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Parental perspectives on the provision of education for children with speech and language impairment

Brendan Martin Carleton B. Sc., P.G.C.E., M. Ed.

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ABSTRACT

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PARENTAL PERSPECTIVES ON THE PROVISION OF EDUCATION FOR CHILDREN WITH SPEECH AND LANGUAGE IMPAIRMENT

Brendan Martin Carleton

This research investigates the experiences of a group of parents whose children have speech and language impairment. A review of the existing literature revealed many problems facing parents who seek appropriate educational provision for their children. There appears to be a lack of a coherent and consistent system which automatically ensures appropriate provision without a great deal of effort on the part of parents. Fifteen sets of parents from three different Local Education Authorities, whose children are all in a residential special school, were interviewed. Analysis of the data from these interviews showed some themes emerging, and these were used to shape a questionnaire which was sent to fifty-three sets of parents. Analysis of this data revealed some instances of good practice, but for the majority of the parents, the process was problematic, time-consuming and stressful.

Contents

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Confidentiality

All of the people referred to within the text are real people. Their names have been changed in order to protect their identities and ensure confidentiality.

Chapter 1: Introduction

> *Educational research is neither as useless nor as powerful as some people think. Rather, educational research is a very human and therefore fallible process, which nonetheless has some distinct advantages over personal knowledge.* (Borg and Gall 1989, p.1)

The role of educational research has not always been fully understood. Rose (2002) suggests that teachers have, in the past, considered research as an activity which is removed from classroom practice. The impact upon teachers and pupils' learning was not well defined. The National Education Research Forum, (NERF), was established by the DfEE in 2000 to;

> *...develop a strategy for educational research, shape its direction, guide the co-ordination of its support and conduct and promote its practical application.* (Rose 2002, p.44).

This government initiative emphasises the important role which research can play in teaching and learning. Rose goes on to argue that teaching should become a research-based profession. He concludes by saying;

> *The importance of researching special education is as great now as it has ever been in the past. As we begin to embrace a more inclusive education system, it will be essential that we monitor and analyse those approaches that support pupils in becoming more effective learners and teachers in developing strategies to ensure that all pupils receive their educational entitlement.* (p.47)

The aim of educational research according to Gay (1996), is;

> *...the formal, systematic application of the scientific method to the study of educational problems...to explain, predict, and/or control educational phenomena.* (p.6)

He claims that educational research is the most difficult type of research, dealing as it does with people, and their unpredictable behaviours, in the educational setting with all its variables. Thus, explaining, predicting and controlling situations is difficult. Of course, there are patterns of behaviour which can be observed and which can help to make some predictions. Gay suggests that there are four steps involved in the research process:

Selection and definition of a problem The first stage involves the identification of an area of interest and the defining of a specific research problem from this. The problem needs to be refined into a manageable study.

Execution of research procedures The data is collected in whichever way or ways is most appropriate. These are defined in the research design.

Analysis of data There are a great variety of data analysis techniques. Again, the research design, coupled with the data collection methods will dictate the relevant analysis technique.

Drawing and stating conclusions The conclusions follow from the results of the data analysis and reflect the original research questions.

Charles (1998) explains the research process as including the following activities:

- *Identifying the matter about which concern exists;*
- *Clarifying the specific problem upon which the research will centre;*
- *Formulating research questions and/or hypotheses concerning the central problem;*
- *Carrying out procedures by which data are collected, summarised and analysed;*
- *Stating the findings determined through data analysis;*
- *Drawing conclusions related to the original research questions or hypotheses.* (p.11)

This research project is concerned with the experiences of parents who have children with Special Educational Needs, specifically speech and language difficulties. For these children their needs are very specific, and appropriate provision is not always straight-forward. There are a number of reasons for this, which include; problematic and time-consuming identification of the difficulties; the multiplicity of difficulties which children may exhibit; the fact that appropriate provision may not be readily available; the large costs which often accompany special educational provision; the fact that appropriate provision may be residential and this has implications for families. Because of the complex nature of the process of acquiring an appropriate provision for their children, parents in this situation are typically more involved than parents for whom education is more straight-forward.

Parents play a vital role in the education of their children, and this is being increasingly recognised. Schools have become increasingly open to parents and they are seen as a key part of the process of education. Recent initiatives have involved parents more and more. Things like home-school agreements, the emphasis on homework, guidelines on reporting to parents and increased parental choice have indicated the importance which the governments places on parental involvement.

In the case of special education, parents have long been seen as important in their children's education. Warnock recognised the value of trying to include parents over twenty years ago, (DES 1978). The newly-introduced Special Educational Needs, (SEN), Code of Practice devotes a whole chapter to working with parents and has much to say about the importance of involving parents.

The present research sprang from an involvement in the field of special educational needs over the last fifteen years. The difficulties which a great many parents faced with the education system were noted. It became increasingly clear that these difficulties impact directly on their children and, to varying degrees, affect the quality of the education which their children receive. Some children suffer a period of inappropriate schooling while lengthy negotiations take place. For some children, their parents are so unhappy with the schooling that they remove them entirely until a more suitable school is found. The difficulties may be to do with stresses and strains felt by the whole family. The experiences of parents whose children have special educational needs is an important area to explore and forms the focus of this research project.

Using Charles' model as outlined above, the first two stages involve identifying the research area and clarifying it into a proposal. The present research is concerned with parents of children with speech and language impairment, and aims to probe their experiences of the assessment process of their children's needs. It is specifically interested in parents' perceptions.

In order to focus the proposal, it was necessary to explore the field further. A review of the literature was carried out for the purpose of laying a foundation on which the research could be built. It was important to find out any relevant research which had already taken place. This could usefully inform the shaping of this project. It would also avoid the pitfall of simply repeating existing work.

As Borg and Gall (1989) explain;

> *The review of the literature in educational research provides you with the means of getting to the frontier in your particular field of knowledge. Until you have learned what others have done and what remains to be done in your area, you cannot develop a research project that will contribute to furthering knowledge in your field.* (p.116)

Anderson (1990) also emphasises the importance of beginning research with a comprehensive literature search. He explains the fact that each research undertaking exists in relation to what has gone before and what will come after. Most research projects will tell only a small part of the story. When results are linked to findings from other projects a bigger picture emerges.

> *Educational research should never take place in a vacuum. It should begin with a preliminary analysis to see what in the particular field has been researched before, what types of study have taken place, when they have been conducted, how and by whom. Educational research is a cooperative field and contributing researchers are obliged to know their field and its previous research.* (Anderson 1990, p.45)

The literature search gave a picture of the findings from a range of research projects in the field of parental involvement in special education. Whilst this can be illuminating, Delamont (2002) urges us not to overlook the gaps in the literature;

> *What does not exist in the literature may be just as important as what other researchers have already written about.* (p.21)

The literature fell naturally into two parts. Some research had looked at the impact upon parents of the assessment process. This forms the basis of chapter two of this thesis. Other research was concerned with parents who had to resort to some kind of appeal against the process. A summary of this literature can be found in chapter three. This review of the literature helped to frame the research questions for this project.

Stage three of Charles' model involves refining the proposal into a set of research questions. These were framed as follows:

⇨ What kind of support do parents receive, and from whom?

⇨ Do parents receive relevant, and accessible, information from their LEA?

⇨ What kind of relationship do parents have with the LEA professionals involved?

⇨ How valuable is the statement of Special Educational Needs to parents?

⇨ What are parents' perceptions of the professionals involved?

⇨ Do parents feel that they are partners in the process of assessment of their children's needs?

⇨ What are the factors leading parents to consider taking an LEA to an SEN tribunal?

⇨ What is the emotional impact upon the parents and/or the family of the process of assessment of their children's needs?

Charles suggests that the next stage of the research process is data collection. He outlines six procedures for data collection. *Notation* is the process of making very brief written notes. *Description* is used when information cannot be measured but only observed as in the case of behaviours. It is a more compete process than notation. *Analysis* in the sense of data collection rather than data analysis, refers to the process of breaking down documents, procedures or behaviours to see how they relate to each other. *Questioning* refers to the process of eliciting responses in the form of opinions or facts from participants. *Testing* is used to obtain data from participants through written or oral examinations. The final procedure is *measurement*. Data is obtained by comparing the performance of participants against an established scale.

The present research is concerned with the views of parents. Questioning was perceived as the most relevant method of data collection. The tools used for questioning are interviews and questionnaires. The design of the project involved both questionnaires and interviews. It was felt that using both methods of data collection would enable data to be gathered from a wide sample, but would also ensure that the data was sufficiently rich.

> *Because interviews can provide depth of explanation within a particular context, while questionnaires paint a broad though possibly superficial picture, it is often a good idea to use both.* (Drever 1995, p.8)

The population for the present study was the parents of children at a special school on the Isle of Wight dealing with speech and language difficulties. Such schools are relatively rare with only a handful of similar schools in the country. Because of the relative lack of provision for this type of special need, Local Education Authorities are often obliged to look for placements outside their own county. Children are placed at the school by some 24 different Local Education Authorities across the south of England.

Parents of children at the school were approached and their co-operation to take part in the project was sought. All were free to decline if they so wished. Only one parent indicated a desire not to be contacted.

Five initial interviews with parents were conducted and these served as a pilot. A further fifteen interviews were carried out with parents from three separate Local Education Authorities. The rationale behind this was that not only would it generate data about parental perceptions, it could also enable a comparison between the LEAs.

After some initial analysis of the interview data, a questionnaire was piloted with parents of students in the school's Further Education unit. The results from these led to the composition of a questionnaire which was distributed to the fifty-three sets of parents of children in the school.

A full explanation of the methodology forms the basis for chapter four.

Once the data had been collected, it was subjected to various levels of analysis. Delamont (2002) emphasises the significance of this stage of the research process;

> *However well the fieldwork has been done, in the end it is the theoretical and analytical concepts that determine whether the work will be remembered, quoted and associated with the author.* (p.169)

The final questionnaire consisted of seventeen closed questions and ten open questions. The former involved responses on a five-point scale, and analysis led to the identification of themes and some direct comparisons. Graphs were produced to facilitate these comparisons. The open questions, by their very nature, led to more varied responses. Themes were again identified, but there was more interpretation of parental comments. Analysis of questionnaire data is presented in chapter five.

With the interviews, some degree of consistency was achieved by the use of an interview schedule. All participants were asked the same set of questions, although there was some scope for elaboration as appropriate. The responses were naturally broader than for the questionnaires, and the analysis reflects this. The richness of the data was conserved by condensing each interview into a mini case study in the first instance. Further analysis then led to the identification of themes. This work is presented in chapter six.

The results from these stages of analysis were then used to draw some conclusions related to the research questions. The discussion and conclusions are presented in chapter seven.

Chapter 2: Literature review - Assessment

2.1 Introduction

> *Parents' hopes and expectations are raised by their reading of the Warnock Report, the 1981 Act and the DES Circular 1/83, and by good practice when they hear of it, and yet it is quite clear that the real experience for parents in terms of the services they receive rarely matches.* (Vaughan 1989, p.33)

In many ways, this quote acts as a fitting introduction to the area of this research. The provision of education for children with special educational needs has had a chequered history. The complex nature of their needs, coupled with the fact that this often has major resource implications has meant that there have been difficulties ensuring appropriate provision for all these children. There is no shortage of literature detailing the vital role which parents play in their children's education. More recently, parents have been much more involved as consumers, playing a very active part in shaping some aspects of the education provided by the state. For children who are able to benefit from mainstream education, parents can be more or less involved, as they choose. For children who need something different, it would seem that the provision of this "alternative" curriculum may not be readily forthcoming for a number of reasons. Certainly parental involvement often plays a much greater part in the education provided for children with Special Educational Needs, (SEN), than for their mainstream counterparts. The complex nature of their children's needs involves a lot of decision-making and parents have their part to play.

This research focuses on the role which parents of children with SEN, (specifically speech and language impairment), fulfil, and examines their own perceptions of the whole process of providing appropriate education for their children.

Parents of children with Special Educational Needs often have a difficult role to play. For many, there are trials and tribulations to be overcome, not just in terms of adjusting to the demands of their children, but in dealing with the professionals involved. This may be the first time that these parents have had to deal with a range of professional people, and it can be confusing at the very least, and possibly quite daunting. Furneaux (1988) cites a number of things which parents need in order to fulfil their role;

> *It is clear that the parents have certain needs which, though relatively simple, are often ignored or neglected. Briefly, they are as follows:*
>
> - *The need for support and reassurance.*
> - *The need for practical help.*
> - *The need for information.*
> - *The need for 'someone to talk to'.*
> - *The need to be shown that they are still regarded as someone in their own right and not just the parent of a handicapped child.* (p.41)

Many of these things are practical things which are explored in this research. It is concerning that Furneaux suggests that these essential things are not always delivered. She goes on to note;

> *Communication between the parents and those who should be dealing with them, although extremely important, is often unsatisfactory. There seems to be a great lack of understanding by all concerned of the best way to approach each other.* (p.41)

The Association For All Speech Impaired Children, (AFASIC), is a charitable organisation which aims to provide information and advice to professionals and parents of children with speech and language problems. In 1993, they carried out a survey to look at parents' experiences of the services offered to children with speech and language impairments. They received completed questionnaires from 441 parents, and identified a number of major issues:

- earlier diagnosis and help were needed;
- parents expressed a desire to be taken seriously by professionals and to have their views valued;
- communication was inadequate between professionals, and also between professionals and parents;
- provision was felt to be based on resources and not on need;
- for many parents, the experience of obtaining provision was a struggle without which no appropriate help would be forthcoming.

The report illustrates these findings with a number of telling quotes from parents;

> *Most of the people we have seen have either not taken us seriously or got the situation completely wrong. They not only completely wasted our time, but could have caused more harm if we had accepted their findings. Such people should be sacked but they don't seem to be accountable to anyone.* (p.8)

Jones & Swain (2001) found parents who had similar experiences. They questioned parents about their views of the Annual Review process. In many instances, parents felt that the professionals did not really understand the needs of their children. One parent is quoted thus;

> *I just feel that in the authority there is very little understanding of our children. I really do feel that until they know our children, then they're going to make the same mistakes over and over again and I don't know how to get them to realise that they need to spend time with parents, children and with staff who are in the know.* (p.62)

The themes highlighted in these reports are recurring ones and are developed further in this literature review. In many ways they act as a starting point for this research.

2.2 Information from LEAs

> *Partnership can only work when there is a clear understanding of the respective aims, roles and responsibilities of the partners and the nature of their relationships, which in turn depends on the clarity of information, good communication and transparent policies.* (DfES 2001, p.8)

This reference from the new Special Educational Needs, (SEN), Code of Practice, which came into force in January 2002, states quite clearly that it is essential for LEAs to maintain good communication with parents, and that the clarity of that communication is paramount. They state that;

> *...professionals should ensure that parents understand procedures, are aware of how to access support in preparing their contributions, and are given documents to be discussed well before meetings.* (p.17)

Research carried out by the Centre for Studies on Integration in Education, (CSIE), and the Children's Legal Centre, (CLC), shows how high parents' expectations become once they are given even small amounts of information, but that parents generally feel very frustrated in their efforts to obtain information from LEAs. Vaughan (1989) looks at the information published by LEAs for parents, and points to the following as indicative of the problem:

- 89 percent of LEAs failed to mention the legal duty placed upon them to integrate children with disabilities or learning difficulties;

- 94 percent of LEAs failed to list parents' duties under the Act;
- 66 percent of LEAs failed to tell parents of their legal right to be consulted, and to receive information;
- 86 percent of LEAs failed to mention the concept of parent-professional partnership in the assessment and statementing process.

