

MOTHERS' EXPERIENCES  
OF A PRIMARY SPECIALIST PROVISION  
FOR AUTISM ATTENDED BY THEIR CHILD

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A programme of independent study resulting in the production  
of a thesis to partially fulfil the requirements of the  
University of East London for the degree of  
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University of East London  
School of Psychology  
Professional Doctorate in Educational and Child Psychology

### **Declaration**

This work has not previously been accepted for any degree and it is not being concurrently submitted for any degree.

This research is being submitted in partial fulfilment of the requirements of the Professional Doctorate in Educational and Child Psychology.

This thesis is the result of my own work and investigation, except where otherwise stated. Other sources are acknowledged by explicit references in the text. A full reference list is included in the thesis.

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June 2013

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# Abstract

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Research evidence suggests that a significant minority of mothers of children with autism are dissatisfied with their child's education. However, research to date has mainly comprised of large-scale 'broad-brush' methodologies which cannot capture the detail of these mothers' experiences. This research sought to explore six mothers' experiences of engaging with a specialist unit for autism attended by their child. Their accounts of these experiences were elicited through semi-structured interviews in order that the data obtained was detailed and reflected individual, subjective experience. Interview transcripts were analysed using Interpretative Phenomenological Analysis, an inductive methodology that is designed to enable the researcher to dig deep into the data and produce a rich descriptive and interpretative summary of participants' experiences. Three superordinate themes were constructed during the analytical process. The first highlighted the importance mothers placed on feeling their child was loved and accepted by school staff. Secondly, the uncertainties and complexities of making sense of their child's autism diagnosis were highlighted, as well as uncertainties relating to priorities for their child's learning, and knowing what expectations to have of the specialist Unit. Finally participants' experiences of learning are described. These learning experiences related to finding out more about their child through contact with the Unit, discovering principles and practice relating to specialist teaching skills utilised by staff, and finally developing their own way of understanding and parenting their child at home.

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# List of Abbreviations

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<b>Abbreviation:</b>	<b>Meaning:</b>
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
BPS	British Psychological Society
EP	Educational Psychologist
EPS	Educational Psychology Service
LA	Local Authority
PECS	Picture Exchange Communication System
TEACCH	Training and Education of Autistic and Related Communication Handicapped Children

# 1. Introduction

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## 1.1 Overview

This introductory chapter will begin with a discussion of the purpose of this research and how it came about. The development of my personal interest in this topic is described, as well as how this fitted with the priorities of a specialist provision for children with autism that existed within the Local Authority I was working in as a Trainee Educational Psychologist. A brief overview of the national context for this research is then given, with particular reference to Government commissioned research, policy and legislation which relates to the two topics: parental educational involvement and autism, which were central to this research. The local context for the research is then described, of the anonymous Outer London Local Authority in which the research was carried out and of the specialist unit for autism from which participants were recruited. Finally an overview of the research that follows is presented.

## 1.2 The inception of this research

I first became interested in the experiences of parents of children with very special needs several years ago, when I worked as a teacher in a special school for children with complex needs, many of whom had an autism diagnosis. My interactions with parents were constrained in a way which I hadn't encountered when I worked in a mainstream school. As children arrived and left on a bus, my communication with parents was through daily written comments in a home-school book, and during occasional review meetings and parents evenings when time was short and there was a great deal to cover. I longed to know more about the parents of the small number of children in my class who I knew so well but who were often so difficult to understand. I would have appreciated sharing the pleasures and challenges of

working with these children with their parents, who knew them even better than I did.

I often felt, during the limited contact I did have with the parents of children in my class, that we were talking at cross purposes. One child suddenly began a phase of very challenging behaviour which I wrote to her parents about in her home-school book, hoping they might have some insight into the cause, or how I might approach managing it. However to my dismay, I received by return a lengthy and heartfelt apology, as though the parents or the child had something to apologise for. On another occasion I delightedly regaled a mother and a small number of professionals with a litany of targets achieved by her child over the previous term during a review meeting, only to look up from my notes to see that she was silently weeping over the delayed progress her child was achieving compared to a typically developing child.

I feel that these first experiences of working with parents of children with complex needs enabled me to develop increased sensitivity towards parents I encountered when working in educational psychology services, first as an assistant educational psychologist in Essex and subsequently as a trainee. However if anything, I found that my opportunities to ask parents about their experiences, and of what professional support they would find helpful, were even more limited than when I had worked as a teacher. My contact with parents was again occasional and very time-limited, and our relationship felt more distant, as contact was often limited to formal meetings.

In the second year of my educational psychology (EP) training, I commenced a placement at the educational psychology service for the Local Authority in which this research is based, which in order to preserve participants' anonymity is not named in this thesis. One of the senior educational psychologists was working with a specialist unit for children with autism based at a local primary school. Knowing that I was looking for potential research opportunities she informed me that this specialist unit was interested in facilitating research into areas of mutual interest, as a way of better understanding and improving its practice.

On an initial visit to the Unit I discussed the manager's priorities with him, one of which related to a new approach to teaching children with autism, called 'attention

autism' which had recently been implemented across the unit. Another priority was to improve home-school relationships, with a goal of enabling parents to be supported by school staff to better manage their children's behaviour and foster their learning opportunities at home. I leapt at this opportunity, and a research focus on exploring parents' experiences of the specialist unit (referred to by the pseudonym the Abbey Road Unit in this thesis), including their impressions of teaching strategies used by the unit, was agreed.

The purpose of this research will be returned to towards the end of this introductory chapter. Before this is discussed, an overview of the national and local context for this research is presented below.

## **1.3 National Context**

In the following sections, Government reports, policy and legislation relating to the central topics explored within this research are described. First a brief overview of parental involvement in education is given. The key characteristics and issues associated with autism are then considered followed by an overview of national priorities relating to the educational engagement of parents of children with autism.

### **1.3.1 Parental Involvement in their child's education**

Since 1967 when the Plowden Report set out the first published guidance for schools regarding how they should communicate with parents, the issue of parents' involvement in their children's education has continuously gained momentum. By the 1980s, a range of legislation had given parents increasing rights to access information about their child's education. Tomlinson (2001) argues that parents' increased rights to choose their child's school and sit on Governing bodies were being given primarily as a way to increase competition between schools and drive up standards, and that this might have been a barrier to genuine home-school links which focussed on building positive relationships between parents and school staff.

In recent years the Government focus on parent involvement has shifted onto its link with pupil attainment through improving communication, with the 1997 white



paper “excellence in schools” outlining ways in which schools could build relationships with parents by providing them with information, giving them a voice and encouraging parental partnerships with schools. However, research efforts to prove a causal link between parental involvement in education and children’s achievement has been complicated by the multiple ways in which parental involvement can be defined, and by the many other interrelating factors which could affect achievement.

### ***1.3.1.1 The nature and efficacy of ‘involvement’***

In a 2003 literature review commissioned by the DfES, Desforges and Abouchar bisect the concept of parental involvement into ‘bottom up’ involvement, which originates spontaneously from parents and includes activities at home as well as contact with school, and ‘top down’ involvement in the form of structured programmes delivered by schools which are designed to engender parental involvement. The former, which is of relevance to this research, is then parsed into seven observable categories including direct activities such as contacting the child’s teacher, and indirect ‘in-home’ activities such as “modelling of constructive social and educational aspirations and values relating to personal fulfilment and good citizenship” (p. 85). In a later Government report, parental involvement is divided into two categories: parents’ involvement in the life of the school, and their involvement in support of their individual child at home. Both authors focus on observable behaviour of parents - on what they do. In a review of best practice in parental engagement, Goodhall and Vorhaus (2011) comment that not only has parental involvement (or parental engagement as they term it) not been clearly defined by the research community, it is also a term which is likely to have multiple meanings for schools, and activities which parents consider to relate to engaging with their children’s learning might not be known about, or even recognised as such by schools.

It is these in-home activities which are identified as most highly correlated to improved educational outcomes for children. However, Desforges and Abouchar state that socio-economic status is strongly related to parental involvement, child attainment, diminished by the vulnerability of the family due to factors such as mental health difficulties, and is strongly influenced by the child taking a pro-active

role in fostering home-school links. Although Desforges and Abouchar found that parental involvement has a positive and long lasting effect on educational achievement, even when other factors are taken into account such as social class and family size, this seems to be a type of loosely termed parental involvement in education which might not be as relevant to parents of children with complex special educational needs.

Goodhall and Vorhaus (2011) suggest that developing skills in working with parents should be included as part of initial and ongoing teacher training. The authors suggest that schools can be unaware of how parents engage with their children's learning. Schools should "recognise that parental engagement includes a wide range of activities, including learning at home, reciprocal communication between home and school, decision making and collaboration with the community" p.86.

The authors highlight that parents can face very real barriers to engaging with their child's school and that schools should adjust their offer to accommodate these.

### ***1.3.1.2 Promoting the involvement of parents of children with Special Educational Needs***

Specific legislation exists for involving parents of children with special educational needs in their education, as the identification and allocation of appropriate support is necessarily more personalised and potentially complex.

The Special Educational Needs (SEN) Code of Practice (2001), which contains statutory guidance for schools, defines special educational needs as follows:

***Children have special educational needs if they have a learning difficulty which calls for special educational provision to be made for them.***

***Children have a learning difficulty if they:***

***a) have a significantly greater difficulty in learning than the majority of children of the same age; or***

***b) have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority.***

***c) are under compulsory school age and fall within the definition at a) or b) above or would do so if special education provision was not made for them***

***(SEN Code of Practice, 2001, p.6)***

This document also emphasises the importance of including parents in the processes of identifying, assessing and supporting children with special educational needs:

***'Parents hold key information and have a critical role to play in their children's education. They have unique strengths, knowledge and experience to contribute to the shared view of a child's needs and the best ways of supporting them. It is therefore essential that all professionals (schools, LEAs and other agencies) actively seek to work with parents and value the contribution they make. The work of professionals can be more effective when parents are involved and account is taken of their wishes, feelings and perspectives on their children's development. This is particularly so when a child has special educational needs.'***

***SEN Code of Practice, 2001, page 16, section 2.2***

It can be seen from the above that statutory involvement of parents in the education of children with SENs has been significant for some time. This is set to increase further with the implementation of the pending Children And Families Bill (2013), which will reform systems for vulnerable children, including those with special educational needs. This bill will give parents even greater control over ensuring that appropriate support for their child is in place, and includes a proposal to devolve the

funding for children with the most significant SENs directly to families in order that they have control over how this is spent (DfE, 2012). In a Government report detailing the progress made towards the implementation of this bill it is stated that many families experience the SEN system as 'impenetrable, bureaucratic and inefficient ,and that it is not sufficiently responsive to their family circumstances' (p. 25), and that the rationale for giving families increased control over how their child is supported is that this will build their confidence in educational services.

It has been shown in the preceding sections how the importance of parental involvement in the education of their children has been emphasised in UK Government commissioned reports and is enshrined in current and forthcoming legislation. An outline of the context of the educational involvement of parents of children with autism will be given later in this introduction. First, a brief overview of autism and related teaching approaches will set the context for considering the needs of parents.

### **1.3.2 Autism**

Autism is currently understood to be a lifelong developmental disorder characterised by a 'triad of impairments' in the domains of social interaction, language and communication and flexibility of thinking and behaviour (Wing and Gould, 1979). The characteristics of autism was first described by Leo Kanner in America in 1943, and were also described by Hans Asperger in Austria the following year, although the latter work was not translated into English until 1981 (Lyons and Fitzgerald, 2007). Autism is currently diagnosed at around 5 years in the UK ( Howlin and Moore, 1997).

Autism is considered to be a spectrum of conditions due to the large amount of variation in skills and abilities demonstrated by individuals with this diagnosis. As it is a developmental disorder, it is common for children to make very different rates of progress towards a lessening of their social communication difficulties as they grow older, with some children making rapid progress and others plateauing at different stages. Additionally children can have very varied ability profiles, with some skills being much further developmentally progressed than others (Charman, Pellicano, Peacey, Peacey, Forward and Dockrell, 2011).

The term Autism Spectrum Disorder (ASD) is currently in common usage as a catch-all label to envelop individuals who have been identified as being anywhere on this spectrum. Recently this term has begun to be replaced with 'Autism Spectrum Condition' (ASC) in order to acknowledge that the condition can bring cognitive strengths as well as weaknesses compared to the neurologically typical. 'Autistic Spectrum Condition' and 'Autism' are the terms I have used in this thesis for these reasons.

Despite the time that has passed since autism was first defined, understanding of the aetiology and treatment of autism is still evolving (BPS, 2006). This long uncertainty regarding both causes and effective interventions for autism means that how to treat/teach children with autism is the subject of ongoing research and debate amongst professionals, parents and individuals with autism.

A sharp rise in prevalence and in public awareness of ASCs has resulted in autism being "no longer thought of as a rare disorder" by educators (DFES, 2006, p.2). This increase in awareness has resulted in the nature of effective educational provision for children with an ASC becoming the subject of scrutiny at local and national level.

### **1.3.3 Education for children with autism**

The unique element of best-practice in the education of children with autism is that social communication skills (which other children will acquire without intervention) will require explicit teaching (Jones, English, Guildberg, Jordan, Richardson and Waltz, 2009). A range of specialist teaching strategies exist for teaching these skills, though research indicates that due to the diversity of the condition, no one intervention can be effective for all children. Where research has been carried out, this tends to show improvements in some but not all children (Jones *et al*, 2009). A glossary of the educational and therapeutic approaches for autism referred to in this thesis is supplied in Appendix 1.

### **1.3.3.1 Inclusion**

For many years a trend has existed in the UK and internationally towards including children with SENs within mainstream schools. This agenda towards inclusion is illustrated by the new draft SEN Code of Practice (2013) which states “there is a general principle in law that children and young people with special educational needs should be educated within mainstream settings” (Indicative Draft: SEN Code of Practice, 2013 section 5.3 p.34), although parents of children with the most complex needs (who have a statement of special educational needs) are able to opt for a special school if this is their preference. A range of provision currently exists for children with autism including mainstream, special schools and specialist resource bases attached to mainstream schools, and this varies between Local Authorities.

#### **1.3.1.2 Parental involvement in the education of children with autism**

It is recommended in Government policy and reports that parents of children with autism, similarly to parents of other children, are supported to be fully involved in their child’s education. For example, Charman *et al.*(2011) highlight the importance of reciprocal communication with parents and carers about approaches to learning and strategies to promote positive social and behavioural outcomes and well-being. However it is acknowledged that there is currently little research into the educational involvement of parents of children with autism, and that further research is essential in order that we can “know which forms of joint school-family working have beneficial effects for children and young people with autism in terms of learning, behavioural and emotional well-being outcomes, and how these might best be supported and implemented (Charman *et al*, 2011, p.46).

Jones *et al.*2009 states that there is some evidence to suggest families which include a child with autism have higher levels of stress and family separation than those with children with other SENs, in part due to the distressing behaviours which some children with autism can display. Clearly the requirement to deal with challenging behaviour at home would impact on parents ability to become involved with their child’s education, particularly in regard to creating the positive parent-child interactions at home which were defined by Desforges and Abouchar (2003) as ‘in-home’ involvement.

## **1.4 The Local Authority**

The research was carried out in an outer London Local Authority (L.A), which is not named in this thesis. The small number of special schools within the L.A (which includes one school for children with autism), are all co-located with mainstream schools. In addition there are several resource bases attached to mainstream schools. One of these resource bases is the Abbey Road Unit (name anonymised), the specialist unit for autism from which participants for this research were recruited.

The Local Authority encompasses areas with striking socio-economic contrast, with some wards being amongst the most wealthy and others the most deprived in the country. 50% of pupils within the L.A speak English as an additional language, which is above the London average and well above the national average. This socio-economic and cultural diversity is reflected in the diversity of the families of children who attend the Abbey Road Unit.

## **1.5 Pen Portrait of the Specialist Unit for Autism**

The Abbey Road Unit is a small unit with 14 children on roll at the time of writing. It is co-located with a mainstream primary school. Children integrate into any mainstream classes their abilities allow them to access, but children spend the majority of their school day within the unit. They access the main site's playground at a different time of the day to mainstream children. One or two children from the mainstream school are usually invited into the small playground attached to the provision at break-times to play with the children on-roll in the Unit.

A range of specialist teaching strategies are used within the provision including the Picture Exchange Communication System (PECS), Intensive Interaction and Attention Autism, which is a teaching approach designed specifically to engage children with ASCs created by Gina Davis, a local Speech and Language Therapist. At the time of this research being negotiated, the specialist provision had recently begun implementing the Attention Autism intervention for part of each school day, and had held several events designed to explain this new approach to parents in

order to foster understanding of what their child did in school and to encourage parents to try using some of the techniques at home with their children.

The aim of the provision is to 'provide a learning environment that supports the learning styles of children with Autistic Spectrum Disorders, and to develop programmes that build on children's strengths, whilst addressing their needs" (p.14 of school prospectus). All children on roll within the unit have an Autism Spectrum diagnosis and are towards the more complex end of the spectrum. All the children attending the provision have significant language and communication difficulties and the majority are non-verbal.

The Unit Manager reported that staff currently actively engage parents in a range of ways, including home-school books, telephone calls home, regular parents meetings and workshops. The teaching staff at the provision also have an expanding outreach and in-house training programme to support the teachers in the attached mainstream school, as well as teachers and other professionals working elsewhere in the borough.

## **1.6 Research purpose**

The purpose of this research is to elucidate the experiences of six mothers of a specialist provision for autism which is attended by their child. It is hoped that in doing so, this research will add a new perspective to what is currently known about parental engagement, and about the experiences of mothers of children with autism. The findings that arise from this research will be disseminated to the specialist unit from which the participants were recruited, and it is hoped that this will enable staff to have an increased understanding of what parents value in terms of support from staff and contact with the unit. It is also hoped that the findings will have wider applicability to the work of educational psychologists in their work with families, and will add qualitative detail to existing research in this area.



Three research questions have been identified with which to focus this research. These are designed to be open and process oriented, in order that participants are free to discuss what is important to them within the confines of the topic under investigation:

- 1. What forms do mothers' engagement with the specialist unit take?**
- 2. What meanings do mothers make of the different ways they engage with the specialist unit?**
- 3. How do mothers understand and make sense of the specialist teaching strategies used in the specialist provision?**

## **1.7 Overview of the following chapters**

In this introductory chapter I have given an account of the personal and practical origins of this research, and set these within a national and local context.

In Chapter 2: Literature Review, the published literature which relates most closely to the current research topic will be reviewed in order to establish what is already known and to identify a gap which the current research can fill.

In Chapter 3: Methodology and Procedures, I will outline the methodology and procedures relating to this research. The theoretical and practical implications of using Interpretative Phenomenological Analysis will be discussed, and I will describe the procedures relating to recruiting participants and conducting semi-structured interview.

In Chapter 4: Findings, the superordinate and subordinate themes constructed following analysis of interview data will be presented. These are exemplified with quotes from participants and my interpretative and descriptive commentary.

Chapter 5 concludes this thesis with a discussion of the implications of the research in terms of the extant literature reviewed in Chapter 2, some applicable theoretical

perspectives and the research questions presented in Chapter 2. Implications for educational psychologists and for future research are also considered in this final chapter.

## 2. Literature Review

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### 2.1 Overview

The aim of the literature review is to provide an overview of current knowledge as evidenced in the published, peer-reviewed literature which relates to mothers of a child with an ASC and their experience of the educational provision attended by their child. A review is given below of the published, peer reviewed research which most closely relates to the topic of the present research. Articles were obtained for review using a systematic literature search, the process of which is detailed below. The key purpose of this literature review was in order that I could gain an initial understanding of the participant group and could identify a gaps in the extant literature.

This initial literature review therefore aims to answer the following questions:

**1. What does the existing research say about parents' experiences of educational provision for children with ASCs?**

And

**2. What is the scope of previous research, and how does the present research extend this scope?**

### 2.2 Details of the Systematic Search

The primary mechanism for obtaining relevant papers for review was an electronic search of relevant databases. An electronic search was carried out of the following online databases: EBSCO Psychinfo, EBSO Education Research Complete, EBSCO Academic Search Complete, SCIENCE DIRECT and WEB OF KNOWLEDGE Web of Science. Searches were made of each database in turn using searches based on key index terms (mothers, autism, education and children plus relevant synonyms) and Boolean connectors as follows:

EBSCO Psychinfo search terms used:

Mothers (OR parental attitudes OR parental involvement OR female OR caregivers OR parenting skills OR home environment OR mother-child relations OR mother-child communication OR parents) AND autism (OR pervasive developmental disorders) AND education (OR school based intervention OR special education OR teaching OR school learning OR learning strategies OR academic achievement OR educational program OR early intervention OR educational programs OR teaching methods) AND children (childhood birth - 12 years OR preschool age 2-5 years)

EBSCO Education Research Complete search terms used:

Mothers (OR mother and child OR mothers of children with disabilities OR parenting OR parents of children with disabilities OR parent and child OR parent-teacher relationships) AND AUTISM (OR autism in children OR children with disabilities OR autistic children OR autism spectrum disorders) AND EDUCATION (OR communication - study and teaching OR special education OR educational outcomes OR ability OR training OR teachers OR education - aims and objectives OR early childhood education OR children with disabilities-education OR special education schools OR school choice AND children.

The remaining databases were also searched using the search terms listed above in order to ensure that all relevant journal articles had been identified. A single search was made of each database using the key index terms and synonyms as outlined above in order to ensure that only the most relevant results were obtained. The results were reduced initially through setting automated inclusion criteria to show only published research in peer reviewed, English language journals.

The large number of articles generated following this initial search were subject to an initial sift using the title of articles and occasional reference to the abstract. From this point in the selection process the following inclusion and exclusion criteria were applied:

Table 2.1 *inclusion and exclusion criteria for the systematic search:*

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>▪ Published research in peer reviewed, English language Journals which aimed to explore, explain or evaluate mothers' or parents' (including mothers) experiences and views relating to their autistic child's education in any setting (inclusive or separate).</li> <li>▪ Qualitative and quantitative studies of any research design were included.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Research relating wholly to children outside the age range of children in the present research.</li> <li>▪ Research which related to mothers of children with a variety of special educational needs and disabilities not limited to autism, where data for the ASC group was not presented distinctly.</li> <li>▪ Research relating solely to children with high-functioning autism and/or Asperger syndrome</li> <li>▪ Descriptive or opinion pieces were excluded.</li> </ul>

After the initial sift by title, 64 papers were selected for closer scrutiny. An annotated bibliography was generated for each of the remaining articles and a second sift was carried out by assessing each Abstract against the inclusion and exclusion criteria after which 23 papers remained. These 23 papers were read in full and a further 11 papers were discarded, leaving 12 articles for review.

In addition to the electronic search, a hand search was made of relevant journals in the University library. No further articles were found in this way. Finally, references cited in the 12 identified articles were appraised for inclusion in the review. A further 2 articles were found in this way, bringing the total number of articles for review to 15. Zetoc and EBSCO alerts were set up in order that any relevant articles published prior to the publication of this research could be incorporated into the literature review, and a further two articles were duly added. A brief summary of each of the 17 articles is presented in the table overleaf:

Table 2.2 Key Features Of Journal Articles Obtained Through The Systematic Search.

	Article Reference	Brief details of Participants	Data Collection Tools Used	Method (Quant/Qual/Mixed)	Country
1	KASARI, C., FREEMAN, S. F. N., BAUMINGER, N. & ALKIN, M. C. 1999. Parental Perspectives on Inclusion: Effects of Autism and Down Syndrome. <i>Journal of Autism &amp; Developmental Disorders</i> , 29, 297	Parents of ch with ASCs (N 113) and DS (149).	Questionnaires	Quantitative	United States
2	STARR, E. M., FOY, J. B. & CRAMER, K. M. 2001. Parental perceptions of the education of children with pervasive developmental disorders. <i>Education &amp; Training in Mental Retardation &amp; Developmental Disabilities</i> , 36, 55-68.	Parents (N 69)	Questionnaires	Quantitative	Canada

3	<p>SPANN, S. J., KOHLER, F. W. &amp; SOENKSEN, D. 2003. Examining Parents' Involvement in and Perceptions of Special Education Services: An Interview with Families in a Parent Support Group. <i>Focus on Autism &amp; Other Developmental Disabilities</i>, 18, 228-237.</p>	Parents (N 45)	Telephone Interviews	Quantitative	United States
4	<p>STONER, J. B., BOCK, S. J., THOMPSON, J. R., ANGELL, M. E., HEYL, B. S. &amp; CROWLEY, E. P. 2005. Welcome to Our World: Parent Perceptions of Interactions Between Parents of Young Children with ASD and Education Professionals. <i>Focus on Autism &amp; Other Developmental Disabilities</i>, 20, 39-51.</p>	Parents (N 8, comprising 4 married couples).	Semi-structured Interviews	Qualitative	United States
5	<p>STARR, E. M., FOY, J. B., CRAMER, K. M. &amp; SINGH, H. 2006. How are Schools Doing? Parental Perceptions of Children with Autism Spectrum Disorders, Down Syndrome and Learning Disabilities: A Comparative Analysis. <i>Education and Training in Developmental Disabilities</i>, 41, 315-332.</p>	Parents (N 209)	Questionnaires	Quantitative	Canada

6	STONER, J. B. & ANGELL, M. E. 2006. Parent Perspectives on Role Engagement: An Investigation of Parents of Children With ASD and Their Self-Reported Roles With Education Professionals. <i>Focus on Autism &amp; Other Developmental Disabilities</i> , 21, 177-189.	Parents (N 8, comprising 4 couples)	Semi-structured interviews	Qualitative	United States
7	RENTY, J. & ROEYERS, H. 2006. Satisfaction with formal support and education for children with autism spectrum disorder: the voices of the parents. <i>Child: Care, Health &amp; Development</i> , 32, 371-385.	Parents (N 244)	Questionnaires (N 244)  Semi-structured interviews (N 15)	Mixed	Flanders, Belgium
8	FISH, W. W. 2006. Perceptions of parents of students with autism towards the iep meeting: a case study of one family support group chapter. <i>Education</i> , 127, 56-68.	Parents (N 11) of 7 children	Semi-structured interviews	Qualitative	United States
9	WHITAKER, P. 2007. Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say — and what parents want. <i>British Journal of Special Education</i> , 34, 170-178.	Parents (N 173)	Questionnaires	Mixed	England



10	DYMOND, S. K., GILSON, C. L. & MYRAN, S. P. 2007. Services for Children With Autism Spectrum Disorders. <i>Journal of Disability Policy Studies</i> , 18, 133-147.	Parents (N 783)	Questionnaires	Mixed	United States
11	MORENO, J., AGUILERA, A. & DAVID, S. 2008. Do Spanish parents prefer special schools for their children with autism? <i>Education and Training in Developmental Disabilities</i> , 43, 162-173.	Parents (N 60)	Interviews (face to face, closed response)	Quantitative	Spain
12	BENSON, P., KARLOF, K. L. & SIPERSTEIN, G. N. 2008. Maternal involvement in the education of young children with autism spectrum disorders. <i>Autism</i> , 12, 47-63.	Mothers (N 95)	Semi-Structured Interviews  Questionnaires	Quantitative	United States
13	PARSONS, S., LEWIS, A., DAVISON, I., ELLINS, J. & ROBERTSON, C. 2009. Satisfaction with educational provision for children with SEN or disabilities: a national postal survey of the views of parents in Great Britain. <i>Educational Review</i> , 61, 19-47.	Parents (total N 125) of ch with ASCs (N 66) and other disabilities (59).	Questionnaires	Quantitative	Great Britain

14	MACMULLIN, J. A., VIECILI, M. A., CAPPADOCIA, M. C. & WEISS, J. A. 2010. Parent empowerment and mental health: Understanding parent perceptions of the educational experience. <i>Journal on Developmental Disabilities</i> , 16, 68-71.	Parents (N 176)	Questionnaires	Quantitative	Canada
15	GREY, I., LYNN, E. & MCCLEAN, B. 2010. Parents of children with autism: Experiences of education service provision in the Republic of Ireland. <i>The Irish Journal of Psychology</i> , 31, 111-124.	Parents (N 14)	Semi-structured interviews	Qualitative	Republic of Ireland
16	STARR, E. M. & FOY, J. B. 2012. In parents' voices: The education of children with autism spectrum disorders. <i>Remedial and Special Education</i> , 33, 207-216.	Parents (N 144)	Questionnaires	Qualitative	Canada
17	ZABLOTSKY, B., BOSWELL, K. & SMITH, C. 2012. An Evaluation of School Involvement and Satisfaction of Parents of Children with Autism Spectrum Disorders. <i>American Journal on Intellectual &amp; Developmental Disabilities</i> , 117, 316-330.	Parents (N 8,978)	Questionnaires	Quantitative	United States

## **2.3 Research findings in the reviewed literature**

The research surveyed can be divided into two areas. The first concerns whether parents of children with ASCs are *satisfied* with the educational provision attended by their child and the second relates to exploring whether and in what ways parents are *involved* in their child's education. These two areas of research are explored in turn below.

### **2.3.1 Satisfaction**

A number of studies surveyed had a particular focus on comparing levels of parental satisfaction with their child's schooling across mainstream and special provisions. The context for this focus is that in many countries including the UK, the US and Spain, there is a policy move towards increasing the number of children with SENs who are integrating into mainstream schools (Moreno, Aguilera and David, 2008). Another stated impetus for UK studies such as Parsons, Lewis and Ellins (2009) is that recent research carried out by the National Autistic Society in the UK had found that parents of children with ASCs were broadly dissatisfied with their children's educational provision, and that this dissatisfaction was greater than that of parents of children with other SENs.

