

**Exploring the use of an autobiographical account in
diagnostic assessment of Autism Spectrum Disorder
with a young child**

Thesis submitted for the degree of Doctorate in Applied Psychology at the
University of Leicester

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DECLARATION

No portion of this work has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

Exploring the use of an autobiographical account in diagnostic assessment of Autism Spectrum Disorder with a young child.

THESIS ABSTRACT

The review of the literature critically analyses eleven qualitative studies (2005 – 2014) that report the views of children with autism spectrum disorder (ASD). It seeks to consider the methods used by researchers in order to identify potential factors that restrict or enable children to give their views. Studies are dominated by male adolescents with a diagnosis of Aspergers or High Functioning Autism with views sought by interview or group discussion, including adapted visual and activity based methods. There is no clear evidence to show which methods are most effective, and there is a gap in the literature with the views of children under eleven years of age, females and those attending special educational provision poorly represented. The findings inform an exploratory study that seeks to consider how a young child might be enabled to give their views in the process of diagnostic assessment for ASD.

Interpretative Phenomenological Analysis is used to review the narrative of a five year old child, and shows the age at which some children can actively participate in giving their views and experiences is lower than previously thought. The researcher reflects on a diagnostic practice model that moves from a reliance on deficit patterns of behaviour to also ask what sense the child makes of their experiences, and to consider how this might impact in clinical practice.

The critical appraisal describes a reflexive account of the research process.

The service evaluation seeks to critically evaluate available data for a community service for children with neurodevelopmental needs in order to inform evaluative practice. Undertaken during a period of organisational review, different approaches to evaluation are considered before collating the service data and considering its application in two different evaluative frameworks. Each approach has specific merits and limitations and combining different approaches is most likely to contribute to sustainable service improvements.

Patricia Woods

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PAPER 1: LITERATURE REVIEW

**The views and experiences of children with autism spectrum disorder
(ASD): A structured review of qualitative studies**

*(Guidelines to authors for journal targeted for Literature Review can be found in
Appendix E)*

ABSTRACT

International and national legislation promotes consultation with children and young people with disabilities about their experiences of daily life and the services that support them. Enabling their participation is complex and there is a paucity of studies focusing on the views of children with autism spectrum disorder (ASD). The review presented here analyses eleven qualitative studies published between 2005 and 2015 that report the views of children with ASD. The review considers the methods used in order to identify potential factors that restrict or enable children to give their views and the aspects of their lives that children are asked about.

Studies are dominated by male adolescents with a diagnosis of Aspergers or high functioning autism reporting on the impact of and their adjustment to, a diagnosis of ASD and their experiences at home and at school. Their views are sought through interview or group discussion, including a range of adaptations using visual and activity based methods. Findings show there is some evidence that children engaging in practical activities during the interview process may result in more effective communication. There is no evidence of any specific technique for seeking the views of children but rather the application of general methodological requirements.

A range of complex factors need to be considered including: a familiar location and relationship with the researcher, the availability of different ways to respond, and sufficient time and flexibility to enable spontaneous adaptations to be made by the adult. The potential application of eliciting children's first-hand accounts of their experiences in the process of diagnostic assessment of ASD is considered, and offers the important potential to contribute to a different narrative of ASD from the traditional deficit one of disorder and impairment.

1. Introduction

Developments in the practice of consulting children are underpinned by the United Nations Convention on the Rights of the Child (1989). They seek to enable children to express their views and ensure they are taken into account in any decisions about them (Aitken & Millar, 2004). Legislation and policy place a requirement on professionals to seek to ensure that the individuality, differing maturity levels and best interests of each child is recognised and considered (Head, 2011). However, it is professionals' view of children with disabilities and their rights that influence their interactions, impact on questions that are asked, of whom and how they are asked, and what happens to the information (Children's Research Centre, 2006).

This review aims to consider what the recent literature tells us about seeking the views and experiences of children with autism spectrum disorder (ASD) and to identify potential factors that restrict or enable them to give their views, in order to consider how children might be best supported to participate in the process of diagnostic assessment for ASD.

Participation is a complex phenomenon impacted by the interaction of multiple personal, environmental and family factors (Law et al., 2004). The term 'participation' is often used synonymously with other terms, such as 'listening to children', 'voice of the child', 'children's views', and 'consultation', and is used to describe a great variety of activities taking place in differing circumstances (Sinclair, 2004). It is important to consider what is meant. Participation and consultation both involve eliciting children's views, but in participatory practice the child's views actively influence decision-making (Hall, 2006; Lundy, 2007; Davey, 2010).

Within diagnostic health services there is a need to take a situational perspective of children's participation, to act in the child's best interest and to balance protection with shared decision-making (Coyne, 2006). It is in

identifying how to support individuals that increasingly autobiographical accounts by adults and young writers are making significant contributions to a richer, more complex set of understandings (Barrett, 2006; Hall, 1998). Individual experiences cannot be measured, they can only be shared in the telling, and it is important to ask what sense the child makes of their lived experiences (Gilling, 2012).

1.1 Clinical context

There is no single way of describing autism that is universally accepted and preferred by the UK's autism community, with the most highly endorsed terms being 'autism', 'on the autism spectrum' and 'autism spectrum disorder'. (Kenny, 2015). The diagnostic criteria used in the UK (ICD-10) refers to autism spectrum disorder (ASD), therefore in the current review the term is used as an umbrella term for autism spectrum disorder (ASD), autism spectrum condition (ASC), high functioning autism (HFA) and Asperger's syndrome (AS), and for the sake of brevity 'child' and 'children' are used to refer to the children and young people who were participants in the selected studies.

Autism spectrum disorder (ASD) is a medical diagnosis with primary consideration of a 'triad of impairments' in social communication, social interaction and social imagination (Wing, 1993). The diagnostic assessment process is essentially multi-informant with strong emphasis placed on adult perspectives and the identification of global characteristics, with comparatively limited regard for the child's views and experiences despite practice guidelines (NICE, 2011). This can lead to the dominance of restricted deficit narratives that maintain the negative stereotyped view of ASD (Billington, 2006; Billington, McNally, & McNally, 2000; Milton, 2012; MacLeod, Lewis, & Robertson, 2013).

1.2 Consulting children with ASD

There is a growing body of research on specific child-friendly approaches that have been developed to consult with children, and it is now feasible to engage with children of a wide range of ages and abilities (Fargas-Malet et al. 2010). Most studies involve children over seven years of age but there is considerable variation in participation especially for those with a complexity of needs (Franklin & Sloper, 2009). Young children and those with disabilities remain more likely to be overlooked in part due to methodological, legal and ethical considerations. These include: locating and gaining access to participants through gatekeepers, consent, assent and the use of proxies, confidentiality, recognition and response to children's views (Nind, 2011), and the complex interrelated factors for any individual with regard to their attention, memory, language skills and ability to transfer information (Nind, 2008; Greco, Bell, Franklin & Mitchell, 2009).

How autism manifests varies significantly between individuals with a specific diagnosis and can impact on the process of consultation in different ways (Preece, 2002). There is no conclusive evidence to identify a single core 'deficit' in autism, with both cognitive and emotional perspectives being considered (Gilling, 2012). The Theory of Mind deficit leads to the expectation that individuals with ASD may have difficulty communicating their own perspective in standard interview (Baron-Cohen, Leslie, & Frith, 1985). They may have limited intrinsic motivation, language and communication difficulties, have difficulty understanding the motives of the researcher, and believe there is a single correct answer contributing to increasing levels of anxiety (Menzies, Waller, & Pain, 2011). Questions about desires and aspirations may be meaningless and possibly viewed as threatening (Beresford, Tozer, Rabiee, & Sloper, 2004).

For some children with ASD the main method of processing information is visual rather than linguistic (Newman, Cashin, & Waters, 2010). The use of

visual approaches such as 'Talking Mats' (Cameron & Murphy, 2008), and concrete resources including toys, photographs, and drawings can help support communication and reduce anxiety in some individuals, but are not always appropriate or effective. Pictures or photographs particularly if new may be misleading and may not add to an individual's understanding if the language used is not also carefully adapted (Walmsley, 2004). Techniques such as the 'Mosaic Approach' aim to combine verbal and visual tools, and have been successfully used with young pre-school children (Clark, 2001; Clark & Moss, 2011; Day, 2010).

There is a range of different methods available that might be used to elicit the views of children with ASD, what is less evident, is how best to undertake this and children with ASD remain a comparatively neglected group (Beresford et al., 2004). The lack of information about how to elicit the views of children with ASD formed the rationale underpinning this review and the formulation of four main aims.

1.3 Aims of the current review

The current literature review aims to consider:

1. The demographics of the children with ASD whose views are sought.
2. The aspects of their lives which children with ASD were asked about and their views.
3. The potential factors that restrict or enable children with ASD to give their views.
4. The methodological issues pertinent to eliciting the views of children with ASD.

2. Method

2.1 Search strategy

A structured search was undertaken in June 2012 and in June 2015 using the following databases: Psych INFO, Medline and CINAHL. The search strategy was designed to include terms relating to autism including: Autism Spectrum Disorder (ASD), Autistic Spectrum Condition (ASC), High Functioning Autism (HFA) and Asperger's Syndrome (AS), and terms relating to participation, including: child voice, views of children, child participation, and child consultation. The paucity of studies focusing specifically on the views and experiences of children with ASD meant there was a need to cross disciplines, research areas and professional boundaries. Title and abstracts of all results were screened and full manuscripts obtained for papers appearing to meet the inclusion criteria. In addition key journals were manually searched and reference lists viewed for additional studies. The number of manuscripts returned through electronic and hand searches and reasons for exclusion are shown as a flow chart (Figure 1).

2.2 Inclusion and exclusion criteria

Included studies were required to be qualitative studies published between January 2005 and June 2015, in English, in peer reviewed journals.

Population

Studies were included if their target population included children and young people aged between 2-25 years with a diagnosis of ASD. Studies that did not directly report the views of children and young people were excluded. Studies with adults were excluded.

Design

Studies were included if they used qualitative methods. Single case studies and reviews were included.

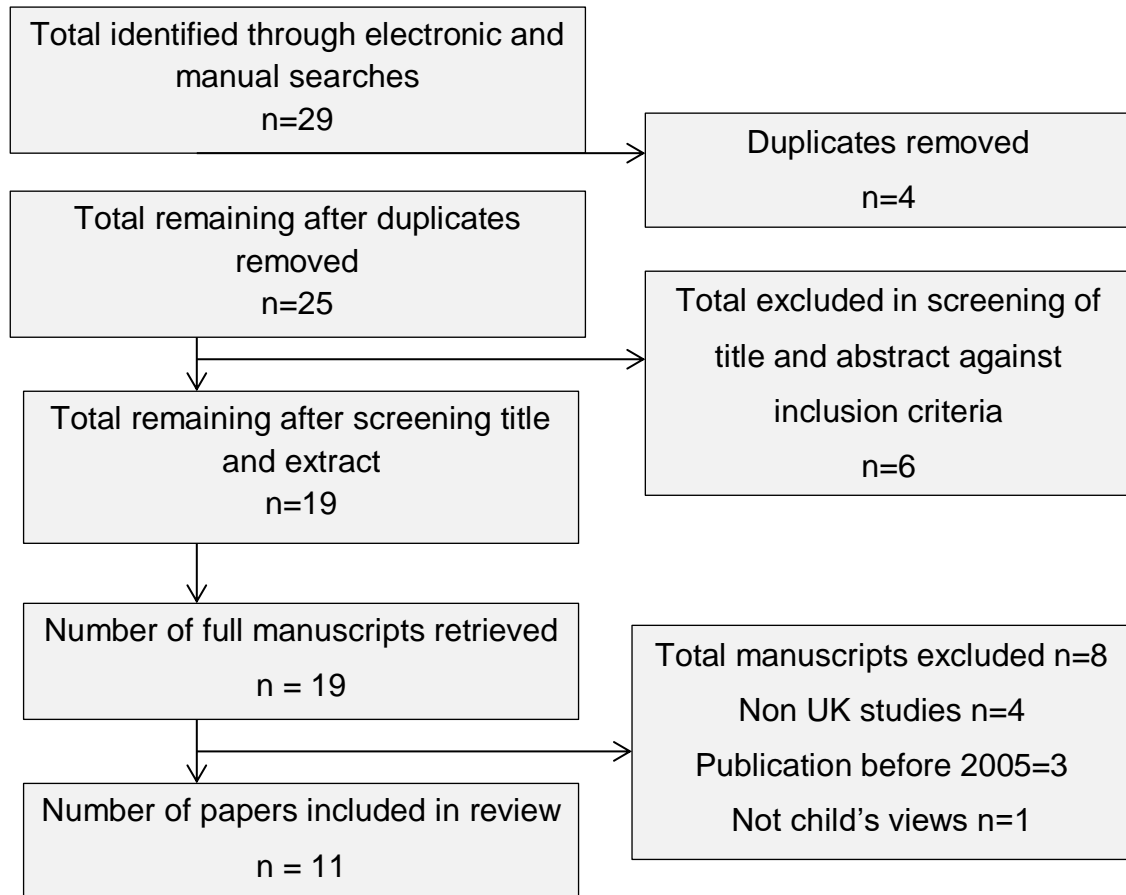


Figure 1 - Process of identifying papers for inclusion in review

Data extraction and quality appraisal

The issue of 'quality' in qualitative research is part of a complex debate about the nature of the knowledge produced by qualitative research, whether it can be legitimately judged, and, if so, how (Carroll, Booth, & Lloyd-Jones, 2012). Some researchers consider appraisal tools useful (Popay & Williams, 1998; Spencer, 2003) while others state that their use stifles creativity (Dixon-Woods, Shaw, Agarwal & Smith, 2004), but if qualitative research is to be used to

inform clinical practice there needs to be some judgment that it is 'good enough' (Toye et al., 2013). There is no consensus regarding the most appropriate critical appraisal tool for allied health research, and no 'gold standard' quality appraisal tool (Katrak, Bialocerkowski, Massy-Westropp, Kumar & Grummer 2004). Carroll et al. (2012) tested the impact of excluding studies on the overall findings of two qualitative systematic reviews, and found that exclusion of so-called inadequately reported studies had no meaningful effect on the synthesis. There was a correlation between the quality of reporting of a study and its value as a source for the synthesis, and Carroll et al. (2012) proposed a possible case for excluding inadequately reported studies from qualitative synthesis.

The Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist was used in the current literature review to facilitate a systematic approach to the extraction of information from each paper for review. All studies passed the first two screening questions (Appendix A, Table 3, page 35), and no studies were excluded in the current review on the basis of their apparent quality in order to avoid potentially eliminating important studies. Additional information extracted included the main findings of each study and adaptations and challenges of the methods used (Appendix A, Table 4, page 39).

3. Findings

3.1 Summary of studies included in the literature review

The search results identified eleven small scale studies that explored the views of children and young people with ASD across clinical and educational settings (Table 1). The issue of locating and gaining access to participants and the process of consent are considered before addressing each of the four aims.

Locating and gaining access to participants was influenced by the layers of gatekeeping at an organisational, family, and individual level before potential

participants were approached, all of which introduce potential bias and skewed sampling. There were a total of 111 participants with sample sizes between four (Ozsivadjian, Knott, & Magiati, 2012) and twenty (Humphrey & Lewis, 2008). Participants were located through different sources: the National Autism Society (Preece & Jordan, 2010), parent support groups (Ozsivadjian et al., 2012) and through their educational setting: specialist college (Dann, 2011; Huws & Jones, 2008; MacLeod et al., 2013; McLaughlin & Rafferty, 2014; Winstone, Huntington, Goldsack, Kyrou & Millward, 2014) or mainstream school (Humphrey & Lewis, 2008; MacLeod et al., 2013; Tobias, 2009).

Students over eighteen years of age were asked for an expression of interest and were self-selecting volunteers (Huws & Jones, 2008). For children under eighteen, consent was sought from their parents and their capacity to give informed consent was judged informally by school staff or other professionals on the basis of their individual verbal skills. Only Brewster and Coleyshaw (2011) completed additional profiling of participants communication skills in order to identify any augmentative communication needs. The parents of the children in the study by Preece and Jordan (2010) that used visual aids raised concerns about their children's ability to participate because of their limited intentional communication. The child's level of engagement and opinions of their parents and siblings about their responses were used as secondary indicators of consent.

Table 1 - Summary of studies included in the literature review

Authors and date	Focus of study	Number of participants (age and gender)	Diagnosis	Methods used	Methods of analysis
Huws et al. (2008)	Views and experiences of having Autism	9 students Aged 16-24 yrs. 6 male 3 female	Aspergers Autism	Semi-structured interviews	Interpretative Phenomenological Analysis
Humphrey and Lewis (2008)	Identity formation and educational experience	20 pupils Aged 11-17 yrs. No information on gender	Aspergers High Functioning Autism	Semi-structured interviews. Pupil diaries Drawings.	Interpretative Phenomenological Analysis
Preece and Jordan (2009)	Experiences of living at home and in short-term care	14 children with ASD Aged 7-18 yrs. 10 male and 4 females Family members.	Aspergers ASD ASD and Severe Learning Disabilities Semantic Pragmatic Disorder (SPD) Autism	Interviews	Thematic analysis
Tobias (2009)	Support at secondary school	10 year 9 and 11 students Aged 14-16 yrs. No information on gender	ASD	Focus groups: Parents and two student groups.	Interpretative Phenomenological Analysis
Brewster and Coleyshaw (2010)	Participation in leisure activities	20 primary and secondary school pupils. Aged 8-17 years 14 male and 6 female.	ASD and or ADHD	Focus groups.	Thematic Analysis.
Dann (2011)	Transition to secondary school	6 year 6 pupils No ages given 5 male 1 female 6 parents and 18 staff	Autism Spectrum Condition	Semi-structured interviews: pupils and parents Focus group: school staff.	Phenomenological and inductive approach

Authors and date	Focus of study	Number of participants (age and gender)	Diagnosis	Methods used	Methods of analysis
Ozsivadijiani (2013)	The nature of anxiety	4 children Aged 11-12 yrs. All male 17 parents (all mothers) of 19 children with ASD.	ASD Aspergers High Functioning Autism Atypical Autism	Focus groups: five parent groups and one child group.	Thematic analysis
Macleod et al. (2014)	Participatory methodology	10 H.E students No ages provided. No information on gender	ASD	Semi-structured interviews: Face-to –face, telephone, or synchronous online options.	Interpretative Phenomenological Analysis
McLaughlin and Rafferty (2014)	Literature review and asking participants 'What is life like for you?'	7 young people No ages provided. 5 male 1 female	Aspergers	Semi-structured interviews: Two sessions.	Thematic Analysis
Winstone (2014)	Exploring self-identity. Comparison of standard semi-structured interviews and activity orientated interviews.	5 young people. Aged 12-14 years All male	Diagnosis anywhere on the Autism Spectrum	Comparison of standard and activity-orientated interviews.	Thematic Analysis
Hill, L. (2014)	Using photo elicitation to explore the experience of secondary school.	6 young people No ages provided. No information on gender.	ASD	Semi-structured interviews	Interpretative Phenomenological Analysis

The following section considers each of the four aims of the current review.

3.2 The demographics of participants

None of the studies provided detailed information about demographics, language skills, cognitive functioning and adaptive skills of participants. Seven of the eleven studies provided details of the age of participants which ranged from seven to twenty-four years of age (Brewster & Coleyshaw, 2011; Humphrey & Lewis, 2008; Huws & Jones, 2008; Ozsivadjian et al., 2012; Preece & Jordan, 2010; Tobias, 2009; Winstone et al., 2014); only Preece and Jordan (2010) included four participants under eleven years of age.

There was no evident agreement on terminology for age banding. Children or young people were used to mean anyone between the ages of seven and twenty-four. Five studies referred to educational provision (Hill, 2014; MacLeod et al., 2013; McLaughlin & Rafferty, 2014), and described participants as pupils or students, the latter being used for secondary age (academic years 9-12) and for those in higher education (Dann, 2011; MacLeod et al., 2013; McLaughlin & Rafferty, 2014; Tobias, 2009). Only Brewster and Coleyshaw (2011) consider the effect of age on experiences. The age of participants was not mentioned by Preece and Jordan (2010) in their analysis, but they highlighted the difficulties for some children in their use of language which other studies did not.

Participants' individual diagnoses were not reported with the exception of Ozsivadjian et al. (2012) and Preece & Jordan (2010), which effectively showed the range of different diagnostic labels used. Only Tobias (2009) explicitly acknowledged the problem of definitions and diagnostic labels and used ASD as 'an umbrella term to encompass the spectrum of autism conditions and to reflect the diversity of diagnosis' (page 151).

Six of the eleven studies reported the gender of participants showing a larger number of males (49) to females (14), reflecting the higher incidence of ASD in

males (Baron-Cohen, Knickmeyer, & Belmonte, 2005; Constantino & Charman, 2012). Yet none of the studies consider gender in relation to children's views and experiences.

The studies are dominated by verbal adolescent male participants who attend mainstream school or Higher Education, mostly with a diagnosis of Aspergers or HFA. A total of eighty-two children were identified by age in seven studies, but only three children were under eleven years of age. Similarly fifty-eight participants were identified by gender with only fifteen being female.

3.3 Aspects of their lives on which children's views were sought

The studies focused on diverse experiences. Therefore to facilitate synthesis of the findings the author grouped children's views into four themes: (1) understanding and impact of a diagnosis of ASD, (2) views and experiences of family life (3) views and experiences of school, and (4) anxiety.

Children's understanding of their diagnosis of ASD

Exploring the issues related to children's understanding of their diagnosis of ASD and experience of disclosure identified the positive and negative effects of labelling (Huws & Jones, 2008; McLaughlin & Rafferty, 2014). Delay in disclosure appeared to be an important factor for several participants reporting a range of reactions, including 'shock' and 'disappointment' and the experience of others knowing something that they did not (Huws & Jones, 2008). For some children a diagnosis provided an explanation of previous experiences and gradual acceptance, but for others not wanting to be labelled or judged led to avoidance of any information associated with ASD. Some children expressed concern about disruption to their plans for the future while others thought that their diagnosis had provided them with different opportunities, including access to support services and educational provision (Huws & Jones, 2008).

All the children had to rework their sense of identity in response to their diagnosis. Some effectively accommodated their diagnosis and others actively avoided it (Humphrey & Lewis, 2008; Huws & Jones, 2008). Those that reported a successful integration of ASD into their identity referenced non-judgmental and accepting relationships with peers, and also showed some insight into the challenges they experienced. These findings highlight the importance of the diagnostic process and the disclosure of the diagnosis of ASD to the child and their parents or carers.

Experiences of family life

Children were generally positive about family life but showed a lack of awareness of the impact of their behaviour on family members (Preece & Jordan, 2010). Preferred activities were solitary, with younger children most likely to engage in activities outside the family home (Brewster & Coleyshaw, 2011). Some children reported friends at school but rarely saw them outside this context. Preece and Jordan's (2010) study considered children's views of short breaks, and revealed that some children missed their mothers and some enjoyed experiencing different activities from those at home. Of the ten children with an allocated social worker, eight had met them and only two recognised them from a photograph and none understood their role raising the important issue of acquiescence.

Experiences of school

Four of the studies focused specifically on experiences at school (Dann, 2011; Hill, 2014; Humphrey & Lewis, 2008; Tobias, 2009). They identified complex issues including bullying, behavioural challenges, social worries and anxiety, but the findings reported by Dann (2011) suggested that the experiences reported by children with ASD were similar to those reported by children with other types of special educational needs (SEN). Some findings challenged the stereotyped view of children with ASD disliking change as some children

viewed transition to higher education as a positive opportunity to reinvent themselves (MacLeod et al., 2013).

Anxiety

A recurrent theme across all studies and the specific focus for Ozsivadjian et al. (2012) was the participant's experience of anxiety. The study demonstrated a clear theoretical framework but the direct reporting of children's views was limited and attributed to the small numbers of child participants (4) compared to adult participants (19). The study explored similarities between parents' and children's reports with both identifying a change of routine, sensory experiences, social worries and increased social demands as potential triggers for anxiety. Communication and relationships with family, peers and school staff appeared to be protective factors, and a network of key themes emerged from the data analysis. Only themes common to each group were reported potentially eliminating some important issues.

3.4 Methods used to elicit children's views and selection of participants

With the exception of the studies by Huws and Jones (2008) and McLaughlin and Rafferty (2014), researcher's acknowledged the potential difficulty for children with ASD with standard interview and group procedures citing this as their rationale for the use of either semi-structured interviews (Dann, 2011; Hill, 2014; Humphrey & Lewis, 2008; Huws & Jones, 2008; MacLeod et al., 2013; McLaughlin & Rafferty, 2014; Preece & Jordan, 2010; Winstone et al., 2014) or focus groups (Brewster & Coleyshaw, 2011; Ozsivadjian et al., 2012; Tobias, 2009).

Direct comparisons between focus groups and individual interviews were sometimes made. Tobias (2009) cited the advantages of focus groups identified by Vaughn, Schumm, and Sinagub (1996) including a possible reduction in social desirability effects, greater anonymity and familiarity with peers enabling participants to feel more at ease, but did not consider how these

factors might impact for children with ASD. Similarly Ozsivadjian et al. (2012) cited Grudens-Schuck et al. (2004) to state that 'the interaction of group members is likely to result in richer conversations and a wider range of themes in discussion'(page 117) but did not reference the potential impact for a child with ASD. Ozsivadjian et al. (2012) was the only study that identified the challenges of groups, and the complex demands on facilitators to ensure discussion is not dominated by an individual and participants remain on topic.

The variability in how the process of interviewing and group discussion was reported made it difficult to undertake comparative analysis; where information was available comparisons were noted and data summarised (Table 2).

