

The stories of parents whose children have been referred for an assessment for Autistic  
Spectrum Disorder (ASD): A narrative analysis

Holly Aldous

A thesis submitted for the degree of Professional Doctorate in Child, Community and  
Educational Psychology

Tavistock and Portman NHS Foundation Trust

University of Essex

Date of submission: 18<sup>th</sup> May 2017

**Abstract** There is an increasing emphasis on the importance of parental voice in education, and specifically within the realm of Special Educational Needs (SEN). For parents whose children have been identified as potentially having Autistic Spectrum Disorder (ASD), their story may have begun long before there is professional involvement. There appears to be a dearth of qualitative research into parental experiences prior to their child's ASD assessment. Therefore, this research explored the narratives of two parents whose children had been referred for an ASD assessment. Within a social constructivist, relativist paradigm, narratives were collected through in-depth interviews that enabled a detailed inductive analysis of each of the unique stories. Findings are discussed in relation to the analysis and related theory, research and policy. The limitations of this research and implications for future projects and Educational Psychology (EP) practice are also discussed, including how reflection on issues of power, hermeneutics, ontology and epistemology may be pertinent to EP practice.

**Confidentiality clause**

To maintain confidentiality, all sensitive information in this thesis has been anonymised through omission or the use of pseudonyms. Data were anonymised at the point of transcription and were stored and destroyed in line with the Local Authority policy.

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## **1 INTRODUCTION**

### **1.1 Chapter outline**

This chapter begins with personal reflections detailing how I arrived at this research project. Next, there is description of the context in which this research sits in relation to legislation, existing research and my own experience. This description commences with an outline of relevant recent legislation, then moves on to a definition of consultation as this is the context within which Educational Psychologists (EPs) frequently encounter narratives. The term ‘narrative’ is then defined and discussed in relation to pertinent up-to-date research and theory, followed by ‘Autistic Spectrum Disorder’ (ASD), which is defined and discussed with relation to prevalence, theory and research. This leads on to a brief discussion on research into the impact of labels, with the chapter concluding with an outline of research documenting the experiences of parents whose children have been referred for an ASD assessment. In each of these sections, the database ‘psycinfo’ was used to search for research on the topic.

### **1.2 The researcher**

I am a trainee Educational Psychologist (EP) completing this research as part fulfilment of my Professional Doctorate in Child, Community and Educational Psychology. This project is a narrative study of the stories of individuals; and as the researcher, I acknowledge that my own story cannot be objectively separated from the study.

This study is not an analysis of my narrative; yet given the qualitative, relativist, constructivist lens of this project, I feel it is important to outline how my interest in this topic has evolved. Since the final year of my undergraduate psychology degree, I have been interested in psychology related to children and young people. Since graduating, I have worked as a member of support staff in a range of educational

settings. These experiences strengthened my passion for inclusive practice and early intervention, and I decided to qualify as a primary school teacher. In my second year of teaching, I completed my Masters in Education (MEd), which included a taught course on 'perspectives on special and inclusive education' and the completion of a thesis.

For my MEd thesis, I completed an action-research project into the impact of nurture groups. Nurture groups are '*an in-school resource for primary school children whose emotional, social, behavioural and formal learning needs cannot be met in the mainstream classroom*' (Boxall, 2002, p.7). I chose this as the subject of my research because inclusion was a passion of mine and my school had just established a part-time nurture group. After completing my research and some further training into the theory and practice of nurture groups, I began embedding the nurture principles into my own classroom practice and encouraging colleagues to do the same. When reflecting on the success of a nurturing approach and the relevant theory linking attachment and early experiences with children's later school experience (Bennathan & Boxall, 2000), I became increasingly curious about how, as a teacher I could help support parents and wider familial systems. In my school, we struggled to promote engagement with many parents. On one occasion when I had an extended meeting with a parent, she explained that her aversion to meeting with teachers was partly due to her own negative experiences of professionals and educational systems.

This posed a challenge as I recognised from theory (Bowlby, 1969) and research (Rutter, 1998) the importance of early attachments and familial environments for child development and school experience, yet struggled to engage with and access the parental experience. In part, it was this desire to work between, rather than within

systems that led me to pursue the training to become an Educational Psychologist (EP). Furthermore, the wish to elicit and analyse parental narratives, especially of parents whose children are exhibiting difficulties at school, evolved from these experiences.

As a trainee EP, I completed some casework in the Social Communication Assessment Service (SCAS) of my Local Authority (LA). This is a priority area for the Educational Psychology Service (EPS) I am placed with, as there is an increasing number of referrals regarding Autistic Spectrum Disorder (ASD) and the SCAS service have recently purchased additional time from the EPS, recognising the importance of having EPs in the diagnostic team. In this team, diagnosis relies on the presentation of ‘symptoms’ from the age of three years, potentially prior to any professional involvement. Part of the diagnostic process involves listening to the narratives of parents in relation to their child’s early development. The diagnostic criteria are explained in more detail later in this chapter, but the assumed early onset of ASD means that the process of assessment is reliant on the use of parental narratives. There is a dearth of research into parental experiences pre-diagnosis (Connolly & Gersch, 2013), which is a stage at which school and early years setting EPs are often first involved.

### **1.3 The research context**

The Special Educational Needs and Disabilities (SEND) code of practice and s36 Children and Families Act (CFA, 2014) cite a focus on the participation of parents in decision-making at individual and strategic levels. This includes the right to name a preferred educational provision and control a personal budget for support (1.21, 2014). Furthermore, this code of practice states that LAs must harness the views of

their local communities, so that commissioning decisions on services for those with SEND are shaped by user experiences, ambitions and expectations. Therefore, guidance and legislation highlights the importance of parent voice in each stage of educational provision.

In the Local Authority (LA) where this research was completed, there is a further emphasis on promoting parent-voice and parent-led initiatives. An example of this is a recent campaign launched to raise awareness of child sexual exploitation; a parent-led group who involved the NSPCC and Barnardo's and were commended by OFSTED and the mayor. Furthermore, there has been a focus in the EPS on how to reduce the number of statutory requests for Education, Health and Care Plans (EHCPs), as the data shows a recent increase, which is putting pressure on already stretched time and resources. In order for this aim to be realised, the EP team has highlighted the importance of consulting with schools and families in order to unpick the narratives that underpin motivation for seeking an EHCP, using this insight to think creatively about formulation. This is an ethical dilemma for services, as financially they are under pressure from budget holders to limit the number of EHCPs issued, yet basing resource provision on cost is not necessarily indicative of the best fit for a child's needs. Furthermore, the CFA (2014) and its influence on provision could prompt friction between parental voice and LA resource allocation, leading LA professionals (such as EPs) to become caught between the two.

Indeed, whenever there are concerns around a child, it is often the role of the EP to consult with families and schools (Burnham, 2013), whose narratives often differ (Abrams & Goodman, 1998). Unlike some EPSs, the LA this research was completed in does not have a model of consultation that all EPs follow. Therefore,

the model of consultation, and proportion of work completed through consultation varies between individual EPs. It is through consultation that EPs and other professionals commonly encounter parental voice. Due to the importance of this role, and the potential impact of ontological and epistemological beliefs on the collection and analysis of parental narratives, the following section outlines some relevant research in this domain to allow for contextual understanding.

#### 1.4 Consultation

The Health and Care Professionals Council (HCPC) proficiency 3a.1 (2012) states that EPs need to understand the theoretical basis of, and variety of approaches to, consultation. Wagner (2000) defined consultation as a way of working collaboratively through a process, and there are multiple models of consultation for EPs. Specific consultative practice employed by EPs varies between individuals and is inextricably linked to personal epistemologies (Burnham, 2013).

There is a body of research into EP consultation with school staff, but there is less research into the use of consultation with parents. However, Osborne and Alfano (2011) investigated whether consultation sessions provided by EPs offer a useful way of supporting foster and adoptive parents. They collected feedback from 101 EPs and 78 parents through the use of a questionnaire. The open ended responses were analysed through thematic analysis. Results suggested that parental anxieties decreased by the end of the consultations, and that they found the sessions useful, citing the most useful element as being able to discuss current issues or concerns with a professional. A number of parents also stated valuing practical advice offered by the EP. When asked what would improve the sessions, the most common parental response was for more time to discuss concerns with the EP. Although this study

does not document directly the outcomes for children, the parents questioned valued the consultation space with an EP, supporting Partridge's (2012) notion that those around children with additional needs value the containment of a consultative space.

EPs engage in consultation with parents frequently and research suggests that this can be emotionally and practically helpful for parents (Osborne & Alfano, 2011).

However, irrespective of the theoretical model employed, EPs must be mindful of ethical considerations and reflect on their positioning and discourse in sessions.

Furthermore, Rupasinha (2015) cited the importance of EPs reflecting on ethnic minority cultural factors when consulting with parents and the potential implications for power and bias. These factors can all potentially impact ethically on the content and impact of the consultation, affect the parent's space to tell their story, and influence what the EP takes from the consultation.

### 1.5 Definition of 'narrative'

The definition of 'narrative' is constantly in dispute (Andrews, Squire & Tamboukou, 2013), yet many researchers deem 'narrative' as coterminous with 'story' in English language (Crossley, 2000). Crossley stated that many researchers attest that human psychology has an essentially narrative structure. Early experimental research suggested that our drive to offer narratives is so strong that people will offer coherent stories for inanimate objects (Heider & Simmel, 1944). In Heider and Simmel's classic study, participants were shown a motion picture including two triangles, a disk and a rectangle and were asked to describe it. The results demonstrated that most people interpreted the picture in terms of actions and animated beings (mainly people). Detailed stories were elicited, with participants attributing shared actions, motivations and personalities to the objects. This early study also supports Ricoeur's

idea of 'emplotment' (1984), where individuals seek to bring order to a disordered world through the organising of a sequence of events into a plot, leading to a narrative form.

Crossley (2000) stated that narratives are an 'organising principle' for human life, where people make sense of episodes, actions and accounts in daily life. Hiles and Cermak (2008) explained a similar idea, contesting that events do not present themselves as stories, but that it is the experience of an event that becomes a story. This stance also introduces the idea that while many people can experience the same 'event', the narratives or stories they internalise will be unique. In 1986, Sarbin wrote that in narrative, mundane facts, fantastic creations, time and place are all brought together and allow for the individual to include their reasons and causes. Consequently, Sarbin's view suggested that as a narrative principle guides human thought and action, any 'slice of life' can be reflected upon. Clandinin and Connelly (2000) defined narrative in a similar vein, asserting that humans understand the world narratively. They stated that, for them, life – as we come to it and as it comes to others – is filled with narrative fragments, enacted in storied moments of space and time, and reflected on and understood in terms of narrative unities and discontinuities. As well as narratives themselves being unique, Hiles and Cermak (2008) also attested that through the stories that individuals construct, individuals also establish an identity position. To the extreme, this idea suggests that individuals are simply the stories they tell about themselves and the stories that are told about them to others.

Thus far, the definitions of narrative discussed describe how humans organise all their daily experiences narratively, and that therefore narratives include any 'slice of life' and may be ubiquitously linked to identity. While Riessman (1993) explained that

narratives are ubiquitous in everyday life, she offered a slightly different explanation to describe the narratives that people may offer in research, suggesting that the presence of research projects may influence what is shared.

Overall, these voices on narratives suggest that humans organise their experiences and understand the world through a narrative lens. In discussing narratives through the lens of research, Riessman (1993) stated that researchers of narratives must also consider that the narrative offered has been, to an extent, chosen for sharing, and therefore may be different to what would be shared with others or reflected on internally.

One of the few areas of objective commonality between the narratives in the current research is that they have been offered by parents whose children have been referred for an ASD assessment. However, this research does not assume any commonality between the participants' narratives or lived experience, and does not assume that participants would share a narrative in a certain structure or sequence. Therefore, in this study a 'narrative' is considered as the unique 'slice of life' that is shared with the researcher, derived from the belief that human beings organise and interpret their experiences according to narrative plots (de Rivera & Sarbin, 1998). The narratives in this research will therefore be gathered and analysed as openly and inductively as possible, owing to the definition's assumption that narratives are unique to the individual. The related ontological and epistemological discussions pertinent to this research are discussed in the methodology chapter.

## **1.6 Definition of Autistic Spectrum Disorder (ASD)**

ASD is the term that is currently used in the LA of this research and is therefore the chosen term for this thesis. This is a collective term for ASD-related disorders; rarer

diagnostic labels such as Asperger's and Atypical ASD will not be referenced as they are no longer considered by many professionals to be included within the ASD criteria. The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-IV, American Psychiatric Association, 1994) included 'Asperger Syndrome'; however, the DSM-5 (American Psychiatric Association, 2013) has replaced the varying labels with the umbrella term ASD.

Another widely used diagnostic criterion is the International statistical Classification of Diseases and related health problems tenth revision (ICD-10) criteria (World Health Organisation, 1992). This presents a number of possible ASD profiles, and states that impaired development must be evident before the age of 3 years. A total of six symptoms from a list must be present at the time of assessment including symptoms related to social interaction, communication, and restricted, repetitive and stereotyped patterns of behaviour, interests and activities. Owing to the complex and potentially subjective identification of ASD, assessment usually involves input from a number of professionals, leading to a differential diagnosis. In this process, EPs are often called upon to offer insight into linking theoretical knowledge and practical implications (Waite & Woods, 1999). The LA included in this proposed research follows the National Institute for Health and Care Excellence (NICE) guidelines on ASD assessment and diagnosis (NICE, 2011) with a multidisciplinary team that includes psychologists, psychiatrists, psychotherapists, speech and language therapists and occupational therapists.

Referrals to this diagnostic team can come from schools or other professionals. Once a referral has been made, there is a wait for the diagnostic assessment start date (at the time of writing, the waiting list is approximately six months). Diagnostic labelling is

an area of controversy (Abrams & Goodman, 1998), as it can impact on the child's experience in both positive and negative ways. This topic will be discussed later in this chapter.

There is not currently a universally agreed upon psychological theory regarding ASD, although many consider that it is a biologically-based condition that involves complex interactions between multiple genetic and environmental factors (Rogers, Ozonoff & Hansen, 2013). Longitudinal research into siblings indicates that ASD is highly heritable, with a recurrence rate of 18.7% (Rogers et al., 2013).

In 1943, Kanner, an American child psychiatrist set out for the first time a psychiatric description of a syndrome he called 'Early Infantile ASD', derived from the original description of schizophrenia (Simpson, 2008). Kanner (1943) described three characteristic features seen in children with ASD: lack of social engagement, communication and speech difficulties and a desire for sameness. Previous diagnostic criteria include these three clinical features and the fourth category of early onset (Simpson, 2008). In 1988, Wing named the frequently cited triad of impairment, which states that people with ASD have core difficulties with: social interactions and relationships, social communication and social imagination, and flexibility of thought.

There are multiple theories cited in literature around the psychological underpinnings of ASD, although there is no definitive answer that accounts for the condition (Simpson, 2008). The most widespread are cognitive theories citing a deficit in theory of mind (Baron-Cohen, 2008), weak central coherence and executive dysfunction. ASD is also a condition often referred to in the media, including the now discredited links between ASD, mercury and the measles, mumps and rubella

vaccination (Simpson, 2008). There is a wealth of theory and research into ASD, however, due to this research's focus on the pre-assessment stage and parental experience, this thesis does not detail this work comprehensively.

### 1.7 Prevalence of ASD

Prevalence of ASD diagnosis has risen substantially over the past ten years, although research suggests that prevalence of the ASD symptom phenotype (that is, symptoms on which the diagnosis criteria are based) has remained stable during this time (Lundstrom, Reichenberg, Anckarsater, Lichtenstein & Gillberg, 2015). It is therefore not clear what has prompted this increase, although research suggests that some diagnoses are sought as a means of seeking further support and resources (DePape & Lindsay, 2015). Prevalence rates of diagnosis vary, with a British study in 2015 citing an increase in proportion of children aged 7 who had a diagnosis of ASD from 1.09% in 1998/1999 to 1.68% in 2007/2008 (Russell, Collishaw, Golding, Kelly & Ford, 2015). Their statistical analysis of a cross-cohort comparison also demonstrated an increase of children in the population with behavioural traits associated with ASD. They concluded that the increase in diagnosis may partially reflect an increase in rates of behaviour associated with ASD and/or greater parent and professional recognition of the associated behaviours. They added that this increase in awareness may be due to an increase in media and charity coverage of ASD.

The variation in prevalence rates has also been linked with the changes in the diagnostic criteria. If some diagnostic criteria include additional elements, compared to other criteria, it could be that more children are diagnosed using a broader criteria.

In the LA of this research, diagnosis is concluded through assessment and discussion of a multi-professional team. Such an approach includes discussion around the implications of diagnosis for individual children, families and schools.

### **1.8 Research into the impact of labels**

Waite and Woods (1999) researched EP views on the topic of ASD assessment and diagnosis. They completed questionnaires with 21 Principal EPs (PEPs) and follow-up semi-structured interviews with 12 EPs from three LAs. They found that PEPs stated that diagnosis was less important than an accurate, formative assessment of need. However, research by Abrams and Goodman (1998) suggested that some parents hold a different view. They completed a sociolinguistic analysis of ten feedback sessions with parents whose children had been diagnosed by a clinical team as developmentally disabled. They found that professionals shied away from the explicit use of labels, whereas parents felt more able to move on when given forthright, unambiguous labels and felt frustrated by delays and evasive answers. Abrams and Goodman (1998) concluded that diagnoses are jointly constructed by parents and professionals, but do not definitively suggest why the use of labels is more helpful to parents, and whether it actually is.

Labelling and categorisation is a contentious issue faced across countries. Research suggests that labelling children may impact on teacher expectations and therefore performance (Rosenthal and Jacobson, 1966). Furthermore, a lack of reflection around notions of ‘difference’ and categorisation might lead to a medical-model approach. This could perpetuate the cause and solution to difficulties being located within child, potentially ignoring pedagogical or school factors (Lawson, Boyask and Waite, 2013 and Paine, 1990). However, the removal of labels is not a decision that

EPs can currently make, as they are often given by other professionals and readily utilised by school staff and families, many of whom find them useful.

### **1.9 Research into the experiences of parents in the assessment process**

Howlin and Moore (1997) surveyed almost 1,300 parents of autistic children, asking about their views of the diagnostic process. The results showed wide regional variations in diagnosis, with parents in some cases experiencing lengthy and frustrating delays. The survey also sought to examine what gave rise to initial concerns, with retrospective parental reports of anxieties in the first years of their child's life. Most often, early concerns centred on their child's delayed language skills, with abnormal social development the second most cited reason. This was also suggested by Coonrod and Stone (2004), who asked parents open-ended questions; finding that most early concerns involved their child's language development. The average age of the child at which parental concerns were felt was 1.69 years. Parents then waited six to seven months on average before actively seeking help or advice.

Howlin and Moore (1997) also examined parental satisfaction around the diagnostic process, collecting 'satisfaction' scores on a scale from 'very satisfied' to 'not satisfied' for 'satisfaction with the diagnostic process' and 'satisfaction with help received'. The study indicated that most satisfaction was felt when the diagnosis was given in the early years, within a year of referral and was a clear one of ASD.

However, statistically, diagnosis did not make a significant difference to satisfaction with help received. However, this study is dated and may not represent current practice. In addition, the data was gathered and analysed through a quantitative lens, offering limited opportunity for parents to expand upon or explain their answers. The

use of a survey method also meant that the authors could neither explore nor define what was meant by 'satisfaction', which may have been interpreted differently.

More recently, DePape and Lindsay (2015) completed a meta-synthesis exploring the experiences of parents who care for a child with ASD, utilising thematic analysis to integrate qualitative research. The analysis revealed the following themes: pre-diagnosis, diagnosis, family life-adjustment, navigating the system, parental empowerment and moving forward. The pre-diagnosis stage was found to have varied greatly between parents, but often involved many attempts at referral. DePape and Lindsay (2015) also found that in this stage, parents often attempted to make sense of atypical behaviours through reference points, such as comparing with siblings and began to seek explanations for what they were experiencing. There was also a theme around misdiagnosis, where many children were initially identified as having hearing difficulties rather than social communication needs. The meta-synthesis also highlighted the impact of the diagnostic process alongside caring for the child on parents' physical, emotional and cognitive health, as well as on their spousal relationship.

Similarly, Marshall and Long (2010) completed a qualitative Narrative Analysis (NA) examining the coping processes of mothers of children with ASD. The interpretations of Marshall and Long were formulated through a mainly cognitive and behavioural lens. Coping strategies were identified, such as a 'cognitive shift' from viewing the ASD label as a problem to a necessity, or coping by adapting their behaviour, such as learning about ASD or seeking a diagnosis. It may be that this is due to a deductive approach, as the authors sought to investigate coping, and therefore as well as seeking a more inductive narrative (in their first interview), they

also asked participants specifically about events that they had found stressful (in the second interview). In their analysis, they analysed the life story as a whole as well as specific components (in line with Mishler, 1999), and acknowledged that they analysed each interview slightly differently due to the unique content. In their discussion, the authors highlighted the power of a narrative approach in offering fresh insights into how the mothers coped with the adversity of the diagnosis. Furthermore, they added that the open approach suggested a greater capacity for meaning making and positive relationships than previous, more closed, positivist research.

Overall, this research suggested that parents often identify differences, difficulties and delays in their child's development prior to professional involvement (Coonrod & Stone, 2004, Howlin & Moore, 1997). The research also concluded that having a child in the family who demonstrates traits associated with ASD may lead to the family experiencing stress, with themes of relief, devastation and blame arising at the point of identification (DePape & Lindsay, 2015). Similarly, the meta-synthesis by DePape and Lindsay (2015) described links between having a child with a diagnosis of ASD with risk of financial strain, poor health and divorce. Furthermore, although professionals may wish to avoid the use of labels (Waite & Woods, 1999, Abrams & Goodman, 1998), parents often seek them and cite finding them helpful (Ho, 2004, Abrams & Goodman, 1998, DePape & Lindsay, 2015).

It is in this complex context that EPs operate, often consulting with professionals, schools and parents who may have differing narratives. However, what appears evident from the research is that parents of children who have been referred for an ASD assessment have lived through a range of emotions and experiences before they

meet professionals, and that there is value in offering a space for them to share their story (Osborne & Alfano, 2011).

As a trainee EP, I have consulted with parents on a number of occasions, but do not have a fixed view on the exact position or content such consultations should take. However, regarding ASD assessment, parental narratives are particularly pertinent as the ASD Diagnostic Interview (ADI) is frequently used with parents as part of the diagnostic assessment. This interview is formed of structured questions that relate to the aforementioned triad of impairment in the context of the child's developmental history. Therefore, it may be that given the recognised importance of parental accounts of their child's early experiences, it is important for EPs and other professionals to gain insight from parental narratives in an open and inductive manner.

#### **1.10 Chapter summary**

Current SEN legislation puts emphasis on parental voice (CFA, 2014), although research suggests that there is often a disconnect between the perceptions of education professionals and the family reality (McKenna & Millen, 2013). Within this legislative context, EPs are commonly tasked with gathering and listening to parental narratives regarding their children, yet the models of consultation varies between EP services and individuals (Burnham, 2013).

Diagnosis of ASD has increased significantly in recent years, and the aforementioned research indicates that parents often identify concerns in their child's early years, prior to professional involvement. Debate around the impact of diagnostic labels varies, with research suggesting that EPs favour accurate, formative assessment over diagnostic process (Waite & Woods, 1999); whereas parents may find labels useful

(Abrams & Goodman, 1998). The research documented in this chapter also highlights a range of parental experiences of the diagnostic process, including feelings of frustration and stress on the family (DePape & Lindsay, 2015).

The next chapter forms a systematic literature review into existing narrative research with parents whose children have been identified as potentially having ASD.

## 2 LITERATURE REVIEW

### 2.1 Chapter outline

The following literature review seeks to systematically establish what insights the current literature can provide regarding the analysis of narratives from parents whose children have been, are, or will be involved in the ASD assessment process.

This chapter starts with discussion of the definition of parent voice. This is followed by an outline of the database search terms, inclusion and exclusion criteria, and results at each stage of the search. A copy of the exclusions table can be found in appendix 1. The selected research is then reviewed against a framework for critiquing qualitative research, a summary of which can be found in appendix 2. The selected research is organised into ‘inductive focus and themes’ and ‘deductive focus and themes’ and the definitions of these terms of and rationale for this approach is set out in this chapter. The chapter concludes with a description of the rationale for the current research project.

### 2.2 Parent voice

McKenna and Millen (2013) define ‘parent voice’ as

*‘the right and opportunity for parents and caregivers to express their thinking and understandings about their children’s and families’ everyday lives and educational experiences in and out of school’’ (p12).*

They completed a grounded theory project into parental voice and participation.

Their model of parental voice, presence and engagement cited the importance of understanding parental participation in children’s lives that is fluid, robust, and specific to time and culture. McKenna and Millen explained that individuals rely on pre-existing assumptions and predictions to glean meaning from their experience, but add that educators can hold misconstrued perceptions that are disconnected from the

reality of students' home lives. Through work with parents, their data suggested that parents did not always see appropriate and constant entry points for their involvement, and that the points offered, such as parent evenings, did not always allow educators to see the parenting practices and circumstances that parents might wish. Furthermore, through focus groups the parents voiced that they wanted educators to know the specific ways that they love and care for their children. The authors stated that this desire had little to do with ego, but emanated from a wish to be respected as capable, loving and supportive parents. Participants also stated that they did not feel educators understood their families at a cultural level.

This research highlighted a parental desire to be more understood by educators, and a frustration at a lack of opportunity for understanding. It is beyond the scope of this research to complete a full literature review into parental views on parental voice.

However, this study followed a qualitative methodology and explored parental views on their voice and participation in their child's educational system. This is pertinent to the current study, which aimed to explore parental narratives within a legislative framework that highlights the importance of parental voice. However, this study is framed within an American educational context, and psychological theory is not referenced. The authors acknowledge that they bring a specific pedagogical perspective, and therefore set of assumptions to the research, but do not go beyond this to define their ontological or epistemological stance.

The UK educational system is based on a similar model to that in America, in that many school staff do not have the opportunity to build relationships and shared understanding with parents. Here, a key role for the EP is not only to elicit the narratives of parents, but also to support schools in hearing them. Indeed, McKenna

and Millen (2013) concluded that the conditions for meaningful parent engagement are found in four elements: being active and deliberate, developed over time, culturally sensitive, and involving both communally- and personally-orientated actions. These conditions are more conducive to positive teacher-parent relationships rather than parent-EP relationships, which tend to be more time limited. It is therefore hoped that this research will encourage reflection by professionals on the role of parental narratives in their practice.

The aforementioned definition of parental voice by McKenna and Millen (2013) is specific and related to the aims of their research. This current research seeks to be more inductive, with the aim of exploring the unique stories of individual parents. A systematic literature review sought to identify existing research into the analysis of narratives shared by parents whose children have been, are, or will be involved in an ASD assessment.

### **2.3 Literature review**

To identify relevant studies for this review, the database PsycINFO was searched on 29<sup>th</sup> December 2016. The term 'parents' was included to identify studies that explore the views and experiences of parents due to the importance of parental voice in current legislation. The term 'ASD' was also included in the search. The final term included was 'narrative'; this term was included to ensure that studies employing a narrative methodology and those that sought narratives were included. A PsycINFO search of these terms produced 145 results. To ensure the inclusion of primary sources, a limiter was set to include journal articles only; resulting in 92 results.

For this review, it was important that the literature had a qualitative methodology. In the introduction, research was outlined in accordance with the themes of the current

research. These studies were therefore not limited by methodology, and included quantitative, positivist research. The purpose of this literature review is to investigate the existing research into the analysis of parental narratives. In accordance with the definition of a narrative used in this research, it is assumed that each narrative is unique to the individual, and does not contain realist 'truths'.

The current research therefore falls within a relativist ontology and social constructivist epistemology, where the experiences of the individual are recognised as unique and context-specific. It was therefore not deemed relevant to include quantitative, positivist research that sought to establish universal 'truths' or 'test' hypotheses. Therefore, the database search included the following methodologies: qualitative, empirical studies, interviews and non-clinical case studies. The following methodologies were excluded: quantitative, literature reviews, systematic reviews, clinical case-studies, clinical trials, treatment outcomes, retrospective studies and twin studies. The resulting return was 55 results.

The abstracts of these 55 results were then read to check that they were relevant to the literature review question. This led to the exclusion of 45 studies. The reasons for these exclusions are detailed in appendix 1.

This resulted in ten articles remaining. The full versions of these articles were read and each was then critiqued using Holland and Rees' (2010) framework for critiquing qualitative research articles. The validity of critiquing qualitative research within a relativist, constructivist paradigm is much debated, as it can be argued that attempting to compare and seek commonality within such a frame is irrelevant. However, this critiquing framework endeavours to establish the robustness of the research and its relevance to the current research. It also contains specific reference to methodology,

which is an important consideration in this literature review, which aimed to explore existing narrative research- a methodology inextricably linked to discussion of research paradigm. A summary critique of each of the ten articles against the aspects suggested by Holland and Rees (2010) can be found in appendix 2.

The critique of the ten articles revealed that they differed with regards to focus and methodology, which in turn affected how the results were reported and discussed. Due to the close relationship between topic and methodology in this research, elements of a meta-study approach (Paterson, Thorne, Canam, & Jillings, 2001) have been used to bring together an analysis of the ten studies. Paterson et al. (2001) devised a meta-study approach to allow a combination of studies that involved close examination of data collected, method, underlying theoretical framework and societal context. Although all the studies in this analysis were found through a search using the term 'narrative', the studies vary in how open the focus of the study is, which in turn affects the method (such as the interview) and how the results are presented and discussed. Furthermore, differences in how inductive or deductive research is offers insight into the ontological and epistemological stance of the researchers.

A meta-study approach is also relevant to the current study as Paterson et al. (2001) framed the approach within the realm of qualitative health research, specifically 'insider research', which shares a history with narrative analysis (Mishler, 1999). Paterson et al. (2001) also highlighted that attempting to generalise from, or compare results between studies is problematic, as their unique, constructivist stances' invalidate such attempts. To explain this, Paterson et al. (2001) used the metaphor of a jigsaw, where each example of 'insider research' is a jigsaw piece- unique but part of a more holistic, larger picture. They cited that a constructivist perspective on

meta-study involves making judgements about the conclusions of studies and extrapolating relationships among concepts, research decisions and policy implications. This approach also prompts authors of a meta-study to reflect on how their own philosophical lens will in turn affect how they analyse the research of others.

Due to the scope of this project, a full meta-study with the formation of new theory is not included in this review. However, the ten studies outlined in the critique in appendix 2 will be discussed with consideration to findings, method, theoretical frame and societal context. Through these considerations, the articles have been grouped into: (a) deductive focus and themes and (b) inductive focus and themes.

These groupings were considered helpful as the respective approaches are intrinsically linked to methodology, ontology and epistemology. In this research, the term 'deductive' is defined in line with the description of Mill (1879) who highlighted that any deductive approach to social phenomena must necessarily begin after the investigation into such phenomena. Therefore, in this review research that has adopted a deductive approach is considered to have approached the analysis of the narratives having already determined focus or themes. Conversely, research that is considered to have adopted an inductive approach is considered to have approached the narratives without this prior determination, with themes and discussion arising directly from the narrative data.

### 2.3.1 Deductive focus and themes

The studies in this section were deemed to be more deductive in their approach to seeking and interpreting the narratives. In this review, this means that the studies

sought to investigate a specific theme with parents whose children have ASD, rather than adopting a more open, inductive approach.

Hines, Balandin and Togher (2011) used semi-structured interviews with sixteen older parents of adults with ASD and aimed to explore the communication experiences, particularly those related to Augmentative and Alternative Communication (AAC) of older parents. The interviews included questions regarding communication and other areas of interest, including work, finances and concerns about the future. Hines et al. (2011) cite a narrative methodology for this study and the project formed part of a larger study into the lived experience of parents with ASD. This study noted that it followed the recommendations of narrative researcher Riessman (1993), although Riessman recommended that narratives should be 'elicited'. It could be argued that in using specific themes for questions, Hines et al. (2011) were seeking answers, rather than eliciting personal narratives.

The analysis stage of this study followed the strategies of Riessman (1993) and NVivo, including cases deemed 'deviant'. It could be argued that the labelling of some narratives as 'deviant' prohibits the adoption of a constructivist narrative stance as it preferences and compares. Riessman (1993) stated that the process of analysis should 'privilege the teller's experience'; yet, despite claiming to follow Riessman's method, Hines et al. (2011) presented the resultant themes under headings formed through the research aims, rather than themes elicited in the narratives. Although the authors took the initial analysis back to the participants for verification (as per a narrative approach), at the start of the results section the authors explained that *'the topic of AAC and communication services was noticeable for its omission'* (Hines et al., 2011, p. 259), prior to describing their analysis on the themes of communication.

The study concluded that themes of communication breakdown arose, and therefore recommended that policy and professional practice ensure that parents are offered support and advice regarding AAC. Although this recommendation arose through a theme in the narratives, that theme was the focus of the questions, the analysis and even the journal (International Society for AAC), and therefore may not be deemed as inductive.

Hines, Balandin and Togher published another study in 2012 exploring older parents' perceptions of their adult children with ASD in order to gain insights into how parents' beliefs about ASD may influence their coping. As with the first study, this analysis began with a focus for the narratives gathered: that the parents would have developed coping strategies. The paper starts with an outline of Lazarus and Folkman's (1984) model of coping. This assumption was then carried through to the analysis and conclusion. This study's relation to the previous one was not explicitly stated, although it appears that the same transcripts were analysed as part of at least three studies submitted to different journals (the third is described in the next section). The 2012 study was published in the journal 'ASD'. The same narrative methodology led by Riessman's (1993) approach is described, but the identified themes differ. The authors explained that the 2012 study followed the previous one, describing how the initial study highlighted that having a child with autism had an *'enduring influence on the lives on the lives of the participating older parents'* (Hines et al., 2012, p17). This finding prompted a desire to investigate coping strategies, hence the 2012 study. The ethical considerations of potentially re-analysing previously gathered data is not discussed in the article. Although it states that the study was passed by an ethics committee, it does not explain whether the participants were consulted in the re-analysis process. This issue also has pertinence as the

narrative method included a second interview where participants could review the transcript and initial analysis. This study noted that most participants completed the second interview, possibly suggesting that they valued the opportunity to review the analysis. If the researchers completed a second analysis with a focus on coping strategies, the absence of a second follow-up interview may have ethical implications. This study concluded that the participants perceived their child as being buried by ASD, with their true nature trapped by the disorder. The authors proposed that focussing on the true person under the ASD and the sort of person they would be if they did not have the condition may constitute a coping strategy that supports parents in maintaining positive perceptions of their offspring.

