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Listening to parents of children with autism: a qualitative study of 'how parents of children with autism perceive the experience of mainstream schooling'.

Doctorate of Educational and Child Psychology

(DEd CPsy)

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Abstract

This thesis sought to gather the experiences and perceptions of parents who have children with a diagnosis of autism and currently attend a mainstream school. Interpretative Phenomenological Analysis was used to explore the data from a qualitative and social constructionist perspective. A wide range of experiences and perceptions emerged despite the similarity of geographical location. Most parents had positive and supportive experiences of mainstream schooling although this was not unanimously the case. Some parents had poor experiences and raised questions and doubts concerning the efficacy of the current mainstream education system. Also highlighted, was the impact of having a child diagnosed with autism on, parental identity, wider relationships with family, friends and professionals.

This thesis argues that, for the parents in this research, parental participation was vital in order to meet the needs of their children and to enable inclusion within mainstream school. Parents achieved this participation by engaging emotionally, cognitively and behaviourally with their child's schooling. These actions also appear to have an important and positive effect on the child and their family.

Parents may be viewed as 'warrior parents' (Lamb, 2009) but this may suggest that parents want to fight for the needs of their child. This thesis suggests that the term 'advocate parent' may be more appropriate and may reflect the experiences and perceptions of parents. Therefore, improvements and adjustments to school policy, practice and procedures are encouraged to facilitate active parent participation.

Dedication

To Stephen, Charlie and William.

I would also like to thanks all those other people who offered their support, encouragement and assistance, not just in the completion of this thesis but throughout the course.

Final comment:

Once (adv.): enough Ambrose Bierce

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Introduction

Education is compulsory for all within the United Kingdom (UK) and for the majority this will mean attending school. Our laws determine that from the age of five until the age of sixteen (or eighteen) all children in the UK have to be engaged in some form of education. Consequently, for approximately thirteen years most children will attend a school or educational establishment that may have intense and long–lasting effects on every aspect of their development and future outcomes.

My position as a researcher is influenced by my personal experiences and beliefs as a mother and a professional. I believe in schools and the positive benefits and opportunities they offer. For me inclusion within school means more than merely being present within a school. It means all children enjoying a personal sense of welcome, happiness, achievement and belonging. I feel that inclusion within our schools is one aspect of developing a fully inclusive society. I do not agree with the de-schooling notion presented by Illich (1971), but having witnessed the unhappiness of some children's school experiences I have found my own pro-school and inclusive ideology challenged. I feel that more needs to be done to ensure that barriers to inclusion are reduced so all children can access the full range of opportunities available and have positive school experiences.

For many years the views of professionals have taken centre stage when discussing what is best for children with or without special educational needs. The dominance of the medical profession and the need to categorise children in order to provide suitable support and provision has also impacted on the power of professional voices (Billington, 2000). More recently insider accounts, legislation on eliciting children's views and the rise of the disability rights movements have raised the profile of individual voices within the sphere of special educational needs. However, gaps within research still remain and one of those appears to be the voices, views and experiences of parents. Whilst parental contribution is acknowledged to be important, it appears to be under utilised and under reported in research, policy development and practice (Runswick-Cole, 2008; Lamb, 2009).

The impetus behind this research has been drawn from a Local Authority's targets and a personal interest in autism, parental voice and the inclusion of pupils within mainstream schools. The Local Authority, in question, has encountered a rapidly increasing population of pupils with a diagnosis of autism. Therefore, the needs of children with autism and their parents have become an increasing priority.

Within the research process, I will explore the experiences of parents who have a child with autism within mainstream schools using a qualitative methodology, interpretative phenomenological analysis (IPA). IPA aims to increase the researcher's understanding of how participants view and experience their own world (Smith, 2004). Whilst it is acknowledged that through IPA a complete and true understanding cannot be attained, the IPA researcher engages both with the participant and the data (through interpretation) in such a way that an 'insider perspective is achieved' (Willig, 2001 p.67).

To this end I intend to explore parents' experiences of mainstream school inclusion for their children with autism. This may include the barriers to and the benefits of inclusion as well as how parents enable the inclusion of their child within mainstream schools. It is hoped that by sharing the experiences of parents (in relation to the inclusion of the children with autism) with schools and the wider Children and Young People's Services within a Local Authority, their policies, practices and procedures related to the inclusion of pupils with autism may be developed and enhanced.

I have chosen to explore one broad research question within this research process.

> *How do parents of children with autism perceive the experience of mainstream schooling?*

This broad research question aims to capture the richness, breadth and depth of parental experiences. I have chosen to focus on parents' experiences of their child's education within mainstream schools. Pupil and professional experiences and perspectives have been highlighted in existing research. I feel that parental perspectives of mainstream education for children with autism are under represented.

Inclusion is implicit within this research and is inferred through the emphasis on mainstream schooling. I feel that the term inclusion, although of key importance to this piece of research is now an over-used term, which can easily be misinterpreted. In other words, inclusion means many things, to many different people. It is a term that is not commonly used within wider society i.e. within everyday language. Inclusion could therefore appear to be professional *'jargon'*. By focusing the research question on parental experiences of their child's education within mainstream schools, inclusion will be implied but parents will be able to discuss and explore their experiences without the effect of professional terminology.

The research question has also been shaped by the epistemological stance that I hold. I acknowledge that I cannot claim to truly know and understand the experiences of parents who have children with autism. As a parent and professional, I have my own opinions and experiences of mainstream schools. I am aware that by researching and exploring these experiences I may affect the experiences being discussed. Thus, the position I take within the research is one of a social constructionist (Burr, 1995) that is established within social and cognitive psychology. I have sought to create a research process that is participant led (bottom up) and therefore driven by the data rather than by a hypothesis created by the researcher (top down). The research question is necessarily broad to ensure that I am able to undertaken a process driven by the data rather than by my own hypothesis or predetermined judgements.

Literature Review

Introduction

In terms of constructing an effective critical literature review I will begin by exploring the vast topic of inclusion. It will not be possible to give a comprehensive evaluation of such an immense area; rather subjects will be explored including key pieces of legislation, policy and research which have impacted on practice within the UK. Autism is clearly another strand, and again this a broad area of research. Due to the nature of this thesis, I am not able to include lengthy descriptions of autism or the many and various related conditions or to discuss the different hypothesis put forward to explain causes and treatments. I will focus on parental views and experiences, the social model of disability and research into policies and practice surrounding autism but related to school inclusion rather than inclusion within families or wider society.

Key Legislative and Research Developments for Inclusion

For several decades, the issue of inclusion has been at the forefront of developing education policy and practice in a number of countries (Visser and Stokes, 2003; Ainscow, 1997; Farrell, 2001). This movement has been endorsed globally through the Salamanca Statement (UNESCO 1994) that reflects the United Nations global strategy "Education for All". Within the UK, there has been an exceptional increase in the number of educational policies linked to inclusion since New Labour came to power in the 1990's (Roulstone and Prideaux, 2008). The Education Act (1993) requires Local Authorities to place children with special educational needs (SEN) within mainstream school. The Education Act (1996) (section 316 revision) took this policy a step further by making it more difficult for schools to deny access to pupils with SEN. In 2001 the SEN and Disability Act further amended the Education Act (1996) in order to positively promote the inclusion of SEN pupils. The Act made it clear that parental choice is a key factor in deciding the educational placement of an individual pupil.

The introduction of the Special Educational Needs and Disability Act in 2001 (DfES 2001) along with the accompanying SEN Code of Practice (DfES, 2001) and more recently the Disability Discrimination Act (DDA, 2005) aim to end the discrimination that many disabled people face. The DDA (2005) now gives disabled people rights in the areas of employment, education, access to goods, facilities and services and buying or renting land or property. The DDA (2005) now requires public bodies to promote equality of opportunity for disabled people. Under current legislation, autism is classed as a disability and is, therefore, covered by the DDA.

Whilst there have been considerable developments, in terms of inclusion, within education policy (UK), the law does not offer the right to an inclusive education. There is only a presumption in favour of mainstream, as discussed by Visser and Stokes (2003). The reality of mainstream education has also been questioned and scrutinized. In an article titled, 'Confusion about inclusion: patching up or system change?' Wendell (2008) explores the developments that have taken place over the last thirty years which have resulted in current inclusion legislation, policy and practice. He raises a number of key dilemmas which influence inclusion. These include the conflict between the standards agenda and inclusion, the issues of equal opportunities for all pupils and the notion of special provision. The main thrust of the article centres on the need for wide spread systemic change. Highlighting the fact that whilst there are pockets of excellent inclusive practice, these are set against conflicting policies and inflexible practices.

The subject of inclusion has also been the focus of research by Norwich (2008). He identified three basic dilemmas which influence how inclusion is implemented. Firstly, the identification dilemma relates to how and why children's SEN are identified. Secondly, the curriculum dilemma, the

National Curriculum is a common curriculum which is taught throughout the continuum of education provision; however, some argue that children with SEN would benefit from alternative curriculum objectives. Finally, the location dilemma applies to where children should learn, in other words the location of the educational setting and therefore whether it is mainstream or specialist. Norwich identified that there is a continuing role for special education but this should be inter-connected with mainstream schools and the mainstream educational process. However, Norwich's research focuses on teacher and professional opinions and does not take into account the views of other key stakeholders including children and parents.

Lindsay (2007) raises the question can inclusion ever be evaluated effectively? Firstly, the many stakeholders involved including academics, parents and schools have not ratified a single description or definition of inclusion. Secondly, the impact of different types of school setting and curriculum upon pupils has not been evaluated. Thirdly the impact of adult support for pupils with SEN varies enormously both within and between schools. Finally, the application and use of SEN categories varies throughout education and society as a whole. Together these factors greatly influence the scope and breadth of research on inclusion.

Roulstone and Prideaux (2008) raise an uncomfortable reality. Whilst policies have been introduced, little has changed for disabled children within mainstream school. They state that:

> On two key measures of the number of disabled children educated in mainstream contexts and the number of school exclusions affecting disabled children, there has been little change.
> (Roulston and Prideaux, 2008, p.16)

Within their article, Roulstone and Prideaux (2008) link New Labour's inclusion ideology to that of functionalism. Functionalism proposes that social systems and their institutions have been born out of the developing and complex industrial society. Functionalism would suggest that education is valuable only to those who have the capacity to undertake paid employment. How does this view fit with the notion of inclusion and special educational needs, when many disabled adults are unable to engage in paid employment? They suggest that New Labour's inclusive policy has failed to critically appraise this stance in terms of reviewing education holistically, in order to clearly understand who education is for and for what purpose.

The key thrust of this piece of research is to maintain the momentum that has been built up behind the notion of inclusive education. Continued debate is required on the principles of inclusion and the way in which inclusion and diversity is celebrated. Successes of inclusion need to be shared and disseminated in order to embrace the wealth of knowledge which already exists. As stated by Roulstone and Prideaux (2008, p17), 'disabled children need more not less inclusive education'. This may suggest that in order to continue to drive the inclusion agenda forward, inclusive policies and practices within education need to be promoted, extended and expanded.

Definitions of Inclusion

Recent government legislation has indicated that:

> Inclusion is about the quality of children's experiences: how they are helped to learn, achieve and participate fully in school.
> (Removing Barriers to Achievement, DFES 2004, p. 6)

It also suggests that:

> All teachers should expect to teach children with special educational needs (SEN) and all schools should play their part in educating children from their local community, whatever their background or ability.
>
> (DFES, 2004, p.5)

Within government policy, the aims of inclusion and inclusive policies are stated as follows:

- Inclusion is a process by which schools, local education authorities and others develop their cultures, policies and practices to include pupils.
- With the right training, strategies and support, nearly all children with SEN can be successfully included in mainstream education.
- An inclusive education service offers excellence and choice and incorporates the views of parents and children.
- The interests of all pupils must be safeguarded.
- Schools, local education authorities and others should actively seek to remove barriers to learning and participation.
- All children should have access to an appropriate education that affords them the opportunity to achieve their personal potential.

(DFES, 2001, p.2)

Government policy may be viewed as wide-ranging and extensive in its nature. Policies and definitions extend to all areas of schools' foci from the curriculum, to key stakeholders, to access and choice. This reflects the rapid expansion of policy documentation over recent years. However, despite this policy rhetoric, the impact of these national policies on schools, parents and children has yet to be demonstrated through research.

Many definitions of inclusion have been put forward from research. Booth and Ainscow (2002) suggest that inclusion is two separate but inter-linked processes. It is a process of increasing the participation of the learner in, and reducing their exclusion from, the curriculum, cultures and communities within mainstream centres of learning. This definition is used within the Index for Inclusion (Booth et al., 2000) which is a set of materials designed to contribute to the development of inclusion within a school.

Humphrey (2008) conceptualises inclusion as presence, acceptance, participation and achievement. For a school to be fully inclusive Humphrey (2008) suggests that all four conditions need to be applied to all children regardless of their abilities, ethnic origin, social class or gender. My own personal beliefs and values around inclusion would fit with Humphrey's (2008) view of inclusion being more than mere presence. It is about an individual feeling valued and being encouraged to realise their potential, whatever their ability, values or preferences.

Whilst being major proponents for inclusion, Lindsay and Thompson (1997) raised a cautionary note towards the current themes within inclusive education. They stated that:

> Promotion of inclusion needs to take account of other values. Is it more important for a child to be educated in a local school or to be educated well?
>
> (Lindsay and Thompson, 1997, p.57)

Hornby (1999) argues against what he sees as a 'one size fits all' approach to inclusion', (Hornby, 1999, p.157). He claims that the focus should be on the needs of the individual rather than attempting to create a definition, or policy of inclusion which focuses on the general rather than the individual.

Hornby (1999) may be suggesting that some researchers present broad theoretical arguments which negate the experiences of individuals and potentially work against the needs of individual pupils.

What is the Impact of Inclusion on Schools and Families?

The impact of inclusion policy on schools and families has yet to be fully addressed through research. This may be as a result of the complexities of researching inclusion as it encompasses a myriad of different policies, practices and procedures that in turn have a wide-ranging effect upon individuals, families, wider systems and societies.

Runswick–Cole (2008, p.172) points out that on one crude measure of inclusion (the numbers of children attending special schools and mainstream schools) there has been little progress. In 1974, 1.3% of pupils attended a special school. By 2004 that figure had only fallen slightly to 1.1% of pupils. Therefore, despite the changes within both legislation and education there has been little change in the number of children attending segregated special schools.

However, the real numbers may never be accurately established. As special schools have closed, specialist units have been established. These units may be attached to mainstream schools meaning that children are on the role of a mainstream school but it does not necessarily follow that they will access the same provision as their mainstream peers. OFSTED (2004) indicated that pupils within mainstream units had very limited opportunities for interaction with mainstream peers. OFSTED (2004) also suggested that only a minority of schools were successfully meeting the needs of pupils with SEN and teachers were continuing to make insufficient adaptations in order to promote inclusion.

Research has also sought to reflect the views of parents. Hartas (2008) points out that parent participation within schooling, both mainstream and special, is essential to the overall success of pupils. He raised the issue of shared responsibility and accountability suggesting that these notions were crucial to improved communication between parents and schools.

> The nature of parental participation in children's education is changing rapidly. A growing body of research points to the positive effect that parental involvement has on outcomes of schooling and on children's well-being.
> (Hartas, 2008, p. 139)

Key Areas of Research within Inclusion

Inclusion has generated a plethora of research articles and publications. Research articles have explored both specific and broad aspects of inclusion, providing accounts of good practice, ethical debates, and the conversion of values into practice and policy. A large number of studies have focused on the impact of inclusion on a small number of pupils with SEN or additional needs (Kasari et al 1999; Leyser and Kirk, 2004). There are fewer articles and publications seeking to tackle inclusion from a whole school or systems perspective (Farrell, 2001; Norwich, 2008; Wendell, 2008).

Other researchers favour exploring the complex social factors, which permeate inclusion and exclusion. For example, Moran and Abbot (2002) obtained the views of practitioners in special and mainstream schools on inclusion (in Northern Ireland). They concluded that two factors were of key importance to the participants within the research study. Firstly, they suggested that initial teacher training and in-service training needed to be improved (focusing on the management of other adults in the classroom). Secondly, they suggested that teachers and teaching assistants should clarify their roles and responsibilities within the classroom in order to promote an inclusive learning environment.

Lindsay (2007) reviewed fourteen papers published across eight different publications from 2001 to 2005 in order to identify comparative outcome studies for children with some form of special educational need. Overall there was scant evidence from appropriate studies. He found no obvious evidence for a positive effect of inclusion. Where a positive effect was evident, it was minor. Thus he points towards the need for more research into the most favourable education for children with SEN in order to develop an evidence base for education policy and practice. Lindsay (2007) suggests that the drive in policy change has been propelled by a desire to promote children's rights and to promote social inclusion rather than being based on research evidence.

In spite of the many developments, and a social shift in focus away from integration and towards inclusion, the challenge for the future appears to be, how schools can embrace inclusion through reducing barriers to learning, culture and society, whilst still maintaining standards (Farrell, 2004). Inclusion remains a complex and controversial issue that tends to generate heated debates (e.g. Brantlinger, 1997). Similarly the notion of 'inclusive schooling' remains, complex, ambiguous and contested (Dyson et al., 2004; Farrell and Ainscow, 2002; Farrell, 2004). The challenge is no longer how to integrate pupils with additional needs in to mainstream school; but how to meet the needs of these pupils using inclusive practices, (Booth and Ainscow, 2002).

Inclusion and the Social Model of Disability Theory

The notion of a social model of disability is almost twenty years old. It was a reaction against the dominant medical and individual models of disability in which disability is located within the individual. To some, disability has become an:

> Artificial and exclusionary social construction that penalised people with impairments who did not conform to social and cultural expectations of appearance, behaviour and economic performance.
>
> (Tregaskis, 2002, p. 457)

The social model of disability is a direct challenge to these traditional assumptions. It defines disability as the product of social, cultural and economic structures. It is suggesting that, disability does not result from the difficulties an individual has, but the difficulties that an individual has within society. In essence, society needs to change and adapt rather than the individual having to adapt to fit in with the mainstream expectations. The World Health Organisation (WHO, 2002, p.18) supports this position and goes further by suggesting that reacting to the issues of disability is 'the collective responsibility of society at large'.

Therefore, within the social model of disability, disability is seen as a construction of society and not the individual. The social model of disability has been used to promote disability rights and has in turn been used to advocate for the removal of barriers (which prevent access) to mainstream society, culture and employment. This perspective has tended to focus on physical access and access to training and employment. The weight of this model has influenced education policy and practice as well as the much wider society both nationally and internationally.

Whilst the social model seeks to challenge society other researchers feel that individuals should be encouraged and supported to adapt within society. This appears to be true of a number of researchers working with people who have an autism diagnosis. Jordan (2008) envisages an inclusive model of education in which equality is accomplished through recognition and celebration of diversity. In explaining the impact of education on individuals she describes education as a 'treatment for autism' (Jordan, 2008, p.11). Therefore, rather than changing society to fit in with individuals, as the social model of disability would suggest, Jordan presents a view that through socialisation, education and schooling pupils with autism learn to adapt and exist within society rather than within a specialised environment.

> Education is more than just another treatment. It is the way citizens are taught the values, understanding, knowledge and skills that will enable their full participation in their community: it is the gateway to full social inclusion.
>
> (Jordan, 2008, P.11)

Autism

From the first description of autism, parental views have been essential in advancing research. Leo Kanner (1943) endorsed the meticulous notes provided by parents as his primary research source. Kanner (1943) noticed that some children experienced difficulties in relation to the understanding of language, communication and social interactions. His research led to the notion of autism which has been expanded to the autistic spectrum condition which includes a number of related difficulties.

Parents helped move research on the genetics of autism forward throughout the 1990s, and during the early 21st century, parental groups have pushed for increased funding for autism research, support and intervention. Parents have often supported research in the course of considering hopeful interventions for their own children. Although some popular treatments may appear to be the result of a frantic search for solutions by desperate parents, it is important to remember that these approaches have also generated reliable and consistent knowledge about autism.

The history of parental involvement with autism research suggests that each parent is an invaluable source of information and localised expertise, not only about their own child but also about autism in general. However, research in the field of autism continues to be dominated by professionals engaged in a search for theoretical understanding.

Pupils with a diagnosis of autism experience difficulties in relation to the understanding of language, communication and social interactions, also known as the triad of impairments (Wing and Potter, 2002). These difficulties may increase their overall vulnerability, exposure to bullying and social isolation (National Autistic Society (NAS), 2006). It is also likely that the preference for routines, low sensory environments and high incidence of sensory integration difficulties amongst pupils with a diagnosis of autism creates challenges to both pupils and teachers within busy, noisy and changeable school environments.

Anecdotal accounts of the number of people with autism in the UK may suggest that there are over half a million people (with autism) out of a total population of around 60 million. Accurate figures are difficult to ascertain as identification and diagnosis have changed over time, along with the way in which information is collated and stored.

> The true incidence of autism spectrum disorders is likely to be within the range of 30-60 cases per 10,000, a huge increase over the original estimate 40 years ago of 4 per 10,000.
>
> (Rutter, 2005, p.3).

Accurate figures on the prevalence of autism are difficult to ascertain. Wing and Potter (2002) reviewed a number of published studies into the incidence of autism. They suggest that early estimates underestimated prevalence. The noticeable rise in numbers is, they suggest, due to improved diagnosis and greater awareness. Over time, diagnostic criteria has been developed and refined as more information about autistic spectrum conditions has become available. Reliable methods for identifying autism have been widely disseminated which has created better public awareness of the disorder.

Wing and Potter (2002) noted that the estimates in recent studies have had widely varying results. They suggest that different groups of researchers interpret diagnostic criteria in a disparate manner which has implications when disseminating and critically evaluating research data. Regardless of this, practically every recent study of prevalence produced estimates of the disorder that are much higher than the original 2-4 per 10,000 children. Wing and Potter (2002) also noted that there is no empirical evidence for an environmental cause of autism (e.g. MMR vaccine, mercury poisoning, and inflammatory bowel disease). They conclude by suggesting there is no clear answer as to whether there is a true increase in the incidence of autism (due to more individuals being born with autism), or rather there are more individuals being identified and diagnosed. The key point, which arises from the research, is that there are more youngsters with the diagnosis which makes addressing the issues surrounding autism an increasingly urgent priority.

Mainstream School Inclusion and Autism

There has been some research in the area of inclusion for children with an autism diagnosis. Research has looked at systemic issues for inclusion, professional views, specific policies and practices and more recently pupils' views and insider accounts.

Dybvik (2004) recognised the increasing impact on schools of the increasing numbers of pupils with autism. Two major points can be drawn from Dybvik's (2004) research. Firstly, the need for co-ordinated planning and staff training which recognises individual need rather than a principle of inclusion at any cost. Secondly, the need for raising peer awareness of autism to encourage social acceptance.

Humphrey (2008, p.42) found that the 'gap between inclusion rhetoric and classroom reality was very wide in some schools'. Humphrey (2008) sought to explore whether government inclusion policies had been fully realised in schools by exploring the pupils' and teachers' experiences of inclusion. Humphrey highlighted the limited amount of research in this area and sought to explore the barriers to inclusion for pupils with autism. This small case study approach identified that clear channels of communication extending from senior management to class teacher and vice versa, a shared clarity on roles and responsibilities and recognition of individual needs are all crucial to successful inclusion.