#### ***2.3.1.1 Parental satisfaction and type of provision***

A study by Kasari, Freeman, Bauminger and Alkin (1999) used questionnaire surveys to gain the views of parents of children with diagnoses of Autism (n=113) or Down Syndrome (n=149) about whether or not they felt inclusion in mainstream schools was the best educational approach. The researchers were interested in whether parental views about inclusion correlated with diagnosis (Autism compared to Down Syndrome), children's ages, and the type of educational provision children were currently attending. These two diagnoses were chosen as the researchers felt that these two groups of children would have very different optimal requirements for their educational setting due to contrasting academic learning styles and social competence, but would be similar in terms of degree of learning difficulty.

Findings suggested that parents of children with autism are less likely to want their child to be placed within a mainstream class than parents of children with Down Syndrome; over half the parents of autistic children in total commented that their child's educational requirements could not be met in a mainstream environment. However, as the authors comment, at the time of this study's publication inclusive practice for children with significant needs was in its early stages and it may be that parental attitudes were in the process of 'catching up' with policy developments. The findings also indicated that parents of children in specialised, separate settings were more dissatisfied compared to parents of children in inclusive settings.

Few conclusions about this finding are drawn by the authors. Perhaps it is possible that the children in more specialised settings may have had more complex needs than children in mainstream settings, and perhaps parents of children with more complex needs would feel less satisfied with their child's education, as they may find their child's level of progress less satisfactory., however as data was gathered in a questionnaire format, responses by parents were not detailed enough to draw firm explanatory conclusions.

An advantage of the research by Kasari *et al.*(1999) is that it has gained the views of a relatively large number of participants compared to the present research. However, the corresponding drawback is that data gathered is broad rather than deep, and many questions remain after reading the results, it is difficult to draw a conclusion or develop a recommendation based solely on this data. It would have been interesting if for some participants, completing a questionnaire could have been followed up with an in-depth interview to explore their answers a little more.

Research by Starr, Foy and Cramer, 2001) similarly used questionnaire surveys to obtain satisfaction measures for 69 parents. In contrast to the findings of Kasari *et al.*(1999), no relationship was found between parental satisfaction and the placement of children in a mainstream or specialist setting. The authors emphasise that their enquiry pertains to parents' subjective perceptions, rather than the pursuit of an objective truth about the provisions their children attend, although this emphasis on the constructed reality of the participants is not explicitly linked to a particular epistemological framework. A large scale (n=244) mixed methods study

by Renty and Roeyers (2006) supported this finding of broad parental satisfaction. These two pieces of research were carried out in the United States and Belgium respectively, suggesting that parents' experiences over a wide geographical area may be similar.

A Spanish study by Moreno, Aguilera and David (2008) which utilised interview-based questionnaires found that parents reported an even higher level of satisfaction than that reported by Starr *et al.*(2001) and Renty and Roeyers (2006). The authors found that parents (n = 60) reported being very satisfied with all types of educational provision attended by their children (mainstream schools, special schools or a unit attached to a mainstream school). However, rather than relate their findings to those of Starr *et al.*(2001) and Renty and Roeyers (2006), the authors contrast this finding with those described by Kasari *et al.*(1999) and Spann, Kohler and Soenksen (2003) who both found that a significant number (over 40% of their samples) were dissatisfied with their child's educational provision. Moreno, Aguilera and David (2008) conclude that "it is not easy to determine the cause of these differences" (p. 171), but suggest that a factor may have been the geographical spread of these three pieces of research, as educational provisions may have varied a great deal between these disparate locations.

In one of the two studies reviewed which took place in the UK, Whitaker (2007) conducted a large-scale mixed-methods piece of research, in which every parent of a child with an ASC diagnosis in Northamptonshire received a postal questionnaire. Whitaker describes the aim of this research being to explore parents' views of the provision their child is currently attending, and differentiates his research from that of Kasari *et al.*(1999) whose main focus was on obtaining parents' views on their ideal educational placement for their child. Similarly to other studies, parents were asked a range of questions in order that factors which influenced their levels of satisfaction could be identified. Again similarly to other studies, the author states that the impetus for this study was the UK Government policy of increased inclusion into mainstream educational provisions of children with ASCs.

49% of the 599 households which were posted a questionnaire by Whitaker (2007) responded. The data collection method was a postal survey questionnaire featuring

a mixture of scaled-questions which were analysed quantitatively, and open ended questions, which were analysed qualitatively using Grounded Theory. Findings indicated that 61% of parents overall were satisfied with their child's educational provision, which (as with the majority of studies surveyed) included special schools and both mainstream schools and specialist units attached to them. However, this research found a much more unequivocal relationship than previous studies between levels of parental satisfaction and type of provision, with levels of dissatisfaction amongst parents of children who were fully integrated into mainstream schools much higher than those whose children attended special schools or specialist units, where fewer than 10% of these parents described themselves as dissatisfied.

Whitaker's findings suggested that this difference was predominantly due to parents reporting higher levels of satisfaction in terms of how well parents thought staff understood their child, and how flexible schools were prepared to be in adapting their teaching strategies and curriculum. However Whitaker also notes that Northamptonshire's ASC special schools all use the TEACCH approach (Schopler, Mesibov and Hearsey, 1995). This county wide specification of a particular teaching method is unusual within the reviewed literature, and is not practised within the Local Authority where the current research was carried out. This level of co-ordination of approach may suggest that special schools in Northamptonshire are particularly well supported at a county level, and this may have had an impact on parent satisfaction.

### ***2.3.1.2 Parents having different priorities***

In an American study of 783 parents of children with ASC diagnoses (Dymond, Gilson and Myran, 2007), the majority of parents (79%) reported that they were satisfied with their child's educational provision. The authors report that participants outlined a wide range of needs and views which sometimes completely opposed each other, leading to the authors' conclusion that "One type of program, placement or classroom is not appropriate for all children with ASD" (p. 143). In general parents felt their children needed smaller class sizes and higher staff:student ratios, but disagreed on degree of inclusion with some advocating total inclusion and some opposing it.

Data collection for the research carried out by Dymond *et al.*(2007) was through a survey questionnaire, but this research differed from the majority of previous studies due to its mixed methods design. In addition to likert-scaled questions on range of topics the survey included an open ended question asking how parents wanted services for children with ASCs to be improved. Responses to this question were first analysed qualitatively using Grounded Theory (GT) and prevalence of each theme was then quantitatively analysed. It would have been interesting if this research had had a deeper qualitative aspect, perhaps through carrying out a more in-depth analysis of the experiences of a stratified sample of participants in order to elucidate the contradictory findings reported by the authors.

### ***2.3.1.3 Satisfaction of parents of children with ASC compared to other conditions.***

Survey-based research by Starr, Foy, Cramer and Singh, 2006) and Parsons *et al.*(2009) indicated that there was little difference in parents' views in relation to whether they had a child with an ASC or another learning difficulty. Parsons *et al.*report that parents were similar in terms of their perceptions of advantages and difficulties of different provisions, and the authors conclude that "the popular media image of children with ASD being disproportionately disenfranchised in the educational system compared with children with other disabilities may be inaccurate", (p.55)

### ***2.3.1.4 Parents' mental health and satisfaction with school***

Macmullin, Vecili, Cappadocia and Weiss (2010) also carried out survey questionnaire based research, this time in Canada. This research had a unique focus in the literature as it investigated how parents' (n=176) feelings of empowerment and their mental health related to the quality of their engagement with their child's education. Despite the authors positioning this research as investigating parental engagement, findings focus largely on parent satisfaction. Findings indicated that parents' mental health difficulties correlated negatively with home-school communication, child's school experience and child's relationship with their teacher. The authors emphasise that correlations, not causations are found and that the direction of influence could be the other way, with the child's stressful

school experiences impacting negatively on parents' mental health. This research opens an interesting debate by finding significant relationships between parent mental health and their satisfaction with their child's education.

#### ***2.3.1.5 Summary of parental satisfaction research***

In summary, a number of articles have been published to date regarding parents of children with ASC's satisfaction with their child's educational provision. Research findings have been quite consistent, with the majority of articles suggesting that most parents are satisfied, but that a substantial minority are not. Additionally, research which compares parental satisfaction with mainstream or special schools suggests that parents of children who attend a special school are generally more satisfied, possibly due to a perception that more tailored teaching can be given. Research to date has mainly been based on questionnaire data which is authoritative in terms of what it can say about large groups of parents, but findings are often difficult to explain due to a lack of more detailed information about parents' views.

#### **2.3.2 Complex needs and involvement**

Zablotsky, Boswell and Smith (2012) found that parents of children with ASCs were more likely than parents of neurotypical children to attend parent-teacher conferences, meet with school guidance counsellors, and help with homework. However, it is also reported that the more complex the needs of the child, the less involved the parents were in their education. This may be relevant to the present research as the specialist provision attended by children of the participants caters for the more complex end of the autism spectrum. Zablotsky, Boswell and Smith speculate that parental involvement was less for children with greater difficulties as these parents may be less satisfied with their child's educational progress, which may lead to them becoming less interested in and involved with their child's education.



### **2.3.3 Involvement in IEP meetings**

In addition to investigating parental satisfaction with their child's educational provision, Spann, Kohler and Soenksen (2003) also examined parental involvement in the process of producing and reviewing their child's Individual Education Plan (IEP). Findings suggested that parents self-reported a high degree of satisfaction and involvement in their child's educational provision in terms of engaging in regular communication with school on a range of topics. Participants in this study (n = 45) were asked 15 questions via telephone interview. Although the questions asked of participants are helpfully reproduced in the article which describes this research, the method of analysis is not specified and it is unclear whether any particular methodology was utilised. It is also unclear whether open responses to each question were given or whether responses were limited to a number of multiple-choice options.

In contrast to the findings of Spann, Kohler and Soenksen (2003) that parents were happy with their level of involvement in their child's IEP formulation, a small-scale US study (Fish 2006) involving parents from seven families found that all participants had had negative experiences of their child's IEP meetings. In this Grounded Theory research, participants were asked to evaluate their experiences of the IEP process and to identify what they felt could be improved in the future. Participants reported frequently disagreeing with their child's school regarding what educational priorities should be. Generally parents felt that they wanted more focus on 'real world skills', more structured opportunities to interact with neurotypical children and more sensitive behaviour management that fitted with their own understanding and managing of their child's behaviour.

The researchers themselves highlight that the negative views expressed by their participants may not be representative, as participants may have joined the support group from which they were recruited due to some level of dissatisfaction with their child's education. Therefore views of the participants cannot be assumed to be representative of all parents of children with autism in the region.

### **2.3.4 Strategies used at home**

Benson, Karlof and Siperstein (2008) explored educational strategies parents use at home, which was not an aspect of involvement scrutinised by any of the other research reviewed. Many parents are reported to educate their children at home in informal ways rather than using structured programmes, e.g. practising teeth cleaning, dressing and other skills for which opportunities to practice organically occur within day to day life. Twelve percent of respondents reported using ABA at home. These parents were more likely to have children who were verbal - parents of non-verbal children were reported to be more difficult to engage in home activities.

As hypothesised by the authors, school pro-activity towards involving parents was main predictor of parental involvement - whether this involvement was at school or at home. The authors recommend that schools ensure they are reaching out to parents, both in terms of their school programme and in supporting them in the educating they do at home. The authors also suggest that a great deal of 'home education' is done as part of normal family routines, e.g. functional skills and play skills, and that more research about what these activities look like and how effective they are for children with ASCs would be helpful. It is a shame that this research was purely quantitative as a qualitative analysis of interview data would have enabled parents' voices to be heard more clearly and for more nuanced insight into the findings to be possible.

### **2.3.5 What do parents want in terms of learning priorities?**

A US telephone survey of 45 parents (Spann, Kohler and Soenksen, 2003) found that parents' top two educational priorities for their children were to develop their social and language skills. These priorities mirror the key difficulties in social communication experienced by children with ASCs. Similar findings were reported by Whitaker (2007) in a large, UK based, mixed-methods study with a questionnaire survey design, where parents (n = 173) were asked to rank their top three priorities for their child's education. Their responses indicated that top priorities were as follows

1. Social skills
2. Staff's understanding of child's uniqueness and difficulties relating to his or her ASC.
3. Staff's ability to manage behaviour.
4. Level of structure to the day.
5. Child's happiness.

Parents who reported that they were generally satisfied with their child's education were less likely to rank their child's happiness as important. Whitaker comments that this suggests that parents who are satisfied might feel very secure that their child is happy in school, and therefore may be consciously thinking less about it than parents who are concerned that their child may not be happy.

Other wants highlighted by parents were speech therapy, increased one to one time with staff and more use of technology which could augment communication. The authors report that social skills training and sensory integration training were also frequently mentioned, although the latter is not an evidenced-based intervention. This highlights the difficulties with soliciting parents' views and then unquestioningly turning them into a 'to do' list for educational provisions, as parents may not always know what is appropriate to ask for.

Limitations in terms of the sample were similar to those for several other studies; the participants were all recruited from parent support groups and therefore may have different experiences and views to parents who are not involved in these organisations. An additional issue with this research is that some findings seem likely to relate much more to parents of children in mainstream settings than those whose children attend a special school or specialist unit. In particular findings regarding negative attitudes from staff and from other parents towards their child's special educational needs and staff unawareness of the facts about autism. However the findings from this study are not reported in a way that makes it clear whether this is the case.

### 2.3.6 Specialist knowledge

Renty and Roeyers (2006) found that parents reported that they were satisfied with the quality of autism-specific education received by their child. This finding was explored further in a 2008 Spanish Study by Moreno, Aguilera and David. Although a high level of overall satisfaction was reported by the parents surveyed (n = 60), parents of children placed in special schools reported greater levels of satisfaction with staff's specialist knowledge in special schools, compared to mainstream or (as in the present research) specialist units attached to mainstream school. The importance parents placed in their questionnaire responses on staff's specialist training suggested that they valued this over and above any other factor.

Parents' valuing of specialist skills and knowledge was also evident in a large-scale study (Dymond, 2007), in which half the respondents reported feeling that teaching personnel needed further training, although it is not clear from reported findings whether the type of educational provision attended by their child correlated with parents' views about this.

In contrast, Whitaker (2007) found that parents' interest in the teaching and learning strategies used with their child was not especially high, and that parents' focus was more on the teacher 'understanding' their child, although this was quite undefined. Additionally, Whitaker found that parents of children in mainstream schools did not seem very aware of specialist teaching strategies that staff could use, and the only specific differentiation they wanted was that their child would be specifically taught social skills. Whitaker comments that "The overwhelming impression gained from responses to the questionnaire was of the relative modesty of most parents' aspirations, and the significant impact of factors, such as quality of home-school communication, which do not entail any autism-specific knowledge or expertise on the part of school staff" (p.176).

Some of the research reviewed highlighted that parents often felt more expert than school staff in terms of autism specific teaching and learning approaches. In some studies, parents seemed to report this as a criticism of their child's school (e.g. Dymond *et al*, 2007). However the findings of Whitaker (2007) suggest that parents

appreciated staff valuing their input as experts on their own child, and that rather than parents expecting staff to have all the answers, they particularly appreciated staff who were “consistently willing to listen and learn” (p. 176), a view supported by the findings of Starr *et al.*(2012). A qualitative study by Grey, Lynn and McClean (outlined below) in 2010 reported that five out of seven participants felt that parents were often more knowledgeable about autism and related teaching strategies than professionals.

A 2010 article by Grey, Lynn and McClean described one of the few studies reviewed which compared satisfaction of parents whose children received different autism-specific teaching interventions. This research involved fourteen semi-structured interviews, half of which were with parents whose children attended an ABA school, and half of whom had children who received an eclectic range of teaching approaches within a specialist unit attached to a mainstream school. Interviews were analysed using Thematic Analysis. This research reported greater overall satisfaction was felt by parents in the ABA group, and suggested that parents valued regular communication and a well-funded, well resourced school. Interestingly parents who participated in this research by Grey, Lynn and McClean particularly valued staff being open-minded and willing to learn, rather than emphasising the value of staff having ‘expert’ status.

### **2.3.7 Parents having low expectations**

Whitaker commented that parents’ ‘demands’ in terms of their child’s education were relatively simple ,for example many parents prioritised areas such as good home-school communication which do not require any specialist knowledge from staff. Other evidence that parents may have low expectations comes from large scale UK research (Parsons *et al*, 2009) which found that parents of children with ASCs and other learning difficulties felt that any difficulties their child was experiencing were due to within-child factors related to their SENs rather than attributable to inadequacies of their child’s school or Local Authority. Parents rated teachers’ encouragement to their child to aim high as neutral. Additionally participants in this research reported that they expected that their child would not find employment after leaving school.

### **2.3.8 Direct communication with school being highly valued.**

Renty and Roeyers (2006) highlighted that for their participants, regular direct communication with school was highly valued. Parents rated the importance of daily communication about how their child had been that day very highly, and valued formal (parents evenings) and informal (chatting) feedback from school. Parents commented that this was valued especially because of children's verbal delay being a barrier to discussing their experiences of school. Parents viewed good communication as a way for them to work in partnership with school for the benefit of their child. Stoner, Bock, Thompson, Angell, Heyl and Crowley (2005) also found that parents highly valued communication. Whitaker (2007) also found that parents placed high importance on quality home-school communication, and that this tended to happen more often in special schools and specialist units, rather than in mainstream schools. This may be due to higher staff: student ratios enabling more intensive communication with home per child, or may suggest a culture of, e.g. writing in home-school books at the end of each day in specialist provisions which may not happen so automatically within a mainstream classroom.

### **2.3.9 Importance for parents of staff understanding and accepting child**

A qualitative study conducted by Stoner *et al.* (2005) found that parents were sensitive to the personality of their child's teacher and that this impacted on their trust in the education system. One parent is quoted to illustrate what, it is stated, was the view of all parents interviewed, that teachers should have "the heart to teach" (p.47).

A major theme of dissatisfied parents in Whitaker's large scale UK survey (2007) was of a desire to feel more certain that staff understood their child. Whitaker points out that it would be helpful to know what parents would specifically want in order for them to feel reassured in this area: "What in the minds of parents constitutes 'understanding'?; what is it that staff need to do?' what attitudes do staff need to demonstrate if parents are to believe that they understand their child?; and what do parents want this 'understanding' to achieve for the child?" (p.174).

Whitaker's participants highlighted that staff should "have some sense of what lay beneath the challenges and difficulties both presented and experienced by the child" (p.175), and emphasised that it was important that staff understood the autism-related difficulties which presented as challenging behaviour, in order that their child's challenging behaviour was managed sensitively and appropriately. Therefore concern about staff's ability to manage their child's behaviour appropriately related closely to staff having an understanding of their child, and of the nature of autism spectrum conditions. There is evidence to suggest that children with ASCs are more commonly excluded from school than children with other SENs (Parson's *et al*, 2009). This might suggest that children with ASCs tend to display more challenging behaviour than children with other SENs. It also indicates, in line with Whitaker's findings (2007), that school staff struggle to find effective behaviour management strategies to use with children with ASCs.

Grey, Lynn and McClean's qualitative study (2010) found that parents' concerns regarding their children's gradual integration into mainstream provision came from apprehension regarding the attitude of mainstream teachers towards their child's difficulties, rather than concerns about their child's difficulties per se. For example one parent is quoted as saying "A lot of teachers, until they've maybe spent time with a child with autism, think that these children are all biters, all screamers, all troublemakers... if we take one... who might be mild...we're going to be lambasted with twenty screamers and biters so let's just say no' (p.119).

Starr *et al.*(2012) also highlight the importance placed by parents on their child receiving support and understanding from staff. The authors highlight that parents can feel apprehensive about their child transitioning from year to year, when the attitude of staff is so important: 'It appears that these satisfied parents go from year to year hoping that "next year" will be as positive as the current year or that next year will be better than the current year but never taking it for granted' (p.211). However, a difficulty with this study is that it is not clear whether findings might predominantly or wholly relate to parents of children attending mainstream provision, where perhaps a concern about staff not understanding their child's special educational needs would be more common than in a special school or specialist Unit.

### **2.3.10 The process of parental involvement**

Stoner *et al.*(2005) and Stoner and Angell (2006) conducted an in-depth qualitative study in which married couples (n=4) were interviewed three times over the course of nine months via semi-structured interviews regarding their perceptions of their interactions with education professionals. The authors state that this study uniquely focuses on the process of parental involvement, rather than descriptively on what parents do to engage in their children's education. Of all the literature surveyed in this review, this in depth piece of qualitative research resonates most closely with the present research in terms of the methodology and the richly descriptive findings described by the authors. The rationale for this research was that previous literature suggested that parent-professional liaisons were not always constructive, and that this potentially fraught relationship has been well researched from the staff angle, but less so from the parents' viewpoint. The findings resulting from this research were published in two separate articles (Stoner *et al.*(2005) and Stoner and Angell (2006)).

A 'collective case study' methodology was used to analyse the interview transcripts. This is an idiographic, in-depth approach with commonalities to the methodology used in the present research. A methodological feature which contrasted with the approach taken in the present research was the triangulation of findings between husband and wife, across couples and through reference to observation and a range of documentation including behaviour graph sheets, IEPs and consultant's reports is emphasised in the research, suggesting an epistemological standpoint of there being an absolute truth.

A relatively detailed account of the findings of this research is given below as I feel that due to the similarities in methods between this research and the present research, a detailed comparison of findings might be illuminating later in this thesis.

### **2.3.11 Parents wanting to know 'what is going on' at school**

Parents focussed a great deal on the quality and frequency of communication between themselves and school in their priorities. The researchers attributed this



firstly to a distrust of professionals which was felt by their participants, and secondly to the children's communication difficulties, as three out of the four children in the study are described as non-verbal and therefore were not able to verbally communicate their school experiences themselves. One parent is quoted as saying "... I never feel like I know enough about what is going on". All participants reported that they regularly inferred how their child was getting on at school through their non-verbal child's behaviour at home, and considered all behaviour to potentially be meaningful communication. One participant is quoted as saying "the kid's behaviour will tell me a lot about what is going on at school. And how he acts by the time he goes to school and how he acts when he gets home from school" (p. 183).

Parents of non-verbal children were found to rely on their child's behaviour as best indicator of what was going on at school. One participant is quoted as saying "It was very rosy in the notebook, and then if his behaviour hadn't started to kick up, then I would not have known". This indicates that the child's behaviour at home served as an indirect communication by the child to his or her parents about school, and that this overrode any direct communication from school if the messages from each source were dissonant.

### **2.3.12 Parents becoming experts**

Participants in research by Stoner *et al.*(2005) felt that they became experts in ASCs through proactive research after their children's diagnoses, and perceived themselves to have equal 'expert' footing to the professionals they were interacting with. The authors conceptualise this journey towards having expert status as a "reactive pattern of self-education" and engaging in ""external, problem-focused behaviour". This is perhaps a rather pejorative framing of parents' decisions to find out about their child's condition. The period of focussed knowledge acquisition embarked on by participants following diagnosis is also ambivalently described by parents, who commented that the process was energetically and time draining.

### **2.3.13 Parents adopting a range of roles when interacting with professionals**

Stoner and Angell (2006) also explored the different roles parents adopted in relation to staff at their child's school. Four roles were identified: *negotiator* (preparing for the IEP, being aware of adopting a diplomatic stance when approaching the education professionals), *monitor* (formal monitoring of child's progress through IEP meetings etc and informal monitoring of appropriateness of provision, e.g. through home-school books, monitoring changes in child's behaviour and assisting in school), *supporter* (the parent giving practical and/or emotional support to the child's teacher, or towards the school), and *advocate* (parents who adopted this role worked in a volunteer capacity to support other children with autism or their families). The authors hypothesise that the role parents took depended on the level of trust they had in the professional they were interacting with.

## **2.4 Summary**

There is a growing body of research that suggests that the majority of parents of children with autism are satisfied with their child's educational provision, regardless of whether this provision is a mainstream school, a special school or a specialist unit attached to a mainstream school. However, the same research suggests that a significant minority of parents (around 30-40%) are dissatisfied with their child's educational provision. This overall finding of satisfaction surveys has been consistently reported by studies which span a considerable amount of time and take place in different locations across North America and Europe.

There is a smaller amount of research (six out of the seventeen articles surveyed) which looks specifically at parents' level of involvement in their child's educational provision. A greater percentage of this research has utilised a qualitative or mixed methods methodology, and some more detailed conclusions are drawn as a result of this. Currently, the body of qualitative research which explores parents' involvement in their child's education is small, and it has not been possible for authors to connect their findings to others in order to begin to tentatively unify some key ideas.

This Chapter has reviewed the extant, peer-reviewed research which relates specifically to parents of children with autism and their experiences of their child's educational provision. In the following chapter I will describe the aim of the present research. The methodological position taken, and the procedures for this research will also be presented.

## 3. Methodology and Procedures

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### 3.1 Overview

This chapter begins with a restatement of the rationale and research questions for this research which were initially presented in the introduction. I will then outline the methodology and procedures relating to this research. The theoretical and practical implications of using Interpretative Phenomenological Analysis will be discussed, and I will describe the procedures relating to recruiting participants and conducting semi-structured interviews.

### 3.2 Rationale

The aim of this research is to illuminate the participants' personal experiences of their child attending an ASD specialist unit. It is assumed that whilst each participant's experience is unique to them, common and contradictory themes emerging from these described experiences will be found, and that these will say something about the collective experience of all participants. Therefore this research has an exploratory function.

### **3.3 Research Aims**

The aim of this research is to illuminate Mothers' experiences of engagement with a primary specialist unit for autism attended by their child. This aim has been stranded into three research questions, which were initially presented in Chapter 1 and are restated here:

- 1. What forms do mothers' engagement with the specialist unit take?**
- 2. What meanings do mothers make of the different ways they engage with the specialist unit?**
- 3. How do mothers understand and make sense of the specialist teaching strategies used in the specialist provision.**

These research questions are designed to be process oriented. It is hoped that they are sufficiently open and flexible to enable as large an analytical scope as possible within the confines of the phenomenon under scrutiny.

In addition to two general questions about the phenomena of maternal engagement with the specialist unit attended by their child, an additional question is asked specifically regarding the experiences of specialist teaching strategies used by the unit. This question's more directed focus reflects the manager of the specialist unit's particular interest in mothers' understanding of the teaching strategies that are used by the Unit.

### **3.4 A qualitative research methodology**

The process of deciding on an appropriate research method starts with considering the research questions, and what they aim to find out. The research questions outlined above relate to gaining an 'insider's perspective' (Smith *et al*, 2009, p.42) into the subjective experiences of the participants. Therefore it was decided to use a qualitative methodology for this research as qualitative methods are suited to

capturing 'the quality and texture of experience, rather than with the identification of cause-effect relationships" (Willig, 2008 p.8).

### **3.5 Choosing Interpretative Phenomenological Analysis**

After considering a number of possible qualitative methodologies, I eventually chose to use Interpretative Phenomenological Analysis (IPA). There were several reasons for this choice: Firstly, IPA is intended to be used in research that is concerned specifically with participants' experiences, and seeks to gain an in-depth understanding of these. I felt that the subject of enquiry in this research was potentially complex and emotive, and that exploring participants' experiences in detail, with the aim of gaining and conveying as rich a picture of their experiences as possible would be very rewarding. Secondly I was intrigued by IPA's explicit philosophical roots in phenomenology and heuristics (described in the following section), and felt that gaining some knowledge in these areas through my preparatory reading would deepen my experience and understanding of what it means to carry out qualitative research. Thirdly, the creative possibilities suggested by the explicit requirement in IPA for the researcher to engage interpretatively with their data were very appealing.

The final influence on my decision to use IPA came in the form of a number of practical, supportive resources: although IPA in its pure form is an analytical stance rather than a set of step-by-step procedures, such a set, intended for use by 'IPA beginners' is given in Smith, Flowers and Larkin (2009). As a newcomer to IPA and to qualitative research at this level I found having clear guidelines to follow very helpful and reassuring. Of equal value was an on-line IPA discussion group and regular in-person IPA workshops held in London, both of which I engaged with frequently over the course of the research.

Two other qualitative methodologies were considered for use in this research. Grounded Theory, similarly to IPA, is concerned with close analysis of participants' experiences (Glaser and Strauss, 1967). My main reason for rejecting Grounded

Theory for this research was that due to its aim of generating potentially generalisable explanatory and overarching concepts and theories, larger sample sizes are privileged. Given the time-constraints of a doctoral thesis I felt that it would be prudent to utilise an alternative methodology which privileged a smaller sample size, in order that my analysis could be at a more satisfactory depth whilst remaining true to the key tenets of my chosen methodology.

I also considered using a narrative methodology to analyse my data. Narrative methods are concerned with the stories people tell about their experiences, and thus how they make sense of them (Willig, 2008). This methodology was similarly creatively appealing to IPA, as in both of these methodologies the researcher is encouraged to interpretatively engage with the participants' accounts. I rejected narrative methodology as whilst I found the concept of using the idea of 'storytelling' as a lens through which to view my participants' experiences very interesting, I was unconvinced that this approach was appropriate for my particular research questions, and felt that IPAs more open stance towards how participants made meaning of their experiences might be more appropriate.

### **3.6 Key characteristics and theoretical underpinnings of IPA**

Interpretative Phenomenological Analysis (IPA) is a relatively young qualitative methodology, developed by Jonathan Smith in the mid-1990s (Smith, 1996). It has gained a great deal of popularity in its short history and research employing IPA is widely published, particularly in the health field where the method originated (Smith 2011b). In recent years, research using IPA has been published in the field of applied psychology, including a small number of articles relating to educational psychology (Gil-Rodriguez and Hefferon, 2011). IPA is described as a 'methodological stance' which is characterised by a focus on lived experience rather than a set of methodological procedures, although an example of a method for carrying out an IPA study is given in Smith, Flowers and Larkin (2009). This method involves a number of analytical steps (outlined in a subsequent section of this research) which result in the organisation of the data-set into a set of superordinate and subordinate themes which describe the phenomena under investigation. Smith

describes IPA as having an 'open' epistemology, enabling data to be interpreted freely by the researcher (2009). Nevertheless, IPA is characterised by its philosophical underpinnings which cover three main areas: phenomenology, hermeneutics and idiography. These three are briefly discussed below.

