recorded talk in the study.

**Looking for patterns**

Rereading the transcriptions continued familiarisation with the data but it was increasingly active in terms of recognising patterns. There were a total of 16 sessions recorded and transcribed, so initially they were analysed separately and each was considered in terms of their own patterns. However, these patterns were then compared for repeated patterns or other relationships between the data forms.

**Research question and CDP analytic concepts**

At the early stage I explored and structured the analysis in terms of these key themes or patterns and discursive devices. Being mindful of the research questions, the key analytic concepts of
interpretative repertoires, subject positions, troubled talk and ideological dilemmas, were considered in relation to the transcripts and particularly the patterns identified. For example, a pattern of the professional giving knowledge and the parent acknowledging it emerged in the diagnostic interviews whereby the parent took up a position of ‘conforming’, i.e. they did not just acknowledge it, but by not intervening, querying, adding or otherwise responding to it, they conformed both to the position of receiver and to the knowledge asserted by the professional.

Once I became more familiar with working with the data I was able to identify interpretative repertoires and subject positions within the patterns and explore the more troubled areas of talk, defining some in terms of ideological dilemmas. It was at this time that the overarching themes and categories for the thesis data chapters emerged as the repertoires, positioning and troubled talk revolved around issues of knowledge, power and (lost/restricted) possibilities. I was looking for consistencies but also differences between the transcripts.

Variation and trouble

Variation is key to CDP (Potter and Wetherell. 1987) and so rather than ignore, manage or factor out variation, it was analysed as meaningful in itself. I asked what work the variation was performing, e.g. whether it changed the speaker’s subject positioning or offered alternative interpretative repertoires or functions (Edley and Wetherell, 2001). At the later stages of the analysis there was more focus on variation and different forms of variation: inconsistencies, troubled talk, contradictions and ideological dilemmas. They mobilised a diverse range of positions and these, more than anything else, offered possibilities in alternative working discourses.

Structuring and summarising analysis

Some reworking of the ideas continued throughout the process of writing up the analysis. The patterns, repertoires and so on overlapped and had to be teased into a coherent body that maintained their integrity and recognised the most logical connections. I was aware that another researcher may structure the analysis somewhat differently but key to the validity of the research was the logic, rigour and evidence base, and my transparency and reflexivity in my own version of their arrangement. What became absolutely crucial to the analysis, as apt for CDP, was the pivotal position of the concept of power (and is why it is an application of ‘critical’ discursive psychology). One of the main reasons I was drawn to CDP is that it has such a potential value for application and specifically to address inequality and imbalance of power. The final step of the analysis was to
consider therefore the implications (consequences or potential consequences) of the findings in the research and, specifically, who was being empowered or disempowered within the discourses and practices of autism assessment and diagnosis. This is where the Foucauldian orientation of the analysis was expressed.

4.7. What is not included in the data

The pre and post-discourses that are condensed versions of the development of other forms of relationship building (Goffman, 1981; O'Keefe, 1995). These are the foundations for Goffman’s ‘footing’ in terms of the interaction (Goffman, 1981) so we can’t see the preplay which the professionals identified as being an important part of their rapport building and contributed significantly to the contextualising of the content of meetings but, perhaps more importantly to the identities formed and acted on in the process of assessment and diagnosis. Parents did not comment on the pre or post meeting discourses but it was made clear to me by the parents that they had interacted with the professionals outside of the recorded periods of talk, e.g. by phone to rearrange meetings. They tended to refer to these unrecorded interactions positively e.g. ‘Dr XX was lovely’, ‘they were very helpful’ and so on, and at times this was framed as comparatively positive to other dealings during previous assessments with other professionals. Of course, CDP also permits analysis of what is missing from the data, e.g. turn-taking, topics of relevance, forms of talk and so on as some omission can be indicative of discursive competence/subject positioning, contribute to the construction of power relations, draw on discourses of etiquette or have a particular performative function. Such omissions were included in the analysis of the study data.

4.8. Criteria For Validation And Evaluation

Potter and Wetherell (1987) argue that four techniques may be used to validate discursive findings and these relate to: coherence, the participant’s orientation, the emergence of new problems and fruitfulness. Coherence of the research concerns the specific analytic assertions made by the research. My work provides coherence throughout the details of the analysis, to the broader picture of autism policy and strategy, and to the procedures of autism diagnosis. In particular, the participants were clearly oriented to the focus of the research in the sense that they are actually using the language in the way that the research states, for autism assessment and diagnosis.
Potter and Wetherell do not just accept that new problems will arise but expect it; language as action should and does create problems in itself. Evidence of such new problems was provided both in the literature review and in the data collected, where the critique in parents’ talk functioned to problematise the current situation in autism diagnostic services. Finally, I will argue that this research is fruitful. In discursive study the analysis should be able to produce new explanations and understandings of discourse. The final theme in the thesis, possibilities, establishes that the main purpose of the research is to explore a range of alternative repertoires in autism diagnosis to the extent of an episteme shift and be applied to suggest opportunities for innovative ways of working.

Reflexivity and transparency, openness, integrity, logic, rigour, evidence, richness, complexity, and so on could also be added to this list of criteria for evaluation as overarching requirements which enable fullest critique of any critical discursive psychological research. However, with limited thesis space, the next section prioritises reflexivity and selects it for special mention.

**4.8.1. Reflexivity**

As one of the core criteria for evaluating qualitative research, reflexivity must have space in the design of the method. Holstein and Gubrium (2004) suggest that the interview itself is an interpretative practice, thus the role of the researcher is noteworthy. I would argue that the entire research project is an interpretative practice born from the ontological assumptions and epistemological aims of the research. The researcher selects the topic, the focus, the research questions, the approach, the criteria for searching literature and information collection and dissemination scenario - it is fair to reflect that there will be some inherent bias of coherence for the direction of the focus, approach and selection of literature and so on. These were in line with ontological assumptions and epistemological aims which have been outlined in chapter 3 but the point to highlight here is that these must be transparent and reflected upon to appreciate what that may mean for the findings/analysis and their uptake.

I am invested in the project too on a personal, as well as academic, level and have attempted to be reflexive of this throughout in all my decision-making and actions by use of the research diary, supervision, presentations, ongoing reviewing of literature and discussion. This project and thesis are me and I am, in as much as I am my thinking, constantly reinvented by them, inseparable and dynamic (Willig, 2013). Analysis is potentially a perpetual process (Billig, 1997; Willig, 2013). It is, and certainly should be iterative, but a decision must be made to stop (I have difficulty with this!).
I have been mindful that my decisions, assumptions and interpretations of the data collected are not the only versions of this state of affairs (Willig, 2013; Horton-Salway, 2001; Wetherell 2001). There is not one truth, rather, this is one version and I claim ownership to that (Willig, 2013) while not to the data. I am responsible and accountable for that. This view of my role encouraged me to be sensitive and to explain and justify in full all my actions and interpretations in the project. It also is entirely in line with the synthetic approach of CDP in that I am part of the process, merged with the participants and the wider social discourses we share, and at times, separate us (Potter and Wetherell, 1987). Hopefully the thesis is a logical and well-evidenced version of autism assessment and diagnosis and can compete with others, particularly the powerful hegemonic so impervious to family compulsion/desire, and be of some benefit.

4.9. Researcher credentials

As this is a sensitive area of research my credentials as researcher are cited as evidence of appropriate knowledge and skills and appeared pertinent in particular to gaining ethical approval and credibility with the professionals. They were not displayed to parents as I wanted my meetings with them to be as a researcher independent of the ‘professional’ team and I felt that raising professional credibility would have been counter-productive. In essence this means that I strategically/instrumentally positioned myself as a professional to the professionals and as a ‘researcher’ to the parents. Nilan (2002) identifies two main subject positions for researchers in qualitative work, ‘the first is constituted within a discourse of control, objectivity, even emotional detachment. The second is constituted within a discourse of immersion, reflexivity and rapport’ (p.364). My position was perhaps neither and both for I exercised some control, suggested objectivity and emotional detachment with my academic credentials, yet my style of interview (see discussion of conversational interviewing) did indeed ask them to immerse me in their narration and I engaged minimally in a joint reflexivity as required in respectful and empathetic responses to their situations. The strategic manoeuvring of my identity and profile was not simply a rapport-building measure and it didn’t exactly position me to access an ‘insider’ perspective but it was calculated to offer the opportunity to collect data that was as open and honest as possible. For example, I wished to avoid, in my interviews with parents, the associations with the clinical professionals. Relationships with professionals had already been flagged as problematic and a connection to the assessment centre may have engendered feelings of hostility or encouraged assumptions that I has privileged knowledge or access to resources. More importantly, being associated with the assessment centre may have produced accounts of their child that were oriented toward the meeting of their needs. Thus the information offered to parents (appendix A) positioned me as a ‘non-clinical’ academic researcher from an independent institution, to
discourage parents from interpellating me as a source of information about autism. For the professionals I was required to own to my qualifications and experience for partnership agreements and for ethical approvals. I disclosed that I have a BA (Hons) Psychology, MSc in Psychological Research Methods, Professional Qualification in Social Work, Professional Certificate in Management and a Professional Diploma in Management and these were presented as evidence of a relevant broad-ranging knowledge and skills base. That I am a senior lecturer and Associate Lecturer in the OU, I supervise undergrad research, including discursive projects, I have 13 years of experience of working with, and conducting research with, adults with learning disabilities (including autism) within Health and Social Care Statutory Providers and was a Management Development Facilitator for an NHS Trust was sited to emphasise extent and level of relevant (i.e. service provider) experience. I found that my experience was raised in my favour at the NHS REC meeting and was key to their approval for me to conduct my interviews with parents in their own homes (as a social worker I had been trained to assess and manage the risk of entering unfamiliar homes) – something which, I had been told, had been denied to others previously. I am also a mother and have no family connection with autism, i.e. no children or family members with autism diagnoses, but, similarly to most people, I have some social contact with autistic people and their families. It is important to be transparent about all of this positioning both in terms of the ‘informed’ aspect of the ‘informed consent’ and in terms of the co-construction in data collection.

Conclusion

This chapter has detailed the process of the research programme from the establishment of a research site and identification of participants through to the steps of analysis, and the many activities in between. It has demonstrated a coherence between the emancipatory ontological position of the research and my methodological decisions. The use of research interviews allowed a focus on the parent perspective, while the collection of natural talk-in-action data facilitated analysis of how parents and professionals are positioned and how and what meanings are produced in their interactions.
Chapter 5
Knowledge and knowing: The battle of incommensurate discourses

Figure 5.1 Divergent word clouds of language used by parents and professionals in the study

‘Your child has to have a diagnosis before they get anywhere, before you really get help’
(Mother Q pre-assessment interview, line 121-122)

This first data chapter explores the range of interpretative repertoires and subject positions in parents’ ‘meaning-making’ and how they position themselves and are positioned by concomitant discourses and practices during this time. The word cloud (Fig 5.1) was constructed from the language used in the study by parents and professionals when they interacted with each other during the autism assessment and diagnostic meetings; the cloud on the left assembles a typical range of words used by parents while the cloud on the right gathers together a range used by the professionals. It provides a snapshot of the differing, and arguably incommensurate, discursive resources (Schegloff, 1998) and discursive genres (Bakhtin, nd) and lays the foundations for understanding the parents’ meaning-making and claims. The cloud provides a basic but effective representation for appreciating the context of the parent’s disconnection, in language, from the professionals with whom they must deal.

The chapter draws mainly upon the data from the interviews with the researcher at the beginning of the process (post-referral but pre-assessment) and at the end (post-diagnosis). Specific details are then extracted for deeper exploration in chapter 6 (the use of documents as a consequence of diagnostic criteria, policy and protocols) and again in chapter 7 (ideological dilemmas and troubled talk). Parents’ discourses of their experience, beliefs and feelings are treated as performing their roles as parents. For example, mobilising their interests, engagement and investment in their children, while supporting their construction of need and worth. The framing of this is directly related to the research questions and so it moves away from a fundamentalist presentation of themes emerging from the data to a synthetic CDP analysis of knowledge and power relations.
explores the range of discourses that are open to parents and how they position themselves or access power to establish or negotiate with professionals within the repertoire.

The essential point of this chapter is to look at how parents talk about autism, their child, themselves, the professionals, the services and the processes and what kind of meanings, positions and relations are mobilised. However, I have used a pivotal concept which is one of the themes of the thesis - knowledge and knowing - to highlight a fundamental discord revealed in the data. The argument in the chapter is that knowledge, as owned by the neoliberal expert, is dominant. It is separated out from ‘knowing’ which is a form of knowledge owned by the parents and it is assigned a significantly higher status in parent talk, despite this consequentially reducing the status of their own knowing. The sharing of information between parents and professional builds on this status, in that parents share their information about their child in depth, but professionals do not share knowledge of autism much beyond offering the statement of diagnosis. Even while parents give over their information, certain aspects of knowing, such as the emotional connection with their child, are actually evaded in the diagnostic. These points are introduced in this chapter but developed more comprehensively in chapter 6.

The final section of the chapter explores the construction of the diagnosis as validation of the parents’ voice and the construction of the process as invalidation. These contradictory assemblages of meaning begin to highlight fundamental problems with the parents’ experience, and help to explain why they fought so hard to get a diagnosis which characterises their child as disordered.

5.1. Knowledge and the estrangement of ‘knowing’

Parents distinguished between professional ‘knowledge’ and parents’ ‘knowing’ in various ways but the following extracts from one parent show the multiple and moving constructions weave about, performing work on domains, action and subject positions.

Extract 1

U. Yeah. As I say, I didn’t know anything about autism. What I thought autism was, was kids were slow in everything, you know, like a disability. I know it is a disability but I mean a worse disability if you know what I mean.  
R. Yeah. Like a learning disability that you would see people in the institutions.  
U. Yeah. Yeah. Em, I didn’t know all the rest of the, as I say, the, all different wee things that K does. She speaks in her accents or she goes high and low pitch. She doesn’t speak with the one tone of voice, you know. She’s nine times out of ten very high. She’s, her sleep pattern, she doesn’t sleep very much. She doesn’t eat very much. She’ll only eat certain things. Clothes, she hates clothes. She hates keeping clothes on her. If she can get her clothes off her, she gets her clothes off her and then getting them back on again. (pre-assessment, l.74-84)
In this two-part excerpt Mother U performs a separation of expert and experiential knowledge which will be further exposed in this section. She relates them and assigns status to each in terms of viewing professional knowledge as ‘more true’ and demoting her own knowledge as she ‘didn’t know anything’ until she could relate it to the expert criteria. Common with many parents is her claim to not know about autism and then to make claims or present descriptions clearly detailing information extremely relevant to autism in relation to the child. Mother U claims to have no knowledge but then outlines the characteristics of her child that relate to autism demonstrating knowledge about both her child and autism to the extent that she could connect the two. This was prior to the assessment meeting and she was subsequently asked about these aspects of Child K in the autism assessment. However, Mother U herself devalues the status of her own learning. Mother U reasserts the existing status of experts as she draws down as resource the dominant discourse of expert (Avdi, Griffin and Brough, 2000). At the same time, she may be drawing on gendered discourses questioning the status of her ability to learn and ‘know’ as a woman and mother (Belenky 1986) or it may be a combination of both.

Searching the internet or reading and watching about autism independently and discussing particulars with family, friends or other parents of autistic children repeatedly was downplayed throughout most of the transcripts. This functioned to furnishing parents’ acquired or self-generated and experiential knowledge with a lower profile to that of expert knowledge. In essence the two interpretative repertoires of expert knowledge and experiential knowledge were almost invariably separated and related specifically and respectively to professionals and parents. It is notable that the professionals neither claimed, nor were presumed to be in possession of, experiential knowledge in the widest sense of understanding the context of parenting an autistic child. ‘U. professionals, unless they have the autistic kids themselves, don’t fully understand the pressures’ (pre-assessment interview, l. 349-350). However, they still held the higher status knowledge and power over diagnosis and support/intervention services.

5.2. Knowledge: Respectfully criticising the neoliberal expert

Parents anthologies were rich with discussion about professionals, some angry and others grateful. However, there was a distinct sense from both anthologies and the data that parents felt they needed professionals, yet were not confident they could get help from them. Parents even
advise each other and there are websites to advise parents how to deal with professionals (e.g. parent advocacy and http://www.healthtalk.org/peoples-experiences/autism/parents-children-autism-spectrum/dealing-professionals accessed on 24-09-17). Some recommend parents should not try to present themselves as ‘knowledgeable’ in meetings with professionals but rather show ‘respect’ to the professionals:

‘We found it helpful to do our homework first… At appointments, we obtained the best results by staying calm and paying due respect to the expertise of the professional, but we remained firm about our desires when necessary’ (Ferris and Ferris, 1998 p 188).

The professional holds the status of neoliberal expert, an acknowledged holder of knowledge and power, so parents appear to offer a manipulative strategy of deference for negotiating needs and services, implicitly attributing professionals as valuing respectful behaviour over need. This ‘respect for the expert theme’ was evident throughout the transcripts in the research, but parents performed a complex negotiation of criticism and praise, constructing an evaluation of professionals based on knowledge, delivery of service and values they demonstrated.

Excerpt 1 below, is from the first 40 lines of the transcript of my first meeting with a parent, Mother Q. It is a powerful exemplar of the complex work being performed from the outset as we see the discourse positioning parents and positioning professionals relative to each other as well as to the parent. Furthermore, this sits alongside the negotiation of responsibility and blame and the management of potential criticisms.

Excerpt 2

R. I suppose there’s a few things I wanted to find out from you; a wee bit about D and what you think is going on with him and the, the referral process that you’ve had, you know, why you. I don’t even know if it was you asked for a referral or not...

Q. No, I had asked my health visitor, right, but she told me at the start it was all in my imagination, do you know. That there was nothing wrong with him.

R. Yeah.

Q. And then I didn’t see her for, like, a year or so. So she never came back and then when he started nursery. Now’s he, he’s not toilet trained or nothing and I went down and I says, ‘Look, he couldn’t come to the nursery because he’s not even toilet trained’ and, em, it was R said, ‘No, bring him in’.

R. Yeah.

Q. But then I got the health visitor back out again and says, ‘Look, there’s definitely something wrong here’ do you know.

R. Yeah.

Q. D was just flying about like a bird, do you know, hitting switches and can’t speak, won’t eat certain foods and then it was like, ‘Right, I’ll refer him to the ASD clinic’. She just wrote that out,
didn’t have nothing to back it, do you know, and sent it away. So they came back and said no, that he wasn’t, that he would have to go on to a child development, a child development list. R. Uh huh.

Q. But then we’ve been going to nursery. He’s seen the child psychologist. It was E, out of the nursery that pushed it.

R. Right. Uh huh.

Q. And the speech therapist. And it was them ones that pushed it for it to go to the ASD clinic and then he was accepted in.

R. Right. Right. Right.

Q. Do you know. Or I would still have been waiting maybe a year or two years down the line, do you know, that way. But it was the nursery that pushed it for me.

R. Right. Did, and why did the health visitor, the health visitor sent in her referral but she’d nothing else.

Q. She just sent that one in just, like, she spent an hour and a half with D and then she said, ‘I’ll refer him to the ASD clinic’. And then she phoned me up and says, ‘They won’t take him into the ASD clinic’ and I went down to E and I says to E, ‘The health visitor says they won’t take him into the ASD clinic’. She says, ‘Well, she’s only done that herself. She hasn’t got any other, nobody to back her up’, do you know. But then it was E out of the nursery got the child psychologist in, S, and then R and then they done.

R. Oh right, ok.

Q. You know, like a report and sent it in and then that’s how he got into that.

(pre-assessment, l.6-41)

Knowledge, knowing and power are entwined in the extract. Mother Q, in her explanation of the referral, begins immediately to position herself, and the professionals involved, with uneven power positions but also with uneven moral capital. The parent establishes the strength of her own position and rhetorically constructs her argument by: her own credentials of knowing her child; her rationale for her actions; concordance from other professionals; and her effort at active help-seeking. She forms her argument but presents it as unheard because the less robust position of the professionals is a more powerful voice – although this is in itself hierarchical.

Typically, help-seeking activities are directed towards those who know more than we do and two features related to this assumed knowledge were represented minimally in the data. Firstly, even within the assessment and diagnostic meetings professional offered up only occasional phrases containing knowledge about autism e.g. in very briefly relating the parents words to the diagnostic criteria (see chapter 6).

The second aspect that was missing from the data was any claim from a parent that the assessment centre professionals did not have expert knowledge about autism, despite the fact that they did not receive more than a nod to autism knowledge and an information leaflet. This suggests professionals do not have to display knowledge or even pass it on to the parents to be validated in the expert position.
This was a significant feature throughout the research. In this extract Mother Q’s report of the interactions with the health visitor critically present this ‘expert’ as not knowing the child or understanding the situation and is in line with criticisms by other parents which focus mainly on criticism of process or professionals’ goodwill. Mother Q further censures the health visitor because she invalidates the parent’s claims and concerns as in her ‘imagination’. The health visitor’s position as a professional allows her to have authority and responsibility over access to help for the child while the parent must negotiate that through this body who invalidates the parent’s claims. A discourse around unfairness and irrationality is established here.

Child D’s behaviour, ‘flying about like a bird’, is clearly presented as an indicator of possible autism so it is picked up by the professional but yet progress on a referral is denied because they did not state the evidence as per particular procedures – the procedure and professional’s incompetency in following them are apparently unfair and irrational as a technical hitch can have devastating impacts on the family’s opportunity to access support. This professional is further criticised because ‘she never came back’ and this raises questions about the professionals caring credentials and even professionalism for not following up with a child. There is a clear suggestion, in ‘and then I didn’t see her for, like, a year or so. So she never came back’, that the professional was not engaged or invested in Q’s child or situation or in supporting Q.

Q attacks the professional on the grounds of professional behaviour and can only question her evidence, stating that she ‘didn’t have nothing to back it’. She supports her claims with reported speech of a criticism by a professional in the nursery, E, (repeated by Mother Q) rather than on the grounds of her own competing knowledge. Otherwise the parents, Mother Q specifically here, would not continue to seek help from the experts. Q constructs herself, engaged with the professionals, as an active help seeker, i.e. repeatedly voicing her concerns and not giving up; ‘I got the health visitor back out again’. Broadhurst (2003) notes that professionals’ discourses and academic papers position the help-seeker as an active agent and highlights the misconstruing that can occur, and how this can work to direct or misdirect blame toward the help-seeker and away from the help-provider. However, the data demonstrates that Mother Q becomes a part of this process and colludes to offer a (potential) miscalculation of responsibility and blame by positioning herself as an active help-seeker.

So why would a parent risk positioning themselves with potential blaming? This question will be explored in greater depth in Chapter 7 but, in brief, the parent must demonstrate worth in order to be taken up without more serious criticism of being a bad parent, an unnecessary user of health and social care services and/or a drain on society (Sointu 2017). ‘Knowing’, therefore, encompasses competence in parenting and is being connected to judgements of being a good
The parents position themselves as active help seekers in the quest for helping their child can mean they are ‘good parents’ in this relationship with professionals that parents often claim is the most challenging part of having an autistic child (Hodge and Brunswick Cole, 2008). In contrast Mother N, below, recounts her experience of approaching educational experts to obtain appropriate facilities for her son, (educational in this case) mobilising less respectful positioning:

**N. Oh, they were fuming. I didn’t negotiate it. I took him out and I told them. They told me that I couldn’t and I says, ‘Well, I have because he’s my child’.** (pre-assessment interview, lines 233-234)

Mother N was unsatisfied and advocating for her child but her confrontational position was met with what she considered to be anger, and she believed some process was hidden from her, i.e. her son was statemented but she ‘wasn’t even aware that the statement was being done’ (l.240). Thus communication, if not co-operation, between them had broken down. This was also the parent who was described by an Assessment Centre professional as having ‘issues’, so she also became labelled in the process of her more direct criticism and conflict with professionals. Parents negotiate through a thorny web of meaning, each turn positioning them variably as draining, active, critical, nurturing, failing and so on. Mother N carried out a substantial amount of work in her talk to bestow her actions and herself with worthiness and value.

Mother Q, excerpt 2 above, outlined a process full of professional intervention which was necessary to get to the point of finding out, officially, if her child was autistic. It began with the health visitor, whom she had to see twice over a period of a year, then the nursery assistant, the child psychologist and then the speech therapist. It becomes evident that not all of the professionals themselves carried sufficient status or expertise to trigger the referral for assessment and that more officious lines of action were required, such as reports and evidence. Within the system being navigated by the parents and the child there is a hierarchy of professionals and a battery of evidence required. However, Mother Q is no longer alone in her resistance to being disregarded because she enlists credited professionals and may thus be vindicated both in terms of her concerns and her unsuccessful, thwarted help-seeking strategies.

5.2.1. Anchoring knowledge to hegemonic medical discourses

**Excerpt 3**

*U. They know more medically and how to, the, em, Dr I was saying to me about when K goes off, you know, on tantrums, how to ease her that way. Because all kids, they are different at the same time. You know, one thing could work for one parent and not for another and she knows. She helps you, not all kids, they’re not all the same either with the same problems so there is things that I didn’t know from the sites that...*
R. Uh huh. Yeah.
U. … The other professionals have helped me, you know, questions and wee worries and just general things, you know. As I say, they were great from the start. If it wasn’t for the professionals I wouldn’t have had as much help and support that I have had. As I say, it was them that put me in touch even with the other parents and, do you know that way so I wouldn’t have had any of that. (pre-assessment, l.353-364)

This extract demonstrates a number of common features mobilised in parents’ interpretative repertoires regardless of whether it is complementary or disparaging talk. ‘They know more medically’, ascertains the source of knowledge and power speaks to the medicalisation of autism and the power of this medicalisation. This is followed up with the devaluing of the parent’s own ability to access or even own knowledge, ‘there is things that I didn’t know from the sites that…’

So this parent is establishing the status both by anchoring it to the medical model and by placing it on a hierarchy of knowledge, comparative to her own but also to the knowledge than she can access online. Furthermore, she then also extends their power by linking any knowledge she can access to the professionals’ wider knowledge, resources and networks, e.g. suggesting that she ‘wouldn’t have had any of that (parent networks)’ without professionals guiding her. This was an extreme case formulation (Pomerantz, 1986) of having nothing without the support of the professionals to highlight just how important and useful they were. Interestingly, this was after Mother U had already detailed how her contact developed with other parents:

Excerpt 4

U. The speech therapist gave me all different online things to go and look at. Em, facebook there’s a couple of, you know, autism groups on there and I joined those and got information. R. Right.
U.….From other parents and then other parents starting adding me so even all them, you know all their, what they go through and I’m like, ‘You know, people don’t know, you don’t realise how hard it is sometimes’. (pre-assessment, l.93-98)

Here it is apparent that one professional (in fact the one who referred K on to the assessment team), had given Mother U the information about online sites and Mother U then developed the networks of parental support herself. What was categorised by Mother U as helpful was a specific piece of information which gave her an opportunity to find information and support around people like herself:

U. The site, online sites is the best or the wee forums and whatnot is the best that I have found because you’ve got other parents going through it and are telling you exactly how it is from experience, do you know. It is very good that way, once you get the right groups to go and look at, as I say. (pre-assessment, 332-335)
Parents were almost uniformly generous about the relatively little bits of knowledge offered by professionals. Their gratitude talk showed appreciation of any small help especially if it enabled them to find more help or information.

5.2.2. Sharing knowledge and knowing

Parents, during the research meetings, discussed a range of issues around the exchange of knowledge in the assessment and diagnosis. This section highlights how parents understood the sharing of information between parent and professionals to be inequitable in terms of the level of information each offers the other. Direct evidence of how knowledge and knowing were shared between professionals and parents during the interlocutions of the clinical meetings will be analysed later in chapter 6 and thus these two sections should be treated as complimentary.

A number of the parents in the study, and in the pilot study, raised the issue of having to spend the bulk of the time during the diagnostic meeting hearing what they told the professionals in the assessment. This was explained to me by one professional as protocol, a strategy to help parents accept and adjust to the diagnosis, rather in line with observations by Carinci (2008) that ‘not all families display the characteristics that allow them to take an active role regarding their child’s education and training… A critical aspect... Was the way in which she reacted to and digested the initial diagnosis’. The professional view was that formulating the diagnosis by grounding them in the parents’ claims was actually more respectful and helpful, and Carinci (2008) indicates that the preferred action is to ensure the mother accepts positively the professional diagnosis. However, parents in contrast, suggested that it was disrespectful, wasted their time, distracted them from obtaining expert knowledge or was manipulative.