In a separate study, Humphrey and Lewis (2008a) explored the views of pupils with autism and the difficulties facilitating their learning within mainstream schools. This study used semi structured interviews and pupil diaries to explore pupils' experiences of education. The study indicated that pupils (with autism) want to be able to fit in with their peers but this process was inhibited by negative pupil perceptions of their differences. This links back to Dybvick's (2004) suggestion that raising peer awareness of autism would be beneficial and supportive for the inclusion of individuals with autism.

Despite the increasing numbers of pupils with an autism diagnosis in mainstream schools and the plethora of research in both inclusion and autism it appears that:

> The process of facilitating their (pupils with autism) learning and participation remains a complex and poorly understood area of education. (Humphrey, 2008, p.46)

Parental Views on Inclusion

The Warnock Report (1978) is often seen as initiating a shift in policy towards inclusion within the UK. These developments within policies sought to strengthened parental rights to express their preferences and, at least in theory, to make choices and decisions for their children. However, in her recent paper, Warnock (2005) appeared to withdraw her previous advocacy of inclusion and instead argued for alternatives to mainstream provision. This report specifically highlighted and purported the views and experiences of parents of children with autism as a key factor in changing Warnock's views on inclusion. Thus, inclusion cannot be considered in isolation from the consideration of politics, disability and impairment (Slee, 2001).

Within the UK, parents are offered a choice of possible schools, but once their child is situated within a particular school, either mainstream or special, do parents have any influence on how the inclusion agenda is approached and put into practice?

Leyser and Kirk (2004) found higher levels of support for mainstream school inclusion amongst parents of children described as having mild retardation, and amongst parents of young children with mild SEN difficulties. They indicate that parents of older children and those with severe difficulties are more likely to be less supportive of inclusion in mainstream schools. Kasari et al. (1999) found that parents of children with Downs Syndrome are much more likely to support inclusion in the mainstream than parents of children with autism. Kasari (1999) suggests that this difference is due to the diverse needs of children (needs of children with Downs Syndrome compared to children with autism) with different diagnoses.

A study by the NAS (Barnard et al., 2000) found higher rates of satisfaction amongst parents whose children attended autism specific specialist provision, compared with lower levels of satisfaction amongst parents whose children attended mainstream school. However, (Barnard et al., 2000) one must note that this research was funded by the charity which also provides the majority of specialist autistic educational placements, which raises serious concerns around potential bias and lack of objectivity.

It is clear that parents hold conflicting and multifarious views on inclusion. Runswick-Cole found that 'in the context of a SEN tribunal, 'parents often focused on securing a mainstream or special school placement for their child' (Runswick-Cole, 2008, p172). Runswick-Cole also indicates that whilst parents' views on the merits or otherwise of special schools or mainstream education are divided, 'they united in the feeling that the issue of inclusion was one where the stakes were high and possible gains and losses great' (Runswick Cole 2008, p.179).

For parents whose children have SEN, feelings surrounding schooling can become complex and conflicting due to perceived (parental perceptions) difficulties and vulnerabilities. The British Council of Disabled People (BCODP, 2005) stated that parents should not be able to choose the type of education for their children The BCODP suggests that professionals would be better placed to make these complex decisions. The reason given by the BCODP suggests that parents are unable to see the potential for their child to be educated in mainstream schools. Are they suggesting that parents cannot be objective? The BCODP also suggested that parents might fear the views of professionals, a suggestion that is backed up within the research of Hodge and Runswick Cole (2008).

The BCODP and Hodge and Runswick-Cole (2008) highlight the role parents have been given within government documentation. They point towards the notion of 'informant' as suggested within the Code of Practice (DFES, 2001):

> By positioning parents as informants this may also reflect the assumption within policy that the decision making power lies elsewhere; parents inform professionals who then decide upon the best course of action.
>
> (Hodge and Runswick-Cole, 2008, p. 180)

The main thrust of this research (by Hodge and Runswick-Cole, 2008) established that some professionals continue to exert their identity as the 'expert' and consider parental views as flawed by being over-emotional and ill informed. Instead of working in partnership with professionals many parents are frustrated by their interactions with professionals who want to hear about a disability and not about their child (Hodge and Runswick–Cole 2008).

Parental Views of Inclusion for their Children with Autism

In his article entitled, 'Provision for youngsters with autism in mainstream school: what parents say and what they want', Whittaker (2007, p.176) states that:

> Relatively little research has focused on parental perceptions and experiences of educational provision in mainstream settings.
>
> (Whittaker, 2007, p.176)

This questionnaire based study sought to gain the experiences, views and attitudes of all parents/carers of children and young people with autism, within one English county. The response rate was almost 50%. Parents were then divided into two groups; satisfied parents (61% of respondents) and dissatisfied parents (39% of respondents). Whittaker (2007) sought to uncover the similarities and differences in experiences, views and attitudes between these two groups. A number of key themes emerged from the information. The two factors which most sharply divided parents were the extent to which the school understood or empathised with their child's individual difficulties and the perceived flexibility of the schools' responses to those difficulties. A further factor was the extent and quality of reciprocal home and school communication. Taken together, positive responses in these areas appeared to be associated with greater satisfaction amongst parents.

Whilst Whittaker (2007) provides a number of clear themes amongst parental perceptions, he also raises a number of methodological questions. Research within the area of autism has mainly concentrated on samples of parents from existing parenting groups rather than an overall sample of all parents and carers who have children with a diagnosis of autism. Whittaker (2007) sought to sample parents from a wider context and yet only included parents of children diagnosed with autism; thus excluding children and families not yet diagnosed or diagnosed with related conditions or atypical conditions.

The main area of concern surrounding the research presented by Whittaker (2007) is how the author separated the respondents into 'satisfied' and 'not satisfied'. An initial question was posed for parents which included a four-point scale. Within this first question, they were asked to rate their overall satisfaction with the education and support being given to their child. Respondents who rated 'very dissatisfied' and 'dissatisfied' were then collapsed into a 'dissatisfied' group and 'satisfied' and 'very satisfied' were collapsed into a 'satisfied' group. Therefore, both the question and the method used could be called in to question as being limited. The question appeared to be unclear; were they asked to consider the context of the present situation or think generally over their child's whole education career to date? The process seems to be unnecessarily arbitrary and subjective.

Studies exploring inclusion and parental experiences have included samples of parents whose children have a wide range of difficulties.

Therefore studies have tended be either highly specific, and therefore difficult to generalise, or have been too broad to draw concise conclusions.

Summary

Kanner (1943) and other psychologists, educationalists and practitioners have recognised that the views and experiences of parents are crucial to the success and failure of children within mainstream school. As the recent Lamb report (2009) identified:

> Parents and carers of children with special educational needs can too readily be seen as the problem and as a result parents lose confidence in schools and professionals. As the system stands it often creates 'warrior parents' at odds with the school and feeling they have to fight for what should be their children's by right, conflict in place of trust.
>
> (Lamb, 2009, p.2)

The Lamb report talks of parent confidence. When parents have open lines of communication their confidence in the school and provision within that school tends to be high and this positively influences pupil development. The main recommendation from this report suggests that relationships with parents should be placed at the very heart of policy and practice. Thus, Lamb is highlighting the significant role that parental views and experiences can have on pupil progress and enabling inclusion within schools.

This research process seeks to combine the vast areas of inclusion, autism and parental voice and influence. One research question has been chosen which seeks to encapsulate the extent and magnitude of parental experiences of mainstream schooling, and therefore for the inclusion of their child with autism. The broad question is:

> *How do parents of children with autism perceive the experience of mainstream schooling?*

Methodology

Introduction

Within this chapter, my epistemological position will be explored. I will discuss how this has shaped the methods and methodologies utilised within this research process.

As a trainee educational psychologist (TEP) I have spoken to some parents about the inclusion of their children with autism and this has influenced my personal views as well as my professional practice. I was a teacher for some six years and I am also a parent of two small boys under the age of five, the eldest of which has recently started school. I firmly believe that schooling should provide a safe environment in which children can experience a range of academic, social and emotional experiences, which allow them to develop and grow. Schooling should not be purely about learning or about attainment and achievement in exams. As a teacher, parental involvement was not high on the extensive list of day-to-day priorities and was therefore sadly neglected. Yet, even with this knowledge, I have been amazed at how little information, I as a parent have received about the activities and experiences my child encounters on a daily basis.

As a teacher I am able to use my previous experiences in order to predict the events of the school day (with some accuracy) much to the amazement of my son. Without this prior knowledge, I am sure that I would feel quite lost and anxious. Therefore, I can appreciate how parents (of children with special educational needs) may feel worried and anxious as their children encounter a school environment.

As a teacher, I can recall being so engrossed in the day by day tasks involved in teaching (planning, lesson preparation and marking) that communicating with parents became an after thought and inconsequential. In other words, communicating with parents was simply not a priority.

Together these different experiences have created a basis upon which my current personal opinions have been constructed. Whilst I feel it is crucial to acknowledge and utilise these experiences within the research process I did not want to begin the research from this position. I wanted to create an inductive, 'bottom up' research process that, whilst acknowledging my own preconceptions, is driven by the descriptions, experiences and narratives presented by the parents. Through a reflexive process I wanted to be able to be implicated within the research process whilst also remaining true to the data. As Willlig (2001) notes:

> Reflexivity requires an awareness of the researcher's contribution to the construction of meaning throughout the research process. (Willig, 2001, p.9).

A Rationale for using Qualitative Methods

I am interested in the way qualitative methodologies are 'concerned with the quality and texture of experience, rather than the identification of cause – effect relationships' (Willig, 2001, p9). As a psychology undergraduate I conducted many experiments based purely upon quantitative methodologies in which I distanced myself from the participants and the processes. As a doctoral student undertaking a small-scale project of my own I was interested in the ability to immerse oneself within the entire research process, a characteristic, which qualitative methodologies support and promote. I also valued the opportunity to complete a piece of research using a process that I would otherwise not have been able to utilise.

My approach to qualitative research methods is encapsulated in this statement by Ward–Schofield (1993):

> At the heart of the qualitative approach is the assumption that a piece of qualitative research is very much influenced by the researcher's individual attributes and perspectives. The goal is not to produce a standardised set of results that any other careful researcher in the same situation or studying the same issues would have produced. Rather, it is to produce a coherent and illuminating description of a perspective on a situation that is based on and consistent with detailed study of the situation.
> (Ward – Schofield, 1993, p.202)

The final sentence from this quote is an accurate description of how I view qualitative research and therefore how I perceive my own research process. I intend to elicit rich descriptions from parents concerning their experiences as parents of pupils with autism in mainstream schools and to consider, explain and represent these in an accessible and constructive format. It is my intention that through sharing these experiences the profile of parental experiences and autism will be raised and this may influence developments in both my own personal practice and within the LA. Therefore, a qualitative method appears to be the most appropriate for this research process as the rigidity of quantitative methodologies preclude the recognition of the depth and richness of individual voices.

Social Constructionist

This theoretical perspective acknowledges that there are different versions and interpretations of reality rather than a single truth (Berger and Luckmann, 1966). The emphasis is placed on individuals making sense (actively constructing knowledge) of their own world through social, cultural, linguistic and historical, influences (Willig, 2001). Taking this stance, therefore, assumes that individuals will view the world differently depending on their own interpretations of those influences.

Within the sphere of qualitative research, a social constructionist perspective is of great importance as it recognises that language as well as social, cultural and historical influences are significant facets to knowledge. A single phenomenon may be described in different ways, therefore different views, perceptions and constructions of the phenomena exist, none of which are true representations, merely different versions.

> It is through the daily interactions between people in the course of social life that our versions of knowledge become fabricated.
> (Burr, 1995, p.4)

As a qualitative researcher it is imperative to recognise that data is not a 'true' representation, but a representation provided by that participant, at that particular time. This contrasts strongly with traditional positivist research which seeks to identify true and objective knowledge.

As a result, social constructionist notions of reality challenge traditional positivist research objectives. In particular the assumption, from a traditional positivism position, that there is only one true view of the world whereas 'social constructionism cautions us to be ever suspicious of our assumptions about how the world appears to be' (Burr, 1995, p.3). In other words there is no truth, merely different versions of a phenomena.

Qualitative methods of research recognise that the researcher is not unbiased or disconnected from the research but fully involved and influential within it. The qualitative researcher understands that their interpretation of the phenomena in question is of key importance to the completion of the research process. To assume that the findings from one piece of research can be replicated in another is improbable and unrealistic. Therefore, within qualitative research the notion of reliability may be considered inappropriate. The social world is complex and unpredictable. The views and experiences of participants, as well as the interpretations of researchers, are not static. The aim of qualitative research influenced by a social constructionist perspective is to present insight and understanding and not to predict or control (Berger and Luckmann, 1966).

The Search for a Research Methodology

A range of qualitative research methodologies were considered, these included Discourse Analysis (DA), Content Analysis (CA), Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA).

CA identifies statements within data in order that they can be grouped together to answer specific research questions, but does not contemplate what is intended by the term or the significance of that term to the participant (Parker, 2005). CA has been successfully used within doctoral research projects and is a useful tool when mixed data collection methods are being employed. However, I wanted to avoid having set research questions which would constrain the research process with pre-determined thoughts and ideas. I sought to start at a position of uncertainty and curiosity, unsure of the themes and subject matter, which may emerge. I wanted to be able to do more with the data than, I felt, CA would allow. In other words, I sought to look behind what the participants were saying in order to investigate the experiences of the individuals. I wanted to be able to explore the data in such a way that I was illuminating the words of the participants rather than describing the data gathered.

GT as a methodology can provide the researcher with a deep understanding of a phenomenon through a process of sampling and analysing data until a theoretical saturation point has been reached and new theory or knowledge has been produced.

> Grounded Theory as a method provides us with the guidelines on how to identify and categorise, how to make links between

> categories and how to establish relationships between them. Grounded Theory has a theory as the end product of this process; it provides us with an explanatory framework with which to understand the phenomenon under investigation.
> (Willig, 2001, p.33).

I found this concept interesting, as it appeared to fit within the aims of my research process, insofar as being a qualitative methodology that can be applied to small sample sizes. However, I was unsure how I would approach the issue of theoretical saturation point. Glaser and Strauss (1967) indicate that researchers need to keep sourcing data until there comes a point where no new data is added. As this research is limited by both capacity (time scale, word length) and experience (I am a complete novice in terms of research skills) I am unsure how to approach the uncertainty of a theoretical saturation point within GT.

DA is grounded within a social constructionist approach and takes language as a key aspect for understanding an individual's construction of reality.

> Whereas other qualitative methodologies work to understand or interpret social reality, as it exists, discourse analysis endeavours to uncover the way in which it is produced.
> (Philips and Hardy, 2002, p.6)

IPA shares with DA a commitment to the importance of language and qualitative analysis. However, DA suggests that understanding is produced through consideration of the language the participant has used. Therefore the emphasis is placed on understanding how language or talk constructs meaning rather than focusing on the actual experience of the phenomena as described by the participant to the researcher. IPA emphasises cognition rather than language. It assumes there is a link between physical being, cognition and verbal responses (Smith, 1996) an assumption which is not drawn through DA.

Research is messy, chaotic and awkward. There are no certainties or truths. There is no single path which results in a perfect outcome but as a researcher, choices, decisions and actions need to be taken. IPA was the chosen methodology for this piece of research because it fitted with the research aim of exploring the lived experiences of participants whilst allowing the researcher to acknowledge their own interpretations of the phenomena. This choice was also based upon the research of Smith, Flowers and Larkin (2009) who emphasise IPA as an appropriate methodology for an in-depth exploration of phenomena that hold significant meaning.

The research question posed seeks to explore the experiences of parents who have children with autism attending mainstream schools. Other methodologies have been reviewed but it is the emphasis on lived experiences which makes IPA a fitting, appropriate and accepted methodology to answer the research question.

Interpretative Phenomenological Analysis (IPA)

The foundations of IPA are to be found within both philosophy and psychology. IPA originated, not in one single theory or body of knowledge, but from several. A number of the assumptions upon which IPA is based are drawn from a social cognition paradigm in social psychology (Smith, 1996). Elements of these foundations are a response against traditional empiricism, which looks for observable relationships, cause and effect (nomothetic), whereas IPA seeks to move towards a more idiographic approach. It aims to increase the researcher's understanding of how participants view and experience their own world (Smith, 2004).

As a methodology IPA fits within a qualitative framework. It provides a flexible framework for understanding and exploring first person accounts, personal experiences and opinions. IPA typically uses semi-structured interviews as its mode of data collection although focus groups, observations and diaries have also been used. It fits within a (less strong form of) social constructionist framework (Smith, Flowers and Larkin, 2009, p.196) as it acknowledges that experiences are shared and created between, and within, individuals. Therefore, IPA views experiences as a construction of personal perspectives merged together with linguistic, cultural and societal influences. Three main areas of philosophy and psychology influence IPA research; these are phenomenology, hermeneutics and idiography.

Phenomenology is the philosophical study of experience (Giorgi, 1997). It values the lived experiences of the individual, focusing on the details (the particular) as well as the general. Traditionally, philosophers who have explored phenomenology have tended to explore experience from their own point of view whereas IPA researchers are exploring the experiences of others. The key idea for IPA is one of a desire and commitment to understanding and thinking about experience. Through phenomenology the researcher may identify that:

> The complex understanding of experience invokes a lived process; an unfurling of perspectives and meanings, which are unique to the person's embodied and situated relationship to the world.
> (Smith, Flower and Larkin, 2008, p.21)

Some of the philosophical roots of phenomenology can be found within the work of Husserl (1982). Husserl focused on the transcendental and sought to use experience and first person accounts to understand consciousness itself. Whilst these radical claims have never been verified or confirmed, Husserl's work raised two key ideas, which remain, pertinent to IPA. The first key factor suggests that experience is worth understanding. Secondly, that there are processes by which preconceptions can be removed so individuals can explore experience itself. Husserl termed this phenomenological 'abstraction' (Husserl, 2001) and indicated that through a systematic process of phenomenological reduction, a researcher might suspend their general philosophical beliefs about the external world, and be able to examine the phenomena in question as though they had just been given consciousness.

Merleau-Ponty (1962) took a different view, suggesting that we as humans are always in our experiences therefore we cannot separate ourselves from them. This notion he termed the embodied nature of human experience whereas Heidegger (1927/1962) talks of 'worldliness' both of which are key elements of existentialism. In terms of IPA research this introduces the notion that humans are meaning making beings who, by sharing their experiences, are gaining a clearer and more comprehensive understanding or essence of their own lives.

Husserl's work has influenced a number researchers and theorists within philosophy and psychology. However, his contemporary Heidegger, who was one of Husserl's students, introduced a number of key concepts which increasingly influence IPA. Heidegger (1927/1962) introduced the notion of hermeneutics, the second key philosophical area upon which IPA is based. Hermeneutics suggests that the researcher cannot explore experiences without interpretation. Therefore hermeneutics is the theory and study of interpretation and as such is concerned with the purpose and methods of interpretation. As Moran (2000) points out:

> Phenomenology is seeking after a meaning which is perhaps hidden by entity's mode of appearing. In that case the proper model for seeking meaning is the interpretation of a text and for this reason Heidegger links phenomenology with hermeneutics. How things

> appear or are covered up must be explicitly studied. The things themselves always present themselves in a manner which is at the same time self-concealing.
> (Moran, 2000, p.229)

Hermeneutics draws attention to how we as humans are sense making and interpreting individuals and explores language as a means of understanding and sharing experiences. This reflects the influence of symbolic interaction within IPA (Denzin, 1989). Symbolic interaction promotes the central and indistinguishable role language and culture play in constructing ourselves. Heidegger (1927/1962) suggests that active interpretations are a constant and ongoing activity which all humans are engaged in.

The notion of categorisation would suggest that humans tend to group objects together into categories to aid understanding. This is a fundamental premise within cognitive psychology. In other words, humans are continually interpreting and defining their own environment through categorising it (categorisation). This process is an ongoing innate human activity. Within IPA research, by engaging with a first person account that has been generated through a shared experience (through talking), the researcher is listening to the account provided by the participant and then interpreting the account through their own eyes (but with a commitment to remain grounded in the data) thus combining phenomenological and hermeneutic assumptions. In other words:

> The participants are trying to make sense of their world: the researchers are trying to make sense of the participants trying to make sense of the world.
> (Smith and Osborne, 2003, p.51)

The final area of philosophy upon which IPA is grounded is that of idiography. In taking an idiographic approach IPA focuses on the particular, on the details. This occurs in two main ways, firstly through the detail and depth of analysis afforded to the transcripts. Secondly, this occurs within the commitment to describe and understand the particular experiential phenomena from the perspective of a particular person within a particular situation. Idiography appears to be a key aspect when exploring validity within IPA research.

Summary of Interpretative Phenomenological Analysis

IPA is a distinct methodology grounded within philosophy and psychology. It draws strongly on phenomenology, hermeneutics and the idiographic. At its core, it is dedicated to the detailed exploration of lived experiences. IPA aims to express these experiences in a natural and representative manner, free from a priori hypotheses and category systems. Heidegger (1927/1962) brings the notion that to understand experience the researcher must interpret the phenomena or experience. In this sense IPA synthesizes interpretation and hermeneutic inquiry alongside phenomenology. IPA also pursues a commitment to exploring in detail the experiences of the participants thus drawing in idiographic analysis.

The premise for IPA starts as a response against empirism. Rather than looking for causal relationships and testing hypotheses, IPA emphasises the role that understanding experiences plays in helping us understand our world. Consequently, the researcher focuses on the individual, as they are the experts of their own experiences. As Hallig (2008) suggests:

> In everyday life each of us is something of a phenomenologist insofar as we genuinely listen to the stories that people tell us and insofar as we pay attention to and reflect on our perceptions.
> (Hallig, 2008, p.145)

IPA seeks to access experiences through a process of 'intersubjective meaning making' (Smith, 2004). In other words, the account given by the participant provides an insight in to the phenomena in question. The researcher engages with this account reflexively as they must acknowledge and set aside their own preconceptions, experiences and assumptions in order to explore the phenomena from the point of view of the participant. Conrad (1987) suggests that an IPA researcher is trying to access an insider perspective, to understand what it is like to walk in the footsteps of another human, whilst acknowledging that this is never completely possible.

Critique of Interpretative Phenomenological Analysis

In critiquing IPA one must look at the central aims and assumptions upon which IPA is based. This includes the importance of language, the type of knowledge IPA gathers and its reliance on verbal accounts of a phenomenon.

When addressing the importance of language within a research process one must consider the way in which the data (language) is collected. IPA research is based on the study of transcripts which provide an opportunity to understand a participant's experience of a particular phenomenon (phenomenology). It relies on participants conveying their experiences through language, thus language is seen as the tool or vehicle through which experiences are captured. Therefore, it can be argued that IPA depends on 'representational validity of language', (Willig, 2001, p.63).

An alternative view is to recognise that language is the key to understanding experiences.

> This raises the question of what is the transcript telling the researcher? Does the transcript tell us more about the way in which the participant talks about the experience or about the experience itself?
>
> (Willig, 2001, p.63).

When considering the type of knowledge IPA researchers gather, one must recognise that IPA assumes that a participant's account tells us something of the thoughts and feelings and therefore ultimately their experiences. It takes a realist approach to knowledge in that it explores the 'what' and 'how' questions and does not attempt to answer the 'why' questions. Phenomenological research does not claim to further understanding of why experiences take place and why people perceive them as they do. Phenomenological research is only concerned with how the world presents itself to the participant and how they interact with it. This may be seen as a limitation.

Within IPA, the influence of the researcher is not seen as a biasing factor or a constraint, conversely it is seen as a prerequisite as it is only through the interpretation of data that understanding can be achieved. The influence of hermeneutics also affects the notion of reflexivity as knowledge relies on describing, understanding and on interpreting information. Therefore, the role of the researcher is seen as a necessary enhancement. In contrast, these assumptions may be considered to be limitations by traditional, positivist researchers.