He concludes by pointing out that a few LEAs were operating outside the law in relation to providing information to parents. When claims are being made that an education authority is neglecting its legal duties, this raises the question of how much impact the wishes of parents will have. The current research looks at the information which parents receive from LEAs and asks specifically whether it is forthcoming in the first place, and whether or not it is accessible. It investigates whether the language used is too technical for most parents. Unlike Vaughan, this investigation looks at the parents' perspective. It will be subjective, because questions will be asked of parents who are directly involved, which is the focus of this research.

Kerr, Sutherland & Wilson (1994) asked parents about their experiences in the process of assessment of their child. They identified a number of key actions which the education authorities should do in order to make the process work best. Among them were:

- make available clear and up-to-date information on their policies, procedures and resources in relation to special educational needs and on the roles of key practitioners, particularly the educational psychologist;
- ensure that all correspondence and other materials are readily understood and accessible;
- give ample notice of meetings, who is to be there, and ask parents if there is anyone they would like to be present;
- provide parents with any key report on their child in sufficient time for the content to be absorbed before the meeting and to offer them the opportunity to

add issues to the agenda;

- provide parents with a record of decisions made at meetings and subsequent actions agreed as soon as possible after the meeting.

Clearly, an overriding concern was to make sure that parents were kept well informed, but in a way that was accessible to them.

One issue to be considered here is the potential language barrier for parents from ethnic minority groups. Warner (1999) conducted interviews with parents of Bangladeshi children in a special nursery. She highlighted the lack of appropriate information in the Bengali;

> *The practical implications of the present study are an indication of the need to provide information about autism in Bengali for Bangladeshi parents.* (p.222)

The new Special Needs Code of Practice makes particular reference to minority groups and people with disability;

> *LEAs need to ensure that information is available in a range of appropriate languages and variety of mediums, so that all parents for whom English is not their first language, and those with a disability or learning difficulties can access the information.* (DfES 2001, p.18)

A research project, (Wolfendale 1997a), evaluated the impact and effectiveness of the Parent Partnership Schemes. Wolfendale studied documents from a total of 67 LEAs with respect to references within them of the parental contribution to the statutory assessment process. She concluded that there has been a significant trend towards parent-friendly, parent-accessible written material for Special Educational Needs. The research points out, however, that this still falls a long way short of increasing parental empowerment which would be the aim of the Parent Partnership Schemes. Wolfendale concludes that although the material is of a better quality, there is wide variation between different LEAs in terms of how easy it is to get hold of. Some LEAs routinely send it to schools; in others it has to be actively sought.

Peck (2002), in her work with parents of children with communication and language difficulties, explains how crucial it is that parents receive information from the professionals;

> *Parents/carers need to be confident that they are being given accurate information so that they can be realistic in their expectations for the child.* (p.42)

2.3 Technical language

Receiving relevant information is one thing; being able to make sense of it is another. Although parents are often referred to as partners in the process, they are not always the first people considered when reports etc. are written. Professionals may be quite at home with specific terminology, but some parents can find it inaccessible. This can create barriers between the parents and the professionals and can be a source of tension. This is an important area to consider in examining parents' perspectives. Cranwell & Miller (1987) point out that reports submitted during statementing procedures have to provide information to three audiences, namely, LEA officers, teachers and parents, and that;

> *It is not unreasonable to assume that there will be occasions on which it will be impossible to address these three audiences to their equal satisfaction.* (p.27)

They suggest that it is parents who are most likely to suffer, and that the technical language which is problematic is often unavoidable. They go on to say that the specialist terminology is often the most precise and concise available. This may well be the case, but it never-the-less may alienate one of the audiences for whom the report is intended. It might be feasible to have a translation of the more technical parts, perhaps even a glossary of key terms. An alternative version of the report aimed just at parents might also be a possibility, although this would have implications in terms of the amount of time involved. There is the danger that some parents might simply feel patronised by a different report.

Hudson (1978) is not so sure that Cranwell & Miller's argument about unavoidable technical language holds true, claiming that educational psychologists are, *"the most prolific generators of jargon in the Western world."* He suggests that technical language is used even when simpler alternatives are possible. However, it is important for professionals to make sure that they do not talk down to parents.

Cranwell (1986) carried out a study exploring the degree of understanding by parents of specialist terminology used in statements. He found some 244 words and phrases in 67 reports and nineteen statements which were identified as problematic on more than one occasion. It is interesting to note that none of the parents in the sample asked for explanations of any of the terms which they couldn't understand. Some ignored those parts, some used dictionaries for definitions and some resorted to guesswork. Could it be that these parents felt somewhat inadequate by their lack of understanding and did not have the confidence to approach the professionals?

In some ways, the problem is wider than is suggested by Cranwell & Miller. Professionals are all trained to a certain level and are all familiar with the terms used. They can be seen as a discrete group. Parents, on the other hand, are a very diverse group with a range of backgrounds. Some will have no understanding of this language while others may be quite familiar with it for all sorts of reasons. One could argue that there are multiple audiences to be addressed.

Cranwell found that there were some parents who experienced a greater understanding of the terminology. In the main, these were parents whose children had received an early assessment, and thus they had been involved with the professionals for a relatively long time. This involvement seemed to count for more than social or educational background.

2.4 Partnership

> *Partnership with parents plays a key role in promoting a culture of co-operation between parents, schools, LEAs and others. This is important in enabling children and young people with SEN to achieve their potential.* (DfES 2001, p.16)

The government continues to recognise the role that parents play in education for their children. The new SEN Code of Practice makes very clear the importance of partnership between agencies, (including parents), and devotes an entire chapter to *Working in Partnership with Parents.* The government states very clearly in the Code of Practice that, *"all parents of children with special educational needs should be treated as partners."* (p.16) The Code goes on to explain that parents should be supported by the Local Education Authority in a number of areas, including, *"having access to information, advice and support during assessment and any related decision-making processes about special educational provision."* (p.16)

Partnership is a term which is becoming increasingly popular in the field of education, but it is one which seems to be misunderstood in many cases. Other terms have been used to describe similar relationships, but they all refer to some measure of co-operation or sharing. The message about partnership comes from the education authorities, but does it mean anything to parents? Since parents are the other halves of the partnership, it makes sense to find out what they understand by the term, and to what extent they feel it applies to their own situation.

The Plowden Report, (CACE 1967), was perhaps the first official report encouraging greater parental participation in children's education, but the Warnock Report, (DES 1978), was the one which focused attention on Special Educational Needs, (SEN). This report called for parents to be seen as 'equal partners' with the professionals, and warned that the whole purpose of the report would be frustrated if they were not. Many of the recommendations of the report became law in the 1981 Education Act and parents' rights were given a high profile.

The idea of partnership as described by Warnock is one which has interested many researchers. The Warnock Report included a chapter entitled, "Parents as Partners" and recommended closer links between parents and professionals. However, it gave no strict definition of partnership and this has led to some debate about what is really meant. Calliste (1993) describes the confusion between the terms, 'involvement', 'collaboration', 'participation' and 'partnership'. In reviewing the literature, Calliste concludes that there is a need for "*radical changes in most professional groups.*"

In supporting the idea of partnership, Wolfendale (1992) suggests that there are four key principles:

- *Rights* - parents have fundamental rights to be involved in some educational decision-making;
- *Equality* - there should be equal status between parents and professionals;
- *Reciprocity* - all involved stand to gain from a productive discourse on behalf of children;
- *Empowerment* - parents should become more confident in working within the educational system.

Wolfendale seems in favour of a productive relationship, and if all sides are in agreement it would indeed seem to be very beneficial. She makes a particular case for the important role parents can play in assessment, arguing that parents are assessing their children constantly in much of what they do. Parents *observe* their behaviour, their moods, their worries etc.; parents *predict* their children's reactions to people and events; parents *describe* their children to others; parents have the intimate knowledge which puts them in the best position to *report* upon their children's behaviour, (Wolfendale 1993, p.151). Certainly, parents have a unique and long-term understanding about their children, which would be invaluable to the professionals carrying out the assessment procedure. Whether they trust the professionals enough, or are confident enough to share the knowledge, is one thing. Whether they were given the opportunity is another. Of course, this does not necessarily mean that parents would be equal partners in the process, but at least they would feel that they were included in some meaningful way.

Work with parents by Peck (2002) emphasises the importance of collaboration. The workshops which she runs, aim to help parents see the importance of their own role and to help them work with the professionals involved;

> *Parents/carers of children with difficulties become very knowledgeable about their children's difficulties and the impact that these difficulties have on learning and behaviour. Parents/carers are in a strong position to support the child. If parents/carers and professionals work collaboratively, sharing their knowledge of the child in different settings, this will benefit the child and support them in making progress.* (p.42)

Sandow, Stafford & Stafford (1987) argue that there is no real evidence that all parents of children with special needs seek a partnership with the professionals, and that only the most articulate ones appear to do so. They interviewed 64 parents of statemented children using a repertory grid technique and found that the concept of partnership was, *"conspicuous by its absence"* (p.129). They found that the term was not used by any of the parents interviewed. It may be that some parents are confused, as are some professionals, by what exactly constitutes a partnership. It may be that some parents send their children to school to be educated and that any problems arising are for the school to resolve.

On the other hand, research by Law et al (2001) indicates that parents are generally keen to be actively involved in the education process. They found, however, that parents were often faced with, *"frustration, struggle and conflict"* (p.136). Much of this centred on differences between the agencies involved. Parents were happiest when the agencies were collaborating effectively.

As Wolfendale (1989) puts it;

> *Despite attempts to define partnership, it is a slippery concept, probably because it is rarely manifested.* (p.107)

It is interesting to note that Warnock revised her thoughts somewhat on the notion of partnership. Seven years after the publication of her Report, she had this to say;

> *In our 1978 Report on the education of children with special needs, we had a chapter entitled 'Parents as Partners' in which we urged teachers to take seriously the parental understanding of the handicapped child and to treat parents as equals. I think, looking back, that we exaggerated. For in educational matters, parents cannot be the equals of teachers, if teachers are to be regarded as true professionals. It is a question of collaboration, not partnership.* (Warnock 1985)

Warnock seems to be moving away from a position where parents have an equal say to one where parents have an important voice, but one that does not dominate the knowledge base of the professionals. The question arises of whether partnership and equality mean the same thing. Warnock seems to think that they do, but it may be possible to have a partnership which is rather more disproportionate. Different partners could have different roles to play. Even at the level of collaboration suggested by Warnock, there are problems. Lunt & Sheppard (1986) looked at the numbers of parents who submitted written advice in the assessment procedures for their children and found that very few took this option. The literature seems to point to a lack of information available to parents and a lack of confidence for many parents. Cullingford (1985) says this of parents;

> *One of the great difficulties parents have faced is the feeling that they do not understand what happens in schools and therefore cannot comment or participate.* (p.5)

There are many strands to this: some parents may feel threatened by the professionals and the knowledge that they carry; some parents may simply not have received relevant information which could help them to understand what goes on.

Lupton & Sheppard (2000) carried out an evaluation of a home-school support project. One of their findings suggested that parents found it difficult to join in with professional meetings;

> *The evidence suggests, however, that they,* [meetings], *served to discourage, rather than encourage, attendance, with parents finding the presence of so many professionals intimidating.* (p.188)

In addition to feeling unconfident, parents can feel threatened by the whole assessment procedure. A survey which looked at the experiences of parents of children with special educational needs reported that parents often felt that they and their households were being judged, rather than their children's needs. Single parents in particular felt they were being discriminated against, (ACE 1989). Parents can also feel that their position is undermined by the professionals. Calliste (1993) gives an illustration of one parent's point of view;

> *They speak as though they know more than me about my own child, or they know better than me about my own child. They won't accept what I have to say. That's what people in authority are like.* (p.78)

Norris & Closs (1999) carried out research into parent/teacher relationships in schools for children with medical conditions. They found many parents who were satisfied with the way the school looked after their children. These parents tended to be the ones who experienced good communication with the school, and felt that the staff took them seriously;

> *Parents described how some school staff had facilitated their children's education. They appreciated staff who listened to them, understood that their worries about health or educational progress were real, and accepted and used the information that they gave.* (p.31)

The other side of the story was the parents who felt that they were not being listened to, or treated as equals;

> *Several parents described how medical crises or inappropriate school responses to a medical need had resulted in conflict.* (p.31)

Norris and Closs conclude that there is the need for much initial training, and in-service staff development, to ensure that communication with parents is more successful. They sum up;

> *Above all there would appear to be a need for staff to develop their interpersonal skills, useful in all aspects of their professional and personal lives, but absolutely essential when working with children with serious medical conditions and their families.* (p.33)

Research by Carpenter (2000) has looked at the impact of children with disabilities on the family. He suggests that the problem has been increasing over the last decade as medical advances have led to greater survival rates for these children. He concludes with the following;

> *The challenge is to enable and empower families, but are we ready to align professional practice with family need? With all the competing pressures on resources in services, can there be a philosophical shift? Perhaps our inspiration for such a shift should be the words of Donald's mother: "You don't know what it feels like to be the parent nobody wants...I wish life was different".* (p.142)

An important point about partnership which needs to be borne in mind is that it is a reciprocal arrangement. It has been stressed many times that parents have an important part to play in the education of their children. In the same way that the LEA has to keep parents informed, parents need to be prepared to keep the professionals up to date with any events. The government recognises this two-way exchange;

> *Parents also have a responsibility to communicate effectively with professionals to support their children's education. In working with schools they should communicate regularly with their child's school and alert them to any concerns they have about their child's learning or provision.* (DfES 2001, p.18)

2.5 Resourcing

Children with special educational needs often require specialist provision which can be very costly. Lunt & Sheppard (1986) point out;

> *The 1981 Act was lauded by many as a parents' charter, yet the degree of real parental participation in decisions about their children's special educational needs, the resources to be provided and placements to be implemented remains, to say the least, variable.*

Allocation of resources is a common theme in the implementation of the Act. Davies & Davies (1985) have the following to say about it;

> *(The 1981 Education Act) purports to offer parents a more direct involvement in the procedure for the placement of their children, opening official channels through which they can voice their concerns or echo their support for the authority's action on behalf of the child. But the Act carefully avoids committing the local authority or the government to any significant investment of additional resources to ensure the success of its policy.* (p.117)

They are clearly critical, suggesting in effect, that without any extra funding, the Act is laudable but doomed. Fletcher-Campbell (1996) states that;

> *Controlling the special education budget has become a critical management issue in a political-economic context of concern over public expenditure.* (p.6)

She illustrates her case with an example of one LEA which had an overspend on the statementing budget in 1992/93 of £154,000, projected to be £198,000 the following year. In another LEA the statementing budget had been consistently rising since 1983, and was financed largely by reductions in out-of-county placements. She quotes from a review by HMI thus: *"fewer than half the LEAs visited have the necessary procedures for allocating resources to schools"* (p.7). By their very nature, children with Special Educational Needs require more resources than their mainstream counterparts. This might be in terms of specialist equipment, training, extra adult input or even structural changes to the environment. If LEAs do not have the funds to meet these resources, then their hands may be tied.

Jones & Swain (2001) investigated the views of parents with regard to the production of the statement. They found that parents had a variety of experiences but that they were often troubled. Resources were felt to be at the root of many of the problems;

> *Parents felt that the vagueness in Statements was a means of controlling expenditure on pupils with special educational needs, rather than Statements being a mechanism for ensuring that their children's individual needs were met.* (p.62)

The government itself realises that the success of the legislation is resource-dependent. The House of Commons Education Committee published findings relating to the implementation of the 1993 Act which stated clearly that without extra funding the Act was unlikely to have the impact it should.