Excerpt 5

N. And when they're giving you the report it's always, 'And mother says' and it's very like you know am I lying or something? Or why would I say that? There's nobody wants to run with their child as long as I'm running to say that there's something wrong or if there's not. I mean, like, wise up. But it's always, it's the way it's worded. It's nearly like, 'Well, we're not saying this but mummy says that this that or the other'. You're like, 'Well, then why ask the questions?' R. Which moves me on to that meeting that you had then where you got the diagnosis and, I mean, I think that's a really important point because I would notice that as well when they... N. Yeah, it's not very, you know, it's not. And to me it doesn't look very. It's nearly like somebody sitting there. I visualise they're sitting there going, 'Oh aye, mummy says this' (in a scathing sarcastic tone). You know it's like, 'Hm' (suspicious tone), you know, when it is obviously quite clear when they can give you the diagnosis, you know, that it's not a load of old nonsense, you know. But they need to word that differently.
R. Yeah.
N. Or else they need to leave that part out of their report that they're giving you and concentrate more on we were at the school, we were in the house or whatever. And these are
the tests and yes, it’s there, you know. I don’t think that needs to be in all this. I mean your
doctor for a start would have all your pregnancy details and deliveries and all the rest of it and
I’m sure them red books are kept somewhere, you know, from the doctors and the health
visitors, their reports. I don’t think that all needs to be in that again. And to go to schools. I
mean they don’t need to know what weight D was when he was born, how long I was in labour
and, you know, and how many sisters and stuff that he has. You know, to me that’s all not. You
know, they’re there in school for to deal with his school and I think that the reports should be
edited that way, you know. But that same report goes to...
R. Yeah.
N. ...Everybody, you know. And I think that that’s, you know. Different me getting the report.
Yes, fine, you want to word it like that, that’s fine. Water off a duck’s back. I don’t like it but it’s
fine. I don’t, that the SENCOs and education boards and all should be getting the same. If that
was narrowed down for the school. It’s a page that they need really, like, you know? It’s not
the way they give it to you and all this. And that first six or seven pages is all, ‘And mother says.
And mother says’, you know, and, ‘Oh, and mother is separated’ and all like. What the, do you
know, like? – It’s nothing to do. Why not, --- all about me and I’m not worried if I’d twenty men
or whatever or husbands or, you know, it doesn’t really matter. I’m here to get my child sorted
and things put in place but whether I’m divorced, single, married, whatever it should not come
into the equation, like, really.
R. Yeah.
N. It shouldn’t and I think that’s really. I don’t know why they need to know that. And if you
own your own home? What has that, what has your financial business got to do with whether
your child should, could be on an ASD? (post-diagnosis, l.236-278)

Excerpt 5 raises a number of issues in relation to information collected or offered and how it is
shared and used between parents and professionals. This is a very long extract but inclusion of
the whole section can be justified by the richness and strength of the content. It will also be
referred to in the next data chapter, Chapters 6, when the specifics of the questions are examined.
Mother N mobilises a discourse of interrogation and intrusion. She suggests that the professionals
do not believe her, ‘am I lying or something’ and so rather than a sharing of knowledge she
positions herself as having to justify and fight for her voice.

‘I don’t know why they need to know that’, questions the professional need to know some of the
information but could also indicate that Mother N is accusing them of not explaining the need for
the information. This is information and ‘knowing’ extracted from Mother N rather than willingly
shared through a mutual understanding of what it means and what function it will perform. The
information thus extracted is shared with a number of other professionals, educational and
medical, when the professional sends them the report. However, Mother N questions this, ‘I
don’t, that the SENCOs and education boards and all should be getting the same’. Interestingly,
she had agreed to the report being circulated while at the diagnostic meeting with the
professional – this conformity to the request was identical for all the parents and this is an issue
raised in Chapter 6. There is a strong sense constructed in Mother N’s excerpt that the
professional has the authority to extract and share the parent’s information while Mother N does
not have the authority to extract knowledge or service on demand from the professional. Mother N implies that she was compelled to conform and to allow her information to be shared, without even questioning why it was necessary. This is evidence of the status of ‘knowing’ relative to knowledge subject positions. The next section begins to review how parents were bound into such an inequitable relation.

5.3. ‘Knowing’ and getting a diagnosis

Most of the parents were very clear that they felt their child needed an autism diagnosis for some time (see table 2 in Chapter 4), excepting Mother U and the only father in the study and both of them were convinced by the time of referral to the assessment team and thus by the time they took part in the study. They would describe their child as having autism-related aspects or behaviours, and that this would help them to access services and more knowledge about the child:

Excerpt 6

T. No, it hasn’t changed any way that I think about it because I’ve always known that’s what it was. I’ve known from he was just over a year old.
R. Yeah.
T. But it was partly because my brother has it. So I sort of way knew. So it hasn’t changed that. The only thing I’m hoping it does help change is, as I say, getting different stuff in place for him so it is. (post-diagnosis, 282-287)

However, parents ‘knowing’ the child was formulated in complex ways, yet different to the professional’s evaluative criteria, as indicated in the word cloud of Fig 5.1. Parents did not usually apply labels to their child but developed descriptive narratives entangled with explanation and management of responsibility.

Q. The simple reason is he can’t cope with it and when he comes out of nursery he sleeps all day so he does. He would sleep for about three hours. He would sleep longer if I let him, yeah.
R. Uh huh.
Q. Em, and in nursery, I went down, he doesn’t even play with anybody in nursery. He does his own thing. Can’t go on wee trips with them because he can’t get on the bus. He doesn’t like getting on buses. Em, so it’s only really sort of way to get him out.
R. Uh hm. Uh hm.
Q. That he knows he has to go out in the morning and then, do you know that way. Em, but in the house it’s D’s way or no way. It’s D’s way or the highway. He would just get up and decide he wants to go out. Now, he was playing in here and his, em, his daddy’s away to collect my wee girl from school so he had to go and get ready. He wanted to go, you know.
R. Yeah.
Q. He’d just get up and play in the street, well, with you’ve to stand in the street with him because he would go on the road. He’d play out there for hours. He wouldn’t come in for you, do you know? If he wants to do that, he’ll have to do that, like. There’s no, we’ve no say in the
matter because he just doesn’t listen so he doesn’t, do you know. If he wants to, em, say, if he wants dinner before everybody else, he’s to get that, you know. He just, he doesn’t take no for an answer and screams at you if he doesn’t get his own way, do you know? (pre-assessment, l.68-89)

Their discussions centred on their behaviours, their worries for the child and about the child, the child’s pains and needs. It was a nuanced, and dynamic construction of their child that extended beyond the boundaries of the diagnostic criteria or any meaning or connotations captured by the term ‘autism’. Holt (2010) shows how parents draw on dominant medical discourse (developing their own medical discourses), rationality and logic, or emphasise the extent of a feature (length of time or intensity) to formulate arguments to combat expert knowledge or simply to be heard. This is evident in the talk of parents in the research as they consider the autism diagnosis, but it was not their primary repertoires.

5.3.1. Affect, emotion talk and parents

Parents used emotion discourse (Edwards, 1999) to negotiate power and subject positions both in terms of positioning themselves and in terms of positioning professionals and services. Affect is a key part of the discursive subject, and we can see this played out in the parent interviews, but it is essentially skimmed over in the academic literature (excepting measures of stress, for example), the policies and protocols of service provision and professional practice.

Parents established values in emotion discourse, e.g. angry that they were kept waiting. Also professionals use emotion talk to position the child and the status autism, e.g. what were they worrying about? Notably absent from any talk about professionals, excluding ‘she was nice’, was any reference to emotion and in fact very little emotion talk occurred in the assessment and diagnostic meetings in comparison to the research interviews. Parents expressed a desire to have their emotion acknowledged and supported: ‘N. I think they should maybe bring you in and sort of ask you how are you doing and. If they, they’re bound to be able to offer you some sort of help until these thirteen weeks kick in. Bring you back for something. Even just to say, you know: “How are you now it’s sank in” or something’ (Mother N, post-referral interview l.334-337). Their affect and emotion talk perform identity and investment work, positioning parents and others in relation to them (Wetherell, 2013).

Excerpt 7 – two related excerpts

U. It is, it is very hard and heartbreaking at times, you know, knowing that she is different. (A, 157-158)
U. It’s frustrating at times as well, you know. I know they say that they (autistic children) get frustrated but parents get very frustrated at the same time.
R. Absolutely.
U. Because we don’t know how to help them because we don’t know what’s, you know, what is wrong.

Q. I sort of way had myself, like, psyched up for it because I knew there was something wrong, do you know. I knew that.
R. Yeah.
Q. So I, sort of, had mentally prepared for that, you know. Em, but I actually, sitting there I was actually relieved, do you know. I went in and here’s me, ‘I can’t break down because I’m actually relieved that he’s going to get help and he’s going to get, you know, whatever help he needs. It’s not all in my mind’, you know. Just stuff like that so I actually found it relieving.

In each quote above the parents talk about ‘frustration’ and ‘relief’ but what is particularly notable is the multiple intersubjective constructions, how connected the construction of these feelings are with their children and particularly with their desire to help their child. The risk of ‘break down’ and desire for their children to get ‘help’ is an expression of love but rather a complex one. Mother U expresses some potential dissatisfaction that her child is ‘different’. She also struggles to accommodate her own frustration with that of her child; ‘they say that they (autistic children) get frustrated but parents get very frustrated at the same time’. She tries to manage her complaint about her own frustration by showing that they do embrace that of her child too and establishes some personal distance from her complaint by expanding it out to ‘parents’ rather than using the ‘I’ expression – conjunction with distancing the complaint from her own child and their specific situation but using ‘they’ rather than naming her own child. Mother U introduces herself in a liminal space of hope for what she might become by expressing what they cannot yet know or do, ‘because we don’t know how to help them because we don’t know what’s, you know, what is wrong’.

She positions parents of autistic children, and thus by default herself, as failing parents. As the child becomes subjectified as an autistic child the parent becomes subjectified as a parent of an autistic child, the core of that version of parenting is to be able to develop a better understanding for that which is not easily expressed or seen, and to access help for their child. At the same time, Mother U has connected herself with other parents of autistic children, mobilising a discourse of solidarity with other parents that opens up new interpretations of her as a subject, i.e. normalised as a parent of an autistic child. This is a group norm rather than a universal norm, not dissimilar to Avdi’s (2000) more positive ‘personalised norms’ for autistic people whereby the person or group can be viewed more favourably. Parents trying to manage similar parenting stresses and anxieties, e.g. about disciplining or letting the child go. And she continues to do this at various points.
highlighting the value of support from other parents which is very different, mainly through conceptions of knowing and affect, than the help from professionals:

Excerpt 8

U. Every parent does have the same ups and downs and I was, we. A girl from England I was talking to last night and she was saying, 'I just need somebody to talk to me. Work away' you know. She said, ‘My head is melted’. Here’s me, ‘I know how you feel’ because I do get the… K was on a bad day yesterday as well. She was a nightmare in nursery and then when she came home it didn’t get any better. It just, she just ploughed on through the day, having her tantrums and her shouting, fits and her slamming the doors and, do you know. You just have to let her go. You ca, if you shout at her it makes her worse. (A, 240-248)

U. Some of the parents I’ll never, ever meet.
R. Uh huh.
U. …But we’re still helping each other with our experiences, do you know? (pre-assessment, l.342-345)

Mother Q (excerpt 7) talks about her own preparation for the diagnosis and clearly indicates that this may fall into the category of ‘bad news’ in terms of ‘there was something wrong’ and having to be ‘psyched up’, however, this is overlaid with feelings of relief because of both the validation: ‘It’s not all in my mind’, and the hope that her child would get help. It is notable that in all data collected in the study, parents never expressed a hope that their child would be fixed or cured but rather they would be helped, understood or accepted better. Mother Q is an exemplar in this fairly typical extract. Contrary to literature on representations (O’Dell and Brownlow,2005) and the focus in funding and research (Pellicano, Dinsmore and Charman, 2013) Mother Q was not going in with a hope that the ‘wrong’ would be made right but rather that her child’s autism would be accepted, she would be validated, and her child would get help, not fixed.

Allocation of blame was pre-emptive in parents talk but this, along with the range of discursive devices parents use in the context to manage their positions is again complex:

U. It was hard but, as I say, I thought it was just K. I thought she was just, you know, at some places I blamed myself (pre-assessment interview, l.120-121)

On the face of it this appears to be a declaration of guilt/blame but Mother U’s brief statement here does a lot of work to manage her case. She actually acknowledges the potential blame and opens up the risk of being positioned as guilty of being inadequate as a parent. However, CDP stresses that talk is indexical, i.e. it needs to be understood within context (Wetherell, 2001) and in this case that means the context of having just been referred to an autism assessment centre. The function of this talk then is about managing responsibility, potential criticism, or even rejection within that context i.e. of being a parent who cannot control or parent their child adequately and is in need of service provision (the context of such service provision as part of the
national framework of health and social care, and thus of taxpayers money, is an additional burden weighing down on the family’s claim and position whether or not Mother U is a taxpayer herself – see O’Dell and Brownlow, 2005, O’Reilly 2014). Hagashi (2013) has already established the necessity to work up a case as a worthy service user and essentially this is what Mother U’s talk performs. Firstly, Mother U acknowledged the situation of parenting her child as ‘hard’. She acknowledges that the child could be blamed and that this would be reasonable as she thought it herself. However, the mother’s culpability is then offered up and she displays a readiness to accept blame, ‘I blamed myself’.

This performs two things; it partially protects her child from criticism (although that is already somewhat managed by the referral) and positions her as a responsible parent and thus both the child and parent are worthy of services, i.e. of the autism assessment. The fact that her child is now referred for an autism assessment may not now be viewed as a product of her poor parenting – she essentially has worked up an argument that she was worthy of service provision and positive regard because it was ‘hard’ yet she was willing to take the blame/consequences (martyrdom). Mother U’s talk positions her as not just blameless but on a morally superior platform because the level of her commitment to her child was akin to martyring herself. In terms of being constitutional of social life (Wetherell, 2001) Mother U’s talk is extremely complex and thorough. It buys into the dominant practices and professionalised, medicalised and service-led ideologies of autism diagnosis and works up an argument (from the inside of these socially familiar and dominant repertoires) to manage the discourses therein that might be damaging for the family. Cromby (2007;2011) considers ‘feelings of knowing’ as more elusive to convey and this includes, for example, powerlessness and suspicion, but employing a CDP approach allowed such ‘feelings of knowing’ to be explored in depth, to understand better what powerless means in terms of the discourse of affect here. Powerless does not just mean having no power but rather, it relates to the desire, the networks of relationships and meanings and affect such as frustration which includes drive as well as emotion. Such affect, in this case powerlessness and frustration, are joint, situated (including situated in the body) discursive actions as integral to the interactions between parents and professionals as they are to all other interactions in life (Shotter 2015).

5.3.2 Temporality

Knowing is a concept that relates to having a deep engagement, investment and understanding of their child’s experience. This section considers the parents use of temporality as an emerging theme within parents’ knowing. Temporality talk functions to emphasise, or give force to the rhetoric of need, to stress privations and concern. It is prominent in the parents talk and
connected to the ‘affect’ category ‘because affective phenomenon are processual, affective qualitative analysis might also benefit from a language that captures something of their temporality’ (Cromby 2011, p. 93). Parents work up a sense of urgency in their desire to get help for, or to understand better their child. Temporality is expressed in explicit terms such as number of years but also in terms of temporal style and as such it mobilises affect by the management of what is expressed, e.g. the force by which it is expressed, the pattern or rhythm, to whom. When we see Mother N, in excerpt 5, report she expressed it openly and in multiple directions, including in the clinical meetings, it became disruptive and she was categorised as a parent with ‘issues’. Mother T below, presents a number of discursive strategies employing temporality:

Extract 9

T. Because I then went and spoke to her and as far as she was concerned, Miss S, had no concerns and I went: ‘Well, every day he’s getting picked up, I says, there is something’.
R. Uh huh.
T. And she went: ‘Oh right, em, oh’ and then after that he seemed to have a couple of, a few good days, really good days in school and at that time Miss P was sent out a letter with questions to fill in from the autism clinic. She just filled it in based on them couple of days that he had, was having a brilliant day and I …
R. Yes.
T. …Could not believe it and I says after everything that you’ve been saying to me and you’ve told me and you’ve filled that letter in like that. ‘But he was really, really brilliant.’ And a week later she turned round and she said…
R. Yeah.
T. …To me: ‘If I had them questions again to fill in, I’d fill them in completely different’.
R. Completely different.
T. Completely different. And I was like: ‘Well, partly down to you and this one box’.
R. Uh huh.
T. I says: ‘This child has to wait another year now’.
R. Yeah, yes.
T. ‘To go through all this again.’ (pre-assessment, l.436-455)

Mother T highlights her level of knowing and her investment in stark contrast to the teaching professional, Miss S. In extract 9 she alludes to Miss S’s investment as fleeting or a snapshot of disconnected times. For example, Mother T thinks about the continuum of ‘every day’ but accuses Miss S of reporting to the autism assessment team on the ‘few good days’, a snapshot of her child. She questions the validity and value of Miss S’s contribution on the grounds of this snapshot approach, citing how different her contribution would have been a week later. The force of Mother T’s own knowing and engagement with her child comes with her charge that he will have to ‘wait another year’. It is also important to situate this in the context that her son was, at this time, in P1, aged 4, and Mother T believed he was autistic from age of 1. There is a force to her message that her son has needs and the pattern of repetition, ‘go through it all again’, echoes the futility of struggle, like Sisyphus, fated to an eternity of rolling a huge boulder uphill. The next
section focuses on the battle for a diagnosis and the relative positions of professional knowledge and parent knowing.

5.4. Knowledge and knowing in motion: Diagnosis as passport

Diagnosis functioning as a passport was probably the strongest interpretative repertoire in the entire data set of parent interviews, and was even implicitly constructed in that way at the end of the diagnostic reports when the professional indicated who the diagnostic report would be sent to and how this may trigger interventions both in school and through social services. In this section the 2 key premises are: that obtaining the diagnosis equated to some level of validation, while the process of assessment and diagnosis equated to invalidation. This forms the foundations for some understanding of the tensions between parents and professionals and will be picked up in both chapter 7 in troubled talk and chapter 8 in the conclusion to the data analysis. However, validation works along notions of knowledge, and for knowing to function as validation it must come from those permitted to generate or own ‘knowledge’, i.e. the experts. The dualistic nature of the diagnosis and process work to ensure parents are never fully validated or endowed with the status of having the knowledge behind the diagnosis.

5.4.1. Before the diagnosis there is the battle

There has already been a substantial acknowledgement in parent anthologies (see chapter 1) and strategy documents (NI Autism Strategy and Action Plan, 2013). Dumit (2006) identifies a number of diagnoses that, while they are conditions that are not wanted, must be fought for because of various reasons, e.g. to obtain legitimacy to access services or to exchange a socially damaging label (bad/parent of a bad child) to a stigma of less damage (autistic/parent of an autistic child). Parents in the study allude to battling both the child’s behaviour and service providers but the diagnosis provides a turning point victory, albeit bittersweet.

Excerpt 11 - battling the child?

_T. Everything is a complete and utter battle, so it is. The only thing that doesn’t be a battle is, see, at the first point of night when he is going to bed and you can say to him: ‘Right, O, come on, bedtime’. (pre-assessment, l.102-104)_

Mother T talks of a battle in a sweeping statement in relation to parenting her child. It is a statement about ‘everything’ though rather than about the child themselves i.e. the ‘everything’ relates to their parenting activities such as putting the child to bed. It is notable that the mother
actually produces this concise example to illustrate and support the point and give weight to her claim. This is a skilled discursive device executed with some competence, i.e. it is not overstated and thus avoids rousing suspicion or fostering boredom. The battle is rallied, or the complaint is made, implicitly against his autism and autistic behaviours as it is assembled around parenting activities and not the character, or even in this case the behaviour, of the child (although this does occur and is managed by discourses alleviating the child of responsibility – see chapter 7).

5.4.2. After the diagnosis the pace picks up

After the diagnosis was offered all parents depicted the process and services moving at a much faster pace:

Excerpt 12

T. So it seems to all now be starting to quicken up so it does which in a way is glad. Em, his epilepsy nurse was on the phone to me the other day and he mentioned the social worker and that again but he says. He’d done a referral before for a social worker and they came out, em because he had no diagnosis then they couldn’t.
R. They wouldn’t.
T. …Do anything, em, come in and help or anything. So he says but the intervention team will do all that for me now.
R. Right, ok.
T. Em, it’s basically because come the summer time he can’t go into any ordinary, like, wee clubs and stuff like that there because he’ll not cope too well with the other kids so he won’t. So he needs to go into somewhere that they’re going to be able to handle him and understand him and I know there’s one down the road here, the N I think it is.
R. Right. Good.
T. Em, and there’s one somewhere else not far from here but you need a social worker refer it to get into them.
R. Right. Ok.
T. So, hopefully, once I get and see these ones and they sort of way help out.
R. So you get, CI refers you to the intervention team but you also need a social worker then to access other services?
T. Uh hm. Yeah to access other services you need a social worker so you do.
R. Right. Right.
T. Em, it all boils down to what the intervention team thinks you need put in place for help so it does. Em, they take into consideration, they says, all the report that C has done. Em, they have a look at all the other reports that was ever done about him and it goes from there to see. I think basically they, the impression getting, I haven’t spoken to them yet. Em, but the impression I got from the letter is they’re really going to assess everything including his schooling and all’ (post-diagnosis, l.20-47)

Mother T states that activity around supporting her child is ‘starting to quicken up’ as soon as the diagnosis was given. This is a construction of the diagnosis as a pass to accelerated services but the next part of the speech is a stark presentation of the diagnosis as a form of passport. Mother T presents a comparison of before and after; after the diagnosis the social worker ‘came out’, whereas before this ‘he had no diagnosis then they couldn’t’. Mother T proceeds to elaborate a
narrative of gateways for services which involves multiple professionals in the different sections of the system. Control is placed entirely in the professionals’ realm with parents negotiating their way through people without any apparent voice in decision-making, ‘they take into consideration, they says, all the report that C has done. Em, they have a look at all the other reports that was ever done about him’. Despite this, somewhat maze-like, route-mapping Mother T does not present herself as complaining or resisting. She appears to put trust and hope in the professional processes and their knowledge, reading into the information she has been sent as an indication that professionals will now act to support her child: ‘the impression I got from the letter is they’re really going to assess everything including his schooling and all.’

5.4.3. Diagnosis as validation: Process as invalidation

Parents talk of need for a diagnosis and relief through obtaining a diagnosis indicated that the diagnosis meant even more than getting access to services – it was a validation of the difficulties they were having with understanding and managing their child, the criticisms and confusion they had over their parenting and the criticisms that had been directed at their children. They have had concerns and questions and thoughts about their child that they don’t feel confident about mastering either in terms of their knowledge or their competence as parents to manage and support the child with. Just having an ‘expert’ appear to hear them and agree with them is a huge relief:

Excerpt 13

N. Yeah. And although it was, you know, it was, em I don’t know. I was very mixed. Like, I cried because it was, em, it was a relief knowing. Not that it changed anything. I mean, he’s still the same wee boy today as he was eight years ago, do you know what I mean? So it didn’t matter but it was kind of like they actually seen it this time and they’ve listened, you know, and they’ve, you know. And I was, that sort of a relief, you know. (post-diagnosis, l.44-49)

Mother N talks of the diagnosis meaning validation. This is similar to other research evidence for people with ‘invisible disabilities’ such as ME whereby people struggle to be heard or acknowledged as having a real medical condition or need (Horton-Salway, 2001).

The diagnosis brings relief and comfort and this has been evident for autistic people (when they receive a diagnosis at a later stage, following childhoods and even adulthoods of confusion, exclusion and unhappiness) as well as for parents (Ortega, 2013: Shapiro, 2006). Mother N reflects the feelings of relief at an explanation, ‘it was a relief knowing’, as well as the end of her
frustration, having been listened to, finally, after numerous attempts. This potentially means that the parent can also be listened to in social contexts, e.g. ‘Now I can say it’s autism... you can help other people understand that you’re not being a bad parent’ (Mother U, post-diagnosis, l.171) or for educational statements and other services. Mother N, in excerpt 13, stresses that this actually does not mean so much to her i.e. that her child is perceived as different because of the diagnosis. She firmly mobilises the diagnosis as a validation of her voice and their needs rather than an explanation of her child. ‘It didn’t matter’ reinforces the established bond of mother and child as beyond the diagnosis. At other times, as below, parents do state that it provides an explanation but it is also typical that the parents prioritise the value of the diagnosis in terms of accessing power and services, having the ‘professionals’ on their side. ‘If you’ve any problems you just lift up the phone’ (Mother Q, post-diagnosis, l.132). To achieve, and in achieving these advances, parents produce discourses of tenacity and righteousness/worth against a process that is invalidating.

Excerpt 14

Q. No, I had asked my health visitor, right, but she told me at the start it was all in my imagination, do you know. That there was nothing wrong with him.
R. Yeah.
Q. And then I didn’t see her for, like, a year or so. So she never came back and then when he started nursery. Now’s he, he’s not toilet trained or nothing and I went down and I says: ‘Look, he couldn’t come to the nursery because he’s not even toilet trained’. And, em, it was R said: ‘No, bring him in’.
R. Yeah.
Q. But then I got the health visitor back out again and says, ‘look, there’s definitely something wrong here’ do you know.
R. Yeah.
Q. D was just flying about like a bird, do you know, hitting switches and can’t speak, won’t eat certain foods and then it was like, ‘Right, I’ll refer him to the ASD clinic’. She just wrote that out, didn’t have nothing to back it, do you know, and sent it away. So they came back and said no, that he wasn’t, that he would have to go on to a child development, a child development list.
R. Uh huh.
Q. But then we’ve been going to nursery. He’s seen the child psychologist. It was E, out of the nursery that pushed it.
R. Right. Right. Right.
Q. ...And the speech therapist. And it was them ones that pushed it for it to go to the ASD clinic and then he was accepted in.
R. Right. Right. Right.
Q. ...Do you know. Or I would still have been waiting maybe a year or two years down the line, do you know, that way. (Pre-assessment, l. 6-30)

This repeated excerpt is being used to connect here how parents understand the process as invalidating their ‘knowing’, their concerns, desires, needs, in contrast to the validation of the
diagnosis. Mother Q’s account here performs a number of actions in positioning her, her child and the professionals and provides a narrative that displays huge tensions and damage. It builds a picture of her invalidation within the process of help-seeking but, ultimately, the diagnosis obtained validates her claims and ‘struggle’ – she describes invalidation by a number of professionals until one finally takes up her cause. I deliberately use the language of the ‘freedom fighter’ because this is a case erected as a fight, a struggle against oppression, not just of her voice, but of her child’s right to have his needs met and to be accepted. This is an informal version of ideological polarisation of the parent’s value and the value of the service, institution and professionals (Van Dijk 2006)

5.4.4. Cost/benefit analysis of obtaining the diagnosis

Excerpt 15

R. But, em, what sort of thoughts did you have through that, you know? Was it?
U. Some of it, whenever she was reading out, you know, different wee characteristics the school had wrote about her or other ones it was, like, got to you... The heart... You know the way she is with others – because I didn’t underst, know, because I don’t see her in school so I don’t know what she’s like except for what the teachers tell you. And every day I was going in somebody else was coming: ‘K did this. K did that’. It wasn’t her. She just comes and looks at you. And the teachers were the same: ‘No, she hit this one today. She did this. She did that’. And it’s things that they had wrote down, sort of, took me a bit, you know, when she was like: ‘No, you don’t need to worry because we do see it all the time. It’s not just’. She just sounds like a monster at times, as I say, you know. But I’ve just got used to it. There is, you get looks and all out in the street and all when she goes into one. Now I can say it’s autism, you know. (post-diagnosis interview, l.156-168)

In extract 15 Mother U expresses explicitly the cost and benefit of persisting with an autism diagnosis. The emotional impact of being hit with all the negativity about Child K from multiple simultaneous directions was intense to the point that Mother U avoids saying the words but leaves them hanging: ‘It was, like, got to you... The heart...’. Having the information written down was particularly intense in comparison to being told each day what Child K had done and this signals the potency of documentation which will be picked up in chapter 6. However, Mother U presents a justification for offering the negative information about her child and enduring the turmoil of receiving further upsetting illustrations about Child K. ‘You get looks and all out in the street and all when she goes into one. Now I can say it’s autism’ (Mother U Post-diagnosis l.167).