### **3.6.1 Phenomenology**

The movement of philosophical phenomenology first came to prominence when described by Edmund Husserl (1859-1938) in his book *Logical Investigations*, published in 1900. Husserl was interested in the relationship between a phenomenon and the person observing it. He argued that it was possible, if the observer was skilled enough at bracketing all their interpretative instincts, for the observer to directly perceive the objective 'essence' of that phenomena (Giorgi and Giorgi, 2007). Husserl developed a 'phenomenological method' which, if followed, was designed to enable the practitioner to reach a direct understanding of whatever they were observing (Smith, 2009).

IPA also draws from the phenomenological constructs of Husserl's student, Martin Heidegger (1889 - 1976) (Shinebourne, 2011). Heidegger's version of phenomenology construes it primarily as an interpretative act, stating that "the meaning of phenomenological description as a method lies in interpretation" (Heidegger, 1962, p.37). Heidegger believed we are inseparable from the things we are experiencing. What we are doing, feeling, thinking, at any given moment is deeply contextual, and that therefore by exploring experiences we are exploring what it is for that person to be (Larkin, Watts and Clifton, 2006). Heidegger, along with other, later phenomenologists including Merleau-Ponty, Sartre and Gadamer, considered the person to be "embodied and embedded in the world, in a particular historical, social and cultural context" (Shinebourne, 2011, p.18). Therefore Heidegger's phenomenology is connected to the broader study of interpretation, or 'hermeneutics' - the second main idea which underpins IPA and which is described in the section that follows.

Although both Husserl and Heidegger agreed that both description and interpretation are important processes in phenomenological enquiry, Husserl's



phenomenology primarily emphasised the importance of description. In contrast, Heidegger's phenomenology emphasises subjective interpretation above description. This distinction is also the key distinction between IPA and other, longer established phenomenologically oriented research methods. Whereas the latter have traditionally espoused a Husserlian aim of obtaining as accurate as possible evocation of the phenomena (or experience) described by participants (Giorgi and Giorgi, 2007), IPA, whilst retaining a commitment to accurately representing the participants' experiences gives equal or perhaps greater emphasis to both the researcher and the participant's interpretations of the experience under investigation. In all forms of phenomenologically grounded methodologies including IPA, the object under investigation is participants' experiences of a particular phenomena and this is made through the examination of the the inner, subjective world which phenomenologists term '*the lifeworld*' (Larkin *et al*, 2006).

### **3.6.2 Hermeneutics**

Hermeneutics is the study of the interpretation of texts, originally those of great importance in the domains of religion, law and literature, and has latterly also described the study of discourse (Kvale, 1996). The goal of hermeneutic enquiry can be described as obtaining "a valid and common understanding of the meaning of a text" (Kvale, 1996 p. 46). In Interpretative Phenomenological Analysis, two interpretative relationships exist: that between the participant and the experience they are describing, and that between the researcher and the participant, whose descriptions the researcher is trying to make sense of. It is therefore very helpful to consider the key ideas explored in hermeneutics prior to conducting research using IPA.

A key concept in hermeneutics is that of the *hermeneutic circle* (Kvale, 1996). This concept posits that a whole text, or discourse, can be understood best when the meaning of the whole is considered alongside the meaning of its individual parts, with the interpretative gaze moving back and forth from whole to part and back again until a complete understanding of the text in its entirety has been reached. The concept of the hermeneutic circle suggests that the whole and the parts are deeply connected, and that in some way, the essence of the whole is contained in every part, but expressed in a different way (Smith, 2007). For the IPA researcher,

this means that the analytical process can be rich and circular, with the analysis becoming increasingly multi-textured as the researcher continues to move from whole to part and back again, travelling around the hermeneutic circle from as small a part as a single word to as large a whole as an entire data-set including the experiences of several participants (Smith, 2007).

The idea of the *double hermeneutic* is also relevant to IPA. This term relates to the two interpretative processes taking place in IPA research: the researcher is making sense of (interpreting) the participant, and the participant is making sense of their experience. This concept highlights the researcher's role of joint meaning-maker with the participant; although the researcher is not a participant, he or she can be thought of as similarly engaging in an interpretative act, and is also drawing on his or her 'experientially informed lens' (Smith, 2009, p.37). In the current research I sometimes felt this double hermeneutic became a triple hermeneutic, where mothers described experiences of the specialist unit that were mediated through their child. At these moments, the child was making sense of their experiences of the specialist unit, the mother was making sense of the child's experiences, and through these was also making sense of the specialist unit, and I was making sense of my participants' experience.

A final key concept in hermeneutics which is salient when undertaking research using IPA is the idea that there are multiple ways to interpret. In IPA the idea that it is possible to interpret the same object in a multitude of different ways is highlighted, and the researcher is encouraged to adopt different interpretative stances towards the data (Shinebourne, 2011). For example Smith, Flowers and Larkin (2009) reference Ricoeur's (1970) parsing of understanding into a hermeneutics of meaning recollection, where the researcher might attempt to faithfully describe and understand exactly what the participants' experience is, and a hermeneutics of suspicion, where the researcher adopts a more interrogative, critical attitude towards the data and actively engages his or her view of the world with the participants' account of their experiences. This requirement for the researcher to consciously attune to whichever interpretive stance he or she is adopting at any particular time chimes with the reflexive approach which is required of qualitative researchers (Willig, 2008).

### 3.6.3 Idiography

Idiography is an approach to carrying out psychological research popularised by Gordon Allport (Marceil, 1977), where a rich, complex and detailed description of a small amount of data is privileged over collecting large amounts of necessarily less detailed data (Uzzell and Barnett 2000). In writing about IPA's commitment to an idiographic methodology, Smith (2004) argues that 'delving deeper into the particular also takes us closer to the universal' (p.42). This commitment is demonstrated in the recommended methodological procedures at every stage of IPA research. This is illustrated in the following examples.

When recruiting participants, researchers using IPA are advised to remember that a small sample size is optimal. This is in order that analysis can be carried out to a satisfactory depth. Furthermore, a small sample size enables the experiences of individual participants to be presented in more detail, in order that a sense of these distinct individual experiences is preserved in the final write-up of the findings. Rodriguez and Hefferon (2001) state that ".....less is more in IPA: fewer participants examined at a greater depth is always preferable to a broader, shallow and simply descriptive analysis of many individuals as commonly seen in thematic analysis, grounded theory or poor IPA" (p.756). IPA's idiographic commitment to getting as close to the participants' individual experiences as possible is next manifested through the analytical requirement to begin analysis with a case by case approach until a 'measure of gestalt' obtained for each individual case before the researcher moves on to the next (Smith, 2004).

In writing up IPA research it must be ensured that the reader gains a sense of each participant as a 'whole person' (Smith, 2009). For this reason pseudonyms are usually given for each participant, in order that they can be referred to by name throughout the analysis and discussion. Additionally the typical presence of relatively lengthy illustrative quotes to illustrate findings ensures that individual convergences and divergences in experience are fully conveyed (Smith, 2011a). It is recommended that quotes from each participant to which a particular theme relates are given in the write-up of a piece of research, in order that the experiences of individuals are interwoven rather than merged, and a sense of the individual can still be discerned by the reader (Smith, 2009).

### 3.7 Criticisms of IPA

IPA has recently been criticised on several points in an article by Amedeo Giorgi (Giorgi, 2010), an American psychologist who formulated the 'Descriptive Phenomenological Method in Psychology' - a research methodology based on the principles of philosophical phenomenology (Giorgi, 2007). Summaries of the criticisms which Giorgi posited in his 2010 article are given below along with consideration of some arguments to the contrary.

In his critical article, Giorgi asserts that IPA doesn't have a clear relationship to phenomenology. He claims that IPA doesn't have anything to do with philosophical phenomenology, and that the relationship between IPA and phenomenology is unclear in Smith's writings. He feels that IPA would better be called 'interpretive Experiential Analysis' (2010 p.6). However, as Smith (2010) points out, an explicit link is made between IPA and phenomenology in Smith's definitive book which describes the method (2009). This link is discussed in the section above.

Giorgi also questions IPA's credibility as a scientific method, suggesting that because IPA does not have a single explicit methodology, research findings are not valid, as it follows that it is impossible to tell what process produced the reported findings, which therefore lack reliability. In his rebuttal to Giorgi's article (2010), Smith counters that an explicit set of procedures does not guarantee the quality of a piece of research, and that whilst there is no requirement to follow a particular prescribed methodology in IPA, this does not preclude the researcher from making the analytical steps they utilised explicit in their write-up.

The final criticism of Giorgi's outlined here is the contradiction of Smith presenting one clear way of doing IPA (Smith, Flowers and Larkin, 2009), but then asserting that the method is flexible and researchers are free to analyse their data as they like. Smith does not appear to have defined the parameters of this flexibility clearly enough to satisfy Giorgi. I have some sympathy with this criticism: speaking as a novice IPA researcher I would have welcomed some examples of how other researchers might approach an IPA analysis. However, I can also appreciate that IPA is a young methodology and its creator wants to encourage other researchers to

develop it beyond his own preferred approach. I feel IPA's central principles are quite clear in terms of how the text should be interpreted, what sort of questions should be asked of the text, and feel that the flexibility suggested by Smith chimes with the emphasis on interpretation and bringing in the experience and understandings of the researcher to creatively make sense of the participants' words.

## **3.8 Epistemology**

Willig (2008) highlights that in order to fully understand the purpose and scope of a research project it is necessary to interrogate its epistemological position. Epistemology is a philosophical concept pertaining to the nature of knowledge - what are the ways in which we can find out about the world? It is linked to ontology, which is concerned with the nature of being - whether objects in the world are considered to exist in an independent, objective reality or whether they can, to an extent, only be constructed by whoever is observing them. Willig (2008) proposes that when embarking on research, three questions should be asked in order to clarify the epistemological and ontological positions taken by the researcher (pp.12 - 13). These questions are reproduced below with my own answers:

### **3.8.1 What kind of knowledge does the methodology aim to produce?should**

Interpretative phenomenological analysis aims to produce knowledge of the subjective experiences of the participants of a particular phenomenon. In this research, the aim is to produce a detailed account of what it is like for mothers to engage (however they define this) with the specialist unit for autism attended by their child.

### **3.8.2 What kinds of assumptions does the methodology make about the world?**

The methodology utilised in this research privileges subjective experience, and is not particularly concerned with objective reality. For this reason, attempts are not made to verify mothers' accounts by comparing them with each other, or triangulating them with data from other sources to attain a more objective understanding of the reality of the specialist Unit. This methodology assumes that the phenomenon of how mothers make sense of their experiences of the specialist Unit is important to know about in and of itself. The fact that these 'ways of making sense' make sense to the participants is sufficient for findings to be of value. This assumption is consistent with the interest in the phenomenology of experience which is characteristic of IPA.

### **3.8.3 How does the methodology conceptualise the role of the researcher in the research process?**

The hermeneutic underpinnings of IPA mean that the researcher is conceptualised as having an active role in co-constructing findings together with the participants. Although the researcher is expected to be reflexively aware of the prior knowledge and assumptions brought to the research, active, creative interpretation of the data is encouraged as one interpretative position which the researcher can adopt.

Thus far, I have discussed the theoretical and conceptual features which influence this research's methodology. In the next section of this chapter I will describe procedures for recruiting and interviewing participants and analysing interview transcripts.

## 3.9 Participants

### 3.9.1 Participant recruitment and selection

The participants in the research were all mothers of children attending a primary ASD specialist unit co-located with a primary school in the Outer London Borough which the researcher worked in as an Educational Psychologist in Training. Smith, Flowers and Larkin (2009) suggest that participants in an IPA study are as homogeneous as possible, in order that meaningful comparisons can be made across individuals. However, the small size of the provision, which had 14 children attending at the time when participants were being recruited, meant that opportunities to select participants on the basis of additional shared characteristics were limited. Consequently the participant group, whilst homogeneous in terms of being mothers of children who attended a particular specialist unit for autism, differed significantly in other aspects including socio-economic status, ethnic and cultural background, the ages of their children and the time their children had spent attending the unit (see Table 3.1).

As IPA requires a close textual analysis of interview transcripts - which assumes that the participant is capable of nuanced communication in the analysed language - mothers who in the provision manager's experience did not have sufficiently fluent English were excluded from the study. An additional original inclusion criteria was that Mothers lived with the Father of their children, however when additional participants needed to be recruited due to attrition this criteria was dropped as there were not sufficient mothers to fill the quota.

Smith, Flowers and Larkin (2009) recommend that a sample size of between three and six is appropriate and sufficient for the in-depth analysis that characterises IPA. Therefore six participants plus one pilot participant were sought, in order that a small amount of attrition would not compromise the design of the study. An initial letter explaining the aims of the research (see Appendix 2), and what participating would involve was sent to seven mothers who met the initial criteria, identified through consultation with staff at the provision. These letters were sent by school staff in order that details of all potential participants remained confidential. Class

Teachers supported the research by writing about the letter in the children's home/school books. One parent declined to take part at this stage and therefore the next suitable parent in terms of the age of their child was invited to take part.

Once participants had returned their expression of interest form to the provision they were contacted directly by the researcher, invited to ask any questions about their participation and an interview date was arranged. One participant initially declined to take part at this stage due to it being temporarily inconvenient. She agreed that she could be contacted again after the summer holidays, and at this point agreed to take part.

### **3.9.2 Participants with English as an additional language: methodological considerations**

Participants' use of language is central to IPA research. Willig (2008) has argued that the validity of a phenomenological analysis relies upon the assumption that participants are able to fully convey their experience through the language in which they are interviewed. Additionally Willig (2008) highlights that an experience can be described in many different ways, and that in IPA it is appropriate for researchers to engage with their data in different ways including linguistically (Smith, 2009). This important role of language in IPA research means that methodological issues arise where participants speak English as an additional language.

In the present research, two participants - Irene and Jenny - self-reported as speaking English as an additional language. Fluency in spoken English was a selection criterion used to obtain my participant group, and in order to implement this and other selection criteria I sought the guidance of the Unit Manager. My impression of Irene during our interview was that she was reasonably confident in her use of English, and I felt that she was satisfied that she had given me an accurate impression of her experiences. Jenny however presented as much less confident in her English fluency. She was frequently hesitant and her sentences often tailed off when she felt unable to articulate her meaning in English. Jenny's hesitancy was of concern to me during our interview, though upon analysis I felt able to reach a sense of her perspective and key concerns as well as with other



participants. Jenny's answers were noticeably shorter than many participants and I spoke more in this interview. At times I suggested words or ideas to her which she always picked up on. I didn't include these elements in my analysis as I feel I was being leading.

On balance I do feel that Jenny's interview was perhaps less rich than it would have been had I been able to interview her in her most fluent language, but I feel interviewing her through an interpreter would have been equally disadvantageous in other ways. For example, having a interpreter present would have complicated the hermeneutic relationship between myself and Jenny, as her experiences would have been conveyed to me through the interpreter's choice of language rather than Jenny's. I feel Jenny was able to express herself well enough within the interview to justify her inclusion in this research, and that the research is enriched by her contribution.

During the process of analysis I was further reassured that despite Jenny's relative lack of confidence in English, there were still opportunities to interpret her account. For example I felt that her relative fluency at certain points in our discussion were clear signals that she was speaking on a topic that particularly resonated with her.

### 3.9.3 Participant characteristics

A table listing participants and some key demographic data is presented below:

3.1 Table To Show Participant Characteristics

Pseudonym and age	Child's Pseudonym and age	Time since child's diagnosis at time of interview	Length of time in Unit at time of interview:	English as first language
Anna (41)	Matthew (5)	2 years 8 months	1 year, 10 months	Yes
Irene (33)	Joel (4)	1 year 1 month	10 months	No
Louise (40)	Rachel (7)	4 years 1 month	10 months	Yes
Jenny (27)	Martha (8)	4 years 5 months	2 years, 2 months	No
Helen (35)	Thomas (10)	6 years 2 months	3 years, 2 months	Yes
Layla (29)	Hasan (7)	2 years 5 months	1 year, 1 month	Yes

## 3.10 Interviews

### 3.10.1 Interview Schedule

Data collection for IPA research has been carried out using a range of modalities (Smith, Flowers and Larkin, 2009), but as with other qualitative methodologies the interview format is most frequently used. Interviewing participants offers advantages in terms of scope for developing rapport through face to face contact, and for within-interview flexibility regarding which topics are discussed and dwelt on depending on where the participant's interests and priorities lie. This is an advantage with IPA research as the aim is for the researcher is to understand the

participant's own experience as accurately as possible. This means that the interview schedule needs to be flexible in order that the issues that are central to the participant's experience can be explored even when they are unanticipated. Smith, Flowers and Larkin (2009) recommend a semi-structured interview format for carrying out IPA interviews.

In order to complete a successful interview the researcher has to tread a delicate balance between ensuring that the interview is flexible enough that participants can talk about aspects of their experience which are highly relevant to them whilst ensuring that the interview does not stray too far off topic. In order to facilitate this aim it is recommended by Smith, Flowers and Larkin (2009) that an interview schedule is constructed. Interview schedules constructed for this research appear in Appendix 3 and 4.

The interview schedule was constructed with reference to the research questions. Smith, Flowers and Larkin (2009) suggest that whilst research questions are the starting point for constructing the interview schedule it is unlikely to be appropriate to ask them verbatim as they are likely to be of a too broad and abstract nature. The purpose of the interview schedule constructed was to set out key areas of discussion to ensure that broad topics relating to all the research questions would be covered. I also devised follow up questions relating to the broad topic areas which served as prompts during the interview. The process of constructing the schedule also provided an opportunity to pre-prepare sensitively phrased, open, non-leading questions which were clear in meaning.

Smith, Flowers and Larkin (2009) emphasise that although the interview schedule may be adhered to initially, it is important that the interviewer feels free to follow up areas of interest to the participant which were not anticipated. Smith, Flowers and Larkin (2009) advise that 'going with the flow' of concerns held by the interviewee should be prioritised, and that the interviewer should be "generous"(p.58) when making judgements about whether a participant's concern is relevant to the research questions as unanticipated areas of interest often yield rich data, and the participant is the "experiential expert".

A draft interview schedule was developed for use in the pilot interview. This consisted of four questions with associated possible prompts and follow up questions. The questions related to background information (Smith, Flowers and Larkin 2009) advise that the interview starts with a straightforward 'ice-breaker' question requiring a factual, descriptive answer in order to begin to engage the participant in the area of interest and start them talking without feeling too under pressure to produce something 'insightful'), strategies used at school, strategies used at home and a final question to ensure the participant had said all they wished to say on the topic.

Following the pilot interview I redrafted the interview schedule into its final form (see Appendix 4). Decisions made in the redrafting process followed further reading, discussion with peer researchers and session leaders at an IPA interest group and reflections on the real-world effectiveness of the schedule when used the pilot interview. The final interview schedule consisted of eight questions as some of the prompts listed in the draft schedule were upgraded to questions as I felt that they covered essential areas of inquiry (e.g. "What sort of things do you do with X at home?"). This number of questions is in-line with the recommendation of Smith, Flowers and Larkin (2009) that 6 - 10 open questions with associated prompts is an adequate number for an in-depth IPA interview. An additional broad question; "*Tell me about your experience of the Abbey Road Unit, thinking about the whole time that X has been there*" was inserted after the initial 'warm-up' question.

This decision followed a discussion at an IPA interest group regarding the benefits of beginning the interview with a broad question relating to the topic of interest in order to begin straight away to enable the participant to establish the focus of discussion, and also related to Gil-Rodriguez and Hefferon (2011)'s suggestion that general questions should be asked at the beginning of the interview schedule, with more specific questions being asked at the end of the interview, in order that the participant, rather than the researcher, dictate the way in which the phenomena under investigation is discussed. Further questions in the finalised interview schedule relate to the same topic areas as in the original draft, which are linked to areas covered by the research questions, and these were asked when it was felt that the participant had not spontaneously covered the same areas already. Finally, some prompts for me to follow at the close of the interview were added at

the bottom of the schedule, in order to ensure that participant's experience of the interview process ended in a contained manner with an opportunity to comment on the experience of being interviewed and a reminder of who they could speak to if they wished to discuss any issues arising from the interview further.

### **3.10.2 Interview Procedure**

A semi-structured format was chosen for the interviews. In this format, an interview schedule with topics of interest and possible questions to ask is devised, but during the interview the researcher is free to deviate from this in response to unanticipated areas of interest disclosed within the interview by the participant. I considered this format to be the most advantageous for the current study as the flexibility it offers is essential for an IPA interview where the aim is to understand the participants personal, subjective experience. The loose structure helped to ensure that areas related to the research questions were covered and served as a helpful reminder of how to phrase questions appropriately and of possible follow-up questions to consider which may have been forgotten in the moment. Unstructured interviews which consist of just a single pre-decided topic related question at the beginning (e.g. What are your experiences of the specialist provision?) followed by a free-flowing participant directed interview are also suitable to be used in IPA interviews, however Smith, Flowers and Larkin (2009) recommend that novice IPA researchers benefit from the additional support offered by the semi-structured approach.

Data was gathered via a semi-structured individual interview with each participant. Open ended and non-directive questions were asked, in order that participants were free to describe their personal experiences. Interviews were semi-structured in order that I was able to prompt the participant to say more if necessary in order to more fully convey their meaning. Smith, Flowers and Larkin (2009) emphasise the importance of the IPA interviewer assuming a naive position, asking for clarity in terms of even the most superficially obvious statement or vocabulary, as a remark that seems to have an obvious shared meaning could actually mean something different to the participant to that which the researcher might assume.

Participants were given a choice of where the interview would take place. As it was so important that participants felt comfortable and able to speak freely during the interview, it was suggested to participants that the interviews were carried out in their home at a time that is convenient to them. A private room at the specialist provision was offered to each participant as an alternative. One participant (Irene) was interviewed at the provision, the others were interviewed at home.

Smith, Flowers and Larkin (2009) recommend that the IPA interviewer says as little as possible. This proved easier with some participants than with others, however in most interviews I tried to limit my interjections to "mm" or "yes" in order to encourage the participants to speak freely to their own agenda.

### 3.10.3 Transcription

I transcribed the interviews myself with the aim of reproducing the words used by participants as accurately as possible. Potentially significant paralinguistic and prosodic features were also indicated as shown in the key below.

#### 3.2 Table to show transcription key

Paralinguistic/prosodic feature	Indicator used in transcription
Pause of less than 2 seconds which stands out from the flow of conversation	...
Pause of 2 or more seconds	(pause)
False starts (when a word or sentence changes mid-utterance or when the initial part is repeated)	Forward slash (/)
Unusual emphasis given to a word or phrase	<u>Underline</u>

Other highly significant paralinguistic features are described in brackets, e.g. (laughs), (sighs) etc. Commas are used to convey the rhythm of the participants' speech as well as according to the conventions of written grammar. Audible hesitations, i.e. "Um" and "er", and any other non-verbal vocalisations were transcribed.

Interviewer speech was transcribed on a separate line except when a short utterance (e.g. Mm, yes or I see) did not unduly interrupt the participant's flow of speech. In these cases the interviewer's remark was bracketed within the participant's speech, e.g. (*Int - mm*).

## **3.11 Data Analysis**

IPA is one of several qualitative approaches where its distinctiveness lies with the analytic focus, rather than a unique analytical technique (Larkin *et al*, 2006). However, the analysis for the present research was carried out with reference to a suggested protocol outlined by Smith, Flowers and Larkin (2009). As this process has much in common with thematic analysis, Braun and Clark's guidance on the latter (2006) was also consulted during the analytical process.

### **3.11.1 The Analytical Process**

The analytical process began with each interview transcript being analysed in turn using the following steps which were taken from Smith, Flowers and Larkin (2009).

1. The transcript was read and re-read, and a free textual analysis was undertaken, with descriptive and interpretative notes being taken on anything of interest. As the transcript was read and re-read, it was hoped that deeper levels of analysis would emerge as the content became increasingly familiar. In order to encourage this, I found it helpful to first describe the "*object of concern*" spoken about by the participant, then to write some speculative commentary as to why the participant might hold this particular concern. Additionally I found it helpful to bear in mind

Smith's advice to look for echoes, contradictions, amplifications, similarities and differences at different points in the same transcript.

2. Once the initial notes were completed, the transcripts and the comments were reviewed with a view to condensing them to 'pithy statements' which represented initial themes. At this stage although a degree of synthesis and abstraction was attempted, themes generally remained at a very descriptive level and were very numerous.

3. The long list of initial in-progress themes were then organised with the aim of condensing the list and raising the level of abstraction and interpretation in their titles and concepts. This was achieved following recommendations from Smith, Flowers and Larkin (2009) including abstraction (merging themes and giving them a new overarching title), subsumption (where one theme is incorporated into another) and polarisation, where seemingly opposite themes are combined under a more abstract title.

4. This process was then repeated with each transcript. Although each transcript was initially coded individually, notes were made during the free-textual analysis stage of any striking commonalities between transcripts in order that these could be returned to later.

5. When a list of themes had been generated for each individual transcript, the transcripts and themes were looked at together and themes for each were ordered to form a gestalt of the themes for all participants.

### **3.11.2 Identifying recurrent themes**

The process of reaching the final set of superordinate and subordinate themes involved frequently moving between micro and macro analytical perspectives, with the aim of ensuring that a clear and unifying overarching set of final themes were constructed which, whilst being tightly synthesised, remained representative of each participants' individual accounts. One method employed to ensure that the final



analysis fairly represented the whole dataset was to check how frequently each of the final superordinate and subordinate themes were represented within each individual interview. Smith, Flowers and Larkin (2009) suggest this approach is one which enhances the validity of findings. Below, in Figures 3.1 and 3.2, are screenshots from MAXQDA, the software I utilised when analysing my data, which show the frequency with which each superordinate and subordinate theme occurred within each individual participant's dataset.

Figure 3.1 Screenshot from MAXQDA showing frequency of superordinate themes within participants.

Code System	Irene	Layla	Louise	Jenny	Helen	Anna
FINDINGS						
VALUING ACCEPTANCE: 'THE CHILDREN WERE CLEARLY LOVED'	35	11	34	17	15	28
UNCERTAINTY OF EXPECTATIONS IN CONTEXT OF AUTISM	25	26	20	8	13	19
LEARNING FROM THE UNIT AND DOING IT 'MY OWN WAY'	25	33	28	28	11	53

Figure 3.2 Screenshot from MAXQDA showing frequency of subordinate themes within participants.

Code System	Irene	Layla	Louise	Jenny	Helen	Anna
FINDINGS						
VALUING ACCEPTANCE: 'THE CHILDREN WERE CLEARLY LOVED'						
'he's happy to go to school so that means it's good'	8	4	4	2	1	5
'the teachers like them and don't judge them'	15	3	16	4	7	13
'all these lovely characteristics are allowed to flourish'	12	4	14	11	7	10
UNCERTAINTY OF EXPECTATIONS IN CONTEXT OF AUTISM						
The 'whole complex thing of autism'	11	14	13	5	4	15
weighing up learning priorities	12	5	4	2	8	2
Being unsure how much to ask for	2	7	3	1	1	2
LEARNING FROM THE UNIT AND DOING IT 'MY OWN WAY'						
Learning about teaching strategies	5	4	4	7	2	8
Learning about child through contact with the unit	14	16	18	13	8	24
Doing it 'my own way'	6	13	6	8	1	21

### 3.11.3 Using MAXQDA: computer-assisted qualitative data analysis software

In order to analyse my interview transcripts, I utilised MAXQDA, which is one of several commercially available types of computer-assisted qualitative data analysis software (CAQDA). The use of CAQDAs has been rising since the rise of the

personal computer (Web, 1999). Robson (2002) provides a précis of the key benefits and drawbacks to using CAQDAs which is reproduced overleaf:

### **Advantages of CAQDAs**

- They provide an organised single location storage system for all stored material.
- They give quick and easy access to material without using 'cut and paste' techniques.
- They can handle large amounts of data very quickly.
- They force detailed consideration of *all* text in the database on a line-by-line (or similar) basis.
- They help the development of consistent coding schemes.

### **Disadvantages of CAQDAs**

- Proficiency in their use takes time and effort
- There may be difficulties in changing, or reluctance to change categories of information once they have been established.
- Particular programmes tend to impose specific approaches to data analysis.

Robson (2002, p.462).

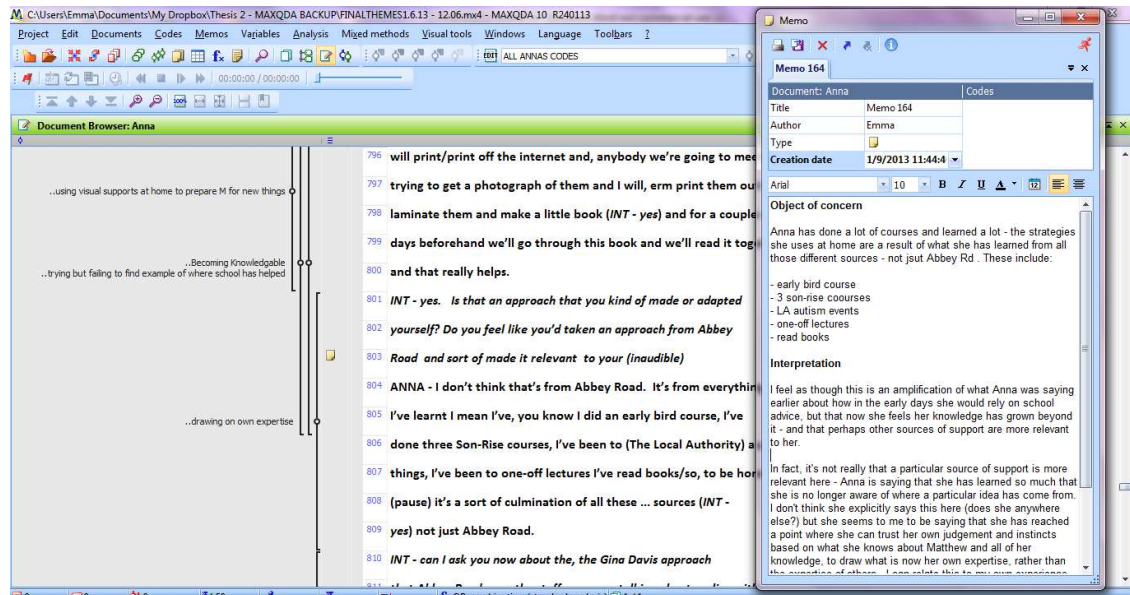
Robson's summary is a fair representation of my own experience of using MAXQDA. I chose to use a CAQDA as I have always preferred to use computer software to organise my personal and professional affairs wherever possible. I was concerned that a traditional 'analogue' method of data analysis, involving cutting up individual quotes and codes and moving them around on a table top was incompatible with my natural tendency towards disorganisation and the prospect of having codes and transcripts neatly stored and immediately accessible on computer was tremendously reassuring.