> *SEN remains one of the biggest challenges facing LEAs at the current time. The increased demands and raised expectations arising from the 1993 Act are likely to be disappointed and the needs of the most vulnerable children unmet unless adequate*

> *resources are provided. Perhaps it is time for a major review of SEN arrangements as advocated by Baroness Warnock during the passage of the 1993 Act.* (House of Commons Education Committee 1996)

2.6 Assessment

Gaining a conclusive assessment of their child's Special Educational Needs is not always a straight-forward process for parents. There can be any number of reasons for this, from the fact that the child's needs may be complex and hard to define, to the issue of costs. Looking at the problem globally, these issues might seem easy to understand, but for each of the parents involved, it is just one case they are interested in and one which they are of course personally involved in. So much can be riding on the assessment process for them. It may be simply an explanation of the nature of their child's difficulties which can bring comfort after a long period of uncertainty. It may be more about the hope of a "cure", or at least some appropriate help. In looking at parents' experiences, the current research explores the different aspects of the assessment process. One of the issues which is tied in here is the relationship between parents and the professionals involved.

The issues of funding and resourcing, apply not only to provision of an appropriate placement, but also to early diagnosis. One could argue that funding does not become a major issue until a special educational need has been identified and therefore early identification is potentially a very expensive business. Bastiani (1987) has carried out research into parents' experiences in gaining early assessment/identification of need. He found that generally, parents were poorly-informed and did not find out soon enough about the appropriate actions they should be taking. In many cases, he found that parents felt the professionals to be obstructive, or inadequate. He gives a number of examples;

> *You know there is something wrong with your child and you're told there is nothing wrong with him at all. Then nine months later your child is mentally handicapped. It's all wrong.* (p.143)

> *After being told that Sidney would catch up given time, Mrs Rodgers let things ride until she noticed that his younger brother was catching him up. Then she went to the clinic determined that something was wrong.* (p.142)

> *I knew myself that she, (her daughter), wasn't a lazy baby. I started to fight from then onwards to see what was wrong with her.* (p.142)

Many parents seem to experience difficulties in gaining appropriate provision for their children without having to go out and actively work for it or put up some kind of "fight". This idea of parents having to become very pro-active is a recurring one. There doesn't appear to be a natural process which automatically comes into operation once a problem is highlighted. Of course, each individual case is different and each authority is different in its procedures and its priorities. However, it does seem apparent that a great deal of stress is generated by these inconsistencies. Sandow (1989) has the following comment to make;

> *The negative perception of the consulting professionals by parents is especially worrying for those who have most influence on the 'statementing' process..... The parents of children who are experiencing problems in school...will be encouraged to adopt the old-fashioned and discredited view that there is something intrinsically wrong with their children and that it is probably their fault.* (p.134)

2.7 Emotional issues

The difficulties encountered by many parents have practical implications, but also emotional ones. Parents can suffer a range of feelings, depending upon how complicated and how drawn out the process might be. In exploring the assessment process from the parents' point of view, these emotional issues would seem to be important in terms of getting a real picture of what it is like for them. Despite the importance of this area, there does not seem to have been a great deal of research carried out.

Holland (1996) has likened the diagnosis of special needs in a child to bereavement, as far as parents are concerned. Her argument rests on the definition of bereavement as a loss of some kind, and in the cases in point, the parents experience the loss of a child as they once knew him/her. She describes a range of emotional components which are likely to occur and recur: shock, numbness, denial, depression, anxiety, guilt and aggression. The severity of the feelings depends upon a number of factors, not least of which will be the severity of the special need diagnosed. If the need is a very visible one, e.g. Down's Syndrome, then the parents are already going to be aware of the problem. If, however, the problem is more hidden, (as with speech and language impairment), then it could come as a complete shock. The professionals need to be very sensitive in their dealings with parents if Holland's ideas give an accurate picture. She suggests that;

> *If the information is not given clearly, and if no follow-up interviews are arranged for when the parents are better able to assimilate the information, they may continue to deny the diagnosis.* (p.25)

Bruce & Schultz (2002) carried out a longitudinal research study, looking at 49 sets of parents of children with some form of intellectual disability. They identified an on-going sense of grief in these parents which they termed "non-finite loss". This grieving manifested itself in many ways, including shock and denial. One mother is quoted as saying;

> *I heard what she was saying I could do with Sam at home, but I knew I couldn't do anything about it - I wanted to be honest to tell her, I couldn't fit it in - but what would she think of me - what sort of mother would she think I was? In the end. it was easier to pretend.* (p.10)

They explain that when parents have been given bad news from professionals, they come to fear what those professionals might say next;

> *When parents have been exposed to a litany of negative information, it is logical that they fear being further traumatised by what a professional person might say about their child in the future. They have learnt to fear the knowledge of professionals, knowledge which may further threaten the integrity of their child. This accumulation of threatening information frequently results in an avoidant response by parents.* (p.11)

Peck (2002) has run workshops for parents of children with language and communication problems. She explains how difficult it is for parents to accept what the professionals are saying to them;

> *On occasions parents/carers may appear to reject professional opinion and deny the child's difficulties but, with time, as part of the process of coming to terms with the child's difficulties, they will come to accept the professional opinion.* (p.42)

Research by Connor (1997) looked at the issues faced by parents in deciding between mainstream and specialist placement. He pointed to the high levels of stress involved in the process and specifically highlighted LEA procrastination, excessive bureaucracy or unresponsiveness as major problems. The areas of concern included: having time from professionals to explain and discuss issues; having their worries taken seriously; having their questions answered; having their views included as a significant part of the planning and decision-making.

Research by Warner (1999) focused on the views of Bangladeshi parents on the schooling of their children with learning difficulties. She found that the emotional problems experienced by parents were not always understood by the teachers;

> *For good working relationships between parents of children with severe learning difficulties and teachers, it is essential that the teachers understand the strain on parents.* (p.222)

Sandow, Stafford & Stafford (1987) describe parents' realisation that their child has special needs as a series of responses, thus:

- "Novelty shock" where the parents realise that their expectations for their child are shattered;
- "Reality stress" where the parents realise that the child now represents an enormous increase in workload;
- "Value conflict" where the parents struggle with their own attitudes towards the idea of retardation in some form. (p.14)

Apart from the physical strain of the work involved in gaining help for their child, it would seem that parents are also having to deal with these feelings. The literature indicates that in many cases, parents are having to cope with the extra stresses associated with the conflicts they encounter with the LEA. The AFASIC study referred to earlier offers many examples of parents' experiences;

> *I hope no other parent has to go through what we went through to get help for our son.* (p.4)
>
> *It has taken over three years to get a diagnosis, and this has only come about by myself being determined to find out more.* (p.8)

Abbott, Morris & Ward (2001) investigated the experiences of children at residential schools in four different authorities. They interviewed parents, children and professionals, as well as observing panel meetings where decisions about placements were being made. They found that many parents felt that they were not getting the support they needed to enable their child to remain at home. A number of parents said that a failure to meet their child's needs at school had caused such emotional distress that their behaviour became very difficult to deal with.

Bruce & Schultz (2002) refer to the importance of good parent-professional communication to help ease some of the difficulties;

> *There is promise of an improved developmental environment for the child when professional persons recognise, and navigate well, the emotional challenges in establishing and maintaining effective interaction with parents.* (p.13)

2.8 The child's perceptions

In trying to understand the impact on the parents and the family, it is important not to lose sight of the child himself/herself. The child's own perceptions are beginning to be seen as important. The 1989 Children Act in particular places a lot of emphasis on the child's account. DES circular 22/89 recommended that the feelings and perceptions of the child should be taken into account and that the concept of partnership should be extended to children and young people. This again raises the issue of what constitutes partnership. Using Warnock's perspective, it would hardly be feasible to regard children as equal in terms of understanding what is necessary for their education.

A recent study looked at 21 Local Education Authorities and how they make decisions about residential placements for children with Special Educational Needs. The researchers found that most education authorities were, *"poor at seeking a child's view when a decision about residential school was being made."* (Abbott, Morris & Ward 2000). They also reported that in two cases, education officers wrongly stated that the Code of Practice ruled out the seeking of children's views.

Armstrong, Galloway & Tomlinson (1993) claim that despite the recommendations, in practice, the child's contribution is often minimal. They carried out an observational study of the formal assessment of 29 children referred to the Schools Psychological Service because of emotional and behavioural difficulties. Their results indicated that the children rarely believed that genuine attempts had been made to involve them in the assessment process, or even to encourage them to contribute. Many of the children were unaware how decisions had been reached. They all described feelings of anxiety at the idea of having some kind of assessment, and felt that this meant that they had something wrong with them. Their anxieties were made worse by the lack of information given to them about the purpose and outcome of the psychological and medical interviews. One girl is quoted as saying;

> *I don't think she found anything wrong with me, but she never told me.* (p.124)

It is not difficult to imagine the anxiety that this kind of situation could cause. It seems that it is all too easy to overlook the very person for whom all the work is being done. Obviously, it depends upon the age of the child, but the evidence from this research indicates that all children would benefit in some way from being included more in the process.

2.9 Support groups

> *All LEAs **must** make arrangements for parent partnership services. It is essential that parents are aware of the parent partnership service so that they know where they can obtain the information and advice they need. LEAs **must** therefore inform parents, schools and others about the arrangements for the service and how they can access it.* (DfES 2001, p.19)

The government places a lot of emphasis on supporting parents and keeping them well informed. The above quote from the Code of Practice makes it very clear that LEAs have a duty to work with parents. They do not have to provide the parent partnership service themselves, but they must ensure that there is one in place. The bold emphasis in the text is as it appears in the Code.

In certain Local Education Authorities, parents have found these partnership services difficult to access. They have either been hard to locate or non-existent. The nature of the difficulties that parents face in coping with the demands of children with special needs, and with securing appropriate support and advice, has meant that many parents have set up self-help groups. These groups are generally formed by parents who have found their way through the system, and are designed to help parents who are new to it. This trend has meant that parents are beginning to become more confident and, in many instances, more vocal. Wolfendale has done a lot of work in this field. As she puts it, *"...parents in education are now a force to be reckoned with."* (Wolfendale 1992)

Hornby (1988) describes a scheme which he calls the, "Parent to Parent Scheme". The intrinsic difference with this scheme is that it involves a training course for parents. He claims that it leads to useful parent-professional partnerships, and that it encourages personal growth in parents.

Paige-Smith (1996) interviewed eight parents of children with special needs, all of whom had been involved in, or innovated, parent groups in England. She found that most parents felt that it was important that LEAs consulted with them on their views, and that educational policies should be formed in consultation with them. The parents considered that it was the job of the educational authority to provide what the child needs rather than fit the child into a pre-existing system. The question of resourcing obviously has implications here and parents were well aware of this. They found that resources were not readily available, and that they had to be persistent with their demands to the LEA to get the resources needed. Often they felt that they were doing this by themselves.

This is an interesting area, and the current research aims to explore where parents found support and help and what were the processes which helped them to manage in very stressful circumstances.

2.10 Statementing

In terms of the statementing process, the existing research showed that many parents found it confusing, and this was one of the reasons they had set up, or consulted, a parents support group. The statement is seen by many parents as the solution to their problems in that it sets the special educational needs of their child in a legal framework. Thus, if the statement has the desired effect it ought to be a great relief to parents. If, on the other hand, the statement has little effect on practice, this could come as a severe blow. Exploring this issue, thus has implications for understanding some of the emotional issues.

> *Most parents knew through their own experiences and from speaking to other parents involved in parents' groups that what was written on statements was not always respected by LEAs.* (Paige-Smith 1996, p.325)

This highlights a situation where some LEAs are not meeting their legal responsibilities. In many cases it is a struggle for parents to secure an assessment leading to a statement, and then to find that this does not guarantee anything must be very frustrating to say the least. Once again, it would seem to be the parents who will put up a fight who secure the provision required. One parent puts it like this;

> *To achieve anything in this area you have to be prepared to fight every step of the way. (*AFASIC 1993).

The parents interviewed were all parents who had demonstrated a willingness to lobby at local government level, and an ability to take political action. This again highlights the fact that there are parents who are able and willing to go to great lengths to secure an appropriate education for their child.

Research by Jones & Swain (2001) investigated the views of parents with regard to the Annual Review process. They sent questionnaires to two sets of parents in two different Local Education Authorities and concluded that *"...there are built-in barriers to the translation of principles into practice".* (p.63) The findings showed that parents did not feel that the statement always had an impact in practice. They quote one parent as follows;

> *It comes back and it's not in the Statement. They say, oh well we've got this, but then when you dissect the wording of the said Statement it's something completely different.* (p.62)

Chapter 3: Literature review - Appeals

3.1 Introduction

> *It is worth noting that, although the authority had to tell the parents the decision that had been made, [with regard to educational provision], no one was obliged to tell them of their right of appeal. It would not be a true picture of what actually happened, however, if the impression was left that the Act was applied with full vigour. Normally it was appreciated that it was far better in the interests of all, not least the child, if willing co-operation was secured. Parents were frequently kept well informed and consulted, but it was not their right; so they were not always consulted, and much resentment was often felt in consequence.* (Furneaux 1988, p.57)

Parents who are not satisfied with the decisions made by the local authority are now able to take their case to the Special Educational Needs Tribunal. It is interesting to note that before the Tribunal was established, most appeals had fallen in favour of the LEA. This situation seems to be changing now with a system which is more sympathetic to the needs of parents and children. However, as of September 1995, the Tribunal had 1000 cases waiting to be heard, with a waiting list of about four months. This indicates not only that the system seems to be inadequate, but also that a large group of parents are dissatisfied with decisions being made.

This current research is directly concerned with parents' experiences of the whole process. Those parents who are unhappy with the arrangements now have an alternative avenue for their complaints. The appeals process and its implications are important for understanding the experiences of parents.

A number of children at St Catherine's School have been placed there as a result of the Tribunal. A lot of other parents went through Tribunal proceedings when they were considering St Catherine's School for their child, but were unsuccessful. All of these parents had had a variety of experiences with the local educational authority and exploring these was important for the research.

3.2 Background

Until the 1993 Education Act, special education was governed by the 1981 Education Act. The 1981 Act introduced a definition of special educational needs which was somewhat convoluted, and according to the Audit Commission (1992) has given rise to problems of interpretation. Many LEAs were either unwilling or unable to fulfil their duties adequately. Wright (1997) thinks that many education officers resented the binding responsibilities from a central government which was determined to reduce the funding available and their control over it. The Audit Commission (1992) concluded that in one in six LEAs, the 1981 Act had either never been implemented or had collapsed altogether. Thus, there were numerous disputes between LEAs, professionals and parents, some of which have led to appeals being lodged.

Before the 1993 Education Act, there were several types of appeal or complaint open to parents:
a) If an LEA refused to assess a child, the parent could complain under the 1944 Education Act that the LEA was acting unreasonably;
b) If the LEA assessed a child and refused to issue a statement, the parent could appeal under the 1981 Act to the Secretary of State;
c) If the parent did not agree with the content of a statement, the parent could appeal firstly to a local panel set up by the LEA and then, if still not satisfied, to the Secretary of State.