The diagnosis is not simply a means to access services, get help to help one’s child but actually is a means to counter more negative labels and constructions for the child’s behaviour from all walks of society, even passers-by on the street.
Conclusion: Bedding into tight corners

Parents’ constructions of autism, the separation and relative status and conflict of their ‘knowing’ in opposition to professional ‘knowledge’ places restrictions on parents in terms of accessing or negotiating power. This demonstrates a constrained and constraining range of repertoires of autism within which parents and professionals operate, as the dominant expert repertoire prevails to the extent of extinguishing other voices, even ‘knowing’ voices. For instance, strategies for accessing help or acceptance of their child rely on the professional and the diagnosis. Support from other parents or internet information is afforded much less value than professional and service provision. The clinical negation of affect in autism assessment subjectifies and pathologises parents and so this incommensurate discursive positioning leaves a key part of the parents’ experience and identity as invalidated or disparaged (Avdi 2005).

This chapter focused mainly on the interviews with the researcher before and after the assessment and diagnostic meetings with the professional, and repertoires constructed therein. The next chapter, chapter 6, addresses the interactive constructions between parents and professionals, and particularly how these are dictated by the documentations of the assessment and diagnostic process. These documents are not simply conduits for carrying knowledge about the child to be applied objectively to the diagnostic criteria and autism label but mould how the child, the parent and the professional can be understood and responded to in turn.
Chapter 6

Documenting an autism diagnosis: A rhetorical collusion to contain an epidemic?

‘The Doctor has gradually ceased to be himself the locus of the registering and interpretation of information, and because, beside him, outside him, there have appeared masses of documentation, instruments of correlation, and techniques of analysis, which, of course, he makes use of, but which modify his position as an observing subject in relation to the patient’ (Foucault, 1969, p.37).

Chapter 5, on the themes of knowledge and power, exposed evidence of the parents understanding of their subjectified and powerless positions focused on the research interviews before and after diagnosis. In so doing it also identified some of their interpretative repertoires about the professionals, service, autism and their child. The main argument in chapter 5 was that these repertoires construct notions and values of knowledge and knowing which are key to the establishment of subject positioning and determine, or undermine, parents’ potential to negotiate power. Chapter 6 extends the discussion of power and knowledge and how it is played out in the discursive space of the clinical meetings between professional and parents. It develops specifically the argument that the use of documents, and formalised clinical discourse and practice, constrains opportunities for parents to think and act within a wider range of repertoires of meanings.

Foucault, in the above quote, argues that the use of documentation and instruments of analysis also re-positions and constrains the professional too, and highlights that this becomes part of the relationalities between professional and, in this case, parent. Documents are key to the rhetorical strategy of professionals to argue, counteract or otherwise manage alternative discourses, constructions or practice (Potter, 1997). This chapter specifically explores the use of the Autism Diagnostic Interview-Revised, the life history questionnaire and the final Diagnostic Report in the meetings but also refers briefly to the other documents, in use e.g. reports from other professionals, information leaflets etc. as part of the fuller context of parents’ exposure to documentation in autism services.

The thesis does not include the original documents but this is not necessary for a CDP approach which focuses on the talk emergent from the application of documentation. The analysis is of the discourse, which is dependent on the documentation usage in the meetings, i.e. it is the ways these are drawn upon and elaborated in the talk rather than the document itself (i.e. it is not a textual analysis) that is the focus for this analysis. In a sense, it could be said that the documentation works as a co-constructor but in the same way as any contextual practice and discourse – it is the macro-level discourse brought directly and visibly into the micro-level talk as it happens.
The chapter begins with an overview of the structure of the transcripts since there are very consistent patterns within the diagnostic and assessment meetings, yet contrasting patterns between them. The section explores what the patterns perform in relation to positioning and meaning-making. Section 6.2 develops this analysis in more detail, focusing on the assessment meetings, while Section 6.3 focuses on the diagnostic meetings. The central point expounded is that use of documents structure, and provide content for, the discursive event of autism assessment and diagnosis. The document-led discourse reproduces and reinforces dominant professional-client power relations. I argue, throughout this chapter, that this results in the disempowering and deskilling of parents.

6.1 Structure of the transcripts: Rhythms and patterns differ for assessment and diagnostic meetings

<table>
<thead>
<tr>
<th>Assessment meeting</th>
<th>1.388-417</th>
<th>Diagnostic meeting</th>
<th>1.180-211</th>
</tr>
</thead>
</table>

This sample snapshot demonstrates the consistent differences of patterns and rhythms during the interactions in the assessment meetings and the diagnostic meetings. Tannen (2007) outlines how rhythm in interactional events can produce different forms of involvement, having varying degrees of influence over co-constructions and being invested in different ways and to different extents. In the assessment meeting above we can see a rapid succession of questions with immediate prompts. There is no small talk and the focus through the pattern is entirely on getting through the question and answer process as set by the schedule of questions in the ADI-R efficiently. Breaking out of such a fast tempo and, at times, staccato rhythm of question-answer would...
present a challenge for the parent who is less in control of the pattern. This is equally difficult in the continuous flow of information as the professional reads out loud the diagnostic report to the parent. Interrupting an expert in their clinical practice risks upsetting the interactional organization of the consultation, namely question and answer turn taking in assessment meetings and the passive reception of information in the diagnostic meetings, as demonstrated by the repeated use of ‘uh huh’ (Schegloff, 1981).

6.1.1. Rapid fire of document-led agenda

Excerpt 1

C. If you pull it back through to the, to the beginning, em, did you plan pregnancy with O?
T. Yes.
C. And were you well in the pregnancy yourself?
T. No, no.
C. What was wrong with you?
T. Em, it wasn’t even at the start, it was like half way through the pregnancy I sort of way started to, it was nausea, feeling of sick.
C. Uh hm.
T. Wasn’t actually sick, and constantly feeling faint.
C. That was about 20 weeks almost?
T. Yeah.
C. And did they ever find a reason for that or did you just go through to the end ok?
T. A couple of times when I went round to the surgery – I used to live round the corner from the surgery then – em, they says a few times my blood pressure ...
C. Yeah.
T. ...Just kept dropping down as well so it did. Em.
C. But that might explain why you felt so faint.
T. Yeah, yeah and the nauseas but, and also whatever way he was lying I had to get a support belt...
C. Right.
T. ... On so he was head was like right down on my hip.
C. So you took a back or hip pain?
T. Both.
C. Uh hm.
T. It was whatever way he was lying you were in absolute agony so you were trying to even walk. Some days I couldn’t even get up to walk ...
C. Uh hm.
T. ... Until he tried to move.
C. And did you get to term with him? Full term?
T. Well, by my dates yes. By the original dates that they gave me I was full term but then one of the times I went up after that they...
C. Changed it.
T. ...They changed it by two weeks but ...
C. Yep.
T. I’d say, yep, full term.
C. Any alcohol, cigarettes or medication through the pregnancy?
T. Epilim.
C. And, eh, what dosage of that would you have been on?
T. I was only on... three hundred morning and night.
C. That’s ok. And did you go on the pregnancy register then for, you know, the way they have a pregnancy register for epilepsy? They ...
T. No I didn’t know about that (quiet).
C. (Sneeze) Sorry. Yeah, em, because, em, there’s been quite a lot of work on looking at children who have been born to mums who have been on anti-epileptic drugs. But you have a pregnancy register in Northern Ireland for anybody who’s taking anti-epileptic drugs.
T. Right. I never knew about it (quiet).
C. Ok, it, maybe, were you, are you just controlled through your GP?
T. I was then, yes.
C. Then that’s probably why.
T. Yeah, yeah.
C. Because if, for example, you went to one of the neurologists they probably would have ...
T. Yeah.
C. ... Whee’ked you into that.
T. Yeah.
C. So, em, was he seen after delivery or anything because of you being on Epilim? The dosage of Epilim you were on at one point was quite low.
T. Yeah, quite low.
C. Relatively.
T. Em, no.
C. No.
T. No.
C. But there were no problems or complica... They didn’t do any screening or anything?
T. Em, I had have an emergency section then with him so I did.
C. OK. What was the emergency section for?
T. I, he started going into stress, so did I, and then I stopped dilating .
C. And what weight was he when he was born?
T. He was eight, eight thirteen?
C. That was a good size.
T. Yeah, he was. Q was bigger so he was.
C. Uh hm (both laugh). Did he need any resuscitation after he was born?  (Assessment meeting, l.371-415)

The relevance of some questions is unclear, but the question/answer pattern and quick fire rhythm of numerous short, frequent, unrelenting enquiries gives parents time simply to answer and not ask why any question is relevant, e.g. ‘and did you get to term with him?’ or ‘what dosage of that (Epilim) would you have been on’. While it is notable that at one point in the transcription Professional C offers the only nod to explaining these questions in the assessment meeting, ‘there’s been quite a lot of work on looking at children who have been born to mums who have been on anti-epileptic drugs’, it is unlikely to actually explain the relevance of the question about the dosage of Epilim in the autism assessment for Mother T. Quietening while admitted to not knowing about, or not being on an Epilim patient register, may be an indication of discomfort at being placed on a vulnerable footing (Goffman, 1959). Sensitive (or rather, insensitive) questioning about pregnancy may trigger a hitherto non-existent sense of doubt or
'guilt' in the mum around her role in potentially 'causing' or 'contributing' towards the autism. This claim was not voiced by parents, but given the history of blaming parents - from Bettelheim’s (1967) accusations against refrigerator moms to Wakefield et al’s (1998) claims that the MMR vaccine caused autism - parents are primed to take undue responsibility, e.g. Mother U accepts potential responsibility, ‘I blamed it on that, you know. I should have maybe kept K the same and M, no injections’, as a result of her decision to have Child K vaccinated with the MMR vaccine (pre-assessment, l. 24-25). There is no explicit explanation why parents did not object to blame-laden question constructions but it could well be a case of fear of opening a Pandora’s Box. If they railed overtly against potential blame then there may be more chance they would be criticised. For most situations the deployment of such questions would raise further, emergent questions in response, e.g. ‘would taking medication, smoking or drinking be responsible for my son’s behaviour? Did I do something wrong, did I cause his difficulties?’ Parent T does not pose any such retorting queries and neither did any other parent in the study. I would posit that the use of such scheduled questions of the ADI-R and NICE protocols, deployed in rapid succession in the context of a time-constrained and power-biased context, closed down the opportunity for parents to explore or negotiate meanings. In the same process the caring remit of the professionals is hampered as they are precluded from reflecting thoroughly on what the implications may be for parents understanding of autism, their situation and for the parent-professional relationship.

The protocol demands a neurodevelopmental and medical history. To achieve this the assessment questions probe far back into the family story and in some detail, albeit with specificity, that ignores other elements of the family story. In this way the document used by the professional sets the agenda and determines what information is appropriate and valued. Through the questioning process the child, parents and family are objects of scrutiny. Part of the process is also to exclude alternative explanations for the child’s behaviour or alternative diagnoses, e.g. diagnostic criteria in DSM IV, ‘The disturbance is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder’. Few parents are likely to be aware of this criteria or medical diagnostic procedures, or thus appreciate why they are being asked about their behaviour and situations.

Help-seeking for autism services provided examples of rehearsed accounts in the data. Parents were asked to repeatedly describe their child’s behaviour and their feelings and thoughts about it. This repeated speech is a practiced ‘rehearsed account of trouble’ (Taylor, 2006, p.100). It performs identity and rhetorical work but the use of a schedule of rigidly structured questions discharged at speed reduces their potential to deploy the practiced accounts:
Excerpt 2

C. Right. You need to see one to get some of those sensory ---. Em, you’ve done really well. You’ve worked your way through that history quite well. Is there anything I haven’t asked you that you have thought about, about D that you would like to add in? Anything that’s worrying you or something, maybe, I haven’t asked you?
Q. No, I don’t think so - because you’re just, you’re running, you tell the same story over again, do you know, so it’s really...
C. You get used to telling it to people?
Q. Yeah. It’s really hard to think, (diagnostic meeting, l.54-61)

It is evident from excerpt 2, and from virtually identical accounts of some events repeated to both me and the clinician and also in the parents’ reports of previous listeners’ comments used as supportive evidence (i.e. they state that other professionals or family members agree with them so have evidently presented their accounts to them on previous occasions), that at least some elements of their accounts have been rehearsed. But what significance does this have? This creates a conflict between whether the accounts will be fine-tuned in line with previous reactions and ongoing reconstructions or whether the schedule of questions may disrupt the flow of how they have preferred and practiced the construction they aim to present.

Disruption is viewed as a positive force in economics, management and technology fields and in discourse it could mean an opportunity to create new innovative ways of talking, positioning and negotiation (Christensen, 2006). Interestingly, of course, disruptive parents in schools and in health care environments are not regarded so positively (Millei, 2005). However, the schedule of questions in the ADI-R restricts such opportunities and constrains parents into lines formulated by the diagnostic criteria of the DSM, thus I argue it produces a context of control/discipline. This practice of consultation and diagnosis Foucault states is historically produced through socially dominant practices of power production, operating from the level of the social to the individual (Foucault, 1980). Discourses of consultation and diagnosis produces a status of particular versions of truth and force participants into particular subject positions (Millei, 2005). The parent position of passive informer and receiver obstructs the activity of questions when offered the opportunity to do so and Mother Q essentially expresses the difficulties around the disruption of retelling their story in the assessment meeting, i.e. she has been left in a discursive trap where it is ‘really hard to think’.

6.1.2. Confirming and conforming to the pattern and rhythm set

As suggested by Tannen (2007) each transcript exhibits a different pattern of involvement and investment, of knowledge and of power. Both sequences are equally compelling and restrictive so
that parents almost never break out of the prescribed regimes of the consultation that are typically integral to most people’s discursive competencies. In the assessment meetings the pattern is question-answer-question-answer while the diagnosis meetings relay is information-acknowledgement-information-acknowledgement and so on. Each is a model of assuming and conforming to particular subject positions, the expert and the help-seeker – in contrast to the active help-seeker propagandised by professional discourses (Broadhurst, 2013). The consultation space produces a passive client. For parents, their talk is of being active in pursuit of help yet passive in the acceptance of the form of help offered, even if it constrains their personal/familial story and raises a number of uncertainties and sustains a frustratingly low level of autonomy. The instruments of such a constraining pattern of interlocution are the ADI-R, agency questionnaires, professional reports and the final diagnostic report. Furthermore, the professional is able to employ the instruments to the full because of the participants’ experience of the consultation context and existing discursive resources. We all know the protocol is to briefly provide an account of symptoms to a GP and we rarely extend consultations into the form of a discussion in the 5 or 10 minutes available. The above section demonstrates how this can mean patients or parents present brisk, successive points under pressure so that only a select amount of information is conveyed. What is conveyed is set by the professional’s questions rather than a free-flow of information from the parent.

Excerpt 3

C. And hearing-wise, it’s been checked, and it’s fine is it?
N. They’re saying it’s fine but.
C. What about vision?
N. Vision’s fine.
C. No squints or problems with glasses or anything?
N. No. No.
C. And feeding-wise, he can chew ok. There’s no ---?
N. Oh yeah. No. Yeah.
C. It’s just he’s restricted?
N. Yep.
C. And he’ll mainly eat chicken, chips, tomato soup?
N. No, chicken soup. He doesn’t like tomato soup. Has to be Heinz chicken soup, not Campbell’s.
(assessment, l. 392-404)

This extract from an assessment meeting shows the level of conforming to norms of consultation as Professional C makes a series of assumptions which Mother N delicately works around to provide limited accuracy while in the process of confirming and conforming, e.g. Professional C frames, as an apparent question, the statement that the child’s hearing is fine and Mother N repeats the wording ‘it’s fine’, mirroring the professional’s speech. However, Mother N states, ‘they’re saying it’s fine’ - while conforming with Professional C’s wording she provides a
disclaimer, implying she does not claim it’s fine. She then attempts to extend their version of the child’s hearing but it is entirely unnoticed or not taken up and Mother N is not permitted the opportunity to elaborate. Furthermore, another assumption around food emerges almost immediately, ‘and he’ll mainly eat chicken, chips, tomato soup’, which the parent tries to accommodate: ‘No, chicken soup. He doesn’t like tomato soup. Has to be Heinz chicken soup, not Campbell’s’. Given that the professional needs to collect evidence of diet and any medical/sensory issues around food this seems an unusually restrictive way to address the question. The parent has to say what he doesn’t like rather than what he does and has been discouraged from giving a full account of her child’s diet and nuances in food preferences. I noted a certain level of passivity in the transcripts in general, from Mother T not cross-questioning the implications of questions about whether the pregnancy was planned or the (prescribed or retailed) drugs she was taking during it, to Mother N accepting an unexplained restrictive steer in ascertaining her child’s diet. I will argue in chapter 8 that this is a direct result of the consultation context, alongside the schedule of ADI-R questions and NICE protocols. Further issues arise, from the protocols, around sharing knowledge which will be covered in the next section.

6.1.3. Sharing knowledge: Inequity by documentation

This section leads on from the section on knowledge-sharing in chapter 5 by developing the points it makes specifically in relation to the subject of chapter 6, how the documentation operationalises the inequitable sharing of knowledge. Professionals have power to collect, and to distribute knowledge, in the form of formal reports from a range of other professionals and to construct one from the words of the parents to share with numerous others:

Excerpt 4

C. So, what I did with the report was I pulled together the information from the history that you had given me, the physical exam with K, the diagnostic assessment that L had done with her, the ADOS assessment. We got information from SF, who’s the ed psych and, em, just pulled it all together. And we also, obviously, had the school questionnaire that we got from the school. So, as you know, K at the time was four years and one month. (diagnostic meeting with mother U, l. 7-12)

Q. Am I going to get that? Yeah?
C. You’re going to get, sorry, I should have said that to you. The letter goes out to, em, I CC it to the parents, the GP, the autism intervention service, the ed psych. R sent you in didn’t she?
Q. Yeah.
C. Yep. I send it to your health visitor as well. Em, and the SENCO for S nursery, who gets a slightly different one. She doesn’t get, em, you’re full report. She doesn’t get your personal history. So that’s who it goes to. So you get a copy, the GP, the autism service does, the psychologist does, the health visitor and the SENCO and, obviously, R who’s your speech and language therapist.
Q. Yeah.
C. So once you get it, you know everybody else has got it.
Q. Yeah.
C. And you can take this because this will be your report. (diagnosis meeting, l.666-684)

During the sharing of information for assessment the professional receives a lot of information about child. Chapter 5 already touched on evidence that the professional can get a wealth of information from other professionals, e.g. from school reports, but they also gather a significant amount of information from the parents through the use of the ADI-R in the assessment meetings. This information ranges, as per the protocols, from family history, to early years milestones to medical information and behaviour reports and was taken over a period of approximately 1.5 hours. This is evident in the previous extracts but what is not clear yet is what expert knowledge is handed over to the parents. The crux of the argument here is that very little expert knowledge is shared with parents and, in fact, there is little rationale provided for the information that is collected or then used to justify the diagnosis. Parents were given a summary of the information they had provided before being told of the diagnosis but few connections were made to the criteria for autism and less in terms of what this meant for their child personally.

This summary highlights the lack of reciprocal relationship that is inherent in a clinical report. The assumed objectivity and, significantly, the privileging of professional knowledge and evaluative constructions are fundamental to the discourses of autism assessment and diagnosis (yet presented in the words of the parent). As parents are presented with a written report of the diagnosis, it takes shape as a fait accompli and no longer negotiable. Even aside from further negotiation we see little discursive space for elaboration or clarification, e.g. when Mother U offers a comment on the child’s gratification from urinating on a scrubbed stair, this generates no further response. Although Professional C provided a brief response initially she continues to read on to a new topic (see abrupt changes in section 6.2.5. below) and is not distracted from the flow of the documentation.

6.2 Assessment meetings

The assessment meeting consisted of one professional interviewing either one or two parents utilising a standardised tool for autism, the ADI-R and following the NICE protocols, while another professional carries out an observational assessment of the child utilising the ADOS (autism diagnostic observational schedule) in a separate room connected by a one way mirror so that the parent and professional with the parent can see the child. This section examines what is
constructed by the use of documents in the assessment meetings and how parents and professionals are positioned by them.

6.2.1 Memory test: Producing the vulnerable parent.

This section will examine the discourse as an exercise in testing the parents’ interest in and memory of their child. Being questioned, I will argue, likens to being tested on their value and competence as a parent:

Excerpt 6

C. When do you remember her starting pointing?
U. Em, I would say within the last two years. It’s pointing and even now she doesn’t say what it is, you know. She just makes a noise and sometimes I actually have to lift her until she actually goes and gets what it is that she wants. She won’t tell me even if she does know what it is, you know. It’s very rarely she’ll say. Even at that she won’t say: ‘I want’. It’s just what it is, you know, apple, ball. She won’t. She doesn’t put sentences together. She can’t, you know. She gets confused, you know, but, as I say, I have, I do try, you know. She refers to herself as a third person. Everything’s K. It’s not me or I or. It’s K wants this or K can’t, K wanted.
C. Uh huh. And do you remember her, you know the way when they’re little in the pram or in the cot, the wee ones will put the arms up to get lifted out. Do you remember K doing things like that?
U. No.
C. And what about sitting? What age was she when she sat? They’re normally around seven to nine months.
U. I think she was about nine, ten months when she, ten months it would have been.
C. And did she crawl?
U. Yeah.
C. What age at, do you think? Was she doing it by a year?
U. A year and a half
C. And when did she walk?
U. Not long after she started crawling.
C. And is she toilet trained?
U. Yeah.
C. When did you get her trained? (assessment, l.305-328)

Sometimes the questions came quick and demanded a lot from the parents in terms of what they could remember. This put them in a vulnerable position, testing their own experiential knowledge of their child – the area in which they were supposed to be the expert, their range of influence and the main source of their identity and status in the consultation context. The professional often reassured parents and gave examples, cues or asked for approximates but this recognises the fact that the questionnaire made challenging demands – it also positioned the professional as the kind helper. Professional C was positioned with more control, setting the agenda and structuring or explaining the questions and doing so benevolently. The parents often apologised
and/or explained that it was hard to remember but this puts them in the wrong footing. They blamed themselves for not remembering and constructed guilt around their parenting in terms of not having this information easily to hand. The professional provided the alternative explanation for this, i.e. that it was difficult to remember the past, but this usually didn’t stop the parents from adhering to their guilt-ridden apologies. If you can’t remember your own child’s milestones this may be viewed as being an inadequate parent (who was not sufficiently interested in their development), lacking intelligence or being incompetent. For example, quite a few of the questions are historical and when asked on the spot they test out the parents’ recall of their child’s early development:

Excerpt 7

N. And to be quite honest it’s quite hard to think back eleven years.
N. Did they smile? Especially when you’ve another baby in the house and you’re thinking: ‘Was that her was doing that or was that the other one didn’t do that?’ (post-diagnosis, l.203-207)

The parent is already understood as deskilled as a parent because they have had to come for help to manage their child and that the main status and power they have is through their claim of knowing their child (as opposed to the professionals’ expert knowledge of autism). When unable to remember the specific detail required this positions them as fairly incompetent and perhaps even uninterested, i.e. not interested enough to remember their own child’s developmental milestones. The testing of parents that involves interruptions and requests for more or repeated information/examples is in direct contrast to the reporting of the professionals in the diagnostic meetings, where the professional reads the diagnostic report with almost no interruption from parents.

Excerpt 8

Q. It was, like, you have to remember from literally day one. That’s the only thing. I’m very forgetful but when the questions she asked me – only answered, you know because they weren’t questions that you would say to yourself: ‘I have to remember that. I have to remember that’. It’s just things you forget, do you know, like, when they first walk, talk, blah, do you know. It’s just wee silly things like that but you need to remember that, do you know… It’s very in-depth about that but if you don’t remember that, like, I think you’re beat (my emphasis)’ (post-diagnosis meeting, l.35-43)

There is a lot potentially in this quote but the sense of ‘you’re beat’ is particularly powerful – it presents an idea of losing or failing in a test or competition. There was a sense that this was a contest between professional and parent with the professional holding the questions and making the adjudication. It is viewed almost as trickery and quite unfair as if the professional’s question were trying to ‘beat’ the parent. ‘I’m very forgetful’ works to defend against any bad parent
criticism. This excerpt also highlights the very different forms of discourse drawn upon by professionals in a clinical setting (aided and abetted or forced by the documentation) and parent or family discourse, ‘because they weren’t the questions that you would say yourself’. The professional does quite a lot of work to get over the technical language and jargon in the assessment, but the very concepts are still incommensurate with ways families understand and talk about themselves and their members.

6.2.2. Insensitive probing of sensitive information

The clinical practice in the field and the development of the assessment tools and protocol is based on the assumption that it is necessary, for the development of accurate diagnosis and appropriate intervention plans, to ask parents to disclose sensitive, private, distressing or embarrassing information. However, this can be obstructed or diverted by insensitive interviewing and inequitable knowledge brokering (Strekalova, Krieger, Neil, Caughlin, Kleinheksel and Kotranza, 2017).

Excerpt 9

Q. Yes, that’s right.
C. Ok and you’re D’s mum?
Q. Yeah.
C. And D is now, he’s just going to turn three, four?
Q. No, he turns four in May.
C. So he’s three years and eleven months at the moment. And what’s your postcode?
Q. xxxxxxxx.
C. And what’s dad’s name?
Q. TD.
C. Is that with an E?
Q. xxxxxx.
C. OK. And are you working at the moment, Q?
Q. No.
C. Is dad working?
Q. No. (assessment, l.5-19)

Excerpt 10

C. That’s great. T, do you and Q have any other children apart from?
T. Yes. Yes.
C. Who else do you have at home?
T. We have a wee girl called L.
C. L. Is that with a Y or a?
T. XX.
C. XX. And what age is L?
T. L will be six, seven, in December.
C. So she’s six years and four months now. And any worries with L at all?
T. No, no, no, no.
C. And is she the only other child you have or do you have any others?
T. I have other children, not to Q though.
C. Ok. Ok. And who, who are they?
T. Eh, R.
C. Uh huh. And what age is R?
T. R’s twenty one.
C. Any concern with R growing up? Any development issues?
T. No. No.
C. And do you have another child as well as T?
T. No. That’s it. That’s it.
C. Em, and is there any family history of developmental problems, learning problems, anything at all?
T. No.
C. So there’s no-one in the family with autistic spectrum disorder. Nothing?
T. No. No.
C. What about speech and language difficulties? Delayed language? Delayed talking?
T. No.
C. And in the family, is there anyone in the family with a history of depression or anxiety or anything like that?
T. Not that I’m aware of. No. No. I don’t know about Q’s side but none on my side. No.
(assessment, l.48-78)

These extracts demonstrate how the parent endures a continuous list of very sensitive and probing questions. Embedded within this schedule, some questions hint of blame. For example, parents maybe read into family questions, questioning whether the professional thinks a family history of autism may mean there is a genetic link and cause, or it may mean that the family have poor parenting, development or skills. Other questions suggest the parent is not quite believed and also leave parents with questions over relevance and responsibility. For example, parents may wonder what relevance their employment status holds. However, in some instances there was a forced disclosure of rather traumatic events. Below is an excerpt of Mother U with Professional C, after Mother U had been asked about her child’s father and had to disclose his death and some traumatic issues around his death:

Excerpt 11

C. What, what’s wrong with you (foot in splint and crutch)? Are you?
U. I stood on, the child broke a cup behind me and I stood on it and I don’t know what that. Four weeks I’ve been on these. I had an MRI scan there on Friday.
C. Uh hm.
U. And I’ve to go back tomorrow to see what. They reckon I’ve damaged internally, you know, muscles and all there really.
C. Uh hm. So were you at the fracture clinic or?
U. Yeah.
C. And do you see anybody for your own mental health then? Do you have any?
U. No.
C. ...Any care?
U. No. They have said about going to support groups and all but I would rather not bring it all up. I would rather just deal with it myself. As I say, I do have my down days but it's only to be expected.
C. And were you not allowing for, like, trauma counselling or anything like that afterwards?
U. When it first happened, yeah.
C. Where did you go to?
U. Oh flip, I can't even...
C. Was it over in E maybe?
U. I couldn't tell you now. (assessment, l.152-172)

On the back of the disclosure about the death, Professional C makes a discursive turn toward the status of Mother U’s mental health. In fact, Mother U had already refocused the conversation toward her child once already by distancing her child from the child’s father, ‘They don’t even acknowledge M. There’s only one or two of them even bother with my wee girl, you know. They don’t class her as part of the family.’ (l.134-136) and progressed to exchanging some detail of her present partner, W, of 5.5 years and his occupation. However, even with such distractions, Professional C returns to probe the sensitivities of Mother U’s own mental health. This is rather in contrast to the abrupt changes which follow the line of the interview schedule but it would be also regarded as discursive violence in mundane conversation. On this occasion the abrupt change, ‘C. And do you see anybody for your own mental health then’ is predicated on the disclosure of trauma despite further enquiry being apparently unwelcome by Mother U. Having already demonstrated that she gives up information fairly readily when she desires to do so (e.g. about her new partner and the accident with her foot), Mother U bluntly states ‘no’ in answer to the initial probe. As a contextual cue this would typically constitute a closure of this version of the assessment discourse and guide the receiver to a more appropriate or welcome mode of talk (Wetherell, 2001). However, expert privileges permit professionals to probe further into sensitive details without immediate, explicit censure. A second probe, ‘any care?’ is skilfully met with placatory detail and a further plea to not explore it further as an exceptional issue ‘it’s only to be expected’. Yet again Professional C enquires, delving into possible therapeutic services and has to be batted back with yet another strategy, a loss of memory. It begins to look like a very skilful dance between the two at this stage with Mother U politely using sophisticated discursive strategies (normalising ‘it’s only to be expected’ and suggesting she can’t recall details, ‘I can’t even...’) to avoid further disclosure or engagement with an upsetting topic and Professional C using all the power that the status of expert allows to repeatedly probe. Regardless, of having permission from both participants to use this data, I have expurgated the extract censorship-fashion in recognition of the sensitivities within this particular section. Mother U does eventually offer up some detail of events but at line 183 she moves to re-orientate the talk to her child, ‘It was her daddy’ but at line 188 Professional C continues to probe, ‘And do you still have
hyperventilation panic?’ Only at this point with Mother U’s firm response, ‘**NO**’ (l.189) does the talk begin to move onto another topic, living arrangements, where the questions continue to be intrusive but not quite so sensitive – ‘**C. Uh huh. And are you living together or are you in your own place and he’s...**’ (l.201).