Table 2 - Summary of factors that may limit or enable children with ASD to give their views

Factors that may limit or enable children to give their views	How factors operated differently in the selected studies
Age and ability	A wide range of ages were included from 7-24 years. A requirement for retrospective memory and good verbal communication skills, and developing self-identity meant that most studies purposefully selected older adolescents or young adults as participants, with the exception of Preece and Jordan (2010) and Brewster and Coleyshaw (2011).
Communication skills	Children's communication skills were largely judged by either parents' and or school staff that knew them well, based on their verbal ability. Only Brewster and Coleyshaw (2011) completed any additional profiling. Studies that included children with limited verbal skills placed a greater emphasis on the use of proxies and observation, and demanded greater skill on the part of the interviewers. Dann (2011) assumed participants may have language comprehension difficulties associated with their diagnosis, and used Talking Mats throughout the interview process. These were preceded by vignettes and questions to check that participants understood key concepts.
Prior knowledge of interview	Some participants were provided with drafts of interview schedules to check relevancy before their interviews (Humphrey & Lewis, 2008), prompt sheets (MacLeod et al., 2013) or an interview outline one week beforehand (Preece & Jordan, 2010). Others provided written and verbal information at the start of interview (Huws & Jones, 2008), and for activity-orientated interviews some practical tasks were completed before the interview (Winstone et al., 2014).
Choice of location for the interview	Some studies gave a choice of location of either home or school to participants; both were problematic as the potential to cause significant anxiety and distress. For some children the complexity of meeting an unfamiliar person in a familiar environment caused significant distress (Preece & Jordan, 2010).
Frequency of contact / familiarity with interviewer	Participants generally had either one or two contacts with the researchers. In some studies these were necessarily staged several months apart to seek pre and post views of school transition. Others studies used a staged process with specific prompts before each meeting for interview (MacLeod et al., 2013). In some studies the researchers were unfamiliar figures introduced to participants at the time of the interview or group discussion (Huws & Jones, 2008). In groups or interviews held in school an educational professional was often present (Preece & Jordan, 2010). Some researchers were familiar to participants by virtue of the fact that they had previously worked in the school (Winstone et al., 2014), while Humphrey and Lewis (2008) ensured the interviewer was a familiar figure around school before the interviews took place.

Factors that may limit or enable children to give their views	How factors operated differently in the selected studies
Practical methods used to support communication	Different visual supports were used, including: photographs, daily schedules and 'Talking Mats' (Dann, 2011; Preece & Jordan, 2010) and visual props (Brewster & Coleyshaw, 2011). Practical activities used included: the use of diaries with a choice of ways to respond: written, electronic or oral (Humphrey & Lewis, 2008), drawing (Dann, 2011; Tobias, 2009; Winstone et al., 2014) and the use of photographs (Hill, 2014).
Influence of adults	Gatekeeping by the school management team effectively restricted sampling (Brewster & Coleyshaw, 2010). Researchers' liaison with parents and teachers before interviews about their child's preferred style of communication resulted in some parents stating they did not want visual supports to be used (Preece & Jordan, 2010). Where the interview or group discussion took place in the presence of parents or teachers, children often deferred to them and the potential for acquiescence must be questioned. For some participants the researcher's use of individualised communication systems and ability to adapt communication spontaneously and also manage groups and time constraints were important.
Time and resources	Only Winstone et al. (2014) acknowledged the disruption to the child's (and schools) daily routine and the potential impact of this. Considerable variability in the amount of time taken for focus groups and interviews was evident, with some activity interviews taking much longer than standard interviews. The different resources, equipment and time involved all have potential resource and cost implications although these were not always explicitly acknowledged.
Other factors	A range of other factors potentially impacted on children's ability to participate in the interviews or group discussions, including: the time of day, the interviewee's physical and mental health, medication, anxiety, and fatigue, the nature of the questions asked and their previous experience of interviews.

Other factors were evident in different studies. For example, some participants had no preparation prior to the start of the interview (Huws & Jones, 2008) while others were given an outline of the interview schedule one week beforehand (Preece & Jordan, 2010). Some participants were given a choice of location for their interview (McLaughlin & Rafferty, 2014; Preece & Jordan, 2010) while others were not (Dann, 2011; Humphrey & Lewis, 2008; Huws & Jones, 2008; Tobias, 2009). In some studies data collection took place in a single event (Brewster & Coleyshaw, 2011) and in others on two or more occasions (McLaughlin & Rafferty, 2014). Researchers were both familiar persons (Winstone et al., 2014) and unknown (Huws & Jones, 2008), with some studies not proceeding until the researcher had become a familiar figure to the participants (Humphrey & Lewis, 2008). The influence of adults was evident in all studies from gatekeeping access to participants (Brewster & Coleyshaw, 2011), providing consent, acting as proxies, to influencing the methods used and interrupting or shaping the children's responses (Preece & Jordan, 2010).

Winstone et al. (2014) provided some evidence that activity-orientated interviews can help to provide clearer, more detailed accounts than standard interviews. Photographs, drawing and the use of diaries were all reported to be helpful in assisting children to give their views (Humphrey & Lewis, 2008; Hill, 2014) but were not used in a comparative way with individuals, so it was unclear whether they yielded any more detailed information from participants than interview or discussion alone.

Researchers made no reference to the limitations of visual support with the exception of Preece and Jordan (2010) who observed that while visual support may facilitate the process of consultation, they may also restrict discussion to the range of symbols or photographs used. Dann (2011) used Talking Mats throughout the interview process on the assumption of language comprehension difficulties associated with autism. Their use was preceded by checks to ensure participants understood the key concerns of the questions.

MacLeod et al. (2013) gave participants the choice of either face to face interviews, email or telephone interviews. Six of the ten participants opted for face to face interviews, three by telephone and one on-line. The authors concluded that participants' selective use of IT and social networking alongside direct contact was similar to that of other young people but gave no supporting evidence. There was considerable variation in the time reported for standard interviews from 15 minutes (Winstone et al., 2014), to 117 minutes (MacLeod et al., 2013), with one online interview lasting 349 minutes (MacLeod et al., 2013).

Findings suggest there is some evidence that activity based interviews and a shared point of reference between interviewer and interviewee may result in more effective communicative exchange. Winstone et al. (2014) provided a comparison between standard interviews and activity based interviews which produced different quality of data, but had significant implications for time and resources. The activity may not be of direct relevance, and simply because an approach is enjoyable for participants or provides more data does not necessarily mean that it provides more insightful or relevant information. Giving participants the choice of alternative methods may help to engage children and enable them to give a clearer view, although a reliance on verbal skills and the ability to articulate their experiences remains. Assessing the efficacy of one method over another may be of limited value when a range of different approaches are likely to be needed that can be combined to best meet the specific individual needs of a child and their family.

The selection of participants in most studies was based on age and verbal ability with only Preece and Jordan (2010) and Brewster and Coleyshaw (2011) including children with a wide range of ages (7-18 yrs.) and abilities. Correspondingly a greater number of adaptations were used in these studies and items were used differently with different children; for some children visuals were used as a prompt for dialogue while some were used by the child to manipulate them concretely. Two non-verbal children with a diagnosis of severe learning disability were included by the use of proxies and observation. In studies that involved younger children and a wider range of ages and

abilities the need for skilled and competent use of individualised communication systems by the researchers was evident, with the ability and resources to adapt communication spontaneously and the need to allow an increased length of time for the interview or discussion.

3.5 Methodological and design issues

All studies were small scale, and used an idiographic method of enquiry aiming to provide rich descriptions about participants rather than aiming to make generalised assertions. Six studies used interpretative phenomenological analysis (IPA) (Dann, 2011; Hill, 2014; Humphrey & Lewis, 2008; Huws & Jones, 2008; MacLeod et al., 2013; Ozsivasjian et al., 2012) and five thematic analysis (TA) (Brewster & Coleyshaw, 2011; McLaughlin & Rafferty, 2014; Ozsivadjan et al., 2012; Preece & Jordan, 2010; Winstone et al., 2014).

Aligned with critical realist epistemology, IPA is a theoretically informed framework or methodology used where the research aim is to explore how participants make sense of their personal world, and to capture a first-person account that places emphasis on the meaning held for the participants of their personal experience (Smith, Flowers, & Larkin, 2009). It may also involve critical analysis of the participants text to gain a sense of things that maybe the participants are less aware of. IPA allows for both these aspects of understanding to provide a more personalised perspective for the reader.

Personalised accounts are clearly evident in the included studies that used IPA with small numbers of participants specifically focusing on: their individual views and experiences of having autism (Huws et al. 2008), identity formation and educational experiences (Hill, 2014; Humphrey & Lewis, 2008; Tobias, 2009) and their views of participatory methodology (MacLeod et al. 2014). Collectively they provide clear evidence to suggest that IPA is a useful way to analyse a child's narrative to gain a uniquely personalised account.

In contrast TA is a method that can be used across the epistemological and ontological spectrum, and may be underpinned by theories other than phenomenology. TA is useful when working with focus groups and usually has a larger sample, as the focus is on the patterning of meaning across participants. In the current review Ozsivadjian (2012) and Brewster & Coleyshaw (2010) used focus groups. Ozsivadjian (2012) highlighted the disadvantages of only a small number of child participants (4), and of reporting only themes that were consistent across five parent groups; therefore exploration of differences and similarities between parent and child reports was not feasible and important information may have been missed.

Participant feedback is an important aspect of IPA and thematic analysis that strengthens the validity of the researcher's analysis and interpretation. Individual feedback was notably absent in all the selected studies with the exception of MacLeod et al. (2013) and Humphrey and Lewis (2008). Participants in this study were all 'academically successful, highly literate and articulate' (page 417). They were attending Higher Education and therefore older than the majority of other participants, and all self-selecting volunteers with perhaps different motivations for their involvement than younger participants. MacLeod et al. (2013) was therefore the only study to consider how researcher / participant disagreement would be addressed, and in this instance both interpretations were reported. Two participants openly disagreed with the researcher, but other participants were described as 'less forthcoming and seemingly less engaged' (page 413). Where participant feedback was sought but declined (McLaughlin & Rafferty, 2014), or collective comments summarised (Humphrey & Lewis, 2008), it raised the issue of potential difficulties inherent in seeking feedback from children whose spontaneous accounts may reflect their perspective at that particular moment in time (Whyte, 2006). It is also important to consider the relationship between the researcher and participants, which was not included in any detail in any of the studies.

The issue of time, maintaining involvement and 'information overload' (page 418) were also identified as important considerations when seeking to elicit children's views, and are particularly pertinent to clinical practice.

4. Discussion

In all studies the views attributed principally to children appear to be based on the assumption of limited adult influence. Yet at every stage the influence of adults and the potential for bias was evident, leaving these studies open to criticism for being authoritarian (Gallacher & Gallagher, 2008) or tokenistic (Kellet, 2005), and privileging those with stronger communication abilities (Nind, 2011). 'Gatekeepers' controlling the process of recruitment, assumptions made of children's agreement to participate or parent's reservations about their children's ability to give reliable information or opinions, the presence of parents or teachers, assent and the use of proxies, confidentiality and the role of the researcher in recognising and responding to children's views were all evident across the selected studies, but not always explicitly acknowledged (Brewster & Coleyshaw, 2010).

Five of the eleven studies were multi-informant and tended to place greater emphasis on adult accounts than the accounts of children with the exception of Preece and Jordan (2010). Tobias (2009) showed an imbalance in reporting eight parent-reported themes and only two on children's perspectives, with no examination of the issues raised by the children and not their parents. Ozsivadjian et al. (2012) acknowledged there were similarities and differences between parents' and children's views but did not explore them because of the comparatively small number of children in the study. Children's views were attributed to their 'having ASD' with only Hill (2014), MacLeod et al. (2013) and Ozsivadjian et al. (2012) making any direct comparison between their findings and studies that looked at similar constructs with typically developing children.

Most of the researchers referenced a potential problem for children with ASD with standard interviews and increased anxiety. They sought to promote children's ability to communicate their views by using adaptations and a range of creative methods in different ways, although some inadvertently caused increased anxiety and distress (Hill, 2014; Preece & Jordan, 2010).

4.1 Limitations of literature review

The findings of the current review need to be interpreted in light of three main limitations:

1. The process of the literature search was conducted by a single researcher which may have led to some bias in both study selection and the process of comparative analysis.
2. The inherent difficulties of appraising studies that focus on a diversity of issues for children with ASD.
3. The studies report the broad issues considered by the qualitative appraisal tool (Appendix A, Table 3, page 35) in widely different levels of detail and clarity.

4.2 Clinical implications and suggestions for future research

First-hand accounts from adults with ASD relate their experiences and the lifelong impact of a diagnosis of ASD but comparatively little is known about the experiences and views of children with ASD. Key factors that emerged from the current literature review might usefully be considered by researchers or practitioners seeking to elicit children's views in a clinical or educational context. These include: a familiar location and relationship with the researcher, some preparation beforehand, the availability of different ways to respond, and

sufficient time and flexibility to enable spontaneous adaptations to be made by the adult.

The understanding of, and views of their diagnosis of ASD reported by participants produced some issues that had not been anticipated by the researchers. These pertained to when and how it was disclosed; suggesting greater consideration needs to be given to the child's and parent's experience of the diagnostic assessment process (Huws & Jones, 2008). This is particularly important in light of emerging research that suggests it is the process and nature of the assessment that impacts significantly for parents and other adults that support the child (Abbott, Bernard, & Forge, 2013; Barrett, 2006).

Autobiographical accounts can provide a valuable source of information that challenges traditional stereotyped views of ASD (Humphrey & Lewis, 2008; Madriaga & Goodley, 2010; Sainsbury, 2000). Emerging evidence from the research literature suggests autobiographical accounts have the potential to significantly influence how some parents and teachers respond to an individual with an ASD (Barrett, 2006). If, during the process of diagnostic assessment professionals seek to elicit what sense a child makes of their day to day experiences of life and enable them to participate in their diagnostic assessment, a more personalised 'rich' description of their needs may emerge.

5. Conclusion

Despite some promising advances in the literature our understanding of the views and experiences of children with ASD remain relatively limited. Most studies are small scale initiatives dominated by adolescents with higher levels of cognitive functioning and spoken language. There are clear gaps in the research literature on the views and experiences of young children under eleven years, females, and those with complex language and learning profiles.

It is important to consider ways in which individuals are able to evidence their abilities rather than presenting a context that reinforces disabilities (Winstone et al., 2014). By seeking methods and techniques to reconstruct the interview environment of diagnostic assessment, while respecting the limitation of time and resources and taking into account the needs of participants as well as the setting, an autobiographical approach might lead to a richer, more complex set of understandings. This has the potential to move away from problem – saturated accounts of a child's identity and a limited 'menu of strategies' for support, and to respond to individual needs (Barrett, 2006).

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Appendix A

Table 3 - Critical Appraisal Skills Programme (CASP): Data Extraction

Study ID and Authors	1. Huws et al. (2008)	2. Humphrey & Lewis (2008)	3. Preece & Jordan (2009)
Was there a clear statement of the aims of the research?	✓ Retrospective accounts of young people with HFA.	✓Part of larger study. Clear objectives stated.	✓Part of larger study.
Is qualitative methodology appropriate?	✓ Seeking subjective experiences of having HFA.	✓Seeking views and experiences of pupils with AS (Asperger and HFA) in mainstream schools.	✓Seeking to examine the experience of families of daily life and respite care.
Was the research design appropriate to address the aims of the research?	✓ Did not explicitly state how they decided on which method to use.	✓Clearly states how study was conceived designed and conducted.	✓ Provides rationale.
Was the recruitment strategy appropriate to the aims of the research?	✓Participants at HE college for young people with ASD. Asked for expressions of interest.	✓No information about numbers asked to participate; only those that did.	✓Dimensional sampling used to identify families from larger group.
Was the data collected in a way that addressed the research issue?	✓ Semi-structured interview with three guiding question and recording of responses. Field notes after each interview.	✓Semi-structured interviews, pupil diaries and drawings.	✓Methods differentiated by need and influenced by family's wishes.
Has the relationship between researcher and participants been adequately considered?	× No critical examination of role of researcher and potential bias during the process.	× No critical examination of role of researcher and potential bias during the process.	× No critical examination of role of researcher and potential bias during the process.
Have ethical issues been taken into account?	✓ Ethics approval and identifies potential for distress during interview.	✓Ethical issues and intrusiveness of research clearly identified.	✓Variation in participants considered.
Was the data analysis sufficiently rigorous?	✓ No examination of researcher's own role and influence.	✓Clear, detailed description of analytical process.	✓
Is there a clear statement of findings?	✓ An extended summary of findings	✓Clear summary with network of themes and categories from data analysis.	✓
How valuable is the research?	✓Potential for further research identified clearly.	✓	✓Includes reporting of difficulties encountered in research process.

Study ID and Authors	4. Tobias (2009)	5. Brewster & Coleyshaw (2010)	6. Dann (2011)
Was there a clear statement of the aims of the research?	✓To examine attitudes of students towards support at secondary school.	✓Commissioned research	✓
Is qualitative methodology appropriate?	✓Seeking attitudes.	✓Asking children what they like to do in their leisure time.	✓ Transition experiences from primary to secondary school.
Was the research design appropriate to address the aims of the research?	✓	✓Seeking views	✓Appropriate but not discussed explicitly.
Was the recruitment strategy appropriate to the aims of the research?	✓	✓Accessed via database of all children in area with diagnosis of ASD and or ADHD.	✓A specific group meeting eligibility criteria for specialist provision.
Was the data collected in a way that addressed the research issue?	✓ Provides rationale for focus groups but not how this impacts for children with ASD.	✓Discussion groups	✓Individual interviews using Talking Mats
Has the relationship between researcher and participants been adequately considered?	×No critical examination of role of researcher and potential bias during the process.	×No critical examination of role of researcher and potential bias during the process.	×No critical examination of role of researcher and potential bias during the process.
Have ethical issues been taken into account?	×No reference to ethical issues	×No reference to ethical issues	×No reference to ethical issues
Was the data analysis sufficiently rigorous?	×No in-depth description of the process of analysis. Gives broad overview.	×No in-depth description of the process of analysis. Gives broad overview.	✓Thematic analysis with selected examples that demonstrate process.
Is there a clear statement of findings?	✓ (Not explicit) Discussed in relation to the original research questions.	✓Clear, concise summary.	✓Findings discussed in relation to the original research question.
How valuable is the research?	✓Some discussion of application to practice.	✓General statement relating issues to inclusion of disabled children.	✓Discussed contribution to issue of support at transition.

Study ID and Authors	7. Ozsivadjian (2013)	8. MacLeod et al. (2014)	9. Mc Laughlin & Rafferty (2014)
Was there a clear statement of the aims of the research?	✓To increase understanding of the presentation of anxiety in children with ASD.	✓Considering methodology of a project consulting with HE students.	× Not as explicitly stated as other studies.
Is qualitative methodology appropriate?	✓	✓	✓
Was the research design appropriate to address the aims of the research?	✓Exploring children's views.	✓	✓Limited justification of the research design.
Was the recruitment strategy appropriate to the aims of the research?	✓Identifies potential bias	✓Self-selecting recruited via email advertisement.	×Not clear how participants were selected.
Was the data collected in a way that addressed the research issue?	✓Discussion group	✓Semi-structured interview with reminders between interviews.	✓Semi-structured interviews.
Has the relationship between researcher and participants been adequately considered?	×No critical examination of role of researcher and potential bias during the process.	×No critical examination of role of researcher and potential bias during the process.	×No critical examination of role of researcher and potential bias during the process.
Have ethical issues been taken into account?	✓Specific reference to confidentiality and boundaries for 'safe' discussion.	× No reference to ethical issues.	✓Reference to how potential participants' supported to make an informed choice.
Was the data analysis sufficiently rigorous?	✓Acknowledges limitations of small numbers and emphasis on parental views.	✓	✓Thematic analysis.
Is there a clear statement of findings?	✓Clear, concise summary.	✓Extended discussion of findings.	✓Extended discussion of findings.
How valuable is the research?	✓Clearly identifies theoretical and practise implications.	✓Discussion of issues relating to participatory methodology.	✓Focuses mainly on implications for role of Educational Psychologists.

Study ID and Authors	10. Winstone (2014)	11. Hill (2014)
Was there a clear statement of the aims of the research?	✓To explore the self-identity of autistic young people through activity orientated interviews.	✓To explore lived experience of mainstream secondary school.
Is qualitative methodology appropriate?	✓	✓
Was the research design appropriate to address the aims of the research?	✓	✓
Was the recruitment strategy appropriate to the aims of the research?	✓Clear explanatory account of selection process.	✓Limited reference to how the 6 participants were identified from a wider group.
Was the data collected in a way that addressed the research issue?	✓Standard interview technique and activity-orientated interview.	✓Photo-elicitation discussion.
Has the relationship between researcher and participants been adequately considered?	✓Researcher known to participants. Some activities facilitated by child's teacher.	×No critical examination of role of researcher and potential bias during the process.
Have ethical issues been taken into account?	✓	× No explicit references to ethical issues
Was the data analysis sufficiently rigorous?	✓Thematic analysis.	✓ IPA
Is there a clear statement of findings?	✓	✓
How valuable is the research?	✓Useful discussion of potential value of activity orientated interviews in clinical practice.	✓Useful references to potential use in person-centred planning.