The LEA panel was not independent as such, since most panel members were from the LEA. In addition, the LEA was not bound by the recommendations of the panel. On the surface, this would seem to be a far from satisfactory situation. If parents were in dispute with the LEA, they would be taking their case to an LEA panel. Add that to the fact that even if they won their case, there was little incentive for the LEA to change its decision. It is not hard to see that only the most determined parents were willing, or able, to follow through this process. The Audit Commission (1992) reported;

> *Local appeals are rare, and most LEAs have had only a handful in the last five years. The number of appeals to the Secretary of State is also low, but is increasing, (approximately 150 in 1991 when 26,000 statements were issued). In approximately two thirds of cases, the Secretary of State found in favour of LEAs. The DfE reports that appeals against a refusal to issue statements took between six and nine months on average to complete, and appeals against the statement took between nine and twelve months on average. The Department's published aim is for decisions to be reached within six months and it is therefore also exceeding the target times for the process.* (p.22)

Compare this figure of 150 appeals in 1991 with the waiting list of 1000 cases in 1995 and it can be seen that either parents have become more dissatisfied, or more vocal, or both. Either way, it is indicative of an unwillingness to settle for less than they regard as the right education for their children. The other interesting thing about these findings is the amount of time taken for the appeals. With only "a handful" of appeals to deal with, the process was still taking a long time, (between six and twelve months). During this time the child is possibly not receiving adequate education, with emotional implications for the parents and family. Considering the increase in appeals under the Tribunal system, the fact that the waiting time had not increased, and indeed had been cut to four months is encouraging.

Goacher (1988) points out that the low incidence of appeals was not necessarily an indication of widespread satisfaction with the outcomes of the assessment process, but more to do with the complex, (and quite threatening), nature of the appeal process. The process was clearly a lengthy one, and the proportion falling favourably for the LEA seems high.

Evans (1998) reports that parents became increasingly frustrated and disillusioned with the appeals procedure during the 1980s, and they resorted more often to seeking redress through the courts. She quotes some high-profile court judgments to illustrate the case.

The appeals committees were staffed by teams of county councillors who made *recommendations* to the LEA, and as such, these could be ignored. Hence, the second option of appealing directly to the Secretary of State. Ramjhun 1995 states that;

> *Their impartiality* (the councillors) *was also questioned as councillors were perceived as protective of the LEA's interests.* (p.89)

Gascoigne (1995) states that;

> *Parents had little or no faith in the appeals process and believed that it was designed to work against them.* (p.143)

She quotes the following example from a mother of a boy with Down's Syndrome;

> *I was advised to go to appeal. I did not, as I knew that what I was asking for had been my son's right for more than ten years and that I had said this enough times without having to commit more time, energy and expense to a system that was likely to abuse us further.*

Bowers (1994) describes similar experiences for parents. He cites the case of a parent who had been through every stage of appeal right as far as the High Court, yet the most stressful and unpleasant experience by far was that of the LEA appeals panel. Penny Platt of the parents' group Network 81 suggested that appeals were just the tip of the iceberg and that resource-led provisioning by LEAs had led to a breakdown in relationships between parents and LEA officers. She explained how telephone help lines received calls from parents describing; *"frustration, lack of communication, rudeness and even threats."* (source: Bowers 1994, p.9)

The appeals process was a very time-consuming business, (and therefore by implication, a very expensive business). Gascoigne 1995 claims that shortly before the Tribunal came into being, taking an appeal to the Secretary of State was taking anything up to two years. This is a huge amount of time from anyone's education, but for somebody who is arguably not receiving the appropriate education, it could be very serious indeed.

3.3 The Special Educational Needs Tribunal

Evans (1998) argues that a more "consumerist" approach to education, which was reflected in the Education Reform Act 1988, was one of the factors leading to change. The production of Parent's Charters also highlighted a change in attitude towards parents. A consultation document, *Special Educational Needs: Access to the System,* (DfE 1992), proposed a number of changes to the system which were designed to give new rights to parents. From this came the Education Act 1993 which established the Code of Practice and introduced the Special Educational Needs Tribunal.

Wright (1994) was very critical of the previous appeals process, likening the LEA panel to a "kangaroo court", and he welcomed the introduction of the Tribunal. He saw it as an important step in ensuring that LEAs took their responsibilities seriously;

> *I believe that the SEN Tribunal will make it more difficult than it has been in the past for LEAs to make special education decisions on the basis of resources rather than individual children's needs.*
> (p.10)

The Tribunal has been established as the independent body to which parents can appeal against decisions taken by LEAs. The main changes with the Tribunal are its independent status, the fact that the decisions are legally binding, the investigative powers of the Tribunal allowing witnesses and documents to be subpoenaed, the possibility of LEAs being ordered to pay costs and the more straight-forward one stage process. These changes are very significant and give the whole appeal process a completely different standing. The changes ought to have given parents more confidence in the system, and the statistics of the number of appeals being lodged certainly seems to indicate this.

Cumbria had only 29 appeals in the first ten years of the 1981 Act, but 27 appeals in the first year of the Tribunal. Harrow averaged five appeals a month under the 1981 Act, but defended thirteen a month during 1995. Suffolk had eleven appeals in eleven years of the old system, but had about twenty in the first year of the Tribunal (source: Wright 1996a). According to Bowers (1994) the DfE were anticipating between 700 and 1000 tribunal cases in the first year. The actual demand was somewhat higher: in 1994/95, there were 1170 cases registered; in 1995/96 this rose to 1622; and in 1996/97 there were 2051 cases. This represents an increase in demand of 39 percent after the first year and then a further increase of 26 percent after the second year. The Special Educational Needs Tribunal Annual Report offers the following explanation for the increase;

> *The rise may result from a wider knowledge of the Tribunal's role, from a greater dissatisfaction with Local Education Authority (LEA) decisions or from a continuing pressure on the resources available for making provision in this area.* (see Evans 1998, p.1)

These figures give an indication of the extent of parental dissatisfaction, but show only the cases where parents do reach that final stage. The Independent Panel for Special Education Advice, (IPSEA), offers help and advice, including legal advice and a free representation service, to parents. They currently receive approximately 3500 telephone calls a year from parents, (Wright 1997). Not all parents will be aware of this service, so the number of parents experiencing frustrations regarding their children's special education is likely to be greater.

Research carried out by IPSEA in 1992 and in 1995 showed that when parents did contact the service for help, one in five of them had already withdrawn their children from school because of disputes over provision, (Wolfendale 1997b). Thus, the 3500 annual calls represent some 700 children out of school. One can only guess at the total number of children affected.

Cost has been mentioned already as an important consideration for parents. Wright (1996a) quotes a figure of £2000 for parents to go through the Tribunal proceedings. He explains that very few authorities made adequate funding available in the budget when the Tribunal was first introduced because they worked on the basis that few parents had appealed in the past. This doesn't sit comfortably with the fact that the government were predicting a significant rise in demand when the Tribunal was set up. LEAs are now having to fund more, and better provision than they had budgeted for. Wright is fairly critical of LEAs in terms of their attitude towards their legal responsibilities and makes the following observation;

> *We must be rapidly approaching the point where the continual strenuous attempts by LEAs to avoid their duty in law to meet the special educational needs of children will cost them more than devising and funding effective provision.* (p.18)

The Tribunal offers a framework which aims to tighten up the loopholes and make LEAs more accountable. Gravell (1997) regards the Tribunal as having improved things for parents to some extent, but feels that things are still loaded in favour of LEAs largely because parents remain unaware of their rights under the law. He has experienced the Tribunal process as a parent and argues that it has great possibilities. However, he is quick to point out that even as an educated and articulate parent who felt he had prepared things in advance, with much professional advice, he still regarded it as the most stressful thing he had been through. He argues that parents need to be able to manage a lot of paperwork and understand the legal aspects fully before having a fair chance.

As with the system prior to the 1993 Education Act, parents are still able to appeal to the Secretary of State, or to the Ombudsman, or take the case to Judicial Review. Judicial Review is used where the local education authority may have acted illegally. Denman and Lunt (1993) describe an increasing trend in this country for parents to resort to a Judicial Review, particularly in the case of Special Educational Needs.

Research increasingly indicates that despite the tighter regulations, not all LEAs are fulfilling their legal obligations. A recent report by IPSEA (1999) states that; *"large numbers of disabled children are not receiving the provision to which they are legally entitled"* (p.2). The very nature of this organisation means that they deal with a lot of dissatisfied parents which possibly defines the way they view things, but never-the-less their conclusions have to be considered carefully. The report highlights a number of cases which have resulted in legal action, and shown the LEA to be at fault.

Wright (1996b) quotes evidence from the voluntary sector to identify a number of problems thus: LEAs refusing to obey Tribunal judgements; LEAs refusing to be specific in statements about the provision children should receive; LEAs denying that speech therapy can be an educational need; LEAs intimidating professional witnesses who agree to appear at Tribunals for parents; parents being unable to appeal against Tribunal judgements because of the "legal aid trap".

A particular case reported by Gravell (1998) describes the lengthy procedure endured by one by set of parents. The LEA had effected cost-cutting exercises which had put the child's placement in jeopardy. The Tribunal ruled that the LEA had acted unlawfully, stating;

> *We are unable to accept the LEA's argument that the decision as to the level of one-to-one support is a matter for the school to decide. It is the LEA's duty to determine and specify Joshua's needs. Furthermore, the resources already in the school cannot be a relevant factor in our view in the LEA's determination of the provision necessary to meet Joshua's needs.*

The Tribunal made it clear that the law is not there to be interpreted by LEAs according to their resource availability, but that it is very specific in terms of assessing and providing for the needs of children. However, the point was made that Tribunals do not create legal precedents and so the decision affected the one child. These particular parents had another child whose case was following a similar course to Joshua's. They did not feel able to go through the whole process again and so took the LEA to court successfully. Despite all this, the LEA still did not comply totally with the Tribunal order. The parents were still requesting speech therapy which the LEA had been ordered to provide. It seems that even the Tribunal procedure does not guarantee that needs will be met.

It has been noted already that many parents might find the whole Tribunal process much too daunting. Wright (1996b) notes a tendency for the Tribunal to be used more readily by articulate parents. He quotes from the British Psychological Society, thus;

> *There is a strong and noticeable distortion in how the Tribunal process is used. Predominant usage is by vocal articulate parents....Members have had direct experience of other less confident parents who, despite encouragement, are too wary of the formality of the Tribunal procedure to want to use it.* (p.24)

This issue is highlighted in recent research by NFER (1998). The high volume of appeals is seen as an indication that there are severe problems, but the researchers believe that the LEAs which have a low incidence of appeals may also have issues to address.

> *Not least of these is how poorer, less articulate parents might be enabled to participate more actively in the decisions made about their children's education.* (p.3)

This research goes on to show that parents are getting more say in how their children with special needs are educated, but on the negative side, pressures have arisen between parents and LEAs. Thistleton sees it as inevitable that conflict will be a consequence of the process. As she puts it;

> *It is naive of either side to think a tribunal is an independent arbitration service.* (1997, p.11)

Stresses and inordinate amounts of time involved are quoted as common problems for both sides involved. For LEAs, resource allocation is a major concern. The research points out that;

> *As Tribunal decisions are focused on individuals, they do not normally take into account the wider responsibility of the LEA to provide for all pupils.* (NFER 1998, p.2)

This, they claim leads to questions about value for money. In particular, expensive residential placements can use up an unduly large proportion of available funds.

The amount of time involved in the process is highlighted in the study by Thistleton (1997). She points out that the average waiting time for a hearing is five months, and that this is bound to lead to stresses all round. Apart from the fact of the stresses involved, she also raises the question of what happens to the child during this time. Since the parents are in dispute with the LEA, they are often unwilling to send their child to the school which they see as inappropriate.

The issue of empowerment for parents is brought into question by Thistleton (1997). In more than half the cases heard at tribunals, the LEA decision is upheld. Thus, parents have less than a 50 percent chance of winning. In addition, almost as many cases are withdrawn by parents beforehand as go to tribunal. This could be for a variety of reasons; Thistleton seems to be suggesting that it is further evidence of parents feeling that their views are not prevailing. Of course, it could just as easily be because LEAs give in to parent's wishes rather than go through the costly Tribunal process.

Carol Beardmore of the Down's Syndrome Association supports parents in their struggles with LEAs. She believes that the Tribunal decisions are losing their impact. She says;

> *I've supported parents for thirteen years and never known anything like it. I feel so sorry for parents. Grown men and women are coming to meetings and bursting into tears because they've had enough - they don't know where to turn to. Parents are totally disempowered. They want to trust public servants and are demoralised.* (Gravell 1998)

Simmons (1997) argues that the Tribunal has given more power to parents, but at the same time, it has created a new set of needs. She believes that evidence and representation are now problem areas within the new system. The Tribunal is interested in the child's needs at the present time and thus it requires evidence of the most up-to-date kind. LEAs have immediate access to this kind of information. Simmons points out that LEAs have been known to send their professionals into school the day before a hearing. In addition she quotes from evidence of LEAs exerting pressure on professionals resulting in them being reluctant to give evidence on behalf of parents. For parents, it is not so easy to collect relevant data, and independent assessments could be prohibitively expensive.

In terms of the hearings themselves, Simmons calls them; *"intimidating and daunting experiences"* (p.37). There is no Legal Aid for representation at hearings and the average cost of the services of a solicitor is quoted as £1000. For many parents, this is going to be another financial hurdle. Simmons also suggests that representation by a solicitor may not be helpful in producing the required outcome because the hearing becomes much more legalistic.

As with all changes to a system, the Special Needs Tribunal has its supporters and its detractors. It has certainly made an important difference for many parents and their children, but as with the previous system, it is mainly the parents who are educated enough to understand the system and follow the process through. With special education being such an expensive area, it is perhaps unlikely that any major change will be effected until there is a significant change in funding policy.

Chapter 4: Methodology

4.1 Introduction

> *Research in education is a disciplined attempt to address questions or solve problems through the collection and analysis of primary data for the purpose of description, explanation, generalisation and prediction.* (Anderson 1990, p.4)

This research project was designed to look at parents' experiences in terms of the assessment of their children's Special Educational Needs. Specifically, it was designed to explore their perceptions of the support available to them, the information they received and the nature of their relationship with the LEA. It aimed to find out what they felt about the statement, about the professionals involved and about the idea of partnership. It was also concerned with the Special Educational Needs tribunal for those parents who had approached it. Finally, it aimed to probe the emotional impact of the whole process.

The starting point in terms of designing the project was to answer some basic questions as suggested by Patton (1987);

- Who is the information for?
- Who will use the findings?
- What kinds of information are needed?
- How is the information to be used?
- What resources are available? (p.8)

The research sprang initially from a personal interest, but like all projects it evolved and changed as the relevant literature in the field was reviewed. The research was felt to be concerned with an area which has received some attention, but has not been explored fully. It was felt to be of interest to a wider audience than just the researcher, - ideally all professionals and parents involved in the field of Special

Educational Needs. Whether or not people agree with the idea of a partnership, there is certainly a working relationship involved at some level, and identifying stresses within that relationship would seem to be of benefit to all concerned.

The information which was needed was as much first-hand data as possible. The two methods of data collection which seemed appropriate were interviews and questionnaires. Drever (1995) compares the two techniques and highlights four considerations when deciding between them. The first point is that interviews give high quality data. The researcher is in control and can deal with any ambiguities or misunderstandings as they arise. By contrast, he considers questionnaires to be inflexible and beyond the control of the researcher once they are in the post. He adds; *"And you never learn anything you didn't ask!"* (p.3)

Drever's second point is that interviews take a lot of time. Apart from the actual time for the interview, there is preparation time, travelling time and possibly some time for social chat. He considers twenty interviews to be a major undertaking, whilst 100 questionnaires would be small-scale. The point is also made that doubling the number of questionnaires would not double the work load.

According to Drever, the processing of interviews is a time-consuming task. Transcripts can take a long time with tapes needing to be played over and over. From the transcripts there may not be any obvious route into the analysis. It may require reading and re-reading of the data to try to make sense of it. With questionnaires, the data can often be transferred into a grid with a clear schedule of numerical analysis. Drever makes the point that although interviews take time to analyse, this process is rewarding as the researcher becomes very familiar with the data and exercises judgement in summarising it.