### 6.2.3. Test or interrogation

Three aspects have been grouped together in this section as they all work to undermine the parent’s subject position in the assessment ‘test’. Firstly, parents sometimes offered answers to questions to find that they were asked the questions again, suggesting their responses were incorrect or inappropriate. Secondly, they were probed for additional information, suggesting they did not meet the full requirements of the question. Again this positions parents as less competent, not knowing the answers or not knowing how to address the questions accordingly. Thirdly, they were asked for examples to illustrate their answers, and this could be considered to be necessary evidence to support their claims. Individually, each is damaging enough to the subject positions of the parents in that they are being tested for reliability and bestowed with inadequacy in addressing questions about their own child, but combined these features of the assessment questions position parents defensively, i.e. defending their claims, their parenting, their child and their worth or right to support services. I argue that parents are vulnerable in this process as, despite needing to defend their claims and rights, they are subordinate, powerless and dependent on the professionals for help and so they cannot defend too vigorously or they may alienate that help. Some even felt they were are not entirely believed.

**Excerpt 12**

**C. And if, say for example, you had her out and about and there were people around, would she ever approach them just to, sort of, interact with them?**

**U. Men. She would with men. Women, not so much.**

**C. And what would she do when she approached men?**

**U. Well, she would just go up and stand in front of them and look at them and she doesn’t say. Sometimes she’ll say, ‘hiya’ or what, if she’s got something, you know, she’ll say, ‘look’. It’s not even, hi, it’s hello, ‘hewo’.**

**C. And if you were out and about or people come into the house, like, you know, family members or friends or, you know, how would she react to them?**

**U. I have had to tell her that they’re coming. Em, somebody comes in out of the blue her face drops and she’ll hide sometimes.**

**C. How does she react to them?**

**U. The only ones that really come to the house are family anyway so...**

**C. How is she with them?**

**U. Oh, it’s only lately that she’s started going and giving, you know, going to get picked up by them to say hello or. My wee sister she loves her aunty G as she calls her, G. Em, before the, my**
mum and my mum’s partner and my aunt G came up and my, her aunty G was the only one that got...

C. Any attention?

U. ...Any attention. It’s only lately that she’s even started giving my mum hugs because my mum thought that she didn’t like her or something. You know that way because my mum always said, you know: ‘How come she’ll go to G and not me?’

C. Yeah, she’ll go...

U. You know, she’ll run past anybody to over to our G.

C. And what happens if there’s strangers? Would she go up to them to be picked up and, no?

U. No. No. No. Eh, we were there

C. What’s she like with strangers then?

U. Hides. Goes nah. Just as I say, we were there at the hospital there last week. We were to see the doctor about the accident and as soon as he went in he says, ‘Hiya’. She hid behind my arm, ‘Ehh’ at him.

C. Uh huh. So she’s not really, she’s not a friendly child then really?

U. Not really, no. She can be. She can be very loving and affectionate but at the same time you do get your wee punches and nips, scrabs, she’ll bite herself and all too for no reason (pause 8 secs). (assessment, l.776-810)

This excerpt shows a repetition of questions, e.g. asking how the child reacts several times even though the mother has said how the child reacts. In fact, the mother doesn’t answer the second question about the reaction and instead diverges to say that only family come to the house anyway. This makes a point that they are socially isolated perhaps and even raises questions about how society accepts and supports the family when children and parenting do not fit the norms, but it is overlooked in order to focus on the specific items to cover on the schedule of questions. When probed, however, Mother U does offer more information but again focuses on the negative, e.g. hitting, punching etc. The professional asking if she is not a very friendly child has broached an implied criticism which in usual conversations would be inappropriate or might illicit a defence or even a counter-attack – as with abrupt changes and probing sensitive topics, professionals in consultations have license to commit discursive violence that would otherwise be prohibited in everyday conversations even with the closest friends or casual acquaintances. However, in this context of consultation it is accepted and responded to with some qualified defence – this is an example of positive framing immediately followed by negative framing which is characteristic of how answers were orientated to obtaining help, explanations and services within a construction of worth. Again, the mother raises points of some concern about her daughter biting herself and harming others. It is left hanging, unanswered and unaddressed, further evidence that parents asking the professional for explanations is not appropriate and will illicit no response. The questioning moved on to another area. The professional also interrupts, when the Mother U begins to provide evidence of how her child would not be picked up, so she gets only the specific information, i.e. no and then further detail of how she is with strangers. She didn’t need the evidence as the ‘no’ was clear enough.
Asking for examples/evidence

The professional often asks for examples or probes for examples surreptitiously. This further reinforces the power relations and positions of the parent and professional by putting the parent in the position of having to justify what they are saying and remember and think about examples – a much more difficult task than it appears. It can be used to suggest that the person is not right, especially if they can’t remember a specific example and just have to rely on a general one or none at all. Being asked for an example means you have not explained properly or you have to defend what you say with evidence rather than have the claim taken on trust. It also links into the idea of ‘objective truth’ in medical and scientific facts i.e. claims should be observable, measurable and evidenced to be verified or accepted as true:

Excerpt 13

C. So she, you said she always, she copies back immediately what you say to her?
U. Yeah.
C. Do you ever get, sort of, copied back things that she’s heard somewhere else or another time?
U. Yeah.
C. What sort of things can you think of?
U. Em, mainly things that she sees on TV or hears on TV. Em...
C. Uh hm. Can you think of an example?
U. There’s one thing in Tom and Jerry where it’s doink on the head and she’ll just randomly come up and go, ‘Mummy’, doink and, you know, that’s she wants, you know, to do that on your head (pause 7 secs). Or if you say sometime, like M had said something, you know, previous about a book or something.
C. Uh huh.
U. A while later then K will come and say, ‘Mummy, a book. M, where?’ (assessment, l.937-950)

Within this context of questions, probes, evidence and repetition, constructions of autism and of the child slip through without contest and so the assessment test can also be viewed as a practice of manipulating (albeit unwittingly or even unintentionally) the meaning of autism, e.g. to support the normal/abnormal binary on which the diagnostic criteria is based. This is a debate I want to raise in the thesis but do not claim to resolve. Throughout the assessment, questions or prompts are framed, unquestioningly, in terms of normality or conformity to social or developmental norms:

Excerpt 14

C. And what about the big movement milestones that you think about a baby? When did he sit?
Normally they do it at around seven to nine months. (Assessment, l.591-592)
C. … Things? Yep. What about, do you know the way, if you think about it, if you watch them in school, em, one child sits down in assembly they all sit down.
T. Uh hm.
While some parents did relate concerns about such deleteriously and discouraging binary constructs during the research interviews, no contestations were raised during the assessment meetings about the nature or tone of the layered assemblages of meanings implicated. In the politics of autism representations, this is a serious limitation in understanding that could be challenged at the very core of how autism and concepts of normal and acceptable are constructed by professionals and society in general (Donnellan, Hill, and Leary, 2010). Opening up possibilities means disrupting such notions, e.g. why should they all do the same and what is the problem with some children being slower to eat? If we all follow normal cues like lemmings it could have disastrous results and what would happen to innovation. There is no space or freedom in the document-oriented assessment to promote diversity, and huge assumptions are made about competency because of the lack of discursive opportunities to renegotiate the boundaries of what is ‘normal’ (Lester, 2014).

6.2.4. Failed use of reported speech – the expert wins!

Parents quite often used reported speech (Horton-Salway, 2001) to support their points, i.e. as support from others in this assessment ‘test’. This evidence can be all the stronger if coming from the reported speech of another professional, so parents borrow ‘expert’ status or gain proxy expertise status of their own. In this way, parents attempt to negotiate access to the power in the meetings that they struggle to get from utilising their experiential knowledge. Experiential knowledge is not written, recorded or otherwise formalised or given authoritative status, and it relies on memory:

Excerpt 15

C. Any invented or made up words or anything like that? Just gobbledegook?

U. Gobbledegook. You know you can’t, an awful lot, even the speech therapist said to me when she was doing it over in the W Centre. She looked at me a couple of times and said, ‘How do you know that’s what she’s saying?’ Usually because I’ve had, just used to doing it. (assessment, l.961-965)

Mother U, in her attempt to mobilise a strong discourse of legitimate and severe need, presents a claimed statement from a speech therapist. In triangulating the locution in this way she positions Professional C against herself and another professional if Professional C does not agree that there are serious issues with her child. This links to the range of discourses that people have available to
them – as per the previous quote, parents don’t keep a record of evidence to support claims about their children’s behaviour. Efforts to draw on reported speech of professionals isn’t always successful or accepted and as Mother U’s assessment meeting continues she escalates her claim that her child has speech and language problems to one for an autism diagnosis:

Excerpt 16

U. So even the speech therapist, I had said to her, you know, when she said about the autism, she says, ’no harm but if it comes back she hasn’t I will be a hundred percent shocked’, she says, you know.
C. Well, we just need to put it all together because for me I need to be very sure in my mind.
U. Oh, I know that. (assessment, l.1194-1199)

The parent here tries to provide some weight behind her claims by a proxy authority in the reported speech. However, the professional counters this claim to use a proxy authority subject position and dismisses the evidence as if hearsay, taking back ownership, ‘we just need to put it all together because for me..’ Again the parent conforms immediately, even though this is essentially a put-down of her claim, and reaffirms her own subject position and lack of power over the process and outcome with: ‘Oh, I know that.’ Mother U has tried to put some attributional distance (Wetherell, 2001) between her own investment in her child’s diagnosis and attempts to access power by triangulating the claim with another professional but it fails and she does not persist with this strategy, adopting a more conformist one and falling back into line with ‘oh, I know that’.

6.2.5. Abrupt changes

Consultation conversations are unlike mundane conversations. The expert status of professionals establishes assumptions around knowledge and permits them to deploy rights and practices in consultations that would not be acceptable in other forms of interaction. As section 6.2.2 above illustrated, for example, professionals will often go beyond the bounds of interaction norms when probing patients for ‘sensitive’ information. However, the discursive violence involved in the practice of abruptly changing topics during sensitive disclosures is extensive and startling. It is also a direct result of the protocol of the schedule of questions and a set timeframe, i.e. the professional is required to complete the questionnaire in their possession within a clinical meeting while the child is being observed doing set tasks. Also, each typically lasted around 1.5-1.75 hours.

Excerpt 17

T. I would say sometimes with his talking, em, and it can be simple words again, sometimes you’d, if I’d maybe say a sentence and there’s ‘with’ in it?
C. Yeah.
T. He goes: ‘What’s with? What do you mean?’
C. Uh huh.
T. There’s words like that. Em, its again at, if you say later on today...
C. Uh hm.
T. ... And he goes: ‘No do you mean today? What do you mean later on today?’ Or if you say this afternoon as well at times...
C. Uh huh.
T. ... He’ll go: ‘But isn’t that today?’ He ...
C. Yeah.
T. Sometimes he can.
C. So its time concepts he ...
T Yeah, as well, he can’t piece together.
C. Has he been in hospital? (assessment, l.695-710)

In the above extract Professional C creates an abrupt change moving from the topic of time concepts to the topic of hospital admissions. Such sudden topics shifts are another discursive mechanism which mobilise authoritative power (West and Garcia, 1988). Mother T provides an account of her son’s questions about the language used in communicating timeframes and implies this is a problem ‘he can’t piece together’. However, there is a deeper implicit question embedded here which is twofold: firstly, Mother T has come to the assessment to get help and to get answers, the basic one being whether her son is autistic, but this raises questions about what this means; secondly, Mother T’s account establishes an implied question about why her son cannot piece together concepts of time and from this it is reasonable to assume she wants to know whether he can be helped and how to help him do this. In everyday conversation such an account would raise expectations of the receiver offering an emotion response (solidarity or empathy or even surprise) but also, perhaps some suggestions about what this would mean or ideas about how to teach him. In the absence of these, a sudden switch in topic would equate to discursive violence and it is likely the narrator would be discouraged from further disclosure. In the discursive space of the assessment, despite Professional C’s expert credentials for relevant knowledge, no responsive comment is offered, barring ongoing ‘uh huhs’ and clarifications. This is strong evidence of a position of non-empathetic interviewing (which will be further discussed in chapter 8). The use of a document/schedule of questions obstructs any empathetic response or attempt to address implicit questions directly. Furthermore, it inhibits knowledge transfer and even collaboration, and establishes uneven power positions.

The document provides a schedule of questions through which the professional must progress to collect all necessary information necessary for a diagnosis to be made. The very form of this progress produces a movement between topics that does not follow a parent’s narrative flow. Instead it moves from topic to topic and frequently creates abrupt changes between the parent’s
answers and the professional’s next question. Where these abrupt changes are felt most is when the parent has developed talk around an implied concern or question, often of a sensitive nature or concern:

**Excerpt 18**

*C. So she doesn’t get involved in groups at all. Nothing?*

*U. No. As I say, it’s very rarely she’ll even let her sister play with her in the house. It’s more fighting and screaming.*

*C. Does she show any awareness that some other child’s hurt? Or does she ever go up and give, touch them in a nice way, you know?*

*U. No. She laughs at you if you get hurt even.*

*C. Can she follow rules of games?* (assessment, l. 702-708)

Here the implied question is ‘why would she laugh at you if you get hurt’ and this issue is likely to causes some concern and is perplexing for the parent. When attending an autism consultation it may be expected that such concerns would be addressed directly. However, here the assessment abruptly moves on to the next question in the schedule. This produces a lack of voice for Mother U, disregards the significance of what she has said and works against validating the her claims.

**6.3 Diagnostic meetings**

This section of the chapter focuses specifically on issues raised by the use of the diagnostic report in the diagnostic meeting. The report was read to the parents in the meeting and then posted to them in the following days, except in one case where the parent was given it shortly after the meeting.

**6.3.1. Reading the report**

The pattern and rhythm of the transcripts for the diagnostic meetings, and it helps to actually read excerpt 20 out loud to get the sense of this, indicate that the diagnostic report was read to the parents. Parents were told the report would be sent out to them and it was evident that it would be sent out to a range of professionals associated with the child and family at the same time *C. Em, the report, once you get it next week, you will know that everybody else has got it*. Excerpt 20 takes us through one such example of the diagnostic report as received by the parent in the diagnostic meeting:
Excerpt 20

C. In looking at her milestones you said she sat at ten months, she was crawling at eighteen months and walked shortly afterwards. Toilet trained about three during the day and three and a half at night.
U. Yeah.
C. And she had continual intermittent accidents after this but not because she wasn’t aware but rather because she didn’t use the bathroom.
U. It’s still the same.
C. Yes.
U. She’ll still go and pee on the stairs and then when she tells you she needs to go to the toilet.
C. Yes, she doesn’t want to go.
U. Especially after I’ve just scrubbed it all. She loves it then.
C. Language-wise you said she’s responsive to her name but she’s unpredictable. She can follow simple instructions. Can follow more complicated ones but doesn’t always comply with the complete, you know, with them.
U. Yeah.
C. Frequently refers to herself in the third person. Good single word vocabulary but doesn’t use it widely. Phrase speech is poor and she doesn’t have a good sentence structure. And you said that she can, em, use, she uses like an amalgamation of single words rather than a proper sentence? (diagnosis, l.65-84)

What comes across more clearly when reading aloud is that the professional is reading off the report and uses a form of paraphrasing when doing so, omitting words such as names or ‘her’. In reading it, the document has primacy and very much sets the tone, the pace and nature of the interaction, establishing and maintaining subject positions, controlling the exercise and direction of power and restricting possible alternative repertoires. Reading from a document offers authority and certainty, there is a flow that is easily available and little opportunity in pauses for the mother to respond or to ask further questions. Essentially, reading from the report closes down further discussion. According to Georgaca (2013):

‘Clinical records are effectively selective reformulations of verbal accounts and previous records and their function is to construct a unified story of the patient in question over and above the various stories told by the different parties concerned, by prioritizing those elements that combine together neatly to paint a picture of a mentally ill person. Clinical records are represented as factual, neutral and objective descriptions and explanations of the patient’s history and condition. This is achieved through systematically removing from the record elements that indicate the professionals’ active role in formulating it and privileging clinical observation over patient perspectives’ (Georgaca, 2013, p59)
6.3.2. Confirming and conforming, and not conforming

This section will explore the pattern: professional giving an account of the child and the parent agreeing. Parents in all diagnostic meetings conformed to the pattern waiting to be told toward the end of the meeting if their child was to be given a diagnosis. The process essentially exposes an implicit if–then conditional positioning/formulation between professional and parent, i.e. if the parent conforms, then they may get help and if they do not, then they may not get help. Hepburn and Wiggins (2005) argue that such a formulation is an inherent vehicle for the creation of ideology (in this case the medical ideology in western society) and how ideology may be ‘oriented to, challenged and defended’ (p.597). It establishes two potential pathways for responding: compliance (the conformity in most of the parents’ responses) or defiance (ranging from the disruptive parent who unintentionally does not follow consultation protocol to the fervent activist). Almost all parents conformed:

Excerpt 21

Q. Yeah.
C. ...You know, you know, that gives more...
Q. Yeah, --that he wants to do this.
C. ...Clues than just doing this. And he might look at you to say: ‘You let me out’. But D just pointed. He didn’t really indicate anything more than that. Em, what the nursery said was that he doesn’t use great eye contact. Em, doesn’t use great descriptive gestures so that difficulty that you see in the home we saw in clinic and we saw, nursery see as well.
Q. Yeah.
C. So it’s not you seeing it in isolation.
Q. Yeah.
C. Other people can see it too. Then we looked at his ability to interact with his age group and what is that relationship like and can he share things and enjoy activities with them. You said that, look, he’s got an older sister whose not that much older than him but he doesn’t really interact with her.
Q. Uh hm. (diagnosis, l.181-207)

Only one parent, Mother N, did not fully conform to the typical pattern, not so much defying as disrupting. I use this example as a contrast to the confirming and conforming pattern. The outcome of Mother N’s challenge to the status quo was that the diagnosis was given much sooner. However, it had a cost in how the professionals positioned her and their relating to her. Later, the professional described that parent to me as someone with ‘issues’ and ‘difficult’ and the professional who took this meeting actually withdrew her data from the research.

Excerpt 22

‘Yeah. But my worry is, you know, I don’t know what yous will come up with here and I’d be perfectly honest with you, if it comes up and they tell me that there’s nothing, just his ACD, I will
be getting him reassessed again because my fear is D's getting older. He's getting bigger, you know, what happens when he leaves school. I can't keep him locked up. It's not fair on him. This is my problem, do you know. Do you understand what I'm saying' (N, line 474-479)

The professional gave the diagnosis at that point in response to this question and the parent promptly broke down.

Adherence to the pattern of confirming and conforming to both the schedule of questions and the report constrains any opportunity to take account of or even really acknowledge that these parents carry a substantial amount of knowledge, not just about their own children, but about autism, albeit from the internet, books, autism organisations or other parents. Let us be clear about them having knowledge of autism – it is entirely and highly likely that a parent whose child has been referred to an autism assessment clinic would do everything to investigate the topic of autism and there is ample information available in our technologically rich world – in fact it is more likely to result in information overload. Not only this but also, as evident in chapter 5, parents talked about having searched for information, networked with other parents and even had previous dealings with professionals and assessments. U even discloses in the assessment meeting that she has attended training at a social services facility but she moderates the status of her claim immediately by highlighting her inability to remember names and getting mixed, although there is no evidence she is mixed up:

Excerpt 23

U. There is, I think, well, she told me there was somebody coming in one day a week to help with the other ones with K.
C. Is that O?
U. Yes, O come in. I've been up to O as well, so I have. It's all these names I forget. I get mixed up sometimes.
C. And what were you doing? Was that training at O?
U. It was just more, eh, information thing about all the different aspects of autism. How you can deal with things and, as I say, I call them tantrums, they call them melt-downs. Whenever she goes, sometimes you can't get her out of it, you know, even when you take away what is bugging her, you know. Nine times out of ten it's M or any other kids. In nursery she lashes out at them if they don’t leave her alone as well. She’ll put sand in their faces if they won’t go away from the sand pit. The sand pit's hers. Nobody is, anything she has is not, nobody, even me, do you know. Her cuddles and kisses, if you try and give her hugs and kisses when she doesn’t want to you’ll get screamed at, hit but whenever she wants them she’ll give you them all day long, do you know?
C. So she's statemented then? I started statementing her. She must be if she's going to G.
U. Yeah, yeah, yeah.
C. Em, and does she separate fine from you? No problem going into nursery?’ (assessment, l.495-514)
Yet, this was almost uniformly ignored in the assessment and diagnostic discursive interactions between the parents and professionals. In not acknowledging existing knowledge about autism then parents’ knowledge of the topic is invalidated and they lose the opportunity to develop understanding by building on such foundations, or to have misunderstandings challenged. Furthermore, it enhances the knowledge and status of the professionals – their knowledge is also not actually exhibited (then it could potentially be shared) but is presumed by the process, the documents and their positions.

Excerpts 24 and 25 provide a contrast which highlight the risks of non-conformity to the pattern of the diagnostic report:

**Excerpt 24**

Q. Yeah.
C. ...You know, you know, that gives more.
Q. Yeah, ---that he wants to do this.
C. ...Clues than just doing this. And he might look at you to say: ‘You let me out’. But D just pointed. He didn’t really indicate anything more than that. Em, what the nursery said was that he doesn’t use great eye contact. Em, doesn’t use great descriptive gestures so that difficulty that you see in the home we saw in clinic and we saw, nursery see as well.
Q. Yeah.
C. So it’s not you seeing it in isolation.
Q. Yeah. (diagnosis, l.192-202)

In the above extract from the diagnostic meeting the assemblage of confirming and conforming turns of speech is typical of the pattern throughout the meeting. The tenacity of adhering to the patterns is demonstrated when Professional C continues her talk, as if unbroken, over the parents extended agreement, ‘yeah, ---that he wants to do this’. The meeting between Mother Q and Professional C ran to 731 lines of transcript. The diagnosis was tentatively offered at line 345, ‘and I do think, Q, probably autism does describe D’s difficulties for you’, then there was some generalised discussion of autism support and the report until at line 689 the diagnosis was firmed, ‘fulfils a diagnosis for autism’. Given that parent Q has conformed and confirmed with everything up to line 345, the rhythm and pattern of the meeting constrains parent Q so much that, even when the first proclamation of a diagnosis is tentative, the habit discourages challenge. Further questions may appear stupid, suggesting a lack of understanding. Certainty is only established at the end of the meeting when the parent discursively cannot undo an hour or more of agreeing and disagreement then would mean both the parent and professional would lose footing (Goffman 1959).

The next excerpt contains a particularly delicate exchange. Mother N disrupts the pattern of passive conformity and repair work is carried out by both parent and professional to manage the
loss of footing and presentation of self. Note that only the dialogue from Mother N is available because the professional directing the meeting retrospectively withdrew her data.

Excerpt 25

N. Yeah. But my worry is, you know, I don’t know what yous will come up with here and I’d be perfectly honest with you. If it comes up and they tell me that there’s nothing, just his ACD, I will be getting him reassessed again because my fear is D’s getting older. He’s getting bigger, you know, what happens when he leaves school. I can’t keep him locked up. It’s not fair on him. This is my problem, do you know. Do you understand what I’m saying?
Prof. ___________
N. You know, I’m doing this from he was no age.
Prof. ___________
N. And he’s eleven now.
Prof. ___________
N. Yeah.
Prof. confirms diagnosis ___________
N. Oh, he would.
Prof. ___________
N. It’s just something for me, not that it makes any difference, do you know what I mean. It’s just then I can say I know why he’s like this.
Prof. ___________
N. Yep (but clearly very upset and crying). Look, I’ve known this all my life (crying).
Prof. ___________
N. Yeah. Yeah, I know.
Prof. ___________
N. ---D so much because what’s going to happen to him? You know, I really do worry about him, you know (still crying).
Prof. ___________
N. No. No, I’m grand. Thank you.
Prof. ___________
N. I don’t’ want anything to happen to me or anything, you know. He’s getting older so quickly, do you know. Where does he go? What does he do?
Prof. ___________
N. Is there supports because I’ve never been offered any sort of support for anything that D’s got.
Prof. ___________
N. That child’s like a prisoner. Can’t go nowhere. (diagnosis, l.474-511)

In this extract, Mother N receives confirmation that her son is being diagnosed with autism. However, the meeting progresses rather differently to the other diagnostic meetings specifically because Mother N breaks with the typical discourse pattern of consultation and expresses her anticipated disappointment and fear for Son D and forces the professional to not only acknowledge (typically with uh huh) but to respond to N querying the professional’s understanding: ‘Do you understand what I’m saying?’. Three significant issues emerge here: 1. The diagnosis is offered almost immediately as a response to Mother N’s upset; 2. Mother N
becomes further upset, cries and expands on her feelings to help explain her upset and 3. The professional withdrew her data from the study, hence the professional has not been allocated a pseudonym letter and their data lines are blank in the transcript.

It is particularly interesting that the professional withdrew her data when this is probably the main excerpt from all the transcripts where the professional demonstrated a deep level empathy by herself breaking, and therefore matching Mother N’s break, with the prescribed protocols. Mother N was permitted to express her feelings and was responded to, although the responses are not available to examine, and, furthermore, the professional actually restructured the process to allow the parent to know the diagnosis before the diagnostic report and protocols dictated in recognition of her distress over uncertainty: ‘I don’t know what yous will come up with here’.

Clinical distance and the processes of the neoliberal professional have produced a context whereby holding such empathy and responding empathically to parent to the relegation of institutional processes and protocols appears to be so frowned upon that this professional was moved to obstruct the release of this part of her work. In contrast, Mother N also provides explanation to account for her upset as it needs to be explained to save her face as a worthy help-seeker. Her value as a help-seeker is established here as a loving and competent mother, upset because her son is ‘like a prisoner’ and thus may be conferred some degree of justification for breaking the rules of consultancy engagement in autism diagnostic meetings. Unbeknown to her she had already been branded, to me by the team leader, as having ‘issues’.