In practice I feel that storing and analysing my data using MAXQDA facilitated the analytical process by enabling immediate retrieval of data. Furthermore, rather than distancing me from my data, which is a concern held by some researchers (Garcia-Horta and Guerra-Ramos, 2009), there were several features of the programme which enabled my connection with my participants' accounts to deepen. In particular MAXQDA enabled a paragraph by paragraph linking of my audio recordings to my transcripts, so that I was able to listen to my participants voicing sections of my transcript at any point throughout the analysis. An additional useful feature not mentioned by Robson was the possibility MAXQDA affords of being able to easily check the frequency of particular codes within and across participant's transcripts (see the preceding section for examples of this in figures 3.1 and 3.2).

Robson cites the ability of CAQDAS to store large amounts of data as an advantage (2002). I concur that this capacity resulted in my analytical process being less constrained than if I had used a 'table top' method, as the amount I was able to write in my exploratory comments about my data, and the number of codes I was able to generate was not limited in the way it would have been if my comments had been confined to the margins of A4 paper or my codes confined to a table top. However, Garcia-Horta and Guerra-Ramos' warning (2009) that this lack of constraints can result in the researcher becoming carried away and generating excessive comments and codes is one I found very prescient, as there were occasions where I found the number of codes and comments I had generated difficult to manage. On balance I found MAXQDA a useful tool with which to store and organise my data which offered more advantages than difficulties compared to traditional analytical methods.

To illustrate the work-flow of MAXQDA, a screenshot is pasted overleaf of a preliminary stage of analysis, with exploratory comments to the right of the transcript and emergent themes presented to the left:

Figure 3.3 Screenshot of initial stage of analysis using MAXQDA, showing emergent themes on the left, the interview transcript in the centre and initial exploratory comments on the right.



## 3.12 Ethics

Ethical approval from the University of East London was granted in March 2011 (see Appendix 8), following the submission of a research ethics form, and the research was conducted within the framework of the ethical principles outlined in the British Psychological Society's 'Ethics and Code of Conduct' (2006) and 'Principles for Conducting Research with Human Participants' (1990). However Brinkmann and Kvale (2007) warn that a 'tick box' approach (p.269) cannot be considered sufficient to guarantee that research is ethical. In qualitative research in particular, the data gathering and analytic processes and findings can certainly be loosely anticipated and planned for, but cannot not wholly predictable at the outset of the research.

Qualitative research is sometimes presented as more ethical than quantitative research because individual voices have the opportunity to be considered and represented by the researcher: in fact this makes it particularly peppered with ethical minefields. Brinkmann and Kvale (2007) argue that qualitative research is 'saturated with ethical issues' (p.263) due to the personal nature of the information

sought from participants, the interpersonal connection typically made between researcher and participant during data gathering through face to face interviews, and issues relating to the dissemination of the research. This section, which pertains to the ethics of this research, is adapted from Brinkmann and Kvale's fields of ethical uncertainty in qualitative research, and the following ethical aspects are discussed in turn: *informed consent*, *confidentiality* and *interview setting and the role of the researcher*.

### **3.12.1 Informed Consent**

Informed consent includes thinking about *who* is giving consent and whether participants feel coerced into giving consent (Brinkmann and Kvale 2007). This is particularly relevant when children are recruited as participants, but is also a pertinent point in the present research as the consent of the Head Teacher and Unit Manager at the Abbey Road school was obtained prior to mothers being recruited. This was procedurally necessary, but resulted in a risk of participants feeling pressurised to participate in research that the leadership team at their child's school was committed to.

Potentially adding to this perceived pressure was the fact that the Unit Manager was involved in recruiting participants. In my planning meetings with the Unit Manager it was agreed that my letter inviting mothers to take part and giving them details of the research would be sent out by the school and followed up with a telephone call from the Unit Manager encouraging mothers to take part. This plan was mutually agreed upon as I felt that without encouragement from a familiar member of staff, mothers may not have seen a reason to participate in the research, and I was anxious to make it as easy as possible for mothers to consent to take part due to the small pool of potential participants. I ensured that prior to making these telephone calls the Unit Manager was briefed to simply remind the participants of the invitation to take part, and to remind them that they were free to accept or decline this offer. Ultimately two participants who were invited to take part declined the offer, which gives some indication that mothers were not unduly pressured to take part.

Informed consent was checked when I met participants to interview them. This involved my reading them relevant information (in Appendix 5), and then asking them to read and sign a consent form (presented in Appendix 6), which highlighted their right to withdraw from the research at any time from prior to the interview to the completion of the thesis.

### **3.12.2 Confidentiality**

Confidentiality was considered from the early stages of this research, when initial letters inviting participants to take part were sent by the Unit rather than by myself in order that I was unaware of any details of potential participants until they had agreed to take part. Care has been taken to ensure that data presented and discussed in this research is anonymised. Pseudonyms have been assigned to participants, their child who attended the unit and the specialist unit itself. Other people described in the research are identified using their most relevant role, e.g. "Unit manager", "Husband" etc. Other places are described by their most relevant function, e.g. "Private specialist school for Autism", and the Local Authority in which the research was carried out has also not been named. Information regarding places and people included in the study which is not highly relevant to the research has sometimes been changed in order to reinforce the anonymity of those involved. For example some genders and ages have been altered. Care has been taken to ensure that audio recordings of the participants' interviews are confined to one password protected computer and have not left the researcher's home.

Additionally, several participants discussed their personal situations in some detail during their interview, leading to sections of their interviews containing information which would make them highly identifiable, or where personal information about second parties was relayed. Where it was possible to alter these parts of the interview slightly without impacting significantly on the participant's meaning this has been done. Where this has not been possible, these very small sections of the transcripts were redacted before being presented in the appendices to this thesis, and quotes from these sections are not included in chapters. Care has been taken to ensure that any changes made to ensure anonymity do not significantly impact on the integrity of the data.

Brinkmann and Kvale (2007) highlight that confidentiality protects participants, but can also mute their voice in the research. There is a potential conflict between confidentiality and the integrity of the research as in order to be transparent about the origin of my findings, interpretations and conclusions I am obliged to evidence these with raw data from my participant's interviews, but this impacts to an extent on participant confidentiality as this data inevitably reveals information about their lives, their concerns, and even their speech patterns, which may be identifying. This is particularly pertinent to this research as the context of it means that some of my participants will inevitably know each other to some degree. In presenting information about my participants and writing the findings and discussion section of this thesis I have considered that if my participants or a member of staff at the unit were to read this thesis there is a chance, despite my best efforts to ensure anonymity that a participant will be recognised, and would of course certainly recognise themselves. With this in mind I have made every effort to be sensitive in my choice of quotations, descriptions and interpretations in order that participants are represented respectfully. Although full-transcripts of my participants' interviews, and my initial, exploratory comments which are 'unbracketed', are presented as an appendix on compact disc (see Appendix 9) this raw data which evidences the analytical process is presented more minimally on paper. A single page from each participants' transcript appears in Appendix 10 and the master table of themes is included in Appendix 11).

### **3.12.3 Interviews and the role of the researcher**

The interview process which is typical of qualitative research and is utilised in the present research is also a source of potential ethical uncertainty. Brinkmann and Kvale (2007) highlight that the intimacy of the qualitative data gathering process - particularly with unstructured or semi-structured interviewing - can lead participants into revealing more than they had intended. This places the researcher in a quandary: should they allow or even pursue such revelations, meaning that the participant/researcher relationship feels inaccurately therapeutic, or disallow it, thus giving researcher the impression of being aloof, which is a problem in itself?

Bearing this pitfall in mind, I made a conscious effort when conducting interviews to avoid being leading or to share my personal agreement or otherwise with what my

participant was sharing. On the other hand I made an effort to be friendly and approachable in order to help my participants feel comfortable. If anything, through nerves and a desire not to be leading I may have come across as a little aloof, particularly during my first interview, with Anna when I felt particularly anxious. Overall however, taking into consideration the appropriate (in my view) nature of the information my participants shared, their affect during the interviews and their final comments when asked how they had found the interview process, I feel that my participants were happy to share the information they did, and did not feel unduly inhibited or 'led on' by my demeanour.

Although I feel that the participants in my study found sharing their stories, views and experience a positive process, my interest was very personal to the participants, and there were several occasions during interviews where participants became emotional. I feel that my professional experience working with and consulting with parents of children with special educational needs enabled me to handle these eventualities with sensitivity.

At the end of each interview, after the tape recorder has been turned off, I ensured that I thanked participants for taking part and gave them an opportunity to debrief regarding the experience of being interviewed. I also ensured that participants were left with my work contact number and email, and felt welcome to contact me about their involvement in the study at any time. I also informed them that the Unit Manager and the school's Educational Psychologist would be available to discuss any issues with them that arose as a result of participating in this research, and ensured that they had contact details for these professionals.

Additional importance facets of ethical uncertainty pertain to the quality of the research, assessed through examination of the research's reliability and validity; and to the nature of the researcher's own influence on the research, which is acknowledged and made explicit through reflexivity. These areas are discussed in the two sections that follow.



### **3.12.4 Validity**

Validity issues relate to the extent to which the design of the study is sufficiently appropriate and rigorous to enable the research questions to be answered. Yardley (2000) has separated validity issues in qualitative research into four main categories: *sensitivity to context*, *commitment and rigour*, *transparency and coherence* and *impact and importance* which I have considered in turn below .

#### **3.12.4.1 Sensitivity to context**

This category of validity relates to the extent to which the research approach acknowledges the specific context of the research and the participants. I feel that my previous professional experience of working with parents enabled me to build rapport and conduct interviews sensitively, in order that participants felt enabled to give an authentic representation of their experiences.

#### **3.12.4.2 Commitment and rigour**

I feel that the choice of IPA as an approach facilitated a thorough and meticulous analysis of the data, as this technique is well documented and has clear guidelines for its completion (Smith, Flowers and Larkin, 2009). Time for researching, conducting and writing up this thesis was built into my timetable as a DECPsy student, and during and following completion of the taught aspects of my doctorate I have ensured that I have planned enough time to approach this research with academic rigour.

#### **3.12.4.3 Transparency and coherence**

I feel that the emphasis the IPA approach places on reflexivity has facilitated my taking a reflective and careful approach to my data analysis. This heading particularly relates to the importance of the qualitative researcher leaving an 'audit trail' of documentary evidence pertaining to each stage of the research from conception to conclusion, which if they so desired, another researcher would be able to follow and therefore make sense of my decisions that moved the research from

stage to stage. This was through keeping a research diary documenting research activities and my in-action reflections on these. I found keeping this diary very helpful in ensuring that I had a reflexive awareness of the impact of my own assumptions, choices, actions and responses on this research as I was creating it.

In qualitative research such as this, involving inductive analysis of transcripts from semi-structured interviews, it is particularly important to ensure that the process of data analysis, from the raw data through to the presentation of the findings is made clear and transparent. At two stages of analysis my analytical process was checked and discussed with peer researchers who had previously completed theses using IPA. This was in order to provide some confirmation that the links I had made between my emergent and later themes and the raw data were logical, and to alert me to other interpretations and themes which I might have missed. In order to illustrate the analytical process, a page of each participant's transcript complete with individual (yellow) and cross case (blue) themes are presented in Appendix 10. A Master Table of themes is presented in Appendix 11. In order to improve the confidentiality and anonymity of participants' data, a more complete documentation of the analytical process is confined to the attached CD-ROM (Appendix 9).

#### **3.12.4.4 Impact and Importance**

Smith, Flowers and Larkin (2009) claim that "The real validity lies in whether [the research] tells the reader something interesting, important or useful' (p 183). It is hoped that this research will be considered to have some importance to several groups, in particular the staff at the specialist provision and to the Local Authority's Educational Psychology Service. I will ensure that participants are fully informed that key findings from my research will be shared to these audiences.

I hope to disseminate the findings of my research to the specialist provision and to the Local Authority Educational Psychology Service (EPS). I will give an electronic copy of my research to the EPS and will prepare short summaries or presentations of key findings to disseminate to the EPS, the Specialist Unit and will also post a summary of key findings to my participants. I will ensure that summaries intended for each of these groups are tailored to their anticipated unique concerns and

priorities, and will be mindful of my purpose being to inspire and encourage rather than problematise or criticise aspects of the issues I have explored.

As a result of disseminating this research, I hope that the specialist unit might gain a greater understanding of mothers' perspectives and responses to the contact they have with the provision. This could enable staff to reflect on how and what to communicate to mothers about how their children are getting on in school. I would hope that educational psychologists will find my research helpful in enabling them to gain a greater insight into what it is like for mothers to have a child who attends a specialist unit for autism. This might result in EPs having greater empathy for mothers during annual reviews or other contact with parents and may change the way they present information to mothers and interpret mothers' responses.

### **3.13 Summary**

This chapter opened with a review of the aims of this research. Following this, I provided an overview of the theoretical and conceptual underpinnings of this research and a description of the chosen methodology: Interpretative Phenomenological Analysis. The practical procedures pertaining to recruitment of participants, preparing and carrying out semi-structured interviews and analysing the data obtained were then described. Finally, I have provided an account of the ethical considerations pertinent to this research. In the following chapter I will present the findings which resulted from my analysis of the data.

# 4. Findings

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## 4.1 Overview

This Chapter opens with pen portraits of the participants. Following this a summary of the three superordinate themes which were constructed during the analytical process are presented, together with a thematic map which shows the relationships between each superordinate theme and its subordinate themes. This Chapter then continues with presentation of the findings which resulted from the analysis of the participants interview transcripts using Interpretative Phenomenological Analysis. Each theme is evidenced with direct quotes from participants, which are accompanied with my descriptive and interpretative commentaries. A short summary concludes this chapter.

## 4.2 Pen Portraits of participants

Some details of each of the six participants are summarised below for the purpose of facilitating a connection between the reader and the mothers' whose experiences are being recounted. In order to help ensure anonymity, some details which do not impact on the research have been altered slightly. Brief details of the context of the interview are also given.

### 4.2.1 Anna

Anna is 41. She works part-time and lives with her husband and two children. Her son, Matthew, attends the Abbey Road Unit and is now in year 1. Matthew follows the Son-Rise Autism programme at home. He was diagnosed as having an autism spectrum condition about two and a half years ago. English is Anna's mother tongue. Anna's interview was held at home and was uninterrupted except for a brief telephone call and a salesperson at the door.

### **4.2.2 Irene**

Irene is 33. She lives with her two children and her husband and is not in paid employment. Irene's son Joel is in reception at the Abbey Road Unit. Joel sometimes follows the Son-Rise programme at home but is taking a break at the moment. He was diagnosed as having an autism spectrum condition about a year ago. English is not Irene's mother tongue, but she currently speaks English and her first language at home. Irene was the only participant who chose to be interviewed at the Unit - the majority of the interview took place in an empty classroom, and the remainder in a small side room.

### **4.3.3 Louise**

Louise is 40. She lives with her two children and her husband and works full-time. Her daughter Rachel is just coming to the end of year 2. This has been Rachel's first year at the Abbey Road Unit as she transferred from a mainstream school at the beginning of year 2. Rachel was diagnosed as having an autism spectrum condition three-and-a-half years ago. Louise's first language is English. Louise's interview took place in her kitchen with occasional minor interruptions from Rachel who was home for half term.

### **4.3.4 Jenny**

Jenny is 27. She lives with her two children and her husband and is not in paid employment. Her daughter Martha is now in year 3 at the Abbey Road Unit. Martha was diagnosed with an autism spectrum condition about three-and-a-half years ago. English is an additional language for Jenny. At home she mainly speaks her mother tongue. Jenny's interview took place at her home, and Martha's baby brother was held by Jenny throughout the interview, causing occasional brief interruptions by making noises.

### **4.3.5 Helen**

Helen is 35. She lives with her two children and is not in paid employment. Her son Thomas is now in year 6 at the Abbey Road Unit - he transferred there at the beginning of year 4 from a mainstream school. Thomas was diagnosed as having

an autism spectrum condition about 6 years ago. Helen has two home languages, of which English is one. Helen's interview took place at her home.

#### **4.3.6 Layla**

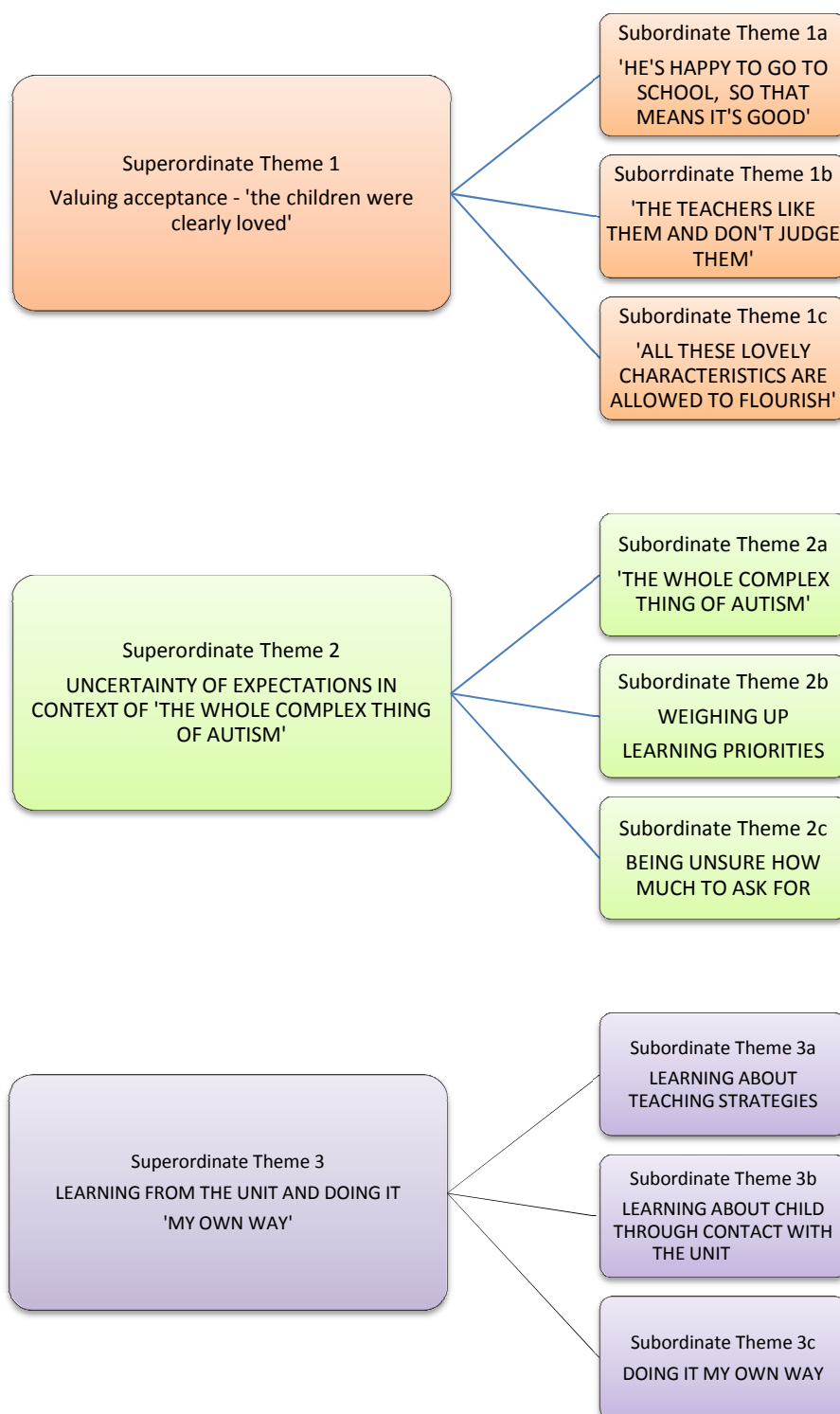
Layla is 29. She lives with her two children and her husband and is not in paid employment. Her son Hasan is now in year 2 at the Abbey Road Unit. Hasan was diagnosed as having an autism spectrum condition about two years ago. Layla has two home languages, of which English is one. Layla's interview was held at home and Hasan's younger sibling was present throughout. Layla's interview ended in a rather rushed way when she had to leave for an appointment, and was interrupted towards the end when she had to get ready to leave.

### **4.3 Thematic map showing all superordinate and subordinate themes**

Before the findings are presented in detail, an overview is given below of the themes found in the form of a thematic map. It is hoped that the findings presented through these themes will convey some key aspects of participants' experiences of the specialist provision for autism. The first superordinate theme presented is *valuing acceptance ('the children were clearly loved')*. This theme describes the extent to which mothers valued a perception of staff's loving and nurturing relationships with their children. The second superordinate theme presented is *uncertainty towards setting expectations, and 'the whole complex thing of autism'*. This superordinate theme summarises the process experienced by mothers of making sense of their child's autism, and of setting expectations in terms of their child's learning and in terms of what they expect from the Abbey Road Unit. The final superordinate theme, *learning from the unit and doing it 'my own way'* describes the learning experiences of mothers as they become increasingly familiar with teaching strategies used by the Unit, learn more about their child through their contact with staff at the unit, and explore different ways of parenting their children in relation to these experiences.

Each of these three superordinate themes is divided into three subordinate themes in order that different aspects of each theme, as well as convergence and divergence between participants' accounts, can be highlighted. Each theme is illustrated with direct quotes to illustrate the divergences and commonalities between the participants accounts, and these are supplemented with descriptive and interpretative commentary. The three superordinate themes and their subthemes are presented in the figure overleaf.

Figure 4.1 Superordinate and subordinate themes summarising the whole analysis

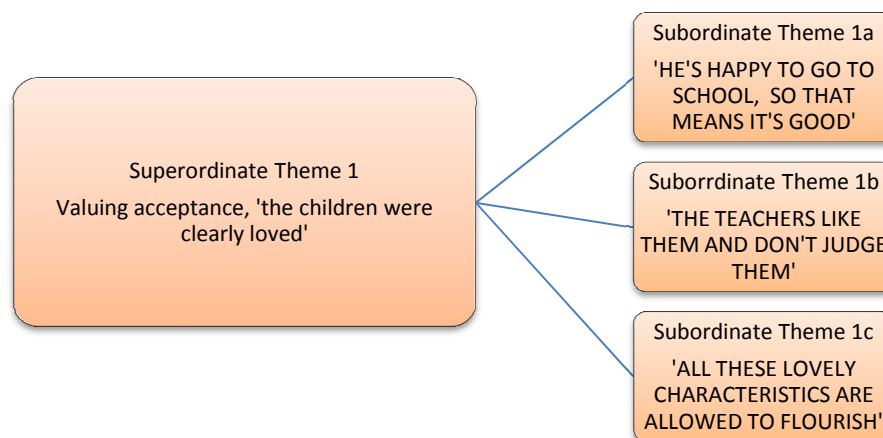




## 4.4 Superordinate theme 1. Valuing acceptance 'the children were clearly loved'

This first superordinate theme reflects the sincerity and passion with which participants often talked about how important it was for them to feel that their child was accepted and valued at school. Subordinate themes are shown in figure 4.1, below.

Figure 4.2 Superordinate theme 1 with subordinate themes



### 4.4.1 Subordinate theme 1a: He's happy to go to school, so that means it's good'

This theme illustrates the importance to parents of their child being happy at school.

In this extract, Irene explores how satisfied she feels about Joel attending the Unit by weighing up her perceived negatives - that the building isn't newer, and it isn't in a nicer area, with her view that "Joel's happy" which is the main thing' (line 580).

*Obviously nothing is perfect, you know, and you always think oh ... if the building was newer or, what else you know ... er I don't know, if it was a nicer area (laughs) you know, whatever. But this is good and you know, it's working for Joel. It's nice, the people that work here, they seem very nice, and er you know, I'm just happy. And Joel's happy, which is the main thing (INT - yes). He seems really happy. So we are like 'okay, he's happy to go to school so that means it is good' (Irene, 575 - 583)*

Irene contrasts this with her experiences of Joel being unhappy in his mainstream nursery, which has resulted in him having violent tantrums:

*it's been very good, for Joel. (INT - yes). Otherwise he wouldn't be happy to come, I know because, when he was going to the nursery he used to um, it was really hard for me to go home? I had to wait for ages and when I left he was always crying. Kicking, by the doors, screaming (INT - mm) and you know and he ... and then I would go back to pick him up and he would be still standing by the door? You know, just waiting for me to go and pick him up. So you know, he wasn't happy there but at the time I thought it's just me, you know attached to him, because we spend so much time together, but it wasn't that, it was just the place. (Irene, 585 - 595)*

In the above extract, Irene gives some suggestion that the importance she places on Joel's happiness in the Unit partly relates to her prior experiences of him being very distressed in a different educational provision. Her account suggests that not only was this traumatic for Joel, but it also lead her to question her approach to parenting - "it's just me, you know attached to him" - as a possible reason for Joel's distress. Interpretatively, this difficult experience for them both is likely to be making Irene especially appreciate her current perception that Joel is happy in school, as this means that she can be reassured both that Joel is happy and of her competence as his mother.

Similarly to Irene, Louise describes Rachel's behaviour at home as a strong communication as to whether she is happy in school. Prior to attending the Abbey Road Unit, Rachel attended a mainstream school for a year, and Louise spoke at some length in her interview about how much happier Rachel currently is at school.

*the most important thing was realising that she was now happy and feeling confident and secure. Because of her behaviour when she was coming home, she was not getting anxious at night time before (INT - yes) you know Sundays, um, you know in the morning when the bus was coming she couldn't wait to get there you know she was waiting at the window getting angry when the bus was late 'bus is here! Bus is here! (Louise, 204 - 210).*

As with Irene, a prior experience of her child being distressed at home may have influenced Louise's valuing Rachel's happiness in school as a main priority. Speculatively, it is possible that children with ASCs are more likely to demonstrate very challenging behaviour at home when they are not enjoying school due to their associated difficulties with emotional self-regulation and communication. Clearly seeing your child unhappy and distressed is difficult for any parent, and perhaps the fact that these parents perceive their children as particularly vulnerable due to their difficulties might make them particularly protective of them.

Anna spoke at length during her interview about very challenging behaviour Matthew has exhibited at home, and how extremely difficult this has been both for Matthew and for the rest of the family to cope with. She describes Matthew using powerful language: "It wasn't Matthew. He was frightening himself. He was literally...beside himself, it was like he was possessed" (580). Anna's experience of this was similar to Irene in that initially she did not make the connection between Matthew's experiences at school and his behaviour at home and wondered if she was somehow to blame for it. Here she describes how she now perceives this connection:

*I I think that the day was very overwhelming for him, (INT -yes) you know, many transitions throughout the school day. Very demanding, for a child with all his difficulties (INT -mm) and, I think that he he/held it together, but the stress with/and the anxiety would be rising all day (INT -yes) and then, he'd come home, it was a safe environment ... and , it had to just ... flood out (INT —yes) and that was the form it took (INT -yes) I mean maybe I'm wrong, but that's my ... perception of it. (Anna, 588 - 595)*

Anna's experience that is represented with this theme diverged somewhat from other participants accounts, as her descriptions of connecting her child's behaviour

at home with his experiences at school were negative, rather than positive. However, Anna's more recent experience echoes the previous experiences of other parents who spoke of their pleasure in knowing their child is happy going to school in the context of previous difficulties.

#### **4.4.2 Subordinate theme 1b: 'the teachers like them and don't judge them'**

A quote from Louise is the in-vivo title to this theme. In the excerpt which contains it Louise sheds some light on why she feels teacher's accepting attitude is important to her, by describing her perceived risk that staff will judge Rachel's needs and behaviours which unavoidably result from her developmental delay.

*as a parent, knowing that your child is going somewhere where the teachers like them, and don't judge them, they aren't, aren't sort of um, or thinking she's "icky" because, you know, she needs to have her nappy changed or, you know she gets food all over her face or, you know that kind of thing where they don't, they don't, they don't, that doesn't bother them, um... you know is, is, is very comforting (Louise, 230 - 236)*

Louise spent some time in our interview talking about the year Rachel had spent in a mainstream class prior to attending the Abbey Road Unit which Louise described Rachel as finding very difficult. Louise is describing what she values about the Abbey Road Unit by contrasting her positive experiences with negative experiences she has had previously, similarly to participants in the previous theme.

In the extract below, Anna recalls her anxieties about Matthew beginning school at the point when he reached school age. Similarly to Louise, by seeing Matthew as a 'square peg in a round hole' Anna seems to be worried that because Matthew is different to other children he might not be accepted. Anna uses the first person in this extract, illustrating that she felt somehow responsible for ensuring Matthew was accepted at school.

