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**Investigation into Factors Associated with
the
Provision of Effective Education for
Children with Autistic Spectrum Disorders**

**A Thesis submitted for the degree of Doctor of
Philosophy**

by

Catherine Tissot

Department of Education, Brunel University

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Abstract

Investigation into Factors Associated with the Provision of Effective Education for Children with Autistic Spectrum Disorder

By: Catherine Tissot

This thesis investigates the factors associated with provision of education for children with autism spectrum disorders. The child is at the centre of this investigation, as the issues and constraints clearly impact on the quality of the provision delivered. Educational provision for children with autism also affects families and social agencies. The family is usually first to recognise that their child is not developing as he or she should. Typically, a diagnosis of autism or autistic spectrum disorder leads the family to the LEA in an effort to get the child's educational needs met within a school setting.

Improvement in educational provision for children can only be obtained when it is based on research in this area. This is especially true for the case of children diagnosed with autism, as research is limited. What research does exist focuses on specific methodologies or proposed causes, and does not explore the effects that appropriate provision has on a child.

To aid this thesis, systems theory has been employed to explore the tensions and dilemmas that exist. This ecosystemic approach is useful when teasing apart the influences both proximal and distal that benefit the child's educational experience. These influences can come from the school, home, LEA or the interactions between and among these partners. This study will examine these influences. Through the use of a case study, the researcher observed a school during its day-to-day implementation of educational provision. In addition, the views of an LEA and parents were sought through the use of interviews and a survey.

The main research findings showed several factors as having influence on the child in regards to educational provision. Investigation into a school showed the difficulties associated with putting provision into practice. When faced with severe staffing shortages, absence of active leadership, and extreme behavioural problems of the children, teaching activity was thwarted. Survey results revealed the difficulties faced by parents in securing provision. Parents reported high levels of stress that this research correlated to longer waiting times, late diagnosis, type of provision, and guidance from specialists. Significant also, was the finding that survey parents reported a statistically significant decrease in the age of diagnosis of the children. Significant findings revealed through LEA interviews found that although striving to work with families, efforts were frustrated by increasing numbers of children, limitations on the number of children accepted into favoured placements, and parental self imposed restrictions on placement choice.

Lastly, this research proposed several key suggestions based on the literature review and the research undertaken to improve and promote best practice in the agreement, allocation and enactment of educational provision.

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Chapter 1- Introduction

The purpose of this chapter is to describe the background to the ideas presented in this thesis and to outline how these led to the research. Next, the rationale for the thesis will be presented. To this end, the first sections will identify the focus of current research attention (in cause and prevalence of autism) and present a brief review of the history of special education and the current practice in the UK at present. This will show the limited amount of research in autism, and the narrow focus of this on proposed causes and methodologies, thus laying the grounds for this research that focuses on educational provision. This chapter concludes by identifying the research question.

Autism is an ailment that affects individuals in three main areas, (known as the Triad of Impairments). Qualitative impairments are seen in the areas of social interaction, communication and in the demonstration of restricted or repetitive behaviours (Wing et al., 1976; Smith et al., 1998). (See Appendix 2 for detailed criteria.)

In the UK, public awareness of autism has increased partially due to the attention in the popular media (i.e. proposed causal link between MMR and autism, suspected increase in prevalence). Over the years, autism and related disorders (Asperger's Syndrome, Pervasive Developmental Disorder, Not Otherwise Specified/PDD-NOS) has attracted the attention of researchers as well.

Current research has focused primarily on two main areas: the cause of autism (MRC, 2001) and teaching methodologies (National Research Council, 2001). Both of these areas are of special interest because they impact on educational provision, the main focus of this study.

1.1. Cause of Autism

There exists no one specific cause of autism, and subsequently most researchers believe that a variety of causes contribute to the ailment (MRC, 2001). To date, the research on the cause of autism has focused on genetic or physiological, environmental, and psychological factors. Possible differences in the beliefs held on the origin of autism impacts on the choice of educational methodologies individuals

advocate and therefore it is instructive to look at this issue. Although the review of the literature will discuss possible causes further, each of these four potential reasons is discussed briefly below.

The possibility of genetic influence was first referenced by Asperger who questioned the heredity of the disorder (Frith, 1991). Later research supported this suggestion (Zwaigenbaum et al., 2000) and concluded that families have an increased chance of having a second child with autism of between 2-6%, which is at least ten times the general population prevalence (Bailey, 1995). There is also evidence from several studies of twins, which shows that pairs of autistic twins shared the degree of autism (Le Couteur et al., 1996; Rutter, 2000).

Researchers looking for possible causes of autism also consider environmental factors. Pollutants such as mercury (Bernard et al., 2001) or increased number of infections (Wakefield et al., 1998) have been investigated. These studies, although interesting, have failed to prove a conclusive link to autism (MRC, 2001).

Physiological factors such as a potential link between colitis (or other inflammations of the intestine) has also been investigated. Wakefield (1998) initially proposed the link between intestinal problems and autism. The resulting media attention has changed the dietary habits of some autistic children, as parents remove wheat and gluten (or dairy) from the child's diet as suggested by Wakefield. Further research has shown no link (MRC, 2001).

Kanner's 1943 study was the first to propose a psychological link as a cause for autism. His paper viewed parents as contributors to the ailment. Later work by Bettelheim (1943; 1967) continued the argument that parents caused their child's autism. Current research refutes this theory (Smith et al., 1998).

At present the cause of autism is unknown. Although different theories exist, none has been shown in the literature to account exclusively for this ailment (MRC, 2001). This is of particular interest to this study, because it shows that there is a difference of opinion that exists regarding the possible causes of autism. What is also instructive to look at is the effect that belief in a possible cause for autism has on the methodological approach to the education of a child affected by autism. As this

research focuses on appropriate educational provision for children with autism, it is worthwhile to explore some of these approaches.

1.2. Educational Methodologies

Theories on the cause of autism can impact on the approach chosen to address the educational needs of the child afflicted. It is therefore helpful to look at the theories underpinning some of the approaches. Although the literature review will discuss educational methods in additional detail (see Chapter 2), a brief discussion is warranted as it helps clarify the rationale for this thesis.

As stated above, there are several hypotheses in research literature as to the cause of autism. Several look for a biological or genetic cause, while others are interested in environmental or psychological factors.

The differing belief in the cause of autism can impact on the approach chosen to meet the educational needs of the child with autism. While this may not be the case of those advocating a biological or genetic causation, those advocating environment or psychological causal reasons, would advocate change in the child's natural environment. Theoretically this could take the form of an altered diet, an emphasis on sensory therapies, or a medical focus as the child's primary means of addressing his or her educational needs as opposed to a primary emphasis on teaching techniques. The different environments of the child (i.e. home, school, etc.) can also differ in their emphasis.

Thus far, this chapter has shown the lack of agreement in the research on the cause of autism as well as disagreement on the best way to address the educational needs of autistic children. Therefore, there exists no universally agreed method to meet the educational needs of autistic children. As there is a lack of agreement, it is of particular interest to this study to investigate the tensions and dilemmas that exist as we tease apart the issues impacting on the provision of education for children with autism.

In addition to current research, other influences are present. The United Kingdom has a history of supporting special education. As the nature of autism is such that children require specialised instruction, an overview follows.

1.3. Perspective of Special Education

The 1981 Education Act, (adapting many of the recommendations of the Warnock Committee) shifted the focus of special education to the individual needs and away from medicalising the child and focusing on the context of learning (Warnock, 1988). The recently revised Code of Practice (DfES, 2001) continues this focus. This document brought many changes, but the two most relevant to this thesis involve guidance for an increase in emphasis on providing education for children with learning difficulties within mainstream provision, and the duty of LEAs to offer advice and information to families on educational provision ('Independent Parental Supporter' Code of Practice, 2001, Section 2:21). Although government does not dictate a 'one size fits all' philosophy, it does continue the thinking of Warnock and advocate a policy of inclusive education meaning that the majority of children with special educational needs should be educated within mainstream provision.

Guidance from the government places an emphasis on the education of all children (including those with special educational needs) within mainstream provision at the child's local neighbourhood school. It also strongly advises educational authorities to establish an independent advisory service to help parents navigate the system and achieve an educational provision for their child. Although advocating inclusive education as one type of provision, it is important for the government to promote informed parental choice. Hence the views of parents are part of a legitimate process designed to empower and give parents a voice regarding the education of their special needs child.

Therefore, the government sees the parental voice as a significant contributor to the determination of educational provision for their child. Although government policy prioritises parent input, research literature has not. Currently there exists no research study asking parental perspective on educational provision for children with autism. As such, this will be a worthwhile contribution of this study.

The next section reviews the current practice in schools. This is important for this research as it looks at educational provision for children with autism, the majority of which is met in schools and the focus of this thesis.

1.4. Current Practice

Autism is a spectrum disorder (Wing, 1971; National Autistic Society, 2000a) with impairments are seen in three areas: social, communication and behaviour. This Triad of Impairments (Wing et al., 1971; Wing et al., 1976) encompasses those children with severe learning difficulties, coupled with antisocial, repetitive or aggressive behaviours at one end, and those who are diagnosed with Asperger's syndrome where the main disabilities lie in the social areas, on the other end. Educational provision for these children varies depending on the specific needs of the individual student.

Several choices for educational provision exist. It is the statutory responsibility of the school, LEA, and parent to determine which type of provision is appropriate for the individual child. For the purpose of this thesis, appropriate educational provision is defined as individualised strategies that target identified learning gaps for a specific child. Effective education is therefore the process by which these learning gaps are addressed. These strategies form part of the educational package provided in a named institution (i.e. school) or methodology (i.e. ABA). Some of the more able students will be able to access the National Curriculum within a mainstream provision. There are others only able to do this with additional support through a dedicated member of staff or in a unit attached to the mainstream school. For others, specialist provision is needed. This can take the form of a separate school specifically for children with special needs, or in autism-specific provision. Some families will choose home schooling for their child.

Within these placements, a choice also exists in the manner in which the child is taught. Some approaches adapt the school or home environment to make it more 'autism friendly' such as TEACCH-Treatment and Education of Autistic and related Communication handicapped Children (Mesibov, 2000) or Options (Kaufman, 1998). Others use a behavioural approach to advocate more social interaction and learning such as ABA-Applied Behavioural Analysis (Lovaas et al., 1974) or Verbal Behaviour (Sundberg et al., 1998). There are also those that advocate a sensory approach, seen to correct an imbalance in one of the senses. These include Auditory Integration Therapy (Stehli, 1992) or Holding Therapy (Welch, 1988). (For additional therapies see Chapter 3 Literature Review.)

As the choices in both provision and educational approach are numerous, this can leave parents, schools, and even LEAs uncertain on the way to best help an individual child. The statutory process by which the parent, LEA and school determine provision to meet the needs of an individual child, can also be restricted due to the limited number of spaces at a autism specific classroom or school, or even the lack of availability of newer autism specific methodologies within the LEA.

The realm of choices in both educational approaches and types of provision presents parents, schools and LEAs with difficult decisions that need to be made to secure education that is appropriate to an individual child. It is therefore apposite that this thesis explores the process of decision-making and the implications this has for the individual child. Although the specific educational methods and potential causes have received attention from researchers, there is no research on the statutory process of providing educational provision for children with autism. This research will target this gap incorporating the views of a school, parents and LEAs.

1.5. The Context of the Research

The autistic child is at the heart of this issue, and the efforts by the school, family and LEA all have the child's interests as primary. This thesis is therefore interested in focusing on the child, and the contribution that family members and institutions make when determining, appropriating and delivering educational provision that best meets the individual needs of a child.

This research proposes to begin to look at the interaction of various contexts of educational provision including families and schools who may independently or jointly deliver educational provision for an autistic child. The child is at the centre and is critical in the extent to which we explore the different aspects of care and delivery of educational provision. This is a unique contribution of the study.

To aid this research, systems theory has been used. This is justified as it has been previously been employed to explore non-specific learning disabilities. Sometimes referred to as an ecosystemic approach, it embraces the concept of the child's development as a product of the people and events in the child's environment (Bronfenbrenner, 1979). Those events that are the most influential are the ones that

have the direct involvement of the individual child. But this is not the entire story. The notion of environment extends beyond the existing immediate situation of the child to include functional systems both within and between individual settings and persons. This notion of environment is under constant change, continuously being updated through new information directed at or with the child, as well as the interrelations between the differing people and institutions. The principle of interconnectedness is essential as it applies not only to the individuals close to the child, but also to those institutions or individuals that interact outside the child's immediate environment.

Keeping the above principles in mind, systems theory can help unpick the many critical aspects of appropriate educational provision for children with autism. As the child is central to this research, it is fitting to place the child as central focus for this theory. Bronfenbrenner (1979) hypothesises that a person's development is profoundly affected by events occurring in both the immediate and secondary environments of that individual. These events can have insightful effect on the individual, even if the individual is not present. As applied to this research, the development of the autistic child is the product of the influences both proximal and distal that influence benefit for the child. These influences form the educational experience of the school or home (or both) and are interacting.

This thesis investigates these influences. It assumes that the child's educational development is the product of a growing child and the interactions with his or her environment. This is a novel aspect of this study.

What are the people and institutions that exert influence on an autistic child in terms of appropriate educational provision? There are many, but for the purpose of this study, the discussion will be primarily limited to three: school, parents and LEA.

In order to achieve appropriate educational provision for an individual child, efforts must be made to listen and incorporate the views of those participating in making the decision and the implications this has for the individual child. It must incorporate the

views of parents, schools and the LEA¹ and work together to determine what the appropriated educational provision is for an individual child.

Participants need to be allowed to share their views freely, in an open and non-judgemental context. An avenue must be established to allow the voice of the individual to be heard, whether it is the voice of the parent, an LEA representative or a faculty member in a school. In practice, the views of an individual are constrained by outside limitations (English et al., 2001). Some examples of this could be restrictions in classroom sizes (limiting additional new intakes), gaps in staff training, unproven methods of education, unrealistic expectations of parents or differences in the general availability of autism specific methodologies between various parts of the country.

These theoretical underpinnings elicit phenomenological methodology. This research explores the lived world of the various actors by seeking the opinions of individuals, and allowing the voices of these individuals to be heard (Silverman, 1993).

Specifically, this research is also explores the views of a school, parents, and LEAs on their experiences of determining educational provision, and acknowledging that these experiences cannot be independent from the way in which the process of securing educational provision is experienced² (Marton, 1994).

A benefit of phenomenological approach is the allowance of mixed methods to address the research aims with the method that best suits the unique aspects of the research (Cohen et al., 2000). It therefore follows that this thesis uses several methods to investigate the research questions. It is primarily comprised of data gained through qualitative methods (research interviews, naturalistic observation in the classroom, and questionnaire). When quantitative methods were employed (parental questionnaire), the desire to capture the views of as many parents as possible made this a more practical choice due to the sample size. The inclusion of

¹ Although it is desirable to have input from the individual child and many authorities have this as a function of the child's statement, this thesis was interested in the perspectives of those legally responsible to determine or enact educational provision.

² The views of the individual student with autism are not explored in this thesis. This is due to the lack of spoken language, usually combined with learning disabilities in a large portion of the autistic population. Excluding this group would leave the portion of this population that are on the more able side, and whose needs are typically met in mainstream provision. Mainstream provision is already the subject of numerous studies, and therefore not a unique interest of this study.

two open-ended questions, did invite respondents to share their views in an unstructured format. Further discussion on the specific methods employed is found in Chapter 3.

This thesis will explore the research question in three individual strands. Strand One concentrates discussion on a school, Strand Two focuses on the parent and Strand Three on the LEA. This allowed the opportunity to explore and discuss emerging findings as presented in the data gathered. The analysis of this data seemed to argue for the presentation through this stranded approach, which form the central core of this thesis. Each strand illuminates findings in its own right. Central findings are discussed individually first.

After the three strands are presented, a discussion follows that will pull together outcomes and reweave central themes. These connect with the original research question and reveal something of the tensions and dilemmas that exist in the broader social context and impact directly and individually on quality of educational experienced by a child with autism. Essential conclusions and implications are presented in the final chapter.

The research is the first to examine the process of securing appropriate educational provision using methodology that allows the individual voice of parents, a school and LEAs to be heard. It also analyses these comments to unpick the tensions and dilemmas evident between the participants and discusses the effect this process has on the individual child.

1.6. The Research Question

The research objective was to explore the events experienced and comments made by the three main participants (school, parents and LEA) on the process of securing an individual child appropriate educational provision.

The main research question is:

1. What are the influences that support or inhibit appropriate provision for children with autistic spectrum disorder from the perspective of a school, parents and LEA officials?

The following questions stem from the main research question:

2. How do the participants consider the current system of appropriating and maintaining provision as working in practice?
3. How does the process of securing appropriate educational provision impact upon the individual child with autistic spectrum disorder?

Chapter 2 reviews the current literature on autism and educational provision, and identifies gaps, explaining the basis for this thesis. Chapter 3 discusses the research methodology. The subsequent 3 chapters (Chapter 4-6) look at the individual Strands. Chapter 4 presents the views of a school (Strand 1), Chapter 5 presents the views of parents (Strand 2) and Chapter 6 presents the views of LEA officials (Strand 3). Chapter 7 pulls together the three strands and discusses the research evidence. Chapter 8 draws this thesis together and discusses the research questions, findings and implications as they relate to appropriate educational provision for an individual child with autism.

Chapter 2 - Literature Review

Far from reaching a consensus among researchers and practitioners, the study of appropriate educational strategies for individuals with autism remains debated. The variety of strategies labelled as 'good practice' leaves both parents and practitioners uncertain about an appropriate path to follow. Although the government provides guidance on the events and their timing through the Code of Practice (DfES, 2001), there is little definitive framework in the literature to guide parents and practitioners toward a specific approach for a specific child. As autism is a spectrum disorder, with a large diversity among those affected, the little guidance that is given is general in nature (DfES, 2002). The large number of choices given to meeting appropriate educational provision potentially leads to tensions and dilemmas between the three partners (school, parent, LEA).

This study in autism will take a closer look at these tensions and dilemmas.

Bertalanffy's (1968) writings on systems theory provide the theoretical underpinnings for this thesis (see Chapter 3). Rapoport's (1986) definition of a system 'as something consisting of a set of elements and fixed relations among them' (p. 79) is helpful in understanding the process of determining provision. The child is at the heart of this model, with those in the child's environment defined as the elements that affect the child. In this thesis, the elements explored are the school, parents and LEA.

It is therefore appropriate to discover the views of those in the child's ecosystem. For the first time it will examine the views of professionals and parents on securing, delivering and evaluating appropriate educational provision for children with autism. In order to inspect these views, it will concentrate on the opinions of a school, parents and LEAs as this thesis explores the main research question (see Section 1.5). To this end, Section 2.1 (and sub-sections) discusses the limited areas of agreement and Sections 2.2-2.4 (and subsections) discusses the areas of disagreement generally present among practitioners and parents. It is fitting for this discussion to explore the vast differences of opinion that exists in the literature in regards to what individuals define as educational provision that is appropriate and the means to provide it.

Section 2.5 will explore the limited research that currently exists on the opinions of the partners (school, parents, and LEA) on the process of educational provision.

The penultimate section (Section 2.6) will discuss issues relating to school management. This is consistent with the sub question, which will provide insight into the day-to-day workings of a classroom within a school.

The last section identifies some of the research literature related to visual teaching strategies (Section 2.7.). This was used in the action research, and it is appropriate to investigate some of the current literature on this topic.

Finally, the chapter concludes by identifying gaps in the literature and linking these gaps to the thesis topic. The chapter finishes by providing insights into what findings could be expected in the context of the research question (Section 2.8.).

2.1. Areas of Consensus

The literature shows three areas of general agreement. These include the history of the ailment that includes the works of Kanner (Section 2.1.1.), the use of the Triad of Impairments to describe autism (Section 2.1.2.), and the agreement that early intervention is an effective tool when working with this population (2.1.3.).

2.1.1. History

The first of the three areas of consensus looks at the history of autism in the literature. Autism has been longstanding. Frith (1989) in her book Autism: Explaining the Enigma shares several examples in both legends and fables as well as actual individuals. She explores the idea in fables of children who were 'stolen' by fairies only to be replaced with difficult or aggressive children. Frith hypothesises that these children were in fact autistic (see also Wing, 1997; Marris, 1999).

History gives other examples of individuals that may have had autism. Perhaps most common is Itard's recount of a child he found living in the wild (Itard, 1962-reprinted from 1801). He describes a child that has lived alone in the Caune Woods in France from the age of four or five until he was repatriated at approximately the age of twelve. Itard's detailed description of his poor social skills and solitary habits indicate autism (Wing et al., 1976).

Other interesting examples of prominent figures linked with autism can be seen in literature or the news. In literature, Sherlock Holmes' interest in obscure details of criminal investigations and his expertise in unusual items is linked with Asperger's syndrome (Frith, 1989). Andy Warhol's use of repeating soup cans in his artwork, combined with his stoic nature in interviews has been suggested as Asperger's syndrome (Stewart, www.autism99.org/flash/papers_front.htm).

2.1.2. Kanner

In spite of the evidence from history that autism has been documented, the first use of the term autism associated with the syndrome is credited to Kanner. In Kanner's 1943 paper 'Autistic Disturbances of Affective Contact', (1943; Kanner, 1943b) and follow-up (Kanner, 1971), he describes 11 children all with similar characteristics. Kanner states that the children have an 'inability to relate themselves in the ordinary way to people and situations from the beginning of life.' (p.242). He continues and describes their 'dread of change' and 'monotonous repetitiousness' (p.246).

There are three interesting aspects of this paper. The first is Kanner's use of the term 'autistic disturbances of affective contact' (1943, p. 217). 'Kanner not only identified the syndrome, but labelled it, and thereby opened a new and fruitful era of scientific exploration...' (Wing et al., 1976 p. 10). This is the first time in print the word autism is associated with the disability. The word 'autism' is thought to have originated from the Greek word 'autos', which means 'self' (Wing, 1997, p. 13) although Eugen Bleuler (1916) was the originator of the term, he used it to describe schizophrenic children.³ Kanner's use of the term and descriptions of the children under his care set the pattern for others working with similar children. It led to widespread use of the term and general acceptance of the syndrome (Schreibman, 1988).

Second, Kanner (1943) suggested that autism is associated with faulty parenting. 'In the whole group there are very few really warmhearted (sic) fathers and mothers' (p.250). He concludes that it may not be due solely to parenting issues when he states 'The question arises whether or to what extent this fact has contributed to the condition of the children. The children's aloneness from the beginning of life makes it

³ Kanner ruled out the diagnosis of childhood schizophrenia due to the lack of a period of 'normal development' in the children he described. (Kanner, 1943)

difficult to attribute the whole picture exclusively to the type of the early parental relations with our patients.’ (p. 250).

Considering the size of Kanner’s original sample (11 children) and the lack of availability of services for children with special needs in the middle of the last century, his conclusion had a tremendous impact on the education of children with autism during the 1950’s to 1960’s (Howlin, 1997a). These comments sparked the work of Bruno Bettelheim and his use of psychoanalysis as the treatment of choice for autism during this time (see Bettelheim, 1943; Bettelheim, 1967; Pollock, 1997). Bettelheim’s work chose to focus on Kanner’s hypothesis of faulty parenting and concentrated on re-establishing the parental bond to create his view of a safe and secure environment for the child. In the process he alienated many parents and Bettelheim’s work is in disrepute among current practitioners (Happé, 1995) and has been deemed ‘harmful’ (Smith, 1996 p. 52).

The third interesting aspect of Kanner’s paper was the fact that at approximately the same time another researcher drew some of the same conclusions about this population of children (Happé, 1995; Siegel, 1996; Cohen et al., 1997). Publishing within a year of each other and working with similar children, Asperger also described the syndrome as autism⁴ (Frith, 1991). Subsequently, Asperger’s Syndrome⁵ (viewed by many as a higher functioning form of autism) now bears his name.

2.1.3. Triad of Impairments

The second area of general consensus is the use of the Triad of Impairments to describe the deficits of children with autism. ‘Everyone with the condition has difficulty with social interaction, social communication and imagination – the triad of impairments’ (National Autistic Society, 2000a, p.1) see also (Happé, 1995).

Even though there is general agreement that these three areas are affected, the severity of each aspect varies greatly among children and leads to difficulties in diagnosis (see Section 2.3.). This has led to the use of the term syndrome or spectrum disorder to describe the differences in autism among individual children.

⁴ For a detailed comparison of Kanner’s and Asperger’s papers see Frith, 1991 p 95-96.

⁵ Asperger’s syndrome refers to individuals with marked deficits in social abilities, but ‘normal’ skills in both communication and behavioural realms.

(See for example Happé, 1995; Siegel, 1996; National Autistic Society, 1999a) This can be attributed to either the various underlying impairments or due to the interaction between the primary disabilities and the environment (Wing et al., 1976).

Because of this difficulty, two main diagnostic guidelines for clinicians are used (Siegel, 1996; Rapin, 1997; Volkmar, 1998). These are the Diagnostic and Statistical Manual of Mental Disorders (the most recent edition is the Fourth Edition, Text Revision 2000, or DSM-IV-TR (Schafer, featnews@list.feat.org)), and the International Classification of Disease, Tenth Edition (ICD-10) (World Health Organization, 1993). (See Appendix 2.) Each of these tools lists various categories with similar characteristics, but different diagnostic criteria (e.g.: Retts syndrome, Asperger syndrome, Pervasive Developmental Disorder- Not Otherwise Specific (PDD-NOS), Fragile X syndrome and others).

2.1.4. Early Intervention

The third main area of agreement among clinicians and practitioners is the value of early intervention (Howlin et al., 1973; Fenski et al., 1985; Siegel et al., 1985; Howlin, 1997a; Heflin et al., 1998; Trevarthen, 1998; National Autistic Society, 2000b).

The idea of helping the child and family as early as possible is widely accepted by both advocates and current legal statutes (Central Advisory Council for Education, 1967; Warnock, 1988; DFE, 1994; DfES, 2001). Unfortunately, although the concept of early intervention is widely embraced among all participants in the education process, the practice of providing early educational programmes for children with autism is sporadic (National Research Council, 2001; PACE, 2001; National Autistic Society, 2002). Provision for a young child is often linked to what is available in the geographic setting the child resides and not what is most needed by the individual child (Evans et al., 2001). Debate among Health, Social Services and Education over who is funding and providing these programmes can lead to delays in delivering services. (Tissot et al., 2001; Barnard et al., 2002) Inconsistencies in the types of programmes offered and the limitations of services rendered lead researchers and consumers to question the effectiveness of them. (PACE, 2001) 'In sum, it is unlikely that most public funded early intervention programs are having substantial impact' (McGee et al., 1999 p. 144).

Although there is agreement among interested parties about the work of Kanner, the description of autism, and the usefulness of early intervention; the specific type of intervention is not widely agreed upon, or even the effectiveness of public programmes. This leads to the first of the three points of disagreement among practitioners; the issue of which specific intervention technique(s) should be used.

2.2. Areas of Disagreement

There are a variety of therapeutic approaches to habituation and effective learning; many practitioners disagree on which one is the most effective. 'There is no consensus among professionals as to how to treat the disease of autism.'

(Schreibman, 1988 p.90). As such, the treatment choices are many and varied and are the first of three areas of disagreement (Dunlap, 1999).

There are several good reviews of current educational approaches for individuals with autism and related disorders (see for example Siegel, 1996; Smith, 1996; National Autistic Society, 1997; Howlin, 1997a; Heflin et al., 1998; Jordan et al., 1998; Trevarthen, 1998; Tissot, 1999). A review of these and other literature reveals the vast array of choices for families and practitioners. It is beyond the scope of this paper to go into depth about every strategy, therefore this section will highlight those approaches that have risen to prominence over recent years and have been or currently are still in practice in the UK. It is not an exhaustive list. The following three categories⁶ are used: sensory interventions/'miracle cures'; home based educational strategies; and lastly, school based, and extended school based educational strategies. Dietary, pharmacological treatments or other therapeutic measures, although frequently used with autistic children, are not considered to be educational in nature and therefore are not included in this summary. (Note: some of these are discussed in Section 2.4 discussing the cause of autism.)

2.2.1. Sensory interventions/'Miracle Cures'

The first category includes interventions that are characterised by the use of very public, successful individual case histories. Usually this is followed by scientific study

⁶ Please note, the assignment to a particular category is based on a general consensus among cited authors in this section.

failing to reaffirm the initial success. Prominent in this category are Auditory Integration Therapy (AIT), Irlen lenses, Facilitated Communication, Holding, and Pet therapy. Although it may seem odd to include some of these in a review of educational approaches, it is the personal experience of this researcher that these are offered at schools or in conjunction with a local LEA. Therefore, they are included in the discussion.

2.2.2. AIT

AIT involves the use of modulated sound in varying frequencies for a period of 10 hours over a 10-day period. It is based on the work of Berard and became popular after the publishing of Steihli's book The Sound of a Miracle (Stehli, 1992). It is based on the belief that distortions in hearing could result in autism (Smith, 1996; Howlin et al., 1997b; Cohen, 1998; Mudford et al., 2000). Although this method does have its strong advocates (Rimland, 1992), recent research has shown little evidence of its effectiveness (Mudford et al., 2000).

2.2.3. Irlen Lenses

Irlen lenses seek to correct a malfunction in an individual's sensory perception. It does this by having the individual wear glasses with various coloured lenses in them (National Autistic Society, 1997).

Donna Williams, a prominent author with autism (see for example Williams, 1992; Williams, 1994; Williams, 1998) states 'The lack of integration of my senses became the lack of integration of my emotions with my body and my mind. These (Irlen) glasses would have changed all that.' It is also worth noting that Irlen Syndrome is suggested to help with a variety of other difficulties including 'clumsiness, motion sickness, low self esteem and absenteeism' (1997, p.3). Howlin (1997a) concludes the evidence to support their use is limited to a small number of individuals who have worn the spectacles, and to the writings of Irlen herself and therefore questions its effectiveness.

2.2.4. Facilitated Communication

The next treatment in this section, and perhaps the most controversial, is Facilitated Communication. This is based on the belief that individuals with autism have an

underlying sophisticated ability and that a motor difficulty prohibits them from communicating (Siegel, 1996). Advocates believe that by applying gentle resistance to the elbow of the autistic individual's arm, the individual will be able to overcome their motor restrictions and point to various letters or words to communicate.

Problems arise when there are the inevitable disagreements over the true author of the message (Powell et al., 1997; Cohen, 1998; Grove et al., 1999). Smith (1996) writes, 'Facilitated Communication not only fails to unlock hidden language skills, it also may cause serious problems... Accusations of molestation often have arisen from Facilitated Communication, and many of these accusations have been directed at parents. Such accusations almost always prove to be utterly unfounded...' (p. 51). Facilitated Communication is a controversial procedure that has generated publicity with no scientifically demonstrated support for its efficacy (Howlin, 1997a).

2.2.5. Holding Therapy

Holding Therapy is based on the work of the Tinbergens (1983). Welch (1988) is perhaps the best-known advocate of this approach, widely publicized in the UK during the end of the 1980's and early 1990's. Heflin and Simpson (1998) state that it is based '... on the belief that autism results from a broken symbiotic bond between the mother (or father) and child.' (p. 195). In order to re-establish this bond, the parent holds the child very tightly while speaking to them for an extended period of time sometimes even for several hours. Again, the current thinking disagrees (Howlin, 1997a). Siegel (1996) associates this 'therapy' with theories of Bettelheim (1967) and his psychogenic view that autism is the result of faulty parenting (see Section 2.4.1.).

2.2.6. Pet Therapies

The last strategy under this section is pet therapy or the involvement of animals. The most common of these is dolphin therapy. Advocates claim that children have been reported to demonstrate drastic improvements after swimming in a tank with dolphins. Although there may be a benefit to the child if he or she enjoys swimming or animals, its therapeutic effect has not been established.

Although each of the methods mentioned in this section have very different beliefs and backgrounds, they all share an almost evangelical advocacy by the founder or an

initial benefactor. This is usually followed by a period of mass publicity and public demand for the service. Families believe that if they pay for this service (usually costing several hundred pounds) that their family member will become drastically better. Unfortunately in the vast majority of cases, there is no rapid recovery. With time, scientific studies are conducted, only to show no link between the therapy and the claims of success. The highly publicised initial case appears to be the only one with a successful outcome. The next section discusses more common approaches, based in the child's home.

2.2.7. Home based strategies

Approaches classified in this section are distinguished by the fact that the primary site services are delivered in the child's home. Parents are also strongly encouraged (or required) to be involved in the treatment programme, as well as generalisation of skills learned. Classified in this section is Applied Behavior Analysis (ABA) or Discrete Trial Training (DTT) (a.k.a. the Lovaas Method) and Verbal Behaviour (VB); the Options Approach (a.k.a. The Son-Rise Program); and the National Autistic Society's Early Bird Project.

2.2.7.1. ABA/DTT and VB

Lovaas pioneered the use of behavior modification through reinforcement and is perhaps the best associated with ABA (Applied Behavioural Analysis) and DTT (Discrete Trial Training) (see for example Lovaas et al., 1974; Lovaas, 1977; Lovaas et al., 1981; Lovaas, 1987; Lovaas, 1993). It is based on the behavioural model of targeting precisely defined behaviours, measuring them and designing an intervention to address these (Schreibman, 1988). Positive reinforcement increases the likelihood of the correct response and is used frequently.

Lovaas' research (Lovaas, 1987; McEachin et al., 1993) is significant because it is one of the few scientifically controlled studies in the area of autism. It showed that 47% of the children in his experimental group were mainstreamed and able to maintain this in follow up studies. Replication of this research is underway (Sallows, In Press).

After training, the family set up a team of individuals that work with the child in a specifically constructed programme that addresses the child's individual needs. This

team works with the child initially on a one to one basis for up to 40 hours a week (Lovaas et al., 1981; Maurice et al., 1996; Chassman, 1999; Leaf et al., 1999). This method has its strong advocates (Green, 1996) and critics (See for example Gresham et al., 1998; Jordan et al., 1998) Lovaas answers these critics, clarifies his work and calls for cooperative research into this and other methods (Lovaas, 2000). Currently this work is being replicated (Sallows, In Press).

Verbal Behaviour (VB) is a specific type of ABA/DTT programme. It is designed for a team of tutors working with an individual child at home for several hours a week in a behaviourally based approach. The difference between the two approaches is that VB places a very strong emphasis on developing spoken (or signed) language (Sundberg et al., 1998). Verbal Behaviour espouses 'errorless learning' where children learning in an environment that is heavily prompted to reduce the chance of mistakes. It also follows the principles of Skinner (1957) where language is broken into different categories. The child's programme is designed to work towards a variety of different types of language, generalising the types of situations and events leading to language usage (Carbone et al., 2000).

Although there is research literature on ABA, the use of VB with children is still relatively new and therefore no research exists on this programme.

2.2.7.2. Options

Options (or the Son-Rise Program) was developed by Barry and Samahria Kaufman to help their son Raun. Their work with Raun, and his subsequent recovery from autism became well known after the publication of two books (Kaufman, 1976; Kaufman, 1981) and the airing of the network movie in the United States based on these. The Kaufmans teach a very charismatic 'home based, child centred program based on an attitude of love and acceptance.' (Kaufman, 1998 p. 19) After an initial training session at the Son-Rise Institute in the United States, families are encouraged to run Option programmes at home. This often takes place in a designated area of the home (or purpose built classroom in the garden) where the child spends numerous hours in one to one interaction with trained staff or volunteers. This is an approach that has anecdotal evidence of success, but no published research investigating it (Ives et al., 2002).

2.2.7.3. Early Birds

The last programme in this section is relatively new, starting in 1997. Early Birds (Shields, 2001) is a National Autistic Society initiative, aimed at training parents to work with their preschool children (National Autistic Society, 1999d). It focuses on training parents to follow basic behavioural strategies to help them at home with their young autistic child, as well as teaching some background information about autism in general. Although a pilot project was conducted (Shields, 2001) and the response from parents has been positive, it is still relatively new. This makes it difficult to assess the effectiveness of the programme.

Although researchers and practitioners agree that early intervention is important, services for young children are very dependent on the area of the country the family lives (English et al., 2001). Parents are increasingly aware of the limited outcomes for autistic individuals and therefore want to ensure the best possible chance for independent living for their family member. If there is no early intervention service available, or a long waiting list, some families will wish to provide educational support at home. The research supporting some of these programmes (ABA) also convinces parents to adopt the approach. Although providing parents with the tools to help their child, these programmes can be quite draining on family resources. They can be both expensive and very time consuming. For those families that can afford it, they have the joint benefit of providing practical support targeting specific deficiencies in the child, and even reducing the stress associated with having a family member with autism (Hastings et al., 2001).

2.2.8. School based educational strategies

Services offered by a Local Education Authority (LEA), most often accessed through a local school, as well as specialised school (set up by charitable organisations or parent groups) are included in this category. But before looking at the various approaches or therapies, a brief review of the history of special educational provision is in order. (For a more detailed description, see for example Pritchard, 1963; Sylvester, 1970; Lloyd-Smith, 1992; Mazurek et al., 1994; Hall, 1997).

2.2.8.1. History of Special Education

'The teaching of autistic children has taken place in a structured way in England only in the last twenty years.' (Furieux et al., 1977, p.5). Although printed in 1977, Furieux's comment reflects the recent nature of specialised education for autistic children. Prior to this time, it was believed that autistic children were the responsibility of the Health Services and in need of psychotherapy (see for example Bettelheim, 1943; Bettelheim, 1967). 'Thus children came to be treated in clinics and hospitals by child psychiatrists and psychotherapists... A major problem with this kind of treatment has been the time available for the treatment programme which is, at best, usually an hour or two a week.' (Furieux et al., 1977 p. 6). In the 1970's this became the responsibility of the education authorities.

Perhaps the most important legislative Act during this time is the 1981 Education Act, resulting from many of the recommendations of the Warnock Committee's report (Beveridge, 1993; Mazurek et al., 1994). This had three main points. First, it shifted focus to the child and his or her individual needs as the responsibility of the Local Education Authority (Warnock, 1993). Second, it focused on integration of children with special needs into mainstream schools and communities (Hall, 1997). And third, it extended the concept of handicap to one of a continuum of ability. This opened up special educational needs to a far wider population than it had previously (Mazurek et al., 1994, p. 453). (See also Warnock, 1988; Thomlinson, 1995) Unfortunately, the 1981 Education Act was a 'well meaning, but toothless legislation...' (Jones et al., 1992 p. 12) because it lacked the ability to enforce the recommendations made.

The Education Reform Act of 1989 and the Children's Act of 1989 brought additional changes. Most prominent are the reliance on market forces to ensure quality, the centralised control of the curriculum, the National Curriculum and the role of parents in education (Jones et al., 1992; Whitney, 1993).

The current provision for special educational services for children with autism varies according to the local LEA, although the general framework is directed on a national level (DfES, 2001). Individual LEAs or schools most frequently offer any or sometimes all of the following with respect to children with autism: Mainstream inclusive education, speech and language therapy (S/L), music therapy, or they may follow

specialised curriculums such as TEACCH (Treatment and Education of Autistic and related Communication handicapped Children) through a specialist school for disabled children.

2.2.8.2. Inclusion

In 1997, then Secretary of State for Education and Employment, Blunkett directed LEAs to place a high priority on inclusion of children with special needs within the mainstream local school. In the Green Paper on special education, he stated:

'while recognising the paramount importance of meeting the needs of individual children, and the necessity of specialist provision for some, we shall promote the inclusion of children with SEN within mainstream schooling wherever possible.' (DfEE, 1997 p. 5)

This is also evident in the new Code of Practice (DfES, 2001). The idea of inclusive education has been debated for several decades (see for example (Central Advisory Council for Education, 1967; Warnock, 1988). Children very affected by autism, at the very disabled end of the autistic spectrum are rarely considered candidates for inclusion, although this is not true for other children with autism (Beveridge, 1993; Visser et al., 1993).

However, Dew-Hughes (2001) did a small research study and found that even children considered quite disabled could benefit from inclusion. She found that they were more independent and showed an ability to work co-operatively and autonomously for much longer than their peers in a special school.

This issue has generated much debate. Jordan (1998) concludes that there is no evidence to show that this method is any more effective than other specialist services. Hornby (1997) also agrees and even advocates that the policy of integration for all children should be abandoned. Kasari (1999) found that this debate also evoked strong sentiment on behalf of parents whose views varied according to the age, diagnosis and current placement of the child. Kasari's study questions the use of general policy to dictate educational placements.

2.2.8.3. Speech/Language therapy

It is not uncommon for children with autism to be referred for speech and language therapy or have provision for it on their statement due to the large number of children

with communication difficulties. In fact, most display no functional speech (Bondy et al., 1994).

Provision may involve traditional speech therapy or instruction in augmentative systems (e.g. PECs, PICs, Sign Language etc.) to facilitate better communication wherever possible (National Autistic Society, 1997).

2.2.8.4. Music Therapy

Music therapy is distinguished from music lessons. It is not about teaching musical skills, but does emphasize interactive music making where the therapist responds to sounds the child makes (National Autistic Society, 1997). In a music therapy session, the child is encouraged to engage with the practitioners through music. This has the benefit of practicing these skills without spoken language. However, Howlin concludes, '...once again, there is no evidence of any long term benefits...' (1997a p. 62) In the state of New York's recently published guidelines, (New York State, www.health.state.ny.us/nysdoh/eip/autism/) the authors state, 'Music therapy has not been demonstrated to have efficacy in a controlled study using generally accepted scientific methodology. Because of the lack of demonstrated efficacy, music therapy cannot be recommended as an intervention method for young children with autism.' (Chapter 4, p.4).

2.2.8.5. TEACCH

Perhaps the most widely recognised approach for autistic children, TEACCH (Treatment and Education of Autistic and related Communication handicapped Children) is commonly used throughout the United States and the United Kingdom in state run schools (Dawson, 1989). (This is discussed in detail in Section 2.7., and the reader is referred to review that section for a more in depth discussion. For additional information see the writings of Eric Schopler and Gary Mesibov.)

2.2.8.6. Specialised Curriculum Schools (ABA, Higashi, CABAS, SPELL)

Often specialised schools are set up to address the particular needs of a specific population of autistic children. This can be due to a particular philosophical approach advocated by an individual practitioner (i.e. Higashi), or a perceived inadequacy in

current state provision for children affected with, in this case, autism (Treehouse, Jigsaw, Priors Court School). In most cases, parents are the leading force in establishing charitable organisations to set up the school.

In the UK, there are several specialist schools for children with autism. The majority of these are run by the NAS (seven schools) or affiliated with them (eight schools). (For a complete listing contact the NAS or visit their web site at www.oneworld.org/autism_uk/) The NAS does not officially support any one particular method or approach, but advocate the SPELL philosophy (Structure, Positive approaches and expectations, Empathy, Low arousal and Links) (National Autistic Society, 1997). The individual schools use a variety of teaching techniques including primarily TEACCH. 'Currently The National Autistic Society nor any Local Education Authority has made a commitment to any particular treatment or therapy.' (National Autistic Society, 1999c).

Other independent schools have been set up to help the specific needs of autistic children. Most recent are Prior's Court school in Berkshire (following an eclectic approach of TEACCH and physical exercise), Treehouse in London (following an ABA approach), Honormead School for Children with Autism in Staffordshire (following the Higashi approach) and Jigsaw in Berkshire (following an ABA and CABAS curriculum). Personal communication with Prior's Court School (Williams, 2000), Treehouse (Eccles, 2000) and Honormead (Nield, 2000) reveal that all have established plans to measure the effectiveness of their provision, using outside sources. As these schools have all been opened within the last three to five years, findings are not expected for some time. This commitment to independent evaluation is unique among special education facilities with the notable exception of the West Midland Project (English et al., 2001).

2.2.9. Conclusions

Wide diversity exists among the many approaches to autism, several of them riddled with controversy. Practitioners, researchers, and parents disagree about the best way to help their child. This section reviewed some of the most common, as well as some

of the most publicised methods available and revealed the following key points related to this thesis:

- Although the choice of educational and therapeutic approaches is quite vast, the research supporting a particular methodology is sparse in most cases. A notable exception to this would be the work of Lovaas on Applied Behavioural Analysis.
- The spectrum of children with autism makes it difficult for one particular method to be helpful for all children, yet the research shows that individual choices are quite limited by what is available in the area in which the child resides or attends school.
- The use of the term 'miracle cures' is still evident in the literature (see for example Options, AIT, Secretin, etc.). This is often based on single case success followed by a huge media interest. This interest generates a large demand for the service or substance on social agencies followed by a lengthy period of time in which researchers investigate it. This usually shows the ineffectiveness of the service or substance.
- There is a noticeable omission in the literature of the evaluation of Local Education Authority Special Schools or established private schools (this is not the pattern for newly established independent special schools). There seems to be little evidence of research into the effectiveness of this type of provision.
- There is very little distinction in the literature between approaches that may be classified as having a therapeutic value and those having an educational value. Others may have value for a child if the child enjoys that particular activity (music, so the child may enjoy music therapy).
- There is little evidence in the literature on the specific strategies that could be successfully implemented to address unique characteristics of an autistic child on the continuum within each of the Triad of Impairments. In other words, guidance does not exist indicating effective techniques to address the specific difficulties in and between areas of the Triad.

2.3. Prevalence

The second of the three main areas of disagreement (treatment, prevalence, and cause) is the actual number of children with autism. It is appropriate for this study of educational provision to include a brief discussion on prevalence because of the effect that the ever-changing number of children with ASD has on educational providers (LEAs) in the UK. As the numbers of children diagnosed change and fluctuate, the number of children with the ailment requesting provision change. Consequently it makes planning and delivering appropriate educational provision very difficult for schools and LEAs.

Logically, if the description of autism is agreed and defined, and if the diagnostic tools (DSM-IV and ICD-10-see Appendix 2) adhere to the agreed description, then the number of children with autism should be a straightforward process of counting those receiving diagnosis. Unfortunately, this is not the case because LEAs and Health Authorities in general, do not keep track of the number of individuals with autism (Thrower, 2000).

2.3.1. Figures⁷

The actual incidence of autism varies according to the source cited and therefore it is difficult to know exactly how many children have ASD (DfES, 2002). The earliest epidemiological study was conducted by Lotter in 1966 and found the incidence of autism to be between 4 and 5 per 10,000 (0.04-0.05%) or roughly one in every 2,000 people. Later, as clinicians became more aware of the disorder, and the diagnostic tools were standardised and broadened to include the spectrum of autism, the prevalence rose. The incidence then was cited to be between 10 and 20 cases per 10,000 (0.1-0.2%) (Wing et al., 1979; Filipek et al., 1999).

More recently the reported figures have increased. The UK National Autistic Society (1999a) cites a figure of 91 in 10,000 (0.91%), but this figure is disputed (see Fombonne, 1997). Fombonne (1999) reports a figure of 18.7 per 10,000 (0.19%) but he reports that his current research will show a higher rate (2000b).

⁷ For a comprehensive review of the screening and diagnostic process in autistic spectrum disorders see Filipek (1999).

Recent epidemiological studies also confirm a high prevalence rate. Baird et al. (2000) cite the rate to be 30.8 per 10,000 and an additional 27.1 per 10,000 for autistic spectrum disorder or 58 per 10,000 (0.58%). Scott (2002) also reports a higher rate of 57 per 10,000 (0.57%) in Cambridgeshire of ASD in 5-11 year olds. This last figure is the one accepted by the Medical Research Council (2001) when it states that autism spectrum disorders affects approximately 60 per 10,000 (0.6%) individuals.

This increase in the reported number of children diagnosed with autism is not just a UK phenomenon. Current figures from the United States also show significant increases. Yazbak states, 'Nationwide, in a one-year period, 97-97 to 98-99, autism has increased by 26% among children ages 6 to 21 attending school in the United States.' (Yazbak, www.feet.org). Centers for Disease Control and Prevention (2000) conducted their own study and found the rate to be 6.7 per 1,000 (0.67%) children (Centers for Disease Control and Prevention, www.cdc.gov/nceh/cddh/dd/report.htm, p. 4). 67 children per 10,000 are very close to the figures reached by Scott and her team. New research investigating the number of children with autism in Atlanta, Georgia (Yeargin-Allsopp et al., 2003) found the number to be 34 per 10,000 (0.34%).

Other recent research shows contradictory results. Researchers from Finland (Kielinen et al., 2000) show the rates to be 20.7 per 10,000 (0.21%) and Iceland (Magnusson et al., 2001) of 8.6 per 10,000 (0.86%). Allowing for the differences in the samples studies (ASD versus core autism), there still is a huge fluctuation in the numbers reported between the various studies.

2.3.2. Increase or Better Diagnosis?

Questions remain as to whether the number of children with autism is actually increasing or if the increase could possibly be due to a broadening of the definition of autism. Perhaps the diagnostic process is detecting autism earlier and therefore it just appears like an actual increase? If this were the case, researchers argue that there would be a corresponding decrease in the number of children diagnosed with unspecific diagnoses (developmentally disabled, mentally retarded) (Charman, 2002). Any of these could explain the rise in numbers, again fuelling the debate among clinicians and researchers.

Researchers disagree on the cause of the increase in number of diagnosed children. The Brick Township (2000) report concludes the increase may be due to a change in the accepted description of autism. Gillberg and Wing (1999) feel it is likely to be due to a difference in the study methods used by the researchers. Fombonne (1999) agrees with this conclusion, but also feels it could be due to the early diagnosis of children. Newly published research by Yeargin-Allsopp and colleagues (2003) argues that there is an actual increase.

Yet, Howlin and Moore (1997b) do not find this to be the case. They conducted a survey of over 1200 parents with autistic children from ages 2 to 49 years. The researchers found that children are being diagnosed earlier; the average age of diagnosis is still around 6 years. This figure is surprising since there are several tools available to both parents and health practitioners to aid the diagnostic process. See for example the CHAT (Baron-Cohen et al., 1996; Filipek et al., 1999) and the work of Sir Michael Rutter's team at the Medical Research Council's Child Psychiatric Unit in London (Berument et al., 1999). Although these are not diagnostic assessments, they are screening tools which are meant to guide practitioners and parents.

Some preliminary findings of new research by Werner (2000) and colleagues show that detection of autism might be possible even earlier than 18-months. Werner and her team reviewed video tapes of the first birthday parties of children who were later diagnosed with autism and concluded that the differences between those children with early onset autism spectrum disorder and other children with typical development can be detected at 8-10 months of age.

With the possibility that autism can be detected much earlier than previously realised, it would be logical to conclude that early diagnosis has had some effect on an increase in the number of children diagnosed with autism. Given time to allow for this occurrence to stabilise, theoretically, the figures should in fact return to their previously lower numbers (if this was the only reason for the rise). The other arguments presented by Fombonne, (1999, 2000), Gillberg and Wing (1999), and Croen (2002) feel that better diagnosis is the underlying cause for the increase. However, these may discount some of the newer research into the cause of autism.

This review of the literature identified several gaps concerning the prevalence of autism.

- Although most recent research seems to be centring on the figure of 60 per 10,000 (0.6%), there still exists a wide gap between accepted prevalence figures published in peer reviewed academic journals.
- The fluctuation in numbers does not allow individual schools or LEAs to plan resources to meet additional unexpected increases in numbers of children with ASD (Evans et al., 2001).

2.4. Cause

The third main area of debate highlighted in this paper is the cause of autism. The issue of causation is included because of its impact on educational provision. The different philosophies about how children are educated are affected by beliefs into the underlying factors that increase or decrease the individual child's degree of autism. This frequently debated issue seems to focus around three main areas: psychological, physiological or genetic, and environmental factors. Although present in all three areas, perhaps this effect is most obvious in the first discussion into those believing that psychological factors caused children to regress into autism.

2.4.1. Psychological

Although most of the recent research and press reports have concentrated on either a biological, genetic or allergic focus, the earliest writings by Kanner provided the first theory of the cause of autism. Kanner (see prior discussion in Section 2.1.2) theorised that autism could be the by-product of faulty parenting and thus be psychological in nature (Kanner, 1943; Kanner, 1943b). Also included is the notion that autistic regression is a means of escaping society (Holter et al., 1971). This led to the rise of psychoanalysis as a treatment for autism (Bettelheim, 1967), which although discounted by many practitioners, (Smith, 1996; Howlin, 1997a) it is still in practice today in countries such as France and Spain. This practice can often have quite a detrimental effect on the family.

2.4.2. Physiological and Genetic Factors

Another set of researchers believes that physiological or genetic factors have the greatest impact on an individual's autism (Wing et al., 1976; Siegel et al., 1985; Wing, 1985; Schreibman, 1988; Rutter, 2000; Medical Research Council, 2001).

'Given that the autistic personality type is both circumscribed and persistent, the questions of heredity must arise.' (As translated by Frith, 1991 p. 84). After 50 years, Asperger's belief is still of value. Currently, the science has still not advanced to the state where it is possible to identify all the factors that cause autism, but the research has made some significant advancements (Schreibman, 1988). Perhaps the most significant research to date with direct influence in the biological and genetic impact in the field of autism is the Human Genome Project. (Department of Health and Human Services, 1995; Cohen, 1998) The Human Genome Project has produced a 'map' of where the genes are located. This should enable scientists to pinpoint any consistent abnormalities found in children with autism, which could in time allow for a precise medical test to diagnose autism (Twombly, www.eurekalert.org/releases/duke-dgu012700.html).

Several studies are already using the data from the Human Genome Project (Konstantareas et al., 1999). It is rare for autism to be directly inherited, due to the fact that individuals with autism usually do not have children, several researchers conclude that there is a genetic component. The research by the Medical Research Council (2001) concludes that there is a genetic component to ASDs, although the actual number of cases may be limited to 5-10% of the entire population of individuals with autism. Other researchers feel the number may be higher, between 30% and 50%. (Siegel, 1996 p. 92)

Other studies focusing on genetics involve looking at family histories or similarities in twins (Hanson et al., 1976; Kotsopoulos, 1976; Rutter, 2000). Folstein and Rutter's studies in 1977 (Folstein et al., 1977a; Folstein, 1977b) was the first to explore this idea and found a significant concordance of autism in both twins when they were identical (monozygotic-MZ) compared to fraternal twins (dizygotic-DZ). Although the sample size was relatively small (21), this is significant given the prevalence rate for autism was thought to be only 2-4 per 10,000 at that time. Other studies with larger

samples where conducted (Silliman et al., 1989). Most notably was a study by Le Couteur (1996) where she investigated autism using a broader definition. In this study, Le Couteur and colleagues found that 90% of autistic identical twins shared degrees of autism, when only 10% of non-identical twins did.

Several other studies of these types have been conducted researching autism (Frith, 1991; Howlin, 1998b). Others point to larger or abnormally smaller brain regions (Courchesne, 1989; Fombonne et al., 1999a; Mostofsky et al., <http://unisci.com/stories/0608961.htm>), although this research is limited due to the relatively small numbers of organs donated for this research (MRC, 2001).

Other interesting research is looking into the possibility that autism began very early in the pregnancy. Rodier (2000) concludes autism initiated very early in gestation period. Researchers at the California Birth Defects Monitoring Program (CBDMP) and the National Institute of Health screened samples of infant blood samples. They found 'strikingly higher levels of four substances crucial in nervous system development in 95% of children with autism and mental retardation' when compared to children with cerebral palsy' (FEAT, www.FEAT.org p. 1). Although this study is only a pilot, further research has been funded with the hope of developing a screening tool in the future.

2.4.3. Environmental Factors

With such a variety of children on the autistic spectrum there are some children who appear different almost from birth, while others appear to develop normally for a period of time and then begin to regress. Cohen (1998) hypothesizes that one of the reasons for this may be the influence of environmental factors. Although researchers in this category believe that there may be some impact from genetic or biological factors, they see environmental factors as having a greater influence upon the onset of autism (See for example Wakefield et al., 1998; Shattock, www.autism99.org/html/).

Recently there has been increased press attention to the proposed negative side effects of immunizations, and/or certain foods (wheat and gluten products). Although there may be many other factors (such as environmental pollutants or dairy intolerance) that proponents believe to have an impact on autism, the discussion will be limited to the first two.

2.4.4. Immunizations

The resulting media coverage about a proposed link between the MMR (Measles, Mumps and Rubella) immunization and the onset of autism has caused concern from both health care professionals and parents alike. Although this debate has been 'in circulation for many years', (Shattock et al., <http://osiris.southerland.ac.uk/autism/vaccine.htm>, p. 2) it has been Wakefield's (1998) research published in Lancet that has brought this issue to the public attention again. The researchers concluded that 'Onset of the behavioural symptoms [of autism] was associated, by the parents, with measles, mumps, and rubella vaccination in eight of the 12 children, with measles infection in one child, and otitis media in another.' (p. 637). This initial piece of research has been hotly debated among clinicians and researchers alike.

Shattock et.al. (www.autism99.org/html/) agree and state, 'it remains our considered opinion that in some 15-20% of the cases of autism with which we have come into contact there are strong reasons to suspect a causative role for vaccines'. He also hypothesizes that it is the 'multi-component MMR vaccine, ... that it is this combination which is responsible for these problems' (Shattock et al., <http://osiris.southerland.ac.uk/autism/vaccine.htm> p. 8).

Health and other public officials disagree with the conclusions of the above researchers (MRC, 2001; Charman, 2002). Calman, (1998) the Chief Medical Officer in the UK states, 'there is no evidence to indicate any link between MMR vaccine and autism' (p.5).

This debate has reduced the number of families having their children immunized and therefore reduced the coverage of the population as a whole. Wakefield (1998) and his team are careful to state that they did not *prove* that measles, mumps, and rubella vaccine caused autism, but noticed a possible association between the two.

2.4.5. Food Allergies

The other environmental factor in this section is the proposed effect that allergies to specific food products may have on children with autism. Wakefield (1998) states that Asperger first recorded this link in 1961, although other more recent researchers are

investigating it as well. Shattock (Shattock et al., <http://osiris.southerland.ac.uk/autism/vaccine.htm>; www.autism99.org/html/) and others propose that autism results when children do not breakdown their food adequately and this is then the food is adsorbed directly in the blood.

Because of this research, a proportion of parents restrict the diets of their child with autism. Frequently, wheat and gluten products are eliminated (see the work of AiA at www.kessick.demon.co.uk/aia.htm). This is based on the theory that when these children cannot digest wheat or gluten, peptides are formed (Whiteley et al., 1999). Peptides get into the brain and cause problems that can make the child's autistic symptoms worsen (FEAT, www.FEAT.org).

Another similar theory believes that these children suffer from a 'leaky gut' and undigested food gets into the bloodstream, which then affects the brain. Research into this area is receiving a lot of recent attention; especially the work of Shattock and Wakefield. Although current studies show mixed findings (Wakefield et al., 1998; Whiteley et al., 1999), continued interest in this area should encourage further research.

2.4.6. Conclusion

The differing opinions of the cause or causes of autism have led to both constructive as well as heated debate among researchers, clinicians and parents alike. The debate has generated some positive outcomes. Perhaps the most obvious is the general increase in information as seen in both the amount of recent press activity as well as the number of conferences and seminars. Secondly, there is an increase in research activity. Until a single genetic or environmental factor is agreed upon, most researchers will feel that 'The most likely explanation is that there are multiple causes, and that some interaction between genetic and environmental factors causes brain development to go awry.' (FEAT, www.FEAT.org).