IPA relies on a verbal account of a phenomenon. Participants need to be able to give rich, descriptive explanations of their experiences. It assumes that through language an individual can represent their inner thought processes their experiences and their views, ideas and opinions. Willig poses the question, 'How many people are able to use language in such a way as to capture the subtleties and nuances of their physical and emotional experiences?'(Willig, 2001, p.64).

Lemon and Taylor (1997) note that participants need to be able to clearly express their experiences verbally. Therefore, IPA relies on a certain type of participant, notably those who are able to coherently express their experiences. If this assumption is valid then it may not be suitable for participants with language or communication difficulties.

Assessing Validity

Discussion surrounding the notions of reliability and validity revolve around the ability to reproduce the same results, if the experiment were to be completed again, and the appropriateness of the methods used in carrying out the piece of research. As discussed earlier, from a position of qualitative research and social constructionist research the notion of reliability may be inappropriate. Therefore, I will focus on assessing validity.

Qualitative researchers have presented different views on assessing validity. Guba and Lincoln (1981) suggest the notion of 'trustworthiness'. This broad notion contains four key aspects; credibility, transferability, dependability and confirmability, it is suggested that these are guidelines for researchers rather than strict conventions. Guba (1981) warns that these aspects are 'primitive' in terms of being at an early stage of development, (Guba, 1981, p.90). Tobin and Begley (2004) suggest that 'qualitative researchers need to be explicit about how and why they choose specific legitimising criteria in ensuring the robustness of their inquiries' (Tobin and Begley, 2004, p.388).

In the seminal text on IPA presented by Smith, Flowers and Larkin (2009) the notion of validity, is addressed via the work of Yardley (2000). I have chosen to use Yardley's principles of validity as opposed to Guba and Lincoln's (1981) notion of 'trustworthiness' within this piece of research.

Yardley (2000) provides four broad principles for assessing the quality of qualitative research. The first principle is 'sensitivity to context' (Yardley, 2000). IPA is founded upon principles of idiographic research, which focuses on the particular. It also relies on a flexible interview process designed to elicit rich and meaningful descriptions upon which the researcher brings their own interpretations, which should remain, grounded within the data. Upon writing up the research process the data is then contrasted with existing literature and theoretical understanding. IPA therefore appears to be sensitive to the context at every level of research design, analysis and interpretation.

The second principle is 'commitment and rigour' (Yardley, 2000). Commitment can be demonstrated through the interaction with the participant during the interview and the care and detail with which the analysis is conducted. Rigour refers to the thoroughness of the study in terms of the sample of participants, the design and implementation of the interview process and the detail of analysis. I have endeavoured to provide clear and consistent information throughout this thesis to illustrate the planning, design and implementation of the research. This degree of openness and clarity leads on to the next set of principles.

The third principle is 'transparency and coherence' (Yardley, 2000). Transparency refers to how clearly the stages of the IPA analysis have been represented within the study. This reflects back to trustworthiness suggested by Guba and Lincoln (1981) and the notion of researcher's explicitly stating their choices and decisions, Tobin and Begley (2004). Coherence refers to the degree to which the methodology and theoretical assumptions have been implemented within the research design. Within this third principle the notion of reflexivity has been crucial to the implementation of an IPA research process. Throughout this thesis, I have attempted to move back and forth between literature and wider reading, and between raw data and interpretation. It has been this conscious reflexivity, grounded within the data, which has generated the thought and decision-making processes necessary to conceptualise and realise the thesis from conception to finished product.

The final principle is the notion of 'impact and importance' (Yardley, 2000). This reflects the depth and quality of the research and consequently the power of the results. I feel this process has importance and impact personally, as a parent and as a trainee educational psychologist, whether the same is true for the participants, colleagues and society, time will tell.

Thus validity and quality are key considerations to qualitative research. As IPA research is a creative and dynamic process that does not follow a specific pattern or set of rules, then validity will ultimately be judged by the reader.

IPA and Social Constructionism

This research process exists within a qualitative framework which includes both social constructionism and IPA. When four areas of research philosophy are applied there may be perceived connections between social constructionist approaches and IPA. Ontologically, both recognise that there are multiple realities which are constructed by individuals via the influence of society. Epistemologically, both suggest that knowledge can be gained by exploring and understanding experiences. Axiologically, the researcher's subjective values, beliefs and perceptions are an important component of the research process. Finally, methodologically, both areas utilise qualitative data collection methods.

Despite these connections some researchers may argue that there is a key difference between IPA and social constructionist research approaches. This difference arises from a conflict within the philosophical roots of the approaches. IPA researchers consider that themes are 'discovered' (Willig 2005, p67) from the data by the researcher through the process of interpretation and a dual hermeneutic system. However, social constructionists may consider that the themes are constructed within the data by the researcher within the research process.

Therefore, in essence, the difference appears to revolve around whether themes exist before the research process takes place and are exposed by researchers or are constructed within the research process itself. In other words, does knowledge exist before it is known and realised?

Kant (1787/1934) suggests that knowledge begins with experience and that experience stems from our senses.

> There can be no doubt that all our knowledge begins with experience.
> (Kant, 1787/1934, p1)

> All our knowledge begins with the senses, proceeds then to the understanding, and ends with reason. There is nothing higher than reason.
> (Kant, 1787/1934, p730)

Husserl (1987) saw experience as providing a gateway to understanding consciousness. Thus, the conclusion of this conflict exists at a fundamental philosophical level and one that appears to draw in many and various philosophical dimensions and therefore is open to continued debate.

On a separate point, some researchers may argue that conflict may also exist as IPA focuses on an individual perspective or rather how an individual perceives a phenomena at one particular time in those circumstances. Social constructionism has a broader focus on society as a whole, how phenomena can or must be understood, given certain cultural influences and social relationships, rather than their meaning from a given perspective.

Focusing on 'critical realism' may align these differences. IPA may therefore be considered by some researchers to be positioned towards the centre of a realist-relativist (constructionist) continuum and implies a middle ground or focus on 'soft constructionist' as opposed to 'hard constructionist' (Smith, Flowers and Larkin, 2009, p.196)

Interviews

Within qualitative research the predominant technique for gathering data is the interview. Interviews allow researchers to access participants' opinions, insights and experiences as well as their construction and understanding of reality. Holstein and Gubrium (1995) state:

> All interviews are reality constructing, meaning-making occasions. Therefore interviewer and interviewee construct data together through their interaction rather than an interview showing a snapshot of the subject's reality.
> (Holstein and Gubrium 1995, p.4)

Jones (1985) states:

> In order to understand another person's construction of reality, we would do well to ask them... and to ask them in such a way that they can tell us in their terms (rather than imposed rigidly and a priori by ourselves) and in a depth which addresses the rich context that is the substance of their meaning.
> (Jones, 1985, p. 46)

In this statement Jones (1985) is acknowledging that an interview allows the researcher to have contact with the participant's reality but that reality is a personal construction by the individual rather than one between interviewer and interviewee as Holstein and Gubrium (1995) suggests. However, there is a growing acceptance of the notion that social interactions are constructive and as a result fit within a social constructivist paradigm. Within this paradigm, human beings are viewed as active practitioners (actively engaged with their environment) who constantly appraise their experiences. The interviewee is no longer a store of opinions, beliefs and attitudes but an active participant in the co-construction of knowledge.

There are many different forms of interviews to consider. Initially, I trialled focus groups which I anticipated would create a comfortable and secure group environment for participants to present and discuss their experiences. I envisaged that the interactions between participants would allow the individual participants to explore, question and challenge existing ideas, thus generating original and fresh themes.

I chose to run a focus group for a pilot study and invited a group of parents from one mainstream comprehensive school to take part in a focus group (these parents did not take part in the interviews for the main study). I felt that the focus group went well; the parents appeared to enjoy the opportunity to talk, the discussion ran over time and a wealth of data was gathered. However, some parents talked more than others, to the point that one parent tended to monopolise the conversation. I knew some of the parents prior to the focus group and I recognised that their contribution to the group was limited and did not reflect the depth and extent of their prior experiences. This insight lead me to the decision that in order gain a rich in-depth view of a parent's experiences I needed to use one to one, face to face interviews.

Structured Interviews	Focused or Semi- structured interviews	Unstructured Interviews
Standardised interviews Survey Interviews Clinical history taking	In-depth interviews Survey interviews Group interviews In-depth interviews Clinical interviews	Group interviews Oral or life history interviews

The Continuum Model for Interviews

Source, Minichiello et al. (1990 p.89)

At the left of the continuum, structured interviews are planned and standardised; the questions are delivered in the same way each and every time an interview is delivered. The responses correspond with designated and preconceived categories. At the right hand side of the continuum the opposite is true. Unstructured interviews are not pre-planned; rather they emerge through the interaction between interviewer and interviewee. The central point of the continuum consists of a mixture of both structured and unstructured techniques.

I felt uncomfortable with both the extreme ends of the continuum. Firstly, the structured interview, with its predetermined questions and categories did not fit with a qualitative, social constructionist approach. I did not want to create my own hypotheses or categories in to which I then tried to fit the participants' experiences. The unstructured interview was an interesting concept but as a novice at interviewing for research purposes I was nervous about undertaking a process which was free flowing and organic in nature. The semi-structured interview appealed due to its ability to combine both a structure with the flexibility to adapt to the participant allowing them to present their story as they wish to tell it.

> Semi- structured, one to one interviews have tended to be the preferred means for collecting such data.
> (Smith, Flowers and Larkin, 2009, p. 57)

Semi–structured interviews exist in the space between structured and unstructured interviews. They are perhaps the most commonly used type of interview within qualitative social research as they allow the researcher to hear the interviewee's life experiences within an environment loosely structured around the research area. Such interviews allow the researcher to establish a balance between maintaining control and focus over the interview and allowing the interviewee the freedom to talk openly without constraint. It was this balance that proved attractive to my research process.

> IPA requires 'rich' data. This is clearly a subjective judgement, but when we say that 'rich' data is required, we mean to suggest that participants should be granted an opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length.
> (Smith, Flower and Larkin, 2009, p56)

Overview of Procedures

Within this section there will follow an explanation of the series of actions or steps taken to complete this research process. This reflects Yardley's (2000) notions of validity as well as Guba and Lincoln (1981) and Tobin and Begley (2004). This section will answer the logistical questions which surround a piece of research as well as issues of validity and quality.

Selecting Participants

In terms of number of participants, I sought the opinion of Smith, Flowers and Larkin (2009). Within the IPA literature, the number of participants used ranges from individual case studies to sample sizes of thirty. For this research process I wanted to limit the sample size to ensure that the process was reasonable and manageable. Ultimately, five participants took part in the research process, all of whom were mothers of children with autism attending mainstream schools. The children in question were all boys aged between 7 – 13 years of age who attended their local mainstream school. Additional information on the children of the participants can be viewed in Appendix 6. No fathers responded to the letters; there are many potential reasons for this. Upon reflection, most interviews took place during working hours when husbands and partners tended to be at work. Through the research it also emerged that mothers, rather than fathers, tended to continue the traditional role of being responsible for the needs of their children.

As discussed within the literature review, I wanted to avoid contacting parents through support groups instead I wanted to identify a group of parents who have children with a diagnosis of autism and who attend mainstream schools. As a trainee educational psychologist within a LA I have a range of schools that I liaise with. These schools exist within one geographical region. I chose to base my research in this area in order to use the existing links within these schools.

I spoke directly to the Special Educational Needs Coordinators (SENCo) within each of the appropriate schools (seven primary schools and two comprehensives). I explained the aims, outcomes and procedures for the research. I asked them to review their SEN registers (an internal school list of all pupils with a range of different special educational needs) and identify pupils with an autism diagnosis (or Asperger's Syndrome diagnosis) within KS2 (7 – 11 years old) and KS3 (11 – 14 years old). I chose to focus research on pupils with a medical diagnosis. I acknowledge that it excluded children and families who may be in the process of receiving a diagnosis or those who have chosen not to take up a diagnosis.

I felt that pupils and families within KS1 (4-7 years old) may not yet have experienced enough of the education system to hold detailed and reflective views, and those in KS4 may have other influences in their lives which impact on their experiences of school. In particular pupils may be engaged in work related training or vocational options which limits their contact with schools. They may also have reached an age where it is difficult for parents to think back (the assumption being that memory fades over time) and reflect on experiences that occurred many years ago.

I asked the SENCos to use their discretion to remove any pupils who I (as a trainee educational psychologist) have had direct contact with. This may have had ethical and practical considerations in terms of potentially needing to represent the research process in formal documentation. I also asked them to remove any pupils where the family may be suffering significant adjustments or distress, such as family separation or bereavements. If more than one family was identified within one school, I asked the SENCo to use a blind sampling technique (pick names from a hat) to select an appropriate pupil and family. I provided a letter (Appendix 4) to the SENCos which could then be passed on to the pupil's family inviting them to take part in the research. Therefore, the parents were self-selecting and by choosing to respond to the letter they were agreeing to take part in a research process.

This procedure avoided gathering confidential information regarding parents' names and contact details. However, it relied on the decision making of the SENCo which may involve bias and prejudice. I felt that as each SENCo was only selecting one participant from their school, then school bias effects would be minimised whilst there are potential individual bias effects that may remain.

Data Collection (Semi Structured Interviews)

As the sole researcher and relative novice in terms of interviewing for research purposes I was aware that this limited research skill may have an impact on the interview process and subsequently the data collected. My aim was to minimise these potential barriers. As Roulstone et al. (2003) indicate there are a number of difficulties which a researcher must consider:

> Challenges faced by novice interviewers conducting in-depth interviews included unexpected participant behaviours, dealing with the consequences of interviewers own actions and subjectivities, constructing and delivering questions and handling sensitive topics.
> (Roulstone, 2003, p. 643).

The aim of an interview schedule is to facilitate 'comfortable interactions' which will provide 'detailed accounts of an experience' (Smith, Flowers and Larkin, 2009, p59). Based upon the format from Smith, Flowers and Larkin (2009) I tried to create a schedule that began with questions which would elicit a descriptive or narrative response and which moved on to evaluative and interpretative questions. The interview schedule (Appendix 1) was shared in formal supervision and informally through peer supervision and as a result went through several adaptations.

The interview schedule (Appendix 1) was then presented informally to two parents (who did not take part in the research). I asked the parents to read through the questions and provide the following feedback. To explain what they thought each question meant, if it was easy to understand and interpret; and if there was anything they would change. I then asked them to look at the sequence of questions, in terms of creating a natural flow from one subject to another. They were also asked if they had any queries, questions or doubts. At this point in the research process, the interview schedule went through a process of adaption and change. In particular, some of the questions were reduced as they were too long, the phrasing of the questions was revised to remove 'jargon' and the order of the questions was amended so they followed a logical sequence from general to specific. The process of sharing the interview schedule and trialling the questions also enabled me to get to know the questions intimately before the interviews took place and to amend the questions so they were open ended, easy to interpret and respond too. I felt this allowed me to be flexible and relaxed in the delivery of the questions.

Interview Procedures

I looked to Bogden and Biklen (2007) for inspiration on practical suggestions which might ensure that the interviews went smoothly. Bogden and Biklen (2007) suggest that each interview should begin with general small talk that helps to establish rapport and put both the interviewee and interviewer at ease. The interviewer should prepare prompts prior to the interview and seek to use interpersonal skills and non-verbal communication to put the interviewee at ease. When delivering questions the interviewer should be mindful to provide enough space and time for the interviewee to consider their response in full and that prompts may be useful for eliciting elaboration. This reinforced the notion that I needed to carefully consider my actions and responses within the interview setting.

In logistical terms, when participants contacted me I gave them the choice of where to conduct the interviews either within a school environment or at their home. All participants chose to hold the interviews within their home which for the participant could be considered to be a safer and more relaxed environment. However, this raised issues of home visiting which were addressed through the standard procedures and policies for home visiting within the educational psychology service in which I was employed.

I was aware that I was being invited into the participants' homes, which I took as a privilege. Upon entering, after greetings and introductions were made I immediately set up the tape recorder but did not switch it on. I wanted to introduce it as soon as possible so the participant could start to feel comfortable with it around. I then ran through the information handout (which had been sent to the participant in advance) section by section, inviting comments and questions (Appendix 3). Once this had been completed I then asked the participant to sign the consent form (Appendix 2).

I had the interview schedule in front of me throughout the interview and a sheet of paper upon which I noted down some key points. For example, if a participant mentioned something during one question, which bore relevance to a further question, I tried to note this down to discuss further.

Within IPA reflectivity is a major issue when conducting interviews. Guillemin et al. (2004) suggests that reflexivity is closely associated to the notion of ethics in practice. Reflexivity is usually associated with maintaining rigour and validity within research. Guillemin et al. (2004) assert that social science researchers should constantly scrutinise their role and their actions within the research cycle. This must be achieved through an active and ongoing process of critical review. Therefore they are actively constructing interpretations rather than stating opinions and beliefs. As Guillemin et al. (2004) point out:

> The goal of being reflexive has to do with improving the quality and validity of the research and recognising the limitations of the knowledge that is produced, thus leading to more rigorous research.

> (Guillemin et al., 2004, p. 263)

However, they add:

> Being reflexive about research practice means a number of things; first, an acknowledgement of micro ethics, that is, of the ethical dimensions of ordinary everyday research practice; second, sensitivity to what we call the 'ethically important moments' in research in all their particularities; and third, having or being able to develop a means of addressing and responding to ethical concerns if and when they arise in the research.
> (Guillemin et al, 2004, p. 263)

In response to this, I endeavoured to reflect upon the interview in a research diary immediately after the interview and then again several days later. Reflections were utilised during the analysis and interpretation sections of the research process.

Transcription

Once the interview was completed the audio recording was transcribed in a line numbered transcript format (Smith, Flowers and Larkin, 2009). All names have been changed to protect identities. As the methodology, in this case was IPA, suggests, nuances of language, pauses and verbal gestures were not included; the transcript represents the spoken words of the participant. An example of the transcript is shown in Appendix 5. For the purposes of reprinting I have adapted the style of the font to differentiate between descriptive, linguistic and conceptual comments. Upon compiling the final document the accuracy and readability of this document has been affected. In practice, coloured pens were used.

Introduction to Ethical Considerations

Ethics within research are not just the completion of a University required ethics review. Ethics should be considered as a dynamic reflective process that is adaptive throughout data collection and analysis process. In designing this research process the British Psychological Society's (BPS), Code of Ethics and Conduct (2006) and the Division of Educational and Child Psychology (DECP), Professional Practices Guidelines (2002) were consulted and followed. Whilst there is an almost never-ending list of ethical dilemmas and solutions within any research process, most can be contained within two groups; firstly, participants and secondly conducting interviews.

Ethical Considerations: Participants

I made an active decision not to contact parents through support groups as I felt this might bias the sample of participants. I chose to conduct research within my area of practice, therefore I was acting as a practitioner-researcher. McLeod defines practitioner-research as 'research carried out by practitioners for the purpose of advancing their own practice' (McLeod, 1999, p.8). However, the research process I engaged with goes further than this as it is essential to the completion of doctorate training. It is not solely about advancing my own practice but involves a range of stakeholders.

I was acutely aware that as a trainee educational psychologist for this geographical region if parents raised specific concerns with me I would be left with a dilemma as to how and when to act upon these concerns. Traditionally, educational psychologists have liased with schools rather than parents as their first point of contact. If this was reversed this may change the dynamics between parent, schools and educational psychology service. However, this may not be a negative consequence; it may provide a useful move towards community psychology and provide an emphasis upon relationships within the wider community.

Following on from this point, I was aware that parents may raise particular concerns and may then expect that these concerns to be responded to in a certain way which may not be applicable or appropriate. Thus, I stated before the research interview that if any issues arose we could have a further conversation about those after the interview. Careful negotiation of these concerns was critical as I was aware that parents and schools could perceive my involvement with the family as being related to my position as TEP rather than a student completing a piece of research. This occurred in two of the interviews and as a result, once the interview was complete I was able to discuss these concerns and negotiate an appropriate response.

Ethical Considerations: Interviews

Ethical consideration encompasses the choice of participants, information provided to participants, the treatment and well-being of participants, the relationship between participants and the confidentiality of all information shared. Guidelines from Sheffield University have been adhered to.

A qualitative research interview is designed to access the intimate details of an individual's reality. Subsequently, 'qualitative research is saturated with moral and ethical issues' (Brinkman and Kvale, 2005, p. 157). Within the context of this research process the research has been ethically reviewed through Sheffield University and as such has been part of a reflexive research process within which ethical considerations have been paramount.

Guillemin et al. (2004) point out that ethical tension is evident in all areas of research. An ethical review is a valuable and important exercise but it does not teach the researcher how to respond to sensitive issues which might occur during the research process. The research process involves the participant detailing and explaining their story. This story may include personal, emotive and sensitive information which may require an appropriate response from the researcher. Guillemin et al. (2004) describe ethics in practice as being a set of personal values, beliefs and attitudes which allow the research to be conducted appropriately.

> The interview is the creation of an unnatural situation, introduced by a researcher, for the purpose of polite interrogation. It is this situation, delicate by definition, which is ethically questionable.
> (Kellehear,1996, p.8).

Thus, Kellehear (1996) feels that interview conditions place an interviewee in a potentially vulnerable position in which ethics must be carefully considered. This is reflected in the care taken to construct information materials which provide a balanced view of the research and highlight the fact that questions may at times be challenging but that participants have to feel confident in discussing issues. If they are not, then disclosure is not demanded. It is the participant's choice to take part and they can only make an informed choice with a broad base of information.

Summary of Methodology and Procedures

The methodology chapter attempts to discuss the epistemological position which the researcher is taking. In this case, the research is based within a qualitative, social constructionist framework. The data collection method (semi-structured interviews) and the data analysis (IPA) adhere to this epistemological stance. IPA aims to explore how individuals make sense of their experiences, it engages with the meaning that those experiences hold for those individuals. At the same time IPA acknowledges that a researcher has their own preconceptions and these are necessary to understanding and interpretation. Alternative methodologies are considered and discussed along with reliability, validity and ethical issues.

Traditional positivist research is judged upon the notions of reliability and validity. Through this chapter these notions have been discussed with reference to a qualitative, social constructionist and IPA framework. Whilst validity and the quality of the research process remain important constructs, the notion of reliability and replicability may be considered inappropriate within this qualitative research context. In addition, reflexivity is referred to as a constant as it acknowledges the role I play as the researcher in constructing and interpreting the data and in completing the thesis.

In terms of validity this notion is compared to the broad principles raised by Yardley (2000) as presented by Smith, Flowers and Larkin (2009), Guba and Lincoln (1981) and Tobin and Begley, (2004). The procedures and ethical considerations inherent in the research are discussed and intend to set a context around the research process which may facilitate subsequent research involving parents.

The Process of Analysis and Table of Results

There are several versions of IPA depending on the particular view (philosophical or psychological) of phenomenology the researcher adheres to as well as the relative importance placed on hermeneutics. This research process is based on Smith, Flowers and Larkin (2009) that they describe as:

> Although the primary concern of IPA is the lived experience of the participant and the meaning that the participant makes of that lived experience, the end result is always an account of how the analyst thinks the participant is thinking. Thus the truth claims of an IPA analysis are always tentative and analysis subjective. At the same time subjectivity is dialogical, systematic and rigorous in its application and the results of it are available for the reader to check subsequently.
>
> (Smith, Flowers and Larkin, 2009, p.80)

The analytic process is described as being flexible rather than fixed. It is idiographic in that attention is continually paid to the detail of the data and iterative in the repetition of moving from transcript data to analysis and interpretation and back again. The transcript is reduced, transformed, expanded and revised.