Table 4 - Extracted data: Summary of main themes, adaptations and challenges

Authors	Focus of study	Main Themes	Adaptations	Challenges
Huws et al. (2008)	Views and experiences of having Autism	<p>Disclosure delay: Existence of an 'absent presence', delay evoking shock, disappointment and disbelief.</p> <p>Providing explanations: Retrospectively providing explanations of previous life events – positive benefit for some.</p> <p>Potential effects of labelling: Positive and negative affects- discontinuation of distressing treatments by others or discrimination.</p> <p>Stereotyping label that could be used by others to make prejudgements.</p> <p>Disruptions and opportunities: Disruption of plans and the source of new opportunities.</p> <p>Acceptance and avoidance: For some initially difficult and then gradual acceptance that enabled diagnosis to be accommodated. For others not wanting diagnosis and avoiding any information associated with it.</p> <p>Summary: Effects or disclosure of diagnosis requires more consideration.</p>	<p>Interviews conducted over a two day period.</p> <p>Interviews 1:1 in a room at school.</p> <p>Prior to start of interview participants given written outline and verbal description of the study. Written consent obtained. Researcher's contact details provided.</p> <p>Open-ended questions – broad and exploratory. Field notes and initial impression kept by interviewer.</p>	<p>Variability in responses: Single interview session lasted between 35-75 minutes.</p> <p>Verbal responses only</p> <p>Participants had not met the researcher previously.</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Humphrey and Lewis (2008)	Identity formation and educational experience	<p>Characteristics associated with Aspergers: Social naivety, difficulty reading moods and demotions, good memory, special interests, different use of imagination, inflexible thinking.</p> <p>Constructing an understanding of Aspergers: Anxiety and stress in school, working with teachers, negotiating difference, and relationships with peers.</p> <p>Summary: Implications for inclusive practice in mainstream schools but larger scale research needed that considers what works, how it works and in what contexts.</p>	<p>Pupil diaries kept for a period of 1 month. Diary specially formatted with prompts. 9 of 20 used diaries. 6 used written format and 3 oral. Difficulties with maintenance: 5 kept diary for a month, 1 for 3 weeks and 3 for 2 weeks.</p> <p>Choice of 3 different recording modes: written, electronic or oral. Drawing was not originally planned but used by one participant to supplement oral and written feedback.</p>	<p>Timing of interview so researcher became a 'known face'.</p> <p>Flexibility and skills of researchers.</p> <p>Maintaining involvement of participants.</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Preece and Jordan (2009)	Experiences of living at home and in short-term care	<p>Experience of daily life: Positive attitude to family life: fondness for parents and siblings, unaware of stress and tension reported by other family members.</p> <p>Isolation: Preference for solitary activities; some reported friends at school but rarely saw them outside this context.</p> <p>Problems at school: Problems reported with other pupils, staff and environment.</p> <p>Experience of social workers and short breaks: None of the participants understood the role of the social worker.</p> <p>Positive activities during short breaks: going out physical and sensory activities, meeting other children.</p> <p>Dislikes: staff making demands - going to bed; aspects of the environment; being away from home and missing parents.</p> <p>Summary: Acknowledge results but also places emphasis on problems and setbacks encountered, and the tools and processes that helped</p>	<p>Adaptations: Outline of interview structure left with family a week before interview.</p> <p>Accessible formats used: individualised visual supports, photographs, daily schedules, Talking mat.</p> <p>Two non-verbal children included through observation at home and in short break setting.</p>	<p>Multi-informant – family members, short break staff, social workers and documentary evidence.</p> <p>Only study to include children with a wide range of ages, abilities and impairments.</p> <p>Acknowledges potential for acquiescence, and influence of others.</p> <p>Where parents were present children tended to defer to them, particularly when visual supports not used.</p> <p>Adult influence on methods used: 4 parents did not want visual supports used in their children's interviews.</p> <p>Children's responses were interrupted and influenced by the adult present, and were often incomplete or inaccurate.</p> <p>Non-verbal children participated by the author 'observing' and being with them.</p> <p>Reliant on skills and knowledge of researcher.</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Tobias (2009)	Support at secondary school	<p>Positive aspects of support: Targeted support at key transitions, mentors, availability of quiet areas, good communication between staff and parents, staff knowledge of ASD, knowledge of individual pupils, individualised support, welcoming ethos, lower student: staff ratios</p> <p>Areas of challenge and possibilities for additional support: Self-awareness and confidence, sense of belonging and inclusion, independence, life-skills and organisational ability.</p> <p>Summary: Provision of good secondary education for children on the Autism spectrum involves a balance between alleviating stressors and preparing for the 'real world'.</p>	<p>Description and drawing of imaginary students at school with ASD: one 'successful' and the other 'unsuccessful'.</p> <p>Compilation of a toolbox of resources that might help to support them during the school day.</p>	<p>Participants were selected by teaching staff.</p> <p>Study also included parents (5) of some of the students.</p> <p>Appears to over represent the voice of the parent in comparison to that of the child. Eight themes based on parent perspectives and only two on the students' perspective.</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Brewster and Coleyshaw (2010)	Participation in leisure activities	<p>Current participation in leisure activities: Younger children participate in more external pursuits accessed through their immediate family. Tendency for most of leisure time in the home became stronger with age, with adolescents often alone in their bedroom.</p> <p>Perceived barriers/difficulties: Difficulties with relationships, safety concerns and need for consistency and predictability.</p> <p>Summary: Children with Autism face significant challenges in achieving an active and varied life outside of school and their home environments. Challenges increase with age.</p>	<p>Adaptations: Questions pre-determined in discussion with staff and differentiated dependent on verbal / cognitive processing abilities. Additional profiling of group participants to identify any augmentative communication needs.</p>	<p>Acknowledges potential for exclusion of children with ASD from consultation because of broad spectrum and communication difficulties.</p> <p>Restriction of focus group to a single session. Parents' voiced reservations about ability of child to give reliable information or opinions.</p> <p>Levels of disability were broadly related to placement at special or mainstream school.</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Dann (2011)	Transition to secondary school	<p>Before transition: Importance of knowing the social and physical environment of new school, support to engage in learning, preparation for change, home / school communication, anxiety around transition, positive views of move, emotional impact on adults.</p> <p>After transition: Factors which facilitated a successful transition: Additional visits, structure and routine established, qualified and experienced staff with good communication between staff and parents, benefits of specialist provision, individualised support, responsibility of all staff.</p> <p>Summary: Experiences of children with ASC at transition reflect experiences reported by pupils with other types of SEN and suggest the need for comparative studies. Also to explore the experiences of different individuals in different mainstream school in different local authorities.</p>	<p>Adaptations:</p> <p>Individual interviews using 'Talking Mats' preceded by vignettes and questions to ensure pupils understood key concepts.</p>	<p>Multi-informant to triangulate views.</p> <p>Emphasis on adult views, with some evidence of differing opinions between adults and children.</p> <p>Comparison with other groups with and without SEN</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Ozsivadijani (2013)	The nature of anxiety	<p>Parents groups: Anxiety triggers: Change or disruption to routine, social / language triggers, specific fears and phobias, sensory triggers, routines and obsessions, too many demands or expectations.</p> <p>Presentation of anxiety: Challenging behaviours, Avoidance / withdrawal, arousal, sensory behaviour, obsessional and repetitive behaviour, somatic indicators, cognitive indicators, cognitive processes, cognitive content.</p> <p>Perceived differences between anxiety in children with ASD and typically developing children: Behavioural indicators, time delay between an event and expression of anxiety, prolonged and more intense, children more difficult to soothe.</p> <p>Children's group: Anxiety triggers: Change of routine, sensory triggers, social worries, worries about being bullied,</p> <p>Behavioural indicators: somatic symptoms, thought processes but little clearly articulated cognition.</p> <p>Summary: Children have difficulty in expressing their anxiety verbally. High comorbidity of anxiety and low mood in ASD group. Dependence on parents and impact on family life.</p> <p>Experiential views from parents and children focus on features more specific to ASD population that are not typically measured on most anxiety measures.</p> <p>Linked to theoretical model of clinical anxiety in ASD (Wood and Garrow, 2010).</p>	Children's group met at the same time as mother's group with breaks for snacks and games.	<p>Recruitment of participants.</p> <p>Discussion in groups can be dominated by individuals.</p> <p>High demands on researchers.</p> <p>Challenge to ensure that parents were referring to anxiety and not non-specific negative affect, such as aversion or discomfort.</p> <p>Comparatively long session for child participants (2 hours).</p> <p>Dominance of parent's views.</p> <p>Lack of detailed information about demographics, language skills, cognitive functioning or adaptive skills of the children involved.</p> <p>Limitation of focus group methodology is that discussion can be dominated by individuals.</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Macleod et al. (2014)	Participatory methodology	<p>Relevance of methodology: Time commitment for participants: Significant difference in how long interviews lasted. Face to face interviews lasted from 47-117 minutes; on-line interviews lasted from 198-349 minutes.</p> <p>Staged interview process and prompts helped to engage participants:</p> <p>Participants asked to discuss and analyse their transcripts and management of researcher/participant disagreement.</p> <p>Follow-up interviews were useful in strengthening the validity and clarity of responses.</p> <p>Summary: Participants tended to opt for face to face interviews.</p> <p>Research perceived by end-users as important and relevant to them is more likely to gain better levels of recruitment and retention.</p> <p>More emphasis needs to be placed on reporting of methodologies.</p> <p>Potential for 'involvement overload'.</p> <p>Small scale studies can inform and influence larger projects and professional practice.</p>	<p>Prompt sheet provided to help participants prepare.</p> <p>Staged interview process.</p> <p>Participants were all academically successful, highly literate and articulate.</p> <p>System of reminders in place to accommodate potential difficulties with time management and self-organisation.</p>	<p>Pilot phase identified potential difficulties.</p> <p>Highlights importance of respectful relationship between researcher and participants.</p> <p>Maintaining engagement of research participants.</p> <p>Participants' use of repetitive phrases and a verbose style of speech.</p> <p>Participants with very succinct style of response.</p> <p>Maintaining involvement through every stage of research process</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
McLaughlin and Rafferty (2014)	Literature review and asking participants 'What is life like for you?'	<p>Something has been taken from me: Why me? Shame and regret.</p> <p>'It' does something to me: Impact on how they viewed and acted upon the world, realisation of chronic impact, changes as they get older, 'its' part of me.</p> <p>Let me be normal: Desire to be treated like others, maintaining choice over whether to disclose diagnosis, identifying challenges from the support provided.</p> <p>Fitting in: Friendships, loneliness and isolation, rejection and bullying,</p> <p>Summary:</p> <p>Potential of young people to understand and communicate their needs.</p> <p>Need for school staff to examine their assumptions about Asperger's.</p> <p>Importance of providing support and advice to compensate for the 'difficulties' at the diagnostic criteria level.</p>	Verbal interview, researcher connected to school, and met with participants either at their home or at school.	<p>Heavily reliant on the verbal skills and motivation of individual participants to share their views and experiences.</p> <p>No respondent validation as all participants declined to check data.</p> <p>Requires additional 'time and space' for participants to consider responses.</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Winstone (2014)	<p>Exploring self-identity.</p> <p>Comparison of standard semi-structured interviews and activity orientated interviews.</p>	<p>Descriptions of the self: More abstract descriptions of self-obtained during activity-orientated interviews.</p> <p>Descriptions of the future self: With concrete stimulus of picture of themselves as they would like to be when they grow up, children produced a more vivid dialogue. Demonstrated personal awareness and an ability to philosophise about life goals.</p> <p>Perceptions of the self as a person with Autism: Struggled in standard interview, but when viewing picture of their class which they had created used self-referential and comparative language.</p> <p>Comparison between self and others: Struggled with standard format but when using self-portraits were able to consider the different visual perceptions of others, explanations of friendships, awareness of the differing needs of others, and articulate the differences and similarities between self and others.</p> <p>Comparison of standard interviews and activity orientated interviews: Quality of responses varied widely: the activity-orientated interviews provided considerably more information with improved quality than the standard format. Greater abilities were identified.</p> <p>Summary: Activity-orientated interviews can be used effectively 1:1 and could strongly support practitioners in clinical and educational settings.</p>	<p>Standard interview lasted approximately 15 minutes; activity-orientated interviews 25-30 minutes.</p> <p>Interviewer known to participants; some activities (drawing) involved child's usual art teacher.</p> <p>Participants prepared for the interview by completing some tasks beforehand.</p> <p>Interviewer had tasks to complete within the interview setting; these activities provided a shared reference point.</p> <p>The use of pictures, mirror behaviour, photographs and favourite things all encourage autistic individuals (and others) to understand themselves in ways which they might not have previously considered.</p>	<p>Time and resource requirements: Interviewer known to participants and had spent time with them beforehand.</p> <p>Some children did not stay on topic in standard interview format, and heavy reliance on physical characteristics.</p> <p>Activity orientated interviews were dependent on support from school as participants had time out of lessons to prepare materials.</p> <p>Could be adapted to form part of the interview.</p> <p>More time-consuming than standard interviews.</p>

Authors	Focus of study	Main Themes	Adaptations	Challenges
Hill, L. (2014)	Using photo elicitation to explore the experience of secondary school.	<p>Anxiety: Related to environmental and social factors. Some strategies implemented to alleviate a source of stress can inadvertently cause increased levels of anxiety.</p> <p>Sanctuary: Support base, special interests.</p> <p>Young people as active agents: Making sense of self and others, self –identity, independence, problem solving.</p> <p>Summary: Children may have the same diagnosis but considerable variation in ways they experience school. Essential to focus on unique strengths, needs and interests of the individual, involving them in planning of any provision to meet their needs.</p>	<p>Participants take photographs of places in school that are of particular importance to them to support discussion with researcher. Acted as an aide-memoire and joint reference.</p> <p>Participants met with researcher on 4 separate occasions.</p>	<p>No reference to recruitment or consent process.</p> <p>Restrictions on participants: Unable to take photographs of places with people or solely people for ethical reasons.</p> <p>One participant worried about researcher views of him as not very interesting: <i>I tried not to worry about you not being interested and tried to just get all the experiences out</i> (page 87).</p>

PAPER 2: RESEARCH REPORT

Exploring the use of an autobiographical account in diagnostic assessment of Autism Spectrum Disorder with a young child.

Abstract

The Child and Family Act (2014) emphasises personalised service provision to which the views of the child are central, promoting person-centred approaches that consider individual strengths, preferences and views alongside difficulties and needs. Despite a growing body of research on the specific child-friendly approaches that have been developed, there is a paucity of studies seeking the views of children with autism spectrum disorder (ASD). Studies are dominated by adolescents who are able to communicate with spoken language. Very few consider the views of young children due to methodological and practical considerations that mean their views cannot be easily accessed.

Diagnostic assessment for ASD is multi-informant with a strong emphasis on adult perspectives and comparatively little regard for the child's views and experiences. The present study seeks to move away from a sole focus on identifying global deficit characteristics of autism, to take a relativist ontological position that assumes individuals construct their own interpretation of their experiences. It is an exploratory study that considers ways in which a five year old child with autism might be enabled to express their views about their lived experiences during their diagnostic assessment.

The researcher uses Interpretative Phenomenological Analysis (IPA) to review the child's narrative. IPA is also used to consider the views of the child's parent and a specialist teacher about the participatory approach used. Findings show the age at which some children can be included is lower than previously thought. The child's views clearly influence those that support him and potentially facilitate a more personalised response to specific difficulties. The participatory process informs consideration of an alternative practice model that moves from a reliance on deficit patterns of behaviour to also ask what sense the child makes of their experiences, and to consider how this might impact in clinical practice and support person-centred planning.

1. Introduction

Increasing attention on listening to the first-hand perspectives of children and young people is reflected in the Child and Family Act (2014) which emphasises personalised service provision of health, education and social care. The new revised Special Educational Needs Code of Practice (DfE., 2014) calls for a more child centred system, placing an emphasis on person-centred approaches that consider individual strengths, preferences and the views of children alongside their difficulties and needs. It seeks to recognise individual difference and link professional advice more closely to the individual. Yet timely and effective consultation remains a challenge as it is often embedded in professional practices and policies that focus on categorising children (Roffrey, 2013). This includes diagnostic assessment of autism spectrum disorder (ASD), where there is little evidence of real participation of children in professional reports as adult agendas and power often override opportunities to really hear what the child can contribute (Todd, 2003).

Diagnostic assessment represents the process of making sense of certain phenomena according to particular theoretical models or frameworks (Swain, Gillman, & Heyman, 2000). Largely impairment-based, assessment of ASD focuses on the individual to identify the extent of deviance from 'normality'. Thereby producing 'thin descriptions' that consider limited aspects of an individual which can support and sustain problems (Gilling, 2012). The need for complex or 'thick' accounts is increasingly recognised (Barrett, 2006; Gilling, 2012), and recently published guidelines for ASD also promote a more person-centred approach (NICE, 2013). This moves the emphasis during diagnosis from giving a name to identifying individual needs and how they affect a person's life, and encouraging professional advice to be connected to what actually happens for the individual.

Gradually emerging autobiographical material combines emotional and cognitive perspectives of ASD to provide invaluable interpretation of the experiences of the individual (Kirby, Dickie, & Baranek, 2015). With limited

evidence in the research literature about obtaining first-person perspectives of children with ASD, their views are often absent from research reports (Kirby et al., 2015). Studies are dominated by adults and adolescents who are able to communicate with spoken language (Brewster & Coleyshaw, 2010; Humphrey & Lewis, 2008; Huws & Jones, 2008; MacLeod et al., 2013). With some notable exceptions, few research studies consider the views of young children under the age of eleven years (Brewster & Coleyshaw, 2011; Kirby et al., 2015; Preece & Jordan, 2010).

The present study seeks to move away from a sole focus on identifying global characteristics of autism to take a relativist ontological position that assumes individuals construct their own interpretation of their experiences. By exploring the lived experience of a young child through a phenomenological perspective, it seeks to raise the issue of how practitioners understand the children they work with and to promote reflective discussion.

1.1 Professional orientation and diagnosis of ASD

Disability is a socially constructed concept that can be viewed from different perspectives depending on the epistemological position held. Different philosophical and theoretical positions can lead to different definitions and descriptions of the same phenomena with different recommendations as a result (Goodley, 2012). Professional discourses are not abstract ideas but are intimately connected to training, institutional and social practices (Willig, 2013). Influencing their assessment of children with developmental disability suspected to lie within the autistic spectrum, the nature of professional's investigation and decision-making is guided by their training and experience, their relevant knowledge of different types of developmental disability and ways of addressing them (Bartolo, 2002). It is important that professionals are aware of the theoretical foundations on which their judgments are made, and the impact this has on how they work with the child and their family (Billington, McNally, & McNally, 2000).

Professional orientation within decision-making structures may be categorised within three major models of childhood disability: the medical model, the social model and relational or compensatory-interaction model (Bartolo, 2002; Goodley, 2012). Informed by positivist approaches that seek to produce objective knowledge the medical model identifies what is 'normal' and what is 'disabled' by focussing on within-child deficits including biomedical, behavioural, emotional and cognitive impairments. Its use is not limited to medical professionals and intervention seeks to change the child towards expected criteria of normality (Baker, 2011; Fisher & Goodley, 2007; Johnston, 1996; Llewellyn & Hogan, 2000).

In contrast the social model conceptualises the same problems as arising from deficits in the child's environment, including lack of socio-economic opportunities and educational provision, the uneven allocation of resources and intolerant attitudes to disability. Underpinned by relativist philosophy that assumes there are no objective realities and that individuals construct their own interpretations of their experiences, it emphasises the social context and acknowledges the impact of the thoughts and perceptions of individuals about a situation (Willig, 2013). The social model seeks to change the social environment, with a focus on ameliorating disability through changes in social policy, culture and institutional practice in order to adapt to the needs of the individual (Marks, 1997).

The relational or compensatory-interaction model considers that causation of disability and appropriate intervention arises from both within-child and environmental factors, but also from the relationship and interaction between them. The model emphasises the large number of variables interacting and multiplying their effects as a result of the interactions taking place (Llewellyn & Hogan, 2000). Intervention seeks to improve the balance between the strengths and needs of the child and the resources of their environments (Bartolo, 2002; Goodley, 2012).

Adults with autism have reported concerns that being defined by the medical model and by their 'disability' can mean their talents, strengths, abilities and preferences are ignored (Milton & Bracher, 2013). In contrast simply describing ASD as 'difference' can mean that real difficulties and needs are not recognised or are ignored. Disability and difference are not mutually exclusive and are a reflection of the environmental context (Endow, 2012). Positive affirmation of difference while recognising difference that challenges can potentially enable diagnostic assessment to become a more supporting process (Monteneiro, 2010).

There has been very limited research to show the impact of different models in clinical practice. The study by Bartolo (2002) was limited to two multi-professional groups and considered four children with very similar developmental difficulties referred to different autism diagnostic services. Findings showed how institutional and disciplinary influences led to different explanations and recommendations.

Diagnostic services for ASD in the United Kingdom are dominated by health services. The make-up of multidisciplinary teams and their level of integration with, and access to other health, education and social care professionals and thresholds for referral differ widely (NICE, 2011). The dominance of health professionals in many multidisciplinary teams means there is a reliance on quantitative methodologies using diagnostic tests that purport to describe specific phenomena objectively and identify the degree of deviance from the norm (Goodley, 2012). This can create a subtle difference of emphasis and diagnosis may depend on the language and power of the professional. Clinical psychology and psychiatry take a psychological-pathological perspective, in contrast to the psycho-social approach to assessment and intervention usually adopted by educational psychologists, specialist teachers and other allied health professionals (Bartolo, 2002). Current discourse uses terminology such as impaired, deviant and failure, which tends to discount the subjective experience of the individual and may prevent alternative interpretations of children's lives being considered (Gilling, 2012).

The extent to which professionals believe an objective view can be obtained varies and in reality a multiplicity of approaches exists. Different perspectives reflecting different theoretical basis are not necessarily incompatible or mutually exclusive, and may be beneficial in the context of multi-disciplinary working. The range of epistemological approaches can be placed on a continuum from positivist to relativist with a social constructivist approach midway between these two extremes (Willig, 2013). The social constructivist approach construes that our knowledge and understanding of the world is socially constructed. It is from this position that the present study is undertaken.

1.2 Why use autobiographical accounts?

Children's problems are almost always defined by other people involved with the child (Llewellyn & Hogan, 2000). For professionals seeking to gain an understanding of the child's perspective there is often reliance on direct reports from parents and teachers and or extrapolation from observation of the child, presuming that is the child's point of view (Gilling, 2012).

Despite an increasing body of literature about how to consult with and empower children and young people (Greig, Hobbs, & Roffey, 2014), with a range of creative ways including: the use of diaries (Humphrey & Lewis, 2008), photographs (Day, 2010; Hill, 2014), daily schedules (Preece & Jordan, 2010), descriptions and drawing (Tobias, 2009), activity-orientated interviewing (Winstone et al., 2014) and on-line options (MacLeod et al., 2013), there is no clear evidence to suggest which method is the most effective or whether there is any one effective method for all. It is most likely that different methods might suit different children and there is a clear gap in the literature on eliciting the views of young children with ASD.

The practice of enabling participation is highly complex. The nature of children's participation, motivation and ability to voice their views are influenced by multiple factors including their level of development and skills, previous experience of involvement in decision-making and social contextual conditions.

An important element is the approach adopted by professionals and the distinct narrative that recounts the child's 'story' (Goodley, 2012). There is a clear gap in the literature on children's participation in diagnostic assessment of ASD.

The primary aim of the present study is to focus on a child's participation in their diagnostic assessment and represent a move to a more constructionist view of this process. By considering the broad issue of what sense a young child with autism makes of their day to day experiences of life other areas for exploration emerged and were developed.

The way in which diagnostic assessment is undertaken and information is provided for parents and teachers is increasingly recognised as important (Abbott et al. 2013). Therefore this study also seeks to obtain the views of the child's parents and teacher.

1.3 Aims

The present study aims to:

1. Consider the lived experiences of a 5 year old child with autism.
2. Critically consider the methods used to facilitate a child's participation in their diagnostic assessment.
3. Gain an understanding of a parent's perspective of their experience of the assessment process.
4. Gain the views of a specialist teacher about the impact of the diagnostic report on their work.
5. Consider a participatory practice model to open up debate and bring consideration of a different perspective of diagnostic assessment for ASD.

1.4 Impact of the present study

Understanding and the appropriateness of professional advice may be dependent on the ability of professionals to have some insight and understanding of individual experiences (Billington, 2006). Research into eliciting children's views and experiences during their diagnostic assessment is important. It has the potential to challenge the dominant negative discourse that can separate children from their peers, family and wider community (Barrett, 2006; Hodge, 2005), to provide qualitatively different insight into the understanding of autism, to link recommendations for support to the individual, to inform the practice of shared decision making and may have a therapeutic effect. Seeking to combine qualitative enquiry with professional practice the key areas of enquiry of the present study were translated into five research questions.

1.5 Research questions

1. What sense does a young child with autism make of their day to day experiences of life?
2. How might a young child be enabled to participate in their diagnostic assessment and their views elicited?
3. What are their parent's views of their experience of diagnostic assessment?
4. What impact does the sharing of information by narrative report have on other professionals supporting the child and family?
5. What can be learnt from the participants in seeking to improve clinical practice and understanding through their applied knowledge and personal insights?

1.6 Research context

The research was undertaken in a children's community health service located in the Midlands which is commissioned to provide diagnostic assessments of ASD for children aged 0-18 years.

2. Method of enquiry and design

The researcher's review of literature that sought the views of children and young people with ASD identified eleven studies. All used an idiographic method of enquiry and either interpretative phenomenological analysis (IPA) (Dann, 2011; Hill, 2014; Humphrey & Lewis, 2008; Huws & Jones, 2008; MacLeod et al., 2013; Tobias, 2009) or thematic analysis (TA) to interrogate the data (Brewster & Coleyshaw, 2011; McLaughlin & Rafferty, 2014; Ozsivadjian et al., 2012; Preece & Jordan, 2010; Winstone et al., 2014). The results of IPA and TA analysis can be very similar, and the differences and similarities between IPA and TA were considered to inform the researcher's decision about which to use for the present study.

Developed as a distinct approach to conducting qualitative research in psychology with a detailed procedural guide (Brocki & Wearden, 2005), IPA is a theoretically informed framework or methodology used where the research aim is to explore how participants make sense of their personal world, with their personal perception or account of an event rather than an objective statement (Smith & Osborn, 2007). This phenomenological approach is rooted in the philosophical approach established by Husserl in the early part of the twentieth century (Giorgio & Giorgio, 2008), but rather than seeking explanation of the essence of experience IPA seeks to 'capture particular experiences as experienced by particular people' (Smith et al., 2009, page 16).

IPA is inextricably linked to theories of interpretation or hermeneutics with a two-stage or double hermeneutic involved, as the participants are trying to

make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world from a psychological perspective (Smith & Osborn, 2007; Brocki & Wearden, 2006).

IPA is also ideographic, concerned with the study of particular experiences of an individual, how they are experienced and in what circumstances. Therefore of direct relevance to the current research study IPA is concerned with trying to understand what it is like from the point of view of the participants, to take their side. It does not seek to generalise and reflects a social constructionist epistemology. Valuing the individual and the development of relationships is an essential prerequisite in order to try to understand and to make sense of their unique experience. The researcher assumes a transactional relationship between themselves and the participants; a key feature of the present study where the researcher is both researcher and clinician. It requires detailed analysis of the data at a micro-level, and is appropriate for a single case (Smith, Osborn, & Smith, 2004). IPA is inductive and the techniques allow for unanticipated themes to emerge during analysis from broad research questions (Reid, Flowers, & Larkin, 2005).

In contrast TA is a method which can be used across the epistemological and ontological spectrum. TA can be used to address a range of different research questions, including those about people's experiences and perspectives but focuses on patterning or meaning across several participants. It is best used when working with larger samples, and for data that does not necessarily capture first-person accounts. TA was not considered suitable for an exploratory study seeking the views of one participant and IPA was selected as the methodological approach and the method of analysis for the current study.

2.1 Ethics

Ethical approval for this study was obtained from:

1. The Proportionate Review Sub-committee of the NRES Committee London – City and East.
2. The Research and Development Directorate of the Heart of England Trust.
3. The University of Leicester Ethics Committee.

2.2 Validity and reliability

Although validity cannot be addressed before conducting qualitative research because of the uncertain nature of the process, it is an essential consideration and responsibility lies with the researcher to ensure integral verification strategies during the conduct of inquiry (Bashir, Afzal, & Azeem, 2008).

In order to ensure validity and reliability in the present study reference was made to Yardley's framework (2000). This seeks to counter positivist criticism of IPA as subjective by referencing four principles that consider the quality of qualitative research including:

1. Sensitivity to context: The researcher sought to strengthen reliability by listening to the audio transcriptions many times to ensure transcriptions were accurate, and to develop a close relationship with the data.
2. Commitment and rigour: A clear research process was followed including:
 - a. The use of raw data (descriptive validity).
 - b. Checking of data and interpretations.
 - c. Checking findings with those the research was conducted with (internal validity).
 - d. Considering findings in relation to existing literature (theoretical validity).
 - e. An on-going process of reflexivity and critical self-awareness of the way in which the researcher's values, experiences, assumptions and preconceptions are likely to influence the collection and interpretation

of data, and how the research process has influenced the perceptions of the researcher.

3. Transparency and coherence: Detailed reporting of the research process sought to enable other researchers to see how the data was obtained and analysed.
4. Impact and importance: The exploratory nature of the present study sought to directly inform further research and clinical practice within the context in which it was undertaken.

2.3 Researcher preconceptions and conceptions

The researcher is directly involved in the assessment and diagnosis of ASD and has often observed the expectation from families and professionals that assessment will identify specific 'truths' based on rigorous testing and analysis and formal knowledge (Swain et al., 2000). Families generally seek diagnosis in the belief that it will be followed by support and an improvement in the child's difficulties. Certain labels are perceived as less stigmatising than others, and diagnosis can frame the 'problem' as being outside parental influences. Diagnosis can also serve to perpetuate parent's lack of confidence in their abilities to support their child (Hodge, 2005; Reid et al., 2005), and can play a significant role in shaping individual identity and quality of life (Swain et al., 2000).

The clinician's approach to, and reporting of diagnostic assessment can influence the response of others, and the diagnostic label can become more significant than the child. There is emerging evidence that enabling parents and children to participate in the process of diagnostic assessment has a significant impact on outcomes for the child and their family (Abbott et al., 2013).

2.4 Participants

There were three participants in the present study: the child, their parent and a specialist teacher for children with ASD. Inclusion and exclusion criteria were identified for the child participant (Table 5).

Table 5 - Inclusion and exclusion criteria for the child participant

Inclusion criteria	Exclusion criteria
Under the age of six years at referral. Verbal. Currently attending or previously attended the assessment service (within the previous 12 months and has a diagnosis of ASD.	Over the age of six years at referral. Prior involvement in a research study. Social care involvement. Non-verbal. No diagnosis of autism.

One male child participant aged 5 years 9 months was recruited to the study. To protect his identity a pseudonym was used and he is referred to as Jack throughout the present study.

Jack lived at home with his parents and older sibling. Jack's mother was the parent of two children with a diagnosis of ASD. Her elder son had received a diagnosis of ASD four years previously. She had withdrawn both children from their local mainstream school to home-educate them, concerned about the way in which the school had responded to reported bullying incidents. This had a significant impact on her professional role in a community support service and on family life as she adjusted her working hours. The specialist teacher for ASD working with Jack's family was an experienced practitioner with a lead role within the locality specialist educational support services, and also a parent of two children with ASD.

2.5 Measures used

Data were obtained through semi-structured interview for each participant. The researcher's first-hand knowledge of the child enabled potential challenges and planned adjustments to be considered (Table 6). Jack's mother and the specialist teacher were provided with the aims of the study and invited to engage in a semi-structured interview at the end of the assessment process.