6.3.3. ‘You said’ formulations

Throughout the diagnostic meetings the professional reads through different sections of the assessment criteria and reiterates to the parents the information they gave. This gives a shape to the diagnostic meetings that is very specific to them, i.e. the large chunks of professional talk that is then interspersed with parents’ consensus. This reiteration was only possible through the use of the documentation since the parents actual words had been paraphrased into the assessment report. This section explores the parents’ constructions of the ‘you said...’ formulations (Wooffitt and Allistone, 2008) from the reading of the diagnostic report to the parents. Below is an example of the formulation being used but the extent of its use can hardly be overestimated. Within the diagnostic meeting some third party information may be offered that the professional has gleaned from education or other professional reports, e.g. speech and language. However, the vast majority is based on the parents’ accounts from the assessment meetings. The professional told me as an aside that they deliberately use this approach so that the diagnosis is justified to the parent with respect to the points they have raised themselves. The professional thought that was
a more respectful approach because they were using the parent’s words – clearly not the way parents saw it and it is perhaps rather patronising, albeit kindly intended. However, what it actually is doing is rather more complex.

Excerpt 26

C. You said he’s probably got about fifty words, a few short phrases. You can’t exactly remember when the language developed but he did, you know you were saying actually he could do funny things like copy Pingu and say phrases out of Pingu which, given that he had trouble with speech was unusual for him. And you said he would follow single word instructions, em, but only if you ask him. Not if other people ask him to do it. (diagnosis, l. 80-85)

The repeated use of the ‘you said…’ formulation links the assessment outcome, i.e. the diagnostic decision, to the parents’ claims very specifically. This can suggest that the parents’ voices were heard and acted upon, that their evidence did indeed form the basis of the diagnostic decision. However, the specificity lies more with the parents’ words than with the autism criteria or with the development of the link. The parents’ comments to the researcher constructed the intention and meaning of this very negatively, i.e. as not believing or as cornering them in an argument so that if they said it and it leads to either a diagnosis or no diagnosis then they can only blame themselves:

Excerpt 27

N. And when they’re giving you the report it’s always, ‘and mother says’ and it’s very like you know am I lying or something? Or why would I say that? There’s nobody wants to run with their child as long as I’m running to say that there’s something wrong or if there’s not. I mean, like, wise up. But it’s always, it’s the way it’s worded. It’s nearly like: ‘Well, we’re not saying this but mummy says that this that or the other’. You’re like: ‘Well, then why ask the questions? (post-diagnosis, l.236-241)

Because they are not given any rationale between their words and the outcome, e.g. how these related to autism and what they meant specifically about how the child was thinking or why they were doing these things, the parents had no other material or evidence to debate or question. ‘Then why ask the question’, indicates the pointlessness of the questions the parent was asked as she articulates distrust and a sense that her answers were not believed or valued. The excerpts below form reflections of distrust of the professionals and the process, and are critical of the negativity reflected back to them to justify the professional decision.

One father, T, below clearly categorises the information at the diagnostic meeting as information they knew and thus not helpful in the sense of taking them further. He also highlights the negative framing the professional used about his son, so constructs the information as actively unhelpful, in
fact. His wife E follows this up with a direct criticism of the professionals and attacks their status as ‘experts’ on the grounds that they were not providing new ‘expert’ knowledge.

Excerpt 28

T. Very negative and we all, we all know that, we know what S is like and you’re telling us, you know... I always like to get to what we get to do about it rather than the continuous going on about how...
E. I know.
T. How negative she is about it, about how bad he is at... (post-diagnosis, l.250-254)

E. It’s rubbish, it really is. I mean they’re experts, they’re supposed to tell you, you know. (l.358)

Conclusion

Parents and professionals position themselves and each other aided by the form and use of the document. Parents are disempowered in a number of ways in this document – they are dictated to or guided by the talk while the professional’s ‘expert’ identity is enhanced, despite the absence of expert evidence. Professionals ‘own’ the documentation so ultimately have power and use the power to set this agenda, thus accessing more power. As their experiential knowledge (the main source of their status and authority) is scrutinized through the assessment, it produces a deskilling of the parent and a lessening of their status. The diagnosis provides a professional evaluation which the parents may use in proxy to gain services but it goes not offer significant new knowledge or give them much opportunity to wield informed influence or control. There is little by way of literature to examine the use of documentation in consultations and this is probably an area for future research to pick up (Mishler 1984, Lingard, Hodges, Macrae and Freeman 2004). However, it is also recognised that the use of very formalised diagnostic reports are an anathema to professionalism too, in that they (especially computerised forms of recording which are not so relevant here) produce the consultation in a way that demotes the assemblage of professional judgement and treats diagnostic and prognostic skills as formulaic and fixed (Heath and Luff, 1996 and 2000).
Chapter 7

Trouble and dilemmas in autism diagnosis

Chapter 5 presented an account of parents’ understanding of the experience of autism assessment and diagnosis which discriminated between the incommensurate epistemologies of parents and professional in the interpretative repertoires of knowledge and knowing. Chapter 6 then analysed how these discourses of knowledge and discursive practices of institutional power, namely the use of assessment instruments such as the ADI-R and reports such as the diagnostic report, produce subject positions that close down possibilities for negotiating a range of repertoires and alternative meanings and positions for parents. The focus of Chapter 7 is the challenge presented by the inharmonious or incompatible range of discourses parents and professional draw upon, and engage in, when a child is assessed and diagnosed with autism.

Autism is a neurodevelopmental category postulated in medical taxonomy but is also a negotiated concept in that it is negotiated by professionals and others, including parents and autistic people themselves (Ortega 2013, Orsini, 2009). The diversity of available discourses (See chapter 1) and openness to alternative constructions is fundamental to parents’ efforts both to develop their own functional networks of meanings around autism and to establish a position from which to negotiate services. However, such variability may disrupt the ontological coherence of accounts because they conflict at the level of ideological foundations for both parenting and professional practice. Contradictions emerge within the variation to a level that cause difficulty for participants’ lived practice of their ideological assumptions and performances. These produce ideological dilemmas for both parents and professionals.

Section 7.1 begins by analysing autism as a troubled category (Cascio, 2012). Parents’ drawing on the cultural discourses of autism, and professionals, drawing on the clinical criteria of autism, move between varying ways of constructing the meaning of autism and the autistic child. The trouble with describing the autistic child, the trouble with norms, and autism as a contested category emerges as accounts function to address different rhetorical demands. These contradictory ways of talking during the diagnostic processes also unearth contradictions within ideological frameworks simultaneously inhabited by speakers. Section 7.2 provides analysis of ideological dilemmas: Section 7.2.1 centres on the dilemmas evident in the parents’ talk while Section 7.2.2 explores dilemmas of the professional. Concepts of child, autism, parent, professional etc are not neutral so each is referenced specifically to a neoliberal framing of their role. In Section 7.2.1 ‘Parent’ is a detached entity in a neoliberal society; the weakening of the
concept of community and society places responsibility for the child almost completely with the parent (Holt, 2010).

This responsibility extends from loving and nurturing to the discipline and control of the child – the section argues that the nature, behaviour and capabilities of the child result in a social rejection such that the state requires the parent to assume responsibility. Hence parents are caught in an ideological dilemma; they attend to the diagnostic procedure to nurture but are also forced to act on the child as an agent of state surveillance, control and discipline where social obligations/expectations/requirements/norms are not met (Eyal et al, 2010). Section 7.2.2 explores the professional’s dilemma between producing themselves as two versions of a discursive professional subject, the caring professional or the expert professional. The analysis references neoliberal concepts of the expert and the contrasting care principles of the NHS (Razzaque and Wood, 2015). It examines this dilemma through two particular aspects: ownership of discursive genres as resources for interaction, and repair work.

7.1 The trouble with autism

Autism has a problematic classification; its ontology hotly debated. Autism is a troubled category because the social discourses, including those associated with the medicalisation of autism, carry contradictory repertoires of autistic people and autism itself (Cascio, 2012). Furthermore, autistic people and their families occupy troubled, highly mobile and contradictory positions in autism-related interactions (Rosenburg, 2006). This section will explore how parents rhetorically negotiate from within such troubled positions during their time in the process of autism assessment and diagnosis. It begins to unravel the contradictory talk and practice of parents attempting to manage the troubled category ‘autism’ and will deal with 3 specific questions:

- Why would parents seek a diagnosis of autism for their child - Diagnosis – soliciting the undesirable
- How can parents claim there is something ‘wrong’ with their child – Declaring love and dissatisfaction
- How do parents negotiate with a hegemonic institutional power - separating the autism from the child – who or what is responsible for the bad behaviour?

7.1.1 Diagnosis – soliciting the undesirable

This section explores the troubled negotiations that occur when parents beseech professionals for a diagnosis that is essentially a ‘life sentence’ and would burden their child with a label that the
media and general public understand very negatively (O’Dell and Brownlow 2005; Nadesan 2005; Osteen 2013). Parents have been accused of colluding with professionals to diagnose and disable autistic people (Bagatell, 2010; Bumiller, 2008, 2013). However, the data from this research of the early processes of help-seeking suggests that participating in the diagnostic process is deeply disturbing for parents yet strategically inescapable. Indeed Hacking (1986) implied, and Eyal et al (2010) explicitly state, that certain factors such as pre-diagnostic adverse labelling or hope-inspiring interventions must be in place to ensure parents are willing to recognise and accept a diagnosis. The diagnosis, according to parents (see chapter 5), provides a passport for services and there can be no progress without ‘colluding’ with professionals (Ryan, 2013, Eyal et al 2010). According to Mallet and Runswick-Cole (2012, p.44) parents are committed to diagnosis, despite the struggle to achieve it and the dread of what it may mean and its consequences; ‘for all the uncertainty surrounding autism, it is the promise of coherent explanations that make us buy (into it). We argue it is the promise of useful information’. Parents co-produce autism with professionals ‘in order to understand and better care for their loved ones’. This is exactly what Mother U constructs in her justification for accepting a diagnosis she initially claims she did not want.

Excerpt 1 (Pre-assessment)

R. You said at one point, you still kinda feel that you don’t want to be told that she’s got autism. Do you still feel like that or what? How would you...?
U. Hm, I think just deep down I’m just hoping that it’s because she’s going to this special school and all, you know. She’s been, she’s going to G assessment centre for P1 and I was hoping that once she started there that speech would come on leaps and bounds
R. Then into mainstream and all of that. Yeah
U. Just, it would be a lot easier, yeah, you know if she didn’t, if she wasn’t assessed with the autism because then I know that she is just a wee bit behind
R. Uh huh
U. But I know, deep down I do know that it’s not going to come back that, you know what I mean. It’s, I’ve got it in my head now that that’s what it is but up until she’s diagnosed I’m still going to have that
R. That hope that, to hold on to
U. ...it’s not. Yeah. Yeah.
R. If, if she does get a diagnosis can you see advantages of having that diagnosis?
U. Yeah, because there’s more things that once she has, I can get more help through groups and all once she’s properly diagnosed. They’ll only give me information and all whereas then I can go and get. There’s groups that take them out with the other kids and all, you know. That will advantage K. As I say, at the minute she doesn’t and she lashes out at them
R. Yeah
U. She doesn’t tell them to go. She can tell you to go away but she doesn’t. She just hits you. You know she needs an awful lot. She’s only in nursery a couple of hours each day and, as I say, the wee clubs go after school, you know, and I go with her so it’ll be help with the support for me and for her and then helping me understand to help her more if you know what I mean. So there’s a lot more advantages once she’s properly diagnosed, you know, of the understanding
of it, getting her the help, you know, because, as I say, there’s an awful of places that she does need help in, you know. She’s going to this G assessment centre for P1 because she’s not, she’s not able for P1 and I know she’s not able for a normal P1. She couldn’t cope. It’ll just be constant tantrums and frustration build-ups and it’s not fair on her either. It’s her you need to think about.

R. Uh huh

U. You need to get what’s best for her and what’s going to help K (pre-assessment, l.409-443)

Many parents talked of their persistence to engage with professionals and achieve a diagnosis. Since the diagnosis is described as a label that is not wanted and because it is feared due to the negative implications of what it means about their children, persistence to achieve the diagnosis highlights the importance it carries for parents. As parents have been accused of colluding with professional, this could be understood as a persistent collusion but parents present their persistence as battles and struggles for diagnosis because it offered possibilities for knowing and for accessing help for their children, ‘You need to get what’s best for her and what’s going to help K’. In the excerpt below, N constructs succinctly an account which highlights range of diagnoses her child was given over time, including a claim in reported speech that child D had already been assessed for autism prior to the previous year:

Excerpt 2

N. The teacher said to me last year, I think it was, just at the parents meeting, ‘Has he been retested for autism again’

R. Uh huh

N. And I said, ‘Look, it’s like a joke’. It is an absolute joke what professionals are telling me, who deal with this every day of the week that, ‘Oh yes, yes’ and, ‘Oh no, definitely, definitely Mrs N and this, this, this’. And then it’s ‘Oh no it’s not. It’s DCD. It’s developmental co-ordination disorder along with he has hypertomia and different things as well’. And I was like, ‘Right, ok’. A lot of his traits is, still appear as in things he plays with, the way he sets things up, bowls he eats out of, you know (Pre-assessment interview, l.42-50)

Mother N’s talk is reminiscent of the ‘fight’ and ‘struggle’ of parents’ anthological accounts. What is mobilised strongly throughout the transcripts for each family is a desperate desire to help their child. This can be seen from many of the excerpts in the data chapters but Mother N says it most starkly to the professional a few minutes after receiving the diagnosis:

Excerpt 3

N. No, I give you my consent for anything that’s to help him. That is all I want. I just want him to have something (Diagnosis, l.588-589)
Mother N, the most visibly outspoken and confrontational parent, essentially offers to agree to anything the professionals want to do on the basis that it will help her child. Manifesting trust in the professional’s expertise Mother N pleads for help for her child. The construction of hope and confidence of ‘help’ arrives with a concurrent loss of hope for his future; hence she has an answer that she pursued but at the same time did not want:

Excerpt 4

N. Uh huh. Does he, will he grow out of that, like, maybe when he’s eighteen or nineteen or something or...
Prof________
N. It’s always going to be (words lost in crying) (Diagnosis, l.603-604)

Mother N becomes upset and cries with the confirmation of the life-long diagnosis. Her position oscillates between despair and hope depending on how the diagnosis is indexed i.e. despair that it is long-term and hope that he now has a diagnosis to account for his difficulties and may receive help.

Social stigma was another theme of the parents’ talk which often serving to contextualise and justify the quest for a diagnosis. Society emerged, in many of the parents’ accounts, as an ignorant and critical spectator – and autism diagnosis as the means to manage the criticism of the parent and child. The social stigma of having a ‘bad’ child was framed as less desirable than having an autistic child in the sense that it was constructed as an unfair assessment of the child.
All the parents talked about the social stigma attached to their child’s behaviours and there was an understanding that the diagnosis would help them deal with that stigma in some way or that it would take some of the stigma away. For some the stigma of bad parenting was identified as damaging too and the fact that autism as a diagnosis did not carry as much negative stigma in this context seemed to be associated with responsibility and control over behaviour and discipline.

Excerpt 5

‘U. And when you’re out and the looks that some people give. Once she is properly assessed and diagnosed people are in trouble because they will hear me, you know. Then, when I know that that’s what it is, they’ll be told that she’s not spoiled because that’s what I get. I get tutted and all’ (Pre-assessment, 179-182)

‘U. they don’t see and don’t understand that it is actually something wrong with the child. She’s not spoilt. She’s not, you know, a wee brat as people... I have, there’s been a few times I have to bite my tongue, you know, with people outside looking at your’ (Pre-assessment, 189-192)
Mother U presents a picture of social surveillance and censure aimed mainly at her child but also at her as a parent. Mothers assumed to be ‘bad mothers’ through contact with social services must do substantial work to position themselves positively while help-seeking (Croghan and Miell, 1998). Mother U is disapproved of, ‘I get tutted’, by the public observers and judged to be spoiling her child. An autism diagnosis, however, can take the blame ‘it is actually something wrong with the child. She’s not spoilt’. The something that is wrong is autism, as if it is an affliction. This is a familiar theme in literature on the medicalisation of autism, as autism is a ‘disorder’, but is also drawn upon from media and cultural discourses (O’Dell and Brownlow, 2005). Parents’ construction of their child having something wrong, at this early time of constructing understanding about their autistic child, is instrumental as it puts in place a convenient template to challenge criticism swiftly and simply, sometimes before the criticism is even formed or expressed. The next section explores how managing criticism of the child as a bad child is performed by discourses which establish autism as the cause of the bad.

7.1.2. My child, the lovable monster

The previous section analysed the phenomenon of parents seeking a diagnosis, arguing that it is unwelcome but required. However, achieving the diagnosis necessitates making claims, during the assessment, of a nature that risk vilification of their own child. This is because autism must be constructed as an entity (a process begun in the DSM criteria), by which to be afflicted. Thus blame can be attributed to ‘autism, the disorder’ while the child is constructed as a victim of autism, unable to control the behaviour, suffering frustration, stigmatisation and marginalisation, and needing relief and support.

The autism referral and assessment requires parents to identify their own child as a problem. Their claims to justify help-seeking must be formulated around the child’s challenging, or otherwise unacceptable or unfathomable, behaviour:

Excerpt 6

T. Oh, how would I describe him? A handful. A handful is what he is. He’s, he’s, don’t get me wrong, he’s a lovable child
C. Uh hm
T. If you were to look at him you would say he’s just like any other normal child. It’s just you can see, you can see that, that, if, eh. See, for instance, trying to get a hair cut. See trying to get D for a cut
C. Hm
T. …it is an absolute wrestling match and convulsions like that
C. Uh hm
T. ...because the shears were put onto his head and it’s the sense of the shears on his head.
Him, crying like that. He’ll go out there and be go into a panic because there’s tears running
down his face. He needs them wiped straight away. There can’t be anything on his face. If you
make D jam and toast and there’s jam on his fingers it has to be taken off straight away. He,
he, he couldn’t be, he wouldn’t lick it or anything like that. He stands like that there and says to
you, ‘Baby wipe’ (assessment, l.160-174)

Mother T performs a number of discursive strategies here for various purposes, common to all
parents in the study. Firstly, she highlights the untypical behaviour, outside of social and
developmental norms. Repertoires around autism are contingent to normative framings in
society and Mother T references the normal child as if to say, he looks normal but isn’t. A
common comparative, normative evaluation was made by parents referencing their other
children, e.g. U stated, ‘M was completely different growing up than K. ...she would have had a
full conversation with you. Granny mush, you know...And K was just, there was nothing.’
(assessment, 107-112). This was also picked up and echoed back to the parents in more
formalised terms of milestones by the professional, ‘so play-wise that’s quite low in comparison
to his age... he should be beyond that sort of cause and effect and container play which you
kinda do around the year level (diagnosis, l.142-146). The child is described in terms which cause
rhetorical damage to the child (and parent’s –see section 7.2.1.) reputation and status as children
are measured against norms and milestones which are established in frameworks outside of their
spectrum of abilities. As she highlights the issues so she, secondly, paints a very negative
illustration of her child. This causes a problem for how others might evaluate her parenting,
which will be dealt with in section 7.2, but it primarily creates a problem for the broader notions
she would want others to have of her child. By accentuating the negative, the parent eliminates
the positive aspects of the child (in contrast to the old song by Johnny Mercer and Harold Arlen
which advocates the opposite in order to ‘spread joy up to the maximum’). So, thirdly, she has
to manage this negativity. Mother T does this in two ways: by stating the positive, ‘he’s a lovable
child’, and by alluding to his lack of control over the behaviours, diminishing his responsibility and
even linking it to his own distress. Autism can be blamed for these behaviours, as stated above,
and so achieving a diagnosis is consistent with the argument Mother T constructs in her talk in the
assessment – if her child is given a diagnosis it confirms he is not responsible, is a victim of autism
worthy of support and his needs can and should be met. The next section will develop more
specific analysis of deploying autism as justification and vindication.
Separating the autism from the child – who or what is responsible for the bad behaviour?

Management of such trouble in talking about autism underlines the trouble created by the concept of autism in the diagnostic and assessment process. One recurring strategy adopted by parents in the study was to remove responsibility for the unacceptable behaviour from the child. Parents made explicit and implicit claims that their child did not understand (their own behaviours or that of others) or cannot control their behaviour. However, this is a complex process.

Parents’ talk performs a range of different functions and produces very different understandings or narratives of the situation. The meanings and story are essentially undetermined until uttered and eternally moving so there are enumerate possibilities. Using these is a process of subject positioning (Harre, 98). For example, autistic people are constructed as sad and pathetic but at the same time aggressive and self-focused; autism can be oriented to as an entity or as diversity within the human population thus creating a debate even in autistic communities over basic terminology such as whether one refers to the person with autism - the entity for affliction - or autistic person - the integral neurodiversity of the person (Bertilsdotter Rosqvist, O’Dell, and Brownlow, 2015). Parents’ movements between these contradictory ways of talking about the child arise from the different rhetorical constructions required in particular situations: in the research interview, in the consultation, with family/friends, with other parents and in the public domain. Such varying repertoires develop over time and across situations but are not entirely separate from one another. Chapter 1 demonstrated such variation and contradiction is evident on the macro level in historical constructions of autism and simultaneously contemporary constructions of autism. Contradictions overlap and weave dynamically through the talk on each occasion, functioning to manage stake accountability and negotiate claims.

Excerpt 7

‘U. She’ll cry and even if she’s crying, you ask her, ‘What’s wrong?’ She doesn’t know what’s wrong. She doesn’t know to tell you that she got hit’ (pre-assessment, l.166-168)

Parents, like Mother U, talk also negotiated their child’s identity in terms of what bits are the child and what bits are the autism. Mother U below begins by presenting her child and her autistic behaviours as all part of the child, ‘I didn’t think any of that was associated with autism where it is, you know, change to routine and all that there ...I just thought it was her. It, it is K, do you know what I mean’ (pre-assessment, l.138-148). The function here is to manage criticism of her as help-seeking, potentially making claims that are unjustified. Appearing to seek help too soon offends the neoliberal society ideology of individual’s taking responsibility for themselves and
their families, so Mother U claims she was prepared to accept Child K as she was, ‘I’ve just got used to it’ (pre-assessment, l.150). She also works delicately here to avoid rejecting her child, in part, by accepting that it is also integral to her, ‘it is K’. However, later in the interview she begins to separate out the child and the autism by allocating strengths to her child which she distances from the autism, ‘She’s very, very smart and intelligent in an awful lot of ways and that’s another reason that he said it can’t be because...’ (pre-assessment, l.305-306).

The complexity within the data demonstrates the extent of ‘trouble’ with the category of autism, the process of assessment and the subject positions of the players. What can be seen in the transcripts is evidence of problem talk, solution talk, emotion talk, ‘why’ talk, blame talk, enabling talk, negotiating talk, resisting talk and so on (G. Miller & Silverman, 1995). These are all constitutive of different ways to understand and produce their experience, drawing on different discursive resources (mobilising discourses of different sources and forms) and positioning people in different ways to address multiple issues within autism assessment and diagnosis. The complexity of talk and the meanings parents construct are in-action conversational accomplishments (Potter, 1996) which is in direct contrast to the professional’s use of the schedule of questions and the written diagnostic report. One final excerpt in this section, excerpt 8, touches on this complexity and what it means to a parent. Mother U worked up a narrative, drawing on various discourses and strategies, which functions to construct a rational justification of the process and her part in it:

**Excerpt 8**

R. Yeah. Well, did you feel that you were able to tell them everything that you wanted to? Em, do you think your ---across

U. Yeah. No matter how bad it made her sound. Yeah. I kept saying that too, you know, it made, sometimes you can talk about her and she sounds like a complete handful and she is but I’ve got used to it. It’s her, do you know what I mean

R. Yeah (post-diagnosis interview, l. 121-125)....

R. But, em, what sort of thoughts did you have through that, you know? Was it?

U. Some of it, whenever she was reading out, you know, different wee characteristics the school had wrote about her or other ones it was, like, got to you, the heart - you know the way she is with others – because I didn’t underst, know, because I don’t see her in school so I don’t know what she’s like except for what the teachers tell you. And every day I was going in somebody else was coming, ‘K did this. K did that’. It wasn’t her. She just comes and looks at you. And the teachers were the same, ‘No, she hit this one today. She did this. She did that’. And it’s things that they had wrote down, sort of, took me a bit, you know, when she was like, ‘No, you don’t need to worry because we do see it all the time. It’s not just’. She just sounds like a monster at times, as I say, you know. But I’ve just got used to it. There is, you get looks and all out in the street and all when she goes into one. Now I can say it’s autism, you know

R. Yeah
Mother U raises the issue of ‘bad parent’ explicitly, rejecting it on the basis of the autism diagnosis her child has now received. However, this leaves a problem as autism is considered a bad thing in itself albeit not as bad as being a bad parent. So how is this ‘badness’ moderated. Mother uses a strategy of discursively removing control and responsibility from both herself and the child, ‘I can’t do nothing about it and she can’t do nothing’, but also, potentially, from autism by suggesting, ‘you do need to help other people to understand their blame is about a lack of understanding’. She does not just blame autism but takes a more circumspect and embracing approach by calling on people to ‘understand’ (Eyal al at, 2010). There is also an attempt at a more positive framing of autism or rather of autistic people with the card and a promotion of their voice ‘My child has autism and has a voice’. Some identity work being done here, moving significantly away from the version of her child as a ‘monster’. Finally, Mother U provides a basic but powerful platform for a more complex understanding of her child, ‘She’s not always screaming’ rejecting the common rather two-dimensional constructions, e.g. in the media, of autistic children.

7.2. Ideological Dilemmas

Chapter 3, outlined Billig’s 1988 concept of ideological dilemmas while Chapter 1 described variable ideological frameworks relevant to autism, parenting and professionals. Lived ideologies typically are not performed in an explicit or coherent way, yet fissures in their enactments can cause trouble to relationships and co-operative practice (Van Dijk, 1993, Billig, 1991 and 1999). The data in the study highlighted a number of available conflicting ideologies which have produced such fissures. A range of beliefs and values, such as beliefs about what is ‘normal’ or ‘natural’, informed multiple ideological positions for both parenting and the professional to negotiate. Radley and Billig, (1996) consider the context of interaction as ideological also and the context of autism assessment and diagnosis is highly ideological. Diagnosis is performed based on the ontological assumptions embedded in the DSM and autism diagnosis is accomplished and
implemented through the practices of various professional bodies in education, health and social care as well as in the general public and academia. The assessment of autism carries what is private into the public sphere of state services so parents and professionals have to negotiate ideologies that are is unstable and fluid in not just in society, such as the ideas about autism, parenting and using services, but ideologies of the professional sphere. This section aims to analyse how parents and professionals engage with the ideologies and negotiate the dilemmas they implicate

7.2.1. Parenting Dilemma: Unconditional nurturer or an agent of control for the state?

Parenting is socially constructed as natural and carries with it a moral ideology; beliefs about good parenting suggest it is about common sense and, therefore, ‘natural’. Ideas of the good parent assumes a natural ability to unconditionally love, nurture and bond and but when children do not conform to the social norms of childhood; another parenting ideology is mobilised by society, state institutions and even by parents themselves (Holt, 2005, Cascio, 2012). This is an ideology of the parent as disciplinarian; the parent becomes responsible for the surveillance, control and discipline of the child on behalf of society and the state.

Analysis of the data suggests that help-seeking parents progressing through the autism diagnostic process must claim their child is out of their control so that they should get support. However, a fissure develops in their lived ideology of parenting: they risk either damaging their own parenting identity as they can be positioned as a ‘bad/inadequate parent’ or they incriminate their child, exposing them as a bad child. If either they or their child are apportioned blame, of course, then they also risk being denied services on the basis that they are not worthy of diagnosis or support (Sointu, 2017, Higashi, 2013). Thus they must manage the damage to the loving parent ideological position while mobilising this second ideological position. In seeking support they report their own surveillance of the child’s behaviour and character and move into a position of colluding with professionals in the act of assigning the label of ‘autistic’ to explain their child (Eyal et al, 2010.). The data produced accounts of parenting a child that are constructed within the context and constraints of the autism assessment and so the analysis was mindful of ‘notions of function, consistency, vested interest, and emotion’ (Potter, 1998, p233).

