SPECIAL OR MAINSTREAM?

A COMPARISON OF PARENTAL PERSPECTIVES ON CHOOSING

SCHOOLS FOR THEIR YOUNG CHILDREN WITH AUTISM

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STUDENT DECLARATION

University of East London
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<u>Declaration</u>

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 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 appended.

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Abstract

Many parents of children with autism report having difficulties choosing between special and mainstream school. The research took place in a Local Authority (LA) in the South East of England and aimed to explore how parents of pre-schoolers with autism in the LA made their decisions about the schools they wanted for their children.

This sequential mixed methods study used a questionnaire to gather quantitative data about the factors that influenced their choices of schools. Both groups of parents described visiting the school, the feeling that staff understood their child and the school's autism-friendliness as being the most important factors in making a decision.

This was followed up by six semi-structured interviews, three with parents who had chosen special schools and three who had chosen mainstream, to explore and compare their experiences and views of choosing schools. The qualitative interviews complemented the quantitative questionnaire in exploring further the factors that influenced the parents' choices. Thematic analysis of the interviews also revealed important insights into parents' views and experiences. Parents talked about the challenges of parenting a child with autism and about the services they had received. They expressed a range of anxieties about their children starting school and highlighted a number of factors as helping them feel that their child would be happy and safe at the schools they had chosen, which were in line with the questionnaire findings. Peer support and empathy for other parents were felt to be very important.

Parents expressed their feelings that accessing services and navigating the school system had been confusing and stressful and that parents would benefit from the system being clearer and more supportive. Comparison of the two groups revealed that pre-school experiences and parent's views of the meaning of inclusion were different for the two groups and may have influenced their decisions about provision.

It was concluded from the qualitative findings that the decision about special or mainstream school takes place in a bigger context and is not reliant purely on school factors.

The research reflects the findings of previous studies that demonstrate caring for a child with autism makes ongoing emotional demands on parents, which need to be acknowledged by the professionals involved with them. Recommendations arising from the findings of this study are explored in terms of implications for EP practice and further research.

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Table of Abbreviations Used

ASD / ASC	Autistic Spectrum Disorder/ Autistic Spectrum Condition Autism is a lifelong pervasive developmental disability that affects the way people communicate and relate to others. These terms are used in the literature and reflect either a specific condition or the historical context in which they are discussed.
LA	Local Authority
Parent	This is taken in the broadest sense to include carers and guardians.
SEN	Special Educational Needs 'Children have special educational needs if he or she has a learning difficulty which calls for special educational provision to be made for them' (Special Educational Needs Code of Practice, 2001, p.6)
SSEN	Statement of Special Educational Needs / Statement Pupils with the most complex difficulties have their needs described in a legal document called a Statement of Special Educational Needs. The statutory assessment process which precedes the drawing up of the Statement involves a number of professionals preparing reports outlining their view of the child's needs and what will be required for the child to make progress. These reports are summarised in the Statement. The process is often called 'statementing'.

Chapter 1 Introduction

1.1 Terminology

<u>Definition of autism</u>

Autism is a lifelong developmental disability that affects how a person communicates with and relates to other people. It also affects how they make sense of the world around them. Autism is part of the autism spectrum and is sometimes referred to as an Autism Spectrum Disorder (ASD). Autistic Spectrum Disorders are described in the American Psychiatric Association (2000) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR). The term 'spectrum' is used because, while all people with autism share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively everyday lives while others require a lifetime of specialist support.

The three main areas of difficulty which all people with autism share are sometimes known as the 'triad of impairments' (identified by Wing & Gould, 1979). These are difficulties with:

- social communication
- social interaction
- social imagination.

Different names for autism

Autism is often referred to by different names, such as an autistic spectrum condition (ASC) or autistic spectrum disorder (ASD). There also terms for different conditions on the autistic spectrum, such as 'classic' autism or Kanner autism, atypical autism, pervasive developmental disorder (PDD), Asperger's Syndrome (AS) or high-functioning autism (HFA). Wing & Potter (2002) state that there are no sharp boundaries separating 'typical' autism from other autistic disorders, including Asperger's syndrome and discuss the problems of establishing prevalence rates and the difficulties of diagnosing and defining autism.

Prevalence

The exact cause of autism is still being investigated. Research suggests that a combination of factors, both genetic and environmental, may account for changes in brain development that lead to autism. It is now widely acknowledged that autism is not caused by a person's upbringing, their social circumstances and is not the fault of the individual with the condition.

A survey by the Office of National Statistics of the mental health of children and young people in Great Britain found a prevalence rate of 0.9% for autism spectrum disorders or 90 in 10,000 (Green, McGinnity, Meltzer & Ford, 2005).

It is difficult to know exactly how many children have autism as it is not always easy to identify; indeed, some may never be diagnosed. As our knowledge, understanding and awareness increase, more children are being identified (Wing & Potter, 2002).

Diagnosis

A diagnosis is the formal identification of autism. Though there has recently been research published regarding screening children for autism (Pierce, Carter, Weinfield, Desmond, Hazin, Bjork & Gallaher, 2011), there is at present no simple test for autism; it is a clinical diagnosis based on observed and reported behaviours (DSM-IV-TR) (American Psychiatric Association, 2000). A diagnosis is usually made by a health professional such as a paediatrician or a psychiatrist. NICE guidelines recommend diagnosis by a multi-disciplinary panel of professionals (NICE, 2011).

As well as the variety of names for types of autism described above, another issue with the diagnosis of autism is variability in the interpretation of diagnostic criteria, meaning that it can be unclear what behaviour constitutes necessary diagnostic features (Bishop, 1989). A related issue is the problem of establishing diagnostic boundaries. As autism shares characteristics with diagnostic categories emerging from other fields (e.g. non-verbal learning disabilities syndrome from neuropsychology, dysfunction in sensory integration from occupational therapy) there has been diagnostic confusion resulting in varying and multiple diagnoses.

The social construction of autism

There has been a lot of debate regarding the diagnosis and label of autism and like the autism itself there is a wide spectrum of psychological perspectives. Some researchers are very clear in their viewpoints that children with autism as neurologically different from 'neurotypical' children and have a medical and biological conceptual framework.

Some researchers take a social constructionist position, posing questions about whether autism is a disorder or a neurological difference that has been socially constructed as a disorder. Molloy & Vasil (2002) describe how Asperger's Syndrome has been defined as a developmental disorder and question whether in fact these children are in a normal range of neurodiversity in children and that the reason for this label is the value of having this category of special education.

There are a number of charities and autism rights movements that call for autistic people, their caregivers and society to adopt a position of neurodiversity, accepting autism as a variation in functioning rather than a 'condition' or 'disorder' to be cured, and therefore advocating the use of the term autism as 'a way of being' (Wing, 2006).

For this reason the researcher has chosen to use the term 'children with autism' in this research, rather than ASC or ASD, to incorporate all children diagnosed as being on the autistic spectrum.

The wide range of children being described as autistic, the variability in diagnoses and the impact of the label of autism means that autism is a very controversial topic. It can be hard to create awareness of autism as people with autism do not 'look' disabled and parents of children with autism often say that other people simply think their child is naughty. There are a range of psychological perspectives about autism. Some see autism with a medical model where the child with autism is seen as being biologically different from a neurotypical child and therefore needs to be 'treated' differently. Some take a social or ecological psychological viewpoint, where the child's autism is not a disorder in itself, but that an issue arises due to expectations about a child being a certain way in certain environment, and the issue is with the expectations and the environment rather than the child. This range of perspectives leads to a range in views about how children with autism should be taught and the outcome of any intervention.

Support

It is presently generally acknowledged that all people with autism can benefit from a timely diagnosis and access to appropriate services and support. For many children specific support for their needs is dependent on receiving a medical diagnosis of autism. Over time, the average age at which autism is identified has come down largely as a function of increased parental or professional awareness of, and sensitivity to, the characteristic signs and symptoms (Bowker, D'Angelo, Hicks & Wells, 2011). Children may be identified prior to school entry or during their time at school. At the pre-school stage, those involved in identification and consequent referral for diagnosis are most likely to be Health Visitors, General Practitioners

(GPs) and the Local Authority (LA) Pre-School Advisors working in partnership with parents.

Charities and autism rights movements also provide information, support and services, and campaign for a better understanding and better world for people with autism. In the LA in question there is a charity that is affiliated to the National Autistic Society, which aims to support children and adults with an ASD and their families. Services include a monthly support group for parents to talk about their experiences and listen to other parents of a child with autism, an August playscheme, and support with multi-agency liaison. Home visits can be arranged to discuss issues, general strategies, behaviour management, support with educational issues or help to work with Social Services. Support is also available to help parents apply for benefits.

Provision and intervention

There are a variety of intervention methods of enabling learning and development which people find to be helpful, and a wide range of views about which interventions are most effective and most ethical. New research is published regularly and our understanding of autism has grown tremendously since it was first identified in the 1940s. As more is learnt about the condition, more interventions become available. meaning that for parents it can be confusing and overwhelming deciding what to do to support their children (Wing & Potter, 2002). Research into provision and intervention for children with autism is summarised in the Literature Review chapter.

It seems there are a number of factors involved in decisions about how to enable children with autism to learn and develop. Whether to choose special or mainstream school provision is one of the decisions parents of children with autism make about which little is known.

1.2 Context and Background

1.2.1 Education: The National Context

In the UK in recent years there has been much debate about special and mainstream schools and the model of inclusion in education. Dyson (2001) states a number of commentators on education have begun to explore the concept of 'dilemmas' as a means of understanding special education. In the UK, Brahm Norwich (1994) indentifies:

> 'A dilemma in education over how difference is taken into account - whether to recognise difference as relevant to individual needs by offering different provision, but that doing so could reinforce unjustified inequalities and is associated with devaluation; or, whether to offer a common and valued provision for all but with the risk of not providing what is relevant to individual needs'. (p.293)

In the USA, Artiles (1998) states:

> 'the ways in which we treat difference are problematic. For example we treat difference by treating certain groups of students differently (e.g. educational programs for limited English proficient students) or the same (e.g. recent university admissions criteria for ethnic minority groups). Interestingly, both approaches to dealing with difference achieve exactly the same thing: they affirm difference. Thus, it appears that to acknowledge difference in any way creates a dilemma that poses seemingly insurmountable choices between

similar or preferential treatment, between neutrality or accommodation, or between integration or separation...' (p.32)

Dyson (2001) suggests these authors point out a fundamental contradiction within the UK and US education systems between an intention to treat all learners the same and equal and an opposite intention to treat them all as different. B

Ainscow (2000) highlights that it is special education that faces these dilemmas in their most acute form, dealing with those students who are most obviously 'different' from the majority. Historically it has been the purpose of special education to address the needs of those who are marginalised. This means recognising difference and at the same time promoting what learners have in common, in terms of their essential human characteristics, their rights and entitlements to education.

Brahm Norwich (2008) compares the way the UK, the USA and the Netherlands hve handled these dilemmas in his book: 'Dilemmas of Difference, Inclusion and Disability: International Perspectives'. He describes how, since the 1960s, the UK education system has generally moved towards a system where there is a greater emphasis on what learners have in common.

The last Labour Government (1997 – 2010) aimed for more inclusive schools with less of a distinction between general education and special education programs and instead, the school is restructured so that all students learn together. National policy was focused on the inclusion of children with special educational needs (SEN). Documents such as the Special Educational Needs and Disability Act (2001), the Special Educational Needs Code of Practice (DfES, 2001) and Removing Barriers to

Achievement: The Government's Strategy for SEN (DfES, 2004) introduced a new programme to develop inclusive practice. It offered advice and support for special and mainstream schools, early years settings and other organisations to develop effective inclusive practice.

The SEN and Disability Act (2001) altered the law to enable a positive presumption of a mainstream placement. This meant that any parent of a child with a Statement of SEN who expressed a preference for a mainstream school placement for their child must have that preference met, unless the LA could show that such a placement would prejudice the efficient education of the other children with whom that child would be educated.

Dyson (2001) suggests that inclusion builds on the strategies of responding to difference, such as flexible teaching styles and materials, resources and changes to organisation and management in schools, and has learned how to maintain students facing considerable difficulties in ordinary classrooms. Inclusion has also added a distinctive value position relating to the rights of marginalised students. It has been suggested that inclusion has led towards conceptualising difference as an issue for all students and towards building an inclusive society (Booth & Ainscow, 1998).

Inclusion is an approach to educating students with special educational needs such as autism. Some see inclusion as being about the child's right to participate and the school's duty to accept the child (Booth & Ainscow, 1998).

Inclusion rejects the use of special schools or classrooms to separate students with disabilities from students without disabilities. A premium is placed upon full participation by students with disabilities and upon respect for their social, civil, and educational rights. Under the inclusion model, children with special needs spend most or all of their time with children without special needs in 'inclusive schools'.

However, inclusion has also caused a great deal of controversy and debate and an 'inclusion backlash'. The emphasis within inclusion on access to common placements and participation in common learning experiences has generated practical and theoretical tensions due to the differences between the learners. There have been calls for 'responsible inclusion' (Garner & Gains, 2000).

In recent years there have been many national policy changes, perhaps most significantly with the election of the coalition government in 2010. In their manifesto the conservative party stated:

> The most vulnerable children deserve the very highest quality of care, so we will call a moratorium on the ideologically-driven closure of special schools. We will end the bias towards the inclusion of children with special needs in mainstream schools. (p. 53)

The new government published 'Support and Aspiration: A new approach to special educational needs and disability' in 2011. This has significant implications for parents of children with autism as it places a great emphasis on parental involvement and choice. Other plans include a new single assessment process and Education, Health and Care Plan by 2014 and a plan that local authorities and other services will set

out a local offer of all services available, again meaning parents will have more choice about how their child is supported.

Lindsay (2003) suggests that:

> Ironically, those who may be seen as less 'correct' with respect to 'true' inclusion may be considered more inclusive of the practices they are prepared to support, promote, foster and develop. Consideration of inclusion, therefore, must take account of conceptual and practical issues and the tensions within and between each domain.' (p. 3)

Dyson (2001) suggests that transformations in special education can be new but at the same time dealing with precisely the same tensions as past resolutions.

1.2.2 Education: The Local Context

<u>The Local Authority</u>

This research was conducted in a Local Authority (LA) in the south east of England which encompasses a number of small towns and rural locations. According to the most recent census (2001) the population is 251,700. The population is predominantly 'White British' (90.2%), with the largest ethnic minority group being 'Asian or Asian British' (3.4%). The socio-economic statuses of the residents are wide-ranging. (Office of National Statistics, 2009).

Recent examination of LA records has highlighted that the proportion of children in the LA with autism is far higher than the general UK population. Wing (1996)

suggests it is possible that there are real differences in prevalence of autism spectrum disorders in different parts of the world, even in different parts of the same country, and at different times. An epidemic of encephalitis, for example, could increase the number of affected children. However, it is very likely that some, even most, of the variation is due to differences of definitions and the difficulty of defining the borderlines of sub-groups within the whole autism spectrum. In the past year in the LA there has been a move from individual paediatricians diagnosing children with autism to a Social Communication Panel of professionals including a paediatrician, Educational Psychologist, pre-school advisory teacher, speech and language therapist and occupational therapist.

Intervention

Nationally, the pattern of intervention and provision for pupils with SEN including autism varies considerably across LAs. Relevant literature regarding research into intervention with children with autism is summarised in the Literature Review chapter.

The LA in which this research took place uses a number of approaches, delivered by a range of specialists. The main approach used in the education of children with autism is the TEACCH approach (Treatment and Education of Autistic and related Communication-Handicapped Children) (Mesibov, Shea & Shopler, 2004). Literature relating to this approach, and other approaches, is critically analysed in the Literature Review chapter. Other approaches employed in the LA include visual supports to present information in a visual way to support children's communication, language

development and ability to process information. Social stories (Gray, 1994) and comic strip conversations (Gray & White, 2002) are also used to help children with autism develop greater social understanding.

<u>Services</u>

There are a number of services and provisions put in place to help children and families with autism at a local level in the LA (documentation will not be quoted due to confidentiality). These include:

Individual Children's Support Service (ICSS)

The Individual Children's Support Service includes a Pre-School SEN Advisor and a team of four visiting teachers that support children and their families, where it is clear that the pre-school child has a significant level of special educational needs (regardless of diagnosis). When professionals believe that a pre-school child has significant social communication needs (whether diagnosed with autism or not) a visiting SEN teacher is allocated to the family. A variety of support is available to the family including, regular home visits to discuss progress and strategies, assessment of a child's needs, help with applications and support to access pre-school settings, liaison with future schools and support in planning transitions to school. This service promotes the use of strategies from the TEACCH approach, described above. Children will often be taught to use a picture timetable and communication will be supported by picture symbols, with the aim being for these strategies to be continued when the child starts school.

Portage Service

Portage is a model of educational provision, originally developed in Portage, Wisconsin, USA, and now found worldwide. It was devised in response to the need to provide home-based services to young children with disabilities and their families. First and foremost, it supports the parents' role as the most important educators and developers of the child. In this LA, this service is provided for children until they are able to access a place in a local pre-school or special needs nursery. In some situations it may be possible to extend this until a child starts at school.

The Autism Outreach Support Service (AOS)

The Autism Outreach Service aims to provide outreach support for mainstream schools, enabling them to successfully include pupils diagnosed with autism. The Service supports schools to develop strategies to ensure appropriate curriculum delivery to pupils who have needs relating to their autism. Strategies from the TEACCH approach are promoted, so that children will have clear visual timetables and visual resources to support their communication.

The Educational Psychology Service (EPS)

An Educational Psychologist (EP) attends the In School Review (ISR) meeting every term in each of their link schools in the LA. An EP also writes the 'psychological advice' report if a statutory assessment is undertaken. The EPS provide advice on strategies and the support a child will require, often liaising with the Autism Outreach Service, but do not comment on placement.

The Communication Team (incorporating Speech and Language Therapy Service)

The Communication Team exists to support the communication needs of pupils in mainstream primary schools, including those pupils with autism. The team comprises of speech and language therapists, specialist language teachers, speech and language therapist technicians and a social skills technician. Usually, a speech and language therapist will undertake an initial assessment and then other members of the Communication Team support the child directly, or support the child's teachers, learning support assistants or parents to deliver the appropriate programme.

In addition there are a number of voluntary agencies (often run by parents) to support families who have children with autism. One of these is linked to the National Autistic Society and another exists to provide advocacy for parents.

Provision

In the LA in which the research took place the services, interventions and approaches detailed above were available to children with autism in mainstream and special schools. The relevant literature relating to comparisons of mainstream and special provision is outlined in the Literature Review chapter. The LA aimed to provide equally effective interventions for children with autism in mainstream and specialist settings. However, there were differences between the mainstream and special provisions, most obviously that in the special provisions all children in had special needs and were in classes of up to ten children, and in the mainstream classes a child with autism might be one of only a few children with special needs in a class of thirty. As with any difference there are pros and cons of each approach, for

example a child in a special school receiving more attention due to a higher staff ratio, but finding it more difficult to socialise with typically developing peers due to lack of experience. Studies exploring parents' views of such pros and cons are included in the Literature Review chapter.

It was the policy of the LA in which the research took place that most children with autism will have their needs met in mainstream schools. Local Authorities are judged on their provision both in terms of effectiveness and value for money (Ofsted, 2004). Placements for children in special schools were much more expensive in the LA and therefore it was the position of the LA that they had a responsibility to ensure that if a child's needs can be met in a mainstream school they should not attend a special provision. The LA's SEN guidance states:

> '...where mainstream provision is capable of meeting the needs of children and young people with SEN, then the education authority and maintained schools should be robust in supporting the aims and objectives of positive inclusion against parental choice, where alternative external provision can be shown to be unnecessary.'

At present there are two LA maintained special provisions for primary aged children with autism:

- A special school catering for children with autism
- An autism unit attached to a primary school

The LA special school is a primary provision for pupils aged 5-11 years with 115 local authority purchased places. Originally designated for pupils with moderate

learning difficulties, the school is increasingly catering for severe learning difficulty and complex needs and since 2004 it has had a designated unit for children with autism. The school provides for pupils across the authority.

The LA autism unit provides for pupils with autism and is based on the same site as a primary school. Sixty children aged from 5-11 years attend the unit and have statements of special needs for their autism. Pupils needs are mainly social, emotional and behavioural difficulties, speech, language and communication needs and moderate behavioural difficulties.

It is the policy of the LA that children will require a Statement of Special Educational Needs (SSEN) to be able to attend either of these special provisions. Children who will go to mainstream school in general do not have statements. The LA Autism Policy states:

> 'A diagnosis of autism in itself does not necessarily constitute a high level of special educational need. Interventions in school will depend on the severity of need and the extent to which the difficulties associated with autism are acting as a barrier to learning.' (p. 5)

Historically some children's placements in out of area provisions and in independent settings had funded by the Local Authority. The LA's SEN Guidance states:

> 'Over the past year in (the LA) we have seen a decrease in new placements made out of area – a major step towards increasing the proportion of our pupils with SEN whose needs are met locally in (LA) maintained schools. We intend this guidance to further strengthen our local capacity for professionals from all the agencies to work in a joined up way to ensure provision for pupils with SEN in (the LA) effectively meets their needs, however complex – and to ensure that parents are involved as partners.'

A very small minority of children with autism in the LA were taught in independent settings or using home-based programmes at the time of this research. The majority of these provisions are funded by the children's families. An examination of the database of children diagnosed with autism as preschoolers and currently in primary school showed that all the children were recorded as having started at a LA maintained school. For this reason the present research focused on decisions about special or mainstream school provision rather than independent or home based programmes.

1.2.3 Education: The Process of Placement Decision-Making

Placement decision making is a long and complex process in the LA in which this research was carried out. It was the policy of the LA that every child attending special provision in the LA needed to have a statutory assessment and Statement of Special Educational Needs written by the LA. It was also LA policy that a statutory assessment will normally only be carried out if the child's needs are complex or it is thought that the child will need to attend a special provision. The statutory assessment produce has many stages and takes up to six months to complete.

<u>Statutory assessment</u>

If it is felt by parents or professionals that a child's difficulties are profound, severe or complex and that they might need to attend a special provision they need to go through the statutory assessment procedure. When a parent, early education setting or school asks the LA to carry out a statutory assessment, it has six weeks to decide

whether to do so. As part of the application the child's family and education setting submit information and evidence relating to why they feel the child needs a statement and usually a special provision.

The child's needs and progress at school are considered by a panel coordinated by the SEN department, in line with the guidance in the SEN Code of Practice, using information provided by the school and parents. The panel is made up of a senior SEN Officer, another SEN officer, an educational psychologist and two members of senior school staff from schools not involved in the particular cases being discussed.

Initial information will also be requested from Social Services and Child Health Services, even though there may be no involvement from those services. The school or early education setting will tell the council about any special help they are already providing to the child. The evidence must show that they child has significant difficulties in one or more of the following areas, against very specific criteria set out in the LA SEN Guidance:

- Communication and interaction
- Cognition and learning
- Behaviour, emotional and social development
- Sensory and/or physical difficulties

Children with autism may have difficulties in all these areas. If this panel agree that there is evidence that the child's needs are significant enough to warrant an assessment an SEN Officer in the LA will be assigned to coordinate the assessment

and to explain the assessment process to parents. Several professionals may be involved in the assessment. In all cases an educational psychologist will write a piece of psychological advice for the assessment. the child's paediatrician may contribute, as well as any other health professionals. The pre-school setting and Individual Children's Support Service (ICSS) professionals will be asked to submit reports.

Parental involvement

Parents have the right to be present at any interview, medical or other test during the statutory assessment. Sometimes the professionals may ask to see the child without them as children sometimes behave differently when a parent is present. Parents will also be asked for their views again. This is separate from asking whether a parent thinks their child should be assessed. Parents are able to suggest any other people or organisations they know whose views may be helpful in the assessment of the child. The LA may then ask for their views. Parents may also send the LA any private advice or opinions collected about the child and these will be taken into account as part of the assessment.

The LA had guidelines to help parents take part in a child's assessment. An EP will always aim to meet with parents to ask about their views of the support their child needs, and this may include any preferences they have about provision and their reasons for this. Parents sometimes received support from parent support groups. The LA may also ask what the child thinks about their special educational needs, usually via the EP.

<u>Decision Making</u>

Once the council's SEN officers have collected all the advice and comments about a child's educational needs, a panel meets to decide whether to make a Statement of SEN for that child. This panel has the same professionals represented but may be different individuals. The statement of SEN uses all the information from the assessment to set out a child's needs and all the special help they should have in a legal document.

They will make a statement if the balance of evidence shows that:

- The child's learning difficulties have not responded to relevant and purposeful measures taken by the school/setting and external specialists over a significant period of time.
- The child's learning difficulties may call for educational provision, which cannot reasonably be provided in mainstream schools in the area via delegated budgets.

If the council decides not to make a statement, it will explain its reasons and provide the parents how it thinks the child's needs should be met in school, in an early education setting or in any other way, as appropriate.

If parents think that the council's decision is wrong and that a statement should be made for their child, they are advised first to talk to the council and the school. Parents also have the right to ask the council for informal resolution of the disagreement and a right to appeal to the First Tier (SEN and Disability) Tribunal.

If a child has a statement then parents then parents can apply for a place at a special provision through the usual school admissions process.

1.3 Research Context

The Local Authority (LA) that commissioned this research had seen an increase in the number of children diagnosed with autism in recent years. There had also been an increasing number of parent-initiated applications for statutory assessments for young children with autism. Many of these applications for assessment had been turned down due to LA decisions that the children's needs did not meet the criteria for assessment and that the needs of many of the children whose parents wanted special provision could be met in mainstream provisions. There was also an increasing number of appeals to Tribunals where parents of young children with autism have disagreed with the LA's decision about provision for their children.

1.4 Research Scope

The scope of this research was discussed by the researcher and commissioners in the LA. It was decided that the research would focus on parental perspectives on choosing special or mainstream schools for their young children with autism. Other provisions and programmes were considered, however it was this decision that the LA were interested to explore. Recent examinations of data in the LA had shown that in the past many applications for assessment and appeals to Tribunal had been because parents wanted independent special schools for their children with autism. More recently these applications and appeals had mostly been from parents wanting

LA special provisions for their children. For this reason the research focused on a comparison of special and mainstream school preferences rather than looking at any other types of intervention or provision. As described earlier in this Introduction there are a wide range of interventions available for children with autism, including home-based programmes. However the authority in which this research was conducted did not provide these interventions and therefore the research scope was limited to choosing LA maintained schools rather than independent settings or home-based interventions.

The LA was keen to gain a better understanding of how and why parents choose particular schools for their young children with autism. In informal discussions questions had been raised about what information about schools parents presently receive and from whom. The LA was keen to explore the factors that influence parents' choices of schools and also to seek their views about the process and services.

Though there is a growing body of research into the views of parents about different types of provision once their children are at school very little is known about how parents make their decisions about the schools they choose. Undertaking this research aimed to give a deeper understanding of parents' experiences and it is hoped this will increase professionals' understanding. This will facilitate the LA to in turn better serve families who are choosing schools for their young children with autism.

1.5 Research Aims

The aim of this research was to explore the factors parents of children who are diagnosed with autism as preschoolers say influence their decisions about choosing schools and their experiences of the process. In particular the research was interested in the differences between the experiences of parents who chose special schools and those who chose mainstream.

The objective of the research was to provide further knowledge about parental perspectives to a range of stakeholders and audiences. These include the LA that commissioned this research to help inform policy, practitioners wanting to apply evidence based practice within the LA and at a national level, and researchers wishing to build their understanding of parents of children with autism.

1.6 Researcher's Position

The researcher has been working with children and young people with autism for more than a decade in a variety of contexts. In her teaching career the researcher taught a number of young children with autism in both mainstream schools, special schools and in a centre for children with autism. The researcher has also volunteered in a residential school and a national centre for autism as a teaching assistant, teacher, assistant psychologist and group leader.

As a Trainee Educational Psychologist (TEP) working for a LA the researcher currently sits on a Social Communication Panel as the EP member of this

multidisciplinary panel for discussing autism diagnosis. The researcher has been involved in a number of cases working with children with autism, their teachers and their parents as a TEP. The researcher has also completed a number of statutory advice reports for children with autism.

The researcher's history of working in both special and mainstream schools for children with autism meant she felt she was able to see the pros and cons of each type of provision. She supported the concept of inclusion but acknowledged that the realities of modern mainstream schools could seem overwhelming for children with autism and their families. She also had an understanding of the processes involved in choosing a school.

The researcher was very interested in the experiences of families. She had found that, although she had been involved primarily in the education of these children, for families this was a small part of their daily lives with their children and their concerns about their children's future. The researcher hoped to gain a deeper understanding of parents' experiences and of their stories and in so doing to give them a voice.

The researcher was very mindful of her position as a researcher commissioned by the LA and also her position working for the LA. The researcher was aware that her own background and feelings would have an impact on the research and for this reason had kept a research diary. She used this to record her reflections during the negotiations of the research scope and aims.

Due to the need for the LA to show it was providing good value for money in education, the commissioners of the research felt they had a responsibility to ensure that if a child's needs could be met in a mainstream school they should not attend a special provision. The researcher was mindful of the LA's reasons for wanting this research to be undertaken and discussed this with her supervisors. It was important to acknowledge that the authority was keen to reduce the numbers of applications for special schools. However, the commissioners were keen that this be a truly exploratory piece of research and wanted to understand parents' experiences. There was no expectation that the research would automatically lead towards a reduction in special school applications. The commissioners were interested in what had made some parents feel confident about their mainstream provisions but also the experiences of parents when choosing schools.