Ho, Yi, Griffiths, Chan and Murray's 2014 study also started from a premise that then formed a theme of the overall research. Ho et al. (2014) utilised an Interpretive Phenomenological Analytic (IPA) methodology and Narrative Analysis (NA) to investigate the context of professional-parent partnerships along the pathway of diagnosis. As with Hines et al. (2011), Ho et al. (2014) utilised semi-structured interviews to explore pre-determined themes; however, the interview schedule consisted of 36 questions, which may not have offered participants an opportunity to offer an extensive narrative. Use of such a rigorous schedule may imply that the narrative was more of a co-construction between interviewer and interviewee. Also, as with the research of Hines et al., this study formed part of a larger study, potentially impacting on the clarity of purpose and researcher stance.

The interview data of Ho et al. (2014) was analysed through NVivo (computer software used to organise and analyse qualitative data) and NA. The analysis was based on the temporal order of the diagnostic pathway, although whether this

occurred inductively is unclear. Each stage of the pathway was discussed with reference to Parent-Professional Partnerships (PPP) and concluded that the obstacles faced by parents throughout the diagnostic process were exacerbated by poorly developed PPP. The authors also recognised the variation in narratives, concluding that the pathways for each individual varied widely, but that overall, parents felt lost and frustrated during the journey. They therefore recommended the development of evidence-based guidelines for parents and professionals to help with navigation of the assessment process. This study adopted NA and followed the temporal sequence associated with this method; however, as with the study of Hines et al. (2011), the focus appeared to lead the method, results and recommendations.

Desai, Divan, Wertz and Patel (2012) sought to explore Indian parents' experiences of caring for their child with ASD through an IPA methodology. The study sought narratives from twelve parents, from which themes were analysed to document their experience. Participants were specifically selected to reflect key differences in the local population such as religious and geographic background. It could be argued that this selection indicates that the epistemological stance of the research is not constructivist, but rather assumes some commonality among experience, possibly through a more social constructionist lens. Furthermore, the method consisted of in-depth interviews that were closely scheduled; including questions that assume commonality of experience, such as '*what do you think was the cause of xxx differences?*' (Desai et al., 2012, p636), which may have assumed that the narratives would include the notion of their child being 'different'. The questions contained a temporal sequence that was mirrored in the presentation of results, which identified four temporal phases: celebration and social cohesion, behaviours incongruent with expectation, parental and professional observations, and finally the impact of this

behaviour on children's uncertain futures. The thematic results also indicated three main constituents of the parental experiences, which arose more inductively through thematic analysis: learning to meet new and unfamiliar challenges as parents, caring for their child's needs, and finding an engaging niche with a sense of belonging for their child in everyday life.

### 2.3.2 Inductive focus and themes

This section reviews studies that approached the narrative data in an open manner, with themes and discussion having arisen from the narratives detailed, rather than prior to analysis.

The aforementioned authors Hines, Balandin and Togher published another study in 2014. The relation to the previous study is not explained in detail but analysis suggests that the same narrative data was analysed but in a more inductive way and without the deductive focus on communication or coping. However, it is not clear whether the interview answers around communication were included in the analysis and if the interview transcripts were the same; multiple interpretations of the same data may invalidate conclusions. This study was the last of the three and, given the more deductive nature of the previous two studies, the fact that more deductive questioning might have been used prompts questions around methodology that is associated with an inductive approach. It may be that a more deductive method was utilised to gather the data, which was then analysed more inductively. Such an approach questions the coherence of the methodology, transparency and trustworthiness of the research.

The study stated that it followed the stages suggested by Riessman (1993) but, unlike the previously described studies, results are presented as themes that arose through

the analysis, rather than being linked to research aims and questions. The study concluded that the lived experience of parents with an adult child with ASD forms a balancing act between promoting the wellbeing of their child, spouse, other offspring and themselves. However, like the previously described studies, the recommendations by Hines et al. (2014) assumed a level of generalisability that opposes a relativist, constructivist stance; arguing that policy should ensure an ongoing quality of life for adults with ASD as their parents will not be able to care for them indefinitely, especially given the stress involved in maintaining this role.

Mackay and Parry (2015) adopted an IPA methodology to analyse video and interview narratives of ten young people with ASD and their parents in a UK context. The questions were arranged in a temporal sequence to evoke the narratives, but the analysis was thematic and ethno-methodological (to give scope to disclose the methods and resources used by participants). This study differs to the other nine in this review as it included and compared the narratives of both children and their parents, and does not mention utilising NA or a narrative methodology; however, due to its recent publication and UK context, it was deemed of value for inclusion. The findings are presented thematically and compare the themes between the parental and child accounts. The authors concluded that both the parental and child narratives appeared influenced by medicalised versions of ASD, evidenced through use of professional language.

The study also highlighted differences in the narratives, such as how parents characterised obsessions and rituals as restrictive, whereas the children did not refer to rituals and spoke positively about obsessions and interests. Although comparisons move this research away from a strictly relativist and constructivist frame, the authors

noted a desire to contrast their qualitative research with the majority of empirical research into ASD that adopts a medical, realist, positivist approach. In addition, rather than offering global recommendations for policy and practice, the authors stated how the research would affect their personal practice, with more client-focussed intervention based upon shared interpretation of perspectives. This hints at a reflective and social constructionist stance that fits with the method and analysis, where space is given to consider social and cultural influences on the narratives studied.

Another study included in this review that suggested a mirroring between medical models of ASD and the narratives shared by parents is that of Loukisas (2016). This study examined online blogs written by mothers documenting their experiences of having children with ASD. Loukisas used content analysis to establish themes from the blogs (deemed narratives). This method is inherently more inductive as there is no researcher with pre-formed ideas entering an interview; just a blog offered as a personal narrative. Although more inductive, this method has limitations as the authenticity could not be established and there are ethical issues relating to informed consent and the participants' knowledge of the research.

Loukisas' analysis demonstrated that the mothers viewed ASD through a developmental perspective, speaking temporally and with concern about their child's lack of progress along an 'expected' developmental timeline. Unlike the previously reviewed studies, the theme of time and sequence can be more easily accepted as an organic theme, as there was no interview prompting the narrative with temporally organised questions. As with the study of Mackay and Parry (2015), this research considered medical and sociological influences, and concluded that while most

mothers tended towards a medical model of disability, some erred towards a social or hybrid model. Such analysis again suggests a social constructivist paradigm to the research, though not explicitly stated.

The method of analysing narratives posted on the internet was also utilised in two further studies by Fleischmann, both included in this review. Fleischmann (2004) qualitatively analysed twenty personal stories posted on websites by parents whose children had a diagnosis of a pervasive developmental disorder. The narratives were analysed following Labov's (1972) textual analysis method. In this study, Fleischmann acknowledged a further study (2005) that utilised the same data but using grounded theory. She explained that the grounded theory results were used in the 2004 study only as a vehicle to validate the findings from the Labov method (1972). In the 2004 study, Fleischmann presented the analysis under Labov's headings (such as 'abstract', 'orientation', 'complicating action' and 'evaluation'). While it could be argued that such a formal approach to analysis is deductive, the themes that arose through these categories may be viewed as inductive, and Fleischmann states that the method was utilised flexibly in accordance with the individual elements of the narratives. The 2004 study concluded that *'parents perceive themselves not as victims but, rather, as 'daring mountain climbers.'*' (p41). The findings suggest that the participants construct stories in which they have undergone a 'metamorphosis' that allows for positivity and coping. In addition to the specific content of the narratives, this method prompted additional themes that were linked to the fact that the parents had decided to post their stories online; Fleischmann suggested that a primary force behind the posting of their stories online was a desire to help others, evident as a theme derived from the individual NA. Furthermore,

Fleischmann (2004) suggested that the internet allowed parents to create an online network and support system.

Fleischmann's 2005 study analysed the same self-published website narratives using a grounded theory methodology where themes were identified, distilled and then a main category highlighted from which the grounded theory evolved. The core category was identified as '*the coping process and growth experienced by parents*' (p302). This study also acknowledged the 2004 study reviewed above, stating that the two analyses had different findings but that they were 'in keeping with' each other. This transparency is helpful in reviewing the study as it offers insight into the theoretical and philosophical lens of the research, possibly suggesting a more critical realist stance. A grounded theory methodology also highlights the inductive nature of the research, especially if the grounded theory approach was prompted by the NA. As indicated by the core category of the 2005 study, coping was a major theme of this research, with Fleischmann adding that it mirrored 'the hero's story' with a path towards empowerment to cope with adversity. 'Coping' was also highlighted as a theme by Hines et al. (2012 & 2014), although it is unclear whether this construct has a shared meaning across studies and narratives.

Fleischmann suggested that the findings indicated that information passed on to parents (through professionals, educators and the media) can help change parents' self-perceptions. While assuming a level of commonality, this tentative recommendation appears to acknowledge the individual nature of experience, in contrast to the studies by Desai et al. (2012) and Hines et al. (2011, 2012 & 2014), which offer more concrete recommendations for policy and practice.

The final study in this review is by Benderix, Nordstrom and Sivberg (2007). Their case study was commissioned by a government department in Sweden, with the aim of evaluating a residential group-home for children with ASD that was set up by the parents of the five children who were to attend. Hermeneutic phenomenological interviewing was used to elicit narratives from the parents as their children entered the home, then again two years later. The authors analysed the narratives thematically then collaboratively arrived at a 'common assessment'. As with all the previously reviewed studies, the themes reported in the study represented the findings of all the narratives analysed, although, exceptions were noted within the thematic discussion. The study concluded that before their children were in the group home, parents struggled, feeling exhausted and isolated. Analysis of the narratives two years later suggested that parents questioned the ethics of their decision and experienced guilt and relief. Although the authors caution that the results should be considered tentatively (especially given the case-study frame), they suggest that:

*'The current view that children with disabilities should not be separated from their parents should perhaps be questioned in the case of children with ASD and learning disabilities' (p640)*

This statement may move this study away from a narrative or constructivist approach as it may generalise the results of individual narratives in a case study to a population.

Although none of the studies included in this review explicitly state their ontological or epistemological stance, elements of their methodology, findings and recommendations make their theoretical lens more apparent. As stated by Paterson et al. (2001), researchers need to reflect on their own positions when reviewing research. The ontological and epistemological position of the current research will be explored in detail in the next chapter; however, the definition of a 'narrative'

described in the introduction suggests that they are unique to individuals. In this research project, this is considered indicative of a stance towards the relativist, constructivist end of their respective philosophical spectrums. Claiming common conclusions across cases and universal recommendations for policy and practice suggest the existence of a universal 'truth' or 'reality', possibly indicating a realist ontology. This review appears to indicate a gap in the area of research into narratives that sit within a narrative methodology and utilise NA. The definitions of narratives discussed in the previous chapter suggest that they are unique to individuals and, as such, a more openly relativist, constructivist stance might be helpful in seeking to explore individual narratives, rather than potentially straying from the ontological and epistemological paradigms of a narrative methodology by generalising results or identifying common themes.

Another aspect apparent through this review is the dearth of NA with parents of children with ASD in a UK context, as many of the studies reviewed were within a different cultural context such as Sweden (Benderix et al., 2007), Goa (Desai et al., 2012) and Hong Kong (Ho et al., 2014). This is an important consideration, as many of the studies suggest that culturally specific constructions of ASD may impact on parental constructions and narratives (Mackay & Parry, 2013 & Loukisas, 2016). Furthermore, a constructivist stance on narratives might suggest that narratives are unique, individual constructions that exist within unique social, cultural and geographic contexts.

Finally, the reviewed studies include parents whose children have been diagnosed as having ASD, and all refer to a process or temporal journey in their narratives. The studies of Fleischmann (2004 and 2005), Loukisas (2016), Desai et al. (2012) and

Benderix et al. (2007) all indicate that narratives ended more positively than at the pre-diagnosis stage. The current research aims to aid the work of professionals (including EPs) working with parents. Such work tends to occur at the beginning of the diagnostic process, yet there appears to be a dearth of research into parental narratives at that stage.

It is therefore suggested that overall, despite increasing power and resources being assigned to the parental voice, there remains a dearth of research exploring the narratives held by parents whose children have been referred for a diagnostic assessment. Consequently, the primary aim of this research is to explore the narratives of parents whose children are at the start of the ASD assessment process. The anonymised research will be shared with the SCAS and EPS. Owing to the constructivist, relativist paradigm this research sits within, it is not assumed to impact on service delivery, but it is hoped that the professionals that read it might use it as a prompt for reflection on their own experience in practice. It might also be of specific use to EPs who frequently consult with parents prior to diagnosis and have to determine what questions to ask and establish how to link parental narratives with their ongoing assessment and formulation.

From this introduction and literature review, the following **research question** was posed:

**What is the experience of parents whose children have been referred for an ASD assessment?**

#### 2.4 Chapter summary

The start of this chapter defined and discussed ‘parent voice’ due to the pertinence of this concept to legislation (CFA, 2014) and the current research. The literature

review sought to systematically review existing narrative research into the experience of parents whose children have been assessed for ASD. Aspects of a meta-study approach (Paterson et al., 2001) were drawn upon to promote a focus not only on the data collected, but also the qualitative method by which the research was undertaken and the underlying theoretical framework on which the study was based. This is relevant to the current study as ontology, epistemology and methodology underpin an aim for inductive focus, rather than a focus on positivist data and conclusions.

This literature review detailed ten studies; four of which were felt to have adopted a more deductive approach, and six of which were considered to be more inductive. Three of the deductive studies detailed aims and focus based on existing research that informed the narrative elicitation and analysis, including themes such as communication (Hines, Balandin & Togher, 2011), coping (Hines, Balandin & Togher, 2012) and parent-professional partnerships (Ho et al., 2014). The final study considered deductive approached their analysis inductively, yet their participant selection and data collection was targeted and specific, leading to a more deductive design. The six studies that were considered to be more inductive utilised more open designs and approached the data in an inductive way, with themes and discussion arising from the narratives.

This chapter concluded with a discussion of how the findings of the literature review highlights a gap in existing research, and how consideration of this alongside the aforementioned discussion and definition of terms has led to the current research question.

### **3 METHODOLOGY**

#### **3.1 Chapter outline**

The literature review chapter highlighted the necessity of close links between ontology, epistemology, methodology and analysis in inductive narrative research. Therefore, this chapter begins with an outline of the potential theoretical considerations of research both more generally, then with specific reference to this research project. Following an outline of the theoretical orientation and rationale for this research, this chapter moves on to a methodological discussion. The methodology selection process and rationale is detailed, followed by a description of the participant recruitment. The method of data collection is then explained, followed by discussion of a variety of narrative analytic methods. Validity and reliability is discussed within the context of this qualitative research, followed by a consideration of relevant ethical issues. This chapter concludes with some thoughts as to how this research methodology may be specifically relevant within the current legislative context and a professional setting.

#### **3.2 Theoretical considerations**

There are differences of opinion on the epistemological, ideological and ontological commitments of narrative enquirers. The poles of opposing paradigms are outlined below. The stance of the proposed research is then formulated through consideration of the research question and relevant theoretical considerations.

##### **3.2.1 Ontology**

Ontology in research realms refers to the nature of reality adopted by the researcher (Fox, Martin and Green, 2007). A realist paradigm posits that there is a real, objective world that is independent of belief, perception, culture and language. This position poses questions regarding what the form and nature of reality is, and

therefore what there is that can be known about it. If a real world is assumed, questions of causality and how things occur can be objectively examined (McLeod, 2001). In this paradigm, only questions that relate to matters of 'real' existence and 'real' action are admissible, with questions concerning subjective matters falling out of the realm of scientific enquiry.

A contrasting ontological position is relativism. This paradigm moves away from 'true' and 'false' and acknowledges that there are multiple realities. Within postmodernism there are varying positions, some denying that reality exists (a staunchly relativist position), and some simply wanting to emphasise the complexity of our process of understanding it. Robson (2011) stated that qualitative social science research rejects the view that 'truths' about the social world can be established, and that this is inevitable given the nature of the subject matter (people). This belief assumes that unlike objects, people are conscious, purposive actors who have ideas about the world and attach meaning to their surroundings and experiences.

Within the relativist ontology, there exists a spectrum of belief, ranging from the 'extreme' relativists who consider that there is no defensible basis for choosing one account over another; to the more critical, moderate end who attest that there are reasonable grounds for making such a choice, which is supported through a scientific attitude of working systematically, sceptically and ethically. Robson stated that extreme relativists are "avowedly non-scientific", adding that, "moderate relativists have made a central contribution to qualitative social research" (p.17, 2011).

### 3.2.2 Epistemology

The epistemological problem of how we acquire knowledge of reality, and how reliable and 'true' that knowledge might be, occupies the discourse of contemporary

philosophers as much as it did Plato (Von Glaserfeld, 1984). Regarding research, epistemology refers to the philosophical views held by the researcher into how knowledge is known (Creswell, 2009).

A researcher's ontological viewpoint will inform their epistemological philosophy. If a realist ontology is held, then the posture of the knower must be one of objective detachment; a positivist epistemology within a quantitative paradigm. A traditional positivist approach to research is based upon the premise that there are absolute 'truths' or 'realities' that can be independently found and measured. Within the research domain, a positivist stance demands that that researcher take an observer role, and that other researchers analysing similar data arrive at similar conclusions. Positivist research usually involves hypotheses being empirically devised and tested in a controlled research setting. This paradigm is often regarded as beginning with theory and following a clearly defined linear sequence of data collection and analysis; with concepts measured (quantitatively) and patterns identified. Advantages to this stance include a capacity for generalisation of results, elimination of extraneous variables and potential use for prediction (Cohen & Manion, 1994). However, limitations of a positivist epistemology include a lack of ecological validity due to the artificially controlled setting, the lack of appreciation of culture and other ethical considerations (Cohen & Manion). As aforementioned, this poses a problem for the positivist study of people, as Robson (2011) described, because people are subjective and conscious, and therefore potentially unpredictable.

A contrasting epistemological stance is that of constructionism and constructivism, which align with a more relativist ontological position within a qualitative paradigm. Social constructionism attests that social properties are constructed through

interactions between people, not as having a separate existence (Robson, 2011). This leads to the notion that meaning does not exist independently, but is constructed between people and interpreted; leading to as many realities as there are people.

Berger and Luckmann (1966) suggest that the construction of reality can be described by three processes; externalisation (the telling of an idea), the sharing and discussion of it (causing it to appear factual) and internalisation (into societal conscious) that allows it to be passed on through generations. This emphasis on context prompts a move away from the study of individual behaviour and behavioural absolutes to an appreciation of behaviour as rooted in historical and socioeconomic contexts (Gergen, 2009). This postmodernist stance takes a pluralistic view of behaviour which encourages a shift in methodologies away from the discovery of universal truths to an increased focus on individual accounts for behaviour. However, Raskin (2002) noted that social constructionists prefer this term to constructivism as they reject individualistic and rationalist accounts, which they see as isolating and solipsistic. Social constructionism is more reluctant to privilege knowledge developed in one context over another, making it more relativistic than constructivism, and might suggest that some constructions are better than others (Raskin, 2002).

Gergen (1999) stated that constructivism is a strong intellectual and therapeutic tradition that has deep roots in rationalist philosophy. Gergen explained that constructivism proposes that each individual mentally constructs the world of experience; where the mind is not a mirror of an external world, but instead creates the world as we know it. Gergen compared this to constructionism and explains that while they both emphasise the human role in constructing reality, the fundamental difference is that for constructivists the process of world construction is psychological

and internally constructed, whereas for constructionists there is an emphasis on the social construction that arises through social relationships.

Gergen (1999) cited Piaget, Kelly and Von Glaserfeld as constructivist psychologists. Von Glaserfeld (1984) stated that in radical constructivism, individuals seek a 'fit' between their personal constructs and the experiences they encounter, rather than seeking absolute matches or 'truths'. This train of thought leads to an 'assumption' of constructivism: that all cognitive activity takes place within the experiential world of a goal-directed consciousness (goals based on past individual evaluations). This theory of knowledge is related by Von Glaserfeld (1984) to Darwin's theory of evolution, describing how animals who 'fit' the environment survive, and those that do not, die off. Similarly, radical constructivism argues that individuals hold cognitive constructs based on experience, as these theories meet the environment, they either 'fit' and enable us to make predictions, or they do not fit, become devalued and are discarded.

Gergen (1999) argued that there is no reason to avoid a hybrid of these two approaches, such as the occasionally termed 'social constructivism'. In this case, it is proposed that individuals mentally construct the world, but they do so largely with categories supplied by social relationships. In this vein, a social constructivist therapist may be interested in the narratives an individual brings to therapy, but those narratives would be treated as psychological. Gergen (1999) suggested that in such an approach, the therapist would be interested in exploring what the narratives or constructions mean to a person, and how central they are to the way of thinking. Gergen (1999) concluded that the hybrid term social constructivism borrows from both positions, and opens up a new range of possibilities. This notion of exploring

narratives through the lens of individual and social constructs offers a fit with the aims of this research, the justification for which is discussed in the next section.

### 3.2.3 Orientation and rationale for the philosophical orientation

The principal aim of this research concerns exploration of the experiences of individuals. A constructivist view is typically seen as an approach to qualitative research and assumes that individuals develop subjective meanings of their experiences (Creswell, 2009). The aim of research completed within a constructivist epistemology is to rely as much as possible on participant views (Creswell, 2009), as an individual's experience is unique to them, with no one reality that transcends individuals. Raskin (2002) suggested that constructivism challenges psychologists to refocus their attentions on the critical importance of the human meaning making process, which is a dynamic accumulation that happens over time and adjusts with new experiences. However, even within the realm of a constructivist epistemology, there are a range of voices and definitions.

Radical constructivism is deemed by Von Glaserfeld (1984) as 'radical' because it breaks with convention and proposes that knowledge represents a dynamic organisation of a world constituted by personal experience, rather than an 'objective' ontological reality. Knowledge is therefore accumulated in the attempt to order the flow of experience by establishing repeatable experiences and relatively reliable relations between them. This fits with the current research question, as it acknowledges that an individual's experience of an event is dependent upon an accumulation of constructions of previous events and experiences that have occurred over time. In the aforementioned classic study by Heider and Simmel (1944), participants offered detailed stories; attributing shared actions, motivations and

personalities to objects. A radical constructivist stance might posit that the participants in this study might draw upon their past experiences and constructs, finding a best 'fit' to create a hypothesis in the present moment. However, the fact that many of the stories contained shared themes or constructs may be viewed from a social constructivist stance as supporting the notion that individuals uniquely construct the world using some shared concepts that have been socially constructed. Alternatively, a radical constructionist might argue that the commonalities were perceived through the researcher's unique lens, rather than demonstrating similarity between the perceptions of others.

Von Glaserfeld (1984) warned that it should be clear that an adaptive 'fit' between previous and new constructions of experience should not be interpreted as homomorphism or an absolute reality, which has been a careful consideration in this research project, in which individual's narratives are to be considered carefully separated from the constructions of the researcher and other participants. The approach adopted in this study therefore shares ground with a radical constructivist position as thoughts, actions or words of participants are not considered a truth, and cannot be deemed to 'match' with the spoken experience of another. This posed a question in this research, as a constructivist stance might suggest that the participant and the researcher operate within different spheres of experience that are unique and un-converging.

A radical constructivist stance suggests that how the data is received and analysed is based purely on the researcher's individual experience and perception. For such an analysis to happen an element of interpretation or hermeneutics is inevitable (Willig, 2013). This consideration emphasises the importance of returning the initial analysis

to the participant so that it might be deemed by them to 'fit' their own construction of their experience and narrative. This also seeks to address the issue of power in whose voice is represented in the final product (Riessman, 1993). In this sense, the researcher must be considered a co-producer of the data, as it is impossible to avoid consciously and unconsciously bringing experiences and constructions both into the interview and the analysis (Brinkman and Kvale, 2015).

Riessman (1993) argued that when analysing an individual's experience, the researcher must avoid the tendency to read the interview simply for content or as evidence for a prior theory as this derails the individual experience. However, she added that although a narrative approach must privilege the teller's experience, interpretation cannot be avoided. This idea is inseparable from the epistemology, as a constructivist stance would similarly highlight the importance of acknowledging the existence of different experiences of the data, and an element of double hermeneutics. Riessman (1993) stated that it is therefore essential to open up the hermeneutic issue to the reader, so that there is openness around how the researcher was situated in the personal narratives collected and analysed.

A radical constructivist stance also highlights that an individual's construction is dynamic and the result of an accumulation of experience (Von Glaserfeld, 1984). This means that the narratives given to the researcher were offered as a snapshot at a fixed point in time. Similarly, the researcher holds an individual construction of reality and cannot be completely objective in the process; hence the stories included are more like paintings than photographs, with interpretation a constructive process unique to each participant and reader (Ochberg, 1996). A radically constructivist-

relativist stance may be deemed problematic for the justification and perceived 'usefulness' of the research.

Lieblich, Tuval-Mashiach and Zilber, (1998) do not advocate total relativism that treats all narratives as works of fiction, nor do they view them as works of fact (realism). In this vein, the present research should not be considered as wholly at the radical end of the constructivism spectrum. As aforementioned, the hybrid term 'social constructivism' has been suggested to imply that individuals psychologically construct their world, yet do so with some socially constructed concepts. It is felt that this stance offers the researcher and participant the opportunity for personal, unique narratives that include concepts that have an element of shared social construction. This is relevant to the impact aspirations for this research, as although the constructivist bent implies that narratives are individual, EPs and other professionals encounter parental narratives on a daily basis and are tasked with integrating them into their formulation. The method formulated through consideration of the research question and theoretical positioning of the research and researcher is outlined in the next chapter.

### **3.3 Methods**

This research falls within a relativist / social constructivist paradigm, exploring the unique lived experience of parents waiting for an assessment for ASD for their child. The methods and data are qualitative and followed a sequential exploratory design, consisting of a data collection phase then a data analysis phase.

Dewey (cited by Clandinin & Connelly, 2000) stated that one criterion of experience is continuity; that a person's imagined past or imagined future is based on a temporal stream of experience. Meaning making fits with stories of individuals, which have

evolved over time through unique experiences. Furthermore, the social constructivist position of the research asserts that the stories of the experiences that form people's lives are both individually and socially constructed in the past, present and future (Clandinin & Connelly, 2000). Interpretive Phenomenological Analysis, Discourse Analysis and Narrative Analysis are discussed below as they are all used to explore the experience of individuals within a social context. These methodologies are then compared in relation to this research and the chosen method is discussed in greater detail. A discussion of various other potential methodologies is outside the scope of this assignment.

Subsequently; issues of validity, reliability and ethical considerations are also outlined. This chapter concludes with an outline of the relevance and impact of this research; an area that will be revisited in greater detail in the discussion chapter.

### 3.3.1 Research strategy: methodology selection

#### 3.3.1.1 Interpretive Phenomenological Analysis (IPA)

IPA is an approach to qualitative analysis with a psychological interest in how people make sense of their experience (Larkin & Thompson, 2012). IPA requires the collection of detailed, reflective, first person accounts from participants. There is then an established, phenomenologically focussed approach to the interpretation of the transcripts; aiming to extend beyond the concepts that have arisen. Therefore, the outcome of an IPA study requires a balance between 'giving voice' and 'making sense', which can be facilitated through supervision (Larkin & Thompson, 2012). Epistemologically, IPA is interpretive and is therefore interested in a person's relatedness to the world around them. It also recognises that researchers access the accounts through a process of intersubjective meaning making within a social context. IPA includes the thematic organisational coding of transcripts first at an individual

level, then across interviews. This involves an evolution of interpretation, where themes are dynamic and reorganised throughout analysis.

### 3.3.1.2 Discourse Analysis (DA)

DA is a broad and diverse field that includes a variety of approaches to the study of language (Georgaca & Avdi, 2012). Generally in this domain, discourses are defined as 'systems of meaning' (Georgaca & Avdi, 2012) that are situated in and related to the interactional and wider socio-cultural context where language is considered social action. DA therefore examines language construction and formation; analysing themes, variability, rhetoric and context. Epistemologically, DA is linked to the development of social constructionism and therefore holds that reality is constructed and maintained through systems of meaning and social practices. It also operates within a relativist ontology; assuming that there are no objective grounds on which the truth of claims can be proven or disproven. Unlike IPA, discourse data is not reliant on interpersonal interaction between researcher and participant. Instead, DA can be applied to any kind of text (indeed, anything that has meaning). This also means that DA tends to fall short of involving participants in the research process, largely due to its interpretive nature (Georgaca & Avdi, 2012). However, some DA studies are used therapeutically with the participant after analysis to encourage reflection on positioning, prompting a shift in the participant's subjectivities (Willig, 2013).

Both IPA and DA could be used to analyse the experience of parents whose children have been referred for an ASD assessment. IPA in particular would be useful to explore thematically how parents make sense of their experience. DA would allow for detailed analysis of the language used by parents alongside consideration of the

multi-systemic levels of context. However, one of the objectives of this research was to examine the stories of parents, prioritising their voice in accordance with the current legislation that empowers parent-voice in decision making. Therefore, the thematic analysis of IPA, where narratives are coded and re-organised did not seem appropriate as it may preference the researcher's interpretation and risk moving away from the inductive approach sought. Similarly, a DA approach may prompt more deductive interpretation; and the study solely of language is not directly relevant to the research question or aims of the study. It is hoped that this research will provide insight for EPs to reflect upon when consulting with parents; where the aim of the consultation is to listen to the parent's story in order to inform their psychological formulation. Therefore, the fragmentation of transcripts is not a relevant endeavour. Indeed, Riessman (1993) highlights the importance of attention to sequence when analysing people's stories.

#### 3.3.1.3 Narrative Analysis (NA)

The introduction to this research detailed background to the term 'narrative' and offered the definition utilised in this study. As with the breadth of definitions of the term, there are many different approaches to NA. The specific analytic method used in this study is detailed in the next chapter. The history of NA as a methodology, and its comparison to IPA and DA is also discussed.

Unlike IPA, NA examines narratives as independent wholes and does not attempt to draw themes across individuals (Murray & Sargeant, 2012). It also allows participants to offer a narrative with self-selected parameters, rather than the content or structure coming from the researcher through their questions. In NA, the voices of the participants are treated with respect, and the researcher then conveys their

message to the public (Gergen, 2009). NA allows for some aspects of IPA and DA, as examination of the narrative accounts includes interest in the character, language and connections with experience. It also allows examination of the temporal flow, which is important for the chosen research question which aimed to explore the parental story leading up to their child's referral for an ASD assessment.

Interest in the character and role of narrative can be traced back to ancient times, but in the 1980s narrative approaches started attracting the attention of psychologists (Murray & Sargeant, 2012). Mishler (1999) is one author credited with this increase in interest. Mishler's attention was first drawn to narrative approaches and stories in his studies of medical interviews, in which he found that patient's stories of their illness experience were ignored or interrupted by physicians (Mishler, 1999). This origin relates well to this study as one of the aims of this research is to offer professionals who consult with children's parents regarding medical or psychological concerns a chance to reflect on narratives offered. As aforementioned, current legislation promotes the power of parental voice; this requires professionals to appropriately support parents by listening to and hearing their narratives.

Gergen (2009) stated that one of the most active lines of content-oriented enquiry is that which explores the narratives that people use to construct their lives and realities. He added that NA research stands in contrast to traditional scientific research; where researchers test hypotheses about abstract principles, and the researcher's voice dominates with competing voices suppressed or disproved. Similarly, Riessman (1993) stated that NA takes as its object of investigation the participant's first-person story. Unlike more realist research, the current research utilises the term 'narrative' to acknowledge that individual autobiographical stories contain private constructions

that mesh with external experience. Riessman (1993) explained that narratives are ubiquitous in everyday life and this is a belief shared in this research. Many qualitative interviews are based on a question-and-answer format, which is not considered by Riessman to be narrative talk.

Murray and Sargeant (2012) suggested that narrative psychology stems from an assumption that people organise their interpretations of reality in everyday life into the form of narratives. They added that narrative research is interested in the stories people tell themselves and others about their experiences, and that these narratives must be considered a snapshot, told in a specific context at a specific time. The use of narrative methodology results in rich, unique data that cannot be obtained from other methods (Lieblich et al., 1998). It is through narrative that individuals bring a sense of order to the world and define a sense of self (Murray & Sargeant, 2012).

Lieblich et al. (1998) added that a narrative methodology offers a clear route to exploring and understanding the inner world of individuals, at the same time as shaping and constructing the narrator's personality and reality.

Burr (1995) suggested that stories are often complex, and that we do not choose to share all stories with all people. She added that some narratives may even be personally hidden, unconscious stories that we are unable to readily articulate. The purpose of the current study must therefore be considered within this frame, holding the knowledge that the narratives offered to the researcher were influenced not only by the past experiences of the participant, but also by the presence of the research project and the presence and analysis of the researcher; with conscious and unconscious processes potentially at play, influencing the story that has been offered.

### 3.3.2 Research strategy: participants

A purposive sample was sought for this research. In purposive sampling, participants with particular characteristics are selected because some aspect connected with those characteristics is being investigated and is therefore essential to answer the research question (Robson, 2011).

The number of participants included in narrative research varies. Emerson and Frosh (2004) state that NA was founded on the detailed investigation of a very small number of subjects, whose stories are of intrinsic interest rather than a source for generalisation. Bryan and Loewenthal (2007) sought quality over quantity and adopted a case-study approach, ensuring coherence of the narratives and following a gestalt principle. The relativist ontology and social constructivist epistemology followed by this research holds that knowledge is a unique, dynamic organisation of experience that is understood through the lens of unique past and personal constructs. Accordingly, the participants' experiences and narratives are unique constructions and there is no value in comparing or generalising beyond or between participants. This philosophy means that, unlike positivist research, there is not the requirement to recruit a large number of participants, as there is no aim to evidence a 'truth'.

For this research project, the administration assistant who processes referrals at an ASD assessment clinic sent out letters of invitation to the first four preceding referrals the service received. Four letters were sent out as this was deemed to be the maximum that could be analysed in the level of detail required for this research. The letters gave the parents two weeks to opt into the study. As well as ensuring anonymity and promoting freedom of participation, this recruitment technique is true to the inductive nature of this project. After three cycles of letters being distributed,

two parents opted into the study (whose names have been anonymised). The first participant, David, is the father of Jay, a sixteen year old boy who had been referred for an ASD assessment. The second participant, Hannah, is the mother of Lily, a six year old girl who had been referred for an ASD assessment.