Excerpt 9

_C. Ok. When did you first get concerned about O? When do you think your worries first started to come?_
_T. (sigh) Oh... he was only about.... maybe about a year old, just over a year old?  
_C. So about that thirteen to fourteen month level._
T. Yeah, yeah. He, em, I used to work full time then...
C. Uh huh
T. ... so he was in a crèche.
C. Uh huh
T. And his behaviour then even towards other kids ...
C. Uh huh
T. ... the other babies even around him. If ...
C. Hm?
T. ... maybe some snatched toys off each other, he was really, really aggressive ...
C. Uh huh
T. ... for that age. Em, and then as he started to be able, when he was walking about and that....
C. Uh hm
T. ... he, he always made me, they said he would always go and sit on his own. Now my niece was also in the same crèche...
C. Uh hm
T. ... and there's five months between those two.
C. Uh hum
T. They would have said you actually would have thought they didn't know each ... other
C. Right
T. ... 'cause he would not have went over near her...
C. Uh huh
T. ... so he wouldn't have. He would never would have went ne.. even bothered with her
C. Uh huh
T. He preferred to sit on his own in the crèche and play on his own. As I say, he lashed out as he got up and was able to move a lot more and was walking about and he got his teeth.
C. Uh huh
T. There was one really bad episode: he bit a child in the face
C. Uh hm
T. And the face was horrendous, like, the mark that he left on the wee ones face
C. Uh hm
T. I had then started bringing him over to the doctor's surgery to the health visitor that was there
C. Uh hm
C. But every time I brought him over it was a different health visitor. There was no set one, it was locums
C. Right
T. Every time. Em, uh. I don't know how many times I ended up bringing him and I was just told, look he's a baby, they will bite, they'll do this, they'll do that. But to me his behaviour just wasn't right...
C. Uh huh
T. ... for that age. It was, to be very aggressive at times so it was (assessment, l.99-147)

Mother T responds in more depth than is strictly required by the initial question ‘when’, understanding the situation and that the unpicking of ‘concern’ is required. She develops her ‘concerns’ and these are presented in the most extreme terms. In presenting such extreme examples and using highly emotive language, ‘he was really, really aggressive’, ‘horrendous’, ‘lashed out’ Mother T risks mobilising several negative formulations of her child.
This presents Mother T with a dilemma between the two lived ideologies of parenting i.e. the help-seeking parent and unconditionally nurturing, loving parent. In formulating such an illustration of her child as a rationale for her help-seeking argument, several interpretations of her as a mother are opened up and some of these could damage the very argument she wants to present. For example, if the description of her child’s behaviour is received as the actions of an unruly child, out of the mother’s control she could be understood as an incompetent/irresponsible parent who turns too readily to the assessment centre for help/an excuse not to control her own child.

Impressively at such an early stage of the interaction between parent and professional, Mother T pre-emptively manages such potentially damaging counter-productive interpretations by employing a range of discursive manoeuvres. Firstly, she notes that her child was just over a year old when concerns were raised and so this is almost too early for her to have likely lost control of her child or parent him so traumatically that he became aggressive – it is possible but not probably. Secondly, Mother T draws upon the crèche example to triangulate her claims. The behaviours identified as problematic occurred away from her zone of influence to some extent and so cannot be attributed to her parenting directly. It was also viewed by others and so her testimony can be corroborated. Thirdly, in describing her child’s behaviour as oscillating between ignoring his cousin, ‘he would not have went over near her’ and then being aggressive toward her, Mother T constructs a more complex pattern of behaviour which suggests that this is not a simple case of lack of parental control or the child’s temperament. Fourthly, Mother T presents herself as a caring and reasonable person in a wider sense because she is concerned for the child hurt by her own child, ‘And the face was horrendous, like, the mark that he left on the wee ones face’. She does not attempt to blame or justify her child’s behaviour but highlights the pain and injustice for the victim. She is a fair member of society despite the injury being inflicted by her own child. She does not explicitly provide excuses for her child or herself as to so do may incur a guilt which she does not own i.e. ‘methinks you doth protest too much’ accusation. She does not protest and thus avoids initiating a construction of guilt. Finally, after managing the risk of criticism as a ‘poor parent’, Mother T begins to work up a narrative around her active help-seeking, and enhancing it through juxtaposition with the shifting, dismissive health professionals. Later in the meeting her claim is verified through elaboration of the child’s sensory difficulties and a long-awaited concurrence with one professional who eventually recognises Mother T is justified in her concerns, ‘Em, she says, ‘Look, I can’t diagnose anything’ she says, ‘but there is something there’ she says, ‘I would say there’s something’ and it was here that done the very first ever referral …’ (assessment l.186-187). In this way, Mother T manoeuvres skilfully through the dilemmas of working up a help-seeking, responsible parent with a child in need and the risk of being understood as an incompetent and unworthy parent with a bad child out of control.
In other interview accounts parents talk also seemed to be a reaction to an implicit assumption of criticism of their parenting. Such talk defended against an unspoken criticism or declared how parents continued to adhere to the usual patterns of parenting i.e. doing normal activities, setting boundaries, teaching and disciplining.

Excerpt 10

‘U. Em, whenever you’re wanting, if we want to go somewhere, if she doesn’t want to go it’s a fight getting her into the car. You have to listen to the screaming just, you know. You don’t, I don’t give up doing things just because she doesn’t want to, you know. I still’ (A, 130-133)
‘C. Hm. And what, does she sleep in her own room or your…?
U. Well, no, in with her, she’s bunk beds with her big sister. She wouldn’t go into her own room. We did try.
C. Is she on the bottom bunk?
U. Yeah
C. And does her sister sleep through whenever she’s up and about? What does she do in her bed?
U. She’ll play. She’ll get up and get herself toys to play with or talk away to herself. Well, gobbledegook away to herself
C. And you haven’t red out (meaning: cleared out) the room yet of all the toys to make it not play…?
U. Oh, I do it regularly but she…
C. It creeps back in’ (assessment, l.456-467)

In this excerpt, Professional C asks about sleeping arrangements at home and begins with an unfinished question which seems to avoid making a judgement by framing it as an ‘either/or’ scenario i.e. either is fine as both are explicit options. However, the question, ‘does she sleep in her own room or your…?’ carries potential criticism because one of the options offered is ‘your…?’ suggesting the parents’ room, which is not ‘normal’ for a 6 year old child. However, Mother U immediately begins to refute the accusation and defend the fact that the child shares a room with her sister: ‘well, no…we did try’. Being met with the question, ‘Is she on the bottom bunk?’ seems unnecessary for an autism assessment but would be necessary if Professional C wants to check Mother U’s management of the night-time routine; for example, by ensuring the child is not climbing over her sister and that her sister’s sleep is not disturbed. This is potentially hearable as a cross-examination of parenting competence rather than about autism. The professional moves into a second potential criticism when she asks ‘you haven’t red (colloquialism for cleared) out the room yet…?’ which carries a suggestion of blame; the fact the child gets up to play with toys could be the fault of Mother U leaving the toys out to distract/attract the child. If this is the case, then the argument for an autism diagnosis, and hence support services, is diminished and she could just be accused of poor parenting. Interestingly, this is introduced with the conjunction ‘and’ which we see her use throughout the assessment to soften the abrupt
changes in topic. ‘And’ is a conjunction used to connect related parts of sentences or clauses. However, in the transcripts ‘and’ is often used by the professional where no actual connection exists between sentences, topics or turns but it suggests or creates a continuation to some extent on its own. It was used very effectively in the assessment meetings to smooth over the abrupt changes caused by adherence to the schedule of questions (see Chapter 6). However, in the excerpt above, it softens the implied criticism that the question carries (see section 7.2. below). Again, Mother U has to defend her parenting and the professional co-constructs the scenario with her, agreeing with ‘it creeps back in’ to explain it and avoid the negative parenting connotations.

Within this short extract there are a number of instances where Mother U must defend her lived ideological position of being a good parent, and worthy, within the context of being a help-seeking, socially responsible parent.

Mother T also makes frequent reference to examples of her good parenting and to excuse her child’s behaviour:

Excerpt 11
‘T. If I’m making dinner and he’s in there watching something or sitting playing and wants a drink…
R. Uh huh
T. …he’ll, ‘Mummy, I want a drink!’ ‘In a minute. Wait ‘til I do this’, peeling potatoes or something. .
R. Yeah
T. ‘No, I want a drink now, I want it now!’. Everything has to be done…
R. Yeah
T. He just can’t seem to control that part of having to wait.
R. Yeah
T. Say the longer he has to…I just, I make him wait but, I mean, your talking about then he’ll just lift whatever’s round him and starts throwing it. He’ll come out and attack you.
R. Yeah
T. ‘I told you I…” he’d shout at you, ‘I told you I wanted that now, right now’. Now, it’s just then a constant battle.
R. Uh huh
T. Then when he gets a drink, he’ll go away again…
R. Right
T. …so he will. But I have just done it with him that, ‘No, you have to learn that you can’t get things just right now’ (pre-assessment, l.49-69)

Mother T provides reported speech of her strategies to teach self-control to her child ‘No, you have to learn that you can’t get things just right now’ to work up an identity of a socially responsible parent. To achieve management of the dilemma, however, she also has to show that this is a position which is borne out of love. Her talk that ‘He just can’t seem to control that part of having to wait’ sets up the foundations of her concern and her actions both in delaying his
drink and in seeking professional intervention. She produces his lack of control and her concern for him as a nurturing parent to justify her help-seeking and disciplining ideological position.

Below is another example of managing this combination but in this case the reason given is ‘relief’—relief from what is unclear but it implicitly claims a sensory pain/need as he is pushing down physically on legs. The parent mobilises a thoughtful and experimental parenting approach, allowing him to experience this relief in a controlled way on her hand and positioning her efforts, both to get the diagnosis and to allow him to hurt her hand, as an attempt to help him and thus worthy:

Excerpt 12

‘T. And you’re going, ‘O, you’re hurting me’, and he goes, ‘Right, right, sorry.’ And really, he stops but, it must, I don’t know, it must, I don’t know...
R. Yes?
T. ...give him sort of relief or something when he is actually doing it...
R. Yes
T. ...’cause I actually let him do it on my hands sometimes, go...
R. Uh huh
T. But the bruises that he’s left you with ‘cause he’s actually pushing that hard down...R. Uh huh
T. So he can be and you’re like ‘Oh’. I mean, if I s--., the only thing, I mean, if I could just know some other relief things for him to try...’ (assessment l.654-664)

Parenthood is defined by the child’s well-being (Austin and Carpenter, 2008) so it is the ideological concept of parenthood (motherhood by default – Holt, 2010) which is threatened by the child not thriving or meeting all developmental milestones. However, parents at the autism assessment must present as unable to ensure the child’s well-being. The dilemma over presenting as a good parent but as failing to achieve the goals of good parenting can be managed by the characteristics of the child that may earn them a diagnosis. However, this produces a thin line across which the parent can be viewed as ‘blaming’ the child for their own failure and this further comes into conflict with being a loving, positive parent. Parents use a range of different strategies to defend against challenges to their worth or parenting status. One strategy is to challenge the ‘expert’ status of the professionals, but more often in the data affect talk was used to reinforce the lived ideology of the loving parent of the distressed and constrained child:

Excerpt 13

‘N. Is there supports because I’ve never been offered any sort of support for anything that E’s got...That child’s like a prisoner. Can’t go nowhere... I know he’s a great child, you know. I mean, you know, he can be so lovable in his own way...because he’s not affectionate – which hurts sometimes too. But, I don’t know (upset and has difficulty talking). Like he is great. I just
want him to have a life, you know. See this, like, you know, E looks out the window and he wants to go out to play but nobody wants to play with him. It hurts’ (diagnosis, l.510-516)

Excerpt 14

‘B. (Father) we want him to enjoy his life...that’s the biggest motivation, you know, him being able to enjoy his life’ (post-diagnosis, l.489)

Excerpt 15

‘A. (Mother) if I could make things a bit easier or better or...for C... yes, if I could make things a bit easier or better or .. for C or can he have this behaviour? Should I not, you know, tell him off for doin’ this an ...How do I deal with that, you know. Last thing you want to be doing is upsetting C or, you know, telling him off for something he can’t help doing, you know’ (post-diagnosis, l.186-189)

A parent can be a loving parent in control of the child when the child responds well to soft disciplining but, when they do not, a parent must make a choice about how much of each parenting ideology they live. Here emerges the conflict for parents whose children do not fundamentally or readily meet cultural, social, educational, medical and psychological norms. So on the one hand Mother A can be understood as an inadequate parent for having to seek help from Trust services, for not being able to manage her son’s behaviour and even for not apparently understanding her own son, but Mother A contests this potential understanding of her as a parent. Mother A positions herself as a caring parent, but with questions and parenting challenges as a result of Child C’s autism. These challenges are not owned or the responsibility of Child C or of Mother A’s parenting because they are presented as out of his control. In fact, her parenting efforts are clearly formulated as thoughtful, exploring options and trying to achieve an understanding deeper than simply reacting to the situation at face value. This is reflective parenting – ‘How do I deal with it’ to replicate/illustrate the reflective process as evidence of better than just good enough parenting.

7.2.2 Professional Dilemma: clinical objectivity and the caring practitioner

The reply to the parents’ dilemma in help-seeking is the professionals’ dilemma in care-giving. Chapter 2 outlined conflicting ideological positions for professionals, situating this in a neoliberal culture economically and morally invested in individual responsibility with authority figures sanctioned by the state to conduct practices of surveillance and control over those who are economically and socially vulnerable (Eyal et al 2010). This economic driver creates the principles propelling the loving parent to operate as an agent of the state and it is the driving social construction behind the dilemma of the professional (see chapter 2). On the one hand, clinical
expertise is based on scientific principles and medical knowledge, and so there is an emphasis on objectivity, testability, reliability and measurement (against norms) from scientific principles and on biological bases of behaviour, etiological foundations, symptomology, diagnostic criteria, treatments and cures. On the other hand professionals work in what is constructed as a social care environment and have a nurture agenda. As detailed in Chapter 2, this agenda focuses on being person centred, respecting and accepting diversity, compassion, trust and so on.

The argument presented in this section is that professionals experience a dilemma in practice between the activities driven by the ideological assumptions of their clinical role and the demands of their professional care role. Some of these contradictions are evident in chapter 6 as the constraints of documents and schedules of questions addressing diagnostic criteria present challenges to demonstrating care, respect and empathy. This point will be developed somewhat here by reviewing repairs to discursive damage during the assessment and diagnostic process. These repairs provide evidence of the tensions and dilemma raised between the clinical collection of information and imparting of a diagnosis and the facility to demonstrate care principles.

At the most basic level, we see the professional struggle with the choice of first names or surnames, perhaps more so because of the presence of the recording device and the knowledge that the interaction will be listened to and analysed by a third party. The conflict is also evident in use and then abandonment of medical terminology. Finally, repair work carried out by professionals speaks to their unconscious awareness of the rift between caring and the rather callous and uncaring form the clinical procedures take in delivery – use of ‘and’, ‘uh huh’, and humour.

Much has already be written about the medicalisation of autism and so I will not prioritise an analysis of medical terminology or practice – this is already evident in the use of documents and processes of chapter 6. However, there is a unique opportunity for future work to develop an argument that builds on the medicalisation of autism in terms of the dilemmas raised for the professional and how this mobilises subject positions and constructions of responsibility and authority.

Ownership of terminology and processes

The use of expert language and the ownership of procedures, authoritative criteria of IQ/DSM, is one way that professionals perform being an expert or being a caring professional (Bakhtin 1986, Becks, 1992 and Gidden, 1991). In the talk between parents and professionals, each adheres closely to their domains and genres of speech. While parents can borrow some medical language
and professionals work to make the medical and developmental terminology accessible, both professionals and parents are positioned as drawing on particular forms of knowledge, status and realms of operation. This is a product of not just training but the protocols and instruments of diagnosis – the criteria of the DSM and the language of the ADI-R – but it conflicts with the ideological framework of the caring professional and the principles laid out in documents such as the PPI handbook. Extract 17 below provides an example of how the players are positioned in the processes and language of the diagnosis.

Excerpt 17

C. I mean, he has a good IQ. His IQ verbally is 101 and his performance IQ is 90 so there’s not a big, em, discrepancy
T. Uh huh
C. … between the two that suggests that he has areas of weakness
T. Yes
C. … there. And his full scale IQ is average so he’s very able to be in mainstream school
T. Yes
C. … with that IQ there. And he is getting help and support which is appropriate and I think that that is very well targeted. You know, they’ve looked at getting him R support
T. Yes
C. … and stuff. When we went into the criteria for aspergers syndrome, when you look at a diagnosis for autism or aspergers it isn’t easy to say we’ll do a test
T. Yes
C. … and the test will tell us so we look at a criteria. So we looked at the, the DSM IV criteria for aspergers syndrome with O and the first bit they talk about is looking at their social interaction. And it’s looking at the quality of their social interaction and the first part talks about their non-verbal communication because non-verbal communication is probably one of the strongest ways that we communicate

The above excerpt includes several examples of the deployment of specialist jargon. Billig (1988) argues that professional language is essentially embedded in technical and discipline-related jargon, and it is partly this which gives them power. However, in the data we see an attempt to moderate and equalise their roles by matching language to the assumed parental linguistic range. The language is framed in the context of helping the child, even into the future. The use of IQ scales speaks to the normalisation of development utilised in autism assessment, while the reference to the DSM IV criteria establishes credibility for autism/Aspergers to be held in the medical domain. The technical language used in relation to what the professionals ‘look at’ is in contrast to the language of the parents reported in the ‘you said…’ formulations which is a more conversational style e.g. Professional C, ‘What you had said was O has little appreciation of sarcasm or humour. He becomes cross and takes it quite serious’.

The ranging use of ‘you’, ‘we’, ‘I’, ‘they’ is also significant as it positions the contributors and receivers of knowledge. When the professional states ‘I’ it is an authoritatively assertive statement. She takes credit for the diagnostic discovery (Billig, 1988) despite basing much of it on
appropriated knowledge. The management of the appropriation of knowledge also has to be worked up within this context because the professional could lose face or positioning if it is too obvious that she has not generated new underlying knowledge for the diagnosis.

Excerpt 18

‘N. (mum) ‘Oh aye, mummy says this’ (in a sarcastic tone). You know it’s like, ‘Hm’ (suspicious tone), you know, when it is obviously quite clear when they can give you the diagnosis, you know, that it’s not a load of old nonsense, you know….they need to leave that part (i.e. the parents answers from the assessment, recorded in the diagnostic report) out of their report that they’re giving you and concentrate more on we were at the school, we were in the house or whatever. And these are the tests and yes, it’s there’ (post-diagnosis, l.)

Mother N makes an allusion to blame in this section of talk. It is constructed as manipulative – because ‘it is obviously quite clear when they can give you the diagnosis’ - and disparaging – her sarcastic tone on ‘Oh aye, mummy says this’ suggests that she took this up as them not believing her.

This section of the diagnostic meeting involves the professional orienting the parent toward the future service provision and for this parent there was quite a bit of information offered.

Excerpt 19

C. And, and each child on the spectrum can be different and you have to look at each child’s individual strengths and weaknesses, which is why when you look at an intervention programme there isn’t one intervention that fixes everybody
Q. Yeah
C. Because each child needs to have intervention tailored to where their difficulties are
Q. Uh huh
C. At the moment D’s big difficulties are the anxiety levels and the distress and the language, and then that impacts on his, em, ability to interact
Q. Uh hm
C. And I think his learning is an issue there. So if you’re sort of thinking of where D needs to be targeted it’s probably like helping developing his language skills, support him academically and try and deal with that distress and anxiety
Q. Uh hm
C. ...that he’s having when you separate from him
Q. Yeah
C. You know, I think those are the big things. Em, there is a pack that I’m going to give you today. This is produced by RASDN, which is the Regional Autism Spectrum Disorder Network. It’s a parents product, produced document and then it goes through, it’s really a guide. It talks a wee bit about what autism is. Sort of looks generically, you know
Q. Yeah
C. Well, I mean generically, it just talks about the big topic of autism. But then it breaks it down into the practical support. So as a family that might be quite good for you so, for example, they
talk about ‘What is autism spectrum’, What do you expect?’, ‘You’re caring role as a parent’, ‘You’re family’, em, that seems to be the same page, isn’t it? It is. Don’t know why that would be ---. Em, ‘How do I get the help that I need’ and ‘Education needs’, ‘Treatments’, ‘Understanding behaviours’, ‘Financial benefits’. So they go through all of those sorts of things for you. Em, ‘Social and leisure activities’. And then the purple stuff is more when you go into adolescence

Q. Uh huh

C. Ok? But it’s quite a handy wee thing just to start you off

Q. Yeah

C. …with your reading. The other thing I would like, with your permission, to do is refer you to the intervention service that we have within C Trust. What I would be asking them to do is to meet with you first of all to look at where you would feel you’re needs need to be targeted. They would offer parent training on ‘What is autism’ and they do that through groups with parents so that

Q. Yeah (diagnostic meeting, l.432-471)

The extract above illustrates what can happen when the expert and care ideological positions collide; in a process of ongoing referrals and information-giving, the expert does not invite discussion or provide a safe place for disclosure. Questions from parents, that may direct the agenda or reveal vulnerabilities such as lack of knowledge, were almost never produced in this discursive climate. The expert professional ideological assumptions prioritises knowledge which endows status and power while the caring professional is compassionate to provide and address the needs of the client - the result of the collision is an ‘information-feed’ that fills the ideological gap.

To clarify, albeit briefly, the ideological position of the expert is to have knowledge and the ideological position of the caring professional is to empathise. Within the extract above the professional begins to orientate toward a personalised service, ‘if you’re sort of thinking of where D needs to be targeted…’ but returns immediately to the generic information, ‘there is a pack that I’m going to give you’.

The oscillation between personal and generic, positive and negative framings, intimates the dilemma facing neoliberal caring experts in service provision but is confusing and unhelpful for parents (Abrams and Goodman, 1998). Forcing these positions together, the dilemma has produced a discourse which tries to acknowledge the needs of the parent without actually hearing these directly from the parent. The professional mobilises the expert subject position, addressing needs as framed by the professional and giving them relevant knowledge. What has actually been missed is that the identification of need is not ‘client-focused’ on the micro-level. The professional does not ask the parent what they want, how they feel or even give space for the parent to question or ask for specific information or support – until the end when the pattern of conforming is set and parents may have forgotten what unvoiced questions may have arisen
throughout the lengthy meeting. Instead, the professional relies on the more macro-level dominant constructions of professional clinical protocols and structures to inform the direction her talk takes.

This all looks extremely helpful because the professional appears to be offering a lot of information and ongoing help. However, it also amounts to a tension raised by the ideological dilemma facing a caring professional – the caring professional providing help and the clinical professional adhering to procedures which delay help. The procedure delays further the help that parents are seeking, obscuring the fact that many of them have struggled for many months, if not years, to get to this point and what the professional offers in the meeting is a passport to uncertain services and a diagnosis with a degree of uncertainty around what it means for their child (Braden, Bothwell and Duffy 2010).

Conclusion

Each ideological position of the professional, expertise or care focused, generates different understandings and responses on the part of the parent in the assessment. Parents position on getting the diagnosis for their child is ambivalent – on the one hand they want it because they want a way to understand their child and have reasons for difference, challenges, needs and to be worthy of accessing services and basic kindness and support in general. On the other hand, it is seen as a life sentence to be feared and accept with despair. Risks are significant for a parent seeking help in the neoliberal society, e.g. the launch of ‘Parenting Orders’ within the 1998 Crime and Disorder Act can criminalise parents who cannot control their children and has heightened the atmosphere of blame and stigma (Holt, 2008). Parenting has become a state disciplined aspect of domestic life (Foucault, 1977) but no more so for families with children outside the established norms. Despite multiple contestations in the discursive space of autism diagnosis, it is not possible for parents to present their own account of needs or to contribute freely in the conceptualisation of their child’s diagnosis.

Professionals face their own dilemma, between adhering to caring principles and practising clinical distance. While policy documents often link the two in guidelines, the discourses of clinicians demonstrates the challenges of integrating the lived ideologies of care and clinical practice.
Chapter 8
Conclusions

This final chapter is broken into two parts. The first part presents a review of the literature in light of the analysis of the data, each section focusing on the original research questions and the themes of knowledge, power and possibilities. The first section, 8.1. introduces a light metaphor to highlight the issues with the incommensurate discursive positions between parents and professionals in autism diagnosis. Section 8.2 explores the interpretative repertoires that are evident in the parents’ and professionals’ talk, highlighting the theme of ‘knowledge’. Subject positions and ‘power’ are discussed in section 8.3. Finally, in section 8.4. the negotiation of power and positioning is discussed, referring briefly to the ideological dilemmas and troubled talk that emerge in these negotiations. This last section moves on to explore ‘possibilities’ when the chapter considers the contributions the research could make to practice.

Part two presents a review of the theoretical and methodological research itself. It will apply criteria for evaluating qualitative research, such as reflexivity and transparency. It will also consider the expediency of the research questions and the power of the methods of data collection and analysis to elicit rich information and extract perceptive and valuable results.

Part 1 Conclusion to the data

Autism assessment and diagnostic meetings are profoundly important because the meanings surrounding autism and the position of parents are constituted contingently in the discourse therein (Butler 2004). Parents can be pathologised by recursively narrow, constraining or ambiguous ways of talking about autism, specifically during autism diagnosis (Avdi 2005). These initial networks of meaning provide the building blocks or anchors to future understanding, a heteroglossia that is pulled in divergent ways by the official diagnosis (centripetal forces) and their own informal knowledges and associations (centrifugal forces).

The contribution of this thesis is to develop better understanding of the complexity involved in the (mutual) construction of meanings, positions and the emerging dilemmas for parents with children diagnosed with autism and for the professionals who are responsible for diagnosing. I have drawn on a metaphor of two orchestras of different natures to illuminate the partnership of parents and professionals in autism diagnosis.
8.1.1. Incommensurate discourses: A Metaphorical Orchestra Performs ‘Autism, the collaboration’

‘In 1999, Daniel Barenboim and Edward Said founded the West-Eastern Divan as a workshop for Israeli, Palestinian and other Arab musicians. Meeting in Weimar, Germany – a place where the humanistic ideals of the Enlightenment are overshadowed by the Holocaust – they materialized a hope to replace ignorance with education, knowledge and understanding; to humanize the other; to imagine a better future. Within the workshop, individuals who had only interacted with each other through the prism of war found themselves living and working together as equals. As they listened to each other during rehearsals and discussions, they traversed deep political and ideological divides. Though this experiment in coexistence was intended as a one-time event, it quickly evolved into a ‘legendary orchestra.’ http://www.west-eastern-divan.org/ accessed 24-12-15

Originally I conceived of an orchestra metaphor to elucidate the relationship between univocality and multivoicedness of discursive practices in the assessment of autism. Parents and professionals are each heterogeneous groups and each has draws upon a multitude of different voices as discursive resources. However, the data analysis reveals that the participants in the study did not meet or work ‘together as equals’ as in Barenboim and Said’s orchestra. In autism diagnosis, divergence in experience and expertise and incommensurate exchange more often typifies the encounters between parents and professionals. So the metaphor becomes a story of two orchestras of very different natures, a classical and a jazz orchestra.

In this metaphor, the generic professional is symbolised by the classical orchestra, with its establishment position, extensive formal training and access to funding, albeit finite and insufficient – ‘funding bodies in the UK still tend to classify all musical genres other than European classical music as one homogenous category’ (Oakes, 2003, p.166). The parents of autistic children are symbolized by the Jazz orchestra and may suffer from similar processes of marginalization. Jazz promoters in the UK continue to resist the subordinate classification of jazz as marginalising but claim there is a pressure to modify the art to become more acceptable to the establishment, accessible to a wider market and to access funding. Pressure to dilute the genre comes not only from the funders but from other external sources, both in the music industry and in the public arena.

This creates a positioning dilemma for jazz in that its practitioners must become less of what they are to access funding to be what they are. The paradox is that jazz funding is often provided on the basis of its unique and educational value to the arts; yet to access the funding that uniqueness
must be weakened, it must become more generic/universal and less intellectually credible (Oakes, 2003). The jazz band must conform to the establishment definitions and criteria, their aims and interests but this establishment by definition themselves are not jazz musicians in general and clearly do not formally recognise jazz as an equal status group comparable to classical musicians. I present the parents as the jazz orchestra, less established, with more limited funding and supported at times by institutions but included at times in the establishment rather than actually part of it. Their autonomy is compromised and they use similar strategies of conformity to resist and progress their own ways.

Like parents and professionals talking about autism, within each of these orchestras there is a univocality, a music of one part but made up from the multivoicedness of each. The repertoire of the classical orchestra includes Brahms, Sibelius and Strauss and uses violins, flutes, oboes and harps. The jazz orchestra draws upon Monk, Coltrane, Ellington and uses trumpets, saxophones, piano, drums. Still there is significant overlap – some jazz players are classically trained and some classical players enjoy playing jazz. Some of the instruments are the same (albeit played differently). And they are all musicians. Each is a grouping of musicians with some knowledge and experience of the work and influences of the other.