With this increase in information, there are still areas where there are gaps in knowledge which relate to this thesis:

- There is no one known specific cause of autism that is agreed by all practitioners and researchers. Consequently this means that the various players in determining

educational provision may have differing outlooks as to what is the cause and subsequently what the effective interventions may be. This can lead to disagreements among those involved in determining the specific provision for an individual child or even the consistency of any subsequently determined approach for this child (i.e. school adhering to a gluten free diet)

- The research has not determined a link between the various theories of the cause of autism and the degree or nature of the ailment. Consequently there is limited use of the current research in determining provision for an individual child. Global dictates may come from government (for example the policy on inclusion), but this does not take into account differences that may occur due to the proposed causes of autism and related disorders.
- Although discounted in current research, past beliefs may still influence current practice. Although the underlying theories have been disproved, these approaches are still in current practice. Again, a strong belief in one approach or another (or even the underlying theories behind them) can cause disagreement among those determining provision.

2.5. Determining Provision

The previous sections have described the large body of research on the potential causes of autism and some of the approaches to helping those affected. It has also demonstrated the diversity of opinion that exists.

The research question provides the focus on the influences that support or inhibit appropriate educational provision from the perspective of a school, parents and LEAs, so it is appropriate to investigate the views of these three partners.

A review of the literature pertaining the views of a school is sparse. Helps' (1999) explored the views of classroom teachers within mainstream and concluded that most had very little evidence of special training, even though autistic children were included in their classroom. Mavropoulou (2000) found similar results in Greece. Other research concentrated on the general process of mainstreaming autistic children (McGregor et al., 2001). What these studies concentrated on is the views of teachers addressing the needs of autistic children within mainstream provision. There are no

studies addressing the issue of severely affected children and/or provision in a specialist school.

There is a wealth of anecdotal evidence about the views of individual parents in the press. In addition, the parental voice is included in reports from the charity sector (PACE, 2001; National Autistic Society, 2002), or other project reports (English et al., 2001). The sample of parents included is either limited in number (PACE, 2001; National Autistic Society, 2002) or both geographically and in number (English et al., 2001).

The view of an LEA on the process of determining educational provision is not available. Speculatively, this may be due to the difficulty in stating views in a publicly attributable way or perhaps LEAs are content with this process. This is unknown because no literature has been published on this issue.

It is important to note that the current Code of Practice and Good Practice Guidelines (DfES, 2001; DfES, 2002) have resulted from a consultation process involving limited numbers of LEAs, school personnel and parents. Although laudable, this consultation was limited in the number of individuals it could reasonably be expected to include.

Both the research question and the theoretical underpinnings of this thesis direct it towards an investigation of views. Current literature demonstrates a lack of research in the influences of obtaining appropriate provision from the perspectives of a school, parents and LEA.

2.6. Educational Management

The previous sections have all dealt with specific areas within the field of autism (history, types of educational provision, causes, prevalence, determining provision). Although this section discusses general educational management tools, the research does not link this specifically to the field of autism education. It is bridging this gap that is of interest to the present study, specifically targeting the literature on effective schools and their management.

The factors that an individual school has under its control are of particular interest to this study (see discussion on Strand 1). Although the literature on this topic is vast,

for the purpose of this thesis the following five topics will be discussed: History, Educational Leadership, Communication, Structured Sessions with High Expectations and Relations with Partners. Although this is not an exhaustive listing, these are five common themes seen in the literature (Reynolds et al., 1996).

2.6.1. History

One of the seminal reports on school effectiveness was conducted in the United States in response to President Johnson's War on Poverty in the 1960's. Coleman's (1966) study was designed to identify the extent and sources of inequality of educational opportunity among six racial and ethnic groups. It concluded that a largest influential factor on school performance was the family background characteristics, showing a stronger relationship than any school factors (Coleman, 1990; Scheerens, 1992; White et al., 1997).

Later research concentrated on what factors schools could influence (Edmonds, 1979). Although showing that the home environment had a large effect, the Plowden report (Central Advisory Council for Education, 1967) did not draw such drastic conclusions and showed that schools had control over factors that could influence educational outcomes of children. Brookover (1979) also concluded that schools could make a difference. Recent research agrees and shows that teacher variables could be more important than home (Dean, 2001) and confirmed the desire to establish characteristics that would determine the effectiveness of an individual school (Silver, 1994). The problem that exists is devising a 'listing' that fits for a school.

The listing has in the past typically been defined in terms of quantitatively measured outcomes (Davies, 1997). For example, Rutter (1979) used exam results and truancy rates as two of his determining factors. The practice by the government of publishing exam results is another example of this.

The search to define specific factors is not a simple procedure (Huse'n, 1979). Problems exist when defining measures. Most rely on some form of standardized testing, even if other factors are included (See for example Beare et al., 1989.; Murgatroyd et al., 1994; Silver, 1994; Morrison, 1998). Frequently these measures are not the same as those of the wider school community and 'cannot provide

accurate information about the contribution of a school' (Sammons et al., 1997, p. 131).

Broad qualitative outcomes as suggested by Davies (1997) and Edmonds (1979) can be an alternative. Many of these are cost free and in control of school heads (for example: firm leadership, positive reinforcement, defined goals, good relationships with pupils and parents). Therefore this literature review will concentrate on some of the qualitative factors that are mentioned by several of the authors cited above. This author recognises the difficulty in discussing each topic as a separate entity, as these factors do not exist independent of each other. To aid the discussion, the following four categories were chosen due to the fact that they were cited by several authors: leadership, communication, structured sessions with high expectations, and relations with outside partners.

2.6.2. Educational Leadership

The issue of strong leadership is a frequent theme in the literature when defining successful schools (Mortimore et al., 1988; Beare et al., 1989). Sammons (1997) states, 'Almost every single study of school effectiveness has shown both primary and secondary leadership to be a key factor.' (p. 89). Scheeren's (1992) review of the research found that of the 18 studies he explored, all 18 concluded the importance of strong leadership in determining effective schools (p. 50). He clarifies this point further by distinguishing effective school heads from average ones by being actively involved with the teaching process, both with pupils and teachers alike. This is not only true of established 'successful' schools, but seen as critical in advancing schools that could be defined otherwise. Strong leadership (especially from the Head) is essential to turning around schools that are 'failing' (The Economist, 2000).

2.6.3. Communication

Clear two-way communication is seen as another essential element of an effective school (Rutter et al., 1979; Mortimore et al., 1988). Unambiguous communication allows staff to successfully accomplish some of the characteristics of effective schools such as shared vision and agreed purpose, positive reinforcement, involving staff in decisions, and also allows for agreement among practitioners regarding the practice

and enforcement of rules (behavioural issues or school rules) (Sammons et al., 1997). All staff must be able to share their ideas in an environment that supports this as good communication can reduce resistance to change and increase teamwork (Morrison, 1998).

Strong leadership and good communication are closely linked. A good leader is also an effective communicator. He or she can efficiently share their ideas and ideals with their team. Skilled communication allows the leader to convey their vision for the school with all partners, who will be allowed to debate and take on board that vision. This is a key aspect of a successful school (Bennett, 1995).

2.6.4. Structured Sessions with High Expectations

Recent research identifies the fact that children learn best when teaching is done in an organised and purposeful way (Rutter et al., 1979; Mortimore et al., 1988; Tizard et al., 1988). Children should be given guidance and allowed some freedom within those guidelines (Reynolds et al., 1996). This also goes hand in hand with a high expectation from the part of the teaching staff that children will perform to a high standard. The belief that children will do well, contributes significantly to the success of individual children and, consequently, to individuals. 'Quality of teaching is at the heart of effective schooling.' (Sammons et al., 1997, p.103).

2.6.5. Relations with Outside Partners (Parents, agencies)

Individual schools do not exist in a void. The very nature of schools is such that they are public institutions (i.e. funded by outside resources either on a fee basis or by government monies). Schools have participant players from outside partners that have the right and responsibility to have a voice in the success of an individual school (Bennett, 1995). These partners can be both parents as well as governmental agencies.

Parental involvement is a key element of successful schools (Mortimore et al., 1988). The link between the pupil's home background and their school performance was one of the key findings of the Coleman (1966) research (see Section 2.6.1.). Although later research revealed other critical factors that could influence school performance

(particularly the high expectation of school staff for students to achieve) the influence of the home environment is still seen as significant (Central Advisory Council for Education, 1967; Edmonds, 1979). Dean (2001) makes a strong case for schools to do more to ensure a strong partnership with parents.

Outside agencies also have an important role to play. The most notable among these is Ofsted (2002). Regular monitoring of schools by an independent agency is key to providing checks and a balance on the educational product a school is offering.

2.6.6. Summary

The last four categories may appear obvious to outside observers. They are included to demonstrate that school effectiveness literature supports the claim that qualitative items evidence school effectiveness. This partial listing shows skills that schools can work towards improving. It is also shown in the literature to have an effect on the quality of their provision.

What is absent from the literature are the following:

- Application to the field of autism education. The literature describes general categories of either primary or secondary schools. It does not specifically apply this data to specialist schools.
- The frequent use of qualitative measures to demonstrate effectiveness. Discrepancies exist between school effectiveness research that is quantitative in nature and school improvement facilitators (seen in articles and books) that are qualitative in nature (Scheerens, 1992 p. 103).
- The evidence of the above factors in an individual specialist school. Can these be applied as indicators to highlight successful practice?

2.7. Types of Visual Strategies

The final topic discussed in this literature review addresses the main focus of the action research in the case study. The aim of the action research was to promote learning by the children at St. Joseph's school through the use of visual strategies. Therefore it is appropriate to review the research literature on this topic. For the

purpose of this thesis, visual strategies are defined as teaching techniques that incorporate instruction that can be seen in addition to a limited spoken direction.

There are two major groups of visual strategies: those that rely primarily on movement or gesture (Sign Language) and those that involve external materials (PECs-Picture Exchange Communication System, TEACCH-Treatment and Education of Autistic and related Communication handicapped Children or Nina Lovaas' Reading and Writing Programme). This section will briefly describe four widely used visual systems (see Figure 2.1.) and then compare the attributes of each. It is important to note that each system has its proponents and opponents. It is not the purpose of this thesis to engage in an in-depth discussion on the arguments involved in this debate, but to briefly describe each system (Bonvillian et al., 1981; Donnellan, 1985; Mesibov, 1997; Lovaas et al., 1999-prepublication copy).

<u>Movement based:</u>	<u>Materials based:</u>
Sign Language Gestures Facial Expressions	Reading and Writing Programme TEACCH PECs (Symbol Systems)

Figure 2.1. Visual Systems in Schools

2.7.1. Movement Based Systems

Most of the literature discussing the use of sign language to help children with autism dates from 1970's and 1980's (Fulwiler et al., 1976; Salvin et al., 1977; Kiernan et al., 1982). Research based in the United States saw it primarily as a way to encourage speech in children who did not have spoken language (Benaroya et al., 1977; Carr, 1979; Yoder et al., 1988). The UK system of Makaton was initially used to address the needs of the hearing impaired. It is now used in special educational classrooms as a means to improve communication in learning disabled children, as well as autistic children (Walker, www.makaton.org/). Makaton is a series of hand movements (which are sometimes also represented as icons as well), each depicting a concept or idea. The communicating partner makes these hand movements when communicating ideas or concepts to the child. The child can also make them to respond.

In addition to sign language, gestures and expressions are also frequently used when communicating. These can vary from pointing a finger at a critical item (e.g. pointing to a chair when wishing the child to sit down) or a facial expression to indicate a concept (e.g. smile, to show that the communicating partner was pleased with the work of the child).

2.7.2. Materials Based Systems

The three main materials based systems are TEACCH, Nina Lovaas' Reading and Writing system, and PECs (or other icon based systems).

TEACCH is based on the work of Eric Schopler at the University of North Carolina, Chapel Hill. It is a state-wide programme designed to meet the needs of autistic individuals throughout their lifetime. It is built on the premise of adapting the environment to accommodate the deficits of the child. It structures the child's world through the use of pictorial schedules to visually represent events in the child's day or steps necessary to complete a task. It also alters the child's space by having specific areas of the classroom for specific tasks (i.e. workstations for individual work, areas designated for group activities) (Schopler et al., 1982; Schopler et al., 1995; Mesibov, 2000).

N. Lovaas' Reading and Writing programme also uses written pictures to communicate with children. In addition, it teaches the child to read words by matching these with the pictures. It does this both receptively and expressively and then eventually leads to having the child write (or type) as a means of communicating his or her thoughts (Lovaas et al., 1999-prepublication copy).

The last of the materials based systems is PECs. Designed by Bondy and Frost(1998), PECs is a system using small cards to represent items the child wants and desires (favoured toys or food items). The child is encouraged to take the card to the communication partner as a way of requesting the item. The adult gives the item to the child in exchange for the card. Once the child understands how to access desired items, the system is used to teach concepts or other abstract ideas (Bondy et al., 1995).

Each of these systems discussed above is generally based on behavioural theory, pairing the successful completion of a task with something that is desired by the child. The use of socially acceptable reinforcement after a completed task is believed to increase the likelihood of the task being completed successfully again (Romanczyk, 1996). The value of social reinforcement to autistic individuals is a topic that has generated some debate. Briefly, it centres on the value of social reinforcement for children afflicted by an ailment that is distinguished by deficits in social awareness (See Chapter 2 for discussion). It must be kept in mind that autism is a spectrum disorder, and that individuals affected have variation in both the degree and specific discrepancies within the Triad of Impairments (Wing et al., 1976). It is beyond the scope of this thesis to go into an in-depth discussion on this topic, but would refer the reader to some of the works by Jordan or Howlin (Howlin, 1997a; Jordan et al., 1998; Jordan et al., 1999b).

2.7.3. Visual Systems Compared

Each of the systems listed above has advantages and disadvantages and these must be matched with the strengths and needs of any individual child. It is helpful when comparing them in reference to an individual child, to investigate the following points:

- Primary purpose - All children need to have their educational as well as basic needs met, but does the particular child have greater needs in one or the other?
- Responsibility of the main communication partners - Does the system selected assume that others also understand it? If sign language is chosen, do close family members understand it?
- Generalisation - Can the chosen system 'grow' with the child as he or she begin to become competent in it?
- Independence - How practical is the system in the community? Is the child likely to be in an environment where he or she is dependent on others to understand this system?
- Self-stimulatory behaviour - Some of the materials based systems are Velcro based which can be an issue if the child likes to flick or flap items. Sign based

systems may also be problematic if the child frequently uses his or her hands inappropriately.

- Preparatory work - This varies quite a bit between systems. Some of the materials based systems are dependent on others continually making new materials. Signing systems need others willing to learn sign language.
- Expense - In addition to keeping current with new icons, materials can become worn which will add to the overall cost of materials based systems. Training in all visual systems is also a cost factor.

These factors are used to compare the visual systems in Figure 2.2.

	Visual Systems			
	Sign Language	Reading and Writing Program	Symbol system	TEACCH
Initial primary purpose	Communication	Educational	To get primary needs met	Educational
Fine motor skills of the child	Fine motor dexterity necessary	Minor amount needed	Minor amount needed	Minor amount needed
Responsibility of main communication partners (CP)	-Must be knowledgeable of sign system -and often child's 'own' signs -Need to be attentive to any communication attempts by child	-Create and maintain repertoire of words -Must be literate	Create and maintain repertoire of symbols	-Create and maintain repertoire of symbols or pictures -Adaptation of environment
Generalisation	-With other signing partners using the same sign system	-Can be slowed down due to grammar rules -Can lead to writing or typing	-Dependant on access to symbols -Symbol can be too general (General Crisp symbol versus Hula Hoops symbol) for advanced work	-Environmental adaptations can restrict generalisation -Structures can be generalised to new settings
Independence	-Difficult with general public -Not dependant on access to external materials	-Easily understood by general public -In some stages, dependent on access to external materials	-Easily understood by general public -Can be too general -Dependent on access to external materials	-Set routines can increase independence -Child can become dependant on routines
Self stimulatory behaviour	-Interferes with some signs	-Materials need to be adapted	-Materials need to be adapted	-Materials need to be adapted -Environmental adaptations?
Preparatory work	-Training	-Training -Make materials	-Training -Make materials	-Training -Make materials
Expense	Communication Partner (CP) training -Manuals	-CP training -Manuals -Ongoing materials to create and replace cards (Velcro/ laminating paper)	-CP training -Manuals -Ongoing materials to create and replace cards/book (Velcro/ laminating paper)	-CP training -Manuals -Ongoing materials to create and replace cards (Velcro/ laminating paper)

Figure 2.2. Visual Systems Compared

This section described the various types of visual strategies and the unique aspects of each. It also discussed the factors considered when choosing a specific method for an individual child. Chapter 4 will further describe the use of this with the children in the action research.

2.8. Chapter Summary and Identified Gaps

This chapter has highlighted the current and historical works pertaining to the field of autism and school effectiveness research.

First, it showed the very limited areas of agreement among clinicians and practitioners in the field of autism education. These included the agreement that Kanner was the first to use the term 'autism' to describe this population, the need for early intervention and the use of the Triad of Impairments to describe this population.

Secondly, a greater discussion is on areas of disagreement. Defining the best educational approach or way to work with this population has generated copious amounts of written work and research discourse. The cause or even the actual number of children and adults affected is uncertain.

Third, the review of the literature revealed the lack to research into the views of the three main partners (school, parents, LEAs) on the process of securing appropriate provision for a child.

Last, school effectiveness research was examined. Based on the current and historical studies, a partial listing of four topics (common to most of the prevalent research in the field) were discussed. These were leadership, communication, directed teaching and positive relationships.

This search through the literature has also flagged some important issues that will be investigated for the first time in the balance of this thesis. The research question directs us to look at the process of securing educational provision for children with autism. The tensions and dilemmas that exist are of particular interest. Including:

- There are a large variety of approaches to educating or helping children with autism, but very little consensus on which method or methods are best suited to meet the needs of children affected by the hugely differing outward presentations

of this ailment. As a spectrum disorder, individual children can have very different areas of difficulty, but still have autism. This lack of consensus among both practitioners and parents about the best way to address a child's difficulty can impede agreement on the best approach for an individual child.

- The cause of autism is unknown. Researchers, practitioners and parents may disagree on the cause of autism in a child and therefore how best to address the child's needs. The personal beliefs of those in the decision-making positions can direct provision decisions towards those beliefs. If other partners (School, Parent, or LEA) disagree, the process of agreement can be impeded.
- The view of the participants (schools, parents, LEAs) on the process of determining educational provision is not known. There are anecdotal reports from parents (seen in literature distributed from charities and popular press), but this is not evidenced in the research. The view of a school and LEA has not been the subject of research, and is therefore largely unknown.
- Although the number of individuals with autism is increasing (be it real or perceived) how is this translated into the actual experience of arranging educational provision for an individual child? This issue has a fundamental impact on the planning and resourcing provision, but has not been addressed in the literature.
- Although the literature on school effectiveness is vast, its scope is frequently quantitative in nature and lacking application to a specialist school meeting the needs of a very narrowly defined population of students.
- What are the implications of this for the individual with autism? Bertalanffy's (1968) work (see Chapter 3) on systems theory provides the theoretical underpinnings for this thesis. It is therefore appropriate to explore the contributions of those in the child's ecosystem to discover the impact on the child.

These are the gaps that will be addressed in the balance of this thesis. Specifically, it will look at the issues surrounding securing and maintaining appropriate educational provision from the perspectives of the three main players: an individual school (Strand 1), parents or carers (Strand 2), and LEAs (Strand 3).

Chapter 3 - Methodology

In this chapter a range of theoretical and methodological issues relevant to the research question will be considered. Many of these emerged from the literature review (see Chapter 2), from early discussions with St. Joseph's School and the researcher's previous discussions with parents. This chapter will investigate each of these and outline the considerations made when methodologies were chosen.

This chapter explores the research paradigm used for this thesis. It will start with a brief look at Systems Theory (Bertalanffy, 1968) and its application to this research. Next it will discuss the issues considered when determining an educational research project including the three main methods used for this investigation: interview, case study (including action research) and survey. The discussion continues with a look at each of these methods and how they relate to the research question and current researcher's views on any limitations of these three methods. Validity and reliability are considered next. The chapter ends with a review of triangulation.

3.1. General Systems Theory

Bertalanffy's (1968) original work in General Systems Theory started as an effort to address a concern he had in the research and theory of biology. His concern stemmed from the failure of the accepted approach (at that time) to accept the culture of an organism when investigating it. In contrast he, 'advocated an organismic conception in biology which emphasizes consideration of the organism as a whole or system, and sees the main objective of biological sciences in the discovery of the principles of organization at its various levels' (p.10).

Since its initial descriptions, Bertalanffy's ideas have been applied to other areas (Rapoport, 1986). General systems theory provides a broad theory of organisation that is applicable to a wide variety of fields (mathematical, social, scientific etc.).

In the case of this research, the research question directs investigation into the provision of appropriate education for children with autism. The child is central to this. Systems theory provides a useful tool toward increased understanding this process. It presupposes that the child is at the centre of a 'system' and that there is a

dynamic order of 'parts and processes standing in mutual interaction' (Bertalanffy, 1968, p.220). It furthers our understanding of the process of determining provision by investigating the tensions and dilemmas that exist in the two-way flow of influences that occur between individuals and intuitions in a child's environment. These interactions and influences constantly provide feedback within the system to create the fluid concept of a physically and academically maturing child. This two-way causality is a key feature of this model (Bronfenbrenner, 1979). Although the autistic child is central to the model, the interactions with and between the child and others in his or her environment are an essential element of this research (see Figure 3.1).

Each individual or institution interacts with the other elements in the system. Each brings its own history and unique characteristics with it. These intermingle in the form of transactions to produce outcomes. These outcomes are in the constant process of change under the influence of feedback that continually updates the process. It is this process, the interactions between the individuals or institutions that are of interest to this thesis. In particular, unique perspective of the three main participants (school, parent and LEA) on the tensions and dilemmas inherent in the process of determining appropriate educational provision for a child with autistic spectrum disorder.

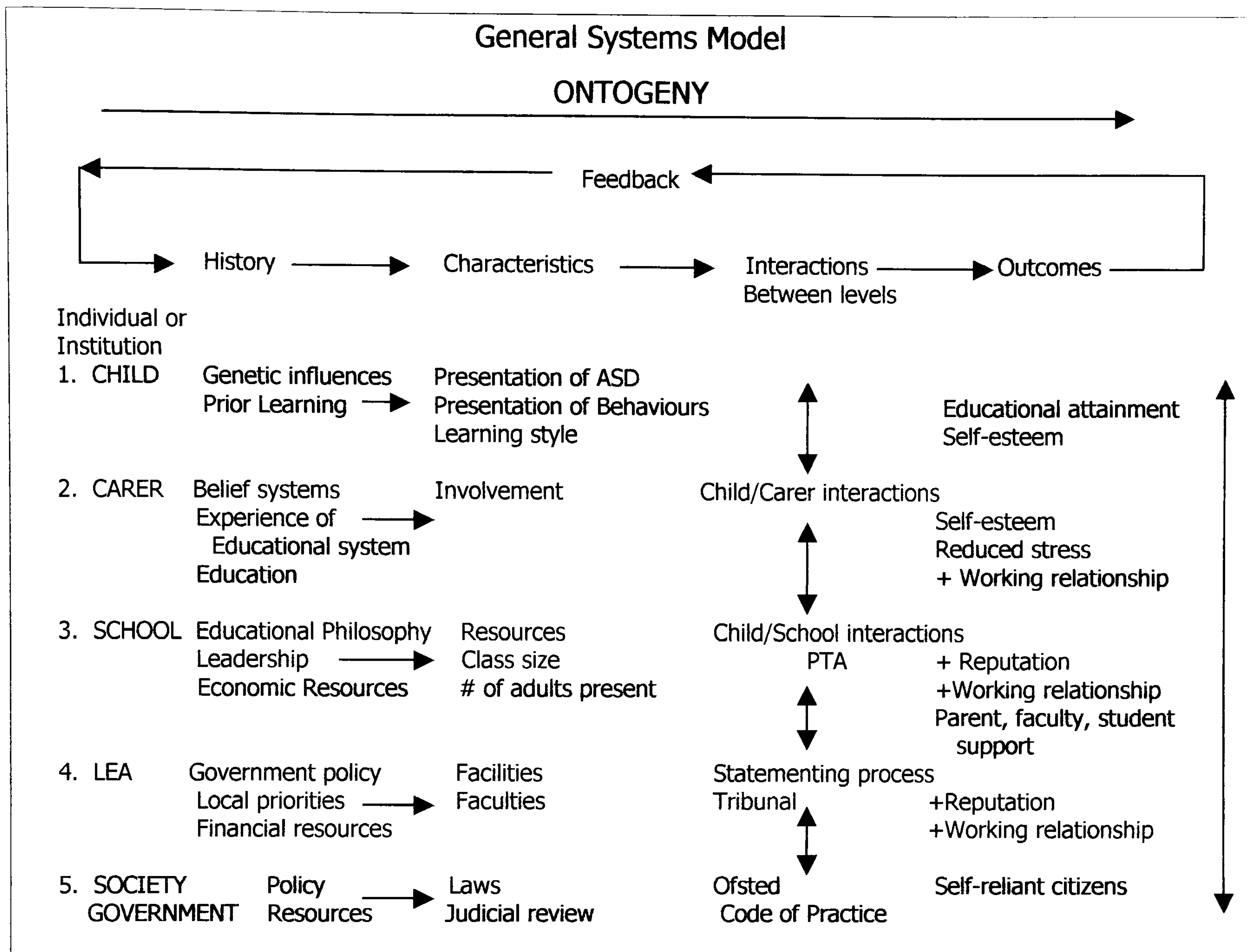


Figure 3.1. General Systems Model for Educational Provision

3.2. Methodology

When determining the methods used for research, it is essential to look again at the research question and theoretical perspective to tease out of it the aspects that hope to be gained by answering the research question (Crotty, 1998). Simply put, it is then a question of matching these aspects with the type of methodology that best addresses them in terms of both nature and analysis. This in turn leads to a method that supports the epistemology, theory, and methodology. In this research, a better understanding is sought of individual experience in relation to the concepts and events leading to personal interpretation of appropriate educational provision. This operates at the level of school/classroom, home and educational authority (LEA). Second, to explore the implications for the individual with autism.

At this point, a very brief review of educational research methodology is warranted. Research begins with an epistemology (theory of knowledge in the theoretical perspective) and theoretical perspective (philosophical stance) (Crotty, 1998). In this

research, constructionism is the epistemology that informs the theoretical perspective of phenomenology. As previously described above, (see Figure 3.1) the interactions that produce tensions and dilemmas between members of the child's environment are a key aspect of this research and a means of addressing the research question.

Phenomenology embraces 'the study of direct experience taken at face value' (Cohen et al., 2000, p.23). It advocates going to the source to obtain knowledge and not being too heavily reliant on outside influences. It has several elements that are key to exploration of the research question.

It is seen to embrace the multiple realities that exist (Hamilton et al., 1977). Silverman (2000) highlights the importance of this as it relates to educational research. He feels that the world is defined by an individual's unique experiences, resulting in a personal view. This aspect is to be embraced, and is critical when investigating educational research (Creswell, 1994). Second, it is seen as based on real world experience, and exploring the individual views on that experience (Hammersley, 1992). Third, it allows the use of any techniques to explore what is happening and give evidence to illuminate this.

The next step, to determine the research method, is again related directly to the research question. Continually revisiting the research question reveals the many layers that compose it. At first glance, although there are three strands (school, parent and LEA), the concept of 'individual experience' is universal to all three and most apparent. Following along, the next layer could be to attempt to 'get underneath' the experience and look at it in terms of the interactions that take place between these individuals and institutions. The third layer, and perhaps the most challenging is to analyse the recurrent themes both in terms of members within the same strand, as well as between strands and then relate them to the child with autism.

It is important to also note that this research involves the experiences of individuals in the lived 'world'. To investigate this 'world' an appropriate method has to be employed to enable an individual person to generate their personal story and account of events (Hamilton et al., 1977). In addition, a method is needed to enable the researcher to make 'sense' of the different stories told. Language is not economical.

Words have meanings that have been acquired by the individual through personal experience in a cultural context. See for example the works of Heidegger (Collinson, 1987; Rosen, 1998). Whilst some experiences are shared within a wide social group, some are familial, and some intensely personal. The meanings, which individuals attribute to 'words', are a complex composite of public and private interpretations (Kvale, 1996). Public meanings may be said to reside at the intersection of different interpretations. Private meanings are a reflection of the complexity of an individual's cognitive and emotional representations of lived experience. It is this aspect of the individual experience that this research is interested in investigating.

Each of these layers has aspects that lend itself to one method or another. It is therefore necessary to take a closer look at these methods in terms of current practice both in published studies as well as methodological textbooks; but also keep in mind the limitations posed on any individual study of social science. Cohen, Manion and Morrison describe this process as a 'fitness for purpose' (2000, p. 73); matching the research paradigm with the research purpose and research question. Most importantly, the research question and theory determine the method. 'The problem defines the methods used, not *vice versa*.' (Hamilton et al., 1977, p. 13).

3.3. Primary and Practical Research Points

As stated above, this researcher is interested in investigating the experience of the individual, whether that is an employee of a school, an LEA professional or individual parent regarding educational provision for their autistic child.

The individual's views, experiences (both present and past), and future outlook are seen as defined by their world (Silverman, 1993). It is important for this research to allow the individual person the freedom to explore these concepts, in a context conducive to that. Having defined the research question, in the first instance, as an exploration of the views of personnel toward achieving their vision of appropriate educational provision, there is a defined scope to the broad area in question. In other words, this research narrows the field to focus school staff on the issue of interest: the research question. Consequently, this also has an effect on the choice of method used.

The next step is to investigate the types of research strategies available and match this with the points discussed above. Several points were considered essential when investigating a research method (See Figure 3.2.).

1. Ability to relate personal experience on the topic
2. Ability to freely explore individual views on the topic
3. Ability to include the natural environment as an influence on this topic

Figure 3.2. Primary Research Points

In Strands 1 and 3, the decision to use words to generate data was based on the three areas (staff views, staff environment and staff experiences) deemed essential for the research. This researcher wanted to allow school and LEA staff the opportunity to tell their story in their own words in the easiest way possible for them. Therefore several practical characteristics were also considered (see Figure 3.3.).

1. Time limitations (especially senior staff)
2. Convenience for individuals to respond
3. Ease of completion
4. Opportunity of the researcher to explore issues with the individual
5. Accuracy of account
6. Anonymity of staff/parent
7. Rate of return

Figure 3.3. Practical Research Points

The views of senior staff, middle management and teaching staff were all seen as essential in understanding the way a particular school puts its view of appropriate provision into practice. This was also the same for individuals within LEAs. Therefore, a method had to fit not only the research question and goals of the research, but also the practical limitations that exist when working with any individual from any given institution as well as the analysis. According to Kvale (1996), content and purpose precede method (p. 95). In addition, the researcher 'tries to make his/her data gathering compatible with the study population's other commitments.' (Baszanger et al., 1997). The practical limitations must also contribute to this decision making process.

Keeping both the three primary and the seven practical points in mind for this investigation into the first and third strands, these characteristics fit well with phenomenological research.

The issue explored in these two strands (1 and 3) is the staff's view of how they achieve appropriate provision. It aims to look at this in the context of their experience, their environment and their emotions and focus on this process without the limitations or restrictions of some of the quantitative methodologies. This research focuses on understanding the interrelationships that exist (Stake, 1995), and as such places its emphasis on words rather than numbers (Miles et al., 1984) to generate the data for this area of analysis. These factors led this researcher to look more closely into ethnography, which investigates data generated through social texts: spoken, transcribed, or detailed event descriptive language (Denzin, 1997).

3.4. Ethnography

The field of ethnomethodology explores an individual's account of everyday activities (Garfinkel, 1967). It investigates how an individual attaches meaning to commonsense knowledge (Leiter, 1980) and looks to better understand the unique way that an individual establishes that meaning. Denzin (1997) describes ethnography as 'that form of inquiry and writing that produces descriptions and accounts about the ways of life of the writer and those written about.' (p. xi). In general, ethnography studies the real lived world of the individual by investigating it through the individual's 'structured units of experience' (Bruner, 1986, p. 7) or spoken and written descriptions of events. (Denzin, 1997).

3.4.1. Ethnomethodological Commitments

Some of the early ethnographic studies were very detailed accounts of a process that an individual(s) went through and the meaning that process had for them (see for example Garfinkel's (1967) description of Alice's sex change operation, (Hargreaves, 1967) description of a secondary school or (Rutter et al., 1979; Wragg, 1979) for a description of schools). Although the scope of this thesis is beyond a very detailed individual investigation into one specific area, there exist several characteristics of ethnography that match the previously outlined essential points of the research

question (see Section 3.2.). Handel (1982) identifies two 'commitments' that ethnomethodologists make. It is therefore necessary to take a closer look at these two (reflexivity and indexicality) and relate them to the research question.

3.4.1.1. Reflexivity

Reflexivity is defined by Leiter (1980) as 'a product of social phenomena that makes...social facts the product of interpretation.' (p. 138). In other words, the way an individual researcher interprets a situation is based, in part, on the individual experiences and orientations that they bring with them (Hammersley et al., 1995). The two aspects are linked. The individual and the meaning derived from their world are seen as overlapping. The 'world' of the individual gives meaning to the talk and behaviour in it, and at the same time, the 'world' is given meaning by the those same factors (Leiter, 1980). Because an individual defines something as real, it is real to that individual (Handel, 1982). It is this aspect that is of interest, the individual views or private meanings that this research wishes to explore.

The world is fluid, and is constantly changing which has an impact on the shared meanings of society as well as the individual private meanings of each person (see Figure 3.1.). This is true of research as well. Research is an active process; the representations presented are the result of items noted by the researcher, which have been deemed interesting or useful by that researcher (Hammersley et al., 1995). These observations and notes need to be recognised as being influenced (to some degree) by the past experiences and thoughts of the researcher (Coffey, 1999).

How does this relate to the research question? Reviewing the three main methodical concerns for this investigation, (see Figure 3.2.) Points 2 and 3 identify this aspect as critical for the research. All individuals must be allowed the opportunity to freely explore their views, within their natural environment. This is seen as essential for the staff to relate their views on the research topic. The staff need to be able to share their views on appropriate educational provision within their own environment and 'world' since it is this that has helped shape their view.

In addition, this researcher embraces the active process of this research. This researcher acknowledges self-involvement in the research process (Maturana, 1991) and welcomes the opportunity to investigate the beliefs of others (Coffey, 1999). It is

the reflective nature of the research question that is of interest, and critical to understanding the different perspectives of appropriate educational provision. The different individuals, each with different backgrounds, ideas, perspectives and expectations bring unique contributions to the research at hand. Working with this aspect is critical to this thesis.

3.4.1.2. Indexicality

The second characteristic of ethnography as identified by researchers is the concept of indexicality. Defined as something that can hold different meanings in different settings for different individuals (Handel, 1982), it is also seen as a critical aspect to ethnographic research. Meanings are seen as 'practical accomplishments' (Bogdan et al., 1975, p.16) that individuals obtain. These meanings may have different definitions for different individuals, or they may be shared (Cohen et al., 2000). What is important to ethnographers is the investigation into that meaning as integral to the research and the 'world' of the individual (Agar, 1980). The meanings given must be accepted as true for the individual at that given time and place.

How does Indexicality relate to the research question? Again drawing the reader's attention to Figure 3.2, Point 2 states that school and LEA staff need to be able to freely explore their views on appropriate educational provision. This allows for individual views and does not assume that other individuals working in a similar setting will share the same views. They may have similar views on the research topic, or they may have strongly opposing views. The use of ethnographic methods allows the research to explore these questions in a format that encourages individuals to freely define their own views.

In conclusion, the two critical elements of ethnographic research (indexicality and reflexology) are strongly linked to the three crucial elements identified as integral to the research question.

3.5. Interviews

Keeping both the practical needs of the individual staff involved as well as the goal of the research in mind, several methods of data collection were chosen for investigation into the three strands. The first of these is the use of a semi-structured interview

with staff members of an individual school (Strand 1) and LEA representatives (Strand 3). This type of qualitative research is defined by Kvale (1996) as 'a sequence of themes to be covered, as well as suggested questions. Yet at the same time there is an openness to changes of sequence and forms of questions in order to follow up the answers given and the stories told by the subjects' (p. 124).

In the current body of educational research, the use of an interview to gain data is well established. 'Interviewing provides a way of generating empirical data about the social world by asking people to talk about their lives.' (Holstein et al., 1997, p. 113).

Although the use of a semi-structured interview is frequently used to investigate the thoughts of individuals or parents of children with autism (see for example Mesibov, 1997; Howlin et al., 1997b; Vostanis et al., 1998; Randall et al., 1999; Howlin et al., 1999a; Weiskop et al., 2001), its use with teachers or other staff members involved with autism, is not as common. When this research does exist, (see for example Helps et al., 1999; Mavropoulou et al., 2000) researchers tend to choose the use of questionnaires as their primary means to gather data. There are few examples of the use of interviews with teaching and other staff, specific to the area of education of individuals with autism.

Contrary to what is most frequent in published research in the field of autism, this researcher chose not to follow the example of Mavropoulou (2000) and Helps (1999) in this section of the research for several reasons:

- The research question is concerned with investigating the personal experiences of school staff in the 'real world', it was felt that the semi-structured interview better met this objective.
- This researcher was concerned not to impose a detailed agenda but rather to facilitate its emergence. The use of a semi-structured interview allowed this flexibility.
- There is also the need to allow the individual to freely explore their individual ideas concerning their environment, emotions and experience. It was felt the semi-structured interview supported this aspect.

These three points highlighted some of the strengths of the semi-structured interview. These strengths must be matched against the previously listed practical limitations on staff and staff time as well as the limitations that exist on any one particular type of research. In other words, the ability of staff to explore their own personal views and environment, fit well with the relative openness of a semi-structured interview format (Kvale, 1996).

But what is still needed is a look back at the research question and identified Primary Research Points (see Figure 3.2.) and Practical Research Points (see Figure 3.3.) to see how these match Cohen, Manion, and Morrison's (2000, p. 73) idea of 'fitness for purpose' regarding the use of a semi structured interview. A further look at the three Primary Research Points and the Practical Research Points is necessary. In addition, the next section will match them with the method chosen.

3.5.1. Interview as it Relates to the Research Criteria

The nature of the semi-structured interview allows flexibility and enables the interviewer to pursue items that may not have been included in a set schedule of a structured interview or questionnaire (Kvale, 1996). It is this flexibility that helps address the first of the Primary Research Points (see Figure 3.2.). Staff must be allowed to freely explore their personal views on the research topic. By providing a structure (research question), yet allowing those interviewed some freedom for exploration, the semi-structured interview met the first criterion.

The second criterion, staff ability to include their natural environment, is also linked to the semi-structured interview. This researcher wanted to make sure those participating in the research felt able to openly discuss the research topic. Therefore, it was deemed essential that those involved had the opportunity and support of their natural work setting. Times were arranged in advance, and with the support of senior staff, a private, quiet setting was arranged.

The third criterion, staff ability to relate their personal experience was also seen as better addressed in an interview. It is designed to allow the maximum flexibility to ensure those interviewed have the opportunity to discuss and develop areas that they consider relevant to the research topic. There is no set agenda, and this allows the individual the ability to explore their individual understanding of the research question

and how it relates to his or her personal experience. The semi-structured interview also enables the researcher to probe areas for clarification or of particular interest. These aspects are seen as critical and can potentially be lost in other forms of data collection (for example a questionnaire).

The Practical Research Points (Figure 3.3.) are also addressed in this format. The first three of these deal with real life practical limitations of time on members of any staff. The senior staff in particular have many demands on their time, and research interests unfortunately rank low in many cases. To overcome this, an efficient way of collecting data, that was not overly time consuming or placing an undue burden on the staff was needed. An interview could be conducted in less than one hour, without the staff having to write anything at all.

The fourth issue, the ability of the researcher to explore issues of interest to the research question, yields itself again to an open framework of the semi-structured interview. The researcher can ask for clarification or check an understanding of a particular aspect. This can sometimes be lost on a questionnaire. The fifth issue, accuracy of account also relates to this same point. Meanings can be checked in an interview, which might have been misinterpreted in a questionnaire.

The next issue is the confidentiality of staff. Staff need to feel comfortable with the researcher and free to discuss what can be difficult issues. Anonymity is one way to accomplish this and no transcripts were shown or discussed with other staff members. Closer investigation into the specific setting chosen (a specific residential school), the number of interviews requested (three) and the position of those interviewed (founder, senior staff, and teacher), the responses generated could very well indicate the staff responding anyway. Instead, other methods were chosen to reassure staff that their responses would be kept confidential. All interview transcriptions were done by the researcher and only shown to the individual interviewed, to check for authenticity. Topics discussed were consistent across interviews, but specifics were not relayed to anyone else. This was a condition of each interview and faithfully adhered to by the researcher. Those interviewed were assured that topics discussed in this thesis would not be linked to them directly, and all names and identifying details altered. In addition, the final thesis will have restricted access.

The last issue, rate of return is also increased by use of an interview. The researcher can assure that the interview is conducted (or rescheduled if needed).

The use of a semi-structured interview was seen as appropriate for both the primary and practical reasons identified. It met the main requirements of the research. It does however, have some limitations. These are described in the next section.

3.5.2. Interview Limitations

Research methodology is never a perfect science. There are always some limitations present whenever research is put into practice (Silverman, 2000). This is especially true when conducting research in the real world, as this research is. In such, it has to accept some limitations of various chosen methods. Some of these in relation to the semi-structured interview are listed below (see Figure 3.4.).

1. Subjectivity of individual respondent.
2. Lack of uniformity.
3. Subjectivity on interpretation of data.
4. Error

Figure 3.4. Limitations of the semi-structured interview

The first limitation is defined as the subjectivity of an individual respondent. This is described as the bias of opinion of the individual being interviewed. When conducting an interview, the very nature of it is to request a clarification of the opinion of the person interviewed. Therefore, what the interview does is generate the interviewee's opinion of specific topics or themes. Consequently, the interview can be defined as the individual's views. Is this really a limitation? Kvale (1996) sees this dilemma from a different perspective. He states, 'In fact a strength of the interview conversation to capture the multitude of subjects' views of a theme and to picture a manifold and controversial human world.' (p. 7). Silverman also shares this view when he states that the actual bias of the data generated should be celebrated (Silverman, 2000).

This researcher agrees with both these researchers, and again refers the reader to the Primary Research Points (Figure 3.2.). Seen as critical to this investigation is the desire for those interviewed to freely explore their views (Point 2). Although individual opinions could be seen as a limitation to the use of a semi-structured interview; in this research it is deemed essential.

The second issue identified in Figure 3.4. is the lack of uniformity of the interview. The nature of the semi-structured interview is such that although themes are determined by the research question, discussion varies from individual to individual as comments are explored. Kvale (1996) feels that this can yield a different focus to each individual interview, even if the shift is only a slight one. Oppenheim, (1992) takes a different perspective on this point. He states that the real issue is 'stimulus equivalence' (p. 86) or the requirement that the interviewer ensure that those interviewed should understand the question in the same way as every other person interviewed. This is the definition that this researcher chooses to acknowledge in regards to the interviews. In other words, although there were inevitably some differences in specific wording of concepts covered in the semi-structured interviews, the concepts themselves remained consistent across the interviews conducted.

The last two areas of limitation listed in Figure 3.4. (Subjectivity and Error) are areas that are present to some extent or another in all research (Cohen et al., 2000) and consequently are present in semi-structured interviews as well. Unlike the first two, where the differences can be embraced as an essential part of the semi-structured interview, these last two points need to be acknowledged and consciously dealt with to ensure that the research undertaken can be considered robust by others in the field. Therefore, it will form part of the discussion around the broader topic of validity and reliability and dealt with in depth in Section 3.8. As these topics will also relate to the use of a case study and questionnaire (as in Strand 1 and Strand 2), the section on validity and reliability will follow the sections discussing the use of a case study and the questionnaire.

3.6. Case Study

In addition to using the semi-structured interview as a means of exploring the views of school on the notion of appropriate educational provision, a single classroom case study was also used. This section of the thesis will therefore focus on defining what is meant by a case study (and action research undertaken as part of the case study), relating its use to the Primary Research Points, both in terms of its 'fitness of purpose' (Cohen et al., 2000, p. 73) and limitations, and finally looking at current educational research in this area.

Hammersley (1992) defines a case study as, '...the phenomenon (located in space/time) about which data are collected and/or analysed, and that corresponds to the type of phenomena to which the main claims of a study relate.' (p.184). It provides a 'detailed and intensive analysis of a single case' (Bryman, 2001, p.501). In this incidence; the phenomenon looked at is the implementation of an educational provision for children with autism within a single classroom of a residential school. In order to assess the robustness of the classroom and the readiness to embrace change, a small action research study was conducted.

Action research includes the active involvement of the researcher (McNiff et al., 2002). It is a combination of both action and research in an attempt to understand, inform and improve practice (Cohen et al., 2000). It involves having the researcher active in an effort to bring about improvement or change. In the case of St. Joseph's School, the researcher introduced a small innovation (visual study emphasis), helped educate the staff in its key aspects, and then assisted in the implementation of these aspects. This led to an examination of the tensions and dilemmas posed to adults through an agreed attempt to introduce and sustain innovation. The use of action research led to the wider discussion of the case of St. Joseph's School and its implementation of educational provision.

The case study generated a large body of data including the generation of a research log based on twice weekly observations of the classroom over a period of 10 months, monthly quantitative counting of aggressive behaviour of the children during various activities of 10 minute duration, review of formal and informal staff notes and log books on children, and review of formal school records on children (including histories, specialist reports, and correspondence). Stake (1995) states, 'What one does in the field...needs to be guided by the research questions.' (p.50). Therefore a closer look at the research question by reviewing Figure 3.2 Primary Research Points, and Figure 3.3 Practical Research Points is necessary.

3.6.1. Case Study as it Relates to Research Criteria

First, a discussion on the Primary Research Points is warranted. Seen as essential to the research were the ability of staff to explore their personal view, the inclusion of the natural environment and the importance of the personal experience of staff. The

case study for this thesis happened at St. Joseph's School (all names and identifying details for the school as well as the individuals themselves have been changed). A discussion follows on each of these points to detail their relation to the use of a case study.

The first of the three Primary Research Points deals with the importance of exploring the personal view of staff. 'Observations work the researcher toward a better understanding of the case.' (Stake, 1995, p. 60). The observations for this research were conducted over a period of several months where the researcher visited the classroom twice a week. This weekly exposure to a variety of staff at various times of the day (and days of the week), led to an intimate and informal relationship being formed with the classroom staff. Consequently, this increased willingness to share individual views. This research is very interested in these views and it is essential to the research question. Therefore, the use of a case study to investigate the views of staff fits well with the first of the Primary Research Points.

The second Primary Research Point is the need to involve the natural environment of staff as an influence on this topic. The use of a case study involves staff members going about their day-to-day duties, within the working environment. Cohen, Manion and Morrison (2000) state that one of, 'their [case studies] strengths is that they observe effects in real contexts...' (p.181). Stake (1995) also describes this as an important aspect of a case study by stating, 'The physical space is fundamental to meanings for most researchers and most readers.' (p. 63). Observations can give the researcher 'an insight into the real dynamics of situations and people' (Cohen et al., 2000, p. 185) and it is this aspect that is crucial to the research.

The personal experience of staff (third Primary Research Point) also fits well with the use of a case study. The biweekly sessions at St. Joseph's allowed the researcher to get to know staff and view their every day experience (in addition to allowing for descriptions of past experiences as mentioned above). This rich source of data is critical to understanding the view of staff on the issue of appropriate educational provision. Eisner and Peshkin (1990) describe this process as 'Each vision enriches and stretches our perception of the classroom.' (p. 355). This is the goal of the research, to gather data about the classroom in a form that can relate to the reader the richness of the data.

3.6.2. Case Study Limitations

The use of a case study to further investigate the thoughts of staff in Strand 1 fits well with the Primary Research Points outlined in Figure 3.2. But research conducted in the real world is never a 'perfect match' between method/s chosen and the goals of the research. There are always some 'trade offs' in research. (Hammersley, 1992). Keeping Hammersley's point in mind, let's investigate some commonly cited limitations of the use of a case study and explore current research literature in regards to these points (see Figure 3.5.).

1. The findings may not be representative of the population in general.
2. Descriptions chosen are selective and thus biased.
3. Research is biased.
4. Direct involvement of the researcher in the case study.

Figure 3.5. Limitations of a Case Study

It is important to examine each of these points in turn, starting with the issue of population representation. Of the four listed limitations, this is the one that has perhaps generated the most debate. Current research literature has many differences of opinion on this issue. Hammersley (1992) feels that generalisations are not possible from a case study because the case may not represent the larger population. Stake (1995) agrees when he states, 'Case study research is not sampling research. We do not study a case primarily to understand other cases.' (p. 4). Woods (1996) takes a broader view of this topic and states that 'The data may not be generalizable, but the theory is, and it is open to modification by future research.' (1996, p. 55). Bryman (2001) agrees and states that researchers '...aim to generate an intensive examination of a single case, in relation to which they then engage in a theoretical analysis.' (p. 51). Researchers disagree. Clearly this issue is not cut and dry, producing a universally accepted stance agreed by all ethnographic researchers.

Looking back at the research question provides direction on this issue. As stated in the introduction to this chapter, the focus of the research has many layers. These layers all share some similarities, even though they focus on three very different partners in the process of securing appropriate educational provision for children with autism. The parallel aspect, common to all three is the 'individual experience'. This research concentrates on the experience of the participants involved, eliciting an

individual story, in their own setting, in their own words and actions. As such, this researcher did not wish to impose a rigid agenda in the hopes of creating global generalizations. Instead, this researcher wished to support the emergence of any themes. This heavy emphasis on the individual does have some drawbacks, one of which is this researcher's recognition that any emerging themes (either among those within one strand or between several strands) would only be used to generate a deeper understanding of the concepts of the thesis and as such, global generalisations would be not be warranted. Therefore, although it can be seen as a source for speculation for further research, generalisations to the population as a whole are not forthcoming.

The last three points in Figure 3.5. all deal with the issue of bias. Point 2 addresses the observations themselves; Point 3 the subjectivity of the researcher's notes and Point 4 the view that just having the researcher present in the setting may cause some bias to the events that occur. Although a discussion is forthcoming in Section 3.8. on validity and reliability, further attention to the issue of bias is warranted here. These three points will be taken together in a general discussion on the issue of bias in case study research.

The very nature of this case study is such that repeated visits over a length of time are assumed. Consequently, data was generated through the use of written comments in field log books, containing descriptions of events that occurred, comments made by staff and general comments on the staff environment. Hammersley (1992) feels that all data generated in this manner is 'selective and can never reproduce the phenomenon described.' (p.187). Woods (1996) however feels that this can be overcome and generally the truth can be 'teased out' (p. 55) of the data.

The risk of bias is part of any qualitative research paradigm. The researcher is involved with the staff and students, and actively encouraging their open participation in the research (Woods, 1996). As such, the interaction that occurs could not have occurred without both party's involvement. This can yield some influence on the events that take place.

The purpose of this research is to investigate the feelings of staff on the aspect of appropriate educational provision. Encouragement is sometimes needed to focus the discussion of staff on the research topic in the least obtrusive way possible. The data generated may be seen as bias by some respected colleagues, but it is this aspect that is instrumental to the detailed exploration of the research question. Stake (1995) summarizes this concept well when he states, 'The intent of qualitative researchers to promote a *subjective* research paradigm is a given. Subjectivity is not seen as a failing needing to be eliminated but as an essential element of understanding.' (p. 45). In conclusion, although this researcher recognises the innate bias of the data generated, it is also seen as a contribution to the research and therefore viewed as one for the purposes of this case study.

This will also mean that the data is presented with the recognition that it will inevitably contain some degree of bias, and should be embraced as other researchers suggest (see for example Stake, 1995; Woods, 1996). Yet, it is important to take on board the comments of other respected researchers to try to limit the innate bias in case study research. Hammersley (1992) suggests using a case study with other types of research data gathered. This advice was followed and the case study in this research forms one part of the total data generated for Strand 1.

In conclusion, the use of a case study for this research is well founded both in terms of the current practice research literature to date, and the current methodological literature. It does have some limitations, but these are recognised by the researcher and presented as such in this thesis.

3.7. Survey

The previous two sections of this chapter dealt with the use of interview and a case study to explore Strands 1 and 3. The third method used for the purpose of this thesis is a survey and it was used to investigate the thoughts of parents on the process of securing appropriate educational provision.

The first interviews (Strand 1-school staff) and the case study brought to light some interesting ideas by staff (as well as the personal experience of the researcher) regarding some comments made by parents to staff on the difficulties surrounding

this process. It was therefore determined to investigate these concepts further through the use of a nationwide survey. Although this survey was primarily designed to solicit quantitative data, qualitative input was requested in the two final questions. The next section will explore the use of a survey and relate it to the research criteria and then investigate some limitations of its use.

3.7.1. Survey as it Relates to Research Criteria

As in the previous two sections, a closer look at Cohen's 'fitness for purpose' (2000, p. 73) is warranted. This section will also study some of the current literature and published research with respect to the use of a survey. Finally the primary research points and the limitations of a survey will be discussed.

First, a review of current educational research in the field of autism is necessary. The use of a survey to investigate the opinions of a sample of the population is well established in both research methodology as well as common practice. This holds true with both educational research in general, and autism specific educational research as well. (See for example Mavropoulou et al., 2000; McGregor et al., 2001) What is also interesting to note is its usage when samples are specifically targeting parents and their views (See for example Howlin et al., 1997b; Vostanis et al., 1998; Midence et al., 1999; McGregor et al., 2001).

This is not only true of journal articles, but also of research conducted by various charitable organisations or support groups that is not subsequently published in peer reviewed literature (Portway, 2000; Barnard et al., 2001; English et al., 2001; PACE, 2001; Barnard et al., 2002).

It is important to note that although this type of research can be considered to make a valuable contribution to the field by giving parents an avenue to express their views as well as influencing further research or political debate. Therefore, the use of a survey is well founded in terms of current research and current practice in the field (VanDalen, 1979; Oppenheim, 1992; Cohen et al., 2000; Bryman, 2001) as well as use in an ethnographic study (Woods, 1985).

Which type of questions should be included in an investigation that could best meet the needs of this particular research? Are qualitative or quantitative questions best

suitable for gathering the data required? The answer to this question lies in the Primary Research Points and Practical Research Points (Figures 3.2. and 3.3. respectively).

The reader will notice that the first three points are identical to those listed previously (Figure 3.2.). But in addition, another research criterion was added for this particular strand (see Figure 3.6.). The additional criterion was added for several reasons.

1. Ability to freely explore individual views on the topic
2. Ability to include the natural environment as an influence on this topic
3. Ability to relate personal experience on the topic
4. Ability to reach a large sample of the population

Figure 3.6. Primary Research Points for Strand 2

First, the researcher's personal experience as founder of two national charities that support parents in their efforts to secure what they see as appropriate educational provision has put me in contact with many parents. Conversations over the past ten years have shown the individual experience of parents is quite varied. This applies to both the types of educational provision available as well as access to an individual choice. Secondly, the experience of staff at St. Joseph's School also revealed that conversations with individual parents of children subsequently placed at the school showed quite a wide variety of experience. Finally, since the experiences were quite varied, it was seen as vital that an effort should be made to try to include as many different opinions of parental experience as possible, thus a wide sample from many different individuals was seen as a critical aspect for Strand 2.

The Primary Research Points for Strand 2 (Figure 3.6.) led to the use of a questionnaire in this research and also to the usage of both quantitative and qualitative questions on it.

The first primary research point, the free expression of individual views (or to choose not to express a view) was the first to determine the types of questions used in the survey (Cohen et al., 2000). As stated, a wide variety of experiences were sought, from many different individual parents. This means that an avenue for that expression needed to be catered to. Although it can be argued that both closed

questions and open-ended questions can gather data that elicits the opinions of respondents, this aspect is primarily associated with open-ended questions. (Oppenheim, 1992; Cohen et al., 2000; Bryman, 2001) Thus, two open-ended questions were included in the questionnaire.

These were placed at the end, to allow parents the opportunity to freely express their views on this topic (Oppenheim, 1992) and continue on additional sheet(s) if necessary. It also left respondents the opportunity to omit this section. Few chose to do this, but this choice was also seen as very important. Because one of the Primary Research Points was the freedom to explore their individual views, this must also include the freedom not to explore their individual views. Leaving these questions until the end, gave parents that option while still answering the other questions. If these were presented earlier it was felt that parents, many stressed or overwhelmed by their frequently demanding child, might decide not to complete the questionnaire. Bryman (2001) suggests placing these types of questions at the end. This may allow the respondents to just avoid answering the final questions and still feel there was merit in returning the survey. (The use of open-ended questions will be discussed further in the following section on the limitations of surveys. See Section 3.7.2.)

The second point deals with the natural environment. The surveys were posted to parent's homes or distributed to them via their child's school. In either case, the surveys were for completion at home, at the leisure of the individual respondent. The use of self-administered questionnaires (Oppenheim, 1992) was seen as essential in allowing the respondents the ability to explore their own individual circumstances and include these as they so determined in their responses to various questions.

There is another reason why this aspect is important. The nature of autism is such that it is sometimes confused by members of the public (or even sometimes the medical or educational professions) as a conditional response to poor parenting (see for example the works of Bettelheim, 1943; Bettelheim, 1967). This can make some parents uneasy about responding to a questionnaire where their individual opinion on educational provision is sought. Some parents may even regard this as a 'sensitive topic' (Oppenheim, 1992, p. 140) and need reassurances that their responses will be kept confidential. Allowing completion of the questionnaire in the individual's home

may encourage some respondents to complete it who may otherwise be apprehensive.

The third Primary Research Point is the individual's ability to relate personal experience. This is an interesting area, as debate could again arise on which of the two types of questions (open-ended or closed) best allow this to happen. Open-ended questions allow for the free expression of view, as previously discussed, but this comes at a price: the ease of analysis and the ability to target a large audience with limited resources (VanDalen, 1979; Oppenheim, 1992; Cohen et al., 2000).

Therefore, it was determined to allow for a small number of open-ended questions (two) to address the issues of freedom to express views, and personal experience (Black, 1999). There is also the need to balance this against the next Primary Research Point: that of a large sample. Personal experience is essential, but this research wanted to gather the personal experience of a large group of individuals. This made the use of too many open-ended questions unpractical and therefore the majority of the survey opted for closed questions. VanDalen (1979) advises that '...presenting respondents with carefully selected and ordered questions is the only practical way to obtain data' (p. 152).

The last Primary Research Point for Strand 2 was the need to have a large sample. This has been already touched upon above and is seen as a major advantage of survey usage (Scott et al., 1999). It is widely recognised as easy to process answers and compare response as well as easy for respondents to complete (Oppenheim, 1992; Bryman, 2001). A large sample of the population of parents having autistic children was sought to respond to the variations of experience that this population was thought to have. As the target was to gather information from as many different parents as possible, it was hoped that this might reflect the wide variety of experience that was relayed to this researcher by both personal experience and the comments from staff at St. Joseph's School. Therefore, a large sample of the population was sought and this is consistent with the use of a survey to gather data.