The first step in this process is to read and re-read the transcript. I opted for listening to the audio whilst reading through the transcript. This allowed me to make initial notes about the interview, to record striking features (key facts and information) and my own personal thoughts and reflections on the interview. Within each interview discrete sections become apparent, some descriptive, reflective, thoughtful and some apparently extraneous.

The next step involved reading through the transcript and making detailed notes and commentary. As suggested by Smith, Flowers and Larkin (2009), I focused on three distinct areas of commentary namely; descriptive, linguistic and conceptual. Initially, I addressed descriptive comments by highlighting key words and phrases as well as comments of importance. These were taken at face value with no observations or explanations. During a second read through I addressed linguistic comments, the use of metaphors and interesting phrases. I then reread through the whole transcript for third time, along with the descriptive and linguistic comments, in order to generate conceptual comments. I was interrogating the data, to question how the participant arrived at this version of events and what it meant for them. I felt this process was crucial in maintaining validity insofar as the analysis remained focused on and grounded within the words of the participants and not by my views or interpretations. An example of a complete transcript can be seen in Appendix 5.

The process of rereading the document allowed me to become familiar with the flow and content of each individual interview transcript. From this position I then started to develop emergent themes. This aspect of analysis I found challenging, reducing the transcript and my notes to concrete and coherent themes whilst maintaining the complexity and the interrelationships within the original data. I chose to express the themes as statements, which were designed to encapsulate the essence of the whole experience whilst reflecting on specific parts, a very Gestalt principle.

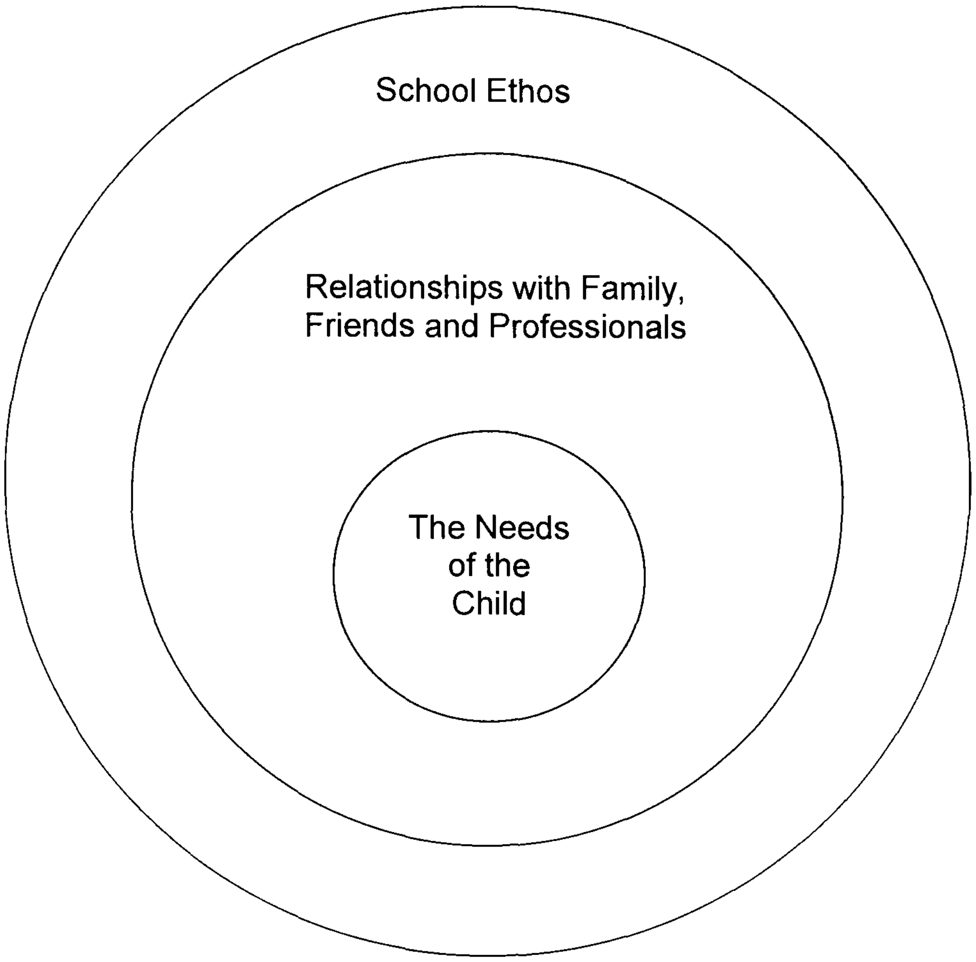
The next step draws together the emergent themes by searching out connections and associations. At times, I found that themes emerged in different areas within the transcripts and from different participants which meant that although the same theme emerged there was a slightly different emphasis or importance for each participant. Drawing together themes was achieved in a number of ways. Firstly, themes were drawn together through a process of abstraction where links were made between and within similar concepts. Secondly, through numeration where the frequency a theme appeared was noted informally and the more common themes become more powerful and others less so. Finally, themes were drawn together through a process of conceptualisation which emphasised attending to any cultural and social issues and themes. Once all the transcripts had been analysed I was then able to look across the transcripts in order to generate a master table of themes as suggested by Smith, Flowers and Larkin (2009). A table (Appendix 7) was developed to visually demonstrate how different themes are nested within super ordinate themes.

Reflecting back on the process and looking at the basis of it written down it appears simple and uncomplicated. I found it to be far from simple and uncomplicated. The five transcripts were as diverse and individual as snowflakes. Finding strands that drew the transcripts together was extremely challenging and gave rise to questions and doubts about my choices, decisions and ultimately the methodology I chose for this research process. However, I felt the process needed to run its course. My doubts and frustrations are perhaps akin to all qualitative researchers. The process is not neat and logical and sequential as quantitative research tends to be. I found it to be demanding and messy and yet still thought provoking and encouraging.

Schematic representation of the (data) Super-Ordinate Themes.

The diagram represents the relationship and the importance of the various super-ordinate themes from the parent's perspective according to their experiences. These dimensions do not appear to be fixed but are flexible and accommodating. At the centre are the needs of the child. This is the paramount concern for the parent. Surrounding this are the relationships between family, friends and professionals. These relationships respond to the needs of the child creating a supportive network. Around this is the school ethos which is connected to the relationships between family friends and professionals and thus responds to and influences the needs of the child.

Figure. 1 A Schematic Representation of the Super-Ordinate Themes



Within this short section I have sought to explain the process of analysis that resulted in the table of super ordinate themes (shown in Appendix 7). This table is designed to give an overview of the data, to provide a useful insight into the themes that emerged. It gives a sense of the lived experiences of the participants without interpretation or discussion. Within the following section, the (detailed) analysis and discussion of the themes will be joined. Each super ordinate theme will be introduced and addressed with reference to wider reading and interpretation.

Analysis and Discussion

Introduction

The focus of this research process was to explore parental experiences of mainstream schooling for their child with autism. I found it interesting to note that, although not specifically asked about, all five parents gave rich and in-depth insights into the diagnosis process. For all of the parents, the process of diagnosis was intertwined with school experiences possibly because the diagnosis generally took place during their child's (nursery or foundation) early years education. Teachers were often either the first professionals to raise concerns about the development of the participant's child or were the first to give front line support, encouragement and feedback on the process and procedures.

A. Super Ordinate Theme – Emerging Identities

Introduction

This theme encapsulates the change or adjustments that occur when a diagnosis of autism has been placed upon a child and the impact it has on the individual and/or the parent. For many of the parents the diagnostic process occurred alongside school experiences. SEN difficulties tend to arise when one child's development is compared to another. This is often referred to as a developmental perspective. This comparison begins with siblings but takes on larger and more profound dimensions upon entering school. The identity of the child and the identity of the parent also appear to be inextricably linked within this process of comparison.

> Our sense of ourselves as people, our identity can be seen as constantly being sought after, contested validated, maintained.
>
> (Burr, 1995, p.46)

Indeed, identity is a complex and multifaceted notion which is influenced by our language, society and culture. Identity changes and adapts throughout our life span.

> Identity avoids the essentialist connotations of personality and is also an implicitly social concept.
> (Burr, 1995, p.30)

Within this super ordinate theme I have drawn together, themes which involve a journey towards an emerging identity. The starting point for this journey is 'the diagnosis' itself, the realisation of parents and families that their child is different to other children and how the diagnostic process was negotiated. The next theme of 'developmental perspective' is intrinsically linked to the diagnosis. This notion was expressed very strongly by several parents and as such I felt it needed to be a theme within its own right. The next theme is the 'impact of the diagnosis' specifically in terms of emotions of the parent. The final theme is the 'adjustment' that emerges as a result of the process of diagnosis and as a consequence of the new experiences encountered.

Theme - The Diagnosis

For the majority of parents, the diagnosis was a struggle, a struggle on many different levels from the practical to the emotional. It is clearly a very emotional and life defining series of events and one that, even after several years, still created deep emotional reactions. Indeed this is reflected within wider literature as well as the comments from the parents in this research.

> Parents complain about delays and evasion in the telling, being given false assurances, being told in an abrupt and uncaring way, having the negative consequences of their child's condition emphasised.

> (Dale, 1996, p.51)

> *The diagnosis, the assessment, they were battles to get through because I had to fight tooth and nail for everything* (Hazel)

> *They were sort of going round the edge because if they gave him a title then they would have to sort of acknowledge it. (Sarah)*

Perhaps these experiences reflect the difficulties involved with the diagnostic process. It is not as simple as making an appointment with a GP and receiving a prescription. The initial starting point and the diagnostic process was different for each family. However, one aspect common to the parents in this study was each pathway involved an interaction between several different services: speech and language, behaviour support, GP, health visitors and education services. From these early interactions and consultations each family was then referred to a Child Development Centre within which several services came together to provide a diagnosis.

> *I found it stressful, having to go to the Child Development Centre, people coming to the house, in to school. (Emma)*

Whereas, other parents appeared to find the opportunity to talk to different professionals less demanding and onerous it appeared that some parents found the opportunity to talk beneficial, proving insight and understanding.

> *It was sort of picked up so early that they had a plan in place from then onwards. (Alison)*

> *They answered all the questions I'd got and they also gave me a lot of help as to what I could do at home to help out. (Jane)*

Therefore the process of diagnosis was varied and this may have impacted on the feelings and emotions that the final diagnosis elicited. For Emma and Sarah who found the experience of obtaining a diagnosis difficult, stressful and demanding they both described the final diagnosis as a relief.

> *It was like a relief really, that there was something and it was not just about bad parenting, you know, because I did feel a bit like a failure at times, not understanding him. (Emma)*

> *I think at one point it was probably like a relief and thinking then that it was probably not our fault. (Sarah)*

For both of these parents the relief of the process coming to an end also reveals a relief at not being to blame for the difficulties encountered. This highlights the impact that social and cultural influences have upon identity in terms of parents. Perceptions from the popular media may suggest that guilt and parenthood appear synonymous within our society. These mothers appeared to feel this pressure acutely until the point of diagnosis when they could finally remove these feelings and emotions as an external cause was found which means they were not to blame. Parallels may be drawn with Attribution Theory (Heider, 1958). This implies that when faced with a stressful event people will make attributions, to understand, anticipate and manage their environment. However for Jane the experience was different.

> *Heartbreaking. As soon as I found out, I'm tearing up now just thinking about it, when we first found out we knew it was coming as a lot of people had said they thought it was autism, but there's a big difference between someone saying they think your child's got autism to your child's got autism. (Jane)*

For Jane even having been pre-warned by other people the news came as a shock and one which, to this day, is hard to reconcile. None of the parents found the diagnostic process easy or comfortable. It was different for all and perhaps it is these differences that mean that for some the experience is easier to accept.

Oakley (2004) suggests that diagnosing and labelling children is dis-empowering for parent and child.

> By labelling a child as having a psychiatric disorder we are removing their very essence of ability to change and develop, to control oneself and ones environment. We are encouraging passivity in the child, the parents and their teachers and externalising the locus of control.
>
> (Oakley, 2004, p.71)

This is true if the individual and family are constrained by the social discourses of patients with disabilities being passive, needing help and unable to change. However, a recent campaign 'Time to Change' headed by Stephen Fry aims to end the stigma and discrimination that surrounds mental illness and disorders. Resemblance can be drawn with the stigma which surrounds all disabilities. Fry (2009) states:

> Once the understanding is there, we can all stand up and not be ashamed of ourselves, then it makes the rest of the population realise that we are just like them but with something extra.
>
> (Fry, 2009, p.1)

This statement highlights the essence of inclusion and an inclusive ethos which recognises that people are inherently different. This in itself should not be seen as a negative reflection, with knowledge, understanding and empathy social stigmas or discourses can be changed.

During a discussion about his diagnosis of Bi-Polar Disorder, Fry (2009) suggests that the diagnosis came as a relief, which reflects the experiences of some of the parents within this study. He then knew what the problem was and was able to deal with it. Within this society a diagnosis can be useful; as well as providing an explanation for a difficulty it can also provide access to support and resources such as medical, financial and social. This is particularly true in the sphere of education as a diagnosis of autism can provide access to specialist autism outreach teams that both promote and support inclusion.

I would suggest that a juxtaposition exists between being constrained by a diagnosis and being enabled by a diagnosis. These positions are difficult to balance, judge and critique. Oakley (2004) points out a diagnosis can also be disempowering, affecting an individual's identity and their personal sense of self, agency and locus of control. In order to counter Oakley's stance one must draw on the benefits of receiving a diagnosis. For some a diagnosis can be empowering and can create the motivation and drive to succeed. It can lead to effective medical treatment, health and educational interventions. A medical model of treatment would indicate that the first step towards resolving a difficulty is the correct diagnosis. Once this is established then effective, evidence based interventions can be implemented.

Theme - The Developmental Perspective

From the earliest stages of conception and through pregnancy a developmental perspective is utilised and exploited. Midwives and Health Visitors compare babies to nationally accepted standards, parents compare their children to other children and in school comparison to others continues to be drawn. Mothers are encouraged to read guidelines on their baby's development which involve stages and comparisons with 'normal' development. It is therefore not surprising that a developmental perspective was apparent within the experiences of the parents in this research.

> *Then I started to compare him with my eldest child, looking through all his books at what he could do for a certain age. (Jane)*
>
> *He (doctor) wanted an inspection somewhere ... because of how he was behaving at that age. (Sarah)*
>
> *Something didn't seem right. (Alison)*
>
> *I didn't think they had the right to say that at two years of age, he wasn't doing what he should be doing. (Jane)*

What happens when a baby or child does not develop along those 'normal' lines? If a child were not developing normally then one conclusion to draw could be that the child is abnormal. Is this an appropriate conclusion to draw? What is the impact on parental identity and the identity of the child when a label of disability is given? Can these assumptions of normal development be questioned or challenged by the parents or the child? This draws in the notion of power within social situations and social discourses.

> Prevailing discourses are often attributed to be powerful discourses that have strong implications on the way we feel we can and should behave and these are strongly tied to our society.
> (Burr, 1995, p.46).

Within the experiences of these parents, doctors and professionals are placing their views, their opinions and ultimately (labelling) a diagnosis upon a child. Parents may or may not be given the option to take that diagnosis; they certainly have the right to refuse to engage and therefore not take the diagnosis. It is unclear if the parents in this research knew this or were presented with this option. None of the parents talked about the views of the child being elicited or appraised. Within our society the views of professionals are held in high regard and therefore questioning these would be difficult.

> *I felt really sorry for him and when she mentioned how an autistic child lives, in their own little world, and as soon as she said this, I was so upset and sorry for him that he's got to live this way and I still do I just wish that I could take it all away from him and he could live a normal life. (Jane)*

Jane's experience shows how a professional giving their view can be seen as the correct view, the only view. This world that the professional had created became the world that her son was going to live. It wasn't the warm and friendly home that I visited to conduct the interview, it was something lonely and isolated. This world was a view, an opinion, created by a professional, possibly as way of illustration and suggestive of a textbook example of autism, and not related to the individual in question. It is therefore a struggle for Jane to reconcile the child she knows and loves with this textbook example. Is this the reason that Jane still becomes tearful when the diagnosis is discussed? Perhaps she continues to see the world of autism through the eyes of this professional and not through the eyes of her child?

Grey (1993) illustrates a referral process which is challenging for parents to navigate. A process whereby professionals talk of developmental delays, poor parenting and diagnosis, all of which are examples of complex 'jargon' terminology which parents may struggle to comprehend. Grey (1993) also describes frustration with referrals, referral routes and waiting lists all of which add to the potential annoyance and dissatisfaction of parents. Simultaneously, this frustration may lead to defensiveness and distrustful attitudes and views from parents that can present unique challenges for the professionals.

However, a developmental perspective is also useful. Assumptions drawn from a developmental perspective form the basis of criterion-based assessments are used throughout education. The notion of inclusion being more than just presence within a classroom relies on a child being able to achieve at their own stage or level. Without guidelines on levels of development and stages of progress (which impact on the planning and presentation of teaching and learning activities) the practicalities of inclusion would be increasingly complex and arduous.

Theme - The Impact

As other themes have highlighted, the experiences of the parents are dissimilar and diverse. For some the impact of a diagnosis involves personal reflection and a process akin to grieving and bereavement (Blacher, 1984). Parents have to come to terms with the changes that diagnosis brings and this may be described as a series of stages such as a mourning process. Olshansky (1962) talks of adjustment as a process of coming to terms with sorrow or an expansion of a grief process.

> *I was so upset and so sorry for him that he's got to live this way and I still do ... I just wish that I could take it all away from him and he could live a normal life. It's devastating to find out. (Jane)*

For Jane, the feelings of loss appear to be wrapped up with the loss of a normal life and this appears to be a direct consequence of a reliance on a single developmental perspective presented by a single professional. There appears to be no alternative perspective or discourse available for this parent to grasp, comprehend and accomplish. The feelings of loss can further affect one's ability to take on board new information.

> The feelings of loss, grief, guilt, injustice and despair already identified will have a significant affect on their ability to take on board additional news and information which will clearly have a significant impact on their own future and that of their family.
> (Wall, 2004, p.37)

For another parent, the diagnosis was a relief but it appears it was not the end of a process, as hoped for. The diagnosis brought comprehension and understanding but this did not appear to be widely acknowledged. The need for knowledge and understanding may reflect a personal coping strategy that involves needing to have as much information as possible. It also reflects a professional judgement of diagnosis being a disability. Does having a diagnosis of autism necessarily mean that the individual is disabled? The Social Model of Disability would point towards society's conception of disability rather than the individual having a disability.

> *Before (diagnosis) it was like not understanding what the problem was… I think some people there still refused to accept that it was actually a disability that he had not like a behavioural problem. (Emma)*

Another parent whose child appears to be struggling with his own identity puts the views of the child forward. The impact is transferred from the parent to the child but is clearly felt throughout the family as the new information concerning the diagnosis appears not to be shared with friends and acquaintances. The diagnosis appears to the elephant in the room, something most people are aware of, but may not wish to discuss.

> *He fights desperately not to be seen as different or wanting anyone to know about his autism.* (Hazel)

This may extend to issues within the classroom. It is clear from this parent that her son does not want people to know he has a diagnosis of autism and yet all the staff within in the school are aware. Do they know how he feels about his diagnosis and are they understanding towards that? How inclusive can a classroom be if difficulties, problems and challenges are not faced and addressed? The challenge faced by this parent is a difficult juggling act between highlighting the needs of her child, without making these actions apparent to her son. It is clear that this parent therefore takes time, care and consideration before approaching school which takes energy both emotionally and cognitively.

Theme - Adjusting

Identity is often compared to the notion of self. The concept of self is intrinsic to phenomenology. It is considered an integral part of consciousness and as such is essential within the sense-making process that forms a phenomenological approach. Making sense of oneself allows an individual to create a unique viewpoint and from this platform other perspectives can be viewed. The diagnosis, its impact and the developmental perspective have changed the family unit. This change has been a process or a journey whereby the parents, usually and exclusively in this case the mother, has come into contact with a variety of professional, services and settings. These experiences have ultimately created change. For some the change has been personal and involved developing knowledge, skills and approaches and for others the change brought out basic human responses of anger and protection. For each of the parents in this research the process of adjusting produced different responses.

Cognitive Adaptation Theory (Taylor, 1983) presents a way of understanding the process of adjusting to these stressful events. Three themes are offered, firstly searching for a meaning, secondly searching for mastery and finally a search for self-enhancement (Taylor, 1983). Within the notion of a search for meaning attempts are made to find reasons for or answers to the question 'why?'

> *It was upsetting for me because I didn't know what to do; I didn't know what was wrong. (Hazel)*

> *I found it easier to understand than my husband at the time. I sort of did a lot of research into it, I read up, you know on what they were assessing and tried to understand it as best I could. (Emma)*

The unknown is a frightening place and to these parents, not knowing was a difficult and upsetting concept. This led them on a search for knowledge in order to answer their questions and search for answers. Clearly, professionals can play a vital role in this search, as they may possess knowledge, skills and experiences that can enlighten parents. However, parents need to remember that professional opinion is just that, an opinion, it is not from a social constructionist perspective, the truth. Within the sphere of a social constructionist there are no truths just a range of different perspectives and realities.

Cognitive Adaptation Theory (Taylor, 1983) suggests that within a search for mastery, an individual may attempt to take control of the events which are unfolding. This can be linked to the desire to manage, to organize and to be prepared. Families may try to organise themselves around the needs of the child and help to prepare him or her for the day ahead and ultimately for their future.

> *We've already got next years timetable stuck on the fireplace for him to start to learn it. (Sarah)*

> *I have to do a lot of preparation before he gets to school because otherwise he'll walk out without his things. (Hazel)*

> *Most of what he learnt was what extra I was doing at home. (Alison)*

The notion of self–enhancement would suggest that an individual will then seek and use social comparisons in order to 'enhance self and restore self esteem' (Taylor, 1983, p.1164).

> *I mean if some poor devils got to work full time then they can't be doing lesson planning in their free time.* (Alison)

Alison is able to work part time and so give her time to teaching her son. She is therefore making a downward comparison towards people less fortunate who cannot afford to give up work. This comparison appears to enhance her self-esteem and self-concept as a teacher and a mother for her son.

Within a social constructionist perspective, there is a relativist notion suggesting that each discourse is equally valid; they are relative to each other. Therefore the views of a parent, the child and the professional all have equal weighting (Burr, 1995). However, this may not be as simple as it appears, for each individual a particular discourse may be viewed differently. Within the diagnostic process, parents hear a variety of discourses about their child and this may impact on the future roles and identities of both parent and child. These identities may be reflected in these short extracts and include the protector, the teacher, the wise and knowledgeable, the assertive parent and 'good parent'. Perhaps they show how these parents would like to viewed and the roles or discourses which they value the most.

> *When you are sort of in that position you learn quick, don't you. You have to. You learn very quick. (Sarah)*
>
> *Having to be really very abrupt, which I don't find easy but errm that's what I had to do to get there. (Hazel)*
>
> *I don't know how they'll accept him or treat him, I think I'll be there, in front of him, to protect him, or at least I'd like to be. (Jane)*
>
> *You're not just a Mum ... you're almost like a teacher. (Alison)*
>
> *I always felt I wasn't doing it right in their eyes, you know, and I was constantly trying to prove myself. (Emma)*

These roles may not be those the participants would necessarily place upon themselves but are my interpretations from the data provided. I would suggest that these are the most helpful roles the parents have at this particular time. It is through these roles and the emotional, cognitive and behavioural investment that they provide that parents are enabling the inclusion of their child with autism in mainstream schooling. For without the parents adopting these roles, the experiences of the children would clearly be very different.