However, bring them together and what might happen? Will they prepare in the same way? The Jazz band may know what it is going to want to play and may have scores but these are treated much more loosely – they may not even have a score. The classical orchestra may have their score very carefully prepared, practiced it very precisely and each will have made careful notes on the process of playing the pieces. Will the pieces of music be agreed easily?

The classical music scores could prove very challenging for the jazz players in their complexity and the need to play them so precisely each time. The classical players may follow the jazz scores but can they improvise and understand the rules of improvisation? Which group of musicians is likely to dominate and why? The classical orchestra with its established backing and home, funding, preparation and beautifully prepared scores is more likely to be able to set the agenda in most situations, although these may flounder in dealing with improvisation. For the jazz parents, each performance of their story is unique. They have told it over and over and it is practiced but it changes in every telling in according with the context and their experience at that time – a joint construction each time with the audience, other players and context of the specific time. It means something unique to them each time.
The jazz parents play freeform and although they have practiced their story/piece they are not intent or even able to reproduce this exactly. They are only playing a snippet of what they might want and each voice only contributes a small element, a component in a larger piece. They could play for days without exhausting their repertoire and with each improvisation it can change enough to produce an infinite number of variations, all with a meaningful contribution to add to the story.

The classical professional also has the resource to contribute ad infinitum but their purpose is different – they are attempting to get a set story, to match the music with the finite notes as efficiently as possible. The notes have been practiced many times and variation is to be factored out as far as possible. In essence it is a constraining practice as per the requirements of the diagnostic procedures. No-one will ever hear the jazz parents’ repertoires and story in full as they will never end and will always change but as the classical professional must adhere to the schedule of notes and criterion the version they will hear will be particularly constrained, jointly constructed by their range and protocols and the parents’ efforts to fit in as much of their improvised tune within these constraints – there are only so many notes that may be fitted into a musical rest and only so much a parent can say to an item on a questionnaire. But we should not concede to all-out war:

“When open war broke out again in Gaza in 2009, Barenboim began the Divan’s performances by reading a shared statement of the orchestra which said: “We aspire to total freedom and equality between Israelis and Palestinians, and it is on this basis that we come together today to play music.” http://www.west-eastern-divan.org/ accessed 24-12-15

Collaboration, in as true a sense of the word as possible, is worth it. There will be setbacks and some of the possibilities will be closed; some that are open will be negative and there will be tensions created from numerous sources that will restrict, distract and wreak destructive chaos but working together with professionals, jointly arranging the composition, is an opportunity (not the only one) for parents’ voices to be heard, for them to mobilise their vision of their world, and to open up possibilities in reconstructing a better experience. One of the underlying goals of this dissertation has been to create a space in which the exploration of such possibilities are moved to centre stage.
8.1.2. What interpretative repertoires are evident? Knowledge and knowing

Knowledge is situated in both time and place with knowledge genres located firmly within ‘epistemological communities’ (Whelan, 2007). From the data and literature two communities of knowledge and discursive positions emerged, locating themselves and each other relatively. Within each community (while not homogeneous), participants share experiences, knowledge, language, values, and principles for measuring or evaluating the other group and their practices (O’Dell, Bertilsdotter Rosqvist, Ortega, Brownlow & Orsini, 2016). Between the epistemological communities differences emerged in all these areas. I characterised the parents understanding as ‘knowing’, a dynamic, complex and flexible concept notably containing language of affect, in contrast to the ‘knowledge’ of professionals which, although not entirely fixed, draws upon more rigid ideas of neurobiology, developmental stages and relatively static diagnostic criteria and procedures (albeit ones constructed and reconstructed over time and this raises questions of validity and reliability addressed in Part 2 of this chapter).

I argued that these two orientations to autism, knowing and knowledge, produce incommensurate regimes of meaning-making and discursive genres (Elby, 2009). Chapter 5, knowledge and knowing, argued that a need for a diagnosis is established through institutional and medicalised discourses of autism and these embed in social practices (Hacking, 2002). As a result of the institutional ownership of autism, primacy is given to professionals’ knowledge as agents of the institution. When incommensurate discursive genres of parent and professionals come together they do so on the professionals’ ground, the diagnostic procedure. The practices of assessment and diagnosis contrive to produce an uneven power dynamic between parents and professionals. Within such a context the range of repertoires are restricted but, furthermore, opportunities for creative, individualised or personalised repertoires about autism and parenting an autistic child are inhibited and rebuffed along the way (Hacking, 2002).

8.1.2.1. Knowledge and The neoliberal expert

Parents’ interpretative repertoires of professionals was in line with the conflicted position and power of the neoliberal ‘expert’ detailed in ch2. Parents are told often that ‘they are the experts on their child’ (Autism NI, 2016) and indeed I was told this directly by one of the professionals in during the fieldwork. This is problematic in the process of assessment and diagnosis for they are positioned as not the expert on an aspect of their child that is virtually all encompassing i.e. their autism. Incongruous conferring of authority can lead to a range of alternative formulations of intention from the building of rapport to the interpellation of parents as collaborators. Mother N
Parents and professionals orientate in talk to these relative identities and positions. The professionalisation of autism gave rise to ‘expert’ status and led to professionals, parents and teachers’ interpretation of the child and their behaviours as ‘autistic’ (Donnellan et al, 2010). Explaining them in one simple classification in the DSM, to make categorisation and management easier, led to a more binary approach in which the categories good/bad, normal/abnormal, positive/negative became central. These classifications were rendered starkly visible in the clinical assessment process (Lester, 2014). In contrast, parents continued to talk in more complex and inquiring ways, such as wondering why their child behaves in certain ways and what they could be getting from it.

Parents and professionals both have ubiquitous knowledge, according to Collins and Evans (2008) and Milton but expert knowledge is restricted and requires socialisation into ‘practice communities’ (Milton, 2014, p.795). Experts’ meaning-making is dependent on, not just their use of language per se, but on the way they use it (Collins and Evans, 2008), and how concepts have particular connotations within the speech/’practice’ communities. These communities are closed to parents and thus the way the concepts are understood are very different. They may be using the same words but their meanings are very different.

8.1.2.2. Knowing and Affect

I deliberately linked knowing to affect in the data chapters as knowing includes a deeper understanding, empathising and connection to the child and autism, and researchers are enjoying a more holistic analytic space as a result of the recent ‘affective turn’ in psychology and health/clinical research (Wetherell 2013). Knowing as a parent of an autistic child includes establishing a deep appreciation and interest in the child and her situation, a parental connection to them that is marked by strong emotions and intimacy. It requires parents to become ‘affected’. Knowledge on the other hand, is not so emotive or affect-related. In fact, part of the professional remit is to remain at a clinical distance, to not get emotionally involved (rather in contrast to the caring aspect of the role). Affect is also another vehicle of experiencing, exercising or negotiating power (Wetherell, 2013).

How then do I understand affect or emotion presented in the discursive data of this dissertation? I accept there is a biological or physiological element involved in interactions with the
environment, giving rise to feeling. I therefore also accept the potential limitations of a purely linguistic approach to studying emotion devoid of sufficient considerations of embodiment. However, affect I treat as ‘pre-personal’, relational and constitutive of experience in that it is a compound of the body, the social and the psyche (Cromby 2011). From this ontological stance the concept is entirely compatible with the epistemological interests of critical discursive psychology, arguably more than other discursive or linguistic methodologies. CDP’s epistemological aims and tools provide the means to explore the complex networks of affect in the discursive subject, which forms the understanding, function, action of the affect; ‘interweaving of the material, the social, the biological and the cultural, exploring processes of their co-joint figuring and articulation’ (Wetherell, 2013 p.350). There are many definitions of affect and many perspectives on the turn to affect from various disciplines but I will use Blackman and Cromby’s (2007, p. 6) “force or intensity” that works on “the movement of a subject that is in the process of becoming” because parents during the process of referral, assessment and diagnosis are in a liminal space of becoming a particular subject, a parent of an autistic child. This is distinct, and perhaps desirable (albeit problematically, as evident in Chapter 7) from being a parent or even a parent of badly behaved or odd child (Stenner et al 2013; Rattray 2016). Particularly relevant to the study is Cromby’s (2011) claim that affect is ‘interpellated (‘called out’) and co-constituted by influences operating through social relations, language and social practice’ and I have argued in Chapter 2 that parents are interpellated as parents of autistic children by their contact with professionals and the diagnostic procedures. This interpellation relates to their identity, affect and positioning. Subjectification and interpellation are significant part of the being given an autism diagnosis for one’s child and this a construction of affect. The next section examines the acknowledgement of affect in autism diagnosis by means of a discussion of empathy.

8.1.2.3. Empathy

Based on the empirical analyses presented in earlier chapters, the argument I offer here is that the use of protocols and documents during the entire process of referral, assessment and diagnosis (and likely onward from then) determine that opportunities are not really available to either hear the parents’ own stories or to develop a true collaboration between parents and professionals. The process of using documentation in autism assessment is not a particularly empathetic process and I want to contrast the assessment transcripts with practices of empathetic interviewing, credited with eliciting richer disclosures and respect and acceptance for interviewees. So what is empathetic interviewing?
“The ability to perceive the meaning and feelings of another and to communicate those feelings to the other person” (Brunero et al., 2010, p. 65).

It is true that the professionals in the study tried to develop rapport and to present an apparent discursive space for questions, but arguably this is ultimately akin to the tokenism of Arnstein’s (1969) ladder of empowerment. That is, parents were invited to ask questions, but this was at the end of a long and gruelling consultation and also when their implicit questions had not been picked up or addressed. For this reason, parents would not have been encouraged to engage in any genuine interrogation of the professionals’ assumptions. Instead we have a discourse/practice of distraction (Van Dijk, 2006). The use of the documentation appears to cover everything and is very detailed and yet it does not address the actual questions or issues of parents bar one broad question ‘is my child autistic’. Although, as Van Dijk notes, the interlocutors on either side of the interaction (professional or parents) may not view the exchanges in the meetings as controlling, the importance of such a regulatory approach to the practice of delivering the assessment and diagnostic service relates to both how the interviewee feels and experiences the process and also to the quality and amount of information (Strekalova et al, 2017).

Poor quality, and specifically less empathetic professional-client/patient interactions have been found to result in poorer client understanding of their situation e.g. of autism, their child and the interventions or options available. It has been found to inspire less trust in professionals/service providers, and a lack of empathy results in more conflict (Bellet & Maloney, 1991), less actual compliance (e.g. with interventions) and a general reduction in care and help-seeking skills. Less empathetic interactions were also found to reduce the sense of agency (Street, Makoul, Arora, and Epstein, 2009).

Patients/clients are likely to feel helpless and less inclined to believe professionals can or want to help. As a result patients/clients are less likely to invest and engage with professionals and their interventions (Street, Makoul, Arora, and Epstein, 2009; Haskard Zolnierek & Di Matteo, 2009). In relation to chapter 6 the interview essentially is the means of brokering knowledge between parent and professional, and empathy is the key to optimal brokering.
8.1.3. How do parents and professionals negotiate position, power/agency?

8.1.3.1. Parents’ and professionals’ interaction – partnership

As elaborated in Chapter 6, the data suggests that interaction during the assessment and diagnosis meetings tends to be formulaic and constrained, determined more by the documentation than open dialogue between parents and professionals. Milton (2014) and Collins and Evans (2002) discuss ‘interactional expertise’ as an expectation that the professional can interact effectively with the parent or other client. However, they identify difficulties with this form of expertise as it requires a standpoint which puts them alongside the parent, rather than on a higher status, and with a ‘mutual understanding’ (Milton, 2014 p. 795). Each participant and their knowledge and interpretative repertoires are situated but of a different nature. As the orchestra metaphor suggests, ‘specialist expertise requires immersion in the language and practice of expert communities’ (Milton, 2014, p795), otherwise referred to as expert habitus (Mackenzie and Leach Scully 2007). Expert knowledge was largely tacit in the interactions analysed in this dissertation, e.g. even when offering up the diagnosis there was little of the ‘expert’ knowledge revealed. Rather, the parents’ own knowledge was fed back to them as justification for the diagnostic outcome, with other supportive evidence provided from external reports (from schools etc.) and the ADOS as add-ons. The ADOS findings were not extensively detailed or discussed.

Parents were constrained by the consultation context and the pattern of the meetings with the professionals. Gumperz (1972) suggests that people draw upon cues, ‘contextualisation cues’, which help us identify and fit in with the discursive genres. So parents and professionals do this together. It determines their discursive practice and behaviours toward each other, and provides an understandable context and repertoires that they can use to maintain harmony in the consultation dance. What was particularly interesting, as illustrated in chapter 6, were the occasions when participants moved out of this standard mode of relating and conversing, e.g. the parent who goes off the invisible script or the professional who gave an opinion rather than the official diagnosis. In these cases, both parties tended to be dissatisfied and attributed rather negative qualities to the individuals e.g. that they were unprofessional or had ‘issues’. In terms of a parent at a consultation the contextualisation cues and genre that they understand means they are not expected to ask questions or refuse information. This is a highly constrained partnership or interaction, affording limited discursive space for either parents or professionals to negotiate. In part, the process reflects a set of standardized procedures and protocols designed to manage various forms of ‘risk’.
8.1.3.2. Standardising procedures to manage risk

The growing prominence of risk assessment has ironically produced consequences of greater risk and less benefit to parents, families and the autistic person, largely through the implementation of protocol-led professional/clinical practices that protect the state, neoliberal social interests, institutions and professions. This covertly protectionist strategy is resilient in the face of challenges from autistic people and their families, and even from advocacy organisations, because of the very covert nature of the underlying agenda and the use of professional discourses and practices.

One proviso to this is that some in the autistic community denigrate the actions of parents as collusions, colluding with professionals, society and the state to control autistic people, to change or make them ‘normal’ (Bagatell, 2010; Bumiller, 2008, 2013). I do not entirely disagree with this position and, in fact, have a considerable degree of sympathy with it. However it is not the argument I want to engage with in this thesis, nor is it within the remit of this research to address the argument. What I would contribute in a small way to that particular debate is that, at this early stage, parents may have no other option other than to collude. The evidence here suggests that alternative discourses and practices are not readily available and even if engaged are unlikely to achieve results to support either parents or autistic children. This is illustrated by the playing out of ideological dilemmas (cf. Billig et al., 1988) within the assessment and diagnosis process.

8.1.4. What ideological dilemmas are evident and how are they managed?

8.1.4.1. Dilemmas

At stake in the contested space of autism diagnosis is the parents claim to know their child and the professional’s claim to knowledge (Horton-Salway, 2004). However, parents also need to defend their worth and that of their child i.e. they have to provide a case for their parenting and their child’s character (Holt, 2010). What we see is characteristic of a ‘looping effect’ (Hacking, 1995) whereby a person integrates the knowledge of expert diagnostic criteria and related characteristics and practices, e.g. into parenting or help-seeking, thus adapting their behaviour and having a looping effect back on the expert understanding of the parent of the autistic child, further reinforces the expert and parent positions.
Parents have been accused of collusion with professionals and I noted in chapter 1 a response to criticisms that parents have not exercised agency to resist professional dominance and control over their autistic child. Yet, ironically, there is a strong argument in the data to suggest that parents use conformity as resistance, as a strategy to resist social judgement and gain services and support. Certainly the pattern of confirming as well as conforming would add weight to this case. Some of these dynamics were explored in depth in Chapter 6. However, I want to problematise this relationship as a conflict, consistent with the parents’ talk of their ‘battle’ and ‘struggle’, to generate some new thinking.

8.1.4.2. Conflict

‘we found it helpful to do our homework first... at appointments, we obtained the best results by staying calm and paying due respect to the expertise of the professional, but we remained firm about our desires when necessary’ (Ferris and Ferris,1998 p 188).

This quote was drawn upon earlier in the thesis to highlight inequity in power and the relationship between knowledge and power. In the quote, parents offer their own experience to help other parents in their dealings with professionals. The parents construct the relationship clearly as a negotiation if not a manipulation, involving active generation of knowledge but careful management of its release and use. Such skilful and wily negotiation would not be typically characteristic of a friendly relationship but could be associated more with defensive manoeuvres to resist subordinate positioning, e.g. in oppressed groups such as women, black, LGBT or disability groups (Riddell and Weedon 2014). Should we, in fact, reformulate the professional-parent interaction in assessment and diagnosis as conflict construction and resolution? Brown and Levinson’ (1978 and 1987) expose the threat to each party; there is a threat to the parent’s status and worth, and a threat to their child’s acceptance and ability to be in the world. However, there is also the threat to the professional status, power and control over resources. These positions are established and maintained as part of their identities in discourse and a threat to them is serious and negotiated through the discourse in the assessment and diagnostic meetings. Brown and Levinson speak to some of the contributing factors of conflicts such as the opacity or even impenetrability of issues, missing information, opposing investment/interests and even fallacious policies and procedural obstacles, unpalatability or inappropriateness.

In reformulating these encounters between professionals and parents as conflict then we can see similarities in how O’Keefe (1995) suggests these are managed in the discursive interactions, i.e. damage is ameliorated and repaired/redressed by repressive strategies such as avoidance of
affect talk, indirect communication (e.g. asking questions about whether their pregnancy was planned is actually about asking if the baby was wanted), the use of humour or the use of ‘and’. For example, the professional uses ‘and’ at the start of many of her questions in the assessment meeting (see chapter 6). This is a conjunction whose purpose is to connect two parts of speech but isn’t actually connecting two logical parts in many instances and instead is often used to introduce a new topic in the questions and manage the abrupt changes in the ADI-R schedule. It is used in this way to construct an implied follow on from parents’ speech when actually there isn’t a continuum but is an abrupt change (Schegloff, 1982). In interactions where conflict of interests or over position exist, ‘identity and relationship issues are suspended or ignored. This creates a stance in which the relational significance of messages is viewed as fundamentally irrelevant to the core questions of argumentation, and in fact as an intrusion of non-rational processes into rational decision making’ (O’Keefe, 1995, p.786). Instead, Brown and Levinson (1978 and 1987) argue that these issues are key to mutual negotiations, to how each influences the other and accomplishes a (potentially shared) aim, and thus are key to understanding the processes of the co-construction of assessment and diagnosis.

While the thesis argues for a move toward a more open negotiation of autism, Goffman (1959) recognised that this led to a questioning of ‘accountability’ for identity and conduct (accountability can be a product of identity). The identities of professionals and parents in the interaction are dependent on each other, i.e. they are only realised by the acceptance of each other’s identities and conduct and conformity to the discursive process and social/clinical practice (O’Keefe, 1995). The process and the protocols, force the parent to act, not as a competent parent, but as a problem-burdened parent of a broken child and forces the professional to act as a clinically-distanced diagnostic tool rather than a caring helper. The nature and implications of this process has been explored in detail throughout the earlier chapters of this thesis. The next section explores possibilities for moving forward through fundamental changes in how the concept, relationships and diagnostic practices might be considered – a step toward a shift in episteme.

8.1.5. Possibilities for application

The purpose of all research is to make a positive contribution and add to knowledge to the field. However, the participants – both parents and professionals - in this study explicitly expressed their hope that the research would make a difference to the process of autism diagnosis and particularly the experience of parents. Within the hierarchical systems of social institutions and intransigent discourses of autism diagnosis, there is already a shift toward greater participatory
processes, conceptualisation and knowledge production (Raymaker and Nicolaidis, 2013).
Chapters 1 to 3 introduced a number of potential drivers for change, for opening up possibilities: autistic people’s activism, family/parent activism, changes in professional values of care, new approaches to diagnosis and shifts in local autism strategies. The call for change is both bottom-up and top-down, at both the macro-level and micro-level, but it is inconsistent and sometimes ineffective. Strategy and policy risk giving the appearance of championing the cause of autistic people and their parents whilst leaving existing institutional systems and power relations intact (Autism NI, 2016). Despite this skewing of the problem, and the solution, there is an opportunity to grasp.

I do not intend to propose a naïve approach to change. An underdeveloped approach to change would be easily challenged: ‘agencies of resistance produce outcomes that are uncertain, fragile and contested and whose effect can be the subversion of formal policy intentions’ (Prior and Barnes 2011, p.264). Prior and Barnes are talking about organisations that actually set out to challenge the establishment while Autism organisations tend to be parent-led by parents who have already been subjectified and oppressed in their early dealings and we see these organisations attempt to access power and position through a pseudo-professionalising stance rather than through activism.

Yet the resistance to change emerges from the modern aversion to risk. My theme of possibilities produces a ‘plurality of heterogeneous claims to knowledge, in which science does not have a privileged place’ (Giddens, 1991, p2). The public and society at large are stakeholders too. Risks are produced primarily in knowledge about them and can be accentuated or minimised by how they are constructed ‘thus the media and the professions engaged in defining risk ...become key positions in society and politics’ (Beck, 1990, p54. Autism has become a political issue in recent years, from relative obscurity through to increasing prevalence and parent and autistic people advocacy and professional efforts to define and manage risk and resource. The risk of challenging mainstream approaches to autism is that it threatens the established norms, e.g. of development, of proper parenting, social relations and social practices. Protecting autistic people and their families and society from risk of ‘autism’ has mobilised a complex structure, processes and systems e.g. of diagnosis, organisations, authorisations and protocols. Risks such as autism must be extinguished or reconstructed in some way to minimise their impact.

Autism has, in short, become a risk management exercise. ‘If risks are not scientifically recognised, they do not exist, at least not legally, medically, or technologically and socially, i.e. they are not hindered, treated or compensated’ (Beck, 1990, p67). Science and truth are equivalent. This is the difficulty yet there is a shift away from medical diagnosis of the
psychological which emerges in part from a crisis in ethics. Beck holds that this crisis in ethics is the result of awareness of false conclusions through a misadventure of rationality. Change culture also increases this drive exponentially and this is evident in both academic and applied expert environments. The professional business is ever-transforming to create and meet new needs and risks. Many of the risks of autism are actually a consequence of modernisation but autism has become the risk itself and the responsibility for that has been bestowed on the autistic person and their family.

‘acknowledging the ambivalence inherent in constructions of expertise and scrutinizing one’s assumptions and practice, rather than denying the authoritarian aspects of health care, would provide the basis for more ethical and respectful clinical practice’ (Avdi, 2000, p.336)

8.1.5.1. Don’t rock the boat – simple change

It would be possible to present a list of simple adjustments to diagnostic practice that may make the process a little less painful. In terms of the use of documentation, which closes down opportunity to discuss and enforces the confirming and conforming pattern discussed in chapter 6, I could recommend that part of the questionnaire could be sent out to parents so they could spend time at home, conferring with others or with their child’s Personal Child Health Record (‘red book’). As Mother N suggested (See chapter 5, p.120), medical records could be collated without having to probe parents for information long forgotten or that is potentially painful. They could be given the diagnostic criteria and explanations for the questions on the ADI-R. However, this raises a multitude of other questions and issues and does not approach the fundamental issue of the crisis in ethics or the negotiation of knowledge and power, and it does not touch on the dilemmas outlined in Chapter 7. The next sections take two examples of more radical change building on some of the ideas in Chapter 2 and reflecting on the issues raised in the data.

8.1.5.2. Open Dialogue

Open Dialogue is a person-centred approach to psychosis where therapeutic discussions only take place with the client and their close contacts present. At least two therapists attend meetings in the client’s space, rather than a clinic, and there they discuss openly their understanding and approaches with each other and with the client and their close contact. Part of the rationale for referring to the open dialogue approach in this conclusion comes from ‘The Six Steps of Autism Care’. The third step is ‘formulation’ and this is a key in-depth analysis of the child in relation to
whether they display autism characteristics - but it is carried out without the child or parents present:

‘Formulation is a collaborative process which brings together all of the knowledge and information acquired from the assessment and diagnosis process. 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. Thus, for example, information about the wider needs of the family are relevant. Formulation therefore, allows for an understanding of how difficulties arise and are maintained in the system that surrounds a child/young person, as well as their wider environment, of societal and cultural norms.’ (p.18)

It is a step such as this that open dialogue attempts to address and which is so damaging for the professional/parent relationship and for the power and knowledge of the parent. Even in the Six Steps document, which is one of the protocol papers used by the research site, there is less information about this step than all the other steps. It raises questions: how is part of the process, what does it entail and what are the objectives and timeframes? It is more general than other steps.

In step four the professional must feed back to the family and then ‘Parents/carers and AST staff should work jointly together regarding the proposed next steps, which will inform the tailored Intervention Care Plan’. Since the parents have not been part of step three, ‘formulation’ and the discussions about the needs of their child and family they are already at a disadvantage and may face formulations with which they do not agree or understand fully. Yet they are to jointly work with the AST staff to establish a tailored care plan based on a construction of their child and family to which they are not privy.

In contrast to this analysis of the realities of practice, a client-centred approach is the main principle for all health and social care guidelines.

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<th>Important Open Dialogue factors</th>
<th>Challenges of Open Dialogue</th>
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### Non-medical dialogue

#### Integrating Open Dialogue meaningfully

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<th>Non-medical dialogue</th>
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<td>Shared ownership</td>
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‘Table 3 Superordinate and subordinate themes extracted from the thematic analysis (Razzaque and Wood 2015, p935)’

Razzaque and Wood (2015) conducted a survey with NHS staff at an Open Dialogue conference, asking their views on Open Dialogue after they had heard about it and asking them how it would work in the NHS. Conference attendees expressed positive views, stating that it adhered well to the ‘care’ values and principals of the NHS: ‘most important shift in attitude seen in mental health services for years’ (staff participant, p935). However, Razzaque and Wood identified a number of challenges for current professionals and institutions – see Table 1. These highlighted again the contrast of the core values and the actual practice, which did not characterise the core values. This contrast resulted in troubled talk and ideological dilemmas (Chapter 7). This table indicates particularly that there would need to be a cultural shift and institutional changes of some magnitude in order to move to practice that did indeed share knowledge and acknowledge and embrace affect (Chapter 5). It challenges the medical discourses and their dominance in clinical practice (Chapter 6). The data analyses in the thesis are clearly in tune with the Open Dialogue Conference attendees who, Razzaque and Wood claimed, indicated there would be a struggle to let go of the established dominant medical model and saw the application of such values and open dialogue itself as unattainable, peripheral and complementary.

### 8.1.5.3. Parents take control

PPI and other approaches emerging from professional, policy and parent organisations call for partnerships and joint working. Prado Salas and Zamoro-Bonilla (2015) claim that the joint discourse can be a different entity altogether from individual ones and thus should be treated as a thing in itself. The mechanisms and productions will also be different to that of an individual. Hence they explore the concept of ‘collective agency’ and here we can explore whether this is evident in this fieldwork. On the basis of the evidence in the thesis I would argue that this is not, in fact, yet happening and that there are numerous obstacles to overcome – equity can be difficult to achieve at first. In contrast I offer the scenario of parent control and refer to the discussion of conflict – parents may need to win a battle to have some chance of a war ending.
Case study of mother N

Mother N asked the professional, during the diagnosis meeting, if her son will no longer need the label at a later point in his life. She does not get such reassurance and becomes very upset as another hope is removed. This was the most emotionally charged meeting and transcript of the study as Mother N laid bare her desires, fears and feelings. Chapter 5 argued that affect discourse was essentially closed down by the genre of the consultation discourse and clinical practices such as the use of interview schedules and reports (Chapter 6). Mother N defied the typical consultation practice between professional and client and produced dis-preferred turns of her own which diverted the usual course of giving the diagnostic report. She does this not just with questions and critical statements but with expressions of affect that have to be responded to with more than simple acknowledgement. Mother N was permitted to continue to ask questions and to express confusion ‘I thought it was just, like, for kids’ (l.622) and feelings, ‘I was putting myself cuckoos with it’. It is evident Mother N has moulded the agenda and discussion at this point in a way that did not happen in the other diagnosis meetings and she continued to do so:

N. Will the school be told then he is autistic now
Prof
N. Or what way does that work or?
Prof
N. Oh no, I want you to let them know if I thought it would ease up on him a bit or something
(l.694-700)

And she makes a demand which was absent in the other transcripts:

N. Ok. Would you write it down for me because I’ll go out of here and not even remember what you said (l.727-728)

Mother N takes a certain amount of control. She exerts power, not over the diagnosis, but over the process of giving and getting the diagnostic report. The professional in this instance appears to have engaged in a co-construction with Mother N on an empathetic level i.e. recognising, accepting and responding directly to the affect in her discourse (Brunero et al, 2010). It has already been asserted that this professional withdrew her data and we might infer that she was concerned about her performance in the meeting, perhaps because she broke the clinical practice protocols or because she felt she lost control. However, the main point to highlight here is that the parent gained some power, her talk becomes knowledge seeking and produces succinct aims for her own knowledge gathering, essentially of her own volition. From a co-construction heavily determined by the professional agenda and practices, it becomes a co-construction which includes the parent’s agenda. Few of the other assessment or diagnostic transcripts, even in
parts, display this agenda, although it does run through parts of the research interviews, both pre-assessment and post-diagnosis.