The researcher was mindful that undertaking research based on parental views might mean that her findings might not be in line with the commissioners views but was assured that once the research topic had been agreed she could carry out this research as independently as possible and aim to truly represent the parents' views on their experiences.

Chapter 2 Literature Review

In line with the research aims, the aim of the literature review was to critically review previous studies into parental views and to investigate factors contributing to these views and their resulting decisions. Palmer, Fuller, Arora & Nelson (2001) raise a similar question: 'what leads some parents to enthusiastically embrace the inclusion model while others strongly oppose the practice?' (p. 468).

Relevant studies regarding the range of interventions for children with autism and the effectiveness of different educational provision for children with autism are reviewed, followed by a systematic review of research around parental views and experiences of making decisions about schools for their children with autism.

2.1 Intervention for children with autism

As outlined in the Introduction, autism is a perplexing developmental disorder and a striking feature of autism is its variability. This variability in children is also found in the responses of children with autism to intervention, and among pre- and school children with autism there is a huge range of intervention approaches that serves to demonstrate the range of needs, and levels of need, among children with autism.

Some of these interventions are designed to address the core symptoms of autism – such as poor communication and social skills – while others are designed to address other issues – such as anxiety and self-injurious behaviour.

Existing surveys (e.g. Kasari, 2002) have indicated that there have been few studies of the efficacy of many of the interventions available, thus offering little empirical evidence by which to guide parents or professionals in their choice of action. A study by Green, Pituch, Itchon, Choi, O'Reily, & Sigafoos (2006) used an internet survey involving over 500 parents of children with autism and identified over 100 different programmes which had been or which were currently in use. This section of the Literature Review will summarise the relevant literature relating to intervention for children with autism.

Behaviour modification

Perhaps the best known interventions for children with autism are those focusing on behaviour modification. Lovaas (1987) described an early intensive behavioural intervention with a group of 19 children with autism and stated that '47% achieved normal intellectual and educational functioning, with normal-range IQ scores and successful first grade performance in public schools'. Lovaas' (1987) research led to the development of Applied Behaviour Analysis (ABA) providing evidence that the behavior of autistic children can be modified through teaching. ABA has become an established and extensively studied intervention (Smith, 2001; Goldstein, 2002). It is based on principles of operant conditioning (Newsom & Rincover, 1998) where desired skills are broken down and intervention targets are based on task analysis and the child's task performance. Intervention targets are addressed through massed trials of antecedent–behaviour–consequence chains. Teaching occurs in a non-distracting environment until the skill is acquired. After initial skill acquisition, the

emphasis is on systematically generalising skills to activities typical of the child's daily life.

It has been claimed that ABA has the most evidence for its efficacy with children with ASD (e.g. Granpeesheh & Tarbox, 2008) but it remains controversial and many have questioned the ethics of the approach and whether, despite recent modifications to the approach, the skills taught using ABA are generalisable (e.g. Whalen, 2009) and whether it lives up to the expectations it has created (Shea, 2005).

A recent study by Tzanakaki, Grindle, Hastong, Hughes, Kovshoff & Remington (2012) asked 'How and why do parents choose early intensive behavioural intervention for their young child with autism' and suggested that, although the evidence, of effectiveness of Early Intensive Behavioural Intervention (EIBI) for children with autism is growing, very little is known about the process parents go through in deciding to implement such a program. They interviewed 30 mothers whose children had been on an EIBI program to investigate more systematically how and why they chose EIBI. Typically mothers were informed about EIBI through other parents, books and the internet. Their expectations of treatment outcomes ranged from their child being cured of autism to no clear expectations. Some families had access to funding through their local educational department, some had to fund part or the whole program themselves, whereas some received funding after a dispute with their educational department.

Sensory and dietary treatments

Sensory integration approaches provides guidelines and strategies for facilitating children's ability to automatically process complex sensory information, improve motor coordination, reduce over-or under-reactivity, and improve emotional adjustment as well as social functioning (Ayres & Mailloux, 1981). These approaches provide systematic and individualized 'doses' and types of sensory experience, coordinating sensation with motor planning, using a variety of equipment and sensory-enhancing materials tailored to a child's interests.

Alternative treatments, such as dietary treatments (commonly vitamin or mineral supplementation), auditory integration therapy (designed to reduce sensitivity to particular sound frequencies), music therapy, and scotopic sensitivity treatment have also been found to be effective in some cases (Wong & Smith, 2006).

Specialist Teaching Approaches

Specialist teaching approaches include Treatments and Education of Autistic and Related Communication-Handicapped Children (TEACCH), which stresses the need for structure, elements of behavioural and cognitive interventions, direct teaching of chosen skills, and the use of visual cues to highlight tasks to be done, and work or play areas.

TEACCH is a structured teaching system developed at the University of North Carolina in the 1970s by Schopler (1994) and was defined by as a global approach

based on a close collaboration between parents and professionals. Parents are given the role of 'co-therapists'. TEACCH has been specifically designed for children with autism; it takes into account the disorder's features and tries to minimize the child's difficulties using structured and continuous interventions, environmental adaptations and alternative augmentative communication.

The TEACCH approach involves the physical organisation of the teaching area for both academic and functional teaching. Visual schedules are used that show students what activities they will do and when and work systems are used that inform students about what and how much activities have to be done. Tasks are also organised to inform students on within-task actions (Schopler, Mesibov & Hearsey, 1995).

Many studies have shown the effectiveness of the TEACCH program, which has been implemented in many different countries and adapted to different situations, for example home-based, mainstream schools, special schools and residential centres (Probst & Leppert 2008; Tsang, Shek, Lam, Tang & Cheung, 2007; Siaperas & Beadle-Brown 2006; Norgate 1998; Ozonoff & Cathcart 1998; Panerai, Ferrante & Caputo, 1997). As the TEACCH program can be implemented in both special and mainstream settings it has been described as a tool to help the inclusion of children with autism (Mesibov & Howley 2003; Ijichi and Ijichi 2006).

Other methodologies that have built on these principles include Structure, Positive, Empathetic, Low Arousal, Links (SPELL). The TEACCH basic methodology is used in many of the centres run by the National Autistic Society (nas.org.uk). Its

components also underline how the fundamental need among children with autistic spectrum disorders is a clear routine, and specific help to generalise what is learnt from one setting to another, in an atmosphere in which one seeks to maximise positive relationships and reduce child anxiety by seeking to perceive or anticipate which settings or experiences may be threatening.

Other Specialist Approaches

Other specialist approaches include the Picture Exchange Communication System (PECS). Flippin, Reszka & Watson (2010) describe the PECS as a popular communication-training program for young children with autism. They undertook a meta-analysis to review the current empirical evidence for PECS in affecting communication and speech outcomes for children with autism, and their results indicated that PECS is a promising but not yet established evidence-based intervention for facilitating communication in children with autism from the age of one to eleven years. Small to moderate gains in communication were demonstrated following training but gains in speech were small to negative and they raised concerns about maintenance and generalisation.

Son-Rise is a home-based program for children with autism and other developmental disabilities, which was developed by Kaufman (1995) and his wife for their son, who is claimed to have fully recovered from his condition. The program is a parent-directed, relationship-based play-therapy. However, as described in the Introduction, the consensus within the medical community is that there is no cure for autism.

Williams & Wisharts' research (2003) found that involvement with the Son-Rise Program led to more drawbacks than benefits for the involved families over time.

Another type of intervention are those that specifically aim to support inclusion. An example is the use of 'Circles of Friends' to support and enhance integration of children with autistic spectrum disorders within mainstream schools and to foster social interaction with a wider peer group. Whitaker, Barratt, Joy, Potter & Thomas (1998) studied Circles of Friends and reported that the parents of all forty focus children in the study found that their children were more sociable and outgoing.

Comparing approaches

Panerai, Zingale, Trubia, Finocchiaro, Zuccarell, Ferri & Elia (2009) researched the effectiveness of different educational approaches for children with autism over a period of three years. They compared the TEACCH program implemented at a special school, the TEACCH program implemented at home and at mainstream schools, and a non-specific educational programme. They found the TEACCH program to be effective, with results measured using the Psycho-Educational Profile-Revised (PEP-R) (Schopler, Reichler, Bashford, Lansing & Marcus, 1990) and 'showing positive outcomes in the natural setting, and revealing its inclusive value' (p. 874).

Reed, Osborne & Corness (2007) studied the effectiveness of 3 early teaching interventions (ABA, special nursery placement, and portage) for children with autism in a community-based sample over 10 months. Measures of autism severity as well

as intellectual, educational, and adaptive behavioural function were administered. In contrast to reports in some previous research (Lovaas, 1987), there was no evidence of recovery from autism. Children in the ABA condition made greater intellectual and educational gains than children in the portage program and nursery program. However the nursery program produced the largest in adaptive functioning and this raises questions regarding what the priorities are for improvements are in children with autism.

In general most authors agree that promoting interactive play, the use of clear, visual structure, and the understanding and use of language are key aims for many intervention for children with autism. However, Kasari (2002) describes the fact that researchers and intervention specialists cannot agree on the content, type, and intensity of services that will ultimately promote changes. Kasari (2002) describes how the research-identified early core predictors of later development have not been systematically implemented into intervention programs for children with autism and therefore it is not currently possible to predict which children will need what type and intensity of treatment for which developmental behaviours.

It should be noted that the approaches outlined are relevant to schools which provide specifically for children with autism and not all of these would be routinely available for children placed in mainstream schools. In the LA in which the present research was conducted the TEACCH approach was routinely employed in both the special schools attended by children with autism and elements of this approach were employed in mainstream schools across the LA. Elements of various approaches are often tried in a range of permutations and mainstream provisions can be augmented

by importing some additional strategy - for example, the combination of PECS with admission to nursery or infant schooling employing elements of TEACCH.

2.2 Provision children with autism

As described in the Introduction chapter, a major driver towards the inclusion of children with special needs including autism has been concern that children's rights are compromised by special education. This debate often has political overtones as illustrated by Mary Warnock's views. Having previously been a major figure in the development of children's right to inclusion Warnock (2005) challenged the policy of inclusion, expressing particular concerns about students' social and emotional outcomes and highlighted children with autism as being especially at risk of poor outcomes. As well as the rights debate around inclusion a related, though separate issue, described above in section 2.1, concerns the relative effectiveness of different educational approaches. This section reviews some of the relevant literature into the relative effectiveness of inclusion and special provision for children with autism.

A survey by the Office for Standards in Education (Ofsted) concluded that the outcomes of inclusion were poorly monitored, with few schools and LAs evaluating their SEN provision systematically enough to test effectiveness and value for money (Ofsted, 2004).

Parsons, Guldberg, MacLeod, Jones, Prunty & Balfe (2011) highlight the considerable debate regarding the most appropriate and effective ways of supporting the learning of children with autism. They conducted an international review to

synthesise empirical research and expert evidence to identify best practice in educational provision for these children. Their findings showed that there is insufficiently strong evidence regarding the effectiveness of one type of intervention approach compared with another and they suggest that a range of educational provision should be maintained in order to cater appropriately for a wide diversity of needs. Interventions most often researched were those involving intensive behavioural techniques and some studies, as outlined above, showed these can be successful in teaching specific skills to some children. Parsons et. al (2011) found that there was limited consideration of educational provision more widely in the literature, including the effects of type of setting (as distinct from a specific type of intervention or learning approach). They concluded that more research is needed on other types of educational interventions currently used by parents and in schools as well as greater collaboration between researchers and practitioners to establish what works best for children with autism.

Research into the outcomes for students with autism in mainstream classes is relatively scarce (Barnard, Prior & Potter, 2000; Humphrey & Lewis 2008a) and has predominantly focused on the assessment of negative outcomes such as bullying, anxiety, social isolation and loneliness (Bauminger & Kasari 2000; Chamberlain, Kasari & Rotheram-Fuller, 2007). More recently attention has turned to factors that can enhance the educational environment for children with autism. Humphrey & Lewis (2008b) identified school-based factors implicated in successful inclusion, such as: differentiation of work, developing a predictable and ordered environment, placing the children with autism in quiet, 'well-behaved' classes and providing access to a knowledgeable member of staff for advice on autism-specific issues. Successful

inclusion may also be pursued using peer-mediated intervention strategies which have been shown to have a positive outcome for students with ASD and their mainstream peers (Kamps, Barbetta, Leonard & Delquadri, 1994; Dugan, Kamps, Leonard, Watkins, Rheinberger & Stackhaus, 1995).

Given the limited amount of research comparing special and mainstream schools and the range of researcher perspectives it is not unexpected that parents of children with autism will also have a range of perspectives regarding the 'right' provision for their own child. As parents' perspectives are the focus of this research this area will be critically examined in some detail.

2.3 Parents' perspectives

2.3.1 Details of Systematic Search

Searches were undertaken through bibliographic databases, specifically EBSCO (Elton Bryson Stephens Company)'s PsychINFO, comprising PsycArticles, PsycBOOKS and Psychology & Behavioural Sciences Collection. Searches were conducted in September 2011.

Three key terms were used to search for articles. The search terms 'parental views', 'autism', and 'inclusion' were expanded to include variations such as 'parental choice' 'ASD' and 'mainstreaming' and were broadened further by using EBSCO's thesaurus. This generated variations on the terms such as 'parental perceptions', 'autistic spectrum' and 'special education', which helped ensure more articles were included.

The initial search for studies using all three terms yielded only 2 articles. The search was therefore repeated specifying the inclusion of two of the three terms, which yielded 35 articles. Some titles were discarded because they were deemed unhelpful to the research topic, for example articles that were not peer reviewed and studies that took place within a clinical setting were excluded to ensure appropriateness and relevance to the context being studied. As this research area is very current, studies more than 15 years old were not discussed in detail, though are referred to if particularly relevant.

All the studies selected have at least in part included references to parental views and perceptions, and researched into provision for children with autism exclusively or along with or comparing to other disabilities or needs. The key studies critiqued here in detail have used a variety of methods, including questionnaires in the form of postal surveys and online surveys, and interviews with parents. Some articles were reviewed more thoroughly because they were specifically relevant to the topic under investigation. A large number of the studies discussed here refer to the same literature, depending on their foci and theoretical perspectives, and commonly referred to studies were identified and sought out, along with additional relevant articles from the reference sections of the key studies. These were then accessed via electronic databases on 23rd September 2011.

Table 2.3.1: Studies critiqued in the Literature Review

Date	Author	Origin	Participants	Methodology
1999	Kasari, Freeman, Bauminger & Alkin	USA	113 parents of children with autism and 149 parents of children with Down's Syndrome	Postal questionnaire sent anonymously to parent associations. Responses about current and ideal educational placements and programs compared
2001	Palmer, Fuller, Arora & Nelson	USA	140 parents of children with severe disabilities including autism	Postal 'inclusion survey' with rating statements, compared as statements in 'support' or 'resistance' to inclusion
2004	Leyser & Kirk	USA	437 parents of children with a mild, moderate or severe disability including autism (15)	'Parent opinion about inclusion / mainstreaming' questionnaire. Four factors related to opinions about mainstreaming analysed.
2006	Renty & Roeyers	Belgium	244 parents of children with ASD	Postal questionnaire on parental satisfaction with support and education and follow-up interviews with stratified sample of 15 parents.
2008	Bitteman, Daley, Misra, Carlson & Markowitz	USA	186 parents of preschoolers with autism	Data from telephone interviews with participants about services received and satisfaction compared with nationally representative sample of 3,104 preschoolers with other disabilities
2007	Whitaker	UK	173 parents of children with autism	Postal questionnaire with rating items and open-ended questions about experiences, views and satisfaction. 'Satisfied' and 'unsatisfied' groups compared.
2009	Parsons, Lewis & Ellins	UK	66 parents of children with autism 59 parents of children with other disabilities	Online questionnaire responses about education provision from two groups compared
2010	Frederickson, Jones & Lang	UK	Staff from 26 mainstream schools; 7 with ASD resource bases and 19 without	Semi-structured interviews with a key member of staff from each school

2.3.2 Details of Research Findings from Systematic Review

The studies detailed in Table 2.1 are reviewed critically in turn and their relevance to the present study explored. The first three studies are from the USA and involved using postal questionnaires to elicit the views of parents of children with disabilities including autism. It is interesting to note that chronologically more studies have been carried out in the USA in the past and more recently more studies are being published in the UK in this area. The USA has a longer tradition of an emphasis on individual rights and choice and a historically more litigious culture. As the UK moves towards an education system that is more based on the choices of parents it is interesting that more research is seeming to focus on the views of parents.

Literature on Parental Perspectives

'Parental Perspectives on Inclusion'

(Kasari, Freeman, Bauminger & Alkin, 1999)

Kasari, Freeman, Bauminger & Alkin (1999) published one of the first widely cited studies that looked at impact of, among other factors, the child's diagnosis of autism on parental perceptions of inclusion. This study compared the views of parents of children with autism with those whose children had Down's Syndrome, and the aims related to investigating whether the diagnosis and ages of the children would affect how parents view inclusive educational environments. By comparing these categories of children the authors are adopting a biological and within-child framework in which to carry out their research.

Kasari et al. (1999) devised a series of questions related to inclusion and posted the questionnaire to parents on the mailing lists of two large parents associations. The survey had three main sections. Descriptive information about the family and the child was solicited. The next two sections asked for information about their child's current educational placement and its advantages, followed by what parents viewed as the advantages of their ideal programme for their child. Responses were received from 40% of parents of children with autism, equalling 113 responses, and 53% of parents of children with Down's Syndrome, equalling 149 responses.

Their main findings were that, while about a quarter of parents from both groups commented that inclusion was ideal as long as specialised services were available (e.g. TA support, speech and language therapy), over half the parents of the autistic children commented that their children's current educational needs could not be met in an inclusive environment. This highlights the disparity between the ideology of inclusion and what many parents feel is their reality.

In comparing parents' views of mainstream and special provisions, Kasari et al. (1999) reported a number of findings relevant to the present research. They found the parents of children in special education settings were much more likely to cite teachers as an advantage of their child's current placement than those in mainstream settings. Those in mainstream settings were more likely to cite peers as an advantage. Where parents choose special schools this tended to be for reasons of the child's level of functioning or particular educational needs. For example parents reported that their children would be overwhelmed by a mainstream classroom or needed a particular autism-friendly instructional approach. Where

parents chose mainstream it tended to be because they viewed inclusion as a positive approach to increasing their child's socialisation skills, and some made comments from a real world or social justice perspective, stating they felt it was the 'right thing to do'.

The authors discuss their findings in relation to earlier studies examining parents' views of children with a variety of diagnoses and found a number of similarities. Parents voice concerns about greater teacher-child ratios in mainstream classrooms (Collins, 2005), express a desire for specially trained teachers (Turnbull & Winton, 1983) and are concerned about the social acceptance of their children (Bennett, Lee & Lueke, 1998). However Kasari et al. (1999) note that in their study all these concerns were greater for the parents of the autistic children. They explain this by citing research (Rogers, 1996; Rutter, 1996) that suggests specific teaching approaches work best for children with autism that may influence what parents of children with autism decide their children need educationally. The authors also discuss the typical differences between the characteristics of the groups of children, in terms of their social skills, social motivation, and their ability to learn from other children and argue that children with different types of disability may need different types of provision based on this within-child model of their disabilities.

Though there were significant differences in the views of the two groups of parents about ideal provision, the two groups had no significant differences in the levels of satisfaction with their child's current provision. This is very relevant to the present study. Overall, parents were generally satisfied, but about 40% of both groups would like to change their child's provision. However, based on parents' additional

comments, Kasari et al. (1999) concluded that parents of children in special provision seem more conflicted about what is educationally best for their children, as suggested by the disparity between what they feel is ideal and what they want for their child in the real world.

A number of limitations to this study should be considered. When postal questionnaires are used in this area of research the response rates vary greatly and rarely exceed 50%. Although this questionnaire had a reasonable response rate (40%) it is not clear how representative this is of the sample, and the question of whether parents with particular views or experiences are more likely to reply. Also the data from this study came from parent associations, and may reflect views that differ from the views of families who are not participants in their local parent support groups. This may be partly due to the possibility that parents who join support groups have particularly strong views, or difficult experiences influence them to seek this support.

Another criticism specific to this study is around the categorisation of these children. Down's Syndrome is considered a discrete disorder and the possibility of large within group differences, as well as between group differences, being important is not discussed. Another factor not mentioned is that children with Down's Syndrome can also have autism, although their autism can be difficult to diagnose, indeed it is estimated that around 7% or children with Down syndrome also have autism (Down's Syndrome Association, 2009).

<u>'Taking Sides: Parent Views on Inclusion for Their Children with Severe Disabilities'</u>
(Palmer, Fuller, Arora & Nelson, 2001)

Palmer, Fuller, Arora & Nelson (2001) investigated a slightly different population of children in the USA. They researched parents' views on inclusion for their children with severe disabilities, including autism. The authors take a personal construct psychology perspective, suggesting that views on inclusion are likely to vary from parent to parent, in part due to the variation in their children, and that attitudes towards educational practices are inclined to be multidimensional and difficult to determine.

Participants in this study were selected based on their children being registered on the local authority education databases for services for children with severe disabilities. Of the 3,267 parents who met the study criteria and were subsequently contacted, 995 parents agreed to be involved in the study and were contacted for participation, and a total of 476 surveys were returned from these, representing 15% of the initial number of parents contacted.

Parents written comments regarding inclusive practices were gathered through the use of an 'inclusion survey', which involved reading descriptions of inclusion programs and rating to what extent they felt the programs were a 'good idea' for 'most or all' children, and the extent to which they felt the program would be a 'good idea' for their own child. Parents were also given the opportunity to provide further written comments, and 30% of recipients did so.

They analysed the data qualitatively, dividing the comments into those which reflected support and those which reflected resistance to inclusion. The authors then compared parents' responses to the scale with the additional comments and found that, while 45% of responses to the scale were somewhat positive, only 13% of the additional comments supported inclusion. They suggest this may be that parents of children in special provisions feel the need to justify their choices, given the current trend towards inclusion. This also supports Kasari et al.'s (1999) assertion that parents of children in special provision are more conflicted.

Palmer et al. (2001) aimed to use their analysis of the statements to explore the question 'what specific reasons do parents have for supporting, or not supporting, inclusive placement for students with significant disabilities?' After dividing the statements into those supporting and resisting inclusion they grouped these statements into categories. The thematic category containing the most reason statements supportive of inclusion were those indicating beliefs that the child would experience improvements in academic or functional skills due to higher expectations or additional stimulation, and a fear that special provisions would not provide a challenging curriculum for their child. Other belief statements included a desire for their child to improve their social skills, though it should be noted that this comment was outweighed by fears about friendships by 9:1. Other comments related to the benefits of having their child attend a local school, and views that their children should not be segregated and should be part of a larger society.

The thematic category containing the most reason statements why parents were not supportive of inclusion consisted of beliefs that their child's disability precluded them

from benefiting from participation in a mainstream classroom, citing characteristics such as a their child's lack of self-help skills, lack of language and sensory impairments. The next largest category consisted of statements related to beliefs that inclusion would overburden or negatively impact upon mainstream teachers and other children. Parents expressed empathy for teachers being overwhelmed by large class sizes, poor teaching conditions and teaching children with diverse needs, and also with other children whose learning they felt might be impacted by the presence of their child. The next category comprised statements relating to parents desiring their child be educated in an environment that emphasised basic living and functional skills. Other categories included statements relating to parents' fears about their children's welfare, and concerns that their child might be neglected, or harmed, ridiculed or overwhelmed. Comments also included concerns about the lack of specially trained staff in mainstream schools, and parents wanting their children around others with similar needs and developmental levels.

The authors note that, due to the focus on a specific group of parents and due to the lack of randomisation of the sampling technique, their findings cannot be generalised to other groups of parents. 15% is a relatively low response rate, and only 30% of these made comments that were used in the analysis. Also 36% of parental comments the authors categorised as containing no reason statement that fitted into one of the categories that had emerged, meaning over a third of parents comments were discounted.

Some individual comments that were of interest to the present study included those where parents commented that their child's age was a factor in their views on

inclusion, several stating that if their child had started in mainstream they may have continued, but now that their child has been in special provision they would not consider moving them to mainstream, which is particularly interesting in light of the focus of the current research on parents making decisions about their pre-schoolers.

The most interesting conclusion reached by the study, however, related to the importance of parents perceptions of mainstream. Almost half of the parents said they would feel positive about inclusion if their child was supported as described in the questionnaire, but very few seemed to feel that mainstream schools would be nurturing and accommodating for their child. The authors suggest 'if the (mainstream) classroom is viewed as a place where the teacher is overworked, overwhelmed, and undertrained, the students are intolerant and lack control, and the curriculum is inflexible and irrelevant, then parents are unlikely to camp out to enrol' (p. 480).

Literature on Factors influencing Parental Perspectives

<u>'Evaluating Inclusion: an examination of parent views and factors influencing their perspectives'</u>
(Leyser & Kirk, 2004)

A study by Leyser & Kirk (2004) in the USA examined the experiences, views and attitudes of parents whose children have had a wide range of difficulties and disabilities, including autism, and their perceptions of issues associated with inclusion. They refer to Kasari et al.'s (1999) and Palmer et al.'s (2001) research,

stating that very few studies have examined parental attitudes to inclusion. In this slightly later study the concept of partial inclusion some of the time is discussed, as well as views of mainstream and special provisions.

Leyser & Kirk (2004) aimed to examine the attitudes of a wide sample of parents towards inclusion, and the association of certain variables with the parents' perspectives. They mailed a questionnaire to around 1000 parents and received 417 responses, however only 15 of these were from parents of children with autism. Their questionnaire asked for background information about the parents and the child, followed by a section about attitudes to inclusion. The performed a factor analysis to examine four pre-determined factors related to inclusion, namely the 'benefits', 'satisfaction with special education', 'teacher ability and inclusion support' and the 'child rights' factors.

Over 85% of parents reported strong support to the general concept of inclusion/ mainstreaming, and many strongly identified with the principle of preparing not only the children with disabilities but also their classmates without disabilities to live in the real world. However, around 70% of parents felt that children with disabilities should be educated in a special setting at least some of the time. The majority of concerns raised by parents about inclusion were regarding the emotional wellbeing and possible social isolation of the children. Concerns were also expressed about a child's access to individualised instruction in a mainstream setting, and more than a quarter felt it would not be possible for mainstream teachers to adapt their classrooms and teaching to include students with disabilities. Parents also expressed concerns that regular teachers would not want to teach their children with

disabilities, and fears about how they as parents would be treated. Many comments suggested that support for inclusion would be conditional, for example parents' comments that, 'so much depends on the individual teacher', the program and the school system.

Leyser & Kirk (2004) found a number of factors influenced parental views. The level of severity of the child's needs was found to be significant, with parents of children with mild and moderate disabilities more positive about inclusion than those with children with severe disabilities. The parents of younger children were also more positive. They also found that the amount of time children had been in education affected their views, and the proportion of time their children currently spent in mainstream and special settings. They suggested that parental schooling was also a factor, with more educated parents more positive about inclusion but less positive about teacher ability.

Leyser & Kirk (2004) state in their discussion that the child's welfare is paramount to parents. The main benefits of inclusion recognised by the parents in this study were the potential social and affective outcomes for their children and the positive effects of inclusion on their peers, who are likely to become more accepting to individual differences. However many expressed concerns about whether their child would be socially isolated in a mainstream classroom and whether inclusion would hurt their child emotionally. The research found that parents were also concerned regarding the instructional skills and the availability of time by general classroom teachers, and expressed their views that special education teachers were better skilled to support their children's needs. Leyser & Kirk (2004) conclude that this means more training

needs to be offered to teachers, in part to give them a better understanding of the perspectives of families of students with disabilities, as well as strategies to promote communication and collaboration with parents.

Several limitations of this study should be considered, particularly regarding its relevance to the present study. Data were collected from parents in one mid-western state in the US, meaning these findings cannot be automatically generalised to the UK population. The way the questionnaires were disseminated was not described in detail, as the researchers did not send them directly but through local organisations and schools. The response was around 40%, but again it is not clear how representative this is of parents because of the way the questionnaire was distributed and also potential bias caused by reasons certain types of parents may choose to or not to respond. The authors themselves suggest that other methods of data collection, such as parental interviews, should be used to obtain further and richer information from families.

These three studies carried out in the USA had many interesting findings relevant to the present study. They highlight some of the strengths and weaknesses of using postal questionnaires, some even referring to the fact that supplementing these findings with parental interviews would yield richer data. All these studies compared the views of parents of children with autism with the views of parents with other disabilities.

The next two studies reviewed, one from Belgium and one from the USA, use parental interviews as well as questionnaires to gather data about parental satisfaction with support for children with autism.

Literature on Parental Satisfaction

<u>'Satisfaction with formal support and education for children with autism spectrum disorder: the voices of the parents'</u>
(Renty & Roeyers, 2006)

Renty & Roeyers (2006) conducted research to identify and describe factors associated with variations in the level of parental satisfaction with formal support and education for children with autism in Belgium. They were concerned about the reported shortcomings found in evaluations of services for children with autism. 244 participants were recruited via an advertisement in the national journal of the autism parent organisation, and by being invited by staff at an autism diagnostic centre. Researchers developed a survey which asked these 244 parents for general information about their child, the diagnostic process, pre-school support and their experiences of their child's education. The data resulting from the questionnaire were supplemented with information obtained from semi-structured in-depth interviews with a stratified sample of 15 parents, discussing the same themes as the survey in greater depth.