In line with the suggestion of Sandelowski (1995), this sample size permits the deep, case-oriented analysis that is a hallmark of qualitative inquiry and results in a new and richly textured understanding of experience. This in-depth analysis of a limited number of narratives offers relevance to the work of EPs, whose focus when in consultations with parents is often with understanding individual or family narratives, rather than seeking to generalise between or beyond them.

### 3.3.3 Method of data collection

The method of data collection was face-to-face narrative interviews, with participants able to choose where the interviews would take place. The first interview was completed in a private room at the clinic where the researcher is based. The participant explained that he would rather meet at the clinic, as it was near to where he lived and because he was living in a hostel where there might not be a private room available. The second participant requested that the researcher come to her home, with the interview completed in her living room. This participant had two young children and a dog, who were also present during the interview. Giving participants the choice of interview location aimed to offer participants practicality and promote a positive environment where they may feel most comfortable with sharing their narrative. Due to the constructivist narrative approach adopted in this study, it was not considered problematic that the interviews were completed in different environments, as comparisons between the narratives were not attempted.

Brinkman and Kvale (2015) described one purpose of narrative interviews as exploring a specific course of action significant to the narrator, leading to a short story. Murray and Sargeant (2012) suggested that while the research may focus on a particular event, a narrative approach offers the opportunity to contextualise this within the narrator's broader life history and social context. Due to the participant-led nature of the narrative approach, prediction was not attempted; indeed Riessman (1993) stated that narratives often emerge when you least expect them and, as long as the researcher can relinquish control, any question can generate a narrative.

Brinkman and Kvale (2015) stated that in a narrative interview the interviewer may start the interview with a question about a specific episode, period or theme or can ask for a life story. The invitation that was used with all participants to prompt the narrative in this research was based on the question:

**“I am interested in the narratives of parents whose children have been referred to SCAS, in your own words, can you tell me the story that has led you to this point?”**

After the initial request for a story, the main role of the interviewer adopting a narrative approach is to remain a listener, abstaining from interruptions. Brinkman and Kvale (2015) stated that even through clarification questions, nods and silences, the interviewer is a co-producer of the narrative. Riessman (1993) described a technique where the interviewer reflects some words of the narrative back to the narrator, prompting them to add further detail. Riessman (1993) also advocated 'probe' questions when participants became 'stuck', such as “can you tell me more about that?... What was that experience like for you?” She asserted that narrative interviews are conversations in which meaning is co-created. As explained by

Riessman, this means that interview practice needs to give considerable freedom to both parties, with each free to clarify uncertainties. In this research, the researcher used their skills as a psychologist to elicit the narrative without leading the narrative, such as the use of active listening and other elicitation techniques advocated through a process consultation approach (Schein, 1999). Transcripts of the interviews including interviewer input are included in appendix 3 and 4. The method of reflecting back the participant's words was used several times throughout the interviews and attempted to maintain the narrative without being deductive and putting the interviewer's ideas or influence unduly into the narrative. The phrasing of interviewer interjection varies throughout the interviews and is reflected on in the analysis. Due to the social constructivist epistemology of this research, variation in interviewer input is not deemed to invalidate results, as the narrative is viewed as a unique co-construction between participant and interviewer.

#### 3.3.4 Method of data analysis

Hiles and Cermak (2008) explained that growing interest in the narrative field led to a wide variety of approaches to the interpretation and examination of narratives.

Similarly, Riessman (1993) stated that unlike some forms of qualitative analysis, there are no sets of procedures for the analysis of narratives, and that analysis cannot be easily distinguished from transcription. This is drawn from the core gestalt premise, where the narrative remains whole, not segmented at the point of analysis.

Similarly, Emerson and Frosh (2004) stated that NA holds a loose formulation, and is almost intuitive in its use of terms defined by the analyst. Indeed, Riessman (1993) discouraged her students from tightly specifying questions as analytic induction, by definition, causes questions to change and new ones to emerge throughout the process.

In the following sections of this chapter, some commonly cited approaches to NA are described, all of which were reflected on in the analysis of this research. Due to the inductive and constructivist stance of this research, a specific method of analysis was not determined prior to the start of the analytic process. Mishler (1999) explained that narrative analysts should explore what can be gleaned from different approaches prior to pursuing a unique, particular one and this approach was adopted for the current research. In the analysis chapter of this thesis, the particular method employed for each narrative will be outlined, alongside discussion of how and why that method was utilised.

#### 3.3.4.1 Linguistic Analysis

Linking to the aforementioned methods of DA, some narrative researchers take a linguistic, discursive approach and structure narratives like poems (Gee, 1991). Gee's model of poetic condensation makes use of accentuation, pauses and rhythm in the participant's speech to transform interview transcripts into poems which then constitute the data to be analysed. Gee argued that interpretation is like visual perception; an amalgam of structural properties and creative inferences drawn on the basis of context and prior experience. Specifically, Gee (1991) printed the working transcript of narrative text in terms of: lines and stanzas, focussed speech and main line plot segments. Gee (1991) based his analysis on linguistic elements, such as the identification of prosodic phrases and speech elements.

This research is concerned with the lived experience of participants, gathered through a narrative methodology. Therefore, reliance solely on linguistic focus for analysis is less appropriate, as DA is not the chosen methodology and a narrative approach often includes analysis of language, structure temporal sequence and content (Riessman,

1993). Murray and Sargeant (2012) stated that characteristics of narratives that researchers must be aware of included: theme, plot, structure, characters, narrator, setting, time and causality. They added that these elements need not all be analysed formally, but must be considered by the researcher and selected elements examined in accordance with the individual narrative. This was the case in the current research.

Emerson and Frosh (2004) explained that a narrative methodology is sensitive to subjective meaning making, social processes and their interpretation in the construction of personal narratives around 'breaches' between individuals and their social contexts. A narrative stance would posit that all individuals, including the researcher, are storied. The landscape on which this research was planned, implemented and written up was influenced by the narratives of the participants, the researcher and all those involved, with each narrative based on past present and imagined future experiences (Clandinin & Connelly, 2000).

#### 3.3.4.2 Life-Story Analysis

Linked to the influence of past, present and future, Riessman (1993) cited Ginsburg's (1989) examination of the difference between the story and the plot, considering the wider political and social context. She explored how participants constructed their positions narratively and how their accounts compared linguistically and substantively. Ginsburg's reporting included quotes and summaries, with her authorial voice and interpretive commentary 'knitting' disparate elements together (Riessman, 1993).

Ginsburg noted the difference in narratives between the story and the plot. The story (fabula) is the raw, temporally sequenced, or causal narrative of a life that includes the expected arrangement of a biography according to western narrative and social

conventions. Ginsburg (1989, cited by Riessman, 1993) distinguished this from the plot (*sjuzet*), which emerges from unexpected twists that draw attention to differences from the conventional story. Comparison of plot lines across a series of first person accounts is highlighted by Riessman (1993) as a way to approach NA. Here, causal sequence is examined to locate the turning points that signal a discrepancy between ideal and real, the cultural script and the counter-narrative. The researcher analyses the discursive strategies (such as employed by Gee, 1991) alongside the story in a broader sense. This approach is linked to a social constructivist epistemology, with an acknowledgement of how the 'stories' and 'plots' of narratives are constructed socially but shared uniquely.

Josselson (1996) explained that participants should be free to read the transcription and initial analysis, react and make use of it for their own purposes. This was the case in this research, where a second meeting occurred between the researcher and each participant. Here, the transcript of the interview and initial analysis was offered to participants, who were then given a chance to respond. In line with the advice of Riessman (1993), although the participant responses were listened to and reflected upon in the analysis, the views of the participants were not taken as authoritative judgment.

#### 3.3.4.3 A Combined Approach

Mishler (1999) attempted to draw together some disparate elements of NA, citing a focus on the representation of the narrative, the linguistic strategies, and the cultural, social and psychological contexts and functions of the stories. As aforementioned, Riessman (1993) cited the importance of an inductive approach, and Mishler (1999) similarly made clear that there is therefore no single or 'best' way to define or analyse

a narrative. Therefore, just as the narratives are considered unique, the method of their analysis should be opened up, allowing exploration of multiple approaches before using a method that is as unique as the narrative studied.

Hiles and Cermak (2008) endeavoured to develop a model of narrative inquiry that is firmly rooted within a psychological perspective. They referred to this approach as 'narrative-oriented inquiry', and argued that narrative is essential to the meaning making process, such that events and actions can be understood, despite the fact that the 'reasons' for them are not fully known. This model draws upon psychologically-focussed approaches to narrative inquiry, and embraces both the data collection process and a range of data analysis approaches. The authors stated that the model was designed to be a '*dynamic model of good practice*' (p.152), inclusive and pluralistic, but not exhaustive and definitive.

The model begins with the research questions, with an assumption that this shapes the narrative interview. From this point, the model moves to include the audio text then the raw transcript. The inclusion of this stage in the model is in line with the comment by Riessman (1993), who stated that transcription is inseparable from analysis. Hiles and Cermak's (2008) model then moves on to a stage at which point persistent and repeated engagement with the transcript and raw data is necessary. After this stage, Hiles and Cermak suggest that the transcript 'segments' or 'discourse units' are numbered. The authors then list six interpretive perspectives, which integrate three key sources: Herman and Vervaeck (2001), Lieblich, Tuval-Mashiach and Zilber (1998) and Emerson and Frosh (2004). The six interpretive perspectives are:

#### 3.3.4.4 Sjuzet – Fabula

As aforementioned in this chapter, this perspective involves dividing the working transcript into sjuzet and fabula. This frame posits that stories are made up of two inter-related and inter-penetrating parts; what is being re-told (fabula) and how it is being re-told (sjuzet). Sjuzets include words or phrases that are concerned with emphasis, reflection, asides, interruptions and remarks, indicating sequence, causality or significance in the story. This also indicates where the participant is positioning themselves in relation to the fabula. Hiles and Cermak (2008) suggested that this should be completed prior to further analysis, shortly after transcription.

#### 3.3.4.5 Holistic – Content

This draws on Lieblich's (1998) ideas and describes that a broad perspective of the general theme of the fabula can be gleaned. It also explores how specific segments of the text can shed light on the story as a whole. This method requires an initial identification of a 'first impression', holistic themes, then themes within the narrative. The aim of this perspective is to identify a 'core narrative' that is vivid, meaningful and permeates the whole text (Hiles & Cermak, 2008).

#### 3.3.4.6 Holistic – Form

The focus of this perspective is on the form rather than the content, with consideration given to the narrative typology, narrative progression and narrative cohesion. This lens focusses on how the story as a whole works to create meaning.

#### 3.3.4.7 Categorical – Content

This approach moves away from holistic interpretation and focusses on breaking down the text into more self-contained areas of content, which are in turn subject to thematic analysis. This method is similar to content analysis or thematic analysis as

found in different methods and methodologies, and therefore it could be argued that it does not form a distinct narrative approach in itself.

#### 3.3.4.8 Categorical – Form

This fourth approach focuses on the formal aspects of the narrative, specifically including the *sjuzet*. Linguistic features and plot devices that offer the story emphasis and style are examined. This level of linguistic analysis shares a level of focus with discourse analysis and the analytic method of Gee (1991).

#### 3.3.4.9 Critical NA

Each of the previous five methods introduce different perspectives to understanding narratives. This final category explores the functionality of the story, and how the narrator is positioned within it. Emerson and Frosh (2004) described this critical analysis as ‘psychosocial’, combining linguistic, discourse analysis with a focus on the active constructing processes through which individuals attempt to account for their lives. This approach involves microanalysis of both the *fabula* and *sjuzet* and therefore Hiles and Cermak (2008) suggest that it is best undertaken after other forms of analysis.

The final element of the model is the concept of transparency. This element requires analysts to be open and explicit about the methods that they have used and the assumptions present. Transparency and other considerations regarding reliability and validity relevant to qualitative research will be explored later on in this chapter.

Models and examples of NA are considered to be dynamic and should evolve in accordance to an inductive response to the narrative data (Hiles & Cermak, 2008).

The aspects of the aforementioned NA techniques utilised in the current study will be detailed in the analysis chapter of this research. While these techniques were drawn

upon, the overall method of analysis was formed inductively, and therefore unique to each narrative, providing epistemological and ontological coherence.

### 3.3.5 Validity and Reliability

Yardley and Marks (2004) stated that the common procedures for establishing the validity of quantitative research are generally more familiar to psychologists than the procedures for qualitative research. The ontological and epistemological position of this research is such that it does not seek an objective truth; therefore, assessing how well this study captures characteristics of an objective reality is not a relevant endeavour. The nature of narrative research typifies the struggle of assessing validity, as such a 'quality control' would imply the use of generic measure or criteria across studies, which does not fit with the unique and individual voice and experience valued in NA. Furthermore, the constructivist nature of NA also precludes the use of assumptions, which many quantitative forms of analysis rely on.

Similarly, assessing reliability in research typically involves assessing the possibility of obtaining the same results at different points in time with different researchers; assuming again an amount of objective reality (McLeod, 2001). A narrative should be considered by the researcher and readers as a context-specific and time-specific snapshot of an individual's interpretation of reality (Murray & Sargeant, 2012). Therefore, as with validity, the concept of reliability as a measurable attribute is not relevant here.

However, judgement on research is necessary, and with this comes a necessity for shared language on which to base this (McLeod, 2001). Howard (1985, cited by McLeod, 2001) listed epistemic values that can be applied to all studies: predictive accuracy, internal coherence, external consistency, unifying power, fertility and

simplicity. However, these pertain to research denoting a ‘theory’, and therefore may be more appropriate for alternative methodologies such as grounded theory.

McLeod cited a second strategy for assessing qualitative research through the use of a distinctive set of criteria for qualitative research: a ‘quality-control’ measure. Mearns and McLeod (1984, cited by McLeod, 2001) suggested that the facilitative therapist factors identified by Karl Rogers (1942)- empathy, congruence and acceptance- have an important role to play in qualitative research. McLeod (2001) has stated that this is possible when the researcher approaches the work with openness and integrity. A social constructivist narrative approach embraces this principle, valuing the individual’s story while acknowledging that it is not devoid of context and researcher interpretation.

In keeping with an ‘ethos’ of qualitative research, Yardley (2000) devised some open-ended, flexible principles to inform the quality of a study. Given the intrinsic flexibility required in an inductive analysis, these principles are relevant to this research, and are discussed below:

#### 3.3.5.1 Sensitivity to context

Yardley (2000) stated that research needs to exhibit sensitivity to the theoretical context and prior findings from similar research. She explained that quantitative methods use standardised measures to ensure ‘horizontal generalisation’ across settings. By contrast, qualitative methods aspire to ‘vertical generalisation’ and are linked to more abstract concepts and previous research.

This research aimed to be inductive in approach, as NA requires that the data (the narratives) hold centre stage. Therefore, an in-depth understanding and sensitivity to the methodology of narrative and its philosophy, ontological and epistemological

standings was necessary. This inductive approach also highlighted a need for this research to be sensitive to the data. In this case, sensitivity was demonstrated through the minimal researcher input during the data collection phase, and then the analysis which kept the narratives intact and endeavoured to avoid over-inference by returning the narrative transcription to the participants.

Yardley (2000) also emphasised the importance of sensitivity to the socio-cultural setting of the study. In this research, the researcher utilised their skills as a psychologist in training to create a containing space in the interviews. Part of the role of the psychologist is to reflect on socio-cultural influences, and this was also the case in this research. Elements as are highlighted by the social graces by Burnham (2012) who uses the acronym GRRRAACCEEESSS to include aspects such as gender, race, religion, culture, age, and class that can impact consciously or unconsciously on the data. In line with the social constructivist stance of this research, such influences do not invalidate the research, and as the narratives offered were a unique snapshot of experience, the role of such influences cannot be definitely identified, but can be reflected upon. In line with the suggestion of Riessman (1993), the interview transcripts were returned to the participants in a second meeting. This further promoted sensitivity, as although (in line with Riessman) the views of the participants were not taken as authoritative judgement; they were listened to and considered.

#### 3.3.5.2 Commitment and rigour

Yardley (2000) explained that commitment refers to prolonged engagement with the topic, the skills used and immersion in data. Regarding this research, the researcher has been engaged in the topic of parents and children with ASD for the past nine years in roles working in schools. The researcher has also been involved as a student

in developing theoretical and research knowledge in this area through training as a teacher, a masters in SEN and engagement in doctoral training. EP training has also immersed the researcher in the practice and theoretical underpinning of working therapeutically in consultation with parents; providing skill development relevant to narrative interview methods. Regarding commitment to the data, in line with a narrative methodology, the researcher transcribed the interviews to prompt inductive immersion in the narratives. Participant numbers were limited to allow for thorough analysis of each individual narrative, which, as cited by Yardley (2000), does not detract from the rigour but promotes it. Rigour also refers to completeness of the interpretation, which in this study was achieved through immersion in the data and in-depth NA, which was also discussed and reflected upon in supervision. Furthermore, within a constructivist, relativist paradigm, the interpretation of the research is not presented as a truth or representation of a population. The aim of this research is in part to allow a point of reflection for professionals reading it and, in line with circular hermeneutics, it is acknowledged that readers will interpret and reflect on the research individually.

#### 3.3.5.3 Transparency and coherence

This refers to the clarity and cogency (Yardley, 2000). The narrative approach in this study sought to offer the narratives of parents, and although the analysis is inductive, the research 'story' was ultimately constructed by the researcher. Coherence here also refers to the fit between the research question and philosophical stance of the research. As detailed previously, the relativist ontology and social constructivist epistemology is suited to the narrative methods and research question. The theme of coherence also feeds into the analysis, which considered the narratives as wholes and recognised the impact and lens of the researcher. The stages of the data collection,

analysis and reflections throughout were recorded chronologically and the process is outlined to ensure transparency for readers. Regarding transparency for participants, all participants were fully informed regarding the nature of the study, the purpose and what being a participant would entail. Parents received a letter outlining this prior to them opting into the study and it was also reiterated to them in person at the first meeting, when signed consent was obtained (see appendices 3 and 4).

#### 3.3.5.4 Impact and importance

Yardley argued that the aspect of a study's utility is a decisive criterion (2000). She added that this can be measured through relation to the research objective. At the start of this chapter, the objective was detailed, citing legislation that has placed an increasing importance on the parental voice in relation to children with SEN. This research aims to illuminate examples of parental narratives in the domain of childhood, as there is a dearth of relevant and current research in this area (especially in the pre-diagnosis stage). It is hoped that the research will prompt reflection among professionals who are working within this legislative framework and regularly consult with parents whose children are going to be assessed for SEN. As commented by Yarley, this impact is also unavoidably political, as it exists in a social context at a specific point in time; it therefore also serves a social purpose and may impact on the social context of those involved and those who read the study. Indeed, as referenced in the critical NA of Hannah's story, social and political factors may also have influenced participant motivation and positioning.

The impact of the study is also emphasised by its close fit between research and practice. The participants were gained through a clinic where professionals consult

with parents on a daily basis, and the study will be offered to staff there to read and reflect on at an individual level.

#### 3.3.5.5 Reflexivity

The orientation of the research and researcher mean that the research is not objective or detached from the content of the interview or the analysis. Past experiences and influential thoughts, feelings and bias were reflected upon throughout the planning, data collection and analysis of the research, both personally and through supervision. This aspect will be detailed further in the discussion chapter.

#### 3.3.5.6 Member checking

As stated by Josselson (1996), it is important for narrative researchers to share the transcribed interviews with the participants, allowing them the opportunity to respond and make amendments. This ensures that the narrator feels that their story has been heard, that it accords with their experience and that they have included all the detail they feel is pertinent. This aspect of the data collection also offered testimonial validity; with participants offered the opportunity to indicate whether the initial analysis of their narrative accurately fitted with their experience. Bloor (1997, cited by McLeod, 2001) warns that in both member checking and triangulation, the validity of new information may be in question when participants assess the accuracy of primary data. As aforementioned, a narrative is taken as a snapshot in time.

Therefore, when the participants were given their narratives back; they were asked whether the transcript was true to their story at that primary point in time, rather than as influenced by subsequent experience. Given the relativist ontology of this research, a multi-voiced text can be acknowledged, with secondary edits by the participant adding to the narrative in a transparent and enriching way. In this research, the participants were given the transcripts of their narratives and offered the

opportunity to discuss the themes that had arisen through the analysis. These meetings are described at the end of the analysis of each narrative, in the next chapter.

### 3.3.5.7 Generalisability

Bryan and Loewenthal (2007) stated that conventional NA follows a gestalt principle for individual narratives, meaning that fragmentation should be avoided. Bryan and Loewenthal (2007) added that, although case studies may be compared to identify recognizable patterns across cases, there is no substitute for looking at cases as separate and unique without an attempt at illuminating commonalities for generalisation. Emerson and Frosh (2004) suggested that making sense of individual experience is of intrinsic interest in narrative research, rather than its use as a source for generalisations. In line with this principle and the constructivist epistemology, this research does not attest that the narratives or analysis can be generalised or compared in any way. The aim was to highlight the importance of listening to and analysing the unique experience of individuals, not to presume shared experience.

Riessman (1993) explained that the ontology of a narrative approach means that the narratives cannot be read as *'a mirror of a world "out there"'* (p.65) and that the readings of narratives are themselves located through the lens of the reader.

Therefore, concepts of generalisability, impact, importance and purpose are difficult to define as they are unique to the reader's experience. If a relativist ontology is realised, and there is no definitive 'truth', comparison, generalisation and assumptions about how others might use or receive the research cannot be proven or even attempted.

### 3.3.6 Ethical issues

A copy of the participant invitation letter and SCAS cover letter (sent out to parents by an administrator at SCAS) is in appendix 5. A copy of the participant information sheet and consent form that the researcher and each participant signed at the interview is in appendix 6.

Mishler (1986) discussed the power differential in interviews, and added that the challenge for the interviewer is to reduce this imbalance and encourage the narrator to expand upon their account. When the researcher takes the time to listen, the narrator will enthusiastically take advantage of the opportunity to tell their story, which can be an empowering experience (Murray & Sargeant, 2012). In this research, participants opted in before meeting the researcher; this attempted to avoid the influence of a power imbalance on the participant's decision to take part. However, the participants were aware of the role and position of the researcher. The potential effect of this on the narratives is discussed in the following chapters.

Josselson (1996) argued that the concept of informed consent is “oxymoronic” (p.xii) in narrative research, given that participants can at the outset only have a vague idea of what they might be consenting to. However, to promote informed consent, ensure confidentiality and data protection, an administrator at SCAS issued all parents of children referred, in a set time frame, a letter inviting them to participate in the research and outlining the process of involvement. Participants were informed that their involvement in the study was unrelated to their involvement in the SCAS assessment process.

Upon meeting for the first time, the right to withdraw (up to the point of data anonymity) was explained and the consent form signed by participants detailed the

requirement and scope of the study. Data collected was stored securely and destroyed in line with the LA policy. Data was anonymised at the point of transcription.

While the sharing of narratives can be empowering for participants, it can include upsetting or challenging themes. Therefore, time was allocated at the end of each interview for debriefing and signposting, although this was not required in either interview. Researcher support was accessed through supervision.

### 3.3.7 Relevance and impact of research

Participating in narrative research is cited as potentially beneficial for those that take part. Murray and Sargeant (2012) stated that providing participants with the opportunity to describe their experiences in detail can be invigorating. Thus, while the narrative interview was not a therapy session, it may have been experienced as therapeutic. Furthermore, Murray and Sargeant (2012) add that through narratives, people may be moved beyond the text to the possibilities of action, emphasised through the participant's opportunity to read and react to the transcripts. Josselson (1996) described how researchers writing about participants' lives may expose them to consequences that were not foreseen, enabling them to make use of the reflection for their own purposes.

As aforementioned, the importance of parental voice is currently intrinsic to government education policy, especially in the field of SEN. It is also an area of importance to the LA of the proposed research, which promotes parent-led initiatives across the borough.

Leading on from the introduction and literature review chapters of this research, this project endeavours to add to the existing literature, and fill a current gap in research around parental narratives pre-diagnosis. It is also hoped that this research will add to

the limited body of narrative research from a relativist, social constructivist stance in the area of child and educational psychology.

Finally, an intrinsic part of the role of EP is consultation with parents. EPs often encounter parents whose children are undergoing SEN assessment, and it is the EP's role to consult with them in an attempt to explore and understand their experience. It is hoped that this research will offer EPs and other professionals the opportunity to reflect on the narratives analysed and any resonance this might have with their own experience. It is also hoped that this research might provide an opportunity for reflection on the role of eliciting and analysing narratives and how ontological and epistemological beliefs might shape understanding and practice. Consequently, this research might assist the professional discourse and practice of EPs.

#### **3.4 Chapter summary**

This research is considered to fall within a relativist, social constructivist paradigm, which implies that individuals psychologically construct their world, yet do so with some socially constructed concepts. This assumption had implications for the methods of the current research, which endeavours to place the participant narratives at the forefront of the study. A narrative analysis was concluded to offer the most appropriate methodology as it seeks to examine narratives as independent wholes, whilst not seeking to find pre-determined themes or to attempt to compare accounts. Furthermore, such a design allows for an inductive approach with open interviews where participants can self-select their narrative parameters and content. Varying approaches to narrative analysis were detailed; due to the inductive endeavour of this research, the specific form of analysis was not determined prior to analysis. The

analytic method employed for each narrative in this study will be detailed sequentially in the next chapter.

## 4 ANALYSIS

### 4.1 Chapter outline

This chapter begins with the aspects of the analyses that were shared for both narratives. Each narrative is then analysed individually, with the unique analysis documented sequentially. The method of analysis is detailed alongside the findings to promote transparency and the temporal flow that is central to a narrative approach (Gergen, 2009). Each analysis ends with a summary.

### 4.2 Analysis Commonalities

Due to the constructivist epistemological stance of this research and the use of a narrative methodology, the analysis sections are written in the first person. As a constructivist, relativist researcher, I do not attest that my analysis is a 'truth', or that it is simply a representation of the participant's narrative. This analysis was informed by the narrative methods utilised by preceding authors (including Gee, 1991; Hiles & Cermak, 2008; Herman & Vervaeck, 2001; Lieblich, Tuval-Mashiach & Zilber, 1998 and Emerson & Frosh, 2004). Furthermore, the initial analysis was offered back to the participants for their reflection. However, each analysis is considered a unique construction and therefore it is felt that the use of the third person might detract from the constructivist stance and imply a more universal and objective position.

In line with various NA authors (such as Riessman, 1993 and Hiles & Cermak, 2008), a narrative approach to this study was sustained throughout each stage of the research, informing the literature review, methodology, interviews and transcription. In this study audio-recorded interviews were transcribed verbatim. I completed the transcription to ensure immersion in the narratives and to allow for dynamic and inductive analysis. In NA, close and repeated listenings, coupled with methodic transcribing leads to insights that shape how researchers choose to represent the data

(Riessman, 1993). In line with the recommendations of Murray and Sargeant (2012), paralinguistic elements, such as emphases and pauses were indicated. The idea of attending closely to the linguistic features of narratives was promoted by Gee (1991), whose technique was drawn upon in this analysis.

In line with the model outlined by Hiles and Cermak (2008), the NA in this study began with re-visiting the research question:

**What is the experience of parents whose children have been referred for an ASD assessment?**

Returning to this question was a repeated endeavour throughout analysis and ensured that it was held in mind, with the analysis framed through this lens. Similarly, repeated reading of the transcripts were often accompanied with further listening to the interviews, engendering a ‘closeness’ and immersion in the narratives. Due to the inductive aim, each narrative was analysed individually and while a constructivist, individual approach was sought, it should be noted that the analysis was entered into after I had read into varying narrative methods. While I made no attempt to analyse the two narratives similarly, I analysed the second after the first and therefore may have been unconsciously influenced.

The analysis of each narrative is detailed sequentially below. Each analysis begins with an introductory paragraph with information on the participant including a description of their family and the context for their child’s assessment. This information was gleaned through the narrative interviews and is intended to facilitate reading of the analysis.

The analysis is described and presented in the order that it was completed to promote transparency in the method and to encompass a raw temporal flow, a core value of a narrative approach (Gergen, 2009). Due to the inductive, constructivist approach, ‘conclusions’ are not stated as this is considered too deductive; readers are left to take and reflect on the narratives and analysis within their own frame of reference. The working transcripts are included in the appendices to promote transparency and as an acknowledgment that, due to the constructivist stance and recognition of the hermeneutic circle, each reader will interpret the narratives and the analysis in a unique way. In this chapter, quotations from the transcripts will be presented as indented passages of italicised text, accompanied by the extract number that match with the original transcripts.

### **4.3 Analysis of David’s narrative**

#### **4.3.1 David**

At the time of the interview, David was living in a hostel with his son, Jay. Jay’s mother left the family home when Jay was three years old. Following this, David moved with Jay to another part of the UK to live with his mother (Jay’s grandmother). When Jay was in primary school, David and Jay moved back to London, where Jay was first assessed for ASD in a London clinic. They then moved back to live near David’s mother, following which Jay’s mother moved nearby. David then moved back to London to work and Jay lived with his mother. When Jay was a teenager, his parents gave him the choice between continuing to live with his mother, or moving back to London to live with his dad (David). Jay decided to live with David. David applied for Jay to attend the secondary school he had attended as a student, although the LA would not accept his statement of SEN and requested

further assessment, including the referral to SCAS. David chose to complete the interview at the clinic where I am completing my training.

#### 4.3.2 Outline of the analysis of David's narrative

After transcription, I identified the *sjuzet* and *fabula*; literature suggested that this was a good starting point as it both forms a springboard for further analysis and prompts deep immersion in the data (Hiles & Cermak, 2008). Focus on the *fabula* then led to consideration of holistic-content analysis, where one consistent theme was described. Consideration of this dominant theme then inductively led to further thematic focus through a categorical-content lens. In turn, this analysis of themes initiated closer analysis of the *sjuzet*'s influence on the narrative, which prompted a categorical-form approach. The analysis of this interview concludes with a critical narrative analysis phase, where David's positioning in relation to the preceding analysis is explored. Although a staged, sequential process of analysis was completed, themes and discussions within and between layers of analysis overlap. This is due to the inductive nature of the analysis and the importance of considering each narrative as a whole.

#### 4.3.3 Identifying the *sjuzet* and *fabula*

In line with the method described by Hiles and Cermak (2008), rather than numbering the transcript lines (which felt too arbitrary), I broke the interview text down into segments. Each segment formed roughly a self-contained episode, which I identified through reading and listening to the narrative, identifying segments of text that attended to sentence content and speech intonation. Each episode was numbered and will be included with the quotes included in this section (allowing for sequential identification). As with all aspects of this NA, my identification of the transcript

segments was unique to my interpretation and therefore should not be considered definitive.

Following the numbering, I identified the *sjuzet* and *fabula* of the narrative; *sjuzets* are words considered to affect how the story is told, with the *fabula* referring to what is being re-told. In line with the tradition, I underlined the *sjuzet* in the working transcript (appendix 3), with words, phrases and in some cases, whole sentences included that concerned emphasis, reflection, asides and remarks.

This process took several readings, and resulted in the *sjuzet* bracketing the *fabula*, which could be read as a simple, coherent story. Ginsburg (1989, cited by Riessman, 1993) defined the *fabula* as the ‘expected arrangement’ of a narrative’s temporal sequence; and the *sjuzet* as emerging from the ‘unexpected twists’. Whilst this approach was reflected upon, it was considered to be too deductive a distinction for this NA.

From the working transcript, it was noted that the *sjuzet* in David’s narrative consists mostly of remarks and emphasis with words such as: ‘like’, ‘just’, ‘but’. Sentences and phrases often started with: ‘I mean’, ‘but’, ‘like’ and end with: ‘you know’.

Extra-linguistic features mainly consisted of ‘err’ and pauses. Distinction between the *sjuzet* and *fabula* prompted me to read the narrative focussing on one and then the other. Focus on the *fabula* prompted analysis from a holistic-content perspective (Hiles & Cermak, 2008).

#### 4.3.4 Holistic-Content analysis

This analytic perspective was outlined by Lieblich et al. (1998) and involves exploring and establishing links and associations within the entire story. I read David’s narrative and noted general ‘first impression’ themes, which I then held in

mind as I continued my readings, noting further examples and contradictions. I then read the narrative through again having established a focus (the main theme that was meaningful throughout the narrative). The ‘focus’ theme of this stage of analysis arose as ‘separation and closeness’.

#### 4.3.4.1 Separation and closeness

Separation and closeness was a theme felt to weave throughout this narrative in various guises. The narrative began with the description of Jay in his infancy and early childhood, with a separation identified between how he presented at home and at nursery:

*4. I mean, he was a textbook child when he was little, you know, like he slept, he slept fine, all night. I mean, he had a bit of colic, which was normal, you know. But yeah, he was text book...*

The phrase ‘textbook’ was used twice in this section of the narrative to describe Jay as a young child at home, but this contrasts with a separate description of Jay at nursery:

*8. I never saw no problem at home. But at nursery he was a handful, they were telling us he was a handful.*

The theme of separation developed when David spoke about the identification of Jay’s SEN, with this being located externally to Jay, David and their relational experience:

*27. ... She like spotted that there was something different about him, she was the first one to pick up on it.*

*I mean... I don't know what, but like, she spotted that there was a difference about him... like, you know, the Asperger's thing.*

This was the first explicit reference to an SEN-or ASD-related terminology, and is attributed to the observations of a teacher. The term ‘the Asperger’s thing’ further highlights the separateness of this label from Jay.

Later in the narrative, David recounted receiving a recent school report and showed me a copy of it on his phone. He then described confusion around a perceived discrepancy between the reports of professionals:

*57. But it's hard to understand sometimes the differences in the reports how, how he's doing. Like, they said he had like a learning difficulty when he was little... but then he's doing really well now.*

As well as this theme referring to a more abstract sense of separation between Jay's behaviour and the identification of SEN, David also spoke about the physical separation of Jay's mother from the family:

*20. I mean, it had been a hard time. His mum left when Jay was three. She just left, it was hard, hard for us.*

David's narrative also described how Jay has not spoken to him about his feelings around his mother leaving, but spoke to a therapist at a clinic, again locating the discussion outside of the family:

*36. I mean he finds it difficult to talk about his mother to me. And I think, like he spoke to her about his mum and how he felt about his mum leaving. I like, was quite surprised that he spoke so much about it I guess. He just like, opened up to her.*

*37. I think he was a bit angry about her. Like he spoke quite bad about her; I guess he was angry at her leaving.*

Physical separation and coming back together appeared a dominant theme in the fabula of David's narrative, as he described several moves that saw Jay and David spend time both together and apart. In the end, it is decided that Jay will live with David, and at this point in the narrative, there appeared to be a shift in theme from one of separateness to closeness.