Woodcock and Tregaski’s (2008) argue that parents viewed assuming greater control over autism diagnosis and services as simply an extension of their rightful parenting role. This is not a small point by any means, as such removal of parental authority and autonomy may have a serious impact on the family experience and parents’ engagement with services, interventions and, potentially, their child (Carinci, 2008). Woodcock and Tregaskis suggest ‘an approach that seeks to validate and recognize parental ‘private’ knowledge of the individual nuances of the impairment as applied to their child will be felt as more supportive, and services will be shown to be more inclusive in their responsiveness to individual need’ (p 66).

The findings of my doctoral research provide some support for Woodcock and Tregaski’s (2008) claims that parents were in a better position to see developmental changes, know their child’s needs, match their child to the assessment criteria and recognise how best to allocate service. Parents do not simply have lay expertise of their autistic child, they also have expertise without qualifications that goes far beyond the public lay understanding of ‘autistic children’ (Collins and Evans p.49). This is not as well recognised as it ought to be – while professionals surely acknowledge a parent’s experiential expertise about their child this is extracted from the ‘autism’ aspect of the child. Taking an ‘expertise without qualifications’ approach helps us to appreciate better that the parents are experts in the autism aspects of their child. Collins and Evans (2008) identify ‘mismatched salience’ (p.41), similar to the concept of incommensurate discourses between parents and professionals, i.e. each is coming from a different understanding, experience and knowledge base and so they fail to really understand the nuances and complexity of what the other is saying. Parents don’t even know how to ask (the right?) questions while professionals are straightjacketed into a schedule of questions regardless of what the parents raise. Parents will have a lot of unrecognised knowledge which is hard/impossible to access in an autism assessment with a structured ADR-I, and professionals have knowledge which is withheld, ‘concealed knowledge’ (Collins and Evans, 2008, p.41) at the point where the professional team come together to discuss the observation of the child, the parents interview and other reports (from school, speech and language therapy, psychologists etc) (p.41).

A parent’s own expertise is specific to the child, to the child and family’s context and is the knowledge that is most valuable for discriminating and making more specific judgements – Collins and Evans p.50) explain that we need to understand the difference between local (parent) and ubiquitous (professional) discrimination. Parent ‘knowing’ must have paramountcy.
In reference to Collins and Evans ‘problem of extension’ (2008, p.10) - whereby sharing of expert, a priori knowledge may upset the boundaries between professional and parent - I argue that these boundaries need to be disrupted, that the parent has the right and ability to have and use the knowledge and finally that the parent also has the right and ability to make a judgement of the expert and the knowledge they present to them, if this is sufficient in detail and clarity. Parents already do make judgements about the professional and the services but these are based on meta-criteria of credentials, track record and, frequently a problematic reputation – what is essentially a social level of judgement (Collins and Evans, p.46).

Conclusion to part 1

The analysis and discussion highlights that the privileging of knowledge and positions of status work to subjectify parents and reduce their voice. There are already a range of approaches to include parents’ voices and meet their needs, and this is praiseworthy. However, the analysis of the interactions between parents and professionals demonstrates the pervasiveness of their subjectification and raises questions about the impact potential of developments such as PPI. The thesis concludes that more radical change is required, to the institutional policies and professionals practices but also to the conceptualising of diagnosis and knowledge. The self-help environment in mental health and self-advocacy in learning disability has been has been developing prominently in Ireland for some years. However, these assume some aspect of individual agency and this is something that the autism diagnosis negates. Furthermore, strategic change tends to be about integrating autistic people into existing communities, normalising the autistic person to fit in rather than diversifying the community to accommodate the person (Neville, 2013). But knowing this and giving people what they apparently want/need doesn’t seem to fully achieve the positive partnership desired by most professionals and parents. Within the repertoires of knowledge we looked at incommensurate discourses, the lack of sharing and contest between knowledge and knowing. At stake in the contested space of autism diagnosis is the parents claim to know their child and the professional’s claim to knowledge (Horton-Salway, 2004). However, they also need to defend their worth and that of their child i.e. they have to support a case for their parenting and their child’s character (Holt, 2010). The use of documents is particularly restrictive. The shape of the transcripts provides evidence of how documents control and close down challenges; the sense of being tested, the invasion of sensitive and personal questions and the abrupt changes invalidate parents’ knowing and diminish their position to the point of making them vulnerable. The network of professional reports triangulates the professional case and further weakens the position of the parents. In this context negotiation
is closed down. The thesis presents an argument in favour of problematising the protectionist approaches used by professionals which elevate professional and institutional subject positioning at the cost of reducing parent agency and efficacy. The mechanisms of protectionism produce and rely on autism being a troubled category, parenting ideological dilemmas, clinical/caring ideological dilemmas and a host of other obstacles to opening up possibilities. They maintain ‘the discursive struggle to create and control systems of shared social meanings’ (Fischer, 2003, p.13).

The process of referrals and assessments/diagnoses constitute core social action of autism; doing autism and autism diagnosis is accomplished through the discursive competencies (Garfinkel, 1967) of parents and professionals but with very different positions and drawing on very different regimes of knowledge. ‘Some mobilisations of discourse become more stable and pervasive than others’ (Edley and Wetherell, 1999, p 182). Given the power of DSM 5, legislation, policies, protocols and the scientific status of medical models of autism, it is unlikely that professionals will feel the need to bend to accommodate the parent’s speech in any substantial way. In the parent discourses we see a resistance to this and strategies to manipulate, but little by way of hybrid discourse. Furthermore, even when hybrid talk is attempted it does not produce novel meaning making.

Beck’s (1991) claims that reflexivity is evaded by means of the status of science and ownership of this status by ‘experts’ and social structures which produce institutionalised and systemic assumptions of ‘truth’ and its authority. Most changes, and we can see this in the newly devised DSM 5 criteria for autism, focus on changes to structures and procedures rather than on the fundamental reflexivity of the topic, content, meaning and consequences – reflexivity at this level would require the unearthing of different epistemologies, ontological assumptions, discourses and a reordering of social relations and the identities therein. He argues that modern society operates on an idealised model of risk that does not support such a level of reflexivity. The parents and professionals, remain stubbornly in separate discursive genres and regimes of truths in this neoliberal episteme.

Part 2 Reflections

Reflection is a critical part of the process of qualitative research (Parker, 2002). The theoretical and methodological approach alongside the standpoint of this research best aligns with the recent movement of critical autism studies:
‘In contrast to the prevailing deficit construction of autism, which is individualising and pathologising, a critical abilities framework not only respects the complex personhood of autistic individuals, but also reveals how the construction of autistic identities holds important insights for how to rethink, and extend, ideas associated with cognitive ‘normalcy’ (or ‘ability’) and difference’. (O’Dell, Bertilsdotter Rosqvist, Ortega, Brownlow and Orsinie, 2016, p.169).

8.2.1. Theoretical and methodological approach

I would argue that this research assumed a respectful ontological stance of being anti-discriminatory and focused on the emancipatory interests of parents with autistic children. The aim was to problematise the topic area and explore how discourses in autism assessment and diagnosis constructed a hegemonically-restricted network of meaning and worked to position both parents and professionals in inequitable subject positions. The methodology of examining talk both in action and in research interviews, elicited rich and complex data. The analytic approach to the data aimed to promote dialogue, not just about what was constructed in the immediate talk but also, about how it was drawing down from wider macro-level discourses in practice and policy.

Billington et al (2000) call for complex accounts of the autistic child rather than the reductionist assessment structures in current schedules. My work calls for a move away from reductionist approaches at the diagnostic stage with parents. These more complex accounts can support improvement in relationships rather than just addressing behavioural issues – in parent and teachers accounts relationships can be seen as of more salience than behaviour, as behaviour is transient and moderated by relationships anyway.

“Once one allows individuals to move away from the question and answer mode of the survey to a more conversational exchange, then their statements are more reflective of ‘private’ rather than ‘public’ accounts” (Radley and Billig, 1996, p.231)

With more open conversational and discursive data, we get freer connection of topics, points, events and movement between topics. This results in greater variability in the talk so we see people move between positive and negative accounts of categories such as ‘autism’ and practices such as ‘autism diagnosis’ (Potter and Wetherell, 1986). Use of the documentation and standard questioning approach, for example, elicited at times a very public account in comparison to the more private accounts in anthologies when a parent tells their story (Cornwell, 1984), e.g. as
revealed in some of my interviews. That being said, in my fieldwork, I was aware of difference in the accounts parents gave me and the accounts provided in the assessment but also struck by many similarities.

This also links with the notions of open and closed public spaces e.g. the clinics and intervention centres are closed spaces and most medical or social services centres are very closed but much of the internet is a very open space (the internet has warranted lots of research of its own in this sense though as it is more complex than this). This works to reinforce the status of professionals and physically locates them in an elite place that affirms their status as ‘experts’. The professionals are clearly ensconced for the most part in what may be seen as ivory towers while parents are flailing around in the mud of real life. Within these open or closed, public or private spheres, there are rules about behaviour, acceptable ranges of normal interaction, forms of talk etc.

8.2.3. Omissions in data

CDP incorporates one advantage which is particularly relevant to the assessment meetings – a CDP approach can consider what is absent in the talk, what is being left out and what ‘leaving out’ performs. What is left out of most of the assessment discourse between professionals and parents is empathy. This was a very significant strength of the analytical approach as I have begun to consider affect as one of the most important discussion points arising from the research.

8.2.4. The interview: semi-structured and open-ended

The meetings between the researcher and participants were planned as semi-structured interviews. However, these morphed at times into what Potter and Hepburn (2005) term ‘open-ended’ or ‘conversational’ interviews in qualitative research. This was a result of taking a deliberate stance against a survey or structured interview approach and instead being ready to respond to the parents empathically and equitably as far as possible – and without compromising the aim of collecting their data. Instead, follow-up questions were designed to follow the direction provided by the parent, and when necessary, my own answers to their questions or emotional responses were offered. For example, if asked if I was involved in diagnoses or had an autistic child I could explain I wasn’t and did not. I noticed for example that I tended to offer more at the end of the interview and this seemed to be linked with some sort of closure process – sharing and then ending so that there was less discomfort with the process.
It was appropriate to analyse the interviews as a co-construction. The conceptualising of the interviews as a co-construction gave me some permission or right to offer comment/reaction but did not give me free reign be too directive or to attempt to reframe their thinking on the spot, e.g. contradicting or challenging parents. Potter and Hepburn (2005) summarize some of the problems with the use of open-ended interviews. They note that they are often used in ways that disregard the significance of co-construction in interaction (by focusing on select extracts from participants and using forms of transcript which disregard the ‘interactive’ aspects that are intrinsic to meaning-making). There are also complex and difficult to analyse issues with respect to the stake or interest that each party may show in what they are saying but these are there in any event. I argue that being open and transparent about them means that there can be greater appreciation of the stake and how it also works into our meaning-making (Horton-Salway, 2001). This was the approach I took but my participants in the research interviews talked very fluently and the questions I designed seemed to be sufficiently open to encourage them to talk – it was possibly also the case that these parents were keen to talk about their children and their experiences, at least out of the frustration they felt.

8.2.5. Limitations

I have indicated several limitations of the thesis in the introduction. This section will focus on emerging limitations through the fieldwork. The main limitations arose from a research design vulnerability in the fieldwork. Despite the anti-discriminatory and emancipatory standpoint of the research and the focus on parents’ experience and meaning making, practicalities relating to accessing participants and obtaining ethical approvals determined that I had to partner with the research site, the assessment centre. The fieldwork necessarily was reliant on the assessing institution to identify potential parent participants among its referrals and this procedure for recruitment was governed by the diagnostic protocols that were being examined. It was not a limitation in the sense that it was appropriate for the critical discursive psychological approach to be applied to the collection of data in the real world context (Potter, 1998). However, it did compromise the standpoint and also permitted part of the procedure to be institutionally controlled.

This led to a second issue with the fieldwork. A screening process was carried out by the research site, whereby some parents referred to the assessment centre were not invited to take part in the research. I was told this incidentally in conversation with the team leader and told some families had not been sent the information and request to take part in the research because they had ‘issues’. The screening of families prior to research access is a considerable limitation for the
current study but one which can be incorporated into the analysis to take into account that the families who have participated were the families screened by the assessment centre. It is also notable that some other issues could be raised around self-screening too. Due to the limitations and focus of the thesis it is possible simply to note that parents and professionals self-screen and some thoughts could be developed around the tensions and motivations to take part in research.

8.2.6. Ethical considerations

With such a sensitive and political topic, a number of ethical questions and dilemmas emerged. For example, I had to consider: who is the research for, what is the research for, who do the ethical approval procedures protect and why? The ethical approval procedures were lengthy and multiple but provided much needed space to consider potential risks and their management. However, ethical approval layers may grant permission not to engage; potential researchers deem the lengthy and involved procedures for ethical approval troublesome and, in view of regulations and requirements, they often doubt whether the resulting restricted contributions would be worthwhile (Ryan, 2013). I was informed at the Trust clinical training that only 4% of proposals there progressed to completion of a study.

As a result of the ethical approvals and partnership working with the assessment centre the professional participants in the research received a significant amount of information about the researcher in comparison to the information offered to the parents. My intention was to be as open, honest and transparent as possible; however, this was not possible in equal measure simply because of existing knowledge, protocols and positions. This raises a debate. Should research, which specifically aims to challenge established power relations, itself mimic the established order to access participants and ensure the research is actually conducted – or was I instead selling out the parents and replicating inequality to achieve my own goals. This is a debate that deserves greater exposure than can be offered here but I do want to be transparent about such a dilemma and acknowledge my part and discomfort within my part.

One last ethical concern to mention here is regarding who owns the interpretation (Willig, 2013). The data is owned by the participants and consent was given, and withdrawn in one case, but the data continues to be owned even when consent can no longer be removed, i.e. when submitted as a final thesis or published. However, the interpretation is not only owned by the researcher, albeit they have primary responsibility. In CDP, all language and meaning is jointly constructed and the interpretation can only take this direction as a result of the orientation offered by the participants. The interpretation is, therefore, validated by a transparent reflection of their
orientation in the empirical chapters. The next section deals specifically with how the participants’ recorded data was translated into empirical material for interpretation.

8.2.7. Transcription

Various approaches to transcription can be seen across discourse papers and I have outlined my approach in Chapter 4. Reflecting on the process of transcription, I was struck with how inaccurate my transcription was at first draft and I took pains over several listenings to check and correct the transcript – I checked with other transcribers and found similar experiences and I reflected at the time how this may have implications for how interlocuters may, in fact, often be caught up in misunderstanding as a result of the gap between what is said and what is actually received. This is not part of the research process that can or should be rushed.

On reflection there would have been some advantages to a more fine-grained transcription, providing timings on pauses and so on. For example, I had to make some interpretations more tentatively because the transcriptions did not support them with as much strength as a more detailed transcription would: T. Right. I never knew about it (quiet) (Assessment, l.384). My claim that Mother T was uncomfortable at having to admit she didn’t know about and, therefore, didn’t register on the pregnancy register for epilepsy when she was pregnant is not as strongly evidenced as it may have been if I had added the timed pauses and intonation.

I also made the point that ‘questions came quick’ (Chapter 6, Section 6.2.1.) but specific timings may have supported this better than the reliance on the pattern of the transcript to show the flow and get a sense of relentless rapid questions. The advantage of having fine-grain analysis had to be weighed against the practicality of data management and in consideration of the epistemological aims of the approach. It was not practical or entirely necessary for this research and could have distracted from the synthetic analysis of macro and micro-level discourses. It does, however, suggest research from conversational analysis could be complementary to CDP.

8.2.8. Validity and reliability

These are snapshots in time with a limited group of participants and so there would typically be some constraints around the generalisability of the findings. However, with that proviso, it is also fair to say that the protocols of NICE and the diagnostic instruments are standardised across many contexts of time and place. From this premise, it is reasonable to suggest that the findings should be viewed in the wider sense, i.e. relevant not only to these participants but to the institutional
practices that adhere to the recommended approaches to autism assessment and diagnosis. Clearly there will be variability and indeed CDP argues that the variability is the most relevant point (Potter and Wetherell, 1987), however, the structures, systems and processes are institutionally determined to be rigid.

8.2.9. Role of the researcher

Much of the data for this thesis was extracted from my interviews with the parents so this section aims to put that into the context of their relational knowledge and power i.e. the data constructed in such meetings was contingent on this relationship and thus the analysis must take account of what was being performed on these multiple levels. So how was I positioned within these meetings and what did that mean for the data collection and the subsequent analysis? This is an important part of the analysis and not just in terms of reflection. The meanings, choice of topic and words, positions taken and given were all co-constructed within the context of research interviews. They are conducted with a researcher (not a friend or family member, not an entire stranger) and while not an autism professional in the sense of being a service provider it is likely that the parents viewed me as a professional of sorts and with privileged access to, and contact with, the professionals they relied upon (or at whose mercy they felt). In the method chapter, it has already been made clear that the researcher is a participant and co-constructor of the data. The approach to the interview was largely to utilise only scant, open questions to encourage the parents to offer their own stories as far as possible but it was also clear that in order to dignify their disclosure a more conversational approach was taken, primarily at the beginning and end. The information provided to parents prior to obtaining consent explained that the researcher was not a professional and was aligned to an academic institution rather than a service provider. However, this had variable baring on the mobilising of the researcher position. For example, I seemed to be considered as one of the professionals or a provider by some participants, being asked for information or advice, while others tacitly understood I could not influence services or did not know the professionals or services. Yet it was also clear that I was certainly not viewed as a friend or confidant.

Conclusion

As a concluding thought, I want to identify a potential area of future research, which was raised by the professionals at the assessment centre when I first approached them – what happens to children and parents with autistic characteristics who do not receive a diagnosis? As explored in this thesis, achieving the diagnosis provides some resolution to the dilemmas of the parent at the
end of the process. It enables them to get interventions and support. It also justifies their case for soliciting an essentially unwelcome diagnosis, resolving to some extent the ‘troubled’ position in which they find themselves. If the child receives the diagnosis, blame for the behaviours transfers to ‘autism’, and parent and child avoid being held completely responsible. However, this does not happen until the end of the process and, as noted, it can still leave questions and doubt. Much is constructed in this gap that is then carried through further social relations. However, what happens if the child does not get a diagnosis after the parent has gone through a difficult, if not traumatic process, leaving both themselves and their child potentially vulnerable?
References


American Psychological Association (2013) Diagnostic Statistical Manual of Mental Disorders. 5th edn. Available at: www.dsm5.org (accessed on 1 September, 2017)


Runswick-Cole, K. (2007). ‘The Tribunal was the most stressful thing: more stressful than my son’s diagnosis or behaviour’: the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDisT). *Disability & Society, 22*(3), pp.315-328.


Appendices:
Appendix A

Research Project Information for XXX Assessment Team
Parental and professional discourses on autism

Research Question: What discourses/talk do parents and professionals engage in when a child is assessed and diagnosed with autism?

Focus: This research will focus on the experiences and meaning making of approximately six families in relation to the diagnosis of their child’s autism. It will explore their experiences from the point where concerns were raised through to formal diagnosis. The study will include discursive analysis of the interactions encountered during the diagnosis process with professionals.

Rationale: The prevalence of autism has been on the increase in the last 10 years with a current estimate of around 1 in 100 of the UK population being diagnosed with autism (http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=235&a=3527, 2008). While research into the causes and treatment of autism is prolific, some recent research has noted the impact on family life and support. However, a critical time in the process of raising a child with autism is the initial period of assessment and diagnosis. Through the discourses and relationships between parents and professionals the meaning of having a child with autism is mutually constructed.

Research has already suggested that parents and children with autism benefit when parents can be engaged positively in the process of assessment and support development. (Koegel, Schreibman, O’Neil, & Burke, 1983). It is clear from the statements of parents, however, that positive engagement is not always achieved. Carinci (2008) identifies this as a problem owned by the family when he states that ‘not all families display the characteristics that allow them to take an active role regarding their child’s education and training’. However, he found that ‘a critical aspect … was the way in which she (the mother) reacted to and digested the initial diagnosis’ and that this impacted on the families perspective and ability to adjust.
This study aims to explore the roles of both professionals and parents in constructing these experiences and characteristics, arguing that such characteristics are interactional constructions through discourse which are initiated at the first point of contact and through assessment and diagnosis.

Methods and Data Collection: The proposed study will take a ‘critically discursive psychological approach’ (Wetherell, 1998), examining talk in meetings between parents and professionals and how it draws on familiar ways of talking about autism. Data will be collected from the time of a child’s referral for assessment through to formal diagnosis. The main method of data collection will be audio recordings of interviews with parents and of the customary meetings between parents and professionals, along with textual information from correspondence, reports, assessments etc.

Your Participation in the Research

I am requesting your cooperation in collecting data for this project. With your agreement your interviews with the participant families will be recorded (by you) and the recordings will be transcribed and analysed by the researcher. All names and identifiable details will be removed at the point of transcription. Reports and correspondence may also be used in the analyses but again names and identifiable details will be removed. A report, anonymised, will be provided to the assessment team within a year of the completion of data collection.

My suitability as a researcher for this proposed project: The criteria for suitability are categorised below under qualifications and experience:

Qualifications: BA(Hons) Psychology and MSc in Psychological Research Methods along with a Professional Qualification in Social Work

Experience: I have 13 years of extensive experience of working with, and conducting research with, adults with learning disabilities (including autism). This included support, education and counselling work with families, carers and a range of professionals. I am a senior lecturer in the OU, and Associate Lecturer on the honours level social psychology course and supervise undergrad research, including discursive projects.

I intend to submit the work from this research project to obtain a PhD qualification.

Ethical considerations: I am aware that this is a very sensitive context. I will abide by the BPS Code of Ethics and Conduct and the BPS Ethical Principles for Conducting Research with Human Participants but also have a firm grounding in ethical practice in social work. Respecting all participants, their privacy and dignity, informed consent will be obtained in writing with participants having written details of the aims and approach of the study and the competencies and role of the researcher.

Please ring me at my office in the Open University in Ireland on …., or email …., if you wish to discuss the study at any time. You may also contact my supervisor, Mary Horton-Salway on …. or by email at …. Complaints should be directed to Professor …, Associate Dean (Research), Social Sciences, Walton Hall, The Open University, Milton Keynes, MK7 6AA or ….
ASSESSMENT TEAM CONSENT FORM

**Study:** Discourses in Autism Assessment and Diagnosis

**Researcher:** Karen Hagan

*Please read the following points carefully and sign below when you fully understand and agree with these terms. Direct any questions to the researcher before signing.*

I agree to participate in the above study. This will involve:

- audio recordings of meetings with families
- further possible discussions with the researcher at my request
- sharing written documents about children’s assessments
- my, and my teams, details being changed to ensure my anonymity

I understand that my meetings with families in the NHS centre and with the researcher will be audio recorded and this, along with NHS records, assessment documents and correspondence between me and the families, will be used in the study. All my information will be kept secure and in complete confidence within the research team and the assessment team.

I also understand that the recordings will be destroyed at the end of the study and that I can withdraw my participation and the use of any information collected from me at any time.

Signed:  

Print Name:  

Researcher:  

Date:  

Study:  

Researcher:  

Date:  

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Research Study

Guidance for Parents

The information provided here refers to autism since that is the focus of the study. However, in no way is this meant to suggest that your child will be diagnosed as autistic.

The study and who is doing it?

A research study is being carried out by Karen Hagan, from the Open University, in conjunction with this centre. The study aims to explore how parents and professionals talk together when a child is being assessed and diagnosed, specifically with autism. Clearly we will not know which children will be given a diagnosis of autism (and your child has not been assessed or diagnosed) until a later stage so we are initially including a large number of families referred to the centre and the numbers involved will be reduced as the children’s situations become clearer.

The research has been passed by the NHS and Open University Ethical Committees.

What is the point of the study?

Research has already suggested that parents, and children with autism, benefit when parents can be engaged positively in the early process of assessment and obtaining support services. This study aims to explore the roles of both professionals and parents in constructing the experience from the first point of contact and initial assessment. It is hoped the study may offer insight into a more positive process of diagnosis.

What will I have to do?

You don’t have to do anything. If you do not wish to take part in the study you should not sign the consent form. You may ring me at my office in the Open University on xxxx if you wish to discuss consent, or at any other time during the study.

If you are willing to take part in the study, however, you will need to sign and return the consent form. I will then arrange to meet with you to discuss the referral and to answer any questions you may have about the study. This meeting will be recorded. Then you just proceed with the centre as you would otherwise have done, with the exception that meetings will be recorded and both the recordings and copies of any documents, such as letters or assessment notes, will be given to me. I will not attend any of the meetings so as not to intrude. I will continue to keep recordings and copies of documents until the centre informs me that their assessments are complete and I have collated it. I will then meet with you for a final time to discuss the process and to answer any further questions you may have. Again, this last meeting will be recorded. Also keep in mind that you can withdraw from the study at any time by contacting me directly to let me know or by telling the team leader at the centre.

What will happen to the information you collect and the recordings?

All copies of documents will be destroyed after the information has been collected and analysed. This may take up to three years. During this time they will be held in a locked filing cabinet in my home and at the end of this period they will be destroyed through the Open University system of disposing of confidential information. When analysed, some of the information will be used in the final report and may be used in published reports at a later time. However, all names and identifiable features will be removed so your contribution is anonymous and it will not be possible to trace it back to you in any way.
PARENTAL CONSENT FORM

**Study:** Discourses (talk) between parents and professionals during child assessment

**Researcher:** Karen Hagan

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*Please read the following points carefully and sign below when you fully understand and agree with these terms. Direct any questions to the researcher before signing.*

I agree to participate in the above study. This will involve

- two meetings with the researcher in addition to the usual assessment team meetings
- further possible discussions with the researcher at my request
- sharing written documents about my child’s assessment
- my, and my family’s, details being changed to ensure my anonymity

I understand that my meetings with the assessment team in the NHS centre and with the researcher will be audio-recorded and this, along with NHS records, assessment documents and correspondence between me and the team, will be used in the study. All my information will be kept secure and in complete confidence within the research team and the assessment team.

I also understand that the recordings will be destroyed at the end of the study (Oct 2013) and that I can withdraw my participation and the use of any information collected from me at any time before then.

Signed: ____________________________________________

Print Name: ____________________________________________

Researcher: ____________________________________________

Date: ____________________________

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N.B. Questions, comments or complaints should be addressed to Karen Hagan (…, …) or the research supervisor Mary Horton-Salway (…, …).
Appendix B

Interview Guide

The guide is simply that; these are suggested questions to ensure that the interview focuses on autism and the process of assessment and diagnosis. It aims to explore the meanings the participants construct around autism and, to this end, open ended questions will be employed to encourage participants to talk openly and freely about their understanding and experiences. Other questions may be added at the time of the interviews in response to what participants are saying, to clarify questions or to prompt further depth but these cannot not be pre-emptively identified here.

Initial Interview

1. Can you tell me how you came to have a referral to the XXX Assessment Centre?
2. What did you think about the process?
3. This research is about autism assessment and diagnosis and you have been asked to take part because your child has been referred for an assessment. We don’t know, at this stage, what the outcome of the assessment will be, of course, so I need to ask you about autism even if it ends up not being relevant to your family. Would you tell me about your understanding of ‘autism’?
4. What thoughts do you have about your child going for assessment?
5. What do you hope you and your child might get from the assessment?
6. Do you have any questions about the research?
7. Are you still happy to take part in the research?

Final Interview

1. Would you tell me a bit about your experience of taking your child through the assessment and diagnosis process at the XXX assessment Centre?
2. What does ‘autism’ now mean to you?
3. What do you think an autism diagnosis will mean to your child?
4. I will be sending you a report about the research within a year but is there anything you want to ask me now? You can contact me again using the contact details you have been given if you have any questions or issues about the research at a later time.
5. How did you feel about taking part in the research project?

Thank you!