The study revealed that 51% of parents were satisfied or very satisfied with the diagnostic process, and those who were dissatisfied mainly attributed this to the late

diagnosis of their child. Parents also attributed great importance to the disclosure of their child's diagnosis to them. Parents stressed that how this was communicated, the clarity and the amount of information given to them about autism and support available was very important. Many parents complained that the search for appropriate support and a school place for their child had been very difficult and taken a long time. They complained of difficulties with referrals, admission criteria and the supply of appropriate services for their children.

The authors compared parents of children in mainstream and special provisions and found that the parents of children in special schools were more satisfied. A number of factors were found to impact upon satisfaction, but of utmost importance was the quality of reciprocal communication between parents and the school, and for parents to have information about their child's daily functioning. Parents talked about the commitment and enthusiasm of professionals, continuity of staffing and how fundamental it is that staff understand their child.

Overall they concluded that parental satisfaction with received support and education generally is predicted by parental involvement in formal support, knowledge of available service provisions and the time between their raising initial concerns and receiving a diagnosis and support. They found that, regardless of the age and level of severity of the child's autism, parents attach equal importance to issues such as close cooperation with professionals, the commitment and enthusiasm of professionals, and autism specific knowledge and skills.

This study is perhaps less representative than other studies so far reviewed, as the education system in Belgium is in some ways more different to the UK than the USA. Also at the time of writing the authors reported that there were no autism-specific schools Belgium. Again the use of a questionnaire sent through parent support group channels has an impact on the representativeness of those who responded. The authors do not go into details about how they selected which parents to interview however these interviews yielded rich data which adds to the body of knowledge of parental views and experiences.

<u>'A national sample of preschoolers with autism spectrum disorders: special education services and parent satisfaction'</u>
(Bitteman, Daley, Misra, Carlson & Markowitz, 2008)

Bitteman, Daley, Misra, Carlson & Markowitz (2008) undertook a study of special education services and satisfaction of the parents of pre-schoolers with autism in the USA. They explored the services received by young children with autism and parent satisfaction with these services and contrasted children with autism with children who have other disabilities.

Bitteman et al. (2008) contacted a stratified sample of parents of children with disabilities, seen to be representative by selecting children randomly from groups based on regions, types of provisions accessed and the wealth of the area across the USA. 3,104 parents were contacted, with a sub-sample of 186 children with autism. A parent of each child in the sample was asked to complete a telephone interview about their child and the services they were accessing. Teacher

questionnaires were also used to obtain information about the programmes and related services the child received.

They found that parents of children with autism were generally satisfied, with 87% of parents reporting the quality of services they were receiving as good or excellent, roughly the same levels as parents of children with other disabilities. On average they found that children with autism and other disabilities were roughly the same age when someone first raised concerns about their development, parents took the same amount of time to locate services and start receiving them. This is interesting in light of Renty & Roeyers (2006) findings that parents were dissatisfied with the amount of time it took for their children with autism to start receiving services.

There were several differences in Bitteman et al.'s (2008) findings between the families of children with autism and other disabilities, even controlling for severity of need. Children with autism were found to be receiving support form more different types of service, and though support with occupational therapy, learning strategies, etc. was received by both groups, 'the odds of children with autism receiving these were still significantly greater' (p. 1515). In addition, 46% of children with autism received behaviour management programs compared with only 13% of children with other disabilities. Perhaps most interestingly, pre-school children with autism spent three times more of their total hours per week in special pre-school settings than children with other disabilities.

A pattern emerging from these studies in the USA and Belgium is that how parents feel about inclusion and services for their children is in some ways very different for

children with autism than for those with other disabilities. Many parents seem to endorse the practice of inclusion in theory but would or do have significant anxieties and fears for their children in mainstream classrooms in reality.

The following papers in this broadly chronological overview are all from the UK, increasing their relevance to the present research. It is interesting that a topic that has been researched in other parts of the world seems to be gaining prominence in the UK. These studies particularly focus on children with autism, either exclusively or as a comparison with children with other disabilities.

Research that it is important to mention, as it is so often cited, is research by the National Autistic Society (NAS), including Barnard, Prior & Potter (2000) and Batten, Corbett, Rosenblatt, Withers & Yuille (2006). These studies have identified serious concerns among the parents of children with autism attending mainstream schools. Both these NAS studies found high rates of satisfaction among parents whose children attended autism-specific specialist provision and much lower satisfaction levels among parents whose children were in mainstream schools. However, it must be noted that the studies cited above were carried out to further the campaigning role that is part of the core purpose of the NAS and that all the participating parents were already members of the NAS. It must be borne in mind that since the decision to join an organisation that offers support and advocacy may well be linked to certain experiences or needs, (Mandell & Salzer, 2007) it not possible to know the extent to which these views can be generalised to wider population of parents of children with autism. However, the findings and views expressed in these studies are an important part of the dialogue in the research about provision for children with autism.

Literature on what parents want

<u>'Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say - and what parents want'</u>

(Whitaker, 2007)

Whitaker's (2007) UK study into 'what parents say – and what parents want' regarding provision for youngsters with autism cites these NAS studies as some of the few that have focused on parental perceptions and experience of provision for children with autism, stating that they may not be sufficiently representative.

Whitaker (2007) sought the views of every parent of a child known to have autism living within one LA. Questionnaires were sent to the parents and carers of 599 children in the county who had a formal diagnosis of autism. Parents' views were sought irrespective of their child's placement, however the study focused on the views and experiences of those parents whose children were educated in mainstream settings as part of regular classrooms. 353 of these children, just below 60%, were educated in mainstream settings. The parents and carers of this group returned 173 questionnaires, a response rate of 49%, which Whitaker (2007) reports as being very similar to the responses from the parents of children in specialist settings.

In contrast to Kasari et al.'s (1999) study, Whitaker's (2007) focus was not on what parents perceive to be the ideal but on their actual experiences and perceptions of the provision being made for their children. It used rating scales and open and

closed questions to elicit parental views. Parents were also asked to rate their overall satisfaction with their child's placement.

Of the 172 parents and carers of children in mainstream school who responded to the questionnaire, 61% rated themselves as satisfied or very satisfied, with the educational provision being made for their children. This is higher than the levels reported by the NAS (Barnard et al., 2000). However, Whitaker (2007) caveats this finding with a number of statements that meant this is no grounds for complacency. The fact that almost 40% of parents rated themselves as dissatisfied means that a substantial minority of parents have very real and often urgent concerns about the quality of provision being offered to their children. Many of the parents who described themselves as satisfied still identified significant areas of concern with their child's current provision. Levels of dissatisfaction with mainstream schools were found to be very much higher than for special schools and units, with fewer than one in ten parents of children in special provisions describing themselves as dissatisfied. He found that parents of children with statements were significantly more satisfied than parents of children without, but did not find age to be a significant factor, as reported by previous studies (Kasari et al., 1999, and Leyser & Kirk, 2004).

Whitaker (2007) divided the parents into two groups, depending on whether they reported themselves 'satisfied' or 'dissatisfied'. He points out that parental satisfaction itself provides no guarantee that a child's needs are being met appropriately and, as previous research indicates, parental satisfaction is often related to factors such as the quality of communication with the school. He lists parents' top priorities based on his rating scale, stating the young person's progress

in terms of social skills, staff understanding of the individual's difficulties, the capacity of staff to manage the child's behaviour, the level of structure offered and the child's happiness to be most important. Most of these items were common to both groups, the only significant difference being that the child's happiness was seen as the most important by the dissatisfied parents, but received relatively few nominations from the satisfied group.

Whitaker (2007) found that most striking difference between the 'satisfied' and 'dissatisfied' groups of parents and carers in this study was in their responses to the statement 'most staff understand my child'. Over two-thirds of 'satisfied' parents agreed or strongly agreed with this statement. In very marked contrast almost three-quarters of the 'dissatisfied' parents disagreed or disagreed strongly. Over 80% of 'satisfied' parents and carers felt that they had a good relationship with their child's school. The corresponding figure for 'dissatisfied' parents was substantially lower at 41%.

He reports finding it striking that very few parents comment on the 'technologies' of teaching, and that parents did not seem to expect mainstream staff to have expert knowledge of specific approaches to teaching children with autism. With the exception of wanting direct teaching to develop social skills, they did not seem to be seeking substantial modification to the curriculum for their child. For many more parents (42% of those who responded) it was much more important that staff appreciated the implications of their child's diagnosis, and were able to empathise with their child as an individual living with autism. A willingness to accept the autism

factor when dealing with challenging behaviour was seen as hugely important by parents. He states 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 the quality of home-school communication, which do not entail any autism-specific knowledge or expertise on the part of school staff.' (p. 176).

Parents just seem to want their own expertise, insight and knowledge about their child to be valued. Whitaker (2007) concludes that it is not only the capacity but the willingness of mainstream schools to address the diverse, complex and often challenging needs of children with autism for them to be successful and for parents to be satisfied.

Though this study took place in the UK and is therefore more relevant to the present study there are a number of factors to consider in terms of how representative the findings are. The research took place in one borough in a different part of the UK, and though all parents were contacted it is not possible to know how representative those returning questionnaires were of the entire population of parents. Whitaker (2007) describes in detail how certain factors such as the percentage of responses from parents of children in different ages groups and with statements indicate this might be a more representative sample than other studies, and have better internal validity.

Literature on views and experiences

<u>'The views and experiences of parents of children with autistic spectrum disorder about educational provision: comparisons with parents of children with other disabilities from an online survey'</u>
(Parsons, Lewis & Ellins, 2009)

Parsons, Lewis & Ellins (2009) reviewed many of the above studies and stated that there are mixed messages in the literature with respect to whether parents of children with different disabilities have different views, experiences and expectations of educational provision, or whether parents of children with SEN experience similar challenges and frustrations. They sought to further examine the views and experiences of parents of children with autism about educational provision through comparisons with parents of children with other disabilities.

Parsons et al.'s (2009) study formed part of a larger project investigating the views and experiences of disabled children and their families. One of the areas of interest related to the impact of UK disability legislation, and the authors asked participants what they know about their child's disability rights. This indicates that that the authors were taking a socio-political perspective and advocating for parents who perhaps are not empowered.

In this study they used an online survey to collect and compared the views of parents of children with autism and other disabilities about educational provision across mainstream and special schools in the UK. The link to the survey was posted on a

number of websites for national organisations that provide information, guidance and support for families with disabled children.

Parsons et al. (2009) received 125 responses, 66 from families of children with autism and 59 with other disabilities. The majority were aged 5-16 years, with 51% in mainstream schools, 25.5% in special/ist, 9% in mixed and the remaining 13% did not fall into these categories. They found no association between autism and type of educational provision, so children with autism did not seem to be over-represented in any particular form of provision.

Most parents in both groups stated they had asked their child's school to change in some way to support their child. Some parents commented that, while they were generally content about the current provision, they had fought many battles along the way and had been unhappy in the past. Neither group was reported in any way as blaming the schools or LA's for their child's difficulties, many said that is 'just the way s/he is'. Parents in both groups expressed concerns about the future and their child's ability to get a good job.

There were, however, two significant differences between the groups of parents. Although a majority of parents in each group said their child attended the school of their choice, parents in the autism group were significantly less likely to agree that they had enough information to decide which setting was best for their child, and significantly less likely to agree that they were able to choose the setting.

Their results also showed that whilst there are some differences in experiences between groups of parents, their views were more similar than different both in relation to positive aspects of provision as well as areas for improvement. Interestingly, their findings led them to argue that improvements in educational provision need to support all children with special educational needs or disabilities rather than singling out a group of children with particular needs. They discuss in detail the pragmatic acknowledgement by parents of the practical realities of the everyday difficulties of their children, and the inadequacy of a social model of disability for capturing the reality of everyday life for many such families (Shakespeare, 2006).

There are a number of limitations to this study. Using an online survey meant that only computer-literate parents could take part, and the method of disseminating the link meant that only parents with knowledge of support groups could access they survey. As with much of the research in this area, parents from these contexts were self-selected, and findings could therefore over-represent particularly strong views or unusual experiences. The survey collected information about the family's ethnicity, socio-economic status, and location in the UK, and the authors state that the participants were very much skewed towards professional parents. This is unsurprising given the use of an online survey (Tourangeau, Rips & Rasinski, 2000). The authors did however, feel the geographical spread of responses made their findings more generalisable to the general UK population.

Literature on provision options

<u>Inclusive provision options for students on the autistic spectrum?</u>

(Frederickson, Jones & Lang, 2010)

Frederickson, Jones & Lang (2010) studied views of inclusive placements for children with autism. They state in their introduction that parental views of inclusive placements are consistently more positive where there is an autism resource base in the school, and their study was designed to investigate characteristics of the provision available to pupils with autism in mainstream schools with and without a specialist autism resource base.

Frederickson et al. (2010) take a more positivist position than many other researchers in this area, seeking to find out the facts about differences in provision and what is actually provided in different settings. They gathered information from semi-structured interviews with staff in 26 schools, 7 of which had autism resource bases and 19 without. They provide a very robust justification for their methodology, linking the issues in the literature with their areas of questioning, namely levels of inclusion and support, the strategies used to support pupils with autism, both at an individual and whole school level, and changes considered desirable.

The results are presented clearly in terms of the whole school and individual strategies that each type of provision uses, based on the information from the interviews. The key differences seemed to be around the knowledge and understanding of staff about autism, with this unsurprisingly being greater in schools

with an autism base. The authors argue, however, 'it was clear that schools without resource bases could make comparable provision given appropriate staff training and awareness' (p. 71) They recommend that greater use of evidence-based peer-mediated strategies to support social inclusion across all types of placements may be a valuable direction for future development.

Frederickson et al.'s (2010) study has slightly different limitations to many of the others reviewed here. Information was collected from one source only, the school staff, and it was commissioned by a Local Authority (LA) so there is a significant danger of a self-serving bias. The study was limited to this one LA which, although is very relevant to the present research, cannot be considered representative. The study also focuses on the inputs and the provision the children receive, and does not appear to consider the outcomes, and the experiences of the children and their families given these inputs.

2.4 Conclusions

The theoretical frameworks of the authors in the research reviewed in this section are never explicitly stated but the way discussions and questions are phrased and posed highlight a range of models. Many of these studies use a within-child model of disability, as the diagnoses of the children are part of what define the research. In several of the studies the parents expressed the view that their ideology is one of inclusion and that they believe strongly in the rights of their children to be included in society. However, many express the view that the social model of disability is inadequate for explaining the reality of their lives with children with autism.

The studies reviewed use a number of research techniques, predominantly questionnaires and interviews. Some authors suggest that using a combination of these techniques would be ideal to gain an overview of parents' views and also in-depth data about their experiences.

This critical review of the research indicates that there are a large number of factors that can influence how parents feel about inclusion and the type of provision they want for their child. The data gathered from parents in all these studies demonstrate how confused and conflicted they feel about making decisions about what's best for their child when there are so many theories and approaches available to them. The evidence from these studies indicates that these choices are more challenging and complex for parents of children with autism than other disabilities. Many parents voice real concerns about their children's emotional and physical safety and wellbeing.

A range of theories underpin research about the reasons for parents views and preferences. The research suggests that, while parents' views of the world, disability and social justice are important, parents who are making important decisions regarding what is best for their child are unlikely to be perceived as social or educational experimentation with their child's wellbeing at stake. Negative reactions held by some may be in part a backlash from those who feel that the philosophy or ideals of inclusion have been imposed on them without their consent or input, for example one parent commenting that inclusion is 'like any other fad, it is being

evangelised as a cure-all. It isn't. It's terrific in some cases. In others, it is child abuse.' (Palmer et al. 2001, p. 482).

Although there is a growing bank of research into parental views about inclusion and provision, there seems to be little research into how parents make their decisions about provision when their child is still in pre-school. Some of the research reviewed indicates that parents of younger children are more positive about inclusion and its benefits to their children. However, even parents of pre-schoolers have shared their fears about mainstream schools not being able to meet their children's needs. The purpose of this research was to explore how parents of pre-schoolers with autism decide on their preferences for mainstream or special schools.

Chapter 3 Methodology

The purpose of this chapter is to make explicit the research approaches employed in the present study. A rationale is offered for the procedures that were used in order to collect and analyse the data. Consideration is also given to issues relating to ethics, validity and reliability within the study.

3.1 Purpose of Research

The purpose of this research was to gain a deeper understanding of the factors that influence how parents of young children with autism make decisions about the type of school provision they want for their child and their experiences and views of making these decisions.

This is an exploratory piece of research using a mixed methods design, with a quantitative stage being followed by a qualitative stage.

The quantitative stage of this research had two parts. The first part was an a exploration of the demographic data held by the LA about the proportions of pre-schoolers who had started school at special and mainstream provisions over a six year period. The second part explored the factors which influenced how these parents decided on the type of school provision they selected for their young children with autism. To do this quantitative data was collected from parents via an online and postal survey.

The qualitative stage was an exploration to further explore these facts and to gain an insight into parents' experiences and views of the process of making these decisions via semi-structured interviews.

The main purpose of the research was to gain a deeper understanding of the way in which parents make decisions which is why the qualitative stage had a heavier weighting in terms of data collection and analysis. The quantitative stage carried less weight, but provided an understanding regarding the factors effecting how these parents make decisions, and it was expected at points this would converge with the qualitative findings.

3.2 Research Aims and Objectives

The research aimed to explore the following questions:

Quantitative phase:

Research Question 1: Over a six year period what proportion of pre-schoolers with autism attend special and mainstream schools when they start school?

Research Question 2: Over a six year period what is the trend for pre-schoolers with autism starting at special and mainstream schools?

Research Question 3: How do parents of children with autism rate their children's special and mainstream schools?

Quantitative and qualitative phase:

Research Question 4: What factors do parents of children with autism say influence their choice of school?

Qualitative phase:

Research Question 5: What do parents of children with autism say about their experiences of making the choice about which schools they want for their children?

Research Question 6: What do parents of children with autism think would improve their experience of choosing a special or mainstream school?

3.3 Ontology and Epistemology

3.3.1 Ontological Position

When establishing the research methodology the first principle was to decide upon the research paradigm (Doyle, Brady & Byrne, 2009). Morgan (2007) defines research paradigms as the set of beliefs and practices that guide a field. It is important to choose a suitable paradigm in order to yield the most valid and reliable data. The contrasting paradigms that informed this study are positivist (quantitative) and interpretive (qualitative) methods. Each approach has a different view and understanding of parents' experiences regarding the choosing of schools.

Quantitative research

Quantitative research has been described as a formal, objective and systematic process in which numerical data are utilised to obtain information about the world (Burns & Grove, 1991). This empiricist tradition goes back to the early days of scientific research when the types of problems being investigated did not include human behaviour (Verma & Mallick, 1999). This approach suggests that researchers should eliminate their biases, remain detached and uninvolved with the objects of their research and test or empirically justify their stated hypotheses (Tashakkori & Teddlie, 1998). The commissioners of this research wanted some quantitative findings to be included in the research as they were keen to have some 'hard' data about pre-school children with autism in the LA.

However, the commissioners also wanted to know more about the experiences of parents when making decisions about the provisions they want for their children, and their thoughts about how they could best be supported. An interpretive approach was needed to explore the latter brief.

Qualitative research

Qualitative research tends to be concerned with meaning and how individuals experience and make sense of the world around them (Willig, 2001). This is sometimes referred to as the interpretive approach as it considers meanings and searches for evidence in context. The aim of using this method is to reveal valuable qualitative data about parents' experiences of making decisions about provision

within the LA. It offers parents the opportunity to comment on and further understand the process and factors involved in decisions made by parents in the LA.

The interpretative approach seeks to generate and explore hypotheses rather than test hypotheses, and lends itself to using more descriptions than factual statements. Interpretive methods seek evidence in context and are based on the belief that subjectivity is important, rather than isolating factors and variables. An interpretative approach lends itself to data derived from semi-structured interviews. Rich in-depth data derived from semi-structured interviews gives detailed information concerning parents' experiences and views.

3.3.2 Epistemological Position

Epistemology is the branch of philosophy dealing with the theory of knowledge. Philosophical ideals often remain largely hidden in research but they still influence the practice of research and need to be identified (Slife & Williams, 1995). The researcher's philosophy of how knowledge is acquired will have an influence on how the researcher goes about their research. There is a wide spectrum of epistemological positions adopted in research. At each end of the spectrum are positivism (also known as empiricism), often used in quantitative research, and constructionism (also known as relativism), often used in qualitative research focusing on individual experiences. The researcher chose pragmatism as an epistemological foundation of the present study as a middle ground between these two positions, since this fits with the mixed methods approach adopted, encompassing quantitative and qualitative methods.

Pragmatism's position is to find a workable solution by establishing a middle ground between a range of philosophical dogmas (Johnson & Onwuegbuzie, 2004). Pragmatists advocate using whatever methodological approach works best for a particular research problem (Robson, 2002). This has led to mixed method approaches where both quantitative and qualitative approaches are used within a piece of research, where different questions are being asked.

The LA that commissioned this research wanted an analysis of 'hard' data about the factors which effect how parents of pre-schoolers with autism make decisions about the types of schools they want for their children. This required working with quantitative data and therefore working within the positivist paradigm. However, the main thrust of the investigation was to understand parents' views and experiences of making these decisions, which requires working with qualitative data collection and analysis and adopting a constructionist (or interpretative) position. Therefore, pragmatism was used as an epistemological position because pragmatism is not committed to any one system of philosophy and reality. Pragmatism is viewed as a way to avoid many ethical and philosophical disputes that have traditionally existed in research.

The pragmatist position was compatible with researcher's working context and ethos of real world research. The epistemological position of pragmatism is well suited to the aims of this research and the variety of research questions posed, and fitted with the methods adopted in order to answer the research questions.

For the purpose of this research a mixed methods approach was chosen in order to collect qualitative and quantitative data to address the research aims and research questions. These approaches draw on different epistemologies, and though these might appear to be conflicting, it is becoming more commonplace in research to combine two approaches. Silverman (2000) suggests there are distinct advantages to be gained from the juxtaposition and integration of these two styles of research in order to reach an informed conclusion. The researcher felt a mixed methods approach would enable her to capitalise on the advantages from both quantitative and qualitative measurement techniques.

Willig (2001) states that qualitative research allows the researcher to tap into the perspectives and interpretations of participants, and that qualitative research tends to be open-ended in the sense that the research process is not pre-determined or fixed in advance. As a result, unjustified assumptions, inappropriate research questions, false starts, and so on can be identified, and the direction of the research can be modified accordingly. Using an interpretative approach however means that alternative interpretations of the research data are always possible and all researchers working from within the pragmatist paradigm need to address the role of reflexivity in the research process.

Greene, Kreider & Mayer (2005) argue that mixed-method inquiry provides stronger validity and less obvious bias and is therefore more defensible. They argue that using multiple perspectives develops a more complete portrait of our social world, and is therefore more comprehensive.

Pragmatic methods of research using mixed methods have been described as the third research paradigm, sitting between qualitative and quantitative. It is defined by Johnson & Onwuegbuzie (2004) as 'the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study' (p. 120). Johnson & Christensen (2004) outline the advantage of using mixed methods research in terms of combining the strengths of both quantitative and qualitative research processes.

3.4 Research Design

A mixed methods approach meant that both quantitative and qualitative data was used to meet the pragmatic research brief. The researcher acknowledged that the LA required some numerical data and that these numbers were valuable. The data collected in the quantitative part of the research provided core information that was required to understand the size of the issues. This quantitative information can be seen as the 'facts' which underpin the research. A large amount of quantitative data could be collected and the large number of participants gave weight to the quantitative data.

In contrast the qualitative data in this study explored a very small number of parents' experiences of choosing provision. This added individual personal experience and enabled a deeper understanding of the quantitative data about the factors that influenced how parents made these choices in the LA. Though more emphasis was placed on the qualitative findings in the research the author felt that in this mixed

methods research both the quantitative and qualitative parts were valuable. This research design fitted with the researcher's position of pragmatism.

The following are the primary reasons for using mixed methodology in this study:

- Mixed methods enhanced the richness of the data by gathering a range of information on the same issues (i.e. factors affecting how parents of pre-schoolers with autism decide their provision preferences).
- Using mixed methods enabled the researcher to overcome the weaknesses of either quantitative or qualitative methodologies.
- The researcher was able to ask a broader range of research questions due to not being confined to a single approach.
- The value of this approach lay in the integration of data from several sources, which leads to enriched information and clarification through the convergence of data sources (Cresswell, Fetters & Ivankova, 2004).
- A mixed methods approach complimented the epistemological position of pragmatism, which was at the core of the research.

3.5 Description of Sequence and Weighting

A two-staged mixed methods sequential design was used, including quantitative and qualitative data collected over two consecutive research stages. Due to the sequential nature of the research, the participants and procedures undertaken to collect and analyse the data for each phase is outlined in turn.

The qualitative and quantitative datasets provided opportunities for complementarity, which resulted from one method clarifying and illustrating the results of another method. The term complementarity is used to distinguish the additional purpose of clarifying meaning or more fully explaining results.

In this study the analysis of interview data about parents' experiences and views about their preferences will add further and richer information about the trends in the factors identified in the LA. More weight was given to the qualitative data collection and analysis.

Timeline:

Table 3.5: Timeline of Research Activity

Date	Research activity
Autumn 2010	LA database accessed and analysed
Autumn 2010	Questionnaire designed
Autumn 2010	Questionnaire piloted
Spring 2011	Questionnaire sent
Spring 2011	Questionnaire data analysed
Summer 2011	Semi-structured interview designed
Autumn 2011	Semi-structured interview piloted
Autumn 2011	Semi-structured interviews conducted
Winter 2011	Semi-structured interview data analysed

The quantitative and qualitative stages are described in turn.

3.6 Quantitative Stage

3.6.1 Description of Participants, Number and Selection

Quantitative data was collected and analysed from the Individual Children's Support Service database, which held information on all the primary school-age children in the LA who had received a diagnosis of autism while they were pre-schoolers. This enabled information to be collated about where these children had started school. In total the parents of 153 children were sent questionnaires, as detailed below, and 33 returned completed questionnaires.

3.6.2 Procedures

Questionnaire design

Robson (2002) states that a good questionnaire provides a valid measure of the research questions, gets the co-operation of respondents and elicits accurate information. The researcher's central task was to link the questionnaire questions to the following research questions:

Research Question 3: How do parents of children with autism rate their children's special and mainstream schools?

Research Question 4: What factors do parents of children with autism say influence their choice of school?

For this research the research questions were asked explicitly as part of the questionnaire, for example 'What are the factors that affected your preference of school for your child?' The researcher aimed to make the questions accurate and exhaustive, in a number of cases by listing options and providing the opportunity to include response options not imagined by the researcher.

To help ensure the validity of the questionnaire a number of specific techniques were employed by the researcher. Following the advice of De Vaus (1991), the researcher took care to avoid problems in wording questions. The specific points relevant to the design of the questionnaire that were relevant to this research included the following:

1. Avoid jargon and keep language simple.

2. Keep questions short.

3. Avoid double-barrelled questions.

4. Avoid leading questions.

5. Avoid questions in the negative.

6. Ask questions the respondents are likely to have the knowledge to answer.

7. Try to ensure the questions mean the same thing to all correspondents.

8. Remove ambiguity.

9. Avoid direct questions on sensitive topics.

10. Ensure the question's frame of reference is clear.

To help ensure that the parents completed the questionnaire a number of steps were taken to enhance the likelihood of parents returning the questionnaire. Robson

(2002) states that the appearance of the questionnaire is vital. An online tool was used to ensure a simple and attractive layout. There was a simple design with clear instructions about how to respond. The contents were arranged to maximise co-operation. A paper copy of the questionnaire was sent to give the opportunity to respond by post or online. This copy was identical to the online copy. (see Appendix 1).

Pilot study

The author designed the questionnaire as above and before sending it sought advice from a number of stakeholders including the Educational Psychology team. Minor amendments were made in terms of layout. The author then took the draft questionnaire to the LA Autism Steering Group which included a number of parents of children with autism, members of the Autism Outreach Service, a pre-school advisory teacher, head teacher and a number of therapists. Further minor amendments were made, such as including 'access to therapists' as a potential factor for parents when choosing schools.

3.6.3 Strategies for Data Capture

The questionnaire was sent to participants during the spring term of 2011. Quantitative data was obtained from an online and paper questionnaire sent to the addresses of parents meeting the criteria for the sample, accompanied by a letter of explanation (see Appendix 2). All participants were fully informed about the purpose of the research, the method of data collection and of their individual rights with

regard to confidentiality, anonymity and consent. Sending information by letter provided participants with time to read over and digest the information. The letter informed parents that their consent would be assumed should they choose to complete the questionnaire.

The questionnaires were completed online or returned in the post to the researcher. These questionnaires provided a range of information, focusing on the factors that the parents said affected how they formed their preferences for the schools they wanted their children to attend. Questions were also asked about older siblings, support groups and preschools attended. A satisfaction rating with their child's provision was included.

This technique has been widely used in the literature and has the advantage of accessing a large sample of participants. Questionnaires also assure comparable findings, where quantifiable data can be gained and replication is possible, increasing the reliability of the data. However, this assumes that all participants interpret the questions in the same way, and that the data can be directly compared. In reality it can be argued that there is always an element of personal interpretation in the answers respondents give, and therefore wording the questions the same way cannot ensure reliability. Structuring interviews rigidly can mean a lack of flexibility, as participants are not allowed to expand on the information given.

3.6.4 Data Analysis

The data was analysed to address the research questions using descriptive statistics, which examine trends and patterns to answer the research questions. Results are presented pictorially, using tables and graphs, in the next chapter.