Lamb (2009) talks of the diagnostic process creating 'warrior parents' parents who feel they have to fight for the rights of their child. This may be a consequence of adjustments which take place as a result of stressful and challenging situations, as suggested within the Cognitive Adaption Theory Taylor (1983). It may also be a consequence of the challenging and demanding interactions that are inevitable within a long and complex diagnostic process.

Theme - Responsibility within Families

Responsibilities arrive because one feels an emotional connection to something or someone. In this case the responsibility is towards the child who has a diagnosis of autism. Responsibility is evident throughout the family.

> *It used to be our daughter who looked after him (at school) and she still does.* (Sarah)

> *Luckily his sister was in school at the time and showed them how to cope with him when he kicked off.* (Sarah)

Within this family the siblings have played a crucial role in positively influencing and enabling experiences of school, from proving positive play at break times to training the teachers in calming strategies used within the home. Therefore, school inclusion appears to be enhanced by family members. However, are schools aware of this and is it something to be encouraged or to be monitored? Would this trust and care within a family unit have been created without the obstacles and difficulties they have faced? This young man has certainly benefited from having older siblings at school who have been willing and able to show care and compassion towards him. Just as the voice of parents has been under represented within literature the voice of the sibling is distinctly lacking.

Responsibility is also felt in terms of trying to prove oneself, that the parent is not to blame or not responsible for these difficulties. Responsibility may also be a reaction to increased anxiety that in turn may be wrapped up in a new identity as the protector for a child with a disability. This reflects back to the developmental perspective and the notion of a child who is not progressing along 'normal' lines. It also draws in the social model of disability and the way in which society constructs the disabled person as someone who needs ongoing help, support and protection.

> *I'm terrified for him being unhappy and not telling me. (Hazel)*

> *It's that crystal ball that you'd like to know that he's going to have a normal life. (Jane)*

This sense of responsibility may lead some people to take extraordinary steps to address these concerns. For one parent cutting down on working hours in order to dedicate this time to her child is a positive step but in this extract she describes her time as free which appears to devalue it. As though parental efforts at home could not be as good as the efforts of people who get paid, in other words the professionals do a better job.

> *I've done a lot at home because I know my time is free. (Alison)*

Responsibility is also evident from within the classroom. It is clear that some teachers have conscientiously addressed the needs of the child with autism. As a consequence they have noticed that changes need to be made and have implemented different practices and procedures as a result. Responsibility may be seen as a double-edged sword. Feelings of responsibility may make individuals improve their practice and procedures but can this guarantee a truly inclusive classroom? Are teachers making these changes because they believe in inclusion and inclusive education or are they avoiding blame and accountability?

B. Super Ordinate Theme 2 - The Importance of Relationships, Family and Friends

Introduction

All the children discussed within this research were part of a family unit that included mothers, fathers and siblings. It should not be surprising that families featured strongly in the experiences of the parents despite the focus of the interview being on school inclusion. It is clear that inclusion is enhanced and supported by the relationships between and within the family, friends and the professionals. Within this super ordinate theme 'family dynamics', 'friends' and the 'fear of bullying' have been drawn together. I have also included 'interactions with professionals' as this is also about relationships and these formal relationships appear to have great influence.

Theme - Dynamics of Family Relationships

This theme follows on from a previous theme of emerging identities. The dynamics of a family are closely related to the identity of the individual members and part of this relates to the coping strategies employed and the choices that have been made which have direct influence on the overall dynamics of the family.

> Stressors that originate within the family have direct effects on all members and on the relationships between them.
>
> (Frude, 1991, p. 54)

For some families this may be an individual process whereby the mother keeps hold of the anxieties, responsibilities and concerns. This is not to say that other family members do not feel these emotions but that the mother feels that she alone is accountable. The experience for these mothers must be difficult, as they appear to feel that they are coping single-handedly.

> *I've taken it all onboard myself, to be honest. (Alison)*

> *I tend to get wrapped up in my own feelings. (Jane)*

For another parent the impact on family dynamics is described through the scenario of her son arriving home from school having encountered difficulties and challenges. The mother feels that she has to know what is going on which may reflect a coping strategy, needing to have the information and then being able to move forward. The family dynamics are clearly affected in that the mother feels she has to question her son throughout the evening, something that may potentially create discord, as he doesn't wish to be questioned.

> Certain styles of interaction are likely to create a tense atmosphere within the family, or impair communication, so that there is an overall reduction in the family's ability to function effectively.
> *(Frude, 2001, p. 37)*

Employment is raised as an issue, whereby one parent feels she was unable to work because of the number of medical appointments her son needed to attend. This may have significant consequences both financially and emotionally, in the short and long term for the whole family. These consequences have both positive and negative associations, for some the loss of employment can be difficult for a number of reasons, financially, emotionally and socially; but for others the benefits of spending time at home outweigh any negative consequence.

> *I couldn't have worked with him he had so many appointments. (Sarah)*

Having a diagnosis may lead to accessing benefits and financial resources, which meant that one mother was able to reduce her working hours and consequently focus on her child. Within this statement, a changing role and identity are also indicated.

> *We've got Disability Living Allowance and so I was able to cut down my hours so in a way it's been a big change in role from working full time to doing this. (Alison)*

Going through the diagnosis process and gaining knowledge and understanding has led to other benefits which appear to have positively influenced family life. Other families may take for granted the ability to be able to sit together for this mother it was clearly an important step forward which only came about once a diagnosis had been provided. The final diagnosis led to increased knowledge and understanding of her son which in turn created change within the family which enabled a calmer family atmosphere to prevail.

> *We can sit together for a length of time because that's always been impossible.* (Emma)

> *I went on parenting courses and tried to you know make sure that it wasn't anything I was doing wrong. (Emma)*

Theme - Interactions with Professionals

This theme has been included in the super ordinate theme concerning relationships because the interactions with professionals are key interactions and associations that parents engaged with throughout the diagnosis process and continuing through school. These relationships were diverse and varied both within and between parents.

> *They (teachers) were the ones who would spur me on to do things because they said I was much more powerful than them in trying to get results so I felt a lot of responsibility was put on me but I felt I got a lot of support. (Hazel)*

For Hazel some of these relationships were positive and encouraging. For Hazel, who mentioned that she had to become more assertive in order to pursue a diagnosis for her son, the support from school staff appears to have been invaluable but this also brought a burden of responsibility. Therefore, one might question who the diagnosis was for; the parents, child or school?

> *She made me and my son feel really ...very welcome and she didn't make him feel that he was any different to anyone else. (Jane)*

For Jane, the support gained from one individual was seen as crucial not only to herself but also her son, allowing her a sense of the 'normal' amongst the differences.

One parent points out that when her child is happy with the support he is receiving, then she is also happy. This hints at the positive effects that familiar and consistent support can have on family life.

> *He's had good support from friends, teaching assistants and teachers, so I've been quite happy. (Emma)*

For other parents, interactions with professionals may not be positive or rewarding. The impact of these negative interactions may range from a minor irritation and annoyance to more significant feelings of loss, lack of trust, confidence and faith. For one parent the negative relationship they experienced with a school led to the whole family moving house in to a new education authority. Positive relationships are founded upon good communication. Whether it was symptomatic or causal of failing relationships is unclear. However, parents who perceived negative relationships with schools and professionals also tended to discuss poor communication.

> *I've found things out incidentally over the years. (Alison)*
>
> *We'd actually sold our house and jumped authorities, because I was just that fed up ... fed up fighting school. (Sarah)*

Indeed, the Lamb report (2009) refers to 'warrior parents' created as a consequence of the loss of trust which accompanies poor communication and ineffective support. In situations such as this inclusion may become a peripheral concern as other issues and factors attain greater importance.

Hartas (2008) seeks to improve the relationships between professionals and parents suggesting terms such as active parental participation and joint responsibility and advocacy as a way of describing supportive parental participation. Hartas (2008) is highlighting the key role that parents can have in enabling the inclusion of their children.

> Active parental participation can be achieved through parents and professionals being responsive to, and respectful of, each others' views, and through parents being capable of exercising agency, enacted with self-reflection, advocacy, and a sense of shared power and responsibility.
> (Hartas, 2008, p.150)

Theme - The Importance of Friends

As children grow ,the desire for independence also grows and with this the need for peer support and appreciation. Dybvik (2004) indicates that peer awareness is a crucial issue in promoting inclusion. He suggests that children should be taught about issues of disability, inclusion and social justice in order to develop their thinking, understanding and empathy. For one parent there is a clear link between sporting aptitude and being popular but the same could be true for any shared activity. To be recognised and appreciated for one's actions is a universal pleasure for humans and a central theme within inclusion policy.

> *If you're popular and people like you then your school experience is so much better and through sports that's what happened to Jack. (Hazel)*

The need to turn to friends appears to be particularly true as children reach the transition to secondary school. It appears that this transition is seen as a defining moment in which parents have to relinquish control and influence over their children.

> *I think a big part of transition is learning to stand on your own two feet... it's going to be a question of sink or swim from here onwards. (Alison)*

> *I think he will know he will be leaving the school and teachers behind and I think he will turn to his friends for support and I think I will do as well. (Jane)*

It is clear that there is a great deal of fear and anxiety around transition to secondary school. The use of the metaphor 'sink or swim' by one parent hints at the life or death status within which issues of transition are viewed. When faced with these potential dangers is it not natural for parents to become anxious? It is therefore important that schools recognise that these anxieties are genuine and appropriate given the circumstances. This anxiety should therefore be anticipated and planned for, rather than denied and dismissed. Parental anxieties may be viewed as challenging or destructive towards the school but perhaps with the use of reframing this anxiety can be channelled into positive actions and outcomes.

Theme - The Fear of Bullying

The need for friends is balanced by a fear of bullying. Indeed children with autism have been shown to be at increased risk of bullying. A recent report from the NAS suggests that around forty percent of children with autism have experienced bullying but ninety percent of parents of children with Aspergers Syndrome report that their child has experienced bullying (NAS, 2009). Whether these are true or accurate figures which can be generalised across the whole of the UK is debatable. However, it does seem to suggest that parents' fear or perception of bullying is greater than those of the children and young people. The reasons for bullying, as well as the consequences of bullying, are a separate issue that will not be discussed in this piece of research. However, the fear of bullying emerged as a theme in terms of how other children behaved and potentially how the behaviour of individual pupils may be explained.

> *If they had just done it on the spur of the moment I could of just thought yeah it's a prank, but I think they had planned to do it which somehow makes it worse. (Hazel)*

> *I certainly think the instances of bullying are higher if the children are not engaged in something. (Alison)*

> *He just tends to sort of start fighting ... running wild and letting off the steam that he's held in the classroom.* (Emma)

Given the wide variety of experience and perception, it is clear that bullying is a challenging and demanding area for schools and for society to address. It is not simply the reactions of others but the reaction of the child with autism which might come into question. There might be questions of equality and fairness within policy and procedure when inclusion might seek to differentiate these for individuals with differing needs. For inclusion is not about treating everyone equally, it is about recognising, celebrating and enabling differences.

C. Super Ordinate Theme – Insights into School Ethos

Introduction

This super ordinate theme drew together all aspects of the experiences directly related to school. It recognises the variety of encounters, emotions and views which surround mainstream education. I have chosen to start off by highlighting the 'positive experiences' which were in the majority, followed by 'support from schools'. This has then moved on to 'questions and doubts' that parents have about schools. The next theme encapsulates the experiences of parents' 'ignorance and resistance'. Finally this section concludes with 'what parents want from schools'.

Theme - Positive Experiences

The majority of parents within this research process indicated that they and their children had positive experiences of school. For some the experiences have always been positive.

> *He loves school, loves being with his friends, loves his teachers. (Jane)*

For others, it has been a positive relationship that has developed whereby their children have developed and changed and as they have grown, so the experiences have changed both for parent and for child. A link could be drawn here to an earlier comment that 'if he is getting the right support and is happy then I am happy' (Hazel). Perhaps as schools and the staff within those schools have got to know the children then they have built up relationships both with parent and child which have improved the experience from the parents' perspective.

> *It's easier as he's got older, easier in that he seems to be getting more out of school. (Alison)*

> *I think school realised that they needed something else. It had been identified so they implemented it and he was fine. (Sarah)*

> *So they really built his confidence up a lot from when he started at junior school to finishing it. He has more confidence now and will try new things whereas he wouldn't before. (Emma)*

Theme - Supportive Schools

When parents talked of schools a common theme was that of support. It may be that school staff were instrumental in the diagnosis process or they provided other forms of encouragement and assistance. Parallels are drawn between supportive practice and inclusive practices in other words support is one aspect of inclusion. This continues to mirror the sense that if the child is happy with the support they are receiving, then the parent is also happy.

> *So school have been, really supportive with every obstacle ... and as long as I know he is being supported the way he wants to be supported and he needs to be, I'm really happy. (Jane)*

Part of this support appears to be the ability to contact and talk to staff in schools. This draws in the different identities and coping strategies that develop through the diagnostic process. In particular the desire to have knowledge and understanding around their child's difficulties may create a situation whereby parents have an increased desire to know. This reflects the Cognitive Adaptation Theory in which individuals search for meaning to explain their situation (Taylor, 1983). This may be particularly true where a child is unable or unwilling to give that information or when this information is negative and potentially difficult to hear.

> *She's always on the end of the phone. (Sarah)*

> *He's been quite well supported and I know we've sort of had ups and downs and things. (Emma)*

It is interesting to note that when the experiences of parents are compared to the definitions of inclusion set out in the literature review there is cohesion and agreement. In particular, some parents' experiences relate to Humphrey and Lewis (2008b) notion that inclusion involves presence, acceptance, participation and achievement.

> *He's not sort of been excluded from things and left isolated, he's been included, he's been involved and he's been allowed to sort of shine. (Emma)*

Theme - What Information do Parents have about School?

> *I'm one of those who likes to go down to school and look over the hedge and watch the children playing ...and I'd look in to the playground and see him playing on his own and I'd stand there and cry. (Jane)*

This is such a powerful image, a parent peering over a hedge and watching her child and crying. Jane's description of the professional giving a diagnosis and explaining how a child with autism lives in their own world must have been running through her mind. It is almost the image that confirms the views of the professional; her child is indeed playing on his own and is at that moment completely alone in the world. What is missing from this image is the voice of the child and I cannot know what he was thinking or doing at that precise moment but he is described as playing on his own, not standing on his own or sitting on his own, but playing. He may well have been happily engrossed in an individual activity and may not have appreciated being interrupted by someone joining in and spoiling it. Jane goes on to describe talking to school about her son playing on his own she describes their response.

> *They said they had noticed it but that's how he likes to be and they were not going to force him to play with someone ... he would get integrated with other children but he had to do it when he was ready. (Jane)*

This reflects a very open door and child centred ethos which acknowledges differences but does not force a different perspective on the child. It also points to the parent and school having a relationship whereby questions can be asked and answers provided without power dynamics being involved. This image also drew out an idea about the information that parents have about schools.

> *I get very limited information. (Hazel)*

Schools are complex and changing systems that incorporate a wide variety of practitioners, practices, knowledge and skills. We have all been to school and therefore have some idea about what it was like then, but what about now? Referring back to the Cognitive Adaption Theory, Taylor (1983) suggests that parents may search for meaning and for mastery, in other words they may look for knowledge and to control. As parents have very little control and only limited knowledge about school and what takes place on a daily basis, this may lead to heightened levels of anxieties and concerns. Therefore, control is of central importance to some parents. They are able to maintain this sense of control for their child within their own home but not within schools. This leaves of void and a sense of loss which fuels anxieties and concerns.

Theme - Questioning and Doubts about Schools and Education

Questioning and doubts about learning and the current system of education stood out clearly as distinct areas within parental experiences. For some this questioning was more prevalent in the early years, as with Sarah's description of her son spending his time in nursery sitting behind a bookcase. This may reflect an ethos in which a child's behaviour is seen as paramount to their learning and participation. A feeling that is also reflected in the second quote from Emma.

> *He took a bit of settling in to Nursery, but then they said he was just quiet, he's no trouble at all, he sits behind the bookcase. (Sarah)*

> *You know you could see that he hadn't learnt anything through the time he'd spent there. (Emma)*

Another parent questions this apparent focus on behaviour, indicating that at parents' evenings she has to remind teachers why she is there.

> *You have to stop and remind them (teachers) what you're there for and I want to know educationally, how he's doing, you tend to find people talk about his behaviour rather than his schoolwork. (Jane)*

Autism is primarily recognised as difficulties within the spheres of understanding language and communication, understanding social behaviour and being able to think and behave flexibly (Jordan, 2008). The focus for teachers may therefore be on behaviour and social and emotional aspects of learning, rather than academic progress and achievements. This may reflect back to the notion of diagnosis and the way in which diagnosis is attributed. As Selfe (2002) suggests 'diagnosis relies solely upon behavioural criteria'. If this is the case then is it creating a discourse or an expectation that behaviour is the most important factor for a child with autism?

For all parents there were clear questions and doubts which emerged through the interviews, for one parent these doubts lead to a complete change in role and identity. This parent recognised the difficulties her child was having focusing and attending to teaching and learning opportunities within a mainstream classroom. These difficulties were relayed through a home school diary. If her son had had a difficult day, or had not understood some aspect of teaching, she then spent the evenings repeating the teaching activities until she was sure that he had understood the concepts. The impact on her personal role and identity, and upon the family dynamics, has already been discussed in the previous theme.

> *What I'm saying is that what you do as a parent can help and I question how far he would be now if I hadn't put in all this effort. (Alison)*
>
> *You're sort of released into the education system to plod along as best you can. (Alison)*

This final quote raises an important contradiction. This parent and other parents generally spoke of positive experiences and supportive schools, and yet questions and doubts still arose. For some these questions were minor inconveniences, for others those doubts lead to changes and adaptations that significantly affected the family dynamics. Alison also hints at a lack of support for parents and children within the education system and feelings of failure and underachievement despite the fact that most parents were positive about schools and used the word supportive.

Theme – Ignorance and Resistance

I began with positive experiences of mainstream schooling and whilst most parents talked of feelings of support and trust for schools some had very differing experiences at one time or another. Indeed, Roulstone and Prideaux (2008) questioned exactly what changes for the parents and children have resulted from the massive increase in inclusion policy. They suggest that on two key measures of inclusion, one of which is exclusions from schools, there has been little change. Teachers' lack of knowledge concerning autism was seen as a difficulty and whereas for one parent sharing this knowledge and understanding appeared to be sufficient for another parent there appeared to be much more reluctance to change and adapt to the differing needs of their child.

> *The teachers, to be honest did not understand much about autism when he was diagnosed because I got a book and had to lend it to one of the teachers because they didn't know what they were dealing with either. (Hazel)*

> *I think it was more a lack of knowledge by the school and staff and ignorance of not knowing what to do, plus a lot of resistance. (Sarah)*

For another parent her concerns centred on her son being overlooked, as he did not have any overt behaviour difficulties. He needed clear, personal and direct instruction and if this was not provided he just sat and waited.

> *I think in school he could be easily overlooked because he'll just sit there. (Jane)*

Children may be seen to be behaving in an appropriate or inappropriate way but are teachers looking to understand behaviour from an individual perspective and ensure that difficulties are addressed correctly?

> Overall, one in five children with autism has been excluded from school, and one in four children with Asperger Syndrome. Of these, 67 per cent had been excluded more than once.
>
> (NAS, 2006, p.4)

This parent describes her son as being bubbly in the morning and if he is in this mood she recognises that he is going to struggle throughout the day. She feels that by sending him to school she is setting him up for failure or placing him in a situation that he may not be able to manage.

> *He didn't want to go to school and every day we were battling to get him there. (Emma)*

Theme - What Parents Want From Schools

> *Just a lot of little things. (Sarah)*

The parents within this research process did not talk of complex and expensive resources, strategies and initiatives. Indeed as previously discussed the word inclusion may not have been used but the experiences, perspectives and demands parents place on education correlate with notions of inclusion. The quote above highlights the feeling that it is not necessarily the big interventions that make a difference it is the small things. For this parent, a change of seating place and the use of a different cleaning product meant that her son was calmer in class and was able to eat his lunch. These small changes lead to much larger changes in pupil behaviour throughout the day.

Barrett et al. (2002) put forward a notion of noticing and adjustment whereby teachers pay close attention to the individual needs of the child and change their practices and policies accordingly. Could this notion represent the needs of children who have a diagnosis of autism?

Roulstone and Prideaux (2008) raise the notion of functionalism, which is the idea that education exists in order to prepare people for employment. They, therefore, question whether the current education system meets the needs of individuals who may struggle or be unable to gain and maintain paid employment. This point is also raised by one parent who suggests that school should provide a greater range of activities which includes a focus on life skills as well as academic study.

> *Stick more life skills things in as part of the curriculum. Silly things like going to the shop and not telling the shopkeeper how much change you want. (Sarah)*

Another factor, which has already been raised, is that of relationships and communication. These appear to be crucial in reducing the anxiety for parents. They need to know whom they can contact, when and where. For parents this should be one person who has the time and capacity to develop a working relationship with both the parent and child.

> *If they can interact more with me so I am made to feel welcome to come into school on a more regular basis than any other parent would do. (Jane)*

> *An easier line of communication with teachers. (Hazel)*

> *The ideal would be if teachers and parents could work together. (Alison)*

Hodge and Runswick-Cole (2008) pointed to the positioning of parents as 'informants' within government documentation as perpetuating the assumption that professionals are best placed to make decisions about children's education. Within their paper they challenge this assumption and point towards the benefits of parents and professionals working together to make joint decisions and joint actions that hold the child as a central focus.

Inclusion within schools was also seen as crucial to some of the parents. A view that reflects the findings from Whittaker (2007) who found that schools who communicated well and tried to understand and empathised with the difficulties faced by the child were rated highly.

> *To be involved with things that are going off and to have people who understand his problems. (Emma)*

Summary

In completing the detailed analysis and discussion, parental experiences were found to be diverse and divergent. This may be due to the fact the autism itself is a 'highly complex and idiosyncratic syndrome' (Selfe, 2002). Therefore, if this complex mix of individual differences is set against the myriad of individual differences that exist between and within families and educational settings then the analysis of experience will also be complex and intricate.

Drawing together super ordinate themes that represented all participants was a challenging and demanding activity. The themes are, therefore, fairly broad and include 'emerging identities', the 'importance of relationships, family and friends' and 'insights in to school ethos'. These themes have been discussed through my own interpretations, reference to wider reading and reflexive processes.

Conclusion and Recommendations

Conclusions

One broad research question was presented:

> *How do parents of children with autism perceive the experience of mainstream schooling?*

Despite the focus of the research being on school inclusion, other factors and issues were drawn into the discussions. I sought to represent the experiences of the five participants within the study through three themes. The first theme 'emerging identities,' explored the changes that occurred as a result of the final diagnosis. All parents within this study gave intricate and detailed accounts of this process usually when asked to describe their child's school experience so far.

This may suggest either that diagnostic procedures or the final diagnosis remain of key importance to the parent or that this was a major issue when their child first started school. I would suggest that diagnosis can be linked to inclusion through a medical model of disability, for without the appropriate diagnosis resources, support and empathy may not be available. Support structures and services enable inclusion to be effective and according to a medical model it is only by recognising differences (providing a diagnosis) that the difficulties can be addressed effectively through evidence based practice. The assumption being that without a diagnosis, support structures and services may be misdirected.