Upon re-listening to the interview, it was also noted that there was a shift in tone at this point, with David adopting a lighter tone of voice. The narrative became fuller with fewer pauses, longer descriptions and fewer interviewer comments. David

described the importance of maintaining closeness between himself and Jay. He began this stage of the narrative by telling me that Jay now attends the school that David went to as an adolescent:

72. *Jay likes it, you know that he comes to the school I used to go to.*

David then started to talk about the future, and embarked on detailed descriptions of Jay and the unique traits and fears that make him vulnerable. Alongside these descriptions, David added caveats stating that Jay is less vulnerable when he is close to him:

73. *I don't mean to sound, like, big headed but he likes to be with me, you know, like, near me...*

74. *he still needs me.*

88. *But he doesn't worry if he's with me. I don't mean to sound big headed but if he's with me going anywhere he's fine*

David also described ways that he helps and supports Jay in daily life, keeping him close and safe:

106. *but like, he needs me.*

107. *We do things together all the time, like go to the cinema or for a walk around the heath.*

108. *I think he feels safe with me.*

David spoke about Jay's upcoming work experience placement, and through a mutual desire to maintain closeness, the vulnerability of separateness came through again:

126. *He's got work experience this year coming up soon I think. I wonder if he can come and work with me...*

*... but I think he'd like that...you know, being with me.*

In this half of the narrative, the theme shifted from separation between Jay and how he was portrayed or received at school or in a clinic, to a more enmeshed description that highlights David's personal construction of Jay and how this led to a desire in David to maintain closeness between them. David appeared concerned about the idea

of being separated from Jay in the future, and this construction of Jay as vulnerable may indicate why David might want Jay to remain with him.

#### 4.3.5 Categorical-Content analysis

As I analysed the holistic theme, I found that this thread evolved through the narrative and encompassed themes that could be categorised in different ways. One of the unique elements of NA is the importance of maintaining the cohesiveness of each narrative. Hiles and Cermak (2008) indicated that categorical-content analysis involves breaking the text down into relatively self-contained areas of content and completing analysis akin to thematic analysis. Lieblich et al. (1998) suggested that this stage of analysis should begin with the use of a research question to select a subtext to focus on, move to the definition of themes, then the assigning of episodes to themes and finally drawing conclusions. While this model was used as a basis for this stage of analysis, due to the focus on an inductive approach, I allowed themes to emerge from the text through repeated re-readings. It should be noted that this was the second stage of analysis, and therefore the theme of separation and closeness had already been tentatively established.

In this stage of the analysis, I re-read the transcript and gradually sketched themes beside sections of text (as seen in appendix 3). I then listed the themes and began to group them into broader themes, which are outlined in this section. A list of the initial themes and the broader themes they were grouped into can be found in appendix 7. I allocated each of the broader themes a colour to highlight the transcript (also detailed in appendix 7), allowing for easier consideration of how the themes appear throughout the narrative. Due to the importance of maintaining a sense of the narrative as a whole, I went through the transcript noticing the pattern of the themes,

with some dominating certain parts of the narrative. Below, I outline the themes in the temporal order that they appeared in the transcript, maintaining narrative form. To promote this coherence further, themes are not discussed in silos, with overlap between themes and analysis reflected upon throughout.

#### 4.3.5.1 Jay's strengths and difficulties

This was the first theme to appear and is the most dominant in terms of volume of data. The first code in this theme was pride, with David starting the narrative with a proud statement and positive attributes:

4. *So, Jay... is my boy, my son, he's sixteen years old... well, I guess he's a young man now.*

*Pause*

*I mean, he was a textbook child when he was little...*

David then described the aforementioned split between home and school reports of his behaviour. A little later on in the narrative, this theme emerged again with reference to David's speculation around Jay's feelings. David explained his hypothesis:

35. *Jay saw a therapist. And like, he didn't want to go but like I think after a few sessions he was like happier to go and talk. I mean, I don't know what he spoke about. But I think he...*

36. *I mean he finds it difficult to talk about his mother to me. And I think, like he spoke to her about his mum and how he felt about his mum leaving. I like, was quite surprised that he spoke so much about it I guess. He just like, opened up to her.*

David explained how Jay's behaviour was challenging when he was living with his mother, but that he was doing well in school. At this point, pride was again demonstrated as David showed me Jay's report on his phone.

In the second half of the narrative, there was an extended passage that is almost exclusively about Jay. It began with a detailed description of his 'ticks', and then outlined his engagement in the cadets and his affinity for history. This passage contained a positive memory from when David took Jay to a museum. The end of this passage details Jay's 'irrational fears' and how David manages this:

89. *But he needs like preparing before you go on journeys, so I explain to him, like, we're going to get the Northern Line...*

90. *Once we missed our stop and he was worried, but because he was with me he was fine, like, he feels safe.*

As well as falling within the theme regarding Jay, this passage is also significant in the emergence of the 'safety together and reliance' and 'worrying about the future' themes (detailed later in the chapter), as David outlined more of Jay's behaviours that he feels make him vulnerable if he is not around to keep him safe. However, David linked these vulnerabilities to Jay's positive attributes:

91. *Another thing that worries me is that he will talk to strangers in the street.*

92. *Like, he really likes people and is so kind.*

93. *But like, I really have to watch him and I worry that he's not safe.*

94. *He'll like go up to strangers in the street and introduce himself and be chatting to them.*

*He's so thoughtful of others. He always wants to give people on the street money...*

This pattern continued for most of the second half of the narrative, with David outlining Jay's behaviours, such as his fears, online behaviour and social interactions, whilst linking these to Jay's positive attributes, such as being 'kind', 'thoughtful' and 'friendly'. Here, there was a notable increase in the number of statements coded as worry and safety (a separate theme), where David linked these behaviours and attributes to potential vulnerability if David were not there to manage Jay's environment and keep him safe, prompting anxiety in David about the future.

At the end of this passage is another section coded as pride, where David again detailed Jay's positive attributes:

*117. He wants me to be happy. Like if he sees things are getting me down, or if I'm like a bit ill... he, err, like he wants me to be better and will like try to make me laugh.*

*118. He just is like that, you know... kind.*

The theme of 'Jay's strengths and difficulties' highlights how David's narrative described a range of behaviours that cause Jay difficulty in navigating daily life. However, these behaviours are described alongside many positive attributes that David assigns to Jay. As well as this contrast, David also described a split between how Jay is experienced by him at home and how Jay is experienced by others at school.

#### 4.3.5.2 Decisions and change

This theme first appeared when David eluded to their move back to London, and the transitions between homes are a dominant feature of the fabula in this narrative, with the pair moving four times. Another thread within this theme is that of Jay's assessments and diagnoses. This appears to mirror the physical transitions, with requests for assessments re-visited several times.

This theme also included mention of Jay's mother:

*20. His mum left when Jay was three. She just left, it was hard, hard for us.*

...

*... Jay's mum decided to move there...*

Many of the sections coded within the theme of 'decisions and change' occurred near sections coded 'David's job', with moves attributed to David's search for work and motivation to 'provide' for the family. The decisions and transitions associated with

Jay's mother are also dominant in the fabula, and repetition of the word 'hard' suggests that the decisions of Jay's mother prompted challenging feelings for David.

This theme also included the decisions that were made by professionals:

17. *He had like a few appointments there but then he was discharged.*

...

28. *They had him assessed.*

...

128. *So he's down to go to the clinic again for another assessment for autism.*

The decisions regarding Jay's assessment were all attributed to other people and it might be that David may not have felt he had agency over these decisions:

58. *So you rely on the experts really don't you?*

#### 4.3.5.3 Professional hypotheses

The decisions regarding Jay's potential SEN are associated with 'experts' and therefore appear located outside of David's relationship with Jay. However, David's narrative included several examples of the hypotheses offered by professionals:

13. *...But then, like, err, they found that he had glue ear, so...*

*... maybe in school it was frustration*

...

27.... *I mean... I don't know what, but like, she spotted that there was a difference about him... like, you know, the Asperger's thing.*

...

57. *... they said he had like a learning difficulty when he was little...*

These ideas are offered in the narrative as statements, and unlike other aspects of the fabula, are not associated with language portraying David's experience or emotion.

#### 4.3.5.4 David's job, life and feelings

This theme is first introduced when David described the challenge of maintaining a working life whilst receiving regular calls from school to come and pick Jay up due to his behaviour:

*9. But like, I was working, you know, like it was hard because, like I'd go to work each day and be constantly thinking, like, will they phone me? Then if they did, I'd have to drop everything and go and pick him up. It was just impossible...*

This passage is the first time in the narrative that David referred to his emotions, and it appears that David found the split between holding down his job and caring for Jay difficult. Eventually, this pull became too great, and David quit his job, prompting the first move.

As aforementioned, David tended to attribute their moves to his work, and therefore it appears that David's ability to work and provide for him and Jay are intrinsic to the narrative:

*48. It's important that I work, you know, like, can provide.*

Indeed, this notion is so highly valued by David that it prompted his move alone back to London, a move that appears linked to feelings of guilt, especially as David described the difficult period where Jay lived with his mother:

*49. So I came back to London and Jay was with his mum. It was hard I think, like, she struggled with him.*

...

*67. I mean, obviously I didn't want to leave him...*

The remainder of passages coded within this theme were linked to David's difficult feelings regarding Jay and the future, and his desire for Jay to '*do well*'. This will be discussed in the next theme.

#### 4.3.5.5 Worry and not knowing

This theme first appeared at the start of the narrative when David described the experience of trying to keep his job going when Jay's school were struggling to contain him. The theme then does not reappear until towards the end of the narrative, when David spoke about the future and his worries about Jay growing up and becoming independent. This suggests a circular form to the narrative; and links to the theme of 'symbiosis', which will be discussed later in this analysis.

The code 'not knowing' included passages where David referenced not being aware of how much Jay '*ticks*' at school, not knowing what Jay spoke about in therapy and also, at the end of the interview when David spoke about the waiting and uncertainty associated with the ASD referral process:

*137. And you just don't hear anything... it gets a bit frustrating.... No knowing how long, you know?*

However, the majority of this theme is associated with David's anxiety around the future:

*109. But yeah, I think about the future and it gets to me a bit... you know, not knowing.*

As mentioned in the first theme, the second half of the narrative is dominated by David outlining Jay's behaviours and attributes that make him vulnerable, alongside passages outlining how these vulnerabilities can be mitigated by David being with Jay. David's anxiety may be linked to a sense that Jay is dependent on David to keep him safe, yet Jay is keen to be independent:

96. *I worry because he doesn't have a sixth sense about that stuff, like it might not be a good idea to talk to every homeless person you meet.*

97. *It's the same with traffic. He's much better than he used to be, but I still have to remind him to stop and look both ways, he doesn't have the sixth sense to do that. I have to remind him and be with him.*

98. *I know he's getting older, but I worry, you know?*

*Pause*

99. *I think about, err, him living on his own, err, he's very independent, well, he likes to be independent... and, well, yeah, it makes me nervous.*

100. *Like, he does this online gaming, where they talk and stuff, online... they talk about the game and stuff. As I said, Jay's friendly... but one evening I heard him talking about school. Err, I told him, 'don't tell them what school you're at', but he doesn't like think like that.*

101. *So I've written a big sign...*

David may have been communicating anxiety about Jay being ready to live independently, and fears that without him being there to manage his environment (such as writing signs), Jay might not be safe.

#### 4.3.5.6 Symbiosis

This theme refers to the relationship between David and Jay, and overlaps with the previous theme and the holistic theme. This theme first emerged when David described Jay's primary school (coded as 'protective'):

29. *It was a supportive school, you know? Like small, the staff really knew the children. It was a small community that I think was good for Jay, like safe.*

This is the first mention of David's sense that familiarity is safer for Jay. Later in the narrative, this idea became more specifically related to how David feels that he is the best person to be with Jay and keep him safe:

88. *But he doesn't worry if he's with me. I don't mean to sound big headed but if he's with me going anywhere he's fine,*

In his narrative, David said the phrase 'needs me' (with reference to Jay) four times, and in each instance the phrase referred to the future. This appears to indicate a

strong link between David's thoughts and feelings about the future and the sense that Jay is reliant on him. The name of this theme is symbiosis, although there is less explicit content in the fabula of the narrative to indicate that David 'needs' Jay. However, David did refer to his difficulty leaving Jay, and spoke fondly about their shared experiences. Similarly, David subsequently stated:

105. *But, with Jay... like... I know it's going to happen, like him growing up and wanting to live on his own...*

106. *but like, he needs me.*

107. *We do things together all the time, like go to the cinema or for a walk around the heath.*

108. *I think he feels safe with me.*

109. *But yeah, I think about the future and it gets to me a bit... you know, not knowing.*

This passage began by David speaking about his worry about the future and he went on to cite that they share activities 'all the time'. Here again, attention to this sjuzet may indicate that David also relies on such experiences with Jay, even though it is framed within statements stating Jay's reliance on him. David stated that the thought of the future is difficult, and it may be that the thought of a life without such closeness to Jay is uncomfortable.

#### 4.3.6 Categorical-Form analysis

Lieblich et al. (1998) outlined this approach, emphasising the importance of exploring linguistic features and plot devices. As with the previous analysis, due to the importance of maintaining the coherence of the narrative, this analysis had some overlap with the previous layers; this is considered a strength in NA (Hiles & Cermak, 2008).

Aspects of the sjuzet added emphasis and focus throughout David's narrative; therefore, the analysis in this section focuses on linguistic features present throughout the narrative and links to aforementioned inductive themes. An example of this is in

the memory of David and Jay going to a museum. This passage was cited above as being within the theme of closeness and symbiosis; and it is attention to the sjuzet that demonstrates the importance of this passage. It was the only part of the narrative where David gave a warm laugh, highlighting the importance of this memory to him. Similarly, the passage quoted in the preceding section (line 105) is described within the categorical-content analysis section, yet the meaning is heightened through appreciation of the sjuzet.

Throughout my re-readings of the transcript, I was struck by the number of repeated statements in the sjuzet. A search of the transcript revealed that '*you know*' was a sjuzet phrase repeated 52 times. While this may simply have been a characteristic of David's speech pattern, it is noted that 'not knowing' was a code in the content analysis. It may be that consciously or unconsciously, David was expressing a desire to know or a discomfort with not knowing. However, it may also be that I, as the interviewer and analyst, was influenced by the sjuzet in my thematic analysis. Either way, it appears that this is a strong theme of both the sjuzet and fabula.

Similarly, the word '*like*' occurs 147 times in the narrative. Again, this may be a personal speech pattern, yet this may also connect with a theme identified in the content of the narrative. Indeed, closeness is part of the theme identified in the holistic analysis, as well as occurring as a code (together) in the 'symbiosis' theme above. The word '*like*' is a synonym of alike, similar, the same; which fits with aspects of the fabula, such as Jay attending the same school as David, them losing weight together and David suggesting that Jay would enjoy doing his work experience at his work. This is also related to the overall theme identified from the

holistic-content perspective, and is therefore a thematic thread woven throughout multiple layers of analysis.

#### 4.3.7 Critical NA

Hiles and Cermak (2008) presented this stage of analysis as the ‘functionality’ of the story, where consideration of how the narrator positions themselves is considered.

Emerson and Frosh (2004) situated this layer of analysis within a psychosocial frame; defining this approach as a combination of the critical gains of discourse analysis and a focus on the active constructing processes through which individuals construct their lives. Hiles and Cermak (2008) indicated that this approach requires analysis of the *sjuzet* and *fabula*, and is best placed as the final stage of analysis. Emerson and Frosh (2004) indicated that they approached their analysis from a social constructionist epistemology and it should be noted that this differs from the current research, which resides within a social constructivist frame. Therefore, this layer of analysis focuses on the individual (David) and his constructions and positioning, rather than how concepts or themes have been socially constructed or link to wider social discourses.

When the whole narrative was revisited through the lens of considering David’s position in the narrative, two critical themes arose, both overlapping with themes in previous layers of analysis. The two critical themes identified in this analysis of David’s story regard how David positions himself with respect to professionals and with Jay.

##### 4.3.7.1 David’s position in relation to professionals

Throughout the narrative, David appeared to position himself ambivalently towards the professionals mentioned. At the start of the narrative, David appeared to distance himself from the reports of school staff that suggested Jay behaved differently at

school. This distance was exemplified through the use of *'they'* throughout the narrative to refer to professionals and their hypotheses about Jay, often without assigning a name or job title.

However, this distance did not appear indicative of a negative attitude towards professionals, with some references framed positively:

*27. And there was this great staff member there who, like, picked up on the difference with Jay...*

It may be that ambivalence and positioning at a distance represents positioning of David away from Jay's possible SEN, and the related uncertainty:

*27. I mean... I don't know what, but like, she spotted that there was a difference about him... like, you know, the Asperger's thing.*

There may also be an element of frustration that is related to the ambivalence and distance from professionals:

*57. But it's hard to understand sometimes the differences in the reports how, how he's doing. Like, they said he had like a learning difficulty when he was little... but then he's doing really well now.*

*Pause*

*58. So you rely on the experts really don't you?*

Here, David expressed the difficult feeling associated with the conflicting reports of professionals, but went on to cite reliance on them, which may indicate a feeling of helplessness that feeds into his positioning. This was revisited at the end of the narrative, where David described his attempts at getting Jay into a school, and his current experience of waiting for assessment:

*121. Over the summer I tried to get Jay into (names school) but they said that because of his statement they needed to get the funding first so they could help him. So it took a while...*

The fabula of David's narrative included reference to several '*assessments*' of Jay, and it may be that his experiences led to an ambivalence and degree of separation from professionals and their hypotheses as a defence against the associated feelings of anxiety, frustration and helplessness indicated through the sjuzet.

#### 4.3.7.2 David's position in relation to Jay

While positioning himself away from professional hypotheses and constructions of Jay, David positioned himself as an advocate for Jay's strengths and sensitivities. As aforementioned, David's most extensive sections of prose were where he fondly describes Jay, positioning himself as the holder of unique insight into Jay and what he feels that Jay needs. In doing this, David may be highlighting Jay's reliance on him:

*75. The future, like, it scares me a bit, you know. Like he still really needs me.*

*76. He has these.. things that he does, you know, like ticks...  
... I tell him to stop, you know, when I notice him doing them.*

*77. I don't know how much it happens at school.*

When studying the sjuzet here, the wording suggests that David may be expressing his unique position in relation to Jay. An example of this is where David stated, '*ticks I call them*', referring to a unique word in David's lexicon that only he has access to, emphasising the exclusivity of their relationship. The theme of Jay's reliance on David is highlighted in the 'symbiosis' theme outlined above, and David's positioning in this appears as a critical theme throughout the narrative in both the fabula and sjuzet.

Another aspect of David's construction of himself in relation to Jay regards his positioning as a provider for Jay. Notably, the only aspect of David's life outside of his relationship with Jay that entered the narrative is repeated references to his need to work. This is an important theme in the fabula and was cited as the catalyst for their

moves and the difficulty in maintaining a job while Jay was unsettled at school. This theme again denotes a sense of dependency. Overall, in relation to Jay, David appeared to position himself as needing to be close to keep him safe, leading to anxiety around a future where Jay may become more independent.

When I re-read the transcript during this stage of analysis, I noted the absence of other people in the narrative, possibly further highlighting the importance and exclusivity of David and Jay's relationship. Other than professionals, who, as previously described are positioned at distance, the only other people included in the narrative are David's mother and Jay's mother, neither of whom are referenced in the second half of the narrative. Indeed, David's mother is only referenced twice (described as being '*loved*' by Jay and helping to raise him). Jay's mother is spoken about more negatively, being mentioned in relation to her leaving the family, how Jay felt about her leaving ('*angry*'), her decision to move near to them, and the time that Jay lived with her and her partner:

49. ...*she struggled with him.*

50. *He was angry at her...*

Throughout the narrative, the word '*cope*' is used four times, each in relation to occasions where Jay is not with David; Jay's first school '*couldn't cope with him*' (line 9), Jay's mother '*couldn't cope*' (line 62 & 64) and David worried that Jay '*might not cope*' with having work experience away from him (line 126). This suggests that even when another person enters David's narrative, their appearance further highlights David and Jay's symbiosis.

#### 4.3.8 Member checking

As aforementioned, sharing transcripts and analysis with participants is important in NA, as it promotes the notion that participants have been heard and that the analysis

fits with their experience (Josselson, 1996). Therefore, the purpose of the second meeting in this research was for the participants to feel heard and have space to reflect, rather than to add data to the NA. Taken from the description by Josselson (1996), this research defined a narrative as a ‘slice of life’, offered at a unique time, and this was explained to David at our second meeting. After the transcription and analysis had been completed, I met David and re-iterated that the interview was to be considered a reflection of his experience at that time, but that he was free to read the transcript and share his thoughts, including any changes he wished to make. I also explained that his reflections in the second meeting would not be analysed. David read a copy of the interview transcript that did not include any analysis (such as coding or underlining). David offered his reflections and did not wish to make any changes to the transcript. David declined the opportunity to discuss the themes that had arisen through the analysis.

#### 4.3.9 Summary of the analysis of David’s narrative

The holistic-content analysis of David’s narrative revealed the theme of ‘separation and closeness’, which documented aspects of both physical and psychological proximity. The categorical-content analysis built on the holistic theme and revealed themes around Jay’s experience and vulnerabilities, professional involvement as well as some themes potentially linked to anxiety in relation to change, symbiosis, the unknown and the future. Close analysis of the *sjuzet* within the categorical-form analysis further supported the themes of ‘not knowing’ and ‘separation and closeness’. Finally, the critical narrative analysis drew attention to David’s reference to professionals, including how he may have exhibited ambivalent feelings towards them and their hypotheses. Reflection on David’s positioning in relation to Jay brought the focus back to a sense of closeness, symbiosis and exclusivity. Themes

that arose through this analysis will be discussed further and tentatively situated amongst existing research and theory in the discussion chapter.

#### 4.4 Analysis of Hannah's narrative

##### 4.4.1 Hannah

At the time of the interview, Hannah lived in a flat with her three daughters and partner (who is father to Hannah's youngest child, Carly). Lily is Hannah's middle child and was of primary school age, Carly was a baby and Hannah's eldest child was thirteen years old. The family had experienced involvement from a myriad of professionals, including from social services and CAMHS. Hannah had some family history of mental health needs. Lily had previously been assessed for ASD but did not meet the criteria, she had since been referred again, this time to SCAS.

Hannah requested that the interview be completed in her flat. On the day of the interview, Lily was home (off school with illness), as was Hannah's youngest child, Carly.

##### 4.4.2 Outline of the analysis of Hannah's narrative

The interview context meant that there were multiple voices and interjections in the narrative. In the transcript, I included the asides and conversations that took place in the living room, where I sat. I have not included the conversations that occurred outside of this space to preserve the privacy of the family. I did not consider it appropriate to omit all the asides, as they punctuate and invariably influenced the narrative given. In the transcript (see appendix 4), I have marked with 'I-' the lines that I (the interviewer) spoke, and 'Lily-' the lines that she spoke. All other lines were spoken by Hannah. Extra-linguistic features, such as emphasis, speed or eye gaze are written in parentheses.

As with the previous narrative, numbers are placed beside segments of text, identified as units of the narrative in accordance to my interpretation of the content and spoken aspects of the narrative. I then identified the *sjuzet* and *fabula* in an attempt to further

immerse myself in the data. Reading of the fabula led to the identification of a holistic-content theme. When studying the holistic thread, I noticed a feature of the form, prompting holistic-form analysis. Patterns in the form then led to further analysis from a categorical-content perspective. Upon re-listening to the interview after the categorical-content analysis, my attention was drawn to how extra-linguistic features affected the themes, leading to categorical-form analysis. The *sjuzet* in this narrative was extensive and therefore referred to throughout the analysis, specific attention to the *sjuzet* led to consideration of Hannah's positioning with regards to me, leading to a final stage of critical NA. This analysis is detailed sequentially below. Although a staged, sequential process of analysis was completed, themes and discussions within and between layers of analysis overlap. This is due to the inductive nature of the analysis and the importance of considering each narrative as a whole.

#### 4.4.3 Identifying the *sjuzet* and fabula

This process involved repeated re-readings and listenings to the interview. Due to the setting of the interview, there were large sections of the transcript that were asides to the main fabula, including where Hannah spoke to Lily, and where Hannah answered the door to a neighbour, and then spoke about the neighbour to me. While not considered the fabula of the narrative, these asides are included in the analysis, as they were woven throughout the interview and often acted to emphasise or exemplify aspects of the fabula.

Once I had identified and underlined the *sjuzet*, I read the narrative omitting the *sjuzet* to gain a sense of the fabula, what was being told in the story. This felt particularly important given the volume of *sjuzet* in the transcript. As I read through

the fabula then through the narrative again as a whole, I noted down my initial, overall impression. As I did this, I consciously held the research question in mind. This led me to consider holistic-content analysis (outlined by Lieblich et al., 1998), seeking to establish links and associations within the entire story, through focus mainly on the fabula.

#### 4.4.4 Holistic-Content analysis

After several re-readings of the transcript, I identified 'power' as a thread that appeared woven throughout the narrative. I re-read the transcript and noted how this theme switched between passages, including: a sense of disempowerment, internal power, external power and attempts to seek power.

##### 4.4.4.1 Power

Hiles and Cermak (2008) suggested that placing a holistic theme within a summary of a full interview can help to identify a 'core narrative'. In Hannah's narrative, she alternated between giving examples of how she has felt powerless and silenced by the system of professionals around her, and giving her own suggestions for how the system could be improved, which may be an expression of the knowledge and power she gained through experience.

When talking about encounters with professionals, Hannah spoke of being ignored and forced to wait:

*3. ... they brush you off. They don't think they'll keep you. They don't think 'ok then we don't believe it's autistic or we don't believe it's certain things so we're gonna sign you off now and put you onto another one'... so you've gotta wait. They don't think... so then they put you onto another 6 month waiting list...*

Later on in the narrative, Hannah explained how she does not feel that she has a voice unless something bad has happened:

23. Erm... yeah so... the fork stabbing... that's the only time they listened to me...

The power assigned to the professionals, often referred to as 'they', was highlighted when Hannah spoke about only having a sense of power when a professional spoke on her behalf:

52. um yeah, so then, as soon as I got rid of him (the Key Worker), er, no one wanted to ring back my phone calls or ring me back, and it was like, just because I hadn't got a professional to speak for me... I had no voice, you know?... That's how I felt, well, how I still feel now... Like, in seven months, it's been seven months and I haven't spoken to anyone and now, I've got a social worker... everyone wants to ring me again...

In the narrative, this switched when Hannah made statements related to her knowledge and personal experience, giving her confidence in thinking that Lily has SEMH needs:

14. So yeah, I would look after all my little cousins, so I know different traits. My other cousin's got autism, one of them's mentally ill. So like, I've kinda, not diagnosed her but... you kind of look at the traits and realise...

84. Because, in a way, the doctors, what they hear is that you can't cope, when actually, no! I can cope, and like I know when to cry and when not to cry, and when to hold my anger and not to, it's that I want to find out what's wrong with her, so that I can deal with that.

The theme of power in Hannah's narrative conveys a sense of Hannah being at odds with professionals in Hannah's quest for validation of her beliefs about Lily. Indeed, the theme of powerlessness was also present in passages where Hannah talked about the cause of Lily's difficulties:

62. but I would expect her (eldest child) to have the problems, like with what she's seen.

63. With her (looking at Lily), everything was ok, we lived together, was a happy family, we moved to Wales, it was nice, you know. So you'd expect the oldest to... they say with trauma, it can you know, be a trigger and set off things.

Here, Hannah outlined confusion around why Lily experiences difficulties, which again may suggest a sense of powerlessness and desire for clarity and understanding. Through reading of the narrative as a whole, including the sjuzet, the theme of power was exemplified through Hannah's interactions with Lily, with Hannah powerless in understanding Lily's behaviours and multi-faceted personality:

46. ... *this is happy lily, which I can deal with, it's angry Lily that I don't understand... mad Lily and angry Lily that I can't deal with... you can never get through to her...*

Here, Hannah explained the difficulty she faces in dealing with the unpredictability of Lily's behaviour; and the previous quote (passage 84 above) suggests that she felt that a diagnosis would give her the power to 'deal' with the challenges. At various points in the narrative, Hannah spoke about how her experience has led to a sense of authority regarding what could improve the process. This aspect was present towards the start and end of the narrative, suggesting a circular form.

#### 4.4.5 Holistic-Form analysis

When analysing the holistic theme, I noticed similarities between the start of the narrative and the end and I therefore moved my analysis to a holistic-form perspective. Lieblich et al. (1998) cited that with this layer of analysis, consideration is given to the narrative typology, narrative progression and narrative cohesion. Hiles and Cermak (2008) suggested that this involves focus on the fabula, rather than the sjuzet and can allow narratives to be categorised according to their story form and typology.

The previous layer of analysis revealed that Hannah's narrative included several references to Hannah's beliefs about how professionals practice. Indeed, the

narrative started with a passage where Hannah suggested ways in which she feels the system could be improved:

3. *There are easier ways, I mean they could do it easier ways and getting it over and done with rather than...*

*...If they actually would have kept you on and stayed with you and spoke to that person again you would have been done, been diagnosed with and done another two people in the time that you've actually done that one person...*

At the end of the narrative, Hannah again spoke hypothetically about service improvement, mainly around better communication and a more empathetic approach:

89. *... I wish people would communicate better, you know, it would just be so much better...*

90. *And be like, on your side, in your corner. And for them to speak to each other, cos you say one thing, then another thing and they could have spoken in the same office rather than... asking me to send this letter or that email, when they've probably just bumped into each other.*

91. *Cos that's what me and my family worker like had done... and for them to say that like, 'we understand you' and 'we haven't forgot about you' cos the wait list is so, understandably, long and like, 'we hear you'...*

Having these passages at the start and end of the narrative create a circular form to the narrative, and may offer insight into Hannah's motivation to share her narrative for this research project. Frye (1957, cited by Hiles & Cermak, 2008) proposed that the basic structuring principle of the narrative imagination is formed mainly by structures of desire. This may be the case for Hannah's narrative, as she started and ended her story with the desire and belief that the experience could be better. Hannah's story was peppered with experiences of frustration and disempowerment that could form a motivating force for desired change.

The identification of this circular narrative form was identified through consideration of the fabula of the story. The focus on the start and end of the fabula prompted the next layer of analysis, where the content was analysed more thoroughly.

#### 4.4.6 Categorical-Content analysis

At this stage in the analysis, I revisited the transcript, noting initial themes on the transcript (appendix 6). This led to initial themes, which were then synthesised into broader themes (outlined in appendix 7). Highlighter colours were then assigned to each broad theme, to allow for examination of how they appear in the narrative.

Below, I have outlined the four overall themes, which each include references to the initial themes. To maintain the temporal focus to the analysis (highlighted by Riessman, 1993 and Mishler, 1999), the themes are presented in the order that they first appear in the narrative.

##### 4.4.6.1 Professionals

This theme was the first to appear in Hannah's narrative and is woven consistently throughout, highlighting both positive and negative experiences. Hannah explained how not receiving a formal diagnosis prompted a sense of being dismissed and made to wait:

3.     *they brush you off. They don't think they'll keep you...*  
        *... so you've gotta wait.*

As described in the previous layer of analysis, there is a sense of the power of professionals that runs throughout the narrative; and the use of the phrase '*brush you off*' is potentially an example of Hannah expressing how she feels insignificant and vulnerable to omnipotent professionals. Furthermore, the code of 'time' and 'waiting' first occurred in this passage and being made to wait indefinitely could signal powerlessness.

This theme also included several passages where Hannah reported instances of professionals disagreeing with her assertion that Lily has a diagnosable disorder:

15. *So then they was like 'no...it's fine, it could be just like a phase... leave it, leave it...'*

Hannah's 'voice' is a separate theme described later in this section. Although it is related to that of professionals, many of Hannah's references to being dismissed were followed by her defensive comments and explanations of why she should not be:

12. *er I went to the doctors, they said to me, 'obviously er, it could be the terrible twos',*

13. *and I'm like, yeah but I got a child who's thirteen...*

Hannah also offered a hypothesis for why she felt professionals did not hear her:

23. *and they didn't listen to me when they thought, they thought I was a young mum...*

The idea that Hannah was dismissed and not heard because she was a young mother was expressed twice in the narrative. Again, this may link with the theme of power, with disempowerment being linked to a perceived stigma. A sense of disempowerment was also present as Hannah described being passed between professionals; school staff 'safeguarded' Hannah, which prompted her to be allocated a social worker. Hannah was also passed between professionals in relation to Lily's ASD assessment referrals. Indeed, the identity of individual professionals included in Hannah's narrative are difficult to follow in the transcript, possibly reflecting confusion and the number of professionals involved in Hannah's experience.

The theme of disempowerment was again exemplified in Hannah's sense of only being heard when other professionals spoke for her:

24. *and like, all these professionals... and the mental health professionals only listened to me when I've got the other professionals behind my back.*

This point in the narrative marked a split in Hannah's descriptions of professionals that had a particularly strong influence on her experience:

55. *Social workers, not really helpful, but key workers, yeah...*

Hannah spoke positively about getting a key worker (Hannah appears to use the titles 'key worker' and 'support worker' synonymously to describe one person), who she experienced as helpful primarily because she felt that he was an advocate and support:

53. *but having a key worker is helpful... someone who can vouch for you, speak to you...*

However, Hannah's experience of social workers was less positive, and the result of negative experiences, such as when the school raised safeguarding concerns, and when she experienced domestic violence. She described the difference between social workers and key workers:

56. *But the way that they go around it it's... it's the way they speak to you... it's the wordings that they word, the way they make you feel, it's different. Social workers are there obviously to, not judge you, but to know every aspect of your life... with the social er support workers, they're there to support your life.*

58. *It's mad, I mean, social workers are meant to be there supporting you and your family, but they're more authority... so they more come in to like, to judge you in a way, that's the only word that I can really actually use... to judge you, to see what you are doing wrong, what you can change in your life, when you don't need to change your life...*

This split in how Hannah has experienced professionals could, again, relate to the theme of power, with key workers experienced as working with Hannah and being led by her, as opposed to social workers who were imposed on Hannah and perceived as judging.