3.7 Qualitative stage

3.7.1 Description of Participants, Number and Selection

Qualitative data was collected from semi-structured interviews with parents about their views and experiences of choosing schools. Participants were those who had volunteered to participate by indicating their willingness and providing their contact details at the end of the questionnaire. Two participants were excluded for ethical reasons because they were known to the researcher through her work as a Trainee Educational Psychologist in the LA. The remaining six volunteers took part in the qualitative part of this research. Willig (2001) states that 'qualitative research tends to work with relatively small numbers of participants. This is due to the time consuming and labour-intensive nature of qualitative data collection and analysis' (p. 17). Cresswell (2009) states that researchers are free to choose the methods, techniques and procedures of research that best meet their needs and purposes.

Table 3.7 shows a brief overview of information on each of the participants who took part in the semi structured interviews. This information was collected via the postal survey.

Table 3.7 Information relating to the interviewees' children:

Name	**George**	**Max**	**Raphael**	**Fred**	**Lily**	**Harry**
School	M	M	M	S	S	S
Age	7	6	4	7	4	7
Gender	M	M	M	M	F	M
SEN Code	SA+	SA+	SA+	SSEN	SSEN	SSEN
Siblings	two older sisters	younger sister	older brother	none	none	None

Legend:

SSEN = Statement of Special Educational Needs

SA+ = School Action Plus

M = Mainstream Primary

S = Special School

Three parents of mainstream children were interviewed and three parents of children at special schools were interviewed. All of the children had attended pre-school. The parents were all the birth parents of the child and were all mothers. Five of the six the children were male.

3.7.2 Procedures

Qualitative data was collected via semi-structured interviews with parents to provide richer data and add depth to the quantitative data collected. The researcher considered many factors when making decisions on how to capture qualitative data using interviews.

Semi-structured interviews were chosen because the author wanted to understand the complex nature of parents' views and experiences. As each parents' experiences and views were different the author was keen to allow them the freedom to express their perspectives. The semi-structured interview technique helps parents to respond in a conversational manner while being reassured by the flexible structure and direction of the questions. Using the combination of structured and unstructured techniques fits with the author's epistemological position of pragmatism, as pragmatists do not see the world as absolute unity. Creswell (2009) states that mixed methods researchers look to many approaches for collecting data rather than subscribing to only one way. It was the aim of the researcher to give reassurance to the participants by providing a structure to the interview but also to give them the freedom to tell their stories.

Semi-structured interviews were used to give flexibility and the opportunity to pursue lines of inquiry that emerged during the interview and allowed the parents to give a detailed account of their views and experiences. Smith, Harre & Langenhove (2005) state that semi-structured interviews and qualitative analysis are especially suitable where the researcher is interested in experiences or issues that are personal. Semi-

structured interviews were deemed to be appropriate as the research questions being investigated in the present study focus on participants' experiences and views. In this way the researcher can explore the participants' perspectives and opinions through the flexibility of the interview structure.

Semi-structured interview formulation

The researcher adhered to Smith et al.'s (2005) sequence of four stages for producing an interview schedule. The four stages are:

1. Determine the overall issue to be tackled in the interview and think about the broad range of themes or area of questioning you want the interview to cover. In this study this was informed by the findings of the quantitative phase of the research, and by previous research in the area.

2. Arrange areas of interest into an appropriate sequence in a logical order, leaving sensitive topics until the latter point of the interview to allow the respondent to become relaxed and comfortable.

3. Think of appropriate questions related to each area/theme/research question in order to address the issues identified.

4. Formulate prompts and probes which may follow from answers given to some of the questions.

The researcher also adhered to Smith et al.'s (2005) recommendations regarding the principles of constructing interview questions, which are:

1. Questions should be neutral rather than value laden or leading.

2. Jargon should be avoided. The language of the respondent should be used and questions framed in a way that will ensure they feel familiar and comfortable.

3. Try to use open ended questions as closed questions encourage yes/no answers. It is the intention to encourage the respondent to open up about his or her thoughts and feelings.

These were specifically related to the research questions (see Appendix 3):

Research Question 4: What factors do parents of children with autism say influence their choice of school?

Research Question 5: What do parents of children with autism say about their experiences of making the choice about which schools they want for their children?

Research Question 6: What do parents of children with autism think would improve their experience of choosing a special or mainstream school?

Pilot study

To improve the validity and reliability of the interview questions the semi-structured interview was piloted by talking through the interview questions with a parent member of the Autism Steering Group. The pilot responses were not included in the data analysis. This ensured that participants involved within the research fully

understand what is being asked of them (Hayes, 1997). This pilot interview tested the comprehensibility of the questions included within the interview schedule and ensured that there were no unforeseen ambiguities. Any new avenues that could be investigated further in the final interview questions could also have been highlighted. This pilot interview also allowed the researcher the opportunity to gain experience of conducting the interview and using the recording equipment. This improved the accuracy and the descriptive validity of the data collected.

3.7.3 Strategies for Data Capture

Interviews were arranged with parents during the autumn term of 2011. All participants were fully informed about the purpose of the research, the method of data collection and of their individual rights with regard to confidentiality, anonymity and consent. Participants who had expressed an interest were contacted by telephone. All six participants remained interested in participating and mutually agreeable dates and times for the interviews were arranged.

At the beginning of the interview the researcher reminded parents how the interview was going to be conducted and consent was given to record the interviews. The researcher explained why a recording of the interview is being made and how it was going to be used. The researcher explained this to participants to ensure they were comfortable and relaxed in the presence of an audio recording device, and obtained consent (see Appendix 4).

Participants were then interviewed using the semi-structured interview. The researcher modified each semi-structured interview as she felt appropriate. Cresswell (2009) describes how a semi-structured interview is open to modification according to how the researcher perceives what is appropriate, for example changing the order of questions if a participant seems keen to talk more about a particular area. The researcher also gave additional explanations, left out questions that seemed inappropriate or that have already been answered by the parents' other responses, and this was particularly useful if the opportunity to include additional follow up questions occurred. This process allowed unexpected themes to emerge and to be investigated.

Questions were asked in an open-ended format in order to develop a dialogue in which parents could discuss their experiences openly, whilst ensuring that key topic areas were covered across the sample. The author used consultation techniques such as circular questioning during the interviews. Circular questions are characterised by a general curiosity about the possible connectedness of events rather than a specific need to know the precise origins of a problem (Tomm, 1988). This was also particularly useful given the research questions around whether there are particular factors that affect preferences, for example advice from others. This enabled the researcher to go back to interesting comments and prompt the participant to unpick the meaning behind the comment in more depth and explore where this view or perception has come from. The parents were given the opportunity to add any further comments at the end of the interview. The interview structure was flexible enough to allow for following up issues raised by the

interviewee that may not have been anticipated. Participants were given a short de-brief and were thanked for their time and effort.

3.7.4 Data Analysis

Interviews were audio taped and transcribed verbatim by the researcher. In order to maintain reliability, transcripts were double checked to make sure that they did not contain mistakes during transcription. In order to ensure reflexivity of the researcher's own position and bias a research diary was kept. This helped the researcher to track feelings, prejudices and assumptions and identify areas of researcher bias (Robson, 2002).

The data obtained from interviews with parents was analysed using thematic analysis. Banister, Burman, Parker, Taylor & Tindall (1994) describe thematic analysis as an appropriate means by which to analyse interview data when answering specific research questions. It provides a way of identifying and analysing patterns or themes within a dataset (Silverman, 2000). This method was selected as a way to present a broad range of findings about individuals' views and experiences, while also drawing out themes and commonalities.

Thematic analysis is widely used in research in psychology. Braun & Clarke (2006) state that it can offer a more accessible form of analysis, particularly for those relatively new to qualitative research. It was also chosen as Braun & Clarke (2006) suggest that thematic analysis can generate unexpected insights as it enables researchers to be flexible and unexpected themes and insights can be explored.

Thematic analysis was deemed by the researcher to fit well with the position of pragmatism, as it is not tied to a particular epistemological position. Many forms of qualitative analysis are theoretically bounded. Braun & Clarke (2006) describe how Interpretative Phenomenological Analysis (IPA) for example is specifically tied to a phenomenological epistemology.

Thematic analysis can be used in an inductive way, known as 'bottom up', where themes are not pre-determined (e.g. Frith & Gleeson, 2004) or in a theoretical, deductive way, known as 'top down', where the themes to be analysed are decided before data is collected on these themes (e.g. Hayes, 1997).

In the present study thematic analysis occurred at an inductive level. Although some data had been collected about the factors affecting parents' preferences, the themes to be analysed about their views and experiences were not pre-determined. The aim was to draw out common themes from the parents' narratives in order to develop a coherent sense of parents' views and experiences of choosing schools.

An inductive approach was also deemed to be appropriate as this research was of an exploratory nature. The aim of using this approach was that the parents' conversations and the themes generated through the analysis are strongly linked as they are generated from the data, rather than being decided in advance. This also gives the opportunity for unexpected themes to be identified and analysed.

The five stages of thematic analysis outlined by Braun & Clarke (2006) were used in this research.

Stage 1: Detailed reading of the data

The data obtained from the interview transcriptions of the interviews with parents were read a number of times and initial thoughts were noted. Braun & Clarke (2006) explain that 'immersion usually involves repeated reading of the data, and reading the data in an active way – searching for meanings, patterns and so on' (p. 87). Initial notes were recorded from the first readings that related to concepts and phrases the researcher considered interesting or significant, and related to the findings of the first phase of the research (see Appendix 6).

In stage 1 concepts included how hard it is to be a parent of a child with autism and how difficult the process had been. The parents shared a range of advice and phrases included that there was a need for 'emotional support for parents' going through the process.

Stage 2: Generating initial codes

After the data was familiar to the researcher, the researcher created codes based on the concepts and phrases that were relevant or striking (see example transcript, Appendix 7).

A coded response to a question in one of the interviews is shown below:

'So to start with Ginny maybe you could tell me a little bit about George?'

Yeah he's a loving child. He's always inquisitive. He always wants to know what's going on, he needs to know in advance really. He's always saying 'what are we doing, where are we going', you know, 'who's going', things like that. He's generally a happy child but he just needs to know where his boundaries are really, as soon as you start changing things and things like that which can be quite difficult, when it's sort of day to day life where it doesn't always work by structure all the time he gets a little bit apprehensive but generally he's quite happy, you know a contented boy which is good. There was a time when he wasn't but hopefully now he's sort of settled down and he's doing really well.	1. Loving child 2. Happy child 3. Needs to know things 4. Difficult in the past

After reading each section several times relevant phrases and concepts were coded. In this section the researcher felt that it was striking that the first thing the parent said about her child was that he was loving, so this was coded as 'loving child'.

In this section the mother also mentioned 'he's a generally happy child' and ' he's quite happy, you know a contented boy' which the researcher also felt was significant as even when she was talking about some of the things her child found difficult

seemed keen to stress that he was happy and this was important to her. This was coded as 'happy child'.

In this section the mother also talked about her soon being 'inquisitive' and that he 'needs to know things in advance' and 'needs to know where his boundaries are'. The author coded this as 'needs to know things'.

The author noted that although the mother had talked about her child being happy she mentioned 'there was a time when he wasn't but hopefully now he's sort of settled down' which the researcher felt was significant given the context of the interview being focused on times in the past and coded this as 'difficult in the past'

When all the data had been initially coded and collected and the researcher was left with a long list of the different codes identified across the data set (see Appendix 8).

Stage 3: Searching for themes

This stage involved sorting the different codes into potential themes and collating all the relevant coded data extracts within the identified themes. The author used visual representations, including the use of post-its grouped into in order to organise the codes into different possible sub-themes and themes.

The researcher found that some of these groupings of codes related very much to her questions, for example the first interview question asking parents to tell her a little about their child meant that many codes related to what their children are like:

What my child is like	1. loving child
	2. happy child
	47. thinking things could be worse, being grateful for his abilities
	48. happy he's trying and happy more than academics
	174. happy
	175. can get upset - child
	199. lovely / loving
	221. child - confused challenging
	223. he's improving
	281. starting to see positives o ASD
	285. happy
	286. settled

Many other comments and codes that struck the researcher were not as directly in response to a question, for example the researcher felt that there was a possible theme or subtheme that could be formed based on the comments made about support from other parents:

Peer support, other mums getting them through	158. feeling like only people in world going through it
	159. importance of not feeling alone
	169. peer support really important

	170. feeling isolated until you meet other mums
	248. good to hear other experiences
	249. start to be grateful things are not a lot worse
	308. support from friends
	362. need to open up about it, talk

At this point the researcher had 32 candidate themes or subthemes (see Appendix 9). Some of the initial codes went on to form main themes, whereas others simple formed sub themes. In addition some of the initial codes were discarded through the processes detailed in stage 4.

Stage 4: Reviewing themes

Once the set of possible themes had been devised and refined these were reviewed. This was a two-phase stage. The first phase involved reading all the extracts for each theme to see if they formed a coherent pattern. During this phase it became evident that some of the candidate themes were not really themes, for example if there are not enough data to support them, or the data are too diverse. Other themes needed to be broken down or collapse into each other (e.g., two apparently separate themes might form one theme, shown with the 'visit' and 'talking to school' candidate themes becoming 'talking to school staff' example below).

The researcher used Patton's (1990) dual criteria for judging categories - internal homogeneity and external heterogeneity. Data within themes needed to cohere

together meaningfully, while there also had to be clear and identifiable distinctions between the themes.

The researcher felt that most of the candidate subthemes were coherent. However some of the potential subthemes, for example when reviewing the 'visit' candidate subtheme the author felt that the data, though all being comments about visiting, were too diverse and were relating to factors and experiences that overlapped with, for example the 'talking to school' candidate subtheme:

Visit	127. respectful environment on visit
	188. had visited the school she wanted
	265. visited unit

Talking to school	20. feeling of being reassured by school
	41. school were confident they could meet his needs
	49. communication with teachers good
	98. went round schools
	99. met head of special - fantastic
	123. liked head on visit - very supportive
	125. factors - head
	192. head is outstanding
	202. reassured by school
	218. feeling school had ASD expertise

These two candidate subthemes were combined to form:

Talking to school staff	20 41 49 98 99 123 125 127 188 193 202 218 265

The researcher also felt that when checking the subthemes for coherence that codes relating to 'understanding my child' and 'ASD understanding' were very much overlapping and that part of 'understanding their child' it was important to parents that their children were understood in the context of being individuals as well as children with autism and this could not coherently be separated.

The author also felt that the codes relating to 'size' could be included in the subtheme relating to specific school based factors including 'specialist equipment / specialists' as when reading the codes in context these subthemes seemed to the parents to be part of a similar factor and not distinct and separate from each other in the parents' experiences.

Once the researcher was satisfied that the candidate themes adequately captured the contours of the coded data the subthemes were arranged into a candidate 'thematic map' (Appendix 10). In this map the researcher grouped the candidate subthemes into potential themes.

Level two involved a similar process but in relation to the entire data set. At this level, the researcher considered the validity of individual themes in relation to the data set,

but also whether the candidate thematic map accurately reflected the meanings evident in the data set as a whole.

In this phase the researcher re-read her entire data set to ascertain whether the themes made sense in relation to the data set and also to code any additional data within themes that had been missed in earlier coding stages. Braun and Clarke (2006) state that the need for recoding from the data set is to be expected as coding is an ongoing organic process.

At this point the researcher noted that she had included a code ('21. tried to ask George') about a parent asking her child his views about schools in a potential theme about asking advice from others. On rereading the researcher felt that although this was only one code it was significant and striking and should be separated into a subtheme about 'asking the child'. It is important to note therefore that the identification and inclusion of themes was not necessarily based on prevalence. If a theme was considered to have an interesting or useful insight into the research question and offered insight into the understanding of qualitative data it was be included in the findings.

Once the researcher was satisfied that the thematic map made sense and 'accurately' represented the data she moved on to the next phase. The researcher was mindful that her interpretation of what counts as 'accurate' representation was dependent on her theoretical and analytic approach. The researcher felt that at this point the thematic map represented her understanding of the parents' experiences

and views and this was supported by looking at the responses to the initial readings of the transcripts in stage 1 of the thematic analysis (Appendix 11).

Stage 5: Defining and naming themes

In the final stage the thematic map was finalised and the groups of subthemes were given names as were the wider themes they were arranged into. This was done by reading the contents of each subtheme and devising names for the subthemes that incorporated and summarised the 'essence' of the subthemes and determined what aspect of the data each subtheme and theme captured (Appendix 12).

Following this the researcher went back to the transcripts to extract statements from the raw data that the codes responded to provide evidence for the existence of each theme within the various categories. For example in theme 2 the following extracts were selected to provide evidence for each subtheme:

Subtheme 2.1:   Health – early experiences

                         '*We nearly lost our little boy due to their negligence*'

Subtheme 2.2:   Health – MMR

                         '*As soon as he had his MMR vaccine everything changed*'

Subtheme 2.3:   Health – the diagnosis

                         '*It was hard, very hard, being told he was autistic*'

Subtheme 2.4:   Processes – SSEN

                         '*It seemed to take forever*'

Subtheme 2.5:   The need to fight

'I had to battle with her'

This is demonstrated in full the next chapter: Findings.

3.8   Ethics

This research was conducted under the ethical guidelines of the British Psychological Society (BPS, 2009). Before the commencement of the study permission was gained from the LA and ethical approval was granted by the University of East London (see Appendix 9). A risk assessment was also completed, and permission to access the database of all children who had received an Autistic Spectrum diagnosis while in pre-school was granted from the LA. At all times the researcher was safe. The researcher was supported throughout by a Local Authority Educational Psychology Service Senior Psychologist, for example in the event of emotional disclosure.

The responses to the survey were anonymous. The names, genders and identities of participants were not be documented in any way to ensure they could not be identified. It was explained that the privacy of participants was maintained by not revealing any personal or identifiable information, thus ensuring confidentiality and anonymity. It was explained to parents that during the recording of the interviews they could use their child's name freely. Parents were reassured that after the transcription of the interview their child's name would be replaced with a pseudonym so their child could not be identified in any way.

The research probed the interviewee's experiences and views. It was explained to the parents that should they find any topics sensitive or difficult to discuss that could they can stop the interview at any time. The parents were debriefed and given the opportunity to talk about anything that had occurred during the interview. If additional help and support extra support was required it would have been available via a co-ordinated multi-agency approach such as the EPS, Autism Outreach Service, or the parent support group for parents of children with autism. However, no parents found the interviews distressing on no further support was required.

Questionnaire responses online were accessed by a password known only to the researcher. Paper copies were kept locked in a secure location in the LA offices. Interview tapes were transcribed by the researcher. Information was kept securely on the Local Authority computer system. All surveys and tapes will be destroyed following the research, using the Local Authority's secure systems for destroying confidential information. Data will be stored in a secure cabinet at the Educational Psychology Service and electronic data will be stored in the Service's confidential "W" drive. To access electronic data at the LA two passwords and a username are required. All audiotapes will be destroyed after successful completion of the doctoral research transcription.

Chapter Four: Findings

The results chapter contains two sections that report the findings from the two-staged sequential exploratory procedure.

4.1   Quantitative findings

Using the sample of all primary school aged children who had received a diagnosis of autism as preschoolers in the LA (n=153), the researcher investigated trends in the data from the database. These figures refer to the sample of parents of children who were diagnosed with autism before starting school and were at primary school in 2011. The data collected for these research questions was analysed using Microsoft Office Excel 2007. These data sets are classed as descriptive statistics and therefore do not require further analysis. Percentages have been rounded up to the nearest whole number.

The specific research questions were:

Research Question 1: Over a six year period what proportion of pre-schoolers with autism attend special and mainstream schools when they start school?

Research Question 2: Over a six year period what is the trend for pre-schoolers with autism starting at special and mainstream schools?

Table 4.1.1 shows that in the LA at present 54% of children who were diagnosed with autism as preschoolers attend mainstream schools and 46% attend special schools.

Table 4.1.1: Numbers and percentages of children with autism in the LA starting at special and mainstream primary schools over a six year period

	Special	Mainstream
Number of children	71	82
Percentage of total	46%	54%

These results show that a similar number of primary-aged children with autism in the LA go to special and mainstream schools.

This data was then examined in school entry years to explore any trends in the proportions of children who received diagnoses of autism going to special and mainstream schools.

Table 4.1.2: Numbers of children with autism in the LA starting at special and mainstream primary schools each year over a six year period

	2005	2006	2007	2008	2009	2010	2011	Total
Mainstream	6	19	17	15	9	10	6	82
Special	9	12	10	11	10	7	12	71

Table 4.1.3: Percentages of children with autism in the LA starting at special and mainstream primary schools each year over a six year period

	2005	2006	2007	2008	2009	2010	2011	Overall
Mainstream	40%	61%	63%	58%	47%	59%	33%	54%
Special	60%	39%	37%	42%	53%	41%	67%	46%

Examination of this data shows that the proportion of children going to special and mainstream schools has been quite consistent over the past six years.

Parents of the 153 children identified were sent the research questionnaire.

Responses

Of the 153 questionnaires sent there were 33 returned meaning that there was a total response rate of 22%. A greater number and proportion of the responses were from parents who had chosen special schools for their children.

Table 4.1.4: Responses to the research questionnaire

	Special	Mainstream	Total
Number of children	71	82	153
Number of responses	21	12	33
Percentage responses	30%	15%	22%

The quantitative data from the questionnaire returned by parents was then analysed.
The specific research questions were:

Research Question 3: How do parents rate their children's special and mainstream schools?

Research Question 4: What factors do parents say influence their choice of school?

Parents were asked to rate their satisfaction with their child's school from 1-5. There were a range of responses, as detailed in Table 4.1.5 below:

Table 4.1.5: Range of parental satisfaction ratings with special and mainstream schools

Response	-	0	1	2	3	3-4	4	5	Total
Mainstream	1	0	0	1	2	1	0	7	12
Special	1	0	0	1	2	0	5	12	21

The average ratings were then calculated for the special and mainstream schools to compare parents' satisfaction with their children's special and mainstream schools, show in figure 4.1.5.

Figure 4.1.5: Average parental satisfaction ratings with special and mainstream schools
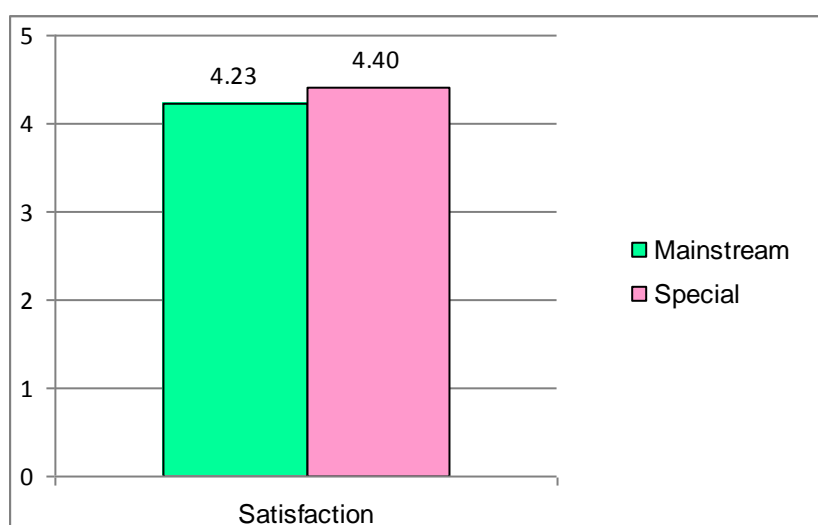
The findings of this part of the survey indicate that parents are similarly satisfied with their children's schools, with the same range of responses and very similar average responses.

In the next part of the questionnaire parents were asked to think about when they made the decision about the school they wanted for their child and were asked to rate a number of factors from 1-5, with 1 being 'not important' and 5 being 'very important'.

The average ratings for each factor for parents of children at mainstream schools and parents of children and special schools were calculated separately and together, as shown in Table 4.1.6 and Figure 4.1.6, below.

Table 4.1.6: Average ratings of how important different factors were when parents of children with autism were choosing schools

	Feeling staff understand my child	Autism – friendliness	Visiting	Size of school / classes	Access to therapists	Location	Advice from professionals	Advice from pre-school	Advice from other parents
Mainstream	4.92	4.92	4.83	4.33	3.92	3.67.	3.25	2.92	2.00
Special	4.76	4.57	4.38	4.33	4.24	3.10	3.48	2.60	2.15
Average	4.84	4.74	4.61	4.33	4.08	3.39	3.37	2.76	2.08

Figure 4.1.6: Average ratings of how important different factors were when parents of children with autism were choosing schools
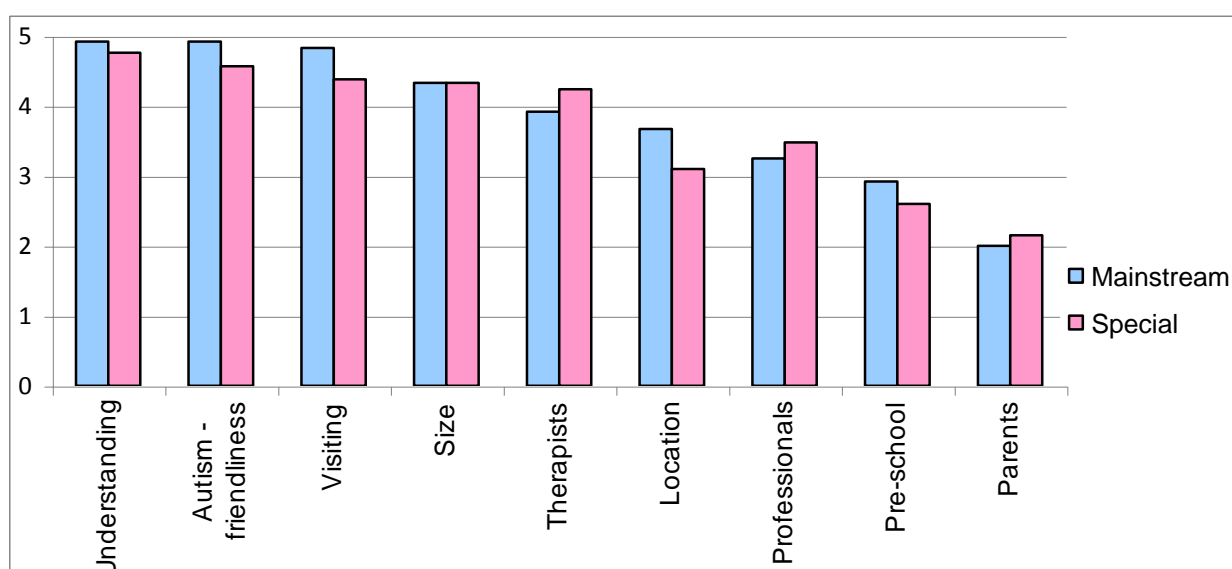
The data shows that the most important factors for both groups of parents were:

1. Feeling staff understand my child

2. Autism -friendliness of the school

3. Visiting the school

Parents were given the opportunity to make additional comments and some did so about these factors:

Feeling staff understand my child

> *'The school has an excellent understanding of our sons condition and needs.'*
> *(mainstream)*

Autism friendliness of the school

> *'I wanted my daughter to have access to a provision where all staff had an*
> *exceptional level of understanding autism.' (special)*

Visiting the school

> 'Every child is different! When visiting schools you know the correct school as
> soon as you walk round! i.e. calmness, caring, etc.' (special)

Other comments relating to factors that parents felt were important were made:

Size of school / classes

The size of the school and classes was also rated highly by both groups and was commented on by parents who had chosen special and mainstream schools.

>*'Small classes and good behaviour' (special)*

>*'For my child to be in a small class' (mainstream)*

Access to therapists

Parents of both groups of children rated access to therapists (such as speech and language therapists and occupational therapists) highly, with those who had chosen special provision rating this slightly higher on average.

>*I knew that due to my daughter's specific needs she would flounder in a mainstream school due to class size and lack of direct access to specialist therapists'. (special)*

Location

Location appeared to be quite important to both groups of parents, with parents who had chosen mainstream schools rating this slightly more highly. Only one parent made an additional comment about this being a factor:

'The school was/is really close to home.' (mainstream)

Advice

Parents gave advice from other parents, their child's pre-school and other professionals comparatively low ratings but named advice from professionals as being the most important of these:

'At the time I was not sure, but I had support from (paediatrician), who visited the school. We had a number of meetings to ensure they understood my daughter's needs.' (mainstream)

One parent commented on finding advice from different professionals conflicting and confusing:

'Told by different people different things, etc. Paediatrics said his needs are severe, council said mainstream was better for him so was confused.' (special)

Another parent was not specific about who had advised her but feeling that there was agreement about her child seemed to be important:

'We all thought that he would cope and thrive in a mainstream school.'

(mainstream)

Responses to additional questions on the questionnaire were also analysed and additional comments included in the appendices (Appendix 5).

4.2 Qualitative findings

The qualitative data from the analysis of the semi-structured interviews complemented the quantitative data to answer the research question:

Research Question 4: What factors do parents say influence their choice of school?

The interviews also sought to gain a deeper understanding of parents' experiences to answer the research questions:

Research Question 5: What do parents say about their experiences of making the choice about which schools they want for their children?

Research Question 6: What do parents think would improve their experience of choosing a special or mainstream school?

Inductive thematic analysis was applied to the six semi-structured interviews as detailed in the methodology. Each theme encompasses data from both special and mainstream parent groups. Many of the subthemes were common to both groups of parents. Some subthemes include data from only special or mainstream parents. Six themes were identified and organised in relation to the research questions:

Research Question 5: What do parents say about their experiences of making the choice about which schools they want for their children?

Theme 1: 'Having a child with autism' refers to parents' reflections on being a parent of a child with autism and the complexities this brings.

Theme 2: 'Experiences of Processes and Services' refers to what the parents said about the processes they had already been through before choosing a school for their children.

Theme 3: 'Anxieties about school' refers to the feelings and concerns parents had about their child going to school.