The second theme, 'the importance of relationships, family, friends and professionals', explores how relationships can enhance and support inclusion within school. The parents and families who took part in this research are investing a huge amount of effort emotionally, cognitively and behaviourally to support their children with autism through mainstream education. I would suggest that these thoughts and feelings appear to be transformed in to positive actions and behaviours (from both parents and siblings) which support, organise and enable the child with autism to function more effectively within the mainstream school environment. Similarly, the actions of professionals also impact on the experiences of children and families.

Data from this research project indicates that active parental support appears to be one of a number of factors which enables the inclusion of children with autism in mainstream schools. The mainstream schools within this research project are experiencing the benefits of this support but may not recognise these efforts (no professional voices have been included in this research). Research data suggests that parents in this study felt that teachers were generally unaware of the extent of the support they, as parents, provided. Parents may be viewed, as Lamb (2009) suggests as 'warrior parents', which instantly transforms the parent into an attacking force rather than a parent who is experiencing anxieties and stress as a result of the care and concern they hold for their child. Perhaps instead of 'warrior parents' the term 'advocate parents' could be used to imply that parents do not wish to fight to secure the recognition of their child's needs but they would rather promote and support their child through mediation and negotiation.

The final theme, 'insights into school ethos', directly explores the experiences and perspective of parents towards mainstream schooling, and, therefore, to issues of inclusion. This research data presents a positive picture of parental experiences of mainstream schooling for their child with autism. Most parents, within this research process, expressed positive experiences; they found schools to be supportive and inclusive environments. In particular, when they felt their children were happy and being supported appropriately, they in turn were happy.

Parents within this research process did not request or discuss particular interventions or strategies instead they pointed to recognising individual differences and making small adjustments to the school environment. This research suggests that these small adjustments lead to bigger and more extensive changes to the behaviour, learning and inclusion of their children with autism. These changes can be recognised and implemented more effectively within a child centred and inclusive school ethos. Parents within this research study also pointed to communication as being a key aspect in the recognition of difficulties and challenges and consequently in the generation of solutions. Clear and effective lines of communication are essential to the parents in this study.

However, these generally positive experiences expressed by parents in this particular study did not preclude doubts and questions and uncertainties. Some parents in this research process) had very poor experiences of schools. Questions and doubts reflected Roulstone and Prideaux's (2008) notion that the current Labour government and education system as a whole needs to address 'who' and 'what' education is for? Currently education is highly geared towards children achieving targets and sitting exams in order to achieve qualifications which will then lead to employment. How does this process enable children who may not be able to achieve those qualifications or for whom employment may be an unrealistic goal? Parents within this study suggested that they would like the education system as a whole to recognise and celebrate a greater variety of need and include life skills as an option within the curriculum.

This argument reflects a perceived conflict within education between the standards agenda which focuses on raising attainment and the inclusion agenda which aims to increase the participation and recognition of all students. These two very different agendas appear to strongly influence the ethos of individual schools. In other words schools may appear to be driven by either an inclusive agenda or a standards agenda. The school ethos this will ultimately impact on the experiences of the children and families involved. This leaves the question of how do parents identify and recognise these influences in order to either choose a suitable school or influence a particular school?

Response to the Research Question

Parental participation is a crucial factor in pupil success. As indicated by Hartas (2008):

> The nature of parental participation in children's education is changing rapidly. A growing body of research points to the positive effect that parental involvement has on outcomes of schooling and on children's well-being.
> (Hartas 2008 p. 139)

This thesis highlights not only the importance of parental participation but also the variation that exists within both parental participation and parental experiences of mainstream schooling. Therefore, this thesis suggests that parental participation occurs at different levels:

- Emotionally – as highlighted through the impact of the diagnosis and the adjustments that are made as a result. In particular, the impact on parental identities and how this is translated into thinking empathetically about their child's experience of mainstream schooling.
- Cognitively – parents engaged thoughtfully about the issues of teaching and learning within the context of children with autism. This general understanding was explored reflexively towards specific individual needs.
- Behaviourally – The emotional and cognitive engagement was then transformed into practical day-to-day activities that directly facilitated inclusion within a mainstream schooling.

It is clear that for the parents in this research, parental participation in mainstream schooling has a significant positive impact on the inclusion of children with autism and is seen as being an important aspect of meeting the needs of their child and enabling inclusion within mainstream education.

Implications for Educational Psychology Practice

There are several ways in which this research has implications for my own professional practice as well as the educational psychology profession as a whole.

In terms of educational psychology, there appears to be a dominant theme which involves resisting labels as they are seen as destructive and disempowering for the child and for parents. However, the parents in the study generally wanted and welcomed a diagnosis. Therefore, should educational psychologists recognise and respect parental wishes over and above professional views and values?

A recent case highlighted these issues. It involved a 16 year old student who was recognised as having difficulties on the autistic spectrum but whose parents had been advised (by educational psychology and schools) not to go for a diagnosis as school would be able to include him and meet his needs. However, upon entry to college he experienced a number of difficulties and it become apparent that without a diagnosis recent legislation (Disability Discrimination Act, 2005) that aims to promote and protect the needs and rights of people with disabilities could not be applied.

This creates an interesting relationship where the agenda for inclusion is looking forward towards society changing and adapting in order to become more inclusive and less reliant on diagnosis and yet government legislation and education policy and practice are lagging behind. This is assuming that a position could be reached where a diagnostic process and a formal diagnosis were irrelevant to the supply of resources and support structures. One may question if this is a realistic goal?

Within my own practice I feel I need to spend time understanding the needs, dynamics and experiences of the family to appreciate the identity and the dynamics within a family and how this influences coping strategies. The Cognitive Adaption Theory (Taylor, 1983) may provide a basis for therapeutic conversation in which parents are encouraged to search for meaning and realise mastery over their new situation. Within this, I also need to take account of the significant effect diagnosis can have upon a parent and family and to try and understand how they have rationalised this.

I have also come to realise how important a social contructionist perspective can be within the sphere of educational psychology. In particular, the daily encounters of an educational psychologist involve hearing problems from different perspectives, usually the teachers, parents and the child. I feel I need to spend more time exploring these stories, as they are stories or narratives, which have been created around a particular issue and a particular child. It may be possible from this position to then encourage change through solution focused approaches. By elegantly challenging and encouraging insight into the stories, issues and problems may be altered or realised in different terms.

I also feel that I need to develop and utilise an understanding of positive psychology. Throughout the research process autism was presented in a negative light. I have purposefully moved away from referring to autism as autism spectrum disorders because I feel the connotations of using the word disorder reinforce a negative association. A balance needs to be sought and positive stories of autism need to be found and presented to individuals with autism, their parents and within wider society.

Within the LA, I will share the research findings through informal and formal contact. In particular I would like to disseminate these findings within schools to encourage them to review and revise their policies for working with families and children. I also hope to share these findings with other services based in schools and communities i.e. Parent Partnership Service and the Autism Communication Team.

For the wider profession of educational psychology, I feel it also highlights the beneficial effects of professionals and parents spending time creating relationships which support and enable inclusion. Within this relationship I feel that educational psychology can have a role as 'critical friend' gently and persuasively challenging social and cultural notions of autism and disability which parents may have internalised.

Future Research

From this piece of research, several areas of future research have been identified these include:

- Exploring how active parental participation can be promoted.
- Exploring positive experiences of parenting a child with autism
- Exploring positive school experiences from a variety of different perspectives (pupils, professionals and parents).
- The impact a diagnosis of autism has on siblings.
- Exploring how professionals can support siblings of children with autism.

Limitations

Limitations and vulnerabilities are apparent with all pieces of research. Issues related to this piece of research include; generalisability, selection of participants, the interview schedule, and issues related to being a practitioner – researcher within the chosen methodology.

In terms of generalisability, this research presents the experiences of five parents from one particular geographical region. It does not make claims to represent the experiences of any other individual parents or groups of parents but endeavours to present the views of a small number of parents which may then be meaningful and enlightening to a wider audience.

In terms of selecting participants for this research study, the participants for this research process were selected on a number of different criteria. They were drawn from one geographical area rather than a broad geographical area. Specific criterion was also set which included the parent of a child who was in Key stage 2 or Key stage 3. The child also needed to have a diagnosis of autism (Aspergers Syndrome was accepted). By setting criteria the sampling of participants was restricted and therefore may be considered a biasing factor. Conversely, this may be considered to be an inevitable limitation since qualitative research relies on small homogenous samples of participants to maintain a useable amount of data to prevent data overload. However, even within this restricted sample, differences between participants were still wide and complex, these differences were highlighted within the variation of perceptions and experiences.

An interview schedule, which resulted from a single broad research question, was created to facilitate the delivery of semi-structured interviews. It may be suggested that any interview schedule which poses questions places the researcher's preconceptions, assumptions and ideas to the forefront of the interview and therefore defines the research process as a whole. Some researchers may consider any boundaries on the interview process as biases the process and therefore restricting the data produced.

This research process included the methodology IPA. I feel that the chosen methodology has provided a viewpoint through which the experiences of parents have been presented and interpreted. However, as with any methodology there are weaknesses. In particular as Willig suggests:

> An interview transcript or a diary entry tells us more about the ways in which an individual talks about a particular experience within a particular context, than about the experience itself.
> (Willig, 2001, p.63)

Thus, Willig (2001) is proposing that it is language that shapes our understanding of experience, rather than the experience shaping our language. IPA would counter that in accordance with a social cognition perspective that there is a link between someone's account of their experiences, their cognitions and their physical state. This is not to suggest that cognitions and experiences are static, they are complex and malleable. They represent the individual making sense of their lived experiences whilst also being part of those experiences.

Leading on from this point, the issue of subjectivity is intertwined with qualitative work and IPA. Subjectivity is apparent within both the participant and the researcher and is potentially considered to be a limitation. This refers back to the original discussion of qualitative versus quantitative research and the search for truth and knowledge.

> Knowledge is the presentation of events themselves to the experience, not how they actually were.
> (Willis, 2008, p.243)

In terms of ethical issues being a practitioner – researcher, researching in my own geographical area of educational psychology practice in local schools was a challenge. I hoped that the relationships I had built up with school staff would prove beneficial in approaching potential participants. I also hoped that through this process I would be better able to understand the needs and wishes of parents within the community that I worked. However, if I had based the research within a different area if the situation arose where intervention was required I would still be obliged to take action in terms of referring to another educational psychologist. The notion of a practitioner- researcher is a useful one and one, which helps us to think about and address ethical dilemmas as they arise.

With hindsight, and additional experience of qualitative research, an unstructured interview and narrative analysis may support the presentation of individual experiences, perceptions and feelings of individual parents in greater depth. However, on reflection, I feel that the use of IPA has been productive and informative. It has provided the opportunity to produce a rich and intriguing insight into parental experiences of mainstream inclusion for their children with autism. I feel that the use of IPA has addressed the initial broad research question in a consistent and faithful approach culminating in a useful piece of research.

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Appendix - 1

Interview Schedule

Interview Schedule

1. Can you describe what you see as inclusion in school?
2. From your point of view, tell me about the *'child's name'* school experience?
3. What factors do you think have been barriers to their school experience?
4. What factors have positively influenced their school experience?
5. How would your wider family describe *'child's name'* school experience?
6. From your point of view, what would be the main difference between *'child's name'* having a good and a bad day at school?
7. How does this make you feel?
8. What do you think about the move to secondary school?
9. What are your hopes for the future in terms of *'child's name'* school experience?

Appendix – 2

Participant Consent Form

Participant Consent Form

Title of Project: Listening to parents of children with autism: a qualitative study of 'how parents of children with autism perceive the experience of mainstream schooling'.

Name of Researcher: Karen Davies

Participant Identification Number for this project: ___________

Please initial box

1. I confirm that I have read and understand the information sheet for the above project and have had the opportunity to ask questions.

   ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

   ☐

3. I understand that my responses will be recorded using a digital recorder and anonyised before analysis. I give permission for members of the research team to have access to my anonyised responses.

   ☐

4. I agree to take part in the above research project.

   ☐

Name of Participant Date Signature

____________________________ ____________ ______________________

Lead Researcher

__________________________ ___________ ______________________

To be signed and dated in presence of the participant

Copies: participant / research file

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants.

A copy for the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Appendix – 3

Information Sheet

Information Sheet

This sheet is intended to give you information regarding the background of the research, the research process and contact details. Please take this sheet away with you.

Research Project Title: **Listening to parents of children with autism: a qualitative study of 'how parents of children with autism perceive the experience of mainstream schooling'.**

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with myself/others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.
Thank you for reading this.

What is the project's purpose?
This piece of research aims to explore parental experiences of inclusion for their children with an autism diagnosis. Rather than focusing on parents who have joined a support group I hope to involve around 6 – 10 parents (both mothers and fathers) from a specific geographical region. The active part of the research project (data collection) will run from around Easter 2009 until July 2009.

Why have I been chosen?
Thank you for responding to the letter sent to your home address. As you know letters were sent out inviting you to express an interest in the research. All participants were contacted in this way.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. You can still withdraw at any time. You do not have to give a reason.

At any point, up to July 2009, you could also request that the information you have provided is not included in the project. Please contact me using the details on this sheet.

What will happen to me if I take part?

We have met today in order to conduct a face to face, semi structured interview. I am interested in hearing your experiences. I have designed an interview schedule which has a number of key questions and prompts. This is to aid discussion and provide a framework for the interview. The interview could last from 30 – 60 minutes.

The interview will be recorded in order to ensure that all information is captured. This will be kept on a digital recorder until it is transferred to a password encrypted laptop. The information (interview) will then be transcribed and anonyised before a process of analysis is completed.

What are the possible disadvantages and risks of taking part?

This project involves using face to face, semi structured interviews. All interviews potentially raise difficult and challenging questions. Within this project, you may be asked about complicated and demanding situations which may produce an emotional response. Please feel that you are able to discuss these experiences but there is no obligation or pressure to do so. If you would rather not discuss particular aspects of the interview schedule please make me aware of this.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for participating in the project, it is hoped that by sharing parental experiences this will enhance inclusion policy, procedures and practices in relation to autistic pupils in mainstream schools.

What if something goes wrong?

If you feel unhappy or concerned about anything, which has taken place during the research process you, can either talk directly to Karen Davies the lead researcher. If you would like to make a formal complaint pleases contact: Kathryn Pomerantz,
Lecturer in Educational Psychology,
Co-Director, Doctor of Educational
and Child Psychology (DEdCPsy)
Tel: (0)114 222 8145
Email: K.A.Pomerantz@Sheffield.ac.uk

Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any reports or publications.

What will happen to the results of the research project?

The research project serves two purposes. Firstly it is part of the Doctorate training programme for training Educational Psychologists at Sheffield University. This means that a bound thesis will be produced and a copy held within the university. A separate part of the course requirements is the production of a paper that is submitted for publication. However, there is no guarantee that it will be published.

Secondly, this research forms part of the research of the Educational Psychology Service within a Local Authority. I intend to present the research findings through the Local Authority as well as through school based training events. I hope that by raising awareness of parental experiences policies, procedures and practices may be enhanced.

Who is organising and funding the research?

Rotherham Educational Psychology Service and Sheffield University are jointly supporting the research project.

Who has ethically reviewed the project?

The School of Education within Sheffield University have completed a careful ethical review process. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

Will I be recorded, and how will the recorded media be used?

The audio recordings of your interview made during this research will be used only for analysis within this research project. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

Contact for further information

Lead Researcher

Karen Davies

Address deleted

And finally,

Thank you for taking part.

Appendix 4

Letter Inviting Participation

EDUCATIONAL PSYCHOLOGY SERVICE

XX
XX
XX
XX

Tel. No: XX
Fax. No: XX
Email: **XX**

Date:

Principal Educational Psychologist – XX

Direct Line:	Extension:	Please ask for:
XX		Karen Davies

Dear Parent/Guardian,

My name is Karen Davies and I am currently working as an Educational Psychologist within XXXX Council whilst completing the doctorate training in Child and Educational Psychology at Sheffield University.

I am conducting a piece of research in to parental experiences of inclusion. I am particularly interested in the inclusion of children within Key Stage 2 (KS2) and Key Stage 3 (KS3) with an autism diagnosis who attend mainstream schools. Specifically, I would like to find out your experiences of inclusion for your child with autism; issues which have improved or been barriers to inclusion and transitions, within and between schools. I would like to talk to a wide range of parents from different schools within a single geographical area.

I have asked the Special Needs Coordinator within your child's to send out letters to the parents of children (within KS2 and KS3) with an autism diagnosis. I would like to interview between 6 – 10 parents who are happy to take part in an interview which will take around 30mins to one hour. Interviews will take place either within school or through a home visit, during work hours. The interviews will be recorded using a digital voice recorder and then converted into typed transcripts which will be anonymous. The transcripts will be used within the research and the original recordings kept secure and will not be used for any other purpose. Once the research project is complete the original recordings will be destroyed.

There may be many more parents interested in taking part with the research project than are needed. Therefore, due to the limitations of the research expressing an interest in the project may not mean that you will be able to take part.

If you are interested please add you contacts details to this letter and return it to the special needs coordinator within your child's school. They will then assign a number to your information so that they can randomly, blind select participants. If you have any questions about the project please contact me using the details below.

All parents who have expressed an interest will be contacted (by myself, Karen Davies) within two weeks of the date on this letter to explain if they are able to take part in the project.

I hope that by sharing the experiences of parents with the Local Authority, schools and other professionals the inclusion of children with autism will be enhanced.
Many thanks
Karen Davies
Educational Psychology Service

Appendix 5

Example of Analysis from one Transcript

Please note that this transcript is presented in a rough format for the purposes of highlighting and demonstrating the analysis process.

Transcript from Interview 2

Jane (not her real name)

- Descriptive comments are shown in plain font
- *Linguistic comments use italics*
- Conceptual comments are underlined

Interview transcript	Exploratory Comments	Emergent themes
K. Can you tell me about Leon's school experience so far.? J. Right, errm he attended Day Nursery from 9 months up to about 2 years of age. He didn't ... seem to keep up with children of his age so when we went to parents' evening it was pointed to us that may have got a problem. Ermm .. we didn't act upon it we didn't want to know, we just assumed that they didn't have the ability or the knowledge to be able to say.. that he had a problem. We just, we thought... thought that the Day Nursery staff didn't have the educational knowledge to help, so it wasn't until he was due to start normal school, when he had his pre school examination, when the Health Visitor visits, that I mentioned he had speech problems and he wasn't communicating as well as was expected for that age, that errm ...it was highlighted that he did have a problem, they thought it was just a speech and	Early years experience Not keeping up – comparison to other chn but who is making this comparison? Pointed out – didn't notice? Didn't want to know assumptions Questioning ability Questioning knowledge and ability of nursery staff Educational knowledge '*Normal*' school as opposed to? health visitor support – more open with health visitor – is the health visitor perceived as	Voice of Professional - Professional knowledge and experience Comparison to other children – differences become apparent – developmental paradigm Is this Assumption? What do we really know about the development of children with ASD Parents unaware of differences Initially questioning professional opinions Power and professional knowledge and experience

language problem. When he started school, his school teacher also assisted with that and said that she thought that there was more of an underlying problem more than just speech and language. And then we then got referred through to various groups, speech and language therapy, Child Development Centre, Hospital errm ...and it was later diagnosed, I think when he was in Foundation 2 or Year 1 that he had ASD. School have been really, really good, errm ... they've prompted me on various things I can do to help him , errm ...various things that I'd not thought about errm such as cutting paper, which he couldn't do ...something I'd never picked up on when at home ... so school have been really good with helping me out to bring him on as well, so he's not just doing everything at school. K. Going back to when he was at the Nursery, how did you feel when the Staff were voicing their initial concerns? J. Angry. I didn't think they had the right to say that at 2 years of age, just under 2 years, he wasn't doing what he should be doing. He's got an older brother, so we assumed that having an older brother, his brother was doing all the talking for him. We came home really, really angry with the Day Nursery. We very nearly pulled him out for that reason, we just thought that errm ... he was being picked on, because he wasn't doing what they wanted him to do by a certain age. We felt he was being pushed to one side, errm we didn't think there was a problem so we were really	knowledgeable? Speech and language – wasn't communicating as expected for his age – comparison to other children – developmental paradigm Teacher assisted *More of an underlying problem* – not just S&L – did the teacher suggest what the underlying problem was? Referred on to groups Diagnosis followed – 1 -2 years later School have been really good (hesitation is this questioning?) Prompting, things I'd not noticed – how does she feel that she didn't notice? *Helping me to bring him on as well* Recognition of key role parents play in development of children but reliance on the power of the professional *Angry* – no hesitation about this answer – still very raw – *didn't have the right to say, he wasn't doing what he should be doing* – comparison to other children Influence of older brother –	Support – key importance, answer questions, give advice, accessible Initial concerns around - speech and language Developmental perspective - Strength of the developmental paradigm in child development – is comparison appropriate for all children? Assumption - Is there a place for an alternative paradigm or alternative developmental profile? Diagnosis – length of time Supportive School – importance of their role – prompting, noticing, supporting Supportive school – parent team Role of parent – enhanced by

angry at that and just forgot about it and tried to carry on until it was highlighted when he was about ready to start school. So yes, I was really angry about it. K. So when the School voiced their concerns, how did you feel then? J. Errm, I think that I knew then. I knew there was a problem because it was errm when the Health Visitor visited, she asked, she did everything with him and then asked me if I'd got any concerns and that's when I said he's not speaking as I thought he should for his age, then I started to compare him with my eldest child, looking through all his books at what he could do for a certain age and Leon couldn't do that for a certain age. So I kind of knew there was a problem and ... my mother-in-law kept saying certain things as well. Say,... she laughed at him once , it's really silly , she was here while were all having tea, and errm when it got to pudding time, Leon just said alublub and I knew that meant yoghurt, I said oh you want yoghurt, and my mother-in-law laughed and I took offence at that. It was because I understood his language... and errm when she started laughing I questioned her on why. She said it didn't sound anything like yoghurt and she wondered why, how I understood his words and then it clicked then, that when I spoke to people and when I spoke to Leon... I spoke for him as soon as he said something I could then explain what he said, so I knew there was a problem then. So when he did start school I didn't take it... I wasn't offended by it.	talking for him Nearly took him out of nursery because of this *He was being picked on* – very strong statement indicating the influence of the staff potentially creating the difficulty – staff causing the difficulty. *Being pushed to one side* – Again negative towards the nursery staff and his treatment *Really angry but just forgot about it and move on* – very difficult situation Repetition of angry – still angry? Questioning own knowledge Knew there was a problem Concerns about communication Then I started to compare – *active comparison* – looking through personal records So I knew – and my mother in law kept saying things – influence of family in recognising something was different Communication *Mother in law laughed* – I took offence	professional – Power and the voice of professional Anger Comparison to other children – developmental perspective Influence of Assumption Perceived negative attitude from staff Perceived negative attitude from staff Anger Anger – shock? Questioning self Conscious knowledge but not acceptance Speech and language Comparisons – developmental perspective – reliance on assumption Negative attitude from family