Table 6 - Potential challenges and planned adjustments for the child interview

Potential challenges	Planned adjustments
Developing and maintaining rapport with the child.	Three previous meetings with Jack and his mother to establish a relationship.
Gaining assent and the child's understanding of the purpose of the interview.	Check Jack understands the purpose of his attendance on each occasion, with his mother present throughout to provide secondary confirmation that the interview should continue.
Audio-recording equipment being a distractor to the child.	Audio-recorder shown to Jack and for him to have an opportunity to investigate and ask questions.
The time of day and the location that interviews took place.	Interviews were planned at a similar time of day to previous appointments using the same rooms to ensure Jack's familiarity with his surroundings.
The presence of Jack's mother.	To provide secondary verbal and non-verbal information about Jack's understanding and his behaviour, to help contain any anxiety, and to support the maintenance of his attention.
Maintaining Jack's focus of attention	Shorter interview time, impromptu breaks, opportunity for preferred topics and special interests, a choice of methods of responding (written or spoken).
Managing Jack's high level of physical activity and distractibility.	Impromptu breaks that include opportunity for increased physical movements. A low-distraction environment with resources kept to a minimum.
Maintaining topic.	Broad themes for questions were identified, but no pre-planned secondary questions that might detract interviewer and interviewee from the interaction.
Minimal responses or extended commentary.	Recognition that more prompts and researcher commentary may be required with potentially more closed questions (Boyden, Muniz, & Laxton-Kane, 2013).
Enabling other means of communication.	Pen and pencil available throughout to facilitate drawing or writing responses rather than speaking.
Researcher using semi-structured and play-based interviewing techniques.	Maintaining the need for flexibility and not being concerned by being 'off-topic'; accepting the possibility that no data would be obtained.
Time constraints.	Shorter interview time.
Resources.	Pen and pencil, and two favoured toys were available (fire-engine and small car) and placed on the side of the table where Jack sat with the researcher (as in previous appointments).

2.6 Procedure

The researcher met Jack on two occasions for one hour, two weeks apart. Sessions were recorded and transcribed. Consent was obtained from Jack's mother, and assent from Jack sought using an accessible version of the consent form. The researcher was interested in identifying topics and issues raised by Jack in order to consider the impact for him on his day to day experiences. Specific questions were not predetermined but were based on broad themes identified from the researcher's review of current literature that sought the views of children and young people with ASD; these included day to day experiences of family life and school. All the potential adjustments shown in Table 6 were implemented by the researcher during the process of the two interviews. The researcher's language was frequently modified to accommodate Jack's interests, his understanding, and perceived level of motivation and engagement. Recognising the need to attend to contextual factors that might influence what was said in the interview, and to maintain a reflective approach research notes were made to record thoughts on the process after each interview.

The two interviews were conducted differently. The first interview was conducted in a less structured and more fluid way than the second, with only a pencil and paper available for Jack to use should he wish to do so. The second interview was also conducted with a pencil and paper, but also used visual prompts in the form of small line drawings showing different emotions. These were used to gain a view of Jack's understanding of different emotions in order to prompt discussion of when Jack may have felt this way.

The interview with Jack's mother and specialist teacher included broad themes that sought to gain their views within conversation, rather than use a list of prepared questions. The interview with Jack's mother took place first and she was asked to consider her experience of Jack's assessment. She was joined later in the interview by the specialist teacher who was asked to consider her views of Jack's diagnostic report. Specifically she was asked to consider

whether including Jack's perspective in his diagnostic report was helpful and how it might impact on her work.

2.7 Data analysis

Data analysis followed the analytical procedures for IPA as detailed by Smith et al. (2009) and summarised in Table 7.

Interviews were transcribed verbatim, and after a preliminary stage which involved listening to the audio recording while reading the transcript many times in order to become familiar with the 'voice' of the participant, the staged process of data analysis and interpretation was followed. Data analysis was not a linear process and earlier stages were often revisited in order to check details and validity.

The process of identifying units of meaning began by the researcher looking through the transcript and noting down anything that seemed interesting or significant. These notes were recorded on the left hand side of the transcript as potential themes, and included summarising statements, making connections and also making some preliminary interpretations. The potential themes were written on individual cards and different groupings identified to form subordinate themes and superordinate themes. The process which traced how emergent themes were integrated to form subordinate -themes and superordinate themes is shown in Appendix B (page 112).

Table 7 - Staged process of data analysis completed for each participant

Stage	The process of data analysis
1	<p>Initial analysis and identification of potential themes:</p> <p>Potentially important text was identified by line number in conjunction with initial interpretative notes and potential themes.</p> <p>This process for each participant is shown in Appendix B, page 112 (Tables 11,14 and 17)</p>
2	<p>Developing connections between themes.</p> <p>Comments that could be grouped together were listed and links were identified. This included any significant non-verbal behaviours and pauses.</p>
3	<p>Creating an overview of emergent themes.</p> <p>This process for each participant is shown in Appendix B, page 112 (Tables 12, 15 and 18).</p>
4	<p>Integration of emerging themes to form subordinate themes and Superordinate themes.</p> <p>The material was organised to show the links between the emergent themes, subordinate themes and superordinate themes, and enable the analysed data to be tracked through the process.</p> <p>This process for each participant is shown in Appendix B, page 112 (Tables 13, 16 and 19).</p>
5	<p>Writing a narrative account of themes.</p> <p>A full narrative account was written including quotes from the transcription to take the reader through the interpretation theme by theme. The researcher also reflected on how their own experiences, values and social context influenced their attempt to ascribe meaning to the individual's experience</p>
6	<p>Conceptualisation.</p> <p>The relationships between themes for each participant were considered.</p>

For each participant the themes identified were based on the frequency within the transcripts which they occurred, and also on specific account that captured their individual perspective. A full narrative was completed to take the reader through the interpretation by theme.

3. Results

This section highlights and examines the views of each participant that emerged from within the interview process; it is divided into three sections:

1. Child's views.
2. Parent's views.
3. Teacher's views.

Each section begins with an overview of the superordinate themes identified and their subordinate themes before considering them individually.

3.1 Child's views

Jack's current story told of his reduced opportunity to play and be with other children. This was directly attributed to his non-attendance at school, itself a consequence of experiencing bullying incidents at school and compounded by his sibling's preference for playing alone. Jack reported that he missed his friends and the activities that took place at school, but was very clear that he would not return to the same school. He had observed and listened to his mother report her concerns to the researcher, and he placed the researcher in the role of 'teacher' or authority figure in his expectation that they should know about his experience.

Three superordinate themes relevant to the perceptions of Jack's lived experiences emerged from the analysis (Table 8):

1. Personal and social relationships
2. Personal and social experiences.
3. Personal identity.

Table 8 - Superordinate themes and subordinate themes (child)

Superordinate themes	Subordinate themes (frequency of occurrence)
Personal relationships (19) (Specific people identified in the transcript).	Immediate family – Sibling (7); Parents (2) Extended family (1) Peers (2) Imaginary friends (3)
Personal experiences (25) (Emotional, social and behavioural experiences identified in the transcript).	Negative experiences (5): Bullying (1), Loss of opportunity (4) Positive experiences (20): Different learning experiences (4), Engagement in favoured activities and special interests (6), Personal achievements (3), Sensory experiences (7)
Personal identity (Emerging sense of self through experiences).	Family member (1) A sibling (1) Influencing others (2) Communication style (1) Skills, knowledge and interests (5) Emotional literacy (4)

Personal relationships

The theme of being with other people was a strong commentary throughout the interviews with Jack speaking about his parents, siblings, peers and holograms of his friends.

Immediate and extended family

Jack acknowledged he was a member of a family: '*When mummy and daddy got me my name was Jack, that's my mummy and daddy named me Jack* (line 41). He delighted in his own addition of a name aligned with one of his favourite

interests: (laughing) *'I changed my three names to four (laughs); my last name is unicorn'* (line 38).

Jack spoke most frequently of his sibling, directly and indirectly referencing him on seven occasions (lines 11, 91, 45, 53, 239, 251, and 253), often to comment that his brother would not play with him:

'I feel a bit angry when Harry doesn't let me play with him' (line 25).

'Harry doesn't like playing with me' (line 91).

Jack had also commented about this during previous appointments with the researcher and it was seen as a recurrent and important theme for him. He had regular contact with other children but did not have the frequency of interactions that would be afforded in a school setting, and his sibling was his main source of child-interaction.

Jack acknowledged different aspects of their relationships, including sharing items:

'It used to be my brother's but it doesn't fit him anymore' (line 11).

'We got an Amazon delivery and one of them was for me and Harry, it came from Amazon that delivery was for me and Harry' (line 45).

Jack also acknowledged his extended family; his nanny (line 151) whom he enjoyed visiting.

Peer relationships

When Jack was asked about other children, he identified being unable to see his friends as a negative aspect of not attending school, reporting: *'I don't see my friends at school'* (line 97); *'That makes me sad'* (line 99). In the second interview Jack identified the person in one of the drawings as *'bored'* (line 215), when asked by the researcher how he could tell, Jack commented *'Because he's in the corner and he wanted to play with his friends'* (line 219).

When considering what was important to him, Jack spoke of being outside at school and playing games. He recalled and described the visual aspects of the physical environment at school rather than people. For example:

'Play tag' (line 98).

'Out on the playground at playtime' (line 99).

'The rainbow playground and the caterpillar playground' (line100).

'It was a rainbow and had a shelter when it was raining. It was a ginormous umbrella sitting in the ground, it was metal and really big and it could go in and out' (line102).

Jack identified activities at school where he was happy explaining the related activities and the presence of other children. For example: *'Play tagyes the rainbow playground and caterpillar playground'* (line100) and *'The sand and water'* (line107). When asked by the researcher why they made him feel happy, Jack stated *'Because they had friends there'* (line111). Although Jack spoke of missing activities and people at school, he was consistently clear that he was not returning to the same school (line 104).

Imaginary friends

Jack was asked what things he would like in a 'nice' school (line 129), and he responded '*Holograms of my friends*' (line130). When clarification was sought by the researcher Jack confirmed non-verbally (line132), and when asked about real friends he laughed and added:

'...and some holograms, I like holograms (line134)

'and a dinosaur zoo, different dinosaurs like (inaudible) that's the one with the golden eyes, tyrannosaurus rex is the biggest of the dinosaurs but did you know' (line136).

When the researcher summarised his views as missing his friends, Jack offered the same solution:

'Holograms could play together; there could be a hologram of me and hologram friends' (line162).

Personal and social experiences

The subordinate themes for this superordinate theme were grouped into negative and positive experiences (Table 8). For Jack positive experiences dominated at a ratio of 4:1.

Positive experiences

Jack identified a number of positive experiences some of which were a consequence of him no longer attending school. For example, he sometimes visited his mother's place of work, and commented '*But sometimes we have to go places like (place name)*' (line147), which when the researcher asked about how he felt about that (line 148), he stated '*Happy, Happy*' (line 149).

Jack also had opportunities to engage in his favoured activities: *'going on the Wii Nintendo'* (line 57) and *'going on my Samsung Galaxy Tab 2'* (line 69), and to talk about his special interests: dinosaurs (line 136), unicorns (line 38), and fire-engines: *'my dream is to be a fire-engine'* (line 167).

Jack was pleased with his personal achievements and liked to show his knowledge and skills: *'I want to write it.....'n..a..n..n..y', Nanny! I can spell!* (line 153), and identified things that he liked to learn about: *'Maths and science and some of the (inaudible) when they bash into each other'* (line 141).

A key feature of Jack's presentation was the additional sensory experiences that he sought by increasing his level of physical movement (lines 2, 7, 287), making additional noise (lines, 4, 160, 165) and seeking additional pressure (line 118). Jack showed some self-awareness of his sensory needs: *'I just like the sound of the (making clicking noise)'* (line 143). His mother was observed to use a number of approaches to help him calm; Jack benefited from being held tightly in a hug and his mother rubbing his back firmly.

Negative experiences

Bullying was mentioned only once during the interviews; *'I was getting bullied by Henry. Write his name'* (line 94) but Jack had previously spoken of this experience to the researcher during administration of the Autism Diagnostic Observation Schedule (ADOS).

Jack had a keen sense of justice, directing the researcher to write down the name of his reported assailant, spelling it out carefully while looking closely to make sure that the name was written correctly. The consequences of Jack's experience of bullying reoccurred throughout the interviews focusing on the loss of opportunity to see his friends at school and limited occasions to play with other children.

Jack was always very clear about not returning to his previous school and became very agitated and distressed when returning to school was mentioned: *No! No! No!* (line 104).

Experiencing self

Jack used the terms *sad* (line 89, 93), *happy* (line 149), *angry* (line 186) and *bored* (line 215) in the context of relational experiences either with his brother or other children. Jack also changed his non-verbal behaviour to demonstrate his emotion, which provided clear indicators of his feelings in specific contexts, particularly those in relation to bullying and his brother. Jack showed his ability to choose his preferred means of communication either spoken or written (line 72 and 85) and to direct others (line 94).

Jack's thoughts, feelings and behaviour were brought together under the overarching theme of experiencing self. Jack did not know of his diagnosis and his narrative shows aspects of the process of Jack learning about himself and the construction of his identity within the context of his family and school experiences.

3.2 Parent's views

Jack's mother related her previous and current experience of diagnostic assessment and the emotional impact for her by identifying features that were important to her and some of the difficulties she experienced.

Three superordinate themes relevant to the views of Jack's mother emerged from the analysis: the experience of diagnostic assessment, the model of assessment and translating theory into practice. The superordinate themes are illustrated in Table 9 with their subordinate themes.

Table 9 - Superordinate themes and subordinate themes (parent)

Superordinate themes	Subordinate themes (frequency of occurrence)
Parental experience of assessment	Adjustment to diagnosis (4) Developing knowledge (1) Seeking support (7)
Model of assessment	Demands (6) Collaborative working (5) Shared understanding (4) Reporting (5)
Translating theory into practice	Applied knowledge of child (2) Idealistic support (1) Resource limitations (1)

Parental experience of assessment

Adjustment to diagnosis

The reporting by Jack's mother of her experience of his diagnostic assessment included her comparative views in relation to her experience four years previously with his sibling. Her use of terms such as '*stressful*', '*emotionally draining*' (line 59) and '*shock to the system*' (line 56) illustrated the emotional impact. She recognised her need for support and further information at the point of diagnosis, emphasising her feelings of '*disappointment*' at the lack of opportunity to seek answers to her questions:

'When I walked out of (brother's) assessment I had a million and one other questions that I couldn't get answered, I had the disappointment' (line 50).

A contributing factor to her heightened anxiety and emotional response was the use of terminology by professionals:

'With Harry it was a shock to the core because it was so intense. But you do need a jargon buster. This is why Harry's was so emotionally draining. There is still (inaudible) it's just hard; it's just jargon' (line 237-9).

To validate her views Jack's mother referenced other parents who had reported similar experiences:

'When I've talked to other parents, when they go through assessment days, it's so stressful and it's just emotionally draining' (line 29).

'It's not just me saying this' (line 46).

Developing knowledge

Jack's mother's response to receiving a diagnosis for her elder son was to develop her knowledge by seeking as much information as possible:

'I only speak the lingo because I'm a walking encyclopaedia. I've read so much' (line 86).

Her use of the term '*speak the lingo*' likened learning about ASD to learning a foreign language; it was difficult, took time and was a situation with which she was unfamiliar. She adopted the approach of becoming an 'expert', by seeking information, acknowledging her preference for small amounts of information at a time to enable reflection:

'With Jack's (assessment) I could ask as we went along, as and when' (line 51)

'If there was a question or any issue or a problem I could say' (line 53).

Seeking support

Jack's mother recognised the benefit of her accumulated knowledge and understanding and her established support network:

'I'm lucky; I've got 1, 2, and 3 oh at least 4 years of background knowledge. I'm with autism [REDACTED], I do workshops and open days, and I've got good support and a support network' (line 95).

She identified a sense of abandonment after receiving the diagnosis for her elder son and the difficult experience of waiting for further support:

'I took it (report) to school and oh I don't know; where do I go from here? Whereas with Jack's, maybe it's because I know a lot more about autism spectrum now. It's right there and I can go, right, I know where I can go from here' (line 23).

'There is a very big gap between when you get your initial diagnosis and when you have your first proper meeting with a specialist teacher, and then there's a gap between that meeting and when they go into school' (line 54-55).

Jack's mother had an established network that enabled her to find information that she needed. Having strived to seek support she also identified feelings of dissonance:

'I did feel a bit bad, because we had a lot of time with us, and we get a lot of support' (line 148).

Model of assessment

Personal demands

During the process of diagnostic assessment Jack's mother's main concern was his attendance at hospital and to secure appropriate educational provision for him. A statutory assessment of Jack's Education, Health and Care needs (EHC) was being completed by the local authority. These events placed considerable personal and organisational demands on her and were the source of additional stress. Jack's mother identified the need for the diagnostic assessment to collate the information on a child:

'It's important to pull it all together. With Harry I was just going everywhere and I had paperwork coming out of my ears, and with this (report) I wouldn't have to, It's going to cut parent stress by half' (line 160).

Collaborative working

As a parent and as a professional it was important for Jack's mother to develop a relationship with the professionals that were working with her child. She felt validated that her knowledge of her child was incorporated into the report. For her this meant she was heard and believed:

'It's not just me saying this; it's come up in the report' (line 23).

She contrasted her previous experience of diagnostic assessment and identified a specific problem for her:

'I kept being told you can't just go on all the positives you've got to look at the negatives as well' (line 213).

She welcomed Jack's assessment over time while acknowledging some of the pitfalls:

'Even though there were a lot more trips it gave me time to think about things, ok, to think about things. I could ask as we went along, as and when' (line 25).

Shared understanding and reporting

Jack's mother considered the difference between the narrative style of his report and the clinical diagnostic report of his brother. It was important to her that it reflected her son's character and positive skills and knowledge as well as challenges:

'The first bit is really good; a parent could happily read straight through and go yep, yep, so as a parent I can contribute and say yes, yes' (line 88).

When asked what the impact for her personally on receiving Jack's report, she commented:

'I want (pause) I want to say it's a lot better for me' (line 43);

'As his mum I can look at it and say this is Jack to a tee' (line 22);

'It really was a lot more encompassing. It wasn't just he's ASD it was everything about him plus the way he felt as well (line 27).

Jack's mother reported that previously her knowledge and information about Jack's brother had not been acknowledged in the written report:

'With Harry there were things cropping up, but they weren't mentioned on the actual report; it's just a rubber stamp' (line 25).

While she acknowledged the professionalism of the team concerned and accuracy of the diagnostic outcome she felt left trying to make sense of her own observations and wondering what the assessment had actually achieved:

'It was not telling me anything I don't know.....you're telling me this but not giving me an overall picture' (line 24).

'It was these are the criteria he met. I just kind of read it and thought; well I know' (line 33).

Translating theory into practice

Applied knowledge of child

At the time of Jack's diagnostic assessment his mother had extensive knowledge and understanding of ASD and how it impacted for her two children differently. She was effectively translating information into practical approaches to support them in different contexts.

Identifying support

A primary concern was educational provision. She identified her previous frustration at attending several meetings at school, being asked the same questions and having to explain and repeat herself many times:

'I had to go through a million and one other appointments just to get to the point where we are with Jack' (line23).

'We were being asked the same questions 3 or 4 or 5 times, that's going to be frustrating for anybody' (line 57).

She felt including comprehensive information in a single report was helpful and had the potential to save time:

'Jack's was an assessment of how his ASD and the rest of him are. All interacting in one person' (line 36).

'Jack's had all factors ASD, ADHD, asthma and eczema, everything really. It's the whole child, how it affects him and, how it will impact in school' (line 124-5).

Expressing some confusion about the part of the report pertaining to his special educational needs:

'I did get a bit confused with some of the content (line 80)

'the headings and strategies..... this needs maybe a bit, a basic definition – of specific jargon' (line 222)

'you have set phrases' (line 229).

She identified the role that a specialist teacher might provide in helping to translate the terms used in the report. Specifically how they relate to educational provision and helping to ensure implementation of the recommended approaches.

Resource limitations and practical considerations

Jack's mother assumed that the narrative approach was more time consuming (than the single day assessment model she had experienced with his brother), but felt it was helpful for those children with complex needs like Jack:

'I can't knock it but we don't live in an ideal world. Realistically we can't do this for every child' (line 150).

'It's going to be great for children with multiple aspects; for children with additional needs and ASD' (line 155).

She also noted that the approach adopted would not always 'work', and recognised that other people may be best placed to elicit a child's views:

'...with Jack it's great, if you'd tried to do it with Harry I guarantee you'd have got a brick wall. If you'd asked Mrs Smith (class teacher), and asked her to do it, he would not have shut up' (line 184).

3.3 Teacher's views

Analysis of the teacher's transcript identified three superordinate themes: the model of assessment, service constraints and professional practice. These subordinate themes are shown with their constituent subordinate themes in Table 10.

Table 10 - Superordinate themes and subordinate themes (teacher)

Superordinate themes	Subordinate themes (frequency of occurrence)
Model of diagnostic assessment	Report style / structure (2) Participatory practice (1) Child's views (1)
Service specification	Constraints and challenges (6)
Professional practice	Influencing service delivery and practice (14) Professional demands (2)

Model of diagnostic assessment

Participatory practice: teacher role within diagnostic assessment

The service criteria of the specialist teaching service for children with ASD mean the service only becomes involved with a child after a diagnosis is confirmed. This differs from other specialist teams within the educational support service who may be working with a child and their family before and or during the process of diagnostic assessment. In some instances a collaborative model of assessment is employed with specialist teachers contributing their skills and knowledge of the child in the context of their school setting. There was a strong sense that this is an effective and more professionally satisfying model that enables teachers to have an important contribution to the diagnostic process.

But I completely agree this is a much better way of working. The services come together. It's not as we would like it to be' (line 63).

This aspect was a source of concern for the service lead while acknowledging the practicality of service restrictions in the context of increasing demand.

In the present study the specialist teacher had already met Jack as she was supporting his brother. So when she received his report she had already formed a view of Jack and his needs:

When I read it (report) I felt, and I've got the benefit of I know Jack and I know his family so I could picture him, but I got a real sense that if I hadn't met him I knew more about him the way this has been done (line 89).

Having considered the impact of reading the report containing Jack's views the specialist teacher placed the child's view as an essential component, but attributed the impact of their inclusion to rarity of occurrence:

'I think this section about his views is really powerful' (line 40).

'Because you don't often get that do you? It's always parent's views and clinicians view, you don't capture the child. So I think no matter what age it's really important to be able to do that' (line 42).

Service specification

The constraints of service criteria and the feeling of having a limited role within the diagnostic assessment as a practitioner were an emergent theme:

'We work very differently because we can only pick up children at the point of diagnosis. So we haven't got that background work so that's different (line 139).

A key theme identified by the specialist teacher was the challenge of increasing demands on the service, compounded by a reactive crisis response in schools (line 167), despite the service seeking to undertake preventative work.

Professional practice

A key function of the specialist teacher's role is to 'translate' the diagnostic report into a need-based plan, which seeks to counter the deficit focus of the diagnosis by identifying positive aspects of the child and appropriate practical support. Jack's diagnostic report sought to present his strengths and interests in the context of his difficulties and to provide recommendations closely linked to his needs. The specialist teacher identified that she would adopt the same approach as the researcher:

'We would have the report, we would do the same but we need to build a relationship and we would need to do quite a bit of work to be able to understand him and to be able to comment, to be able to put in a report for an EHC assessment' (line 50).

'For clinicians who do not have your dual role, the specialist teachers would be putting in help with strategies. That's where there would be joint working. The clinicians are experienced in diagnostic assessments, but we can help with well, what do we do about it in school; they wouldn't put that' (line 65).

The teacher's writing of a needs-based plan for every child seemed driven in part by her observation that diagnostic reports are largely ignored: *'so schools don't really pay attention to the diagnostic report'* (line 167), and by her aim to provide a preventative service. It was also a source of considerable pressure: *'I was trying to write them all from scratch which is just daft'* (line 165). The teacher recognised that the plans increasingly focused solely on the triad of impairments because of increasing demands:

'We try to incorporate other aspects but because we need to ensure that every child has got one, it's becoming more focused on ASD, because we can't cope with the demand' (line 171).

Acknowledging the diagnostic report provided *'the essence of Jack'* (line 89), and was helpful to inform her own practice:

'So I think for me as a professional, actually it gives me loads of information' (line 42).

Asked whether the narrative approach used with Jack impacted on her work, she confirmed that it did. In the context of increasing demands it seemed to raise the issue of professional boundaries and potential overlap between the Educational Psychologist researcher and specialist teacher:

'Yes! Because you've got the plan there, which is what we're writing and so this is kind of "off you go" (line 59).

There was an implicit assumption that a participatory approach and personalised report took more time (than the deficit model) yet there was no evidence presented to support or to refute this: *'This would be ideal but it's the capacity side of things' (line 71).*

Researcher reflections on analysis and interpretation

The researcher scrutinised their role in the shaping of the data collection and analysis process, aware that interpretations may have been biased around aspects of their own thinking that the researcher expected to find. To reduce bias the emergent themes were discussed with a clinical colleague with experience in qualitative research in order to verify interpretations.

The researcher had an established relationship with both Jack and his mother and had also worked with the specialist teaching service for many years, although not directly with the lead professional involved in the present study. Some studies report researchers actively seeking to develop relationships with participants before undertaking data collection (Humphrey & Lewis, 2008), and this was deemed to be an essential requirement in the current study. The researcher's relationship with Jack and knowledge of his style of communication enabled adaptations to be made during the process and also helped to inform analysis and interpretation. Seeking feedback from the participants on experiences that the researcher was implicitly part of was considered to be an important part of the process, and has been a feature in other studies (Abbott et al., 2013).

More prompts and closed questions were used with Jack than with the adult participants, and the researcher reflected on whether the interactions were adult dominated. Initial concerns that the narrative would not yield any pertinent information proved unfounded. Analysis and interpretation of Jack's narrative gave the researcher a surprising amount of information about his views and experiences. Jack liked information to be detailed and for things he regarded as important to be written down. This was shown by Jack's specific request for the name of the child that he held responsible for bullying him to be written down. The similarity with his mother was evident. For Jack's mother it was very important for her to be listened to and to have her knowledge and views validated by them being included in the written report. Also to have the regular opportunity to ask questions, to reflect on information and to develop her shared knowledge and understanding with the researcher/ clinician, and for the process to be flexible and respond to her family's needs.

Analysis and interpretation of the teacher's views raised important issues about systemic and organisational issues within the locality context, and both the purpose and the use made of the diagnostic report by various parties.

Internal validity by checking researcher interpretations with the participants only occurred with the teacher participant, with them giving confirmation that their views had been interpreted appropriately. A change of circumstances prevented validation of their views by either Jack or his mother.