Theme 4: 'Empathy for parents' refers to the feelings parents have about other parents in similar positions

Research Question 4: What factors do parents say influence their choice of school?

Theme 5: 'Factors in making a decision' refers to the specific factors that parents said informed their final decisions about schools

Research Question 6: What do parents think would improve their experience of choosing a special or mainstream school?

Theme 6: 'What parents need' refers to the parents' advice to other parents and changes they would like to see

For each of these six themes a number of subthemes emerged from the analysis. The themes and subthemes are outlined in Table 4.2 and Figure 4.2 below.

Table 4.2: Overview of themes and subthemes

Theme 1: **Having a child with autism**	1.1 My child now
	1.2 Coming to terms with autism
	1.3 Everyday life
Theme 2: **Experiences of Services and Processes**	2.1 Health - Early experiences
	2.2 Health - MMR
	2.3 Health – The diagnosis
	2.4 Education – SSEN
	2.5 The need to fight
Theme 3: Anxieties about school	3.1 Concern about whether the school would meet their child's needs
	3.2 Concern the child wouldn't cope
	3.3 Concern for other children and teachers
	3.4 Concerns about judgment from other parents
Theme 4: Empathy for other parents	4.1 The importance of peer support
	4.2 Desire to help other parents
	4.3 Cultural factors

Theme 5: Making the decision	5.1	Pre-school factors
	5.2	Talking to friends
	5.3	Talking to school staff
	5.4	Trusting advice from professionals
	5.5	Asking the child
	5.6	Facilities and access to specialists
	5.7	Understanding their child
	5.8	Wanting their child to be included
	5.9	Wanting their child to shine
Theme 6: Advice about what parents need	6.1	Access to professionals
	6.2	Professional support
	6.3	Peer support
	6.4	Clarity
	6.5	Provision

Figure 4.2: Overview to illustrate the themes
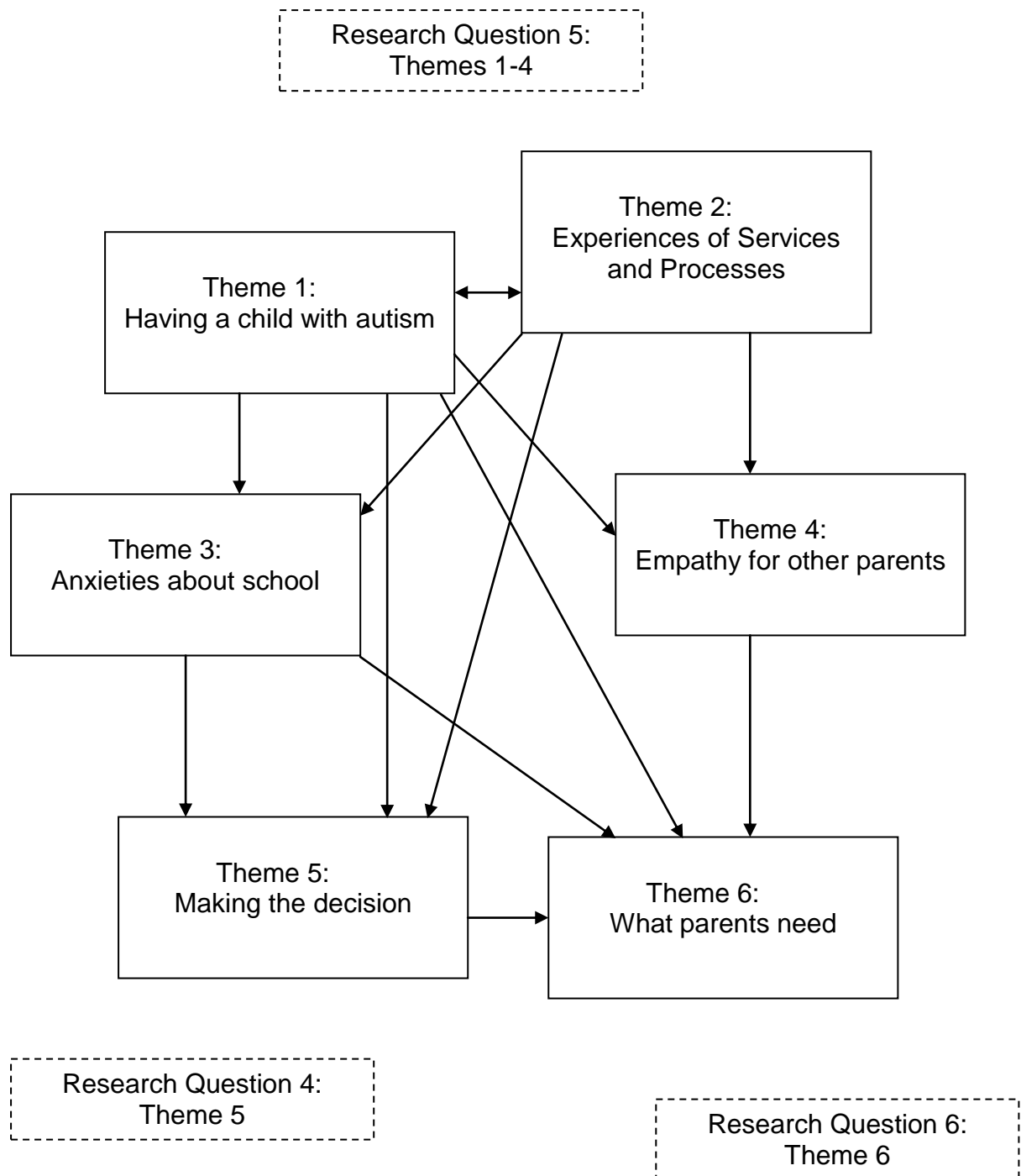
Research Question 5:
Themes 1-4

Theme 2:
Experiences of Services
and Processes

Theme 1:
Having a child with autism

Theme 3:
Anxieties about school

Theme 4:
Empathy for other parents

Theme 5:
Making the decision

Theme 6:
What parents need

Research Question 4:
Theme 5

Research Question 6:
Theme 6

What do parents say about their experiences of making the choice about which schools they want for their children?

Theme 1: Having a child with autism

This theme refers to the many comments parents made about what it was like being the parent of a child with autism. All parents talked about this, with all but one parent talking at length about the impact of having a child with autism on their own everyday family life.

<u>Subtheme 1.1:</u>   <u>My child now</u>
'Generally he's quite happy'

The parents were initially asked to tell the researcher a little bit about their child. Although the descriptions of the children varied, all the parents interviewed said that their child was happy or content.

'A gorgeous 4 year old, very lively, always on the go, yeah, just full of life. Happy, always happy.'   *(L – special)*

'Raphael's quite a happy boy. He's very bubbly and very energised.'
(R – mainstream)

'He's happy' (F – special)

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It was interesting to note that many of the mainstream parents talked about the fact that their child was now happier and more settled, but didn't talk as much about how their child had actually changed, whereas the parents of the children in special schools talked about improvements in their children.

'Generally he's quite happy, you know a contented boy which is good. There was a time when he wasn't but hopefully now he's sort of settled down and he's doing really well.' *(G – mainstream)*

'He's improving, that's the best thing' *(N – special)*

Their child being happy seems to be very important and a real priority for these parents in the context of choosing a school for their child but also in general.

Subtheme 1.2:   Coming to terms with autism

'The shock of 'our child's not going to have the life of other children''

The parents were asked about when they started to have concerns. Both groups of parents talked a lot about what it was like coming to terms with their child having autism. Some of the parents described how they 'just knew' before anyone else that their child was different:

'She'd only eat food that was white and she wouldn't look at me when I did nursery rhymes and that so at ten months old I knew, I just knew that Lily was autistic.' (L - special)

Parents from both groups also talked about the difficulties accepting their child was different and how they found it very hard to take in, and the mix of emotions around finding out their child had autism:

'When Mia (advisory teacher) first said to us that our son might have special needs we were in denial. 'Special needs?! Don't be so ridiculous! Our child doesn't have special needs!' … but obviously, when we started comparing him to his peers, 'cause obviously something wasn't quite right and he was delayed, so that's kind of, when we got over the initial shock of our child's not going to have the life of, you know other children, so that's when I went into that shock I suppose and denial.' (F - special)

One parent talked about how she and her husband reacted differently to the news:

'I was quite relieved 'cause I knew there was something wrong, or difficult or whatever, so I was quite relieved... but my husband found it quite hard, cause obviously being his boy, and things, 'there's nothing wrong with him, he's fine'…at first he didn't really want to know.'

(G - mainstream)

Both groups of parents described how this was a difficult time for them and had been a long process of acceptance and gaining a knowledge and understanding that was not over:

'It's like a rollercoaster. One minute you're high up and you think you can cope with it and the next minute you're down and thinking I can't cope with it, and it's obviously causing you so much distress. And you think no I've got to keep strong and keep, and you've got to think about the young ones obviously, so it's just a lot, it's trying to cope with it.'   *(R – mainstream)*

Subtheme 1.3:   Everyday Life

'*Just normal day to day life is a hassle*'

All the parents, to a greater or lesser extent, talked about the impact of having a child with autism on their everyday life. I did not ask a question about this specifically but it was a topic the parents seemed to want to talk about. For some parents this was specifically about being a parent of a child with autism:

'It can be exhausting to look after him. Sleeping patterns and everything, nothing is the same. He will wake up in the middle of the night 12 o'clock 'mummy I want to count the stars' if you're lucky enough it's summer, he can count the stars, but when it's winter it's not so easy!'

(H - special)

Other parents talked about the impact on their relationship with their partner, and one parent talked about how difficult it had been to manage having a child with autism when she had another young child.

'We sort of separated but we've got back again now, but it could have been worse.'   *(F - special)*

'It's not quite the life we wanted 'cause it's stressful, just normal day to day life is a hassle, you know but we're lucky.'   *(F – special)*

'He used to at one point when Ivy was a little baby he was in the same pushchair … he wouldn't want something and he would just go into absolute meltdown, err, kicking screaming everything with little Ivy next to him in the seat and he used to really frighten me as to whether you know he's gonna kick his little sister or something.'   *(M - mainstream)*

This aspect of having a child with autism seems to be common to both groups of parents and all the parents talked about how different it is to be a parent of a child with autism. It was interesting to note, however, that when talking about the difficulties they face in everyday life, some of the stories told by the parents of children at mainstream schools were in the past tense as the parents were talking about difficult times before their children started school, whereas the parents of the children in special schools (and one of the mainstream parents) talked very much about what life is like now for them and described daily life now being very different and difficult.

'I'm still smiling. Just. I would never have any other children. Ever!'

(F – special)

Theme 1 Summary

This theme encompasses what parents said about what it's like to be a parent of a child with autism. Their child being happy and settled seems to be really important to these parents and all had positive things to say. However, the emotions around coming to terms with their child having autism seemed very raw and the fact that their children have autism seems to have had a big effect on these parents. Although they were positive about their children there was a strong message of how hard and emotional it is being a parent of a child with autism.

Theme 2: Experiences of Processes

Theme 2 incorporates the comment parents made about the health and education processes they had been through with their children before getting to the stage of choosing a school for their children. The parents were asked about their experiences of the autism diagnosis process. The parents of children at special schools were asked about the Statutory Assessment Procedure they had been through to get their child's Statement of Special Educational Needs (SSEN). None of the children at mainstream school had been through this process.

<u>Subtheme 2.1:</u>   <u>Health – early experiences</u>

'*We nearly lost our little boy due to their negligence*'

Several of the parents talked about their child's early life and their experiences of health services. One special and one mainstream parent spoke at length about their child's early life and a very difficult early experience they had had when their child was a newborn. .

'*I'm not happy with the hospital at all. We nearly lost our little boy due to their negligence.*'   *(M - mainstream)*

'*We got fobbed off so many times and, even though I was a healthcare professional myself, the experience as a patient and as a parent was quite negative.*'   *(F - special)*

The need to talk about this difficult experience seemed very strong for these parents and was an important part of their narratives about their children. These very stressful and upsetting experiences were obviously still a strong part of their stories.

<u>Subtheme 2.2:</u>   <u>Health – MMR</u>

'*As soon as he had his MMR vaccine everything changed*'

While talking about their child's early life none of the mainstream parents interviewed mentioned the MMR vaccine, however all the special parents did so:

'The MMR vaccine… just before that he was ok, fine. Not as bad as now. I still saw tendencies of autism in him but as soon as he had his MMR vaccine everything changed, because he had a really bad toxic allergic reaction to it, his body reacted very badly to it, and he started to change. He became aggressive. Kicking, screaming, everything like that.'

(H - special)

'She did have some words and then, and I'm not saying it was MMR but once she had that, I think that that age she was at developmentally she just then stopped. Yeah, the words, the ten words and whatever she did have she just then chose not to speak which is probably the age it would show anyway.'

(L - special)

'And we had the three lots of vaccinations, not the MMR but the three lots and his was under the paediatrician and I kept saying you know something's not right.'   *(F - special)*

It is interesting to note that it was only the parents who had chosen special schools that mentioned the vaccine, whether or not their child had had the vaccine and whether or not they attributed their child's autism to the vaccine. It might be that these parents, who have decided their children need to be educated differently, feel that their children are more different than the way the parents of children at mainstream schools feel about their children. Talking about the MMR could indicate that these parents have a more medical model of disability or are more conscious of

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biological reasons to explain their child's autism, even if their child did not have the MMR.

<u>Subtheme 2.3:</u>　　　<u>Health – the diagnosis</u>

'*It was hard, very hard, being told he was autistic'*

The parents described a range of experiences of the process of obtaining their child's diagnoses. Some of the parents, of both special and mainstream children, found the process very straightforward whereas others found it long and difficult:

'I think it wasn't, I don't think it was that difficult.'　　　(R - mainstream)

'It was probably sort of about a year before... people sort of started listening, sort of taking note.   '　　　　　　　　　(G - mainstream)

Parents also talked about how this process was related to coming to terms with their child having autism and how the formality and finality of the process affected them:

'It was hard, very hard, very confusing. Especially being told he was autistic. Even though you know at the back of your mind he's got autistic tendencies when you see it in black and white.'　　　　　　(H - special)

It is interesting to note that the parents who found the process and system of getting a diagnosis more difficult were those who felt finding out and accepting their child had autism was more difficult. It is possible part of the reason these parents fond the

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diagnostic process difficult was that they were not ready to be told or did not feel that their child did have a problem at this point. The two parents who talked most about struggling to accept their child's diagnoses were interestingly both parents who had chosen special schools.

Subtheme 2.4:   Processes – SSEN

'It seemed to take forever'

The parents of the mainstream children talked about the statutory assessment process in terms of the decision not to pursue statutory assessment for their child. These parents had been advised that their child should not need a statement and talked about accepting this. One parent talked about hearing that the statutory assessment process was very difficult and this being part of her decision for her child to go to mainstream school.

'Yeah all they kept on saying to me was that they didn't think was that bad. The preschool was a bit apprehensive; they said 'you need to make sure every area is covered'. The school itself they just kept saying we'll keep an eye, we'll keep a close eye on him and monitor him.'

(G - mainstream)

'I've heard from other friends that 'oh it's so difficult to get the statement in place, I've had a really hard time' and I thought, 'I think that's the same thing that's going to happen to me if I have to do it for Raphael'. So I thought no, he can go into mainstream, we'll see what it's like.'   *(R - mainstream)*

The parents of children at special schools had varying experiences of the statutory assessment process. Two parents who had made the request for a statement talked about it being very difficult:

> *'I think that was what they didn't like in a way. I just felt like I was on their case really. You know when you just think 'oh no, I just hate hearing my voice'. I just feel sorry for parents who don't know what they can achieve and I just think it's really hard, isn't it.'*　　　　　　　　*(L - special)*

> *'I had to keep e-mailing back and forth, back and forth and there was always something missing, like 'you need this thing'. It was a really, really long, I know it take s a long time to get a statement done but it seemed to take forever.'*　　　　　　　　*(F - special)*

Another parent of a child at special school found getting a statement for her child very straightforward:

> *'He got the statement when he was in nursery. As soon as he started.'*
> 　　　　　　　　*(H - special)*

The statement (SSEN) seemed to have different meanings to the different parents. All the children in special schools had statements but the parents who had put in parental requests seem to have had a much more difficult experience of the process than the parent for whom the school made a request for her child.

<u>Subtheme 2.5:</u>   <u>The need to fight</u>

'I had to battle with her'

The parents of children at special schools repeatedly talked about the need to battle and fight, which were terms that the mainstream parents did not use. The parents of children at special schools talked about the need to fight particularly with the local authority and in relation to the statementing process.

> *'I was on the phone to Lavender (SEN Officer) probably four times a day, four times a day, about everything that was going on... Again we got the EP involved.'*   *(H - special)*

> *'It's hard work, it's a battle. Once you get to the other side you know it's worth it but it's a shame you have to go through all that 'cause you've been through enough already.'*   *(F - special)*

This topic was not raised by the mainstream parents, apart from when one parent referred to hearing that getting a statement was very difficult from friends who had been through the process (see R quote, subtheme 2.4).

The difficulties that the parents who had chosen special schools talked about often related to the statementing process and provision. It is interesting that the parents who had requested statutory assessment themselves, and did not meet their

allocated SSEN officers and only spoke to them on the telephone, talked about battling and fighting with them and feeling like they themselves were a nuisance.

These parents were positive about many other professionals they had come in to contact with and it is possible that the frustrations they were experiencing with the complex statementing system were exacerbated by this impersonal relationship with their SEN Officer, feeling like they were unsupported and having to make all the effort.

> *'There wasn't enough support with how to go through the process of it, apart from Flora (Advisory Teacher). Flora was the best one out of everybody. She talked us through what she could but still I had to fight with everybody.'*　　　　　　　　　　　　　　　　*(H – special)*

> *'Yeah I had to battle with her (SEN Officer). I didn't like… probably because I was emotional at the time, I don't know, probably, but didn't like her manner and her approach towards me. And I felt like I had to battle with her. And she was just like 'you haven't got this done, you haven't got the proper…' you know, and I was like 'help me out here! I haven't done this before!'*
>
> 　　　　　　　　　　　　　　　　　　　　　　　*(F - special)*

It might have been easier for the parents to be frustrated with a faceless professional than those who they had met face to face, and they might have been more likely to relate their frustrations about the system to somebody impersonal.

Theme 2 Summary

Theme 2 illustrates that before getting to the process of choosing a school for their child these parents have already been through a variety of processes and many have had difficult and traumatic experiences. Parents described 'negative' early experiences in hospitals, the 'very hard' experience of autism diagnosis and the 'battles' around getting statements for their children. Parents also talked about the confusion of having so many professionals involved with their children:

> *'You understand we've letters upon letters about all sorts of things and I'm not 100% all the time, I mean we used to get letters… we used to get a letter through, we'd be sitting there going I didn't go to this meeting and then there'd be a note at the bottom… and I'd be like oh you've sent me a letter for this!'*
>
> *(M – mainstream)*

Themes 1 and 2 show that having a child with autism and all the processes involved in this can be extremely hard for parents, and this leads in to themes 3 and 4, describing the anxieties they then feel about their child going to school, and the empathy they feel for other parents in a similar situation.

Theme 3: Anxieties about school

This theme refers to the concerns that parents expressed about their child starting at school. The subthemes were common to both groups of parents.

Subtheme 3.1:   Concern about whether the school would meet their

child's needs

'Would it be too much? Was the school going to actually do what

they said they was gonna do?'

Parents expressed concern about the school providing learning opportunities that their children could access, and whether the school would make the necessary adjustments for their child:

'We didn't think he would go into mainstream 'cause they was saying about

whether or not he would… take in the information that was being given to him

and would it be too much? Was the school going to actually do what they said

they was gonna do? It was a big concern.'

(M - mainstream)

The parents of the children at mainstream schools all talked about needing to keep an eye on the school and the importance of communication with the school, indicating that these anxieties were still present.

'I was to keep an eye on it and had every right to keep checking.'

(G – mainstream)

Subtheme 3.2:   Concern the child wouldn't cope

'I was worried he wouldn't be able to cope with it'

Parents also expressed concerns about their children coping in a school environment given their autism. Parents were of course keen that their children would be happy and safe. They talked about their child's anxiety levels and friendships as being of concern:

'Whenever he went into a school environment he would just, he would respond, he had this anxiety where he'd put on a funny voice, he wouldn't talk, and when he did talk it would be in a funny voice, and they couldn't get anything out of him. He was just so anxious I was really, really concerned.'

(F – special)

'Yeah I was only worried that he wouldn't be able to make friends and he would be antisocial and on his own and he wouldn't be able to cope with it in a mainstream school.'   *(R - mainstream)*

Some of the comments parents made were concerns specifically about mainstream schools:

'Lily wouldn't sit. She gets very anxious, if it's her turn to do something she will cover her ears and flap, she's very defiant, says no all the time, I just couldn't visualise her and how on the go she is twenty-four-seven. She wouldn't access the curriculum I don't think'.   *(L - special)*

It was interesting that both groups of parents talked about these concerns and for some these were allayed and the parents decided on mainstream but for some they felt their child's needs could only be met in special provision.

<u>Subtheme 3.3:</u>   <u>Concern for other children and teachers</u>

'I just didn't think it would be fair to anyone'

Parents from both groups mentioned being concerned about the impact of their child in a classroom because of their autism and the disruption their child might cause:

'He's quite disruptive, and disruptive at times, so he needs 1:1 throughout the whole day sort of thing, and at the moment he hasn't got a statement in place so obviously he's got the few hours of help but not throughout the whole day. So when he hasn't got the help, that's when he's disruptive and sort of does things on his own terms.'   *(R - mainstream)*

One parent spoke specifically about the learning of other children, stating that as a teacher herself she could see it from the point of view of the teacher, though her child's needs were her primary concern:

'Still she would disrupt the learning of the other children, which I wouldn't think would be fair on them because all the teachers and resources would be spent on Lily just to maintain her in a classroom that wasn't suitable for her and yeah I just didn't think it would be fair to anyone, especially not to her, to be

somewhere that was unsuitable at this age. I can see it from the teacher's

point of view.' *(L - special)*

Again it is interesting that both groups of parents shared these concerns. It seems some were reassured that the school could manage their children and their children could manage the school, whereas others decided their children would be better in special provision.

<u>Subtheme 3.4:</u>   <u>Concerns about judgment from other parents</u>

                'All these parents were all screaming at him'

Parents from both groups talked about difficult experiences where they had felt other parents had not understood their child's autism and behaviour. This seemed to be a factor when thinking about their child going to school.

'He was playing, and the other mothers just take it so seriously, and they just started screaming at him, on the sides of the pitch, saying what is that boy doing, and he looked up, so petrified, cause he had the ball, and he was just like, cause all these parents were all screaming at him… And they made a big fuss about it.' *(M - mainstream)*

'When he had tantrums we used to have really bad ones of throwing, where he's going to hit his head on concrete, and I'm wondering what the damage is gonna be and it's some people are like shut up! And why would you say that to a small child?!' *(H - special)*

Concerns over their children being understood and accepted was an important factor for parents when deciding on schools, not only by school staff but also by other parents. Parents from both groups talked about experiences of others not understanding their children and speaking to them in a way they had found upsetting.

Theme 3 Summary

It is clear from what parents said that they had a lot of anxiety about their child starting school. Some of these anxieties were about school in general and how their child would cope in a school environment and some were specific to mainstream schools. These concerns were varied, including concerns about staff and other parents as well as concerns for their child.

Theme 4: Empathy for other parents

All the parents described how they wanted to help others in their situation, and how important peer support had been and still was for them in parenting a child with autism.

Subtheme 4.1:   The importance of peer support

                            'They've all done it too'

When thinking about what other parents need the importance of friends and family was highlighted, but also the need to be able to share and make sense of their experiences with other parents who have had similar experiences.

> *'When you're sitting there and just bursting into tears any everything and why am I doing this, they've all done it too, so it's really good to have that kind of peer support with other parents going through the same stuff with their kids.'*
>
> *(F - special)*

This feeling of benefiting from talking to and hearing from other parents of children with autism seemed common to both groups of parents.

Subtheme 4.2:   Desire to help other parents

'I started a network up with the mums'

All the parents talked about how their experiences had given them the desire to help other parents, either individually or as part of a group. For the parents who identified peer support as being a key issue for them their desire to help others was in the form of supporting other parents socially and emotionally:

> *'I know from my own experience within the school I started a network up with the mums there to kind of support each other and we even go out once a month for a meal and everything to support each other because people who've got ordinary children don't understand how hard it is sometime just to do the normal functional things in the day. So it's our mummy time away from*

the kids but it's also a time we can share our experiences, relax, cause normally when we're all together we've got the kids there it's all don't do think, don't do that, you can't concentrate.' (F - special)

The parents who had talked about their difficulties with the system talked about how they had supported or would support other parents going through the same experiences by helping practically with accessing what they believed the parents would need:

'She applied for statutory assessment and was told no because her Lily was too young, although she older than what Lily was when Lily was statemented. So I was like, no go back, so I wrote her parental statement form for her.'

(L - special)

'Hopefully I'd like to think with my sort of help, I think I did help. I made her come on the autism parenting support programme with me and, umm, yeah just yeah, err, she... I got her in touch with my girl at the speech therapy, she got in immediately. So yeah I think I did help.'

(M - mainstream)

It was interesting that when asking what would help parents every parent had a story of a way that they had helped another parent.

Subtheme 4.3:   Cultural factors

> *'They're frightened or they don't want it to be known that their child has a problem'*

Two of the parents interviewed were from ethnic minority backgrounds. Both talked about wanting to help other families from similar backgrounds.

> *'And funnily enough, which is sort of haunting me, when I went to (Eastern Europe) a lady behind me in the plane… she was taking her child to a priest. The teacher has told her her child is possessed by the devil, which they told me the same thing. So there is a lot of discrimination out there still, considering we live in England, a developed country, it's the 21st century for crying out loud!'* (N - special)

One parent spoke about how her experience as an Asian parent having a child with a disability and how she felt very strongly about wanting to help others in her community, and how this had been a big part of her dealing with her experiences.

> *'I hope obviously I can help in the future if necessary in any situation, and I do work for an organisation, it helps the (South Asian) community because they're quite deprived. You never see the (South Asian) community sort of out there, trying to access services, they always sort of decline service, I don't know if they're frightened or they don't want it to be known that their child has a problem…. all these Asian families who has a child with a disability who don't feel that, they can't go out there and access a service… I'm really sort of proud of myself and I feel really good about it.'* (R - mainstream)

It seems that many of the parents feel part of a small group with shared experiences of having a child with autism, regardless of their background, and many feel empathy and a desire to help parents in the same position. The two parents from ethnic minority backgrounds seemed to feel this keenly, perhaps as a result of being part of an even smaller group in their communities, identifying with those from the same cultural background who are parents of children with autism.

Both of these parents also talked about their community's views of disability and the difficulties with acceptance and understanding of children with autism.

Theme 4 Summary

The parents interviewed all talked about wanting to help others. This indicates that they feel a real empathy with other parents in their situation. It seems parents feel that what they have been through and their anxieties are substantial and perhaps that they would have liked more help and emotional support than they received.

Themes 3 and 4 found that the parents of children with autism have a number of anxieties and perhaps feel under-supported when arriving at the time of choosing a school for their children.

What factors do parents of children with autism say influence their choice of school?

Theme 5: Making the decision

Theme 5 refers explicitly to the factors parents stated were important when they were making their decisions about which schools they wanted their children to attend. This is a large and varied theme and subthemes are organised as follows:

Subtheme 5.1 analyses comments made about pre-school.

Subthemes 5.2 to 5.5 analyses the comments parents made about who they talked to.

Subthemes 5.6 and 5.7 contain the comments parents who chose special schools made about the equipment and expertise they felt the special school they had chosen offered.

Subthemes 5.8 and 5.9 analyse the comments made about their child in relation to their peers and includes the parents feeling about their child's inclusion.

Subtheme 5.1:   Pre-school factors

         'The preschool he was at is joined on to the school'

Some of the children were attending the mainstream school that was either linked or attached to where they had been at nursery. All these parents had also had a positive experience of their child's pre-school.

> *'The preschool he was at is actually joined on to the school. So I felt that although he was struggling educationally and settling down into the routines, it was him feeling happy in the situation and his friends he was with and things like that.'*
>
> *(G - mainstream)*

> *'The teachers also reassured me because Stars pre-school, their children usually gets transferred, they have a link with Star Street, which is the school.'*
>
> *(R - mainstream)*

The promise of a smooth and supported transition for their child was something that these parents all said was important.

> *'He'd come along so well when he went to the pre-school which is next to the school um and at the pre-school if you go there they kind of use it as a transition to go to the school so they would do a lot of outings, they would use their playground, they would use their side of the school, so it became very easy, so when the children did come to go there they would just oh I'm not that gate any more I'm literally here, so it was that as well, because we thought change, he don't like change, and there he was comfortable.'*
>
> *(M - mainstream)*

In contrast, two of the parents who had chosen special schools had had very difficult experiences with pre-school:

> '*They had to make groups, put the children into groups. At that point Harry was on none of the lists, yet he was still the only child who was still there from when the nursery opened in the first place and I felt like I was stabbed in the stomach when I saw all the children and Harry's name was on none of the lists. So from the very beginning I knew that that was discrimination.*'
>
> *(H - special)*

Two parents had had a much better experience of a special needs nursery:

> '*So when he was two and a half I took him to the preschool, just a normal one cause he wasn't diagnosed before we got there. Unfortunately it was my mistake, I thought it would help him, but in hindsight it didn't and knowing what I know now I would have put him to go to a special needs nursery and he did go to a special needs nursery for about six months before he went to school.*'
>
> *(F - special)*

> '*So he was going there as well, which helped him, again 'cause he was accepted as he was. He got the chance to go in the Christmas party, to go on the trip, things he was excluded completely from in his mainstream nursery. You know whatever they do in schools these days Harry was always sent home.*'
>
> *(H – special)*

A positive experience at pre-school and a pre-school link with a mainstream school seem to be hugely important in whether or not the parents decided to choose mainstream schools for their children.