In addition to the Primary Research Points, the Practical Research Points (Figure 3.3.) also have an impact on the use of a survey. These points have been dealt with individually in Section 3.5.1. but a closer look at these specifically as they deal with Strand 2 is warranted.

The first three Practical Research Points deal with the issues of convenience and that of avoiding imposing limitations of those responding. One of the advantages of a survey is that it can be completed at the leisure of the respondent. (Oppenheim, 1992; Black, 1999; Bryman, 2001) This allows for the respondent to choose the time and place of the completion of the survey. It is therefore very easy for the respondent to complete it in a time or place that suits their needs best. One of the major advantages to the use of a survey is the benefit of both cost effectiveness and saved time (Kvale, 1996; Bryman, 2001).

The fourth Practical Research Point deals with the opportunity of the researcher to explore issues with the individual respondent. This is often limited by the use of a questionnaire, especially one where closed questions are employed. Again, this is an issue discussed above and was seen as a trade off when considering analysis of a large number of respondents. Two open-ended questions were included in the questionnaire, to try to address this issue to some degree.

The fifth Practical Research Point deals with accuracy. It is this reason that so many closed questions were included. 'Generally, though, it is desirable to design the questions in closed form so that quantification and analysis of the results may be carried out efficiently.' (Borg et al., 1983, p. 419) Borg suggests that the use of statistical analysis will yield a 'truer' picture of the experience of parents in the process of appropriate educational provision. (The specific types of analysis used will be discussed in detail in Chapter 5.) Accuracy could also imply a lack of 'interviewer variability' (Bryman, 2001, p. 130). This means that the respondent is not influenced by the researcher's presence. The respondent is able to complete it in the way that is most meaningful to them, without being influenced by the researcher's presence.

Anonymity of those involved (Practical Research Point Six) can also be effectively dealt with by the use of a survey. The parents involved chose to complete the survey. There was no pressure placed on them, and the survey also allowed the individual to remain anonymous. It offered the individual the opportunity to share their experience without having to disclose too many identifying details (general comments about the age of child and LEA were requested). The use of a survey also created a measured gap between the researcher and the respondent. This enabled those responding the opportunity to share their thoughts in the security of knowing

that no one could identify the individual respondent. This allowed individuals to respond in the way they saw fit, encouraging openness. It also allows for the absence of interviewer effects or any variability arising from this (Bryman, 2001). Therefore, the use of a survey supports the anonymity of those responding.

Lastly, the rate of return is considered. This is another interesting issue in that other methods (such as interview) have a higher rate of return. Kvale (1996) cautions that interviews should be used for a certain purpose, and in certain cases, other methods are better suited to address the research questions. This is one of those cases. One of the reasons Kvale states is when research involves large groups. He feels qualitative interviews may not suit the research as stated. This is a case where a Primary Research Point must overrule the influence of a Practical Research Point. In other words, the primary objectives of the research must determine the method used. Cohen, Manion and Morrison's concept of 'fitness for purpose' must determine the type of method used. Although there may be other methods that will ensure a better rate of return, in the case of Strand 2, the Primary Research Point of reaching a large audience must overshadow that of a high rate of return. The use of a survey is still best suited to meet the Primary Research Points, as well as a majority of the Practical Research Points and therefore was used for Strand 2. (This issue will be discussed further in the next section.)

This section has examined the use of a survey not just in terms of the research literature and practitioners/charity surveys in practice, but also in respect to the research question and Primary Research and Practical Research Points for Strand 2. But, Cohen (2000) reminds us that there are always some drawbacks with any chosen research method. The next section will investigate some of these limitations and review how respected researchers view them.

3.7.2. Survey Limitations

The previous section described how use of a survey met the conditions established by the research question. This section will investigate some of the limitations as identified by respected researchers. Figure 3.7. summarises these points.

1. Inability to prompt or reword items
2. Inability to probe further into interesting responses
3. Rate of response
4. Duplicate mailings

Figure 3.7. Limitations of a Survey

The first two issues above are somewhat linked. They each involve the inability of the researcher to communicate with the respondent when they are completing the survey (Bryman, 2001). This includes clarifying questions and limitations in exploring more interesting responses. Remembering that parents were given the option of remaining anonymous means that some potentially useful or interesting data may be lost. The lack of direct communication with the respondent limits this kind of probing and any assistance offered (Saslow, 1982).

This research did keep these two limitations in mind and tried to limit the effects of them in the following two ways. The first is through the use of the pilot and subsequent revisions to the questionnaire (Borg et al., 1983; Cohen et al., 2000). Although this will be discussed in further detail in Chapter 5, it is important to note that a pilot of the survey was conducted and those involved were invited to either write any comments on the survey itself, or communicate these to the researcher directly. This resulted in several draft versions; each was then subsequently piloted. The final version was written incorporating these comments.

The second way in which these limitations were addressed was through the use of two open-ended questions. Although it is recognised that the use of a questionnaire could not offer the researcher the ability to individually explore concepts with parents, it did offer parents the ability to explore their ideas to the extent they saw fit (Oppenheim, 1992; Bryman, 2001). Although the researcher could probe these comments on an individual case basis, it did still generate a large body of rich data on the research question and the possible effects the process of seeking appropriate educational provision had on families.

The third and fourth limitations listed in Figure 3.7 deal with the lack of control over the rate of return of the survey. As stated, this questionnaire was distributed in one of two ways: by directly posting it to the individual family (via a charity database) or distribution by their child's school. In either case, a covering letter (and in some

cases another letter by the charity or school involved) was the only contact the researcher had with those receiving the questionnaire. Although follow up letters were sent to schools that did not reply to the initial letter of request, no follow up letters were sent to individual families⁸.

In addition, the charities that agreed to participate in the distribution of the questionnaires had strict controls over their databases due to the Data Protection Act. In all cases, the researcher was not allowed to take the mailing list off site and all labelling needed to be done at the office of the specific charity. One charity requested sealed envelopes and then had their office staff complete the labelling and distribution. Therefore, it was impossible to cross check mailing lists and avoid duplicate mailings. Several respondents did comment that they received additional copies of the survey, but it is unlikely that this will account for all duplicate mailings. Subsequently, this is a real limitation of the use of a postal survey in general, and of this particular one as well. As this issue is frequently identified in research literature, the advice from other researchers on how this problem was addressed is explored.

Cohen (2000) and Oppenheim (1992) offer advice on ways to counter this limitation. Cohen (2000) suggests including a cover letter explaining the purpose of the research and other details, including a FREEPOST return envelope, and to avoid posting at certain times of the year. In addition, Oppenheim (1992) suggests ensuring confidentiality, and to look at such issues as length and format of the questionnaire. This advice was adhered to and appropriate adjustments made before a final draft was distributed.

Although there are limitations in the use of a survey to gather data for Strand 2, these limitations were identified and appropriate safe guards put in place before the questionnaire was distributed. The advantages were then weighed against the limitations and it was decided that with appropriate safe guards in place, the questionnaire would still meet the research criteria identified. The final section of this chapter will explore the issues surrounding validity and reliability of the research.

⁸ Besides the prohibitive cost, it would have been impossible to keep track of individual respondents due to the limitations of the Data Protection Act on Charity databases, as well as the anonymity offered to respondents.

3.8. Validity and Reliability

Thus far, this chapter has focused on describing the process undertaken to establish the methodology and methods used in this research. It has linked the research question, and its critical considerations to ethnography, the use of a semi-structured interview for Strands One and Three, the use of a case study for Strand 1, and a survey for Strand 2. This section will explore the concept of validity and reliability and then investigate it both in terms of the research literature as well as the research conducted for Strand 1, Strand 2 and Strand 3.

First, a very brief definition of the terms 'reliability' and 'validity' is justified. 'Reliability is concerned with the question of whether the results of a study are repeatable.' (Bryman, 2001, p. 29). In other words, reliability is the ability of an independent individual to replicate the findings, as well as consistency in the measures used (both in terms of type of measure and the way it is used). Consequently, the methods used must be similar and true to what other researchers are using for similar research conducted (Cohen et al., 2000).

Validity refers to the 'integrity of the conclusions that are generated from a piece of research.' (Bryman, 2001, p. 30). Simply put, it is concerned with the researcher's interpretation of the data generated. In summary, reliability could generally be seen as more of an 'external' process, where concerns would be focused on comparison with other research that has been already been established as reliable. Validity would then be seen as a more 'internal' investigation, where it would be concerned with consistent interpretation of the data generated (Cohen et al., 2000).

Another concept that is sometimes confused with validity and reliability is the concept of 'truth'.⁹ Carspecken (1996) describes this as the individual belief in accuracy of the statements and concludes that all claims of truth are fallible and can be disproved at some time either at present or in the future. He cautions the researcher not to seek a 'final truth' (p.57), but to concentrate on validity. This researcher took Carspecken's advice and will not concentrate on producing one final 'all encompassing' conclusion, or even undertaking a rigorous verification of the data that was generated in

⁹ The concept of 'truth' is distinctive from the concept of data being 'truthful' and presented in an accurate manner. This researcher wholly accepts the responsibility of presenting a truthful picture of all data generated.

interviews with outside sources. As Denzin states, 'Ethnographers collect and tell multiple versions of the truth.' (1997, p. xv). This statement would apply to this piece of research as well.

In general, the traditional concepts of validity and reliability have a strong positivist heritage. As this thesis did not set out to conduct positivist research (with the exception of the statistical analysis of the survey¹⁰) the traditional tests of validity and reliability would not apply to the majority of this thesis. What is necessary is the application of the broader concepts of validity and reliability to this research. Investigating the works of respected researchers on this topic and generalising these concepts to the research at hand achieve this.

3.8.1. Definitions

What specifically distinguishes a piece of research as valid and reliable? These terms have been defined in the last section. What would be helpful in answering this question is a listing of general criteria that constitutes valid and reliable research from respected researchers in the field. After this is established, it is simply a matter of matching this criteria to the methods used for each of the three strands.

As the nature of the three methods used for this research are distinctly different, the efforts to ensure validity will also vary (Denzin, 1997). There will be distinct differences, but there will also be some general concepts applicable to all three. For example, the same procedures undertaken to ensure valid quantitative research will not be applicable to qualitative research, but there will be some general rules that apply to each. The specific procedures used are to be examined in detail in the forthcoming analysis chapters of this thesis. First, a look at the general concepts as stated by respected researchers and its application to the three methods is undertaken.

There are many respected research authors, each with their own distinct contribution to the field of research validity (See for example Carspecken, 1996; Denzin, 1997; Denzin et al., 1998; Cohen et al., 2000; Bryman, 2001). It is beyond the scope of this thesis to investigate each in detail; instead it will look for general areas of consensus.

¹⁰ Data generated from the survey was analysed using standard statistical measures. These are described in detail in Chapter 5.

Therefore, highlighted below are the contributions of the following authors: Carspecken (1996), Hammersley (1998), and Cohen, Manion and Morrison (2000).

First, Carspecken (1996) highlights three areas that need addressing when conducting research to ensure validity. (See Figure 3.8.)

1. Data or field records produced are true to what occurred.
2. The analysis performed on the data was conducted correctly.
3. The conceptual basis of the analytic techniques used is sound.

Figure 3.8. Valid Research according to Carspecken (1996 p.57)

Hammersley (1998) takes a somewhat 'looser' definition. He describes validity as more of an issue of 'good practice' and argues for a more 'common sense' approach. His criteria are listed in Figure 3.9.

- How plausible is the claim made?
- How credible is the claim?
- Where neither above are met, we require evidence to be convinced of its validity.

Figure 3.9. Valid Research according to Hammersley (1998, p. 143-144)

The last researchers discussed on this topic are Cohen, Manion and Morrison (2000). They make a contribution to this discussion by describing several distinct types of validity. Those specific to the research methods are summarised in Figure 3.10.

- Internal validity-Do the conclusions accurately depict the data?
- External validity-Can the results be generalised to the population?
- Content validity-Do the instruments used fairly cover what it states it should?
- Construct validity-Are the underlying assumptions consistent with those of other respected researchers?

Figure 3.10. Valid Research according to Cohen (2000, p.107-111)

Although the above comments are varied, there are central themes consistent in each. First, all three include the need to establish that the methods used were conducted professionally, accurately and do depict the events that occurred. Second, they highlight the need for the analysis to be conducted accurately and reflect the data generated. Third, all stress that conclusions generated need to follow logically

from these first two points. Finally, all share the need to make sure that conclusions are generally consistent with other researchers. This is summarised in Figure 3.11.

1. Is the research conducted professionally, accurately, and true to the events as they occurred?
2. Is the analysis conducted accurately?
3. Are the conclusions drawn logically?
4. Are conclusions consistent with other respected authors in the field?

Figure 3.11. Summary of Valid and Reliable Research Criteria

These four points will be discussed as they relate to the three methods chosen for this research: semi-structured interview, case study and questionnaire.

3.8.2. Criterion One: Professional Research

The first criterion examined that is applicable to all methods chosen, is the issue of the research itself. Is the research conducted in a professional and accurate manner? This is perhaps the most central issue when assessing valid and reliable research. Specifically, this would deal with the planning before the research is undertaken, as well as during its course. This concept seems to be centred around five areas: supervision, ethical consent, and permission from participants, multiple observations and confidentiality of those involved. Each of these issues will now be addressed as they apply to the research.

All three methods chosen were conducted under the supervision of Prof. Roy Evans. His input was also sought in early pre-research meetings with St. Joseph's School, and the Ethics Committee at Brunel. (See Chapter 4 for additional details.) All children¹¹ involved in the case study had a written consent form signed by their parent/s (including video taping). In addition, parents were given the researcher's contact details. The school also granted written consent for the research and any videotaping that was done. This researcher shared notes generated with staff as requested, and with Prof. Evans. Throughout the case study, multiple visits were made at different times of the day, and different days of the week. This resulted in access to various staff members throughout the course of the research. All names and identifying details were kept confidential, and those participating in any aspect of the research

¹¹ The extreme nature of the disability of the children involved meant that informed consent from them, although desirable, was unrealistic and therefore not obtained.

had the opportunity to withdraw at any time. Interviews were arranged at a convenient time for those involved and they were requested to read the transcript and make changes if errors were present. Carspecken (1996, p. 88-89) highlights each of these techniques as contributing to validity.

3.8.3. Criterion Two: Accurate Reflection of the Data

There is some overlap between the concepts in Criterion One and Two. As previously stated, both interviews and case notes were open to those involved. This provided a vital check as to their accuracy. But Criterion Two goes beyond the simple checking of factual events. Denzin (1997) cautions that transcribed text does not take into account the social cues present, and that any interview or observation is only to be taken as a snapshot of events that happen in any observation. Carspecken (1996) also agrees and adds that the researcher also biases the situation just by his or her presence. In addition, Carspecken (1996) feels that the research individual brings with them an individual history that can influence the choice of the events recorded, emphasis on events or even when to stop recording events. Therefore, how did this research counter these effects and accurately reflect the data generated?

First, as already stated, there were checks in place to make sure that the data recorded accurately depicted the events as they occurred. These were at the school, as well as during and after interviews. The use of a semi-structured interview in itself allows for checks on the data as it is being generated (Stake, 1995). As conversations occur, issues can be revisited to ensure clarity. Secondly, the innate bias of the researcher can be overcome to some degree by concentrating on the facts or events in a descriptive manner. Understanding must be therefore that the events are a 'snapshot' as Carspecken (1996) warns, and not to be interpreted as overreaching generalisations. He states that, 'the same object can be examined for a large variety of reasons, under a large variety of motivations and yield the same findings' (p. 6).

In addition, it must be recognised that opinions were sought as a primary focus of this research. As such all interviews, the questionnaire and the case study generated data that was the opinion of an individual. It is therefore bias data. The purpose of this study was to seek this information, not to meticulously verify each statement as it occurred. 'Truth and facts are socially constructed, and people build stories around

the meanings of facts. Ethnographers collect and tell these multiple versions of the truth.' (Denzin, 1997, p. xv).

The postal questionnaires for Strand 2 were piloted, revised, distributed, and analysed according to accepted standards for quantitative data (Fielding et al., 2000). Brunel University as well as the charities and schools that distributed the questionnaires granted appropriate consent. All identifying details of individuals were changed. Further discussion of the specific tests used to reduce error or show statistical significance will be discussed in Chapter 5.

3.8.4. Criterion Three: Conclusions Flow from the Data

The third criterion deals with conclusions. It is important at this point to distinguish between conclusions from the data and generalisations to a population. As previously stated, this research is not intending to produce global generalisations applicable to each of the three Strands. Instead, it strives to allow the data to speak for itself (Hargreaves, 1967; Stake, 1995). Assumptions will not be applied to the population of all families of children with autism, as a whole.

First, as discussed in Section 3.5.1, the strength of a semi-structured interview is the ability to explore the views of those interviewed and to allow themes to emerge. This is seen as essential to the research and one of the major reasons why this method was chosen. At no time was a rigid research agenda dictated and followed, but every effort was made to allow the data to dictate its own conclusions (Kvale, 1996).

The case study followed a similar philosophy. The events were recorded as faithfully as possible, open to comments from various staff members. Even so, Hargreaves (1967) cautions the need to seek objective measures. This is also seen in Carspecken's (1996) views on truth and validity. Carspecken cautions that the description of events from person can change from one point to another yielding a 'layered subjectivity' (p. 75). It is acknowledged that the various staff members may have their own perspectives on the background of events, and thus yield differing interpretations of the events that unfolded. This is allowed for with the use of various methods to investigate the data and triangulation. (A more detailed discussion on this aspect follows in Section 3.9.)

The questionnaire also yielded some interesting conclusions. As the majority of the questions were quantitative in nature, analysis took a more positivist approach (Black, 1999; Fielding et al., 2000). The two final questions were open-ended and looked for patterns and themes among groups of respondents. This analysis took a more qualitative perspective (Silverman, 1993; Silverman, 2000).

3.8.5. Criterion Four: Consistency with other Researchers

The final criterion discussed in this section discusses the methods used in this research in comparison with other research recognised as valid and reliable. (For the purpose of this discussion, it will be assumed that valid and reliable research is that which is published in peer-reviewed journal, or that which is longstanding.) What this criterion seeks is consistency in research approaches, or a valid reasoned, explanation why the work of established researchers in the field was not followed. In other words, 'Does the research at hand use methods similar to other respected investigations in the field in question?' and if it does not, 'What are the reasons why?'.

Of the four criteria for validity, this is the one that has been discussed in previously in other sections in this chapter. Each method has a section of this thesis devoted to this particular aspect (see previous Section 3.5.1 for Semi-structured interviews, section 3.6.1 for Case Study, and 3.7.1 for the use of a Survey). Although it is suggested that the reader refer to these sections for detailed discussion of this aspect, a brief summary follows.

This researcher sought to explore the views of three different samples of the population of individuals involved in the education of children with autism. Perhaps the most common way to investigate the view of parents is the use of a questionnaire. This is evident by the works of (Mesibov, 1997; Howlin et al., 1997b; Vostanis et al., 1998; Randall et al., 1999; Howlin et al., 1999a; Weiskop et al., 2001). Although these are just a sample of the respected authors in the field using questionnaires, most issues of the research reported in the two main journals in the field, Autism and The Journal of Autism and Developmental Disorders usually contain at least one article using this method when researching the views of parents.

The second most common way to find the views of individuals is the use of interview. Although this is frequently cited when the views of parents are sought, (see for example Mesibov, 1997; Howlin et al., 1997b; Vostanis et al., 1998; Midence et al., 1999; Randall et al., 1999; Howlin et al., 1999a; Weiskop et al., 2001) it is not so common when the subject of the interview is a staff member. The issue of its use in this context was discussed in Section 3.5, but to summarise this researcher felt that the advantages usually associated with its usage with parents also apply to staff members. In fact, this researcher feels that the limitations of its use (access to population and time limitations) probably result in the fact that it is not commonly used with this group.

Therefore, in conclusion, the four criteria summarised by respected researchers is consistent with this research. Specifically, this research followed the established procedures recognised as 'good practice', it accurately depicted the data, it allowed conclusions to be drawn from it, and it is consistent with what other researchers are doing in the field.

The last section in this chapter will now focus on the issue of triangulation.

3.9. Triangulation

The last task in this chapter is to try and draw it all together, to look at the issue of the usage of three very different methods. This chapter began with a discussion on the epistemology and theoretical perspectives of this thesis (see Section 3.1. - 3.2.). Following phenomenology as the theoretical perspective allows for the usage of any technique to explore the events unfolding in the research. Above discussions have clarified why each method was chosen, and how it fits with the Critical as well as Practical Research Points. Current research and the thoughts of respected researchers on each of these methods have also been explored. But what is still needed is a section addressed to the issue of the use of three methods to explore a thesis, and not simply a concentration on one method, be it quantitative or qualitative.

Although it is not uncommon to use several methods (Miles et al., 1984), triangulation is an intriguing concept that can generate some strong feeling both for and against it.

It has its supporters and critics alike and is used for both qualitative and quantitative methodologies. For the purpose of this thesis, it is defined as the usage of several methods to explore an aspect (Denzin et al., 1998; Cohen et al., 2000). In addition, it is usually explored as a means to 'cross check findings' (Black, 1999, p. 273) and as such a means of verifying data.

Using the first definition above, this study did use several methods to explore the thesis of appropriate educational provision. The three methods used (semi-structured interview, case study, and survey) have been described in detail previously (see Sections 3.4-3.6). But how does Black's (1999) definition, using triangulation to check previously gathered data, apply to this thesis? Further attention is needed to this issue, using the following points in Figure 3.12.

1. Three strands all different populations
2. Use it to spark other questions
3. No global generalisations
4. Multiple checks on quantitative data gathered
5. Check data for accuracy

Figure 3.12. Triangulation topics

The first issue under this discussion is the research topic itself. It is seen as an investigation into the issue of appropriate educational provision for children with autism, but it looks at this from the perspective of three different samples of the populations (school, parent, and LEA). As such it is interesting to theorize if Black's (1999) definition does apply. If the three methods chosen were kept separate and applicable to a strand only, Black's definition would not apply. This is the case for Strand 2 and Strand 3, but not for Strand 1. In Strand 1, both semi-structured interviews and the case study were used.

Is it a case then of Strands Two and Three being totally independent of the others? Again this is not a 'black and white' issue. For the most part, this researcher does strive to let the data drive the results and not be influenced by what data has been previously generated. But in reality, the nature of semi-structured interview is such that it is fluid. It can be adjusted to probe certain themes. The researcher brings past experiences and knowledge to the interviews. This does have influence and, however slight, it must be recognised. The previous discussion on this topic showed

that this is an advantage to this research and must be embraced (Kvale, 1996; Silverman, 2000).

There is an additional comment on the influence of one method on another and that is Point Two: interest sparks. Chronologically, Strand 1 interviews and the case study were completed first, followed by Strand 2 surveys and then Strand 3 interviews (see Figure 3.13).

Research Timeline (in years)

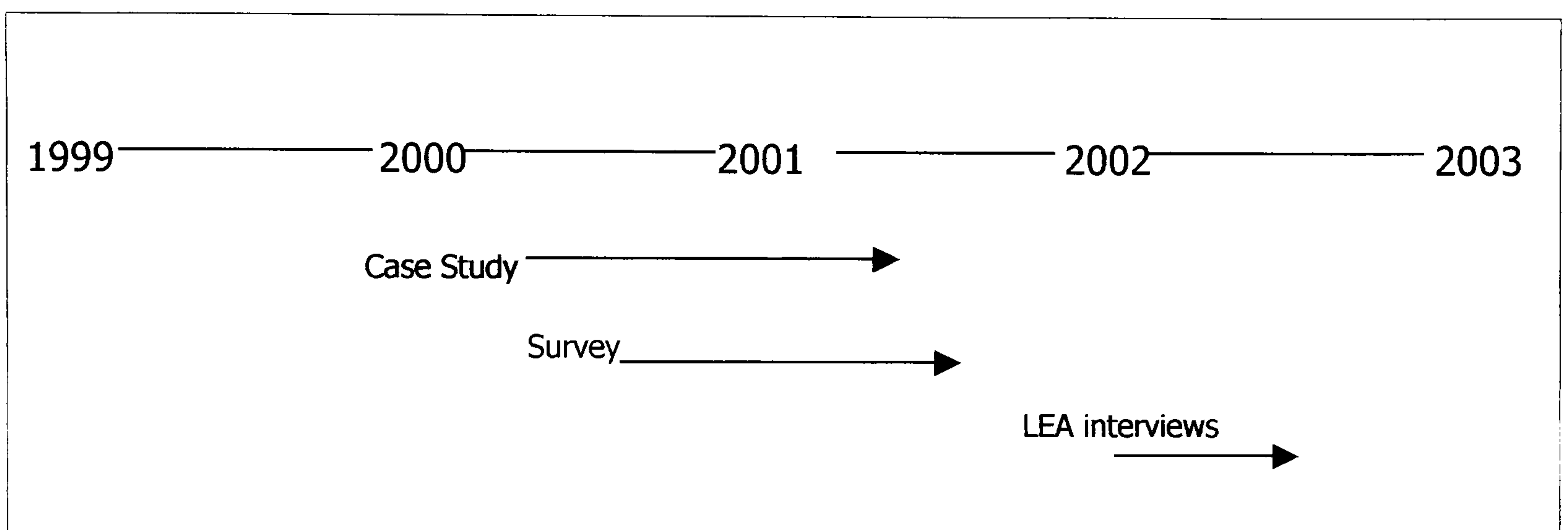


Figure 3.13 Research Timeline

Comments made by staff about the experience of parents at the school prompted some questions on the survey. The same can be said with the choice of individual LEAs to interview for Strand 3. LEAs were approached based on which had the highest response rates from parents on the questionnaire. All those LEAs with at least 15 returned surveys were contacted. [Note: Bracknell Forest LEA was not approached. This researcher has a disabled son receiving services funded by Bracknell Forest LEA. Repeated past contact with the SEN Coordinator may be perceived by outsiders as bias on the part of the researcher or cause the SEN Coordinator to be guarded in the responses given. Therefore, Bracknell Forest LEA was not approached for an interview.]

Point three above involves the use of global generalisations. As previously stated, it is not the goal of this thesis to generate global summaries of populations on the research topic. At best, summaries can only be generalised on the sample (seen as a snapshot of how the parent was feeling on that particular day and time that the questionnaire was completed) and interpretation by this researcher will be restricted

to this. Therefore, no effort was expended on behalf of this researcher to meticulously verify data generated by comparing methods on a particular strand. The different methods were used to explore the research question, but not intentionally double check previous data generated.

There is one exception to this rule, and that is addressed in Point Four. In the quantitative data generated in parts of the survey, statistical methods were employed to minimize error by analysing data according to set positivist procedures.

Recognised statistical procedures will be adhered to for Strand 2 data on the survey and to those questions that were quantitative in nature (see Chapter 6).

Finally, the global issue of using triangulation to check data gathered is addressed. As previously stated, multiple methods were used in this research, but primarily as a tool to generate the views of the three different partners in the process of securing appropriate educational provision for children with autism. It must be stressed again that it is not used as a tool to cross check what others have said. Silverman (2000, p. 46) reminds us that 'all data is subjective' and that everyone has a different perspective on events that occur. In conclusion, this researcher wholeheartedly agrees with Denzin's summary in that, 'The meanings of a subject's statements are, therefore, always in motion.' (1997, p. 5).

3.10. Chapter Summary

In conclusion, Chapter 3 investigated the methodology used for this research, explored the three methods chosen and related these to the research question in terms of identified Critical Points. This was then placed in the context of current research and identified the strengths and limitations of each of these methods. It was found to be consistent with both current practice and best practice in the field.

Chapter 4 - Strand 1

The last chapter discussed the research protocol that led to beginning the case study at St. Joseph's School¹². This chapter will describe the many different facets of provision in the context of an individual school.

Adopting a systems theory (Bertalanffy, 1968) perspective allows the exploration of the ways a child can be influenced in terms of educational provision by those in his or her environment. As the classroom is the typical setting for educational provision, it is appropriate to investigate the tensions and dilemmas within a system of heavy interaction. St. Joseph's is a very unique school due to the intense demands from a very disabled population of autistic students. The students live at St. Joseph's School, (except for limited home visits), as it is a 52-week provision for these individuals at the extreme end of the autistic spectrum. The school has 26 children, from ages 10-19. The school makes an interesting contribution to the theory because of the nature of the living arrangement, where children interact with staff more, perhaps, than their family. It is important to explore the different links in the system and suggest where the tensions or stressors may or may not exist within this school system.

The case study is an attempt to peel back the layers in a school and look at the perceptions of the management, classroom staff and provide a context for insights into school provision. It looks at all facets of the organisation, including the philosophy, systems and practice and demonstrates the dilemmas that can take place when implementing educational provision. This showed the thoughts and individual views of direct teaching staff on the events in the classroom setting. Initial notes in the case log reflect the negative views of staff on the senior management, but there was little evidence on how they perceived their own roles as agents with the ability to change the perceived practice. The case study also showed the views of managers in terms of philosophy and vision, to be well articulated. The classroom vision appears less well imbedded, and differences appear between teachers, carers and management. What were the factors in the dynamics of the classroom that work against the vision of the Principal being played out?

¹² All identifying details have been changed.

To explore this question, a small piece of action research was designed to examine the tensions and dilemmas posed to school staff through an agreed attempt to introduce and sustain innovation. It was designed to explore the extent to which consistency of approach and teamwork was robust in a novel circumstance. Investigating the impact in the day-to-day experiences of a Visual Teaching strategy (using written words or pictures as a primary teaching tool), allowed a means to assess the quality of educational provision for an individual child and the readiness of the school staff to embrace change. It was introduced to see what could be achieved if the action researcher provided the leadership and support to implement the change. Upon the gradual withdrawal of the researcher, the staff failed to maintain goals achieved by the children, and reverted to prior practice. This study permits investigation of the critical issues that impact this. The chapter concludes with a discussion of emerging themes and data that support these themes.

4.1. Visual Strategies Action Research

Autism is seen as a continuum disorder, with vast differences between the individuals affected (Wing, 1971; National Autistic Society, 2000a). The review of the literature (see Chapter 2) shows the tremendous variety in both philosophies as well as programmes to meet the educational needs of these individuals. Yet the success of most of these approaches is limited (Quill, 1997).

The difficulty comes in addressing the requirements of that proportion of the autistic population whose needs are not met with traditional classroom approaches. In this thesis, traditional classroom teaching approaches are defined as spoken teacher instruction directing child activity. For the portion of the autistic population addressed at this school, spoken instructions and directions that occur in traditionally taught classrooms do not typically have the associated receptive meaning. Consequently, these instructions are 'lost' and the child can miss the learning opportunity. Peeters (1997) refers to this group as '*dyssymbolic* with regards to what they hear: they have specific difficulties analysing the meaning of abstract auditory information' (p. 72).

4.1.1. Visual Learners

Although a child may have difficulty associating meaning with verbal instructions, this is not necessarily true of instructions that take a more visual form (National Research Council, 2001). These are generally two-dimensional (i.e. written words, icons [black and white cartoon like images] or pictures) but can also be three-dimensional (i.e. gestures, expressions). For the purpose of this thesis, this subgroup will be referred to as visual learners. Visual learners are children who process and retain information better if it is presented in a format where it is written down and can be seen, as opposed to information that is primarily heard. It is this particular subgroup of autistic individuals that is the focus of the action research.

Grandin (1995), an autistic author, describes what it is like to be a visual learner.

'I think in pictures. Words are like a second language to me. I translate both spoken and written words into full-color movies, complete with sound, which run like a VCR tape in my head.' (p. 19)

Although Grandin describes being a visual learner as a 'tremendous advantage' (p. 19) this is not necessarily true for all autistic individuals. The lack of the natural ability to derive meaning from spoken words often results in autistic children that have no, or severely limited spoken language. Siegel (1996) states,

*'With autistic and PDD children in particular, the **language channel** is often the weakest. This is often the case with children who seem able to tune out much of the language addressed to them, and do not easily learn new words just by hearing other people use them.'* (p. 242-243)

The balance of research evidence and practical experience suggests that spoken language is not registering much, if any, meaning for this subgroup of autistic children. It is therefore important to look at other ways to encourage the exchange of meaningful information (Quill, 1985; Siegel, 1996; Peeters, 1997; Quill, 1998).

4.1.2. Visual Strategies

One approach is through the use of visual strategies. As previously mentioned, these can be two-dimensional or three-dimensional representations of a particular concept used to communicate and teach that idea or concept. These take the form of

pictures, icons, photographs or gestures to enhance the understanding of spoken words communicating an idea. The use of visual systems can strengthen the child's understanding of the communication in his or her environment (Peeters, 1997; Quill, 1997).

'Using visual environmental supports to mediate communication interactions and support understanding provides a nontransient foundation essential for more effective communication... When visual supports are used to give these children information and direction, child comprehension increases significantly.' (Hodgdon, 1995b p. 268)

It is important to remember the following points about visual strategies:

- Visual strategies do not exclude vocal exchange. The limited use of key words is usually encouraged to try and reinforce the receptive meaning of spoken words.
- Visual strategies should be viewed as a temporary support mechanism for communication and reduced when appropriate to the individual.
- The goal of visual strategies is to enhance the meaning of communication for the child. No one particular approach is right for every child in this subgroup and alternative types of visual strategies may need to be tried before a 'best' approach is discovered for any one individual child.

One of the most prolific authors on the subject of visual learners, Quill (1985; 1995; 1997; 1998), identifies specific cognitive difficulties in children with autism that make the use of visual systems preferable. She feels that autistic children have difficulties shifting attention. This makes it hard for them to follow a normally changing conversation or obtain meaning from social events. In addition their 'cognitive deficits entail a constrained ability to analyze and integrate information cohesively and flexibly. ...they are left with a series of fragmented experiences...' (1997 p.699). Lastly, their ability to remember nonverbal material is better than verbal material. These all make the use of visual systems preferable.

Peeters (1997) highlights 9 reasons why a visual system can compensate for an ineffective verbal system (see Figure 4.1).

Visual Systems and Autistic Children

1. Makes abstract concepts more concrete.
2. Communicates concepts that cannot otherwise be understood.
3. Helps individuals cope and prepare for changes.
4. Increases independence.
5. Reduces failures and behavioural problems.
6. Reduces stereotyped behaviours and therefore increases socialisation.
7. Reduces dependency on specific primary care individuals and decreases anxiety when staff or environmental changes occur.
8. Helps autistic individuals understand and manage the concept of time.
9. Reduces passivity.

Figure 4.1. Visual Systems (Summarized from Peeters (1997))

Hodgdon (1999) concludes that students on the autistic spectrum do not understand their world very well. 'They tend to be visual learners living in a very auditory world.' (p. 65). The use of visual strategies can help rectify the situation and make better sense of the world around them for these children.

4.1.3. Communication

Before considering some of the various types of visual approaches and relevant literature, it is important to discuss the concept of communication. It is essential to note that because a particular child does not use spoken language or visual strategies, it does not necessarily follow that they are not communicating (Howlin, 1998b). Although Webster's Reference Library Concise Edition, English Dictionary defines communication as 'to impart, to share; to succeed in conveying information...', others use a broader definition. Layton et. al.'s (1995) definition of communication is particularly descriptive. It states that it is the ability to let someone else know your

needs and desires, verbally or nonverbally. This is critical to understanding the subgroup for discussion in this experiment, as Schreibman (1988) states that 50% of autistic children are functionally mute (p. 106). Bondy and Frost (1995) estimate this number to be as high as 80% (p. 322).

Just as society can communicate the need for motorists to slow down on a particular stretch of motorway by posting a police officer with a speed gun, and infants can communicate that they wish to be picked up by outstretched arms, non-speaking autistic individuals also communicate without the use of spoken words. 'Most communicate a great deal, although how they attempt to communicate may not always be socially desirable, and what they are attempting to communicate may prove difficult to establish' (Howlin, 1998b p. 107). This can lead to a very ineffective communication system from the point of view of the child, which many believe is demonstrated by antisocial behaviour (National Research Council, 2001). Some researchers have proposed a link between the inability of an autistic individual's ability to express his or her needs or wants, or understand when others express their needs or wants, and disruptive behaviour. The most frequently cited example of this in the literature is aggression (see for example Schopler et al., 1994; Koegel et al., 1995; Layton et al., 1995; Hodgdon, 1995b; Howlin et al., 1998a). Cohen (1997) states that a 'lack of an effective communication system is associated with increased tantrums, aggression, and even self-injury' (p. 109). Hodgdon (1995a; 1995b; 1999) states that the lack of an effective communication system is one of the fundamental deficits in children with autism and that often leads to behavioural problems. 'As more is learned about autism, it appears that challenging behaviour may... [be] a result of certain other characteristics: difficulty establishing and maintaining attention, interpreting verbal communication, and developing skills such as sequencing and organization' (p. 265). Hodgdon (1999) summarises this concept nicely when she states, '...communication difficulties can be a *primary* reason for many behaviour problems' (p. 26).

The proposed link by the researchers listed above between the lack of communication and aggressive incidents is an interesting one. It makes the assumption that the individual autistic child is consciously attempting to communicate and therefore purposefully exhibiting antisocial behaviours to get their needs met. It also assumes

the individual autistic child understands the concepts of cause and effect and the aggressive act is a frustrated response due to the child's inability to access the desired entity by their purposeful attempts to communicate. Further, it assumes that the individual autistic child understands the mental state of others, and can therefore direct the activity of another individual based on their own actions (Theory of Mind- the belief that autistic individuals lack the social understanding of the beliefs and reasoning of others) (Baron-Cohen et al., 1985). Theory of Mind is frequently debated among researchers, most notably by the writings of Baron-Cohen (1985; 1993; 1995).

The link that some researchers (Hodgdon, 1995b; Cohen et al., 1997) have chosen to make between aggression and a lack of a means to communicate effectively, assumes that the empirical evidence gathered proves the theoretical hypothesis. The position taken by this researcher is to see if there will be a decrease in aggressive behaviour by giving some means of communicative intent to the children in the study. It does not make the assumption that the two are invariably linked, but wishes to see if, in practice, this may be a by-product of increased communicative ability in the children through the use of visual strategies.

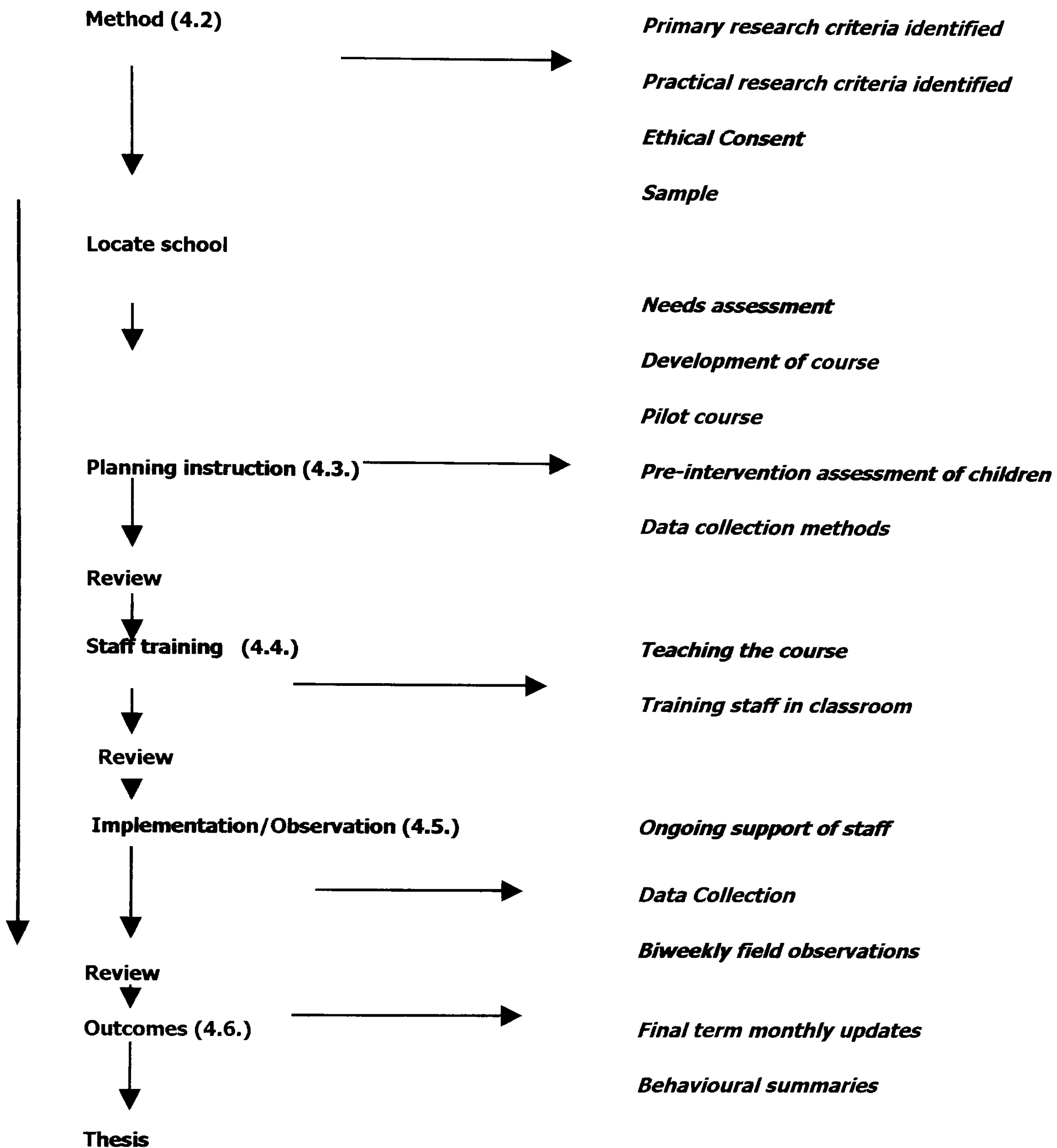
The literature has demonstrated that researchers believe there is a strong link between aggressive behaviour and the lack of an effective communication system. The literature also proposes that visual strategies may be an effective way to address this. It is this particular aspect that is of interest to the action research. What impact would there be on an identified group of children severely affected by autism that had limited means of communication and frequent aggressive tendencies, if visual strategies were used to improve communication?

This section defined and described the various visual systems used in education. The next section will describe how some of these systems were used in action research.

4.2. Method

The following flow chart shows the course of action the research took. (Note: the section of the chapter (in brackets) that discusses the topic, follows each of the main themes listed on the left.)

Action Research Flow Chart



This is the first of five sections that will describe the events of the action research. It will describe the process involved in planning the research including the research criteria, ethical considerations and the sample.

Several primary and practical research criteria were identified for choosing a school in which to conduct the case study (see Chapter 3 for further discussion). These are listed in Figure 4.2.

Primary Research Criteria	Practical Research Criteria
<ol style="list-style-type: none"> 1. Autism specific educational provision 2. Diagnosis of autism required 3. Primary school aged children 4. School consent 5. Parental (and student, if possible) consent 	<ol style="list-style-type: none"> 1. Location 2. Willingness to focus on visual teaching strategies

Figure 4.2. Research Criteria

Both the primary and practical research criteria contribute to the investigation of the experiment because of the experiment is interested in visual teaching strategies for primary school aged children with autism. This means that the school chosen must provide education for this population (Primary Research Points 1-3) and consent to the research (Primary Research Points 4-5). In addition, a school should be within a convenient travel distance for the researcher (Practical Point 1) and openly cooperate with the research (Practical Point 2).

Initial inquiries to the local autistic society (a branch of the national support group for families affected by autism) led this researcher to several schools. Further telephone discussions eliminated two schools because they did not meet the research criteria listed above. The third school, St. Joseph's School¹³ met all the research criteria (Primary Research Criteria 1-4 and Practical Research Criteria 1-2), and granted school consent for the research. Although the school could not grant consent on behalf of the parents (Primary Research Criterion 5), they did not believe this would be a problem.

As the school met the first four Primary Research Criteria, the next step was to secure ethical consent from the university and once granted, secure consent from parents of the children participating (if possible).

In the letter to the Head of the Department of Education of Brunel University in 1999, five ethical issues were identified for consideration. These are highlighted in Figure 4.3.

¹³ All names and identifying details of the school and individuals involved in the case study have been changed.

Ethical Considerations

1. Parental consent
2. School consent
3. Measurement
4. Treatment
5. Withholding treatment

Figure 4.3. Ethical Considerations

The first issue was the need to obtain parental permission. This would include: the consent to access files/records, to conduct assessments and to collect other data, permission for this researcher to work with their child (on a limited basis), and an agreement that identifying details of children would be kept confidential. Secondly, although the school gave initial oral consent, the school permission should include the consent for this researcher to be on the premises, conduct sessions with staff and work with children (on a limited basis). A signed consent form would also need to be obtained to allow the researcher to videotape some of the work with the children.

Thirdly, measurement would take several forms. It would include the usage of video footage, interviews, and a daily logbook as well as ongoing measurement of the individual child's progress. (See Chapter 4 for additional details on data collection.)

The last two issues deal with the treatment itself. All visual teaching strategies to be employed were recognised approaches and widely used with the autistic child. Therefore they are not considered experimental or potentially harmful to the children involved. Lastly, an acknowledgement that within the resources available, all children meeting research criteria would be served.

Ethical consent was granted on 24 February 2000 with the recommendation that the research adhere to British Educational Research Association Ethical Guidelines (BERA, 1992). In addition, although not a requirement of the school, a current police check on this researcher was secured and a copy of this given to the school.

In January 2000, a Briefing Sheet and Consent Form was sent to each parent of the five children¹⁴ in the Junior Classroom. (See Appendix 3.) All five parents involved signed the consent form and agreed to have their child participate in the research

¹⁴ All identifying details of individuals have been changed.

project. Although desirable, consent from the individual children involved was not feasible. All of the children had severe learning disabilities and were under the legal age of consent. This fulfilled the last of the Primary Research Criteria (Primary Research Criterion 5) and therefore, all of the Research Criteria were met.

There were five children in the Junior classroom, which made up the sample for the small experiment. All five children had severe learning disabilities, in addition to a diagnosis of autism. A brief summary of them and the areas targeted can be seen in Figure 4.4.

Name	Age at start	Contenance (Y/N/Partial)	Communication (S=sign, G=gesture, SW=spoken words, N=none)	Target area	Methods used
Darren	9	N	N	Request items wanted	PECs (Picture Exchange Communication System)
Gerry	11	P	G	Stay on task	Reward chart
Raja	9	N	S, G, SW (limited)	Eat food without throwing it	Charting system
Daisy	11	Y	S (limited)	Exit mini bus without aggression	Reward chart
Alex	10	N	N	Contenance	Photo programme

Figure 4.4. Summaries of children

4.3. Planning Instruction

This section will discuss the training of staff and the pre-intervention assessment of the children. Specifically, it will discuss the needs analysis, the development and piloting of the training course, pre-intervention assessment of the children, and data collection.

After the school was located and appropriate ethical consents granted, a needs analysis was conducted. A 'needs analysis is research designed to render decision-making informed rather than conjectural and speculative' (Cohen et al., 2000 p. 391). Although the school stated they followed visual strategies, the extent to which

this policy was put into practice and training provided was unclear and a needs analysis was seen as necessary (Bramley, 1996; Buckley et al., 2000).

The senior management and school staff at St. Joseph's embraced the idea of using visual strategies when working with children with autism, but lacked a formal way of conveying this teaching technique to staff. Around the school (and on staff key rings) were black and white symbols (PICs) that staff were encouraged to use when communicating with children. Previous meetings with the Principal also highlighted the school's view that they encouraged the use of symbols, although no formal instructional programme or in-service training existed on the background, content and implementation of this visual strategy for working with the children.

It was considered important to involve the teaching staff and middle management in their views on the use of visual teaching techniques at St. Joseph's School (Bramley, 1996). Early discussions and pre-intervention observations (noted in the research log) revealed that the symbols in the classroom were rarely used. Those held on key rings were used more frequently, but still inconsistently. When asked how effective the staff felt the symbol system was, replies ranged from one senior manager that felt it was very effective and useful; to several classroom staff that felt it was more of a practical hindrance. Concerns arose over the practical implementation (missing cards, access for children or missed communication opportunities).

Any elaboration on the present system must involve the staff who will be putting it into practice. The involvement and enskilling of the teaching staff was seen as essential to ensure full engagement with any new strategy. This would also ensure that other conflicting interests (changing staffing patterns, staff control issues) would be addressed by their opportunity to be directly involved with training and programming decisions made (Morrison, 1998; Wills, 1998).

The needs analysis identified key areas that required attention. These were developed into a training course of 9 two-hour sessions taught by the researcher.

Two local LEA run special schools closest to this researcher were contacted to see if they would be interested in having the pilot of the training course offered without cost to their staff. The response from the second special needs school contacted proved

positive and the researcher conducted the course over a 9-week period at the school in the evenings. Following the initial course and student evaluation, it was adjusted to incorporate feedback from the school and staff. This formed the 9-week course that was taught at St. Joseph's.

Each of the children involved in the action research were assessed prior to any intervention. In reviewing the research, a link was proposed between behavioural incidents and lack of communication skills in children with autism (see Section 4.1.3 for prior discussion). Initial data was taken on children to measure behaviour incidents to see if there would be any change during or at the end of the research. Ten-minute segments were observed for each child throughout various times of the day and week, during different activities. A counter was used to keep track of the times the child was aggressive to either him/herself or to other students and staff. Aggressive behaviour was defined as negative physical contact between the child and staff, other students or themselves. This was repeated monthly for the course of the case study and follow up period. (See Appendix 5 for further details.)

The last topic in this section discusses data collection methods. A school's ability to measure progress in a child should be demonstrated in four ways: it should be auditable, tangible, independent and replicable (See Figure 4.5).

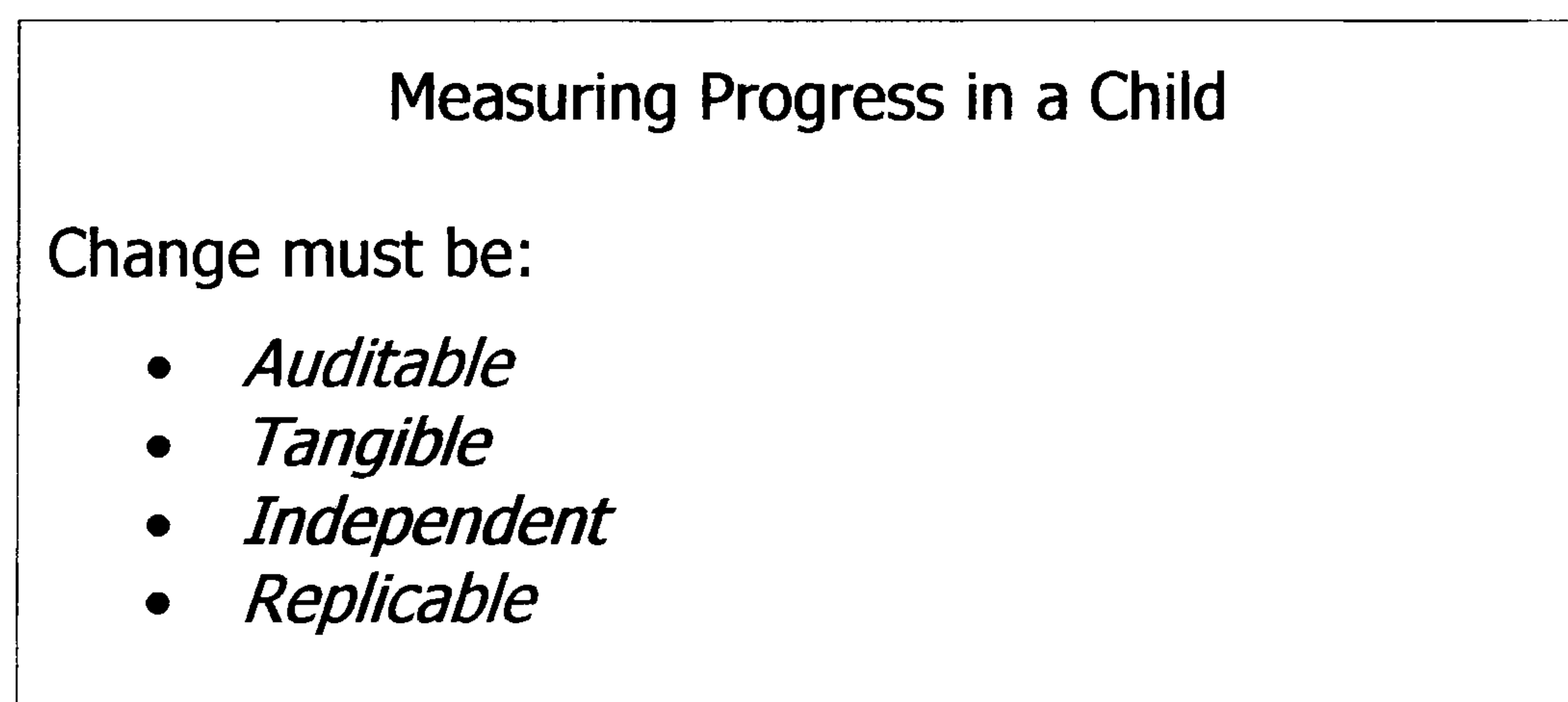


Figure 4.5. Measuring Progress in a Child

Schools must demonstrate that outside bodies have found progress to be robust and is not just the opinion of the school or staff involved. Traditionally this is demonstrated in one of two ways: examinations and/or outside assessments by independent bodies.

Student progress is used as one way to show that educational provision meets the national guidelines. Teacher evaluation may be considered by some to be subjective.

A way to counter this is through the use of national exams, standardised and independently scored to ensure neutrality in marking. This is something that is auditable (by standardised national exams), tangible (test scores), independent (outside exam bodies) and replicable (standardised exams should yield similar results in all settings).

As previously stated (see Section 4.2, Figure 4.4.), the children at St. Joseph's demonstrate challenging behaviours. Frequently they have been excluded from one, and in some cases, many specialist schools. The families of these children can no longer have them living at home due to their extremely challenging and/or aggressive behaviour. Most are nonverbal, severely autistic, severely learning disabled and incontinent. Due to the strong negative correlation between IQ and degree of autism (Mesibov, 2000), it would follow then that the school's population generally has a very low IQ. This is therefore a serious impediment to the use of national exams, since these children would generally be in the lowest percentile, and as such, standardised testing is not written to incorporate their ability. In a school like St. Joseph's, the children are not at a level where national exams could be administered and taken.

This would not only apply to national exams, but also applies to many standardised exams of intelligence. There are several problems with administering a standardised exam to this population.

- The children in the classroom do not consistently respond to spoken language and are not able to communicate reliably by words, gestures or adaptive measures to questions asked.
- The tests themselves are not standardised on this small, severely disabled percentage of the population and therefore no comparison can be made between this group and the population that these tests have been standardised on.
- The tests themselves are typically age limited. Therefore some of the Infant Scales (Bailey for example), which do have items these children could score on, are invalid due to the fact that the children at the school are beyond the upper age limit for the test.

- Progress made by these children is, in general, very slow. Use of yearly standardised testing would most likely show little, if any change.
- Other assessments such as the Psychoeducational Profile Revised (PEP-R) (Schopler et al., 1990) specifically designed for the autistic population do not yield scores, but lists of skills emerging in very defined categories. These again require a certain amount of compliance and cooperation from the child being tested. Yearly administration would yield little change from year to year.
- Yearly administration of standardised exams would prove time consuming and costly for the school.

Therefore, the use of exams or standardised assessments does not provide an appropriate way of assessing the school's provision.

If exams are not functional for this group of the population, or have value for the purpose of this thesis, how can the effects of teaching and learning be assessed? Traditional assessments do not apply, but what can apply is the national and international body of knowledge that exists that can be used as a yardstick on which to determine if a school qualifies as a 'good school' (Hargreaves, 1967; Rutter et al., 1979; Fullan et al., 1991; Fidler et al., 1999). Is the data generated by the staff and the behaviour log tangible, auditable, independent and replicable?

- **Tangible-** The data generated was a faithful log of conversations with staff and descriptions of change that occurred. This feedback came from a variety of staff over the yearlong case study.
- **Auditable-** The data listed (both notes and tally counts in behaviour logs) was gathered from weekly visits to the school during the case study. This data was open to all at the school. Therefore, the data collected was done in an open way in full view of participants. In addition, a short summary was presented to the principal and one Trustee to update them on the progress of the research.
- **Independent-** This researcher had no formal ties to the school, and did not receive compensation from the school for time spent doing the research. The researcher's role was that of independent observer.

- Replicable - Like all case studies, the work at St. Joseph's School reflects the events that occurred on a specific time, date, staffing and student pattern. It would therefore be impossible to replicate the events as occurred.

Therefore, the method of monitoring student progress by discussing an individual child's programme and behaviour measurements (see Appendix 5) is seen as a valid tool for the purpose of the action research study¹⁵.

The difficulty arises when the individual charting mechanisms designed by staff for the monitoring of individual programmes are not used regularly and reliably. Although this action research was designed to document progress following behavioural principles, despite repeated attempts by the researcher to get the staff to document the children's progress, notes in the research log show that this was not forthcoming. Instead, what is presented is data based on feedback, dependent on the staff opinion of the child's progress and beyond the direct verification of the researcher. (See Section 4.7 for further discussion.)

4.4. Staff Training

The revised training course was run by the researcher and taught at St. Joseph's School from May 2000 to September 2000 (with a break over the month of August) for the staff in the Juniors' class and some residential staff (all those attending were chosen by the Head of the Department). It consisted of a 9 weekly two-hour sessions.

Staff attending the course decided on targets for students and devised educational programmes based on visual strategies to address these targets.

The researcher provided ongoing feedback and consultation on the programmes devised by the staff.

4.5. Implementation and Observation

Work with the children began in September 2000 and continued throughout the school year. Over that time the following happened:

¹⁵ The school does use the P Levels of the National Curriculum to assess learning, but progress is very slow and therefore would not be sufficient for the purpose of this research.

- Staff designed the programming, created the materials needed and the charting mechanism to measure progress.
- Staff altered programmes as necessary. This included moving programmes forward, if they were successful or adapting them if they were challenging to the child.

The researcher monitored the programmes and provided feedback to staff. The researcher visited the school twice weekly to check on the progress, record staff comments in the research log and discuss amendments if necessary. The researcher was also available by email or telephone during that period.

As an example of how an individual programme was implemented, it may be helpful to briefly discuss one individual case. Figure 4.4 shows a summary of Alex, a nonverbal boy of 10, with a target to become toilet trained. Before initiating the programme, Alex would soil himself two or three times daily.

In preparation, a staff member took photos of the toilet, with a neutral background. All of the identical photos were enlarged, laminated and Velcro was attached to the back. One of these photos was attached to the outside of each of the main toilets stalls that Alex had access to, as well as inside the classroom, break room and bedroom of Alex.

After each meal and break time, Alex was taken to the photo and encouraged to remove it from the wall. He was then encouraged to match it to the identical photo outside the toilet (attaching it with the Velcro), lower his trousers and sit on the toilet. Staff were instructed to wait outside the cubicle. Each time Alex was taken to use the toilet this procedure was followed. Staff would remove the photo and replace it afterwards.

Whenever Alex would touch or remove the photo from the wall, he was taken to the toilet. If Alex soiled, he would be taken to the photo, directed to remove it and then escorted to the toilet to have his clothes changed. This procedure was designed for usage in both the school and residential settings.