4. Discussion

This section summarises the main findings of the present study before discussing the interpretations developed from each of the participant's accounts; how they relate to the five research questions and link with psychological theory and knowledge. The implications for clinical practice, the key limitations of the present study and potential areas for future research are also identified.

4.1 Summary of research findings

The present study found it was possible to use an IPA framework in the context of a child's diagnostic assessment to gain an understanding of their views and experiences at a younger age than previously thought. Jack's important relationships and experiences were similar to those of many five year olds, concerned with sibling relationships, family, play and school experiences (Osborn, Butler & Morris, 1984).

The IPA framework also facilitated an understanding of his mother's experience of the assessment process, and of the views of a specialist teacher on the impact of receiving written information about Jack. His mother's experiences of diagnostic assessment strongly echoed research findings in current literature (Abbott et al. 2013). The views and experiences of the specialist teacher raised questions about organisational and systemic issues that impacted on her professional role and multi-agency working. This was perhaps not surprising given the extended period of review that educational support services were experiencing at the time.

Research question 1: What sense does a young child with autism make of their day to day experiences of life?

Jack had no awareness of or understanding of his diagnosis and the present study sought to elicit his views of his day to day life. Very few studies include the views of young children in part because research is often focused on problematic aspects of experiences, and researchers question the ability of young children to understand the concepts (Kirby et al., 2015). In contrast the present study sought to consider the aspects of his life that Jack chose to talk about.

The breakdown of the relationship between Jack's mother and school staff as a consequence of the staff response to Jack's experience of bullying , was cited by his mother as the main reason for her decision to home-educate Jack and his brother (Kendall & Taylor, 2014; Lewis & Parsons, 2010). Jack's understanding of his day to day experiences focused around his non-attendance at school as a direct consequence of his experience of bullying. He was unable to see his friends, and had restricted opportunities to play with others. He was reported by school to have reacted physically to being pushed by another child, reflecting findings of a study by Farmer et al. (2014) that showed younger children with ASD were more likely to be rated as reactive rather than proactive. Children with a diagnosis of ASD and those with co-morbid conditions are reported to be bullied more than typically developing peers, and it is more likely to occur in mainstream schools than in specialist provision (Zablotsky, Bradshaw, Anderson, & Law, 2014). A key feature of Jack's views and an important consideration for his mother in her wish to find a different school was that he reported friends (Daniel & Billingsley, 2010), and had a desire for friends (Kasari, Freeman, Bauminger, & Alkin, 1999), although at times he liked to be by himself (Calder, Hill, & Pellicano, 2013).

Establishing and maintaining friendships play a significant role for children with ASD in their overall experience of school and the protective role of friendships is well recognised (Calder et al., 2012). Jack identifies the conflict and tension

in wanting the pleasure of the company of other children and the distressing experience of being overwhelmed by others and bullied. Jack identified 'holograms' to function as friends seeking to maintain the pleasure of friendships and lose the painful aspects.

Jack personified the objects of his special interests: dinosaurs, unicorns and fire-engines, perhaps to nurture positive relationships (Gleason et al., 2000), to help Jack feel safe, and in moments of boredom to connect him with others (Billington, 2006).

Jack's non-attendance at school also provided him with freedom and he was effectively sought to learn in different practical ways. His recollection of being outside and the detail of the school playground without people could similarly be interpreted as providing him with the pleasure of active learning without the competing and perhaps overwhelming demands of other children.

For many children with ASD their experiences of sensory processing can result in sudden unusual or unexpected behaviours (Kirby et al., 2015). Jack was aware of his sensory seeking behaviours and the inclusion of his perspective on these behaviours in his diagnostic report has the potential to develop a different understanding of his needs (Barrett, 2006). These behaviours sometimes interfered with Jack's commentary and were seen by the researcher as potential indicators of a lack of understanding and increasing levels of anxiety. They were most evident at transitions, at times when Jack appeared to lack comprehension, and when he was tiring. These behaviours appeared to help Jack to self-regulate and acknowledging these were an important aspect of being with Jack. They were interpreted as a need for clarification by the researcher, or to accommodate the behaviour for a period of time, or as an indication that the interview needed to stop.

Jack's narrative shared similar themes to those reported in the literature for older children with ASD, including his desire for friends. Positive experiences for Jack dominated negative ones at a ratio of 4:1, raising the question of

whether a negative trajectory might be avoided by providing educational professionals with a clearer understanding of what autism might mean for Jack.

Research question 2: *How might a young child be enabled to participate in their diagnostic assessment and their views elicited?*

To consider this question the researcher reflected on whether Jack participated in the diagnostic process or whether he just had fun, but concluded that Jack was enabled to contribute meaningfully to planning for his support as his views influenced his mother and teacher. His mother recognised that he wanted to attend a different school for both social and academic reasons. For the teacher, the use of Jack's narrative sought to help her provide a clearer understanding for education professionals in his 'new' school of what autism meant for him; enabling the production of a personalised needs-based plan, rather than a 'one-size fits all' solution (Hodge & Chantler, 2010).

The practical aspects of the sessions with Jack were complex including the timing and location of the interviews. Jack was interviewed in the same room on each occasion. The selection of methods in the present study was essentially informed by the researcher's first-hand knowledge of Jack; with the aim of keeping distractions to a minimum.

Gaining informed assent was difficult and although the researcher considered Jack was willing to participate, the presence of his mother to confirm that she too felt he was happy to continue was essential. A recent study by Hebron et al. (2015) that sought the views of children with ASD relating to their experience of school, did not directly include the youngest child (5 years) as he was considered too young to fully understand the research and therefore unable to give informed consent. Consequently this study referred to less information from children than from adults, concluding that future studies should include children's views to a greater extent. Although reference is made to observation and diaries no suggestions are made as to how and with whom these might be used. Hebron et al. (2015) raise the issue of focusing on potentially upsetting

topics such as bullying and the need to be mindful of the impact. In contrast the present study started from the position of asking 'what is life like for you', enabling topics to be raised by the child rather than the researcher. Crucially in the present study the experience of bullying was identified as important by Jack, not by the researcher.

Specific details and a broader sense of what was important in Jack's life were obtained through IPA and a rigorous analysis of his narrative. Contextual information helped to analyse Jack's narrative through IPA to provide a detailed account. Neither the methods used during interviewing nor the method of analysis were compared with other methods and it is unclear whether these would yield similar or different information.

IPA is a research methodology and in the present study was also used as a tool in the diagnostic process with the specific aim of seeking Jack's views. Time was not a major factor in obtaining data (two hours) but the detailed analysis inevitably took much longer. This may have been easier with a young child, because the length of utterances were short when compared to those of the adults.

In common with the study of children with autism discussing complex emotions reported by Losh and Capps (2003), the researcher found that Jack took longer and needed many prompts. He described visually salient elements of his experience with a clear account of the physical environment of the playground, suggesting that he was using alternative strategies for interpreting emotional encounters rather than placing them in a personal causal-explanatory framework. Reflecting developmental research that suggests children under the age of eight years use factual information when giving an account, as interpretative information which articulates desires, emotions, beliefs and thoughts are not prevalent until late in adolescence (Pasupathi & Wainryb, 2010).

Jack was enabled to give his views by the following:

- Jack's relationship with and the presence of his mother.
- The relationship established with the researcher.
- The researcher's first-hand knowledge of Jack's skills, interests and communication style.
- Knowledge and expectation of his experience at the location for the interview.
- The methodological approach.

Research question 3: What were the parent's views of their experience of the diagnostic assessment?

Diagnosis of autism is a complex and emotional process, and can be a significant source of stress for parents and the family system (Reed & Osborne, 2008; Reed & Osborne, 2012). The views expressed by Jack's mother were about her two different experiences of diagnostic assessment. This comparative review was initiated by her, and not prompted by the researcher asking her to specifically reflect on the differences. Her initial experience showed marked similarities with recent research findings. She reported the well documented emotional impact of shock and distress and feeling uncertain, deskilled and unsure of what questions to ask.

It is recognised that the response and needs of parents differ considerably (Reed & Osborne, 2012). The way in which the diagnosis is communicated and information provided are key factors in determining the level of parental satisfaction with disclosure (Brogan & Knussen, 2003). Parental responses and recollections may be reflective of their own emotional reactions and dissatisfaction related to the process or to the outcome of a diagnosis (Braiden, Bothwell, & Duffy, 2010), and may differ according to the age of their child at diagnosis. Parents of older children often express relief having long thought something was wrong, while those of younger children report shock.

Jack's mother's previous experience of diagnostic assessment with his sibling was a single contact with clinicians and receiving his diagnosis came as a great shock. This inevitably impacted on her views of her experience in the present study. She subsequently developed her knowledge of ASD and was aware that the likelihood of a sibling having an ASD is increased (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010). Having recognised similar behaviour in Jack to his brother she approached his assessment with the knowledge that a diagnosis was a likely outcome.

It is recognised that the response of mothers and the wider family to diagnosis is a key influence on effective outcomes for the child (Abbott et al., 2013; Braiden et al., 2010; Reed & Osborne, 2012). Jack's mother highlighted the importance for her of timely support and being kept informed throughout the process. A critical aspect was the inclusion of her observations and information in the written report, providing confirmation for her that she had been listened to and believed. It was important for her to consider in conjunction with the clinician how autism impacted for her son and not simply be provided with 'a rubber stamp' against diagnostic criteria. Parents often note that the unmet need at diagnosis being specifically how ASD impacts and shows in their child, and a balanced emphasis on their child's strengths as well as difficulties (Hodge, 2005).

The quality of Parent-Professional-Partnership is increasingly recognised as influential in lowering parental stress, increasing parental confidence and with more positive parent-child interactions, thereby increasing the amount of intervention and support the child receives and improved outcomes (Brookman-Frazee, 2004). On receiving his sibling's diagnosis Jack's mother identified feeling similar uncertainty to other parents and asked the same question: '*where do we go from here*'? (Abbott et al., 2013). Also reporting '*a gap*' between receiving diagnosis and subsequently receiving support (Braiden et al., 2010).

Research question 4: *What impact does the sharing of information by narrative report have on other professionals supporting the child and their family?*

The outcome of their child's diagnostic assessment is usually discussed in person with parents, but professionals are often reliant on receipt of a written report. In the present study this involved a specialist teacher. Her view that *'schools don't really pay attention to the diagnostic report'* perhaps reflects the focus of her professional role helping teachers to consider how ASD impacts for a child in their class and school context.

A study by Barrett (2006) suggested that using autobiographical accounts in training helped teaching professionals to develop understanding, empathy and to lead to practical teaching and learning outcomes. The present study sought to question whether this might happen with a diagnostic report that provides a personalised narrative.

The teacher participant was a specialist teacher rather than Jack's class teacher or other educational professional in his school. The inclusion of Jack's autobiographical account was significant for her personally and professionally. As a parent of two children with ASD the inclusion of child views were seen as 'powerful', but rare.

As a professional it raised a number of organisational and systemic issues unique to the locality context, namely the involvement of 'other' specialist teachers in the diagnostic assessment process unlike the Autism Team who were constrained by service criteria that prohibited their working with a child and their family until they received a formal diagnosis.

At the heart of professional practice are core values and personal commitment that are inextricably linked to professional knowledge and understanding, skills and abilities and professional actions (General Teaching Council for Scotland,

2012). The teacher's commentary highlighted the continual challenges of the requirements of her professional role within a changing organisational and political climate of increasing demands and reduced resources.

Central was her core belief in the importance of effective working partnership and developing positive relationships with the children, their parents and other professionals. The way in which she approached her work was collaborative and empathic; essential prerequisites to achieving positive outcomes for the child and their family. The potential overlap of professional roles between the researcher and herself evident within this approach was raised, and appeared to be interpreted as a cause for concern in the context of local authority review.

Research question 5: What can be learnt from the participants in seeking to improve clinical practice and understanding through their applied knowledge and personal insights?

The researcher reflected on the key points that emerged from analysis of the views of the participants: child, parent and teacher, before considering the potential impact on professional practice.

Jack provided clear evidence that it is possible for a young child with autism to participate in their diagnostic assessment to provide their account of their experiences. His participation influenced adult decisions about how best to support him through a return to mainstream school. The diagnostic report included Jack's views and experiences and while these impacted on the specialist teacher supporting him while he was educated at home, it is unclear whether this would influence school staff in any way.

It raises the question of how a child with ASD becomes defined by their diagnosis. Essentially this occurs through their experiences at school and at home and the challenges they experience as observed and interpreted by others. In considering Jack's presentation there was clear evidence of the triad

of impairments which met ICD-10 diagnostic criteria, but by reframing his behaviour and considering it in the context of the things which he identified as important, an individualised profile of this young boy seeks to promote a different understanding. Any problems with learning or behaviour might then be considered as the outcome of the interaction of the learning process and Jack, rather than being solely attributed to his diagnosis.

Jack's sense of self and personal identity is naturally evolving through his experiences and relationships. Seeking an understanding of Jack's views is an on-going process; it requires professionals and educational settings to promote a context in which his views can be heard. Essentially it is the form that listening takes that depends on the theoretical and methodological approaches that professionals adopt.

4.2 The potential impact on professional practice

The present study shows that including the child's perspective has the potential to add a different dimension where their needs and interests are more likely to be advanced. This differs from the use of standardised assessment, questionnaires and self-report measures in that the child identifies aspects of their lives that they consider are important. It is important to include a personal perspective and may help to support person-centred planning (DfE, 2014).

By including open-ended discussion of personal views and experiences, the assessment process supports better communication with the child, their parents and other professionals and can provide practical advice linked to the child's key developmental differences. The impact of autobiographical accounts on teaching staff is significant (Barrett, 2006), and compares with the often 'disabling' effects of a diagnostic label that perpetuates negative or stereotyped attitudes (Hodge, 2005). No single approach is suitable for everyone and it is how children's views are elicited is dependent almost entirely on the epistemological approach of practitioners. In practice there is a multiplicity of approaches and the promotion of theoretical reflection by clinicians, may

support the use of a practice model that includes a firm understanding of what autism might mean for the individual child and their family. With emerging literature about the qualitative aspects of service provision and the impact on outcomes it is an area that is of increasing importance.

The present study leads to suggesting a practice-model that highlights the central role of the clinician's approach to considering the interrelationship of the child's perspective, within-child factors, and parent and professional views (Figure 2).

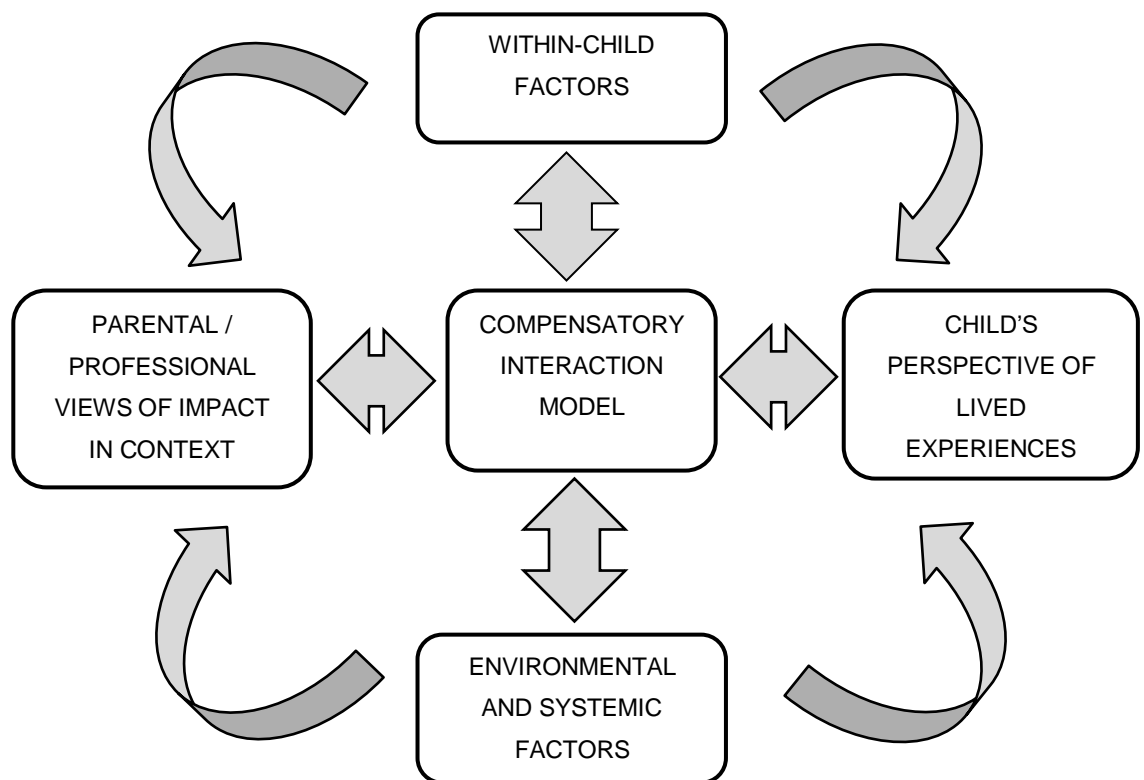


Figure 2 - Compensatory-interaction model and diagnostic assessment of ASD

Essentially it seeks to encourage practitioners to reflect on their epistemological position and theoretical models which influence their work. Methodology is important and narrative ways of structuring conversations to develop 'thick' rather than 'thin' descriptions (Gilling, 2012) are informing a small but growing body of literature that incorporates the perspectives of children with autism about their lived experiences (Kirby et al., 2015).

4.3 Key limitations and strengths of the present study

The aim of the present study was to explore a young child's participation in their diagnostic assessment, together with the views of their mother on her experience of participatory assessment and the views of a teacher on receiving the assessment report.

In seeking to interpret individual narratives IPA proved to be a useful framework for analysis, but the present study made no comparison with other methods that may also prove useful. It identified considerable challenges working with a young child that led the researcher to use a range of planned adaptations to enable a narrative of the child's views and experiences to develop. Although the study gives no indication of how children of a similar age (or older) with different verbal aptitude might share their experiences, generalisability was not an aim; studies that lack generalisability can still be included in 'the collective process of knowledge accumulation' (Flyuberg, 2006, page 10).

It is of note that the views of Jack's mother mirror and complement notable trends in recent literature, particularly in terms of the Parent-Professional-Partnership and the quality of communication. The findings may have some internal validity within the context of the specific service in which the research was undertaken with regard to parent's and teacher's views.

4.4 Implications for future research

Two key areas for future research emerged from the findings of the present study:

1. Further research into the use of IPA to analyse the views and experiences of children during their diagnostic assessment for ASD. This could include children of different ages and abilities, and consideration of the individual and contextual factors that restrict or enable the child to communicate their views effectively.
2. There are many functions placed on the diagnostic report of a child with ASD. Further research into the impact of, and use made by parents and teachers of a child's diagnostic report might include a comparative analysis of different styles of reporting.

5. Concluding comments

Reliance on standardized tests to determine deficits and map them onto ICD-10 or DSM-5 criteria are considered important components of an autism assessment (NICE, 2011), but sole reliance on these procedures results in critical gaps in our understanding of the child. Legislation and diagnostic practice guidelines for ASD now promote professional practice that seeks to enable the participation of children and young people and to elicit their views on their experiences and support person-centred planning.

Interweaving qualitative enquiry and professional practice, this exploratory study approached diagnostic assessment from a social constructionist perspective. It informed consideration of a relational practice model, and offers new insight into what might be achieved through the use of IPA as an interpretative framework in the context of a child's diagnostic assessment. By considering the child's dialogue and that of their parents within a model of

collective thinking, a different understanding and relationship can be established which engenders a more collaborative partnership approach.

Adopting a holistic and less deficit-led approach requires professionals to relinquish power by resisting the 'temptations of certainty' associated with diagnostic practices (Swain et al., 2000). This may facilitate criticism of objective and unbiased observations and enable professionals to reflect on the terms constructed around individuals. It is now recognised that the conduct of diagnostic assessment is important. Recent research is beginning to explore the qualitative aspects of the diagnostic process, with recognition that how the process is conducted is a major factor in the provision of cost-effective, responsive services that work for children and their families (Abbott et al., 2013). It is possible to operate a diagnostic practice model that preserves ethical practice, is child-centred, and still operates effectively and efficiently.

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Appendix B

Stages of Data Analysis (Child)

Table 11 - Stage 1 of initial transcript analysis (child)

Potential themes	Line numbers and participant transcript or non-verbal behaviours <i>(italics)</i>	Interpretation and initial notes
Sensory experiences: <ul style="list-style-type: none"> • Movement • Noise • Touch • Taste 	L2: <i>jumping</i> , laughing and singing NaNaNana, yep. L4: Nananananan (singing). L7: <i>Dancing and jumping</i> L21: Nanananana (singing and dancing) L118: <i>(Leaning across the table with his feet out behind him)</i> . L158: Clicking noises. L160: I just like the sound of the clicks L163: Nnnnnnnneeee Nnnn <i>(dancing up and down)</i> L284: Sometimes I do try to lick electric things. L287: <i>Jumping</i>	Seeking additional movement and noise. Occurred at beginning during transition from reception to room, and at the end of session. Seeking additional pressure by lying prone with tummy pressed onto table: occurred when talking about his previous school: bullying experience and missing peers. Sensory seeking: self-awareness. Reported (potentially dangerous) behaviour

Potential themes	Line numbers and participant transcript or non-verbal behaviours (<i>italics</i>)	Interpretation and initial notes
Sibling relationship	<p>L11: No it used to be my brothers but it doesn't fit him anymore.</p> <p>L45: We got an Amazon delivery and one of them was for me and Harry.</p> <p>L53: Yes but they're different parts, and it came from Amazon and that delivery was for me and Harry</p> <p>L91: Harry doesn't like playing with me.</p> <p>L239: When Harry keeps bugging me</p> <p>L251: This is fun. I feel a bit angry when Harry doesn't let me play with him.</p>	<p>Using his brother's clothes.</p> <p>Sharing items</p> <p>Sharing / Repetition (2)</p> <p>Lack of opportunity for social play with brother: Feeling angry</p> <p>Angry / Repetition (2)</p> <p>Interpreted as link with anxiety, when activities not led by Jack.</p>
Being someone / something else	<p>L19: Because it looks like, did you know it's actually of Luke Skywalker.</p> <p>L38: I changed my three names to four, my last name is unicorn</p>	<p>Alignment with favoured character</p> <p>Becoming something / someone else. Importance of 'refuge' in another persona.</p>
Personal identity	<p>L35: <i>Writing his name in full</i></p> <p>L38: I changed my three names to four, my last name is unicorn</p>	<p>Adding his ideas. Influencing others.</p>
Parents	<p>L41: When mummy and daddy got me my name was Jack, that's my mummy and daddy named me Jack.</p> <p>L43: Daddy told me.</p> <p>L151: And we go to nanny's</p>	<p>Identifying with and being part of a family</p> <p>Parents giving him his name.</p> <p>Extended family</p> <p>Support and security</p>

Potential themes	Line numbers and participant transcript or non-verbal behaviours <i>(italics)</i>	Interpretation and initial notes
Favourite activities at home.	<p>L47/8: Pattern blocks, big cars and choo choo train, but you have to guess which the colour is...</p> <p>L57: Going on the Wii Nintendo</p> <p>L59: And Angry Birds Trilogy and you grab it, and a (unclear).</p> <p>L61: We've got Angry Birds, I mean Angry Birds Trilogy, and we've got Raving Rabbits TV party and Raving Rabbits go home.</p> <p>L69: Yep, Yep, Yep, Yep, Going on my Samsung Galaxy Tab 2</p> <p>L143: Yes bite size learning and learning ladders.</p>	<p>Puzzles</p> <p>Computer games</p> <p>I.T. for learning : managing style and rate of learning</p> <p>Preferred learning style</p>
Methods of non-verbal communication.	<p>L72: I'll draw the Samsung Galaxy Tab 2 (spends a minute drawing)</p> <p>L76: Mmmm, this is an arrow that makes it go back to the game menu (continues drawing in some detail).</p> <p>L78: Continues drawing.</p> <p>L84: Silence as Jack keeps drawing.</p>	<p>Sharing information by drawing not speaking.</p> <p>Controlling the means of communication – the subject is very important to Jack.</p>
	<p>L13: They're moshy monsters from</p> <p>L17: Look at all of them, Lego and star wars. This jacket has a hood.</p> <p>L19: Because it looks like did you know it's actually of Luke Skywalker.</p>	<p>Sharing information by showing.</p> <p>Enjoying sharing information with adult.</p>
Social interaction with adults	<p>L78: continues drawing</p> <p>L80: No No not yet</p> <p>L82: It's a (unclear).</p> <p>L84: Silence as Jack keeps drawing</p>	<p>Sense of humour: making adult wait and guess what he is drawing.</p> <p>Taking on a different role / control</p>

Potential themes	Line numbers and participant transcript or non-verbal behaviours <i>(italics)</i>	Interpretation and initial notes
Emotional literacy	L93: Sad L99: That makes me sad L279: Yes when I'm not playing	Emotional literacy Self- reference
Peer relationships	L11: No it used to be my brothers but it doesn't fit him anymore. L97: I don't see my friends at school. L106: I was getting bullied by Harry. L117: Yes for both classes. L126: Because they had friends there. L219: Because he's in the corner and wanted to play with his friends.	Directly links the experience of not seeing his friends to the negative experience of bullying.
Seeking support	L106: I was getting bullied by Harry, write it down. L100/1: Jack hands researcher the pencil.	Using an adult as a scribe. This is very important for Jack.
Imaginary friends	L19: Because it looks like, did you know it's actually of Luke Skywalker. L130: Holograms of my friends. L162: Holograms could play together; there could be a hologram of me and my friends. L167: My dream is to be a fire-engine. L 281: No friends	Creating imaginary friends. Jack's solution to managing relationships.
	L141: Maths and science and some of the (unclear) L143: Yes bite size learning and learning ladders. L150: It's good to go different places	Academics: subject preference and learning style. Active learning

Potential themes	Line numbers and participant transcript or non-verbal behaviours <i>(italics)</i>	Interpretation and initial notes
Missing experiences:	L110: Play tag. L122: The sand and the water. L126: Because they had friends there. L141: Maths and science and some of the (unclear).	Positive aspects of learning at school. Proximity of peers Preferred subjects
	L188: He look sad –eggy (laughs) L193: Light bulb	Literal interpretation Visual humour
	L195: Religious L197: Religious is a funny word. 199: I have no idea	Good expressive vocabulary used with some awareness of not understanding.
Negative experience of non-attendance at school	L97: I don't see my friends at school. L102: But I can't see them	Peer relationships – Loss of opportunity for social interaction by non-attendance at school.
Negative experience of attending school	L104: No! No!	Bullying / distress – significant impact on emotional well-being.