Subtheme 5.2:   Talking to friends

        'I spoke to lots of friends in the area'

All the mainstream parents talked about asking friends about school and mentioned the fact the school was local, though if it were in their child's best interests they would have travelled for school. All the parents had talked to local friends and done some other research into the school.

> *'It's a really nice school. I spoke to lots of friends in the area, that have got children going there and they all said great things about the school so it was a little bit of research, it's obviously handy that it's down the road, but if he had to go to another school somewhere else it wouldn't be an issue.'*
>
> *(M - mainstream)*

> *'My family, my friends… we've always heard a good reputation about the school and I think that was one of the things.'*   *(R – mainstream)*

Subtheme 5.3:   Talking to school staff

        'I'd met the teachers and I really liked them'

All the parents talked about how the staff they had been in touch with at the school were important when they were making their decisions. Comments varied from those about good communication and support, and feeling that they had the understanding and expertise to meet their child's needs.

'Yeah I'd already checked out the school, I'd met the teachers and I really liked them I met the head teacher Miss James and I just felt comfortable and I knew that he would if I did. They were very friendly and it's a really nice school.'   *(M - mainstream)*

'The staff are lovely and polite and really supportive as well.'

(R - mainstream)

'The head of the unit is outstanding, she's brilliant with what she knows.'

(L - special)

Both groups of parents felt that the staff were important and all mentioned staff when talking about how they decided on a school. However what it was they liked about the staff seems to have been slightly different, with the parents who had chosen special schools talking more about the knowledge and patience of staff rather than being nice and friendly.

<u>Subtheme 5.4:</u>   <u>Trusting the advice from specialist professionals</u>
                    'She said he should be ok at mainstream'

All the parents had received support from the ICSS (Individual Child Support Service) and were unanimously positive about the service and the support workers. The parents had all been advised that their child should be able to succeed in mainstream with reasonable adjustments. One parent talked about how she had received support and encouragement from her child's paediatrician in relation to advocating for her child in school.

'She just basically said to me I think in my opinion, and you know we've been doing this a lot of years now, he will be fine in a mainstream school um because he obviously is very on the mild side. He's going to have a lot of issues, he's going to have a lot of things that he's not going to like, he's not going to know, he's not going to know what to do about, but he would if he was at a special school.' *(M - mainstream)*

'Another lady as well on the advisory teacher side, I can't remember her name, she also assessed him for the finding side of it, for the 1:1, she said he seems fine, she said he should be ok at mainstream as well and I think I was quite content thinking everyone's there behind me and hopefully if there is a problem they will help me later on if they feel that there are issues I knew in (mainstream) they're going to observe him, they're going to keep an eye, and hopefully they'll be able to tell me 'no Amelia he's fine, you don't need to worry about it' or if there was a problem or is a problem then they would say 'no, there is a problem, we're going to get SENCo involved to take it further' so I'm quite happy.' *(R – mainstream)*

Parents also talked about the fact they felt that the school would do what they needed to do to meet their child's needs. All the mothers talked about continuing to communicate closely with child's teachers and trusting that steps would be taken in the future should issues arise with their child's progress or behaviour.

Subtheme 5.5:   Asking the child
                   'He really wanted to go'

Only one parent said she had asked her child what his view was about the school he wanted to go to.

> *'We spoke, we did speak to George and sort of ask him if he was happy to go to that school. We tried to explain that there was other schools that he could go to that would help him in his situation. Obviously he was still quite young so he probably didn't understand but he… really wanted to go, so it was bit of a chance that we took and we kept an eye on it.'*
>
> *(G - mainstream)*

Subtheme 5.6:   Access to specialist resources and professionals
                   '*They do have what she needs*'

The parents of children at special schools all talked about the facilities and access to specialist professionals they felt their child would have access to by attending a special provision:

'They do have the speech there, they do have what she needs, they have the OT support in there, the teachers are highly skilled, the class sizes are no more than ten.' (L - special)

'They have so many different activities. They have the sensory room and they have the quiet room and they have speech and language therapy and they have so many different things. Oh it's heaven on earth for autistic children!'

(H - special)

'All the technology and the opportunities they had as well, there seemed to be everything there and lots of equipment, especially with the technology, but the fact that they had so much sort of teaching support as well and opportunities, they seemed to do so much for the children that that's what sort of made me decide there. That was the only place we were going to consider.'

(F - special)

Subtheme 5.7:   Understanding their child

     'They accepting him the way he is' [sic]

The parents of the children in special school spoke about how important it was that they felt that the school understood their child and the implications of their child's autism:

'He's… they accepting him the way he is. They know what autism actually means. Everybody say oh, he's autistic but they don't understand the true

meaning of autism and what comes with autism. So they understand the true

meaning of autism.' *(H - special)*

The parents also talked about how they understood their child's autism would affect their behaviour and how it was important to them that this was understood by school staff and managed calmly and appropriately:

'There have been incidents where she's had a set to with another child but school are really good, they deal with it, the inform me, and I know that Lily's not innocent in everything and they just deal with it, I can't blame them at all. The class teacher has had the patience of a saint.'

(L - special)

'You know, of course they do have their meltdowns sometimes the children but the way it was managed, nobody was shouting, you know everybody was giving each other respect… Umm... It was calm as well, you know. And I thought 'this is the environment I want for Fred'.'

(F - special)

This seemed to be a key factor for parents who had chosen special schools.

<u>Subtheme 5.8:</u>   <u>Wanting their child to be included</u>

'That would be taking him away from all of his friends'

All the mainstream parents said they had considered special provision, especially when their children were first diagnosed, but they had all decided 'to try' mainstream for various reasons.

'I thought automatically that as soon as you got a diagnosis or something wasn't right that you wouldn't be able to go to mainstream. I didn't realise that there was ways and means they can put in place to help them fit in so I sort of broadened my mind a bit, I sort of found out a lot more.'

(G - mainstream)

The parents talked about wanting their child to be with their friends at the local school, and one parent expressed the view that her child would have the same issues at a special school.

'He's going to have a lot of issues, he's going to have a lot of things that he's not going to like, he's not going to know, he's not going to know what to do about, but he would if he was at a special school, but that would also be worse because that again would be taking him away from all of his friends'.

(M - mainstream)

One parent talked about how she wanted the experience of being a mother at a local mainstream school.

'So yeah it was really at an early stage that I thought it would be nice for him to go to mainstream because it would be nice for me to be a proper mum, to

take my son round the corner to the local school, which I didn't have that
experience [sic].'   *(R - mainstream)*

All the parents said that if they had felt that their child needed a special school that they would 'go down that road' but that they really wanted their children to be part of the local school community if possible.

The parents of children at special school also talked about wanting their child to be included, but had a different view of what this inclusion would look like and had decided that this was best done in a special school community:

'And with the school Fred goes to they care for each other and they respect
each other and those are the sorts of principles we bring Fred up with
anyway. Everybody, you know there are so many different variations of
abilities at Fred's school they're there together as like one big family and
that's what we sort of liked.'   *(F - special)*

<u>Subtheme 5.9:</u>   <u>Wanting their child to shine</u>

'*I wanted her to be one of the ones that shone, rather than the*
one that floundered'

Parents who had chosen special schools for their children all talked about their child's special skills and strengths, and about how they wanted their child to be able to shine at school.

'He's one of the top sort of intellect wise in his school cause he's got really good abilities but still got autistic traits and on the spectrum.'

(F - special)

'So I just didn't think it was fair on anyone, and also on Lily, to be the one that everyone looks at, where as in the unit she's actually got a chance to be one of the better ones in the class, and I wanted her to be one of the ones that shone, rather than the one that floundered so yeah.'

(L - special)

Theme 5 Summary

Theme 5 analyses what parents said about the reasons they chose specific schools. Pre-school experiences seem to have been key for these parents in determining whether they chose special or mainstream schools. Seeking advice from friends, school staff and other professionals was important. These parents had obviously spent a lot of time thinking about and researching schools.

The parents who chose special schools talked about the specific equipment and therapy that their child could access at a special school, and also how important it was for staff to understand their child's autism. These parents seemed to feel that their child needed different things to mainstream children, and perhaps indicates that they see their child as more different than the parents who chose mainstream schools.

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Both groups of parents talked about how important they felt it was that their child be included, but this seemed to mean different things to each group. The mainstream parents seemed to value inclusion in terms of their children being around their friends and being part of their local school community. However one parent who chose special school had experienced her child being excluded from activities in mainstream pre-school and saw inclusion as her child being able to access all activities offered within a group of peers with autism. The other special parents talked about wanting their child to have a chance to shine among their peers with autism, which they felt they perhaps would not be able to do in a mainstream setting.

These comments are very much related to subtheme 1.1 which discussed how parents prioritised their child's happiness.

Research Question 6: What do parents think would improve their experience of choosing a special or mainstream school?

Theme 6: Advice about what parents need

This theme encompasses parents' views about what the needs are of parents who are going through the process of choosing a school for their child, and also the advice they would give parents in this position.

<u>Subtheme 6.1:</u>　　<u>Access to professionals</u>

'Listen to the experts 'cause they do know what they're talking about'

Parents from both groups spoke about a variety of professionals who had helped them during the process of choosing a school for their child. They had a range of comments to make about professionals from a range of agencies and much was said about how important the knowledge and expertise of these professionals had been.

Many participants said they would advise parents to follow the route that they had, by accessing first a paediatrician and then the services offered through the local authority:

'Obviously they would, you know if they've got a consultant that would be a good way, because obviously not all consultants are the same but that is where I got a lot of my support and they also know what else is out there for you. I was told to go to the multi-professional centre and I done a lot of my courses there to do with sensory issues, sleep patterns, all things like that, so that helped.'　　　　　　　　　　　*(G - mainstream)*

'You like to think you know a lot, but I think the best thing to do in those circumstances is to listen to the experts cause they do know what they're talking about. And once they had, once if their child did get a diagnosis   umm there is help out there'　　　　　　　　　*(M - mainstream)*

One parent also mentioned independence parent advocacy groups:

'I think there's a lot…. There's the advocacy one and there's another one, they provide advocacy….the county Autistic Trust. Yeah so it is a lot… the autism parenting programme helps, the therapy centre, you can get so many things, like you can get trained to use the sensory room. And so there is plenty of help.'   *(H - special)*

Parents said that the route they had taken in terms of a diagnosis and accessing support through initially contacting a doctor had worked well for them, though their coming to terms with their child's autism was a factor in this.

Subtheme 6.2:   Support

                        'There is support there, you know'

Parents from both groups spoke about some of the support they had received in this process and the value of the professionals input in terms of support as well as their professional knowledge and expertise:

'I had someone else I could still get the support from, so I do think it you know, there is support there, you know.'   *(R - mainstream)*

'Rose (Advisory Teacher) - angel! And she sort of explained to me in quite a lot of detail what I had to go through… Oh and the Educational Psychologist we had, Nancy, she was really lovely.'   *(H – special)*

It is interesting to note that the parents rated very highly the professionals who they met with several times and who worked directly with their children. As these children had received their diagnoses as pre-schoolers they had Advisory Teachers who worked with them and would have met the parents and this relationship seems to have been very important to the parents.

Part of the role of the Educational Psychologist in statutory assessment is to meet with the parents and ask them about their views and wishes and to listen and this seems to have been appreciated by the parents.

Subtheme 6.3:   Peer support

            'It's really good to have that kind of peer support'

Very much related to Theme 4: Empathy for other parents was the suggestion that parents would really benefit from peer support:

> *'Within where your child goes to school or whatever provision they're in to make a network with the other parents if you can because they're all going through the same thing. When you're sitting there and just bursting into tears any everything and why am I doing this, they've all done it too, so it's really good to have that kind of peer support with other parents going through the same stuff with their kids.'*   *(F – special)*

Parents talked about how important it was to share their feelings:

'So it has been a really, really emotional rollercoaster for me, but I think I've been strong. At times I've bottled things up but at times I've sort of opened up and cried about it to relieve the stress, if I don't then I'll go insane myself. I think I'm coping quite well to be honest, even though I'm crying that's a good thing that I can talk to you and let it out, then at least I've let it out.'

(R – mainstream)

Subtheme 6.4:   Clarity

'All you need is to have an idiot's guide to the whole system'

Parents from both groups however, while acknowledging and valuing the support of peers and that available professionally, made comments about the issues with support being that it is not clear to parents how to access the support from services:

'There is support there, you know, you just got to know where to get it from really, and I think that maybe they could improve on, be a bit more open as to where they can get help from.'   *(G - mainstream)*

'It's just knowing where to ask.'   *(H - special)*

'So there is, I think especially in this area there is a lot of help. Many parents we know of autistic children just weren't aware of this. I think that's where a little bit of more money can be invested, in advertising it, people with autism.'

(H - special)

Parents also commented on the way that the clarity of the process could be improved and how this could be communicated to parents.

'And that's the thing, you know if you're aware of a system you know, well at this point you should have done x, y and z, but if you don't know you're just waiting, waiting, endless waiting and then you're 'oh I didn't realise that should be done.' It's just keeping pushing and knowing what comes next in the process and I don't think that's made clear enough in the health system or in the education system saying 'right we've got this process this is what you should be expecting after that and this is how long it takes and this is what you have to do to get to that place and these are the options available after that'. There's nothing like that there. Do you see? All you need is to have a flowchart that's like that, that, that, that, that, so you can follow it down. You know, like an idiot's guide to the whole system.'   *(F - special)*

This rich quote expresses the frustration that this parent felt with the lack of clarity in the system, not knowing how long things should take and what to do next as a parent. Another parent suggested a forum:

'I think there should be meetings. I think that if your child's going forward, if they've agreed to statutory assessment, before you've written your things I think then you should have a meeting, and I think, I don't know I just think there should be more than just, I do. It should be like a forum, you know how you have the autism forum it should be like that, a forum for parents, just

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because a lot of parents don't know where they stand and they don't know what they need to do.'

<div align="right">*(L - special)*</div>

The parents talked a lot on this subject and many had ideas of how the system could be improved. It was interesting that the parents who had more comments and ideas about radical changes to the whole system were those of the parents who had talked about battling with the statementing system and who had chosen special schools.

<u>Subtheme 6.5:</u>   <u>Provision</u>

     'There's not enough provision'

One difference in the advice that mainstream parents would give was around the type of provision they thought the children of friends might need. The parents of the mainstream children tended to suggest that parents should try mainstream school and see how their child got on.

'My advice for the mainstream school with her son was 'try mainstream and if it's not going to be right then he will, he will be better off in a special school but if you don't try the mainstream you will never know, will you? And would you have made the right decision?'   *(M - mainstream)*

However, all the parents of children at special schools talked about how there should be more special provision and discussed the issues around why they felt there were not more specialist provisions:

'You don't want to have to do that just to get them a proper standard of what you feel's a good education, and there's not enough provision. I'm really concerned about primary and secondary provision for special needs kids. And not enough variety either. But it's the money'.

(F - special)

'There should be more units, far more units in (LA), more hubs.'

(L - special)

'It's a very big difference. I wish there were many. There should be more schools around, considering there are many children; I mean (LA) is the highest all over England, the highest autistic children. There are so many parents out there that are so desperate to found a place for their children.'

(H - special)

It is perhaps unsurprising that the parents who felt they had struggled to get their child a place at a special school felt that there should be more specialist provision, but noteworthy nonetheless.

Theme 6 Summary

The parents had a wide range of advice and suggestions about what would help parents of children with autism choosing schools in the future. Many of the comments from both groups of parents related to aspects of support with having a

child with autism and the lack of clarity about how the system works and how to access support. There appear to be differences between the views of the parents about the system of choosing schools, with the parents of children at special schools feeling that the processes should not only be clearer but also should be changed and feeling there should be more specialist provision.

Chapter Five: Discussion

This chapter comments on the findings of both quantitative and qualitative results. The limitations of this study and implications for further research are discussed and implications for EP practice and the LA made clear. Information regarding the feedback to stakeholders and the self-reflection of the researcher are explored.

5.1 Commentary on Findings

In this section the findings are commented on in relation to the research questions. Comparisons have been made between the responses from the qualitative data, the quantitative data and the literature.

The first two research questions used a local authority database to describe the number and proportions of pre-schoolers starting at special and mainstream schools in the LA. This provided information on the sample of participants for this research.

Research Question 1: Over a six year period what proportion of pre-schoolers with autism attend special and mainstream schools when they start school?

The data analysis showed a similar proportion of parents of children diagnosed with autism as pre-schoolers and now in primary school had chosen special and mainstream schools.

Research Question 2: Over a six year period what is the trend for pre-schoolers starting at special and mainstream schools?

Of the children currently at primary school in the LA who had been diagnosed with autism as pre-schoolers it was interesting to note that, although there was some variation in the numbers and proportion of children starting at mainstream and special schools, this has been quite consistent over the past six years.

The sample of parents identified by this database analysis were contacted and asked to take part in the research by completing a questionnaire that answered research questions 3 and 4.

Research Question 3: How do parents rate their children's special and mainstream schools?

The questionnaires returned by special and mainstream parents indicated that parents are similarly satisfied with their children's schools, with the same range of responses. This is in line with Kasari et al.'s (1999) study and Bitteman et al.'s (2008) study discussed in the literature review chapter and in contrast with Whitaker's (2008) study that found many parents were dissatisfied with their child's mainstream school provision.

Research Question 4: What factors do parents say influence their choice of school?

This key research question was explored through both the quantitative and qualitative phases of the research. In the survey parents were asked to rate factors based on their importance and in the interviews parents' comments on this choice formed:

Theme 5: Making the decision

The factors that parents rated most highly on the survey were the school's autism friendliness and the feeling that staff understood their child. In the interviews the parents, particularly those who had chosen special schools, also talked about feeling that the staff understood autism as being a very important factor. This is in line with Whitaker's (2008) findings that the most striking difference between 'satisfied' and 'dissatisfied' parents in their study was in their responses to the statement 'most staff understand my child'. This is also in line with Fredrickson et al.'s (2010) findings that positive parental views of provision is linked to the understanding and knowledge of autism of the staff.

Parents in the present study cited a number of other specific factors as being important. Class sizes were thought to be important by most parents, as Kasari et al. (1999) found. Parents who had chosen mainstream schools commented on the benefits of their child attending their local school and being part of the school community which is in line with Palmer et al.'s (2001) findings, described in the literature review.

All the children who were attending mainstream were at schools either linked or attached to where they had been at nursery, and the parents had also had a positive experience of their child's pre-school. A positive experience at pre-school and a pre-school link with a mainstream school seem to be very important in whether or not the parents decided to choose mainstream schools for their children.

All the parents had talked to a range of people about the schools they had chosen. All the mainstream parents mentioned the fact the school was local and that they had talked to friends about the local school. As described in the literature review, Palmer et al. (2001) highlighted a school being local as an important factor for parents when choosing schools. All the parents talked about how the staff they had been in touch with at the school were important when they were making their decisions. Comments varied from those about good communication and support, and feeling that they had the understanding and expertise to meet their child's needs.

Kasari et al. (1999) found that parents of children in special schools were significantly more likely to cite teachers as being important in school choice, however the present study found that all parents valued having staff who were supportive and understanding of their children.

Many parents who had chosen special schools said they felt that mainstream schools could not meet their child's needs. This is in line with Kasari et al.'s (1999) study, discussed in the literature review chapter, which found that, while about a quarter of parents surveyed commented that inclusion was ideal, over half the

parents commented that their children's current educational needs could not be met in an inclusive environment.

Although there were differences between the factors that the parents felt were important about schools, such as facilities and class sizes, versus being local and having a good reputation, the main difference between the two groups of parents seems to be what their vision was of their child being included.

For the parents who chose mainstream schools factors such as a good experience of mainstream pre-school and supportive external professionals and school staff seem to have helped them make a decision that deep down they were hoping they could make. All these parents said that if their child 'had to go' to special school that they would come to terms with that but that they really wanted their children to be part of the local school community and making friends with a range of children.

The parents who chose special schools cited more specific factors about why their child needed a special type of schooling but also seemed to have different views from the mainstream parents about what inclusion looked like. These parents talked about wanting their children around others with similar needs and developmental levels (as Palmer et al., 2001 also reported) because they want their children to be able to shine.

<u>Research Question 5:</u> What do parents say about their experiences of making the choice about which schools they want for their children?

Four themes emerged from the interviews with parents about their experiences. Though the interviews focused on the choices they had made about schools, parents talked about these in the context of their lives as parents of children with autism and other significant experiences.

The researcher reflected that the first two themes set a context for making the choice of school, as the parents talked about having a child with autism and their experiences of process involved in having a child with autism. The next two themes follow on from these, encompassing the anxieties that, given these experiences, they felt when making the choice about which schools they wanted and how this led them to feel empathy for other parents in their position.

Theme 1: Having a child with autism

As described in the findings all of the parents talked about what is what like to have a child with autism and the challenges they face as parents. They were not directly asked about this but seemed to want to share how difficult things had been or still were. Two of the mainstream parents, while acknowledging that their concerns were not 'sorted' talked about the most difficult times they had had with their children as being in the past, whereas all the special parents talked about their children still being very demanding and parenting them as being very challenging.

Both groups of parents talked a lot about what it was like coming to terms with their child having autism, the difficulties accepting their child was different and how they found it very hard to take in. Both groups referred to the mix of emotions around

finding out their child had autism. These feelings have been expressed by other parents in other studies, for example Mansell & Morris, (2004), who describe parents feeling relief and grief and many other emotions. Carpenter (2005) suggests that parents who have recently received a diagnosis for their child are 'frightened, upset, grieving and constantly vulnerable.'

Both groups of parents described the impact of having a child with autism on their everyday life. It seems decisions that parents make about having a child with autism, such as choosing a school, are very much effected by the daily challenges of parenting a child with autism.

Theme 2: Experiences of Services and Processes

These parents' experiences of health and education were an important part of making a decision about the school they wanted for their children. Two parents talked about very difficult experiences they had with their children when they were very small. The MMR vaccine was mentioned by all the parents who had chosen special schools, whether or not their child had had the vaccine and whether or not they attributed their child's autism to the vaccine.

The debate continues in the media over whether the MMR has played any part in causing autism, though the NHS website now states that this has been 'completely discredited' (nhs.uk, 2012). It is perhaps unsurprising that when parents describe their experiences that they mentioned the MMR. However, it is interesting that the parents who have decided their children need to be educated differently from other

children mentioned the MMR, as if the questions they are asking about their child's autism are more medical, biological and within child.

The parents described a range of experiences of their child's diagnoses and, in the case of the special parents, their statements. Some of the parents, of both special and mainstream children, found the process very straightforward whereas others found it long and difficult. As described in the Literature Review chapter, Renty & Roeyers (2006) reported that many but not all parents complained that the search for appropriate support and a school place had been very difficult and had taken a long time, which is similar to the findings of the current research.

The issues parents face securing support for their children was discussed in the Lamb Inquiry (2009):

> In many places and for many parents it [SEN provision] can and does work well, but for too many parents it represents an unwarranted and unnecessary struggle. For some, what should be easy becomes hard; where there should be support there can be indifference; and when there should be speed there is delay. It is no wonder that confidence breaks down in these circumstances. The system needs to feel more like one where 'everyone is on the same side' as another parent put it, with everyone focusing on the best outcomes for all our children. These proposals are designed to put the system further on side of disabled children and children with SEN and the parents trying to do the best for them. (p. 6).

This seems particularly relevant to the parents of children at special schools, who all talked about the need to battle and fight, which were terms that the mainstream parents did not use. The special parents talked about the need to fight with schools, healthcare professionals and the local authority rather than in relation to any one process. These feelings of stress and frustration seemed to be compounded for some of the parents who were struggling to accept their child's diagnoses at the

same time. Added to this the adversarial feeling of the process and not having the opportunity to meet with their SEN Officers has left many parents feeling that they have had to be much more 'pushy' and assertive than was comfortable for them to get what they felt was an appropriate standard of care for their child.

This issue is linked to political developments while the current research was being undertaken. There has been much media debate over the coalition government's pledge stating, 'We will end the bias towards the inclusion of children with special needs in mainstream schools,' (Conservative Party Manifesto, 2010) as highlighted in the introduction.

Theme 3: Anxieties about school

The anxieties that parents expressed about their child starting at school were common to all the parents interviewed. These findings link very strongly to the findings of previous research reviewed in the Literature Review.

Both groups of parents expressed concerns about the school being able to meet their children's needs and whether they could provide learning opportunities that their children could access. Kasari et al. (1999) found that over half the parents of the children with autism that they questioned felt that their children's needs could not be met in an inclusive environment. Palmer et al. (2001) reported that many parents felt that their children's disabilities precluded them from benefiting from participation in a mainstream classroom.

The parents of the children at mainstream schools all talked about the importance of communication with the school, which Renty & Roeyers (2006) found to be a very important factor in parental satisfaction. The parents expressed concerns about their children making friends at school, which were similar concerns to the participants in Leyser & Kirk's (2004) study who felt anxious about their children being socially isolated in mainstream classrooms.

Parents from both groups mentioned being concerned about the impact of their child in a mainstream classroom because of their autism and the disruption to the mainstream class and the pressure on the teacher. Palmer et al. (2001) reported that parents in their study expressed empathy for overburdened teachers and felt that inclusion of their child would overburden and negatively impact upon mainstream teachers and other children.

Theme 4: Empathy for parents

Every parent interviewed in the present study described how they had helped another parent, and how they wanted to help others in their situation. Several talked about the importance of peer support and how isolated they had felt at times being a parent of a child with autism. The two parents interviewed from ethnic minority backgrounds seemed to feel this keenly, perhaps as a result of being part of an even smaller group in their communities, identifying with those from the same cultural background who are parents of children with autism.

It seems that this empathy comes from the parents' strong feelings about how hard it is to have a child with autism and to negotiate the various processes involved with getting a diagnosis and in some cases a statement. Wanting to help others indicates that these parents felt that they would have liked some support when going through these processes. By sharing their experiences they felt they could help other parents, and also themselves through peer support.

The findings of these sections indicate that parents of pre-schoolers with autism feel they have already had so much to deal with when they arrive at the point of choosing a school. Having a child with autism has had a huge impact on these parents lives and the practical and emotional demands appear to have been very much in the parents minds when they came to make their decisions.

These experiences appear to the researcher as a significant factor in how parents make the decision about the type of school they want for their child, as well as the specific factors they described in response to Research Question 4.

Research Question 6: What do parents think would improve their experience of choosing a special or mainstream school?

Parents' expressed many views about what the needs are of parents who are going through the process of choosing a school for their child, and also the advice they would give parents in this position. These comments formed:

Theme 6: Advice about what parents need

Parents from both groups spoke about a variety of processes and various professionals who had been involved with their child leading up to and during the process of choosing a school for their child. Bitteman et al.'s (2008) study suggests that parents of children with autism can receive support from a significantly greater number of agencies than children with other disabilities, and parents in the present study talked about feeling confused and overwhelmed by the numbers of appointments and reports they have to deal with.

Parents rated very highly the professionals who they met with several times and who worked directly with their children. Two parents mentioned the Educational Psychologist as a professional who was kind and supportive. Carpenter (2005) suggests that 'the role of the professionals involved with such parents is 'to catch them when they fall, listen to their sorrow, dry their tears of pain and anguish and, when the time is right, plan the pathway forward.' (p. 181). Being sensitive to what parents are going through is obviously very important for professionals supporting parents of children with autism when they are choosing schools.

All the parents talked about the complexity of the various processes and systems parents have to go through to access support for their children. Several talked about how this could be made clearer, with parents who felt they had battled with the statementing system having the most comments and ideas about radical changes to the whole system.

All the parents of children at special schools talked about how there should be more special provision and discussed the issues around why they felt there were not more specialist provisions. Whitaker (2007) found that parents of children with autism were significantly less likely than other parents to feel that they had been able to choose the provision they wanted for their child, and the parents in the present study seemed to agree that their choices were very limited.

5.2 Limitations of Findings

A number of limitations to this study should be considered.

5.2.1 Limitations of Quantitative Findings

The population of participants in this study were obtained from the LA Individual Children Support Service database. From this the details of all children who had obtained a diagnosis of autism before starting school were obtained. These names were cross-referenced with the LA 'Impulse' database to ensure accurate and up to date address records and the parents of all these children were contacted by post. It is possible that some parents might have changed address and if they are no longer receiving services form the LA would not have received the survey.

The postal questionnaire method of data collection is commonly used in this area of research. The response rates vary greatly and rarely exceed 50%. This questionnaire had a response rate of 22%, which is rather low. This means that there was a large proportion of parents whose views were not known. The parents who

responded might have very different views from the parents who did not respond and their views therefore cannot be seen to be representative. An examination of the database revealed that 54% of these children had gone to special schools and 46% to mainstream schools. Of the respondents to the questionnaire 64% were parents of children at special schools and 46% parents of mainstream children, a greater proportion of the respondents than would be representative were parents of children at special schools.

It is possible that the respondents to the questionnaire had either particularly strong views or difficult experiences that they wished to communicate, and though their responses are still valid and useful to the knowledge base it is important that these are not generalised to all parents, either locally or nationally.

It must be noted that the parents contacted for this research were from one local authority. Each LA in the UK has particular practices and policies and these will have affected the views of the parents in this research.