The last point which Drever makes is about the skills involved in interviewing. Teachers spend a lot of time in the classroom asking questions, but interviewing is something more than that. He suggests;

> *An interview is not a conversation. It is a formal encounter, with a specific purpose, and both parties are aware of this.* (p.4)

The data required for this project, needed to be as in depth, but also as broad as possible, taking into account views from as many people as feasible. A questionnaire seemed to be the best tool for ensuring breadth, whilst interviews would provide the depth. It was felt that interviews would be useful for identifying some of the issues in the first instance. Face-to-face meetings would allow for greater exploration of the ideas as they emerged. One draw-back with interviews is the amount of data that can realistically be collected in a limited time scale. Questionnaires have the advantage of reaching a much wider audience, but are limited in terms of being fixed in the data being requested. There is also the issue of ensuring that the questionnaires are responded to. The ideal solution seemed to be a series of initial interviews to gain a good grasp of the key points, followed up by a questionnaire to increase the yield of data.

Resources, in terms of time and funds, were an important consideration. With one self-funded researcher working part-time on the project, it had to be designed carefully to make it manageable within the time frame. Several blocks of time had to be allocated for the interviews, many of which were at some considerable distance from the researcher's home area. The questionnaires were easier to fit in to the part-time schedule. Patton (1987) is quick to point out that there are no hard and fast rules for a research design;

> *Any given design is necessarily an interplay of resources, practicalities, methodological choices, creativity and personal judgements by the people involved.* (p.9)

Borg and Gall (1989) consider that there are four types of research knowledge. *Description* involves a process of observation and recording of events or phenomena. It aims to build a picture of the way things are. Many new discoveries have arisen because of painstaking descriptions of particular things, for example stars and stellar events.

Prediction involves using a body of knowledge to make informed decisions about future events. In a sense, this takes the descriptive research a stage further, making use of the observations made. Collecting data about test results in schools can lead to predictions about future performance.

The third type of research described by Borg and Gall is *improvement* which concerns interventions that improve student learning or some related outcome. They also describe this type of research as developing knowledge which can control a phenomenon.

Explanation is the last type of research in their model and involves making theories to account for the observations. Borg and Gall regard this as the most important of the four, subsuming the other three. In some ways they have a point, as explanation is the culmination of the other types of research, and has a very practical use. A theory about why some students learn in a particular way allows an effective programme of teaching to be developed. However, explanation can not exist in isolation. Theories can only be developed, and certainly only proved with any degree of certainty, when a body of knowledge has been collected. Explanatory research builds on descriptive research.

The present research is largely descriptive. It aims to collect data about parental perceptions as they are now. It is not concerned with predicting or improving, although it would be possible to make some informed statements about possible improvements from the parental perspective. It would certainly be possible to outline some predictions which could form the basis of further research.

Explanation would require more data to confirm or otherwise the ideas which could be developed.

Anderson (1990) describes four levels of educational research, namely *descriptive, explanatory, generalisation* and *basic or theoretical,* (p.7). Descriptive research tries to answer the question, "*What happened here?*" (Historical), or the question, "*What is happening here?*" (Contemporary). Explanatory research looks for the causes of events or phenomena. It is concerned with explaining whatever has been observed, but not broadening out from there. The third level, generalisation, aims to locate the observed results in the wider context, e.g. "*Would the results for this particular school be the same for a different school?*" The theoretical level of research tries to discover the underlying principles which are at work. This study was largely concerned with identifying what was happening or what had previously happened, and was thus primarily within the first, descriptive, level. The discussion does look at possible causes for some of the themes, and the issue of generalisation is discussed, so the second and third levels also come into it.

Wolfendale (1999) makes some interesting points about the nature of research carried out with parents. She considers that parents should be considered as more than just contributors in the project; they should be thought of as partners. There are four key principles highlighted for consideration:

<u>Rights/entitlement</u> Parents should fully know their rights and be kept informed throughout. They should have access to as much information as possible and be free to withdraw whenever.

<u>Equality</u> Wolfendale feels that both parties should be partners in the research, "*...each bringing different but equivalent experiences to that joint enterprise.*" (p.167)

Reciprocity Each person involved should be contributing and sharing information, expertise and responsibility for actions and decisions, bearing in mind that the researcher should be ultimately responsible for the project.

Empowerment Parents are regarded as more than passive subjects of the research. They have a right to express their views and to influence the research process.

4.2 Qualitative and quantitative research

> *The prespecified intent of quantitative inquiry contrasts with the relatively unprespecified intent of qualitative inquiry, which fastens on the ordinary, inexhaustible, awful, and enormous complexity of the circumstances of the social phenomena we investigate. Since qualitative inquiry is potentially responsive to the totality not the abstraction of an object, it is responsive to that which quantitative research is likely to preclude.* (Peshkin 1994, p.273)

Traditionally, research has been seen as either qualitative or quantitative and the methods and strategies employed fell within one or other. Peshkin sees the two as quite distinct. He seems to be suggesting that qualitative research is more dynamic in the way that it depends on the interplay between researcher and researched. He sees quantitative research as much more fixed and rigid in its approach.

Gay (1996) sees the difference largely in terms of whether the data involved is numerical, (quantitative), or not, and whether the setting is natural, (qualitative), or not. He defines qualitative research in the following terms;

> *Qualitative research involves intensive data collection, that is collection of extensive data on many variables over an extended period of time, in a naturalistic setting....where they naturally occur, as they naturally occur, not in researcher-controlled environments under researcher-controlled conditions, as is the case with quantitative studies.* (p.208)

Qualitative methods are regarded as those allowing the researcher to study selected cases in some depth and detail. They produce a wealth of detailed data about a small number of people. They produce descriptive detail and quotations, and do not try to fit people's experiences into standardised pre-determined categories. Quantitative methods measure the reactions of a large number of people to a limited set of questions, allowing for comparison and statistical analysis, (Patton 1987).

According to Atkinson, Delamont & Hammersley (1993) qualitative research in education developed in Britain in the late 1960s and early 1970s as a direct consequence of the expansion of the university sector at a time when people were beginning to question traditional approaches in education. They suggest that there was a reaction amongst scholars against more quantitative approaches, and that they became more interested in looking at schools and education in general from the point of view of the participants.

If there are indeed two distinct approaches with their own associated methods, then the design of this research would seem to be framed more within the qualitative paradigm, although there would seem to be elements of the two. This research project was concerned with the experiences of a discrete group of parents. It aimed to gather in-depth information from these parents, certainly collecting descriptive detail and quotations from as part of the process. There was also, however, an attempt to broaden this out with a wider group of parents.

Cohen and Manion (1989) discuss the relative strengths of qualitative and quantitative methods at length. They quote Burrell and Morgan in summing up the two thus;

> *This perspective [quantitative] expresses itself most forcefully in a search for universal laws which explain and govern the reality which is being observed.*
> *[In qualitative research] the emphasis in extreme cases tends to be placed upon the explanation and understanding of what is unique and particular to the individual rather than of what is general and universal.* (p.8)

This study was very much concerned with exploring the experiences of selected individuals. The size of the study, and the limitations as discussed, made it difficult to draw broad generalisations. However, within the selected field of study some pointers could be hinted at.

Bogdan and Biklen (1992) describe five features of qualitative research:

- it has the natural setting as its data source;
- it is descriptive;
- it is concerned with process rather than simply outcomes;
- it has no pre-conceived hypotheses, rather theory emerges;
- it is interested in participant perspectives. (p.29)

These points fit well with the research project. The study was centred within different family groups, it was interested in the descriptive views of the participants and revolved around discovering issues rather than trying to prove a point. There was no hypothesis to be tested, only a desire to understand the situations as they existed. As Bogdan and Biklen point out;

> *(Qualitative researchers) seek to study the concept as it is understood in the context of all who use it. It is multiple realities rather than a single reality that concern the qualitative researcher.* (p.42)

The research was centred around the experiences of parents, and aimed to find out their perceptions about various issues. As they suggest, there are many different experiences which people will have had and they will all be different, (multiple realities). This does not mean, however, that one should not search for patterns to link different people's experiences together.

Recently, the idea that the qualitative and quantitative approaches are two distinct and opposed ways of studying the social world has been challenged. Scott (1996) suggests that;

> *...the two methods do not belong within separate research paradigms and thus can sensibly be used within the same investigation.* (p.59)

Scott uses an extensive argument put forward by Hammersley to back up this idea. The key points can be summarised thus:

- qualitative research uses terms which relate to number;
- accuracy may not necessarily be best expressed numerically;
- valid data can be collected in artificial settings rather than just the natural setting;
- participant observers do alter the natural setting to some extent;
- qualitative researchers do not focus on meaning to the exclusion of behaviour;
- ethnography sometimes involves the testing of previously formulated hypotheses;
- inductive and deductive elements are involved in all types of data analysis.

The present research collected data about experiences which, in the first instance, were not numerical. However, as the ideas and themes emerged, it was essential to quantify it in order to give it context. If a theme emerged from one interview, it was important to know if it was an isolated experience, or whether it was more general. If so, how many parents had the same experience? Interviews were used to collect in-depth data. The nature of this data was descriptive rather that numerical. The analysis involved breaking this down into themes which might be similar, but not exactly identical between interviewees. Questionnaires were then used to collect data from a much wider audience. The format of the questionnaire meant that the data was much more concise and much more tightly related to specific issues under investigation. This data leant itself much more easily to numerical analysis. Percentages of parents who had similar views could yield interesting patterns. Thus, it would seem to be more in line with Scott's ideas of having elements of both quantitative and qualitative research.

As interviews and questionnaires were the key methods of data collection it is relevant to look at how these are usually located. Questionnaires are traditionally placed within a quantitative setting. Scott (1996) argues that the items in a questionnaire may be located along three continua: factual/opinion, open/closed and structured/unstructured. Thus, the questions may be closed, factual and pre-set, aimed at collecting very specific answers. On the other hand, they may be open-ended, allow the respondent to set the agenda and be primarily about the perspectives of the respondent. Looked at in this way, the questionnaire could be seen to embrace elements of both qualitative and quantitative approaches.

Likewise with interviews, they are traditionally placed in the qualitative paradigm. They can be unstructured, and used to collect a range of opinions and views, the actual nature of the data collected depending very much on the dynamics of the interview. On the other hand, they can be highly structured and used to collect very specific factual data of a quantitative nature, so as with questionnaires, there would seem to be elements of both approaches with interviews.

For the current research, a semi-structured approach felt to be the most appropriate. A strict set of questions was required to pose to all parents to ensure that a similar range of data could be expected. However, in a face-to-face situation, there is valuable scope for expanding upon some of the responses in order to gain depth. Therefore, an interview schedule was prepared for all interviews, but with a proviso to allow parents to expand on issues as necessary. In the same way, the questionnaire was prepared with a series of closed questions to allow comparisons, but also some open questions to allow more depth.

Scott goes on to argue that the way we conceive of the purpose of our research will shape the way we approach it and the way in which we use the different aspects. He sums up by saying;

> *Methodological framework or research paradigm may be defined as a distinct way of approaching research with particular understandings of purposes, foci, data and what they refer to. Thus different and contrasting methodological frameworks may embrace the same data collection method, but because that method is used to collect data in different types of ways and thus different data, it is possible to distinguish between them.* (p.61)

4.3 Validity

Trust is a key consideration in any research where the responses of participants are involved. There could be a number of reasons why people may answer inaccurately. The respondent may stand to gain in some way by misleading the researcher, or s/he may have no interest in the area at all and not be worried about giving inaccurate information. Alternatively, the respondent may be simply bored or in a bad mood and see it as a bit of fun to invent answers.

In some cases, the respondent may be keen to be seen in a good light, or may wish to please the researcher. S/he may therefore give the answers that are thought to be required. This could be particularly relevant in the workplace where management may see the answers. When asking questions about the past, people may simply have difficulty in remembering details. People may find it difficult to be accurate when being asked to estimate answers. The other factor which could lead to inaccuracies is badly worded questions. Piloting the questionnaire helped to eliminate problems of this kind. Using interviews as well as questionnaires gave some triangulation which helped with the validity generally. Referring to documentation, when available, proved the accuracy of answers in some cases.

Dillman (1978) argues that many of these problems can be overcome by using what he calls, *"total design method"*. This basically involves being aware of all these possible difficulties and giving minute attention to each stage of the research process. However, the point that McNeill (1985) makes is very pertinent;

> *This (honesty) is always a nagging doubt about any survey-style research. It must be accepted that what we are collecting is people's answers to questions, which is not necessarily a true picture of their activities.* (p.13)

In this instance, there was a relationship of sorts with all the respondents. Even if parents did not know the researcher personally, they all had a relationship with the school which was in some way being represented. All parents were free to participate or not as they wished, so it could perhaps be argued that if they took the time to respond their answers ought to be reasonably trustworthy.

In exploring the issues around the "trustworthiness" of the data which the research would yield, the ideas of Woolgar (1988) proved extremely thought-provoking. He argues that it is basically impossible to relate the explanations which might be offered to the object under study because of three issues which he terms indexicality, inconcludability and reflexivity. Indexicality is the idea that explanations are linked to times and places, and will change as times and places change. Inconcludability suggests that explanations can never be conclusive and can always be added to. Reflexivity refers to the impact that the researcher and his/her previous knowledge have on the explanation.

He seems to be arguing that research findings bear little relation to reality, and whilst these ideas clearly have some foundation, it is perhaps extreme to think of them as rendering all research as null and void. Certainly, research takes a snapshot in time of a particular event or set of circumstances and in the first instance it is doing no more than that. However, it does enable us to identify patterns and make some judgements about similar scenarios. It may not offer proof, but it can offer degrees of probability. If it is not possible to generalise from the data, it is certainly possible to ask questions about the idea of generalising. Perhaps one of the aims of research is not so much to answer questions as to frame further questions.

Indexicality can loosely be equated with external validity which is a consideration in all research. It is true that not all findings can be generalised, but this is not always desirable anyway. The present research was a multi-site case study which was designed to highlight some specific difficulties in specific cases. The possibility of generalising is discussed, but it is perhaps enough to flag up areas for future study. Johnson (1999) argues that the problem can be addressed by reporting sufficient detail about particular instances and the theoretical framework so that others can assess how the data link with theory and thus whether or not they can be transferred to other settings.

She suggests a number of ways of dealing with the issue of inconcludability. Firstly, she suggests welcoming the perceptions of others on the findings. Secondly, she points out that triangulation helps to validate the findings and make them more conclusive. She also argues that research should develop and change as it progresses and that the ideas will alter and become more conclusive through this development. These approaches were all incorporated into the design in some form. Triangulation was felt to be a necessary part of the design and so both interviews and questionnaires were used as data collection tools. Cohen and Manion (1989) describe the advantages of triangulation;

> *It has been observed that as research methods act as filters through which the environment is selectively experienced, they are never atheoretical or neutral in representing the world of experience. Exclusive reliance on one method, therefore, may bias or distort the researcher's picture of the particular slice of reality he is investigating.* (p.269)

Reflexivity refers to the influence which the researcher has upon the data. Delamont (2002) suggests that; *"good research is highly tuned to the interrelationships of the investigator with the respondents"* (p.8). Research exists as a dynamic between the parties involved and can not be looked at in isolation. As Hammersley and Atkinson (1983) put it; "*(the researcher) cannot escape the social world in order to study it"* (p.15). In some ways, this has to be an acknowledged part of any research, but accepting it and defining the limitations which it might create is essential. In the present study, the researcher's relationship with the school, and thus with the parents had to be acknowledged and accepted.