Potential themes	Line numbers and participant transcript or non-verbal behaviours <i>(italics)</i>	Interpretation and initial notes
Preferred activities / locations at school.	<p>L110: Play tag</p> <p>L112: (Laughs) yes the rainbow playground and the caterpillar playground.</p> <p>L114/5 It was a rainbow and had a shelter when it was raining, raining. It was a ginormous umbrella sitting in the ground. It was metal and really big and it could go in and out.</p> <p>L117: Yes for both classes</p> <p>L122: The sand and the water.</p>	<p>Preferred activities and locations: outside spaces and opportunities for movement and practical activities.</p> <p>Reference to large group and presence of other children.</p> <p>Visual event memory</p>

Table 12 - Overview of emergent themes and their occurrence in the transcript (child)

Emergent themes	Occurrence within the transcript by line number
Sibling relationship	11,45,53,91,239,251,253
Parents	41,43
Extended family	151,153
Friends at school	97,126,281
Imaginary friends	130,132,134,162,219
Personal achievements	153,274,275
Bullying	106
Loss of opportunity	97
Alternative learning experiences	47-8, 50-1, 142, 147
Learning style	101,143
Favoured activities/ special interests	57,59,61
Alternative means of communication	72-86
Sensory seeking behaviours	2,4,7,21,118,158,287
Showing things to adult	15,17
Emotional literacy	26,93,99,149,190,203,205,215,247,277
Change of school / avoidance of bully	256
Not seeing friends at school	97,102
Preferred areas of learning	141
Personal achievement	153,274,275.

Table 13 - Linking emergent themes, subordinate themes and superordinate themes (child)

Emergent themes	Subordinate themes	Superordinate themes
Sibling relationship	Immediate family Extended family Peers Imaginary friends	Relationships
Parents		
Nanny		
Friends at school		
Imaginary friends / Holograms		
Bullying	Bullying Loss of opportunities Different learning experiences Specific interests Personal achievements Sensory experiences	Personal Experiences
Not seeing friends at school		
Unable to play with others		
Boredom		
Changing schools		
Alternative learning – I.T. and visits		
Sensory needs		
Containment of difficult emotions		
Sharing	Family member Sibling Skills /knowledge Communication style Influencing others	Personal Identity
Verbal or written communications		
Avoidance of bully		
Learning style		
Preferred areas of learning		
Personal achievements		

Stages of Analysis (Parent)

Table 14 - Stage 1 of initial transcript analysis (parent)

Potential themes	Line numbers and participant transcript	Interpretation and initial notes
Educational placement	4	Parent's priority concern and a recurring theme through assessment. Brought EHC paperwork and school information to interview but not diagnostic report – Not important?
Detailed written information	20, 21, 22	Emphasis on detailed information that reflects personal qualities and positive skills. Importance of information in written format.
Expert model	24, 28, 33, 44, 46, 213, 200	Not helpful, didn't add anything, 'rubber stamping', repetitive, emphasis on negative aspects and meeting criteria, inequality, being told – frustration, not listened to and/ or believed.
Holistic perspective	27, 36	Encompassing the whole child, and recognising her child from report.
Validation	45	Important information was not written down – not being believed
Abandonment	44	Where do I go from here?
Emotional response	51,56,60	Disappointment, shock, stressful, emotionally draining.
Seeking information	51, 209	Developing knowledge and skills, networking, finding my own way, seeking support. Understanding the jargon. Knowledge is power – equalising relationship with professionals

Potential themes	Line numbers and participant transcript	Interpretation and initial notes
Length of appointments	60	Shorter but more frequent provided opportunity for reflection, asking questions, greater flexibility for family. Importance of not being overwhelmed / easier to deal with and cope with. Developing relationship, emotional containment.
Individualised assessment; providing information	25, 105	Being treated as an individual, an overall picture, more encompassing; tell me something I don't know.
Professional roles	122	Seeking support, understanding how services work. Getting to know professionals that will help child and parents.
Professional jargon	208, 239	Learning the lingo – being able to converse with professionals in the same language. Being validated.
Multiple needs	155, 158	Complexity, multiple services / teams. Need for co-ordination; helping parent to understand how it all fits together.

Table 15 - The overview of emergent themes and their occurrence within the transcript (parent)

Emergent themes	Occurrence within the transcript by line number
Preferred approach	49,60,200
Emotional responses	51,56,60
Comparative experience	24,25,
Seeking support	50,54,237
Seeking knowledge and information	51, 209
Personal demands	47,158/9
Validation	45
Listened to (not being told)	213
Opportunity to reflect	50
Asking questions when necessary	51
Parental knowledge	44/5
Individualised practice	105
Personalised information	36
Links with different support services	44
Pressure on resources	46
Educational placement	4
Style of report	20,22,24-6,27-9,35,125
Diagnostic criteria	25,33
Clinicians approach	43
Missing essential information	28
Assessment over time	38
Professional jargon	208
Parents as partners	219

Table 16 - Linking emergent themes, subordinate themes and superordinate themes (parent)

Emergent themes	Subordinate themes	Superordinate themes
Preferred approach	Comparative experience Adjustment to diagnosis Developing knowledge and support network. Solution focused	Experience of assessment
Emotional responses		
Comparative experience		
Professional jargon		
Seeking support		
Seeking knowledge and information		
Personal demands		
Participation		
Validation	Participatory practice Shared understanding Relationship with clinician/other professionals. Knowledge of support services	Model of assessment
Clinician's approach		
Listened to		
Planned approach		
Opportunity to reflect		
Asking questions when necessary		
Knowledge of services		
Individualised practice		
Personalised information		
Family impact	Applied knowledge of child and ASD Utilising support Knowledge of support services. Resource limitations	Translating theory into practice
Links with different support services		
Pressure on resources		
Parental responsibility		
Educational placement		

Stages of Data (Teacher)

Table 17 - Stage 1 of initial transcript analysis (teacher)

Potential themes	Line numbers and participant transcript or non-verbal behaviours (<i>italics</i>)	Interpretation and initial notes
Professional role / boundaries	122, 132	Unique professional role of researcher working for local authority and NHS. Potentially threatening role - ' <i>you've got the plan there, which is what we're writing</i> '
Detailed information/ holistic view	126	Potential to reduce repetition
Informing professional practice	98	Provides ' <i>loads of information</i> '. Helped to identify appropriate resources.
Impact of child's voice	80, 89, 94, 96	Personal reflection / emotive response ' <i>loved what he said</i> ' ' <i>pertinent</i> ', ' <i>powerful</i> '. Regards child's views as essential. A real sense of who he is. Comparative explanation – usually only get parent and clinicians views.

Table 18 - Overview of emergent themes and their occurrence in the transcript (teacher)

Emergent themes	Occurrence within the transcript by line number
Holistic view	103, 126,163
Informing practice	93, 98
Professional boundaries	122, 132
Professional role in diagnostic assessments	145
Impact of child's voice	96
Impact of diagnostic report / school	166
Personalised account	89, 102
Quality of information / structure	90
Resource constraints	164/5,175
Increasing demands	173
Collaborative working	143,147
Doing things differently	134, 140, 143
Crisis response in school	167
Needs-based plan / ASD specific	170,171
Service criteria	92
Professional jargon	223
Personal beliefs	80, 94,97,99,116,165,246
Professional overload	135,165
Organisational/ systemic issues	134,146

Table 19 - Linking emergent themes subordinate themes and superordinate themes (teacher)

Emergent themes	Sub themes	Superordinate themes
Holistic view	Reporting style/structure Participatory practice Impact on teacher	Model of assessment
Participation of parent		
Quality of information		
Child's views / personal account		
Written information		
Professional jargon		
Service criteria	Constraints and challenges	Service criteria
Resource constraints		
Increasing demands		
Crisis response		
Professional role		
Personal beliefs	Influencing service delivery and practice. Professional demands	Professional practice
Informing practice		
Professional overload		
Doing things differently		
Professional boundaries		
Needs-based plans		

PAPER 3: CRITICAL APPRAISAL

Overview

There is an increasing emphasis placed on person-centred approaches that consider individual strengths, preferences and the views of children alongside their difficulties and needs, seeking to recognise individual difference and link professional advice more closely to the individual. Yet the process of diagnostic assessment for autism spectrum disorder (ASD) is largely impairment based using diagnostic tests that assert to describe specific phenomena objectively. With a focus on description of within-child factors and the presentation of information as 'absolute truths', there is a comparative lack of child voice within professional practice and reports. With the increasing emergence of autobiographical accounts from children and young people with ASD that provide interpretation of individual experiences, I questioned how exploring the lived experience of a young child through a phenomenological perspective during their diagnostic assessment might provide a qualitatively different picture of them. I also questioned how the participatory approach that sought to facilitate gaining a child's views would impact on their parent's experience of the assessment process, and on educational professionals.

The aim of this paper is to present a reflexive account of the experience of conducting the research study and the personal and professional learning that occurred. Derived from my research notes made during the process, including observations, issues, questions and decisions, I consider:

1. The choice of project
2. Conducting the research
3. Personal learning and the impact on professional practice
4. Critiques and limitation of the research
5. Future research

1. Choice of Project

1.1 Professional context

Although the core function of the Educational Psychologist (EP) remains the same recent years have seen increasingly stringent working environments within Local Authorities and wide-spread changes to public service delivery (Al-khatib & Norris, 2015). There has been an increasing diversification of EP services and EPs working in different contexts including private and public health services.

Diagnoses of autism spectrum disorder (ASD) continue to be a focus of EP's work often as members of multidisciplinary teams (Gilling, 2012), and I have undertaken this role in two different local authorities and currently in the National Health Service (NHS). It is interesting and helpful for me to recognise that as other EPs move into various health services that they too find 'foreign discourses', which cause them to 'question the ontological basis on which practitioner psychologists operate' (Al-khatib & Norris, 2015, page 17). My experience of the different structure of diagnostic teams and processes in different contexts were significant factors in my choice of research topic.

Professionals aligned with the medical model of disability often assert that a diagnosis of ASD leads to 'a clearer understanding of the problem', while advocates of the social model of disability cite concern that a diagnosis serves to 'pathologise the child' resulting in stigmatisation as the diagnostic label alters how other people treat the individual (Barrett, 2006; Russell & Norwich, 2012). These opinions are not exclusively restricted to specific disciplines and work settings, although discipline and institutional orientation are significant and influential factors (Bartolo, 2002). In current practice in the UK diagnosis of an ASD is often a requirement for access to services. The potential negative impact of labelling on the child, their parents and education professionals that

support them are often underestimated. They are rarely voiced in the context of a service and team whose primary function is to 'diagnose'.

Recent research and practice is gradually recognising the importance of the process of diagnostic assessment, and the involvement of the child and their parents is recognised as significant in achieving positive outcomes (Abbott et al., 2013). In a process dominated by systematic pathways and standardised assessments that provide limited perspectives and 'thin' problem-saturated descriptions of a child, I questioned how greater consideration could be given to the participation of the child and eliciting their views. I wanted to focus on finding out 'what life is like' for a young child with autism, rather than focus only on the 'triad' of deficits (Wing, 1993).

An account by Billington et al. (2000) co-authored with the parents of a child with autism encouraged professionals to reflect on their first-principles and consider how these influence their work. Similarly Goodley's paper (2012) encouraged researchers and practitioners to: 'stand back from the current discursive context to question how we understand the disabled children with whom we work' (page 55). I agree this is important. I have found myself increasingly concerned by certain narratives that are presented as absolute truth and certainty that could have a potentially disabling effect on the child, their family and other professionals that provide support (Hodge, 2006). For example: descriptions of challenging behaviours in a clinical context with the assumption of a causal link to the requirement for highly specialist intervention and educational provision.

Contextual Issues

In the national context of legislative requirements that provide impetus to involve children more in their assessment and care, the exploratory nature of the research study sought to be informative and encourage debate and dialogue in the context of the locality service in which it was undertaken,

specifically regarding the participation of children and young people in their diagnostic assessment. It was also envisaged that it may help to inform further areas of research, such as service user feedback from children and young people.

Cognisant that the research was being undertaken during a period of organisational review that was likely to result in changes to the structure of the service, the exploratory nature of the study was essentially a pragmatic choice. The study needed to be small scale and manageable with no additional time or resources; a specific requirement was that the research process made no demands on any health service colleagues. Consequently I narrowed the focus of my research to exploring the use of an autobiographical account with a young child. In particular I was interested to know more about their experiences and the perceived impact of their involvement in their diagnostic assessment on their parent's and teacher's views.

Professional Role

At the time of starting my research study I was working only with children under the age of six years. A service level agreement (SLA) between the Local Authority (LA) and the National Health Service for 20% of my full time post was in place. This sought to provide psychological advice for those children having a statutory assessment of their special educational needs (SEN) also undergoing diagnostic assessment for social communication difficulties / ASD. The service underwent reorganisation in 2014/15 and my professional role changed. The diagnostic service was reorganised to one team for children and young people aged 0-19 years. Funding from the LA for the SLA was withdrawn, and once again I worked across the full 0-18 year age range.

1.2 Choice of methodology and design

On investigating the current literature on the views and experiences of children with ASD, it was evident that this was very limited compared to the extensive amount of research literature on the aetiology of ASD and interventions. Despite the increasing emphasis on children's 'voice' in health services, there is limited evidence to support this (Moore & Kirk, 2010; Cavet & Sloper, 2004).

The nature of my exploratory research question dictated the choice of qualitative methodology. I did not seek to generalise but to provide some insight into the life of one young boy with autism. My lack of recent experience of undertaking qualitative research was a significant concern for me. I took some time to consider issues relating to epistemology and the relationship with research methods and my role as a practitioner. I was drawn towards the critical realist perspective which provides a reality that exists independently of human observers but which is multi-layered and validates individual experience. Thereby recognising that individual experiences are not reduced to a diagnostic label and personal accounts of experiences could meaningfully reflect individual's internal worlds.

I explored different qualitative methods and from a literature search of studies that sought the views of children and young people with ASD I reviewed eleven studies which used either Thematic Analysis (TA) (Brewster & Coleyshaw 2011; McLaughlin & Rafferty, 2014; Ozsivadjian et al., 2012; Preece & Jordan, 2010; Winstone et al., 2014) or Interpretative Phenomenological Analysis (IPA) (Dann, 2011; Hill, 2014; Humphrey & Lewis, 2008; Huws & Jones, 2008; MacLeod et al., 2013; Tobias, 2009). I considered the similarities and differences between TA and IPA as the reported outcomes in studies using these approaches can appear quite similar. Importantly IPA is a methodology or theoretically informed framework of how the research is done, whereas TA is simply a method for collecting and analysing data. The ontological and epistemological underpinnings of IPA research are critical realism and social

constructivism, with a focus on questions about individual experiences and perspectives. IPA is usually conducted with single or a small number of participants. In contrast TA can be used across the epistemological and ontological spectrum and is often used with larger numbers of participants, as it does not share IPAs ideographic focus.

IPA emerged from the field of health psychology two decades ago and is increasingly used in a variety of different contexts seeking to understand individual perspectives. I found that IPA had recently been used with adolescents and children as young as seven years of age (Gudgeon & Kirk, 2015; Back et al., 2011; Griffiths et al., 2011). I recognised that there may be specific challenges for me in working with a younger child, as IPA usually starts with a key research question that is likely to elicit strong emotions and the requirement that participants are able to articulate and reflect on their experiences during the interview process. These were both questionable points in my proposed study and I embarked upon the research with the uncertainty of whether the child's day to day experiences would elicit any emotional response, and whether the methods used would enable the child to articulate their experiences. I ran the potential risk of having no data to analyse. Despite this double uncertainty I wanted to gain a better understanding of IPA and whether it was a suitable approach to use to gain the views of a young child in the context of their diagnostic assessment.

Having read the literature on this approach I was acutely aware of the potential pitfalls and criticisms of poorly constructed studies, with analysis that can be too descriptive rather than analytical and interpretative (Hefferon & Gil-Rodriguez, 2011). I felt that the process would encourage personal reflection and consideration of an approach with which I was not familiar, thereby adding to my experience in many different ways and potentially impacting on my professional practice and that of others. Some degree of uncertainty was contained by the fact that IPA allows some degree of adaptation to context and suggests that additional data collection from a variety of sources be used in order to contextualise the data from the interviews.

2. Conducting the Research

2.1 Collecting and analysing the data

I was both reliant on and limited by my professional role within the locality service; being a researcher-practitioner in a team that historically does not have an active research culture was a significant feature of my research study. As the study involved a young child within the health service, ethical approval was required from multiple organisations and was more time consuming than I had anticipated.

The initial selection of a child participant was based on information at the point of referral to the locality service and the application of clearly defined inclusion criteria. Once identified, the child, given the pseudonym of Jack was allocated to me as the case lead for his diagnostic assessment. The family's previous experience of diagnostic assessment for ASD was shared with me during my first meeting with Jack and his mother. I initially thought that this previous experience of a different diagnostic assessment process might be problematic, particularly in light of the 'politics' around the service review and organisation. In reality it was helpful in providing a baseline for Jack's mother in reflecting and evaluating her experiences of diagnostic assessments for both her children. Often research studies report on parental experiences but parents have little to compare their experience to. Jack's mother made frequent comparisons between her initial and current experience of receiving a diagnosis for her two children.

Gaining Assent

I was particularly concerned about gaining assent and facilitating participation, and acutely aware of the need to be attuned to positive and doubtful indicators of assent for such a young child. I was aware that Jack's responses might be overly acquiescent or ambivalent. I tried to ensure that Jack was always aware

of what our meeting would involve in order to give him the opportunity for informed assent. On the two occasions that I sought assent I received different verbal responses. On the first occasion that I asked Jack why he came to the centre to see me, he said 'to have fun and to have a talk', and on the second 'I don't know'. Asked if he was happy to talk about his views and to 'place a tick on the paper with his pencil' if he was always resulted in him doing so. It was unclear whether Jack gave informed assent, but observations of his approach to discussion and his behaviour, together with his mother's confirmation that she felt he was happy to continue were used as essential secondary indicators of assent.

Facilitating Participation

A number of factors based on my review of the literature, professional experience and specifically my first-hand knowledge of Jack were important in facilitating his participation; particularly the timing and location of the interviews and ensuring that environmental distractions were kept to a minimum. I faced uncertainty as to the amount of structure and prompts Jack might require. A flexible approach was necessarily adopted and additional time, patience and careful consideration of potential adaptations and situations that might occur were required. This included potential changes in Jack's behaviour and levels of anxiety and distress. In practice it was very difficult to plan for a situation where multiple factors impact.

The two interview sessions took place in a small low-distraction room with which Jack was quite familiar. Two small toys: a fire-engine and a specific toy car which he had enjoyed playing with on previous occasions were placed on the table, with paper and pencils for drawing. The second interview included these items and some small line drawings showing different emotions with which Jack and I undertook an activity to consider what emotion he thought they showed when he had felt like that too. Findings from my review of recent research literature seeking the views of children with ASD, suggested some

evidence that activity based interviews and a shared point of reference between the interviewer and interviewee may result in more effective communication exchange (Winstone et al., 2014). I had anticipated that the first session with less structure would yield less data and the second interview with a more structured session would yield more data. It was the other way round.

Jack was a very active young boy and engaged in significant sensory seeking behaviours. On reflection I felt that the first session with less structure enabled me to be more spontaneous and creative in response to Jack's behaviours. The first session was more child-led in contrast to the structured second session where the topics were essentially adult-led and required Jack to have greater imaginative flexibility. Having a semi-structured but planned agenda and visual resources potentially distracted us both from the main purpose of the interview.

The timing and positioning of the interview session within Jack's assessment was important. By the time interviews took place I knew Jack well and had developed a positive relationship with him. He had already chosen to share some important information in a previous meeting prompted by a question in a standardised assessment tool. It is possible that he felt able to share other information having already done so and having observed his mother do likewise. I wondered whether Jack placed me in an authoritative 'teacher role' in his wish to see justice done about his experience of bullying.

It was very important to be sensitive to the context throughout and appreciate the interactional nature of data collection within the interview situation. This was difficult and I was mindful that the interpretative element was influenced by my professional and personal experiences which may have meant the prioritisation of certain themes, e.g. bullying, social relationships, exclusion from school and home tuition. This became more evident after engaging with the text, through detailed and systematic analysis and from considering psychological theory.

Transcription and Analysis

I personally transcribed the data which was helpful as I was already familiar with Jack's voice and the content of the obtained data. The analytical process was interesting and challenging, but far more time consuming than anticipated. My initial concerns that I would have 'no data' were unfounded, as emergent themes became apparent quite quickly. By continued reflection and by returning to the original script I tried to ensure the themes were well grounded and the analytical process was transparent and auditable. Even while redrafting and editing the research paper, I was struck by potentially different connections between themes and made some changes at quite a late stage in the write-up.

I also considered how I was situated socially and emotionally in relation to the respondents, as the interplay between personal biographies and multiple social locations needed to be considered during analysis (Mauther & Doucet, 2003). Jack's mother and the specialist teacher were both parents of two boys with ASD. They shared the experience of having been through the diagnostic assessment process for both their children and both held professional roles within community support services. Both had commented and were acutely aware of the emotional aspects of their experiences and the impact on their respective families. This helped to secure their working relationship on the grounds of shared experiences. My personal experiences differed and arguably I might never fully understand their experiences of being a parent of two children with ASD. Our professional roles had inherent similarities and we appeared to hold similar values in the way that we approached our work, placing those individuals that we aim to support as a central focus of our professional approach. Both Jack's mother and teacher made reference to increasing professional demands and limited resources and we were all working in services undergoing review and facing potential change.

Write-up

The write-up phase of the research process was a cyclical process of doubt and anxiety. This was compounded by the challenge of working full time in the context of impending organisational change, uncertainty of my professional role and job security, and serious health issues in my immediate family. Gradual recognition of the personal need to formally suspend my studies for six months was difficult and in practice spanned several months beyond this time frame. There was a considerable gap between obtaining the data, beginning detailed analysis and writing the first draft. The process of recommencing was daunting and it took considerable time and effort to reengage with the data and the process of undertaking a research study.

However the break ultimately prompted me to reflect and to rationalise my approach to studying in the context of multiple demands on my time. The 'distance' from data collection enabled me to critique the research and identify limitations more readily. The process of repeating literature searches, rewriting earlier sections of the literature review and completing the write-up of the research study enabled me to identify further links and finally gain greater clarity of purpose. The process of revisiting the literature was helpful to ground the study firmly within the body of current research.

3. Personal learning and impact on professional practice

The process of undertaking exploratory research was interesting and at times an arduous and very uncomfortable experience. The task of trying to integrate a research role within my changing work context was extremely difficult and I underestimated the impact this had on me personally. The experience of being a post-graduate distance student was also very different from my post graduate educational experiences and professional training. Reflection and supervision helped my attempts to try and normalise the impact of the research process. One unexpected outcome has been my realisation that I have the capacity to

tolerate the messiness of using a qualitative approach, and to manage a significant unplanned break within the process.

The essential literature review and background reading served to firmly confirm my critical realist / social constructivist position and helped me to justify my perspective clearly in the context of recent research. The access to and availability of literature through the use of information technology, is very different from my experience during my professional training over two decades ago. The tendency to become engrossed in a linked but not highly relevant piece of research led to the realisation that several hours can pass in this pursuit. I essentially had to become far more disciplined but I see this as an integral part of the process, and while I have had to curtail this practice it enhanced my knowledge and improved my analytical skills. I have also had to improve my IT skills, which has similarly been the source of much frustration and very time consuming.

Perhaps most significant for me personally has been the process of reflecting on the systemic and organisational factors that impact on my work. There are strong cultural differences between the LA and the NHS that impact on the role of an EP within them. With the opportunity to reflect I recognise the personal and professional impact on me of the change of my working context to the NHS. Despite maintaining some formal links with the local EP service, this meant the loss of being part of an EP service with the opportunity to meet regularly within a context of some shared understanding. It has further highlighted for me the importance of professional groups, peer supervision and the complexities of working within multidisciplinary teams.

I have always appreciated the importance of good quality supervision throughout my professional career. It is without doubt an essential component of the research process. I would not have continued the research process after the period of suspension without the personal and professional support I received.

A major consideration for me in recent years has been how to practise psychology in a way that fits with my epistemological position yet delivers what is expected from my job role. I have, as a result of my recent research moved to increasingly using narrative approaches to engage in conversations with others: children, parents and other professionals, seeking to listen to their lived experiences and preferred stories. In doing so I have been able to once more adopt a more measured and reflective approach to my work. Critically the process reaffirms for me the importance of how an assessment is approached rather than what is done. I allow specific time to reflect and consider the next step in the process with an individual and their family. This is not withstanding commissioning and service requirements but I believe that an individualised approach produces better outcomes for the child and family and therefore the service.

I currently work with children and young people across the 0-18 year age range. Applying the same narrative approach I seek to facilitate the involvement of children and young people of various ages. This has resulted in one young person co-authoring their diagnostic report. This was a significant departure from usual practice, and the impact of this on the adults supporting this young person was profound and facilitated positive outcomes. I have specifically considered the use of IPA within a clinical context. While the initial phase of analysis and more detailed interpretative elements take considerable time they may be practical in certain circumstances with certain children and young people. For example: young verbal children such as Jack or older adolescents who may be reluctant to engage with formalised assessments but are able and willing to share their experiences in a narrative way.

Ultimately the process of undertaking the research study reaffirmed my epistemological position and my views about the importance of qualitative research. The literature review undertaken for my research study helped to inform further research within the locality service, involving service user feedback. This has included trialling the use of three different methods for children to give their views and experiences of the assessment service. Initial

findings suggested preferences for different methods emerging from different age groups and it is anticipated that this will help to inform future evaluative practice. The collation of children's views as service users are inextricably linked to their experience during their diagnostic assessment, and are gradually helping to promote reflection and discussion of the complexities of how assessment is undertaken. In a small but significant way this has helped to raise the profile within the service of different approaches and enabling practice, and promote the importance of 'real-life' research conducted within clinical settings.

4. Critiques and limitations of the research

Despite the limitation of being a small exploratory study, the study offers some important findings. Essentially IPA can be used as an approach to elicit the views of a verbal young child with autism, and their lived experiences can be uniquely considered within their diagnostic assessment and applied within a real life context.