*how am I going to ... fit this ... square peg in a round hole (INT- mm)?  
It's not going to happen. (Anna, 119 - 121)*

Elsewhere in her interview, Anna speaks frequently about her valuing of innovative and effective teaching practice. The importance she places on staff having a warm relationship with her child is illustrated in her ending this quote, in which she mostly speaks of the importance she places on teaching strategies, by highlighting that the most important thing for her is that "the children are clearly loved":

*we could see, the results of these new techniques and how brilliantly they worked. And , the atmosphere of peace ... and calm, the children were clearly, loved which is the most important thing by the staff.  
(Anna, 60 - 63)*

Jenny spoke animatedly when she described the positive relationship between Martha and her teacher:

*JENNY - the teachers told me her, their relationship is er, like last year she got er the teacher help her, she's (Class Teacher)? She's just love, they just love each other (laughs) (Jenny, 719 - 721)*

Irene's described her decision not to apply for Joel to attend a specialist ABA school with many more resources than the Abbey Road Unit illustrates that for her a warm and loving environment is also her priority:

*we went to see the (private ABA school) (INT - yes) and you know it was fantastic coos it was like a five star hotel I don't know if you've been (I -I have, yes) and I just said to my husband 'I want Joel to come here that's where he must come, he must come here!' and um ... so we went to see we had a meeting and we didn't like it. We didn't like the fact that people were so cold [...] I didn't feel like Joel's going to do well there so I just thought I don't want him to go there any more (Irene, 41 - 52)*

#### 4.4.3 Subordinate theme 1c: 'All these lovely characteristics are allowed to flourish'

This theme represents participants wanting their children's positive qualities to be recognised, nurtured and appreciated by school staff. Participants spoke animatedly of their child flourishing both in terms of expressing their personalities and in terms of reaching their learning potential. Several parents made explicit links between their feeling that their child could flourish at the Abbey Road and the fact that it is a specialist unit.

A quote from Anna supplies the in-vivo title for this theme. In the quote below Anna describes how important it is to her that Matthew is being taught in a specialist setting. Like several participants, it seems that Anna equates specialist provision with personalised teaching.

*all these lovely characteristics have been al/allowed to flourish , (INT -yes), and the thought of Matthew having been ... put into a mainstream school, even with a one to one, is too horrible to contemplate*

Irene expands on this theme, equating the special school environment with the opportunity for her child to feel socially included due to being in an environment with children with similar needs:

*[in] mainstream [...] you know, they don't get to mix much with the other children, they are always behind. [...] they're, they're always on the side doing something else, or you know maybe throwing tantrums because it's too noisy, because there's too much going on, it's not the same, you know. So we're really happy that he gets to be in a place like this (Irene, 505 - 514)*

Louise particularly valued the feeling that staff had taken the time to get to know "the real Rachel":

*they've now got to k/know the real Rachel . Which is someone who's actually got quite a wicked sense of humour (laughs) [...] it's just, you know they've, they've got to know her as a person (Louise, 169 - 189)*

Of all the mothers interviewed Louise spoke most about the idea that her child had locked up potential. She speaks of staff's interest in understanding Rachel's learning style and what motivates her as a sign that Rachel is valued in school, suggesting that Louise values personalised teaching approaches, which are not necessarily 'off the shelf' specialist strategies:

*Well I think the fact that they're curious, er, means that they're interested, means that they are likely to do a better job, I think. You know it's, it's if you know that your tea/the teacher of your child is really interested in getting the best out of your child, and is adjusting their methods if you like to the child, rather than trying to, you know, do some proscribed method (INT - yes) , that they're actually thinking about things, and experimenting and seeing what's working with your, you know, looking at all the knowledge at they have to sort of work with the very particular nature of your, of your own child (Louise 555 - 564)*

Jenny, as with several other participants, described her perception of the value in her child attending a specialist provision rather than a mainstream provision. In the following quote she describes how she feels that Martha's curriculum in the specialist unit would be tailored to children with learning styles associated with autism spectrum conditions.

*Well I thought it's quite good for her, because they, not like in normal primary schools, I knew she would be struggling cos she's very, very active. And she wouldn't, er, attempt to do normal activities that they do in the, er, with the primary schools. And er, with The Abbey Road Unit what I thought is um, that they, um, they arrange the activities to make er interest, er autistic children (INT - mm) that they paying attention to their, mm, activities. They're right for their, er abilities as well, yeah. (Jenny, 24 - 31)*

Of all my participants, Helen spoke most vividly of her hopes for Thomas to thrive in the future. She contrasts this hope with the "greatest fear" that Thomas would be lost in the educational system. In talking about this Helen suggests that this issues are true of "any parent that has a child [...] with learning difficulties". Interpretatively

this shift from speaking on a personal level to speaking 'for all parents' might indicate that the issue of having high expectations for children with special educational needs is very important to Helen. This idea is also supported in Helen's comments in later sections of her interview which will be explored in the discussion of subsequent themes.

*I think the greatest fear of any parent that has a child, you know, with learning difficulties or special needs is that, you don't want your child to be lost in the educational system. You want your child to grow up to be somebody successful. I don't just want my child just to go to school. Just to make up the numbers, no. I want my child to grow up to do better than I did. I think that's the wish of every parent. And that's my wish. (Helen, 345 – 352)*

Layla also talked about a desire for her child to flourish, but she perceives that different things would enable this than the small group setting and personal and specialist teaching methods described as being utilised by the Abbey Road Unit. Layla spoke at some length during her interview about her desire for Hasan to attend a local private ABA school, and seemed in much of what she said to be conflicted about Hasan's attendance at the Abbey Road Unit. In the following excerpt from her interview, Layla is describing her decision making process about where Hasan should be educated. She comments that "they're not going to go to mainstream [so] you want the best special school for them..."

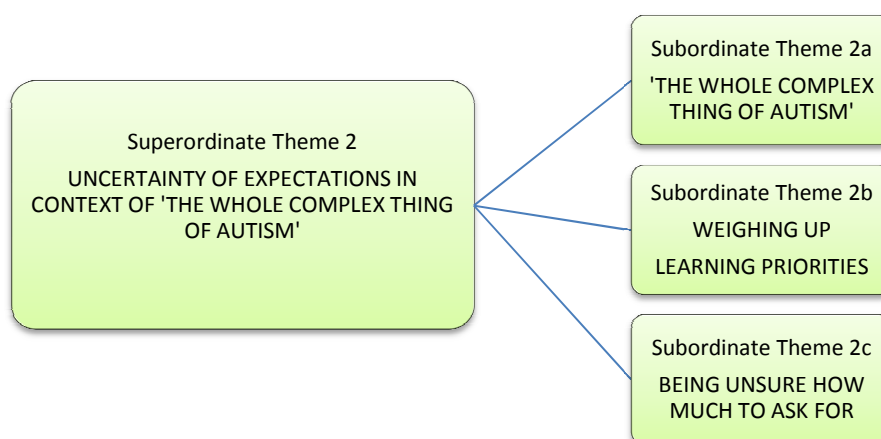
*it's lovely that they've got sensory rooms and they've got one-to-ones and (INT - yeah), children get the best out of it, you know, and that's what you want for your child just to get the best/ they're not going to go to mainstream, they're going to a special school you want the best special school for them (INT - of course), and then it's hard that you can't afford as a parent to take them there (INT - yes), it's really a ... shame , so... (Layla, 207 - 213)*



## 4.5 Superordinate theme 2: Uncertainty of expectations in context of 'the whole complex thing of autism'

This theme relates to the range of expectations of the unit and of their children's progress that participants spoke about. Deciding on expectations did not seem to be a straightforward process, and this possibility is explored further below.

Figure 4.3 Superordinate theme 2 with subordinate themes



### 4.5.1 Subordinate theme 2a: The whole complex thing of autism'

When I asked parents about their expectations of teaching and learning at school, responses often led to participants commenting on, as Irene is quoted as putting it above, 'the whole complex thing of autism', and how participants understanding of autism and related subjects impacts on their hopes and expectations for their child.

Louise believes that children with autism spectrum conditions are often underestimated, and relayed this story to me to illustrate this:

*I sometimes feel quite sad when I think that children with classic autism, some of them have so much potential, and, you know there's one little girl that I know who, um, who's, you know was quite severely autistic apparently when she was two, um, and is in the specialist Unit now, but is, you know, to me she doesn't seem, you know you can tell she's not quite right, she's a little bit sort of um innocent and, and whatever, but she's incredibly ... I mean she's an incredibly talented artist (INT - wow) and going, I think she's going off to (a prestigious art school) and, but her Mother, she didn't give up, she took her to every...specialist she could, you know, she took her to Nordorf Robbins, she took her to some sort of psychotherapy thing, she took her to, um, you know, cranial specialists and did everything for her and er, now she's almost normal, and you sort of thing "gosh should I have done that, should I have, you know, if I did that intense sort of therapy, um, would I be able to get more out of my child"? (990 - 1006)*

The above quote suggests that for Louise it is very important that a child's diagnosis of autism doesn't limit the expectations made of them.

Anna spoke positively about the educational strategies and progress Matthew has made during the time he has attended the Abbey Road unit. However towards the end of the interview she commented that in fact she did not, at the time of our interview, see education as a priority for Matthew, as she felt that "ameliorating his autism" was her first priority.

*the truth of the matter is that I'm not interested in academic attainment for him. I don't care — I know he's clever (INT - yes). What I'm interested in is ... ameliorating his autism (Anna, 885 - 888).*

Anna spoke in our interview about her choice to give Matthew therapeutic approaches to autism. Interpretatively, for Anna this suggests that she conceptualises Matthew's difficulties associated with his diagnosis as having the potential to be significantly lessened with the right therapeutic intervention. In this way Layla and Anna are quite similar, as Layla spoke at length during our interview about her efforts to identify and provide Hasan with therapeutic approaches

At the time of our interview Layla had a very specific view of what she felt would be the best education for Hasan, and this was in the form of him attending a nearby

private ABA school, or failing this to receive ABA input at the Unit - which she told me had not been possible. Her comments below describe how difficult she has found not being able to access her chosen therapeutic approach:

*We can't afford it at the moment it's just, it's, it's a nightmare really, unless you get some sort of charities to help you (INT - yes), but um, yeah, I don't know. I think, you've just got to try each option I mean if it doesn't work it doesn't work, but ABA is, I've been told by the person who's actually, you know, been reading up on it, um, it is effective for most children they say (INT - mm). So why, I don't know why the (a local GLD ASD special school) don't do it either. And The Unit's not doing it, can they not just try, at least, to do it and to establish it? It's just ... but really it's sad cos you feel like as a parent that they, they're not really doing everything that they say they are. (layla 745 - 755)*

The frustration Layla seems to be feeling due to the inaccessibility of ABA for Hasan at the time of our interview, together with her reading of its efficacy seemed to be very overwhelming to her during our interview, as she spent a large portion of our time together discussing it.

There seem to be some commonalities between how Anna and Layla understand and are responding to their sons' autism. She and Anna both have hypotheses about what might help their child, but Layla hasn't been able to access these things as effectively as Anna, and is hoping to access therapeutic treatment through an educational provision. Anna is seeing the provision purely as education rather than therapy, and perhaps this is why she seems more content with it than Layla often presented as.

Louise was the only participant who spoke explicitly about her frustration with feeling that her child's progress in the future was an unknown due to her diagnosis. Louise also remarked that she wished staff were able to give her a clearer picture of what Rachel's progress might be like, as she felt that perhaps staff sometimes withheld information due to a desire not to speculate, or not to disappoint her.

*one of the things I used to always ask um when she was at (mainstream nursery) is "what do you think as a, as a professional, that, you know, do you think that Rachel will ever, be able to be, um,*

*independent, or will she always need to be cared for, or, you know, what, what, what is her potential? (INT - yeah) And I guess it's not possible for them to ever know. Um, but, you know there's lots of, um, etiquette, or, or rules I suppose that are on their side about what they can and can't say to parents, I think. (Louise, 835 - 845)*

An observation regarding Louise's point is that for neurotypical children the contrast couldn't be greater, as there are published guidelines used by schools in terms of expected levels and rates of progress which are widely understood by parents and children and which are often shared by staff as part of best practice.

Below, Helen describes her perception that others might place limiting expectations on her child due to his diagnostic label of an ASC. Whereas Louise's main concern is around children with autism all being treated the same without regard for their learning style, Helen's is that children with autism might not be academically stretched enough

*the label – because I regard it more of a label, autism is more so that it's meant to be so that the child can have help. That's what it's meant to be. It's not meant to be a hindrance. It's not meant to limit the child, it's meant to help the child, it's meant to help the child get the need, you know? The needs that they need, really. It's not meant to be like a tag, so like their wearing it like on the front and at the back and (INT - yes) and, and well “oh dear, he's got autism, alright then, oh sit over there please”. It's not meant to be that way, okay? A lot of them are very intelligent, very clever but its (pause) how, between what's in their head and their mouth, how do I get what's in my head to say what I've got up here (INT - mm) you know? Some of them there's, it's diff/they find it quite difficult (INT - yeah) and when they can't, they get frustrated, you know? (Helen, 652 - 665)*

#### **4.5.2 Subordinate theme 2b: Weighing up learning priorities**

This theme relates to the idea that different types of learning were competing in the mothers' minds to be considered priorities, or to be discussed with staff at the Unit. Mothers variably discussed the following learning priorities:

Learning of skills which are typically delayed for children with an ASC - that is, skills related to social communication; learning of functional skills relating to

developmental delay, learning of 'skills for learning' such as developing attention and concentration, and progressing with skills in academic subjects such as numeracy and literacy.

In Irene's comment below she initially responds to my question about whether Joel is doing what she expected him to be doing in school by saying no, but then realises she has misunderstood my question to be about how Joel is different to a neurotypical child.

*INT - Is Joel doing what you expected him to be doing in school?  
IRENE - Well no. But you know I know that this is how it's going to be. But what do you mean like you know like er, a neuro-typical child like in reception? Or ... (Irene, 236 - 239)*

Interpretatively this response suggests that for Irene, expectations for how her child would achieve and make progress begun before he was born. It seems likely to me that this would be a normal part of the process of preparing to have a baby, and for most parents, any reasonable expectations would quite likely be met. Joel's diagnosis not only means that Irene now has to develop new goals and expectations for her child, but her comment also suggests that letting go of her prenatal expectations was a conscious process. Her comment that "this is how it's going to be" suggests that this process of letting go of previous expectations was part of accepting Joel's diagnosis.

After this brief misunderstanding Irene goes on to describe her experience of Joel's academic progress at the Unit in very positive terms. She comments that "he's doing more here than what I was expecting":

*IRENE - Ah I think he's doing more here than what I was expecting because um ... I didn't think that he was going to be able to put his name together like I saw him doing you know on the, on the videos that they showed me he was trying to write his name. I know that he knows the alphabet because I, you know I've been working with him, a lot. But you know to see him doing things like that and also, now he recognises you know many more colours than I've taught. (Irene, 240 - 249)*

#### 4.5.2.1 Prioritising social communication and language skills

Jenny particularly prioritised the development of Martha's speech and interaction skills:

*JENNY - Mm. Er, maybe and, to be, that would be more social, social with the others. [...] and her language [...] and her language, yeah. Interactions...and as well with the, like er, literature or maths (laughs)*

Helen similarly reported that developing social communication and language skills were her main learning priorities for Thomas:

*Well, especially speech and language [and] understanding people's space, you know, things that, you know, ordinary kids don't, you know, don't have to [...] learn about (Helen, 186 - 198)*

Irene also reported prioritising social skills for Joel, again suggesting that difficulties associated with Joel's diagnosis were a key concern. During her interview she spoke at particular length about her valuing the development of Joel's social skills, and how she perceived that being with children with similar needs to him at the Specialist Unit would result in his social integration and promote his social development.

*You know, I think you know, children with autism, they like to be on their own, but they also need to be pushed into socialising (INT - mm) and that's what they do here as well, you know. And Joel's like that you know Joel/he doesn't really play on his own, I have to play with him all the time (laughs) so you know I just thought 'this is great' you know they are all together sitting in a circle and taking turns, you know learning how to be you know one of, you know plays with not many people but still socialising with other kids (INT - mm) it's nice. It's important because you don't live on your own all your life you know (I-yes) you need to learn how to be with other people (INT - yes). So I like the fact that he was going to be able to do this here. (Irene, 71 - 82)*

#### 4.5.2.2 Prioritising functional skills

Several parents mentioned toilet training as a learning target, always as a collaboration between school and home:

*we're trying to potty train him at the moment and he's doing very well (pause) yes, they're helping us at school, so that's fantastic (Irene 326 - 328)*

#### 4.5.2.3 Prioritising academic skills

When I asked Helen specifically about targets she was working on with Thomas she immediately mentioned developing his language and communication skills as the current priority. However later on in our interview Helen spoke about her academic goals for Thomas. She described his interest in the computer and commented.

*oh I can see him doing a GCSE level, I can see him actually doing a GCSE level (INT - yeah). Because I see him now, and how he does and how fast he is on the computer and typing in words (INT - mm) and accessing, you know (Helen, 293 - 297)*

However, Helen also spoke about her concern that children with ASC's academic potential are often overlooked due to them being "labelled" as having learning difficulties. Helen spoke in general terms about this subject, indicating that it is one she feel relates to the universal experience of children with ASCs and their education, rather than solely to Thomas:

*But like where I see where, the gap between the unit and the mainstream is (pause) that the children in the unit haven't the opportunity to have someone who is specialised in actually harnessing their gifts. You know, harnessing the gifts and talents that they have. So it's not like everybody in general, it's like a generalisation that, well, because they have special needs they're abilities are limited (INT - yeah) It's, It's, It's, It's, It's not treated like that, it's like "well let's see what, whether they'll know how to do this, let's see whether they'll be able to do this, let's see whether he'll be good in this (INT - mm), let's*

*see whether he'll be good in sport, let's see whether he'll be good in music, let's see whether he'll develop interest in maths, let's see whether"...you know? If they're given that kind of opportunity. So, I don't know how that could ever be possible, I don't really know. It's, with, with, I think it's (pause) with the, both with the mainstream and with the, the unit, it's like there's quite a lot of generalisation, you know, and there needs to be, where children are treated more like as, um, when it comes to their gifts, their talents, their abilities, they're treated more like individuals (Helen, 628 - 643)*

Helen speaks when prompted about briefly observing Thomas in class when she goes to school for visits. Although she speaks neutrally, or even positively about the learning activities she has seen Thomas engaged with, interpretatively Helen feels Thomas could be more academically challenged at school. This is based on her comments that she is aware that Thomas already have the skills she has seen him work towards at school, and her comments above regarding her belief that greater academic challenge should be offered to Thomas and to all children with ASC diagnoses.

Below, Layla comments that her priority for Hasan is to make academic progress with his numeracy. However when she describes the actual progress he is making this is in terms of Hasan's development of 'skills for learning' in terms of his concentration.

*I mean yeah, he should be learning a lot of numbers and a lot of, you know. And because last year was so chaotic and difficult with his behaviour (INT - mm), cos they said this year he's more calming down a bit and he's more sort of ... you know, being, sitting there sometimes for twenty minutes to do his one-to-one work (INT - yeah). He's, he's, he's getting a lot easier now, that he's getting more co-operative, so yeah, definitely.(Layla, 853 - 862)*

The following quote also from Layla illustrates a tension between wanting to prioritise learning needs but concern about basic skills and wellbeing getting in the way of this.

*I think his learning as well I need, you know, yes, his eating is not great and you do worry about that cos -some days they say he hasn't*



*eaten anything all day (INT - yes). Which is quite worrying (pause) and his learning as well, you know...(Layla, 1132 - 1136)*

### **4.5.3 Subordinate theme 2c: Being unsure how much to ask for**

Helen's comment below illustrates how the mothers reported sometimes being hesitant to make clear their hopes and expectations for what the Unit could offer their child. Prior to this excerpt Helen had been sharing with me her academic hopes for Thomas, and her belief that children with ASCs should be set high academic expectations and be entitled to high quality teaching and learning opportunities. Helen had told me that she regularly attends parents meetings and contributes confidently to planning Thomas's learning targets. I asked her whether she had requested further, more specialised teaching for Thomas in computing, which Helen had reported was a strength for him:

*INT - have you had an opportunity to, um, ask the staff at the Abbey Road Unit about whether Thomas could be extended in his areas, where he has particular interests? HELEN - you know what? I have never. You know? Because, erm, I have never to tell you the truth because, um (pause) I look at it like, you know, I see the Unit (INT - mm), and I see what they have to offer. And I, um, it has never really occurred to me to really to ask, no. I see what they do already. What they do is just brilliant, you know? But I have never asked, no, I haven't. INT - do you feel you've had the opportunity to? When you meet, for reviews and that sort of thing? HELEN - you know what, it has never really crossed my mind to ask. It has never really crossed my mind. But deep down I've always wished, if it were possible (INT - yeah), but I've just felt maybe it's not possible, you know, so I've never bothered to. INT - can you explain any more about, about why it's never/ it sounds like it's not that you've thought "oh should I say this, oh no I won't", it's never crossed your mind... HELEN - sometimes I feel maybe the money, you know? Maybe the, the funding just isn't there (INT - yeah). Maybe the funding for the, for the Unit, to have that kind of, you know, to have that kind of, you know erm, you know, maybe lessons? Or, erm, what will I call it, um, maybe these opportunities for these children to go further in their gifts and talents (INT - mm), maybe because the funding is not there? (INT - right) So that's why, yeah. Because it would require funding, it would require a lot of money. (Helen 255 - 288)*

Unlike Anna, Layla and Louise, Helen did not articulate any hopes that her child's autism related difficulties could be completely overcome in the future. Instead, Helen's view seemed to be that with the right teaching, it is possible for children with ASCs to achieve great success in their specific areas of academic strength without their autism having to disappear in order for this to be achieved and celebrated. Helen described herself as an active contributor to the Unit's target setting regarding her child's speech and language development, which perhaps reflects her acceptance of his specific difficulties which relate to his ASC diagnosis. However in the excerpt above she also voices her frustration at not being able to discuss ambitious academic targets for her child at the same meetings.

Anna's wish about the school was that they had communicated more promptly and clearly about a class change which had not been successful for Matthew and which had resulted in him displaying very challenging behaviour at home over a period of several weeks. In the quote below Anna articulates this wish but then puts herself in the school's shoes and imagines reasons which might explain this oversight:

*that's the one thing I felt the school let us down a bit, (INT – mm) in terms of communication, cos we didn't know this was going on at school. And I think in fairness to the school was the reason they didn't was because they knew that we had enough on our plates (INT - mm) and that this was an internal problem (INT – mm) do you know what I mean about, what to do about this, the fact that, this class apparently didn't settle down very well (Anna, 459 - 471)*

In the quote below, Irene describes wishing that staff at the provision were able to ensure Joel drank enough. However she quickly gives a reason why the Unit staff may not be able to ensure this, suggesting that because staff have several children in their care who may be similarly unable to take care of such basic needs themselves, she shouldn't complain:

*think about, for example oh ... does he drink enough when he's at school? Because I know that you need to follow him to drink, you know, and obviously they have so much to do in here, with all the kids who all have different, you know, challenges, and they need to deal with them even though it's a good, you know, ratios. You know, two kids for one, er, teacher or assistant. Um, but still, you know even one child sometimes. I/ sometimes Joel is hard to deal for me you know at*

*home (INT - mm). You know I can't, you know, when I have both of them, for me it's really hard. But, so I can imagine him, you know, for him to have a drink here is ... it's ten times harder than for me at home maybe here it's fifty, or twenty I don't know ... so things like that, he doesn't drink much when he comes here. (Irene, 616 - 628)*

For Layla, the lack of resources and small unrenovated building the Unit is housed in continue to trouble her despite feeling that the teachers are "really welcoming and really nice"

*Er, yeah. I mean the Abbey Road Unit , yes, I mean I thought the teacher/I thought the girls were really welcoming and really nice ... um, you know, for the parents and the things that they/but I just felt like the Unit was really small (INT - mm) they were all you know, I just felt like the facilities were not great (Layla, 218 - 230)*

Louise wonders whether parents could support school to provide more resources:

*you do wonder if, if you had money and resources and, or you lived in an, an area where um, you know, where there, where there was you know the parents themselves perhaps all got together and put more pressure on the sch/you know, er the school and worked more with the school to, I mean it's like with, you know with normal schools where you get these schools where all the parents get involved and they're all about, sort of um, you know making that school the top school, er and that, that, that's, you wonder if those, that kind of er thing would work with special schools as well and um, and there, there is more that can be done, to, to move um, move Rachel on. (Louise, 1008 - 1027)*

Jenny comments that she hasn't seen other "special schools" though she is quite happy with the provision. Jenny's caveat that she hasn't seen other special schools suggests that perhaps a different experience for mothers whose children attend specialist units is that many, like Jenny, will never have visited a special school before and are unsure whether they should demand similar or different things of the school as they would a mainstream school.

*I haven't seen the other schools, with special needs. I haven't been to visit it, so I don't know what the different things with The Abbey Road Unit and the other special schools are (INT - yes). But I'm quite*

*happy with er, the school and I've got the other children so they can be in the same school. So it's more easy.(Jenny, 670 - 675)*

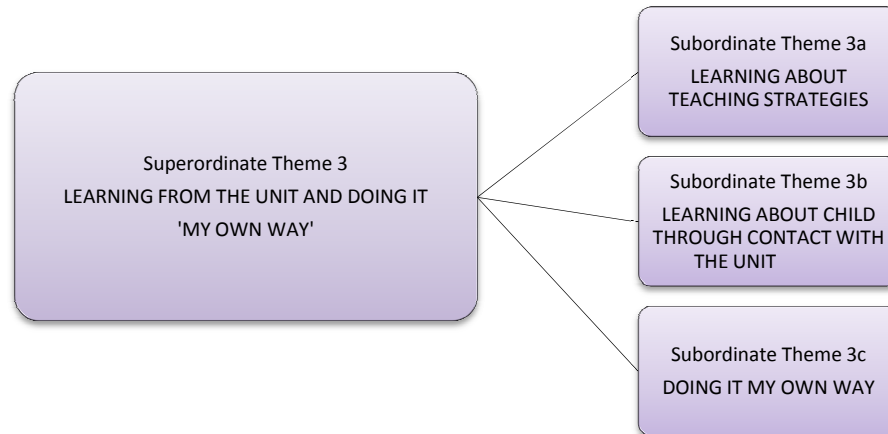
## **4.6 Superordinate theme 3: Learning from the unit and 'doing it my own way'**

This theme represents participants valuing what the unit has to offer, in terms of optimising their child's learning with specialised teaching strategies, giving them new information about their child and in offering support. Some participants also talked about valuing the opportunity to do things 'their own way', sometimes still with the support of the Unit, and of their reasons for this, and this is reflected in the final subordinate theme. An overarching message of this theme is of participants' embarkation on a learning process following their child's diagnosis of autism, which continues in the ways in which they experience their child's educational provision. Of all the participants, Anna spoke most explicitly about the learning curve she had travelled along as a consequence of her child's autism, and her quote below sets the scene for the discussion of different aspects of mothers' learning which follows:

*Something that's really important that people should bear in mind is that ... these parents are still new parents to that child I mean four, five that's nothing! You know, they're a baby for half of that, literally, when you probably don't even know they're autistic. And so you've only had a year or so ... to get used to the idea which is nothing for something like autism, when suddenly you're thrust into this whole ... you know I didn't know what a senco was, or an EP or a, (INT –yes) you know the terminology alone! The, the, you know statement? I've never heard of a bloody statement! Why would I? And so your learning curve is immense [...] And then you're still full of grief and ... fear for the future, fear for the present, er, er, you know (pause) and I think that, um ... professionals are so expert and experienced in these things they, they can forget that ... you know the parents are still on the nursery slopes with all of this. (Anna, 637 - 656)*

The subordinate themes associated with this theme are shown in the figure below:

*Figure 4.4 Superordinate theme 3 with subordinate themes*



#### **4.6.1 Subordinate theme 3a: Learning about teaching strategies**

This theme concerns mothers learning about and making sense of teaching strategies in the school and home contexts. The mothers interviewed were generally positive and knowledgeable about some of the specialist strategies used in the provision. They had gained this knowledge through attending parent information evenings, observing their child in class or seeing their child engaged in learning activities on videos during home-school review meetings. Several parents spoke positively of their experiences of taking advice from school staff regarding how to implement these teaching strategies at home. Other parents described their difficulties with implementing strategies at home.

Irene describes being impressed with the effectiveness of teaching strategies, resulting in Joel responding better than she was aware he was able to. The fact that Irene has seen these teaching strategies being used first hand in class (rather than during a demonstration for parents) seems to have amplified her positive

impression, as she comments that the fact that Joel's peers who she regards as having similar ability levels also responded straight away to the strategies used. In this excerpt Irene emphasises the effect of the strategies used, and that the positive effect she saw made her interested to learn more about the mechanics of the strategy that staff were using:

*At home it doesn't work? So I said to him for example "okay Joel, cartoon time is finished, it's breakfast time" (INT - mm) no (laughs) no, it's not (laughs) I have to carry him, er say to him "okay I turn the tv off if you don't come" and then it's like (inaudible). But you know in here it's like okay they have their signing, and they point to children and they just follow the instructions and it's quite like 'how do you do that!' (laughs) you know?(Irene, 224– 228)*

In the following exchange, Layla seemed more knowledgeable of the strategies used by the Unit than she realised. When I asked her directly about the strategies she had learned about, to follow up on some previous positive comments she had made about a parent training workshop, she seemed unsure of the specifics of it:

*is it, is it TEACCH? The principle called TEACCH? INT - yeah there is, that is a strategy, yeah. LAYLA - Yeah, I think they used that as well, they used, INT - Do you remember what that involved? LAYLA - Um, I think it's just looking at each child, yeah I think what they're trying to say is that they don't sort of put every child together, they sort of see the child's progress and sort of go from (Layla, 884 - 893)*

However later, although she didn't name it, Layla demonstrated a clear understanding of the 'attention autism' intervention utilised by the provision, and the purpose of this intervention. This followed my asking specifically about what she had seen Hasan do in a video shown to her at parents evening.