At the end of the narrative, Hannah spoke about how she wished professionals would practice, and cited a desire for professionals to improve communication between them and have more empathy:

91. *for them to say that like, 'we understand you' and 'we haven't forgot about you' cos the wait list is so, understandably, long and like, 'we hear you'.*

Hannah's narrative suggests that she has experienced many professionals in relation to her concerns about Lily. She explained that doctors have dismissed her, school staff have opposed her views and social workers have judged her. However, she felt more helped by key workers, because they have listened to her, been led by her and been an advocate for her.

#### 4.4.6.2 Lily

Most of Hannah's experiences with professionals (included within the narrative) have been triggered by her concerns about, and relationship with, Lily. Indeed, Lily was present in the flat during the interview, and much of the sjuzet of the narrative was based around Hannah's interactions with Lily during the interview.

When I asked Hannah about where she felt her story began, she started talking about Lily's behaviours in relation to a diagnosable mental health condition:

12. *It started at two, when I... when she had OCD, well, to me she had OCD... different, weird traits. Instead of her talkin, she would scream at me, 'Arrrrg'.*

Throughout the narrative, it appeared that Hannah was expressing a belief that Lily has an undiagnosed disorder and that she would like for Lily to have a diagnosis:

27. *Why do I need a psychologist for one? I need her diagnosed with something because I can't... I can't be dealing with her anger. Cos her anger started to come out then... and if she didn't do it right, or like colouring in outside the lines, she would rip it up, 'Arrgh!' (speech very fast) And she wouldn't explain it, so like a psychologist could help... but I need other things as well...*

This frustration at being referred to a psychologist might be an indication that Hannah felt that the professionals located the 'problem' in Hannah, rather than Lily.

Throughout the narrative, Hannah explained the challenges she faces in managing Lily's behaviour, including references to 'the OCDs' and 'traits', which could be considered medical language, in line with her desire to get a diagnosis for Lily.

Hannah also referenced different sides of Lily's personality and behaviour, mainly in the sjuzet:

46. *Arrr, god help me... nah, it's alright, no, she's not that bad, this is happy Lily, which I can deal with, it's angry Lily that I don't understand... mad Lily and angry Lily that I can't deal with...*

Hannah appeared to compartmentalise aspects of Lily and alongside her reference to medical terms and diagnoses, this may be an attempt to separate Lily from her challenges and act as a form of coping for Hannah.

#### 4.4.6.3 Hannah

Another theme concerns how Hannah spoke about and portrayed herself. Hannah mentioned being a 'young mum' multiple times. This appears to be linked to her lack of empowerment, both in relation to how professionals treated her, and the authority she has internalised:

49. *... It's been hard... it's been frustrating... because, I'm not that kind of person... see, over the last six years I've become a bit more experienced... but when I first got with them, when I first decided to ask... everyone just... looked down at me, or I felt they did... and, the way they spoke to me, I mean because everything, I didn't know professional talk much, and I mean obviously for me, for over the six years I've realised that their kind of talk is not being nasty, it's just the way to be professional, the way they word their words, do you know what I mean? I've kind of grown into that, but it's very frustrating, very frustrating...*

Here, Hannah linked feelings associated with treatment from professionals with a concept of herself as inexperienced. At the start of the narrative, Hannah spoke about having experience with parenting through having had her eldest child when she was

young and looking after cousins as she grew up. She explained how this offered her insight into Lily's presentation:

14. *So yeah, I would look after all my little cousins, so I know different traits. My other cousin's got autism, one of them's mentally ill. So like, I've kinda, not diagnosed her but... you kind of look at the traits and realise...*

Similarly, Hannah spoke about other family members who have mental health issues, explaining how this increases her knowledge and understanding:

63. *... they say with trauma, it can you know, be a trigger and set off things. Like with my mum, my mum's been ill... and his mum's been ill, his mum's got severe bipolar...*

Hannah talked at length in the middle of the narrative about experiences that appeared to portray her as a person who cares for others. She spoke about looking after her cousins, and after an unwell neighbour called at the door she explained warmly how she looked after her:

70. *now they want to do a biopsy and she's scared... and her daughter lives, like far, and so... I'm her little, like, second daughter. She comes up, has a little cup of tea and a chinwag...*

Also in the sjuzet, Hannah spoke about rescuing cats and dogs, and through a slip (when talking about rescuing her dog), mentioned looking after other local children:

69. *Ahh, yeah, I rescued him...yeah... I rescue a lot of children... children!?*

*(both laugh)*

*Ahhh, feels like it in this block...*

As well as passages where Hannah appeared to present herself as a carer, there were also passages where Hannah talked about her behaviour in a less positive way:

34. *... I'm getting her to school, and I've, I've shouted and (small laugh 'huh') got, got aggressive...*

50. *... and they never ring you back... and then when you do start ringing them back you do start to get aggressive, in a way, because I'm putting a tone on because I've had enough...*

These passages described Hannah's behaviour in response to the stress and frustration of Lily's behaviour and professionals.

#### 4.4.6.4 Voice

At the start of the interview, Lily interrupted Hannah, and Hannah responded by likening the narrative interview with Lily's therapy sessions:

7. *No, look, boo, come on now darlin'. I've said this, do I do this in your place, when you're talkin' to Sharon at XXX (names CAMHS service)? Do I?*

*Lily - Yeah!- Is this your XXX (names CAMHS service)?*

*(Laugh), yeah*

This aside to Lily appeared a light-hearted comment; however, it may suggest Hannah viewed the narrative interview as potentially therapeutic or an opportunity to be heard. Hannah's frustration at not being listened to or understood by professionals is a dominant theme in the narrative, and it may be that Hannah wanted to take part in this research project as it offered an opportunity for her voice to be heard by a professional.

Later on in the narrative, Hannah became increasingly frustrated by Lily's interruptions:

77. *Lily – Is it recording?*

*Yes! Darling, it's recording me, asking me how I feel about you and all these services...*

This passage fell within an extensive section of sjuzet, as Lily interjected and Hannah attempted to distract her. It may be that frustration with being prevented from being heard is mirrored in both Hannah's experience with professionals and her experience

in the interview. This may be further reflected through Hannah's description of difficulty in communicating with Lily:

46. ... you can never get through to her...

Indeed, Hannah also spoke about frustration with not being heard at a more functional level:

37. ...I can't really understand my social worker *in a kind of way, on the phone, because she's French African, and oh, the barrier's a bit, thingy...*

38. ... *Plus, my phone's a bit broke too...*

The more substantial passages included in this theme revolve around how Hannah felt she had not been heard by professionals (described in the 'professionals' theme).

Hannah spoke positively about her support worker, detailing how he helped her 'vocal wise'; recognising that professionals only listen to other professionals.

Hannah spoke about the support worker in a positive way, although this is described in relation to Hannah's sense that she was not able to do this herself. Hannah's positioning will be explored in more detail later in this analysis.

#### 4.4.7 Categorical-Form Analysis

Given the high volume of *sjuzet* in Hannah's narrative, this was analysed alongside the *fabula* in the previous layers of analysis. It therefore did not feel necessary to complete a separate analysis of the *sjuzet*. However, Hiles and Cermak (2008) noted that this layer of analysis can also consider linguistic features, which had not yet been examined in-depth in this analysis.

During my transcription of Hannah's narrative, I noted that on some occasions in the narrative, Hannah's speech became fast, and on two occasions she laughed briefly as she spoke, punctuating her narrative. The first passage when Hannah laughed in this

manner was as she spoke about an incident where Lily stabbed her sibling with a fork:

21. *Then, the only time that they actually (slight laugh) did listen to me was when she stabbed her, with a fork, my eldest child...*

The next time Hannah did so is when she described an incident that led to Lily's school raising safeguarding concerns to social services:

*... I'm getting her to school, and I've, I've shouted and (small laugh 'huh') got, got aggressive and they've thought that I can't handle it... when it isn't.*

35. *When you've got a child who constantly (emphasised) has got an obsession with certain things and the way you're doing it, and if you're not doing it right... and if you're tired... you do snap (speech very fast). I've never screamed, never been like, nasty in that kind of way. I've shouted in the street, and sayin to her, when she's far away, 'hurry up, we need to get to school'.*

36. *So, the school said to me that I needed to get... well... they safeguarded me...*

As well as the laugh, Hannah's speech became very fast, with short sentences as she described an experience that, as with the fork stabbing, may have been stressful and anxiety provoking for Hannah (both at the time and in re-telling the story). Hannah's speech became fast again as she described exacerbation at wanting a diagnosis for Lily. Hannah again laughed when she explained how Lily's school wrote a report blaming Hannah's parenting for Lily's difficulties; this again may have been a difficult experience, potentially emphasised by the presence of a laugh.

Upon re-listening to check that I felt the laughs Hannah gave were similar, I noted that she laughed briefly again as she listed the reasons why she has been allocated social workers:

55. *I've had three social workers in the last year, the first was for my eldest's dad. Erm, the second one was for her dad too (laughs as Lily shouts), oh my god, they're all from her dad...*

In another part of the narrative, Hannah alluded to experiences of domestic violence regarding her previous partners. As with the aforementioned passages, it may be that Hannah's laugh indicated a level of anxiety or the punctuation of a difficult part of Hannah's narrative. Towards the end of the narrative, Hannah responded to Lily's increasingly excitable behaviour (during the interview):

79. See, she just don't calm down, a normal child calms down, you know (laughs) ahh, I shouldn't laugh, it makes her worse, but you know, sometimes I've just got to laugh. I just don't know what to do...

Here, Hannah herself linked her laugh with an acknowledgement that it may be a laugh out of exasperation, rather than happiness or humour. There were other instances where both Hannah and I laughed together, and this led me to consider my position in Hannah's narrative and what this might mean about Hannah's position. I therefore moved into a critical analysis phase of analysis.

#### 4.4.8 Critical NA

At the end of the previous layer of analysis I reflected on points in the sjuzet where I am drawn into the narrative, such as when we laugh together in response to Hannah making a slip about rescuing children (passage 69). This shared laughter also occurred when Hannah joked with me about having children:

88. Have you got kids?

I – No...

Don't!

(both laugh)

Similarly, when Hannah's dog entered the room, Hannah asked me if I have a dog, and we had a few exchanges (in the sjuzet) about this. I am also brought further into the narrative by Hannah when she asked whether I knew certain professionals. Upon

re-reading the narrative, I was left curious about how Hannah had positioned herself in relation to me in the narrative. Before opting into this research, Hannah knew that I was completing professional training to become an EP, and was based at a clinic attended by Lily and herself, and she requested that the interview take place in her flat. As identified in the previous layers of analysis, Hannah's relationship with, and feelings about professionals form a dominant theme in her narrative, and she specifically spoke about psychologists at one point:

27. *Why do I need a psychologist for one?*

As discussed in the 'holistic-content' analysis, Hannah spoke about holding knowledge through her experiences, but felt silenced by professionals. Hannah documented frustration and negative experiences about professionals, as well as more positive experiences with a key worker. It is not possible to infer how Hannah positioned me with regard to her feelings about myself as a professional; however, this may be linked to Hannah's motivation in participating in the research. As described in the 'holistic-form' analysis, Hannah may have been motivated by a desire to be heard and to improve the service and system of professionals she has encountered. Although Hannah's motivation cannot be assumed, it may be that by drawing me into the narrative (and her home), she was attempting to create a space for her story to be fully heard by a professional, which is something she reported difficulty with in the past: *they just don't listen* (passage 23).

#### 4.4.9 Member checking

After completing the transcription and analysis, I arranged a second meeting with Hannah. I explained to her that the narrative she had offered was considered unique to her experience at that point and that she could read and reflect on the interview

transcription. She read a clean copy of the transcript and explained that she did not wish to make any changes. I then offered Hannah the opportunity to discuss the themes from my analysis. She explained that she did not wish to do this. She added that she would like a copy of the research in the future if it is published (in a condensed form). I confirmed to her that if it was published I would contact her and arrange to send her a copy.

#### 4.4.10 Summary of the analysis of Hannah's narrative

Identification of the *sjuzet* and *fabula* led to the holistic-content analysis, which examined how the theme of power emanated throughout Hannah's narrative, both in relation to a sense of powerlessness in the face of professionals and in relation to her own knowledge and experience (which may have engendered power in Hannah).

This sense of power through experience was noted at the start and end of the narrative, which led to analysis of the form of the narrative. The holistic-form analysis drew attention to a circular form that provided insight into potential motivations for Hannah's involvement in the research. At the categorical-content phase of analysis, the holistic theme of power was further explored through specific themes around Hannah's experience of professionals, her narrative around Lily (including Hannah's belief that Lily has a diagnosable condition), how Hannah conveys herself in the narrative (including as a carer and a young mum) and a theme relating to Hannah's voice (again related to power).

Due to the significant role of the *sjuzet* in Hannah's narrative, the categorical-form analysis involved analysis of this in greater detail. Here, it was suggested that aspects of Hannah's speech and laughter may have indicated some discomfort around familial memories. The critical NA stage drew attention to how I, the researcher was drawn

into the narrative, including what implications this might have for our respective positioning. This and other aspects of the analysis will be discussed in more detail in the discussion chapter, where themes will be tentatively situated amongst existing research and theory.

## 5 DISCUSSION

### 5.1 Chapter outline

This chapter draws together a discussion of the research findings and methodological issues relevant to the research. It begins with a discussion of the research findings, including exploration of how the analysis findings relate to relevant existing research and theory. This starts with discussion of themes that arose in David's narrative, including the idea of defending against anxiety and his experience of the diagnostic process. Discussion of themes that arose in Hannah's narrative include: seeking a diagnosis, relationships with professionals, positioning, power and socio-cultural influences. Some themes discussed in relation to psychological theory are pertinent to aspects of both David and Hannah's narrative (such as power, unconscious processes and socio-cultural factors). The implications of these findings for EP practice are then discussed, specifically with regard to consultation, ontology, epistemology, hermeneutics and parental voice.

The discussion then examines pertinent methodological issues; detailing strengths, limitations and reflection on the methodological choices made. The chapter then moves onto a reflexive account, with particular consideration given to my positioning and reflection on practice throughout the process. The chapter concludes with planned dissemination of findings and potential implications for future research.

### 5.2 Discussion of findings

In order to discuss the findings of this research, it was important to revisit the research question:

**What is the experience of parents whose children have been referred for an ASD assessment?**

It was also important to revisit the ontological and epistemological position, as this defines how the findings of this research are framed. This research falls within a relativist, social constructivist paradigm (Gergen, 1999) and therefore proposes that individuals mentally construct the world, but do so largely with categories supplied by social relationships. This means that there is no belief that a 'truth' can be revealed or defined, and that individuals construct their own unique meaning (Gergen, 1999). Riessman (1993) highlighted the importance of hermeneutic transparency in NA, although for analysis and discussion of findings to occur, she conceded that a degree of interpretation is inevitable.

Due to this paradigm, the analysis was completed inductively, although pre-reading of varying NA methods was completed to provide a background knowledge base. For this discussion, where appropriate, links will be made with how these themes resonate with themes in existing theory and research. Epistemologically, this research resides in a social constructivist frame, which invalidates the endeavour of seeking commonalities between individual's experiences. However, it is acknowledged that this research is contributing to a body of existing narrative studies, and that an element of comparison and situating is necessary. As well as situating the analysis of this research among the research reviewed earlier in this thesis, this chapter will take the interpretation process a step further and will endeavour to offer tentative links with psychological theory. It is acknowledged that this takes the discussion away from its constructivist stance, and that such links are influenced by my personal interpretation, lens and experiences.

Riessman (1993) argued that when analysing an individual's experience, the researcher must avoid the tendency to read the interview simply for content or as

evidence for theory, as this downplays the individual experience. However, she added that although a narrative approach must privilege the teller's experience, interpretation cannot be avoided. Therefore, this discussion privileges the narratives of David and Hannah and themes are discussed in the temporal sequence they occur in the narrative. The themes are referenced in relation to the themes and discussion of previous research and related theory. This approach aims not to present an incontestable 'truth', but to situate this research in its field and present its unique position and contribution.

Unlike a grounded theory approach, this research does not attempt to create a theory through the findings and it is beyond the scope of this research to complete further literature reviews in response to the data. In line with the analysis and constructivist lens, the findings of each narrative are discussed individually, with no aim to establish commonality between them.

### 5.2.1 Discussion of David's narrative

#### 5.2.1.1 Split between accounts of Jay and his difficulties

In David's narrative, the theme of a split between how Jay was experienced at home by his Dad and at school by professionals was prevalent throughout the layers of analysis; including the holistic theme (separation and closeness), categorical-content (Jay's strengths and difficulties, professional hypotheses) and critical NA (David's position in relation to professionals). In their grounded theory research, McKenna and Millen (2013) concluded that educators can hold misconstrued perceptions around children and parenting, disconnected from the reality of students' home lives. This finding may resonate with David's narrative; where there appeared to be distance between David and the professionals he has had involvement with. McKenna and Millen (2013) also discussed power-imbalances between parent-

educator partnerships, with a belief in schools that the parental role is subordinate and primarily to support the teacher. David's narrative may suggest that his experience was in line with this, with a distance and perceived power imbalance, as conveyed in his cited reliance on '*experts*' (line 58). This suggests that his relationship with professionals may not have been equitable and collaborative.

In the analysis, the theme of separation was discussed in relation to David's distancing from professionals and Jay's difficulties. Towards the start of his narrative, David mentioned '*the Asperger's thing*' (line 27), and alluded to the fact that Jay has had multiple assessments. However, he did not talk about the diagnostic label when he discussed Jay's needs and vulnerabilities at length towards the end of the narrative, even referring to personal language he uses to describe Jay's behaviours: '*ticks I call them*' (line 76). This limited use of medical language suggests a contrasting finding to that of Mackay and Parry (2015), who concluded that parent and child narratives appeared influenced by medicalised versions of ASD.

Abrams and Goodman (1998) suggested that professionals shied away from the explicit use of labels, whereas parents reported a more positive experience when their children received unambiguous labels. David's limited reference to diagnostic terms may indicate that he has not experienced labels for Jay as helpful, and instead appeared to align their use with professionals.

Although David made limited reference to diagnostic labels, the analysis suggested that he may have separated himself and Jay from professional hypotheses and accounts of Jay's behaviour. Lawson, Boyask and Waite (2013) reviewed research on the construction of difference and diversity in education, concluding that adults around children can use labels in an attempt to locate the 'problem' away from their

sphere of influence. They gave the example of teachers using labels as a means to placing the ‘problem’ within child rather than within their pedagogy, possibly to avoid the potential anxiety. It may be that in a similar vein, David distanced himself from the ‘problem’ as a defence against the anxiety he experienced regarding Jay and particularly his future, attributing the use of labels to professionals.

#### 5.2.1.2 Splitting as a defence against anxiety

Throughout the layers of analysis (including the holistic-content theme of separation and closeness, the categorical-content themes of: decisions and change, worry and not knowing and symbiosis, the categorical-form analysis and the critical NA), there were aspects of David’s narrative that indicated that he may have experienced some anxiety regarding Jay, his needs and his future independence. In the narrative, this was accompanied by repeated assertions by David that Jay needs him. It may be that there is an element of projection of feeling from David onto Jay, with these assertions possibly indicating that David himself does not want to be separated from his son.

Splitting is frequently cited in psychodynamic theory as a defence against anxiety, referring to a mental process that enables people to make distinctions and integrate experiences (Burgo, 2012). Melanie Klein developed Freud’s ego psychology through a focus on the self in relation to ‘others’ in the environment; formulating ‘Object Relations theory’. In this theory, ‘others’ or ‘objects’ are real people or internalised images (Waddell, 2005). Klein observed how infants initially understand objects as part-objects in terms of their function, such as the ‘good’ available breast and the ‘bad’ unavailable breast, with infants therefore inhabiting a split world. Over time and through an emotionally supportive environment, Klein (1946) explained that children can reconcile, tolerate and integrate split aspects of the same object. Klein

(1946) described this integration as a move from a split, paranoid-schizoid position to an integrated depressive position. Movement between these positions is considered to be dynamic throughout life, with a move into a paranoid-schizoid, split state when anxiety is high and unwanted feelings become unbearable (Klein, 1946). Therefore, within this theory, splitting becomes a central mechanism for dealing with unpleasant aspects of the self and objects. Klein explained this further as splitting of objects and splitting of the ego (Klein, 1946). Splitting of objects refers to when qualities or intentions of others are attributed as either all good or all bad. Splitting of ego refers to the splitting off of unwanted or feared aspects of the self, which are then projected out and attributed to others.

Projection is a related psychodynamic concept, which has varying definitions.

Potentially pertinent to David's narrative is Freud's association of projection with expulsion (Freud, 1895 cited by Spillius, Milton, Garvey, Couve & Steiner, 2011), where it is suggested that people transfer repressed or unwanted feelings onto others. In 1946, Klein introduced the mechanism of projective identification as a process whereby the receiver of the projection takes the projection on and experiences the feelings as though they belonged to them. This process is also referred to as counter-transference (Salzberger-Wittenberg, 1970).

Through a psychodynamic lens, it may be hypothesised that David had experienced some splitting of the ego; with unwanted feelings around Jay's needs and David's anxiety around separation from him being split off. Such a defence might have allowed David to expel his fears around the future and Jay's increasing independence, and prompt them to be attributed to Jay, evidenced through his repeated use of the phrase '*he needs me*'. Furthermore, it may be that such projections are being 'taken

up' by Jay, enacting projective identification, such as when David explains that Jay would like to complete his work experience with David (line 126). However, as this analysis only included David's narrative, it is not possible to know whether Jay has taken on the projection, or whether such a process is indicative of David's experience and unconscious defensive processes.

The defences of parents have been documented in research as influencing parental narratives and the experiences of their children. Karpelis (2010) completed a case study where a psychodynamic approach to clinical social work practice facilitated intervention with a father whose child suffered from separation anxiety symptoms. Following his clinical work on the case, Karpelis (2010) concluded that the father, through projective identification, had unconsciously projected his own vulnerabilities and fear around separation and loss onto his child, who formed a receptacle for her father's unbearable emotional state and 'took on' the projection, enacting it through behaviours that presented as separation anxiety disorder (Karpelis, 2010). The author's intervention involved working with the parent, acting as an infant caregiver to receive the projections and allow space for processing them, prompting a more integrated parental experience. Through this space, the father was able to enhance his understanding of his dependency needs, freeing the child from the projections and prompting the end of her 'symptoms' (Karpelis, 2010). While this case study involves documentation of a therapeutic case, the influence of the unconscious processes of ego splitting, projection and projective identification on both parental and child experience is highlighted, as may be suggested in David's narrative.

David's anxiety about the future and not knowing were central themes throughout the analysis of his narrative. This was also a dominant theme in the analysis of Desai et

al. (2012), who characterised the narratives they analysed as displaying sequential themes. In the third phase identified, parents were reported to become concerned about their child's fate and eventual place in adult society. Specifically, they described how parents portrayed the long-term future as a distant and uncertain horizon and how they held concerns around the possibility that their child's strengths and needs may preclude capacity for self-care, social-relationships and education. This finding resonates with David's narrative, where he spoke specifically about Jay's difficulties with self-care, social interactions and uncertainty around Jay's school experience. Desai et al. (2012) relate this anxiety around their child's 'normalcy' to the point at which parents observed their child entering the outside world (around adolescence). Again, this resonates with aspects of David's narrative, where he gave descriptions of times when he noted Jay's vulnerabilities when interacting with the 'outside world', such as when talking to strangers online and to homeless people in the street.

The next phase in Desai et al.'s (2012) thematic stages described how parents aimed to accept their child's limitations and develop them realistically in relation to given social realities, and to attempt to change the social realities so they would become more welcoming for their child. This may also be related to aspects of David's narrative, as he described how influencing Jay's environment and keeping him close ensured that he is safe (such as writing Jay signs and attempting to arrange work experience with him). This links back to the dominant themes of separation, closeness and symbiosis that were identified inductively as consistent threads woven throughout David's narrative.

Despite these potential unconscious processes and feelings of anxiety, David presented an integrated description of Jay's strengths and needs. David mentioned that Jay had some social difficulties (such as being overly trusting), and had some anxieties (such as his fears and 'ticks') that are each in line with the features of ASD (Simpson, 2008), yet David did not link these with a label or diagnosis. This may resonate with the NA of Hines et al. (2012), who suggested that the parental narratives they analysed presented a notion that their child's 'true nature' was 'buried' under the ASD. This may link with how David appeared to separate the medical or professional view of Jay from his own experience of him, although David did not reference a belief that Jay is affected by the potential label or disorder.

The split identified early in David's narrative between Jay's presentation in his early years as '*textbook*' at home, yet a '*handful*' at school (both line 8) contrasts with the findings of Howlin and Moore (1997). This study found that parents of children later diagnosed as autistic first cited their initial anxieties to have been felt in the child's first years of life, mainly around language and social skills. However, David's description of Jay's early years does appear aligned with the findings of Desai et al. (2012), which described how the earliest phase of the child's life was a period of 'relative normalcy'. These variations in narrative accounts highlight the unique experience of individuals, emphasising the importance of a relativist stance when completing NA.

#### 5.2.1.3 The diagnostic process

A theme that arose in David's narrative that was also mentioned by Ho et al. (2014) and Howlin and Moore (1997) is that of frustration at the lengthy diagnostic assessment process, potentially influencing the ambivalent feelings discussed in the

critical NA stage of the analysis (within the theme of David's position in relation to professionals). Indeed, at the end of David's narrative, he stated:

*141. ... this process, like I think people need to know that it's not quick, or clear really, you go round the houses with it all a bit...*

This may indicate that David's motivation for sharing his narrative arose partly through a desire to communicate the ambiguity and frustration of the diagnostic process, which is in line with the NA findings of Ho et al. (2014). This also links with the findings of Fleischman (2004), who suggested that the parents in their study may have published their narratives online to help other parents.

DePape and Lindsay's meta-synthesis (2015) reported that parental experience of the pre-diagnosis stage varied greatly between individuals, but they highlighted a theme around the common misdiagnosis of hearing difficulties rather than social communication needs. This appears in line with David's narrative, as he noted an early professional hypothesis around Jay having glue ear. DePape and Lindsay (2015) also documented the impact of the diagnostic process on parents' physical, emotional and cognitive health. As discussed in the NA, David did not reference his health, with reference to his own wellbeing mainly occurring at the start as he described the difficulty of maintaining a job while managing Jay's difficulties at school. This may align with the theme of a 'balancing act' between promoting the wellbeing of parents and their children, identified in the NA of Hines et al. (2014). In David's narrative, this balance was eventually tipped, with David deciding to move to be with his mother so that he could manage Jay and maintain a job.

As discussed in the literature review, the majority of the existing narrative research in this area included parental narratives post-diagnosis. This difference from the current

research may be reflected in the differences in the themes identified that relate to the narrative form. Fleischmann (2004) used Labov's methodology (1972) and analysed the narrative data temporally. The analysis indicated that overall, parental narratives began positively (with warm anecdotes and descriptions of their child) and ended positively, with empowered themes indicating a sense of parents having regained control and reached their children by successfully meeting the challenges that ASD presents. Fleischmann (2004) discussed the analysis through examination of transformation in parents' coping, concluding that the ASD diagnosis constituted a 'turning point' for parents, leading to more positive perceptions of their own efficacy and a more positive perception of their child. These narratives appear to differ from the form of David's narrative, and this may relate to the stage that David was in (pre-assessment). Although David's narrative included many warm accounts of Jay, these descriptions (found particularly towards the end of the narrative) are tempered by reference to Jay's vulnerability and David's anxiety about the future.

### 5.2.2 Hannah's narrative

#### 5.2.2.1 Seeking a diagnosis

In the analysis of Hannah's narrative, it was noted that she began her story with language that may be considered medical, referencing 'OCD' and 'traits' (lines 12 and 61). Furthermore, there was a theme throughout the narrative suggesting that Hannah may have located the difficulties she encountered with Lily as residing within Lily, resisting suggestions from professionals that the difficulties may be alleviated through work with Hannah, rather than through assessment of Lily (specifically evident in the categorical-content themes of professionals, Lily and voice). Mackay and Parry (2015) noted that the narratives of parents they analysed contained a high level of medical language, and concluded that the parents had arguably been

influenced by the medical and psychological perspectives that ASD has evolved through. Furthermore, they suggested that this medicalisation had led parents to problematise children's behaviour as pathological. This finding may resonate with Hannah's narrative, and also relates to Hannah's explicit desire to obtain a medical diagnosis of ASD for Lily.

Hannah's wish for a diagnosis for Lily also correlates with the findings of Abrams and Goodman (1998) who suggested that, while professionals shied away from the explicit use of labels, parents in their study reported a sense of satisfaction upon receiving a diagnosis for their child. As with Hannah, the parents in this study also reported frustration at being made to wait by professionals and by being given evasive answers.

#### 5.2.2.2 Relationships with professionals

In Hannah's narrative, themes around her relationships with professionals ran throughout the layers of analysis (including the holistic-content theme of power, the categorical-content themes of professionals and voice and the critical NA). These are linked to Hannah's experiences, her sense of being heard, and possibly her motivation for taking part in the research and the positioning of herself and I in the narrative.

A dominant theme highlighted in the analysis of Hannah's narrative is the sense that she felt she has been judged and dismissed by professionals. McKenna and Millen (2013) described how their parental participants inadvertently demonstrated a lack of agency in communicating with teachers and schools. They explained that the parents appeared to be responding to an embedded belief in 'teacher as expert', which unintentionally led to a shared belief that parents are less capable of knowing and sharing information, demonstrated through behaviours such as expecting

professionals to initiate communication. In her narrative, Hannah referenced her attempts at sharing her beliefs with school staff and described how she was ‘brushed off’ and corrected. McKenna and Millen (2013) also described how their participants reported more negative school encounters and communications than positive ones, including reference to frustration at an inability to reach teachers on the phone. In the analysis of Hannah’s narrative, attention was paid to how Hannah’s struggle to get phone contact with professionals was coupled with being made to wait indefinitely, linking with the aforementioned power imbalance.

Hannah also referenced being judged by professionals, and talks about her attribution of this to her status as a ‘*young mum*’ (line 86). McKenna and Millen (2013) argued that the erroneous assumptions professionals can hold about parents are particularly harmful when combined within the context of a vulnerable group (such as those on low-incomes or from minority groups), as they have fewer opportunities to prove the assumptions wrong. This point prompts discussion around the position of Hannah’s narrative in the context of the research project, and how it may have offered an opportunity for Hannah to rebut some of the assumptions she has experienced. The potential impact of socio-economic status and culture will be discussed in more detail later in this chapter.\

The categorical-content analysis of Hannah’s narrative suggested a split between how Hannah experienced different professionals, with some portrayed as all good (the keyworker such as in line 56) and some as all bad (social workers such as in line 58). This may be an enactment of splitting (as aforementioned in the discussion of David’s narrative). Hannah may be demonstrating a splitting of objects (Klein, 1946), where Hannah is attributing wholly good and wholly bad qualities and intentions to others in

response to residing in a paranoid-schizoid state (Klein, 1946) due to anxiety around Lily and her needs.

Pellegrini (2010) completed a study into the use of psychodynamic theory in educational psychology; specifically, how splitting and projection can manifest within education and EP practice. Pellegrini (2010) explained that split labelling of professionals is common in education, documenting a case study where a mother described her child's class teacher as good, but projected anger onto all other staff, asserting that her son's needs were not being met. Pellegrini (2010) hypothesised that the mother was unconsciously utilising splitting and projective mechanisms as a defence against anxiety around the child's difficulties and needs, which were also being witnessed at home. This case study may resonate with Hannah's narrative, where she appears frustrated and challenged by Lily, and may project these unwanted feelings out, splitting professionals into good and bad.

As outlined in the analysis, as well as describing her own experiences with professionals, Hannah also included suggestions for how she felt professionals could 'improve' their practice; primarily around better communication from and between professionals. Loukisas (2016) and Fleischmann (2004) analysed the narratives of parents who had posted their stories online. Fleischmann (2004) reflected on what motivated the parents to do this and concluded that it may have been a combination of altruism and the desire to help others, but also that the process of publishing their narrative online may have offered a therapeutic opportunity. It may be that, in a similar vein, Hannah's motivation for opting into this research was altruistic, an attempt to inform other parents and also to support the development of service delivery. Indeed, the theme of 'Hannah as carer' arose through the narrative with

reference to her caring for family members, animals and neighbours. The idea of the sharing of a narrative being experienced as therapeutic was also present in Hannah's narrative, as she compared the narrative interview to Lily's therapy at the clinic.

Unlike the aforementioned studies that analysed online narratives (Loukisas, 2016 and Fleischmann, 2004), Hannah's narrative was also shared within the context of the research project, which offers further potential insight into her motivation and positioning. Through the analysis of the *sjuzet* of Hannah's narrative and the critical layer of analysis, it was noted that Hannah actively brought me into the narrative on several occasions. In the analysis, this led to reflection on how Hannah positioned me, both with reference to me as a researcher and as a professional.

#### 5.2.2.3 Positioning

Positioning was analysed and discussed as part of the critical NA in both narratives. Harré (2015) stated that traditional methods of psychology research tend to pass over individual patterns of action, yet people are constantly constrained by their beliefs about the context they exist in. From this stance, Harré (2015) describes 'positions' as beliefs about the rights and duties of individuals in specific moments and contexts; drawing on philosophy and systemic theory. In this frame, positions are implicitly and explicitly ascribed to individuals by reference to powers and vulnerabilities. As a cited 'sister discipline' to narratology, Harré (2015) cited that this approach may be a relevant lens through which to discuss positioning in Hannah's narrative. Harré's (2015) definition of positions prompts reflection on the beliefs that Hannah may have held regarding the rights and duties perceived in the specific context of the research interview. As discussed in the analysis of Hannah's narrative, a dominant theme was that Hannah appeared to feel silenced, ignored and dismissed by professionals,

possibly indicating a perceived enforced disempowerment in the context of Hannah seeking a diagnostic assessment for Lily.

It may be that Hannah's view on the potential 'rights and duties' of a position in the research project meant that she felt it was an opportunity to move into a more empowered position. When invited to take part in the study, Hannah was made aware that I, the researcher, was a trainee EP at a local clinic. In Hannah's narrative, she stated that she has had contact with professionals from the same clinic, and had been referred to a psychologist. The invitation to opt into the study included an explanation that it was an opportunity for parents to share their stories and it may be that (consciously or unconsciously), Hannah opted into the study and invited me into her home as an opportunity to move into a position where the 'right' of the participant (Hannah) was to voice their story and it was the 'duty' of the researcher (the professional) to listen. When I met Hannah for the second time to share my transcript and initial analysis, I felt that she presented as more quiet and withdrawn. She read through the transcript but declined the opportunity to discuss my analysis. This meeting was not transcribed or analysed as part of the NA, therefore interpretation, discussion and reflection on this meeting is detailed in the reflexive section later on in this chapter.