K. How did you find engaging with the different services – you talk about speech and language and the CDC? J. Speech and language, the therapist was brilliant, she was really, really friendly, made me and Leon feel errm very welcome and she didn't make him feel ... that he was any different to anybody else, not as if he was special in any way. Errm, she was really, really good. Felt that I had known her for years, she just had the ability to make you feel welcome, errm I really like her then she left. When she left we never got that support, the support centre just dropped off, but because we'd had such a really good speech and language Therapist, it made me feel more comfortable and as long as Leon is comfortable I'm comfortable as well... You can tell by his facial expressions, he won't cry or anything, but you can tell when he's not happy and he was always happy with her so if he was happy then I was. K. And the CDC? J. They were very good as well. Errm they answered all the questions I'd got and they also gave me a lot of help as to what I could do at home to help out. Errm they did a lot of – it's called "Small World" and it's something I'd never picked up on that he wasn't playing that way , it was picked up on by school and then the CDC team advised me on how to help and they came into school and advised school. So rather than him doing homework that the other children were doing they would send him some	Questioned mother in law (MiL) MiL couldn't understand how a mum could understand her own child *It clicked* – sounds like a light bulb turning on – a moment of revelation *I spoke for Leon* - parent interpreting for their child and for other people – two way interpreting So a number of events brought differences to her attention – wasn't offended because now they had recognised and acknowledged these differences for themselves Speech and Language – brilliant Friendly – feel welcome *Made Leon feel he wasn't any different* – not special in any way Connection – *known her for years* Hesitation and then she left, Never got that support – the same support, the same connection – relationship lost – highlighting the importance of that relationship to professional recognition Strong early attachment – confidence in later attachments – importance of the first contact, first	Speech and language Impact of relatives views Realisation – not picked up and then noticing differences – developmental paradigm Parental advocacy realisation Speech and Language – supportive and welcoming Not feeling different Loss - Relationships lost - lost connection and support which never returned Loss of relationship with first person who provided the support Formal support - other service

Small World home.. So what they were doing at school I was doing at home, so we could expand it that way. Errm so from the CD team I got a lot of support that way as well. They highlighted things that I'd overlooked and not seen. You tend to think that your child is just normal in what they do, I thought he just didn't like to play that way. I didn't realise that every child should be able to do Small World, I think that if you've not experienced it before you just assume that your child just doesn't like doing that. It wasn't that – he just didn't know how to. K. So through that work he learned how to. J. Yes. It took, it did take a long time and even when he brought it home, we'd get all the toys out and I'd get Alex involved as well. It took a very long time to get him to want to play. He would just sit on one side and watch me and Alex play. You just see that…I thought he just didn't want to do it but he didn't know how to get involved and eventually he came and plays now with his younger brother , who's just over 3 years younger than him, and they're about on the same, Andrew and I say they are on the same wavelength. You can see the way that Leon plays – he plays at that level of a four year old. He loves Small World now and the things he should have been doing at that stage. So the child Development Team helped me – they brought things to light that I'd not picked up upon. K. So when it went from a Speech and	impression with parent and child being a positive one You can tell he's upset by his facial expressions – are these obvious to all or just people who know Leon? Always happy with S&L Good not brilliant – answered questions – sounds more formal Practical intervention – helping parents to help at home. Small world – imagination and role play Repetition on *never picked up on* what are the emotional consequences of this? It was picked up by school – professionals noticed – reliance on views of profesional – is reliance the correct word? Small world for homework – developmental paradigm Support from CDC Highlighted things I'd overlooked and not seen *Tend to think you child is normal* – the alternative would be to think your child was abnormal – is this how having a diagnosis of autism makes you view your child? I didn't realise that every child should be able to do small world – reliance on developmental paradigm – social and cultural expectations	Never picked up on by parents but picked up by professionals Voice of professional & power Strength of developmental paradigm Impact of advice on family and pupil – recommendation become homework – at expense of other approaches or work Never picked up on Loss – of the child you thought was normal Strength of developmental paradigm Power of professional voice Major assumption from professionals that all children should follow exactly the same patterns of development – Strength of developmental paradigm - impact of this perspective and

Language difficulty, which was highlighted initially, to an Autism difficulty, how did you find that? J. Errm, Heartbreaking. As soon as I found, tearing up just thinking about it, when we first found out we knew it was coming as a lot of people had said they'd thought it was Autism, but there's a big difference between someone saying they think your child's got autism to Your child's got Autism. As soon as she mentioned it my eyes all filled up. I felt really sorry for him and when she mentioned how an autistic child lives, in their own little world, and as soon as she said this, I was so upset and sorry for him that he's got to live this way and I still do. I just wish I could take it all away from him and he could live a normal life and I could take it all off from him. It's devastating to find out. There is a big difference between thinking your child's got it and knowing that he has. Errrm, I fell into a trap once, about two years ago, when they have the IEP's, and his IEP had done really, really well at school, it was fantastic and I sat there with a big grin on my face and I thought he'd overcome autism. I thought it's brilliant – he's getting to where he should be and his Teacher stopped me and said she thought I had my wires a bit crossed here because although his IEP has gone very well, it doesn't mean that he's ever going to overcome autism and she said he will have autism for life…. and that something again … that I tried to talk my self out of thinking that he had autism, that it's something he would grow out of. It's errm devastating to find out… that they've got ASD.	– placed there by professionals Assume they don't do it because they don't like it It wasn't that he just didn't know how to Questioning It took a long time – therefore would he have come round to it eventually on his own without the intervention? Plays with his younger brother – comparison – same wave length – same developmental age – developmental paradigm He loves small world now – but later on talks of his computer games being his favourite activity Has it become a routine? Repetition of not picked up on – Key element of parents not knowing or recognising but professionals about to spot difficulties – professionals then giving the support Hesitation then *heartbreaking* – still very raw Knew it was coming but still very difficult – recognition but not belief – has all hope gone? Difference between think and know – the finality of the	exclusion of other perspectives and approaches Loss – missing out on play experiences Strength of developmental paradigm Not picked up – parents not noticing but professionals having the insight Impact of the diagnosis – loss Emotion – heartbreak Loss – all hope is gone Loss – finality Loss – of the normal child replaced with a child who is not what you expected, not what you wanted Loss of normal life Loss – emotion = devastating Hope still there – traps View of the professional Loss – repeating itself Uncertainty

K. How do you think that has affected his experience of school? J. Errm, I don't know really – I don't know…he's not one to say - he won't tell me emotionally how he's feeling. You've got to read into Leon yourself. If he comes home and he's really quiet and he goes into himself, then I know he's had a bad day. The majority of the time he loves school, he doesn't like school holidays. He loves being at school, loves being with all his friends, loves his teachers. In year 2, he's got this relationship where he had to have a cuddle every time he walked into class and a cuddle before he left class. He thinks the world of everybody in school… even the Head Teacher, it's like that's his family so, when he's not with me, he's with his family at school, he loves it. So I think his transition from home life into school has been really good. Every year when we've prepared him for moving from Year 1 to Year 2 and Year 2 into Year 3 we've assumed he would take it really badly, but he has just sailed through. I think it's because he just takes every obstacle really well, whether he keeps it all bottled up, I don't know, he's not one to explain his feelings or anything, so I think his school life is going really well. K. So when he's at school, what is the difference for you and your family when he's had a good day or a bad day. J. If he's had a bad day he will come home and he'll want to sit on his own. He's very much into handheld computers or errm play stations and I	diagnosis – not a relief but an ending *I felt so sorry for him* – sorry as in upset, sympathetic or concerned? Then she mentioned – someone else's view of how a person with autism views and lives in the world. I was so upset and sorry for him having to live this way – taking that professional view as the outcome, the reality and the view of their child who hadn't been any of these things prior to the diagnosis. I just wish I could take it all away from him and he could lead a normal life – so he's not going to live a normal life – he's abnormal with an abnormal future. *Devastating* - Fell in to a trap – who had set it? Was it a trap? Still hoping he can overcome his autism – but this is dashed by the professionals – but what does this mean overcoming his autism? Happy- getting to where he should be IEP has gone well – doesn't appear to be any anger at teacher for pointing this out – acceptance of professional	Positive experiences of school Good relationship with teacher Positive experiences of school Positive experiences of school Preparation for change – professional expectations leading to assumptions Positive experiences of school Good and bad days Escape from life Barriers to protect or to hide? Personal coping strategies within the family – traditional roles – mum dealing with children – father working

think that is his escape from life. Err, he could be on that from first thing in the morning to last thing at night if you allowed him to be. He puts a barrier up then, that's Leon doing what he want's to do and he can forget all about everything else. Errm, so if he's had a bad day at school he will just go into himself and not discuss anything with anybody, errm … just go into himself, if he's had a good day, he'll want to play with his brothers, he'll go outside and play and ..that's the difference. If he does come home and he's had a bad day and he just wants to play, we'll leave him for a while and we'll keep questioning him to see if he's okay. When .. then when he wants to he will come and join in again. He will eventually tell you what has happened, he gets very upset then when something has happened which he doesn't like. He's not overcome it, but is learning to accept it, but he doesn't like noise and that can affect him really bad as well. He's really sensitive with his ears, doesn't like you touching his ears or anything, he's very sensitive in that way, so the slightest think like that can upset him.	view Belief that autism is something he would grow out of – static nature of the diagnosis – that it doesn't change and therefore the person doesn't change? Experience of school and being labelled autism – he's not one to explain – uncertainty - has there been any comparison to his older brother? Recognition of day to day problems and positive experiences – need to know Leon to know when he's happy ect Majority of time he loves school – loves friends, teachers. Very close relationship with teacher – similar to close instant relationship with S&L therapist	Sensory integration Change Views of the professional – one view of a person with autism – not like her son Description of his feelings if he doesn't understand what's happening = lost & confused Expression of emotion Expression of emotion Expression of emotion Supportive school Supportive school Supportive school Supportive school Supportive school
K. How would your wider family describe Leon's school experience, your husband and relatives?	Mum relates his feelings about school staff to a family – *wider family* – he loves it	Supportive school – actively promoting inclusion
J. Errm … his wider family doesn't really have much to do with school because I am at home all the time. I'm the one who takes him to school and picks him up from school. When I was working, my mother and father in law would take him to school and my sister in law and they never had any problems … the	Transition from home to school – positive Preparation every year for change – helped him to accept change – Assumed he take it badly – is this the voice of the professional telling parents he	Supportive school – actively promoting inclusion Supportive school – actively promoting inclusion – encouraging

same with home life, they don't treat him any differently to his siblings either. Errm, they have never brought anything to my attention so I don't know what their feelings are with that. I kind of get wrapped up in my own feelings with Leon and me and Andrew will discuss things more, we're quite a close family unit with the children, so we tend not to involve other people too much in things, don't tend to get support in that way, we support each other and errm … we try to get each other through it all. So I don't know about anybody else, me and .. my husband is always at work so he doesn't get much opportunity to take him to school and pick him up, but if he does pick him up from school, Leon's face lights up and he loves his Dad to come to the school. And if he's doing any plays or assemblies he wants you to be there watching him … and if his Dad gets the opportunity to be there, he's … really excited at the fact that Dad's going to be there to watch him. K. Just going back to what you were saying about noise being an issue for Leon, are there any other barriers, within the school that you've come across or anything really that is a barrier to Leon being fully involved in a whole range of activities within school? J. Errm, the big thing is noise because that is something I have experienced with him. If he's told something is going to happen, it has to happen, if not, he can be quite upset by it. If they are organising a school trip and he's to be partnered up with someone, if he's not partnered with them, he looks quite lost and he'll stand there looking over the	would take it badly? Does he keep it bottled up? If it's bottled up when is the explosion? Belief that school is going very well Bad day – quiet wont say anything, withdrawn Computers give him an *escape from life Puts up a barrier* – barrier to stop people coming in or to stop himself coming out? He can forget all about it – assumption that he doesn't think about it – blocks it out Recognition that he goes in to himself but then the unknown of what happens then Good day - he'll just play with his brother – Bad day - We'll keep questioning him to see if he's okay He'll eventually tell you – when he's ready *Sensitivity to noise* – leaning to accept it Can affect him badly – *Sensitive with his ears* – easily upset Wider family don't have much to do with school, although	co-operation and engagement Insight in to the world of school Insight in to the world of school Loss – alone Supportive school – actively promoting inclusion Overlooked – hidden nature of difficulties – can be easy not to spot them Overlooked – hidden nature of difficulties – can be easy not to spot them Wasted year Teaching rest of class but not Leon Overlooked Lost year Focus on social

place and wondering what's happening. So, he can be quite lost in that way so he's not very strict through his autism but if he's told something's going to happen in a certain way, it has to happen that way or else he looks quite confused and lost. K . Does that lead on to any other difficulties.? J. He just started throwing the odd tantrum and stamping his feet and he does a really sad face and his mouth comes down and that's his way of showing his disappointment and he'll hang his head down. Errm, if he gets upset, he just gets teary he won't stand there and scream or anything, you can just tell by the look on his face how upset he is with you. So he'll... I don't know whether he stamps his feet at school but he does at home, just stand there and stamp his feet, cross his arms and a big long sad face, head hanging down. So that's his way of showing his disappointment in you or disapproval in anything, he won't really lash out or.. or scream out loud or anything. K. In terms of managing noise or the routines, I take your point is not a sort of routine, but he's told one thing and it happens differently, have their been any strategies that have been used within schools to address those issues? J. Errm.. yes, to errm, when he was in Foundation they used to have a chair next to the teacher so when they were doing, having story time all the children had to join in and that really used to	they did pick him up When I was working – reliance (not reliance assistance) on other family when needed They don't treat him any differently – why? Don't know their feelings – although earlier MiL laughed at Leon's speech – was this a pivotal point in that it is now not mentioned in the family? Mum and dad rely on each other- private, don't involve anyone else and they do not ask? I don't know about anyone else and possibly don't want to suspect or guess? Leon and his dad – dad works a lot Really excited when Dad turns up To long!! Noise and sensitivity Not routines but the expected – trusting people to follow through on the plans Lost if things change *So he's not very strict through*	development and behaviour Focus on social development and behaviour – not education Focus on social development and behaviour – not education Strengths Strengths and positives – is this a barrier Focus on social development and behaviour – not education Supportive school practices Supportive school

upset Leon if all the children were shouting , like in Jack and the Beanstalk, the children were all shouting “Fee Fie Fum” it really upset Leon. So the teacher's way round that was to have a chair at the side of her. His class friends have always been so understanding – that was always Leon's chair and every child knew not sit on that chair because Leon always sat next to the teacher and he used to hold on to the book and I think because he was then facing the children and wasn't actually involved by sitting in with them he could accept the noise a little bit more. And eventually they would try and integrate him more – he'd sit at the edge of the class and then start getting him sitting in the middle of it. And errm... Just before or just after Christmas they had a music teacher come in this year and they did drums and various instruments. Errm ... he didn't like the drums – he couldn't accept that loud noise but he used to pluck the viola and he really enjoyed that so noise is getting, probably becoming a little more acceptable. The teachers will find a way so he does get involved, so instead of being close to a loud instrument he'd be put near the quieter ones, so he'd be sat to that side ... so he's always been included. They won't think that because the children might shout out in this story Leon can go and do something else, they found a way to keep him involved and make him involved As soon as they knew he was happy with that and had got used to it they'd start moving him closer into it. K. How does that make you feel as a parent?	*his autism* – interesting use of words Repetition of confused and lost Leading question – difficulties Tantrums – stamping feet – pronounced facial expressions Facial expressions rather than noise Don't know if he does this in school Over pronounced expressions and non-verbal cues Hestistation possibly because of the rubbish question. Strategies in school at story time Leon's chair – actively involving him in the activity rather than excluding him from it - inclusive practice recognition of individual difficulties integrate him – encourage and support	practices Supportive school practices Professional view Supportive school Positive about school Worries and concerns Worries and concerns Worries and concerns Insight in to school

J. Really happy, because I like to know that he's not being left out. It really upsets me if I see him on his own, errm … an example of that is playtime. Errm…I'm one of those when I like to go down to the school and look over the hedge and watch the children playing and there was a time when I took his younger brother to school and I'd look into the playground and see Leon playing on his own and I'd stand there and cry – I didn't like the fact that he was on his own. I questioned them at school and they said they had noticed it but that's how he likes to be and they were not going to force him to play with someone or someone to play with him. And eventually, then, he would get integrated with the other children but he had to do it when he was ready. So school have been really, really supportive with every obstacle… and as long as I know he is being supported the way he wants to be supported and he needs to be, I'm really happy. Yeah, so I can take him to school and leave him and not worry at all and I've always been that way. If I question it they always have an answer for me. K. So in terms of barriers, you were saying before that he doesn't have any overt behaviour problems, but because he's the other way in that he kind of withdraws slightly , could you just tell me a little about that, because you were saying earlier that that in itself might be a little bit of a barrier. J. Yes. I think a lot of people don't realise because he hasn't got the	Music – again support him in an appropriate way to ensure he remains with the class but in a way which is acceptable to him *Teachers will find a way so he does get involved*, inclusive practice *They found a way to keep him involved and make him happy* – happy is clearly important *Once happy – continuing to encourage more involvement and engagement* Really happy he is included *Upsetting to see him on his own – personal, social and cultural expectations* – developmental perspective – children playing together *One of those who look over the hedge* – parents peering into the world of school – *and cry* – he's on his own and mum powerless to do anything – separate from school *Raised concerns with school* – gave an honest answer – not forcing him to play – waiting until he is ready – opposite approach to the small world play which was very much imposed on him.	Worries and concerns Insight in to school Worries and concerns Worries and concerns Worries and concerns Role of friends – seen as crucial as he gets older – less of a role for Mum to be protector but friends will become the protector – assumption that he will need this Identified key person - needed in school Uncertainty – the unknown Identified key person – for parent and child – someone to go to – to talk to – who can advocate for him Uncertainty – the unknown

behavioural problems, they don't realise he's got ASD, so he can be overlooked very, very easily. He used to be in a football team but people tend to treat him as an adult because he'll stand there with the adults and the dads will be stood there with their arms crossed and shout something so he'd copy and shout something, and they were really sweet about it. I think in school errm he could very easily be overlooked because he will sit there erm… and, if he's not told what to do, and if he doesn't understand what to do, he'll just sit there and not do anything. A couple of years ago, I think when he was in year 1, we'd go to parents' evening and there would be nothing in his book and he would not have written anything… errm and that was the only year that I did find problems in school and it was because they lost a full time teacher so they'd got supply teachers in all the time. He wasn't getting the support throughout that year that he needed, so they were obviously teaching the rest of the class and Leon would just sit there and think … I don't know what to do … and rather than asking, a big problem for him in asking for help and it's something that they found they had to work on when he got a full time teacher coming in and he would just sit there all the way through a lesson, he didn't know what to do and I don't think his teacher … whether she was aware of his ASD, I don't know, but she just didn't seem to include him. I mean, I looked at his books, I think at the end of the year, he'd probably got about 3 pages with a little bit of scribble on, so he had a bit of a lost year in Year 1. where, I think he got overlooked a lot	Repetition of really to reinforce supportive Difficulties termed as obstacles – to be overcome to be jumped over, hurdles to be leap over before one can move forward. Repetition of supportive and supporting So I can take him to school and not worry – this is now so did you worry in the past? Long question!! Don't realise because he doesn't have behavioural problems – easily overlooked. Is there an assumption that he should have behavious problems? Treat him as an adult – think he's sweet but Mum seems to be saying there's something wrong in this In school *overlooked* – just sit and wait until he's told what to do, if he's not told he won't do anything. Wasted year in Yr 1 – supply staff Nothing written down The only year I had problems in	Turning to his friends rather than his brothers? Interesting that he wouldn't seek support from his brother Identified key person pupil is confident with Worries and concerns Worries and concerns New Friends – acceptance? Uncertainty – the unknown Role of parent – the protector – Mum talking all worries and concerns on for her child

K. So in terms of the communication within the school – do you think that's been an issue? J. Errm, I don't think, I don't know whether it's because there was so much change in school that year. The Head … she was going through a lot of family problems, errm she wasn't in school a lot and then it was passed down to the Deputy Head and then another member of staff and I just don't think that many people got … not just Leon, but a lot in that class, did not get what they needed that year. It was a complete lost year. So I don't think it was just Leon down to his ASD that was left out, I personally feel that it was a class thing, because they didn't have that full time teacher that they needed. Errm, it just went complete role reversal in Year 2, he built up such a brilliant relationship with his teacher. The only thing I do find with parents' evenings and I sit down and hear that Leon's a wonderful student, he's always there to greet you in the mornings with a big smile on his face and you have to stop them and remind them what you are there for and I want to know, educationally, how's he doing, you tend to find that people talk about his behaviour rather than his school work ..because he meets you with a big smile, he really is a pleasant child and they tend to look on that rather than his education. I suppose it's because that's what he's good at. He's good at making people smile.. errm and making people feel good, and I think teachers do tend to look on the positive side, so because of that, they tend sometimes to forget	school Wasn't getting support – always appears to be the word support when referring to school Teaching the rest of the class but not Leon – because he didn't understand – was he the only one? Questioning if the teacher was aware of his autism End of year looked at books and there was scribble – the lost year He got overlooked Hesitation , don't think then don't know Providing an excuse or context for the situation, explaining and showing understanding Not just Leon – other's affected Complete lost year Not down to Leon and his ASD – Autism used in a possessive as though it's his to own Didn't have full time teacher Role reversal in year 2 – full time teacher – brilliant – same word as the S&L therapist Parents evening – behaviour	Key people in school Key People Key person – know him Key person – relay info – two way communication Familiarity with school and staff Uncertainty – the unknown Barriers could be internal barriers – protect or to hide Uncertainty – the unknown Worries and concerns

what Leon's done at school, so they'll spend 5 minutes telling me what a good child he is and 2 minutes telling me about what he's like educationally wise. It's nice to know that your child is a nice child, but I think sometimes the schoolwork can be overlooked.	rather than academic focus – 10 min conversation Wonderful student, bib smile Need to know about academic, educational side of things	Uncertainty – the unknown
K. You've mentioned a lot of positive things about school, in terms of relationships that Leon has built up with his teachers and the relationship that you've got with the teachers. Could you tell me a little more about those and about other things that have been really positive that have really meant that he's been included within school, like any other child.	Talk about behaviour rather than school work Smile and pleasant child – overlook his education I suppose it's what he's good at, making people smile and making them feel good Teacher's looking for the positive side – barrier – tend to forget about education	Do all these themes combine – the uncertainty, not noticing generate the worries and concerns create the need for Mum to be the protector which is never resolved??
J. He's really good with his sport, he loves sport so he can bring his medals in. He didn't used to do "Show and Tell" because he didn't know, because of his speech and language problems, not just speech and language, it's also understanding, he didn't understand life in general and what a lot of things mean and once he got into football and started getting medals and trophies, he brought them into school and they allowed him to do "show and tell". That's how, by talking about something he's interested in he can then also ask questions, so from other children bringing in football medals and trophies he could then put forward his questions. So the teachers knew that if it was something that Leon was interested in, they'd ask Leon first of all to ask a question, because it prompted him learning how to ask a question, with a what, why, how so they'd integrate it with the interests that	School work overlooked Good at sport – winning medals Helped to engage him in other educational activities Helped speech and language problems Helped understanding in general, life and others Talking about things he's interested in and then being able to ask questions about other peoples experiences. So the teachers knew – adapted to his needs,	Uncertainty – the unknown Anger School supportive of the individual Uncertainty about the future Need to feel comfortable and welcomed – relationships with professionals