If Alex was successful in eliminating on the toilet, the staff would give him lots of verbal praise. If Alex did not eliminate, but stood up (indicating he was finished) he would be encouraged to pull up his trousers and come back to the classroom. If neither happened, he would be given several minutes and then directed to stand as above.

Staff were asked to chart Alex's progress and the researcher noted updates at each visit in the research log.

4.6. Outcomes

This section will describe the two methods used to collect data on the children's programmes (see Figure 4.6 for a summary of the children, target area and visual strategy used). First it will look at the individual programmes and then it will describe the behavioural log.

As previously stated in Section 4.4. and 4.5., the staff working with the child determined individual programmes. Although the researcher provided initial training and ongoing support, the classroom staff did the day-to-day work with the children. Below are several charts of the children over the course of the ten-month case study. (See Appendixes 4 and 5 for individual charts and additional details.)

	Daisy		Gerry		Darren		Alex		Raja~	
	#	%	#	%	#	%	#	%	#	%
Progress noted	5	12	13	34	7	15	14	37	2	50
Neutral	0	0	0	0	0	0	1	2	0	0
Lack of progress noted	6	15	10	26	5	11	7	18	2	50
Programme not done	22	54	13	34	29	63	14	37	0	0
Child absent	8	19	2	5	5	11	2	5	0	0
Total number of observations*	41		38		46		38		4	

*The total number of observations varies due to disparity in the start date of individual children's programmes.

~Staff discontinued Raja's programme shortly after it began. No other target was identified or replacement programme started.

Table 4.1. Individual Programmes, Child Summaries

Table 4.1 above shows the individual children's progress under several categories. As stated in Section 4.3., the data collected is a faithful account of the opinion of staff

members (as documented in the research log) on the individual progress of the children. It is documentation of staff comments on their reflections of how the individual child was progressing, and not on the objective criteria that was established. (In fact, it was noted in the research log that there was little evidence of any systematic monitoring of student's progress. When specific mechanisms were drawn up, the research log shows that they were completed on what appears to be a random basis.) It is broken into four possible categories, followed by examples.

- Progress- included in this category are comments such as:

'Great success with Darren and PECs! From standing position, several independent requests.'

'Daisy worked well, compliant, and came off the van.'

'Gerry worked 15 minutes before it was only 5 minutes. He is excited when time is running out and earns his 5 stars for the computer'

'Gerry got his star chart and sat down at his desk! He wanted to work for his computer time and waited for Lisa (teacher) so he could start working!'

- No Progress

'Alex wet today at 11:00, gone to the toilet at 10:40'

'Big incident during Christmas week after a long van ride' (Daisy)

'Why is aggressive behaviour increasing while using chart?' (Gerry)

- Neutral

'Alex wet constantly at home, but not at school'

- Nothing noted

'Not been done for a while'.

'Star chart is missing.' (Gerry)

'I don't know' (response by staff when asked about progress)

Although most are self explanatory, the neutral category exists to allow for one observation where both progress and difficulty was noted for Alex.

	October	Nov.	Dec.	January	February	March	April	May	June	July
Daisy +	1/2	3/6	0	1/8	0	0	Daisy was moved to another class.			
-	1/2	0	0	0	4/8	0				
NN	0	3/6	5/5	7/8	4/8	3/3				
Jerry +	Not started	5/5	4/6	2/8	0	1/4	0	1/2	0	0
-	started	0	1/6	3/8	4/8	1/4	1/2	0	0	1/1
NN	yet	0	1/6	3/8	4/8	2/4	1/2	1/2	1/1	0
Darren+	4/5	1/6	0	2/8	0	0	3/3 visits	0	0	0
-	1/5	1/6	1/6	0	0	0	no teaching	2/2	0	0
NN	0	4/6	5/6	6/8	8/8	4/4		0	1/1	1/1
Alex +	Not started	3/4	3/6	4/8	3/8	0	1/2	0	0	0
-	started	0	2/6	0	1/8	2/3	1/2	1/2	0	0
NN	yet	1/4	1/6	4/8	4/8	1/3	0	1/2	1/1	1/1
Raja +	1/3	1/1	Programme discontinued and not replaced.							
-	2/3	0								
NN	0	0								
Monthly Average	6/10	13/22	7/23	9/32	3/32	1/15	1/4	1/6	0/3	0/3
	4/10	1/22	1/23	3/32	9/32	3/15	2/4	3/6	0/3	1/3
	0	8/22	8/23	20/32	20/32	10/15	1/4	2/6	3/3	2/3
Percent	60	59	30	28	9	7	25	17	0	0
	40	5	17	9	28	2	50	50	0	33
	0	36	52	63	63	67	25	33	100	67

Table 4.2. Individual Programmes, Monthly Summary ('+' = progress, '-' = lack of progress, 'NN' = nothing noted)

Both Table 4.1 and Table 4.2 show the raw data and individual progress for the children. Table 4.1 shows percentages, while Table 4.2 breaks this data into monthly summaries. These figures show some interesting trends.

- Programme not done. For most of the children, the research log notes reveal that their individual programmes were not practised with staff over time. Although Gerry and Alex show equal percentage of notations in the research log notes for observations where programming and no programming was done (37% in both cases), this does not apply to Daisy and Darren. In the case of these two children a greater percentage of time was spent with no programming than when structured programming was followed (Daisy: 54% versus 12%, Darren: 63% versus 15%). In the case of Raja, her programme was discontinued and not replaced after four visits due to the request of the teacher, even though the data reveals some initial success with it.
- Lack of progress noted. During the visits to the classroom, the researcher asked about the children's progress and the research log notes reveals the large number of times that staff shared that no progress was occurring. This is shown in both charts (noted as a '-' symbol in Table 4.2). As this number increases, so does the number of times that no work was being done ('NN').
- Monthly Summary. Table 4.2 shows that the trend of increases in both the 'Lack of Progress' and the 'Nothing Noted' categories over time yields corresponding decreases in the 'Progress' category. However, it must be noted that frequency of observations decreased near the end of the case study and the fact that during the main focus of the action research, the researcher was not present in the classroom at all times. Therefore the notes in the research log can only depict the events that were either described by staff or witnessed by this researcher.
- The average percentages for the children over the 10-month case study are shown in Figure 4.6.

Child Programme Summary

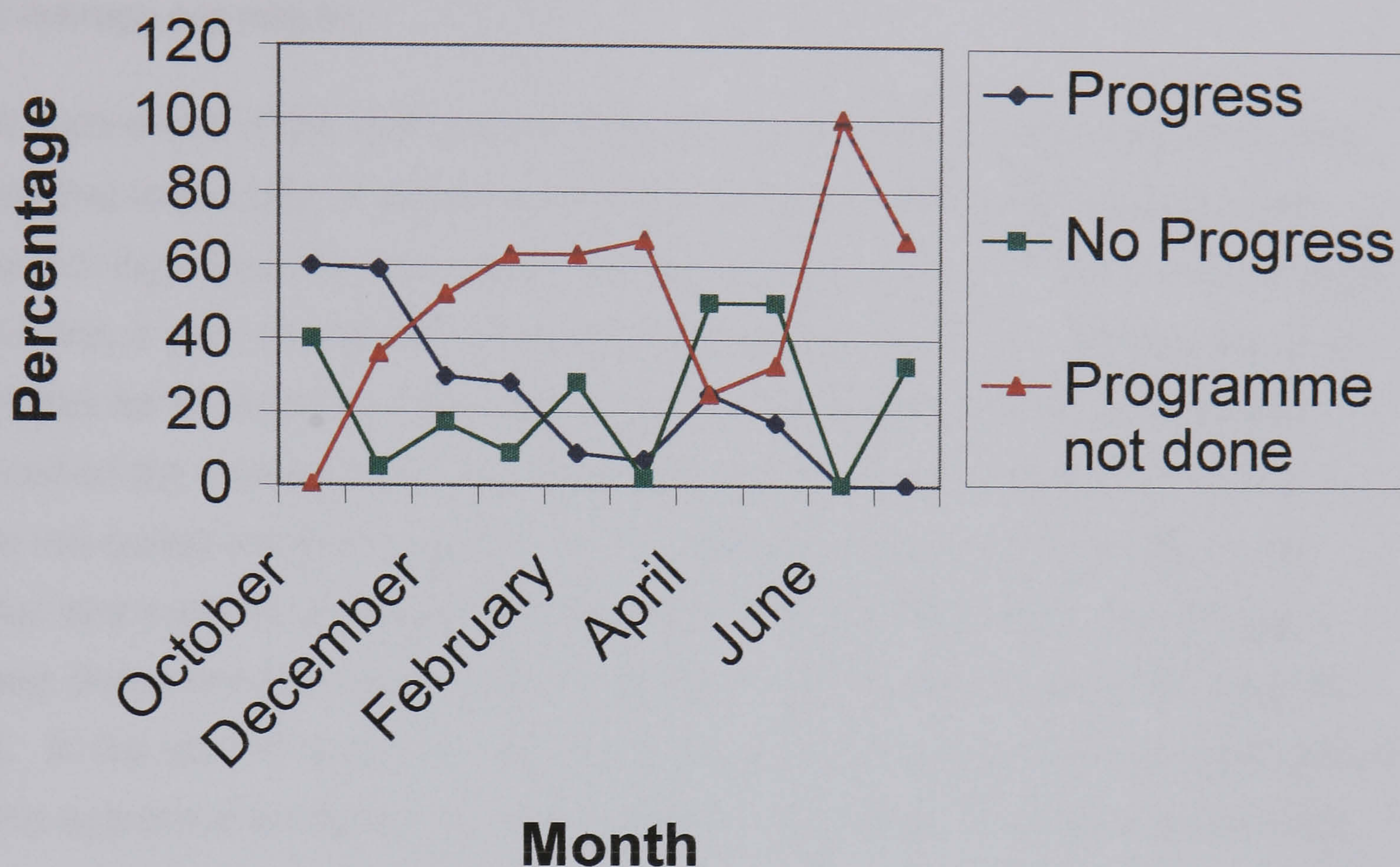


Figure 4.6. Child Programme Summary

In addition to the data generated on the individual programmes, data was kept on the aggressive behaviours of the children. This was appropriate due to the hypothesized link proposed in the literature between aggression and a lack of an effective means of communication (Howlin, 1993). The types of aggressive behaviour differed among the children, but included: pinching, hitting (self and others), hair pulling, head banging (self and others), kicking, scratching and biting (self and others). As described in Section 4.1.3., the literature suggests a link between aggressive behaviour and lack of communication (Howlin et al., 1987). The work with the children on visual strategies was intended to explore any potential link and therefore data was collected. As described in Section 4.2., a tally count of aggressive behaviour was taken in ten-minute time frames. These were recorded both as baseline data and during the 9-month case study. The data generated is summarised in Table 4.3 and Table 4.4.

The first of these tables (Table 4.3) shows the summary of the data collected both as baseline (numbers in regular type) as well as during the 9-month pilot (numbers in

bold font). The first three columns show averages. The first column is the number of aggressive incidents over the total number of ten-minute tally sessions. This yields the mean number of aggressive incidents per ten-minute tally (column 2) as well as the average per minute.

The second half of the chart breaks this data down further. It categorizes the data according to the type of activity the child was engaged in (as documented in the research log) when the ten-minute tally began. It is important to note that although desirable, it was not possible to ensure equal distribution of tally sessions across all activities for all children. This may be due to child illness/absence or restrictions placed on the child by staff (for example Raja was not taken into the community). The raw scores are also included. This is to enable a fuller understanding of the range that exists for individual children. Closer investigation shows that although Daisy, Daren and Alex show data close to their individual mean, Gerry and Raja do not. In the case of Gerry, the mode would most likely depict a more accurate picture of his aggressive behaviour, as it did not occur very often. But Raja is a child with extreme variation, and therefore the range in her score, from a low of 0 (as seen in one tally taken at a break time) to a high of 393 (also taken during a break time) is vast.

As stated in Section 4.2, the ten-minute tally sessions occurred at various times of the school day and days of the school week. If the total number of tally times for the five children were added together under each category, the chart reveals some interesting data. (This number is under the individual categories.) It is fascinating to note the large number of tally sessions that occurred during break times for the children. This is more than double that of one to one teaching times (22 versus 45). If the group and one to one teaching times are added together, there still is a large proportion of the tally times that occur during break time (22 teaching + 17 group = 39 total compared to 45 break time). The research log therefore reveals that the children spent considerably more time on break or free time activities than in teaching time, during the action research observations.

Another way of looking at the aggressive behaviour data is to break it into the months of the year. (See Table 4.4 and Figure 4.6.) The July data presented in the first

column is the baseline data and the balance of the chart reflects the data from duration of the case study. Averages are presented in bold, with the raw data below.

Aggressive Behaviour Pre-intervention Baseline and Research Summary*

Child	AB/total sessions	Average per 10 minutes	Average per minute	Baseline Observations per Activity (Raw scores per activity) Data from action research study. Observations (Raw scores)					
				1:1 Teaching (8/22)	Group (13/17)	Break/Free time (26/45)	All school (6/4)	Transition (7/9)	Bus/Community (4/7)
Daisy	22/11 43/17	2 2.5	0.2 0.25	1 (0) 5 (0, 16, 0, 0, 2)	1 (2) 3 (0, 0, 0,)	5 (1, 0, 5, 0, 1) 4 (0, 3, 0, 1)	1 (6) 1 (0)	2 (7, 0) 1 (0)	1 (0) 3 (11, 2, 6)
Gerry	4/9 3/23	.44 .13	0.044 0.013	1 (0) 10(0,0,0, 3, 0, 0,0, 0, 0,0)	1 (0) 2(0, 0)	4 (3, 1, 0, 0) 7(0, 0, 0, 0, 0, 0)	1 (0) 2 (0, 0)	1 (0) 0	1 (0) 2(0,0)
Darren	122/14 78/21	8.71 3.71	0.871 0.37	4(13, 17, 7, 5) 2 (11, 2)	5 (11, 5, 13, 4, 1) 5 (14, 0,4,0,12)	3 (0, 2,16) 6 (3, 0, 3, 0, 4, 3)	0 1 (9)	1 (24) 6 (5, 0, 0, 0, 0, 8)	1 (4) 1 (0)
Alex	163/12 92/19	13.58 4.84	1.36 0.48	0 3 (5, 1, 3)	3 (76, 0, 48) 5 (44, 4, 0, 0, 0)	4 (16, 0, 0, 0) 8 (2, 8, 3, 0, 15, 0, 0, 3)	2 (0, 6) 0	2 (1, 16) 2 (1, 3)	1 (0) 1 (0)
Raja	716/17 2504/24	42.11 104.33	4.21 10.43	2 (51,41) 2 (63, 64)	3 (0, 21, 48) 2 (70, 138)	10 (82,30, 9,41,8,49, 12,42, 35) 20 (59,111,69, 41,54,87, 187,393,169, 1,103,66,166, 110, 0,58,166 144,177,8)	2 (2, 160) 0	1 (85) 0	0 0

*Baseline data was collected over seven visits in a one-month period. Numbers in bold collected during 15 tally visits over 10 months.

Table 4.3. Aggressive Behaviour Summary

Name	July	October	November	December	January	Feb.	March	April	May	June	July
Daisy	2 (22/11)	3.2 (16/5)	5.3 (16/3)	3 (6/2)	0	0	1.5 (3/2)	NA	0	2 (2/1)	0
Gerry	.44 (4/9)	0	0	1.5 (3/2)	0	0	0	0	0	0	0
Darren	8.71 (122/14)	NA	12.5 (25/2)	2.5 (5/2)	0	2 (4/2)	4 (12/3)	0	1.6 (5/3)	8 (16/2)	5.5 (11/2)
Alex	4.84 (163/12)	15.3 (46/3)	4 (12/3)	2 (4/2)	2.5 (5/2)	0	9 (18/2)	0	.5 (1/2)	3 (3/1)	1.5 (3/2)
Raja	42.11 (716/17)	77.66 (233/3)	57 (228/4)	137 (274/2)	281 (562/2)	58 (174/3)	NA	66 (66/1)	94.4 (472/5)	155 (310/2)	92.5 (185/2)

Averages	11.67	19.2	15.76	29.2	56.7 (/43.4)	12	3.6	13.2	19.3	33.6	19.8
Averages Without Raja	6.76	7.75	8.1	2.25	2.5	2	4.7	0	1.2	5.25	3.5

Table 4.4. Aggressive Behaviour by Month. Average scores (raw score/observations)

Although Raja is included in the data collection, it is interesting to see if her high numbers have any overall effect on the data. During the month of March, Raja was absent on the day the data was collected, and therefore she does not have a number listed. In addition, January shows an extremely high number. This could be due to the effect of one tally session in January where a number of 393 was recorded. (See Table 4.3 for breakdown.) If this number is replaced by the average tally count for Raja (260) the revised average of 43.4 is calculated. Although still a high number, it is closer to the others and perhaps a more realistic account of the month.

In looking at the averages without the influence of Raja's high numbers, a pattern starts to emerge (See Table 4.4). It shows that the months of October and November are above the baseline. A considerable drop follows in the scores during December, January, and February. March is high, but then April and May show the score dropping and gradually increasing again in June and July. The pattern presented shows a general trend toward higher scores in the beginning of the experiment and at the end.

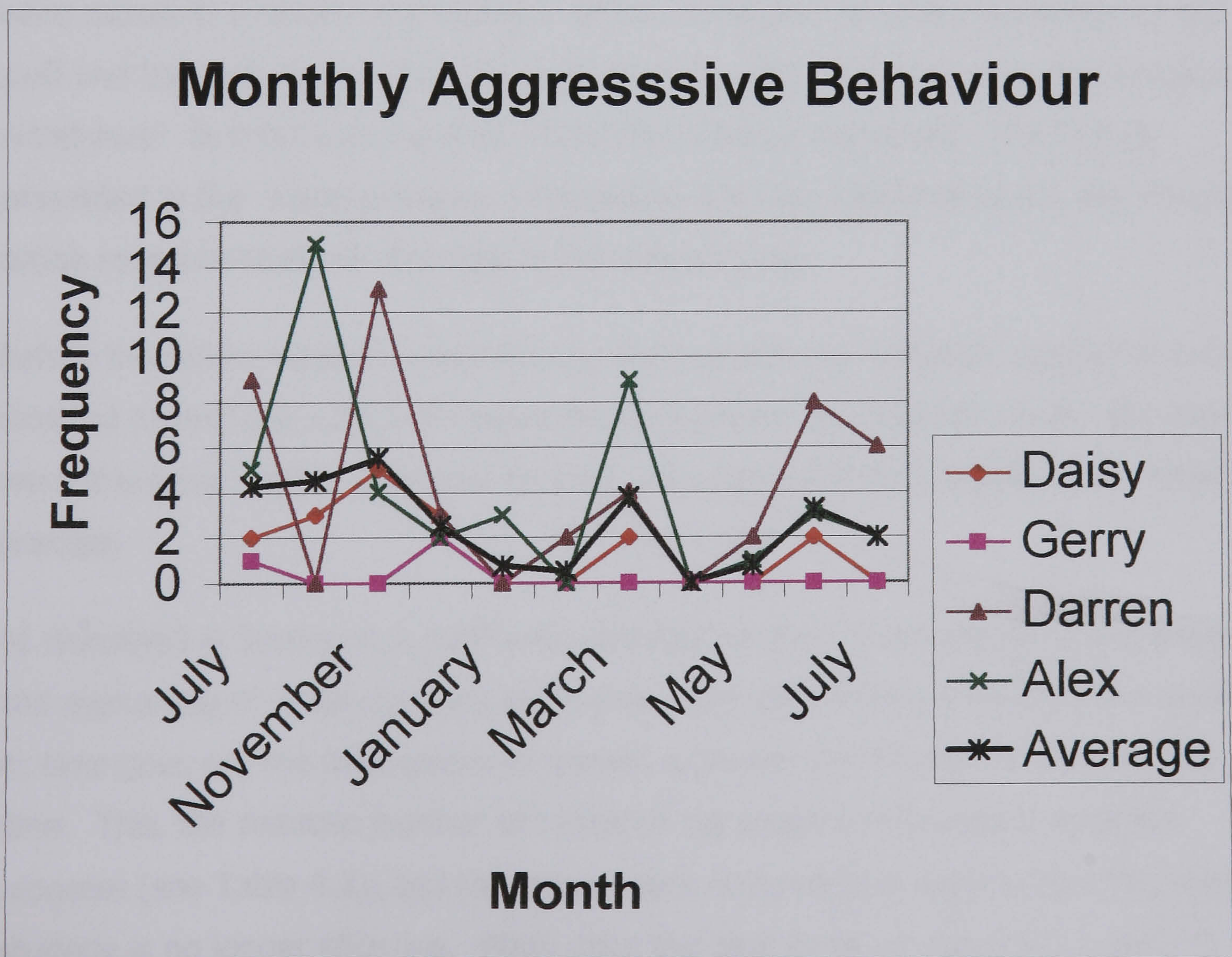


Figure 4.7. Monthly Summary of Aggressive Behaviour (without Raja)

In summary, the data presented above shows the trend of a higher proportion of free time (than time engaged in structured teaching), as well as a drop in the aggressive behaviour during the middle of the action research.

4.7. Action Research Summary

The data collected in the research log during the 10-month period at St. Joseph's School presents some interesting results. Table 4.2 shows a pattern where children showed initial growth in areas targeted by trained staff. This pattern does not continue for the duration of the action research. Tables 4.3 and 4.4 reveal a higher number of aggressive incidents at the beginning and ending of the action research. Table 4.3 shows the high proportion of time the children spent in unstructured activity.

The results of the action research were surprising. The data shows that children in the Junior class made initial gains, but then lost them. The action research was designed to assess the extent to which consistency of approach and team workings were robust in a novel circumstance. If the researcher provides leadership to the staff and the tools to practice new skills learned, what happens when the researcher withdraws? In this case, the data shows the children regressed. The figures presented in the charts previous, summarizes the data gathered during the 10-month action research study as recorded in the research log.

Before the action research commenced, the research log revealed negative comments directed toward the school management as reported by classroom staff. But absent were this same staffs' comments on their own perceived contribution to the observed practice.

As discussed in Section 4.3, staff were actively involved in the planning, implementing and evaluating of visual teaching strategies. The staff initially embraced this strategy. As time goes on, the data gathered reveals a greater percentage of unstructured time. This, the reduced number of research log notations showing a student's progress (see Table 4.2), and the researcher's observations suggest that this teaching strategy is no longer effective. What does the data show us about this trend? It is

therefore important to take a closer exploration of the data gathered to see what suggestions it reveals regarding this case.

4.8. Case Study

There are many factors that influence a child within the context of a classroom. This thesis adopts the writings of Bertalanffy (1968) as the theoretical model that can explain the influences that exist on a child. Bertalanffy's General System's Model is applied to see the child at the centre. The individuals and institutions the child knows or belongs to interact in various layers depending on the history, characteristics and interactions that occur with the child. This is a fluid model and is constantly changing under the influence of both time and changes in knowledge and experience. The small action research study provides insight into some of these factors, but the classroom is only one aspect. The case study focuses on the classroom, but within the intuitional framework of the school. The theoretical underpinnings of this research lead this study to investigate school wide issues, not just those of the classroom or classroom staff (Rapoport, 1986).

There were two primary sources of data for the case study, Strand 1: hand written descriptive data of the events and conversations that occurred in the classroom over the period of the case study (research log), and verified transcripts of three interviews that occurred with staff members.

Included in the research log were:

- Descriptions of events that occurred or general classroom features
- Paraphrases of comments and direct quotes made by staff members
- Monthly tally counts of children's aggressive behaviours taken during a 10 minute segment of time at a various times and activities
- Individual children's programmes and status
- Internal and External literature on the school (School Prospectus, OFSTED report)

Included in the semi structured interview data were the interviewee's comments on the following:

- Philosophy or ethos of the school
- Strengths and challenges of the school
- Personal comments on educational provision at St. Joseph's School by staff

As previously stated, these interviews were tape recorded, transcribed by the researcher, and then verified by the respondent to be a factual account of the conversation. (All identifying details were changed.) In addition, this researcher took notes during the conversation to allow the recording of thoughts that occurred during the interviews (Cohen et al., 2000). There was a large amount of data gathered during the case study. This was grouped into broad categories determined initially by the research question. This allowed the body of data to be organised and therefore analysed (Silverman, 1993). A coding procedure followed which was used for both the field study notes and interview data. These were coded independently of each other and then reviewed for general themes. (See Methodology Chapter 3 for additional details.)

In carrying out the analysis, the following procedures were adhered to:

- All research log notes and interview transcripts were read in their entirety to get a 'feel' or 'sense' of the data. This is an important part of the analysis process because although the researcher was present at the interview and during the field study, the transcript along with the research log notes forms a link back to that time and place that enables the researcher to get back in touch with the themes that are occurring from the data (Kvale, 1996). These notes were read several times, enabling the researcher to organise the data that emerged (Miles et al., 1984). It is important to remember that the research did not determine the specific themes, but set a framework for themes to come from the data (Kvale, 1996).
- After general themes started to emerge, coding began (Silverman, 2000). A further reading of each interview was done to check appropriateness of the codes.

- The next step grouped the codes into categories based on the general themes. Again, the interviews were read and codes were checked and altered if appropriate.
- Lastly, the codes were labelled. The themes that emerged are discussed in the next section.

4.9. Emerging Themes

The research question directs investigation into the influences that support or inhibit appropriate provision for children with autism. It is therefore instructive to look at the practice of a school in its implementation of educational provision. During the course of the action research and case study, several themes began to emerge.

The school's Prospectus describes the use of some visual strategies as a tool to help with communication (use of Makaton and PICs). The senior management encouraged this use and were happy to have this researcher work with the staff on the application of visual strategies with the five children in the classroom. Training occurred for the staff, both as a separate course and within the actual classroom. Follow up was provided by the researcher to encourage generalisation of the skills learned, both on the part of staff and students. (See prior discussion in Section 4.3.)

Despite these measures, when the researcher withdrew from regular contact with the classroom staff, the gains made were short lived (see Table 4.2). It is clear that there are inconsistencies between the stated practice (as evidenced in school literature-school prospectus) and what is happening in practice. What factors influence the school's provision and their definition of appropriate educational provision? What themes emerge from the data collected from the logbooks, informal conversations with staff, semi-structured interviews, monitoring of aggressive behaviour of the children and outside inspection reports?

The remainder of the discussion of Strand 1 will look at the themes that influence the school's concept of appropriate educational provision for children with autism by examining the day-to-day practice in the Junior class at St. Joseph's school. This data

is generated through class observations, informal discussions with staff, interview data, behaviour log, and outside inspection reports. (See prior discussion in Section 4.4. for additional details.)

It is helpful when discussing a complex issue such as appropriate educational provision to think of it as a model that has many factors influencing the final concept. All of these influences exist on a continuum that is flexible and reactive to the other factors that shape not only an individual's perception of their world, but also the school as a whole. During the course of the study at St. Joseph's, eleven factors emerged from the data as having influence on the school's concept of educational provision. (See Figure 4.10 Continuums Influencing Appropriate Educational Provision.) Listed below are the two ends of a continuum, with any individual school falling between these two extremes. Although it is difficult to consider any of these aspects in isolation, each of these factors listed in Figure 4.8. will be examined from the data gathered during the 10-months at St. Joseph's School.

Continuums Influencing Appropriate Educational Provision

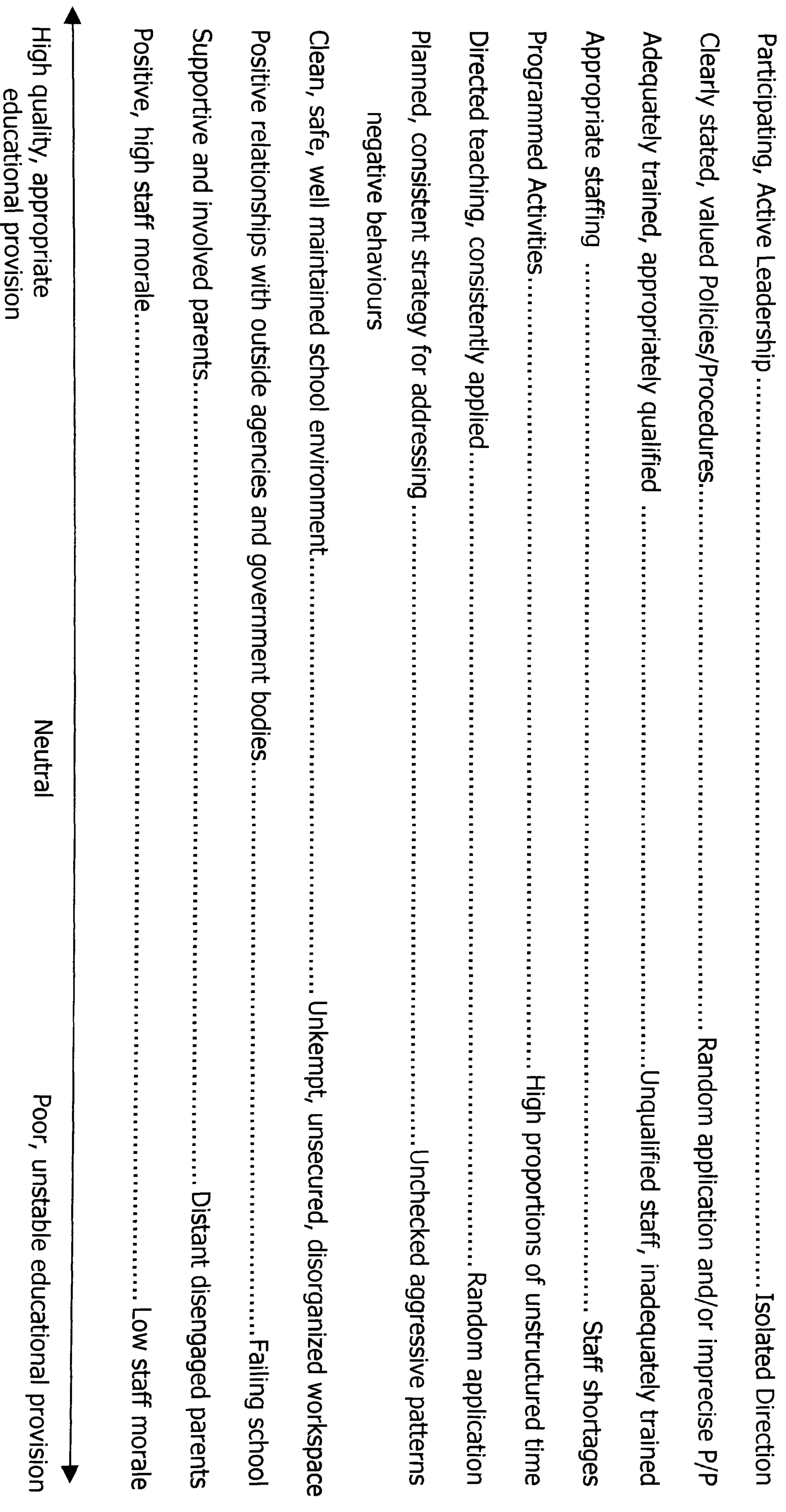


Figure 4.8. Continuums Influencing Appropriate Educational Provision

These 11 continuums have emerged from the data and are discussed individually in the sections following.

4.10. Theme One: Leadership

The first of the eleven themes that emerge from the data concerns leadership. The theme of leadership is a common topic for discussion in the literature (Bennett et al., 1992; Preedy et al., 1997; Fidler et al., 1999). This section will discuss the issue of leadership from the perspective of staff members and agency reports. It will concentrate on their views of the management.

The view of the staff about the school leadership was a common theme that emerged from the data. There were repeated references to Sarah, the Principal of the school, in both the logbook (from the direct care staff in the classroom) as well as the semi-structured interviews (conducted with the teacher, head of department and Sarah).

Comments from the various levels of staff within St. Joseph's School reflect the difference in perception of the leadership by classroom staff of the senior management team.

'Sarah does not have any idea what goes on in the classroom. Let me give you an example. When we were having all the problems with Daisy and I was outside her room. I filled in the form that was outside her door [for aggressive behaviour in children]. Then I get told off because I filled in the wrong form. No concern about how we are doing with Daisy, just that we filled in the wrong form.' Classroom aide.

'I believe the senior management team don't have a true perspective actually what's happening in the classroom and what is happening in the residential units. ... They expect all these things to happen in the classroom, but they are completely unaware of the dynamics of the classroom, you know the timetabling, staffing, and I just don't think they think through things properly.' Class teacher.

'...So I just feel in essence, that they just haven't got a true idea. I haven't seen Sarah in the classroom for well over a year.... I haven't seen Mark, I haven't seen Kathy [two deputy heads].' Class teacher

How does this compare with the view of the school principal? Comments revealed in the semi-structured interview disclose a different perspective.

'It's a massive thing. [communication] I mean even with the staff, it's a huge task. ...I think, I think of the quality management system at St. Joseph's. Each department knows it's job and this is what we do and this is what we say we do...' School principal.

'...everybody has a say and an opportunity to contribute. So staff will feed up what they want, we present it to parents, and professionals and they have the opportunity to say yes or no.' School principal.

'Now, if I can see children at a meal or go to assembly I think I have done quite well that week. If I go into the classrooms, I feel that is seen more of a bonus. And those are hard. And that's why Kathy and Mark [deputy heads] have much more of high profiles in terms of curriculum and going into school.' School principal.

The most recent OFSTED inspection (Fall, 1997) also comments on the school's management. It is important to note however, that these comments were made three years prior to the case study and may not be an accurate reflection of events during the time of the case study.

'The leadership of the school is sound.' (p. 23)

'The school operates a quality management system in which all its procedures are audited and monitored.' (p.23)

The data shows clear inconsistencies in the views stated by the various members of staff.

4.11. Theme Two: Policies and Procedures

The difference in the perspectives from senior management and employees at entry-level positions can be seen beyond their views on leadership. It is also apparent in reviewing the data on Theme Two concerning the school's established policies and procedures.

A school, like any institution, has to ascertain guidelines for the group of individuals who work for the school. This category reflects not only issues relating to staff rights and responsibilities, but also impacts on global issues such as the school ethos and the image the school wishes to present to society at large (for example: parents, LEA and social service representatives). Rules and regulations are either mandated by various state authorities (health and safety codes, employment regulations) or created by staff to express the unique contribution of the school (for example school ethos). Each plays a part in creating the school's distinctive view of their educational provision.

The first aspect investigated under this category is the view of staff on the school's unique perspective of education: school ethos, behaviour management policies and

intake procedures. Secondly, employment practices are investigated including time off, qualified teacher presence, and employee evaluations.

4.11.1.1. School Ethos or Philosophy of Education

An important aspect of this section is how the staff define the disposition of the school; its fundamental value and spirit. During the interviews, the three levels of management were each asked what the school ethos or philosophy of education was. Each, in turn, had a different perspective on this issue.

'Well, I've never actually been told the actual philosophy of the school. It hasn't ever been stated "this is it" to me. ...[I] have formed my own belief of what the philosophy is...[but] it would be nice "this is what we are aiming to do as a school, you know, this is how we go about it." You know, because it is helpful as a new person in employment to know what you are actually doing, otherwise you get six people going in six different directions.' Class teacher.

When asked to describe what she perceived this to be, she stated,

'I believe it is definitely catering for the children's individual needs.' Class teacher

In other words, the teacher states the school's main objective was the individualised education of the children. This is a contrast to the Head of the Department who states:

'I think that the school aims to provide a safe environment for the children that are here...They have probably been excluded from every other school they've been in too and there has been no other provision for them. So they have come here ...to be a safe environment for them and also an environment that will provide them with a good quality of life.' Head of department

The Head of the Junior Department views safety as primary in the school's perspective on their educational provision, and then the quality of life of the individual child. It is interesting to note the difference between the teacher, who views educational goals as most important, and her supervisor who sees safety as the primary focus of the school. This is different again from the views of the principal and founder of the school. She describes the school and her drive to set it up in as a reaction to inadequate current practices.

'...that group of children I looked after are all still in quite secure environments so they were extremely challenging young people and I was really concerned about the stress that it put on families...[children] who weren't getting respite care at all whose parents were even more stressed...' School principal

But when describing the school ethos, the discussion centres on 'positive practices'. When asked to explain this she replied,

'... my whole philosophy on this whole person approach where we would really not focus on specific behaviour, but we would focus on lifestyle of a child. Improving their lifestyle...this was a place that they could come and relax. That they could have hand and foot massage, and enjoy life have music and such without us making huge demands.' School principal

During the interview Sarah (school principal) frequently mentions her view that the children have come from very depressing situations. At St. Joseph's the focus is on improving this imbalance. Sarah's concentration was on the quality of life of the child, where the teacher believes the school focuses on educational issues and the Deputy Head sees safety as the main emphasis.

The prospectus offers a mixture of views. It states:

'Every child, however disabled, is entitled to develop in an environment which is conducive to learning. This environment should be one that is safe, caring and enjoyable and where children may grow towards independence.' (p. 4)

Its main focus is on the school environment encouraging children to grow towards independence. Although it mentions the two areas highlighted by the staff members (education, and safety), the stress is on environment, which is the main emphasis of the school principal. Contrary to what is deemed necessary in the literature (Murgatroyd et al., 1994) the school's vision is not one that is readily agreed by all working there. 'Unless there is a large degree of shared staff commitment to the core values and mission underlying the strategic plan, it will not be put into practice successfully. Strategic planning must become embedded in the culture of the organization if all staff are to work together in the same direction towards common goals.' (Preedy et al., 1997, p.6).

4.11.1.2. Student Behaviour

The second theme discussed in this subsection is how the school views the behaviours of the children. Again there is a difference of opinion stated by the Principal and Teacher as seen in the interview transcripts. Although each interview was semi structured, those interviewed were encouraged to give examples to provide better understanding to the researcher of their answers to the issues discussed. Independent of each other, both the teacher and the Principal gave an example of

how they would handle a child who did not wish to get up in the morning. The different approaches shed some light on the differences that exist between these two individuals.

'...and we discovered that mornings were just so difficult for him...and it was, it was really observations of that child. We use that kind of model for many children in the school. We make...that's why breakfast time is a much more relaxed time. Children don't come down and all sit around the table. They just come down when they are ready and serve themselves. You know they go back upstairs and listen to music, go for a walk. You know it's a very easy start to the day.' School principal

The principal had the view that mornings are very relaxed for the children. The teacher saw this very differently. She describes how she handles a girl that does not wish to come down after breakfast.

'...one incident this morning, staff couldn't get Daisy dressed. I went up and said, "Daisy, it's time for school. Now it is time to get dressed". And she got dressed.' Teacher.

The teacher describes the above incident as one in which the child is aware of the teacher's expectations and meets them. The Principal prefers to alter the expectations on the child to make meeting the expectations easier.

4.11.1.3. School Entrance Criteria

The last area discussed in this subsection is the entrance criteria for children into the school. These have changed over the years and the Principal admits that the diagnosis of autism was not always necessary to get into the school, although challenging behaviour was. Currently the prospectus states (under the Admission section) that:

'The school caters for the needs of pupils with the most severe challenging behaviours, communication difficulties, autism and severe learning difficulties' (p.10)

Although not specifically stated, the layout of the school also places some restrictions on the type of child they take. All bedrooms for children in the school are on the first floor. There is no lift, and therefore children with physical disabilities would pose a problem. Although the diagnosis of autism is listed in their prospectus under Admissions as necessary, and the building has self-imposed limitations, these are inconsistently applied.

'...[senior staff] just don't think through things properly. For example, Raja's buggy. [girl in wheelchair] Taking on a student with limited mobility in such that she needs to be in a wheel chair. ...So as now we have Raja, we've had staff who've had to go to physio because of her going up the stairs, mobility problems... Ideally she needs ground floor accommodation.' Teacher.

Although there are rules governing which children are accepted at St. Joseph's School, the data from the interview and research log references some of the staff concern at its inconsistent application.

4.11.2. Employment Practices

This section deals with three areas: time off policy, qualified teacher presence, and staff evaluations.

4.11.2.1. Time Off Policy

Inconsistency in time off policies has generated several comments in the research log and transcribed interview data from staff members. When asked about the holiday coverage over New Year's Day, the Head of the Department replied:

'There was no strategy or planning done. Forty staff were given the day off and there were no cooks or cleaners. Senior staff members were expected to watch the children, do the cooking and cleaning.' When asked how this could be, she continued, *'If Sarah [School Principal] likes you, she just says yes [to time off] without thinking'*. Head of department

Staff stated inconsistencies in procedures for staff illness in the research log. The aide¹⁶ who was put in charge of the classroom during the absence of a teacher would not come in for work or call in sick for several days at a time.

'Lori has not been in all week. There was no call yesterday as well, she just doesn't show up.' Classroom aide. When asked if her wages were reduced to reflect this, the aide said no.

4.11.2.2. Qualified Teacher Presence

Class coverage by the Senior Management team was also unpredictable. There was no policy about having a qualified teacher in the classroom or coverage by a member of the Senior Management Team in lieu of a qualified teacher.

¹⁶ Throughout this thesis, the term aide will be used to refer to any member of the school staff that was not a qualified teacher or member of the school's management team. Some aides were employed to work in the school classroom only, while others worked in the residential units as well.

'Kathy [Deputy Head] was in on Tuesday morning, but did not come back in the classroom in the afternoon or on Wednesday.' Classroom aide when asked who was in charge of the classroom.

4.11.2.3. Staff Evaluations

Employee evaluations were another inconsistency between stated policy and practice. Although not a statutory requirement for the school, a new policy was put in place that mandated 3 monthly reviews for all staff. No action was seen in the classroom in the 14-month interim between the enactment of the policy and the interview with the classroom teacher.

'Since September last year they have been saying they will start this, but not once' Teacher

'So there are no staff evaluations?' Researcher.

'No. All staff are suppose to have 3 monthly supervisions, I've had none in my two and a half years of being here. Not one.' Teacher.

The second theme that emerged from the data dealt with the school's awareness and adherence to policies and procedures. The next theme discusses staff training and development.

4.12. Theme Three: Staff Training and Development

Staff training is the third theme from the data. The Principal speaks frequently about how much she values staff training and this is evident in the research log by the frequency at which staff members are given leave to attend training sessions and the fact that there is a full time member of staff dedicated to training. This is also an important goal of the school where it is listed first under Aims in the School Prospectus:

*[School name] aims to provide consistent education and care throughout the 24 hour day with a fully integrated and multi-disciplinary **staff team fully trained and carefully selected and police checked.***

The induction package for new members also stresses training and includes several sessions on issues as far ranging as first aid to PICs (the school's picture communication system). But this extensive training, though laudable, has the effect of limiting access to school resources:

'the school has wonderful resources...and they are not used to their full potential, I believe....' Teacher

'How would you increase their use, or what would you do differently?' Researcher

'Tell SCIP training to go elsewhere. ...For use of the barn, it always seems like courses are in the barn [school gymnasium].' Teacher

Therefore, although staff training is seen as a high priority by the principal of the school, the constant turnover of staff and outside demand for specific training has the consequence effect of reduced access to school facilities by classrooms.

Both the school and staff members are committed to training. It is viewed as an important part of staff development. Even though ongoing training sessions are available to staff, staff members are often faced with a lengthy wait for spaces on courses, as noted in the research log. This is perhaps most evident in the behaviour management training course, SCIP (Cornick et al., 1996). Although this is seen as an essential aspect in managing children's aggressive behaviour,

'...staff have to wait quite a long time before they get on a course.' Head of Department.

'...the plan is to take Daisy to her room if she has another aggressive incident, but the staff are not able because they are not trained.' Teacher

In addition to training opportunities, another issue is the opportunity for staff development and career progression. The transcribed interview with the teacher shows she views her position as a temporary placement.

'So, you know, I think I have learned a lot being here, but also, I think I need to, just, move on? ...I just feel if I stay here too long, I will become stuck here and I won't be able to move on because I don't know anything else.' Class teacher

The management team takes a different view. They see an opportunity for staff to be supported in their efforts to try new roles.

'Another thing I really respect is that she [school principal] gives people chances. ...She is willing to give staff; it doesn't matter whether you are a teacher, a care worker, whatever. She gives staff a chance to come into the field and see whether they like it.' Head of department

'...we take in a lot of you staff who have the desire, commitment and passion. Not the skills and expertise to start with, but we can give them that.' School Principal.

The school management declare that they take on staff who are not necessarily experienced in working with handicapped children. They claim that they provide training to develop skills needed for direct care of severely autistic children. Direct

care staff views this job as a temporary position which leads to the next section, a discussion on staff shortages.

4.13. Theme Four: Staffing Levels

As key elements to the implementation of any educational approach, the staff is seen as crucial to delivering appropriate educational provision to children in all educational settings. This is also true of the staff at St. Joseph's. Theme Four investigates this area including Classroom staffing (Section 4.14.1.), Teacher presence (Section 4.14.2.) and Lack of teacher presence and staff (Section 4.14.3.).

A closer look at the day-to-day practice of staffing the school reveals several intertwined layers. It is important to remember that although these layers will be discussed individually, no one layer exists in a vacuum. As such, the influence on others is difficult to define and should not be viewed as an individual element, but rather one of many factors influencing the day to day running of a classroom by real staff in a real world.

4.13.1. Classroom Staffing

Severe staffing shortages are a persistent problem at St. Joseph's school. This is a particular concern not only because of extensive training investment by the school in staff who leave after a relatively short time, but because of the severe nature of the disability of the children. It takes a fair amount of time for a member of staff to get to know the individual child as well as time necessary for children to feel comfortable with staff. Research indicates the positive association between staff stability and children's behaviour (Rutter et al., 1979). Figure 4.9. shows the endemic understaffing present in the Junior classroom. The classroom was fully staffed less than ten percent of the time. The comments the staff had on this and the teaching are discussed in the next two sections.

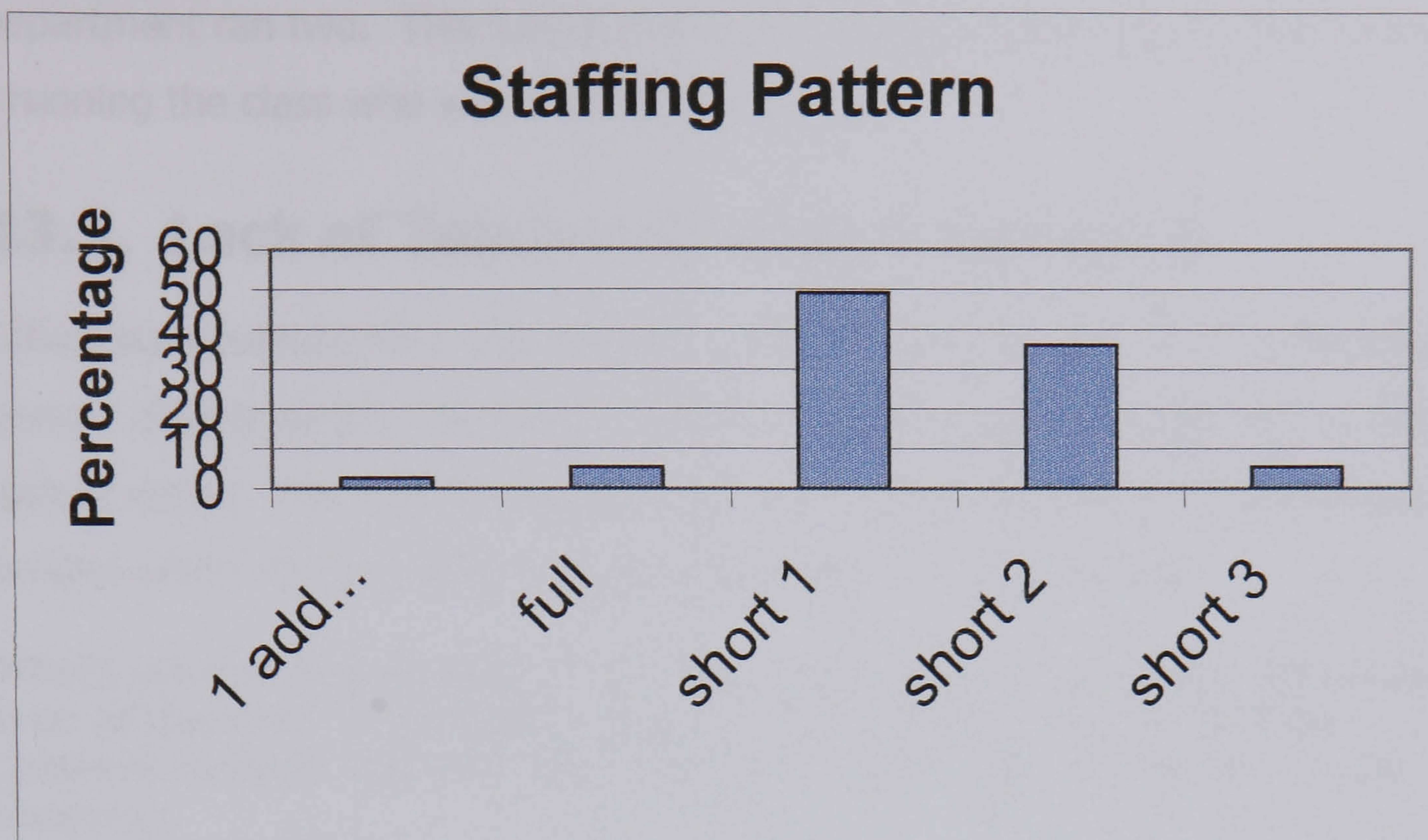


Figure 4.9. Staffing Patterns

4.13.2. Teacher Presence

'All pupils have a right to be taught by effective teachers who are appropriately trained and qualified.' (SENTC et al., 1996, p.4). Research shows a clear link between this and school effectiveness (Scheerens, 1992). In general, the teacher is seen as the manager of the classroom, and Lisa (teacher) is an example of this at St. Joseph's Junior class.

During the course of the case study there was a change in teachers. Although the standard 3-month notice was given, no replacement was found for a period of 15 visits by the researcher (10 weeks) after the teacher had left. During this time a supply teacher was in the class for four of the visits and the Head of Department for an additional two visits. Due to the lack of a permanent teacher, one of the aides (not a qualified teacher) was given overall charge of the class, but her repeated unexplained absence meant that the class was without someone to direct activities for three visits (two weeks). During this time a pattern emerges from the log notes of student activities. It shows a lack of planned activity during the days that a regular teacher was not in the classroom (see Table 4.5). Reviewing the research log notes on student activity and comparing this with the presence or absence of a regular teacher (non supply staff) reveals this pattern. During the 41 visits made to the classroom, 21 had a regular teacher present, four had a supply teacher and the Head

of Department ran two. This leaves a total of 24 observations where there was no one running the class who was a qualified teacher.

4.13.3. Lack of Teacher Presence and Staff

The third area considered in this section is that of the reaction of staff to teacher presence. Subsequently, the lack of direct classroom leadership also has an effect on classroom aides. The staff frequently shared concerns over their perceived lack of leadership within the classroom. Some examples of this are below:

'What's going to happen now? [Two teachers] left and all the responsibility is on me to do all the work. Two full time jobs to someone already working full time.' Comment made by classroom aide, who was asked to assume leadership of the classroom.

'I am really worried about next week.' Classroom aide after hearing there would be no qualified teacher in the classroom.

'There is no work prepared for today. There is no teaching staff and no lessons. No wonder the kids are bored.' Classroom aide.

'What are we suppose to do now?' Classroom aide.

'I don't know, just keep them busy' another classroom aide.

4.14. Theme Five: Programmed Activities

The lack of a qualified teacher and adequate staffing also had an effect on the time spent by children in directed programmed activities. During the times when a regular qualified teacher (RQT) was present, planned programming was noted in the daily logbook more than three times more often than when an RQT was not present. On 12 of the 21 observations (57%) where a RQT was present, the log notes reference the children engaged in activities. This number drops to 3 of 18 observations (17%) when there is no RQT present. (There were 3 neutral observations where both periods of activity and inactivity were noted when a RQT was present and 2 when one was not.)

The notes reflected a high proportion of inactivity when there was no RQT present or the substitute teacher was in the classroom (18 observations). There were 13 references (13/18 observations or 72%) to inactivity or lack of planned activity during this time. This is compared with only 3 observations (3/18 observations or 17%) where activity is noted in the logbook. This is summarised in Table 4.5.

When these figures are compared to the total number of class observations, (see last two columns in Table 4.5) the figures show the effect that a regular qualified teacher had on the classroom. When present, the log notes reflect a much greater chance, almost twice the likelihood of having children engaged in directed activity (29% versus 15%). This trend is reversed when there is no qualified teacher present, or a substitute teacher is directing activity. The logbook shows that in this case, children had a 7% incident of noted activity while inactivity was noted 32% of the observations. In general, when a qualified teacher was present, the research log reveals that the children had a much better chance of being engaged in directed activity.

Type of Classroom Leader (number of observations)	Active/engaged children noted (% of observations)	Neutral	Inactivity noted	Activity % per total visits (n=41)	Inactivity % per total visits (n=41)
Regular Qualified Teacher (21)	12 (57%)	3 (14%)	6 (29%)	29%	15%
None or Substitute (18)	3 (17%)	2 (11%)	13 (72%)	7%	32%
Head of Department (2)	1 (50%)		1 (50%)	2%	2%

Table 4.5. Classroom Leadership compared with student activity

4.15. Theme Six: Directed Programming

Another aspect to the discussion of the last section on the amount of engaged activity time the children were occupied with, is the actual consistency in the teaching approach used. The school prospectus states:

'all the staff have been specially trained in methods which involve setting targets and differentiated objectives which a pupil can achieve' (p.37)

Although the prospectus states all staff has been trained, there is little evidence from the research log to support this claim in practice. Teaching needs to be structured (Scheerens, 1992, p. 83) and purposeful (Sammons et al., 1997, p.103). Several examples of practice are shared below.

Child reviews occurred at regular intervals. In accordance with national statutory regulations, each child had an annual review. In addition, quarterly reviews were conducted to review progress and establish goals for the child. Staff members jointly wrote these reports, with teachers taking primary authorship. Day to day notations on progress of specific education and behavioural goals was sporadically written. (The exception to this was the general notes on behaviour 'Darren was in a good mood today', which were regularly logged in a separate logbook). In fact, the classroom lacked systematic evidence that children's progress was monitored. This begs the question of how the regular review meeting were being evidenced.

The research logbook notes several examples of staff inconsistency when it comes to programming. For example, the speech and language (S/L) specialist had included an additional step in the PECs programme that she was using with Gerry. She had Gerry take the PECs symbol to one staff and receive reinforcement from another staff (notes on 14-12-00 and 8-3-01). This is contrary to the method taught by the PECs originators, Bondy and Frost (1998) and different from the approach used in the classroom. In effect, the S/L staff's way teaches the child that two adults are necessary to get his requests met, when Bondy et al. teaches only one adult is needed.

Missing materials were also a concern for staff and frequently noted in the research log. When the researcher would ask about a child's progress, it was not uncommon to get a reply that the particular programme could not be worked on due to missing materials. This was a particular issue when programmes extended beyond the school classroom (toilet training for example) where the residential side could not work on them due to lack of materials. Therefore in the few cases where there were set programmes and procedures in place, staff did not work on them because they could not find the necessary items needed.

The staff at St. Joseph's school shared their frustration at the lack of shared direction by management on specific programmes to address the needs of the children.

'...we never meet as a team.' Jan (classroom aide)

This could be due to the lack of a qualified teacher, general staff shortages, or perhaps the fact that specific training for new staff members had not yet occurred.

The consequence of this was that the children experienced a large proportion of unstructured time, which could have been more fruitfully used in engaged teaching activities. Research concludes this contrary to good practice (Mortimore et al., 1988). This is a marked difference since the last Ofsted report which concluded that in most subjects:

'Lessons are well planned and activities are well suited to the needs of the pupils.' p.16

4.16. Theme Seven: Negative Behaviours

Clear discipline policies and procedures are essential (Sammons et al., 1997). This is particularly true when the children are at the very disabled end of the autistic spectrum (Harris et al., 1996), as are the children at St. Joseph's School. All the children in the Junior classroom have behavioural issues including physical aggression to self (Raja, Alex), physical aggression to others (Raja, Daisy, Darren), to inappropriate actions (i.e. faecal smearing-Gerry). In all cases, it is the severity of the behavioural problems and the failure of other local agencies and schools to minimize these behaviours, has resulted in placement at St. Joseph's. The most recent Ofsted report (1997) concludes:

'The teachers and teaching assistants within each department meet regularly to review and plan the work of the department. This is an effective structure and much valued by staff.' p. 23

The researcher did not witness this finding of Ofsted inspectors. The log notes document several examples of individual approaches unique to the time, place and staff member applied to behavioural programming, resulting in inconsistency among staff. This led to unpredictable strategies for addressing increasingly difficult behaviours demonstrated by the children. The staff did not appear to be working together to address concerns and this is reflected in the log notes. When asked, staff members could not state knowledge of a programme designed to reduce negative behaviours.

For example, the research log notes also reflect an increasing number of aggressive incidents with Daisy beginning the last few months in 2000 to the end of the study. She was becoming increasingly more physically aggressive to staff and other students. The research log notes the failure of staff to agree a strategy to address

her increased aggression. The following comment from a member of the classroom staff:

'I have real concerns about Daisy and staff shortages.' Classroom aide.

The severe nature of the behaviours of the children in the Junior classroom made a consistent approach to managing these behaviours essential. This was noted in the last Ofsted report (1997 p.16) as a strong point of the school. Unfortunately, there was no notation in the research log to indicate a unified approach to addressing the aggressive behaviours of the pupils at the school, or the residential side, or both during the 10 months that the researcher was present.

4.17. Theme Eight: Environment

Research show that the school environment is an important factor (Scheerens, 1992p. 92) and this is also an issue of concern for staff.

*'The environment is not **that** friendly towards people.'* Head of department

Although the school had many good facilities (newly completed purpose built swimming pool, and farm yard with animals) the actual classroom was another matter. The log notes mention lengthy delays in finishing the classroom repainting project, plants growing through the ceiling, broken windows, and flooding, as well as cleanliness issues (teachers cleaning floors that have not been cleaned in days, pulling large cobwebs off the ceiling, very strong odours from the toilets). The floor was not regularly cleaned on a daily basis and teaching staff were noted as doing this on three occasions in the research log.

'This floor is horrid. Two weeks ago I cleaned it, last week it was not cleaned at all. We need to spray in the loo because it smells so bad.' Teaching aide.

Although the school had many wonderful resources (pool, sensory garden, etc.) the staff shared their frustration at their inability to access them. In particular, it is noted the difference between the day-to-day working environment (school classroom) and the rest of the site spaces.

4.18. Theme Nine: Outside Agencies

As a residential school, St. Joseph's school is subject to regular inspections from outside agencies. This includes both Ofsted and Social Services. (Note: St. Joseph's school is not accredited by the National Autistic Society, and consequently has not been scrutinized by this agency.)

The last Ofsted inspection occurred in 1997. As these inspections are on a 6-year cycle, the next one should be scheduled for the academic year September 2003.

The most recent Ofsted report generally gave a good review of the school. It mentions the school management and the teaching as being positive. It also commends the management of the children's behaviour. However, it does note that:

'Planning for the curriculum development especially in mathematics and history is unsatisfactory.' p. 6

In addition, Social services regularly inspect the school. This did occur during the time the researcher was in the Junior classroom. Although the researcher did not see the report, the Head of the Department shared its findings that the staircase needed to be dusted. This was followed up on was done.