I adopted an interpretivist paradigm and a major limitation of the research is that I worked alone to interpret data; a different person may have drawn different conclusions. As in many of the research studies focusing on the views and experiences of children and young people with ASD (McLaughlin & Rafferty, 2014; Dann, 2011; Tobias, 2009), there was no formal validation from the child participant. I present a subjective reality. In common with all small scale qualitative studies the findings cannot be generalised, but may facilitate 'internal' generalisability which considers whether the findings might provide some insight into practices within the specific setting that the research has been conducted (Silverman, 2006). For example, the themes that emerged from the parent's perspective link with existing knowledge and theory to identify the importance of relationships and communication with professionals during the assessment process. Similarly the specialist teacher identified some

important themes reflecting systemic and organisational issues unique to the locality setting.

From a realist perspective it is feasible to consider that the participatory approach adopted during the research study would suit some children and their parents, but without further research exactly what suits whom and in what context remains unclear (Pawson & Tilley, 1997). A major factor was Jack's verbal ability and an experience that was particularly important to him. This study does not consider how the views of a young child with different verbal abilities might be sought.

It is important to consider the practicalities of the approach used in order to gain a clear idea of its potential influence on clinical practice. I recognise the potential criticism that transcript analysis in the research context is a time consuming cyclical process. However, it was possible to identify key themes quite quickly, perhaps because the narrative of a younger child was short compared to those of older participants. This may potentially be a time-effective way of eliciting the views of younger children as the time required for the completion and analysis of some standardised assessments can also be significant.

Dissemination

The research study attempted to explore the use of IPA, a research methodology in a clinical context to determine the views and experiences of a young child with ASD. It considers the strengths and limitations of the approach and the potential for further research. Given the increasing concern for and emphasis on individualised person-centred planning (DfE, 2015), it will be important to present my findings to the local service and to the wider community of practitioners in health and educational services. This may support the aim of professional reflection to raise the question of epistemology and of how we understand the children we work with.

5. Future Research

As an exploratory study the present study has the potential to inform further research including using IPA with children of different ages and abilities, in order to consider whether this is a useful approach to elicit children's views in a clinical context.

Future research needs to accommodate the realities of the complex clinical context and a key question arising from this study is the need to consider the impact of contextual factors upon the diagnostic assessment process. Taking a realist perspective further research might usefully seek to identify the specific contexts and mechanisms that support positive outcomes for a child and their family. A realist approach offers to complement quantifiable, measurable evaluations by providing an explanatory analysis aimed at discerning what works for whom, in what circumstances, in what respects and how (Pawson, Greenhaigh, Harvey & Walshe, 2005).

6. Conclusion

The research process has enabled me to reflect personally and professionally about how I construct my own and other's experiences, providing me with an opportunity to re-philosophise my own assumptions and practices (Greig, 2014).

There is considerable pressures placed on health and education professionals to provide a 'good enough' service, and increasing evidence that how we undertake assessment and how information is presented provides an essential opportunity for 'others' to consider the child differently. A deficit-focused diagnostic report tells little of the individual and may promote negative assumptions and limit effective support. Reality is multi-layered and experiences multi-storied; they should be judged tentatively and we need to listen carefully to what children and young people can tell us.

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PAPER 4: SERVICE EVALUATION

An Evaluative Review of Service Data

Executive Summary

Evaluation is essential for accountability and to drive improvements and efficiency savings while controlling costs. This evaluative review is based in a small scale community based assessment service for children with complex medical needs and neurodevelopmental disorders (0-18 years), undertaken during an extended period of review and scrutiny by National Health Service (NHS) managers and Local Authority (LA) commissioners. The emphasis is on identifying and critically articulating available data and information, seeking to identify potential gaps to provide an evidence base for discussion with the clinical lead of the service to inform evaluative practice.

Four aims were identified:

1. To provide a summary review of different approaches to evaluation.
2. To collate and review available service data (2010-13).
3. To demonstrate the application of two different evaluative approaches.
4. To identify gaps in existing data and to make specific recommendations about evaluative processes.

Different approaches to evaluation have specific merits and it is essential to be clear about how and what we are trying to evaluate. The summary review of different approaches to evaluation emphasizes the importance of matching the approach used to the type of information that is required. For example, if we want to know how many children are seen in a quarter, numerical information is required. If we want to know about children's experience of the service then a different approach is needed. The review highlights the need for effective planning of evaluative processes within the model of service delivery rather than an 'add-on' in response to specific enquiry or local initiatives. Essentially improvement is an iterative process that needs fine tuning for on-going sustainability and should not be viewed as a project or one-off event.

The process of collating service data and considering the information provided by different approaches demonstrates the service's reliance on minimal statistical data, with no understanding of value or impact including service user experience. The reliance on numerical data highlights the danger of trying to 'fit' the available data to more complex issues, and raises the essential question of whether the service is using the right approaches to obtain the information required.

In applying data to two different approaches this study seeks to further illustrate the importance of considering the approaches used. Friedman's Results Based Accountability (RBA) Matrix was selected as it was being used concurrently by the Local Authority to view quantity-quality and effort-effect dimensions, in partner educational support service. The application of the RBA matrix demonstrated significant gaps in service data. Critically, this approach did not contribute to an understanding of how the service works and why it works better in some contexts than others. Therefore the final stage of the study demonstrated the potential use of a realist approach to think about the intangible variables of the organisation, including the social and behavioural aspects that have a significant influence.

Central to improving services is the understanding of how provision should be best delivered and findings from this evaluative review of service data, revealed there is limited quantitative data and no current qualitative data to answer this question. The service review led to a number of recommendations as follows:

1. Consider the approaches used that are required to evaluate different aspects of the service.
2. Rationalise and set data priorities with key partners, including what data are reported, how and with what frequency.
3. Use lean principles to review and rationalise the assessment process from referral to discharge.

4. Embed evaluative components in the process by identifying and tracking appropriate indicators.
5. Use appropriate qualitative and quantitative outcomes, including service user feedback (children and parents).
6. Use a realist approach to understand more about how the service works most effectively.

1. Introduction

An urgent need for both private and public services is improving quality and efficiency while controlling costs, and evaluation is important to meet accountability requirements and to drive improvement and efficiencies (Hollander & Kadlec., 2010). Practice and policy need to be informed by evidence, and practitioners are encouraged to ensure their work is evidence-based but evidence will vary in different circumstances (Timmins & Miller, 2007). Particularly pertinent in the current political and economic climate of diminishing resources, increasing public expectations about the quality of care (Department of Health & Farrell, 2006), and a change in the way that health services are commissioned (Department of Health, 2011), this evaluation was undertaken in a small Tier 3 Children's Community Health Service located in the Midlands during an extended period of review and potential reorganisation.

It was important to be mindful of the complex political, economic, organisational and social factors operating in a small service under close scrutiny by National Health Service (NHS) managers and Local Authority (LA) commissioners. There was with a critical limitation of the lack of mandate from senior decision-makers with clear parameters placed on the nature of any evaluation by the clinical lead of the service. It was agreed that it would be timely to critically review the data being used for evaluative purposes. The emphasis of the current study is on identifying and critically articulating pre-existing knowledge, to identify potential gaps and to provide an evidence base for discussions to help inform evaluative components of service planning.

1.1 The locality context

The locality service is commissioned to provide specialist assessment for children with complex medical and neurodevelopmental needs aged (0-18 years). The service underwent reorganisation in 2009/10 and is undergoing further review. It consists of two teams: an 'under 6' team providing

assessment, diagnosis, intervention and support for children with complex medical and developmental needs (aged 0-6 years), and an 'over 6' team providing assessment, diagnosis and support for children with social communication difficulties / Autism Spectrum Disorders (ASD) (aged 6-18 years). Both teams are multi-disciplinary with representation from clinical psychology, educational psychology, speech and language therapy, occupational therapy, health visitor and community paediatricians; some clinicians work in both teams and some in other community health and education teams.

The two teams operate different models of service delivery. The 'under 6' team model is predicated on the recognition that assessment of young children with neurodevelopmental needs is a complex dynamic process, and it is not a single event. Children with the most complex difficulties are often referred at a very young age. Intervention may be required and their development may need to be monitored and reviewed regularly, often over an extended period in order to consider their profile of changing needs. It involves a number of different professionals and services. The clinical case lead role to provide a key point of contact for parents and other professionals, and to co-ordinate the involvement of different clinicians and collaborative working are critical features of the 'under 6' model of service delivery. The 'over 6' model of service delivery aims to complete diagnostic assessment for ASD in a single contact, with two or more clinicians meeting with the child and their family.

The organisational context of this study is significant. The local authority commissioners were in the process of undertaking a systematic review with key partner services in educational support services. The review was based on lean principles, a philosophy taken from the Japanese manufacturing sector that aims to make operational efficiencies by eliminating waste (Liker, 2006). Service commissioners increasingly concerned with the lengthy wait time for diagnostic assessment for ASD were seeking to gain a greater understanding of the process, flow and outcome measures, and were keen for similar lean principles to be applied to the locality service.

Widely adopted across public services including health care with evidence of small-scale localised productivity gains (Kollberg et al., 2007; Toussaint & Berry, 2013), lean review is not without criticism. It is known to have limitations in complex social environments because at least part of the explanation of success or failure will be found in the reasoning and personal choices of participants (Mazzocato et al., 2012). The local authority was also using a specific management tool, Friedman's Results-Based Accountability Matrix (RBA) with some educational support services to look at data to see quantity-quality and effort-effect dimensions. Therefore this approach was applied to existing service data to see what information it would provide.

In common with many small-scale community initiatives the locality service had limited data and inappropriately long-term outcome measures associated with quality of life and mortality (Lhussier, 2008). These could not be measured easily but were often assumed to have a direct causal link with service delivery when they were the consequence of multiple factors operating at local and national levels. Concern with the apparent lack of contemporaneous data and a reliance on historical data obtained as a project or one-off event, led to the question of the use being made of 'evaluative data' and prompted consideration of two basic questions:

1. What data does the service have?
2. What does it tell us?

These led to the identification of four aims for this evaluative study.

1.2 Aims of the evaluative study

1. To undertake a review of the different approaches to evaluation.
2. To systematically collate and review the service data for the period 2010-13.
3. To apply the existing data to two different evaluative frameworks

4. To identify gaps in existing information and make specific recommendations about evaluative methods.

2. Procedure

Evaluations usually start with discussion of what information is required (Lilford et al., 2009), but it is the philosophical question of what approach should we use that is critical in determining the type of information that is obtained. The first stage of this study reviews the different approaches to evaluation and the different kinds of information that they produce.

2.1 A review of different approaches to evaluation

Pawson et al., (2005) considered the different forms of intervention in health, including: clinical treatments and procedures, health-care programmes, models of service delivery and health policy, and emphasize the importance of matching these to appropriate methods of evaluation and review. For example, the efficacy of clinical treatments and procedures are evaluated in randomized controlled trials which aim to remove any human impact.

This positivist approach to evaluation is based on the assumption that there is an external reality that can be objectively measured. Goals and outcomes can be unambiguously defined and facts and values are clearly distinguishable. Positivist evaluations focus almost exclusively on outcomes by collecting and analysing figures to show whether a treatment programme or procedure has 'worked'. Many evaluations start with a logic model which provides visual mapping of mechanisms, and links inputs and processes with expected outcomes and impacts. This approach generally employs quantitative methods to collect data, produces statistical statements about the relationship between variables and seeks to make causal links between inputs (activities) and outputs.

Logic models are a primary focus in health care which is outcome orientated with a focus on clinical effectiveness, and has led to the development of innumerable guidelines, protocols and pathways that are well established in the NHS (Currie, 2000). There are clear methodological rules or steps to follow in this scientific approach, leading critics to claim that logic models do not model the complexity of the real world (Greenhalgh et al., 2009).

Many health programmes occur in politicised situations where goals and criteria are contested, and outcomes need to be considered in terms of the behaviours, values and beliefs of those involved. In contrast to the positivist approach an interpretivist approach makes no claims about causality and is based on a very different philosophical assumption of a socially constructed reality. With an explanatory focus it aims to offer a way of understanding the nature and function of these relationships, and to understand the mechanisms of how complex programmes work with reference to settings and context (Walshe & Luker, 2010). Increasingly researchers argue that a positivist approach provides limited useful information as programmes do not affect individuals in identical ways (Pawson & Tilley, 1997).

Positivist and interpretative approaches have different quality criteria and produce very different kinds of information. Sitting philosophically mid-way between these approaches is realism. A realist approach to evaluation is a theory driven approach with explicit philosophical underpinnings. Pawson and Tilley (1997) consider that certain outcomes are produced and an intervention does or does not work because of the reasoning of 'actors' within it. This approach provides an explanatory analysis aimed at discerning what works for whom, in what circumstances and in what respects how (Pawson & Tilley, 1997). Designed to work with complex social interventions or programmes realist evaluation is increasingly used in health care (Mazzocato et al., 2010).

In order to consider how a realist approach might be used within the locality service, it is important to have an understanding of the framework for this

approach. Rather than a systematic pathway to be followed, realist evaluation (RE) presents a set of principles that are meant to improve the thinking that goes into decisions about how services should be structured and delivered (Pawson et al., 2005). RE is based on three main concepts:

1. Mechanisms: These are the structures of the social programme, the things about the programme that bring about change, e.g., a person's behaviour changes as a result of how a process interacts with their beliefs, values and reasoning.
2. Context: This considers the social norms, values and relationships and levels of knowledge and understanding which collectively set limits on the programme efficiency.
3. Outcomes: These are the process that results from mechanisms interacting within a specific context.

RE starts and ends with programme theory, which describes how the intervention is expected to work in a particular setting and context. RE is a bottom-up approach which means that the first stage is to develop initial programme theories based on what is believed to work from a review of the current literature, the knowledge and experience of the practitioners involved, and the assumptions of those that 'designed' the intervention about how it will work (Pawson & Tilley, 1997). The evaluation design and data gathering are influenced by these theories in order to test if the programme is working as anticipated, and the evaluation findings inform how the programme or service could be modified or implemented more effectively. The second stage is to develop more precisely how Contexts and Mechanisms are most likely to give the desired Outcomes. These are configured as Context, Mechanisms, Outcomes (CMOs) which are then evaluated. RE does not impose the use of specific methods of data collection and analysis. Methods are selected on the

type of data that is needed to test the initial programme theory and usually involves quantitative and qualitative methods.

Different approaches to evaluation have specific merits and it is essential to be clear about how and what the locality service are seeking to evaluate. Having established this, an effective evaluation framework provides a useful structure for thinking about the main elements of a programme or service delivery and how they are supposed to work. The framework may focus on formative and or summative aspects which may be determined by different levels of outcome (Table 19), although in practice evaluations often combine two or more elements.

Table 20 - Key features of different types of evaluation

Type of Evaluation	Key questions asked and features
Process Evaluation	What services are being delivered and to whom? Tracking types of services and quality Descriptions of what actually occurs Quality of service
Immediate short-term impact	What is the immediate impact? Change in knowledge, attitude and behaviour of target population. Does the programme meet its stated objectives?
Intermediate outcome	What are the medium term outcomes? Behavioural changes Skills and knowledge changes Accessing appropriate services and support.
Long term and social outcomes	Social and Health outcomes. Disability Quality of life Morbidity Mortality

2.2 Service data 2010-13

The second stage of the review involved identifying different sources of service data (Table 21). These were mapped on to a grid (Table 22) to identify the type of evaluation that the data may inform; either formative (process) or summative (outcome), with the latter divided into short-term, intermediate and long-term outcomes.

Table 21 - Service data sources 2010-13

Data Source	Summary
Demographic data	Age of child at referral, gender, ethnicity, reason for referral and by whom.
Performance data	Referral rates, numbers waiting, numbers of active cases and diagnostic outcomes.
Clinical Audit	An audit of how well the service met the standards of the NICE guidelines for Autism (2011) completed in 2012.
CQUIN (Commissioning for Quality and Innovation in Health care) Project	A review of service user feedback obtained during a pilot project about service user experience during the period January – March 2012.
Children's Services Balanced Score Card Reports (BSC) 2012 -13.	Quarterly analysis of questionnaires returned anonymously by service users (parents) on completion of the assessment process for their child.
Service evaluation 2012	Evaluative review of the 'Under 6 team' completed by a clinical psychology trainee on placement with the service in 2012.
Parent Group Feedback	Feedback from parent support groups.

Scrutiny of the data sources revealed several inconsistencies and issues with the available data, which included demographic data for both teams being held separately. With no systemic overview there was no agreement of terms or categories of data resulting in difficulties in collating reliable basic data for the service. For example: The age and gender of accepted referrals were recorded

but was not consistently recorded for referrals that were not accepted. Review of data occurred at ad hoc intervals when specific queries arose.

Performance data were similarly unreliable. Accepted referrals were totalled on a monthly basis and mapping of these identified cyclical trends in accepted referral rates. With no identification and analysis of the variability in service capacity available, the critical relationship between capacity and demand was unknown (Silvester et al., 2004). The number of completed cases was recorded by one team and not the other, diagnostic outcomes were not consistently recorded and used a range of different terminology.

Clinical audit using the NICE guidelines for Autism (2011) was implemented by both teams at different times. This provided a useful snap-shot of team standards but gave no overview of service standards. There were no plans to undertake a clinical audit at regular intervals. As historical data it provided no information about current clinical standards.

A local and national initiative by Commissioning for Quality and Innovation in Health Care (CQUIN) sought service user feedback and was completed in January-March 2012. The CQUIN project used pre and post measures with a small sample of twenty parents to identify their main concerns, what they hoped to gain from their involvement with the service and whether this was achieved. In common with other services the number of post ratings was very low (3) and could not be generalised. This was a one-off project which produced specific recommendations for embedding evaluative practice within the assessment process. These were not implemented.

Balanced Score Card reports of service user feedback are a Trust requirement; part of the government attempt to benchmark local NHS organisations and one of the key development of the Performance Assessment Framework (Li-Cheng, 2007). The questionnaires used are not service specific and some of the questions do not readily apply to the locality service. Returns, as for other

community children's services are very low, but usually positive with the exception of the long wait time to access the service.

Collation of the available data had not been done previously and identifies significant problems, notably no agreement of terms, methods of recording or analysis for basic numerical data. Qualitative information is piecemeal and sporadic, usually obtained through a single event with no systematic plan for evaluative components integral to the model of service delivery.

Mapping the data to consider the type of evaluation that it may contribute to is shown in Table 21. This highlights an overreliance on numerical data that provides limited information about process and immediate outcome.

Table 22 - Data source mapping and potential contribution to evaluation

Information	Date	Type of data	Type of Evaluation			
			Process	Short-term outcome	Inter-mediate outcome	Long-term outcome
Demographic data	2010-13	Statistics	✓	X	X	X
Performance data	2010-13	Statistics	✓	✓	X	X
Clinical Audit	2012	Statistics	✓	✓	X	X
CQUIN Project	2012	Statistics with some narrative views	✓	✓	X	X
Children's Services Review Report	2012-13	Quarterly analysis of statistics	✓	✓	X	X
Service evaluation	2012	Statistics and practitioner views	✓	X	X	X
Parent Group Feedback	2012-13	Statistics with some narrative views	✓	✓	X	X

2.3 Friedman's Results-Based Accountability (RBA) matrix

The RBA framework is a management tool used to look at data priorities to see quantity-quality and effort–effect dimensions (Friedman, 2005). It effectively distinguishes between two types of accountability: results and performance. The main components are shown in Figure 3 and were applied to the available service data.

	Quantity	Quality
Effort	How much did we do? Number of patients served Number of services/activities	How well did we do it? % of activities /services performed well.
Effect	Is anyone better off? What quantity / quality of change did we produce? % with improvement in skills, attitude, behaviour, circumstances	

Figure 3 - Main features of the Friedman Results-Based Accountability matrix

The three dimensions: Quantity, Quality and Effect were considered in relation to available service data.

The number of patients served was identified by the number of accepted referrals shown in Table 22 (* Under 6 data only).

Table 23 - Accepted referrals 2010-13*

Year (April-March)	2010	2011	2012	2013
Accepted referrals	138	171	187	111

This data immediately identified a major issue. The data held gave no indication of the total number of referrals to the service or the acceptance rate. Despite many hypotheses there was no substantive evidence to explain the change in accepted referrals, in particular the increase in the period 2010 /11 and significant decline in 2012/13.

To determine the quality of service delivery there should be specific measures that tell if an activity was performed well or poorly. Three sources of data had some qualitative components (Table 23):

1. The NICE audit (January 2013)
2. The CQUIN project (March 2012)
3. Children's Services quarterly analysis (2012-13) of Balanced Score Card (BSC) reports.

Table 24 - Potential sources of data for qualitative evaluation

Source data	of	Date	Number	Tools	Summary of findings
Under 6 Team audit		January 2013	n = 35	NICE Audit tool.	Defined criteria met 100% for 5 of 8 indicators.
CQUIN Project*		March 2012	n = 20	Goal-based outcome measures	3 post measures - 2 showing an increase in parents' confidence and 1 less.
BSC Reports*		2010-2013 Quarterly	n = 22	Trust service user experience questionnaire	All positive except for wait time.

*The CQUIN project and BSC reports include numbers for the whole service.

The number of participants involved was comparatively small compared to the total number of children referred to the service. Both the CQUIN project and

BSC reports were completed by parents and no qualitative feedback was obtained from children.

Finally, asking how, in measurable terms if anyone is better off, cannot be answered with the available data. There are multiple stakeholders, e.g. children, parents, teachers and other professionals. The service complies with Trust requirements to seek service user views about their experience of the service; it is not team specific and has very limited returns. There is no data from other stakeholders.

In summary the application of the RBA framework to existing data illuminated significant gaps in evaluative processes. The basic question of how many children were seen in a defined period and the relationship with the referral rate could not be determined as essential data was not being collected.

2.4 Considering the potential use of a realist approach to evaluation

The third stage of this evaluative review used the guiding principles of RE to show how this approach might give different information. The study stops short of undertaking a RE because the essential component of discussions with key stakeholders and an effective governance process is missing; there is no mandate for this and the views presented are the researcher's own. Initial programme theory was developed from current literature and through the researcher – practitioner having frequent discussions with colleagues, which enabled on-going reflection and consideration of potential factors (mechanisms) that impact on practice and affect outcomes. For example, Abbott et al., (2013) note the importance of the communication between clinician and parents, and clinicians working with young children report that their assessment with the child and their family is always more positive when parents are clear about the reasons for the referral, know whom they are meeting with and have been well informed about the process of assessment.

There are always multiple CMO configurations at different levels, and some examples of potential CMO configurations for initial programme theory at different levels are shown in Table 25. Essentially in practice these would be prioritised through discussion between practitioners and the decision makers (Lomas, 2000), as it is their questions and their assumptions about how things work that form the focus of analysis, and enables the key questions to be identified (Pawson et al., 2005).

This critical component is missing in this review; the examples shown in Tables 25-27 reflect the literature and researcher's personal view of key issues at different levels. Examples of plausible CMO configurations are suggested to show how a different approach might yield different information. They serve to illustrate an example of how a realist approach can identify features of the contexts and mechanisms that potentially lead to good outcomes. Through on-going discussion between key decision makers and practitioners, specific CMOs are prioritised and agreed. The second stage of RE maps the agreed CMOs and planned evaluation, and appropriate qualitative and quantitative methods are used to check the evidence to support or refute these hypotheses.

Table 25 - Potential CMO configurations at an organisational level

Context	Mechanisms	Outcomes
Practitioners in universal and Tier 2 services maintain their responsibility for the child and their family.	A positive, supportive relationship between specialist team members and community teams promotes open dialogue and consultation.	Appropriate referrals with relevant information at an appropriate time for the family
Decisions made at referral meeting are consistent.	Referrers are familiar with the access criteria and provide appropriate evidence. Clear access criteria are applied consistently.	Reduction in the number of queries about decline of referral.
Practitioners support the child and family and make referral at the 'right' time for the family.	Community practitioners have good knowledge of the needs of the child and their family. Community practitioners know clinical priorities and criteria for referral to the service. Community practitioners receive a consistent response from the service.	Clinical priorities are efficiently identified at referral meeting. The appropriate allocation of the clinical specialist for the lead role.
Practitioners in universal and Tier 2 services value the specialist service	Regular and accessible communications support working relationships.	Effective collaborative working relationship. Families experience of transition between services is positive.

Table 26 - Potential CMO configurations at service user level

Context	Mechanisms	Outcomes
Parents are well informed about the specialist service. Parents are aware of the reasons for their child's referral to the service.	Parents are in full agreement with referral Parents are aware of possible outcomes. Parents have clear information about the assessment process. Referral information is completed by the child's parent and professionals together to provide information from different contexts. Parents and professionals actively engaged in assessment together.	Genuinely informed consent. Parents agree with the outcome of assessment and defined needs. Parents report satisfaction with the service.

Table 27 - Example of CMO configurations

Context	Mechanism	Outcomes
Parents main concerns are identified and responded to.	Referrer informs and supports parents during the assessment process. Referral is made at an appropriate time; considering child's and parent's needs	Parents report they were listened to. Parents actively engage in the process and report a positive experience.

For example, the hypothesised CMOs identified in Table 27 could be investigated by a range of different methods, including tracking patient's journeys, observations, questionnaires, and semi-structured interviews with parents and with practitioners in the team and in other services. This enables a better understanding of the mechanisms that impact on the service and the more detailed nature of an interpretive inquiry can potentially provide better insight into what works well and for whom (Timmins & Miller, 2007).

Realist evaluation offers a way of considering the varying effects and potential interaction between different variables as to why they work and if they do by considering the individual characteristics of organisational social environments (Pawson & Tilley, 1997).

3. Discussion

3.1 Combining different approaches to evaluation

Critical to developing better knowledge of the service is a good understanding of the different approaches and what they may deliver before refining the questions and methodology; different approaches yield very different information. If the information required is simply how many children were seen and the length of waiting time, statistical data are needed. But if the service

really wants to know how efficiently, effectively and safely the service was delivered and what circumstances produce the best outcomes, then a combination of different approaches is needed. The danger of focusing on achieving national access targets and financial balance at the cost of delivering acceptable standards is well known, while provision of a high quality service for only a few is neither ethically nor financially viable. It is the balance of these aspects through achieving quality, flexibility and speed that the service strives for.