5.2.2 Limitations of Qualitative Findings

The researcher interviewed a sample of six parents. Three of these were parents of children at special schools and three of these at mainstream school. There are number of limitations to consider relating to this small and specific sample in terms of generalising the findings.

All of the parents were mothers rather than fathers and therefore these findings were specific to mothers and could not be generalised to the experiences of fathers. They were all birth mothers and experiences might have been different had they been adoptive parents.

This sample of parents highlighted a number of rich issues however the small size of the sample reduces the ability to generalise the findings to a wider population. These parents were all from one LA and the local practices and policies will have affected the parents' views and experiences.

Another limitation is that the researcher interviewed each participant only once. Interviewing the participants more than once may have yielded richer data and given the researcher more of an insight into their experiences. The children of the parents were also different ages, due to the sample that volunteered to be interviewed. This was controlled across each group. How recently the parents had been through the experience of choosing schools might have had an impact upon how they felt about it. Interviewing the parents over time would have yielded richer data.

Other factors such as the gender of the child might have had an influence, compounded by the small sample size. Factors such as parental education that the literature suggests might have an impact on parental views on inclusion (Leyser & Kirk, 2004) were also not controlled for and could have influenced the data.

A common limitation with research involving autism is the nature of autism as a spectrum and the huge range of implications that this has for children with autism.

Every individual has unique strengths and difficulties and the severity of their needs varies greatly, meaning that this is not a homogenous group of children. Autism is often called an 'umbrella' term for a range of needs and when comparing parents experiences it is important to note that their individual children will be very different, and that this will impact on their experiences. In this research the parents interviewed all said their children were verbal and that they had had to think carefully about their choices of schools, however for ethical and practical reasons the severity of the children's condition was not questioned in depth. The author acknowledges that the severity of a child's needs is a significant factor for parents when choosing special or mainstream schools.

Qualitative research is a reflexive process in that the researcher has an effect on the research and vice versa. It is important to acknowledge that interviewer's manner, style and characteristics will have affected what was said in the interviews. Interviewing parents about their experiences was emotional for the parents and the interviewer often had a strong emotional response to the stories of the parents. Research supervision was vital for the researcher in order to talk through the experience and reflect on how to remain neutral during the interview process, while being supportive of the parents. Some very emotive comments and personal feelings were captured in the interviews. It is likely that such rich data was collected because participants felt comfortable in their own home where the interviews took place and felt free to discuss intimate feelings.

Transcription and thematic analysis was carried out by the interviewer. The advantages of transcribing the data herself included the researcher being able to ensure that the transcripts were accurate.

Limitations relating to the method of data analysis should also be considered. Thematic analysis as a qualitative data analysis method has some weaknesses. The researcher chunked instances of behaviour into categories. The researcher feared that some of richness of the data might be lost through this process, as not all data is coded and grouped into subthemes and themes.

The same researcher conducted the interviews and analysed the data. In such cases there can be a concern that the analysis of the interviews was biased because it was carried out by the interviewer, however this was mediated by a peer reading the research.

5.2.3 Limitations regarding the LA and participant sample

The researcher acknowledges that both the qualitative and quantitative findings of this research are very specific to the participant group who were interviewed and the specific LA in which the research took place.

As stated in sections 5.2.1 and 5.2.2 the participant sample was very small and it is important that the findings not be over generalised, either to the LA as a whole or beyond. Although there were some common themes in the findings about the parents interviewed it is important to recognise that six is a small number of parents

and to acknowledge that any commonalities, though interesting, could occur for a number of reasons, including by chance.

Section 1.2.2 describes the LA in which the research was carried out and the types of schools and services available to children with autism. The features of the LA and the support available would very much have effective these parents experiences and views. Home-based programmes were not available in this LA, for example, which may have influenced parents decisions to seek special school placements where their children would receive autism-specific support. The researcher also speculated that other features of the LA, including lack of support groups for parents in the LA, could have contributed to the findings that parents have feelings of confusion and want to help others.

The researcher was very mindful of her position within the research. Parents may have viewed her as an employee from the LA and this could have affected what they shared with the researcher. The researcher explained her role and the purpose of the research in her letter to parents (Appendix 2) and information sheet for parents (Appendix 4). The researcher also explained that their involvement was confidential and that taking part in the research was would in no way affect the services that the parents would receive from the LA to encourage parents to feel confident sharing their views.

5.3 Implications for further research

It would be interesting to research the experiences of a wider range of parents, including those from other parts of the country. The views and experiences of parents living in other local authorities with different schools and different policies and practices regarding support for families of children with autism and school choice could be sought.

Including fathers and adoptive parents would provide another set of views and experiences. Fathers and adoptive parents are an underrepresented group in the literature, which often focuses on the experiences and views of birth mothers, as in the present study. It would be interesting to see how the views of other parents are similar or birth mothers and how they differ.

Given the importance of the rights of the child and eliciting children's views, asking children what they want would be a fruitful way of obtaining pupil voice. Further research could more directly investigate the experiences of children starting special and mainstream schools and the factors that affect how they experience these provisions.

Future research could also investigate professional's views on schools for children with autism and how these are selected, and triangulate these views with parents' views and children's experiences. Advice from professionals was found to be a factor in how parents made their decisions about the schools they wanted for their children and research could examine professional views and explore their experience of the

process. This could help inform how to organise services to best meet the needs of families of young children with autism.

A particularly fruitful piece of research might involve gathering data from similar participants over time, as the decision explored in the present study seemed to be a small part of the stories of these families. Exploring initial feelings about diagnosis, first experiences of pre-schools and services and processes such as statementing, for example, would enrich and add depth to the literature exploring parental views of inclusion.

There is merit for further research in this field as it could inform LA commissioning when meeting the needs of children with autism and their families.

5.4 Implications for the Local Authority

The findings suggest that the parents in this LA can find choosing a school for their young children with autism very difficult and that they can have a lot of anxiety about the process and whether they have made the 'right decision'. The author suggests that there is a need in the Local Authority to recognise this anxiety and consider ways to support these parents.

Some of the parents in this study felt very confused by the process and several made comments about how the process could be changed or made clearer for parents. It is pleasing to note that since this research was undertaken the LA SEN department has published new guidance relating to SEN procedures and it would be

beneficial and timely to consider how to disseminate this to parents and how to make the information accessible.

Implications for EPs are discussed in the next section but specifically for this LA it is worth considering closer collaboration between the EPS and the ICSS (Individual Children's Support Service) pre-school support. In the LA at present the only pre-schoolers to receive support from an EP are as part of statutory assessment.

Several of the parents talked about wondering if they had made the 'right' decision, however there are many points of view about what is best and it is generally acknowledged that a 'one size fits all' approach is not effective with children with autism (see Literature Review section 2.2). More information about the schools in the LA and the approaches they use with children with autism would also be very helpful. This would ensure that parents make more informed decisions and therefore feel less anxious and uncertain about whether they have done the 'right' thing in terms of school choice.

The research identified the benefits of a 'forum' for parents where they could talk to other parents and professionals about issues such as choosing schools and the related processes. Some other boroughs offer such services, for example including sessions on types of schools and the process of school selection as part of weekly groups for parents of children with autism. The research indicates that such a development would be worthwhile. This would also help parents feel they are helping others, another important finding from this research.

5.5 Implications for Educational Psychologists

The findings suggest that parents find choosing a school for their young children with autism very difficult and that they can have a lot of anxiety about whether they have made the right decision.

Holland (1996) studied the role of Educational Psychologists (EPs) when working with parents of children who have Special Educational Needs, and suggested that parents' emotional responses to their children's diagnoses are like bereavement, highlighting that the process of adaptation is long and painful. Holland (1996) recommended using basic counselling skills, including active listening, understanding and empathy when working with these parents.

Building positive relationships with parents is vital to the work of the EP. Often parents feel 'done to' as opposed to 'worked with'. If parents feel they are part of a collaboration they may feel less helpless and more in control of their child's education.

Analysis of the interviews shows that Educational Psychologists were only mentioned in relation to the Statutory Assessment Process. This finding demonstrates an aspect of Farrell's (2006) review of the functions and contributions of Educational Psychologists. He stated :

> There was a universally held view that EPs have been too heavily involved in statutory assessments and that this has prevented them from expanding their work so as to make more effective contributions that can maximise the added value to ECM outcomes for children. (p. 96).

In light of the finding that many parents experience the range of processes involved in parenting a child with autism, including school choice, as being very challenging, there might be scope for EPs to use their skills to support parents and families during difficult periods more directly. The findings of this research indicate that parents really valued the professionals with whom they had built up a relationship and there is perhaps scope for EPs to have a more significant role with these families.

It should also be noted that EPs views of inclusion could also be a factor in considering the implications of this research. EPs were mentioned in the current research in relation to advice and support during the process of statementing and any particular view the EP had on inclusion and special and mainstream provision could certainly have influenced parents' decisions. This is particularly relevant in many LAs where the EP has potentially conflicting responsibilities, with LAs keen to encourage mainstream provision choices for cost reasons.

Other implications to consider for EPs are the increasing opportunities for EPs to conduct research with the changes in the profession. Following the present study being conducted Warner (2012) published findings of a pilot project to offer support for children with disabilities by an EP service. This project aimed to give families the opportunity to talk to an EP about the impact of a diagnosis being given to their child, in most cases autism, and found that parents said 'talking really helped'.

5.6 Self-reflection and reflexivity

In order to ensure reflexivity of the researcher's position and reduce bias, a research diary was kept. This helped the researcher track feelings, prejudices and assumptions and identify areas of researcher bias (Robson, 2002). Regular supervision both through the LA and university also supported the researcher's reflexivity.

The researcher reflected on Cresswell's (2009) suggestion that researchers need to 'explicitly identify reflexively their biases, values, and personal background, such as gender, history, culture and socioeconomic status, that may shape their interpretations formed during the study' (p. 277).

The researcher reflected on the fact she had had a very positive personal experience of education and was undertaking this research as a local professional and not being a parent herself, and how this would be viewed by the parents. The researcher has a history of working in both special and mainstream schools for children with autism. This meant the author felt she was able to see the pros and cons of each type of provision. However the researcher was conscious of her present position working in an LA where specialist provision is oversubscribed and there is a perceived need to encourage more parents to 'try mainstream'.

The researcher was very aware that her long history of working with children and young people with autism and their families meant that she cared greatly about

producing something that would do justice to the experiences that had been shared with her.

Many entries in the research diary involved the researcher feeling reluctant to made headway with the research due to a fear of not succeeding or producing something good enough. Learning is an emotional as well as cognitive process and the researcher found it hard to commit to an area of research and to 'go for it' despite encouragement from supervisors.

The area of research was very important to the researcher and she felt a strong feeling of empathy towards the mothers she was interviewing. There was a fine balance between wanting to ask the key research questions and also wanting to listen to what the mothers really wanted to talk about and to be supportive. The researcher reflected on how her feelings impacted on her findings. Ahern (1999) states that:

> The ability to put aside personal feelings and preconceptions is more a function of how reflexive one is rather than how objective one is because it is not possible for researchers to set aside things about which they are not aware. (p. 408).

Some of parents became quite emotional talking about their experiences and it seemed that the feelings and concerns they had for their children had had a great effect on their mothers. Several actually thanked the author for listening and seemed to find the process quite therapeutic.

A common entry into the research diary throughout the research period was the struggle to meet the demands of working for the LA and finding time to carry out and

write up the research. Concerns focused around being torn between becoming a skilled Educational Psychologist and the time it took to develop skills as a researcher. Another area included wanting to develop positive working relationships with members of the various teams while having to be quite persistent to obtain information from them required for the successful completion of the research. Supervision to explore these dilemmas was provided.

This experience has had a huge impact upon how the researcher will now work with parents who have a child with a disability or an SEN. The researcher hopes she has been a sensitive professional in the past but this research has brought a much greater understanding of how parents feel when required to revisit painful issues and realities.

It is a common perception amongst many professionals in the LA that some parents are very difficult and demanding and put pressure on the LA to provide extra resources. Undertaking this research has shifted the researcher's thinking to appreciate that some parents are highly anxious about their child and seek support to ensure an understanding of their child's behaviours.

5.7 Conclusions

This research looked at the choices that parents make about special or mainstream schools for their young children with autism. It examined what parents felt was important and also their experiences leading up to and including choosing a school for their children.

It found that parents, whether they choose mainstream or special schools, have many experiences, anxieties and desires in common, all of them wanting their child to be safe and happy and wanting what is best for them. Parents said that feeling that staff understood their child and that the school was autism-friendly were most important and that visiting the school was also important.

The researcher concluded from the findings of the quantitative and qualitative stages of the research that the decision about whether to choose a special or mainstream school happens in a very complex context. The researcher found that perhaps some of the most powerful comments the parents made in the research were about the fact that choosing a school for their child is only one small step along their journeys as parents of children with autism.

Parents shared additional feelings about the future on their questionnaires:

> *'At the present time I am happy with this school as it supports my child's needs, but I think that in the future my son may need something other than mainstream.'* *(mainstream)*

> *'Secondary schools are now my priority, having passed the 11+ I am currently making choices of Grammar schools, I am nervous to say the least.'*
> *(special)*

The parents interviewed also talked a lot about their feelings about the future.

'And what I fear as well in the future is there's secondary school… I'm looking at trying to save up and maybe getting private education, 'cause there's still not enough provision. So I don't know what the future holds but I've got about three and a half years to try and sort it out!'   *(F - special)*

'It's not a case of 'right, we've sorted it, they'll be fine'. It's an all the time and getting them to understand life and all sorts of things…. But yeah now I've had that support I'm more confident to help him and get the support for him so that's good really.'   *(G - mainstream)*

One parent spoke about the fact that, even though her child was coping well in mainstream, she continues to worry that at some point things might get worse:

'I always worry about that and I'm waiting to hear and waiting for that to happen. Waiting for them to actually say 'right, you know this disorder thing? I think it's happening now.'   *(M - mainstream)*

Choosing a school for their child was a important hurdle for these parents and seemed to be perceived as the first of many the family would have to go through and that their child would have in their lives. Having a child with autism is an 'emotional rollercoaster' for these parents and the professionals who support them should remember and acknowledge this when working with these families.

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Appendices

Appendix 1: Content of questionnaire posted and online

**Study of how the parents of young children with autism
decide the schools they want for their children**

YOUR CHILD

What is your child's year and month of birth?	MM/YY
What is your child's gender?	M/F
Is this your first child?	Yes / No
If no, how many older children do you have?	0/1/2/3/4/5/6/7/8/9
When did your child receive a diagnosis of ASD?	MM/YY
What level of support does your child receive at school, in relation to the Special Educational Needs Code of Practice?	General Classroom Support/ School Action/ School Action +/ Statement
If your child has a Statement of Special Educational Needs please specify when they received this:	MM/YY

PRE-SCHOOL

Did your child attend pre-school?	Yes / No
If yes please specify which pre-school:	

SUPPORT GROUPS

Did you attend any support groups for parents of children with ASD before your child went to school?	Yes / No
If yes please specify which groups:	

YOUR CHILD'S CURRENT SCHOOL

Which school is your child now attending?					
Was this school your first choice?	Yes / No				
If not, what was your first choice of school for your child?					
Please indicate your current overall level of satisfaction with your child's school out of 5:	1	2	3	4	5

FACTORS AFFECTING YOUR PREFERENCE OF SCHOOL

Please rate the factors that affected your preference of school out of 5: (where 1 is not important and 5 is very important)		1	2	3	4	5
	Location Size of school / classes Advice from other parents Advice from pre-school Advice from others professionals Visiting the school ASD friendliness of school Feeling staff understand your child's needs Access to therapists					
If other factors affected your preference please specify what these were:						

Is there anything else you would like to say about your experience of deciding on a preference of school for your child?	

Thank you for completing this survey.

If you would be interested in being interviewed about your experiences and views please enter your details here:

Thank you

Appendix 2   Introductory letter to parents

Dear Parent / Carer

**Study of how the parents of young children with autism
decide the schools they want for their children**

My name is *my name* and I am an Educational Psychologist in Training in *Local Authority name*. As part of my Doctorate in Educational and Child Psychology I am doing some research about the decisions that parents of young children with a diagnosis of Autistic Spectrum Disorder (ASD) make about the type of school that they want for their child. As you are a parent / carer of a child with a diagnosis of ASD that has started school in the past couple of years I would like to invite you to take part in this study. You are not obliged to take part in this research and it will not affect the services you receive from the local authority.

It would be very helpful for this research if you could complete an online questionnaire about the factors that contributed to how you choose your preference of school for your child. The questionnaire takes about 10 minutes to complete. It will be assumed that if you complete the questionnaire you consent to the information you provide being used in this research.

www.surveymonkey.comxx

Following this part of the research I am planning to interview some parents to get a deeper understanding of their experiences of going through the process of choosing the school they want for their child, and their views about provision in *Local Authority name.* If you would be interested in being interviewed please enter your contact details at the end of the survey.

The information that is collected from the survey and the interviews will be confidential. Both your and your child's names and identities will not be documented in any way to make sure that you cannot be identified from the material. Please note that if you submit information on the online questionnaire you will not be able to withdraw from the research as the data will be anonymous and therefore your particular responses will not be able to be distinguished from other sets of responses. Parents who are interviewed will have the opportunity to check the accuracy of the transcripts (the written record of the interview) if they want to, and also to meet with me to discuss the findings of the research interviews. This is part of a doctorate and parts of the results might be published in the future.

If you have any questions about this research please do not hesitate to contact me.

Thank you.

Yours faithfully,
My name

Appendix 3 Semi-structured interview questions

Introduction:
- Can you tell me just a little bit about your child?

Decision:
- What were the important factors for you when deciding which school you wanted child's name to go to?
- How do you feel about the level of information and support you received when making this decision? Who did you talk to?
- What do you think made you feel confident that your child would be happy and safe at the school you chose?
- Did you have concerns? What were your main concerns?

Background:
- Can you tell about your child when he was very little? What was he like?
- When did you start to have concerns?
- Who did you talk to then? What support did you receive?
- Can you tell me a little bit about your experience of getting a diagnosis of ASD?
- Can you tell me a little bit about your experience of getting a statement for your child?
- When did you start thinking about the type of school you wanted for your child?

Feelings about provision:
- How do you feel about the school provision your child now has?
- If one of your friends had a child who was going through the same process of deciding on a school preference – what help/advice might you offer? What support do you think they need?

Conclusion:
- Have you been able to say everything about your experience? Is there anything you would like to add?

**Study of how the parents of young children with ASD decide
the schools they want for their children**

Thank you for agreeing to take part in this interview about your experiences of going through the process of choosing the school you wanted for your child, and your views about provision in *LA.*

You are free to withdraw at any time from the interview. I will record the interview to help me remember what you say. Should you choose to withdraw from the interview any data that you have given will be destroyed and not used in the research.

Informed consent

Please sign below to confirm that you consent to taking part in this research.

I understand that the information that is collected from this interview will be confidential. I understand that neither my, or my child's, names or identities will be documented in any way to make sure that we cannot be identified from the material.

I understand that the purpose of this interview is research and that taking part in this research will not in any way affect the services that I receive from the Local Authority. The overall findings of the research will be shared with the Local Authority but I understand that my personal data will not be shared. I understand I will remain anonymous and will not be identifiable from the documented research.

I understand that if I find the interview questions sensitive or difficult to discuss I can stop the interview at any time. I understand that if I need any support following the interview it will be available to me via the Educational Psychology Service, Autism Outreach Service, or the parent support group for the parents of children with an Autism Spectrum diagnosis.

I understand that I can withdraw from the interview at any time. I understand that this is part of a doctorate and parts of the results might be published in the future.

Name: _____

Signature: _____

Date: _____

Thank you

Appendix 5 Additional Quantitative Data Analysis

Other factors that were suggested might have an impact on school choice included whether parents had attended support groups, whether the child had attended pre-school and whether the child had older siblings.

Support groups

	Special	Mainstream	Total
Number who attended support groups	7	7	14
Percentage who attended support groups	33%	58%	42%

Interestingly a greater proportion of parents who had chosen mainstream schools reported having attended support groups in the past.

Pre-school

	Special	Mainstream	Total
Number who attended pre-school	19	12	14
Percentage who attended pre-school	90%	100%	94%

All the children who went to mainstream schools and all but two of the children who went to special schools had attended a pre-school. One parent made a comment about this being a factor in her decision to choose mainstream:

> *'We wanted to see if H could cope with a mainstream as he coped well at mainstream pre-school and progressed well.' (mainstream)*

Older siblings

	Special	Mainstream	Total
Number of children with older siblings	10	7	17
Percentage of children with older siblings	48%	58%	52%

Around half the children for whom parents responded had older siblings. There was a slightly higher proportion of children with older siblings attending mainstream schools. However none of the parents commented on having older children already at school in being a factor in choosing a school for their children with ASD.

Other factors

Parents made a number of additional comments about why they had chosen a special or mainstream school. Parents who had chosen special schools wrote about their child's individual needs and how these could not be met at mainstream:

> *'Mainstream would definitely not be suitable for my son, so I was adamant that he go to Autistic School.'* (special)

> *'Because of her needs - those would not be met at a mainstream school - bit of a silly question.'* (special)

Parents who had chosen mainstream schools wrote about wanting their child to have 'normality and to be included with 'normal' children and in society:

> *'Want as much normality as possible for my child to develop'*
>   *(mainstream)*

'For my child to mix with other children without ASD.' (mainstream)

> *'If he went to special school he wouldn't of had the interaction with other 'normal' children just those that were like himself which in this case I think would have put him back.'* (mainstream)

'I feel he needs to learn how to manage himself in situations that may occur in real life he has to fit in and feel comfortable in society (with support and understanding)' (mainstream)

Additional comments

At the end of the questionnaire the parents were invited to make any additional comments. These included comments about early years provision, the statementing process and places in special provisions.

> *'The early years was very good, but the crossover to school is very poor in mainstream schools.'* (mainstream)

> *'The statement process was very long. Could run smoother.'* (special)

'I was told by the council that he should go to mainstream, which is utterly

ridiculous, so in the end he stayed at his pre-school for a extra-year while we

waited for a place at a appropriate school.' (special)

Appendix 6 Stage 1 of Thematic Analysis
Initial notes from first readings of transcripts

Initial notes related to concepts and phrases that the researcher considered interesting or significant from first reading of transcriptions

All parents talked about their children being happy but hard work.

Many mention difficulties when the child was a baby, special mention MMR. Trauma, brain damage.

Some had issues with father not accepting autism, denial from both parents, one family had other issues at the same time – cancer. They talked about needing to know other families. Huge impact on family described, marital problems , separation, 'not the life they wanted'.

When choosing schools some knew the school the wanted, had visited schools, all were very happy with the school, one mentioned corruption – not meeting needs of children.

All talked about services - AOS and ICSS good. Advisory teachers good, portage good, baby massage good, therapy centre good, all seem happy with services in terms of SaLT and OT.

Some felt LA was not forthcoming. Special parents mention funding, feeling LA was focused on money.

Timing around diagnosis , statements and school choice has been an issue for some. Feeling Dr and parents have tended to agree, battles have been with education rather than Drs, except around birth. Good experience of doctors. SEN – a battle, very difficult. Having to phone every day to push SSEN. Lack of understanding and people to help with statements, families didn't know anything about statements. SEN processes not clear, parents felt hated by SEN.

Range of advice for other parents – real need for parents having to go through process. Concern felt for parents who don't know, aren't as educated. Need for support for co-ordination of appointments, emotional support for parents. Suggestion of a panel, discussion group for parents. Need for more provision, feeling that there's not enough provision because of money. Wanting someone to help you co-ordinate everything. A flowchart about statements, an 'idiot's guide' would be useful.

Other support received from autistic trust, advocacy groups, training programmes

Parents feel their experiences contributed, belief diagnosis easier as mum informed, one educated as a nurse, one mum had knowledge of mainstream. Belief their own assertiveness is what got the child a special place

Factors parents liked about school included adults / TA help for child, good experience of SEN nursery, fantastic head teacher - met on visit, the child is included – not excluded from school trips / swimming etc like in mainstream.

Child can be top intellect wise in special and child shines rather than flounders. Child accepted, liked the calm environment. Liked the respectful ethos. Class sizes, school could meet needs, ASD knowledge, class teacher patience, SALT, OT, technology, feeling school is small and personal, liked Head.

Worries about unit – feeling separated, still needing to keep an eye on if he's being looked after, copying other children. Still concerned about secondary – not appropriate for their child.

Concerns about mainstream / all schools included lack of autism knowledge / understanding – 'possessed' child, child vulnerable to bullying, school too big and overwhelming, anxiety. Experiences of discrimination, bad experience of nursery.

So to start with Ginny maybe you could tell me a little bit about George?

Yeah he's a loving child. He's always inquisitive. He always wants to know what's going on, he needs to know in advance really. He's always saying 'what are we doing, where are we going', you know, 'who's going', things like that. He's generally a happy child but he just needs to know where his boundaries are really, as soon as you start changing things and things like that which can be quite difficult, when it's sort of day to day life where it doesn't always work by structure all the time he gets a little bit apprehensive but generally he's quite happy, you know a contented boy which is good. There was a time when he wasn't but hopefully now he's sort of settled down and he's doing really well.	1. Loving child 2. Happy child 3. Needs to know things 4. Difficult in the past

So what were the important factors for you when you were deciding which school you wanted George to go to?

Umm… it was basically obviously I wanted him to be happy. The preschool he was at is actually joined on to the school. So I felt that although he was struggling educationally and settling down into the routines, it was him feeling happy in the situation and his friends he was with and things like that. But obviously, from my point of view, I needed to know that the school was gonna do what was right for him so he could learn and education was gonna follow smoothly, and not sort of be… 'cause he panics that he's not like his other friends and he sort of knows that so I wanted that to sort of be into one really. So it's just sort of making sure that he was happy and he was gonna get the support really, so yeah.	5. Happy – most important 6. Pre-school joined on to school 7. Already knew he was happy 8. Anxiety about school meeting needs

Thank you. How do you feel about the level of information and support you received when you were going through that process of making a decision and who did you talk to at that time?

Umm… to start with we felt very isolated, we felt very on our own, because George, all the time he had structure he was fine really, you wouldn't really know that there was anything wrong… but obviously his learning wasn't sort of doing what it should have been doing at the stages cause he was sort of, 'cause he was doing his thing he was sort of being left. Umm… so he wasn't sort of playing up, he wasn't sort of struggling, things like that, and I was saying he is struggling but because they didn't see anything they didn't	9. Relief when school accepted he had a problem 10. Mix of emotions around diagnosis

sort of do anything. That was at the preschool. And it just happened to be that one day they changed the routine and they didn't say anything to any of the children and he just completely flipped you know his behaviour was terrible, he was kicking out, he was crying and for the very first time, although it was sad to see him go through that, it was a relief because they actually see what we was saying was right.	
Then from there obviously he had Dr Heather who was his consultant at the hospital, which was ever so good, and she sort of basically gave us avenues to go down, wrote letters to the preschool giving them advice of where they can go for help, umm and I had… I can't think of her name but she was like a… I think it was through (LA) Council when they sort of check them for their… they was all connected in, and basically they was all connected together and I had a lady that was liaising with the preschool into the school and making sure that she was, the teacher was gonna be aware of George's situation and things like that.	11. Some confusion around the number of professionals 12. Feeling everything went well
I was a little bit disheartened at one point because I don't think the school actually understood the routines for George, he was going over, they were doing like an intake, and he would go over a couple of times a week, there was an area, there was his teacher, then the last week before the summer they said they was gonna have a new teacher. So all that what they'd built up for him had been wiped out completely, so that was a bit disheartening.	13. At first not sure school understood
I was lucky cause they got a lot of pictures for George, they done like a little book for him, with pictures of him in the school hall in the playground, with teachers, just so he could look at it and go that's where I'm gonna be so he could familiarise himself with it. So yeah eventually we got quite a lot of support and did they did sort of start taking note.	14. Some nice transition strategies, feeling the school have tried to some extent
But it was really the consultant at the hospital that was pushing these things and was telling us, we was told we could go on like parent things and it was good like that so we started doing it and we expected them to do it, and eventually after a long struggle they did sort of pull their weight really so yeah so hopefully it's done him good, so…	15. Dr was pushing for school to support 16. feeling the school might not have done so without Dr pushing?

Did you think about any other schools at that time?

We was kind of thinking that he would have to go into a special school, we didn't think he would go into mainstream	17. initially thought he'd

'cause they was saying about whether or not he would settle and take in the information that was being given to him and would it be too much? Was the school going to actually do what they said they was gonna do? It was a big concern	need special 18. Concern he wouldn't settle or cope 19. Concern about whether the mainstream would do what they said they would
But after we spoke to the preschool, and that they'd had meetings with the school and the teacher he was going to and they looked at his records, the strategies that they was gonna teach, they put our minds at rest.	20. Feeling of being reassured by school
'Cause we spoke, we did speak to George and sort of ask him if he was happy to go to that school. We tried to explain that there was other schools that he could go to that would help him in his situation. Obviously he was still quite young so he probably didn't understand but he, because his siblings was at that school he really wanted to go, so it was bit of a chance that we took and we kept an eye on it.	21. Tried to ask George 22. He was happy at mainstream nursery
A lady was there that was sort of making sure that there was things in place like sort of visual things and it did go really quite smoothly, and they accepted.	23. AT was helpful with transition
He didn't really want to go into class at first, and he wouldn't line up on the playground cause there was too much noise, and did have a little bit of a battle saying look he's not coping with this, and I spoke to the consultant and she said you've got every right to go and say you want to break this down for him and I started to wait for everyone to go in and then I would take him in, and then I would take him to the teacher the next week, when everyone had gone in, and then she'd follow him in and eventually he lined up with everyone else, so you know, if they'd done what they'd done right at the start it probably would have been even easier but you just have to try it don't you.	24. Mum took advise from Dr when he started school, she encouraged mum to go in and tell them his needs
I think some teachers they didn't want to, they don't like labelling I don't think. When you come to them and say oh my child's got this they say ok we'll settle them in and that's great for most children, but for George you know and his routines they need to understand that you do have to do things a bit differently.	25. Feeling some teachers didn't like labelling, didn't acknowledge he was different
I thought automatically that as soon as you got a diagnosis or something wasn't right that you wouldn't be able to go to mainstream. I didn't realise that there was ways and means they can put in place to help them fit in so I sort of broadened my mind a bit, I sort of found out a lot more.	26. At first thought diagnosis would mean couldn't go to mainstream

	27. Learned a lot, broadened mind when got diagnosis

Could you tell me a little bit about when George was little, before he started school?