4.19. Theme Ten: Parental Teamwork

The literature review highlighted the importance of parental involvement in the education of children. Customer driven policies (Murgatroyd et al., 1994) are essential to this effort and the general consensus is that schools that work with parents provide 'dramatic and long lasting effects' (Dean, 2001, p. 216). The school's prospectus actively promotes the involvement of parents. It welcomes parents to join the parent's group and informs them of a monthly newsletter that is for parents. Although the research log does not show an awareness of either of these, it does reference a weekly letter (and telephone calls) that children sent to their families. The parents of the children are known to each other and they communicate between themselves. The latest Ofsted report states:

'The school's partnership with parents and the community is very effective.'

The research log references the apparent weakening of the parent/school relationship, in so far as it became apparent during an enquiry where parents sought to involve Social Services on a matter of Health and Safety.

4.20. Theme Eleven: Staff Morale

The last theme discussed in this chapter concerns staff morale. The morale of the staff directly working with the children was generally low and regularly referenced in the research log. This was noted in as early as the first week of the action research. The staff described their feelings as the following:

'...we are fighting all the time, fighting to get the room clean, fighting to get the staff. Last week I didn't come in because I was too upset.' Lori

The staff also shared the feeling of a lack of appreciation on the part of senior management.

'It would be nice to get a thank you, but nothing.' Jan's comment when she ran into the school principal on her last day of work after four years.

In general, the staff concluded:

'...Staff morale is not good at the moment.' Teacher.

Eleven themes emerged from the large amount of data gathered during the ten-month case study. These were presented to try to draw a cohesive picture of an individual school and its day-to-day operation as it puts in practice appropriate educational provision for the children in attendance. What these themes highlight is a discrepancy between management and direct care staffs' state as their views.

4.21. Conclusions

It is very important for a school, any school, to have a shared understanding of and agreement on the goals and purpose of the institution and the ways it will meet these goals (Preedy et al., 1997). This shared conceptualisation was not evident in the data produced during the undertaking of the case study at St. Joseph's school.

The Literature Review (see Chapter 2) highlighted the gap in the literature concerning the influence a specialist school has on its educational provision. Systems Theory purports the investigation into the influences that exist on the individual child with

autism, the focus of this thesis. As generally the main provider of educational provision, it is appropriate to explore the contributions of a school. In the case of St. Joseph's School, it is essential to include this in the discussion due to the nature of the child's provision, namely 24 hours a day, 52 weeks a year.

St. Joseph's school has demonstrated its effectiveness to outside agencies (Ofsted, Social Services inspections), but has failed to share its vision with direct care staff. The point of this study is that the educational provision provided to the students at St. Joseph's School is not the sharp, targeted education as it should be. The quality of education is clearly less effective than it could and should be and this begs some powerful and interesting questions about how this situation can exist.

The research data generated can provide some insights into the dynamics of this school. The small piece of action research did not work, and the children lost gains made (see Figure 4.8). The data shows an examination of planning (to include target setting, regular monitoring of student progress, record keeping etc.) to be sketchy. No special qualifications were required as necessary to head the classroom, and consequently there were large periods of time when a qualified teacher was not directing the teaching activity (see Section 4.13.2). Figure 4.9. also shows data on the adequacy of staffing. It reveals that the classroom was fully staffed less than ten percent of the visits from the researcher. In principle, the school maintains good relationships with parents, in practice the data from staff interviews and the research log reveals a tenuous one with three of the parents of children in the Junior classroom.

Issue of effectiveness of provision is questioned by the clear inconsistencies, tensions and dislocations between the school's brochures and evidenced practice at St. Joseph's school during the case study.

Therefore successful effective intervention for populations of children with autistic spectrum disorder may be better served if:

1. Appropriately qualified and trained teachers are always present to provide good leadership and guidance on a daily basis.

2. Classroom aides and other staff practice routine record keeping. This should include a full understanding of the significance of recording and target setting. All classroom staff should be trained and systematically use chosen strategy.
3. School leadership and management should be such that it can respond rapidly, flexibly and contingently to staffing needs of individual classrooms.
4. Staffs behave responsibly in terms of their own absences. Organisational management should reinforce this.
5. Parents are actively engaged and encouraged to support their own child at home. Schools should actively promote mechanism to cement or bond home school relationships.

This chapter described the case study conducted at St. Joseph's School. A small piece of action research allowed the exploration of how a school enacts a coherent approach to providing educational provision for five very disabled autistic students. The research log and transcribed interviews provided a rich source of data over the course of the 10-month study. This data revealed the view of managers that the philosophy and vision was well defined and articulated. The data also revealed the classroom staff's knowledge of this to be less well defined. Clearly, the quality of educational provision was less than adequate during the time of the study. Several reasons were explored for this difference and suggestions for improved provision was listed.¹⁷

The next chapter will explore further the role of parents. It will investigate their views through the use of a postal survey in Strand 2.

¹⁷ The experiences at the school are recognised as events that occurred at the time the researcher was there, and may not be representative of the school as a whole, or the school as it exists today. Also, the failure to maintain gains made by the children should not be seen as solely a failure of visual learning techniques.

Chapter 5 - Strand 2

The last chapter (Chapter 4) discussed the case of an individual school and its unique way of addressing the educational needs of the autistic students. This chapter will explore the views of parents¹⁸ on obtaining appropriate educational provision. Strand 3 (Chapter 6) will look at this issue from the perspectives of senior LEA officials.

As in the previous chapter, the use of Systems Theory (Bertalanffy, 1968) to examine the many interactions and influences on an individual child is a useful tool to aid understanding. Just as it is appropriate to scrutinize the school environment because of the large part this typically plays in the life of an individual child, it is also important to seek the views of the family. The home environment has arguably the most significant influence on the child, and therefore it is a critical area to explore (Bronfenbrenner, 1979). The unique tensions and dilemmas of the family unit provide a distinctive contribution to this thesis. As a critical aspect of the main research question (see Section 1.5), it is appropriate to explore this area.

Past experience in the charity sector of this researcher has put her in contact with a wide variety of parents of autistic children. Anecdotal conversations over several years reveal a picture of parents stating unhappiness at the process of securing educational provision. As personal experience, there is no rigorous evidence for it. There are no hallmarks of scientific theory and it cannot be proved or disproved as such. What is also uncertain is the uniqueness of this perceived pattern. Does this supposed tension exist on a national level or is it restricted to the charities and areas of the country of the researcher? What is the nature of this perceived tensions or dilemmas and how do parents perceive their ability to address this issue and secure appropriate educational provision for their child?

A review of the literature (see Chapter 2) has shown no studies requesting the opinions of parents on the process of obtaining and securing appropriate educational provision for their child with autism. Chapter 2 has demonstrated a shortage of

¹⁸ The use of the term 'parent' is inclusive of all legal guardians of the children focused on in this thesis. This would include carers, and those adults who reside in the primary residence of the child.

specialist provision (National Autistic Society, 2002) as well as the importance of the right education for this disability group (National Research Council, 2001). Do we know what parents think on this issue? No, because we have not asked them.

Consistent with both systems theory and the gap in the literature is the need to ask parental views on the process of securing provision for their child with autistic spectrum disorder. As it is also a main aspect of the research question, this chapter will explore the views of parents on securing educational provision.

5.1. Introduction

This chapter will define the purpose (Section 5.2) and method (Section 5.3) for the questionnaire used to investigate parental views. It will then explore the sample (Section 5.4) and procedures (Section 5.5) used. It continues with an analysis of the data (Section 5.6) and a discussion of the outcomes (Section 5.7). The final section is the conclusion (Section 5.8).

5.2. Purpose

The purpose of Strand 2 is to investigate the views of parents on their personal definition of effective educational provision. Specifically, parental views were sought in four main areas:

1. Parental opinion on obtaining the educational provision or placement of choice,
2. Satisfaction with this process,
3. Views of the working relationship with the educational provider (school, in most cases) and
4. The effect that this process had on the family.

5.3. Method

An original pilot questionnaire was developed to address the four items listed in Section 5.2. (See Appendix 7 for sample.) The questionnaire was designed for use as a postal survey and most items included were quantitative in nature. The exceptions were the final two questions that were open-ended and therefore qualitative in nature. This allowed respondents the opportunity to express, in their own words, their comments about the process of securing provision for their child. (For a more detailed discussion of the methodology see prior discussion in Chapter 3.)

The original questionnaire was piloted in two ways. First, a set of parents completed the initial draft with the researcher sitting close by. Each parent was asked to fill in the questionnaire while the researcher noted any difficulty or comment they had. Revisions were made to the questionnaire and a second set of parents was asked to complete the revised questionnaire without the researcher's presence. These parents were encouraged to write their comments on the questions along with any answers they wished to supply. Comments made by colleagues were also incorporated into a final version before it was distributed.

All the schools listed on the National Autistic Society's web site were initially contacted by letter requesting permission to distribute the questionnaires to the parents of pupils with autism, as well as two schools that the researcher had past experience with. In addition, three national and three local charities supporting families of children with autism were also approached. Two national (n=1 352), two local charities (n=300) and 16 specialist schools (n=500) agreed to distribute the surveys. A total of 2,147 surveys were distributed to families in the UK between April and June of 2001. (This number has been adjusted to take account of those returned as undelivered.) A small number of families (n=5) requested additional copies of the survey, as they had more than one child with autism, making the total number of surveys distributed 2,152, see Figure 5.1 below. The total number of returned surveys is seen in 738, representing 34.3% rate of return.

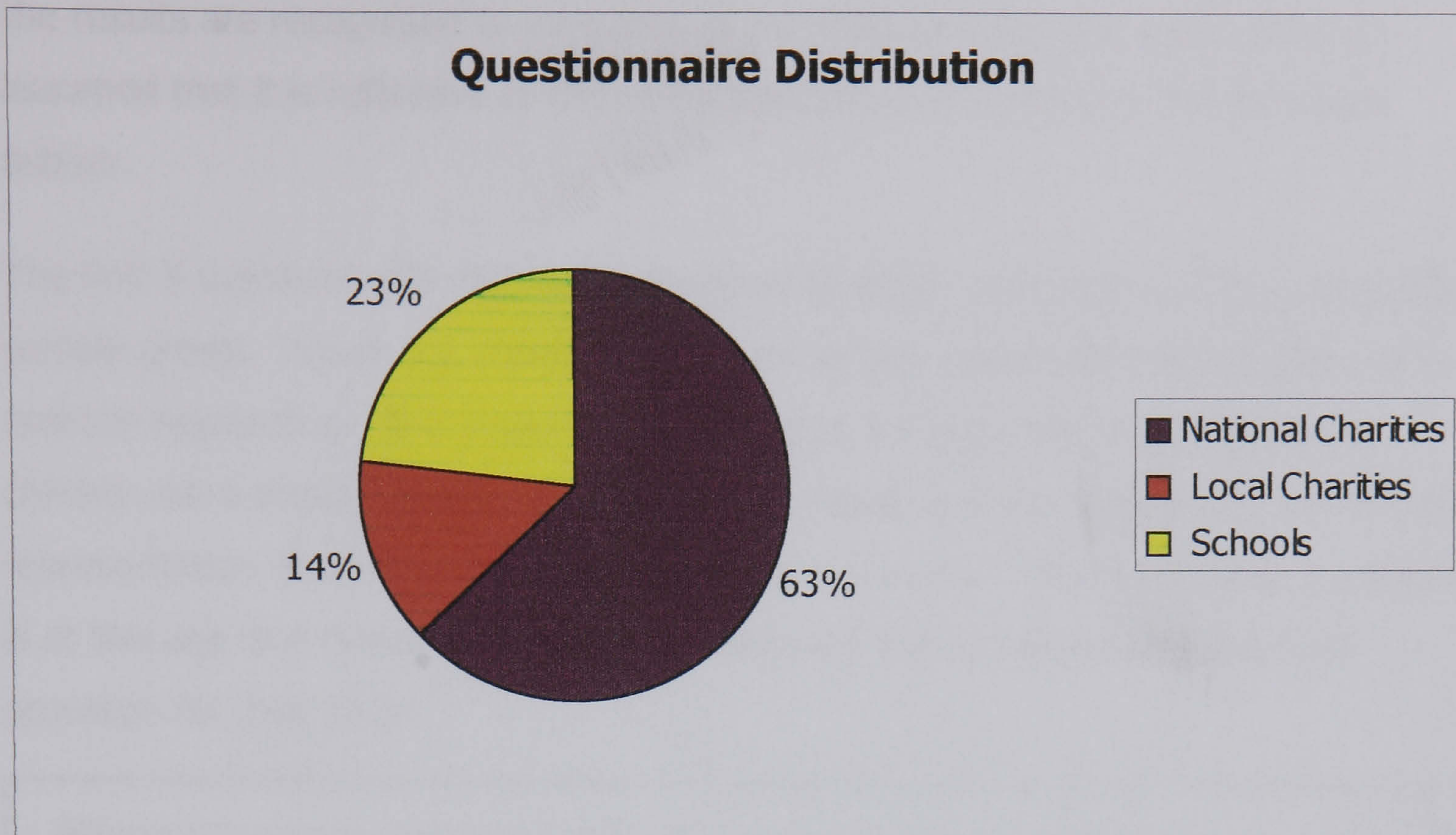


Figure 5.1. Questionnaire Distribution

It is important to note that it is impossible to accurately account for the number of individual families receiving duplicate copies in error. All charities involved followed Data Protection guidelines, which does not allow for cross checking of database names between the charities and schools which agreed to participate. Also, individual schools distributed the surveys directly to their student's families, so some of the names of the parents receiving questionnaires are not known to the researcher. The questionnaire allowed respondents to remain unidentified so an accurate figure of the total number reaching families (though desirable) is unachievable. It is realistic to assume that many of the families with school-aged children would belong to one (if not several) of the charities involved. All the families involved could conceivably belong to several charities, making an accurate account of all questionnaires unrealistic.

5.4. Sample

It is acknowledged that the questionnaires distributed are an opportunity sample and therefore not necessarily a representative sample of the population of families of children with autism in the UK. Because questionnaires were posted to parents via charity mailing lists or distributed through schools, and it was designed as an anonymous questionnaire, it is not feasible to ensure respondents' right to anonymity and obtain detailed descriptions of their family characteristics. The discussions stating

the results are recognised as indicative of the respondents only, and cannot be assumed that it is reflective of the entire population of families of children with autism.

The first 8 questions (Q1-Q8) were designed to elicit a description of the responding sample group. Figure 5.2 shows a histogram of the date of birth of the children in families responding. It is important to note that although the mean age of the children were those aged 8 and 9, the mode shows that the sample had the largest representation from families with children aged 5 and 6. This is significant, because it is at this age that families are typically first faced with decisions about school provision for their child.

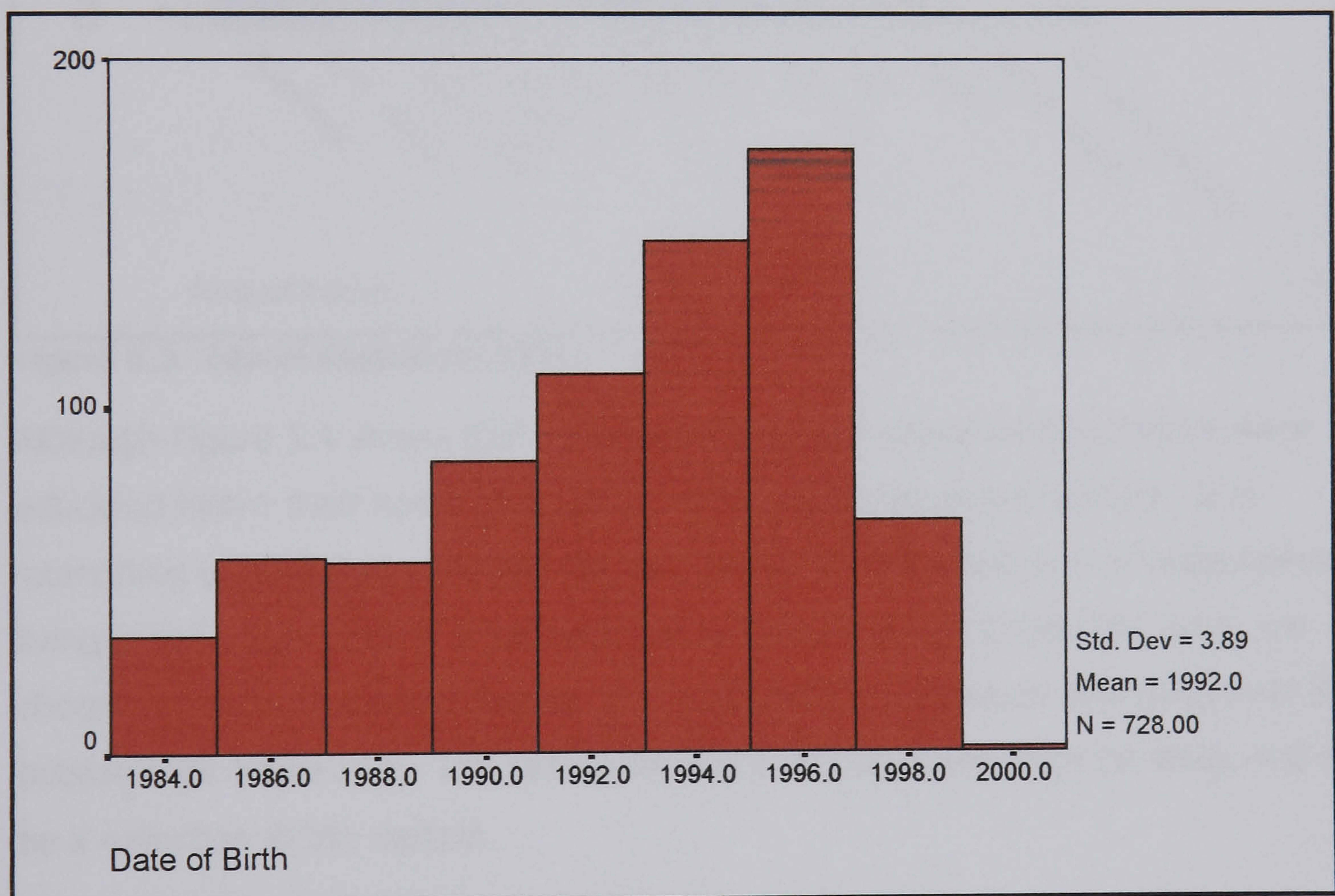


Figure 5.2. Date of Birth (Q1)

Although the questionnaire was designed so that respondents could remain anonymous, Q2 to Q5 asked for general details of the LEA of residence and LEA where provision was made (if different), as well as a generic description of the current educational provision received. These are summarised in Figures 6.3 to 6.7. 75% of the LEAs (n=155 of 207 LEAs (The School Government Publishing Company, 2001) in the United Kingdom had families residing in them that returned at least one

questionnaire. This data is grouped into regions to make the data easier to comprehend. (See Appendix 7 for a complete listing of the LEAs and regions.)

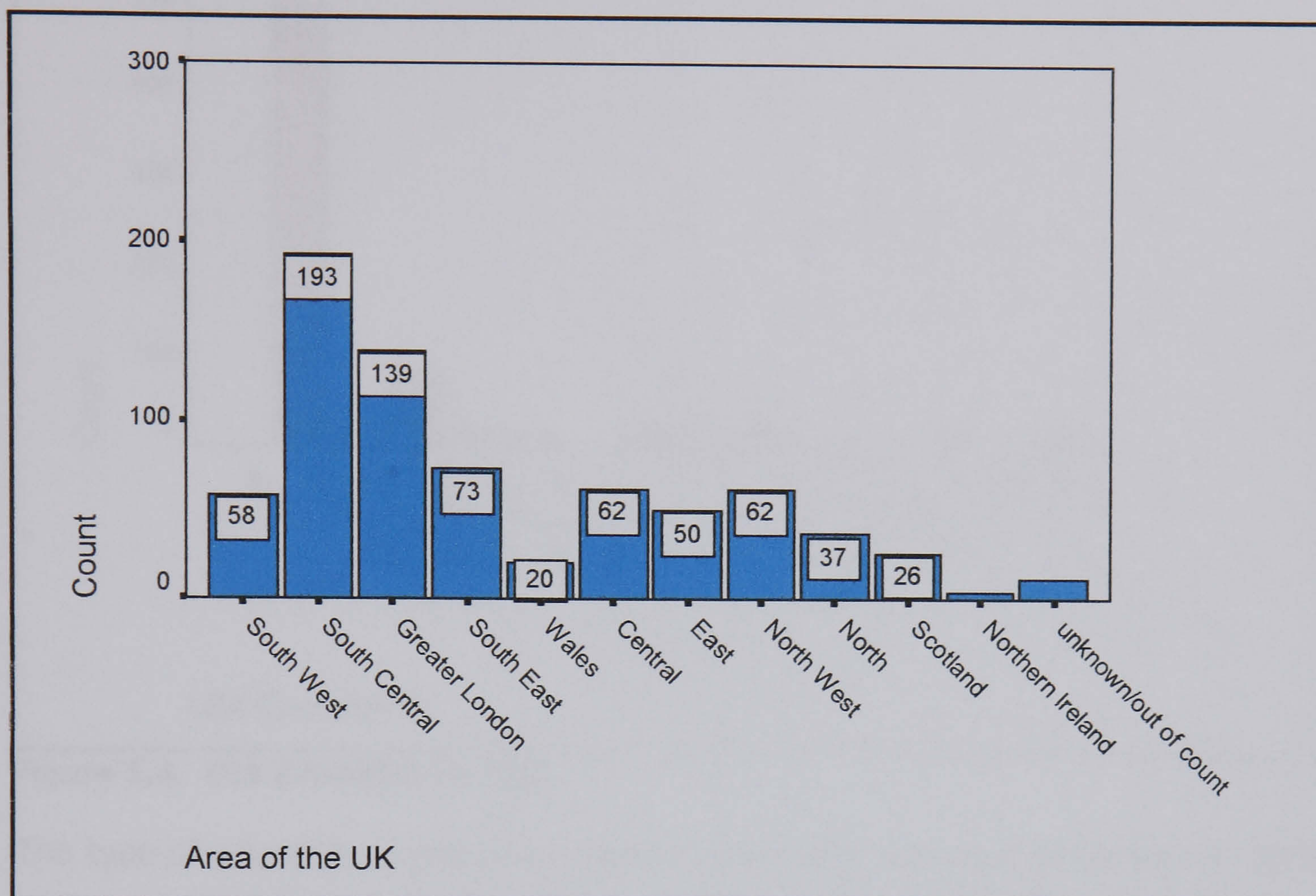


Figure 5.3. LEA of Residence (Q2)

Although Figure 5.4 shows that 68% (n=497) of the respondent's children were educated within their home LEA, 32% (n=238) were educated outside. It is interesting to note that although the data shows a high proportion of respondents living in the South Central area, even those that are living outside this area, are choosing the South Central Region of the country (n=82) when educating their child outside their home LEA. The reason for this is not apparent from the data, but may be a reflection of the sample.

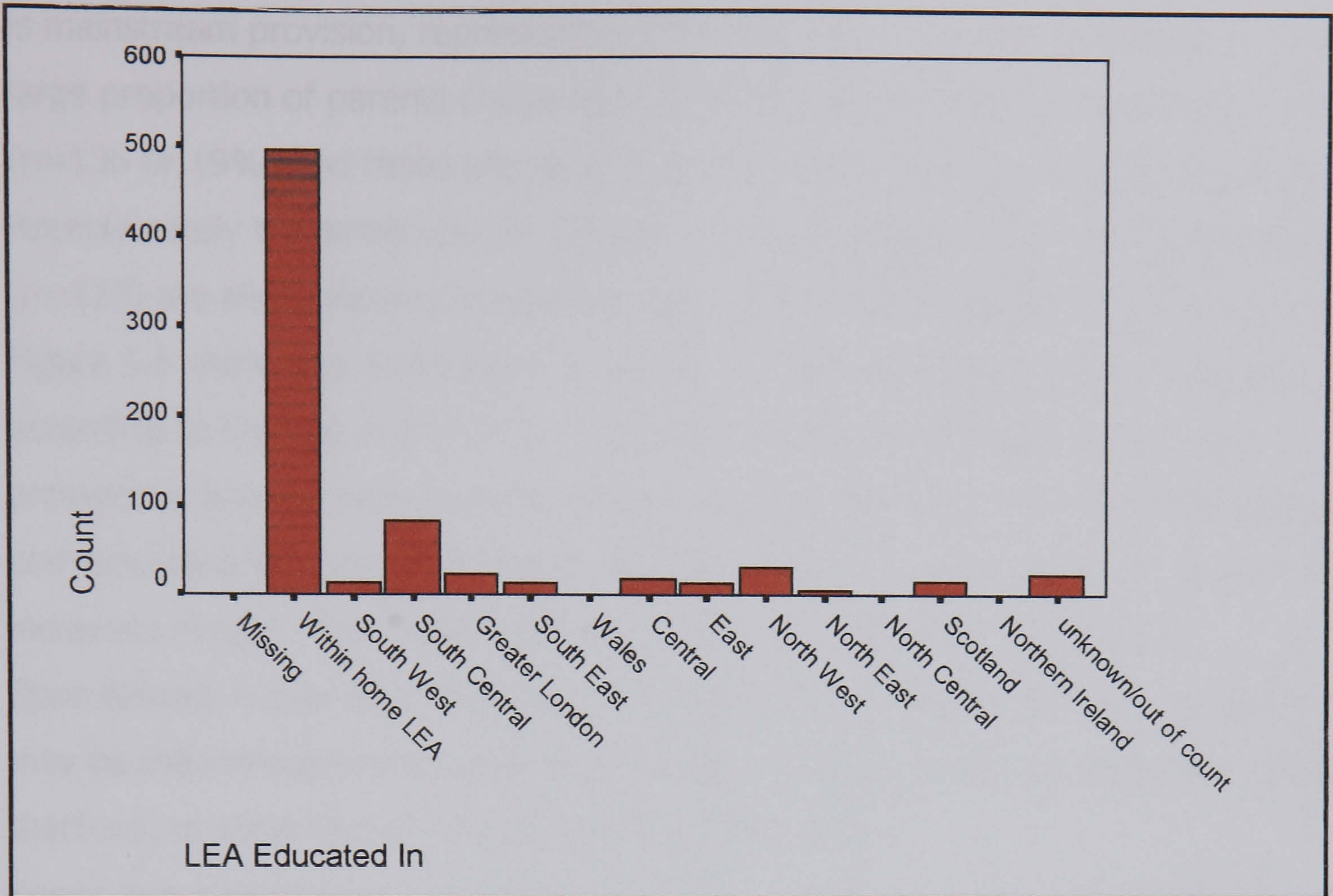


Figure 5.4. LEA Educated In (Q5)

The type of educational provision represented in the sample is addressed in Q3 and shown in Figure 5.5. The data shows that of all the listed choices, the most frequently cited

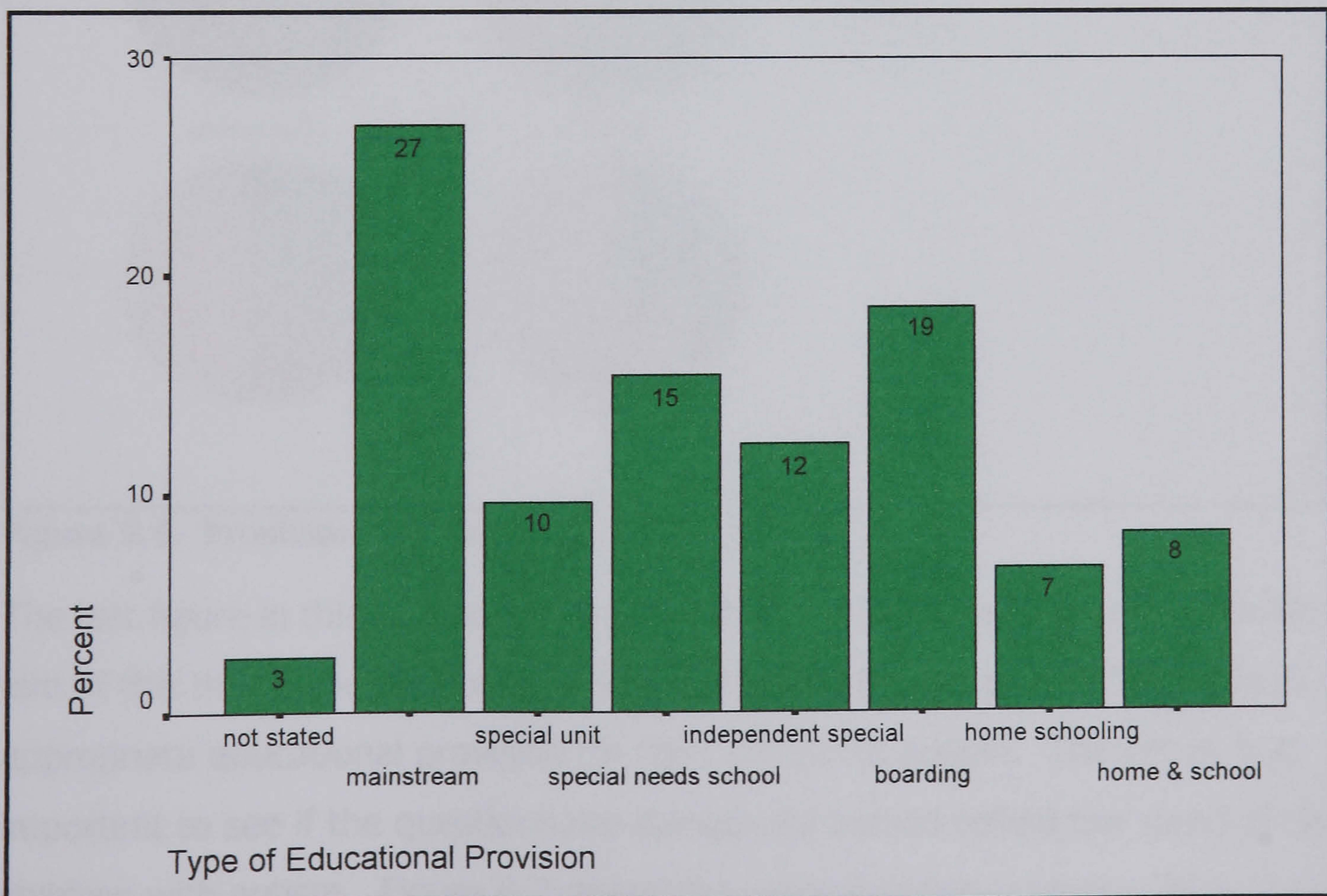


Figure 5.5. Type of Educational Provision (Q3)

is mainstream provision, representing 27% (n=198). It is also interesting to note the large proportion of parents choosing to educate their children in a boarding school (n=136 or 19%) and those choosing to educate their child to some degree at home. Approximately the same number of parents choosing LEA special needs schooling (n=113) are also choosing to educate their child at home (in part or whole, n=108). Figure 5.6 shows the distribution of children in each of the educational settings, according to the age of the child. The data reveals that although mainstream provision is popular with younger children (blue section), this number decreases and a corresponding increase in boarding provision (gold section) is apparent as the child increases in age. The reasons for this shift are not apparent in the data. Speculatively it may be a function of the government's recent policy on inclusion, it may be the increased pressures of secondary schools (changing classrooms, changing teachers) or other factors that contribute to this shift.

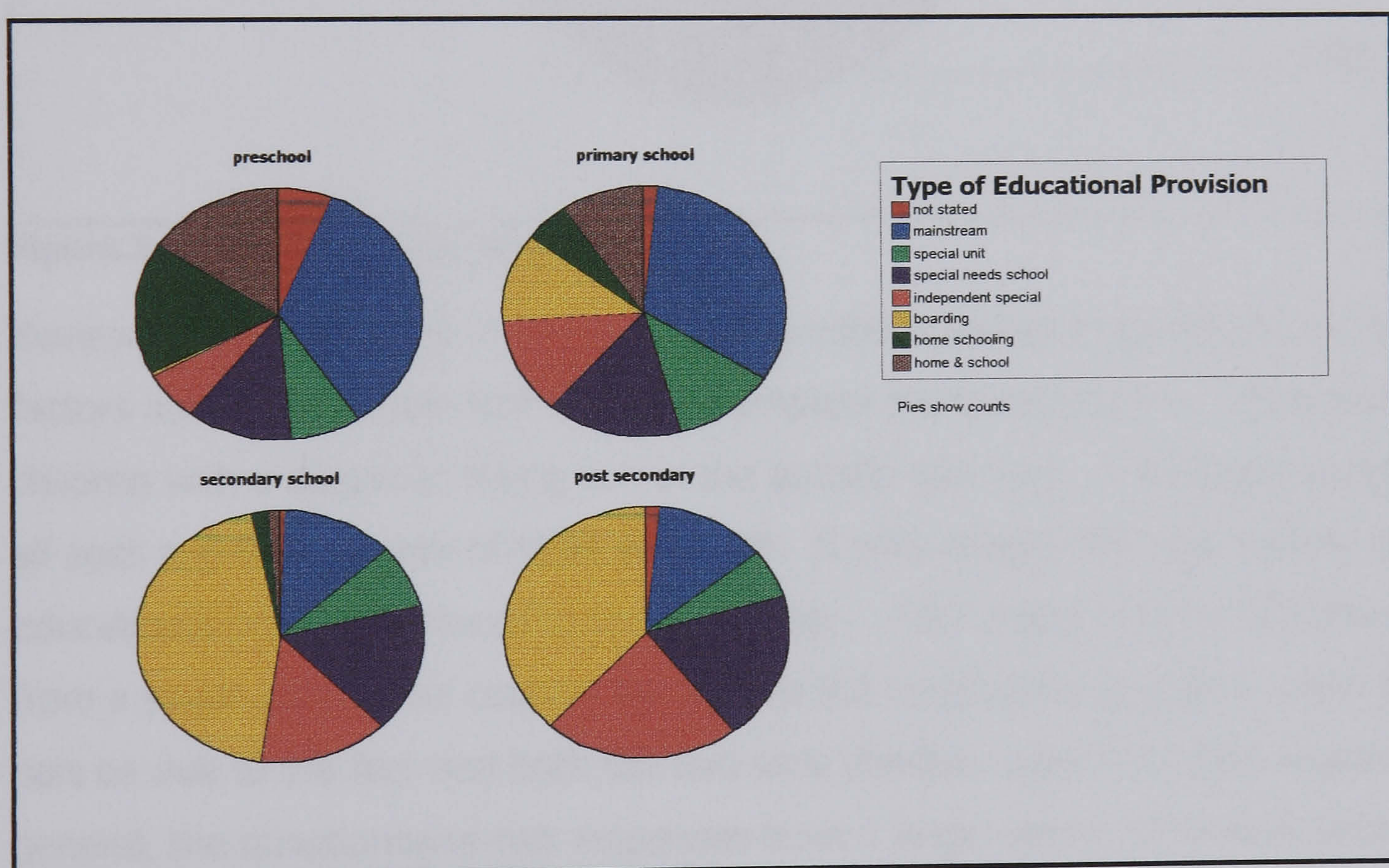


Figure 5.6. Provision related to Age (Q3)

The last figure in this section looks at the primary (Q8) diagnosis of the children. The aim of this thesis and the focus of Strand 2 are to look at parents' perception of appropriate educational provision for their child with autism. Therefore, it is important to see if the questionnaire sample did indeed reflect the views of parents of children with autism. Figure 6.7 reveal the overwhelming majority (84%, n=620) of those responding had children with a primary diagnosis of autism. If Asperger's

Syndrome (12%, n=87) is also included, this number raises to 96% of respondents had a child on the autistic spectrum.

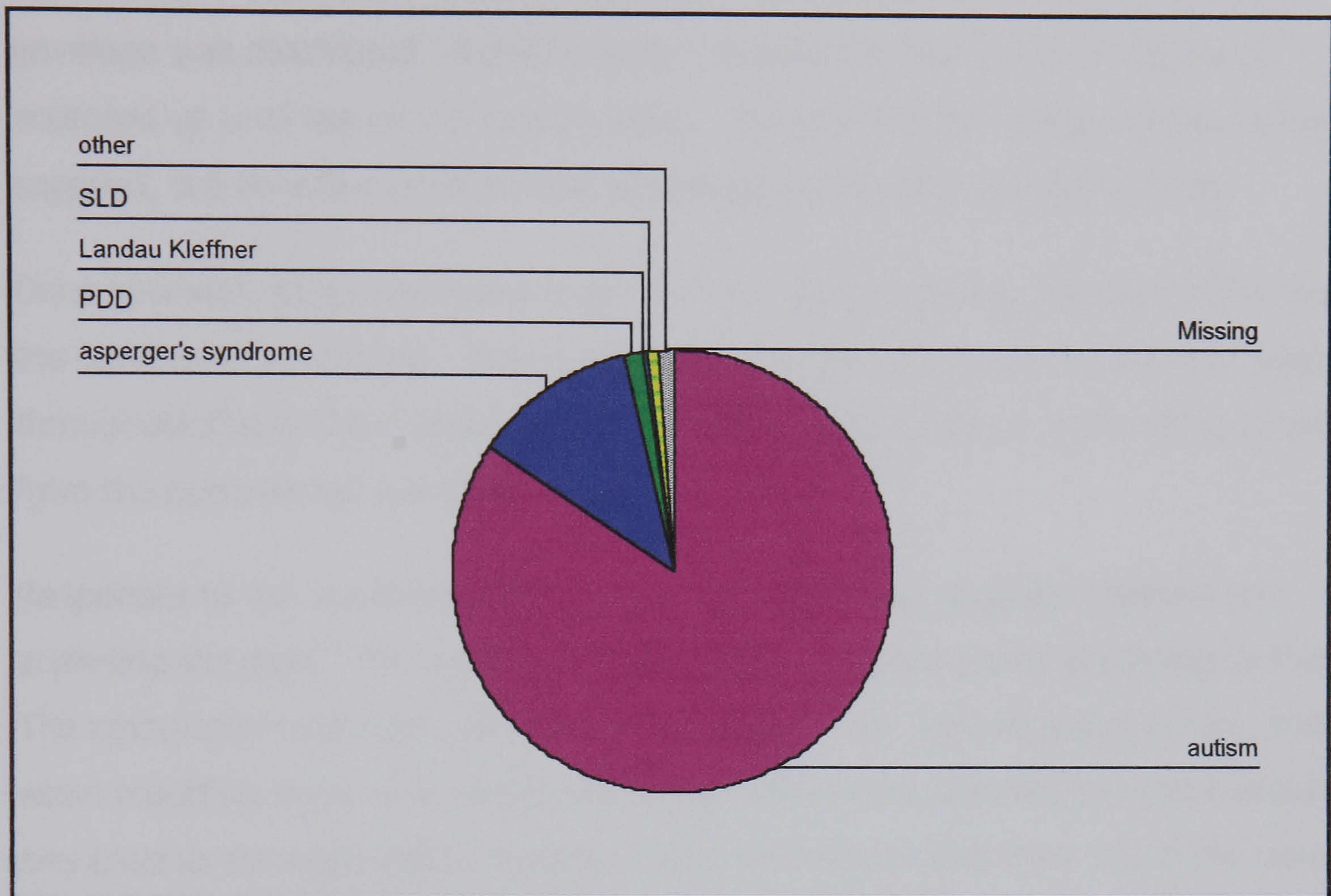


Figure 5.7. Primary Diagnoses (Q8)

Reviewing the responses to the first eight questions shows a variety of descriptive factors about the sample that chose to complete the questionnaire. Most have children with a diagnosis falling within the autistic spectrum. This group represents all ages and the majority of LEAs in the UK. It also reflects the wide variety of educational provision offered to this population. The largest number of responses from a single area of the country came from the South Central region, which may in part be due to the fact that both the two local charities were from that region. In general, the questionnaire had responses from a large variety of families from most parts of the country with a diversity of educational provisions.

5.5. Procedure

A description of the procedure has been discussed previously in the Methodology chapter (see prior discussion in Chapter 3) therefore only a brief description is warranted.

After receiving the charity or school approval, all surveys were distributed to the charities or posted in bulk directly to the schools. An introductory letter from the researcher, a letter from the charity/school, the survey and a FREEPOST return envelope was distributed. Returns were requested before July 2001, but were accepted up until the end of August 2001. The researcher's contact details were supplied, but very few families took advantage of this and pursued contact.

Once received, all surveys were given a chronological number assigned in the order the surveys were opened. This number became the case number, and was used throughout the analysis when referring to an individual case or when citing quotes from the open-ended questions.

Responses to the questions were coded and SPSS¹⁹ was used for collating and analysing the data. The two-open ended questions were coded according to themes. The researcher read each questionnaire at least twice. First to assign codes, and then when inputting these onto SPSS, where the codes were checked to ensure accuracy. Any code in the open-ended questions that was used in less than 1% of the surveys was later recoded or dropped. These were considered outliers and were grouped into a generic 'other' category.

5.6. Descriptive Data

The presentation of the data will be divided into the four areas stated in the purpose (see Section 5.2) and representing the four aims of the questionnaire: parental opinion on obtaining educational provision (Section 5.6.1), satisfaction of this process (Section 5.6.2), working relationship with educational provider (Section 5.6.3) and the effect the process of securing educational provision had on families (Section 5.6.4).

5.6.1. Obtaining Educational Provision

The first section discusses parent's perceptions of the process of obtaining educational provision. Although 90% of those responding had children with statements of special need (Q17), a significant number of the remaining 10% fall into the preschool age grouping. Figure 6.8 clearly shows the number of children without statements

¹⁹ Throughout this thesis the use of SPSS will refer to Statistical Packages For the Social Sciences For Windows (2001) Version 10, Chicago: SPSS Incorporated.

decreasing from 21% in the preschool years to around 4% in secondary and post secondary years. Thus, the vast majority of the sample had formal LEA documentation of their child's special educational needs.

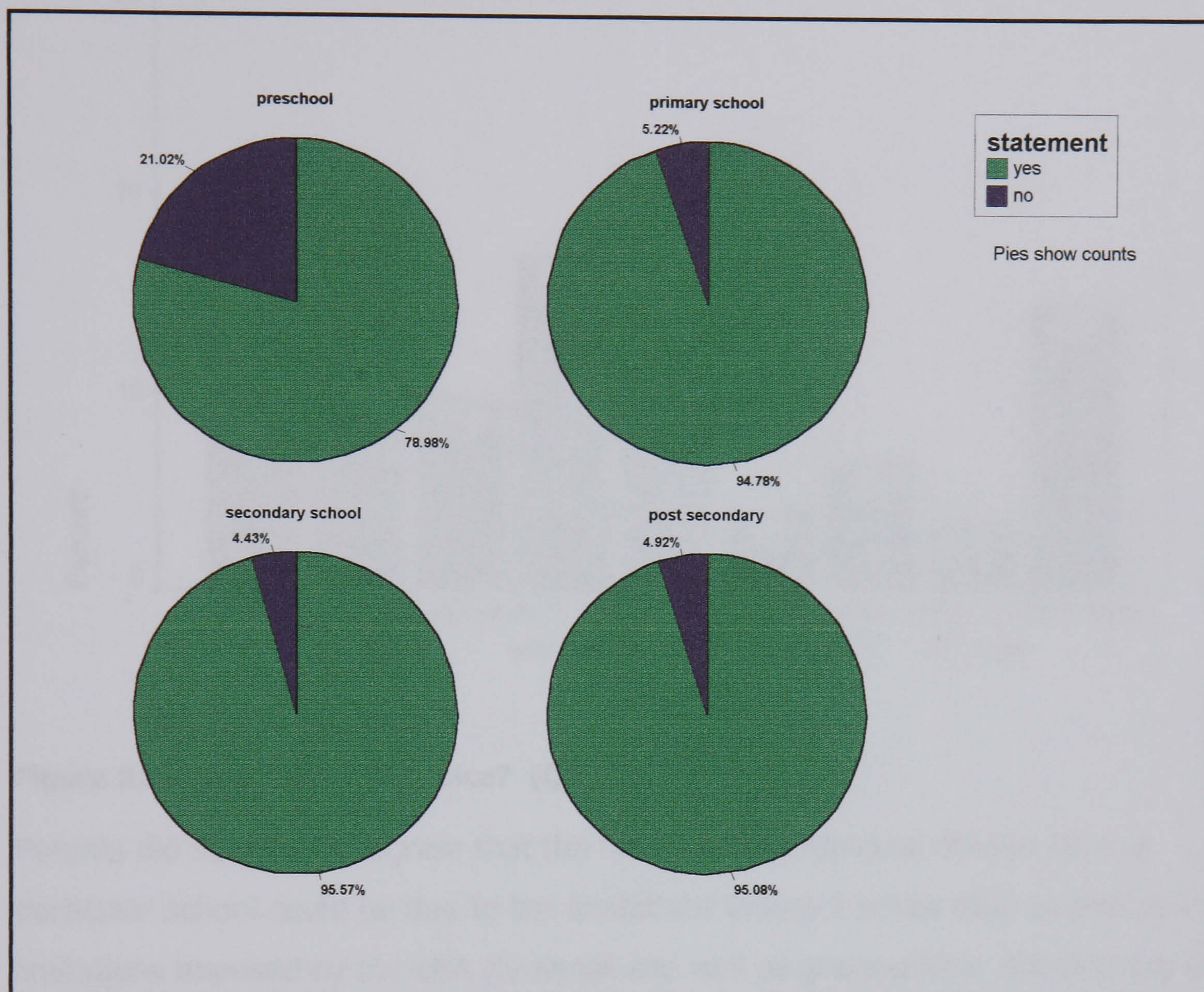
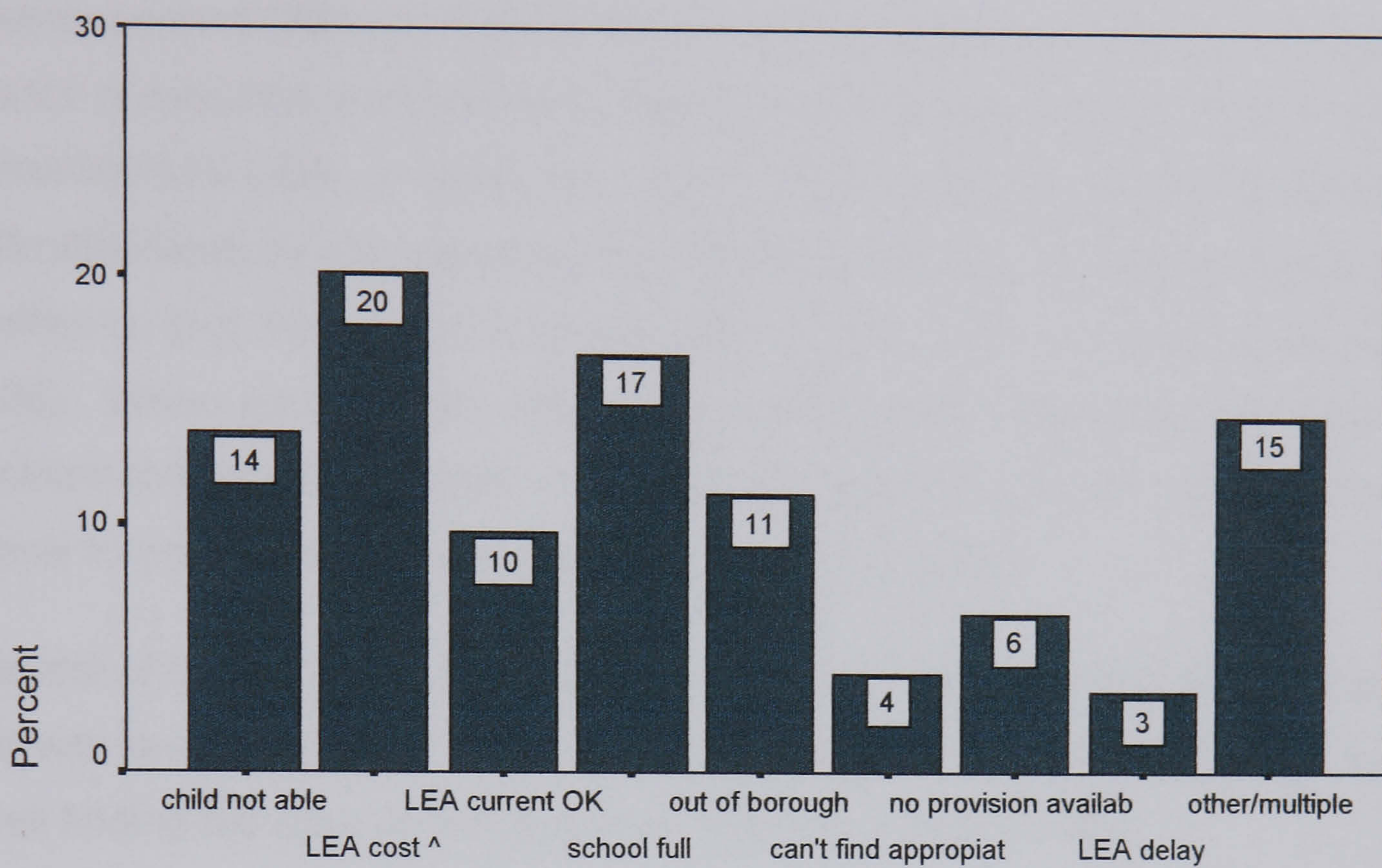


Figure 5.8. Percentages of Children with Statements (Q17)

The next questions addressed the issues around parental choice. Parents were asked if the current educational placement was their first choice and if not, what type of provision was. They were also asked a follow up question on their opinion of why their child was not in their first choice provision. All parents were then asked how they got or were working toward obtaining the placement of choice and details of this process. (Q26-33)

The vast majority, more than three quarters of families (79%, n=584) had their children educated in their placement of choice. It is interesting to look in detail to those that did not to get the parental perspective on why their child was not educated in the parent's choice provision. This subgroup was asked their opinion why their child was not in the provision of their choice. Figure 5.9 shows the reasons given.

Most frequently cited is that the parents' felt that the LEA viewed the costs as too high, followed by a lack of places at the school.



Why Not First Choice?

Figure 5.9. Why Not First Choice? (Q27)

Parents did seem to recognise that the failure of an individual child to be in a particular school could be due to the limitations inherent in the child as well as the limitations imposed by the LEA (financial and well as geographic). Considering that the National Autistic Society (National Autistic Society, 2002) states that there is a severe shortage of provision available, it is unexpected to find that only 4% of the subgroup felt that they could not find appropriate provision, or that the particular type wanted was not available (6%).

Even though almost 80% of those surveyed felt that they had obtained their first choice provision, this was not just simply a matter of agreement with the LEA (Q29). Only a little over a third (36%, n=268) of families stated this to be the case. Sixteen percent (16%, n=119) describe this process as a 'negotiation', while almost one quarter (24%, n=177) believed it to be a 'persistent and protracted negotiation'. As autism is continuously listed in the Tribunal Report (Special Educational Needs Tribunal, 2000-2001) as the highest specific type of disability in registered cases (second only to the generic category of 'literacy'), it is not surprising that 11% (n=84) of families

underwent this procedure. A small minority (1%) resorted to other legal proceedings, which included the ombudsman, contacting an MP or the Home Office.

Seventy percent (70%, n=514) of those responding did not obtain outside legal council or specialist assessments to help secure their placement of choice. Of the remaining third (30%, n=224), the reasons given present an interesting picture of the difficulties faced by this sub grouping. The most common reasons given are that families contact representation for independent reports (6%, n=43) or advice (5%, n=36). Others felt they were left with little alternative, stating they felt it was difficult to obtain the provision of their choice without specialist help (4%, n=26) or the LEA's refusal to provide the statement or placement (3%, n=23).

The cost of this service is also interesting. Of this subgroup, 30% (n=63) stated the cost was less than £1000. Those receiving legal aid was only 10% (n=10), while those finding the costs to be more than £4000 was 16% (n=35).

Parents shared diverse replies when asked about the time it took to reach agreement with their LEA about educational provision (Q32). The Code of Practice (DfES, 2001) states that the time limits for an LEA from receiving the request (6 weeks) to seeking the advice and making a decision (10 weeks), informing parents (2 weeks) and issuing the final statement (8 weeks) should take a total of 26 weeks or between 6 and 7 months (p. 120, Section 8:134). In practice, this was the case of the questionnaire sample for approximately half of those completing the questionnaire. See Figure 5.10.

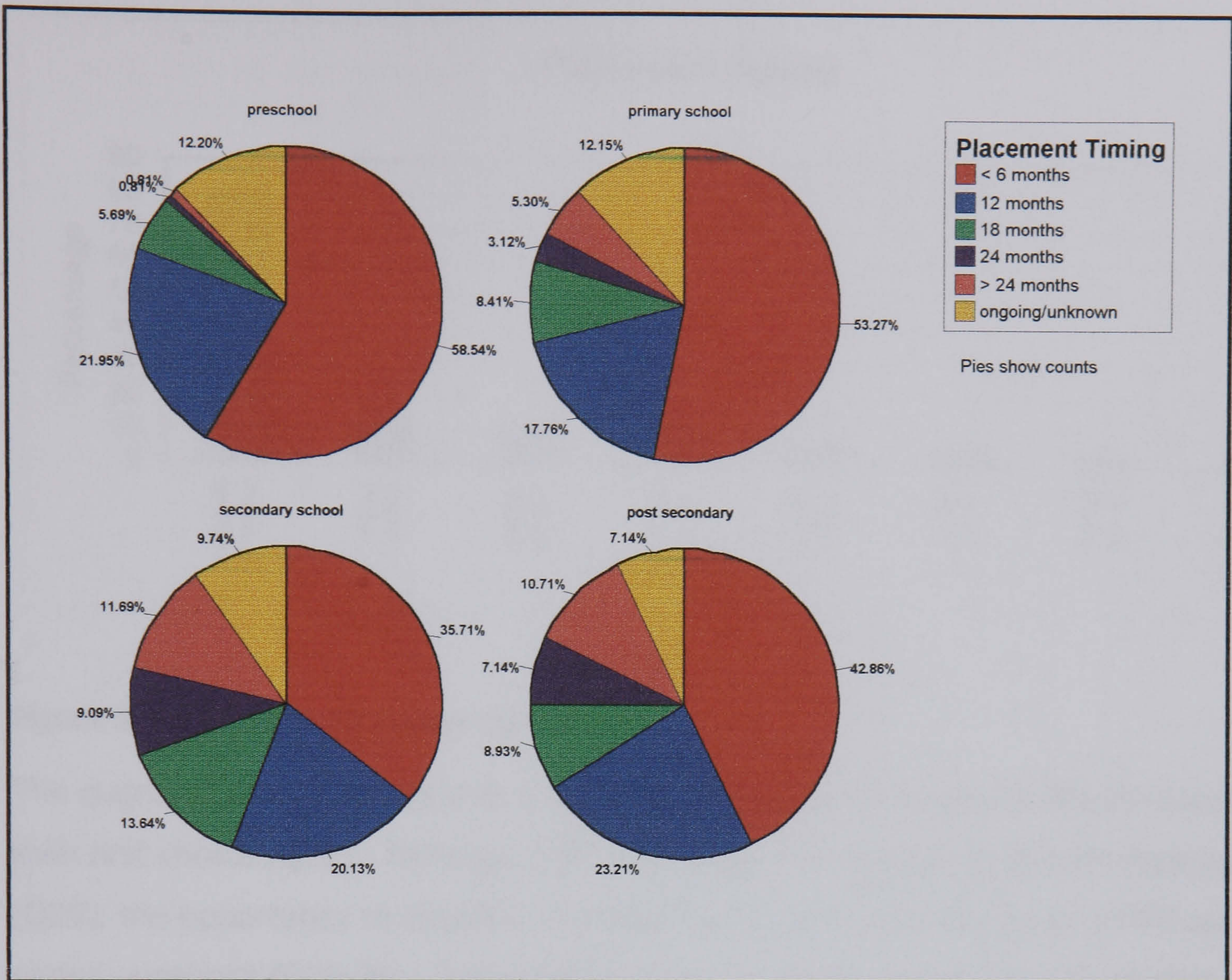


Figure 5.10. Placement Timescales (Q32)

It is interesting to see that those parents securing placements for preschool children found the process faster than those in secondary or post secondary group. (Speculatively, this could be linked to the larger proportion of mainstream provision for this group.)

Parents offered their opinion regarding the reasons behind these delays. Question 33 asked the parents for reasons why they experienced delays of over one year (see Figure 5.11.).

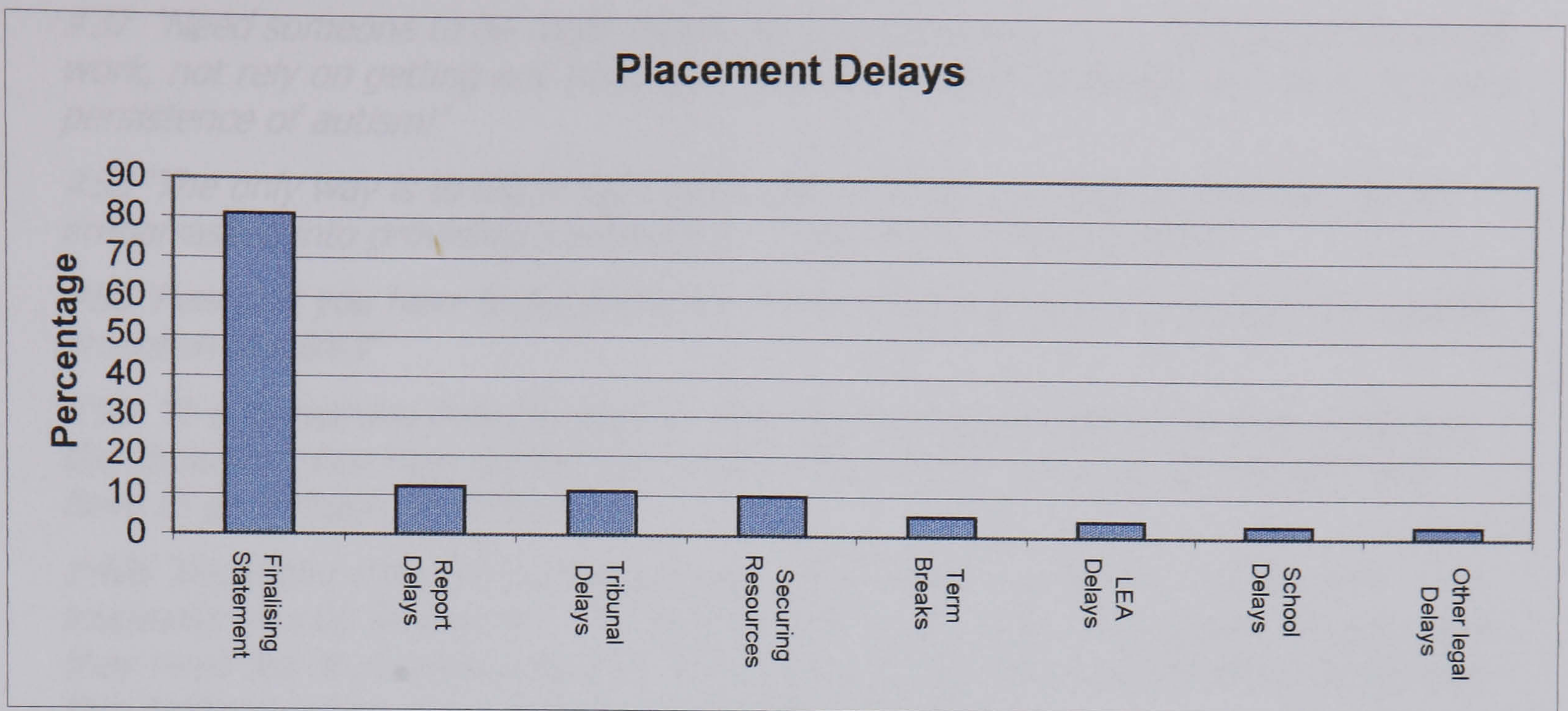


Figure 5.11. Placement Delays (Q33)

The quantitative data shows that a majority of parents have secured the provision of their first choice (Q26). Although many described this process as one of negotiation (Q29), the opportunity to describe in detail their experiences was given in the open-ended questions (Q38-39). The qualitative data enabled respondents to express opinions in their own words and therefore gives a richer view of the data. Parents stated they have obtained the provision of choice, but the open-ended questions reveal greater detail about the process. In looking at the qualitative data, two themes start to emerge and are discussed next: persistent parents and timeliness.