All the parents involved in the study had children placed at St Catherine's School and were familiar with the researcher, either directly or indirectly. This may have influenced the way in which they responded to the questions. In addition, all these parents were now happy with the provision which had been made for their child and could have felt that they wanted in some way to be seen to be co-operative. These parents had also been through the assessment process and so they may well have felt more able to say what they felt now that decisions had been made. If they were still in the middle of negotiating with the LEA, they may well have felt cautious in case anything jeopardised their case. Careful wording of the questions was thus seen to be essential. In the initial letter, it was pointed out very clearly to parents that the research project, although relevant to the work of the school, was never-the-less quite separate. The findings may have an effect on processes in the future, but would not influence the provision for their own children. It was made very clear that participation was voluntary, and that confidentiality would be observed.

4.4 General Approach

St Catherine's School is a residential school for children with primary speech and language difficulties. The role of the researcher within the school is as Head of Education. This entails day-to-day management of the school, and overall responsibility for all matters relating to the curriculum. It involves regular contact with parents through informal visits, interviews, annual reviews and open days, as well as contact via telephone and letters. The children are placed at the school by various local education authorities and there are currently some 53 children on roll, with a further eighteen in the further education unit The focus of the research was the parents' experiences of assessment of their children's special educational needs. In order to generate as much in-depth data as possible, a multi-site case study approach was adopted. Interviews were used to generate the initial data, followed by questionnaires.

4.5 Procedure

Children at the school come from 24 different local education authorities. Some of these authorities have only one or two children placed at the school, others many more. The spread of parents in all the different education authorities was looked at and then a sample was chosen from three different authorities. The idea of choosing three different authorities was to see if there were significant differences between them. The basis for the choice was the number of available parents in each authority. Parents were contacted by letter to give them the background to the study and to offer them the possibility of opting out if they so wished. Willing parents were then contacted by telephone, and interviews at their homes were arranged, with two being organised at the school when the parents happened to be visiting.

Five initial interviews were set up with parents on the Isle of Wight as a pilot. These gave confidence in the interview technique as well as helping to frame the questions for the main interviews. A full schedule of fifteen interviews across the three LEAs was then set up. The data from these interviews was analysed and themes were drawn out. These themes helped to shape the questions for the questionnaire which was piloted with parents of students in the further education unit. Minor revisions were made and the questionnaire was then sent to all parents of children at the school.

A second questionnaire was devised and sent to a total of eighteen parents. These were parents who had contacted the school during the previous year because they were going through tribunal proceedings.

4.6 Research Questions

The review of the literature highlighted a number of important issues worthy of further investigation. Coupled with the initial ideas which triggered the research in the first place, these seemed to fit around a number of key themes:

Awareness

- parental awareness of relevant legislation
- parental awareness of their role in the assessment procedure
- parental awareness of partnership

Communication

- parental perception of communication between themselves and the professionals

Power and control

- parental understanding of the issues related to power, empowerment and control

Outcomes

- the issuing of a statement
- the provision of an educational placement
- the role of the annual review

Trauma

- the impact upon the parents
- the impact upon other members of the family

These themes all seemed important, but needed sharpening in order to fit within the scope of the project. Eight specific questions were drawn up which the project aimed to explore:

⇨ What kind of support do parents receive, and from whom?

⇨ Do parents receive relevant, and accessible, information from their LEA?

⇨ What kind of relationship do parents have with the LEA professionals involved?

⇨ How valuable is the statement of Special Educational Needs for parents?

⇨ What are parents' perceptions of the professionals involved?

- ⇨ Do parents feel that they are partners in the process of assessment of their children's needs?

- ⇨ What are the factors leading parents to consider taking an LEA to an SEN tribunal?

- ⇨ What is the emotional impact upon the parents and/or the family of the process of assessment of their children's needs?

4.7 Sources of Data

There were 53 parents to choose from, spread through 24 different authorities. A key consideration was the number of parents who could realistically be visited within the scope of the project. With this in mind, it was decided to focus on three separate authorities. This approach allowed for the possibility of comparing findings between the three. The authorities were chosen according to the numbers of parents in each, making sure there were enough to generate a sample. Some authorities had only one child placed at the school; the three authorities chosen had eight, eight and ten pupils respectively. It was decided to interview five sets of parents in each authority, which was manageable in terms of time, and would produce enough data. Much research quotes ten percent as an acceptable sample size, and this number of interviews would represent approximately thirty percent. Ary, Jacobs and Razavieh (1996) suggest that the absolute size is more important than the percentage, but that size alone does not guarantee a representative sample. In the present study the selection involved nonprobability sampling because the numbers in each location were limited.

Parents were contacted within each authority and interviews arranged as mutually convenient. Parents were chosen on a random basis in that there was no logic behind the order of telephoning and the eventual interviews depended upon who was successfully contacted, and who was available. In six cases, the parents were divorced and mothers had custody in each case. In all other cases, both parents were contacted, but fathers were present in only four interviews. In most instances this was an issue of timing, with fathers being at work.

The majority of interviews were tape-recorded. Field notes were kept to give some background information about each family. In some instances, documentation was made available by parents. This took the form of reports, letters, statements or assessments.

4.8 Instruments

In the first instance, a standard letter was sent to selected parents. This gave a very brief outline of the aim of the study, and meant that the telephone contact was not "cold". Any parents not wishing to participate in the study were given the opportunity to express this.

Interviews

> *The purpose of in-depth interviewing is not to get answers to questions, nor to test hypotheses, and not to "evaluate" as the term is normally used. At the root of in-depth interviewing is an interest in understanding the experience of other people and the meaning they make of that experience.* (Seidman 1991, p.3)

Seidman explains that interview research hinges on an interest in people's stories because they are of worth. The present research is concerned with the stories that parents have to tell about their experiences in dealing with a Local Education Authority. It would not be true to say that it is not concerned with attempting to get the answers to questions. There are some very definite research questions to be answered, but the process of gaining those answers is through parents' stories.

Silverman (1993) considers two approaches to interviews which see the interaction between interviewer and interviewee as quite different. The *positivist* approach is concerned with collecting "facts" about the world. It attempts to generate data which is independent of the researcher and the research setting, usually through the use of standardised questions in the interview and a very tight interview protocol which strictly defines the level of interaction in the interview. The positivist is interested in comparable interviews which are not influenced in any way by the researcher.

The second approach is *interactionism.* This approach sees interviews as examples of symbolic interaction. The social setting and the relationship between the interviewer and interviewee are intrinsic to understanding the data which is obtained;

> *Whatever the topic addressed by the questions, interviews are social events based on mutual participant observation. (p.94)*

Silverman is not particularly arguing in favour of one or the other. He does suggest, however, that hard and fast facts are not always going to be the outcome of an interview, and that the traditional view on this is to see it in terms of, *"a moral shortcoming on the part of the respondent".* (p.114) He is referring to concealment or lack of intelligence, and prefers himself to see interviews as, *"compelling narratives".* (p.114) He concludes;

> *Interviews share with any account an involvement in moral realities. They offer a rich source of data which provide access to how people account for both their troubles and good fortune.* (P.114)

Borg & Gall (1989) describe steps to be taken to ensure that interviews produce comparable data. They suggest that the opening statement, the interview questions and the closing remarks should all be structured. Planning is essential to ensure that the interview situation is not altered in any instances. They describe the interview as;

> *...a unique research method in that it involves the collection of data through direct verbal interaction between individuals.*(p.446)

They go on to explain that this interaction is the source of both the main advantages and the disadvantages. Adaptability is seen as one advantage over questionnaires. The answers to the questions can be used throughout the interview to alter things and to respond to things as they arise; clarification can be sought, or further detail on an issue. They suggest that this can lead to greater depth in the data collected, and go so far as to claim that it is possible to obtain information that the respondent would not reveal under any other circumstances. This is likely to be sensitive or personal information, possibly to do with negative aspects of their feelings towards themselves or others. This does beg the question of whether an element of coercion would be involved in this instance. Respondents who would be unwilling to reveal information on a questionnaire for example, find themselves telling all to a persuasive interviewer. There are ethical implications to be considered here.

Higher response rate is seen as another advantage of interviews. Borg & Gall give examples of research showing a greater percentage of responses with interviews than with questionnaires, and more complete responses, i.e. less gaps in the answers.

A disadvantage of the interview is the fact that it can be misused. Its ease of administration can lead some researchers to use it to collect quantitative data which would be more accurately measured by other means, for example administering tests or checking records.

The other main disadvantage according to Borg & Gall, stems from its adaptability. Whilst this has advantages in the right hands, it can lead to errors in the data;

> *The flexibility, adaptability, and human interaction that are unique strengths of the interview also allow subjectivity and possible bias that in some research situations are its greatest weakness.* (p.448)

Cohen and Manion (1989) discuss the issue of bias in interviews, claiming that it can be the source of invalidity. They specifically ask, *"...whether the questions asked look as if they are measuring what they claim to measure."* (p.318) The questions posed in an interview need to be phrased and delivered very carefully to generate the data required. According to the authors, factors to be aware of which can lead to bias are:

> *...the attributes and opinions of the interviewer; a tendency for the interviewer to see the respondent in his own image; a tendency for the interviewer to seek answers that support his preconceived notions; misperceptions on the part of the interviewer of what the respondent is saying; and misunderstandings on the part of the respondent of what is being asked.* (p.318)

In planning the interviews, these points had to be carefully noted and taken into consideration. Being personally involved in a project can make it difficult to step outside of it somewhat and see the possible errors. Being as thorough as possible in the preparation, and trying to be aware of all the possible pitfalls goes at least some way towards preventing them.

According to Delamont (2002) there are three types of interview. The first involves quick questions posed during an observation session. The second type is a formal interview with a set interview schedule. The last is a life history interview which would most likely take several sessions to complete. The present research is mainly of the second type, but there is an element of the third type involved. Parents were asked a set of questions, but the aim was to discover at least part of their history.

The interview has many advantages as a research tool. It can be more flexible than the questionnaire. If the interviewer is skilled and confident, and can develop a rapport with the respondent, s/he can draw more information from them. The problem of the question not being understood, or being misinterpreted, can be avoided with the researcher present. Likewise, the problem of the response not being understood, and therefore mis-coded during analysis, is unlikely to happen. Depending upon whether or not the interviewer is sticking to a tight schedule of closed questions, s/he can develop each question further, according to the response in order to gain the type of information required. A problem with this is that it could very easily lead to bias, with the interviewer driving things in a particular direction. Having a second person, who is less connected with the project, conducting the interviews, could reduce this risk, but would add considerably to the cost and could introduce another unknown dimension to the results. The constraints of the present project meant that all the interviews were conducted by the researcher. This hopefully gave a clear understanding of the data and any misunderstandings were cleared up as they arose.

Cost can be a serious consideration with interviews. Participants might need paying, and travelling expenses may have to be met, (interviewer and/or respondent). In the present study, the respondents took part voluntarily and no payment was necessary. Respondents were spread over a wide area geographically and thus travelling costs were an issue and had to be met within the research budget.

Interviews are more time-consuming than questionnaires both in terms of carrying them out, and analysing the data. Approximately half a day was allocated for each interview, which incorporated travelling time. Most interviews were tape-recorded with the consent of the participants, and the subsequent transcribing of the data was a time-consuming task.

The interviews were semi-structured. There was a set of guiding questions prepared which ensured that the relevant areas were covered, but parents were encouraged to elaborate as necessary and describe any pertinent details as they saw fit. The aim was to gain a clear picture of each parent's experiences and so there needed to be flexibility in the structure of the interviews.

In terms of carrying out the interviews, Drever (1995) proved to be a useful source of ideas. His advice about conducting the interviews is to keep things as simple as possible;

> *Develop a simple schedule and stick to it.... When beginners get into difficulties it is most often because they feel obliged to 'get involved' in the interview. As a result they talk too much and so get drawn off the schedule or start leading respondents.* (p.49)

Drever suggests that everyone has a tendency to make initial judgements about people when they meet them. Thus, respondents will make a judgement about the interviewer and it is therefore important to make a good impression, or more importantly, not a bad one; *"...appear fairly anonymous but friendly; tidy and businesslike, but not aggressively smart"*. (p.51)

Maintaining some distance during the interview can be beneficial in that it keeps the roles of interviewer and interviewee separate. This helps the interviewee to realise that he/she has to explain things. It is necessary to make it clear that the role of the interviewer is to understand the viewpoint of the interviewee, not to evaluate it. Responses back to the interviewee should be of the order of, *"I understand"*, rather than, *"I agree"*.

The process of interviewing is not simply a case of sitting down and running through a series of questions. This would be little more than a questionnaire. There are a number of skills to be employed if the interview is to run smoothly. Anderson

(1990) refers to four particular skills which need to be practiced: *active listening, openness and empathy, paraphrasing* and *summarisation of content.*

Good active listening on the part of the interviewer, demonstrates respect, and a sense of being interested in what the respondent is saying. Anderson argues that this has the effect of enhancing the respondent's self-respect and secures an atmosphere of trust. In this situation, the respondent feels more comfortable about expressing freely his/her views. In order to facilitate active listening, a comfortable setting is desirable, and the interviewer should be physically relaxed. To indicate to the respondent that one is listening, it is a good idea to give good eye contact, to lean forward sometimes and to respond with relevant comments at appropriate moments.

Openness refers to posture and expression as well as an attitude of accepting what is being said. The aim is to encourage the interviewee to share the information with the interviewer. Anderson suggests that empathy is important as long as it does not lead the interviewee; he or she should not feel obliged to go further than they wish. Value judgements are to be avoided; the point is to listen but not to take sides.

The point of *paraphrasing* is to demonstrate to the respondent that the interviewer is listening. It also increases validity by checking what has been heard. The interviewer repeats back to the respondent what has been said, in a slightly different way. The respondent has the opportunity to correct any errors.

The final point of Anderson's is *summarisation*. The aim is to condense and crystallise what has been said. It brings together the key points of the interview. Whilst it is similar to paraphrasing, it covers a longer period of time, summing up a series of points rather than clarifying one. As well as sharpening the interviewer's understanding, it can help focus the interviewee on what follows.

Drever (1995) highlights three non-verbal devices which are useful. Firstly, eye contact is important. It should be intermittent, such that the interviewer is neither staring, nor avoiding eye contact. Timing is the second device. The interviewer has to judge carefully when to speak, so that the respondent isn't cut off, but so that the interview flows. Long periods of silence can be awkward. The final point concerns tone of voice or pace of speech. Drever suggests that a question delivered quickly implies a short response, whereas a slow delivery gives the idea that the response should be more considered.

The following questions were used in all interviews:

- How was your child's problem first diagnosed?

This gives some background to the situation and gets the parents thinking back to the early days when the problems were coming out.

- Which professionals were involved?

The research is concerned with parents' perspectives of the whole assessment process, and one aspect is the nature of the relationship between the parents and the professionals involved.

- Could you describe the relationship you had with the LEA?

This question explores not only the practical details of transactions between the parents and the LEA, but also the parents' feelings associated with them. Inevitably, when talking about the things that the authority did, (or didn't do), parents will describe those things in terms of how they were affected by them.

- What is your understanding of the term, "partnership", (and would you say it applied to your relationship with the LEA)?

The term "partnership" is one which has become more and more popular recently. It is one which is often described as being essential, but one which, according to much of the literature, is not well understood. As parents are the others in this *partnership, it seems important to find out what their understanding of the term is. It is then vital to ask whether they feel that this applies to their own situation.*

- What kind of information did you receive about the help your child could be offered?

Exploring the literature indicates that relevant information which ought to be forthcoming does not always reach parents. In some instances, parents only receive information once they have actively sought it.

- Where did you receive the information from?