He was quite young, he was about 2, well 18 months, 2. He was just always on the go, his sleep pattern wasn't great and although I tried not to compare with my older children you could just see that there was something… the way he understood things, the way if you moved anything he was sort of, he would get upset. It wasn't having a paddy it was, you could see him getting quite distraught by it and he would different places you would go to, supermarkets and you know bigger places, you see kids sort of messing around but he was finding it hard to cope with. I sort of kept sort of saying to my doctor his sleeping's, his eating's different you know there was just a number of things, and it did take quite a while, it was probably sort of about a year before he, people sort of started listening, sort of taking note. They tried him with medication to help him sleep because they just said maybe he's one of those children that don't need a lot of sleep sort of thing but you know I just noticed a difference in him you know going out and doing different things so…	28. Knew something was wrong compared to her older children

29. Mum could see something wrong, took a year before doctor took note |

Who did you talk to at that time?

Umm… so I went to, the last appointment I went to, I went to the doctor and so basically my husband come with us, umm, and he was having to hold George, and he was like climbing up the walls, and the doctor just said I understand something isn't right, you know, and referred us to Dr Heather at the hospital.	
We had sort of a meeting with her went through things and it was quite quick really, talking to other mums, that he got a diagnosis within the year. But we had to go back up a couple of times a month, that they wanted to do, oh, like, to check his hand eye coordination, loads of things. And sort of contacted the preschool for the SENCo and made sure that the abilities there were up to scratch. And that was when, when they really went through it with a fine tooth comb, that's when they was noticing that he wasn't actually, he was learning but he wasn't storing the information, as easy as he should have been. So we had like the SENCo and the consultant really, that was the main people that was dealing with him.	30. Once got to paediatrician it was smooth, issue was getting there,

31. Lots of assessment, linked up with school

32. Dr encouraged pre-school to |

| | observe him and that's when they noticed |
| | 33. Only people – SENCo and paediatrician |

So you've told me there a little bit about your experience of getting a diagnosis is there anything else you'd like to say about that?

| There was, I was quite relieved 'cause I knew there was something wrong, or difficult or whatever, so I was quite relieved. so I was dealing with this on my own, you know, labelling him a naughty child and 'oh you're giving in to him' and things like that and I wasn't I was just trying to work out what was better for him and still giving him the discipline...umm... | 34. Mix of emotions around diagnosis - relief |
| But my husband found it quite hard, cause obviously being his boy, and things, 'there's nothing wrong with him, he's fine'. So obviously that made it a bit more difficult because I had appointments and at first he didn't really want to know, didn't want to hear anything, but you know now he's done a couple of parenting courses and he's relating more to him so that's done us the world of good. That's a lot better. | 35. Dad in denial at first

36. Dad had benefited from parenting courses, now accepting |

Did a getting a Statement for George ever come up?

| Yeah all they kept on saying to me was that they didn't think was that bad. The preschool was a bit apprehensive; they said 'you need to make sure every area is covered'. The school itself they just kept saying we'll keep an eye, we'll keep a close eye on him and monitor him. And they have to do reviews on the children, things like that. I did go to the hospital, when he had his hand eye coordination done they suggested a sloping board so it would help him to write cause his muscles were a little bit on the weak side but generally it wasn't a statement that they was concerned with. They just sort of... yeah. He's got 10 hours 1:1 and things, which was good. | 37. Statement not needed, all said

38. Mum happy school meeting needs but a bit of anxiety, needing to keep an eye |

When did you start thinking about the type of school you wanted for George?

| Well we started thinking about it probably at quite an early stage, when they're sort of saying about primary schools and that sort of thing. I was talking to other parents and trying to sort of go through the school and try to find out what was the best situation. | 39. Talked to other parents
40. Talked to pre-school |
| But because I think that they was so confident that they was | 41. School |

gonna manage with what they was doing with him and things like that, that they kept saying he wasn't that bad, and I spoke to the consultant and she was happy that he would manage mainstream on the condition that they was gonna put these things in place and that I was to keep an eye on it and had every right to keep checking. So I was, you know, it was pretty set really that he would manage on that school so I didn't really have to go any further into it.	were confident they could meet his needs 42. Dr encouraged mum to keep an eye on school
If they'd have said differently then obviously I might have had to. I personally wanted him in mainstream because he was being managed and I think if he'd gone into… he copies quite a lot and I think that he would have sort of copied the worst behaviour more so, and that's, would have made more problems for him when we had enough to deal with, so I tried to keep him there really.	43. Wanted him in mainstream 44. Anxiety about him copying other children in special

So now how do you feel about the provision that George has now?

Well he… umm… does get the 10 hours. He's just gone up to Year 3 so that was a little bit of a struggle because he's kind of gone from sort of playing learning to having to sit down. He's happy, he's still happy to go to school, which I can tell a lot from, the way he is.	45. Happy at school
I've just had parents evening and they've said that they cannot grade him on his writing and they do feel that he's very vacant in class, and they're not sure whether he's not understanding the work, whether too much is going on, so we've got a couple of meetings going on, they do and in-school review, so he's gonna be brought up in that, so we're gonna go from there really.	46. Concern mainstream might be a bit much for him
But generally you know I'm happy that he's doing well. He is, he is below and he is under but I've always thought about what could've been and that he couldn't have learned anything you know they are always working with him and they are willing to try and put things in place for him and so generally I am quite happy with you know, he might not be doing 100% in education but he is wanting to do it and he does try and that what I'm wanting.	47. Thinking things could be worse, being grateful for his abilities 48. Happy he's happy and trying more than academics
I communicate a lot with the teachers. I did have a little bit of an issue with the Head, just because know whatever I would go in and say it was just being forgotten about, umm, but that's just how I've looked t it. I'm not saying that's what has happened. The teachers are in there, they're teaching him, they see him every day, so I've just said that I will liaise with them if there are any problems.	49. Communication with teachers good 50. At times felt ignored by head – not

	taking it seriously
But his behaviour and that is fine, and that's probably what I was worried about more so cause when he gets home he's just like a bomb, you know, going off but I said as long as he is behaving and trying to learn then we're half way there. So he is pretty good.	51. Behaviour good at school – big concerns
You know he is a boy and learning is boring to him so you got to just distinguish what's him being a boy and what's his issues, and they're pretty good at working that now, and they always help us with doing things at home they'll always tell us this is what we're doing with George. This is what you can be doing with him and that helps as well. He knows he's got to do it, everyone's sort of saying the same things to him, which helps him.	52. Accepting him as a little boy, not just seeing his autism

53. Consistent messages from home and school important |

If one of your friends was in a similar position, trying to choose a school for their child with autism, what advice would you give them, and what support do you think they would need?

Obviously they would, you know if they've got a consultant that would be a good way, because obviously not all consultants are the same but that is where I got a lot of my support and they also know what else is out there for you.	54. Get a paediatrician
I was told to go to the therapy centre and I done a lot of my courses there to do with sensory issues, sleep patterns, all things like that, so that helped. And when you cover all of that sort of stage you can understand what they need within a school day, so then I would say go and look at schools, go and talk to the SENCos and what they offer. What sort of hours do they get, and things like that.	55. Parklands

56. Look at schools

57. Talk to SENCos |
| And with the preschools what I didn't realise is that they do get people who would liaise with preschool and the transition to the school. I mean I had one of those for about 6 months, 8 months, something like that which was nice cause I had so much support in the end form the preschool that I was then worried about starting again, but where they got someone to liaise from there to the school and they done his transition with me, I had someone else I could still get the support from, | 58. Surprised by transition – how good

59. Liked AT transition support |
| so I do think it you know, there is support there, you know, you just got to know where to get it from really, and I think that maybe they could improve on, be a bit more open as to where they can get help from | 60. Support is there

61. Just need to know where to |

	get it – needs to be clearer
but you know the therapy centre was fantastic and they done so many different things to help you understand so you knew then what to ask for the school. But yeah, it was sort of the consultant and things, yeah.	

Do you feel you've been able to say everything you wanted to say about choosing a school for George? Is there anything else you want to say about your experience?

Umm, no… well to do with school it's just ongoing really, that's I think what people generally forget. You get a situation sorted and you think oh that's fine that's sorted, but with the way they are, the way they learn and the way they express themselves it changes all the time, so you do need that ongoing support and I think that's where people have go to realise, it is an ongoing thing. It's not a case of 'right, we've sorted it, they'll be fine'. It's an all the time and getting them to understand life and all sorts of things…. But yeah now I've had that support I'm more confident to help him and get the support for him so that's good really.	62. People forget it's ongoing 63. Never sorted 64. Concerns about the future 65. Get more confident about supporting child in the future having gone through school process

Appendix 8 Stage 2 of Thematic Analysis
List of codes

1. Loving child
2. Happy child
3. Needs to know things
4. Difficult in the past
5. Happy – most important
6. Pre-school joined on to school
7. Already knew he was happy
8. Anxiety about school meeting needs
9. Relief when school accepted he had a problem
10. Mix of emotions around diagnosis
11. Some confusion around the number of professionals
12. Feeling everything went well
13. At first not sure school understood
14. Some nice transition strategies, feeling the school have tried to some extent
15. Dr was pushing for school to support
16. Feeling the school might not have done so without Dr pushing?
17. Initially thought he'd need special
18. Concern he wouldn't settle or cope
19. Concern about whether the mainstream would do what they said they would
20. Feeling of being reassured by school
21. Tried to ask George
22. He was happy at mainstream nursery
23. AT was helpful with transition
24. Mum took advise from Dr when he started school, she encouraged mum to go in and tell them his needs
25. Feeling some teachers didn't like labelling, didn't acknowledge he was different
26. At first thought diagnosis would mean couldn't go to mainstream
27. Learned a lot, broadened mind when got diagnosis
28. Knew something was wrong compared to her older children
29. Mum could see something wrong, took a year before doctor took note
30. Once got to paediatrician it was smooth, issue was getting there,
31. Lots of assessment, linked up with school
32. Dr encouraged pre-school to observe him and that's when they noticed
33. Only people – SENCo and paediatrician
34. Mix of emotions around diagnosis – relief
35. Dad in denial at first
36. Dad had benefited from parenting courses, now accepting
37. Statement not needed, all said
38. Mum happy school meeting needs but a bit of anxiety, needing to keep an eye
39. Talked to other parents
40. Talked to pre-school

41. School were confident they could meet his needs
42. Dr encouraged mum to keep an eye on school
43. Wanted him in mainstream
44. Anxiety about him copying other children in special
45. Happy at school
46. Concern mainstream might be a bit much for him
47. Thinking things could be worse, being grateful for his abilities
48. Happy he's happy and trying more than academics
49. Communication with teachers good
50. At times felt ignored by head – not taking it seriously
51. Behaviour good at school – big concerns
52. Accepting him as a little boy, not just seeing his autism
53. Consistent messages from home and school important
54. Get a paediatrician
55. Therapy Centre
56. Look at schools
57. Talk to SENCos
58. Surprised by transition – how good
59. Liked AT transition support
60. Support is there
61. Just need to know where to get it – needs to be clearer
62. People forget it's ongoing
63. Never sorted
64. Concerns about the future
65. Get more confident about supporting child in the future having gone through school process
66. Need to talk about difficult medical experience
67. Knew early there was something wrong
68. Problems around MMR time – didn't have it but that time
69. Feeling of being fobbed off my doctors, when they (parents) knew what was wrong
70. Excellent Dr – the one that listened
71. Feeling have to advocate for your child
72. Worry another person wouldn't be able to deal
73. Strain on family
74. Not being able to do normal things
75. Appreciating it could have been a lot worse
76. Needing to persevere
77. Had OT, physio as pre-schooler
78. Very emotional, up and down for mum
79. Feeling of having to push
80. Feeling that her knowing the system helped
81. So many appointments can be overwhelming
82. Strain on parents relationship
83. Separation
84. Compared to others he's brilliant
85. Not the life wanted
86. Lucky – could have been worse
87. Bad experience of mainstream nursery, couldn't cope
88. Had better experience of SEN nursery

89. Had to keep him at home for a year as no SEN place
90. Mainstream pre-school – not meeting his needs, too distressing for him
91. Comparing child to other typical children – not doing same
92. Feeling guilty about putting him in mainstream pre-school
93. Having to push for everything – diagnosis and statement
94. Feeling pushed to try mainstream
95. Having to push for special
96. AT brilliant and supportive, kept mum sane
97. AT and mum, made decision together
98. Went round schools
99. Met head of special – fantastic
100. Had to battle council
101. Not enough provision in LA
102. Need a spectrum of provision
103. Had to push for statement, to get access to chosen school
104. Fears about the future
105. Fears about secondary
106. Thinking about private for secondary
107. Just cause in special primary it's not over
108. Concern for other parents less able to fight
109. Concern for parents with needs, lost in system
110. Need to advocate for your child
111. Feeling of being overwhelmed, all your fight goes, you've been through enough
112. Needing more emotional support
113. Needing someone to organise you
114. Good – AT
115. Therapy centre good
116. Portage lady lovely
117. Had an issue with one physio but others good – issue was him not listening to her
118. 'I understand my child more than anyone' – feeling she knows best
119. Wanted small classes
120. Fear about mainstream – classes too big
121. Wanted more adult support, TAs
122. Hard first 2 years in special
123. Liked head on visit – very supportive
124. Wanting to give something back
125. Factors – head
126. Children calm and well managed on visit
127. Respectful environment on visit
128. Liked technology on visit
129. Didn't want one school because of own school experience
130. Mainstream schools too big – daunting
131. Not units – not wanting child to be part of a school community, not isolated
132. Special school – feeling of big family
133. AT transition support helped with anxiety about transition

134.	He was anxious starting school
135.	Concern about special – copying more severe children
136.	Not wanting child around more severe children
137.	Constant communication with teachers
138.	Still feeling the need to keep an eye even though he's in special
139.	Wanting to make sure his needs are met
140.	Fear for the future
141.	Real battle to get statement – acknowledges she was emotional at time
142.	Felt like SEN were being pernickety
143.	Not enough support with SSEN process, not clear
144.	AT helped with SSEN process but need to be given clearer process guidelines
145.	SSEN process felt really long and hard
146.	Complaint and issue with LA
147.	Not enough provision
148.	Frustration more is not being done about provision
149.	Hard process
150.	The fact it's long made it feel hard
151.	Being in denial when it was first suggested child might have SEN
152.	Taking time to get over the shock of child's needs and not getting on with process soon enough
153.	Every step a battle
154.	Not wanting more children
155.	Happy with special school
156.	Not considering mainstream for secondary even with head's advice
157.	Autistic trust were helpful pushing for special
158.	Feeling like only people in world going through it
159.	Importance of not feeling alone
160.	Mum's need- support network of other mum's
161.	Feeling regular mum's don't understand
162.	Would want – a forum or more structured network for mums, per support
163.	More support through process, someone to help when you can't cope, surviving day to day let alone pushing for things
164.	Clearer process, diagnosis and SSEN linked up?
165.	Even with really good AT support would want a flowchart, feeling a bit more clear about process
166.	Powerless feeling when you don't know what to do, frustration about waiting then finding out you should have done something
167.	'All you need is to have a flowchart'
168.	Lots going on - -education and health not linked up, all appointments overwhelming
169.	Peer support really important
170.	Feeling isolated until you meet other mums
171.	It's all a battle
172.	You've been through enough already without having to battle
173.	Not enough provision - it's the money
174.	Happy

175. Can get upset – child
176. Clear form start not mainstream
177. Knew process and phoned LA every day
178. Not wanting her to sink in class of 30
179. Wanted small classes
180. Wanted autism specialism
181. Concern mainstream teachers don't have training in autism
182. AT was really good
183. 'nothing from LA'
184. felt like special provision wasn't an option
185. EP listened
186. Thought about other special provisions but no mainstreams
187. Feeling LA didn't want special due to funding
188. Had visited the school she wanted
189. Access to SaLT and OT
190. Teachers highly skilled
191. Class sizes no more than 10
192. Head is outstanding
193. Thought of other specials but unit best met her need
194. Pure autism – highly skilled
195. Concern whether she'd cope
196. Concern about after infants - might move for juniors orsecondary
197. Couldn't picture her coping in mainstream because of her   behaviour
198. Concern she'd disrupt other children – not fair
199. lovely / loving
200. Concern about autism and implications
201. Concern about the future
202. Reassured by school
203. Waiting for something to go wrong
204. Had speech therapy
205. Very difficult child to parent
206. Concern about younger sister and safety
207. Comparing your child to others
208. Done parenting group – helps to know more about autism
209. Blocking out really hard time in the past
210. Really happy with input – wonderful women at hosp, children's centre etc
211. Going to get maximum progress
212. Good experience of progress at mainstream nursery
213. Easy transition as mainstream attached to preschool
214. AT assessed and said he'd cope
215. Feeling that he'd have the same problems in special
216. Not wanting to take him away from his friends
217. Not liking change – keep him where he is
218. Feeling school had ASD expertise
219. Good experience of pre-school staff managing his behaviour, understanding him
220. School have been great
221. Child – Confused Challenging
222. Attributes autism to MMR

223.	He's improving
224.	Accepted at his school
225.	Exhausting to parent him
226.	Sleep issue
227.	Not accepting it when first suggested to them he had problems
228.	Bad experience of mainstream pre-school – too big
229.	Pre-school teachers lack of understanding – possessed
230.	Came to terms with autism through looking on internet
231.	Husband in denial for longer
232.	Preschool upset mum- saying he had autism
233.	AT – angel! Explained process
234.	Lots of issues at home, really stressful for family
235.	Everyone at LA great – ICSS, EP, SEN
236.	Felt bullying into diagnostic process by nursery
237.	Feeling nursery didn't want him, fight for his right to be there
238.	ICSS helped with conflict with nursery
239.	Corruption
240.	Feeling rejected compared to regular children, in mainstream him being excluded from normal groups
241.	Feeling other parents don't understand
242.	Issue with referral to paediatrician being held up by dad's denial
243.	Good experience of paediatrician, understood he had autism
244.	AT supportive through diagnostic process
245.	Was hard and confusing – process, being told he had autism, mix of feelings
246.	Referred to AOS by Dr – really good
247.	Went to parenting programme
248.	Good to hear other experiences
249.	Start to be grateful things are not a lot worse
250.	Good experience of SNN
251.	Liked that he was included in everything - parties, trips he was excluded from in mainstream
252.	AT suggested statement
253.	Chose school before diagnosis – timing issue, so had to choose a mainstream
254.	Feeling guilty about putting him in mainstream, would have preferred to keep him at home
255.	Listened to other parents when choosing school
256.	Mainstream said they'd cope but didn't
257.	Feeling they weren't giving him a chance to try
258.	Fighting the pre-school – bad experience
259.	Contacted advocacy group
260.	Pre-school wasn't putting anything in place, no IEP
261.	Dr advised her take him out of that school
262.	Pre-school class teacher had no autism expertise – mainstream
263.	Feeling discriminated against in mainstream
264.	Was on the phone to SEN loads, got EP back involved
265.	Visited unit
266.	Main factor – he's happy to go
267.	They would accept him

268.	They understand ASD
269.	They use appropriate strategies to motivate him
270.	Recognising things could be worse with a more severe child
271.	SEN really supportive
272.	Definitely try all groups, try 'everything'
273.	Don't wait to do something
274.	Don't go for mainstream
275.	Feeling children are more excluded in mainstream
276.	He's included in everything in special
277.	SaLT in special
278.	Facilities in special
279.	Haunted by thoughts of other parents who are desperate to find a place for their children
280.	Concern about lack of ASD understanding in general
281.	Starting to see positives of ASD
282.	Access advocacy groups
283.	Difficult for family
284.	Other parents not understanding, judgemental
285.	Happy
286.	Settled
287.	Teachers saying he's disruptive, has 1:1 all day
288.	Concerns over cause of behaviour
289.	Happy to go along with SENCo
290.	Can ask for advice / ring SENCo any time
291.	Taken to ASD forum – mum kept informed
292.	SENCo – experienced
293.	SaLT important
294.	OT accessed in pre-school and at mainstream
295.	Concern about whether he's cope in mainstream
296.	Thought about special
297.	Nursery staff told mum he's cope in mainstream
298.	Trusting - 'you guys know best'
299.	Advisory teacher said he'd cope
300.	Not wanting to argue with authority – too much arguing
301.	Heard from friends SSEN is hard to get
302.	'We'll see' about the future, statement
303.	Just around the corner – mainstream
304.	Wanting to try mainstream – if not coping then consider special
305.	Concern he disrupts others
306.	Wanting to give it time
307.	Having another child to think of
308.	Support from friends
309.	Support from AT
310.	Knowledge from previous child
311.	Sure Start – sensory room
312.	'Good few blocks of sensory'
313.	Happy with SaLT received
314.	Knew school – own and family experiences
315.	Behaviour good at the school
316.	Reputation

317.	Met teachers
318.	Link with pre-school
319.	Reassurance from pre-school
320.	Reassurance from AT
321.	Support from another AT
322.	'Everyone's behind me, if there are issue's they'll help'
323.	Feeling mainstream will monitor him
324.	Understanding school processes – clear communication with SENCo
325.	Needing to play it by ear
326.	Diagnostic process wasn't too hard
327.	Attributing this to having older child with autism
328.	Heard from other parents that diagnosis is hard
329.	Support from family and friends
330.	Wanting to support friends
331.	Really wanting mainstream
332.	Thinking he might need special
333.	Really loving the special school
334.	Deep down wanting mainstream
335.	Wants to be a 'proper mum' at local school
336.	Taking child round the corner to local school
337.	Experience of special relating to the escort taking her son, wanting that experience
338.	Support in mainstream isn't enough
339.	Appreciating the support he has but wanting more
340.	Wanting to be understanding of school
341.	Needing to chase things up with SENCo
342.	Loves the school
343.	Really happy with school
344.	Clean
345.	Polite
346.	Supportive staff
347.	Mum made to feel comfortable
348.	Not feeling like she's a burden
349.	Told her to get in touch with health visitor and GP, paediatrician as the first step
350.	Advice – Sure Start
351.	Access groups and activities
352.	Get child interacting with other children through groups
353.	Being there for her friend
354.	'I know how you feel'
355.	So many questions, needing someone to talk to
356.	Emotional rollercoaster
357.	Feeling you can't cope
358.	Learning about ASD helps
359.	Supporting other parents helps
360.	Really tough
361.	Basic everyday life is really tough
362.	Need to open up about it, talk about
363.	Concern for other parents, especially Bangladeshi community, not able to access / accept help

364.   Wanting to help other families

Appendix 9 Stage 3 of Thematic Analysis
Initial themes and sub-themes

Theme / sub-theme	Codes
What my child is like	1 2 47 48 174 175 199 221 223 281 285 286
What everyday life is like	3 36 73 74 76 82 83 85 154 205 206 225 207 225 226 231 234 283 307 361
Having an autistic child, coming to terms with it	4 9 27 28 34 35 67 78 91 151 152 200 227 230 245 246 287 356 357 358
Early trauma when child was a baby	28 66 69 70 209 313
Getting a diagnosis	10 11 12 29 30 31 32 33 236 242 243
MMR	68 222
Worries about school meeting child's needs	8 13 16 17 19 25 26 38 50 120 130 139 171 172 254 256 338
Worries about child not coping	18 46 134 176 178 195 215 295
Worries about other children and teachers	197 198 241 287 305
Getting a statement	37 94 114 141 142 144 145 182 235 252 256 338
Having to fight	71 79 93 95 100 103 110 111 141 142 153 177 184 239 258 300
Other parents judging	284
Pre-school experiences	6 7 14 22 40 58 77 87 88 89 90 92 212 213 228 229 232 237 250 258 260 262 297 319
Listening to others / professionals when choosing schools	15 21 23 24 42 96 97 214 265 289 299 320 322
Importance of size	119 121 128 179 189 191 269
Visit	127 188 265
ASD understanding	180 181 190 194 218
Understanding my child	52 53 219 224 263
Specialist equipment / specialists	277 278 293 294
Wanting child to be included, with friends	43 44 45 131 132 216 217 240 251 276 303 335
Wanting their child to be one of the better ones	84 135
Talking to friends	39 51 255 298 314

Talking to school	20 41 49 98 99 123 125 192 202 218
Peer support, other mums getting them through	158 159 169 170 248 249 308 362
Means they want to help others	72 108 109 124 160 161 359 360
Helping mums from same culture	279 363 364
Advise parents to access support that's there	54 55 272 273 349 350 351
Needing professionals to be supportive	54 56 59 112 113 143 157 162 163 282 355
Advising parents to get peer support	11 15 169 352 353 354
Advice / need for clarity about processes	60 61 80 81 144 145 164 165 167 168
Need for more special provision	101 102 148 173 187
Fears for the future	62 63 64 65 104 105 106 107 140 196 201 203 280

Appendix 10 Stage 4 of Thematic Analysis
Arranging and reviewing subthemes and themes - draft map

IMPACT

having an autistic child, coming to terms with it

what my child is like

what everyday life is like

early trauma when child was a baby

having to fight

PROCESSES

getting a diagnosis

getting a statement

MMR

worries about school meeting child's needs

worries about child not coping

WORRIE

worries about other children and teachers

other parents judging

peer support, other mums getting them through

helping mums from same

PEERS

means they want to help others

FUTURE

fears for the future

understanding my child

ASD understanding

wanting child to be included, with friends

visit

talking to school

preschool experiences

DECISION

listening to professionals when choosing schools

talking to friends

importance of size

specialist equipment / specialists

wanting their child to be one of the better ones

advise parents to access support that's there

advising parents to get peer support

ADVICE

need for more special provision

needing professionals to be supportive

advice / need for clarity about processes

Appendix 11 Stage 4 of Thematic Analysis
Arranging and reviewing subthemes and themes - thematic map

IMPACT

1.2 Coming to terms with autism

1.1 My child now

1.3 Everyday life

2.1 Health - early experiences

2.5 The need to fight

PROCESSE

2.3 Health - the diagnosis

2.4 Education - SSEN

2.2 Health - MMR

3.1 Concern about whether the school would meet their child's needs

3.2 Concern the child wouldn't cope

FEARS

3.3 Concern for other children and teachers

3.4 Concern about judgement from other

3.1 The importance of peer support

4.3 Cultural factors

4.2 Desire to help other parents

PEERS

FUTURE

fears for the

6.1 Access to professionals

5.7 Understanding

5.8 Wanting child to be included

5.3 Talking to school staff

5.1 pre-school factors

6.3 Peer support

ADVICE

6.5 Provision

DECISION

5.2 Talking to friends

5.4 Trusting advice from professionals

5.9 Wanting their child to shine

6.2 Professional support

5.6 Facilities and access to specialists

5.5 Asking the child

6.4 Clarity

Appendix 12 Stage 5 of Thematic Analysis
Naming themes

Impact of having a child with autism	My child now Coming to terms with autism Everyday life
Health and education processes	Health - Early experiences Health – MMR Health – The diagnosis Education – SSEN The need to fight
Fears about their child going to mainstream or special school	Concern about whether the school would meet their child's needs Concern the child wouldn't cope Concern for other children and teachers Concerns about judgment from other parents
Empathy for other parents	The importance of peer support Desire to help other parents Cultural factors
Making the decision about school - factors	Pre-school factors Talking to friends Talking to school staff (to include 'visiting' codes) Trusting advice from professionals Asking the child Facilities and access to specialists Understanding their child (to include 'understanding of ASD' codes Wanting their child to be included (to include 'local school' codes Wanting their child to shine (from 'wanting their child to be one of the better ones')
Advice about what parents need	Access to professionals Professional support Peer support Clarity Provision

Future theme	Comments to be included in conclusions

Appendix 13 Ethical Approval Letter

UEL
University of
East London

MISS HELEN GRIEVE
FLAT 6
108 CLAPHAM COMMON NORTH SIDE
LONDON
SW4 9SH

Date: 19 May 2011

Dear Helen,

Project Title:	*An Exploration of the Factors that Influence the Decisions of Parents of Pre-Schoolers and ASD About School Provision for their Children*
Researcher(s):	*Helen Grieve*
Supervisor(s):	*Mark Fox*

I am writing to confirm that the review panel appointed to your application have now granted ethical approval to your research project on behalf of University Research Ethics Committee (UREC).

Should any significant adverse events or considerable changes occur in connection with this research project that may consequently alter relevant ethical considerations, this must be reported immediately to UREC. Subsequent to such changes an Ethical Amendment Form should be completed and submitted to UREC.

Approval is given on the understanding that the 'UEL Code of Good Practice in Research' (www.uel.ac.uk/qa/manual/documents/codeofgoodpracticeinresearch.doc) is adhered to.

Yours sincerely,

Merlin Harries
University Research Ethics Committee
Email: **m.harries@uel.ac.uk**