#### 5.2.2.4 Power

The theme of power ran through my analysis of Hannah's narrative (in all layers of analysis) and is linked to the discussion on positioning. In Hannah's narrative, she spoke about feeling silenced by, ignored and made to wait by professionals; and may have used the narrative interview as a space to be heard. The idea that the professionals Hannah has encountered may have exhibited or enacted positions of

power prompts reflection on how power in a wider sense may be understood within the context of Hannah's narrative. Indeed, the theme of power associated with professionals is also present in David's narrative.

Foucault theorised and discussed notions of power in relation to discipline, punishment and how the power of the individual relates to the control of the government (1977). Foucault (1977) cited Bentham's nineteenth century prison reform proposals as a representative model for what happens in society. The model of the 'Panopticon' posited that the 'perfect' prison would be structured in a manner where prisoners believe that they could be being watched by guards all the time, but have no way of knowing whether they are (Foucault, 1977). Following this model is the notion that if people believe that they could be watched at any time, they quickly internalise the 'panoptic' and police themselves. Foucault (1977) questioned how this model of organisation enforces 'normalcy' onto increasing aspects of people's lives, creating a society of:

*'the teacher-judge, the doctor-judge, the educator-judge, the 'social-worker'-judge; it is on them that the universal reign of the normative is based...'* (pp. 304).

This concern may resonate with Hannah's experience, as she documented the feeling of being judged by professionals and mentions all of the professions listed in the above quote by Foucault and adds more (including psychologists). It therefore may be that, in opting into this research, Hannah was claiming back some power that she has felt deprived of through her interaction with professionals. In discussing Foucault's ideas, Clegg (1998) explained that there is not a dichotomy in the discourse of power. He argued that central to Foucault's conception of power is its shifting, unstable expression, where points of resistance are at the forefront of its

presentation. This notion of power as a complex and dynamic phenomenon operating throughout interaction at a societal level may offer a potential context for interpretive consideration of both narratives in this study.

Furthermore, such discussion on power by Foucault (1977) was linked with discussion on knowledge, with the two concepts connected. In the analysis of Hannah's narrative, the same was established, with power and positioning related to knowledge throughout the analysis; most significantly in the holistic-form analysis where Hannah conveyed a sense that her knowledge could inform the practice of professionals.

Although this interpretation and framework moves this discussion away from a constructivist towards a constructionist epistemology, the relation of professionals to invasive surveillance and power may be helpful in understanding potential processes that influenced Hannah's narrative and offer implications for professional practice. An ethnographic study by Lavelle (2015) drew on the ideas of Foucault and the concept of governmentality in her research into the parental '*right to a cup of tea*' (Lavelle, 2015, pp.1) in Sure Start children's centres. Lavelle explained how the children's centres formed a modern Panopticon, where parenting practices were exposed, but also where new knowledge was produced and enacted. Foucault (1977) referenced domains and enclosures that are central to the dispersal of power and regulatory practices, which are essential for the state to maintain control and authority. Lavelle (2015) described how children's centres offered an example of this, with such centres and staff not only becoming instruments of power (government at distance), but also a model of power, bridging between the welfare state and the family as a site of discipline and self-regulation. It therefore could be suggested that

many professionals form such a 'bridge' between the 'state' or 'government' and the intimacies of families, enacting the model of power and maintaining processes of surveillance and 'normalisation'.

While such conceptualisations of power may arguably not be within the control of professionals and EPs (indeed, in 1977 Foucault argued that power does not reside in individuals but is dispersed and pervades society), it may be useful for EPs and other professionals to consider such concepts of power when interacting with parents, especially when the interaction enters more intimate family settings. EPs and other professionals are often officers or representatives of government or state organisations (such as LAs or the health service), and the role of the 'expert' and potentially 'judge' are aspects for professionals to be mindful of when consulting with parents. In this vein, it could be argued that the endeavour of professionals or researchers to collect the narratives of parents in an open and inductive way (with hypotheses and discussion arising from the data) is futile; as it may be that the professional or researcher and parents are enacting the role of the unseen prison guard of the Panopticon and the prisoners.

#### 5.2.2.5 Socio-cultural factors

When considering the ethical implications of this research, it was acknowledged that social and cultural factors can influence qualitative data (Yardley, 2000). Therefore, aspects such as those included in the aforementioned social graces (Burnham, 2012) may have consciously and unconsciously impacted upon the narratives. The discussion above on power is inextricably linked to social-cultural factors that may have affected the dynamics, narratives and analysis. Indeed, Burnham (2012)

references the application of the social graces as crucial points of learning and reflection for practitioners.

Burnham (2012) devised a quadrant for consideration of the social graces that includes two dimensions: visible-invisible and voiced-unvoiced, documenting whether social aspects can be seen and spoken about. In Hannah's narrative, she included reference to a belief that she had been judged and dismissed due to her status as a 'young mum' (line 86). This may form an example of a voiced-visible example from the social graces, as Hannah voicing what is visible about her. Furthermore, at one point Hannah asked me whether I have children (line 88) and I replied that I did not. This may have altered the dynamic, as it was visible that I was of approximately the same age as Hannah, but do not have children, thereby drawing attention to a difference.

Similarly, there was a visible-voiced difference with respect to socio-economic status regarding housing. For Hannah's narrative interview, I went to her flat and she spoke informally to me about her desire to be rehoused in a larger flat, a visible-voiced notion offering insight into her family context and socio-economic status. David's interview was completed at the clinic as David and Jay were living in a hostel, awaiting accommodation- in explaining this, David was voicing an aspect of his family context and socio-economic status that might otherwise have remained unvoiced and invisible. Indeed, it may be that social issues such as housing may have impacted both on how the participants experienced professionals and on the narratives. Mills, Schmied, Taylor, Dahlen, Schuiringa and Hudson (2012) explored the experiences of professional staff working with young parents in a socially disadvantaged area. Their thematic analysis suggested that a fundamental challenge

in working with disadvantaged young parents was prompting their engagement. The authors highlighted how the parents only wanted to engage in parenting services and programmes if it addressed their needs- which may not relate directly to parenting but related aspects such as housing, money and employment (Mills et al., 2012). This highlights the importance of considering the effect that factors such as finance and housing can have on experience and engagement.

Families with a low socio-economic status are targeted by early intervention programmes for parents (Cottam & Epsie, 2014). Indeed in 2012, David Cameron announced free parenting classes for parents in deprived areas in an attempt to promote improved parenting and reduce the number of 'problem families' (Cottam & Epsie, 2014). The aforementioned Foucaudian discussion on power and the state warns against such state intervention in the lives of individuals, arguing that it is controlling and coercive (Foucault, 1977). Cottam and Epsie (2014) completed a Foucaudian analysis examining the discourses underpinning Parenting Training Programmes (PTPs) in an attempt to unpick the dilemma between professional and lay expertise and power. One discourse that emerged from the analysis (Cottam & Epsie, 2014) was that of victimhood; the authors suggested that such a discourse can position parents to lack personal agency and knowledge, requiring a saviour in the shape of the PTP professionals. Cottam and Epsie (2014) add that such a discourse may also lead to disempowerment and a sense of hostility and defensiveness towards their saviours. This may resonate with the narratives in this study, where David cited a reliance on 'experts' (line 58), and Hannah appeared hostile and defensive towards some professional involvement (such as line 27).

This discussion aligns with the discussion on power in questioning the experience of parents who have had significant involvement with many professionals, including how such involvement can be experienced as disempowering, denigrating and dismissive. Such a discussion is inextricably linked to discussion on aspects of the social graces (Burnham, 2012), as the current legislative and political context places value on the role of professionals in the lives of vulnerable and disadvantaged families in order to promote early intervention (CFA, 2014). Indeed, in her narrative, Hannah specifically mentions that she has engaged in parenting courses for two years (line 59); and both Hannah and David mention involvement with a myriad of professionals. As discussed in the critical NA and earlier in this chapter, such influences of power, knowledge and socio-cultural factors may have fed into the conscious or unconscious motivations of the participants opting into this research - a potential endeavour to seek power, enact knowledge and be heard.

### **5.3 Summary of discussion of findings**

Overall, this discussion has moved this research away from its constructivist core in an attempt to situate it tentatively amongst existing research and theory. Splitting was discussed in relation to difference in accounts of Jay, David's apparent attempts at distancing himself and Jay from his needs and the potential use of splitting and projection as unconscious defences against anxiety relating to Jay and his future. David's experience of the diagnostic process was found to share aspects with the findings of some existing research, including the notion of a lengthy and frustrating process (Ho et al., 2014).

Discussion of Hannah's narrative began with details of how Hannah's apparent use of medical language and desire for a diagnosis for Lily resonates with the findings of

Abrams and Goodman (1998) and Mackay and Parry (2015). Discussion of how professionals are included in Hannah's narrative was then outlined alongside research that shared notions of frustration and negative experience between parents and professionals (including McKenna & Millen, 2013). Furthermore, tentative links were made hypothesising that Hannah's suggestions for professional improvement may have been a motivation for sharing the narrative, as was documented by Loukisas (2016) and Fleischmann (2004). The psychodynamic concept of splitting with regard to professionals was also considered as a potential unconscious defence against unwanted feelings and experiences.

Building on the critical NA, aspects of positioning theory (Harre, 2015) were then drawn upon to offer potential insight into Hannah's positioning of herself and I in the narrative. This discussion led onto broader consideration of power (identified as a holistic theme in Hannah's narrative), linking Hannah's discussion of professionals with Foucaudian concepts of knowledge, power and governmentality. This discussion was then related to potential implications for the work of EPs and other professionals working between state and family systems. Following on from this, there was discussion of the role socio-cultural factors may have influenced the experience and narratives of both Hannah and David, including reference to the social graces (Burnham, 2012) and research into the potential impact of socio-economic status on parental experience of and involvement with professionals.

As explained in the literature review, this research aimed to explore the narratives of parents whose children were in the pre-assessment stage, placing it within a gap left by the existing narrative research. This discussion has illuminated how the narratives of David and Hannah shared some thematic ground with existing research, but also

presented as opposing in some areas. This further highlights the unique nature of narratives, and how their analysis needs to consider not only the content, but the context in which they were offered and any conscious or unconscious dynamics that may be at play in the research relationship. As articulated by James (1982):

*‘Probably a crab would be filled with a sense of personal outrage if it could hear us class it without ado or apology as a crustacean and thus dispose of it. ‘I am no such thing’, it would say; ‘I am MYSELF, MYSELF alone’ (pp. 9).*

The analysis has emphasised the importance of treating narratives offered as unique constructions between an individual’s past experiences, the current context (including at systemic and societal levels), and the relationship between the story-teller and receiver. This has implications for the role of researchers tasked with collecting spoken experiences, an area I will reflect on later in this chapter. These findings also have implications for professionals operating outside of research, who regularly receive, initiate and analyse narratives through their role.

#### **5.4 Relevance to the role of EP and other professionals**

As discussed in the introduction chapter, EPs regularly consult with parents, young people and professionals across a range of contexts (Wagner, 2000). Although the EP proficiencies (HCPC, 2012) cite the requirement of EPs to understand the theoretical basis of, and a variety of approaches to, consultation, research indicates that individual EP practice varies in accordance to their beliefs and values (Burnham, 2013). However, Boyle and Lauchlan (2009) explained that there has been a general shift of EP practice away from individual casework (such as a reliance on individual assessment of children), to more consultative ways of working. Working through consultation involves collaborative work between EPs and the adults who reside in the system around a child (Wagner, 2008). However, definitions and models of consultation vary, including potentially with regard to how inductive they are.

Nolan and Moreland (2014) analysed the 'delicate' process of seven EP consultations through observing and recording the consultations and interviewing the consultant and consultees. They analysed the content through discourse analysis. The conclusion noted that the use of such consultative strategies can provoke social, cognitive and emotional change, but warned that EPs must be mindful of positioning so as to ensure collaboration rather than residing in the 'expert' role, which could be considered a more deductive approach.

Evidence of imbalance in the discourse of EP consultations was reported by Lewis and Miller (2015) who completed a mixed-methods analysis of a complete transcript of a consultation between an EP and a mother who was seeking a statutory assessment for her child. The analysis revealed that the EP made significantly more requests for facts, information and opinions, and spoke more at the beginning and end of the consultation. The authors concluded that EPs must reflect carefully on power dynamics and positioning in consultations.

The narrative methodology, social constructivist epistemology and relativist ontology shaped all aspects of this research and promoted the endeavour to maintain the participants' narratives at the centre. This meant that the interviews contained minimal interviewer input and that the analysis arose inductively from the data. With regards to EP consultation, methods of consultation vary in how close they reside to this methodology. Indeed, there are a myriad of consultation frameworks situated within varying epistemological paradigms (Burnham 2013), some of which are outlined below.

Problem-Analysis is cited to be located firmly within the modern scientist-practitioner movement in applied psychology and is a systematic problem-solving

approach (Monsen & Frederickson, 2008). This model seeks to support EPs (and those in training) in understanding and managing the complexity of their work, guiding them in decision-making, problem-solving and action through the use of a set of pre-defined steps. This phased approach endeavours to attain clear conceptualisation of the 'problem', leading to focussed and specific intervention and evaluation (Monsen & Frederickson, 2008). This model of consultation appears to adopt a positivist epistemology, with an assumption that there is a 'truth' or 'problem' that can be established and overcome through the use of hypothesis testing, intervention and outcome monitoring.

It could be argued that a model of consultation that adopts a different ontology and epistemology is that of process consultation (PC). Schein (1999) developed a PC approach through an examination of the philosophy of helping. This approach rests on the assumption that consultation can only help a system to help itself. In contrast to an expert or doctor-patient model that involve clients bringing a problem or symptoms that can be diagnosed or solved, PC places the expertise with the client, with them owning the 'problem' and 'solution'. In this way, consultee and consultant come together with the aim of developing an effective helping relationship as a team (Schein, 1999). PC also discourages citing 'problems' in-child, encouraging shared exploration and reflection. This model of consultation is removed from positivist assumptions regarding a 'truth' that can be established, and recognises that roles and positions are dynamic and linked to context. Furthermore, a process approach starts from a position of 'pure enquiry', which seeks to elicit narratives in an inductive way, acknowledging that the client 'owns' the problem and the solution. This principle of putting the client's narrative at the centre of the consultation is more in line with a narrative methodology and social constructivist (or constructionist) epistemology, as

it could be viewed as more inductive, placing more emphasis on the narrator with an understanding that their story is a unique construction influenced by past experiences, context and the presence of the consultant.

There are a myriad of models of consultation and frameworks for EP practice and it could be argued that they each have contrasting ontological and epistemological perspectives. It is not the intention of this research to compare or preference models of practice. However, this research has highlighted the importance of reflection on how practice can be influenced by personal beliefs and paradigms. Through a relativist, social constructivist lens, individual narratives have been uniquely shared and analysed to offer insight into parental experiences. Through this process, reflection on my role as a researcher and therefore co-constructor of the narrative and analysis has been necessary and occasionally an uncomfortable experience (detailed later in this chapter). Therefore, it could be argued that whichever model or framework of practice EPs follow, reflection on what this means with reference to ontology, epistemology and personal belief system is important to allow for the data gathered to be analysed in thoughtful way.

The EP role involves eliciting narratives, analysing them and relating this analysis to existing research and theory (through formulation). The belief system of the EP will influence their practice and the outcomes (Burnham 2013 and Fox, 2003). In this research, I analysed the content, form, language and speech of the narratives, as well as considering the context and the role and position of myself, the participant and the research project. These may all be aspects that could offer insight into parental experiences during consultation, prompting personal reflection among EPs on conscious and unconscious process and dynamics that may influence how narratives

are shared and received. As well as reflection on how EP belief systems and epistemologies influence practice, it may also be pertinent to reflect on how the dynamic role of the EP and the wide-ranging tasks influence practice. It could be argued that some EP 'tasks', such as assessing children for exam arrangements, offer less opportunity for an inductive or narrative approach. Indeed, research by Osborne and Alfano (2011) suggested that in EP consultations, parents and carers value both opportunity to talk through their anxieties, but also value the more expert, advice-giving role of the EP. It may therefore be that different tasks and expectations of EPs prompts positioning and influences practice; potentially a further area for EP reflection.

As research was gathered within a constructivist paradigm, there is no assertion that the themes that arose in the narratives of David and Hannah represent the experiences of others. However, both narratives contained themes that were pertinent to their relationships with professionals, and potentially associated power dynamics. As a practitioner-researcher, this prompted reflection for me on how my presence (and that of the research project) may have influenced the narrative shared. This reflection may hold an implication for EP practice, as although EP interaction with parents is not always within a research context, it is within a context that may have potential implications for power dynamics and other unconscious processes. This research has demonstrated how reflection on such processes (at an individual, groups and societal level) can offer insight into the analysis of what is shared by parents.

As well as offering a potential point of reflection for EPs completing consultations with parents, appreciation of listening to individual parental narratives as communication of their experience is also an important aspect for school staff.

McKenna and Millen (2013) investigated the importance of school staff attending to parental voice, concluding:

*'If we listen closely to parents—their wishes and dreams, fears and concerns—we find that there are lessons and suggestions that emanate from a deep sense of caring. Educators must be able to view such listening opportunities as an asset in order to be the best educators possible.'* (pp.10)

EPs are positioned between systems, and therefore it is often the EP role to bridge these systems (such as home and school), creating opportunities for collaboration. It may be that EPs can support school staff in understanding the importance of listening to parental narratives and support them in reflecting on their own personal beliefs and assumptions that may be enacted in communications between them and parents.

Indeed, with legislation (including CFA, 2014) emphasising the importance of parental voice, the implications of this research may be pertinent to all professionals who work with parents.

The issue of hermeneutics (interpretation) might also have implications for reflective EP practice. The EP role involves interpretation at multiple levels. It is often the job of the EP to integrate information from multiple sources, create formulations and hypotheses and make recommendations based on their interpretation. Therefore, a degree of hermeneutics is inevitable in practice, and it could be argued form a strong purpose for supervision, where such issues can be discussed and reflected upon. In referencing narrative research methods, Lieblich et al. (1998) stated that by being in the room (with a participant), some interpretive choices have already been made, adding that it is an illusion to assume that listening, reading and interpreting are separate stages of a process. It could be argued that in this description, what is referenced as a participant could be substituted as a client within the role of an EP.

The philosophy of an individual EP will invariably influence their practice, as a more positivist stance may lead to seeking a universal 'truth' in their work and therefore take a different approach to interpretation. A more relativist, constructivist EP stance may reflect on hermeneutic loops, viewing the stories and reports of individuals as unique constructions that are specific in time and context and reflecting on how their interpretations may be interpreted by others. Fox (2003) explored the implications of EP epistemology on practice in his paper on the increasing professional emphasis on the use of; 'evidence-based practice' (Fox, 2003, pp.91). Fox's paper (2003) questioned the discourse that positivist, realist research is the 'gold standard' (pp.93), suggesting that such a closed approach is devoid of consideration of context, experience and beliefs. Fox concluded that it is important for EPs to reflect on how they personally construct the world in order to understand their conceptualisation of issues such as inclusion that are central to EP and educational practice. Fox (2003) added that such reflection is crucial as there can be a tendency for EPs to 'flip' (pp. 100) between epistemologies when faced with differing constructions to their own (such as moving from a constructivist to a positivist position when challenged).

It is therefore hoped that this research might prompt reflection among professionals on how their personal beliefs and paradigms might influence their practice and the interpretations they make. It is further hoped that these reflections might be onwardly disseminated to schools and other contexts where professionals encounter and interpret the narratives of others on a daily basis.

### **5.5 Methodological issues**

The specific ontological and epistemological stance of this research has influenced each stage of the project and places it away from more traditional positivist

‘scientific’ research. As aforementioned, methodology invariably influences discussion around strengths, limitations and validity (Yardley & Marks, 2004). For a detailed discussion of validity and reliability, see the methodology chapter.

#### 5.5.1 Participants

A common limitation cited in narrative research is the limited number of participants. This research included the narratives of two participants. In more traditional, positivist research this sample size could be considered limited due to implications for generalisability and reliability. However, the constructivist lens of this research means that no attempt at generalisation of content was made, due to the assumption that experience is unique to the individual. Furthermore, the limited number of participants enabled deep and multi-layered analysis of each narrative and immersion in the data of each individual, honouring the gestalt principle promoted in NA (Bryan & Loewenthal, 2007) and demonstrating ‘commitment and rigour’ with regards to the topic and data (Yardley, 2000). Indeed, Riessman (1993) cited that a narrative approach is not useful for studies of large numbers or authors who seek an easy and unobstructed view of subject’s lives.

The recruitment of participants was sensitive to potential power imbalances and therefore allowed participants the autonomy to opt-in. While this meant that there was less control over numbers of participants, it honoured the inductive nature of the research, with the focus of the project coming as far as possible from the participants. The analysis of the narratives endeavoured to consider the context, and this included reflection on participant’s motivations for opting into the study.

### 5.5.2 Validity and reliability

As aforementioned, traditional notions of reliability and validity do not apply to narrative studies. Therefore, in line with the suggestions of Yardley and Marks (2004), this qualitative, narrative research concentrated on trustworthiness, moving the endeavour into the social world (Riessman, 1993). This study demonstrated sensitivity to context through careful consideration of the ontological and epistemological positioning throughout the research, placing the narratives at the centre of the research and allowing the analysis to occur inductively. Over-interpretation was avoided in the analysis, although in the discussion of findings, the themes of the narratives were situated amongst previous research and tentative links to theory described. It could be argued that this moved the research away from a strictly constructivist stance; however, this did not form part of the analysis and demonstrated the position of this research in relation to similar projects. This is also an endeavour relevant to the EP role, where evidence-based practice is promoted. As explained by Riessman (1993), there is a long tradition in science of building inferences from cases and therefore '*fancy epistemological footwork*' is required (pp70) to avoid the problems of induction.

Reference to the sensitivity towards socio-cultural context and power (as promoted by Yardley, 2000), were included in the analysis, when the topic arose inductively, and in the discussion of this research.

The 'impact and importance' of qualitative research is cited to promote rigour (Yardley, 2000). As discussed in the previous section, while the content of the narratives are considered unique, this research holds relevance to the practice of EPs and other professionals who encounter and interpret the narratives of others. This

research is also pertinent owing to the current emphasis on the power of parental voice in legislation.

### 5.5.3 Member checking

To ensure that the narrators were at the centre of the research, the transcribed interviews and initial analysis were offered to participants for them to read and respond to. In this research, both participants attended the second meeting and read their transcripts, although both declined the opportunity to read the initial analysis. It may be that the participants declined the opportunity to discuss the analysis due to time constraints, as both went through the interview transcripts in some detail. Therefore, in future research it may be helpful for researchers to offer two sessions following the interview to allow space for thorough member checking. The first follow-up session might offer an opportunity for the participant to read the transcript, with a separate, further session to reflect on the initial analysis.

After completing the follow-up session with Hannah and David, I discussed it in supervision. This led me to consider alternative hypotheses regarding why the participants declined the opportunity to discuss the analysis. Reflection on the potential processes and dynamics that may have influenced this in relation to the themes of the analysis will be discussed later in this chapter.

### 5.5.4 Discussion of design

This research sought to explore the narratives of parents in light of legislation placing power in parental voice (CFA, 2014). Narrative research approaches were derived through the study of medical interviews, where accounts revealed that patient's stories of their illness were either ignored or interrupted by physicians (Mishler, 1999). Recent research into parental voice suggested that parents often do not feel

heard or understood by education professionals (McKenna & Millen, 2013). This is pertinent to this research, where EPs frequently consult with parents and encounter their narratives. Due to this focus on parental narratives within the context of SEN and consultation with professionals, a NA approach was deemed appropriate. The aforementioned discussion on ontology and epistemology positions this research within a relativist, social constructivist frame, which highlighted the importance of considering narratives and experience as unique constructions of the individual (but that have an element of shared socially constructed concepts (Gergen, 1999)). This philosophy promoted the notion that the narratives should be treated as unique and individual, rather than analysis seeking to compare or contrast across narratives.

The belief that narratives are unique individual constructions places emphasis upon the individual. Such a position shares some ground with a case study design, where the specific case of an individual may be examined (Robson, 2011). A case study design was not considered appropriate for this research as case studies involve a detailed account of a person (or case), focussing on multiple aspects of experience such as context, antecedents, perceptions and attitudes (Robson, 2011). In this research, the emphasis was placed on highlighting the narratives of the participants, which involved the omission of other forms of data that may have influenced the analysis. Indeed, in this analysis, the only data that is known about the participants was derived from their eligibility to opt into the study and what they shared in their narrative. This was deliberate to promote an inductive approach and resulted in a narrative design.

Other methodological approaches considered included IPA and DA. The thematic analysis of IPA involves the coding a re-organising of data, which was not considered

appropriate to this study that endeavoured to analyse narratives inductively and as a whole. Similarly, a DA approach with a primary focus on language and discourse was considered too limiting and deductive, as this research sought to analyse the narratives in an open and multi-layered manner.

#### 5.5.5 Discussion of analysis

The analysis of each narrative in this research was unique and drew upon the methods described in previous chapters (including Gee, 1991, Riessman, 1993, Hiles & Cermak, 2008, Herman & Vervaeck, 2001, Lieblich et al., 1998 and Emerson & Frosh, 2004). The field of narrative research promotes loose formulation around analysis due to the focus on narratives as unique constructions and the inductive analysis of them (Emerson & Frosh, 2004). Indeed, Riessman (1993) stated that there are no set procedures for the analysis of narratives, and Mishler (1995) explained that narrative analysts should explore what can be gleaned from various approaches before starting a unique analytic process individual to the narrative. This was adhered to in this research, with the analysis chapter referencing the methods that were drawn upon, yet overall each forming a unique analysis.

Lieblich et al. (1998) explained that analytic choices are related to the researcher's adherence to objective, quantitative processing or hermeneutic/qualitative perspectives. The analysis of this research aimed to be inductive, owing to the adopted method, epistemology and ontology. However, in preparation for this project, I researched classic and varying NA methods. It could be argued that this influenced my analysis by reducing the constructivist, inductive focus. However, I did not decide on the method of analysis I would use before starting the analysis but rather held the methods in mind as I approached each analysis. The use of

background reading into NA methods may indeed strengthen the ‘persuasiveness’ of the research, an endeavour cited by Riessman (1993) as promoting the robust nature of methods and analysis.

The analysis of each narrative varied in response to the unique form and content. It is anticipated that each reader too would have a different interpretation of both the narrative and the analysis. This issue of hermeneutics has been discussed throughout this research both to promote transparency and as an issue with implications for professional practice. In line with the views of Lieblich et al. (1998), this research seeks to promote the belief that narratives and their readings are as complex and unique as human identity itself; therefore, as in therapeutic practice, conflicts and contradictions form and shape the inquiry. Furthermore, an implication of this research for practice is in promoting that the degree to which revealing a multiplicity of readings can enhance the understanding of an individual and oneself, promoting reflexive practice.

### **5.6 Reflexive account**

This section will outline some of my reflections on the research project and also how the research has influenced my practice. As discussed in the first chapter of this thesis, I arrived at this research area through my experience of working with children with SEN and their parents. Overall, this research has greatly influenced how I reflect upon my professional encounters with parents, and leads me to consider their narratives in a more contextual and reflexive way.

As aforementioned, I do not feel that it is possible to separate oneself fully from one’s research or practice. Therefore, I feel it is necessary to acknowledge that due to my own opinions and training, I frequently draw on and value psychodynamic and

systemic theoretical perspectives (such as regarding defence against anxiety, unconscious processes and systems-psychodynamic theory). This personal 'bias' is invariably present in this research. However, I did actively consider a range of perspectives, and was mindful of my inductive endeavour.

This research resides within a relativist, social constructivist paradigm and at times I found this conflicting with my interpretation of the requirements of a doctoral thesis research project. One area where I experienced this conflict was when I completed the introduction and literature review. I was concerned with whether completing these chapters prior to completing my data collection and analysis would detract from my inductive, constructivist stance. I also experienced this tension during the discussion chapter; I had analysed the narratives individually and inductively, maintaining the unique narratives at the centre of the research as stipulated in NA (Riessman, 1993). It then felt jarring to compare the themes in the analysis with that in the introduction and literature review (and indeed was why I focussed on critical aspects of methodology in the literature review). However, through discussion with peers and in supervision I was able to consider how I could situate my findings amongst those of existing research and theory (in a process separate to the analysis). Indeed, this process parallels the aforementioned tension that resides in EP practice and discourse between evidence-based practice and practice-based evidence (Fox, 2003).

Another point in the research that prompted personal reflection occurred following my narrative interview with Hannah. I found the interview affecting and used supervision to reflect on positioning and the unconscious dynamics that may have been present. Burr (1995) explained that individuals do not choose to share all stories

with all people. This notion prompted me to consider the potential implications for how the narrative offered was reflective of the presence of me and the research project.

In the analysis and discussion, I hypothesised around this, and in supervision I took this reflection a step further, considering how there may have been a parallel process at play in the dynamic between myself and Hannah. Parallel process is a term used within psychoanalysis where there is an unconscious replication of relationships, typically between therapist-client and therapist-supervisor, which is usually initiated by the client. Grey and Fiscalini (1987) suggested that a parallel process phenomenon consists of a series of two or more situations, each involving similar defensive interactions that are usually concerned with authority and dependency, with each situation linked to the next by one person who transports the defensive behaviour (but whose role in one situation is different to the next).

It may be that the respective positions of Hannah and I in the context of the research project enabled this space and purpose to be enacted (with her the participant and ‘story-teller’, and I, the professional and ‘listener’). Yet, when I met with her again for the second meeting, I felt that Hannah was quieter than I expected. The meeting was short and she declined an opportunity to read and discuss my analysis. It may be that rather than being ‘listener’, I had become a ‘powerful and silencing’ professional. This dynamic may have formed a parallel process or an enactment of transference that I had unconsciously taken on. As stated by Riessman (1993), narratives are laced with power relations, which do not remain constant. Transference regards an unconscious process where aspects of prior relationships are projected onto new ones (traditionally referenced within a psychotherapeutic context, Gerlach & Elzer, 2014).

Grey and Fiscalini (1987) described parallel process as a series of interlocking transference-countertransferences. Hannah may have unconsciously redirected the feelings she had for professionals onto me (her experience of professionals being omnipotent and silencing). Upon our second meeting, it may be that I encountered this transference and unconsciously enacted it, resulting in a parallel process that mirrored her experience of professionals holding the power (and their hypotheses), thereby silencing Hannah.

This potential enactment of dynamic power relationships could, again, be linked to Foucault's theory (1977) around the bridging between 'state' surveillance and everyday life. Indeed, the shift experienced with Hannah between the two interviews may support Foucault's notion of power not being linked to individuals but as a dynamic web woven throughout society, and the relation of this to knowledge. During the first interview, it could be argued that Hannah held the power and the knowledge through controlling the narrative she shared, whereas in the second interview this switched as I then held the power through the 'knowledge' of the analysis of her transcript.

Such reflections are tentative and recognised as influenced by my personal lens and experience, yet I feel that such reflection exemplifies the potential power of attending to such processes following meetings with individuals, where there is often more to analyse than simply the content. Indeed, noticing personal feelings and responses and reflecting on them through a psychodynamic lens can offer useful insight both for researchers and professionals. EP researcher Pellegrini (2010) highlighted the usefulness of both an awareness of what unconscious processes might be at play during social interactions and the ability to explore it. However, Pellegrini (2010)

also cautioned that where there is a high level of anxiety in a system or interaction, defence mechanisms are likely to be active in all involved, making it difficult for a consultant to remain in an exploratory position. Pellegrini (2010) added that sensitivity to the emotional climate and the capacity to voice feelings for consultees to reflect on can be more challenging when the consultant is internal to the system. In this research, as a researcher I was positioned outside of the system, yet the participants were aware of my role as a trainee EP, which added complexity to the dynamic. Overall, Pellegrini (2010) concluded that due to the complexity and potential depth of feeling involved in using the self as part of consultation, EPs may avoid such an approach- tending towards more objective, detached, positivist methods as a defence against the difficult situations encountered.

The completion of this research project has influenced my practice as a trainee EP, especially when eliciting, listening to and interpreting or analysing narratives from parents. As a trainee, I have been encouraged by tutors to consider different models of consultation, and as part of my training I have endeavoured to practice a range of approaches. I have found that I tend towards a psychodynamic PC approach and am more comfortable in this 'role'. It may be that this preference is related to my desire to complete inductive narrative research, which shares some commonality with 'pure enquiry', where the client is positioned as the expert and the consultant aims for minimal interjection (Schein, 1999).

Following the completion of this research, I have frequently reflected on my role in consultation, and how unconscious processes in the room or wider system can prompt dynamic transition between roles and positions. I have also reflected on the balance experienced in consultation between 'data gathering' and 'narrative elicitation', and

how either might influence the story shared. This has also caused me to notice how parental stories are elicited in the EHCP process in my LA, and how this could be linked to Foucault's ideas on power and governmentality (1977). The EHCP statutory process purports that parent voice is at the centre, yet in reality I have found that it prompts a rather deductive approach, with the requirement that the consultation with parents gathers 'answers' to a lengthy list of questions, rather than giving weight to the parental voice and the space for eliciting narratives in a more inductive manner.

The variation in EP paradigms and issues of hermeneutics in practice is an area that I will continue to reflect on throughout my career, as reflection on this throughout my thesis has led me to the sense that such domains influence all aspects of EP practice. As in NA, in EP practice, hermeneutics loops are inevitable, and in writing reports attention must be paid to the implications of this. I feel that this is inextricably linked to epistemology, as whether an EP (or other professional) believes that a 'truth' exists and can be stated and measured will impact on both the interpretations they make and report, and how they interpret and use the reports (and interpretations) of others. This is not a debate where an answer can be reached, yet I feel that reflection and active discussion on this, with the bringing of such philosophical debates into EP discourse could create more open and reflexive practice.