Relevant information ought to come direct from the LEA in the first instance. In recent years a number of parent groups have come into being in recognition of the fact that useful information is not always forthcoming.

- What kind of support was available to you? (From where?)

Because of the difficulties which are involved in this whole process, many parents find themselves under a lot of stress. Again, the parent groups have been instrumental in offering support as well as advice to parents. Of course, this is not the only source of support open to parents, and this question explores what avenues are available.

- When was a statement of Special Educational Needs issued?

The statement of Special Educational Needs is an important document in many ways. As a legal document, it should be the means of ensuring that children with special needs receive the clearly defined help which they need. In many cases this is exactly what happens, but the literature indicates that this is by no means always the case. There are cases where the authority assesses the child's needs, issues a statement and the process runs relatively smoothly. There seem to be other cases where parents have to be very pro-active in seeking a statement. Coupled with the issue of parents receiving relevant information, this can prove difficult for many parents.

- What was the effect of the statement?

Because it is a legal document, what is written on the statement should materialise in practice. Is this always the case? Do LEAs adhere to everything on the statement? Are there differences between the different authorities? The other important point about this is that the statement becomes a seriously sought-after document and often takes a long time to be produced. Parents hopes are often riding on this and so if it does not have the desired effect, what does this mean to the parents?

- How did the whole process affect you personally?

The emotional impact of the whole process is one which is of great interest. Because it is such an emotive issue it can affect people greatly. The fact that it is often far from straight-forward, and can take a great deal of time and energy, means that the process can have very serious repercussions for the parents.

- Where there any effects on the rest of your family?

The emotional impact on the parents could be great. It could be drawn out over a long time and could have implications for the rest of the family.

Questionnaires

> *The questionnaire has become one of the most used, useful but also abused means of collecting information. If well constructed, a questionnaire permits the collection of reliable and reasonably valid data relatively simply, cheaply and in a short space of time.*
> (Anderson 1990, p.207)

The questionnaire was devised directly on the basis of the research questions, with reference to the data generated from the interviews. Partly it was designed to see whether the themes identified in the interviews were general for all parents; partly it was designed to expand on new ideas generated in the interviews; and partly it was designed to compare the collected data across the different authorities.

The designing of the questionnaire had to be done very carefully in order that it achieved what was intended. A questionnaire is not a passive instrument, in the sense that the responses will be a reflection of the dynamic between the questioner and the respondent. The structure of the questionnaire, the way the questions are worded, the order etc. will, in some way, be a reflection of the person constructing it. The way that it is responded to will be affected by the relationship between the parties involved, (if any exists), the manner in which it is received, the environment in which it is responded to, the timing etc. Shipman (1988) says;

> *The final answers emerge from this interaction [between researcher and researched] and the meanings that each party gives to the situation. The questions have created this situation and the answers are meaningful only in its context.* (p.78)

With this in mind, it is important to recognise that bias could be an issue here. Being personally involved with the project, it is hard not to have some pre-conceived ideas about the kinds of results expected, (or possibly even hoped for). The wording of the questions could very easily be leading (and possibly not even intentionally so). Recognising the potential for bias goes some way towards helping to remove it. Having a disinterested party check the wording of the questionnaire will have helped too.

Shipman's point raises an interesting question about validity. He claims that the results of the research are a direct reflection of the interplay between the various parties involved. Thus, if the research were carried out by a different researcher, somewhat different results would be obtained. True, the results may not be staggeringly different, but never the less it is an interesting point and could raise serious problems in some instances. A questionnaire coming from a stranger about a topic which is unknown to the respondent may well produce a different response than one from a known party concerning a topic of interest to the respondent.

In looking at the types of questions to be asked, Newell (1993) distinguishes between four main groups; attitudes, attributes, behaviour and beliefs. Questions about attitudes are concerned with finding out what people think about something. Questions about attributes are concerned with factual information, (e.g. personal or socioeconomic characteristics). Questions about behaviour aim to find out what people do, or what they might do in the future. Questions about beliefs are to do with what people believe to be true or false. The questions in this research project were mainly to do with people's attitudes and attributes, - gathering personal information about the respondents themselves and their experiences, but also some information about their own views on the issues.

The structure of the questions themselves can be either open or closed. Closed questions are relatively easy to group and code for analysis. They are easy and relatively quick for respondents to complete - an important consideration when thinking about response rates. Closed questions can lead respondents, however, since possible answers are offered and the most appropriate one may not be there. An advantage of closed questions is that they do not discriminate against less articulate respondents.

Open questions have the disadvantage of producing responses which may be ambiguous, wide-ranging and difficult to categorise. They are time-consuming to fill in which could deter some people. They are also time-consuming to analyse since the range of possible answers could very broad indeed and bear little obvious relation to each other. They do, however, provide the opportunity to collect data of some depth. Stacey (1969) offers the following advice;

> *Closed questions should be used where alternative replies are known, are limited in number and are clear-cut. Open-ended questions are used where the issue is complex, where relevant dimensions are not known, and where a process is being explored.*

In designing the questionnaires, the advice of Davidson (1970) was borne in mind;

> *(The questionnaire) is clear, unambiguous and uniformly workable. Its design must minimise potential errors from respondents. And since people's participation in surveys is voluntary, a questionnaire has to help in engaging their interest, encouraging their co-operation, and eliciting answers as close as possible to the truth.*

Charles (1998) emphasises the need for a questionnaire to be well-presented. Once a questionnaire has been sent off, it is out of the hands of the researcher and therefore work needs to go into it beforehand to encourage respondents to fill it in. The appearance of the questionnaire should be as attractive as possible. It should be uncluttered with only as many items on it as are necessary. The directions should be simple, and the responses easy to make. To encourage as many responses as possible, the covering letter should explain how little time will be needed to complete the questionnaire, and how valuable those responses will be to the research project.

In order to ensure that all these points were covered, the draft questionnaire was piloted. Bell (1987) lists a number of objectives for a pilot study:

- How long does the questionnaire take to complete?
- Are the instructions clear?
- Are any of the questions unclear or ambiguous?
- Are any of the questions too sensitive?
- Are there any obvious omissions?
- Is the layout clear/attractive?

With these points in mind, and taking into account comments from respondents, the final questionnaire was prepared. Seventeen closed questions were devised with a rating scale of one to five. Parents were asked to show how they felt about a range of issues by circling a response. The second part of the questionnaire contained ten open questions where parents were asked to give more detail about the issues. It was felt that this approach would ensure that there would be enough data which would not be burdensome for parents to provide, but that having completed the first part, many parents would be happy to add more in the second part. The following questions were devised for the first part of the questionnaire:

1. How helpful were the LEA?
2. How helpful was the Educational Psychologist?
3. How helpful was the Health Service?

These questions are designed to give some information about the various professionals involved. Not all parents will have had dealings with all of these bodies, but between the questions, a picture of the helpfulness of the professionals should emerge.

4. How involved did you feel?

This question covers a number of issues, including partnership and communication. Parents can feel isolated if they are not fully informed of events and decisions. More than this, parents can feel more involved if they are included in some of the decision-making, rather than just informed.

5. Did you feel that the LEA did everything they could for your child?

This is a fairly broad question, giving an idea of how satisfied parents feel with the actions of the LEA. In some ways, it leads into the next question.

6. Do you feel the LEA were constricted in what they could do because of finances?

Resourcing seems to be a key issue. Special education is a costly business and many decisions appear to be financially-driven.

7. Did you receive information from the LEA without having to seek it?

The Local Education Authority has a duty to keep parents well-informed. The information should be provided to parents as a matter of course, without parents having to seek it.

> *A local education authority must arrange for the parent of any child in their area with special educational needs to be provided with advice and information about matters relating to those needs.*
> (DfES 2001, p.19)

8. Was the information you received clear and easy to understand?

Clarity of information has been an issue for many researchers. Hudson (1978) has been quoted in this document as terming educational psychologists, "prolific generators of jargon". Parents need to receive the information, but also be able to make sense of it.

9. Did you feel supported by the LEA?

The assessment of a child's needs and the process of finding suitable educational provision can be a stressful time for parents. Parents not only need information, they also need some level of support. The LEA may be in a position to provide this.

10. Was your main source of information other parents?

As pointed out above, LEAs have a duty to provide information to parents. In some cases, this does not seem to happen and other parents become a valuable source of information.

11. Was your main source of support other parents?

As with the provision of information, if support is not readily provided by the LEA, other parents who have had similar experiences can provide a good support network.

12. Did you feel like a partner in the process?

Partnership has been touched on already. This question asks directly whether parents felt it applied to their situation.

13. Were you kept fully informed throughout the process?

The provision of information is an on-going process. The assessment process can be a long and complicated procedure. Parents need to be kept up-to-date at all stages.

14. Do you feel that the interests of your child were at the heart of the matter as far as the LEA were concerned?

There are many processes and procedures involved, and the child at the centre of it can be almost overlooked. Financial issues have been mentioned already, and it may be the case that decisions are made for financial reasons rather than for what is best for the child.

15. Was a statement produced fairly quickly?

The statement of special educational needs can be a very important document that has the power to ensure that certain provision if provided. It can, however, take an inordinate amount of time to produce.

16. Did the statement have an immediate impact?

The statement is a legal document and ought to ensure that whatever has been agreed will happen. The literature indicates that this is not always the case.

17. Did you feel that the process overall was straight-forward?

This is another broad question which aims to give an overall picture of how complicated the process appeared to be. There are a number of issues involved, but keeping parents informed with up-to-date relevant information, and guidelines on what to do next would perhaps help to make it less confusing and complicated.

The second part of the questionnaire consisted of ten open questions, covering the same kind of areas as the closed questions, but designed to elicit responses with a little more depth. The questions were devised as follows:

18. What were your main sources of information?

Receiving relevant information has been highlighted as an important issue. It should come from the Local Education Authority; this question asks where it does come from in practice.

19. What were your main sources of help/support?

As well as information, parents also need support. The emotional impact of the assessment of Special Educational Needs can be quite high and their are various groups offering support to parents if the LEA is not offering such a service.

20. How did you find out information about appropriate courses of action?

Similar in nature to question 18, this question explores the sources of information which parents receive.

21. What sort of relationship have you had with the LEA?

For some parents all runs smoothly and the LEA carries out its duties well. For other parents the relationship with the authority is very stormy.

22. Can you describe any involvement you had with the Special Educational Needs Tribunal?

For some parents, the process of assessment is far from straight-forward and they seek redress through the Tribunal. This question is for any parents in such a position.

23. Can you describe the level of partnership which you experienced with the LEA?

Partnership has been discussed at length. The government puts a lot of store in the idea of partnership, but it is not always in evidence.

24. What mechanisms did the LEA employ to keep you fully informed?

This question further explores the area of the provision of information.

25. Can you sum up the effect the whole process has had on your child and on your whole family?

The existing literature shows that for many families there is a very real cost in terms of stress. This can be stress on the child, on any siblings, on the parents or on other members of the family.

26. How could the process be made easier for parents?

This question approaches the problems from a different direction. Parents are the ones who have experienced any problems as they arise. They are in a good position to suggest solutions. The nature of the solutions will also cast light on the nature of the problems they have encountered.

27. What single thing would you change about the system if you could?

This question explores similar territory to the previous question.

Non-respondents

In any research undertaking, it is important to try to ensure as high a response rate as possible. Every person who fails to respond, for whatever reason, is threatening the richness of the data, so effort needs to be put into encouraging those who do not respond first time around.

Interviews do not present quite such a problem. Participants agree beforehand to take part in the interview, and short of changing their minds or forgetting, the interview should take place as scheduled. In an instance where this does not happen, the respondent could be contacted again, and unless there was some reason, an alternative interview arranged. Of course, for interviews arranged at some distance, the travelling time needed might preclude this eventuality.

With questionnaires, there is a very real problem of possible non-responses. Anderson (1990) discusses three problems; namely *non-contact, refusals* and *inability to respond.* The first problem of *non-contact* is concerned with people who are inaccessible. They may have moved, or changed their telephone number. The information held about them is incorrect in some way and thus delivering the questionnaire in the first place is a problem. Unless the inaccuracies can be corrected, it is hard to see what could be done in these cases.

Refusals are a different kind of problem, in that they have been successfully contacted, but for whatever reason have failed to respond. The term *refusal* is perhaps a little misleading as it encompasses not only those who actively refuse, but those who passively fail to. This latter group may just be busy or forgetful and need prompting. Anderson quotes research indicating a refusal rate for telephone surveys at 24 percent. Telephone surveys differ from postal questionnaires in many ways, not least of which is an intrusion factor. People phoned up out of the blue are not always going to be as responsive as the recipient of a postal questionnaire who can fill it in at leisure. There is also the question of whether the respondents are "cold" i.e. unknown to the researcher. If the respondent knows the researcher, it may be more of an incentive to respond.

The third problem highlighted by Anderson concerns an *inability to respond.* This is usually caused by respondents not understanding the questions because they are poorly phrased or formatted.

In order to enhance response rate, there are a number of strategies. A pre-letter can prepare people for the imminent questionnaire and put them in the frame of mind to respond. A letter with the questionnaire is important to explain the nature of the project and its value. The respondent should be personally named in the letter and it should be individually signed. A stamped-addressed envelope can encourage a response; Anderson makes the interesting point that most people would not feel comfortable throwing away a stamp. The questionnaire itself should be clear, reasonably short with easy to understand instructions. A return-by-date gives people an actual deadline to work with, which should help. A vague request like, "please respond as soon as possible", can be put off indefinitely. The disadvantage of a return-by-date is that once the date has been passed, respondents are unlikely to return the questionnaire. A follow-up letter is recommended for all non-responses.

Cohen & Manion (1989) make the point that postal questionnaires can elicit a good response rate if prepared carefully; 40 percent could be obtained in the first instance, and this could be increased to 70 or 80 percent with reminders. They do envisage up to three reminders to elicit this level of response. This has implications in terms of cost and time. Cohen & Manion argue that questionnaires do not necessarily need to be short;

> *With sophisticated respondents, for example, a short questionnaire might appear to trivialise complex issues with which they are familiar.* (p.111)

Clearly, careful consideration of the audience is paramount when the questionnaire is designed. The present research is aimed at parents who are not specialists in the field, but who are certainly knowledgeable. The questionnaire was piloted in the first instance to eradicate any obvious errors. It was four pages long, the questions were well-spaced, and it was typed. It was accompanied by a personalised covering letter explaining the nature of project and its possible usefulness. The research related directly to issues pertinent to the parents and this was felt to be a factor in favour of a good rate of response. After two to three weeks, a second letter was sent to non-respondents encouraging them to reply.

A copy of each instrument can be found in the appendix.

4.9 Analysis of data

> *Data analysis is one of the more interesting aspects of the study for it includes the possibilities of discovery and reconceptualisation of the research questions.* (Cohen & Manion 1989, p.81)

Questionnaires

A three-stage model of data analysis was used for the questionnaires as outlined by Miles and Huberman (1984). Through the process of data reduction, the response categories were combined to give a picture of positive, neutral and negative responses. The numbers of respondents in each category were calculated and presented in table form, which were then used to produce graphs. The responses to the open questions were put into a spreadsheet. Some initial grouping of categories of responses enabled a summary table to be drawn up.

The second stage of data display involved a more comprehensive combining of categories of response. Themes were drawn out and percentages of respondents for each of these themes were calculated.

The full analysis of these two stages is presented in chapter five. The third stage involved drawing conclusions. The responses were related back to the research questions to provide a summary of findings. This part forms the basis of chapter seven.