Collation of existing service data in phase 1 of this service evaluation shows it provides piecemeal information and very limited understanding of the assessment process and outcomes. Subjecting the data to two different approaches shows specific gaps in existing information. There are no immediate outcome measures or evaluative components formally embedded within the process to support monitoring, and current data cannot be generalised to make causal links or assumptions about best practice.

No data provides an objective comprehensive understanding of flow through the assessment process from beginning to end. Accurate data to analyse the changing relationship between capacity and demand throughout the year are essential requirements (Silvester et al., 2004). Lean methodology is good for mapping and supporting process change and can potentially support a better understanding to improve process flow. Yet it is known to have limitations in complex social environments because at least part of the explanation for success and failure will be found in the reasoning and personal choices of different participants. Success depends on a long, non-linear sequence of mechanisms involving policy makers, commissioners, managers, clinicians and service users. The relationships between the different groups are crucial and success is dependent on the cumulative success of the entire sequence. A review using a realist approach might actively explore the integrity of aspects of this chain by examining the relative influence of different parties. It might feasibly consider leadership, resource allocation, staffing levels, interpersonal relationships, competing priorities and influences.

There is a need for robust measures which gives information about the quality of the service against defined criteria. The clinical audit exemplifies the traditional positivist approach to collect data from a sample of cases. Indicators are reported as statistical statements. For example, 89% of diagnostic assessments were started within three months of referral, and 100% of assessments have a developmental history focusing on developmental and behavioural features consistent with ICD-10 or DSM-IV. Regular audit can usefully identify significant changes between points in time, and when used in conjunction with active monitoring of key indicators embedded within the assessment process can provide regular review of quality standards. It does not provide any information as to how or why these changes occurred, and can potentially give a misleading picture if claims about causal links are assumed and results generalised.

There is no information about the immediate impact of the service. The current service specification identifies inappropriately long term outcomes that cannot be measured or assumed to have a direct causal link. Considering the immediate outcomes of assessment for service users, short-term measurable outcomes could be identified, accurately monitored and systematically evaluated.

There are no qualitative data and no usefully detailed descriptions of interpretive enquiry. There is no service user feedback from children or young people.

3.2 Specific recommendations

Improvement is an iterative process that requires fine tuning for on-going sustainability. Too often service evaluation is viewed as a project or one-off event and the locality service is no exception. Continuing with a focus on the use of tools without embracing the underlying philosophy of continuous

improvement can lead to unsustainable improvement (Joosten, Bongers, & Janssen, 2009; Radnor, Holweg, & Waring, 2012).

Essentially it is important for the service to undertake the following actions:

1. Rationalise and set data priorities with key partners and agree how they are reported.
2. Use lean thinking to review the assessment process.
3. Identify and track appropriate evaluative indicators within the process
4. Use immediate outcomes that can be measured: Quantitative and qualitative measures
5. Use a realist approach to understand more detail about how the service works most effectively.

4. Critical Appraisal

4.1 Strengths and limitations of the study

A critical limitation of this evaluative review of service data is the lack of mandate for this work from senior managers. Findings will be shared with the clinical lead of the service to help inform discussion of evaluative practice, but the process has been completed in isolation from key decision makers with communication confined to academic and managerial supervision.

It is disappointing but not surprising that dissemination of findings is very limited. The most significant impact of this evaluative review is the overt identification of significant gaps in service data and raising awareness of the different approaches to evaluation. The question of evaluative practice within the service and the question of data recording and analysis have necessarily been given greater priority, an inevitable consequence of the increased level of accountability and scrutiny taking place. An important outcome has been an

improved understanding of what different approaches to evaluation can provide enabling discussion of the approach used before deciding on specific methods.

There have been some significant changes in the organisational structure of the service following extended review. The service was reconfigured to one team in 2014. Key Performance Indicators (KPI) were identified and agreed with senior managers; essentially all children are seen within a maximum of eighteen weeks of their referral and their assessment completed within thirteen weeks. Practical changes of a move to electronic data bases and clinical recording enables accurate analysis of quantitative service data and regular reporting of KPIs.

4.2 Personal reflection on the impact of the study

The process of undertaking this study reaffirmed my experiences that many service evaluations miss the larger crucial organisational context in which services operate. The process consistently highlighted the complexity and challenges of undertaking an evaluative review in a politicised and changing service with significant restrictions.

Operating as a practitioner-researcher provided a number of potential advantages and disadvantages. A positive aspect of undertaking this review was the opportunity to question evaluative practice, with the aim of providing an overview and analysis that is qualitatively different than what is possible in my day to day role. As an experienced practitioner I inevitably approach my work with various concepts, theoretical models and provisional explanations. It has been interesting to reflect on my role and epistemological position as the evaluative review was undertaken.

One of the more challenging features of realism is the need to adopt an emergent approach to evaluation by developing and responding to findings; building theory from emergent data and ensuring there are several feedback

and evaluation points within the process. A key feature is recognition that learning occurs by the process of the evaluation and not the final report. The process is a bottom - up model and to be effective, requires commitment and support for clinicians to develop the process and for it to be recognised as an important factor and not one that is simply part of a list of tick-box initiatives. While this position seems somewhat distant, the process of reorganisation and review has placed the issue of evaluative practice higher on the local agenda.

The service has now implemented pilot projects for service user feedback from both parents and children, which are due to continue and demonstrate a change to a service that is now beginning to utilise a range of different qualitative and quantitative approaches.

Recent research is beginning to explore the qualitative aspects of the diagnostic process, with recognition that how the process is conducted is a major factor in the provision of cost-effective, responsive services that work for children and their families (Abbott et al., 2013).

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MANDATORY APPENDICES

Appendix C: Statement of Epistemological Position

A significant feature of the large amount of literature relating to autism is the major historical changes that have occurred during the latter part of the twentieth century in evolving definitions, conceptualisations and diagnostic criteria for autism (Feinstein, 2010; Wolff, 2004). Controversy surrounds both the terminology used (Kenny et al., 2015) and the diagnostic criteria in relation to research and practice (Matson & Jang, 2014; Karim et al, 2012). Verhoeff (2013) argues that most histories are implicitly positivist which has promoted the application of the medical model in the search for aetiology, and the dominance of the contemporary understanding of autism which places 'it' as a 'thing' which is discoverable by a scientific approach. Despite being formally recognised as a lifelong neurological condition which is heterogeneous in both aetiology and manifestation (National Institute for Health and Clinical excellence; 'NICE', 2011), there is no simple definitive answer to the question, 'what is autism'?

Neurodiversity and neurological disabilities both refer to the same medical condition. Neurodiversity describes features of neurological difference associated with individual identity, and neurological disability refers to impairment of socially determined life functions (Baker, 2006). Proponents of neurodiversity tend to adopt a social model of disability, distinguishing between a biological condition and disability rooted in inaccessible social and political infrastructures (Baker, 2011). Consequently research has mainly positioned the medical model and neurodiversity in opposition to one another (Kapp, Gillespie-Lynch, Sherman, & Huntman, 2013).

Kapp et al. (2013) critically examined the perceived opposition between the medical model and neurodiversity movement. They determined a more nuanced view of neurodiversity that recognises strengths of autism but does

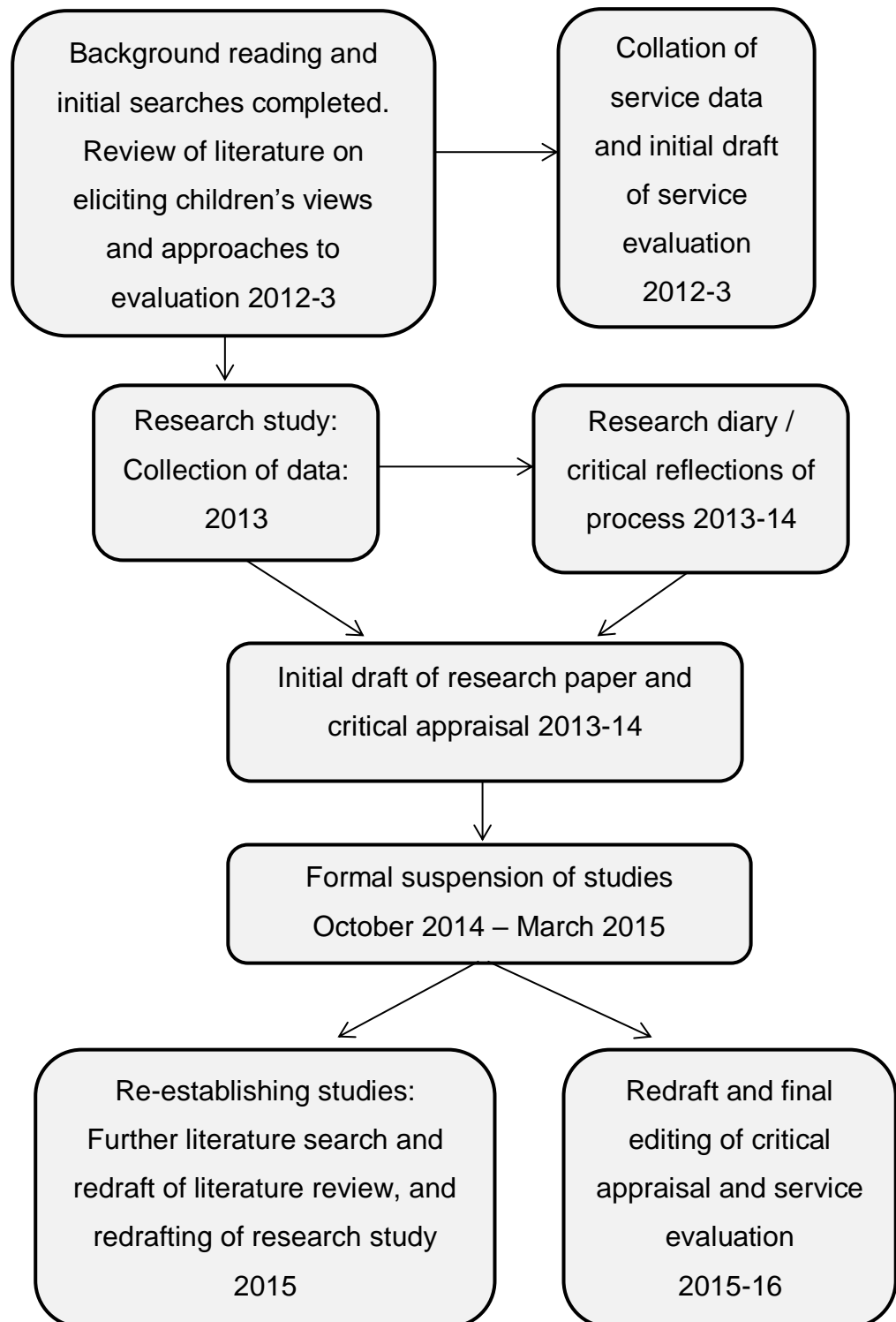
not obscure understanding the difficulties associated with autism. I agree with this perspective. The current research was conducted according to a social constructionist orientation. A postmodern discipline social constructionism is a sociological theory of knowledge which stresses the importance of social relationships and interactions in the construction of knowledge and reality, and provides a suitable framework for research with children. In accordance with my epistemological orientation, in attempting to understand the experiences of a young child with autism I am aware of multiple layers of reality. They include my subjective interpretations of the participant's narratives influenced by my own experiences (Smith et al. 2009), as a child, teacher and as an Educational Psychologist. I acknowledge that each individual makes sense of the world in a unique way.

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Appendix D: Chronology of Research Process

The research process was a cyclical process with earlier stages frequently revisited to check literature and edit former drafts.



Appendix E: Guidelines to authors for literature review journal target

Educational Psychology in Practice

Instructions for authors

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- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly.
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Click [here](#) for information regarding anonymous peer review.

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Appendix F: Information Sheets: Parent, Professional and Child



PARENT INFORMATION SHEET

Title of Project: A different understanding of Autism: Exploring autobiographical accounts in diagnostic assessments

We are asking if you would like to join in a research project to look at different ways of gaining the views of young children.

Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family or friends if you want to.

Why are we doing this research?

It is important that individuals using any health care service are fully involved. This is common practice for adults but far less so for children, particularly young children. The study aims to look at ways of eliciting the child's view and how they perceive any difficulties they may be having.

What does the study aim to do?

The study aims to:

1. Explore different ways of eliciting the child's views.
2. Gain knowledge of the child's individual experience.
3. Consider how sharing knowledge of the child's perspective might impact on those involved in their support.
4. Consider the interrelationships between the different people involved in support the child; to provide an understanding of a real-world situation.
5. Consider the possibility of alternative ways of working that includes a better understanding of the child's perspective and their individual experience.

Why have I been invited to take part?

You have been asked to take part because:

1. Your child has been referred to [REDACTED] for assessment of social communication difficulties.
2. Your child was under 6 years of age when they were referred to the service.
3. They are speaking in sentences.
4. They attend a mainstream school.

How many children will be studied in this project?

1-3 children will be asked to join this project. It is a small case study.

Do I have to take part?

No. It is up to you. We will ask you for your consent and then ask if you will sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

What will happen if I agree to my child taking part?

■ The research will involve working with you and your child in the usual way during the assessment process at ■

- It is usual for parents to stay with their child during assessments. On each visit you may choose to be present with your child.
- The number of visits will depend on what assessments your child needs.
- It is our usual practice to agree an assessment plan over a period of time with you. This may be over several weeks or months.
- The researcher will talk with your child to help identify what is important to them. There are no predetermined questions. Your child will be supported to identify the things that are important for them.
- This might involve playing, drawing, modelling and talking.
- The discussion may be recorded.
- Observations and notes will be taken at the end of each session.
- Case notes will be made in the usual way. These follow Trust guidelines.
- All information will be confidential.
- No individual child or their parent will be identifiable in the research report. All names will be changed including place names. This is a very small study so those people who take part may be able to recognise themselves.

What are the possible benefits of taking part?

We cannot promise that the study will help you, but the information we get may help show how to involve young children in their assessments.

It may show how understanding things from the child's perspective can help those adults involved in supporting them.

Will anyone else know I'm doing this?

We will keep your information in confidence. We will only tell those who have a need or right to know.

We work closely with other people who support the child, for example: their teacher and specialist teacher that may be involved. This is our usual practice.

By agreeing to refer your child to the service you have agreed to sharing information. You can withdraw this at any time. You do not have to provide a reason.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the London and City East Research Ethics Committee.

Contact details

If you have any questions you can contact the lead researcher: Patricia Woods at the [REDACTED]

Thank you for reading this. Please ask any questions if you need to.
--



PROFESSIONAL INFORMATION SHEET

Title of Project: A different understanding of Autism: Exploring autobiographical accounts in diagnostic assessments.

We are asking if you would like to join in a research project to look at different ways of gaining the views of young children.

Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully.

Why are we doing this research?

It is important that individuals using any health care service are fully involved. This is common practice for adults but far less so for children, particularly young children. The study aims to look at ways of eliciting the child's view and how they perceive any difficulties they may be having.

What does the study aim to do?

The study aims to:

1. Explore different ways of eliciting the child's views.
2. Gain knowledge of the child's individual experience.
3. Consider how sharing knowledge of the child's perspective might impact on those involved in their support.
4. Consider the interrelationships between the different people involved in supporting the child; to provide an understanding of a real-world situation.
5. Consider the possibility of alternative ways of working that includes a better understanding of the child's perspective and their individual experience.

Why have I been invited to take part?

You have been asked to take part because you are a key person supporting a child who has been referred to the [REDACTED] for assessment of social communication difficulties.

How many children will be studied in this project?

1-3 children will be asked to join this project. It is a small case study.

Do I have to take part?

No. It is up to you. We will ask you for your consent and then ask if you will sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the assessment process for the child.

What will happen if I agree to take part?

■ The research will involve working with you and the child in the usual way during the assessment process at the ■

- It is our usual practice to agree an assessment plan over a period of time with the child's parents. This may be over several months.
- The researcher will talk with the child to help identify what is important to them. There are no predetermined questions. The child will be supported to identify the things that are important for them.
- This might involve playing, drawing, modelling and talking.
- The discussion may be recorded.
- Observations and notes will be taken at the end of each session.
- Case notes will be made in the usual way. These follow Trust guidelines.
- All information will be confidential.
- As a professional involved, you will be asked your views about the child's presenting difficulties at the beginning and at the end of the assessment process.
- This will involve a short unstructured discussion; there are no predetermined questions and you will be asked what you consider to be important.
- This discussion will be recorded.
- No individual child, their parent or other professionals involved will be identifiable in the research report. All names will be changed including place names. This is a very small study so those people who take part may be able to recognise themselves.

What are the possible benefits of taking part?

We cannot promise that the study will help you or the child directly, but the information we get may help show how to involve young children in their assessments.

It may show how understanding things from the child's perspective can help those adults involved in supporting them.

Will anyone else know I'm doing this?

We will keep your information in confidence. We will only tell those who have a need or right to know.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the London and City East Research Ethics Committee.

Contact details

If you have any questions you can contact the lead researcher: Patricia Woods at the [REDACTED]

Thank you for reading this. Please ask any questions if you need to.



CHILD INFORMATION SHEET

Please read this with your child.

Dear

You will be visiting the [redacted]

Your mum (and dad) will come with you.

The [redacted] has lots of toys for you to play with.



You can bring one of your toys if you would like.

You will meet a lady called

..... will talk to your mum (and dad) while you are playing.

She will play with you too.

Then you will go home (or back to school).

We look forward to seeing you.

Appendix G: Child Assent Form



Centre Number:

Study Number: 13/LO/0345

Patient Identification Number:

CHILD ASSENT FORM

The child will have met the researcher on previous occasions.

A parent or carer will be present.

The researcher will explain:

"We are going to talk about different things that you do each day and how you feel.

We will be doing some drawing and talking, and some playing."

Are you happy to do this?

YES



NO



Have you asked all the questions you want?

YES


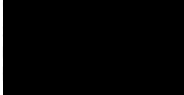


NO



If you do want to do this, you can write your name below.

Appendix H: Letters from Ethics

	
NRES Committee London - City & East Bristol Research Ethics Committee Centre Whitefriars Level 3, Block B Lewins Mead Bristol BS1 2NT Telephone: 01173421386 Facsimile: 01173420445	
06 March 2013	
Ms Patricia Woods Educational Psychologist and Under 6 Team Lead Heart of England Foundation Trust 	
Dear Ms Woods,	
Study title:	A different understanding of Autism: Exploring the use of autobiographical accounts in diagnostic assessment for a child with an Autism Spectrum Disorder.
REC reference:	13/LO/0345
IRAS project ID:	123982
The Proportionate Review Sub-committee of the NRES Committee London - City & East reviewed the above application on 26 February 2013.	
Ethical opinion	
On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.	
Ethical review of research sites	
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).	
We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mr Rajat Khullar, nrescommittee.london-cityandeast@nhs.net.	

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Investigator CV		15 February 2013
Participant Consent Form: Child Consent Form	1	19 February 2013
Participant Consent Form: Parent Assent Form	1	19 February 2013
Participant Consent Form: Professionals Assent Form	1	19 February 2013
Participant Information Sheet: Parent Information Sheet	1	19 February 2013
Participant Information Sheet: Child Information Sheet	1	19 February 2013
Participant Information Sheet: Professional Information Sheet	1	19 February 2013
Protocol	1	15 February 2013
REC application		21 February 2013

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website. Information is available at National Research Ethics Service website > After Review

13/LO/0345

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely,



pp Dr Louise Abrams
Vice Chair

Email: nrescommittee.london-cityandeast@nhs.net

Enclosures: *List of names and professions of members who took part in the review*
"After ethical review – guidance for researchers"

Copy to: *Ms Patricia Woods*
Dr Elizabeth Adey, Heart of England Foundation Trust

NRES Committee London - City & East

Attendance at PRS Sub-Committee of the REC meeting on 26 February 2013

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Louise Abrams	Pharmacology (Vice Chair)	Yes	
Dr Chandan Alam	Experimental Pathology	Yes	
Mr Roger Maran		Yes	

Research & Development Directorate



Medical Innovation Development Research Unit
Office Hours (Mon-Fri): 09.00 – 17.00
Tel: 0121 424 1633
Fax: 0121 424 3167

Head of Research & Innovation: Bethan Bishop
R&D Manager - Governance & Operations: Elizabeth Adey
R&D Manager - Finance & Facilities: Rachel Ward
Please send e-mails via firstname.surname@heartofengland.nhs.uk

Birmingham Heartlands Hospital
Bordesley Green East
Birmingham B9 5SS

Tel: 0121 424 2000
Fax: 0121 424 2200

12/04/2013

Ms Patricia Woods
Heart of England NHS Foundation Trust



Dear Ms Patricia Woods

R&D Code: 2012194PSYCH Re: Study title: A different understanding of Autism: Exploring the use of autobiographical accounts in diagnostic assessment for a child with an Autism Spectrum Disorder.

EudraCT: N/A

I am pleased to inform you that the R&D review of the above project is now complete and has been formally approved to be undertaken at the following sites within Heart of England NHS Foundation Trust.



The following documents were reviewed:

Protocol Version 1 15 February 2013
PIS & Consent Assent Form for Parents Version 1 19 February 2013
Assent Form for Professionals Version 1 19 February 2013
Child Consent Form Version 1 19 February 2013
Child Information Sheet Version 1 19 February 2013
Parent Information Sheet Version 1 19 February 2013
Professionals Information Sheet Version 1 19 February 2013
GP letter Not applicable
NHS NRES Application Form Patricia Woods, 15 February 2013
NRES Site Specific Information Form Patricia Woods, 25 March 2013
NRES Approval Letter 06 March 2013
MHRA notice of Acceptance (if applicable) Not applicable
Any Standard Operating Procedures for the Study
Other documents (please specify):

... continued ...

Version 10.0 May 2012

The conditions of this approval are as follows:

- 1) You adhere to the approved version of the protocol and notify R&D immediately of any changes to the study, including any new staff working on the project, who may require Trust or Honorary contracts issued.
- 2) You notify R&D immediately of any Serious Adverse Events, including Suspected Unexpected Serious Adverse Reactions (SUSARs)
- 3) You adhere to the requirements of the ethics committee as detailed in their approval letter and standard operating procedures which can be found on www.nres.npsa.nhs.uk
- 4) For CTIMP studies, you adhere to the regulations, including good clinical practice, of The Medicines for Human UK Clinical Regulations (SI 2004/1031; SI 2006/1928; SI 2006/294; SI 2008/941; SI 2009/1164; SI 2009/3063; and SI 2010/1882).
- 5) You notify R&D immediately of any Serious Breaches of GCP or the protocol occurring on this site. This applies to both sponsored and hosted projects. Guidance on Serious Breaches identification & reporting can be found at: <http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/News/CON084915>
- 6) You adhere to the applicable R&D Standard Operating Procedures which can be found on <http://sharepoint/policies/default.aspx> under R&D
- 7) You notify R&D on completion of the project

The duration of this approval extends to the date specified in the IRAS ethics application form, except where action is taken to suspend or terminate the opinion or should your research not begin within 2 years of the approval date.

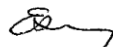
Pharmacy

Should your study require the dispensing of drugs, please do not commence work on the project until pharmacy has issued the green light, as per MHRA requirements (<http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/Frequentlyaskedquestions/index.htm>). The green light confirms that pharmacy has all procedures and documentation in place and can comply with the medicines management aspects of the study. The pharmacy team will email you the green light approval once the above is in place.

May I also draw your attention to the Research Governance Framework which can be found on the internet http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962 and remind you that all research within the Trust should be run to the standards as outlined in this document. Guidance and advice is always available from the Department of Research and Development should you require it at any stage of your project.

If you have any queries please do not hesitate to contact me.

Yours sincerely



Liz Adey
R&D Manager

cc: Dr Jane Yeomans – Academic Supervisor

Version 10.0 May 2012

To: **PATRICIA WOODS**

Subject: Ethical Application Ref: **pjw38-571f**

(Please quote this ref on all correspondence)

02/09/2013 15:06:40

Psychology

Project Title: **A different understanding of Autism: Exploring the use of autobiographical accounts in diagnostic assessment for a child with an Autism Spectrum Disorder.**

Thank you for submitting your application which has been considered.

This study has been given ethical approval, subject to any conditions quoted in the attached notes.

Any significant departure from the programme of research as outlined in the application for research ethics approval (such as changes in methodological approach, large delays in commencement of research, additional forms of data collection or major expansions in sample size) must be reported to your Departmental Research Ethics Officer.

Approval is given on the understanding that the University Research Ethics Code of Practice and other research ethics guidelines and protocols will be compiled with

- <http://www2.le.ac.uk/institution/committees/research-ethics/code-of-practice>
- <http://www.le.ac.uk/safety/>

The following is a record of correspondence notes from your application **pjw38-571f**. Please ensure that any proviso notes have been adhered to:-

Apr 23 2013 7:35PM As this study involves working with a vulnerable group a copy of the lead researcher's CRB check is included.

Jun 24 2013 5:13PM Dear Patricia,

The following changes are needed before your application can be approved:

-Your information sheets need to be much more specific with respect to what
the topic is that participants are being asked to share their views
about

-Your application needs to be much more specific about the specific topics
children will be asked to discuss. What are the specific discussion
prompts?

In particular, please revise you application so fill in the missing information (please pardon the caps):

-This will involve a range of approaches (SPECIFICALLY NAME THEM)
that are standard practice in this process, for example: play based
assessments (ASSESSMENTS OF WHAT EXACTLY?) and observation (OF WHAT?
WHERE WILL THE OBSERVATION TAKE PLACE?), standardised assessments (OF WHAT?), liaison with health and education practitioners (ABOUT WHAT?), and direct work with parents
regarding their concerns (ABOUT WHAT?). Assessment tools and
approaches are chosen in response to the presenting needs of the child
and family. It will also involve direct work with the child to elicit
their views and perceptions of their day to day experiences at home
and at school (WITH RESPECT TO WHAT?)

-Your application needs to make it clearer exactly what role professionals are playing in this research. What data are they providing?

-Evidence of gatekeeper approval from the multidisciplinary service is needed. Please upload to the online application.

-Has research been completed already without ethical approval? If not, please change the dates.

-Please change your course to PsyD

-Regarding the checklist, Item 11: This application needs to go to the NHS. But, if you want to avoid this, you should use the educational route to recruit participants rather than the medical/patient route. Doing so would mean that you wouldn't need to go to L Rec.

Aug 9 2013 12:08PM Dear Dr Flowe

Many thanks for the feedback, I have made the changes as advised.

--- END OF NOTES ---