### **5.7 Dissemination and implications for future research**

Given the pertinence of this research to the EP role, a presentation of this study to my LA EP team is planned for an upcoming team meeting, as well as a presentation at the diagnostic service I recruited my participants through. These presentations will include time allocated for reflection and peer discussion on professional's own epistemologies and beliefs and how this may influence their practice. Finally, I am

scheduled to present this research at my course provider institution in the form of a poster presentation.

I also plan to submit the study for publication in relevant journals that are read by professionals. I also hope to build on my research and further disseminate the findings when I start work as an EP.

Alongside dissemination of this research with the hope that it will prompt professional reflection, it is also hoped that the findings and analysis may prompt further research. Riessman (1993) argued that all methodological standpoints are incomplete and that a narrative approach offers diversity in design and representation. Given the constructivist stance of this research, it is not believed that future research could extend the specific findings of this study (as there is no assertion of generalisability). However, the findings and their relevance to professional practice may provide some opportunities for further learning.

Drawing on the discussion in this research into the potential unconscious processes influencing the narratives, one potential area for future research would be to extend the exploration of how the internal and social worlds of researcher and participant shape their experience. A psycho-social project could offer detailed analysis of the experience of parents whose children are entering a diagnostic pathway. Such a methodology would include an explicit focus on a psychoanalytic theoretical frame, moving it from a purely inductive approach but offering further insight into the dynamics between researcher and participant. The requirement of supervision to discuss such processes would further enhance the potential for reflection, an endeavour I feel is relevant to the EP role.

Drawing again on the theoretical discussion in this chapter and the emergence of potential themes of power relationships in society; a further potential area for research would be for a Foucauldian discourse analysis. Such a methodology would offer scope to explore how power relationships in society (specifically between parents and professionals), are expressed through language and practices.

Related to this, given the aforementioned implications of EP beliefs and paradigm on practice, further research may help to explore how EPs conceptualise this.

Qualitative research could investigate EP's individual beliefs around ontology and epistemology and explore how this impacts their consultation and other forms of practice (such as report writing and reading).

Given the dearth of narrative research into parental experience pre-diagnosis of ASD, it may also be useful for similar research to be completed with parents whose children are starting on different diagnostic pathways (such as for mental health assessments). This would offer professionals in different settings an insight into parental experience and an opportunity to reflect on their role both in the process and when receiving parental narratives. Similarly, given the new EHCP process, it would be interesting and helpful to collect and analyse the narratives of parents at various stages in the statutory assessment process. This would be particularly relevant as many of the changes in the process (from the previous statementing process) are specifically designed to increase the power of the parental voice.

## 5.8 Conclusion

This research is situated within the context of my practice as a trainee EP, in a legislative environment that highlights the importance of promoting parent voice in the SEN realm. This study therefore explored the narratives of parents whose

children had been referred for an ASD assessment. ASD was chosen as it was a priority area for my EPS and is a condition that is generally viewed as having an early onset, typically influencing the lives of children and parents prior to formal professional involvement.

Interest in the unique stories of parents alongside an assumption that stories offered are influenced by past experiences and personal constructions led to a relativist ontology and social constructivist epistemology. The interviews sought to elicit the narratives with minimal researcher input and influence. The analysis was inductive and considered the content, form, speech and positioning. Consideration was also paid to the context, including with regard to the role and presence of the researcher and research project. In line with the research paradigm, the narratives were analysed individually and therefore elicited unique themes and patterns. Some themes align with those that have occurred in previous research, such as the findings of Howlin and Moore (1997) and Ho et al. (2014) which suggested that the diagnostic process is lengthy and frustrating; and the challenging dynamics between parents and professionals as explained by McKenna and Millen (2013). Yet, overall the discussion of findings further highlighted the unique experience of individuals. Potential dynamics and unconscious processes that may have influenced the narratives were also discussed, as well as potential links with broader theoretical notions of power and society. This aspect of the research is considered to hold particular pertinence to EP practice, where themes such as power and voice are central to EP-client encounters.

This research project held ontology and epistemology at the fore of the investigation, and it is felt that reflection on these, alongside hermeneutic discussion, are aspects

that hold the strongest implications for practice. This research also held the narratives at the centre of the project, yet the analysis suggested that the presence of the researcher and research project may have influenced the narrative shared. Similarly, the analysis was inductive, yet was acknowledged to still contain personal biases of the researcher. Reflection on this was considered to enhance the analysis, and it is envisaged that such reflection in EP practice could work similarly. Furthermore, considerations of context, power, positioning and world view were also related to the analysis and are considered central to reflexive EP practice. It is hoped that while no assumptions of generalisation of themes can be assumed, those reading this research might be prompted to reflect on how they interact with, interpret and share the narratives they encounter.

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**APPENDIX 1: LITERATURE REVIEW EXCLUSIONS TABLE**

<b>Reason for exclusion</b>	<b>Number of studies excluded</b>
Studies investigating a specific ASD intervention.....	14
Studies focussing on conditions other than ASD (including Attention Deficit Hyperactivity Disorder, Tourette, Downs Syndrome, Personality Disorder, Developmental Disorder, Williams Syndrome, Language Disorder, Retts) .....	16
Studies investigating behaviours or cognition of people with ASD.....	7
Studies focussing on first person experiences of ASD (i.e. not parental experiences).....	2
Studies focussing on bilingualism.....	1
Studies focussing on religion .....	1
Studies not available in English .....	2
Studies with an Occupational Therapy focus (i.e. on living space) .....	1
Focus on siblings.....	1
<b>Total excluded.....</b>	<b>45</b>

## APPENDIX 2: LITERATURE REVIEW SUMMARY TABLE

Table 1 in this appendix details the following aspects of the research critique (taken from Holland & Rees, 2010): Focus, background, aim, methodology, tool of data collection, method of analysis and presentation and sample.

Table 2 in this appendix details the following aspects of the research critique: Ethical considerations, main findings, conclusions and recommendations, overall strengths and limitations and application to practice.

**Table 1**

Study	Focus	Background	Aim	Methodology	Data collection	Data analysis	Sample
Ho, Yi, Griffiths, Chan & Murray (2014)	The experience of parent-professional partnerships (PPP) in China	Study is part of a larger project into the ways Autism is constructed in UK and Hong Kong. Study identifies a lack of research into parental experience. No literature review.	To explore the experiences and narratives of parents and explore the quality of PPP in a Chinese context.	Interpretive Phenomenological Analysis (IPA)	In-depth life history interviews (semi-structured with 36 questions)	Thematic analysis (no specifics given)	10 (purposive sample)
Hines, Balandin & Togher (2012)	Exploring older parents' perceptions of their children with Autism to	Discusses potential findings based on previous research into coping strategies.	To explore older parents' perceptions of their children with Autism to	Narrative	In-depth interviews using a topic guide and a shorter follow-up interview.	Narrative analysis (NVivo)	16 'older' parents of 13 adults with Autism (some couples were

Study	Focus	Background	Aim	Methodology	Data collection	Data analysis	Sample
	gain insight into coping strategies. (Australian study).	Discusses previous research into parental perceptions of Autism. No literature review. Cites lack of research with older parents.	gain insight into coping strategies.				interviewed together)
Hines, Balandin & Togher (2011)	The communication experiences of older parents who have autistic children (Australian study).	Identifies a dearth of research into communication and related research regarding adults with autism and their parents.	The aim of this study was to explore the communication experiences, particularly those related to augmentative and alternative communication (AAC), of older parents who had an adult son or daughter with autism.	Narrative	In-depth interviews	Narrative analysis (NVivo)	16 'older' parents of 13 adults with Autism (some couples were interviewed together)
Hines, Balandin & Togher	Narratives of older parents with autistic	Identifies a dearth of research into how the specific	The aim of the present study	Narrative	In-depth interviews	Narrative analysis (NVivo)	16 'older' parents of 13 adults with

Study	Focus	Background	Aim	Methodology	Data collection	Data analysis	Sample
(2014)	children.	needs and circumstances of parents of adults with autism change as they age. Outlines research suggesting raising an autistic child is related to stress.	was to explore the lived experiences of older parents of adults with autism.				Autism (some couples were interviewed together)
Fleischmann (2004)	Understanding of the narratives shared by parents of children with autism online.	Outlines difficulties faced by parents with children who have autism and research into the use of the internet as a 'coping mechanism' for parents to share their stories.	Aim is to mobilise the stories of parents with children with autism in order to understand the adjustment process.	'Labov's methodology' for examining text and understanding their significance.	'Data mining' was used to identify sample of online stories.	Textual analysis	20 personal life stories of parents with children with 'autistic attributes'.
Fleischmann (2005)	Analysing the self-published online stories of parents whose children have	Gives background into using the internet for qualitative research and specifically for	Aim is to analyse and develop a theory around self-published online stories of	Grounded theory	'Data mining' was used to identify narratives online	Online coding system, axial coding, grounded theory (once main theme identified).	33 online stories were studied.

Study	Focus	Background	Aim	Methodology	Data collection	Data analysis	Sample
	autism.	studying autism coping.	parents whose children have autism.				
Benderix, Nordstrom & Sivberg (2007)	Parental experiences pre and post putting their children with autism and learning difficulties in a group home.	Background on group homes and research into the stress of caring for a child with autism.  The study was commissioned by the Swedish Department of Child and Youth Care to evaluate the new group home (established by the 5 couples who are participants in the study).	Aim is to describe the experiences of couples who had a child with autism and learning disabilities, who lived in a group home.	Case study	Hermeneutic Phenomenological Interviewing (pre and post their child moving into the home); asking ' <i>what is it like having a child with autism and a learning disability?</i> '	Thematic analysis (by each researcher independently then bringing their ideas together to identify commonality).	Five couples who had grouped together to organise a specialised group home.
Desai, Divan, Wertz & Patel (2012)	Exploring the lived experience of parents whose children have	Background on identification of autism. Research cited into cultural	Aim is to explore the lived experience of parents whose		In-depth interviews (that were translated)	Phenomenological psychological analysis	12 parents of 10 children with a diagnosis of

Study	Focus	Background	Aim	Methodology	Data collection	Data analysis	Sample
	autism within the cultural context of Goa, India.	specificity of views and experiences of autism. Identifies a dearth of research into parental experiences of autism in India over time.  The research was part of a broader study into autism in India.	children have autism over time in the specific cultural context of India.				autism. Participants were deliberately selected to reflect key differences in the local population.
Mackay & Parry (2013)	Experience of autism.	Historical development of autism given and theories of autism outlined.	The aim was rich description and understanding of the experience of autism and the 'journey'.	Phenomenological	Interview and video narratives	Thematic analysis	10 young people with autism and their parents
Loukisas (2016)	Understanding parental experiences of having a child	This study is part of a larger, mixed methods study into disparities in	To describe the posted experiences on personal blogs	Combination of ethnographic and discourse-analysis	Blogs collected as part of wider study.	Content analysis	The blogs of 5 mothers.

Study	Focus	Background	Aim	Methodology	Data collection	Data analysis	Sample
	with autism through a socio-cultural lens.	experience of African American families with children diagnosed with autism.	of mothers who have children with autism in Greece.				

Table 2

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
Ho, Yi, Griffiths, Chan & Murray (2014)	Informed consent, opt-in	Themes: - Feelings of uncertainty and being lost in the process. - Access to Autistic Spectrum Condition (ASC) assessment and diagnosis. - Multiple procedures. - Consultation prior to assessment. - Lack of communication during assessment. - Isolation post-assessment.	<i>'For parents, the assessment procedure was marred by a series of obstacles, which were further exacerbated by a poorly developed PPP' .</i>  Recommendations: - for an evidence-based guideline for parents and professionals to help with navigation of the assessment process.	Strengths: - Thematic analysis - Found a gap in existing research.  Weaknesses: - Not very inductive (study started with investigation of PPP) - Parents found through a support network, therefore parents not connected to the network were not included.
Hines, Balandin & Togher (2012)	This study was approved by the University of Sydney Ethics Committee and the ethics committee of the organisation that assisted with recruitment.	Themes: - Parents spoke about a 'real' person 'under' the autism; personality 'buried or blocked' by autism. - Parents 'making sense' of challenging behaviour. - Autism as irremediable and	The narratives of older parents suggested that their child was 'buried' by autism, and focussing on the 'true' person may be a coping strategy to support parents in maintaining positive perceptions of their offspring.	Strengths: - Outlines stages of narrative analysis.  Weaknesses: - Not inductive (assumes 'coping')

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
		therefore the onus residing with parents.	Recommendations: - Service providers must understand and support parental beliefs about autism that highlight coping. - Rapport building with families is essential.	
Hines, Balandin & Togher (2011)	This study was approved by the University of Sydney Ethics Committee and the ethics committee of the organisation that assisted with recruitment.	Themes: - Lack of meaningful interaction with child. - Communication breakdowns in the community. - Avoiding confrontation rather than confronting behaviours. - Parents did not mention AAC or SALT at all unless prompted. - Low expectations of communication (belief that it was inevitable due to	The results of this study suggest that there may be a role for AAC and communication intervention in supporting the communication skills of adults with autism and their interactions with their older parents.  Recommendations: - Informing parents of AAC and interventions available. - Person-centred approaches to service delivery.	Strengths: - Outlines stages of narrative analysis. - Provides multiple recommendations  Weaknesses: - No mention of relation to study listed above. - Not inductive as sought to investigate AAC.

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
		autism). - Misconceptions of SALT services.	- Longer-term professional-parent partnerships.	
Hines, Balandin & Togher (2014)	This study was approved by the University of Sydney Ethics Committee and the ethics committee of the organisation that assisted with recruitment.	Themes: - Interconnectedness of family members. - Balancing act between caring and meeting own needs. - 'Pull': need to 'manage' daily needs of child. - 'Pull': impact on parent's life. - 'Pull': impact on parent's relationship with wider family. - Acceptance and resignation rather than resentment or anger. - Experiences with formal services.	<i>'These older parents' narratives suggest that their lived experience was one of a delicate balancing act as they attempted to promote the well-being of their son or daughter with autism, while at the same time balancing their duties towards their spouse, other offspring and themselves.'</i>  Recommendations: - Services to be aware of needs of families, even where support is not requested by parents. - Strategies need to reinforce parents' identities and sense of status. - Increased <i>'professional</i>	Strengths: - Inductive narrative approach, allowing themes to emerge without prompting. - Clear narrative analysis approach listed and cited (as with two studies listed above).  Weaknesses: - Unclear links to aforementioned two studies. - Lack of literature review.

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
			<i>empathy</i> '.	
Fleischmann (2004)	<ul style="list-style-type: none"> <li>- No details given of any informed consent from story narrators.</li> <li>- No detail of ethical submission or approval.</li> </ul>	<ul style="list-style-type: none"> <li>- Abstract: 'positive essence' and desire for their story to help others.</li> <li>- The complicating action: In all stories, the diagnostic process and diagnosis constitute the hub of web sites. 17 discuss the stage of prior to diagnosis.</li> <li>Diagnosis and recognition of autism sparked shock, guilt, relief and anger among some parents.</li> <li>- Empowerment of the parent.</li> <li>- Empowerment of the child.</li> <li>- The resolution: all narratives had positive outcomes.</li> </ul>	<p>The authors cite that diagnosis constitutes a turning point for parents. Delay in diagnosis leads to stress but on diagnosis, parents 'take-action' which led to empowerment in them and their children. All narratives ended with a sense of optimism.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>- Professionals could be instrumental in both maximising treatment in the home setting and minimising the attrition that parents face. <i>'They must help parents change their perceptions and attitudes, as a vehicle for changing the way they see their life stories'</i>.</li> </ul>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>- No interviewer bias, leading questioning or issues with the power dynamic of an interview.</li> <li>Clear methodology, analysis and results clearly aligned to Labov's methodology.</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>- To verify authenticity, stories were shown to different parents with children with autism- in a narrative methodology the unique nature of narratives is emphasised, therefore this method may not be true to the epistemology.</li> <li>- Compares across narratives, again questioning the epistemological stance of the research.</li> </ul>

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
				<ul style="list-style-type: none"> <li>- The 'participants' had chosen to publish their stories online and therefore may not represent a sample of all parents with children who have autism.</li> </ul>
Fleischmann (2005)	Ethical issues around the use of online material for empirical research are discussed and guidelines were established, listed and justified.	A central theme regarded 'coping with autism'; with parents undergoing a process in the course of coping with autism in which they change their outlook and in the end are willing to help others in the same situation.	The authors conclude that the central theme of coping is similar to the process a hero undergoes in the analysis of 'everyday hero' presented by Catford and Ray (1991).	<p>Strengths:</p> <ul style="list-style-type: none"> <li>- Addresses ethical issues of utilising online stories.</li> <li>- links findings to theory.</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>- Authors of the online stories may not be representative of other parents whose children have autism.</li> </ul>
Benderix, Nordstrom & Sivberg (2007)	<ul style="list-style-type: none"> <li>- Informed consent included.</li> <li>- Identifying features removed.</li> <li>- Study was approved by the Ethics Committee of the</li> </ul>	<p>Themes before the move:</p> <ul style="list-style-type: none"> <li>- Grief and sorrow.</li> <li>- Changed attitudes towards other people with problems.</li> <li>- Not always possible to</li> </ul>	<p>Grief felt from point of diagnosis. Relief and guilt at putting children in a home (a sense of dilemma).</p> <p><i>'The current view that children with disabilities</i></p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>- Open questioning with minimal questioning allows for an inductive approach.</li> <li>- Sample included all parents</li> </ul>

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
	Faculty of Medicine at Lund University.	regulate child's behaviour. - Total exhaustion. - Social isolation. - Negative affect on siblings.  Themes after the move: - Relief. - Ethically difficult to entrust child to others. - Satisfaction with group home due to child improving. - Parents not satisfied with group home as child not happy there (leading to guilt) - Sharing experiences with other parents. - Hope for the future.	<i>should not be separated from their parents should perhaps be questioned in the case of children with autism and learning disabilities'.</i>  Recommendations: - Services should reflect on the living conditions of families in a similar situation and initiate a dialogue regarding their needs for home-based services and possible sheltered housing.	from group home, meaning it was a thorough case study.  Weaknesses: - Unclear analysis, no theoretical or research cited as a base. - Did not get child views to support conclusion.
Desai, Divan, Wertz & Patel (2012)	Not discussed.	Main themes, detailed as temporal phases: - Positive experiences and	<i>'The findings indicated that parents' experiences of caring for their child with ASD involved three main</i>	Strengths: - Relates findings fully to previous research.

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
		<p>optimism just after birth.</p> <ul style="list-style-type: none"> <li>- Interruptions from the path.</li> <li>- Roadblocks: child's development and parental search for solutions.</li> <li>- Addressing the present while looking towards the future (acceptance).</li> </ul>	<p><i>constituents, which emerged through four temporal phases:</i></p> <p><i>learning to meet new and unfamiliar challenges as parents; caring for their child's basic needs; and finding an engaging niche with a sense of belonging for their child in the everyday milieu.'</i></p> <p>Recommendations outline (offered in the study for each temporal phase outlined in the results):</p> <ul style="list-style-type: none"> <li>- Professional practice can be related to essential concerns of parents (even though their views can differ).</li> <li>- Relationships between policy makers, professionals and parents should be respectful of ways of life and points of view.</li> <li>- Offers of early intervention</li> </ul>	<ul style="list-style-type: none"> <li>- Does not mention ethical considerations or how participants were approached and recruited.</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>- Does not address cultural aspects in the analysis (as cited in the aim).</li> <li>- Only included parents accessing professional services.</li> <li>- Narratives were translated and some words were changed for ease of understanding, altering the authentic narrative offered.</li> </ul>

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
			that fit with the parental phase of experience, readiness and sharing of views with professionals.	
Mackay & Parry (2013)	Informed written consent was obtained. The study also references an acknowledgement of the ethical issues of working with vulnerable children and specifically young people with autism.	<ul style="list-style-type: none"> <li>- Parental constructions of obsession and repetitive, ritualistic behaviour.</li> <li>- Children’s accounts of their behaviour (including food issues and interrelated obsessions/hobbies)</li> <li>- Differences between parental and young person narratives includes the difficulties associated with rituals and obsessions (not viewed as difficulties by the young people).</li> </ul>	<p><i>‘Both parental and young people’s descriptions appeared highly informed by a much medicalised version of autism’.</i></p> <p>No recommendations stated.</p>	<p>Strengths:</p> <ul style="list-style-type: none"> <li>- Discusses discrepancy between study epistemology and cited theories.</li> <li>- Findings related to theory.</li> </ul> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>- Makes comparisons across narratives.</li> <li>- Data analysis varied across participants (some videoed themselves, others completed semi-structured interviews).</li> </ul>
Loukisas (2016)	Ethical approval was obtained from Southern California Health Science Campus Institutional Review	<p>Content analysis suggests:</p> <ul style="list-style-type: none"> <li>- The mothers view autism through a developmental perspective.</li> </ul>	Mothers tended to have a developmental perspective and had mixed perceptions of disability; sometimes closer to a medical model, a	<p>Strengths:</p> <ul style="list-style-type: none"> <li>- acknowledges central role of researcher in describing and signifying the issues</li> </ul>

Study	Ethical considerations	Main findings	Conclusion and Recommendations	Overall strengths and weaknesses
	Board.	<ul style="list-style-type: none"> <li>- The mothers experienced stress, anxiety and burn out.</li> <li>- The mothers struggle to secure positive education and service involvement.</li> <li>- Narratives tended to end positively.</li> </ul>	<p>social model or a hybrid of the two.</p> <p>Recommendations not cited.</p>	<p>discussed.</p> <p>Weaknesses:</p> <ul style="list-style-type: none"> <li>- limited and potentially unrepresentative sample.</li> </ul>

**APPENDIX 3: WORKING TRANSCRIPT OF DAVID'S NARRATIVE  
(INCLUDING ANALYSIS ANNOTATIONS)**

1. *I – Ok, so, as you know, I'm interested in the stories of parents whose children have been referred for a SCAS assessment. Can you tell me your story?*
2. *Umm, (laughs) yes, I mean, where do you want me to start?*
3. *I – Where ever you like, I guess where you feel the story began.*
4. *(laughs) yes, um ok, I suppose from when Jay was young. So, Jay... is my boy, my son, he's sixteen years old... well, I guess he's a young man now.*

Pause

*I mean, he was a textbook child when he was little, you know, like he slept, he slept fine, all night. I mean, he had a bit of colic, which was normal, you know. But yeah, he was text book, didn't have no allergies or nothing.*

5. *I mean, when he was older he has a bit of asthma, so we took him to the doctors for that, you know. But then I think that's gone now, like he doesn't ever use his inhaler, it's just at home now. Err, He went to the doctors, now we're back in [redacted], and they said, like, that he doesn't need to use the inhaler as he doesn't have asthma now. So like...*
6. *But, sorry, what was I saying...*
7. *I – You were talking about Jay when he was little*
8. *Oh yeah, sorry... but yeah, he was textbook as a baby. Then, like, as he was into like the toddler phase, he got like, more of a handful. I mean, not at home. I never saw no problem at home. But at nursery he was a handful, they were telling us he was a handful.*

Pause

*I – can you tell me what that was like?*

*Yeah, err, it was difficult. I mean, he wasn't too bad at home, we didn't see.... But like the school would say that he was kicking and biting and that. Like they would phone and like, it got to the point where they would phone and tell me that he had done something, like got frustrated and lashed out at a teacher, and they would phone me and I would have to go and pick Jay up.*

9. *But like, I was working, you know, like it was hard because, like I'd go to work each day and be constantly thinking, like, will they phone me? Then if they did, I'd have to drop everything and go and pick him up.*

*It was just impossible because you're trying to hold down a job, and like, it's not easy to find work and I'm self-employed. Then like, you're going to work every day wondering if you're going to get a call because school couldn't cope with him. So it got to like most days where I'd have to go pick him up.*

10. *That was the hardest time, like, the thought that he was like lunging at teachers and trying to hurt them... it was hard to hear sometimes... And I had to work, but it got to the point where*

pride

positive

transcend

home/sch  
split  
external  
story of Jay

difficulty

constantly  
thinking

Dad's  
wife impact

home/  
sch/  
split  
mismatch

11. I just thought, you know, something's gotta give.

Pause

I – *that sounds like a hard time...*

12. Yeah, I mean, it's just not something you expect, you know?

Pause

13. ...But then, like, err, they found that he had glue ear, so, like his hearing might have been... like, they said that

14. maybe in school it was frustration, but like, that was after. I mean... I don't know, but they said

15. maybe he wasn't hearing I guess so was getting frustrated and lashing out 'cos he... well,

16. I don't know...

Pause

I – So the behaviour might have been a communication of frustration?

Exactly, I mean, I don't know, I'm not the expert, but yeah, who knows.

17. He had, like, speech and language therapy sessions at the clinic. He didn't really like going there and I don't know how much he really said in the sessions. We went, you know, and saw... err, what was her name? Like 's' ... susan I think. He had like a few appointments there but then he was discharged.

18. So like, I don't know, I don't know whether like, it was the frustration or this glue ear, or like something else.

19. But they discharged him.

Pause

20. I mean, it had been a hard time. His mum left when Jay was three. She just left, it was hard, hard for us. I mean,

21. I had to work, but with Jay and his difficulties being at school. I couldn't really keep going with the job and looking after him, I mean, it was fine, but I kept having to go and pick him up.

22. So I quit. I had to...

23. My mum, Jay's Nan lives in [redacted] so we went there, so he could be with his Nan.

24. His Nan like helped raise him, you know? She was an important part of his life and really helped bring him up.

25. They're close.

26. He went to a small primary school there, like different to London, small like village school.

*unexpected*

*they  
Professional  
hypotheses*

*not  
knowing*

*external  
decision*

*difficultly  
transition*

*Dad's  
job*

*Protective/  
positive  
relationship*

194  
Professionals hypothesis

27. And there was this great staff member there who, like, picked up on the difference with Jay. She like spotted that there was something different about him, she was the first one to pick up on it.

I mean... I don't know what, but like, she spotted that there was a difference about him... like, you know, the Asperger's thing.

28. They had him assessed.

29. It was a supportive school, you know? Like small, the staff really knew the children. It was a small community that I think was good for Jay, like safe. A safe place for him to be, people like know each other.

30. So then he was referred to (assessment service)...

31. I - So you moved back to London?

Yeah, sorry I leapt around a bit there. I mean, I had no work there.

32. And I knew that it was a good place for Jay, err, you know, small and safe.

external decision  
protective /  
Safety  
external decision

Pause

33. But I have to work to support us, err, and I knew if I came back I'd like be able to find work, like pick up work where I had before, so we had to come back.

D's job  
work

Pause

I - You came back to London?

34. Jay went to (name of primary school). They were good with him. Like, I don't have a bad word to say about them. They supported him well, the teachers like understood how to deal with him and generally it was good... you know at the school.

the relationship

35. And, like, he had this assessment.

Pause

I - assessment?

We went to the clinic a few times, and like, Jay saw a therapist. And like, he didn't want to go but like I think after a few sessions he was like happier to go and talk. I mean, I don't know what he spoke about. But I think he...

not knowing

36. I mean he finds it difficult to talk about his mother to me. And I think, like he spoke to her about his mum and how he felt about his mum leaving. I like, was quite surprised that he spoke so much about it I guess. He just like, opened up to her.

Speculation of Jay's feelings

37. I think he was a bit angry about her. Like he spoke quite bad about her; I guess he was angry at her leaving. Like he didn't understand I guess.

38. But we ended up back in Northern Ireland, you know, with Jay's Nan. She helped raise him. Then... err... well, Jay's mum decided to move there...

external decision

39. I - Did she have family there to?

40. No, she just decided to move there...

41. not on her own like, you know, with her new partner.
42. I mean, it was difficult for Jay. He was angry at her, didn't get on with her new partner, and he was getting big, you know, and
43. I just don't think that he understood it all.
44. But, you know she wasn't working either, I couldn't work there, and she didn't work either. It seemed silly, you know, with us both there but neither of us working.
45. I knew I could get work in London. Err, so I decided to come back.
46. I mean, she's his mother, so like, yeah...
47. I came back to my old employer actually, good work...
48. It's important that I work, you know, like, can provide.
49. So I came back to London and Jay was with his mum. It was hard I think, like, she struggled with him.
50. He was angry at her, and didn't get on with her partner. Like, she's his mum.
51. But he was getting big, you know.
52. And like, he wouldn't do anything. And like, he'd just stay in his room and would sometimes refuse to go to school.
53. But like, school was ok, like they supported him and he got the diagnosis of Asperger's and so they understood his needs and his ways.
54. But, like his ticks got worse and I understand that his mum struggled with him
55. His grades were good.

( [redacted] got his phone out)

I've got his report here, I can show you... err... hold on. Sorry I have got it.

Pause

Ah, yeah, here, see- look it's different to reports here but it shows you the average.  
And look, he's like... doing well.

*I - Yeah he's above the average in all subjects.*

Yeah. I mean look at the... English, geography, history... history has always been good for him...

56. he's always had an interest in the wars and the history of the wars with the timeline of the battles and... but yeah...

(puts phone away)

57. sorry about that, don't know if that's useful to ya... to see his reports. But it's hard to understand sometimes the differences in the reports how, how he's doing. Like, they said he had like a learning difficulty when he was little... but then he's doing really well now.

Pause

58. So you rely on the experts really don't you?

Jay's feelings

work

difficulty

Jay's feelings

Jay's behaviour

Home/sch split

pride

pride

pride

professional hypothesis

I – The experts?

Yeah, I mean... no offence, but there have been so many! So many meetings, and you go...

59. I just want to get the most help for him, you know...

60. I – So things were good in school...?

Yeah things were good in school.

61. But his mum, like, he stayed with her for two and a half years.

62. But she couldn't cope with his behaviour.

63. And he's like a big lad. I mean, the doctors said that he needed to lose weight, so we've done it together, you know like swimming and walking. He loves walking around London and on the heath. He did really well, there's no problem now.

Pause

64. I – but things were more difficult with his mum?

Yeah, his mum couldn't cope with him.

65. So we gave him the choice.

66. He was a teenager by then so was able to think through... although, well, I, we... we thought that would be for the best.

67. I mean, obviously I didn't want to leave him...

68. but he was old enough to make the decision... but I think... it wasn't really a choice, you know.

69. Like he loved his nan and being in Northern Ireland, but him and his mum... it was too difficult for him I think, and he never really got on with her partner. So he decided to come over to live with me.

70. I mean, it's not perfect, we're living in a hostel in (area of London). Do you know it?

I – Yes I do, near XXX?

Yeah that's it... I mean, it's not ideal, like sharing and that...but it's really good for school obviously, it's just down the road...

71. You know I used to go here when I was young! It's different now, obviously... you wouldn't recognise it (laughs).

72. Jay likes it, you know that he comes to the school I used to go to.

Pause

He likes it here I think, he's comfortable, settled.

73. I don't mean to sound, like, big headed but he likes to be with me, you know, like, near me...

proffer

Jay's +ve

Jay's behavior together

difficultly

decision

relationships

together

speculation of Jay's feelings together

74. he still needs me.

Pause

75. The future, like, it scares me a bit, you know. Like he still really needs me.

76. He has these.. things that he does, you know, like ticks I call them. They were worse... like before when he was a bit younger... they're better now but they still come out sometimes. I tell him to stop, you know, when I notice him doing them.

77. I don't know how much it happens at school.

78. One is like, sniffing his fingers... it sounds odd but like, when he'd touched something he'd like sniff his fingers. Another one is that he sort of waves his arm aimlessly. He does this without knowing, I stop him. I think it's like when he's unsure about something or it's a new situation or something... Another one, is sort of hard to explain. It's like, he does a sharp intake of breath at the end of a sentence... but he doesn't do that so much now. I haven't heard him do that one for a while.

79. I don't know if he does it in school. It's a bit unusual, they might not know what he's doing... I guess they should know all this stuff about him.

80. But he's settled really well, he doing well so far.

81. He's started the cadets, he loves it, he's really into that stuff, I wonder if it's like the rules that he likes.

82. You have to be clear with Jay, like, explain things really clear.

83. He loves history, like the wars, he's really interested in the World Wars and the facts

84. I remember we went to this museum once, and he was like spouting all these facts, like he really loved it there. He was so happy. And when we went home... he was telling me things... I suppose for like over an hour. He was talking to me about the dates. Even though we'd been there together (laughs), but he just was so into it.

85. He watches documentaries too, like online on iplayer there are loads and he sits and watches them. And he can tell you like loads of facts, so like his memory can be really good. He's into history and all that, and holding dates in his head...

Pause

86. But then some things, I mean like he just has these, err, irrational fears. It used to be worse when he was younger. But even how he's afraid of like the underground, lifts, escalators like in the underground or shopping centres.

87. And he worries about accidents happening, like train crashes and that.

88. But he doesn't worry if he's with me. I don't mean to sound big headed but if he's with me going anywhere he's fine, like we go on the underground together.

89. But he needs like preparing before you go on journeys, so I explain to him, like, we're going to get the northern line to kings cross then get the Victoria line for two stops.

90. Once we missed our stop and he was worried, but because he was with me he was fine, like, he feels safe.

reliance

anxiety about future

reliance

Jay's behaviour

School unknown

Speculation of Jay's feelings

the memory / pride

Jay's behaviour

together

reliance

safety

91. Another thing that worries me is that he will talk to strangers in the street.
92. Like, he really likes people and is so kind.
93. But like, I really have to watch him and I worry that he's not safe.
94. He'll like go up to strangers in the street and introduce himself and be chatting to them.
95. He's so thoughtful of others. He always wants to give people on the street money, you know, like homeless people. There's one outside pret down the road and he'll just go up to them and start talking to them, and wants to give them money. So like, I give him a bit, he's kind.
96. But I worry because, like, most people don't do that, you know?

Safety  
Pride  
Jay's behaviour

Worry  
difference

Pause

*I – You worry...*

I worry because he doesn't have a sixth sense about that stuff, like it might not be a good idea to talk to every homeless person you meet.

97. It's the same with traffic. He's much better than he used to be, but I still have to remind him to stop and look both ways, he doesn't have the sixth sense to do that. I have to remind him and be with him.
98. I know he's getting older, but I worry, you know?