Although the outcome appears to be what the parents wanted for the majority of families sampled, the description of the process from the point of view of those going through it reveals another aspect. The qualitative data reveals that parents shared the belief that it was only through their own persistence that a preferred provision was secured. (Note: All quotes used are taken from Q38-39, with case numbers listed. Names of individuals and institutions have been changed or removed.

#258 'I'm afraid it's a case of 'who shouts loudest' or who makes the most nuisance calls gets treated with a degree of seriousness with regard to the LEA. I had to get my local MP involved to help with the start of Colin's statementing process. It is sheer hell going through the whole process and the effect on the family and child is phenomenal. Fear is the worst. Not knowing if and when the provision they are legally entitled to will actually be there for them when they need it.'

#37 'Need someone to be really blunt with you from day 1. i.e. Tell you to do all the work, not rely on getting any help, get a big file ready and develop the will of iron and persistence of autism!'

#53 'The only way is to dig in your heels and make so much noise that the LEA is embarrassed into providing a education. If all else fails, bomb office'

#88 'Feel that you have to be proactive if not downright 'pushy' to secure the type of provision required'

#90 'It is something that constantly needs chasing and following up and as soon as the statement has been settled for one year the review has to be started and you have to go through it all again.'

#406 'Because I work within the system I know what is available and the stark inequality of who gets what. The parents who push and write and demand get what they need but at considerable cost to their health. Middle class and educated people fare better-working class parents are usually fobbed off.'

#617 Only parents with dogged determination and unlimited stamina will ever succeed for their children in the current system.'

In general, when parents chose to respond about their experiences, they shared the belief that it was only through their own efforts that their child was given an appropriate educational provision. They frequently described the process as needing constant attention and follow up.

Timeliness is another theme emerging from the data. Parents expressed their distress at the length of time it took to secure provision for their child.

#296 'The statementing process is ridiculous. It's far too long and far too complicated. If your child has a diagnosis of something as serious as autism, why should an LEA need weeks to decide if they are going to carry out an assessment and then weeks to decide if they are going to statement them. Obviously a child with a profound disability should have a statement and the preliminary rubbish should be removed from the process in many cases.'

#569 'I felt if I didn't keep on top of the process it would take a very long time. I was a pain but it paid off, and I got my child's statement in a reasonable time frame.'

#587 'Finding a suitable placement for our son and then persuading the LEA to accept our choice and fund it was a long and difficult process. The effect on the family was stress, stress, and more stress. However, the end result is a great improvement in his condition.'

#31 'It took 13 months to get proposed statement-typist shortage!!'

#474 'At age 16 Thomas needs to be relocated into further education. The process is no quicker-the delays are longer, with less apparent reason.'

Although the Code of Practice recommends time guidelines for agreement of statements of special needs, parents in general were frustrated with the length of

time the process took. Many described this process as inefficient and therefore frustrating.

5.6.2. Satisfaction with Process

Most families seemed evenly divided on the question of satisfaction with the parental input in this process (Q18). Using a Likert scale for the responses where 1 was the least satisfied and 10 was the most satisfied, opinions seem relatively evenly spread with a slight upward trend (mean=6.4, SD=2.67). Most of the scores had between 5 and 15% of responses. See Figure 5.12.

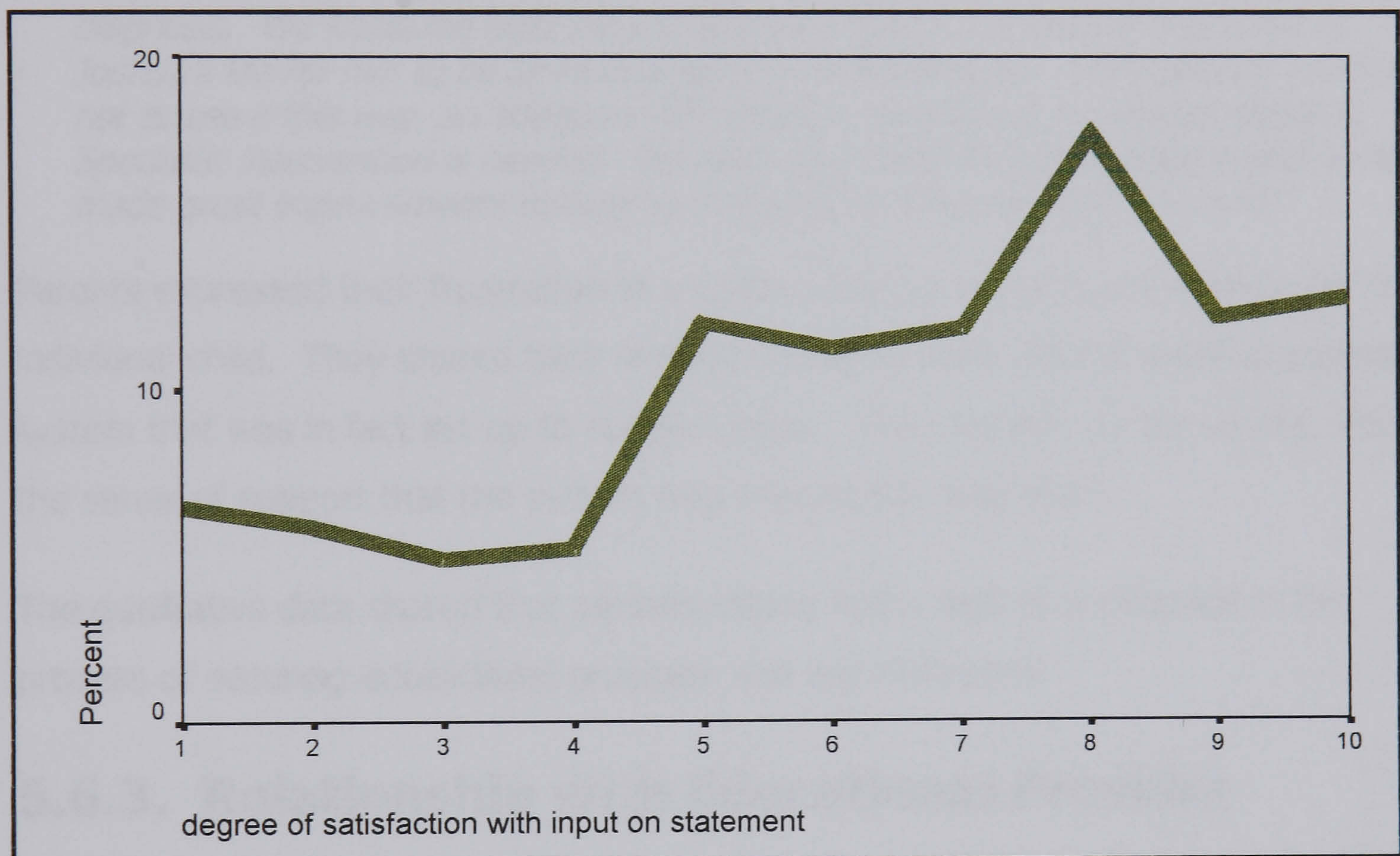


Figure 5.12. Degree of Satisfaction (Q18)

When asked if parents felt that the provisions of the statement were routinely met, 60% (n=349) felt they were (Q19), but a significant minority (40%, n=230) felt they were not. Of this minority, the most common failure noted by parents was the lack of specialist services (8%, n=60), most notably the lack of speech and language therapy. Other parents felt that the process does not work in practice (4%, n=29) or that the only reason it does work was through the parent's involvement, ensuring that the provisions of the statement are met (3%, n=21). (See previous discussion on Parent Persistence in Section 5.6.1.)

The qualitative data also reveals the frustration frequently shared by a large number of parents in the open-ended questions (Q38-39). A sample of these comments follows:

#704 'It is the most difficult situation particularly as a single parent. There are assumptions at the beginning about status and I wonder if it clouds the issues. It can be a lonely place with all the 'experts 'around you.'

#110 'It was hell!'

#112 'It has left us feeling impotent in an area where we are desperate for the right results...The system seems to me a lumbering administrative sequence rather than a genuine attempt to meet the needs of the child.'

#721 'The whole process has been a very stressful, worrying experience since before diagnosis. We know the right educational provision is essential at this point in Joshua's life for him to be as independent as possible later. Unfortunately LEA's tend not to see it this way, an adequate education is not enough for autistic children. Specialist intervention is needed. We work very hard with him at home and he has made great improvements-sometimes it would be nice just to be his mum!'

Parents expressed their frustration at a system that they feel is not working for their individual child. They shared their feelings that they were almost working against a system that was in fact set up to support them. They did not, on the whole, share the sense of support that the system was intended to give them.

The qualitative data shared that parents clearly had a lack of confidence in the process of securing educational provision and felt frustrated.

5.6.3. Relationship with Educational Provider

Parents were asked about their relationship with their educational provider (Q20-25). Comments in this section are divided into two groupings: those pertaining to the school and those pertaining to the LEA.

When parents were asked about their way of working with the school to support their child, the clear majority felt they worked together with the educational provider to determine goals for the child (64%, n=430). Others let the school set goals, (11%, n=76), while about the same amount of respondents tried new goals first, then encouraged the school to do them as well (9%, n=60). Figure 5.13 summarises these findings.

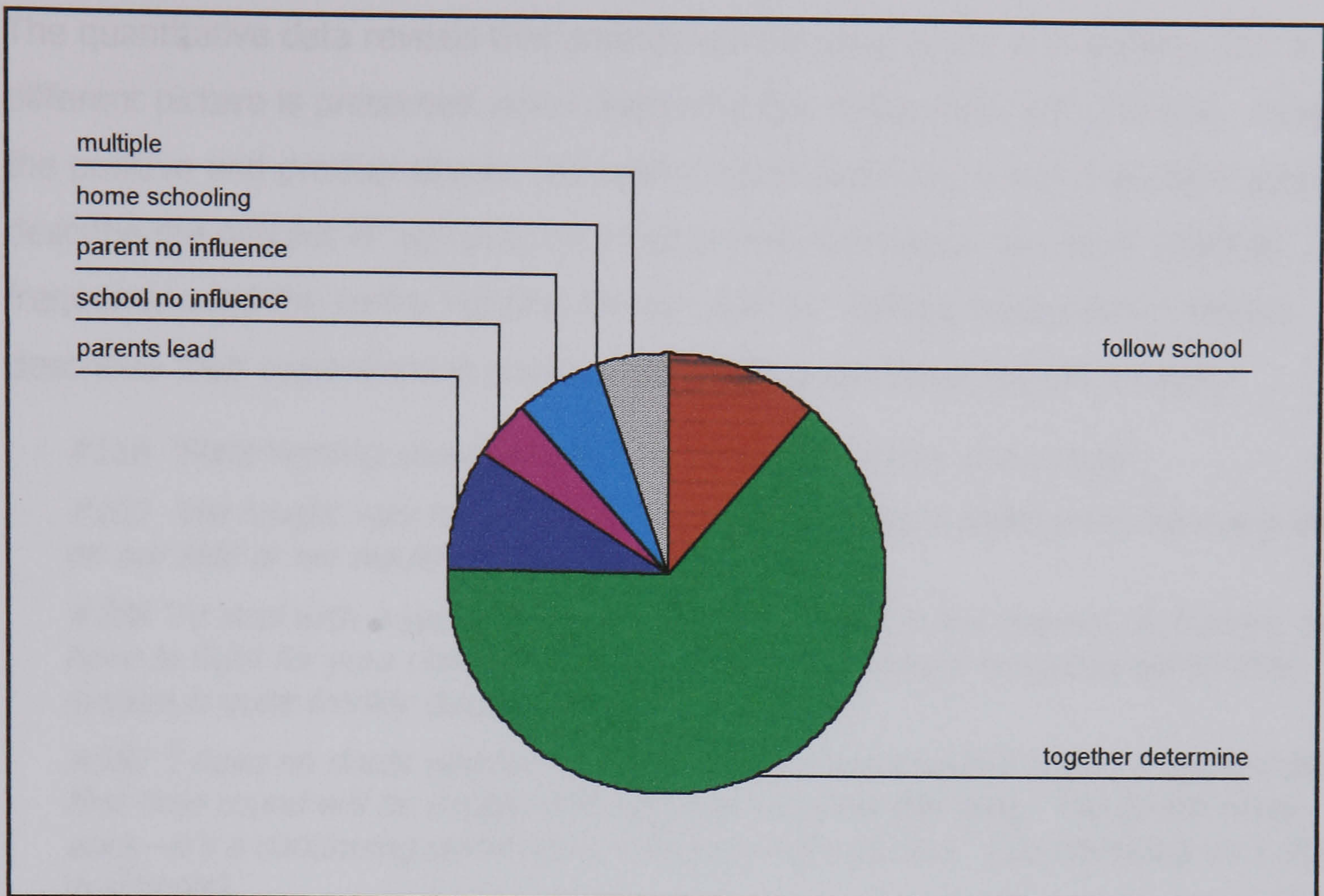


Figure 5.13. Working Together (Q20)

Respondents were also asked about the type of help and guidance the educational provider gave them. This was addressed in two questions, one asking where most help is given (Q23), and the second asking where least (Q24) help is given. Most responses stated that all areas were equally addressed (Q23-40%, n=264; Q24-50%, n=322). Surprisingly, the academic areas were listed second in both questions (Q23-13%, n=83; Q24-12%, n=74), stating a strong minority feel most and least help is given in this area showing a strong difference of opinion among those surveyed. Due to the fact that behavioural problems are frequently associated with autism, it is surprising that this area is listed infrequently. Seven percent (7%, n=49) stated that most help was given in this area, while 11% (n=68) felt that least help was given in this area.

Seventy percent (70%, n=511) of those responding stated they were happy with their child's provision (Q25), most stated the school staff as the reason (41%, n=298), followed by 13% (n=99) who felt that the child-centred curriculum made parents happy with the provision. Those unhappy, listed lack of autism specific provision (8%, n=62) and lack of resources (7%, n=49) as the two most frequent answers.

The quantitative data reveals that parents are working jointly with schools, but a different picture is presented when discussing the relationship with the LEA. Despite the positive end product above, the open-ended questions reveal that many parents describe the process of agreeing on an educational provision as one of 'conflict'. They frequently used the terms 'fighting for my child' or 'fighting the system'. Others described their experience in positive tones, although these are the minority.

#116 'Statementing should not be a fight with diagnosis, it is a right.'

#103 'We fought very hard to get our statement as we wanted it—we needed a lawyer on our side or we would have got nothing.'

#288 'To deal with a system that is supposed to exist in the interest of children, and have to fight for your child's right to a fair and appropriate education within that system is quite frankly disgusting.'

#582 'I have no doubt whatsoever that whatever brick walls I came up against the first time round will be doubly difficult to break down this time. The battle never ends—it's a continuing uphill fight, with seemingly no end.' [Commenting on a change in schools]

#415 'The process has been stressful because in addition to the everyday stress of having an autistic child, we felt we have been faced into conflict with the LEA, which we never wanted. Much of the conflict could have been avoided if there were better discussion processes.'

#457 'The playgroup leader, preschool teacher/counsellor and school head have all been helpful above and beyond what anyone could ever expect. These three pulled out all the stops for us and made what could have been a complete nightmare a mere time swallower. I shudder to think how we would have managed without their support and influence. As the only one of the three still involved, the school head continues to support us vigorously, helping to maintain the high level of LEA support initially granted.'

To illustrate the depth of the critical comments on the LEA, several quotes are given; grouped into the following categories: relationship with the LEA, LEA resources, and LEA bureaucracy.

The largest of these three categories describes the depth of feelings about the relationship with an individual LEA. Although there were some positive comments, most reported otherwise.

#11 'LEA allows parents to have input but then completely ignores what they say!'

#36 Lisa's disability is minor to cope with when compared to the trauma evoked by the LEA.'

#290 'Our experience (and that of other parents we know) is very similar—we have been successful for our children in spite of the LEA not because of them.'

#354 'Dealing with a child with autism is difficult enough. The LEA are inflexible with their decision making. They waste time, refuse to take action, then you apply to tribunal, they back down at the last moment. It's like a big game to save them money. But in the meantime you are left with the waiting and not knowing.'

#726 'The legislation focuses on provision of the child's needs. The upsetting thing is the duplicity and double dealing that LEA officials will resort to in order to avoid meeting the needs of the child.'

Parents dealing with LEAs also mentioned resources frequently. Most comments from parents shared concerns about perceived budgetary restraints on behalf of the LEA that impacted their child's educational provision. A sample of these comments follows.

#25 We have come to the conclusion that our LEA is motivated only to control their budget to the detriment of their responsibility for the needs of the children.

#26 'In our experience we were often told there is no money!-there are no places ect....!!! Why should I need to know this? I never had a piece of paper telling me how much money my other children were costing the state.

#86 'The LEA have proved themselves incapable of making decisions based on the needs of my child rather than their policies and budgets.'

#180 'I would say that if you disagree with the cheapest provision available it will be a difficult and stressful fight to obtain what you believe is appropriate.'

#401 'It is a complete joke to read the government guidelines and assume that a child's needs come first. To the LEA what comes first is: their budgets, their resources, [and] their costs.'

#680 'We are left with a complete mistrust of our LEA who put money before the needs of the child, and whose short sighted, blinkered attitude which does not allow them to recognise that early intervention and appropriate educational provision will save them money long term. I would not wish this experience on even my worst enemies.'

Parents shared their reactions to what they generally describe as a bureaucratic and complex procedure to secure appropriate educational provision for their child. The survey revealed forty three percent (43%) of parents listed complexity of this process as one of three factors that contributed to their stress (Q35).

#444 'The first tribunal named a school it had no right to. That school/LEA went to the high court and referred the matter back to the tribunal this was then delayed because our LEA could not get a educational psychologist to attend as they were all on holiday.'

#447 'It seems that those who know nothing about our son, are those that make the major decisions.'

#423 'The process itself is a long tortuous affair which could be entirely overcome by an interview and brief assessment period instead.... For all going through the process

was hard and upsetting, I was supported by my LEA in a very compassionate and effective manner.'

#685 'A simple process made stressful by lack of application of basic management disciplines.' [Statementing process]

In summary, parents described the relationship they had with educational providers in this section. Distinction was made between schools and LEAs. Parents described their day-to-day contact with a school as generally positive where they worked together to set goals for children. The relationship with the LEA is generally described from a different perspective. Parents generally perceived the LEA in a negative light and attributed any frustration at the process to the LEA and any failings of this bureau. (See following section for further discussion on parental views of LEAs.)

5.6.4. Effect on the Family

Questions 34 to 36 and Q38-39 asked about the effects of agreeing a statement of special needs and finding an educational placement had on the family. Most families found this a stressful process. Using a Likert scale where '1' represented 'not at all stressful' and '5' represented 'extremely stressful'; 65% of families responding (n=455, mean 3.8, SD 1.32) said this was a 'very stressful' or 'extremely stressful' process (Q34). Unfortunately, the reported high stress levels appear to be consistent across age groupings (see Figure 5.14.). In this chart, the percentage of those reporting 'extreme stress' remains relatively consistent in all four-age groupings (between 42% and 46%).

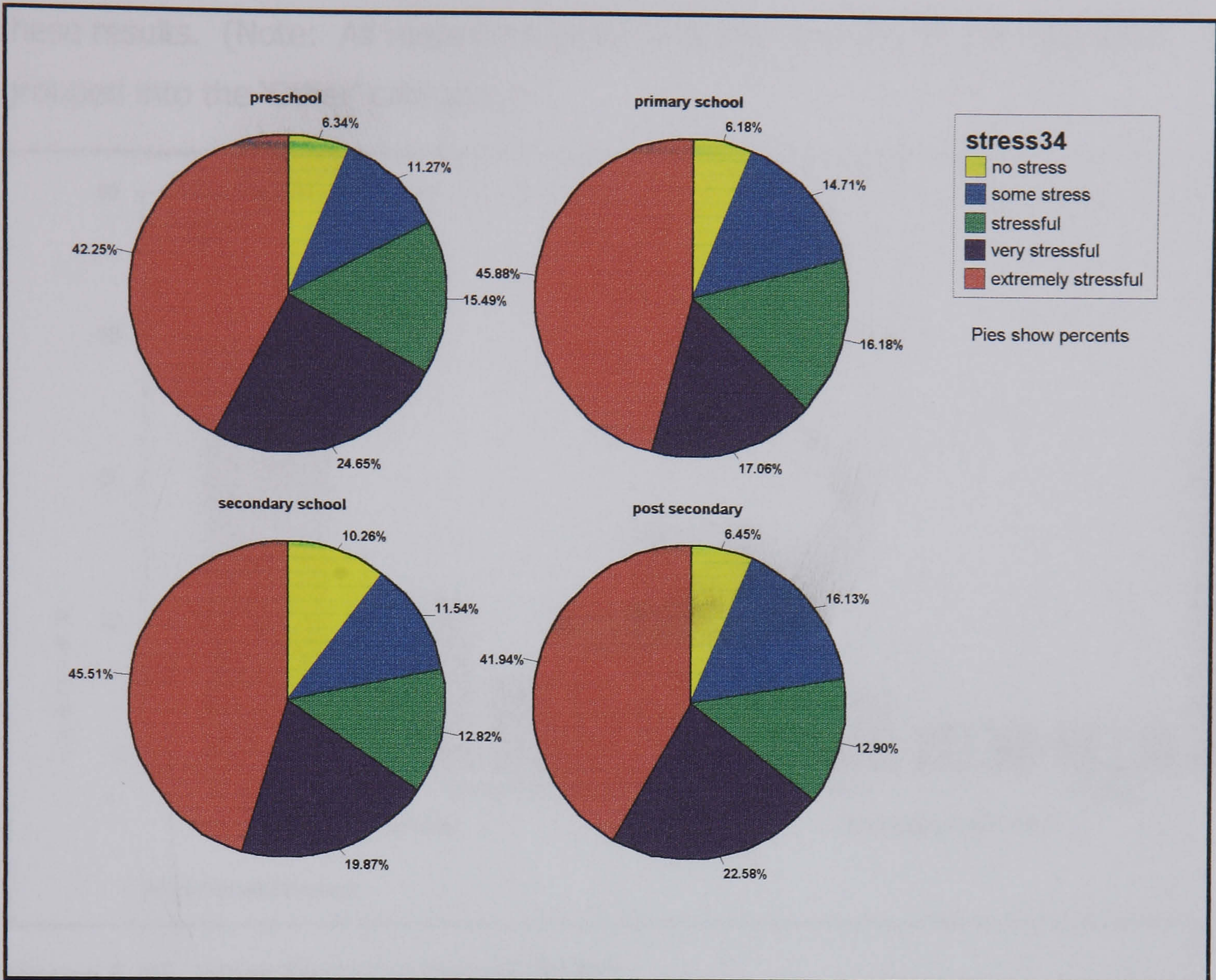


Figure 5.14. Stress Levels (Q34)

What are those surveyed finding stressful (Q35)? Respondents were asked to select three responses from a potential 10, with an additional blank item included to allow respondents the opportunity to list any item not stated. The eleven most frequently listed items are shown below (Figure 5.15).

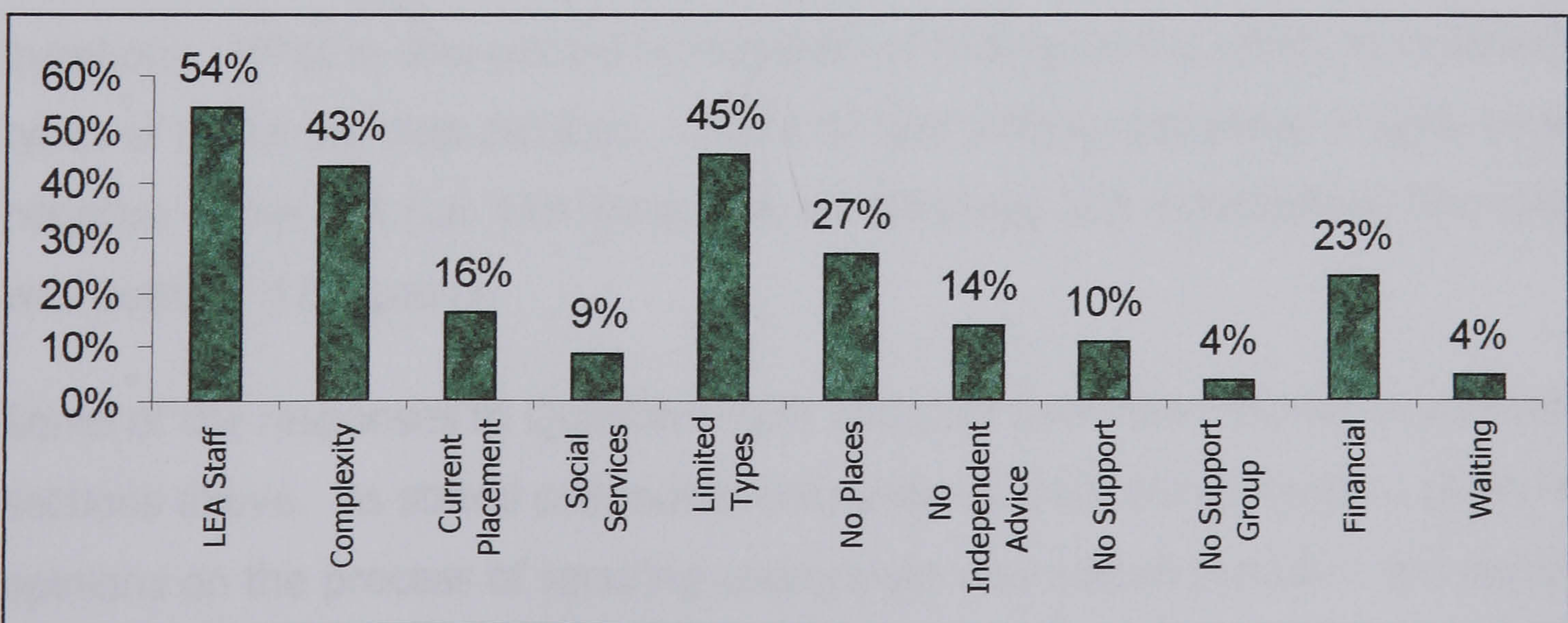


Figure 5.15. Stressful Factors (Q35)

When respondents were asked which of these items caused the most stress for their family (Q36) again, dealings with the LEA staff topped the list. Figure 5.16 shows

these results. (Note: All responses generating less than 3% of the total were grouped into the 'Other' category.)

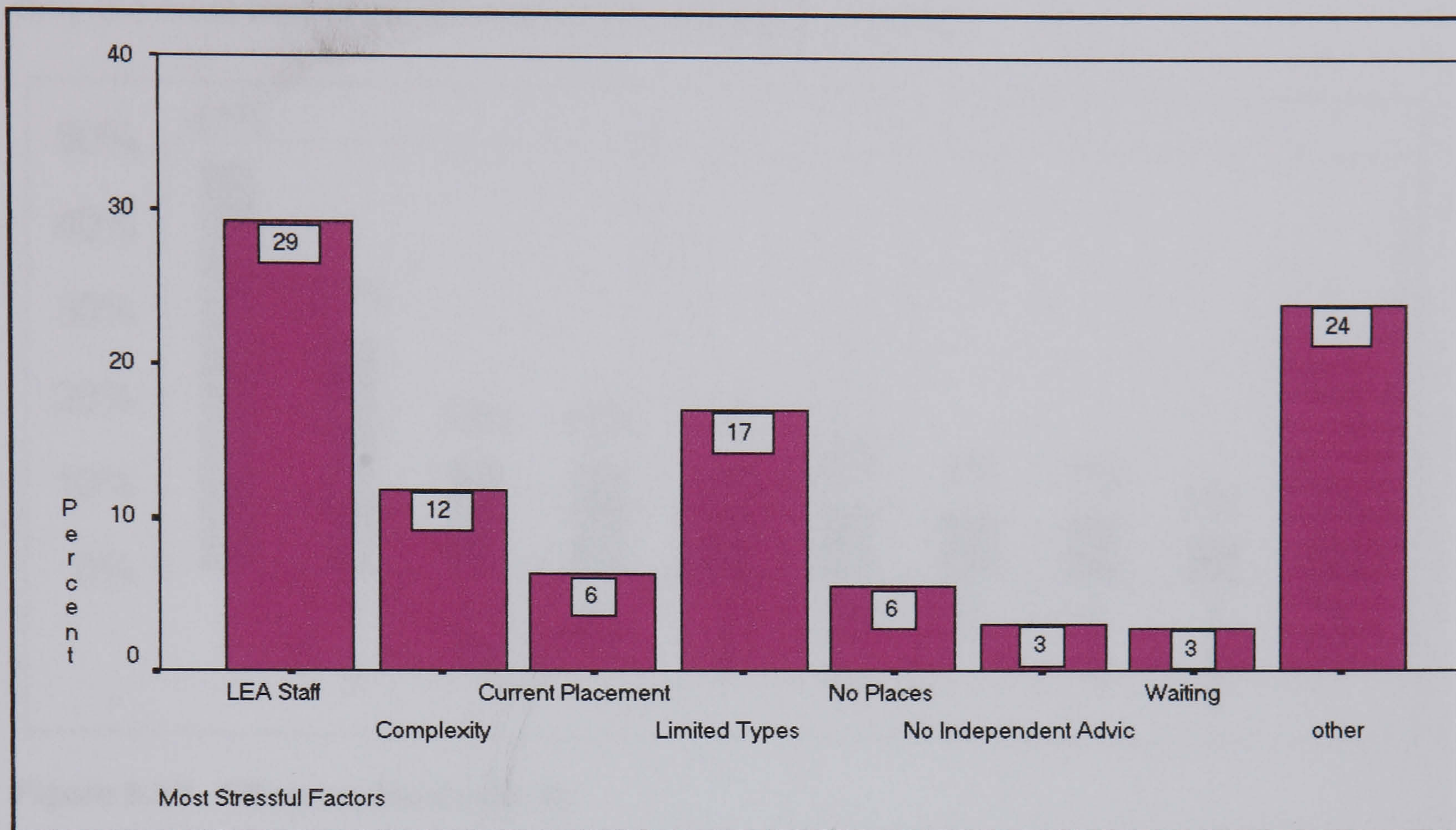


Figure 5.16. Most Stressful Figures (Q36)

Results from Q35 revealed that 54% of responses listed 'discussions with the LEA' as one of their three factors contributing to any stress they experienced, and when asked which of these three factors (Q36) caused the most stress, the survey revealed almost 30% felt that dealings with their LEA caused the most stress. It is not surprising that references to the LEA were frequently mentioned in the open-ended questions. What is unexpected is the depth of feeling on this point, as revealed in the types of codes the data dictated. Of the 32 final coding categories in Q39, 13 were negative of the LEA (i.e. LEA lying, LEA not listening, LEA inconsistent) and only one was positive (LEA good).

Some of the responses to Questions Q38 and Q39 have been shared in the relevant sections above. As stated previously, respondents were encouraged to share their opinions on the process of securing appropriate educational provision and continue on back sheets (or attach additional sheets) if necessary.

Question 38 asked specifically about the family and the results are listed in Figure 5.17. It is important to remember that multiple responses were encouraged, and that only the most frequently mentioned 10 responses are listed.



Figure 5.17. Effect on Family (Q38)

The last question (Q39) was an open-ended question asking for any additional comments that respondents wished to make. Figure 5.18 shows the ten most frequent replies. Perhaps not surprising after the results of Q 36 (stating that dealings with LEA staff was the most stressful), negative comments about LEAs are listed six times on this chart. Some reported positive dealings with the LEA, but these were in the minority.

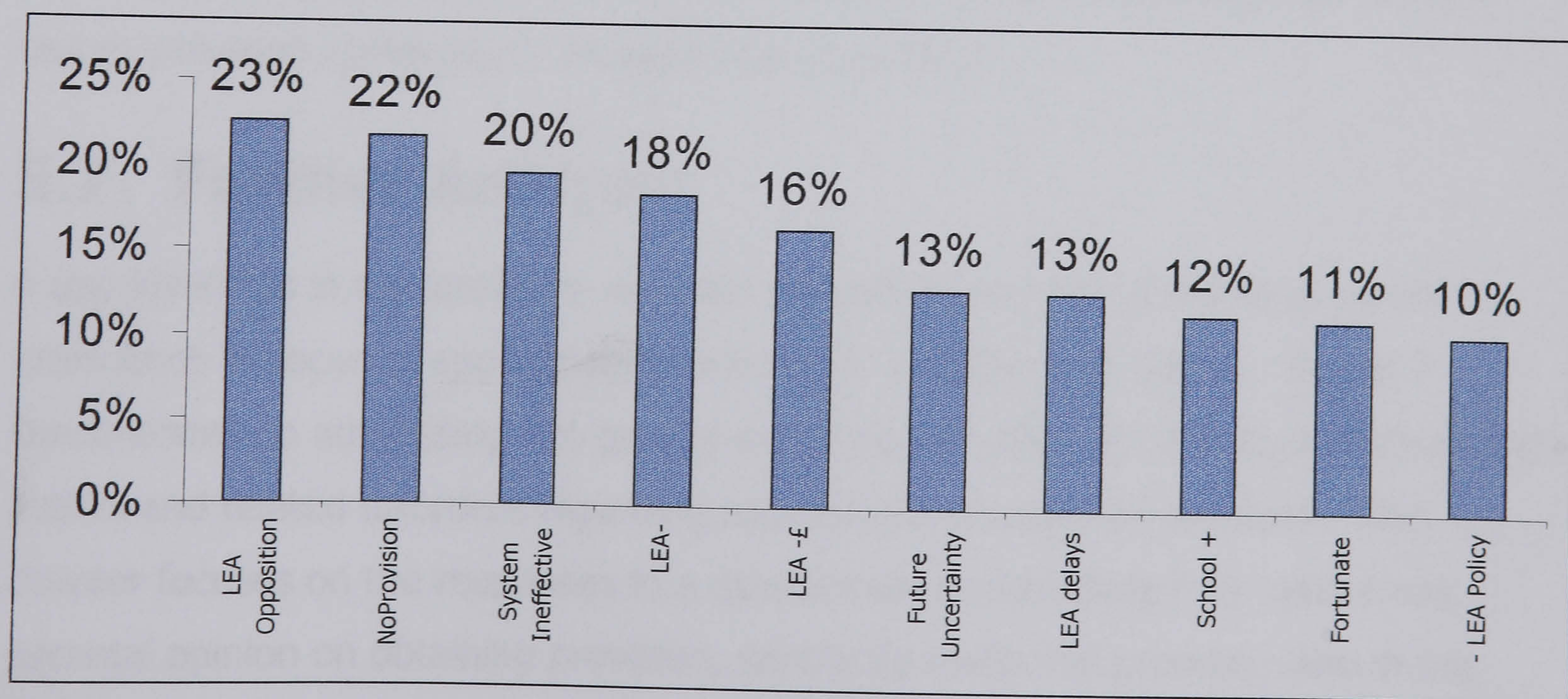


Figure 5.18. General Comments (Q39)

In addition to the comments cited above, parents expressed a view that they felt a lack of understanding on the part of the LEA.

#523 'There is an extremely unpleasant attitude from all professionals involved that parents are ignorant individuals who are on some sort of perverse mission. There is little understanding of how parents feel and that what we are trying to do is above all to help our child and for no other reason. Professionals/LEAs and medical practitioners need to review their condescending approach.'

#539 'It was a battle getting anyone to understand our problems and believe that she was something other than 'naughty'.

#71 'The main problem has always been the LEA. They have been hostile, cynical and arrogant from the onset.'

Section 5.6.4 discussed the results of the survey that impacted the family. Most of the completed surveys showed that families found the process of securing provision stressful. When asked to identify factors associated with that stress, the most frequent answer given was the contact with the LEA. This was a very frequent topic in the open-ended questions and several comments were shared.

This section looked in depth at the comments parents made on securing educational provision for their child with autism. It found that, in general, survey parents were successful at securing their provision of choice and working with the school to help address the needs of their child. It also highlighted numerous emotive responses from parents frustrated at the process. The next section will discuss some additional questions raised in Chapter Three (Literature Review) regarding their experience with the diagnosis of their child and the items parents felt were impacting their ability to secure provision (reflected in increased stress scores).

5.7. Further Analysis

A gap identified in the literature revealed the lack of research directed at parent experience in securing appropriate provision for children with autism. Strand 2 concentrates on addressing this gap by exploring the views of parents of children with autism and related disorders regarding appropriate educational provision. This chapter focuses on the responses to a questionnaire addressing four main areas: parental opinion on obtaining provision, satisfaction with this process, view of the relationship with the educational provider and the effect that this process had on the family.

The Literature Review (Chapter 2) highlighted the need to understand the trend in earlier diagnosis and the need to investigate the views of parents about the process of obtaining appropriated educational provision. Section 5.7.1. looks at the sample and explores trends in diagnosis. Section 5.7.2. investigates the unexpected finding of high stress levels reported by parents and looks for factors that may be associated with this.

5.7.1. Age of Diagnosis

The Literature Review (Chapter 2) highlighted the lack of agreement in the narrative regarding the number of children diagnosed with autism. Although there appears to be an increase in the number of diagnosed children, professionals disagree whether this is an increase in actual number of cases of children with autism or this perceived increase is due to earlier or better diagnosis. (See prior discussion in Section 5.4.2.) The current trend is towards earlier diagnosis. This has an impact on the issue of appropriate educational provision because it could possibly identify one area that impacts on the implementation of provision; the actual number of children identified with the ailment desiring provision. Therefore, it is appropriate to investigate any possible link.

Questionnaire respondents were asked the age their child was diagnosed (Q9) in addition to the year of birth of that child (Q1). The responses showed a range of 29 years, with the oldest child reported born in 1970 and the youngest born in 1999. (The survey was distributed in 2001, so the youngest child reported was 2 years of age, and the oldest was 31.) The mean birth year was 1992, while the mode was 1995.

Acknowledged to be an opportunity sample, this study is not necessarily a representative sample of the population of all families of children with autism. Nevertheless, due to the size of the sample (735 responses) and the range of the ages of children reported, a look at the experiences of the families is warranted. Both the ages of birth and the age of diagnosis are continuous variables; normally distributed therefore the use of a parametric test is appropriate. Preliminary bivariate analysis revealed a relationship between these two responses of a Pearson correlation of $-.520$ significant to $.01$ levels. (It should also be noted that due to the young age

of some of the children reported, late diagnosis is not possible which may in part be responsible for the high correlation seen.)

Howlin and Moore (1997b) concluded that although the age of diagnosis appears to be decreasing, the average age a child is diagnosed is still approximately 6 years of age (p.135). Although these results were reported six years ago, the experience of parents in the survey suggests that there is a vast difference in the age of diagnosis dependant on the age of birth. See Table 5.1.

Date of Birth	Mean	Averaged Means	N	Std. Deviation
before 1983	5.875	5.5 n=70	16	2.1174
1984	5.139		18	2.4423
1985	5.056		36	2.4576
1986	4.950	4.7 n=158	20	2.3781
1987	4.700		20	2.3475
1988	5.186		35	2.2980
1989	3.616		43	1.7554
1990	4.300		40	2.0280
1991	3.790	3.53 n=351	62	1.7800
1992	3.309		47	1.4728
1993	3.208		65	1.2957
1994	3.061		82	1.0841
1995	2.758		95	.6875
1996	2.544		80	.4072
1997	2.406		53	.1975
1998	2.357		14	.2344
1999	2.000		1	.
Total	3.506		727	1.7712

Table 5.1. Mean ages of diagnosis per year of birth.

Note: Families with children born before 1983 were grouped together due to the small number of respondents in this category (n=16).

Table 5.1 shows the mean age of diagnosis of the sample according to the year of birth of the child. The reports of respondents to the questionnaire indicate that there

is a trend toward earlier diagnosis. Families with children born in the early 1980's could expect to receive a diagnosis for their child between the ages of 5 and 6 (comparable to the results of Howlin and Moore (1997b)). Those born in the late 1980's could expect a diagnosis between the ages of 3 ½ and 5, while those born in the early 1990's between 3 and 4 years.

This research, which is the only major UK study conducted since the report of Howlin and Moore (1997b) indicate that the trend to earlier diagnosis continues such that children who would have been diagnosed by 6, are now diagnosed at 2.76 years of age. The data in this study, if averaged over five year intervals, reveal a trend in the mean ages in the group sampled specifically towards increasingly younger age of diagnosis. The average age of diagnosis for children born between 1994 and 1990 is diagnosis at 3.53 years of age. Those born between 1989 and 1985 are, on average, diagnosed at the age of 4.7. Before 1985, the average age of diagnosis is 5.5 years. This research clearly shows that children with autism are receiving a diagnosis much earlier that they were five to ten years ago. This is a significant contribution of this research.

5.7.2. Stress Levels of Parents Securing Provision

In addition to the question of the timing of diagnosis, the Literature Review (see Chapter 2) highlighted the lack of research into the parental feelings regarding current practice in securing educational provision. As the research question directs investigation into this issue, it is appropriate to look at it. The 737 completed questionnaires indicate the huge diversity of opinion that exists within the sample, but some generalisations can be made about the responses.

An unexpected finding of this research was the high levels of reported stress by survey parents. In addition, parents shared their satisfaction with the outcome of the process of securing educational provision. Almost 80% (Q 26) stated that they had their child in a placement that was their first choice and 64% felt they worked jointly with the school in establishing goals (Q 20). This last figure is increased to 84% when the lead is taken by the school (11%) or the parent (9%) and then jointly worked on. If parents have their child in the placement of their choice and are jointly working on their child's educational goals, why does the questionnaire sample report

such high levels of parental stress (Q34) associated with securing appropriate educational provision?

Research supports the logical conclusion that raising a child with autism is more stressful than raising a child without a handicap (Sivberg, 2002). In addition, mothers of children with autism report more stress in their lives when compared with mothers of non-autistic disabled children (Rodrigue et al., 1990). There is no literature on stress levels in parents relating specifically to the process of securing educational provision for their children with autism, but the research in this thesis shows that the survey parents reported high levels of stress. Almost half of the sample (43%, n=316) listed 'extremely stressful' when asked about the process of securing provision (Q34). Sixty two percent (62%, n=455) found the process either very stressful or extremely stressful. Both the quantitative and qualitative results of the survey show that parents describe the process of securing appropriate educational provision as stressful even though the end results appear to be what parents are describing as the provision that they wanted. The literature review highlighted the need for research into the experiences of families, and therefore investigation in this area is justified.

The critical question the results cited above raises is why do parents feel so stressed during the process? What factors, if any, can be associated to these stated high levels of stress? Reflecting on this led to several hypotheses about a possible link between parental responses to survey questions and the degree of stress (measured using a Likert scale of 1 (less stress) to 5 (more stress)) reported by the family. Consistent with the scientific method, it is important to list these as null hypotheses. This will enable the argument of refutation, which if the null hypothesis can be rejected, support can be provided for a possible link between stress scores and the items investigated. The following null hypotheses were tested:

NH1= Later diagnosis and contingent problems have no effect on parental stress.

NH2=Longer waiting times to finalise educational provision has no effect on parental stress.

NH3=Parents involving outside specialists experienced no different levels of stress than parents that did not.

NH4=The type of individual placement a child is in, has no effect on parental stress.

NH5=Parents who have children educated outside the home LEA experience no additional stress.

NH6=Parents reporting satisfaction with their input in the statementing process experience no difference in their level of stress that those parents who state they are not satisfied with the input.

These hypotheses are discussed in the following two sections.

5.7.2.1. Independent Samples T-tests

One way to investigate this question is to propose a hypothesis and then test it with the parental responses to the questionnaire. Reviewing the qualitative survey responses points to a high number of families complaining of time delays in diagnosis (see Figure 5.10).

The first null hypothesis (NH1) is that later diagnoses and contingent problems have no effect on the stress scores of parents. The null hypothesis would therefore be that there is no difference in the amount of stress stated in families that have a diagnosis by the age of 3 and those with a diagnosis after 7 years of age. These two ages were chosen to contrast those with an early diagnosis given during preschool years with those parents who received a very late diagnosis while the child was known to the school system.

The type of data (one categorical independent variable and one continuous dependent variable) indicates that an independent samples t-test should be used to check the null hypothesis. Question 9 was recoded into two variables, the first group had a diagnosis before age 3 ($n=458$), and the second had a diagnosis after age 7 ($n=75$) (Note: children with diagnoses other than this were deleted from this data set to test the hypothesis.) The null hypothesis would therefore be that there is no difference in the amount of stress stated between families receiving a diagnosis before their child reaches the age of 3 and those receiving a diagnosis for their child after the age of 7. These two independent variables were compared with the dependent variable, stress.

There was significant difference in the stress scores for families when they received their child's diagnosis before the age of 3 ($M=3.78$, $SD=1.33$) and those receiving a diagnosis after their child reached the age of 7 ($M=4.12$, $SD=1.15$, $t(533)=-2.354$, $p=.034$).

Eta squared represents the proportion of variance of the dependent variable that is explained by the independent variable. In this example, the magnitude of the differences in the means was small (eta squared=.01). It is safe to reject the null hypothesis and state that those receiving a diagnosis for their child after the age of 7 had significantly higher reported levels of stress than those receiving a diagnosis before the age of 3. It is also safe to reject the Null Hypothesis 1 and state that later diagnosis and contingent problems increases parental stress.

It is interesting to look at the qualitative differences between these two groups in the listed factors that contributed to the reported stress levels. It was suspected that due to the high number of survey parents that mentioned discussions with LEA staff as difficult, that this could potentially be associated with an increase in the reported levels of stress. Of those diagnosed before 3, (Group 1-G1) 60.4% reported this stressful. This is compared with those diagnosed after the age of 7 (Group 2-G2), in which almost the same percentage, 60.3% found this stressful. Similar percentages of parents reported that the complexity of the procedure (G1=41.4%, G2=46.2%), the limited number of types of provision (G1=46.0%, G2=42.3%), the limited number of places at a school (G1=25.1%, G2=25.6%) the lack of outside advice (G1=12.7%, G2=17.9%), the lack of support from family and friends (G1=8.9%, G2=12.8%) and the lack of a support group (G1=3.9%, G2=3.8%). The biggest differences between these two groups in reported stress factors were the ineffectiveness of current provision (G1=12.8%, G2=26.9%) and the cost of provision reported by parents (G1=28.8%, G2=10.3%). It appears that the parents of older children found the current educational provision more stressful and those parents where children were diagnosed younger stated that they were concerned about the cost of the provision.

The age of diagnosis is not the whole story. The qualitative data also suggests a possible link between the length of time families wait to agree provision and the level of reported stress. The second null hypothesis (NH2), suggests that there is no difference in the levels of stress when families have provision determined quickly compared with families that experience a lengthy wait. The null hypothesis would therefore be that there is no difference in the amount of stress stated between families waiting the government recommended amount of time (6 months) and those waiting more than 6 months.

Again, the types of data (one categorical independent variable and one continuous dependent variable) indicate that an independent samples t-test should be used to check the null hypothesis. Question 32 was recoded into two variables, one group were those that had agreed on educational provision within the recommended time limit ($n=321$), and all others were recoded into a second group of individuals waiting more than the recommended time amount ($n=259$). These two independent variables were compared with the dependent variable, stress. There was a significant difference in the stress scores for families with waiting times of 6 months or less ($M=3.3$, $SD=1.4$) and those having waiting times of more than 6 months ($M=4.37$, $SD=.944$; $t(578)=-10.6$, $p=.000$). Eta squared represents the magnitude of the difference between the groups. In this example, it is large (eta squared=.16). This means that it is safe to reject the null hypothesis and state that waiting times longer than the suggested 6 months in the Code of Practice (2001) guidelines contribute to reported stress levels in parents securing educational provision for their autistic child. It is safe to reject Null Hypothesis 2 and consequently state that longer waiting times to finalise educational provision increases parental stress.

In addition to waiting times, other variables were screened in the same manner. Null Hypothesis 3 stated that there is no difference in stress levels of survey parents when they involve specialist input to secure provision. An independent samples t-test was performed with the independent variable, specialist advice sought (Q30-legal council or specialist assessments), and the dependent variable, stress. Question 30 was used to determine those seeking specialist input ($n=219$) and those that did not ($n=455$), and comparing these with the dependent variable, stress. There was a significant difference in the stress scores for families that sought specialist input ($M=4.55$, $SD=.86$) and those that did not ($M=3.45$, $SD=1.37$, $t(625)=-12.8$, $p=.000$). Eta squared reveals that the magnitude of the difference in the means is large (.20), meaning it is safe to reject the null hypothesis and state that those survey parents that involved specialists found the process more stressful. Consequently, parents involving outside specialists experienced increased levels of stress.

Null Hypothesis 4 (NH4) proposed that there was no reported difference in the stress scores of parents in the different types of educational placement. The null hypothesis for Hypothesis 4 is that all types of provision equate to the same levels of reported

stress in parents. The mean stress score reported by survey parents in each different type of educational placement (mainstream provision, special unit, special needs school, independent school, boarding school, home based provision and home as well as school based provision) were compared with the mean reported stress score of the group as a whole. The mean scores of parental stress when children were in mainstream provision, an independent school, or were educated in a mixture of home schooling and school based provision, showed scores that were not statistically different from the mean of the group as a whole. The four other types of educational provision (special unit, special needs school, boarding and home schooling) did yield a significant difference in means. The eta squared results for these were .01, .03, .02, and .02 respectively. Therefore, it is safe to reject the null hypothesis that states that reported stress levels among parents in different types of provision are the same. Although this is not true in every type of provision, it is appropriate to conclude that there are increased levels of reported stress in parents of children educated in a special unit, boarding provision, a special school or those educated entirely at home. This is inconsistent with newer research by Hastings (2001) which concluded that parents following home based educational strategies did not experience any more stress than other families with autistic children receiving educational provision outside the home.

Additional independent samples t-tests were conducted and concluded that the null hypothesis could not be rejected. Whether educational provision was delivered in the home LEA or another LEA was also investigated. The null hypothesis (NH5) in this case would be that parents reported levels of stress would be the same for those with children educated within the home LEA when compared to those educated outside the home LEA. The results of t-tests comparing mean stress scores were insignificant. Therefore, it was not safe to reject the null hypothesis. The data did not support the hypothesis that there is more stated stress in parents with children educated outside the home LEA and therefore Null Hypothesis 5 cannot be rejected.

5.7.2.2. Pearson's Product-movement

In addition to t-tests, a Pearson's product-movement correlation coefficient (r) is used to explore variance. It is used to investigate two continuous variables, as is the case

with the degree of satisfaction parents had with their input into the statementing process and the dependent variable, stress. Null Hypothesis 6 (NH6) suggests that parents expressing greater satisfaction with their involvement in the statementing process had no different reported stress scores from parents that did not report satisfaction with the statementing process. The null hypothesis would be that there is no difference in the scores. This was found to be significant and have a value of $-.3$ ($r=-.297$, $p=.01$), or of medium strength. Therefore it is safe to reject the null hypothesis and state that the greater confidence parents had in their input into the statementing process, the lower the stated stress score in survey parents. Null Hypothesis 6 is therefore rejected stating that parents experience less reported stress when they are satisfied with their input in the statementing process.

5.7.2.3. Data Reduction

In addition to t-tests and the Pearson's product correlation coefficient, data reduction techniques were employed to investigate variance. Unlike the previous two techniques discussed (See Section 5.7.2.1 and Section 5.7.2.2.) which were means of comparing groups to see if they were statistically different from one another, data reduction techniques are used to look at a large set of data and see if it can be summarised using a smaller set of variables. It looks for groupings among the inter-correlations of variables (Pallant, 2001).

Multiple regression was used to investigate the effect of a group of independent variables have on the level of stress (dependent variable) experienced by parents. Although some of the variables were dichotomous as coded, by nature these were representative of an underlying continuity. The data was also screened for outliers that were eliminated from the data set. Figure 5.18 lists the independent and dependent variables screened.

Multiple Regression

Dependent Variable:

- Stress

Independent Variables Screened:

- Type of educational provision
- Age of diagnosis
- Length of time taken to agree on educational provision
- Date of birth
- Age parent first suspected there was a problem
- Degree of satisfaction with input on the statement
- Degree of disability of the child
- How many practitioners seen before given a diagnosis
- LEA family lives in and child educated in
- Level of communication, behaviour, and social interaction of the child
- Statement
- How the parents work with the educational provider
- Most and least help given from school
- If legal help was secured and cost
- Major source of stress
- Future expectations of child
- First choice in provision
- Provision of the statement met
- Happy with provision

Figure 5.19. Multiple Regression

A correlation matrix was performed with the variables listed in Figure 5.19 with the resulting r^2 value of 29.4. In other words, almost 30% of the variance in the dependent variable (stress) is explained in this model.

These same variables were used for the Factor Analysis with the exception of the dependent variable (stress). This was done to explore any relationship that may exist between the data. Those with a positive correlation above 0.3 or a negative correlation below -0.3 and having significance of .01 or less were checked against the results of the factor analysis (Pallant, 2001). The results of these two analyses were compared to see if similar variables appeared significant in both. Those that appeared in both are listed in Figure 5.20.

Factor Analysis

Variables:

- Stress
- Age of diagnosis
- Placement timing
- Age first suspected disability
- Degree of satisfaction with input on the statement
- Seek outside help?
- First choice in schools
- Provision of the statement met
- Happy with provision

Figure 5.20. Factor Analysis

The nine items in Figure 5.20 were subjected to principal components analysis (PCA) using SPSS. This technique attempts to produce a small number of combinations of variables that will account for the variance in the sample. These variables are then transformed into a smaller set of linear combinations where all the variance is used (Tabachnick et al., 1996).

Prior to performing PCA, the suitability of data for factor analysis was assessed by only including those variables with coefficients of more than .3 (positive or negative). Both the Kaiser-Meyer-Olkin (KMO) and Bartlett's Test of Sphericity were performed. The KMO value was .663, exceeding the recommended value of .6. The Bartlett's test was also significant at .000. Therefore this data exceeded the minimum requirements necessary for PCA (Pallant, 2001).

Principal components analysis revealed the presence of three components with Eigenvalues over 1. This explained 25.6 percent, 16.7 percent, and 15.5 percent of the variance respectively, for a cumulative parameter for convergence of 58%.

Catwell's Scree test was also performed which revealed a break between the third and fourth component. Therefore it was decided that three components would be retained for further investigation. See Figure 5.21.

Scree Plot

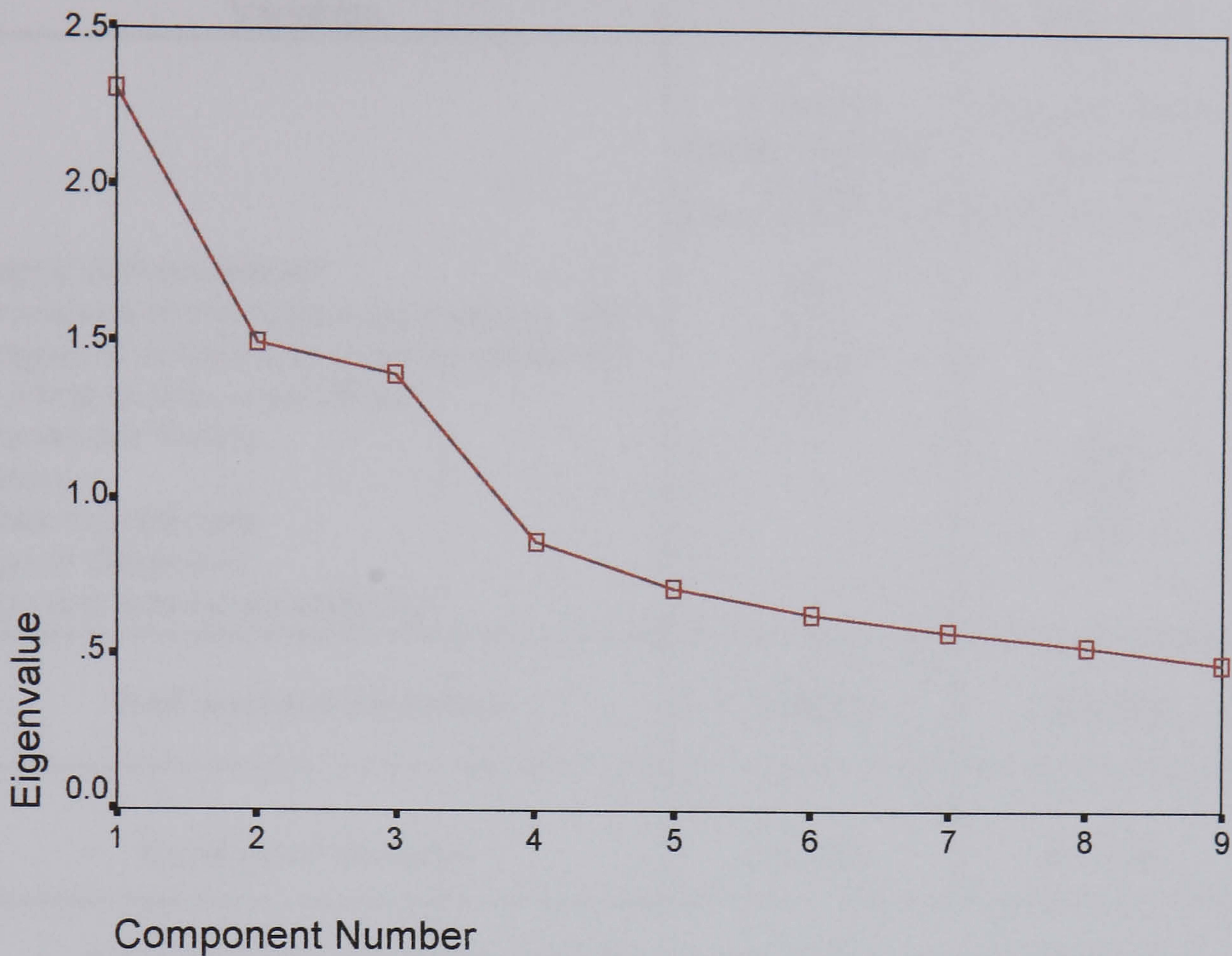


Figure 5.21. Scree Plot

Varimax rotation was performed, the results of which are in Table 5.2. All three components show strong loadings, with all variables loading substantially on only one component. The three-factor solution explained a total of 57.8 percent of the variance, with Component 1 contributing 22.7 percent of variance, Component 2 contributing 19.4 percent of variance and Component 3 contributing 15.7 per cent. In other words, in this reduced data set almost 60% of the observed variance is accounted for.