Leon has. If it's something that he's unaware of, if they're talking about flowers or anything like that, he wouldn't ask a question because he wouldn't know how to ask a question about something he hasn't got an interest in, so school will help him in that way, and we'd have school clubs …he loves his cricket and football and they will make sure he's involved that way. I haven't really got many down sides with school. He just loves being at school. Errm, I do worry about him with his school work and I worry mainly about his integration into Comprehensive school and also with his SATS. I don't know how he's supposed to get the grades he needs with Sats, so I worry a lot about exams. I don't worry too much about what he's doing at school because I know he's happy .. but I do worry about his future.. ever such a lot, and how he's going to cope with exams and I question it lot with school. They've just done Year 3 Sats and I wasn't aware until I was at school the other day that he was in Year 2, they'd moved him down a year to do his Exams, because it was at a more basic level for Leon and I think that they knew he would have been lost doing the exams he should have been doing in Year 3. So I've got no downs really – they seem to know what they are doing with him.	recognised how he could engage and develop – scaffolding the environment for him Prompted his learning – asking questions Assumption that when he doesn't do something it's because he doesn't know how School helped him – support Clubs – sports – makes sure he's involved Haven't got many down sides with school He loves it I worry – is this your role – too worry? Worry – school work, comp SATS and exams Questioning – how's he supposed to get the grades he needs? Worry about exams Don't worry about what he's doing now – he's happy Worry about his future	Insight in to school Role of mother – the protector Role of Mum to be the protector – to help, Is this wrapped up with guilt – not noticing? Expression of emotion
K. But, educationally, you were still saying that you were quite concerned about his work. What concerns you about his work?	How's he going to cope – question this with school Wasn't aware until they'd done them – mum wasn't pre - warned – found out afterwards	Role of Mum the protector
J. Errm, It's just something I worry about all the time. When I look at his writing, I	Basic level exams – doesn't	

know it's not the level it should be at. Errm, when I look at, his numeracy is brilliant. I don't know, I just worry so much about if he's going to know the right things... to help with his exams, if he's going to know the right things, to help him out when he moves into Comprehensive school, is he going to know the right things for his GCSE's, and will he know enough to get a job. I don't worry too much about now, I worry about the future. K. So in terms of his transition to the Comprehensive, how do you feel about that? J. Errm. I think he will turn to his friends, he's going to know that he will be leaving the school and teachers behind and I think he will turn to his friends for support there and I think I will do as well, I'll be asking his friends' Mums, to make sure his friends are looking out for him and errm I think he'll need someone at school who he can recognise and he can go to if he needs help. I think we'll probably go to school and meet a teacher. He takes a liking to one person and if he's got a problem then I think it will be down to that person to realise that he's got a problem. He won't just go and talk to anybody or he won't show his feelings to just anybody, he'll just keep it all back. So I think me and Leon will probably turn to his friends to begin with until he finds that person in school that he likes and feels comfortable with and to show those emotions to. K. Are there any other concerns about Secondary school. We talked about relationships, were there any academic .	mention any other children – did other go down to do the basic level Lost doing exams within his own age group Not a criticism – recognising his difficulties and adapting to them but then uses the word seem – they seem to know what they're doing – not certain I just worry about it all the time *When I look at his wring it's not at the level it should be – levels* – criteria assessment *Numeracy brilliant* *Questioning herself* – worry so much – is it right or wrong to worry Worry about exams and knowledge and coping Worry about transition to the comp Worry about GCSE's and employment *Not worrying about now but the future* Role of friends, seen as important to him and to mum – looking out for him, checking up	Worries and concerns Positive experience of school Worries and concerns Hidden – parents didn't notice, other parents don't notice – autism is something that professionals have brought to the family Complex feelings – is this linked to worries and concerns – trying to reconcile the positives and the strengths with the version of autism presented by the professionals Complex feelings

J. I worry a lot about bullying as well – I don't know how other children will react. At the moment he's coped because he's in a very small class, where children have been with him since day 1 . They've accepted and don't treat him any differently to any body else and they allow him to join in and they pick up on things that he's good at. Now, when he goes to the Comprehensive school, he's picked up a really bad stutter at the moment and I'm worried that people… are going to bully him for that and bully him for not doing what other children are doing and if he's pulled out for special lessons, people, who don't know Leon, I don't how they are going to accept him and treat him – I think I'll be there, in front of him, to protect him and! Or at least I'd like to be. (laugh) en, looking forward to him going up to the Comp, what would make you feel better? J. Having someone there who he is comfortable with, that's going to be a big thing for me and Leon. K. So would that person be somebody that Leon is comfortable with, what about you, would that be someone for you as well, would that be the same person? J. It would be the same person because if Leon is comfortable with them then I know that person is going to know Leon inside out and know he's feeling every day and I would expect that person then to be able to relay that information back to me. Now, whether it's something	Think he'll need someone at school who he recognises and he can go to. Uncertainty We'll go to school and meet a teacher Uncertainty Someone he takes a liking to – instant connection – attachment to one person Won't talk to just anyone, needs to be someone important to him Just keep it all back Turn to his friends – what about his brothers? He'll have one brother at the comp when he starts? Uncertainty – lots of I think - Find someone he feels confident with Worry about bullying – reactions of other children Coping because he has small classes, children he's been with from the start of school They've accepted him, join in treated the same – worried other children won't do the same Picked up a bad stutter - are people going to bully him for that? Special lessons – being pulled out of class	Complex feelings Reconciling complex feelings Reconciling complex feelings Strength of the developmental perspective Worries and concerns Insider accounts – lack of positive stories

that errm they can visit school, or I know that every school has got errm I know where he'll end up going,, they've got someone who visits our Lady's. Now whether it's someone Leon will meet at an early stage so he can build a bit of a relationship, sorry, not a relationship, but make a face known to him, so when she's... looks forward to integrating him into that school, that he's aware of who she is, he's not going to look at her as a complete stranger and think – oh. I'm not going to do this and put barriers up. He's never, I don't want him to create a barrier that he's never had. I don't want to find a problem later on down the line that he's never had before. K. Is there anything else you can think of that might make things easier for you? J. Errm ...I tend to be happy as long as Leon's happy. I worry about things that Leon doesn't worry about – I worry about his future – Leon just tends to get on with the here and now, because he doesn't understand. Errm, I'm not too worried about anything and I don't think I can expect any more help. I expect from his Secondary school what I get from his Primary school, I know I'm not going to get that, it's going to be... they've got many, many more pupils to look after, and have more children as well with disabilities and needing that extra help. I am going to be expecting what I get from this school and maybe, when I don't get that, maybe that's when my frustration will pink...if I'm not getting that help then. K. In terms of inclusion, children within school being included in the whole range	*I don't know how they are going to accept and treat him* – assumption that they have that power and that choice – Leon is powerlss in this situation Mum – wanting to be there to protect him – does Leon want or need this protection Someone he's comfortable with – Same person – for me and for Leon – if he's happy then I'm happy, so Leon will find someone who is accepts and this will be the link person They'll know him inside and out Expect that they'll rely information back to home – Visiting the school Meeting and building relationships Make a face known Aware of people Prevents him putting up barriers Never done this before but it is giving him some power in the situation Don't want him to put up barriers	Positive about autism – do we ever talk about these? Worries and concerns Loss – hope for the army gone Worries and concerns Professional perspectives Needing a protector Worries and concerns Worries and concerns

of different activities, in terms of an inclusive school, could you describe what that would mean to you, what would that be like? J. Errm I expect people to be really focal, errm I like to see exactly what's going on and like to see that every child is happy with what's going on there. I know that when he starts Comprehensive school that I'm not going to have as much involvement because I'm not going to be taking him into school, I'm not going to see his teachers on a more regular basis. Whether they can, if they can interact more with me so I am made to feel welcome to come into school on a more regular basis than any other parent would do, errm, I really don't know how it works, but I want to have more of a the parent/teacher role that we've got at this school, to be able to carry on to the next school, if that makes any sense, I want to be able to have that relationship with his teachers so if I want to know what's going on I don't have to wait until parents' evening. I don't want to wait until the end of school to know that something is wrong, I want to be able to know if something going on at school and Leon is not happy I need to know then and there, so when he comes home and is feeling down, because I won't get the information every time off Leon. I need to know that something's happened, so I can help him through it, if not, it will cause problems with me and his Dad where we get upset if Leon's upset, we get really upset. Errm, that's no good for Leon, he doesn't want to see that we're upset as well by things. Errm, something	Hesitation – is this thinking time? Then, I'm happy as long as Leon's happy I worry and Leon lives in the moment, he doesn't understand I'm not too worried about anything – very worried previously inconsistencies Can't expect any more help – getting enough support or doesn't feel you have right to expect anymore? Expect from secondary same support as received from the primary – then challenging this – I know I'm not going to get that. More pupils to look after More children with disabilities – Leon included in children and children with disabilities, needing extra help– Leon considered disabled and needing extra help. If I don't get that – frustration will pink Expect people to be focal – people as opposed to paperwork? Or something else? Transparency – what's going on Children happy Know I'm not going to have as much involvement when he's	Worries and concerns Loss of normal life Worries enhanced for Leon but not other boys Influence of peers Worries and concerns Worries and concerns Worries and concerns Protection Need for positive insider accounts Protector Worries and concerns Responsibility for parents especially Mum

happened last night. He goes swimming with his brother and his brother's friends and as soon as he jumped out of Mum's car last night, his face was down and his head had dropped and I knew something was wrong then. As soon as he walked in and we asked him, he burst out crying, so I knew something was wrong then and you need to know so you can sort it and make sure he's happy enough, because if not, you know you fall off your bike, I need to get back on it. And I think if we don't that something going on at school, he's not going to want to go school any more and he loves school, but I don't want him to get to the point where his head's down and it's morning , it's time to go to school, his head is down and he doesn't want to go school. I want him to be able to be happy and to want to go to school every day and to want to be with his friends and to want friends to come home after school. I don't want him to lose friends because of his ASD , and not to be able to make new friends because of his ASD. K. So do his friends at the moment, who are in his class, do they know that he has this diagnosis? J. I don't think so, no. They just see Leon as Leon. Errm, a lot of parents don't know until I'm talking to them and it gets mentioned and then it's complete and utter shock. Errm, a lot of people didn't know that he had got a problem. I don't mention it because I want him to be tret differently – I tell people that I'm proud he's got ASD. It sounds a really silly thing to say, but I am proud of it and I'm not going to hide it from anybody. Errm,	at comp – sounds like at present she would like it. Want school to interact and make her feel welcome in the school, more than any other parent – she's not just any parent? Don't know how it works More of the parent/teacher ole – not sure what this means? To be able to have a relationship – to know what's going on and so I don't have to wait until parents evening to find out Need to know then and there if he's not happy *Won't get information form Leon* *Need to know so I can help him,* If not it will cause problems with me and his Dad Leon doesn't need to see us upset No good for Leon to see us upset Something happened last night Knew something was wrong as soon as he left the car – facial expressions	

iIf I tell people, I tell them with a smile on my face because I think… errm I like them to know that he's got this problem, because then at least, if they ask him a question and he looks blank and vacant, I don't want them to think he's being ignorant. Errm, so that's the reason I tell them. I don't want him treating him any differently but it'll sound very silly saying that I'm proud that he's got it, not that I'm proud that he's got it, but I'm proud to tell people that he's got because he's still Leon. Errm, he's still the person he is, he's still special and always will be so, in that way so in that way I'm proud to tell people, not proud that he's got it because I would prefer him not to have it, but it doesn't bother me at all to go round and tell people that he's got it. K. Is there anything else that you'd like to add, anything you'd like to say? J. Errm, I don't think so. I agree that every child is completely different. Errm, I don't think, it sounds very silly, but I'd like to know people who've… I watched a programme the other morning, I think it was on GMTV or This Morning … and it was somebody who'd got ASD or just Autism – and they were out of work and looking for work … and I think it would be nice to know that there are people out there who have got good jobs and whether they have managed to go through University or whether they've managed to do something to allow them to get the job that they want. The thing that me and Andrew keep saying would be good for Leon is probably the Army, purely because if you tell him to something, he does it to the best of his	Knew something was wrong, Leon can't handle it and as parents we need to sort it out, to make sure he's happy Don't want it to get to the point where he's not wanting to go to school He loves school at the moment but recognition that this could change Head down – doesn't like it Happy at school, with friends doesn't mention education and achievement with happiness – happiness is friends Doesn't want him to loose friends because of his autism and not to be able to make new friends *Do people know about Leon's diagnosis* – his friends don't some parents do – they're shocked – what is their expectation? People didn't know he'd got this problem – Is it a problem then and whose problem is it? I don't mention it so he's not treated differently Proud and not going to hide it but conversely doesn't tell people but has told people – complex situation Telling with smile on face –	

ability. He used to suck two fingers and his Dentist just said to him one day … you need to stop sucking your fingers because you're deforming the growth and they are not growing at the right level, the right rate, they're not growing straight and he stopped sucking his fingers that night. Now, usually a child who hasn't got ASD – you need to stop sucking your finger or thumb – they're not going to do it and he did it that night and he's never sucked his fingers to this day. And that's why we think probably the Army would be good, because if they say go and do this he'll go and do it to the best of his ability. But I've since found out that they won't accept people in the Army who've got Autism. So it's starting now making me think what will he do then for a job, I don't know what else he could do and iIt's because somebody said to me that they can't go to war with Autism because they are not going to know what to do. They can't rely on a man saying… what am I supposed to do now … so we looked at the army as a bit of a safety net for Leon, thinking well if he goes in there, he'll do fantastic because somebody will tell him what to do and he'll do it brilliantly. So I worry about the future too much. Andrew always tells me off for it because I always have to plan for years and years in advance and I do it with everything. We'll do this this year, and we'll do this next year and Alex will be such an age next year and we'll be able to do this, I like to be able to work these in advance and so I worry. That's all I worry about, I worry about when he's old enough to do what everyone else is doing and they're leaving school and learning to drive, will	actively trying to put a smile on face but is this a false smile? Don't want people to think he's ignorant So I tell them Sound silly but I'm proud he's got it – it not specified or named, correcting, not proud he's got it, proud to tell people, *He's still the person he is- the same, still special and always will be, happy to tell people because I'm proud of him not proud of the diagnosis* – not proud of the label he's been given Prefer him not to have it – the label or autism and the label? Every child is different - how does this statement fit with a developmental perspective Concerns about the future – impact of the media on worries and concerns and on helping to alleviate these concerns More insider stories Army If you tell him to do something he'll do it to the best of his ability	

he be able to learn how to drive. They're all leaving school and getting jobs, will he get a job. They're leaving school and meeting girl friends and settling down, will Leon meet a girl friend and settle down. It's that crystal ball that you'd like to know that he's going to have a normal life. K. Do you feel the same way about your other boys ? J. No, it's really silly. I know that I have no problems, no issues with his older brother. He sails through school, he's, sails through his exams, he's got no issues. I know for a fact that he will leave school and as long as he doesn't get in with the wrong crowd, he'll get a good job and he'll eventually leave home and settle down and manage that way. I think Leon is brilliant with children and I know that he would make a brilliant Dad one day, but will he ever meet someone who wants him, somebody with his disability, because if he's vacant he will go off and sit on his own, will somebody accept that. So, I worry too much about Leon's future. Will he be accepted in society, will he ever be able to move out and live on his own or will be better living with us for ever. I'd like to meet somebody who's been through it all, settled down, married and got a good job, just to prove that there is a chance that he can do it, without worrying about him... always wanting something that everyone else has got and he's never going to get... So I know now he's okay because he's got me to look after him, he's not always going to have that, so that's why I worry about. I don't	Example of instant change because someone told him to do something Positive aspect to autism – is this the first positive? Concerns about the future looking to long term outcomes Hope for the army dashed – does the army accept or reject people with autism. is this right? Don't know what else he could do? People with autism unreliable? Safety net for Leon from parental perspective Recognition of own personal views – worrying about the future – *I worry too much* I plan years in advance and do it with everything Worrying for the future Like to know he's going to have a normal life – recognition that this is a possibility, that he could have a normal life. Recognition that she feels differently to about Leon than her other boys. Comparison to older boy – sailing through no issues Influence of peers for older brother is peer pressure and wrong crowd for Leon it was bullying	

worry about his brothers because I know they will be able to cope, but when I'm no longer here for him and his brothers have left, and you know I don't know…	Thinking about the future – no concerns for older brother and coping Leon and relationships – being a dad Will someone want someone with a disability? Worrying about Leon and his future Coping with day to day life Or live with us forever – doesn't worry about other boys living with them forever – Meeting someone – insider stories – real life experiences So I know he's okay – concern for his happiness Got me to look after him – but not always going to have that and worry about this as well So many worries Not here to look after him and brother – no mention of brother supporting each other and wider family – lots of responsibility on her shoulders	

Appendix 6

Information on the children of the parents who participated in the research

Additional information on the children of parents who participated in the research.

Pupil (male) A was in Year 8. He received his diagnosis of autism from the Child Development Centre (CDC) during KS1 after school staff highlighted concerns regarding speech and language, play and interaction.

Pupil (male) B was in Year 4 at a mainstream primary school. Staff in the nursery highlighted initial concerns regarding play and interaction. However, it was the concerns raised by school staff which lead to referral on to the CDC and eventually a diagnosis of autism spectrum disorder

Pupil (male) C was in Year 6 at the local primary school. Staff within the school raised concerns regarding speech and language, play and interaction with his peers during KS1. These concerns lead to a referral to the CDC and a diagnosis of Aspergers Syndrome.

Pupil (male) D, Year 7, was initially referred to Behaviour Support Services (BSS) over concerns about challenging and disruptive behaviour. This led to referrals to parenting courses and a referral to the Local CAMHS team which lead to a diagnosis of Aspergers Syndrome.

Pupil (male) E was referred through a hospital medical team for a diagnosis of autism whilst he was in KS2. Parents reported that local CAMHS services refused to recognise and diagnosis autism. He is currently in Year 8.

Appendix 7

Master table of Super Ordinate Themes

Figure 2 - Master table of Super Ordinate Themes

A. Super Ordinate Theme

- Emerging Identities

Theme - Diagnosis

Hazel – I think the diagnosis, the assessments, they were battles to get through because I had to fight tooth and nail for everything.

Jane - It's devastating to find out. There is a big difference between thinking your child's got it and knowing he has it.

Alison – It was sort of picked up so early that they had a plan in place from then onwards.

Sarah – Sort of going all round the edge but not actually, because if they gave him the title then they would have to sort of acknowledge it.

Emma –It was like a relief really, that there was something and it was not just about bad parenting, you know, because I did feel a bit like a failure at times, not understanding him.

Theme - Developmental Perspective

Hazel – He had quite a difficult time, teachers were recognising that he was different from other children.

Jane – Then I started to compare him with my eldest child, looking through all his books at what he could do for a certain age.

Jane- I didn't think they had the right to say that at 2 years of age, he wasn't doing what he should be doing.

Alison – Something didn't seem right.

Sarah – He (doctor) wanted an inspection somewhere ... because of how he was behaving at that age.

Theme - Impact

Hazel – He fights desperately not to be seen as different or wanting anyone to know about his autism.

Jane – I was so upset and so sorry for him that he's got to live this way and I still do ... I just wish that I could take it all away from him and he could live a normal life.

Emma – Before (diagnosis) it was like not understanding what the problem was... I think some people there still refused to accept that it was actually a disability that he had not like a behavioural problem.

Theme - Adjusting

Hazel - Having to be really very abrupt, which I don't find easy bur err that's what I had to do to get there.

Jane – I don't know how they'll accept him or treat him, I think I'll be there, in front of him, to protect him, or at least I'd like to be.

Alison – You're not just a Mum ... you're almost like a teacher

Sarah – When you are sort of in that position you learn quick, don't you. You have to. You learn very quick.

Emma – I always felt I wasn't doing it right in their eyes, you know, and I was constantly trying to prove myself.

Theme -Responsibilities within families

Sarah – it used to be our daughter who looked after him (at school) and she still does

Sarah – luckily his sister was in school at the time and showed them how to cope with him when he kicked off.

Emma – I went on parenting courses and tried to you know make sure that it wasn't anything I was doing wrong.

Hazel – I'm terrified for him being unhappy and not telling me

Jane – It's that crystal ball that you'd like to know that he's going to have a normal life

Alison – I've done a lot at home because I know my time is free

B. Super Ordinate Theme – The Importance of Relationships, Family and Friends

Theme -Dynamics of family relationships

Jane – I tend to get wrapped up in my own feelings.

Hazel – I think if he came home and told me something negative had happened to him it would probably affect me for the rest of the day and I would be questioning him about it which he wouldn't like.

Alison – I've taken it all onboard myself, to be honest.

Sarah – I couldn't have worked with him he had so many appointments.

Emma – we can sit together for a length of time because that's always been impossible.

Theme -Interactions with professionals

Hazel – They (teachers) were the ones who would spur me on to do things because they said I was much more powerful than them in trying to get results so I felt a lot of responsibility was put on me but I felt I got a lot of support.

Jane – She made me and my son feel really ...very welcome and she didn't make him feel that he was any different to anyone else.

Alison – I've found things out incidentally over the years.

Sarah – We'd actually sold our house and jumped authorities, because I was just that fed up, fed up fighting school.

Emma – He's had good support from friends, teaching assistants and teachers, so I've been quite happy.

Theme -The importance of friends

Hazel – If you're popular and people like you then your school experience is so much better and through sports that's what happened to Jack.

Jane – I think he will know he will be leaving the school and teachers behind and I think he will turn to his friends for support and I think I will do as well.

Emma – He's had good support from friends.

Theme -The fear of bullying

Hazel – If they had just done it on the spur of the moment I could of just thought, yeah it's a prank, but I think they had planned to do it which somehow makes it worse.

Alison – I certainly think the instances of bullying are higher if the children are not engaged in something.

Emma- He just tends to sort of start fighting ... running wild and letting off the steam that he's held in the classroom.

C. Super Ordinate Theme

– Insights into School Ethos

Theme -Positive experiences

Jane – He loves school, loves being with his friends, loves his teachers.

Alison – It's easier as he's got older, easier in that he seems to be getting more out of school.

Sarah – I think school realised that they needed something else. It had been identified so they implemented it and he was fine.

Emma – So they really built his confidence up a lot from when he started at Junior school to finishing it. He has more confidence now and will try new things whereas he wouldn't before.

Theme -Supportive schools

Jane – So school have been, really supportive with every obstacle ... and as long as I know he is being supported the way he wants to be supported and he needs to be, I'm really happy.

Alison – School have been supportive.

Sarah – She's always on the end of the phone.

Emma – He's been quite well supported and I know we've sort of had ups **and** downs and things.

Theme -Information about school

Jane – I'm one of those who like to go down to school and look over the hedge.

Hazel – I get very limited information.

Theme -Questioning and doubts about schools and education

Jane – You have to stop and remind them (teachers) what you're there for and I want to know educationally, how he's doing, you tend to find people talk about his behaviour rather than his schoolwork.

Sarah – He took a bit of settling in to Nursery, but then they said he was just quiet, he's no trouble at all, he sits behind the bookcase.

Emma – You know you could see that he hadn't learnt anything through the time he'd spent there.

Alison – What I'm saying is that what you do as a parent can help and I question how far he would be now if I hadn't put in all this effort.

Alison – You're sort of released in to the education system to plod along as best you can.

Theme –Ignorance and Resistance

Hazel – The teachers, to be honest did not understand much about autism when he was diagnosed because I got a book and had to lend it to one of the teachers because they didn't know what they were dealing with either.

Jane – I think in school he could be easily overlooked because he'll just sit there.

Sarah – I think it was more a lack of knowledge by the school and staff and ignorance of not knowing what to do, plus a lot of resistance.

Emma – He didn't want to go to school and every day we were battling to get him there.

Theme -What parents want from schools

Sarah – Just a lot of little things.

Hazel – An easier line of communication with teachers.

Jane – If they can interact more with me so I am made to feel welcome to come into school on a more regular basis than any other parent would do.

Alison – The ideal would be if teachers and parents could work together.

Emma – To be involved with things that are going off and to have people who understand his problems.