*LAYLA - Erm ... sort of um (pause) with the balloon counting he sorts of pops them and sort of tells you how many he's popped (INT - okay) or he's (laughs), with the numbers he's sort of in a table putting things together, it was really nice, like the way the activities, how fun they make it and how much he actually knows, and how organised he gets because (the Unit Manager) sort of does the activity with the group and then they go to their own little stations (INT - yes), to do, and she said "he does exactly what I did" Like he copies like/ some children*

*don't, you know, they just sort of mix things around, but Hasan likes to put whatever she did in that row how she did it... (Layla, 884 - 893)*

Layla's more positive and fluent style in talking about strategies in the second extract might suggest that she is more likely to engage with information about strategies when they directly relate to her child, rather than in parents meetings.

Jenny and Anna both mentioned the Unit's attention autism intervention in positive terms:

*they do quite a lot of activities like that (INT - mm). Scientist things as well, for example, they showed us how, um, with the bottle with the, some soft drink? And they put some salt in there, some sand, and other ingredients and it just splits away (INT - mm) so, it makes things quite more interesting for the children.... (Jenny, 75 - 80)*

*And the children learn very quickly, (INT - mm) that when the ground sheet comes out there's something really exciting coming, and it's worth your while to come and sit down on your bottom and wait for it. Um, and then that's expanded to, um, them doing their own work, um and, they use another technique called 'what's in the bucket?' you know, and you'll have some sort of big ticket, toys in a bucket and they all sit round singing a song you know (sings) 'what's in the bucket, what's in the bucket' and they know that it's worth sitting down still, waiting. Because when the bucket opens there'll be, you know, a penguin that does somersaults or something really exciting (INT - yes) and um these techniques, really work. (Anna, 321 - 354)*

Jenny describes how she values offers of support from professionals at the Unit:

*Well, er, on the parents evening I can meet her speech and language therapist which is quite helpful, so she can, um, explain me how um, the picture exchange is working (INT - ah okay) and she was offering as well to visit me in my home as well to sort it out, how we can do it at home? (Jenny 194 - 202)*

## 4.6.2 Subordinate theme 3b: Learning about child through contact with unit

A view that was voiced most often as part of this theme was the degree to which parents depended upon, and appreciated, direct communication from the Unit in the form of daily written home school books, videos of their children in class shown at home-school review meeting and other face to face or telephone meetings. Several parents explicitly clarified that their desire for direct communication from the unit about how their child was getting on at school was because, as all of the children of the mothers interviewed had communication difficulties direct communication from school was seen as the best substitute available for being able to ask their child 'how was your day'? Excerpts from each mother's comments about how they value direct communication are explored below:

In the following excerpt Irene discusses her appreciation for direct communication that is initiated by school. She remarks that if it was up to her she would "love to come and hide [...] somewhere and see what they do, but you know you can't"

*If I'm concerned about Joel not being well you know, I will never call or ask the teacher oh what did you do yesterday? You know (INT - yes). It's always through the book or when we do um the annual reviews which is every six months I think, or end of term? (INT - yes) Yes? Or, when I come to the workshops or ... things like that (INT - yes). But no, yeah I don't call or come to the school, you know to find out ... I would love to come (laughs) and hide you know somewhere and see what they do but you know you can't (laughs). (Irene, 154 - 162)*

Irene appreciates direct communication because Joel is currently non-verbal. She will stick to the ways school have told her to contact them, which perhaps suggests that she feels this is a firm boundary school has set about the parameters of their communication. Irene will communicate about basic wellbeing in the book e.g. he's not drinking, and she values knowing about this from school:

*That's one of my main issues cos I always write in the book "I notice that he didn't drink" and they say "we try, we try, we try" (Irene, 655 - 658)*



In the following excerpt, Layla describes hearing staff's interpretation of Hasan's challenging behaviour, which is regularly experienced by school staff as well as by Layla at home. Layla describes being offered an interpretation of Hasan's behaviour where it is suggested that his positive attachment to her may underpin his difficult behaviour, which is an empowering reframing of what Layla has described elsewhere in her interview as his exhaustingly challenging behaviour:

*apparently he's, he's more controlling to the people that he's closest to. So out of all the teachers, if she leaves the room he looks for her, apparently (INT - yeah). And he gets her picture, and he kisses her picture and he sort of misses her (laughs) (INT - yeah). And that's the same with me because with his Dad, although he tries to be controlling with his Dad, and his Dad sort of doesn't let him. He, he sort of gives up, a little bit. But with me he's very forceful and he has to be controlling (INT - yeah). So she said, you know, he's very close to her, it's, you know it's, the people that he's closest to is the one that he challenges the most (I -mm), that's Hasan. So they've really have sort of figured out his behaviour (Layla, 591 - 602)*

Louise also gives an example in the excerpt below of how school's information about her child can enrich her understanding of Rachel:

*so hearing about how she, um, interacts with the other children is quite, quite interesting. Um... and er, builds up how, you know, erm, our... knowledge of her. Cos, you know as a parent you get, you always get one perspective of your child (INT - yeah) but, um, they can always be quite different in different environments (INT - mm) so... yeah she's, it's um, er, it's ...er, yeah it's quite interesting hearing all the little stories.(Louise, 476 - 482)*

For Louise, the fact that staff care about and want to get to know Rachel is important, and I wonder whether she likes the fact that they have made an effort in creating this book, as well as enjoying the finished product. Like other participants, Louise highlights the value of hearing from school staff what Rachel has been doing as Rachel is unable to communicate this directly herself.

When she talks about the target setting purpose of these meetings, Louise becomes quite vague:

*So, it's, it's sort of, and then, and sort of and then, and sort of wor/you know, working out what they were going to do, next, like try and address...(INT - yeah) the next, the key.. sort of, what do they call them? Um...er...you know the sort of things that they aim for, I can't remember the term (INT - yes)(unclear) but you know sort of, yeah goals for Rachel (Louise, 161 - 166)*

I wonder, very interpretatively, whether this is because target setting is not a priority for Louise at the moment - elsewhere in her interview she has particularly emphasised the value she places on Rachel's wellbeing, and staff understanding her as a whole person in order that she is able to feel valued and accepted at school - this stance perhaps could be construed as the result of the year in a mainstream classroom which Rachel experienced prior to joining the Abbey Road unit, as Louise talks about this experience as being very difficult as she perceived that Rachel was not accepted by staff.

Another possible reason for Louise's sudden faltering when talking about target setting might be that it is linked to her ongoing reflection on what Rachel's diagnosis might mean for her progress in the future. Louise spoke reflectively about her hopes for Rachel to make progress, particularly with her social communication skills, and is clearly and understandably anxious about Rachel's progress in the future not being predictable. Very speculatively, these issues - which relate to the 'whole complex thing of autism' - might be difficult to raise apropos of nothing in a parent meeting where time is limited and it might not feel appropriate for all parents to raise such 'big questions'.

Jenny seemed to really value coming into school to see first hand the teaching activities which are utilised by the school. She is enthusiastic when describing the 'attention autism' demonstration, and describes the underlying learning goals of the activities.

*JENNY - I mean there's certain activities and to their sort of, er, they show things by experiments as well, like er, using their, for example their umbrella went... put the water on it, and to say the right words for that. So the children know what that, learn what that word means (INT - mm) and they do quite a lot of things to show children by experience as well. And it's quite good.*

*INT - so those experiences, rather than just...*

*JENNY - no, no they do quite a lot of activities like that (INT - mm). Scientist things as well, for example, they showed us how, um, with the bottle with the, some soft drink? And they put some salt in their, some sand, and other ingredients and it just splits away (INT - mm) so, it makes things quite more interesting for the children, they, they find it more, more interesting and they pay more attention to that sort of things. (Jenny, 67 - 80)*

Jenny also values seeing videos during parents meetings and highlights that Martha can't explain to Jenny what she has been going at school. When I ask if she goes to the parent's evenings Jenny's laughing 'yeah, every time' response suggests that she wouldn't dream of missing one. She emphasises again the importance of attending resulting from Martha's communication difficulties meaning that they cannot talk about what she is doing at school - in terms of the progress she is making or the activities she is taking part in.

Jenny also values direct communication in the home-school book in order to ensure that Martha's basic needs are being met, as at the time of our interview she and school staff are doing some joint information sharing and problem solving around Martha's eating. Jenny also mentions that she finds out Martha's emotional state in the home school book.

*I had a home-school book, and the teacher was every day writing whether, what she was doing, whether she was fine or was upset or... (Jenny, 451 - 462)*

Jenny clearly values hearing from staff about how Martha is getting on at school, but unlike the other mothers interviewed she doesn't write in the book herself. Jenny does not state why this is, though perhaps this is due to her lack of confidence in English or the type of relationship she has with school staff.

*INT - what kind of thing do you write, or does the school write? Do you both write in it?*

*JENNY - I don't really do the, write too much to the school, but schools, they give me the information quite, every day? Was she happy, or was she upset about something, er, what activities that she's making, yeah. (Jenny, 581 -586)*

It is clear that Jenny's choosing not to write much in the home school book is not due to her not finding it helpful however as the following quote illustrates:

*it makes me feel, erm, I'm checking her book as straight when she's coming from the school, so I find it interesting (INT - yeah). What she's been doing, how was she at um, or she's bad mood or was she okay? It's' very helpful. (Jenny, 589 - 592)*

Helen also values the home school book for finding out practical information such as if Thomas has been naughty or hurt himself. She also, unlike some other participants, mentions the home school book's function in terms of letting her know what Thomas has been learning, which is something Anna has also mentioned wanting more of.

*actually when he gets home, the first thing he would do is to get out the home-school book and show it to me (laughs)*

*INT - oh really? That's interesting. So it's his way of saying "look Mum..."*

*HELEN - Yeah, and it/ that's when he's been naughty though (INT - oh really?) when he's been naughty, yeah, he will bring it out and point it to me, and say "right, so that's what you've been doing, yeah". (Helen 318 - 332)*

Interestingly Thomas is the only child mentioned by parents as directly using the home-school book himself. Helen reports that he will show it to her straight away when he comes home, especially if he has been 'naughty', and therefore the home school book is directly facilitating Helen and Thomas's communication at home. Helen appreciates having a daily update about what Thomas has been doing, and

comments that she very much missed this when he previously was in a mainstream school when she 'didn't have a clue what he was learning'.

*when he was in the mainstream I didn't have a clue about what he was learning (INT - yeah) I didn't know at all. But in the unit, I am always updated about what he's doing a/every day. Every day. (Helen, 340 - 345)*

Anna stresses the importance of good home communication and like the majority of participants is generally pleased with the level of direct communication offered to parents by the provision (a daily home-school book, termly progress meeting and occasional workshops). She comments that "they write me an essay every night, and I write them an essay back" in Matthew's home school book.

*I would like to know more about ... the detail of Matthew's working day, at school because obviously ... he comes home and tries to tell us things (INT - mm) and we, we don't know what book he's talking about or (INT - yes) we don't know how/ and that can be frustrating. (Anna, 182 - 186)*

Anna also appreciates parents evenings and the opportunity to see Matthew's work, ,as he 'does things at school that he won't do at home' , and therefore by attending meetings, watching videos and seeing photographs she gains insight into Matthew's world which she wouldn't otherwise have access too.

*There was a scrap book together of all his work during the year and I was just, my jaw just was on the floor, because he'll do things at school, that he won't do at home. So, he's actually, academically progressed far further than we'd thought because the little bugger won't do it at home! (Anna, 214 - 218)*

Anna spent a considerable amount of time during the interview describing the consequences of times when the communication with her has not felt adequate. Initially she gives an example of wishing that she had more information about Matthew's learning. However at another point in the interview she describes an episode where she had not been aware that Matthew had been seeming quieter than usual in class, ,and that several of his classmates were "screamers" (516). At this time Matthew's behaviour at home had become particularly challenging and

extremely difficult to manage and this ultimately led to a distressing incident at home. This incident obviously profoundly affected Anna as she spoke emotionally and at length about it during our interview. Anna attributes this episode to school not discussing Matthew's wellbeing with her soon enough for them to jointly problem solve.

*a bit of me when/if I think back thinks "why did the school let us go through all that hell (INT –mm) for months on end, when if they'd talked to us" ... the minute she said there are three screamers , I said "that's it!" you know, he was going to school and it was a living hell for him (Anna, 513 - 517)*

Elsewhere in her interview Anna describes being very satisfied overall with the Unit's staff's willingness to support her, Matthew and the whole family ,and describes valuing staff's interest in how things are at home and offers of support, commenting that she considers this very generous as 'they were getting a little boy who was fine at school' In talking passionately about the benefits of the regular home communication that she has experienced and the consequences that she perceived as resulting from an incident of less effective communication, Anna confirms the comments of all participants about how especially important regular communication is to parents of children who are not able to communicate.

*ANNA - and one of the things we value enormously is the um ... the, the stress placed on good home/school communication. And supporting the whole family. And we've tapped into that we've had to because we've had some very dark times (INT - yes) and we've really needed that help and support as a family. And knowing that it was there has been very very important to our survival during some, particularly difficult periods. So, so knowing that they really mean it when they say/I mean a lot of places might say that. But Abbey Road really mean it (INT - mm) and, you know sometimes I'm fighting them off cos I'll say 'oh we've got this problem at home' – 'We'll come round!!! We'll sort !![.] I think we've got through about twelve home/school communication books, um ( I - wow) because, you know, they write me an essay every night. And I write them an essay back. (Anna, 163 - 180)*

Mothers described primarily learning about their child through direct communication initiated by the Unit. However a lesser theme which emerged was mothers valuing the contact with other parents of children who attended the unit, and also valuing

opportunities to observe other children, as this enabled them to make comparisons between others' experiences and their own, therefore perhaps reinterpreting their own experience and understanding themselves better. For Irene seeing children with more complex needs than she perceives Joel to have made her more appreciative of her son's abilities.

*But I think Joel is not too bad, you know. Because I've seen other children and you know, I think you know, even though there are many things, you know, that needs to be improve but he's not too bad, he's my little boy. So far (laughs) (Irene, 340 - 343).*

Louise also highlighted that she appreciated opportunities to compare her family to others in similar circumstances:

*it's quite interesting going to the seaside with all the other children, is, we've got a child with special needs but we don't know anyone else with special need, parents, other parents with special needs or how Rachel is the same or different (INT - mm) to those other children (Louise, 830 -834)*

#### **4.6.3 Subordinate theme 3c: 'Doing it my own way'**

In one strand of this theme, mothers describe feeling in harmony with the Unit's expectations for their child and choice of teaching approaches, and report valuing working in partnership with school for the benefit of their child. However, this section highlights that sometimes mothers prefer to 'do it their own way' with support from school, rather than rely directly on school for information and advice, and that mothers can find it impractical or even impossible to implement strategies used by the unit at home due to the demands of everyday life.

Jenny describes difficulties in implementing strategies at home due to other events in her life such as suddenly having to move house, and in general a lack of time.

*They suggested to, to do it, at home. But I didn't find it, no time, no time for it really. Because I've been going through quite difficult time when I was moving, and changing the home, everything, but hopefully I could manage it some way in the future. (Jenny, 238 - 244)*

Irene also reports difficulties in implementing strategies at home, but reports that "he found it a bit boring" because "I was too slow" - therefore Irene is blaming her own lack of skill on what she perceives as a lack of success. The fact that at the end of this quote Irene does concede that Joel had achieved the objective and that "he did copy what he was doing" perhaps suggests that Irene's feeling that the attempt wasn't a success is due to her lack of confidence rather than anything more hopeless:

*I wasn't as good as they were (laughs) so he found it a bit boring and like I was too slow for him you know, doing things (INT - aw) but I tried and he did, you know he did copy what he was doing (INT - mm), things like that (Irene, 443 - 445)*

Layla also reports struggling, and compares her circumstances when she tries to deliver teaching interventions to Hasan to school staff's circumstances, highlighting the fact that she is under considerable pressure.

*these girls you know, they're they're, this is their job, they're paid to do this (INT - yes), they can go home at the end of the day, whereas you know when I come, you know, when I come, you know, I dread, like, the holidays, and, I used to really dread the holidays (INT - mm). Cos even now, at the weekend, he's fine on the Saturday cos he's had a long week, but as soon as Sunday's and he's off for another day, he'll do whatever he can to seek attention like (INT - yes), do things, mess, you know, mess making ... whatever it is really. It's, it's a nightmare. (Layla, 930 - 936)*

Louise also reports difficulties in trying to provide learning opportunities for Rachel at home. She reports that

*I often think sometimes I should have researched more, and done more but it...er, er, you know, because... of our/my relationship with Rachel she just doesn't want me to, to act like that way towards her (INT - mm) um... you give up after a while, to/trying to..teach them and do stuff (laughs) (INT - mm) so, so I, I feel it's er, quite nice that, that, that, that you know she seems to... be happy with, erm, being taught by teachers if you know what I mean, so... aren't you? (to Rachel who has just come into the kitchen). (Louise, 264 - 271)*



Anna also describes a willingness to use school strategies, in this case 'attention autism' at home, but explains that for her this isn't realistic:

*They look it. You think 'ooh yes I could do that, I could get a box and fill it with rice and, flour and, put some spaghetti in, put red hair dye in it and 'yeah yeah yeah I can do all that! But (pause) it's not realistic. You're, knackered. [...] you don't have the time, the child's tired, cos he's been at school. You know, you don't have, you know your creativity takes a dive and, [...] you know other things happen like my Mother died, you know, lots/life has to carry on ( INT - mm) you know I, I have to work, you know, and much as you want to and are inspired by all the seminars, the reality is that it's very difficult to turn it into ... a, a you know something regular at home (Anna, 828 - 843)*

This quote from Irene follows her talking about how she is working in partnership with school to toilet train Joel. School staff had demonstrated their strategy, involving using a puppet, and had suggested she might like to try this strategy at home, but Irene comments:

*To do the whole song, you know, and the puppet and everything, it didn't work for me at home to do that? The way they do it here? I just didn't/ I didn't even try to be honest maybe it would have worked. But I just don't know I'm not going to do that. I just did my own way (Irene, 411 - 415)*

Irene also gave an example of where she worked in partnership with the Unit by encouraging Joel to cook at home after realising from feedback from the Unit that Joel enjoyed messy play. Rather than directly trying the activities school utilised Irene extrapolated from this new information that Joel would enjoy cooking, and therefore combined her learning from the Unit with her own ideas about activities she would like to do with Joel.

*IRENE - Yes, yes I was quite surprised that he was able to do so much, you know. Cos I don't let him do things like that at home, you know, taste things like he does here you know, messy play, like, you get flour in his things, and colours, you know, but now I know that he likes it (INT - mm), and that he can do it so I ... I went and bought things like, you know containers to do with him. And, and (INT - yes) you know like I said he knows that he can, you know, do the scrambled eggs, he gets the butter and puts it in the pan, he knows (I -yes) how*

*it goes, what you have to do (INT - yes) (laughs), so it's quite nice to see him doing that. (Irene, 786 - 795)*

Louise comments that she finds it logistically difficult to carry out teaching activities with Rachel at home, but finds the positive in this by wondering whether by doing "homey things" rather than educational activities with Rachel means that the home environment can complement, rather than imitate the environment experienced by Rachel at school.

*you know whereas at school it's much easier to sit her down and play with play dough, or sand and, you know do those things that help develop their mo/fine motor control (INT - yes) and er, I think they're very aware of just of the fact that you know it's hard work for the parents and trying to sort of, you know, school is for learning and doing all those things and, and, and the parents, you know they get their children back at the end of the day and it's, it's time just to be with the child, you know, to, to, be at home and do homey things. (Louise, 748 - 756).*

Louise's comments throughout our interview suggested to me that perhaps Rachel does not demonstrate such disruptive behaviour at home as the children of some other participants, and it is possible that Louise's valuing of more "homey" experiences at home, which to me suggest a restful atmosphere, might be related to Rachel's relatively easygoing personality.

In the quote below, Helen reports that she works in harmony with the school by encouraging Thomas to complete his homework, she comments that he responds to 'everyday' parenting strategies sufficiently well that she does not need to use specialist strategies.

*INT - So you don't feel you need, you don't use any particular, any visual timetable or countdown or anything like that, just, just being firm.  
HELEN - Yeah, just being firm. "You've got homework Thomas, you've got homework. Come and do your homework", and then he would come. (Helen, 426 - 443)*

Anna was unique amongst my participant group in being very committed to running an intensive therapeutic programme (Son-Rise) with Matthew at home. Here she comments that although she doesn't anticipate using teaching approaches used by school at home, it is very important to her that the Unit's approach "chimes" with Son-Rise:

*we do a home learning programme at, at, home, called Son-Rise I don't know if you've heard of (INT - I have, yes) okay, well we run a programme at home. And, er, thank God, you know, Abbey Road has an approach that isn't Son-Rise but it, it, it chimes with the sort of values and ideas of Son-Rise (INT - mm) so for example they believe in um ... harnessing, um, stimulating behaviours instead of just trying to stop them (INT - mm) and recognising that there's a point to them. (Anna, 130 - 137).*

A strong theme for Anna was her changing relationship with the Unit staff as her own knowledge and understanding of autism grew through her own research and reading. She reports elsewhere in our interview that when Matthew first came to the provision she relied a great deal on the advice of Unit staff regarding using specialist teaching approaches such as symbols and visual timetables to enable his behaviour to be more manageable. In the quote below she comments on the personal journey she has been on since this time, and how she has assimilated information from so many sources that she seems to be developing 'conscious competence' in her understanding and management of Matthew's difficulties:

*INT Is that an approach that you kind of made or adapted yourself? Do you feel like you'd taken an approach from Abbey Road and sort of made it relevant to your...*

*ANNA - I don't think that's from Abbey Road. It's from everything I've learnt I mean I've, you know I did an early bird course, I've done three Son-Rise courses, I've been to (The Local Authority) autism things, I've been to one-off lectures I've read books/so, to be honest (pause) it's a sort of culmination of all these ... sources (INT - yes) not just Abbey Road. (Anna, 802 - 810).*

## 4.7 Summary

To summarise, participants' experiences of engaging with the specialist unit were often very diverse, but some key themes have been presented above which represent aspects of all the participants' experiences. These main superordinate themes related to valuing acceptance from the unit's staff, deciding on what expectations in terms of teaching and learning whilst making sense of their child's ASC diagnosis and of learning about teaching approaches and about their child as a result of engaging with the unit, whilst also learning about what worked for them in terms of parenting their child.

In the following chapter these findings will be discussed with reference to the research questions presented earlier in this thesis. I will also consider how these findings relate to the extant literature and will consider their possible implications.

# 5. Discussion

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## 5.1 Overview

In this chapter I will firstly summarise and discuss the findings presented in the previous chapter with reference to the literature reviewed in Chapter 2. The findings will then be considered with reference to three theoretical traditions which were chosen after the analysis had been completed and themes had been identified: person-centred and positive psychology perspectives, personal construct psychology and theories of adult learning.

Following a discussion of the limitations of this research, the exploratory research questions given at the outset of this thesis will be returned to, in order to evaluate the extent to which the findings can provide answers. The impact and implications of this research will then be reviewed in terms of recommendations for future research and implications for educational psychologists. A brief personal reflection on the research process will then lead into some final, summative comments regarding the purpose, methods, findings and implications of this research. These comments will conclude this chapter, and this thesis.

## 5.2 Discussion of findings in reference to the published literature

Each superordinate theme is discussed in turn below, with reference to findings in the literature reviewed in Chapter 2.

### 5.2.1 Discussion of superordinate theme 1, Valuing acceptance ('the children were clearly loved')

Findings from this first theme demonstrated how the mothers interviewed engaged with the unit through looking for signs that their child was accepted by staff.

Superordinate theme one, which described how mothers valued evidence they directly and indirectly sensed of a compassionate and child-centred approach to teaching, suggested that mothers' concerns and in some cases previous experience of their child being rejected by staff due to social stigma about learning difficulties and developmental delay informed this priority.

Subordinate theme 1a (He's happy to go to school, so that means it's good), described how Mothers closely monitored their child's behaviour at home, inferring that calm and content behaviour, or spontaneously getting ready for school were indicators that their child felt a sense of belonging at school. Stoner *et al.*(2005) reported a similar finding in their qualitative research, which they attributed to parents' distrust of professionals, and to the fact that like the children of parents in the present research, the children were non-verbal and unable to tell their parents about their day directly. The latter explanation for parents' curiosity about school certainly is supported by the present research, as all participants explicitly referred to them having to find out about their child's experience indirectly.

However, there was little support in this research for the former finding in Stoner *et al/s'* research, that a lack of trust in school staff was a key driver for parents in their quest to understand more about life for their child at the Abbey Road Unit. In fact this phenomenon could be explained with reference to the importance of their child being accepted and valued for participants, as outlined in superordinate theme one, as mothers may wish to understand their child's experience at the Unit in order to better understand and empathise with them, which are perhaps less easy goals to achieve when parenting a child with a social communication difficulty.

Mothers demonstrated that they were highly sensitive to staff members' attitudes to disability and learning difficulties (Subordinate theme 1b: The teachers like them and don't judge them), and looked for evidence that the teachers would take their child's challenging behaviour or delayed developmental needs in their stride, accepting their children for who they were rather than comparing them negatively to neurotypical children. Several Mothers described the warm, loving relationships that they perceived between staff members and their children, and clearly felt these positive relationships were very important.

This finding echoes Whitaker's finding (2007), from his UK based research which is discussed in the literature review that parents' reported placing most value on teachers understanding their child, rather than on teachers having any specialist expertise. Whitaker frames this as low expectations on the part of the parents he surveyed. However, participants' comments in the present study illustrate how powerful it can be to have a sense that your child's teacher appreciates and accepts your child, if previous experiences have been of your child being judged and rejected. This finding could be framed as a perceived duty on the part of parents of children with complex ASCs to be particularly vigilant and protective in safeguarding their child's emotional wellbeing, due to their vulnerability resulting from their difficulties associated with their diagnosis and societal judgement about unacceptable needs or behaviour.

The final aspect of superordinate theme 1 which was explored was the ways in which mothers described their interest in personalised learning strategies for their children which would find a way around their difficulties and enable them to reach their potential. (Subordinate theme 1c: All these lovely characteristics are allowed to flourish). A perception that staff were interested in their child's academic development and were teaching in a way that suited their child's learning style seemed to be a powerful affirmation that their child was as entitled to be nurtured as any child.

In this theme, mothers often made reference to valuing some of the features of the specialist unit which distinguished it from a mainstream school. In particular several mothers reported feeling that the small class sizes and high staff ratios enhanced staff's ability to enable personalised learning. Mothers also spoke positively about the social inclusion that they perceived resulted from all children in the class having similar needs and it therefore being possible for them to be taught together.

Several articles discussed within the literature review for this research investigated the degree to which parents of children with autism were satisfied with special or mainstream educational provision (e.g. Kasari *et al*, 1999, Moreno, Aguilera and David, 2008, Whitaker, 2007, Dymond *et al*, 2007). Although these findings say something about the aspects of specialist educational provisions which mothers may

find most valuable, it would not be possible to make a generalised prediction that most mothers' of children with complex ASCs would find these aspects of specialist provisions desirable. Several of the mothers in the present study had had negative experiences during their child's placement in a mainstream class which had led to their decision to enrol their child at the Abbey Road Unit, but it is of course likely that there are other groups of mothers who have had equally positive experiences of their child being in mainstream.

### **5.2.2 Discussion of superordinate theme 2, Uncertainty towards setting expectations, and 'the whole complex thing of autism**

Superordinate Theme 2 described the process Mothers engaged in of deciding what their expectations and goals would be for their child, as well as for the Unit. Subordinate Theme 2a: The whole complex thing of autism, described their expectations in terms of how having an Autism Spectrum Condition would impact on what they expected from their child's attendance at the Unit. Mothers reported varied understandings of the nature of autism, which impacted on their expressed priorities for teaching and learning. These included two mothers (Anna and Layla) seeing autism related difficulties as being potentially very treatable with specialist therapies not available at the specialist Unit, possibly leading to less investment in learning targets set at school. Louise also spoke of her hopes that her child's autism related difficulties could dramatically improve in the future, but also spoke of her fears that they would not, therefore conveying her sense of the unknowableness of autism, and therefore perhaps of appropriate learning targets for her child.

Discussion of how parents' understanding of the nature of autism might impact on the way in which they engaged with their child's education is scant within the body of literature reviewed in Chapter 1. Parsons *et al.*(2009) concluded that contrary to popular belief, parents of children with ASCs want very similar things from their child's educational provision as parents of children with other SENs. The findings from this research indicate that this may not be the case, and that the distinctiveness of autism in terms of its unknown aetiology and impact over time on specific individuals can be a powerful influence on parents' hopes and expectations



for their child's learning, and the ways in which they engage with their child's education.

Mothers mentioned an array of different types of learning goals for their children (Subordinate Theme 2b, Weighing Up Learning Priorities) which included those related to basic skills such as toilet training, language and social skills (i.e. skills relating to the specific difficulties associated with ASCs), skills for learning such as developing attention and concentration, and developing academic skills such as literacy and numeracy. Mothers often gave a list of assorted learning priorities which fell into a range of these categories, suggesting that it was sometimes impossible to choose a main learning target to focus on. The extant research into parents' learning priorities for their children suggests that social skills, language skills and improved behaviour are desired targets for many parents (Spann, Kohler and Soenksen, 2003, Whitaker, 2007). The current research illustrates that although parents may be willing to sort learning targets into a hierarchy of importance, this is not the whole story. Parents' experience of the process of deciding on priorities is not straightforward, as many different, equally valuable learning targets compete for their attention.