Component 1, consisting of the first four variables in Table 5.2, involves the parental view of the provision for their child. Therefore, Component 1 is labelled 'Parental Satisfaction with Provision'. Component 2, involving the next three variables, looks at factors associated with the stress of the process of securing provision. Component 2 is therefore labelled 'Parental Stress Issues'. The third component, explores the age of diagnosis and the age parents suspected there was a disability. This component is therefore labelled 'Identification and Diagnosis' (see Table 5.2).

Variables	Components		
	1 Parental Satisfaction with Process	2 Parental Stress Issues	3 Identification and Diagnosis
Happy with provision?	.814		
Provisions of the statement routinely met?	.775		
Degree of satisfaction input on statement	-.664 ²⁰		
Is it first choice in schools?	.530		
Placement Timing		.760	
Stress		.744	
Seek outside help		.736	
Age of Diagnosis			.838
Age first suspected disability			.818
% of Variance Explained	22.667%	19.437%	15.668%
Cumulative Variance	22.67%	42.11%	57.78%

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization. A Rotation converged in 4 iterations.

Table 5.2. Rotated Component Matrix

If 'stress' is removed as a variable, and the remaining variables are run again, the result is a reduced set of variables with the power to predict the parental stress levels. The three complex variables now explain almost 60% of the observed variance without losing the ability to account for similar level of variance as r^2 is approximately the same (27.6% for the full data set and 24.6% for the complex variables).

This finding is a significant contribution to the discussion on stress factors in parents undergoing the process of securing educational provision for their child with autism. If interested, these factors could be used to develop a short screening instrument to detect stress indicators in parents. But perhaps more useful to schools, LEAs and government is the identification of factors that can be targeted as areas to work on to reduce reported stress levels in parents. These key variables are: level of happiness with current provision, key provisions of the statement routinely met, satisfaction with parental input into the statement, first choice in schools, the time it takes to reach placement, need to secure outside help in the process, age the child is diagnosed and

²⁰ On inspection, this item was coded in reverse and therefore yields a negative number.

the age the child is first suspected of a disability. These are areas that social agencies, charitable organisations and governmental bodies can prioritise in their efforts to make this process less stressful in parents.

This section looked at some of the questions raised in the literature review. Specifically it discussed the age of diagnosis, and the factors that can be associated with parental stress levels. It found that the children in the sample were diagnosed at younger ages than documented in the literature review. In addition, this section presented some of the factors that were associated with parental stress. These included delays in agreeing with the LEA on provision, the involvement of outside professionals in the process of securing provision, and parents feeling they had less input into this process. The LEA the child was educated in (home LEA or not) did not have an impact on the reported stress level of the sample.

In addition, the data was explored for possible variance. Sixty percent of the variance in the scores was explained with three components: Parental satisfaction, Parental stress, and Identification and diagnosis. When 'stress' was removed from this reduced set of variables, it was later shown to be able to predict reported levels of parental stress in the sample. Identification of these factors is a significant step forward in working with parents to reduce the stressful experience of securing appropriate educational provision.

5.8. Conclusion

This thesis finds it useful to adopt the model of systems theory in so far as effective educational provision for children with autistic spectrum disorder is influenced on the practice in schools, the views of parents and LEAs. It is the tensions and dilemmas between these groups that this theoretical framework invites exploration of. The search of the literature revealed no published study that asked parents for their comments and feelings on the process of securing provision. This is also an essential element of the main research question (see Section 1.5); therefore it is appropriate to seek the views of parents in their attempts to obtain educational provision for their child with autism.

Autism is a spectrum disorder, with huge diversity among those affected. This is both in the degree of the disability, as well as the educational provision individual families choose to address the handicapping condition. This chapter shared the results of a postal survey of parents. It focused on individual experience of survey parents on the process of securing appropriate educational provision.

The results presented are views gained through an opportunity sample. Although a representative sample of the population of families affected by autism is desirable, it is not assumed that the respondents to the questionnaire were a representative sample. Therefore, general conclusions cannot be assumed to be indicative of the entire population of families with autistic members. Although providing insight into the feelings of families on the topic, conclusions made are acknowledged as limited to the questionnaire respondents only. It is also important to note that this questionnaire was specifically designed and targeted towards families with autistic members. There was no corresponding comparison sample (i.e. families with non-disabled members, families with disabled children who are not autistic), which may or may not have highlighted some of the same opinions as questionnaire respondents.

In the second Strand (2) four areas were highlighted as the purpose of the chapter (See Section 5.2) and as gaps in the literature (see Chapter 2). Views were sought from parents on:

- Obtaining education provision,
- Satisfaction with the process,
- Working relationship with the educational provider, and
- The effect this process had on individual families.

Interesting insights into the parent's perspective of the process of securing educational provision were presented. Although a minority of parents reported positive experiences, the vast majority of respondents found this process to be quite stressful. Although parenting a child with a disability is stressful (Rodrigue et al., 1990), the high levels of reported stress associated by survey parents with the process of securing educational provision, was unexpected.

Six hypotheses were proposed and checked to compare parental responses to survey questions and their reported levels of stress (see Section 5.7.2.). The factors that correlated to higher stress levels were late diagnosis, delays in agreeing provision, the involvement of outside specialist services. Results from t-tests found these to be significant. The average stress scores of parents in different types of educational provision had mixed findings. Some types of provision yielded significant scores, while others did not. Those educated within and outside the LEA were not found to have significant differences in reported parental stress.

The degree of satisfaction survey parents had with their input into the statementing process also correlated with the level of reported stress. The use of a Pearson's Correlation Coefficient yielded a negative correlation, interpreted to mean that parents reported higher levels of stress when they felt they had less input.

Parents, in general, reported high levels of satisfaction with the process of securing provision (see Figure 5.12). The mean score of 6.4 (scale of 1 to 10) showed that parents were generally happy with the process. Respondents also stated that they worked with the school on jointly defining goals and addressing them. When the lead is taken by either the school or parent first and then worked on together, respondents presented a very unified picture, with 84% working together on addressing goals.

The effect that this process had on the family was addressed in the qualitative answers. Most of those choosing to respond to this question shared stories of the difficulties they experienced. Although there were families that reported examples of positive experiences, these were very few.

In addition to the listed aims of the chapter, the data set allowed for investigation into some questions raised in the literature review or in the open-ended questions of the survey (See Section 2.7). Those involving parent's views are discussed below.

- Although parents expressed strong views on both sides, most parents (87%) were happy with the input they had in the day-to-day educational provision for their child (see Section 5.6.3.). This was demonstrated in the positive responses when asked about the way parents worked with educational providers (Q20) and in the

stated satisfaction with input in the statementing process (Q18) and, in general, their happiness with the educational provision (Q25).

- Parents found the process of securing provision for their child very stressful (see Figure 5.14). They listed discussions with the LEA, the limited number of appropriate types of provision and the complexity of the procedure as the three main factors causing this stress.
- The age of diagnosis among respondents has dropped over the years. Respondents with children born 20 years ago were diagnosed much later than children born five years ago in the respondents surveyed (see Table 5.1).
- The survey questions revealed other factors associated with parental stress. Parents reported unusually high levels of stress in going through the process, even though end results were generally what parents identified as their choice of provision. Factors most associated with these increased stress levels were the length of time taken to agree on provision, input from specialist providers and the stated satisfaction with input into the statement. Other factors (LEA of residence, age of child, degree of disability, and the number of professionals seen before a diagnosis given) did not appear to have an association in this sample.
- Key variables were identified that appeared to be indicators to reported stress levels of parents. This exciting finding can be used for future research into areas for outside agencies to target in efforts to reduce the reported levels of stress for parents seeking appropriate educational provision for their child with autism (see Section 5.7.2.3.).

This chapter presented the parental view on the process of securing educational provision. It was based on information obtained from parents through the use of a postal survey. It formed the second strand (Strand 2), of three strands exploring this process. The next chapter discusses the views of the LEA, and forms the final strand of this thesis.

Chapter 6 - Strand 3

The previous two chapters explored the views of a school (Chapter 4-Strand 1) and parents (Chapter 5-Strand 2) on appropriate educational provision. In this final strand, the focus is on the view of the educational authority (LEA) on the issue of appropriate educational provision.

This thesis has found it useful to use Systems Theory (Bertalanffy, 1968) as a tool in understanding the impact that the process of securing educational provision has on a child. It is interested in looking at the tensions and dilemmas between those individuals and institutions in the child's environment. As such, it is a helpful way to help unpick the research question regarding the influences that support or inhibit appropriate educational provision (see Section 1.5.). As the research question is interested in the influences of a school, parents and LEA officials, it is therefore appropriate to include these opinions in this research. Therefore, this chapter will explore the views of senior LEA officials on the process of securing provision for children with autism.

6.1. Introduction

The ten LEAs with the greatest number of survey responses to the parental questionnaire (See Chapter 5-Strand 2) were approached requesting permission to interview a senior member of staff. Of those, five granted permission and these interviews were conducted. This represented two LEAs within the greater London area, two LEAs in the south central area and one in the southwest.

As a starting point, each LEA representative was asked for his or her comments regarding two issues during the semi-structured interviews:

- *Discuss the conflicts and dilemmas faced by the LEA in its attempt to make provision which best fits the needs of a child with autistic spectrum disorder in the context of finite budgets and competing demands across SEN field.*

- *In your experience of this LEA what do you see as the principle means by which you project and maintain an ethos of care and concern? How do you make it happen?*

It is important to note that interviews were semi-structured; the researcher responded to the fluid nature of the interview and probed responses made for additional detail (Kvale, 1996). In addition, some LEA representatives shared booklets and other written information on their unique ways of addressing the needs of autistic individuals in their communities.

As discussed earlier (see Section 3.4 and Chapter 4), 4 of the 5²¹ interviews were recorded, transcribed by the researcher, and then verified by the respondent to be a factual account of the conversation. All identifying details were removed. In addition, this researcher took notes during the conversation to allow the recording of thoughts that occurred during the interviews (Cohen et al., 2000). After the interview, additional comments by the researcher were also added to the notes, which reflected the general themes or any other ideas that occurred to the researcher afterwards.

When all the interviews were completed, the researcher read each of the transcripts and corresponding notes several times. During this, some recurring themes started to emerge (Kvale, 1996). These were noted, and transcripts were reread for examples of text relating to these themes. (See Methodology Chapter-3 for additional details.)

These five themes are: Policies on Provision and Resources, Relationships with Parents, Diagnosis and Statementing, the Role of the Tribunal and Teamwork and Multi-agency approaches. See Figure 6.1.

²¹ Although requested, one LEA representative did not grant consent to taping the interview. In this case, notes taken during the interview formed the basis of the contribution from the LEA.

Themes
1. Policies on Provision and Resources
2. Relationships with Parents
3. Diagnosis and Statementing
4. Role of the Tribunal
5. Teamwork and Multi-agency approaches

Figure 6.1. LEA Themes

6.2. Policies on Provision and Resources

The LEAs shared many interesting comments on their individual views on provision and resources. This section will discuss these in four subsections: Provision (Section 6.2.1.), Inclusion (Section 6.2.2.), Resources (Section 6.2.3.), and Educational methods (Section 6.2.4.).

6.2.1. Provision

The increase in the number of diagnosed children with autism was noted in the literature review (see Section 2.3) and LEA representatives interviewed state that it is having an effect on their provision. This is seen in a number of ways. Two LEAs shared their concern about the pressure on the number of places at a school.

'Yes, sometimes it is not easy...we have insufficient number, going back to the pressure of places...let's say we have five vacancies a year at school, we have for the last panel that we had which was to discuss September in 2002, we had five places and we had 62 children...for whom in essence, the provision described as 'autistic specialist' might have been appropriate...actually that any one of these children might benefit from "autistic specialist".' Interview 2

Additional pressure is placed on LEAs when they have been recognised as making a positive commitment to autistic provision. One LEA described it as a *'benefit and a burden'* (Interview 2) because parents all wanted that one school or provision. Another stated that he did not want *'too much publicity because it causes a system overflow with parents moving into the area'* (Interview 3). This view of good practice is unexpected as it shares the LEA's view on the stresses of a provision that is recognised to be of quality.

The shortage of provision is documented (Loynes, 2001; National Autistic Society, 2002). Two LEAs shared their concerns about the continued development of quality autism provision. Although they were proud of having a good provision in place, the negative side effect of this is that it increased the demand for that particular provision. This was not only from parents currently within that authority, but also from families willing to move into the authority, or even from foreign countries.

'...it is a little bit like the M25, because we doubled the size of these provisions and to be honest with you...where are all these kids coming from?... We have people writing to us from Hong Kong.' Interview 2

6.2.2. Inclusion

The government's focus on inclusion is a frequent theme in all interviews. Inclusion is an important aspect of the recent Code of Practice (DfES, 2001). The five LEAs interviewed shared the view that inclusion is positive in theory, but to enact this policy has some philosophical and practical challenges.

The first challenge discussed by one LEA, is the definition of inclusion in practice. What is the best setting to encourage inclusive education? The literature review (see Section 2.2.) discussed the lack of agreement among professionals and parents on which educational method or approach is most appropriate. LEA representatives also lacked consensus on this issue. Several LEAs discussed a specialist unit attached to a mainstream school.

'a [primary unit] is a step towards inclusion and a step away from inclusion... The irony that I see is that in order to maintain some children in mainstream primary school they are having to take them out of the class in order to manage them. So there may be less social inclusion than you might have in a special school.' Interview 5

Other LEAs see specialist units as a solution for able autistic children.

'I think that probably the best provision is the Unit attached to a mainstream. ...At the moment we haven't got any units at all.' Interview 4.

The second challenge for LEAs is the difficulty in finding the right level of support in mainstream provision.

'Balancing how much [support] is the right amount and how much is intrusive. How much is too much? ...Because if you have somebody with you, I know if there's another adult with me, I won't do the hard stuff.' Interview 1.

'...But in some situations they [the child] are managing and extra support can get in the way... They [adults] just suffocate the child, the child's independent learning.' Interview 4.

The third challenge involves ethical issues. Two LEA representatives interviewed questioned the reason behind this policy and subsequently the need to follow it?

'I think there is a way we need to look very carefully about what is driving us in terms of our motivation about inclusion. And I think sometimes it is about making ourselves feel better rather than saying this is what the person needs.' Interview 5.

'For me the Asperger child requires an environment which is manufactured for that child and that is very difficult to do in a very large mainstream school. What we are talking about is almost disintegration...' Interview 2

'Maybe we are making decisions all the time about what we see as priorities, about what we see as important. Somewhere underneath it, I'm not sure whether we are peddling the same cultural agenda as someone with ASD might choose to follow.' Interview 5

Although inclusive education as a policy is generally well accepted, the implementation of that policy can be problematic for some LEAs. In particular the need to balance the level of support given to maintain a child but not be restrictive, as well as the very nature of the environment, both have been raised as issues on the part of LEAs.

6.2.3. Resources

One of the areas parents expressed strong feelings about in the survey in Strand 2 (See Chapter 5) was the issue of limited LEA resources. A frequent theme survey parents expressed was the view that the main reason their child was not in the parent's choice provision, was due to the cost of that provision. Although this section deals with the broadest definition of 'resources' (individuals, facilities and finances) it will start with a discussion on the LEA's finite financial supply. Mixed views were shared in the interviews.

'...we have some hugely complex, difficult cases, that I have been managing three, four, five years...[but] it wasn't a resources issue ultimately...' Interview 2.

'The blocks are...having to get through the right channels. And funding, funding comes into it.' Interview 4

'The difficult issue is, I think at the top it's bickering over you pay for this; we'll pay for that. It just drives you mad.' Interview 4

Several of the LEAs felt that from their perspective, financial resources do not restrict the type of provision on offer, and can even justify the LEA's commitment to the autistic child.

'We don't say 'no' unless we have to and pay if necessary to do so...'
Interview 3.

'In a sense the borough's commitment to that group of children with special needs is reflected by the amount of money they are willing to spend.' Interview 5.

The facilities of the LEA's are also a resource. As cited above, there are a limited number of places at a school, and an overwhelming number of children eligible for those places.

'Part of the drive around the market, if you like, for autistic schools, is because they exist. If they exist, the market will very soon be found.' Interview 2.

Another area frequently cited by survey parents (see Chapter 5) when asked about the provisions of the statement, was the lack of speech and language therapists. One LEA cites the difficulty in securing this service from the NHS.

'We can use our best endeavours and all of that, but we can't find what doesn't exist... The fact is it doesn't matter if it is in Part 3 or Part 6, to be honest with you they are unlikely to get it. It doesn't matter what the Tribunal says... To find two 30-minute sessions, we have scoured our own NHS trusts, we scoured the independent sector. I've said to parents, if you want to find your own speech and language therapist to work with your child, do so and we'll pay.' Interview 2.

'The therapy or support needs to show that it is working... quite often it doesn't. Because it is not the right approach for the child, but parents won't necessarily accept that it is not working, what they will instinctively think is that they are not getting it in sufficient amount... all that needs to happen is more.' Interview 2.

'...and the Tribunal will say 'put the child there' because it's the only thing that can happen in that child's best interest now. Whatever you LEA are advocating or recommending just can never be sufficient.' Interview 2.

In general, the LEAs felt under pressure to provide places for children with autism when they had a limited number of spaces available and limited access to specialist services. Those interviewed did not feel, in general that restrictions were due to the finite pool of financial resources, but due to unrealistic demands from either parents or Tribunals.

6.2.4. Educational Methods

There are some restrictions placed on LEAs in regards to provision. One LEA openly shared,

'I haven't got the sanction of the members to simply go and spend that money in that way on provision... Because I can't give you that residential place, because I am required to look to our own provision, see what I can do and suggest to you that it is adequate.' Interview 2.

Others are more open to alternative provision. One stated that the LEA was quite happy to fund a home-based programme, because no alternative existed in the LEA at that time.

Another stated the difficulty was not the methodology, but the individuals advocating this particular method.

'It's not easy working with them [ABA provider]. There is a preciousness about the way they approach...they can be uncomfortable to feed it to others... Some parents are difficult to please.' Interview 4.

What parents may perceive as a funding issue, frequently has a broader scope according to the LEA representatives. In some cases, the LEA officers (as noted in interviews) do not have the authority to sanction a provision outside the LEA's own. In other cases, difficulties with outside professionals or even the parents themselves can be the reason provision is not straightforward and a Tribunal follows. The next theme takes a closer look at how LEAs view their relationship with parents and families.

6.3. Relationships with Parents

The second of the five themes (See Figure 6.1) explores the views of the 5 LEAs on their relationships with parents. All of the LEAs were keen to stress their positive approaches to working with parents. Several stressed that good communication was the key.

'I felt that my role [senior LEA official] with an anxious parent,...was to go in and be a person, not a name or title. Communication is part of the 'care'.' Interview 1.

'We need to talk to parents and explain. Communication leads to confidence.' Interview 3.

'I feel very strongly that part of our responsibility is to maintain the dialogue with parents, or at least attempt to. We can't walk away from this.' Interview 2.

All felt strongly that they have a duty to work with parents to determine provision. Parent Partnership schemes were running in all of these LEAs (although it might be run with volunteers). This was in advance of government recommendations.

Interview 3 summed up his feelings on this issue by saying, *'we must listen to our customers, how can you not?'*

It is also interesting to get the views of LEA personnel on 'difficult parents'. All the LEAs interviewed recognised that some parents can be difficult and all stressed that they try to work through difficult situations.

'Sometimes parents are wrong, but very, very few', Interview 3.

'Parents become obsessional about a particular approach or a particular school...Clearly on their own child, this is what we believe is right for our child and will not accept any compromise, however... suitable.' Interview 2.

'You know we do as much as we can. Help parents where we can. But you know there does come a point where parents, nothing is going to please parents.' Interview 4.

Working through these instances can be trying on the part of LEA officials.

'Sometimes it hurts. I try not to consider it as a personal slight on my professionalism [parent contacted MP, counsellors, European Court of Human Rights]' Interview 2.

Sometimes LEAs are faced with very difficult decisions. It becomes quite difficult to balance the needs of the child with the needs of the family.

'Where we failed was...what happens to the child when he was not at school? ...Parents were not willing to engage with Social Services, because they saw that, I believe, as somehow undermining their position.' Interview 2.

'Professionally I'm on the side of the LEA. The side I'm really on is the child. And what we should be focusing on is if parents want something and we don't agree that that's right, in the middle of all of this is the child.' Interview 1.

'It's not just a child' it's a family we are working with...Now, I have to work with them and say "I hear what you are saying, but I have to look at your daughter"...the wrong thing is to send her away, she needs the security of the family [getting social services involved].' Interview 1.

LEAs were keen to stress that they strived to work with parents to agree provision.

'If we get it wrong, we'll admit it and if you're right and we are wrong, we'll do something about it. And if both of us are right then we need to find a way of compromise.' Interview 1.

In general the LEAs described the many positive initiatives that were happening locally in work with parents. One had a joint audit (parents and the LEA) and another had a consultation process ongoing. In general all of the LEAs interviewed actively engaged parents in LEA policy as well as specific input into their own child's provision.

6.4. Diagnosis and Statementing

The third theme (see Figure 6.1) that emerges from the interviews discusses issues surrounding the diagnosis and statementing of children. Strong views on the part of several LEAs that a diagnosis did not help define what is appropriate for educational provision, as well as the general move away from statements led to very interesting commentary.

All of the LEAs agreed that a diagnosis was not necessary to access services from their LEA. Some felt that it did not help the process of determining provision and others questioned the parent's motives in undertaking the process to secure a diagnosis.

'Labels that are given to children, hamper us to be honest with you...' Interview 2.

'...in a way that [getting a diagnosis of ASD] maybe was like dyslexia was like a fashionable diagnosis. And for now ASD is more fashionable...if you have a diagnosis of an autistic spectrum disorder and it puts you in a strong position to ask for certain services. So it can be a key to unlocking resources...' Interview 5.

'If you call it SLD, Severe Learning Difficulties, people will believe this is right or wrong, for their child...because the child doesn't fit that label, but it fits this label. My child is autistic; therefore that's the right place.' Interview 2.

'My concern is that the diagnosis raises expectations... The only arrangements that are suitable for their child is autistic specialist.' Interview 2.

One LEA even felt that a diagnosis could restrict the LEA's efforts to find a placement for the child.

'It is trying to overcome the barriers...I guess prejudice, actually what we are about her is trying to base it on the ability of the child to learn...In terms of your child's ability to learn, your child is on that spectrum of need alongside that child.' Interview 2

This same LEA also felt that a diagnosis did not contribute to understanding the needs of the individual child stating,

'...the diagnosis doesn't tell you anything about the child, other than that he or she is autistic...We could ask the question, so what?' Interview 2.

Another questioned the reliability of a diagnosis.

'I think there is sometimes a difficulty in the interpretation of reports by clinicians and diagnosticians. And something I have found the teaching of staff when I look at files, I will find examples where somewhere in their history somebody...has queried autistic spectrum disorder. ...And then a few reports down the line you discover somebody referring back to that report saying in that report ...received a diagnosis.' Interview 5.

One LEA summarised the views of many of the LEAs when she stated her preference would be to, *'...get rid of those labels.'* (Interview 2).

There were strong feelings on the issue of labelling children with ASD. The LEAs interviewed expressed their views that a label did not help the LEA to define the best type of educational provision. Several LEAs shared their view that a label can even deter parents from a provision that can be beneficial, just because the provision is not 'autistic specialist'. This is contrary to the view of parents who feel a diagnosis will advance their child's chance of obtaining a specific provision to meet their needs, especially when there are so many other children competing for placement (See Chapter 5).

The second sub-category in this section discusses statementing. Several of the LEAs interviewed stated that they were moving away from statementing. One reduced the number of statements by 85% (Interview 3). This generated some interesting comments:

'...now the situation gets difficult is that balance in between the very obvious ones and the ones that don't need one [a statement]. ...parents are demanding that a statement should be made.' Interview 4.

Another described the destatementing move as one where time and space were given to ensure a smooth transition. She stated, *'...just reassure that if that happens we can put back money just as easily as we can remove it.'* (Interview 1).

The LEAs are clearly moving away from the practice of issuing statements to a broad group of children with special needs. The LEAs interviewed stated that they were narrowing this grouping and delivering educational support to children without the need for a statement. Those interviewed were aware of the concerns of parents, but felt these could be addressed.

6.5. The Role of the Tribunal

The penultimate section (See Figure 6.1) discusses the role of the Tribunal and the views of the LEA on its role. Of all the themes discussed in this thesis, this one raised the most diverse views on the part of individual LEAs. One stated that it must be avoided at all costs, while another welcomed it as a way of reaching a decision when parents and the LEA disagree.

One felt that Tribunals should always be avoided, *'I hate the Tribunal process. We should not be putting parents through Tribunals.'* Interview 1. She further explained,

'It's a costly thing. It costs a solid week of my time to make a case, then there is the time of my colleagues who have to come with me to Tribunal...I don't mind doing that, [but] I'd rather give the money to the child.' Interview 1.

Another agreed and felt it was a waste of resources. But several felt it can be helpful in getting past difficult disagreements with parents, or even a way to justify a particular provision that is outside the LEA.

'We do have a high number [of Tribunals]...Because sometimes, to be honest with you I think it's helpful...You get to a point in certain cases where perhaps your position...we try and seek an agreement but ultimately let the Tribunal decide.' Interview 2.

'The Tribunal does a fantastic job. It is valuable if you can't reach compromise.' Interview 3.

'I haven't got the sanction of the members to simply go and spend that money in that way on that provision...[the Tribunal] sort of releases me to some extent.' Interview 2.

Those interviewed had differing views on the role of the Tribunal. One LEA felt it should be avoided at all costs, while another felt it could be a useful tool in getting past disagreements with parents. There is a difference of opinion on the part of those interviewed on this issue, which can be confusing for parents who may be unaware of the view of their home LEA.

6.6. Teamwork and Multi-agency Approaches

The last theme in this chapter discusses the views of LEA officials on working with colleagues; both within the LEA and within other service sectors.

'My preference would be...that the diagnosis...should be a multi-agency approach. We do need to have at least Education and Health, even at that very early age involved in what I would prefer to be a multi-agency intervention.'
Interview 2

This type of intervention would benefit the child, according to that LEA, by, 'creating a virtual team', which would give a sense of where the child was located on the spectrum of autism. This would enable education to focus on specific areas of weakness, according to this LEA.

Another LEA (Interview 4) founded an 'autism focus group which includes all different agencies, health, [and] social services'. This LEA found it to be very helpful at exchanging information and even started an early intervention-training scheme. The aspect they found challenging was securing the funding from above and the bureaucracy that was inherent in this set up.

6.7. Conclusion

Chapter 6 focused on the LEA's view of appropriate educational intervention. This was the final of three strands, the previous chapter (Chapter 5) discussed the view of parents and Chapter 4 discussed the view of an individual school.

The research question directs the focus of this thesis on the influences that support or inhibit appropriate educational provision for children with autistic spectrum disorder. It identifies three main contributors to this discussion, the school, parent and LEA. This chapter focused on the view of the LEA. The view of each of these partners is critical to this thesis because of the influence they have on the individual child. Each interacts with the child (directly or indirectly), as well as with each other to create educational provision. These tensions and dilemmas (see the work of Bertalanffy(1968)) are explored in this thesis.

A series of five interviews was conducted with LEAs that had the highest response rates in the parental questionnaire. These were semi-structured interviews; all except

one were taped. After the interview transcripts were verified as faithful accounts of the interviews, they were explored for themes (see Section 3.4.).

Five themes emerged from the interview data. These were the LEA's policy on provision and resources, parental relationships, statementing and diagnosis, the role of the Tribunal and multi-agency approaches. Discussion of these themes leads to several unexpected views:

- LEAs are finding it difficult to accommodate the demand for autistic specialist places. Several shared reluctant to publicise their quality provision for fear that it will increase demand even more than already exists.
- All LEAs welcomed the policy of inclusion. However good in theory, practical considerations led to many concerns about practice. The use of a Specialist Unit, the level of support for individual students, and the generic application of a policy that may not be what an individual student states that he or she wants, were all areas of debate within and between LEAs.
- The topic of resources was also an area of discussion. All of the LEAs felt strongly that disagreements with parents were, in general, not due to limited resources. One LEA stated that her remit did not allow her to fund placements outside the LEA's own, and therefore this is why parents needed to get Tribunal agreement for anything other than LEA run placements. Another stated that funding issues were more of a 'bickering' from above, than a matter for her to address. Another felt that the increased level of funding in the LEA justified the quality of provision for children with ASD.
- The difficulty in securing support staff was also addressed. LEAs mentioned the difficulty in securing services from NHS employees. One described in detail her unsuccessful attempts to find specialist staff.
- Alternative provision also brought concerns. LEAs expressed their dismay at a lack of cooperation among some of the independent specialist providers. One also shared her duty to place children within the LEAs network of schools, which could potentially restrict parental choice.

- Parents were strongly encouraged by all LEAs to be active participants in the education of their child/ren. All LEAs stressed communication, and the need to work with all parents, no matter how distressed or difficult these parents might be.
- Most of the LEAs interviewed did not greet the actual diagnose of children with autism positively. Several felt that it restricted the types of appropriate provision that they felt parents would accept. This is quite different from the view of survey parents who felt a diagnosis was needed to secure appropriate provision.
- Many of the LEAs were working towards reducing the number of statements in their LEA and shared their efforts at getting parents to accept this change in practice.
- Tribunals were seen quite differently by each of the LEAs interviewed. Some felt they were helpful in reaching an agreement. Others felt that they were a waste of resources, and should be avoided.
- All LEAs shared their wish to work more closely with colleagues in Social Services and Health.

This chapter presents the findings of the final Strand; looking at the views of the LEA. It focused on five interviews with senior LEA officials. They candidly shared their views on working through the system of matching the child with a provision that will best help educate him or her.

This thesis has discussed educational provision from the point of view of a school, parent as well as the LEA. The research question is interested in picking apart the diverse tensions and dilemmas that exist in and between these three groups of individuals or institutions. The topics raised in each of these Strands were diverse. This discussion generated some strongly felt views from all 3 Strands which helped to clarify the fundamental issues involved when working through the system to make provision for an individual child with autism. The next chapter of this thesis draws these concerns together to look at the data gathered from all three strands, and its application to the individual child.

Chapter 7 – Discussion

Strands One, Two and Three presented the results of the data gathered in the case study, postal questionnaire and interviews. Although it is important to explore themes emerging from this data individually, this chapter will take a global look at these themes and reweave them back together in the context of the research question. This will reveal some of the tensions and dilemmas that exist in the broader social context and impact directly on an individual child in the quality of education experienced by that child. The reader is reminded that the child and the child's ecosystem is central to this thesis, and therefore it is necessary to look at this aspect as it applies to appropriate educational provision. Essential conclusions and implications are presented in the final chapter.

The research question directs this investigation toward the influences that support or inhibit appropriate provision for a child with autism from the perspective of a school, parent and LEA. What does this actually mean for the child? This discussion will focus on five central themes, relating each to the child and then discussing these in the context of findings from the three strands. These five themes are early identification, diagnosis, waiting times, input, and provision into action.

7.1 Early Identification

The present study has shown that children are being identified as having autism at a much younger age than current research suggests. This study, which is the only major UK study conducted since Howlin and Moore (1997b), indicates that the trend toward earlier diagnosis (suggested by Howlin and Moore) continues such that children who would have been diagnosed by 6, are now diagnosed at 2.76 years of age. Therefore, it is safe to conclude that children in the UK are being identified as autistic at a much younger age than previous research showed.

Although this study does show that children are diagnosed earlier, it is inconclusive if this results in an actual increase in the number of children with autism. Nevertheless, given that children are being diagnosed earlier, it follows that parents are seeking educational input for their child at an earlier age as well. LEAs are also seeing this

trend. Those interviewed felt that there was an increased demand for educational provision from families of children with autism. Hypothetically, this should have a positive consequence for the individual child, as early identification should lead to early educational input.

For parents it is apparent that once a diagnosis is given, this should also mean that their child has educational difficulties that need to be addressed through appropriate provision. Once qualitative impairments are seen or a diagnosis is obtained, parents exercise their statutory right to educational provision for their child, by seeking provision from their local LEA. The government provides assistance in the form of the Code of Practice (2001) to guide LEAs and parents towards the provision of appropriate educational systems to meet the unique needs of an individual child. The determination of provision is the joint decision of the LEA and parent (and potentially with input from a school). The enactment of this provision requires involvement of all three stakeholders.

What do these three stakeholders describe as influences to support or inhibit the determination of provision?

Parents surveyed reported unexpected high levels of stress. Although the research literature does associate stress with families including autistic children (Harris, 1994), there is no research on parental stress levels and securing educational provision for children with autism. What does this mean for the child? At this point we can infer that children who are living at home as part of a family that experience high levels of stress are probably not living in an environment conducive to their continued development. However, this is speculative, as this research did not address this question. What the research did address was some of the factors that contribute to these high self-reported stress levels, which leads to the second area, diagnosis.

7.2. Diagnosis

The data showed a decrease in age of diagnosis. Although later diagnosis was associated with high stress levels in survey parents, current children with suspect impediments have a greater likelihood of early diagnosis than older children did when

they were young. LEA interviews also concurred. Children are being identified as autistic at younger ages.

Although seen as a helpful measure on the part of parents, LEAs view this phenomenon with mixed opinion. Concern is raised at the expectations that a specified diagnosis may have for a parent requesting provision. LEAs interviewed stated that a diagnosis could narrow focus by parents toward autism specific provision. LEAs stated that in some cases, parents refused to look at any other provision beside autism specific as a means to meet their child's needs. LEAs reported that they sometimes found it hard to focus parental attention on the fundamental learning disability inherent in the majority of children with autism. These LEAs felt that an individual child's learning disability could be addressed within the context of a special school, and not exclusively at an autism-specific provision.

Several LEAs also advocated for an 'expanded diagnosis', which would highlight the child's unique strengths and weaknesses within each of the Triad of Impairments (Wing et al., 1976). Identification at the point of diagnosis of specific gaps in each of the three areas could be a helpful tool to aide discussion in determining appropriate provision. Speculatively, when determination of provision can take at least 6 months (minimum) this could also have a direct impact on a child as interim measures could be taken to start addressing these concerns immediately upon diagnosis.

7.3. Waiting Times

Guidance in the form of the Code of Practice (2001) suggests stakeholders (LEA, parent and school) should agree provision within approximately six months. Survey parents do not report this to be the case and it is a factor associated with increased levels of self-reported stress. Current research literature supports the value of early intervention for a child with autism (Heflin et al., 1998; Trevarthen, 1998). Delays in the agreement of provision, or its enactment typically delay the educational input given to the child. Theoretically, these delays cannot be helpful to increase a child's learning skill.

The nature of these delays can be attributed to several factors. The LEAs reported high level of demand from parents for specialist placements. One stated that as soon

as new units were opened, they were immediately filled. Two LEAs were concerned about the positive publicity generated when opening new services, or receiving accolade for them (i.e. Beacon Status). Those LEAs interviewed stated concern about generating even more interest in these placements, again increasing demand from parents.

The most common reason for delay as highlighted by survey parents was the delay in finalising the statement with 81% of parents that experienced delays of 1 year or more stating this was the reason (see Figure 5.11.). As parents were given the opportunity to circle as many answers that apply in response to Question 33 of the survey, it is unclear from the data why final statements were delayed. One reason listed was the delays experienced by waiting for specialist reports. This research also shows the involvement of specialists to be associated with unexpected higher reported stress levels. It is inconclusive whether it is the waiting that is stressful or the actual contact and interaction with another specialist that adds to the reported stress levels of parents. It could also be that specialists are involved by parents when they have concerns about the LEA agreeing to their preferred provision and this 'expected' disagreement, rather than an 'experienced' disagreement is adding additional stress. Again, this is speculative, as it was not addressed in the research.

Both the qualitative and quantitative data from the survey showed that resources were an issue of concern for parents. Parents list this as a reason for delays in accessing provision, as well as a reason LEAs disagree with parents on their preferred choice in placements. A significant minority of parents felt strongly that this was the reason why the LEA did not ultimately grant their placement wishes. LEAs disagreed with this. Those interviewed felt that the financial and other resources available to LEAs adequately met the needs of the autistic children within their remit. Several discussed the positive initiatives at their LEA to meet the needs of autistic children.

7.4. Input

All LEAs spoke positively about the ways that their LEA works with parents to ensure positive relationships. Most were realistic about not being able to please every parent, but felt confident in meeting the needs of every child and including parents in that process. Survey parents agreed in general, and reported they were happy with

their level of input (see Figure 5.12) resulting in the majority of parents receiving their preferred choice in placement (see Section 5.6.1.). Survey parents that reported higher levels of input also reported reduced stress. Parents that feel their input is valued and acted on reported lower stress levels and speculatively this should have a positive influence on the child.

Survey parents also reported high levels of cooperation when identifying and addressing the educational goals to target in a child. Although literature from St. Joseph's did promote parental involvement as well, data from the case study did not show evidence of this. Arguably, this could also be due to the geographical distance many parents were from the school, or perhaps the complex nature of their child's disabilities.

The survey revealed an interesting aspect to this reported harmonious interaction. Picking apart the data regarding reported stress scores reveals that parents attribute discussions with the LEA staff as the single most listed reason for the perceived stress (see Figure 5.16.). What does the data show about this apparent contradiction?

The Code of Practice places a high priority on parental involvement. This is evident in practice as well according to both the statements from the LEA staff interviewed as well as completed parental surveys, and the data generated from St. Joseph's School.

Parents are attributing their reported stress levels to discussions with the LEA, but the data is unclear of the actual nature of these discussions. Speculatively, this could be explained by a number of reasons. Looking at the other choices listed by parents as contributing to their high levels of reported stress, Figure 5.15 shows that parents found the process too complex, the limited alternatives in placements as well as a lack of space at a placement of choice as the next three reasons they attributed to high stress. As the LEA personnel is the main point of contact for each of these three, parents could possibly be attributing these to LEA staff as well. Consequently, parents may feel that it is not only discussions with LEA staff that is stressful, it is the inability of LEA staff to make the process simpler, increase the choice for parents or increase the number of places at a preferred placement that is also increasing their reported stress.

It could also be argued that parents have emotional involvement in the success of any educational provision for their child. With large caseloads and other demands on LEA staff, it may be difficult to maintain that same level of commitment to the individual child (Paradice, 2001), which could possibly prove difficult for parents to understand. Other reasons are also possible, as this issue was not specifically addressed in the research. Future research in this area is warranted.

7.5. Provision into Action

Once a child is in a school (or other educational provision), survey parents reported high levels of cooperative effort with that school (see Figure 5.13.). This research shows 87% of parents were happy with the input they gave in their child's day-to-day education, as well as the direction received from the school in addressing known targets. The research literature concludes that children with disabilities benefit from joint working from both the school (or educational provider) and the parent (Keenan et al., 2000; Evans et al., 2001). Therefore it is concluded that this has a positive impact on the child and can only nurture further development.

The data generated from the case study was limited to one specific school, and therefore universal generalisations are not appropriate. But it is useful to look at the practice of an individual school and see how it impacts on the educational provision for children attending. Clearly there was a breakdown in the provision of education to the children in the Junior class at St. Joseph's School. Data gathered in the case study showed the reduced number of observations where children were actively engaged in activities. As such, this could not have a positive influence on the very disabled children attending. The data also showed staff shortages, high staff turnover, lack of effective management and the children's aggressive behaviour as contributing factors.

The majority of parents surveyed (90%) had statements of special needs for their child (see Figure 5.8). The LEAs interviewed stated they were moving away from issuing statements for the bulk of children with identified special needs, stating that in a large number of cases, these can be met within mainstream provision. This apparent contradiction could possibly be a function of the sample of parents responding to the survey, or perhaps the government's recent emphasis on

mainstream provision that may not have had the full effects realised as yet. The data does show that many parents felt they needed to get a statement for their child, and therefore it is concluded that more work needs to be done on the part of LEAs and schools to reassure parents their child's unique needs will be met without a statement, if this policy is to be successfully implemented.

7.6. Disagreement Resolution

For the majority (79%) of the parents surveyed, the process of determining provision resulted in their child being placed in the parent's provision of choice. Therefore it should follow that parents are pleased with the placement and wish to support the school and educational efforts. The survey findings support this conclusion (see previous section). To have a cooperative atmosphere between school and home should produce a consistent approach that will better support the child's education. Theoretically this should have a positive consequence for the child.

In the minority of survey parents (11%), there was disagreement between the LEA and family regarding the child's education, which resulted in the need for dispute resolution. Both parents and LEAs described this process as difficult and using resources, both financial as well as time consuming. These same parents all agreed in the difficulty and stress involved in the process, but those LEAs interviewed had mixed feelings. One LEA's view was to avoid these at all costs, while another felt it was a helpful tool when agreement cannot be reached. Still another LEA stated that there were some types of provision that she could not sanction (outside the LEAs own) and that a tribunal would always be needed to authorise these.

7.7. Conclusions

The current body of research literature in the field of autism is limited, with most of it focused on possible causes of the ailment, or specific methods to help children. Researchers, practitioners and parents agree in the value of early effective educational provision, yet to date there is little research into this topic. This thesis addresses this gap.

There are three main stakeholders active in the process of securing and implementing appropriate educational provision for children with autism. These are a school, parents and the LEA. Therefore it is appropriate to seek the views of these individuals and institutions regarding this topic.

Research by Howlin and Moore (1997) showed that the average age of diagnosis is about six years of age. This research found that diagnosis was happening at the much early age of just before the child's third birthday. This would suggest that children achieving early identification of the nature of their disability would also be eligible for early educational support. Early intervention is recognised as having a positive effect on the child (Guralnick, 1997; Evans et al., 2001) and this trend is seen as helpful.

This research was also the first to recognise difficulty with early diagnosis. LEAs interviewed stated that it could restrict placement choice and was not specific enough to direct individual targets. Survey parents identified the concern over lengthy waiting times to access educational provision. Neither of these is sympathetic to an individual child in need of educational support.

Parents in the present survey were happy with their level of input into the statementing process as well as the enactment of education once the child was placed at a school. These were found to be statistically correlated with lower reported levels of stress in these parents.

There was a clear breakdown in the provision of education at St. Joseph's School. As one example of a school, it showed the difficulty in overcoming staff shortages, staff turnover, lack of strong management and the challenging nature of the children as difficult to overcome. It had the effect of limiting the teaching time of the children attending, and subsequently the children regressed.

This research also investigated how disagreements between parents and LEAs were resolved. Although both sides described the Tribunal process as difficult, LEAs felt that it is helpful in making decisions in cases where disagreement does not allow them to be reached. Where parents seek provision other than the LEAs own, agreement by the LEA can only be reached through Tribunal.

This chapter drew the findings of the three strands together and discussed the implications for the individual child. The final chapter will conclude this thesis by linking this with the research questions and discussing the implications of the findings.

Chapter 8 - Research Conclusions

The goal of this chapter is to draw together the findings of the previous chapters outlining the investigations into the three Strands on appropriate educational provision and relate this to the individual child. The findings will start with a discussion of the research framework and its implications. It will outline how the issues for the study were researched. This will be followed by the research questions. It will discuss the methods used to investigate each one and then highlight the research findings. A discussion that will link these three Strands together follows next. It will be accompanied by interpretation based on the current body of literature, the results of the research undertaken by this study, and the new findings that contribute to the advancement of field. The chapter concludes with the research limitations and suggestions for further research.

8.1. Research Framework

The research question directs this research to pick apart the tensions and dilemmas that exist among the three main partners (school, parent, LEA) when determining and providing appropriate educational provision for children with autism (see Figure 3.13 for the Research Timeline). The writings of Bertalanffy (1968) on systems theory provide a useful tool to explore these issues. Adaptation of systems theory for the child with autism (see Figure 3.1) can help increase the understanding of this process. Placing the autistic child at the centre, the model shows the various individuals and institutions that can impact the process of educational provision. These individuals and institutions provide feedback through interactions between and among themselves to create a fluid concept of a physically and academically maturing child. Although the autistic child is central to the model, the interactions with and between the child and others in his or her environment are an essential element for consideration in this research.

The research question, imbedded with the theoretical underpinnings, determines the methodology used (Crotty, 1998). In this research, phenomenology provided the scaffolding for the research methodology of ethnography. This decision to use phenomenology and ethnography was based on the critical and practical research

points (see Figures 3.2. - 3.3.) outlined in Chapter 3. The specific methods were also determined in the same way. The research question directs investigation to look at the perspectives of a school, parents and LEA. Phenomenology allows the use of the best method for the identified task. Investigation into the views of each of these three partners (school, parents, LEA) identified critical and practical research points (see Figures 3.2., 3.3., and 3.6.). These helped determine the specific method followed.

The research began with a case study (see Chapter 4). The case study involved a small action research study that investigated how a specialist school for children with autism implemented a teaching strategy on visual teaching strategies. After designing a course, educating members of staff and supervising staff's implementation of the ideas in the course, it was found that the students were not able to maintain the skills gained (see Figure 4.6.). Over a short period of time, the students lost these skills. Thus the main focus of the case study is to explore the tensions and dilemmas that exist in a school in its efforts to provide education for students attending. It looked at the day-to-day practices in a school and focused on the process of educational provision through the views of those providing it. Daily research notes were kept that documented the children's progress as well as a monthly tally of 10-minute aggression monitoring (See Appendix 5). Semi-structured interviews helped explore the views of the senior management and the teacher. All of these combined to give a 'snapshot' of the practices of a school during the 10 months in a classroom.

To explore the views of parents a parental survey was undertaken. Initial ideas were discussed with colleagues and piloted. Several charities and schools were contacted about distribution, and 2 national charities, 2 local charities and 16 schools agreed to distribute the survey to parents. In all, 2,152 surveys were distributed, of these 738 were returned which is an estimated 34.3% rate of return. Although desirable, it is not possible to calculate the exact rate of return due to the restrictions imposed by individual schools and charities (Data Protection Act) that did not allow the researcher to cross check databases.

The returned surveys provided a huge source of data, most of which was quantitative. The two qualitative questions gave rich insights into the feelings of parents on the

process of securing provision and directed this researcher to possible ways of analysing the information. Frequently, parents used the words 'stress' or 'stressful' to describe the experience. This led the researcher to look for possible ways to account for variance between those parents who described the process as very stressful, with those who did not. These findings were detailed in Chapter 5 (see Section 5.7.2.).

Investigation of the final contribution was through semi-structured interviews with five LEAs. The ten LEAs with the most responses from the parental surveys were approached. Five agreed to be interviewed and these were conducted. Four of the five LEA representatives consented to have the interviews taped. These were transcribed and then validated as accurate accounts by the interviewee. The interview questions explored some general themes that were starting to emerge from the case study and survey. LEA representatives were invited to describe how they make provision for children with ASD despite finite budgets and demands from other disabling conditions, as well as how they convey their ethos of care for the individual child.

The research provided then, a general picture of the process of securing provision from the perspectives of the three main participants. It revealed some shared beliefs and concerns. It also brought to light some disparities between the three parties. These are shared in the next section, which discusses the research question and implications for the individual child with autism.

8.2. Summary of the Main Findings according to the Research Questions

Following are the research questions and a short summary of the methods used to investigate each. After which is a discussion of the findings in the context of the research conducted. Section 8.3. will tie these together and link this with the literature search.

8.2.1. Main Research Question:

What are the kinds of influences that support or inhibit appropriate provision for children with autistic spectrum disorders from the perspectives of a school, parents, and LEA officials?

The research methods: semi-structured interviews with school personnel, and LEA staff; research log, qualitative questions for the parental survey (Question 38-Q39), quantitative questions on the parental survey (Q9, Q18, Q20, Q25, Q26, Q32, Q34, Q35)

The research answers: There were significant contributions from each of the three strands regarding opinion on influences. These are highlighted according to the individual strand.

1. Strand 1 – School

- Leadership- Strong, active leadership was agreed as necessary by all at St. Joseph's, although opinion differed on actual leadership present. It was described as 'lacking' by direct care staff, and felt 'appropriate' by senior management (see Section 4.10.).
- Policies and Procedures – Defined policies and procedures were in place and well articulated by senior staff members, but as documented in the research log, these were less well imbedded and practiced by direct care staff (see Section 4.11.).
- Staffing-Training – A comprehensive staff-training programme was in place, but the research log and interviews show that this was inhibited by frequent staff turnover and shortages (see Section 4.12.).
- Staffing levels – Staff shortages (see Figure 4.9.) caused frustration by the reduced number of staff that was present. This was frequently documented in the research log as a reason (stated by direct care staff) for low morale (see Section 4.20).

- Programmed activities – High proportion of unstructured time (see Table 4.5.) could contribute to limited progress on behalf of individual children (see Section 4.15-4.16).
- Environment – The research log cites several examples of direct care staff stating their frustration at unclean facilities that were described as not being regularly maintained (see Section 4.17).
- Teaching – Although agreed on by trained staff, teaching strategies were not consistently applied as shown by the increasing number of references in the research log to programmes not being done (see Figure 4.6.).
- Behaviour Management – Although agreed on by trained staff, the research log shows that behaviour management programmes could not be consistently implemented (see Section 4.16). Speculatively, this could be due, in part, to staff shortages.
- Outside agencies – Regular inspections by both Social Services and Ofsted yielded generally positive reports (see Section 4.18).
- Parental involvement – School literature listed a strong commitment to parental involvement. The research log, including email correspondence with 3 parents did not feel this resulted in corresponding action to actively include parents in the school environment (see Section 4.19).
- Staff morale – The research log notes the frequent frustration of direct care staff over the course of the 10-month case study (see Section 4.20).

2. Strand 2 – Parent

- Age of diagnosis – Analysis of the survey responses showed the age of diagnosis to be falling; meaning children are receiving a diagnosis at an earlier age (see Table 5.1.).
- Timeliness – Parents reported high levels of stress as well as frustration at the amount of time it takes to agree appropriate provision for their child (see Section

5.7.2.). Over half of those surveyed waited longer than the recommended amount of between 6 and 7 months (DfES, 2001).

- Specialist input – Increased levels of stress were reported in parents who involved specialists (lawyers or educational specialists) (see Figure 5.14).
- Types of provision – There were mixed findings when the type of provision was compared with parental stress levels (see Section 5.7.2.). Parents of those children educated in a special unit, or boarding provision, or in a special school or those educated entirely at home reported higher levels of stress. Those educated in mainstream, an independent school or were educated in a combination of home based and school based provision did not report higher stress levels than the mean.
- LEA child educated in – There were no statistical differences in the stress scores of parents whose children were educated within their home LEA when compared to those whose children were educated outside the home LEA (see Section 5.7.2.).
- Parental input into process – The greater the degree of confidence parents have in their input into the statementing process, the lower their stated stress scores (see Section 5.7.2.).
- Satisfaction with the process – Parents reported satisfaction with the joint decision (LEA and parent) that was eventually made for provision and parents shared that in general they worked with schools on their child's education (see Section 5.6.2.).
- Most parents felt the process of securing provision was very stressful (see Figure 5.14.).
- Several key factors were identified as variables with the power to predict parental stress levels. These were parental happiness with provision, provisions of the statement routinely met, degree of satisfaction with input on the statement, if placement was first choice of parent, placement timing, if parents received outside help, the age of diagnosis and the age parents first suspected there was a disability (see Figure 5.19.).

3. Strand 3 – LEA

- Pressure on specialist provision - There is an increasing number of children diagnosed with autism for a limited number of specialist places (see Section 6.2.1.).
- Inclusion-The LEAs felt inclusion was a good, in theory, but making it work in practice was difficult to get right for an individual child (see Section 6.2.2.).
- Resources - All resources are under pressure, which would include staffing, facilities and finances. Some LEAs felt financial restrictions were not the 'stumbling block' that parents perceived them to be (see 6.2.3.).
- Methodological approaches - The diverse nature of autism leads to a huge menu of educational approaches (see Section 6.2.4.). It was felt that a diagnosis of autism can direct parents either closer to a type of provision (autism specific) or further from individual schools (general special needs school).
- Relationships with parents- LEAs were keen to stress their efforts at maintaining positive relationships with parents. Many have openly promoted the government's emphasis on parental involvement (see Section 6.3.).
- Diagnosis- Generally a diagnosis is not necessary to access services, but may be necessary in some parts of the country (English et al., 2001). Many survey parents believe it is needed in all cases. Some LEAs interviewed feel that a diagnosis can restrict the type of placement that parents will accept (believing parents will only accept autism specific provision) and does not provide enough information to help with educational planning (see Section 6.4.).
- Statements- Several LEAs were reducing the number of statements issued. This is contradictory to parents who perceive their child's statement as a necessary 'guarantee' of appropriate provision for their child (see Section 6.4.).
- Tribunals- The LEAs shared mixed views on the benefit of tribunals. Some felt they should be avoided at all costs (due to the additional stress this places on both

the family and LEA resources) and some LEAs welcomed them as a means of settling disputes (see Section 6.5.).

- Teamwork- The need for joint working between all agencies was strongly supported. Those interviewed shared concerns about difficulties in funding and the perceived bureaucracy that is involved (see Section 6.5.).

8.2.2. Research Question 2

How do the participants consider the current system of appropriating and maintaining provision as working in practice?

The research methods: semi-structured interviews with school personnel, and LEA staff; research log, qualitative questions for the parental survey (Q 38, Q39)
quantative questions for the parental survey (Q17-33)

The research findings: The research findings suggest the answer to this question is mixed. The qualitative data gathered during the case study revealed the example of a school that was not effective at meeting the needs of the children in the Junior classroom. It demonstrated that although the children could learn new skills, these were not maintained (see Figure 4.6.). Several trends were noted during the case study, which it was felt contributed to this. These are staff shortages, high staff turnover, lack of effective management, and the lack of regular scrutinizing of students (target setting and monitoring).

Survey results (see Appendix 6 for copy of survey) found that most parents were happy with their child's educational provision. The sample stated that they obtained a statement of special needs (Q17, 90% of responding parents) and were working with their educational provider to determine educational goals for their child (Q20, 84%). Most parents also reported that they were able to get their child into their placement of first choice (Q26, 79%) and were happy with their child's provision (Q25, 70%). In general, the research findings from the parental survey found parents were pleased with the placement. But a closer look at the data reveals unexpected findings.

High levels of parental and family stress were reported during the process of securing provision for their child with autism (Q34, Q38, Q39). Analysis of the data (see Figure

5.15.) suggests that parents are most stressed about their discussions with LEA staff (Q35, 54% of survey respondents). This is followed by lack of choice (Q35, 45%) and the complexity of the procedure (Q35, 43%). Most parents perceived the LEA in a negative light (Q35, Q39) and stated a strong belief that their successful agreement of a placement of their choice was due to their own persistence. Many parents describe this process as a 'fight' or 'fighting for their child' (Q38-39). Therefore the survey found that parents experienced the process as difficult, even though most reported satisfaction at the outcome.

The semi-structured interviews with LEA officials also revealed that they felt the system was working. All stated that they worked hard to involve parents and engage with schools to meet the needs of the children within their LEA (see Section 6.3.). Many examples of parent partnerships and school support training were given. Although the sample size was limited, there were differences that emerged among the respondents. In particular, the role that a child's diagnosis plays in determining (or even restricting) choice in provision, and the role of the Tribunal in deciding provision (welcomed by some LEAs and avoided by others) proved insightful. A frequent theme in the parent survey was the heavy influence that any financial implications would have in making a decision for (or against) an individual type of provision. LEAs acknowledged a duty to consider the prudent use of their resources, but felt that it was not the influence that parents perceived it to be (see Section 6.2.3.).

8.2.3. Research Question 3

What are the implications for the individual child with autistic spectrum disorder?

The research methods: semi-structured interviews with school and LEA staff, Parental survey (Q13, Q17-33, Q38-39), and research log notes

The research findings: Each strand made contributions to the answer of this question.

Schools have the obligation to put into practice what the statement and stakeholders agree is appropriate educational provision. This typically is a relatively general statement, which allows the school some flexibility in terms of methodology. In theory this is a healthy practice, but when a school is not functioning to its remit, it

has serious consequences for the individual child. This was the case of St. Joseph's School (Strand 1). The individual children were not getting the teaching time or expertise needed to maintain progress on goals (see Table 4.3).

The research literature is vast and, in many cases non specific to the severity of the autism as in the example of the children at St. Joseph's School (Howlin, 1997a; Jordan et al., 1998). The methodology chosen by the school, and promoted in their prospectus is the product of the expertise and experience of the principal (and founder). This can cause confusion when two members of the teaching staff state in an interview that they are either unaware what the school ethos and founding principles are or cite different ones than the principal (see Section 4.12.1.1.). What follows, unfortunately, is a conflict between the belief and agreement (on the part of parents and LEA) to have a child educated in a school that espouses a certain approach that in day-to-day practice it is not able to follow. The direct consequences of this for the child is that he or she is not getting the agreed educational input that is mandated by the statement. In some cases this is not a severe consequence, because other methodologies or newer methodologies emerge where the past one left off. In the case of St. Joseph's, frequently there was no teaching taking place (see Figure 4.3). Speculatively this could be due to a wide range of difficulties (i.e. staff shortages, lack of a teacher, extreme aggressive behaviour of children). Inspections from outside agencies (i.e. Ofsted and Social Services) did not show any discrepancy in this area.

Parents are faced with many concerns. Although the literature review showed the information on autism and methodologies to be vast (see Section 2.2.), it is non-specific to particular combinations of difficulties present in the triad of impairments. As a diagnosis of autism reflects wide variety among those affected, some survey parents stated that they are uncertain about how to meet the needs of their individual child.

Second, even if a parent wishes their child to be educated following a particular approach or methodology, it may not be available locally (Evans et al., 2001). Even when it is, demand for specialist provisions far outweighs supply (National Autistic Society, 2002). In practice, many of the survey parents felt that the provision for their

child was determined by what is available and not based on the unique needs of their child (see Figure 5.19).

Third, children are starting to benefit from the increasing public awareness of autism. Parents are following through on their concerns, and receiving a diagnosis at an early age, when appropriate (see Table 5.1.). Identification of the problem is a welcome first step in helping to educate a child affected by autism.

Unfortunately, several problems can then occur. Many areas of the UK do not have early intervention programmes (English et al., 2001). Those that do have a large demand on those limited spaces (National Autistic Society, 2002). Parents describe the process of trying to get their child one of the places, as having to 'fight' for provision. This can cause tension between parents and the LEA, or even between individual parents. Parents feel they 'need' the diagnosis of autism to have any chance of securing sought after specialist provision (see Section 5.6.3.).

LEAs are striving to work with families to provide for children with autism (see Section 6.3.). They are developing many new initiatives to help with training and communication. Unfortunately, this practice is patchy and described as a 'post code lottery' (Tissot et al., 2001). Comments from the survey parents state the feeling that parents believe contrary to the Code of Practice (DfES, 2001), an individual child will get educational services based on where they live, and not entirely on their individual needs.

Some LEAs describe their recognition of good practice or Beacon Schools as almost a 'burden' because it creates an even greater demand for spaces at those schools (see Section 6.2.1.). Families will up root the child and move into the catchment area of a local school as they see it as the only way to get the child into the placement of choice.

In some cases, the educational methodology of the parent's choice is beyond the remit of the LEA to provide without a tribunal (see Section 6.2.3.).