Safety

Safety  
reliance

Pause

99. I think about, err, him living on his own, err, he's very independent, well, he likes to be independent... and, well, yeah, it makes me nervous.
100. Like, he does this online gaming, where they talk and stuff, online... they talk about the game and stuff. As I said, Jay's friendly... but one evening I heard him talking about school. Err, I told him, 'don't tell them what school you're at', but he doesn't like think like that.
101. So I've written a big sign and put it next to the tv that reminds him not to say what school he goes to, where we live, you know?
102. Err, he's easily led by people, I worry about that. In school as well, he's very trusting, and on like, social networking, facebook and things, I think he talks to people he doesn't see.
103. He's getting interested in girls too, he's already telling me that he's getting to know girls in (names school).
104. And like, he told me the other day that he wants to be a you-tuber; I mean, erm, like I don't even know what that is, like, talking to people online? Do you know?

worry for  
future

Safety/  
vulnerability

anxiety  
about  
future

*I – Maybe posting videos online? Not really sure that I'm up to speed with it all really!... So you worry?*

Pause

Yeah, well...

Pause

I know every parent worries about their children, and growing up, you know?

Worry

The normal things you would worry about.

105. But, with Jay... like... I know it's going to happen, like him growing up and wanting to live on his own...
106. but like, he needs me.
107. We do things together all the time, like go to the cinema or for a walk around the heath.
108. I think he feels safe with me.
109. But yeah, I think about the future and it gets to me a bit... you know, not knowing.
110. I mean, he's doing well and he's much better than he was.
111. But, err, like, even in the morning he's so slow, like, err, he gets so distracted when he's doing his teeth or whatever.
112. I've written a sign for him with a list of what he's got to do to get ready. Otherwise I end up on at him, you know, 'come on, don't worry about that, you need to have a wash'.
113. He has, err, like... what do you call it... err, acne, he has acne but he sorts it himself, you know, he buys the stuff from the supermarket. The err, treatment to was his face.
114. He's growing up...

reliance  
together  
safety  
future/worry/  
not knowing

reliance  
what Jay  
needs  
transitional  
growing  
up

Pause

115. Like, err, as I said, we're in a hostel at the moment, and it's a shared bathroom. So I have a sign, like the sign by the TV, just to remind him because he just doesn't have a sixth sense about that stuff and he just, like, gets off in a distraction...
116. but he's a good hearted lad; like he, err, he values the happiness of others, like me.
117. He wants me to be happy. Like if he sees things are getting me down, or if I'm like a bit ill... he, err, like he wants me to be better and will like try to make me laugh.
118. He just is like that, you know... kind.

pride  
reliance

+ve  
attributes

Pause

119. But so yeah, I guess the story goes to where we are now.
120. It wasn't easy, bringing him back.
121. Over the summer I tried to get Jay into (names school) but they said that because of his statement they needed to get the funding first so they could help him. So it took a while...

reliance  
(on sch')

worrying

- 200  
speculation of Jay's feelings
122. Jay seems happy to be back with me.  
 123. I thought he might really miss his friends, and the space, you know.  
 124. But he seems to have settled really quick.  
 125. He talks about friends and, like, I've had good reports from his tutor. pride

Pause

126. He's got work experience this year coming up soon I think. I wonder if he can come and work with me... I'll put him to work, you know, he'll have to work hard. Um, I need to speak to his tutor to see if he can do it with me at my firm, 'cos he might not cope... Just like manual labour, but I think he'd like that... you know, being with me. together
127. I've already had a lot of meetings about the support he needs in school and that... in [redacted] he had help in his lessons and was doing really well. professional decision
128. So he's down to go to the clinic again for another assessment for autism.  
 129. It's hard to keep track of all the people we see doing reports and assessments,  
 130. I just want to know what's best  
 131. and make sure that he does well in school, you know.

Pause

I really want him to keep doing well, and know what's best.

132. But then, they're asking me and Jay about the future, you know, and it's hard to think... I want him to be safe, and I think that he needs me, you know? not knowing  
reliance

Pause

133. Is that... I mean have I given you enough... seems like I might not have been that helpful, is it?

I - Yes! It's incredibly helpful, thank you so much for meeting me.

Yeah, no... I mean, when I got the letter it made me think, you know,

134. I've been through the process, you know, before. It can be frustrating really... you just want to know what's for the best. not knowing
135. But, you meet so many... you have to go through all the steps, and there's a lot of waiting you know...
136. the school said as soon as Jay started in October that they wanted him to have this autism assessment like... professional decision
137. And you just don't hear anything... it gets a bit frustrating.... No knowing how long, you know?

Pause

138. But anyway, when I got your letter, I thought, yeah I'll go for that, you know...  
 139. And you know, it feels good to talk it all out.

140. I'm not much of a talker really,
141. but this process, like I think people need to know that it's not quick, or clear really. You go round the houses with it all a bit...but yeah, glad it was useful to ya.

*unknown*

**APPENDIX 4: WORKING TRANSCRIPT OF HANNAH'S NARRATIVE  
(INCLUDING ANALYSIS ANNOTATIONS)**

1. I – So I'm interested in hearing the stories of parents whose children have been referred for an assessment at scas.
2. Well, I mean it's been four years, coming on five years.
3. There are easier ways, I mean they could do it easier ways and getting it over and done with rather than... cos I mean, the way that they've done it is they've done a certain assessment every time, and then, when that assessment's done, and if it hasn't come out with a, with a logical explanation, as they say, a diagnosis, and you're not on them actual points, they, they brush you off. They don't think they'll keep you. They don't think ok then we don't believe it's autistic or we don't believe it's certain things so we're gonna sign you off now and put you onto another one... so you've gotta wait. They don't think... so then they put you onto another 6 month waiting list for another mental, er, illness or another team of people. If they actually would have kept you on and stayed with you and spoke to that person again you would have been done, been diagnosed with and done another two people in the time that you've actually done that one person. And I'm not the only person in the thing... in her school, you know...
4. Lily - Mummy!
5. No, babe
6. Lily - Look at picture in the light!... (inaudible child chat)
7. No, look, boo, come on now darlin'. I've said this, do I do this in your place, when you're talkin' to Sharon at XXX (names CAMHS service)? Do I?  
Lily - Yeah!- Is this your XXX (names CAMHS service)?  
Laugh, yeah  
No, I don't do this at yours...
8. sit down and watch Coraline now because you're really starting to annoy me now baby, come on...
9. Lily - I'm not....
10. Right, I'm turning this off...  
Lily - No! No! No!  
Yes, exactly, so sit down
11. I – So, for you, where do you feel that your story began?
12. It started at two, when I... when she had OCD, well, to me she had OCD... different, weird traits. Instead of her talkin, she would scream at me, 'Arrrrg'. So then, er I went to the doctors, they said to me, 'obviously er, it could be the terrible twos',

time

suggesting  
impairmentexplanation  
diagnosis  
dismissed

wait

being listened  
to

time

label

development  
dismissed

13. and I'm like, yeah but I got a child who's thirteen. And one of the eldest of my cousins, that actually, like, I was old enough to babysit, but I wasn't old enough to go out...

I- right

So, yeah, if you see what I mean... back in them times.

14. So yeah, I would look after all my little cousins, so I know different traits. My other cousin's got autism, one of them's mentally ill. So like, I've kinda, not diagnosed her but... you kind of look at the traits and realise... and I see the traits with her and like, her sleeves and things like that.

15. So then they was like 'no...it's fine, it could be just like a phase... leave it, leave it...'  
 16. Then in school she didn't talk to people... only like, gimmic people and stand beside them. She's always be with an adult, things like, just little things.

I - was that in nursery?

Not even nursery, like pre-school, like for twos... a scheme

17. Lily - Mummy! Can I have a... ?

Yes, you can if you sit down and be quiet for the rest of the interview.

Erm... I don't ever bribe, I hate bribing... erm... oh my god where was I?

18. I - So she was two...

19. Yeah so, and like her socks, she wouldn't wear her jeans.. that was the main thing, and she wouldn't talk... she would just shout, like, 'Arrrgh!' and go on a mad one and run off into her room. And like, you'd think... just explain it to me and I'll think about a way... erm...

20. So then obviously the school, the school didn't believe me, and they was like, 'we watch her'.

21. Then, the only time that they actually (slight laugh) did listen to me was when she stabbed her, with a fork, my eldest child... If you see what... it's fine now, like we've got to the point that people can sit in her places... we've gone past her...

This is her spot here (points to where I'm sitting). This is my eldest's here (points to another chair). And she went like that (leans arm over) to get the ketchup, and she's done that and she stabbed her with her fork, cos she was in her space.

And so when that come to me, so I had to literally draw a line like, literally, like, you know...?

I - Here?...

Mum as expert

- behavior  
traits  
dismissed

- behavior  
traits

voice

traits/  
behavior

dismissed/  
not believed

voice  
behavior

22. Yes! It was ridiculous, on the sofa- that was her square... before Carly came along... we had to have a discussion about that one, you know, that Carly is the baby, she needs that spot. You know, just in case she falls off the sofa.

*how to manage*

23. Erm... yeah so... the fork stabbing... that's the only time they listened to me... and they didn't listen to me when they thought, they thought I was a young mum... I'm 31... I mean I know, it's understandable... I mean, I've been through a lot... I've got experiences that you probably wouldn't believe... but it's just, they just don't listen.

*didn't listen/ voice/ dismissed*

I - mmm

Especially young people, I've had it a lot, I mean I've got social workers now...

24. and like, all these professionals... and the mental health professionals only listened to me when I've got the other professionals behind my back.

*voice/ dismissed*

25. Cos, when they signed me off last year, and I only had it for like a year... I obviously got everything else lined up cos I was waitin like a year, and waiting and waiting... and then they got me an assessment with Sarah for an assessment with... which is an autism assessment... done that, that took us three days to do... because obviously she was impatient and what not.

*waiting assessment time*

26. Erm... done that... got that done... she was one under the spectrum... one under the spectrum of it, so... they said to me obviously, 'I'm only a autism specialist... I can only do this... I've got to sign you over to a psychologist'.

*diagnosis missed being passed on*

27. Why do I need a psychologist for one? I need her diagnosed with something because I can't... I can't be dealing with her anger. Cos her anger started to come out then... and if she didn't do it right, or like colouring in outside the lines, she would rip it up, 'Arrgh!' (speech very fast) And she wouldn't explain it, so like a psychologist could help... but I need other things as well- speech and language, things like that.

*diagnosis - need Can't cope traits/behav*

I - mmm

28. So it was like two years going through the assessment, of going to meetings... obviously they wanted to record her, hmmm, so it was an ongoing thing.

*time*

29. Then, um, yeah, so after that, that was it... so now she's six (emphasised). Oh, but like, before that she had, I had Lucy... to open a set thing, and they did that for six months. She writ down and said that she thinks that, er, I was right, that they needed to carry me on with an autistic doctor, or a specialist... not (emphasised) a psychologist... er, so I got that letter back about seven months ago... and now I'm waiting for that...

*assessment being passed on*

30. oh and I got a, er, phone-call from that... oh no a letter from scas from Sarah who did the first, er, first assessment saying 'I haven't forgot about you, I've got some other little girls who's got the same traits... and we would like them to work together', not together as a team, she wants them...

*mixed messages traits*

31. like cos obviously all the doctors are chattin together... and that's been seven months...
32. And now I've got this... I mean, this is the kind of stuff she does at home. It is small in my house, I understand, and I do take her out- she has regular, regular things.
33. Like, everything has to be, everything has to be in... in... oh my god it's gone out of my mind... I hate this... in routine.

I - ok...

If I don't have a routine with her, then, like, it gets a bit messy and she starts to be nasty, most of the time.

34. Erm... yeah, and now I've got social workers because I went to the school... she doesn't want to go to school most of the time, and I'm literally... not, dragging her, but... I'm getting her to school, and I've, I've shouted and (small laugh 'huh') got, got aggressive and they've thought that I can't handle it... when it isn't.
35. When you've got a child who constantly (emphasised) has got an obsession with certain things and the way you're doin it, and if you're not doin it right... and if you're tired... you do snap (speech very fast). I've never screamed, never been like, nasty in that kind of way. I've shouted in the street, and sayin to her, when she's far away, 'hurry up, we need to get to school'.
36. So, the school said to me that I needed to get... well... they safeguarded me again, well not again... they safeguarded me. And now I've got social workers; and now, my social worker Rebecca, don't know her last name, erm, is now getting everything back into order. Which, I've got in contact with, who was it, Leanne again, who said to me that she's going to get them to contact me asap to keep me updated on what's goin on with the EHCP... so I'm hoping to speak to her soon.
37. So the social wanted to go to the school on, when was it, yester' um Wednesday... with... she brought a, er scas, er something assessment. I can't really understand my social worker in a kind of way, on the phone, because she's French African, and oh, the barrier's a bit, thingy, but when I have meetings I do understand her, do you know what I mean?
- I - yeah...
38. Plus, my phone's a bit broke too... er, but I think she did say that one of the assessment team wanna come in and see, just observe her... so, but she was ill, so she had that virus and was all being sick and stuff. And I thought 'great, that one day I actually do want you to go in, you can't go in though!' so... and now, that's it really...

Professional  
Gillidig

behavior

traid

Can't open  
not listened  
to/understood

A behavior

being  
passed  
on

voice

not  
understood  
communication  
prob)

communication  
prob)

39. I've got another meeting... on... next week... and the week after.. and that's to obviously to get everything in order... see what's happening, see who's my social worker, see what's happening at school. She has nothing, no help at all... nothing.
40. And they, but then the school (laughs) write an assessment that says, written a report saying that they believe it's my parenting, no the... not her. They think she's got nothing wrong with her...

I – to you?

No, to me social worker... but in so many words... in the way they do it... they're saying there's nothing wrong with her, she's a normal child, she does what she does.

41. She's only spoken to two other children in the class, which she knows when she was in the year two scheme, so she fmaili.... Familiar... urgh...

I – familiar with them...

42. Yeah, she will come out of her shell... so she will do what she wants to do, she's very smart, very smart...

43. (to baby Carly) You can't have that baby it's broke...

44. Lily... what are you doin, chick? What have you made?

Lily - Apple juice

Let me see it first, because you know it's double concentrated stuff you know... yeah, you know exactly...

(Lily giggles)

Are you kidding me? Are you urgh... are you kidding me? Right, never again! I will make you a juice, do not do it.

(Lily giggles)

We've had this discussion Lils... oh my days...Lils, that is disgusting... that's just raw... that's just... that's double concentrated... not single one...

Lily - so it can be lots?

No, the little it is, the stronger it is...

(to me) Sorry...

I – That's ok...

(to Lily)- Are you gonna watch this?

Lily - Yes!

seeking clarity

dismissed  
locating problem  
in Mum problem

behavior  
trait

(to baby Carly) oh no, have you done a poo?

45. (to Lily) – cos, I can see you fallin off there and smashing your face, and we'd have to go to a and e.... Argh, you're gonna have to go to nanny's tonight, I need a break from this (laughs) oh god... I love Fridays... I love Fridays

I – is that your mum?

Yeah, my dad finishes work

46. (to Lily) – No, you can't... are you serious? Are you serious? You always have to play up, don't you? Arrr, god help me... nah, it's alright, no, she's not that bad, this is happy lily, which I can deal with, it's angry Lily that I don't understand... mad Lily and angry Lily that I can't deal with... you can never get through to her... the house is so small...

(goes into bedroom with Lily)

(to lily as Hannah comes back into the living room) – see, nasty Lily comes out... you can never just be nice Lily...

(to me) – all because I can't find her cover...

(sound of Lily crying in the bedroom)

47. (to baby Carly) – come on dude...

(carries baby Carly over to sit with us at the table)

(to baby) who's this? This is Holly...

(sound of Lily crying)

(sighs) oh god...

48. I – So your experience...

49. Hmmm (sigh)... It's been hard... it's been frustrating... because, I'm not that kind of person... see, over the last six years I've become a bit more experienced... but when I first got with them, when I first decided to ask... everyone just... looked down at me, or I felt they did... and, the way they spoke to me, I mean because everything, I didn't know professional talk much, and I mean obviously for me, for over the six years I've realised that their kind of talk is not being nasty, it's just the way to be professional, the way they word their words, do you know what I mean? I've kind of grown into that, but it's very frustrating, very frustrating...

50. you don't know what to do, you get fobbed off, you go to speak to this one or that one... obviously they've got other patients, that's understandable, but it's like, every time you ring they're always out on a call or... and they never ring you back... and then when you do start ringing them back you do start to get aggressive, in a way,

*Coping  
location of  
problem*

*behavior  
location of  
problem*

*feelings*

*time*

*talk  
professional*

*dismissed*

*# behavior*

because I'm putting a tone on because I've had enough, I mean I've been ringing you the last two weeks and you ain't getting back to me...

51. so then I... so then I got a key worker, and the key worker did really help me because he done all the work for me Rick, Rick James his name was... I don't know if you've worked with him?

I - No...

It's ummm, (names team) he works for...

52. um yeah, so then, as soon as I got rid of him, er, no one wanted to ring back my phone calls or ring me back, and it was like, just because I hadn't got a professional to speak for me... I had no voice, you know?... That's how I felt, well, how I still feel now... Like, in seven months, it's been seven months and I haven't spoken to anyone and now, I've got a social worker... everyone wants to ring me again, because I've got a social worker ringing them up... but it's like, when I wanna ring you, you don't pick up my messages, or 'oh yeah, I'll ring you back', or they ring me at mad times, like when I'm dealing with her, and picking her up from school, and you know, obviously I've spoken to you, and you know I've got a young child... and just...

53. but having a key worker is helpful... someone who can vouch for you, speak to you without you... cos obviously when you ring up people they... cos...

54. so my mum has got mental illness as well, so I've got kind of experience with it, so when I used to ring up they would say 'oh I can't give you information', but when you've got a key worker, all that information, they don't have to be with you all that time. So, if you get that text or get that letter, and you ain't got no credit, he can ring and say 'oh alright then, what is it, I'll give you that number', and they know, because you've spoken to them before, and it says on the system that you've got a family support worker.

55. Social workers, not really helpful, but family support workers, yeah...

I've had three social workers in the last year, the first was for my eldest's dad. Erm, the second one was for her dad too (laughs as Lily shouts), oh my god, they're all from her dad... and then the third one was from the school saying I couldn't cope.

56. But the way that they go around it it's... it's the way they speak to you... it's the wordings that they word, the way they make you feel, it's different. Social workers are there obviously to, not judge you, but to know every aspect of your life... with the social er support workers, they're there to support your life. They're there to help you with and to ask your problems, like, 'what would you like me to help with, like admin wise, in vocal wise' cos they've obviously got more experience than most... I mean I know there are lots of people out there who are good... but they're people who have got good ettec, ettec, there I can't even say it...

in behalf

the keyworker

keyworker = power

voice

not understood

keyworker on side

Mum as expert

Prach call help

SW & KW split

why SW involved coping

KW +ve SW -ve = split

57. (to Lily) We're recording, darling, please, go and play with Carly...
58. It's mad, I mean, social workers are meant to be there supporting you and your family, but they're more authority... so they more come in to like, to judge you in a way, that's the only word that I can really actually use... to judge you, to see what you are doing wrong, what you can change in your life, when you don't need to change your life...
59. I mean you obviously need to work on... I've been on a parenting course, for two years, I done one on my own, and I done one with my other half, her dad, because he's around her.
60. And, like before you've done that they've come round and said 'yeah you done duh, duh, duh, and I don't believe there's anything wrong with her'... they've even rung up her dad and said they don't believe there's anything wrong with her in any kind of way... but she needs her own space, so when they move, they should behave a bit more better'. Well, she goes to my mum's at the weekend, my mum's got a bigger house than me, and she still behaves in that way, do you know what I mean, it's like, she plays up...
61. when people do come she does play on it, but you don't see the way that she's on her own, the OCDs, the behaviours, the way she talks to me.
62. Cos to be honest, with her dad, there was a bit of aggressiveness, but with my eldest's dad there was more violence, and she was about 18 months when I got out of that... and I never got back with him, but she saw a lot of things, I mean, obviously she doesn't remember... but I would expect her to have the problems, like with what she's seen.
63. With her (looking at Lily), everything was ok, we lived together, was a happy family, we moved to Wales, it was nice, you know. So you'd expect the oldest to... they say with trauma, it can you know, be a trigger and set off things. Like with my mum, my mum's been ill... and his mum's been ill, his mum's got severe bipolar...
64. Let me just go and check on this one (Lily)...  
I - Yeah, of course...  
I hate it when she's miserable...  
(Hannah goes into the bedroom then comes back out having checked on Lily)
65. I'm lookin at a house later, won't go nowhere but... and I mean I need to get a new phone as well, my phone is broke, look...  
I - mmmm

VOICE

SW - being judged

H behavior

focus of problem

dismissed

undetermined

dismissed professional hyp

behavior of partner

dv

not understanding

L's wants

desires / needs - practical

VOICE

And now it's starting to affect the whole actual phone itself, so like, I can't actually answer phone calls... so like I couldn't answer the phone to you earlier...

*Communicate  
voice*

66. (a dog runs over)

Arrr(!), you're not afraid of dogs are you?

I - no, no, no...

This is my dog Rolo...

I - aww, he's lovely...

He's a bit smelly, don't let him stand or sit on you...cos he stinks, I need to wash him today, tonight is his wash day...

67. cos my eldest goes to her other nan's... they've got different dads... and she (looks at Lily) goes to my mum's, so...

68. (I am stroking the dog)

Have you got a dog?

I - Umm, no, I'd like to though

69. Ahh, yeah, I rescued him...yeah... I rescue a lot of children... children!?

(both laugh)

Ahhh, feels like it in this block...

70. (knock at the door, Hannah goes to answer)

That's my neighbour from downstairs... she's got, well, she just been, got rheumatoid arthritis, she's got er, a pacemaker, and now she's... they've done one of them things down your throat... and found something at the back of her nose so now they want to do a biopsy and she's scared... and her daughter lives, like far, and so... I'm her little, like, second daughter. She comes up, has a little cup of tea and a chinwag... but I think she shouldn't even come in today with you (looking at Lily) just in case you give her something, cos

Lily - who?

Nancy... cos like, you've had a viral

Lily - who's Nancy?

From downstairs, with Roger and the dog

Lily - but why, but why, but why did you say?

*ask me  
Has  
Carer*

*H as  
Carer*

Because you've had a viral and she's very vulnerable, she's very ill, like, in herself, like...

71. don't do that! (Lily takes the baby's doll) Do you know how much that doll cost? A lot!

Lily – your money?

No, her nan got it for her... it doesn't matter who brought it, give her your doll or her naked doll so she can bite the doll

Lily – her naked doll so she can bite the toe...

72. (I'm stroking the dog, Lily is repeating 'naked doll')

73. Awww, he'll sit there all day if you're stroking him... yeah, I rescue a lot of dogs and a couple of cats...

74. (the baby screams and Lily is saying 'naked doll')

Look at her havin a go at you...

75. (to Lily) You know we're recordin this... go and play with your sister...

(Lily starts to sing)

76. That's not funny through... do you see my happy face? No, it's a sad face isn't it... oh it's nasty Lily coming out now, isn't it, I can see... you won't be going to nanny's now...

77. Lily – Is it recording?

Yes! Darling, it's recording me, asking me how I feel about you and all these services...

78. Lily (to me) – Why are you recording?

I – So I don't have to write everything down

79. (Lily starts jumping on the sofa)

See, she just don't calm down, a normal child calms down, you know (laughs) ahh, I shouldn't laugh, it makes her worse, but you know, sometimes I've just got to laugh. I just don't know what to do...

80. (Lily is screeching)

What about the neighbours? What have I said about the neighbours?

81. (Hannah turns back to me)

Money

Has  
over

Sides of  
Lily  
- hehaha

me?  
being worried  
is

behavior

op'ng

VOICE

What else can I say to you?

82. It's just, I mean, I wish I could give advice to people...

83. but it's just, the doctors don't listen, I mean, it depends on who your doctor is... but you can't just ring up and say 'I believe my child has this thing', because they'll say 'no, you've got to go to your doctor to get a referral'. So, it's basically on your doctor and whether they believe you, and trust you and understand the way that you're feeling and stuff.

84. Because, in a way, the doctors, what they hear is that you can't cope, when actually, no! I can cope, and like I know when to cry and when not to cry, and when to hold my anger and not to, it's that I want to find out what's wrong with her, so that I can deal with that.

85. And people have got the same kind of illnesses... that's what I need, advice from people that have got the same kind of needs.

86. It depends on the people and the age, I mean young mums get stereotyped... I mean, cos I still can't buy lottery tickets I get id'd, and I say 'are you jokin me?' and in the past I would have got really angry, but now I just walk away...

87. (Hannah speaks to Lily about playing with cushions on the floor then turns to me)

88. Have you got kids?

I - No...

Don't!

(both laugh)

89. I - Is there anything else that you want to add to your story?

Just that I wish people would communicate better, you know?

90. And be like, on your side, in your corner. And for them to speak to each other, cos you say one thing, then another thing and they could have spoken in the same office rather than... asking me to send tis letter or that email, when they've probably just bumped into each other.

91. Cos that's what me and my family worker like had done... and for them to say that like, 'we understand you' and 'we haven't forgot about you' cos the wait list is so, understandably, long and like, 'we hear you'. And for the schools to me more, like, when we first moved here...

92. (Lily screams lots and Hannah talks to her in the bedroom)

me  
- desire  
to help  
- ask  
being  
listened  
dismissed

angry  
num of  
expect  
need for  
have  
dismissed  
disempowered

me  
- desire  
for  
power  
voice

Collecting  
the FW  
desire for  
empathy

the

93. For the schools to be more involved, like the school said that she was half statemented cos she was one under the spectrum she was half statemented. But then I spoke to someone and they said that there's no such thing as half statemented.
94. So then, the school wouldn't take her because she was being assessed. If the school had of taken her then had her assessed, that would have been fine, but because she's been assessed they won't take her, or like, one school told me they already had 3 statemented children so couldn't take another... which I don't get because the statemented kids get support.
95. Then when I'd spoken to the support worker we were like, some schools just don't wanna deal with mental health issues... that's wrong...
96. I mean when you wonder why her nan or his mum are like they are... it's because they never had the right, proper help for mental health.
97. For kids it's the worst, if you don't get it for kids, you aren't going to get it nowhere.
98. Do you know what I mean, if you get it early you can do something to deal with it, it took my mum... I mean, she's 57, it's took her over 30 years to get stable, do you know what I mean...

need to  
Suggested  
improvement

FW +ve  
locating prob  
- help

fear for  
future

**APPENDIX 5: PARTICIPANT INVITATION LETTER AND COVER LETTER**

The Tavistock and Portman   
NHS Foundation Trust

Dear Parents / carers,

I am from X Educational Psychology Service and the Tavistock Centre and am completing a Professional Doctorate in Child, Community and Educational Psychology, for which I am completing a research project for my thesis. I would like to invite you to take part in my research as I am interested in hearing the stories of parents whose children have been referred to X Social Communication Assessment Service (SCAS). The research will aim to highlight the importance of understanding parental experience among professionals.

Your participation in this project would involve an interview with me (approximately an hour). I would write up the interview notes then arrange a second meeting with you to check that my transcription and initial analysis reflects your experiences (approximately an hour). The interviews would be completed at a time and location convenient for you.

Your participation in this research is unrelated to the assessment process at SCAS, and the interviews would be confidential and anonymised at the point of transcription.

I regret that due to the focus on spoken experience, only parents who could complete the interview without an interpreter are eligible to participate. Also, due to the unique nature of experience and the limited scope for interviewee numbers in the study, only one parent per family is invited to take part. However, parents are free to discuss their experiences between them and to talk about this in the interview.

If you can take part or would like further information, please email me at [X@tavi-port.nhs.uk](mailto:X@tavi-port.nhs.uk) or call me on X **before Monday 30<sup>th</sup> January**. If you would rather respond via post, please complete the attached slip and return it in the enclosed stamped, addressed envelope.

If I have not heard from you by **Monday 30<sup>th</sup> January**, the offer for involvement will be withdrawn.

Many thanks and I look forward to hearing from you,

X  
XX

Educational Psychologist in training

My name is: .....

I am interested in participating in the research project, please contact me on (email address or phone number):  
.....

**SOCIAL COMMUNICATION ASSESSMENT SERVICE**

Dear Parents / carers,

Please see the attached letter inviting you to participate in a doctoral research project. You have been contacted as your child has been referred for assessment at the Social Communication Assessment Service (SCAS), and the researcher is interested in hearing the stories of parents whose children have been referred.

The researcher does not have your contact details, if you are interested in participating you can contact the researcher directly (details on the letter attached). Your involvement in the research project is unrelated to your child's assessment and entirely voluntary. The research project has been given ethics approval with the IRAS ID 197460.

Thank you for your time to read this letter

Yours sincerely

XX

On behalf of The SCAS team

## APPENDIX 6: PARTICIPANT INFORMATION SHEET AND CONSENT LETTER

The Tavistock and Portman 

NHS Foundation Trust

### Information about the Research

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**Research title:** The stories of parents whose children have been referred for an assessment for Autistic Spectrum Disorder (ASD): A narrative analysis.

I would like to invite you to take part in my research study. Joining the study is entirely up to you, before you decide, I will go through the following information with you to help you decide whether or not you would like to participate. This should take around 15 minutes, please feel free to talk to others about the study if you wish. Do ask if anything is unclear.

**The research question is:** What is the experience of parents whose children have been referred for an Autistic Spectrum Disorder assessment?

The research will aim to promote appreciation of the experiences of parents among professionals and is primarily educational in purpose. Your participation in this project would involve an interview with me (approximately an hour), which would be audio recorded. I would write up the interview notes then arrange a second meeting with you to check that my transcription and initial analysis reflects your experiences (approximately an hour). The interviews would be completed at a time and location convenient for you (therefore unfortunately there will be no reimbursement for travel or childcare). I am hoping to interview 4 parents in total. The audio recordings of the interviews will be destroyed when they are transcribed (written up), at which point they will also be anonymised.

You have been selected for invitation at random as your child has been referred to the Social Communication Assessment Service (SCAS). Your participation in this research is unrelated to the assessment process at SCAS, and the interviews would be confidential and anonymised at the point of transcription. You will maintain the right to withdraw from the study up to the point that the data is transcribed and therefore anonymised. At the end of the study, the anonymised interview data will be destroyed, and the study may be published.

I regret that due to the focus on spoken experience, only parents who could complete the interview without an interpreter are eligible to participate.

**Possible benefits of taking part:**

The results of the study will be shared with relevant professionals and may inform future practice, promoting the power of parental voice. Also, some people who have

completed narrative interviews have reported that they have found the opportunity to tell their story therapeutic.

**Possible disadvantages of taking part:**

Some elements of telling your story may prompt unexpected feeling or emotions. However, you will be asked to share your story and will not be asked to share any information you do not wish to. If you wish, I will be able to provide you with signposting for further support after the interview.

**What will happen to the findings of the study?**

You will be offered a summary of the finished research, it may be published in academic journals. A summary will also be offered to X Educational Psychology Service (EPS) and SCAS.

***Complaints:***

*If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (xxxxxx@tavi-port.nhs.uk). If you remain unhappy and wish to complain formally, you can do this online at: <http://tavistockandportman.uk/about-us/governance/policies-and-procedures/complaints/making-complaint>*

*Or in a letter addressed to:*

The Chief Executive  
The Tavistock and Portman NHS Foundation Trust  
120 Belsize Lane  
London  
NW3 5BA

**Who has reviewed this study?**

*All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee.*

***Further information***

*Please feel free to contact me to ask any further questions at [X@tavi-port.nhs.uk](mailto:X@tavi-port.nhs.uk)*

**Consent letter**

Dear parent or carer,

I would like to invite you to take part in my research which will form the thesis for my Professional doctorate in Child, Community and Educational Psychology at the Tavistock and Portman NHS Foundation Trust.

**Research title:** The stories of parents whose children have been referred for an assessment for Autistic Spectrum Disorder (ASD): A narrative analysis.

**Please read the following points regarding participation in this project:**

- Participation in this project is voluntary and you will have the right to withdraw up to the point that the interviews are transcribed (as at this point the data will be anonymised).
- Participation in this project is unrelated to any involvement in the assessment process at SCAS.
- Participation will involve one interview where you will be asked about your experience as a parent whose child has been referred for an assessment at SCAS. There will also be one follow-up session to discuss the transcription of the interview and the initial analysis.
- The anonymised results of the project will be shared with professionals who work with parents whose children are assessed for Special Educational Needs to highlight the importance of understanding parental experience.

**Please read the following statements and confirm by selecting ‘Yes’ or ‘No’:**

I confirm that I have read this consent letter dated ..... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

**Yes / No**

I understand that my participation is voluntary and that I am free to withdraw up to the point where the information is anonymised without my rights being affected.

**Yes / No**

I understand that anonymised data collected during the study may be looked at by responsible individuals from the NHS Trust or from regulatory authorities, where it is relevant to my taking part in this research.

**Yes / No**

I agree to take part in the above study

**Yes / No**

---

(Participant)

Name:

Date:

---

(Researcher)

Name:

Date:

Once complete: 1 original for participant, 1 copy for researcher

## APPENDIX 7: TABLE OF CATEGORICAL-CONTENT ANALYSIS THEMES

### Themes from David's narrative:

<b>Initial theme (as noted on working transcript)</b>	<b>General theme (recorded as subheadings in analysis chapter) including the colour of highlighting used in working transcripts</b>
Pride	<b>Jay's strengths and difficulties</b>
Positive attributes	
Jay's behaviour	
Split	
Mismatch	
Difficulties	
Speculation of Jay's feelings	
Decisions	<b>Decisions and change</b>
Transience	
Transition	
Professional hypotheses	<b>Professional hypotheses</b>
'They'	
Reliance on school	
Conflict	
Work	<b>David's job, life and feelings</b>
David's life	
David's feelings	
Impact on David's life	
Difficulty	
Worry	<b>Worry and not knowing</b>
Future anxiety	
Not knowing	
Waiting	
Together	<b>Symbiosis</b>
Reliance	
Activities	
Safety	
Vulnerability	

### Themes from Hannah's narrative:

<b>Initial theme (as noted on working transcript)</b>	<b>General theme (recorded as subheadings in analysis chapter)</b>
Key worker	<b>Professionals</b>
Being listened to	
Being believed	
Being understood	
Social workers	
Other professionals	
Collusion	
Professional talk	
Mixed messages	
Fear of future	

Dismissing professional hypothesis	
Desires	
Needs	
Hannah as expert	<b>Hannah</b>
Hannah as carer	
Coping	
Practical help	
Money	
Suggesting improvements	
Coping	<b>Lily</b>
Label	
Diagnosis	
Behaviour / traits	
Location of 'problem'	
Sides of Lily	
Being listened to	<b>Voice</b>
Being dismissed	
Not believed	
Voice	
Not understood	
Waiting	
Location of 'problem'	
Social worker and key worker	
Undermined	
Communication	
Desire to help others	