Finally Subordinate Theme 2c Being Unsure How Much To Ask For outlined the expectations held by mothers of what the Unit should provide, in terms of physical and learning resources such as the state of the building, the provision of certain teaching strategies or in terms of the perceived quality of education and care provided for their children. A recurrent motif of this theme involved participants describing an aspect of their experiences of the provision which they seemed dissatisfied with, but then articulating uncertainty regarding whether their dissatisfaction was reasonable. It could be that this hesitancy on the part of several participants to wholeheartedly convey elements of dissatisfaction was due to the context of our interview. Awareness of the possibility that their comments may be relayed back to the Unit as part of this research's overall findings may have led them to censor themselves. However another possibility, is that in the majority of cases, this vacillation between offering criticisms of, and then excuses for features of the Unit or incidents which my participants had found troubling, represented their ongoing sense-making of what they could expect of the specialist unit.

### **5.2.3 Discussion of superordinate theme 3, Learning from the Unit and doing it 'my own way'**

Superordinate theme 3 described how mothers engaged with the Unit through learning about teaching strategies, using a variety of direct communication methods to exchange information about their child with Unit staff and through considering the relevance of advice and strategies used by the Unit to their parenting role at home.

In Subordinate theme 3a: Learning about teaching strategies, mothers described learning about a variety of teaching strategies used by the Unit. These included some complete teaching approaches (Attention Autism (thought this was often described rather than named), PECs and TEACCH), some strategies derived from these approaches (visual timetables, social stories and using symbols to support communication), and some other autism-sensitive approaches (using puppets as visual prompts to use as part of toilet training – described by Irene), and giving a child regular 'time-out' to de-escalate anxiety – described by Anna).

An additional way in which two mothers made sense of the specialist strategies used in the provision was in relation to their interest in therapeutic approaches which are not offered by the provision, which mothers were aware of through their own research. For Layla, an interest in the possibilities of Applied Behavioural Analysis seemed to eclipse any theoretical interest she might have in the strategies used at the provision. Anna described practical difficulties in trying the Attention Autism intervention, which can be quite messy, at home, but her family's commitment to the Son-Rise programme might also mean that she feels that her need for strategic ways of working with Matthew at home is fully catered for.

The extant literature reviewed earlier does not touch specifically on the consequences of parents' 'infidelity' to the teaching approaches offered by their schools and how this might impact on their interest in the school's own activities, but this was a common finding in the present research, with four mothers mentioning having some interest in trying approaches which would be out of the school's remit to be involved with. Grey, Lynn and McClean (2010) does describe parents feeling that they are more knowledgeable about autism and related teaching strategies

than professionals, though, except perhaps for Anna (although she did not explicitly comment on this) this did not seem to be the case for participants in the present research.

Direct contact with the provision was an extremely common way that mothers engaged with the specialist unit (Subordinate theme 3b, Learning About Child Through Contact With The Unit). All participants spoke of using daily home-school books, which were written in either mutually or largely by the school. Other ways Mothers directly engaged with staff at the specialist unit were, in order of frequency, attending progress review meetings, attending parent training workshops, going on school trips and telephoning staff members. Mothers described taking particular pleasure in videos, photographs and books prepared by staff. This was due to their relatively limited access to knowledge about their child's experiences at school due to their child's communication difficulties. This finding supports previous research which has highlighted the extent to which parents of children with ASCs value direct communication (Renty and Roeyers, 2006; Stoner *et al*, 2005; Whitaker, 2007).

All participants had knowledge of at least one specialist teaching strategy used by the Unit and all had received support and advice about how to manage their child's behaviour or facilitate their learning at home in the past, or were receiving such advice or were hoping to receive it in the future (Subordinate theme 3c, Learning To Do It 'My Own Way). Although mothers talked about receiving this advice in generally positive terms, participants also were forthcoming in highlighting that although they were interested in learning about strategies used at the provision, trying to replicate the way in which these strategies are used at the provision in the home was not always felt to be realistic or practical. However several mothers reported interest in adapting strategies for home, or using them as a starting point for their own ideas.

Staff at the unit reported a perception that mothers often do not seem to implement strategies at home which they have encouraged them to use. The findings described by this subordinate theme suggest that mothers are interested in learning about strategies, and have appreciated doing so, but perhaps would respond to a personalised approach which begun with exploring the principles behind the

strategies, and enabling mothers to develop their own adaptations of strategies which fit with their own interactional style and home circumstances. Research by MacMullin *et al.*(2010) suggested that a negative correlation exists between parents mental health and their ability to engage effectively with their child's school. Although the present research did not investigate mental health difficulties, mothers' descriptions of the challenges of parenting a child with autism highlight the importance of staff being sensitive and flexible when suggesting teaching strategies that could be transferred to home learning.

### **5.3 Theoretical perspectives on the findings**

Three theoretical perspectives are presented below, with consideration of how they might enable the interpretation of the findings to be taken further. The theoretical perspectives chosen for discussion are drawn from person-centred and positive psychology, personal construct psychology and theories of adult learning. These perspectives are considered in turn with reference to superordinate themes 1 ("the children were clearly loved': seeking acceptance), 2 (Uncertainty regarding expectations and 'the whole complex thing of autism), and 3 (Learning from the Unit, and doing it "my own way') respectively.

As will be seen, all three theoretical perspectives discussed highlight the value of understanding the subjective realities of others. Firstly through endeavouring to understand and accept other's experiences as fully and as non-judgementally as possible in order to help them (Rogers, (1961), secondly through appreciating that different people have different understandings of the same object, for example, in this research mothers held diverging understandings of what the specialist Unit should be expected to provide (Kelly, 1965), and finally in considering theories of adult learning and how they can be applied to the meaning-making activities that mothers' report engaging in.

It is important to restate at this juncture that the ontological and epistemological orientation of this research is towards the privileging of subjective experiences. Therefore it is not surprising that the findings constructed from the data emphasise the importance of participants' subjective experiences in terms of how they engage

with the specialist Unit for autism. This in itself is not a finding. The findings relate to the particular nature of these subjective experiences, what they mean for the participants and for the impact of this research. The 'goodness of fit' of these particular theoretical lenses with the data arises because they similarly privilege a subjective epistemological position.

### **5.3.1 Person-centred and positive psychology**

The person-centred tradition in psychology originates from the development of a client-centred therapeutic approach by Rogers (1961). A key concept in this approach was Roger's assertion that the therapist should wholeheartedly demonstrate an "unconditional positive regard" for the client at all times, regardless of the idiosyncrasy or undesirability of the client's behaviour or expressed views. The importance given by mothers in this research, outlined in superordinate theme one, to their child being accepted and loved by school staff, and enabled to flourish, is echoed in Roger's belief that "when I can accept another person, which means specifically accepting the feeling and attitudes and beliefs that he has as a real and vital part of him, then I am assisting him to become a person" (Rogers, 1961 p.21).

Mothers may particularly value a perception that school staff have an attitude of unconditional positive regard because of previous experience of, or fear of stigma from education professionals, as described by several mothers. An additional possibility is that Unit staff, who are comfortable and familiar with children with complex ASCs are able to model an attitude of unconditional positive regard for mothers, so that mothers can see firstly that others are able to accept their child's difficulties and enjoy their positive qualities, and secondly mothers can have permission to enjoy their child themselves, rather than feel they should make excuses or apologise for their child's difficulties. It is also possible that through their children, the mothers also experience this feeling of positive regard, and feelings of pride and enjoyment in their child

Linley, Maltby, Harrington and Wood, (2009) have proposed that the person-centred approach developed by Carl Rogers challenges the "illness ideology and medical model" that is implicit in much of psychological thinking. This reflects two mothers'

reports (Anna and Louise) of a contrast between their negative experiences of medical professionals when their child was first diagnosed, as well as negative attitudes of some staff at previous schools, with the positive and accepting attitude they report experiencing from staff at the Unit.

Positive psychology is a recent branch of psychology which studies human strengths as a counterpoint to the subject's traditional focus on difficulties and disease (Boniwell and Hefferon, 2011). The origins of positive psychology can be traced back to the client-centred therapy developed by Rogers (Linley *et al*, 2009). Positive Psychology is a new and fast-growing movement which currently encompasses a large number of theories and applications, some of which have been educationally based (Boniwell and Hefferon, 2011).

Of particular relevance to this research are four characteristics of 'positive schools' developed by Huebner, Gilman, Reschly and Hall (2009), which bear striking similarities to the values encapsulated in superordinate theme 1 of this research. Firstly, Huebner *et al.* highlight the importance of subjective wellbeing for academic performance, and state that in a 'positive school', emotional wellbeing is prioritised. This echoes Anna's description of the Unit's implementation of specific strategies to promote Matthew's wellbeing, which have resulted in him doing much better in school.

The second of Huebner's characteristics of a 'positive school' is that schools work hard to ensure a 'goodness of fit' between the child and the school environment in order that not only are any difficulties experienced by the student supported, but equally importantly their personal strengths are recognised and are enabled to develop. The authors comment "students are more likely to be satisfied with their schooling if they are treated as persons with strengths who are inherently capable of growth" (p.565). This closely mirrors the importance mothers placed in the current research in their child being given opportunities to flourish (superordinate theme 1c).

The third characteristic of a positive school is that the development of positive teacher-student relationships is prioritised; this was emphasised by many mothers in the present research (superordinate theme 1b). Finally, Huebner *et al.* describe the

curriculum in a positive school as intrinsically motivating, intellectually engaging and enabling students to socialise. These features are all spoken about by mothers' in this research when talking about the Unit's 'attention autism' intervention, which includes visual activities which are designed to be exciting (highly motivating), highly practical and hands-on (intellectually engaging), and designed to enable children to experience joint attention in a group (opportunities to socialise).

It is interesting that when mothers spoke in superordinate theme one about their particular valuing of staff's positive regard for students and the enabling of their child to have the personalised learning opportunities which would enable them to flourish, these were often spoken about in the context of the child attending a specialist provision. An assumption was often made by mothers that the nurturing atmosphere they valued would not and perhaps could not reasonably be expected to be a priority in a mainstream setting. However, Huebner's characteristics of 'positive schools' suggest that all schools should prioritise these features.

### **5.3.2 Personal Construct Psychology**

Personal Construct Psychology (PCP), developed by Kelly (1965), is an approach to modelling how individuals make subjective sense of the world. It is an approach which emphasises the differences of each individual's subjective experiences of the world, and posits that we must not assume that objects, concepts or ideas hold the same meaning for us as they do for others.

PCP is potentially useful in understanding the uncertainty which mothers' described experiencing in superordinate theme 2, in terms of the meanings they made of autism, of setting learning priorities and of the specialist Unit itself. A central concept of PCP is that of the 'construct' - a 'building block' of how an individual makes sense of the world (Beaver, 1996). Every construct is paired with its opposite, and this combination of paired constructs might also be unique to an individual.

An example of how the application of PCP might be used to illuminate the findings of superordinate theme 2 is in understanding Layla's construct of the teaching strategy

Applied Behavioural Analysis. A quote from her interview where she is discussing this is given below.

*ABA is, I've been told by the person who's actually, you know, been reading up on it, um, it is effective for most children they say (INT - mm). So why, I don't know why the (a local GLD ASD special school) don't do it either. And The Unit's not doing it, can they not just try, at least, to do it and to establish it? It's just ... but really it's sad cos you feel like as a parent that they, they're not really doing everything that they say they are. (Layla 748 - 755)*

From her account above, Layla's personal construct of what is "effective for most children" with ASCs seems to be ABA. Therefore it could be extrapolated that her personal definition of this construct's opposite – of what is "not effective for most children" with ASCs, might be strategies which are not ABA.

This consideration of Layla's comments about ABA in the light of personal construct psychology enables a greater empathy with Layla's perspective, and suggests one way of understanding the ambivalence Layla expresses towards the Abbey Road Unit and the strategies used there. Layla may resolve this ambivalence by eventually securing access to ABA for her child. Alternatively, in the light of new experiences in the future she may revise her personal construct of what is "effective for most children" to incorporate other strategies, and thus become more consciously interested in the strategies used by the specialist unit and more satisfied with Hasan's current educational placement.

A key feature of PCP is Kelly's development of a philosophical position termed "constructivist alternativism", which stated that we should regard our interpretation of events as constantly open to revision or replacement in the light of new information or circumstances. Kelly asked that we remember that "the universe has no allegiance to any one personal interpretation of it" (p.76). This is very salient to the uncertainty which is a key feature of mothers' experiences described in superordinate theme two (Uncertainty about expectations and the whole complex thing of autism), which suggests that the many constructs which relate to their experiences of engaging with the specialist unit have the potential to be revised and redefined as time passes.



### 5.3.3 Theories of learning

Superordinate theme 3 (Learning from the Unit and 'doing it my own way' highlights the experiences of learning which participants implicitly and explicitly describe in their accounts. Theories of learning can be broadly categorised as being oriented in the behaviourist, cognitivist, constructivist and humanist traditions. Although theories of learning are most commonly applied in psychology to explain the learning processes of young children, they have also been applied to learning in adulthood (Pritchard, 2009). The ongoing personal meaning-making which participants are engaged in which is demonstrated using personal construct psychology could be conceptualised as a learning activity. The humanist perspective explored above might also be relevant to the participants' experiences of learning. Mezirow's transformative theory of learning, which has profoundly influenced understanding of the nature of adult learning since its inception in 1978 (Kitchenham, 2008) defines adult learning as a process which results in a "dramatic, fundamental change in the way an individual sees the world and himself or herself" (Malone, 2003, p.299). The transformational emphasis of this theory mirrors Anna's remark that for mothers of young children with autism "your learning curve is immense" (Anna, 646).

Learning is often thought about as something which only takes place within an explicitly educational setting. However, learning also takes place outside of formal learning institutions, and can be considered a natural occurrence in everyday life for adults, just as it is for children. Sandlin, Wright and Clark (2013) argue that dominant cognitive and humanist discourses of adult learning are missing a focus on adults and the wider culture in which they live, for example popular culture and informal cultural institutions. The authors propose that "the popular culture has powerful effects on adults' worldviews and should thus be examined as a legitimate arena of adult education" (p.8). This is relevant to the participants in this research, who in having a child diagnosed with autism who attends a specialist provision are having a minority experience which is not widely represented within popular cultural discourse. Normative heuristics for managing the demands of parenting young children and engaging with their school are widely dramatised and documented through all media channels, but for the mothers in this research, these portrayals do not wholly reflect their experiences.

## **5.4 Limitations**

### **5.4.1 Interviewing only mothers**

A possible limitation of this research is the exclusion of fathers from the participant group. I was particularly concerned about this in the early stages of this research, partly because I was aware that in general, mothers of children with learning difficulties are quite well researched and I felt I may be contributing to this bias of privileging mothers narrative within the research corpus, as well as being complicit in the assumption that mothers experiences are bound up with their children's experiences in ways that fathers somehow aren't, or should not be. However on examining the extant literature it became apparent that within the narrow field of enquiry related to this thesis, mothers' experiences have not been qualitatively examined to any great extent.

Furthermore, it is recommended for interpretative phenomenological analysis that participants form as homogeneous a group as possible (Smith, 2009), and bearing this in mind, it seemed prudent to aim to collect a participant group that comprised all mothers or all fathers. The Unit Manager advised me that mothers of children attending the Unit were routinely her primary contact, and given my concerns about recruiting sufficient numbers of participants, it seemed justifiable to make mothers the focus of this research.

### **5.4.2 Interviewing participants whose children are from the same provision.**

Something I did not foresee at the onset of the research process was the ethical, and therefore methodological challenge that would result from interviewing participants whose children all attended the same provision. I had collected some basic demographic details from participants with the hope that I might explicitly report these in my analysis in relation to divergences and convergences in my participants' accounts. However I quickly realised that revealing these details and discussing them at any length would increase the ease with which participants

would be identifiable to each other or to professionals known to them if they were to read this thesis. This was particularly pertinent bearing in mind that in this age of electronic accessibility, theses which might otherwise be accessible only through a visit to a library are just a mouse-click away. Another consequence of my being mindful that participants may be identifiable to a small circle of potential readers is that care has been taken to limit the amount of raw data and initial exploratory comments in this thesis which would have provided a fuller representation of the analytical process (though these are included on the attached Compact Disc). On balance, I feel that there are significant advantages resulting from my participants coming from the same provision however, as it served to homogenise their circumstances to the greatest degree.

### **5.4.3 Carrying out IPA as a new researcher**

Another factor which could be considered a limitation to this research is my own status as a newcomer to Interpretative Phenomenological Analysis. I found it fascinating to learn about this methodology and to conduct IPA research myself, but was mindful during the analytical process that perhaps even more than most qualitative methodologies which allow the researcher a degree of creative interpretation and engagement with the data, I often felt that the potential scope IPA has for a deep interpretative engagement with the data, and the methodological interpretations of its complex theoretical underpinnings, were things I have only experienced the 'shallow end' of. After giving some examples of the interpretative depths that are possible using IPA, Smith, Flowers and Larkin (2009) remark that such accomplishments are "quite sophisticated and we wouldn't expect a novice IPA analyst to be working at this level [...] yet we would hope that as researchers become more confident and experienced that they can push the interpretative side of their work further (p. 106) which is somewhat reassuring. Nevertheless I find it intriguing to consider what an experienced IPA researcher might have made of the rich data I have been privileged to work with.

#### **5.4.4 Interviewing participants only once.**

The participants in this research diverged considerably in terms of the length of time children had attended the specialist unit, which ranged from 10 months to 3 years and 2 months, and some participants, particularly Anna and Helen, alluded to their expectations of the specialist unit and relationships with staff shifting over the years. In order to explore this aspect of mothers' experience optimally, a longitudinal research design in which mothers were interviewed at recurring intervals over months or even years would have been preferable to the research design used here. Alternatively, a participant group consisting wholly of mothers whose children had attended the Abbey Road Unit for a number of years would have opened up an opportunity to ask every participant about their experiences of the Unit over time.

#### **5.4.5 Lack of generalisability**

The small size and homogeneity of the participant group in this research mean that it is not possible for findings to be generalised directly to other populations. In keeping with recommendations for good practice in IPA research (e.g Smith, 2011a, p.10), breadth of analysis from a wide range of participants from different backgrounds, was sacrificed in favour of carrying out a deeper analysis of a small number of participants from more similar backgrounds. It is hoped however that findings resulting from this deeper analysis, whilst not generalisable, can be useful in several other ways, including adding greater insight to similar but less detailed findings from other research in the same area, and conveying a sense of the diversity and richness of individual experiences of the research area to the research readership.

#### **5.4.6 Researcher bias**

Writing on qualitative research methodologies frequently highlights the inevitability of researcher bias influencing results, due to the analytical process comprising of a series of subjective judgements (e.g. Willig, 2008). The particularly free and interpretative analytical process which is a hallmark of IPA ideally requires a rigorously reflexive stance on the part of the researcher. Robson (2002, p.172)

highlights that the phenomenological researcher should endeavour to be as aware as possible of his or her inevitable and unavoidable biases which arise from his or her personal, social and cultural position in the world, in order that these can then be deliberately set aside ('bracketed'). The nature of doctoral research resulted in several factors intensifying the degree of my own bias in this research. These included my being the sole researcher, therefore responsible for both collecting and analysing data, an outcome focussed need to produce findings which fit my own assumptions regarding what was appropriate for doctoral research, and the context of the specialist provision within the local authority in which I worked as a trainee educational psychologist, which may have confused my participants' perceptions of my role, as well as influenced my perception of the provision. Over the course of this research I kept a reflective research diary, and engaged in discussion regarding these issues with my supervisor and peer researchers. However, completing this research has led to my having a much greater understanding of how findings are inevitably informed and influenced by the researcher's prior knowledge, interests, motivations and social and cultural experiences, and with hindsight I feel it would have been useful to explore these issues in more depth in order to strengthen the validity of this research.

## **5.5 Research Questions revisited**

This section briefly discusses the findings in relation to each of the three research questions which were formulated at the onset of this research. These questions were originally presented in the Literature Review (Chapter 2).

### **5.5.1 Research Question 1. What forms do mothers' engagement with the specialist unit take?**

Mothers described engaging with the Unit in a variety of ways. These included directly engaging with the Unit's staff through writing in a home school book and attending meetings at school. Indirect ways of engaging with the Unit included monitoring their child's behaviour at home to infer whether they were happy at school, and implementing, modifying or attempting to implement teaching strategies used by the Unit at home. In addition to these observable ways of engaging with the

Unit, mothers' descriptions of their experiences demonstrated an internal process of making sense of the choices and concepts which the attendance of their child at the Unit exposed them to. This internal process had cognitive, constructivist dimensions, for example of understanding what to expect from a special school, and also had emotional dimensions relating to a desire for their child to experience an 'unconditional positive regard' from staff.

### **5.5.2 Research Question 2. What meanings do mothers make of the different ways they engage with the specialist unit?**

The meanings mothers made of the different ways they engaged with the specialist unit were stranded into three separate superordinate themes. Theme 1 described how mothers' engaged with the specialist Unit in order to establish a feeling that their child was accepted and nurtured by staff. Theme 2 described mothers' engagement in terms of their experiences of uncertainty regarding the meaning of their child's autism diagnosis, their learning priorities for their child and their expectations of what the specialist Unit could or should offer. Finally Theme 3 highlighted the learning experiences described by mothers as a result of their engagement with the specialist Unit.

### **5.5.3 Research Question 3. How do mothers understand and make sense of the specialist teaching strategies used in the specialist provision?**

The findings of this research indicate that most mothers had an awareness of the strategies used by the Unit and were able to describe some key features of these. All mothers considered that it would be desirable to adopt some of the teaching strategies they had learned, or were hoping to learn at home, but they all also described experiencing difficulties doing so. These difficulties were framed as caused by practical considerations relating to the demands of family life. Mothers described how they related their increasing knowledge of teaching strategies used by the unit to their parenting methods at home, not only in terms of replicating them but also in terms of developing adaptations of them which better fit their parenting

approach and practical circumstances, and in terms of doing complimentary activities at home.

## **5.6 Distinctive Contribution**

It is hoped that this research has made a small contribution to knowledge in a number of ways. It has examined a topic using small-scale qualitative methods which has previously predominantly been researched using larger scale studies. The small scale of this research combined with the utilisation of Interpretative Phenomenological Analysis has resulted in findings which convey something of individual participants' experiences. This is not the case with the majority of studies which have investigated mothers of children with autism and their experiences of school. The exploratory, idiographic nature of this research means that the concept of parental involvement has been described in a new way which it is hoped will help to further understanding about the ways in which parents experience engaging with their child's school. Furthermore, this study is unique in exploring mothers' experiences of a specialist unit attached to a mainstream school.

## **5.7 Recommendations for future research**

### **5.7.1 Exploring the experiences of mothers of children who attend other types of educational provision**

It would be interesting to carry out similar research in other educational settings, particularly in a mainstream school. Participants in this research frequently spoke about their choice to educate their child in a specialist unit and the advantages they perceived as resulting from this decision. In particular, mothers spoke of the value they placed in feeling that school staff accepted their child and were able to personalise their learning opportunities. These values were explicitly related by many participants to the small class sizes and the familiarity of staff with the needs of children with autism which are distinct features of specialist settings. It would be interesting to discover whether mothers of children with similar needs who are fully

included within mainstream classrooms similarly prioritise staff having unconditional positive regard for their child, or whether they have other priorities.

### **5.7.2 Exploring the experiences of fathers**

Flippin and Crais (2011) highlight that fathers are currently underrepresented in autism education research. They acknowledge that mothers typically are most involved in the education of children with autism, and suggest that an increase in fathers' involvement would help relieve the stress reported in the literature to be experienced by mothers of children with autism. Therefore a second recommendation is that research on the topic of the present research but which is focussed on fathers would be useful in order to explore what is distinct about their experiences.

## **5.8 Implications for Educational Psychologists**

Some implications of the research findings for educational psychologists (EPs) are considered below in relation to their work with families and children and their work with schools.

### **5.8.1 Work at the child and family level**

Educational psychologists often work closely with families before during and after a child is identified as having an ASC. This research highlights the importance for mothers of feeling that their child is worthy of approval and acceptance. In this regard it is likely that mothers are particularly vulnerable during a time when their child is identified as having difficulties that are likely to be lifelong. It was very clear during this research process that mothers valued the opportunity to tell me what their child enjoyed doing at home, and about the positive and interesting qualities mothers noticed and enjoyed in their children. This has relevance to the way in which educational psychologists might carry out consultations with mothers of children with autism or where autism is suspected. A recommendation resulting from this research is that EPs should ensure that necessary discussion about a child's



difficulties is within the context of a wider, humanistically oriented discussion of the 'whole child' as someone to be accepted and appreciated by parents and other adults regardless of learning difficulties and diagnostic labels.

### **5.8.2 Work at the school level**

Educational psychologists work with schools encompasses many activities including consulting with staff and delivering training. EPs are well placed to facilitate school staff's understanding of the experiences of parents. This research highlights the journey which mothers of children with autism embark on following their diagnosis, and the vastness and difference of this 'new world' compared to that which is inhabited by mothers of typically developing children. A recommendation resulting from this research is that EPs endeavour to convey a sense of this to teaching staff who are used to working with children with autism as they may not automatically appreciate how unknown the world of autism and of special school environments is to parents of primary age children.

## **5.9 Personal reflection on the research process**

At the beginning of this thesis I gave an account of my personal motivations for embarking on this research. I saw here an opportunity to have the conversations that I always wanted to have but had never been able to with parents of children with complex needs; to find out more about the experiences of mothers who are in similar circumstances to the mothers I have been so curious about in the past. I feel that to a large extent I have achieved this goal. The long period I have spent engaging with my participants' accounts of their experiences has enabled me to gain much more of an 'insider perspective' than I have ever found possible in my previous professional roles as a teacher and trainee educational psychologist.

I am very grateful to have had the chance to explore the possibilities of Interpretative Phenomenological Analysis. I feel that this methodology's openness to the researcher interpretatively and creatively engaging with their participants' data was ideal for achieving my personal objective of reaching a better understanding of what it is like to be a mother of a child who attends a specialist educational setting.

Although the process of completing my analysis was challenging, lengthy and often frustrating, rather than becoming jaded and frustrated with my participants' transcripts as time passed, I found myself enjoying a feeling of increased connection to my participants as I tried to understand what it might be like to be 'in their shoes'. When I embarked on this research I found it difficult to know how to begin to empathise with the mothers of children with autism who I encountered in my work. I am not a mother myself, and felt our very different life experiences were perhaps a barrier to open communication. I feel that as a result of completing this research my understanding of the mothers of children with autism who I will work with in the future has been enhanced, and that this will benefit my professional practise.

## **5.10 Concluding comments**

This thesis describes a qualitative investigation of mothers' experiences of engaging with a specialist unit for autism attended by their child. An interpretative phenomenological analysis of these experiences enabled the construction of a range of themes which illustrated convergence and divergence between participants' accounts, grounded in their unique life experiences. Findings highlighted the importance of school staff being perceived by mothers as warm and accepting of their child, the complex and uncertain process of developing expectations in terms of their child's learning and in terms of what expectations were appropriate to have for the Unit, and the value mothers placed on their learning from the unit, as well as in finding their own approach to understanding and parenting their child. Although the small-scale qualitative nature of this research means that the findings are not intended to be generalisable, this research has added to ways of conceptualising the multi-faceted concept of parental educational engagement. It is hoped that dissemination of this research to professionals will enable greater empathy and sensitivity to the unique experiences of mothers of children with autism spectrum conditions, in order that children and their families can experience the lasting benefits of being sensitively supported by school staff.

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# Appendices

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**1 Glossary of specialist teaching and therapeutic approaches referred to in this thesis**

**2. Letter to potential participants**

**3. Pilot Interview Schedule**

**4. Post-pilot interview schedule**

**5. Script to be read prior to interview**

**6. Consent letter presented before interview**

**7. Demographic Information form**

**8. Letter confirming ethical approval**

**9. Appendices on CD-ROM**

a) full transcripts with themes for each participant

b) initial exploratory comments for each participant

c) table of final themes showing all related excerpts

**10. Sample page of each participants' transcript with themes.**

**11. Master Table of Themes**

# Appendix 1. Glossary of specialist teaching and therapeutic approaches referred to in this thesis

Descriptive summaries are given below of the autism specific teaching and therapeutic approaches referred to in this thesis. This overview is intended to give some contextualising information for the reader.