LEAs are aware of the need to work with other agencies to address the needs of the individual child. Several spoke of newer initiatives to try and address the global needs of the child (see Section 6.6.).

8.3. Research Implications

The literature review revealed the limited areas of agreement and diverse areas of disagreement among researchers and practitioners in the field of education for children with autism. Most agree on the value of early intervention (Fenski et al., 1985). It is also clear that there is no single approach that will meet the needs of all children with autism (Dunlap, 1999). Coupled with this is the fact that autism is a spectrum disorder (Wing et al., 1971; National Autistic Society, 2000a), with huge diversity among the population affected.

Against this framework schools, parents, and LEAs need to make decisions about how to best meet the educational needs of children with autism. Children are diagnosed earlier (Charman et al., 2002), and consequently parents wish an early intervention programme for their child. When an individual family is seeking provision for their child with autism, a dialogue develops between the LEA and family, and possibly even a school or unit. This research focused on this dialogue and the resulting process, in an effort to define the influences that can help make the process of securing provision helpful to all parties involved. It investigated the research question by asking those involved what their opinion of the process was. Not surprisingly, this research yielded a wide variety of opinions.

There is guidance from the government in the form of the Code of Practice (2001) for LEAs and Schools on the process of meeting the needs of all children. A process of consultation with 'LEAs, schools, SEN voluntary bodies, the health and social services and others' (p.iii) led to the revised version now in practice. What the Code of Practice did not undertake is an extensive survey to find out what the opinions of parents are (although they were consulted in limited numbers). This research is the first to carry out a nationwide survey to seek the opinions of the consumer, those parents that are actually going through the process to obtain educational provision for their child with autism.

Parenting a child with autism is stressful (Konstantareas et al., 1992; Sivberg, 2002). Rodrigue (1990) has shown that it is more stressful than parenting children with other handicapping conditions. It was therefore expected that parents replying to the survey would be likely to state that they were under stress. What was unexpected, was the high levels of stress and the link of this stress to the process of securing educational provision for their child.

A closer look at the qualitative responses of parents to the survey reveals a sharp contrast with the view taken by LEAs on the process of securing provision. LEAs are actively promoting the involvement of parents in the process, and the survey respondents welcome this. But where the disagreement exists is in the confidence that parents have in their choice of educational provision being granted. Just around half of parents surveyed stated the three main stressful factors as discussions with LEA staff (Q35, 54%), the limited types of provision available (45%) and the complexity of the procedure (43%). These are the three factors parents are finding the most stressful about this process, and it has a strong effect on the descriptions of their individual experiences. Many describe it in negative terms such as, 'mistrust of the LEA', 'long tortuous affair', or even 'it was hell'. Some even described it as a confrontational process, 'fight for your child's right to education', 'the battle never ends', or a 'continuing uphill fight'. What is clear from the qualitative survey data is that the vast majority of families take the view that they will need to be very proactive or 'pushy' to get a quality provision for their child.

The LEAs interviewed acknowledged an increase in the number of children being diagnosed with autism within their LEA (Fombonne, 1997; Medical Research Council, 2001). They also recognise the limited number of specialist places for children with autism. Although government is promoting 'best practice' within the existing LEA provision (English et al., 2001; DfES, 2002), those interviewed did not welcome the additional demand they felt this would bring on already limited places.

What the survey revealed that parents are saying is that they are getting mixed messages. They are encouraged to participate in the process of determining provision (DfES, 2001), but find in practice their participation is not sufficient to secure the provision that they desire.

'[The] LEA allows parents to have input but then completely ignores what they say.'
parent (#11)

What was also unexpected, is the disagreement among the parties about the actual process. Most parents believe they need a diagnosis to have the best chance of obtaining specialist provision.

'Although it seems obvious, early diagnosis is essential...' (#437)

LEAs are inconsistent in applying the government guidelines that state a diagnosis is not essential to receive educational support (English et al., 2001). Although some view it as unnecessary or even, at times, unhelpful, others require it. Parents are very aware of the increase in competition for the limited number of specialist places, and believe that having a diagnosis is one way to advance their child's case.

As there is disagreement in the research about the best way to educate a child with autism (Lotter, 1974; Howlin, 1997a; Jordan et al., 1998), this can lead to disagreement among the three Strands as to the best way to meet the individual needs of the child with autism. Families have researched different approaches and feel quite determined in their belief in a particular educational approach, and believe resistance on the part of the LEA is due to the financial implications.

'If you disagree with the cheapest provision available, it will be a difficult and stressful fight....' Parent (#180)

'The LEA always seek resource led rather than needs led provision...' Parent (#617)

The lack of research on the specific methodology at LEA schools (Jordan et al., 1998) is also questioned by parents as they have few ways to determine the quality of individual methods. As learning disabilities are often associated with autism (Prior, 1979), many children are unable to take national exams. This means that 'League Tables' for exam scores do not typically evaluate teaching quality at special schools. Ofsted inspections occur at 5-year cycles; meaning reports generated can be dated.

How does a parent evaluate what an LEA is recommending to meet their child's educational needs? The network of support for parents in terms of support groups or charities reveal the extent of the problem for an individual family (PACE, 2001; National Autistic Society, 2002). There is a shortage of places at schools with a

demonstrated history of effective provision. This coupled with the intense demand for these places causes friction between the parties.

Once an educational provision has been decided, parents overwhelmingly state their willingness to work with schools to determine and support educational efforts. What this research revealed is the many different distractions that can pull an individual classroom staff away from providing the education they are entrusted to deliver. Parents shared their willingness to be actively involved in this process by their responses to the survey, but could not, in the case of St. Joseph's School, ensure that this did happen. The research shows that parents believe in their ability to go to the source and work directly with the school to make the provision work for their child. Consistent with other research (Hastings et al., 2001) this research showed it was not necessarily the type of provision that caused the stress in parents, but the factors associated with securing that provision.

How does this relate to an individual child with autism? Survey parents are stating that they do not have confidence in the system of securing provision for their child. They state their frustration at '*a system that has conflict at it's core*' parent #226. What are the key factors that this research has identified which impact on the individual child?

a) Time delays

This research has shown (see Figure 6.10) that only about half of those families responding to the survey stated that they had provision for their child within governmental guidelines (DfES, 2001) of approximately 6 months. Research shows that early intervention is effective (Fenski et al., 1985; Blackman, 1995; Guralnick, 1997; Shields, 2001). Government policy supports this view (DfES, 2002). But if the practice of determining provision is such a lengthy process, it delays the delivery of an education to the child. In effect, creating a missed opportunity to address the needs of the child and family at the point where this education is most needed, and it can have a great effect (Fenski et al., 1985; Guralnick, 1997; Simpson, 1999; Evans et al., 2001).

b) Demand for places

Some parents are frustrated at the difficulties they are faced with when trying to secure placement at a specialist school.

'If the waiting lists are at least 30-50 children long when your child is first referred to a special school, what chance do you have?' parent (#432)

If the delivery of appropriate education is delayed for the individual child, it may also have the effect of the family seeking a 'less than appropriate' education for their child, just to have the child in any educational environment. Speculatively, this can mean that the individual child will not progress to the best of his or her ability, due to a lack of a specialist education. There is also a long-term economic impact as a result of this inability to effectively meet the child's needs. (Jarbrink et al., 2001)

'The time to help these children the most is during the early formative years. Years haggling over provision robs them of optimal help' parent (#134)

c) Differences in approaches

The survey revealed the general willingness of parents to work with schools to address the educational needs of their child. The variety of approaches available will mean that inevitable differences exist (Mesibov, 1999). This can leave the individual child with an opportunity to generalise skills learned or, at worse case an inability to make sense of a concept due to potential differences in teaching between home and school (Siegel, 1996).

d) Inability to deliver education

The research at St. Joseph's School revealed a school that at the time of the case study was unable to deliver its educational approaches effectively. Both the staff and the children in that class were very affected by staff shortage, lack of active leadership and other contributing factors (see Chapter 4). The children experienced a period of learning during which time there was a higher staffing ratio and children's aggressive behaviours were better addressed. When key staff members left, this had an effect demonstrated by lost skills on the part of the children.

e) Stress

Having a child with autism is recognised as stressful (Gerrity, 1982; Donenberg et al., 1993). In addition, many survey parents described the process of securing provision as stressful.

'Living with autism is bad enough without having to go through the trauma of securing the right provision. The process has had a lasting effect on our family.'
Parent (#499)

The family life of the child will be affected by the stress that is experienced by the parents and many survey parents described this process as having an effect on their family life. Survey Question 38 (see Figure 6.16) explored some of these issues. Almost half (47%) of those surveyed stated that they found this process stressful. Other effects listed were that it was very hard on the family (27%), problems with other children (13%), family friction (13%), and the financial implications (13%). Marriage problems were cited by 8% of the respondents as well as ill health (7%) and depression (5%). Most families described some ill effect that undertaking this process had on their family. It is therefore likely that this has an impact on the child as well.

f) Parent cannot be a Parent

Another impact that this process has on the child and family is the loss of time the parent is able to be a parent to the child.

'...sometimes it becomes hard to ENJOY our son because we're so busy working to secure his future' parent (#286)

'at this age you should be spending time with your child, not papers.' parent (#724)

Several parents describe the process as needing constant attention. Time devoted to securing provision (especially if it is a lengthy process) is potentially, time taken away from being a parent or even perhaps working with the child.

g) Post code lottery

Educational provision for children with autism varies across the country (English et al., 2001; Tissot et al., 2001; National Autistic Society, 2002). This has a direct

impact on the individual child, as it is not the needs of the child that determine provision, but to some extent the location of the family home.

'...depending on the area that you live in depends on what's available.' parent (#711)

This section has discussed the impact of this research on the three parties involved in the decision making process to determine provision. In addition, it has cited several examples of how this will affect the individual child with autism. The next section discusses the recommendations stemming from all three Strands of ways to help improve the system of allocation of educational provision.

8.4. Research Recommendations

The research above has highlighted the differences in perceptions of both ideas and practice that exist between different individuals, different areas of the country and different agencies. What recommendations can be made to advance 'best practice' during the process of securing provision for children with autism?

Seeking the opinions of a wide number of parents as well as several LEAs and a school showed the huge diversity that exists within the UK around the issue of securing and accessing provision for autistic children. The implementation of educational provision in a school also showed what it is like in day-to-day experience. Using the qualitative responses to the parental questionnaire as a starting point, recommendations regarding changes to this process can be made to reduce stress in parents and provide a better working relationship which should ultimately provide a better educational provision for the child.

- a. **Communication** – Highlighted in both the LEA interviews and survey responses, communication is a critical influence on stress levels in parents. Parents listed this as the most stressful part of securing provision. Although some do, all LEAs need to provide clear, concise, written information, which is specific to the individual LEAs. This should be presented to parents to outline what the LEA's policy is on provision. This should include the LEA's view on individual teaching methodologies, average waiting times for placement agreement, listing of all provision that the LEA is currently funding (and brief

descriptions of these), policy on Tribunals, policy on statementing, a statement about what an LEA officer can and cannot fund and contact details for an independent parent liaison officer. LEAs should also run regular workshops for parents, describing the educational services available, and the fundamentals of the statementing process.

- b. **Diagnosis** – Survey parents stated that obtaining a diagnosis is a necessary first step in the process to secure provision, yet LEAs interviewed state that a diagnosis is not needed, and can even be unhelpful in determining provision. The West Midland report (English et al., 2001) states that some LEAs do require a diagnosis before statementing in practice. Therefore, this is not consistent across the UK. LEAs need to consistently adhere to the recommendations in the Code of Practice (DfES, 2001), which do not require a diagnosis for access to services (see Section 6.4.).
- c. **Expanded Diagnosis by a Trained Clinician** – Those children that are receiving a diagnosis by a specialist, should be given an ‘expanded diagnosis’. This should be seen not as a requirement for specialist provision, but as a tool to providing education to address the specific strengths and weaknesses of the individual child. This could include a broadly defined picture of where their child exists in each of the three areas in the Triad of Impairments. This listing could then be used to help determine provision or even individual IEP goals. A diagnosis is important, as parents need to know why their child is not progressing according to established developmental criteria, but additional information should be shared about areas to target.
- d. **Statementing** – Survey parents expressed concerned about the current philosophy of reducing the number of statemented children (DfES, 2001). They are concerned that this policy will mean a reduction in the quality or quantity of their child’s educational provision and do not want to loose this legal document of entitlement. Two of the LEAs interviewed recognised this concern and described their efforts to address it (see Section 6.4). This is a positive step in gaining parental confidence in this policy. Other LEAs should perhaps consider establishing a proactive approach or even a ‘Quick Response’

team or some other means for parents to get their concerns addressed in a speedy fashion, if parents see the child regressing.

- e. **Timeliness** – ‘Typing shortages’ and ‘staff holidays’ were both given as excuses for lengthy delays in the length of time it takes for some LEAs to agree with parents on a statement for a child. Survey parents described these delays as cost saving measures, because LEAs do not have to make provision during this time. More effort should be made to get statements issued within the Code of Practice (DfES, 2001) guidelines and LEAs should be held accountable for this.
- f. **Lack of Places** – Specialist placements are highly sought by survey parents (see Figure 5.9). With the increase (actual or perceived) in the number of children receiving a diagnosis of autism and the limited number of such places (National Autistic Society, 2002), the LEAs have no option but to create new or convert unwanted generic places in special schools to autism specific ones.
- g. **Joint Agency Approach** – All services need to work together for the individual child and family. LEAs interviewed view Health (and to some extent Social Services) as distancing themselves from the child once they have given a diagnosis. A multi-agency team needs to be set up in each authority to assess, diagnose (if appropriate), and create a care plan for immediate implementation. The West Midlands Project (English et al., 2001) advocates Health, Social Services and Education working together from the point of diagnosis. This would also be beneficial when long term planning is necessary for very disabled children.
- h. **Early Intervention** - Some new programmes such as Early Birds (Shields, 2001) or SWAMP (Webster et al., 2003) have been successful at developing early intervention programmes. Parents generally welcome these (Shields, 2001). These projects (or similar ones) should be made available to all parents who wish for them as soon as the child is first suspected of having a disability or at the point of diagnosis (if applicable). This should be in advance of receiving a statement or agreeing educational provision with a family.

- i. **Staffing levels** – Some schools need to be more proactive in recruiting and retaining staff. Non-monetary incentives (i.e. training) need to be enhanced and shared. This could mean direct involvement by senior staff members or concentrated efforts to improve communication and teambuilding. Recognition for positive contributions from staff should be encouraged.
- j. **Parental involvement** – Positive parental involvement is a stated priority for most schools, although most actively support this, some do not. Parental involvement needs to go beyond a policy statement and into actual practice. All special schools or specialist units should have a working Parent's Committee. Duties could include welcoming new parents, creating 'parent buddies' (as helpers to new parents and to answer their questions), writing a parent handbook, nominating parent/s trustee and hosting regular meetings for parents (if warranted).
- k. **Expanded Choices** – Survey parents frequently stated that they had very little choice when it came to educational provision. Early intervention is well recognised as beneficial (National Research Council, 2001), but this is not available in some areas. Other LEAs only have a limited choice in provision. This is coupled with an ever-increasing demand for these places. Parents, as consumers, are advocating for specialist provision and provision should be adapted to meet this need.
- l. **Social Services** – Parents have described this process of diagnosis and securing provision as stressful, affecting in many cases the physical or emotional health of the parent or family. Rarely was Social Services cited by survey parents as having input. There is a need for counselling or support services for families with children with autism from the point of diagnosis.

This section discussed recommendations for improving the system of securing appropriate educational provision for children with autism. The next section will consider the limitations of the research conducted for this thesis.

8.5. Research Limitations

In the absence of clear public data on the statistical prevalence of autism, it is difficult to judge the impact of autism on educational provision. This research attempted to address this anomaly by investigating the research question from the perspectives of those closest to provision of education: a school, parent, and LEA.

This research has been limited by several factors. First, the investigation into the school's perspective is an example of one school, at a specific time and place. The opinions shared are attributable to those individuals and cannot be seen to be suggestive of the entire population of staff at special schools. It is also recognised that the events that occurred, staffing patterns, and opinions of members of staff are acknowledged as unique to the time and place that data was gathered.

Second, the method used to gather parental opinion was an opportunity sample. As such, it is assumed to be the opinions of those surveyed, and not indicative of the entire population of families of children with autism. The survey was sent to individual families who were either members of a charity or had their child at a specific school. Although this allowed for some diversity in types of educational provision and area of the country, there were no means for cross-checking databases (due to limitations imposed by the Data Protection Act). It also did not allow for an accurate account of all surveys distributed, as parents may belong to a number of charities, or both a school and charity.

In terms of the actual survey, it is recognised that there is a predominance of quantitative questions. The advantage of this was to facilitate the analysis of a large number of responses, at the risk of 'limiting' some of the replies from parents. This was addressed with the inclusion of two qualitative questions. These generated 'richer' data, but in depth analysis of this was limited due to the sheer size of the sample (n=738).

Thirdly, semi-structured interviews were used as a data gathering means. The advantage is that those interviewed had the opportunity to express their views in their own words, and address any issue they wanted to clarify. Although the two main questions were determined in advance (See Section 6.1), the fluid nature of the

interviews allowed for investigation in areas of interest by the interviewee. Another limitation of this tool is its validity and objectivity. Criticisms arise from the very nature of this instrument; the researcher's presence asking an individual's view. Critics argue that having the researcher present and able to explore themes of interest, reduces the validity and reliability. In contrast, this researcher believes that this is an actual strength of this method. Kvale (1996) stresses this as an advantage to the use of interviews. Silverman (2000) also believes that the opinion of the interviewee is what is desired and this should be seen as a good tool for discovering the beliefs of others.

Fifth, there were a limited number of LEAs interviewed. Although the LEAs with the greatest number of survey responses determined which were contacted for possible interview, there were only five LEAs that had agreed and were actually interviewed (out of a total of 207 LEAs in the UK (The School Government Publishing Company, 2001)). Although urban and rural, as well as large and small LEAs were in this sample, all LEAs were located in the south of the country and all were in England. This sample is limited both in number and location of the LEAs. This researcher acknowledges these limitations of the sample of LEAs.

Finally, the researcher is also a parent of a child with autistic spectrum disorder. Her own efforts at securing educational provision may have biased her in interpreting some of the data. But it is through the different methods and the discussion of the findings with others (supervisor, colleagues and other parents) that repeated efforts to overcome this bias have been made.

8.6. The Contributions of the Research

The current research is unique in terms of its investigation of the process of securing appropriate educational provision for children with autism from the perspectives of the three main participants (school, parent and LEA). The views of the participants are explored to determine its implications to the individual child. The contribution of the current research is expressed in three aspects: the contribution to knowledge, to methodology and to the applied aspect.

8.6.1. Contribution to Knowledge

The current research was the first attempt to discover the opinions of school, parent and LEA on the process of providing education to a child with autism. It highlighted areas that the parties agree, while discussing differences that also occur. Although opinions were diverse, the research provided insight into the views of the three parties on what this means for an individual child.

The knowledge gathered enriches the current body of research regarding the implementation of educational provision and the effects this has on the child and family.

LEAs and Schools strive to involve parents in the education of their child. This is seen in documents generated by a specific LEA, as well as government directed practice (DfES, 2001; DfES, 2002). Although selected individual parents are usually invited to give 'parental input' into policy (either local or national), there has not been any attempt to get feed back from a large number of parents or schools on the process of determining provision and its implications for children. Therefore, policy statements are generated on the basis of the opinions of a few individuals. This research has shown the huge diversity that exists within the sample of the population of families that have children with autism. This thesis is the first to explore this diversity relating to the provision of education for autistic children.

8.6.2. Contribution to Methodology and Theory

This thesis is the first to apply Systems Theory to the autistic child's environment (see Figure 4.1). This application allowed for an investigation into the tensions and dilemmas that exist in the contributing partners when planning and implementing educational provision for the child. It explores the interactions that occur between these partners as a means of understanding the process as it relates to a child.

This thesis is also the first to ask the views of parents on the topic of securing educational provision by means of a nation wide survey. Other research to date was limited in terms of the geographic area included or the sample size (English et al., 2001).

8.6.3. Contribution to the Application

This thesis has gone beyond the exploration of the data generated and yielded a comprehensive list of practical applications from the research. Included in the list are several suggestions for improvements in the system of educational provision (Section 8.4). Critical among these are practical ways to improve communication between the parties.

8.7. Suggestions for Further Research

This research has raised interesting questions that merit possible future research exploration:

- To examine the views of the individual child on their educational provision.
- To examine the impact that independent 'parent advisors' make on stress levels of parents when securing educational provision for their child with ASD
- To explore the relationships between parents and LEA/schools. What factors contribute to a 'successful working' relationship?
- To look at 'best practice' in disagreement resolution. How can parents and LEAs work to resolve differences of opinion in the best way?
- To compare the experiences of parents that (DfES, 2001) have children with other handicapping conditions with the parents of children with autism on stress levels when determining provision.
- To compare the experiences of younger children with the allocation of provision. Are the government's recommendations having a positive effect on stress levels of parents?

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Appendix 1 - Common Abbreviations

List of Abbreviations

ABA	Applied Behavioural Analysis
AiA	Allergy induced Autism
ASA	Autism Society of America
ASD	Autistic Spectrum Disorder
CABAS	Comprehensive Application of Behaviour Analysis to Schooling
DfEE	Department for Education and Employment
DfES	Department for Education and Skills
DTT	Discrete Trial Training
IEP	Individualised Education Plan
LEA	Local Education Authority
NAS	National Autistic Society (UK)
NIMH	National Institute of Mental Health (USA)
OFSTED	Office for Standards in Education
OT	Occupational Therapy
PDD	Pervasive Developmental Disorder
PECs	Picture-Exchange Communication system
PT	Physical Therapy
SCIP	Strategies for Crisis Intervention and Prevention
SEN	Special Educational Needs
SENCO	Special Educational Needs Co-ordinator
SIB	Self-Injurious Behaviour
SPELL	Structure, Positive approaches and expectations, Empathy, Low arousal and Links
TEACCH	Treatment and Education of Autistic and related Communication handicapped Children
TTA	Teacher Training Agency
VCS	Visual Communication System

Appendix 2 - Diagnostic Criteria for Autism Spectrum Disorder

DSM-IV Criteria for Autistic Disorder and Pervasive Developmental Disorder, Not Otherwise Specified (PDD, NOS)

A) Qualitative impairments in reciprocal social interaction:

- 1) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
- 2) Failure to develop peer relationships appropriate to developmental level.
- 3) Lack of spontaneous seeking to share enjoyment, interests, or achievements with others.
- 4) Lack of socioemotional reciprocity.

B) Qualitative impairments in communication:

- 5) A delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
- 6) Marked impairment in the ability to initiate or sustain a conversation with others despite adequate speech.
- 7) Stereotyped and repetitive use of language or idiosyncratic language.
- 8) Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level.

C) Restricted, repetitive, and stereotyped patterns of behavior, interests, or activity:

- a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest, abnormal either in intensity or focus.
- b. An apparently compulsive adherence to specific non-functional routines or rituals.
- c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping, or twisting, or complex whole body movements).
- d. Persistent preoccupation with parts of objects.

Abnormal or impaired development prior to age three manifested by delays or abnormal functioning in at least one of the following areas: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

Source: The Diagnostic and Statistical Manual, 4th Edition, American Psychiatric Association, 1994.

ICD-10 Criteria for Autistic Disorder

- A. Presence of abnormal or impaired development in at least one of the following areas from before the age of three years (usually there is no prior period of unequivocally normal development, but when present, the period of normality does not extend beyond three years):
 - 1. Receptive or expressive language as used in communication.
 - 2. The development of selective social attachments and/or of reciprocal interaction.
 - 3. Functional and/or symbolic play.
- B. Qualitative impairments in reciprocal social interaction:
 - 1. Failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction.
 - 2. Failure to develop (in a manner appropriate to mental age and despite ample opportunity) peer relationships that involve mutual sharing of interests, activities, and emotions.
 - 3. Rarely seeking or using other people for comfort and affection at times of stress or distress and/or offering comfort and affection to others when they are showing distress or unhappiness.
 - 4. Lack of shared enjoyment in terms of vicarious pleasure in other people's happiness and/or a spontaneous seeking to share their own enjoyment through joint involvement with others.
 - 5. Lack of social-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; and/or lack of modulation of behavior according to social context, and/or a weak integration of social, emotional, and communicative behaviors.
- C. Qualitative impairments in communication:
 - 1. A delay in, or total lack of, spoken language that is not accompanied by an attempt to compensate through the use of gestures or mime as alternate modes of communication (often preceded by a lack of communicative babbling).
 - 2. Relative failure to initiate conversational interchange (at whatever level of language skills are present) in which there is no reciprocal to and from responsiveness to the communication of the other person.
 - 3. Abnormalities in pitch, stress, rate rhythm, and intonation of speech.
 - 4. A lack of varied spontaneous make-believe play or (when young) in social imitative play.
- D. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities:
 - 1. An encompassing preoccupation with stereotyped and restricted patterns of interests.
 - 2. Specific attachments to unusual objects.

3. Apparently compulsive adherence to specific, non-functional routines or rituals.
 4. Stereotyped and repetitive motor mannerisms that involve either hand/finger flapping or twisting, or complex whole body movements.
 5. Preoccupations with part-objects or nonfunctional elements of play material (such as their odor, the feel of their surface, or the noise/vibration they generate).
 6. Distress over small, nonfunctional details of the environment.
- E. The clinical picture is not attributable to other varieties of pervasive developmental disorder (Asperger's syndrome, Rett's syndrome, Childhood Disintegrative Disorder) nor to a specific developmental disorder of receptive language with specific socioemotional problems, reactive attachment disorder, mental retardation with some associated emotional/behavioral disorder, nor schizophrenia of unusually early onset.

Source: World Health Organization (1994) The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research. Geneva: WHO

Appendix 3 - Briefing Sheet to Parents/Guardians

19 January, 2000

Dear Parent or Guardian:

I propose the undertaking of a study with the co-operation of [name of school]. The intention of the study is to develop new teaching strategies with the aim of improving communication skills in children with autism.

The research will have the following features:

1. Use of cards, pictures or written words to facilitate communication.
2. Pre and Post testing that may involve video taping of the children working.
3. Training of staff.

Any data collected will remain confidential and for investigative purposes only. All details that may identify a child will be kept confidential and replaced by alternatives (for example the child will be referred to by another first name). Further use of video footage will require additional parental permission.

No potentially harmful treatment will be used. All teaching will be conducted in full agreement with [school's] management and staff and is consistent with [name of school's] philosophy.

Parents/Legal guardians may be asked to participate in a short interview conducted at their convenience.

If you have any questions, please feel free to contact either [name of deputy head] or Cathy Tissot at XXXX XXXXX (email at tissot@XXXX.XX).

Sincerely,

Cathy Tissot
Brunel University

PARENTAL PERMISSION FORM

I have read the information provided and have been given the opportunity to have any questions answered.

I understand the implications of the study and hereby give permission for my child to participate.

Print name of child

Print name of parent/guardian

Signature

date

Appendix 4 - Sample of the Research Log

2-2-01

Staff present: Jan, Lori, Terry, Hana (No teacher, down two staff)

Children present: Alex, Daisy, Raja, Darren, Jerry

Alex: Wet twice yesterday, once in school and once on the bus, both after prolonged times away from the toilet.

Daisy: Discussing a new medication for Daisy. Had a very bad week, very obsessive. Staff can't redirect her and her aggression is very random. Starts with her pointing to an item, then staff tell her that she can get it herself, then Daisy will slap the staff member and sign 'help'. These are all things she can do, but won't do. Even if the staff help her, she is still aggressive towards them.

How often is this happening? Get staff to keep some kind of log.

Raja: With Terry in the front hall. She is very happy and looking at books. No self abuse at all. Sitting in her buggy.

Why is she so happy? Must be the first time I have seen her without any self-abusive behaviour. Larry comes in. Feels Raja is happy to watch all the activity in the hall with people coming and going. No demands placed on her.

Bus Trip: Alex, Daisy, Darren, Gerry A bus ride to take Alex on a home visit. Bus meets the parents half way.

Short visit because kids leave early for the day. Sarah is given a copy of her interview for verification. Spoke to Sandy about training for staff on March 23rd.

5-2-01

Staff present: Hana, Sue, Jan, Lori, Valerie, Harry, Victoria (No teacher-one extra staff present)

Children present: Gerry, Alex, Daisy, Darren, Raja

SOCIAL SERVICES VISITS TODAY (Is there a link with the extra staffing?)

Gerry: Star chart needed to sit down. Trousers down all the time. Rough week, will not keep his trousers and pants up. He is up and out of his chair all the time. 'He has weeks like this every so often' Sue.

Is this due to all the new staff? Do we need a new reinforcer?

Alex: Sitting with the group during story time for one page of the story. Then he gets up and wanders around for a page. Then he is directed to come back to the group. He is calm. No self-abuse. Got Valerie's had to take him to the toilet!!! Unfortunately he did not go.

Daisy: Sitting in chair at the end of the room. Seems calm, but by herself.

Raja: In outer room with Harry. She is laying on the mat with a weighted blanket. There are some toys out, but she is just pulling these apart. It is hoped that the blanket may calm her down, but does not appear to be.

Darren: Just wandering around.

Lisa sent copy of her interview for verification. More painting in the room, but there are still large areas where the old blue colour is coming through. There is about 6 inches showing near window. The stations where the children work are all torn apart, must be for the painting.

12-2-01

Staff present: Reena, Ann, Jan, Sue (No teacher, down 2 staff-Lori did not show up for work the last two days, did not call in sick)

Children present: Gerry, Raja, Alex, Darren, Daisy

Daisy: Went home last weekend. Difficult at home. New charting system which includes definitions for each of the areas. 'Obsessive' involves an item, 'Confused' means she is phased out.

Who is doing this chart? Does she work with Daisy at all?

Alex: Very upset. Is he sick? Given pain relief, but won't take it.

Gerry: Sitting, but up and down constantly. He is hyper. Very loose bowels?? Very loose on toilet, wind several times.

Daisy: Started hitting other children. Fork attack at breakfast. Hit the nurse.

Rough morning. Staff shortages. Takes at least 2 (sometimes 3 staff) with Danielle. No teacher. Jan leaves on Friday.

Daisy really out of control. 1 ½ hours of aggression towards staff and kids. She is removed to her bedroom by a 2 person escort. Came back to room after about one hour.

14-02-01

Staff present: Sue, Jan, Ann (no teacher, down 3 staff, neither Lori or Victoria come in to work or call in sick)

Children present: Daisy, Raja, Gerry, Alex, Darren

Deputy Head came in on Tuesday and Daisy was really same as on Monday. Daisy did not even come into the classroom in the afternoon.

Yesterday Daisy had an obsession with the apron. She sat down for break but would not eat by herself. The chair was empty next to her and this was very hard for Daisy.

Wanted staff next to her, but then she would attack them. Staff left her by herself and she would not calm down for up to 30-minute periods.

Deputy head cannot come in and help today, as she needs to do a staff evaluation.

Researcher is directing a plan of action for Daisy. Staff need to set a time limit of five minutes of trying to get her to cooperate and not be aggressive. If not, take her back to her bedroom to calm down.

Raja: S/L therapist takes Raja.

Daisy comes back into main room to see what is going on. Runs into courtyard and comes in and signs 'toilet'. In and out of the room many times. Eva from Seniors comes in for the rest of the morning, so now only down 2 staff. Daisy keeps pointing to 'drink' picture. Break time is finished. Repeated warnings. Count down from two minutes to warn of transition. Transition is OK.

Researcher pulls huge cobweb off of ceiling.

Daisy: Three episodes of being taken to inner room and kids in outer room for protection. Daisy is obsessed with the smock. Esther helped her and is attacked by Daisy. Starts biting researcher, then becomes obsessed about drink. Then smock is a big deal again. Researcher planned to do a behaviour log today, but can't due to staff shortages.

Jan comes up afterwards with tears in her eyes, 'I have real concerns about Daisy and staff shortages'.

Appendix 5 - Charts for Aggressive Behaviour

Name: Alex

Date	Time	Setting/comments	Staff/children	Total
October 16-10-00	9:50	Story, walking around room, hitting head	Jan, Lisa	44
16-10-00	10:40	Break, eating and relaxing in outer room	4/4	2
18-10-00	10:16	Bus trip to Tesco	4/3 kids	0
November 16-11	10:55	Break time, eating at table and free time	Jan	8
23-11	10:00	Before school, free time, stimming on cardboard with fingers, and in library looking at books	Jan	1
	11:25	With tambourine on break and going to toilet	5/5	3
December 14-12-00	10:57	Break time and after break.	3/4	0
	10:27	Genesis, looking at the lights, getting upset, wants to leave	Tina/Sue	4
January 19-1-01	10:01	Letter writing.	Lori	5
22-1-01	9:56	Morning circle, and wandering afterwards.	Sue	0
February 8-02-01	9:45	Music, lots of walking around and touching guitar	4/5	0
March 30-03-01	9:45	Before work, walking around	2/4	3
	11:05	No lesson plans or teaching staff present. Head banging, and head slapping.	4/4	15
April 24-4-01	9:57	Break room, then individual swimming	3/4	0
May 9-05-01	9:32	Breakfast	Hana	1
	11:05	Break and non-structured time	2/3	0
June 29-6-01	10:35	Break and non-structured time	4/4	3
July 16-07-01	10:00	Group activity	Evri	0
	10:20	Movement	1/2	3

Name: Darren

Date	Time	Setting/comments	Staff	Total
October 16-10-00		Ill		
18-10-00		Ill		
November 16-11	11:20	PECs, fine motor work with blocks in bucket	Lisa	11
23-11	10:15	In library looking at books, then returned to classroom	Jill	14
December 13-12-00	11:40	Bus trip	Rusty	0
14-12-00	10:50	After break, walking around	3 /4	5
January 19-1-01	9:57	Before school and letter writing.	Jan	0
25-01-01	10:02	Before work time, sitting at table during group.	Ashley (student)	0
February 8-02-01	9:56	Music wandering in room	4/5	0
	11:30	Story with Lori and Jan. Lit hour, sitting at table.	Lori	4
March 30-03-01	9:43	Before school, walking around	1/4	0
	10:47	Walking around. No teaching staff or lesson plans. Pinching. Screaming.	3/4	3
	11:15	Assembly. Sitting in bean bag. Pinching and biting.	1/2	9
April 24-04-01	9:37	No activities due to window missing in classroom	2/3	0
May 9-05-01	9:45	Music class	Gail	0
	10:50	Break	Valerie	3
	11:15	Sensory activity/ toilet	Lori	2
May 24-05-01	9:57	Transition/sensory room	3/4	0
	11:09	Break	Gail	0
June 29-6-01	9:48	Music	4/4	12
	10:23	Outside at break time	4/4	4
July 16-07-01	10:10	Transition, then movement class	Gail	8
	11:15	Unstructured time, the massage	Charlie	3

Name: Gerry

Date	Time	Setting/comments	Staff	Total
October 16-10-00	10:00	Work with Jan, doing puzzle during break	Betty	0
16-10-00	10:15	Work time, English BBQ sheet	Betty	0
18-10-00	10:16	Bus trip	4/3	0
	12:15	Lunch	3/3	0
November 16-11	10:35	Intro on new token system for computer	Jan	0
23-11	11:20	Computer at break time	Jan/Lori	0
December 13-12-00	11:15	On bus trip to Tesco	Sue	0
14-12-00	10:15	In speech therapy with Ann. Lisa there too. Problems with PECs delivery.	Lynn/ Lisa	3
January 19-1-01	10:27	Puzzle/star chart	Lori	0
	11:27	Assembly with Lori and star chart. Stayed seated the entire assembly.	Lori	0
22-1-01	10:06	Puzzle/star chart	Lori	0
February 8-02-01	11:20	Break and then Literacy Hour.	Sue	0
March 30-3-01	10:13	On computer with new games.	Terry	0
	10:50	Working on a puzzle. No teaching staff or lesson plans.	Terry	0
	11:25	Assembly, sitting in chair.	Terry	0
April 24-04-01	9:47	No activities due to window missing in classroom	2/3	0
May 9-05-02	10:10	1 to 1	Helen	0
	10:40	Break	Helen	0
	10:45	Break	3/4	0
24-05-02				
June 29-06-01	10:55	Puzzle, then computer	3/3	0
	11:25	Painting	3/3	0
July 16-07-01	9:53	Group	Gail	0
	11:05	1 to 1	Edward	0

Name: Daisy

Date	Time	Setting/comments	Staff	Total
October 16-10-00	10:24	Reading books, trouble with the plastic bags and where to put books as library books go in these bags	Valerie	0
16-10-00	10:52	Break time, tying shoelaces. Having staff do it over and over.	Valerie	0
18-10-00	9:29	Break, self abuse hitting shoulder to ear	4/4	3
	10:23	Bus trip. Refusing to get out of van at Tesco.	1/1 Lisa	11
	10:35	In van waiting for others to shop at Tesco.	Lisa	2
November 16-11	11:10	Free time, wanted book and signed help (with Jan's attention) and pointed to book box out of reach. Jan asked if she wanted book and she nodded.	Jan	0
23-11	10:57	Finishing eating. Darren came up and pulled her hair. Reaction, but no aggression to Dan.	Lori	0
	11:35	Working on letter writing. Started well, then just stopped. Would sign that she wanted to cut PICs, then throw scissors etc. Lisa took scissors away for safety. Hitting, pinching, slapping. Lisa very neutral in responses.	Lori	16
December 13-12-00	11:25	Bus trip to Tesco. Problems with going in store.	Lori	6
14-12-00	11:17	Genesis	Valerie	0
January 19-1-01	10:17	Letter writing in outer room, but herself	Kathy	0
	11:15	Going to assembly, assembly	Kathy	0
22-1-01		Late in joining group, Cathy had to leave early so no data taken today.		
February 8-02-01	10:22	Sitting in outer room, not joining group. Lots of aggression this morning. Difficult getting her to classroom.	4/5	0

March 30-3-01	10:03	Walking around. No teaching staff or lesson plans left.	Shelia/Terry	1
	10:40	After break. Sitting on sofa in outer room and then became obsessive about her shoe being laced up. Throwing shoe.	Tina/Sarah	2
April 24-04-01		Not in classroom.		
May 9-05-01		Not in classroom.		
24-05-01	11:40	Independent work	3/4	0
June 29-06-01	10:00	In Senior classroom	Nell	2
July 16-07-01		Not in classroom		

Name: Raja

Date	Time	Setting/comments	Staff	Total
October 16-10-00	11:04	Just back (late) from home visit. Not happy to be back, having a break in outer room.	Lori	59
16-10-00	11:23	Language work. BBQ	2/1 Valerie and Lisa	63
18-10-00 ²²	10:00	In outer room looking at magazines. Loud screaming and even tears. Very upset. Later Language work. Is she starting to get ill too?	Lori, then Jan	111
November 16-11	10:15	Free play with Kathy. Art, play dough.	Kathy	64
	11:10	Break time, facing door only Daisy and Lisa in outer room	Lisa	69
	11:40	Out of buggy with Lisa. Laying on her tummy and Louise over her back. Talking about pictures and toys. 'What's that?' asked several times.	Lisa	41
23-11	11:09	Break time, with only Daisy in main room with her. Then watching Gordon on computer. No one paying attention to her or talking to her.	5/5	54
December 13-12-00		Not in school today.		

²² Wanted to do another timing of Raja, but worked with Raja and Jan instead due to the large number of AG. Tried pressure to side of head, and worked to reduce it. No data.

14-12-00	9:57	Looking at books in main hall. Considered a good session, lots of involvement.	Valerie	87
	11:07	Looking at books, laying on the floor. Later went to Genesis.	Valerie	187
January 19-1-01		Raja on home visit.		
22-1-01	9:37	Requested to go on floor, then great increase in SIB. Repeated attempts to stop SIB with pressure, toys, music, time alone. Is it seizure related? Pain relief given at 10:45	Liz	393
		Cathy had to leave early so no additional data taken today.		
25-01-01	10:12	Raja under her weighted blanket in outer room. Head check for lice by nurse.	Lori	169
February 2-02-01	10:15	In front hall with Terry. Laying over him. Lots of activity in and out of building.	Terry	1
8-02-01	10:06	Music. In outer room, lights off and on mat. Tapping foot.	4/5	70
	11:10	Break in outer room. Trying to get her to play with toys.	Valerie/Lori	103
March 30-03-01		On home visit.		
April 24-04-01	9:14	No activities due to window missing in classroom, in her bedroom	1/1	66
May 9-05-01	9:57	Outer room, by herself	Lori	166
	10:30	Visitor came to see her		110
	11:30	In her room, by herself	Helen	0
24-05-01	9:42	Music	Lori	138
	10:57	In Garden at break	Helen	58
June 29-06-01	10:45	Outer room	Sue	166
	11:05	Outer room	Lori	144
July 16-07-01	10:50	Outer room	4/4	177
	11:25	Outer room, sensory		8

Appendix 6 - Survey

Educational provision for children with autism: A Parent's view

1. Date of birth of child and current age.

DOB: /d /m /year Current age: years month/s

2. In which Local Authority (borough) do you live in?

3. What type of educational provision does your child receive?

1 Local Education Authority (LEA) school, mainstream (Go to question 6)

2 Specialist unit attached to mainstream school

3 Specialist unit attached to a special school

4 LEA Special Needs School

5 Daily provision at an independent school for autistic children

6 Weekly boarding independent autistic specialist school

7 Termly boarding independent autistic specialist school

8 52 week boarding

4. Is your child educated within the physical boundaries of your Local Authority?

1 Yes (Go to question 6)

2 No

3 Don't know

5. In which Local Authority is provision based?

6. Is the cost of provision borne entirely by the LEA?

1 Yes (go to question 8)

3 Don't know

2 No

7. If joint funding supports the provision, circle the relevant partners.

1 Social Services

4 Parents/carers

2 Health Services

5 Other (please state)

3 LEA

8. What is your child's primary diagnosis? (Circle one only)

1 Autism/autistic spectrum disorder

4 Rett's syndrome

5 Landau Kleffner

2 Asperger syndrome (AS)

6 PDD-NOS

7 Severe Learning Difficulty

3 PDD

8 Other

9. At what age did your child receive this diagnosis?

1 Less than 2 years old

5 6 years old

2 2-3 years old

6 7 years old

3 4 years old

7 8 years or more

4 5 years old

10. Who made the diagnosis?
- | | |
|-----------------------------------|---|
| 1 Educational Psychologist | 5 Other |
| 2 Paediatrician | 6 No formal diagnosis has been given (Go to question 12) |
| 3 Clinical Psychologist | |
| 4 Don't know | |
11. How many medical practitioners (GP, Health Visitor, Community Nurse) or specialists (Clinical or Educational Psychologist) did you see to get a diagnosis?
- | | | |
|------------|------------|--------------------|
| 1 1 | 4 4 | 7 7 |
| 2 2 | 5 5 | 8 8 |
| 3 3 | 6 6 | 9 9 or more |
12. In your opinion, how affected by his/her disability is your child?
- 1** (least) **2** **3** **4** **5** **6** **7** **8** **9** **10** (most)
13. At what age did you first suspect that your child suffered from a disability?
- | | |
|-----------------------------------|--------------------------|
| 1 Less than 2 years of age | 5 6 years old |
| 2 2-3 years old | 6 7 years old |
| 3 4 years old | 7 8 years or more |
| 4 5 years old | |

For each of the following areas associated with autism, please indicate which **one** statement best describes your child.

14. Social communication

- | | |
|---|--|
| 1 Speaks in meaningful sentences | 4 Echolalic most of the time |
| 2 Speaks in meaningful phrases | 5 Uses gestures to communicate |
| 3 Uses one/two word utterances | 6 Augmentative system (PECs, sign language) |
| | 7 Does not have a reliable way to communicate |

15. Social interaction

- | | |
|---|--|
| 1 Aloof and indifferent to others | 4 Will play with others when directed by adults |
| 2 Will tolerate others playing alongside him | 5 Active, but odd interactions with others |
| 3 Will play with others for a short period of time | 6 Has developed friendships with other children |

16. Behavioural

- | | |
|---|--|
| 1 Is aggressive to self or others on a <u>daily</u> basis | 4 Reacts to situations in an age appropriate manner |
| 2 Is aggressive to self or others on a <u>weekly</u> basis | 5 Usually reacts to others by moving away from the situation |
| 3 Is aggressive to self or others only when demands are place on him/her or under stress | 6 Is overly compliant and will not react by others in his environment |

17. Is your child covered by a statement of special needs?
1 Yes
2 No (Go to question 20)
18. If yes, how satisfied are you with parental input in this process?
1 (least) **2** **3** **4** **5** **6** **7** **8** **9** **10** (most)
19. In your experience, are all the provisions of the statement routinely met? (please comment)
1 Yes **3** Don't know
2 No
-
-

20. In general, which of the following statements best describes your way of working with the school to support your child?
1 I follow school led goals.
2 I work with the school to determine areas to address and ways to do this.
3 I try new procedures first, and then have the school work on them with me.
4 The school has no influence on what I do.
5 I have no influence on what the school does.
21. Have the requirements of the National Curriculum been disapplied for your child?
1 Yes
2 No (Go to question 23)
3 Don't know (Go to question 23)
22. If yes, have they been disapplied ...
1 In part
2 In whole
3 Don't know
23. In your relationship with the school, in which of the following areas is most guidance/help given?
1 Behaviour management **5** Social skills
2 Communication issues **6** Other (please list)
3 Academic goals **7** All areas equally addressed
4 Self help skills
24. Least help given?
1 Behaviour management **5** Social skills
2 Communication issues **6** Other (please list)
3 Academic goals **7** Sufficient help given in all areas
4 Self help skills

25. Are you happy with the provision your child is receiving at school?

If **yes**, is this due to... (choose 1)

1 Child centred educational provision
2 Well trained and effective teachers and staff

3 It is respite for me.
4 I/We as parent/s or carers are very involved
5 Other (please list)

If **No**, is this mostly due to ...(choose 1)

21 Poor staff/pupil ratios
22 Insufficient resources to meet the specific individual needs of your child
23 Autism specific training of staff inadequate

24 Year to year inconsistencies/staff turnover
25 Extensive disabilities of the child
26 Lack of parental/carer involvement
27 Other _____

26. Is your current educational placement your first choice?

1 Yes (go to question 29)
2 No

27. If no, what was your first choice?

1 Local named LEA school (mainstream)
2 Specialist unit attached to mainstream school
3 Named LEA Special school

4 Daily provision at an independent special school for autistic children
5 Weekly boarding specialist school
6 Termly boarding specialist school
7 52 week boarding

28. In your opinion, why is your child not attending your first choice in educational provision?

1 Child is not able to meet school entrance requirements
2 LEA view cost as too high

3 LEA view current provision as adequate
4 School is oversubscribed
5 Preferred provision is out of borough
6 Other _____

29. How did you or are you getting your child into your placement of choice?

1 Agreement with the LEA
2 Negotiation with the LEA

3 Persistent/protracted negotiation with LEA
4 Tribunal
5 Other legal proceedings
6 Other _____

30. Did you obtain outside legal council or specialist assessments to help secure your placement of choice?

1 No (go to question 32)
2 Yes, please explain your reasons _____

31. If yes, approximately what was (or is expected to be) the financial cost?

- | | |
|-------------------------|---|
| 1 Less than £500 | 6 More than £4000 |
| 2 £500 to £1000 | 7 Legal aid |
| 3 £1001 to £2000 | 8 Unsure or still in the process |
| 4 £2001 to £3000 | |
| 5 £3001 to £4000 | |

32. How long did it take to agree with the LEA on the provision of your choice from the time you requested provision to the time a placement was agreed?

- | | |
|---------------------------------------|---------------------------------------|
| 1 6 months (go to question 34) | 5 More than 24 months |
| 2 12 months | 6 Process is ongoing |
| 3 18 months | 7 Unknown or didn't keep track |
| 4 24 months | |

33. If 1 year or more, was this due to....? (circle all that apply)

- | | |
|---|---|
| 1 Delays in finalising the statement | 3 Delays in securing resources |
| 2 Delays due to term breaks | 4 Waiting for specialist reports |
| | 5 Waiting for tribunal |
| | 6 Waiting for other legal procedures |
| | 7 Other _____ |

34. How would you rate the process of agreeing a statement of your child's needs and agreeing on a school, in terms of stress on the family?

- | | |
|---|------------------------------|
| 1 Not at all stressful (go to question 37) | 3 Stressful |
| 2 Somewhat stressful | 4 Very stressful |
| | 5 Extremely stressful |

35. What are the **three** primary factors that contributed most to any stress experienced? (**Circle 3**)

- | | |
|---|---|
| 1 Discussions with LEA staff | 6 Limited number of appropriate places at a school |
| 2 Complexity of procedure | 7 Lack of access to outside advice services |
| 3 Ineffectiveness of current placement | 8 Lack of support of family/friends |
| 4 Social services | 9 Lack of local support group |
| 5 Limited number of appropriate types of provision | 10 Impact on family financial resources |
| | 11 Other _____ |

36. Which of these factors is the major source of stress experienced?
(Choose a number from Question 35)

37. What do you believe is a realistic future goal for your child when he or she is 20 years of age?

1 University or community college with minimal outside support

2 Independent employment with minimal outside support

3 Supportive employment (in the community) with moderate residential support

4 Sheltered work environment and living at home

5 Sheltered work and living environment in small community setting

6 Sheltered work and living environment in medium or large facility

7 Don't know or never thought about it, too far away

38. What effect has this process had on you and your family?

39. Any other comments about your experience of securing appropriate educational provision for your child? (Continue on back of this sheet if needed)

Thank you for helping with this research. If you are willing to be contacted regarding your answers, please print your details below. Rest assured, all responses will remain confidential and identifying details changed where appropriate. Return completed questionnaires in the enclosed FREEPOST envelope or to Cathy Tissot, Brunel University, St Margaret's Road, Twickenham, Middlesex, TW1 1PT.

Name:
Address:

Telephone:
Email:

LEA Regions

1. **South West-72** returned surveys (58 live in LEA+14 educate in LEA)
 - Bath & NE Somerset
 - Bournemouth BC
 - Bristol
 - Cornwall
 - Devon
 - Dorset
 - Guernsey
 - Isle of Scilly
 - Jersey
 - N Somerset
 - Plymouth CC
 - Poole BC
 - Somerset
 - S Gloucestershire
 - Torbay
2. **South Central-275 (193+82)**
 - Bracknell Forest BC
 - Buckinghamshire
 - Gloucestershire
 - Hampshire
 - Hertfordshire
 - Isle of Wight
 - Oxfordshire
 - Portsmouth CC
 - Reading BC
 - Slough
 - Southampton CC
 - Swindon BC
 - W Berkshire
 - Windsor & Maidenhead
 - Wiltshire
 - Wokingham DC
3. **Greater London-162 (139+23)**
 - Barking & Dagenham
 - Barnet
 - Bexley
 - Brent
 - Bromley
 - Camden
 - Croydon
 - Ealing
 - Enfield
 - Greenwich
 - Hackney
 - Hammersmith & Fulham
 - Haringley
 - Harrow
 - Havering
 - Hillingdon
 - Hounslow
 - Islington
 - Kensington & Chelsea
 - Kingston Upon Thames
 - Lambeth
 - Lewisham
 - London, City of
 - Merton
 - Newham
 - Redbridge
 - Richmond on Thames
 - Southwark
 - Sutton
 - Tower Hamlets
 - Waltham Forest
 - Wandsworth
 - Westminster, C
4. **South East-87 (73+14)**
 - Brighton & Hove C
 - East Sussex
 - Kent
 - Medway C
 - Surrey
 - Thurrock C
 - W Sussex
5. **Wales-21 (20+1)**
 - Anglesey CC
 - Blaenau Gwent CB
 - Bridgend CB
 - Caerphilly CB
 - Cardiff
 - Carmarthenshire
 - Ceredigion
 - Conwy CB
 - Denbighshire CC
 - Flintshire CC
 - Gwynedd C
 - Monmouthshire CC
 - Neath & Port Talbot
 - Newport CB
 - Pembrokeshire CC
 - Powys CC
 - Rhondda Cynon Taff
 - Swansea City & CC
 - Torfaen CB
 - Vale of Glamorgan
 - Wrexham CB
6. **Central-79 (62+17)**
 - Bedfordshire
 - Birmingham
 - Cheshire
 - Coventry
 - Derby CC
 - Derbyshire
 - Dudley
 - Halton BC
 - Herefordshire
 - Leicester City
 - Leicestershire
 - Luton
 - Milton Keynes
 - Northamptonshire
 - Nottingham CC
 - Nottinghamshire
 - Peterborough CC
 - Rutland
 - Sandwell
 - Shropshire
 - Solihull
 - Staffordshire
 - Stoke-on-Trent
 - Telford & Wrekin
 - Walsall
 - Warrington BC
 - Warwickshire
 - Wolverhampton
 - Worcestershire

7. East-61 (49+12)

- Cambridgeshire
- Essex
- Norfolk
- Southend-on-Sea
- Suffolk

8. North West-93 (62+31)

- Blackburn with Darwen
- Blackpool
- Bolton
- Bury
- Cumbria
- Isle of Man
- Knowsley
- Lancashire
- Liverpool
- Manchester
- Oldham
- Rochdale
- Salford
- Sefton
- S Lanarkshire
- St. Helens
- Stockport
- Tameside
- Trafford
- Wigan
- Wirral

9. North East-42 (37+5)

- Barnsley
- Bradford
- Calderdale
- Darlington BC
- Doncaster
- Durham
- East Riding of Yorkshire
- Gateshead
- Hartlepool
- Kingston Upon Hull CC
- Kirklees
- Leeds
- Lincolnshire
- Middlesbough BC
- NE Lincolnshire
- Newcastle U Tyne
- N Lincolnshire
- N Tyneside
- N Yorkshire
- Northumberland
- Redcar & Cleveland
- Rotherham
- Sheffield
- S Tyneside
- Stockton-on-Tees BC
- Sunderland
- Wakefield
- York

10. Scotland-41 (26+15)

- Aberdeen City
- Aberdeenshire
- Angus
- Argyel & Bute
- Clackmannanshire
- Dumfries & Galloway
- Dundee City
- E Ayrshire
- E Dunbartonshire
- E Lothian
- E Refrewshire
- Edinburgh, City of
- Falkirk
- Fife
- Glasgow City
- Highland
- Inverdyde
- Midlothian
- Moray
- N Ayrshire
- N Lanarkshire
- Orkney
- Perth & Kinross
- Renfrewshire
- Scottish Borders
- Shetland
- S Ayrshire
- Stirling
- Western Isles
- W Lothia

11. Northern Ireland-5 (4+1)

- Belfast Area
- North Eastern Area
- South Eastern Area
- Southern Area
- Western Area

12. Unknown/Out of Country-33 (11+22)

SURVEY CODES

Question 3

1. mainstream
2. spec unit
3. sp needs school
4. indep school 4 ASD
5. Boarding
6. home based
7. home based + sch

Question 7

- 5 Charity fundraising
- 6 other

Question 8

1. Autism
2. Asperger's
3. PDD and PDD-NOS
4. Rhetts Syndrome
5. LK
7. Severe Learning
8. Other

Question 9

8. 9
9. 10
10. 11
11. 12
12. 13
13. 14
14. 15

Question 10

5. GP
7. Paed. + clinical psych.
8. Team
9. neonatologist/geneticist
10. 2 + cons. Psych
11. Speech/lang
12. 1,2,3
13. neurologist
14. 1 + 2
15. psychiatrist
16. Not stated/other
17. 1 + 3

Question 14/15

8. ^ 1
9. none

Question 19

4. Y-parent ensures
5. N-doesn't work in practice
6. challenged by LEA
7. no specialist services/resources
8. Y-after Tribunal/fight
9. changed schools-agreed by all
10. N -delays/time
11. - communication
12. staffing

Question 20

7. home school
8. 4 + 5
9. ^ 1

Question 23/24

6. None
8. Other

Question 25

5. Y-Parents provide tutors in mainstream
6. parent arranged Lead
7. Y-mult. Answers/other
27. N-mult. Answers/other
28. N-low expect./more needed
29. N-staff

Question 27

8. ABA/home school
9. ABA + mainstream
10. other

Question 28

6. can't find one
7. No provision available
8. Not ready/able
9. LEA delays
10. Other/ multi

Question 29

- 1 - 5 as on sheet
6. ombudsman
7. MP/home office
8. parents direct
9. own school
10. given up
11. LEA backed down
12. experts
13. other

Question 30

5. Yes, independent reports
6. Yes, advice
7. Y-P not listened to
8. difficult without
9. LEA refusal to stmt/diag/transp/program
10. tribunal/legal
11. school placement -/lack of
12. 5 + 6/7

Question 31

9. 7 + 6

Voluntary/free

Question 32

8. Other

Question 33

- 1 - 6 as on sheet

7.family delay

8.LEA delay

9.School delay

10.Communication

11. Typing shortage

8. Other

Question 35 and 36

11. Ed Psych
12. school out of county
13. placement removed
14. uncertainty
15. lack of guidance-LEA
- 16.
17. communication
18. LEA attitude/policy
19. setting precedence
20. .time/waiting
21. LEA not listening/recog disabili
22. (now 20)
23. home programme
24. lack of parental control
25. loosing/tribunal
26. statement
27. (now 34)
28. late diagnosis
29. guilt/stress
30. (34)
31. child behav. No help/home issu
32. system/school
33. come to terms/boarding school
34. more than 3/1

Question 37

8. ^ 1

Question 38

1. depression
2. ill health/mental health
3. stress/worry
4. hard/devastating
5. marriage problems/divorce
- 6.
7. sleeping problems/tired/exhausted
8. relocate
9. family-other kids
10. family friction/-
11. family finances
12. family stronger now/better
13. Q39. #8
14. Q39 #11
15. friends/isolation/life-NO
16. support-no
17. #15
18. .
19. .
20. LEA --family
21. .
22. .
23. Q 39 #35
24. no effect/minimal
25. work problems
26. time
27. fortunate/happy now
28. coming to terms/get better
29. #7
30. guilt
31. no more kids
32. child get worse
33. accepting disability/placement
34. .

Question 39

1. LEA lying/illegal/change mind/negligent
2. .LEA not recog. child dis/ability
3. .LEA wanting inapp ed. for child/don't care
4. .LEA not wanting best 4 child
5. LEA staff -/-training
6. .LEA feels they know best
7. .LEA not listening/attitude/policy
8. LEA no guidance/support
9. .LEA changes diagnosis/placement removed/funding
10. no alternatives/choices
11. uncertainty/future/2nd school
12. LEA delays/too long
13. LEA league tables
14. Agency communication/cooperation
15. NHS -
16. social services-
17. social services +
18. set up new school
19. finding a school/place
20. Q38 #11
21. finances/resources -LEA
22. lottery/LEA inconsist
23. NHS +
24. support group +
25. .LEA +
26. time +
27. glad over/worth it/happy/fortunate
28. parents know child best
29. .
30. setting precedence
31. fighting LEA/tribunal
- 32.
33. parent makes it work
34. uncertain about provision
35. no appropriate provision/locally/limited places
36. system ineffective/bureaucracy
- 37.
38. going it alone
39. support groups -
40. transport -
41. school -
42. school staff+.
43. balance between pushing/supporting
44. .