Name of approach	Aims and Features	Current evidence base
<p><i>Attention Autism</i></p>	<p>Attention Autism is an intervention developed by Gina Davies, a London based Speech and Language Therapy Consultant (Morgan, 2011). Training and support in delivering the intervention has been given by Davies to educational service providers within and around London for several years, but the intervention is not currently known more widely. Information provided here about this intervention derives from my visits to the provision, from the Attention Autism website (<a href="http://www.attentionautism.com">www.attentionautism.com</a>), from a book chapter written by Davies outlining an early version of her approach (1997), and from an unpublished dissertation by Morgan (2011).</p> <p>The intervention is characterised by a large repertoire of practical and highly sense-stimulating activities which are first demonstrated by the teacher in a group setting. An example might be pouring coloured water into a long translucent tube, and having children take turns to experience having water poured over them as they sit on a chair holding an umbrella. Following the group demonstration children work individually on a related individual task at their table.</p> <p>The key goals of this intervention are to extend concentration and shared attention skills through the use of highly motivating group activities and to foster the development of functional language through the use of carefully chosen phrases by staff members at key points of the practical demonstration (Davies, 1997). Children are not explicitly prompted to verbalise, but are expected to spontaneously begin to imitate the language used by staff when they are familiar with particular activities - for example staff would say "pour it" when about to pour water on an umbrella (Morgan, 2011).</p>	<p>Anecdotal (unpublished to date).</p>
<p><i>Applied Behavioural Analysis (ABA)</i></p>	<p>Applied Behavioural Analysis (ABA) is a highly structured instructional technique developed by Ivar Lovaas in 1970 (Seitler, 2011). ABA along with TEACCH (described below) are amongst the most widely known intervention models for children with autism (Callahan, 2010).</p> <p>ABA is delivered 1:1 and involves discrete trial training, where the skill to be taught is broken down into small steps which are taught individually. This intervention draws deeply on the</p>	<p>Research evidence to date for the efficacy of ABA has shown that it is effective for some children, but overall</p>

	<p>psychological theories of behaviourism which theorise that behaviour can be shaped through manipulating antecedent conditions and providing a reinforcing response by the trainer, usually in the form of an immediate tangible reward (e.g food) for a successfully accomplished task (Lord &amp; McGee, 2001).</p> <p>ABA can be used in schools or as an intervention that is delivered at home with the help of ABA trainers.</p>	<p>there is no evidence to suggest it is superior to other interventions (Seitler, 2011).</p>
<p><i>Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)</i></p>	<p>The TEACCH approach is a widely known intervention for children with autism which was invented in 1972 by Eric Schopler at the University of North Carolina (Jordan <i>et al</i>, 1998). It is characterised by a highly structured learning environment where children are encouraged to work independently at distraction-free individual workspaces with an in-tray of tasks to complete each of which is listed on a visual timetable (Tutt <i>et al</i>, 2006).</p> <p>The structure of the TEACCH learning environment is intended to harmonise with the learning profile of children with ASCs, characterised by a preference for visual rather than auditory prompts (hence a visual timetable of tasks), a calm and quiet environment (provided by the individual workspaces) and an affinity with routine (catered for through clearly presented tasks and timetable) (Mesibov, 2010).</p>	<p>Evidence of efficacy with some children (Mesibov, 2010).</p>
<p><i>Picture Exchange Communication System (PECS)</i></p>	<p>The Picture Exchange Communication System (PECS) is a widely used manualised intervention developed in the late 1980s by Andy Bondy and Lori Frost (Bondy, 2012). Like ABA it is grounded in behaviourist principles and particularly by the book "Verbal Behaviour" published in the 1950s by the influential behaviourist B.F Skinner (Bondy, 2012). It is a highly structured intervention, and in its early stages requires a 1:1 or even 2:1 staff:student ratio. The aim of this intervention is to teach children in progressive stages how to use a symbol-exchange based communication system, therefore it is used with children who are non-verbal or who have not yet developed functional language (Flippin <i>et al</i>, 2010).</p>	<p>Evidence of efficacy with some children (Flippin <i>et al</i>, 2010).</p>
<p><i>Intensive Interaction</i></p>	<p>Intensive Interaction is an approach to developing very early interaction and communication skills developed by teachers Melanie Nind and Dave Hewett in the 1980s (Jeffries, 2009). It is based on the practitioner adopting an interaction style based on that used instinctively by mothers with very young infants (Sharma &amp; Firth, 2012). A key feature of this approach is that the practitioner ascribes intentionality to behaviours shown by the child through imitating or otherwise positively responding to them (Jeffries, 2009), in order to slowly and naturally build a mutually enjoyable interaction at a pace which is comfortable to the child. This approach is primarily aimed at all children with profoundly complex needs which have limited their opportunities to develop the foundations of social and communication skills (Nind, 1999), but is also used with children with ASCs (Nind 2000).</p>	<p>(Evidence of efficacy with some children, Jeffries, 2009).</p>
<p><i>Son-Rise</i></p>	<p>Son-Rise is a home education programme which was developed in the USA in the 1970s (Williams &amp; Wishart, 2003). A key principle of the programme is that similarly to the intensive interaction approach it is child-led and involves the parent or Son-Rise practitioner accepting and responding to all behaviours shown by the child. The programme requires parents to set up a dedicated Son-Rise room at home in which one to one work can be carried out with minimal distractions (Williams and Wishart, 2003). This approach is discussed by two participants (Anna and Irene) who have used it with their children at home.</p>	<p>Anecdotal and single-case study</p>



<i>Biomedical Approaches</i>	A wide range of biomedical treatments exist which have the aim of addressing hypothesised biochemical disorders which might underlie the presenting difficulties associated with ASCs. The most commonly utilised biomedical treatments by parents are the use of vitamin and mineral supplementation (particularly with vitamin B6 and Magnesium), and the implementation of a gluten and casein free diet (Senel, 2010).	Recent Cochrane reviews found insufficient evidence currently exists to support these approaches and recommended more research (Nye <i>et al</i> , 2005; Millward <i>et al</i> , 2008).
<i>Tomatis Sound Therapy</i>	Tomatis Sound Therapy (also known as Listening Therapy) is an approach developed by Alfred Tomatis in the mid 20th century which is less widely used than those described above (Corbett, 2008). The intervention involves the child listening to a range of sounds including specially modified classical music and their own voices through headphones, and it is hypothesised that this experience will result in improved listening skills which will have a positive impact on the development of a wide range of other skills (Gerritsen, 2010).	Evidence for this treatment's efficacy to date is anecdotal or based on single case-studies (Corbett, 2008).

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## Appendix 2. Letter to potential participants

Dear Parent

My name is Emma Read, and I am an Educational Psychologist in Training at the University of East London. As part of my training, I am working part time in XXXXXX this year as an Assistant Educational Psychologist.

As another part of my training, I am currently working on a research study designed to find out about what it is like for mothers when their children attend a specialist Unit. It is hoped that the findings from this research will help Educational Psychologists and other professionals to have a better understanding of mother's views which will help them when they are talking to children, school staff and families.

The working title for my research project is "What are mothers' experiences of an Autism Spectrum Condition Specialist Primary Unit, and what do they think is the impact of their child's attendance upon their approach to parenting?".

I hope that my research will help me to gain an understanding of Mothers' experiences of a specialist Unit. I am still developing my research questions, but I am particularly interested in your experiences of the teaching and learning strategies used at the provision, and how these relate to your experiences of your child at home, as well as your other experiences of the provision.

An additional aim of this research is to contribute to the role of the educational psychologist (EP) in ensuring that the parent's perspective is heard, valued and incorporated into school activities.

The specialist Unit at the Abbey Road school has agreed to work with me on this study. As part of my research, I hope to interview a small number of mothers of children who attend the Abbey Road school specialist Unit to find out their experiences of having a child who attends.

**I am writing to ask if you, as a Mother of a child who attends the Abbey Road Unit, would be interested in taking part in this research. Participating would involve taking part in an interview that would last no more than 90 minutes. The interview would be held in your home or in a private room at the Abbey Road School if you prefer, at a time that is mutually convenient.**

This research is subject to strict ethical guidelines, and all the information I collect will be stored in accordance with the Data Protection Act 1998. The interview would be recorded but all the information collected will be anonymised so that no-one will be able to identify you. At the end of the project, all the recordings and data will be destroyed. If for any reason you decide during the interview that you would not like to take part after all, you would be able to withdraw from the interview without consequences. Should you choose to withdraw from the interview, any data you have given would be destroyed and not used in the research.

If you would like to take part in this study, please fill in the form over the page, and return it to the Abbey Road Specialist Unit or send it to Emma Read, XXXXXXXXXXXXXXXXXXXX, XXXXXXXXXXX London, XXXXXX. I will then telephone you so that you can ask any questions you might have, and so that we can arrange a convenient place and time when we can carry out an interview.

Thank you very much for taking the time to read this letter. I do hope you will be interested in taking part in the research, and I hope to hear from you soon.

Best wishes

Emma Read

Educational Psychologist in Training

University of East London

## Appendix 3. Pilot Interview Schedule

*Interview questions and prompts:*

**1. Tell me a bit about x and how he came to attend the Abbey Road Unit.**

- *Is it the first school x has been to?*
- *Why? When? How?*
- *How did you feel about it?*
- *How was that for you?*
- *How long has x attended the Abbey Road school for now?*
- 

**2. Could you tell me about what x does when he is at school?**

*How do you find out about what x does at school. (Parents evening/visits/letters/home-school books)*

- *What do you think about that?*
- *Are they things you expected him to be doing?*
- *Do staff have a particular way of working with x?*

**3. What is x like at home?**

- *Same/different to at school?*
- *What sort of things do you do with x at home? (any strategies...behaviour management...routines...activities...)*

**4. Is there anything else you'd like to tell me about what it is like to have x attending the specialist school that you haven't had the opportunity to say?**

# Appendix 4. Post-pilot interview schedule

## Interview Schedule with prompts

### A) Background (warm up/info gathering)

#### 1. Tell me a bit about x and how he came to attend the Abbey Road Unit.

Possible prompts: *What was it like for you when he first started attending the Abbey Road? Why? When? How?*

*How did you feel about it? What were you thinking when...?*

### B) Broad question regarding experiences of the Unit.

#### 2. Tell me about your experience of the Abbey Road Unit, thinking about the whole time that X has been there.

Possible prompts: *What, if any, are the best things, for you, about x attending the Abbey Road Unit? Are there any difficulties or things which are less helpful?*

*Can you give me an example of that? What did you think/feel?*

### C) Experiences of teaching and learning strategies used at the Unit

#### 3. How do you find out about what x does at school?

Possible prompts: *Parents evening/visits/letters/home-school books)*

*What is that like? What do you think/feel about (that way of finding out)?*

#### 4. Could you tell me about what x does when he is at school?

Possible prompts: *What do you think about that? Are they things you expected him to be doing?*

#### 5. Do staff have any particular ways of working with x?

Possible prompts: *Messy activities (Attention Autism), symbols? What do you think about that way of working? How do you feel x learns best?*

### D) Experiences of the child at home, and of teaching and learning strategies implemented (if any)

#### 6. What is x like at home?

Possible prompts: *Same/different to at school? Why? What do you do when he does that?*

#### 7. What sort of things do you do with x at home?

Possible prompts: *any strategies...behaviour management...routines...activities...? How do you feel about that approach? Where did you get the idea to use that approach, or did you come up with it yourself? Is that approach something that is used at school? Why do you think that is?*

### E) Final question returning to broad experiences of the Unit.

8. Is there anything else you'd like to tell me about what it is like for you to have x attending the Abbey Road Unit that you haven't had the opportunity to say?

#### At the end of the interview:

1. thank the participant
2. Ask how they found the interview
3. Remind them who they can speak to if they would like to talk about anything to do with the interview (me, school EP, Unit manager).
4. Let them know that I will send them a summary of my research when it is complete.

## Appendix 5. Script to be read prior to interview

As you might know already, I am a trainee educational psychologist in the second year of my training. As part of my training I work for the [redacted] educational psychology service three days a week, and I am also required to carry out a research project.

The project I am working on is a study designed to find out about the experiences of Mothers' who have children who attend an ASD specialist provision. I want to find out what this experience is like, and how it affects their parenting approach and their relationship with their child. There has been some research into this area before, but I don't think that Mothers' experiences of their child attending a specialist provision has really been looked at before.

In order to find out more about this subject, I'll be interviewing a small number of Mothers of children who attend this specialist provision. You've been chosen to take part in this study as your child attends this provision, and you have first-hand experience of what this is like. You will know how you feel about your child's attendance, and know how this experience has affected you and your relationship with your child. There are no right or wrong answers to the questions I would like to ask as I am interested in your own experience.

In order to record your views accurately, I will use a digital recorder. Your interview will be recorded and then after the interview I will transcribe it so that I can look carefully at what you have told me. All this information will remain entirely confidential and carefully stored in a locked facility at [redacted] Educational Psychology Service. When I write up this study I will anonymise all of the contributions. At the end of the project, the transcripts will be shredded and the audio files will be destroyed. There is a possibility that this research might be published in an academic journal. If this was to happen, the anonymised data will be securely kept for a maximum of five years after the research is published. I also hope to share my findings with XXXXX and the educational psychology service.

If you feel at any time during this interview that you do not wish to take part in this project, then please let me know as you are free to withdraw your participation in the study without consequences. Should you choose to withdraw from the interview, any data that you have given will be destroyed and not used in the research.

I would like to thank you in advance for agreeing to participate. I will tell you when I have started recording and when I stop. If you have any questions at this stage I would be very happy to answer them now.

*After the interview, the researcher will:*

1. Clearly state when the tape recorder is switched off.
2. Thank participant again for their contribution to the study.
3. Answer any further questions the participant might have.
4. Leave contact details with the participant for any questions they might have at a later date.
5. Reiterate that the manager of the provision will be available for a confidential discussion of issues raised by the interview and that she can be contacted through the provision.



## Appendix 6. Consent letter presented before interview

### UNIVERSITY OF EAST LONDON

#### Consent to Participate in a Research Project Involving the Use of Human Participants

Research project working title: What are mothers' experiences of an Autism Spectrum Condition Specialist Primary Unit, and what do they think is the impact of their child's attendance upon their approach to parenting?

I have read the letter sent to me relating to the above research project in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to the data. It has been explained to me what will happen once the research has been completed and written up.

I understand that if I have any further questions about the study after my interview has taken place, I can contact the researcher, Emma Read, by telephone at the xxxxx xxxxx, London XXX XXX tel. 000 0000 000. If I would like to discuss further any issues raised by my interview, I understand I can contact the specialist Unit my child attends and arrange an appointment to speak confidentially to the manager of the Unit.

I hereby freely and fully consent to participate in the study which has been fully explained to me.

Having given this consent I understand that I have the right to withdraw from the interview at any point without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCKCAPITALS) .....

Participant's Signature .....

Researcher's Name (BLOCKCAPITALS) .....

Researcher's Signature .....

Date: .....

## Appendix 7. Demographic Information form

Demographic information sheet completed by each participant immediately prior to interview.

### Demographic Information

To begin, I would like to obtain some basic information about you, such as your age, education and occupation. The reason for this is to help me understand some differences and similarities between my participants that might be relevant to my study. The information you provide may be included in the research but care will be taken to ensure it does not identify you, and your name will not be used at any point. You are free to omit information which you would prefer not to disclose.

1. How old are you? \_\_\_\_\_ years
2. What is your highest educational qualification  
(e.g. GCSE, A level, Degree) \_\_\_\_\_
3. Are you currently working  
in paid employment? \_\_\_\_\_
4. If yes, is your paid employment  
part-time or full-time? \_\_\_\_\_
5. What is your current marital status?  
(please tick the appropriate answer)

  - Single \_\_\_\_\_
  - Living with partner \_\_\_\_\_
  - Married \_\_\_\_\_
  - Separated \_\_\_\_\_
  - Divorced \_\_\_\_\_

6. How many children do you have?  
*Please list their ages and whether boys or girls* \_\_\_\_\_
7. Were you born in England? \_\_\_\_\_
8. If no, please state number of years in England \_\_\_\_\_
9. How would you describe your cultural,  
national and ethnic background? \_\_\_\_\_
10. If your first language is not English,  
Please state it here \_\_\_\_\_

Thank you for your help

## Appendix 8. Letter confirming ethical approval



Tina Rae  
School of Psychology  
Stratford

ETH/13/67

25<sup>th</sup> March 2011

Dear Tina,

**Application to the Research Ethics Committee: What are mothers' experiences of an autism Spectrum Condition Specialist Primary Provision, and what do they think is the impact of their child's attendance upon their approach to parenting (E Read)**

I advise that Members of the Research Ethics Committee have now approved the above application on the terms previously advised to you. The Research Ethics Committee should be informed of any significant changes that take place after approval has been given. Examples of such changes include any change to the scope, methodology or composition of investigative team. These examples are not exclusive and the person responsible for the programme must exercise proper judgement in determining what should be brought to the attention of the Committee.

In accepting the terms previously advised to you I would be grateful if you could return the declaration form below, duly signed and dated, confirming that you will inform the committee of any changes to your approved programme.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Debbie Dada', written over a horizontal line.

Debbie Dada  
Admissions and Ethics Officer  
Direct Line: 0208 223 2976  
Email: d.dada@uel.ac.uk

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**Research Ethics Committee: ETH/13/67**

I hereby agree to inform the Research Ethics Committee of any changes to be made to the above approved programme and any adverse incidents that arise during the conduct of the programme.

Signed:.....Date: .....

## **Appendix 9. CD-ROM**

**Including:**

- a) full transcripts with themes for each participant**
- b) initial exploratory comments for each participant**
- c) table of final themes showing all related excerpts**

## Appendix 10. Sample page of each participants' transcript with themes

NB. Yellow themes are from earlier stages of analysis and apply to individual participants

Blue themes are later themes which were applied across participants.

Layla 09/06/2013

126 his speech, which now is actually getting a lot better  
(*INT - mm*).

127 He's really starting to say a few words, he's reading  
some books and

128 ... he's, he's you know, he's picked up on that just from  
September

129 (*INT - yeah*) til now. So a lot has changed, where/ if it  
hasn't

130 changed I would have thought "you know what just  
change him to the (a

131 local GLD/ASD special school) , see how he goes". And  
now I'm in two

132 minds I'm thinking you know, he's doing so well in his  
speech, you

133 know, what's important right now? Is it the outdoor  
play or is it his

134 communication? So I've got to be realistic, you know,  
maybe when he's

135 a bit older he might need more space. But I feel like  
now, maybe he

136 should stay here and see how he goes. But again really  
I'm in two

137 (pause) I haven't, you know fully made a decision of  
whether he's

138 going to go back next September or (*INT - yes*)... You  
know, it's a

139 hard decision for a parent. Apparently they were doing  
some reno,

140 renovations at the Abbey Road School but it's not going  
to be at the

141 Unit (*INT - mm*). It's going to be in the mainstream,  
which is a shame

142 because I feel like you're getting money, why don't you  
invest in the

143 children in the provision as well, cos they need better  
classrooms and

144 they need better play areas and (*INT - mm*), you know,  
it's er ...

145 yeah it's a shame when you compare it to other  
specialist schools like

146 (a private ABA school) (*INT - mm*) and erm, ah I mean  
(a private ABA

147 school) is like a five-star hotel really (laughs). You go  
there and

148 you're just mesmerised by, you know, they've got one-  
to-one, like each

149 child's got his own teacher (*INT - yes*). They do their  
ABA therapy,

150 you know, which I felt like maybe Hasan would have  
done well with that

6

	299	how did you come across that? Or "the Frog Chorus"
	300	What? What are you doing?!
...being surprised by what child can do	301	<i>INT</i> - how funny.
	302	HELEN - yeah so, yeah I, you know, he's always looking up at youtube,
...child's intelligence is hidden but very important	303	so he's always typing in, exploring yeah.
	304	<i>INT</i> - I was going to ask you about if there was any particular
	305	difficulties, for you, about Thomas going to the Unit... from what
	306	you've said one of them is that sometimes you wonder if there is, you
	307	would like more opportunity for Thomas to be stretched. Are there any
	308	other difficulties?
	309	HELEN - er, not really, because there's so much support, the carers
	310	are so, I mean they're so helpful, I, I couldn't wish for anything
	311	more, better, to tell you the truth. I'm so, so grateful. For the
...raising caring (non-academic) input from school for child and fa ...the teachers like them and don't judge them' ...feeling accepted and understood and used (s of to)	312	kind of work, and effort and care that they've just given to my son, I
	313	mean, I don't know, I'm really going to miss the unit ( <i>INT</i> - yeah)
	314	when he's gone. I am. I'm gonna miss them all.
	315	<i>INT</i> - and how do you find out what Thomas gets up to at school? What
	316	are the different ways?
	317	HELEN - Well we have a home-school book ( <i>INT</i> - yeah), where they let
	318	me know about what he has been doing during the day, what he has been
	319	learning, and if he has been, if there has been any accident, if he
	320	has injured himself or anything, they let me know about that as well
...homeschool book ...Your child can't tell you what they've been doing:DirectCom ...Direct communication	321	( <i>INT</i> - mm) through his home school book. (laughs) If he has been, er,
	322	a a bit naughty, they let me know ( <i>INT</i> - mm) as well? Through the
	323	home school book ( <i>INT</i> - yeah) and actually when he gets home, the

...direct communication with school  
 ...I was quite surprised learning about child  
 ...the child as unresponsive - wanting to know more about

...toilet training - school and home collaborating  
 ...basic needs met and basic life skills developed  
 ...prioritising learning targets  
 ...progress - academic and special needs

...feeling child has 'locked up' potential

...parent-teacher meetings

135 first it's like 'oh yes, we'll have her toilet trained in a, in  
 a  
 136 month!' but even they have had to give up, because  
 she just won't do  
 137 it. I mean hopefully she will, eventually (INT - mm)  
 but, um, it's,  
 138 it's just um, she still doesn't have any awareness, and  
 you can sit  
 139 her on the toilet for hours and she won't do anything  
 (laughs) (INT -  
 140 mm) um, and then... so she's got her nappy on or if she  
 doesn't/even  
 141 if she doesn't have a nappy on, she's just kind of up  
 and... walking  
 142 around she.. has no,...control as such (INT - yes). Or/I  
 think she  
 143 can control, but she chooses not... she, she doesn't (INT  
 - yes). So  
 144 um, so there's been, yeah, but it's been, um, a positive  
 experience,  
 145 very positive I think (INT - yes) so, yeah...  
 146 INT - tell me a bit more about the, um, the meetings  
 that you have at  
 147 the school. What are they, how many, I guess you've  
 had.. how long  
 148 has Rachel been at the Abbey Road Unit now?  
 149 LOUISE - Er, well this would be one school year. So  
 September, so I  
 150 think we've had ... we've had one meeting per term,  
 and then there was  
 151 an/er, an actual proper statement review (INT - yes) as  
 well. Um...  
 152 I think for the first couple of meetings it was (class

798 laminate them and make a little book (INT - yes) and  
for a couple of

799 days beforehand we'll go through this book and we'll  
read it together,

800 and that really helps.

801 INT - yes. Is that an approach that you kind of made  
or adapted

802 yourself? Do you feel like you'd taken an approach  
from Abbey

803 Road and sort of made it relevant to your (inaudible)

804 ANNA - I don't think that's from Abbey Road. It's from  
everything

805 I've learnt I mean I've, you know I did an early bird  
course, I've

806 done three Son-Rise courses, I've been to (The Local  
Authority) autism

807 things, I've been to one-off lectures I've read books/so,  
to be honest

808 (pause) it's a sort of culmination of all these ... sources  
(INT -

809 yes) not just Abbey Road.

810 INT - can I ask you now about the, the Gina Davis  
approach

811 that Abbey Road uses; the stuff you were talking about  
earlier with

812 the cornflour and, etc (ANNA - yes). Have you found  
that helpful in any way at home?

813 ANNA - Well again, we tried that, but we had  
problems. Because

814 (laughs) I don't blame him at all but we do ... a game of  
flour or

815 something. And he might enjoy getting mucky or

...using visual supports at home to prepare M for new things

...trying but failing to find example of where school has helped  
...Becoming knowledgeable

...drawing on own expertise  
...in harmony, not synchrony with staff's approach

...Well again, we tried that, but we had problems.  
...In terms of learning, I find it really hard at home'

...balancing ideal in terms of strategies with pragmatism  
...In terms of learning, I find it really hard at home'



639 really. And er, Abbey Road Unit , as I said, the activities  
 640 that  
 641 they've been doing with the children, it was quite more  
 for her (*INT - yeah*) yeah.

642 *INT - you felt, so the, when you said struggling, with the*  
 643 *type of*  
*work she would be asked to do?*

644 JENNY - because she, yeah she would, the type of  
 645 works, and she's  
 646 very active on her own. She couldn't be sitting on, on  
 the  
 647 activities. As I say, my daughter she's in Year 2 (*INT -*  
*yeah*) and  
 648 er, so I can see that they're very different. Martha  
 couldn't be,  
 649 couldn't be do that.  
*INT - it wouldn't suit her.*

650 JENNY - it wouldn't suit her at all.

651 *INT - and is The Abbey Road Unit what you'd expected?*

652 JENNY - I didn't really see any other, mm, special  
 schools for  
 653 children with autism. I haven't been in special schools  
 (*INT - yeah*).  
 654 And it is like special school.

655 *INT - yes, feels like a special school although it's a unit.*

656 JENNY - It is feel like a special school and, but, as well as  
 a  
 657 special school, she could have access to, to what her  
 ability, the  
 658 ability to do some work with the mainstream school as  
 well, so it was  
 659 quite good (*INT - yes*). Because sometimes with her  
 ability, she could  
 660 mix with the other children. It's not happening, but, er,  
 we thought  
 661 it was a good thing.

662 *INT - why isn't it happening? Do you know?*

663 JENNY - I think it's about her ability. She, she wouldn't  
 be able  
 664 to, to do the work like in the mainstream school,

...valuing mainstream&unit - choosing unit  
 ..'all these lovely characteristics are allowed to flourish'

...valuing mainstream&unit - choosing unit  
 ..feeling that 'special' environment means child is included  
 ..'all these lovely characteristics are allowed to flourish'

...feeling that the unit is a special school

...valuing opportunity for integration with mainstream  
 ..feeling that 'special' environment means child is included  
 ..promoting learning targets

...valuing opportunity for integration with mainstream  
 ..feeling that 'special' environment means child is included

## Appendix 11. Master Table of Themes

<p>1. Valuing Acceptance 'The children were clearly loved'</p>	
<p><i>1a. 'He's happy to go to school, so that means it's good'</i></p> <p>Irene: 'Joel's happy, which is the main thing. He seems really happy.</p> <p>Layla: I could see the changes in him, he was really excited to go to school</p> <p>Jenny: Even when it's holidays she always goes to the drawer with her [...] school uniform, and she's checking is there school today or not?</p> <p>Anna: the stress and anxiety would be rising all day, and then he'd come home [...] and it had to just flood out</p>	<p>573</p> <p>74 - 75</p> <p>475</p> <p>593</p>

Helen: it's like he's looking forward to going back to school	158
Louise: The most important thing was realising that she was now happy and feeling confident and secure	204
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<i>1b. 'The teachers like them and don't judge them'</i>	42
Irene: <i>we didn't like it. We didn't like the fact that people were so cold</i>	45
Anna: the children were clearly, <u>loved</u> which is the most important thing by the staff.	60
Jenny: - the teachers told me her, their relationship is er, like last year she got er the teacher help her, she's (Class Teacher)? She's just love, they just love each other (laughs)	719 - 721
Louise: they aren't, <i>aren't sort of um, or thinking</i> she's 'icky'because, you know, she needs to have her nappy changed	230
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*1c. 'all these lovely characteristics are allowed to flourish'*

Irene: when a child is on a school you know, on a mainstream  
[.]they're always on the side 510

Anna: this has given him the best chance in life to ... fulfil  
whatever potential he has 135

Layla: That's what you want for your child, just to get the best 210

Jenny:they arrange the activities to make er interest, er autistic  
children 24

Helen: I don't just want my child just to go to school. Just to  
make up the numbers, 347

Louise: the teacher of your child is really interested in getting the best out of your child, 557

2. Uncertainty of expectations in context of 'the whole complex thing of autism'

*2a. 'the whole complex thing of autism'*

Irene: I think you know children with autism are a bit different from children that have you know special needs 26

Anna: What I'm interested in is ... ameliorating his autism 886

Layla: ABA is, I've been told by the person who's actually, you know, been reading up on it, um, it is effective for most children 736

Helen: "oh dear, he's got autism, alright then, oh sit over there please". It's not meant to be that way, okay? 650

Louise: I saw something on the TV this morning about, I think there's been a lot of stuff around horse riding for, for, for autistic children	767
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*2b. Weighing up learning priorities*

Irene: you need to learn how to be with other people	70
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Layla: I said "listen I want to toilet train him"	291
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Jenny: But I would like her to progress with her speech. With her communication	522
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Helen: Speech and language was the principle one,	186
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Louise: most importantly I guess, life skills

447

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*2c. Being unsure how much to ask for.*

Irene: for him to have a drink here is ... it's ten times harder than for me at home

627

Anna: And I think in fairness to the school was the reason they didn't was because they knew that we had enough on our plates

460

Layla: I just felt like the facilities were not great

230

Jenny: I haven't seen the other schools, with special needs.

670

Helen: it has never really occurred to me to really to ask, no. I see what they do already.

256

Louise: the parents get involved and they're all about, sort of um, you know making that school the top school, er and that, that, that's, you wonder if those, that kind of er thing would work with special schools as well

1023-1027

### 3. Learning from the Unit, and doing it 'my own way'

#### *3a. Learning about teaching strategies*

Irene: they point to children and they just follow the instructions and it's quite like 'how do you do that!' (laughs) you know?

227-228

Layla: it was really nice, like the way the activities, how fun they make it

884

Jenny: it makes things quite more interesting for the children, they, they find it more, more interesting and they pay more attention

79



<p>Anna: So we're now ... much better informed. But when he first began we were much less so (INT – mm). And so they would give us a lot of tips</p>	<p>767-770</p>
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<p><i>3b. Learning about child through contact with the unit</i></p>	
<p>Irene: I would love to come (laughs) and hide you know somewhere and see what they do but you know you can't</p>	<p>162</p>
<p>Anna: one of the things we value enormously is the um ... the, the stress placed on good home/school communication</p>	<p>163</p>
<p>Layla: I like to get in contact with (the Unit Manager) regularly</p>	<p>504</p>
<p>Jenny: I'm checking her book as straight when she's coming from the school, so I find it interesting</p>	<p>589</p>
<p>Helen: the first thing he would do is to get out the home-school book and show it to me</p>	<p>322</p>

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*3c. Doing it 'my own way'*

**Helen:** Yeah, just being firm.

426

**Louise:** I feel it's er, quite nice that, that, that, that you know she seems to... be happy with, erm, being taught by teachers if you know what I mean

269

**Irene:** I'm not going to do that. I just did my own way

415

**Jenny:** But I didn't find er, no time, no time for it really.

239

**Layla:** it's having the energy and time, which you don't as a parent.

930

**Anna:** the reality is that it's very difficult to turn it into ... a, a you know something regular at home

843