Interviews

The work of Drever (1995) was used as a basis for the analysis of interview data. He suggests a three-stage model consisting of data preparation, data analysis and summarising results. For the first stage, transcripts of the interviews were made from the tapes. In order that the depth of this data was not lost, mini case studies were produced.

In the second stage of analysis, interview data from each of the three separate Local Education Authorities were combined and compared to see if there were differences between them. Themes relating to the interview questions were drawn out of the data and parents' responses were calculated. This information was tabulated and graphs drawn.

Chapter six provides a detailed account of these two stages of data analysis. The third stage of summarising the data involved relating it to the research questions and drawing out some conclusions. This part of the analysis is presented in chapter seven.

4.10 Limitations

This research was looking at a very selective group of parents, all of whom have certain things in common. All the children were at the same special school. The nature of the special educational need identified for each child was necessarily the same. The population was relatively small. The number of educational authorities involved was limited; in some authorities there was only one family represented. It was accepted that the research was aiming to identify some patterns within this group only, and thus the limitations were identified but did not detract unduly from the project.

4.11 Ethics

> *A discussion of ethics in research is essentially a discussion of the values of the researcher.....research is a value-laden undertaking; nowhere is this more true than in the area of ethics. Personal values will determine what one considers unethical in the conduct of his or her daily life and in the conduct of his or her research.*
> (Langenbach, Vaughn & Aagaard 1994, p.279)

Ethics is about moral choices and the values that lie behind them. Educational research involves an interplay between researcher and participants in the research. In order that the research is meaningful there needs to be honesty on the part of the researcher. Those who agree to involve themselves in the project must be able to make a decision about it based upon reliable facts. They need to be aware of the nature of the research and the intended audience. Of course, for the research to be truly meaningful, it requires honesty on the part of the participants and this can only be hoped for. This reminds us of McNeill's comment about surveys merely collecting people's answers to questions.

Wolfendale (1999) considers a number of ethical considerations when conducting educational research. She cites 'informed consent' as an important factor, but one which *"...has had limited application within educational research"*. (p.166) Wolfendale goes on to discuss politeness, the shift from the term 'subject' to the term 'participant', honesty and what she calls 'the ethics of intrusion';

> *...the advent of a researcher into the personal or private domain of the participant is bound to influence the research process and the researcher-researchee relationship, which is also a methodological factor. The invasion of personal privacy by researchers can epitomise, at worst, the power imbalance; at best, with the willing engagement of the researchees into the process, the researcher becomes a 'participant researcher'.* (p.166)

Bogdan and Biklen (1992) refer to two issues dominating guidelines on ethics in research with human subjects:

- subjects enter research projects voluntarily, understanding the nature of the study and the dangers and obligations that are involved;
- subjects are not exposed to risks that are greater than the gains they may derive.

The participants in the research were all made aware of the nature of the project before agreeing to take part. They were invited to take part and were given the opportunity to express a desire not to be contacted further if they so wished. The Research and Graduate School of Education Ethical Guidelines for Research provided clear responsibilities and were adhered to throughout.

Parents of children with special needs have a lot to cope with. For some, they may find the process of talking about their children's difficulties cathartic. However, it needs to be borne in mind, that some parents might find the idea quite traumatic. In her research into the views of Bangladeshi parents, Warner (1999) quotes from the work of Scott,& Johnstone (1990);

> *If we accept there is a tremendous burden placed upon parents (of children with severe learning difficulties) then does any person, in the name of research, have any right to intrude still further?* (p.223)

Chapter 5: Questionnaire data

5.1 Introduction

> *The questionnaire is a highly structured data collection technique whereby each respondent is asked much the same set of questions. Because of this, questionnaires provide a very efficient way of creating a variable by case matrix for large samples.* (de Vaus 1991, p.80)

Westmeyer (1994) refers to four stages in the process of analysing questionnaire data;

Reducing the data

The large bulk of data has to be first of all reduced in size to make it more manageable. Some possibilities for achieving this are: combining similar information; tabulating information in terms of frequency; calculating single descriptors like mean or standard deviation; or classifying into categories. Data reduction is the first stage in making sense of the data.

Relating the data

Information in one unit is related to that in another. It is a question of comparing data and looking for connections. With numerical data, this can be relatively easy as long as the values are comparable. Numbers have real value and provided the units being compared are the same, then it is possible to look for similarities or differences. It is important not to try to make interval data out of nominal data. For example, it is not necessarily possible to conclude that something is five times as important as something else. With data which is not numerical, relating it may not be so easy, but it might be possible to relate it chronologically, logically or causally.

Comparing the data

It might be possible to compare the data from one or more units with a "standard", to see if a theory is correct. The standard might be the research hypothesis.

Combining units

It may be possible to combine data from several units to describe events, sequences, trends or cause-effect relationships. This may enable the original question to be answered. It is particularly important here to separate what has been found out from mere inference.

Hopkins (1993) describes the difficulties of analysing qualitative data because there are few agreed formats. He therefore suggests that the truth claims and validity underlying a lot of qualitative work are uncertain. This view is supported by Miles and Huberman, (1984);

> *Despite growing interest in qualitative studies, we lack a body of clearly defined methods for drawing valid meaning from qualitative data. We need methods that are practical, communicable, and not self deluding: scientific in the positivist's sense of the world, and aimed towards interpretive understanding in the best sense of that term.* (p.147)

In an attempt to address the problem, Hopkins refers to work by Becker, who outlined four stages in analysis. These stages are: the selection and definition of problems, concepts and indices; the check on the frequency and distribution of phenomena; the incorporation of individual findings into a model of the organisation under study; the presentation of evidence and proof. Hopkins goes on to refine these and suggests the four stages represent: data collection and the initial generation of categories; validation of categories; interpretation of categories; action.

Hopkins suggests that the act of data analysis is not static but rather a dynamic process. As the data is being collected, hypotheses are developing, so that by the end of the data-gathering stage, there are constructs and categories which are starting to make sense of the data.

Miles and Huberman (1984) describe an interactive model of data analysis, identifying three stages in the process:

Data reduction

This is the process of selecting, focusing, simplifying, abstracting and transforming raw data. During this process, some sense is being made of the data. Patterns or trends might be emerging which will influence the further collection of data.

Data display

Data display involves an organised assembly of information that allows for some conclusions to be drawn. This leads to some understanding, which in turn can lead to some further analysis.

Conclusion drawing / Verification

Ideas, patterns, trends will have been emerging and tentative conclusions will have been forming throughout the process. The final stage is the formal drawing of conclusions and then verification. Although this is essentially the last stage, it can still lead back into further data collection and/or analysis.

Munn and Drever (1990) describe a model of data analysis involving three stages of data preparation, data description and interpretation. In the first stage, the aim is to make the mass of information collected more manageable. Their idea is to draw up a grid and code all the responses. Depending upon the size of the questionnaire, this can make it possible to display all the data on one page allowing for identification of patterns. The second stage of data description is concerned with looking closely at the completed grid and counting the number of times each code appears. It is possible to compare columns and look for combinations of responses or other patterns. The third stage is that of interpretation, where some real meaning is sought from the data.

Munn and Drever (1990) offer some cautionary advice:

- Do not read anything into the data that is not literally there;
- When in doubt, look to the wording of the original question;
- Do not infer anything about motives of respondents for giving a particular answer;
- Do not treat people's opinions about something as if they were attributes of the thing itself; they tell you about the people, not about the subject of the question;
- Remember: the research is not measuring, but merely counting responses.

These models offer possible frameworks for organising and carrying out the data analysis. The nature of the beast, however, prevents a prescriptive method encompassing all research designs. The dynamics of the process will inevitably redefine things as the analysis progresses. The initial design of the questionnaire remains paramount in shaping the analysis and directing the flow of data.

5.2 Analysing the research data

The first two stages of data reduction and data display are presented in this chapter. The third stage of drawing conclusions forms the basis of chapter seven.

5.2a Data reduction

The questionnaire used in this research was in two parts. The first section consisted of seventeen closed questions which required a response on a five-point scale. The second part of the questionnaire consisted of ten open questions which allowed respondents the opportunity to give more detailed responses.

Closed questions

For ease of reference, the first part of the questionnaire is reproduced in the box below (Figure 5.1):

Please answer each question by circling a rating from 1 to 5
(1 = not at all; 5 = completely)

1. How helpful were the LEA?
2. How helpful was the Educational Psychologist?
3. How helpful was the Health Service?
4. How involved did you feel?
5. Did you feel that the LEA did everything they could for your child?
6. Do you feel the LEA were constricted in what they could do because of finances?
7. Did you receive information from the LEA without having to seek it?
8. Was the information you received clear and easy to understand?
9. Did you feel supported by the LEA?
10. Was your main source of information other parents?
11. Was your main source of support other parents?
12. Did you feel like a partner in the process?
13. Were you kept fully informed throughout the process?
14. Do you feel that the interests of your child were at the heart of the matter as far as the LEA were concerned?
15. Was a statement produced fairly quickly?
16. Did the statement have an immediate impact?
17. Did you feel that the process overall was straight-forward?

Figure 5.1 First part of the questionnaire: closed questions

A grid was drawn up listing each question in the first column, and each of the five possible responses across the top row. The responses on each questionnaire were transferred to the grid to give a summary. Of the seventeen questions, fourteen were felt to be directly about the quality of service being offered by the Authority. The other three, questions six, ten and eleven, were about finances and other sources of help and support. In each case, respondents who had given a rating of one or two were indicating a negative response. They were an indication of a poor quality of service. Respondents who had given a rating of four or five, on the other hand, were responding favourably.

The categories were collapsed so that ratings of one and two were combined, as were ratings of four and five. This gave a three level response, broadly equivalent to a negative response, a neutral response and a positive response. (See Figure 5.2). The total for the numbers of responses in each of the three categories was calculated and a pie chart drawn. (See Figure 5.3).

Question	Combined Ratings 1/2 (Negative)	Rating 3 (Neutral)	Combined Ratings 4/5 (Positive)	Total responses
Q 1	18	6	7	31
Q 2	16	0	14	30
Q 3	17	6	7	30
Q 4	6	6	18	30
Q 5	20	3	8	31
Q 6	11	4	16	31
Q 7	23	4	3	30
Q 8	15	9	4	28
Q 9	20	2	8	30
Q 10	9	8	13	30
Q 11	10	3	17	30
Q 12	20	5	4	29
Q 13	20	1	9	30
Q 14	15	7	8	30
Q 15	20	3	7	30
Q 16	14	3	11	28
Q 17	21	3	6	30
Total	275	73	160	

Figure 5.2 Summary of responses for closed questions

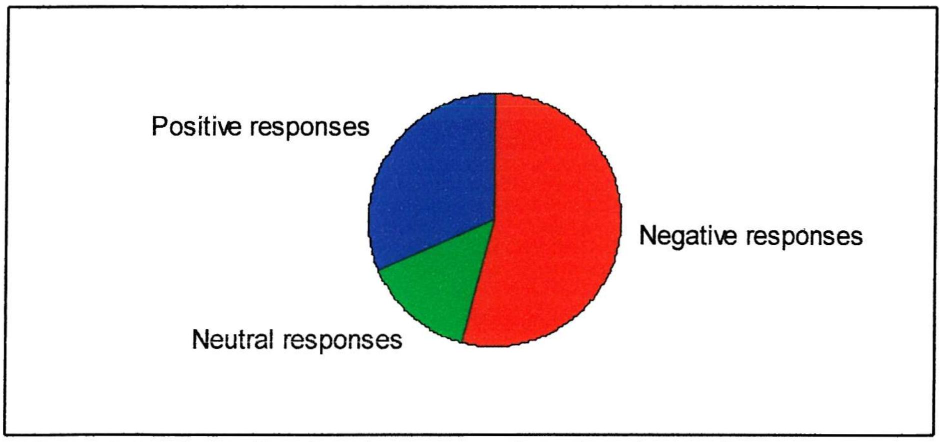

Figure 5.3 Overall ratio of responses for closed questions

This visual representation of the data provided a useful summary and starting point for examining the data. The pie chart shows that 275 responses out of a total of 508, (54 percent), were negative in nature; 73 were neutral, (fourteen percent); the final 160 were positive responses, (32 percent). Thus, over half of the responses were negative and about a third were positive.

The responses for each individual question were displayed in the form of a histogram. (See Figure 5.4). Out of fourteen questions, thirteen showed a higher level of negative responses than positive responses. This represents 93 percent of the total.

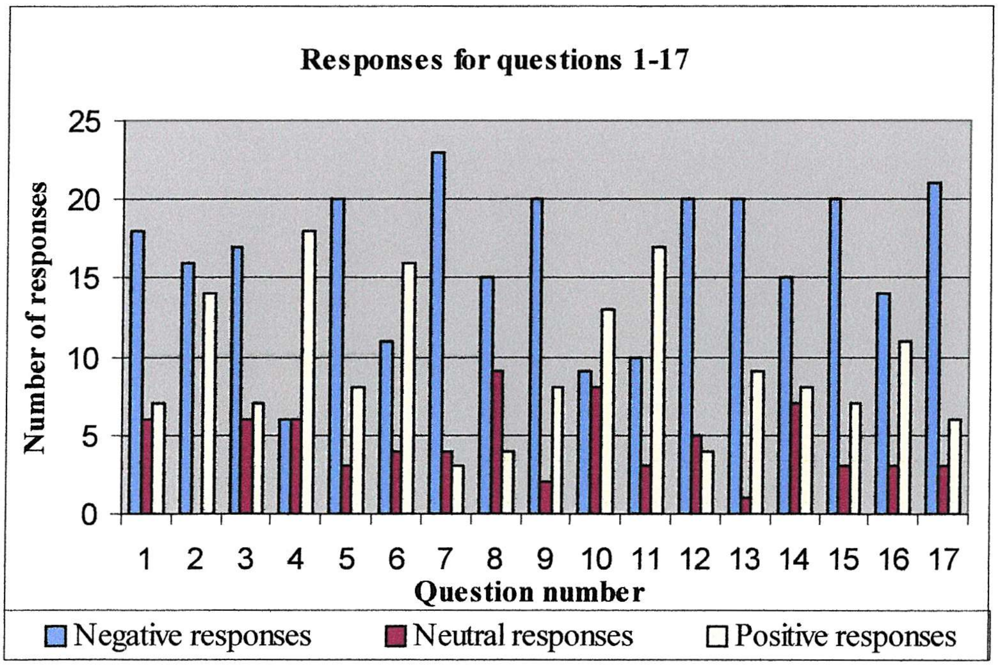

Figure 5.4 Breakdown of responses for closed questions

Open questions

For ease of reference, the second part of the questionnaire is reproduced in the box below (Figure 5.5):

Please answer the following questions in as much detail as you feel able:

18. What were your main sources of information?

19. What were your main sources of help/support?

20. How did you find out information about appropriate courses of action?

21. What sort of relationship have you had with the LEA?

22. Can you describe any involvement you had with the Special Educational Needs Tribunal?

23. Can you describe the level of partnership which you experienced with the LEA?

24. What mechanisms did the LEA employ to keep you fully informed?

25. Can you sum up the effect the whole process has had on your child and on your whole family?

26. How could the process be made easier for parents?

27. What single thing would you change about the system if you could?

Figure 5.5 Second part of the questionnaire: open questions

The first stage of analysis for the open questions consisted of sifting through the answers for categories of response. These were entered in a grid and the numbers of responses for each category were calculated. (See Figure 5.6).

Numbers of responses recorded for each category

Category	No.		Category	No.
Information from I-CAN [1]	3		Drawn out process	1
Information from ACE [2]	2		Good partnership	1
Information from AFASIC [3]	11		Average partnership	2
Information from IPSEA [4]	5		No partnership	21
Information from LEA [5]	3		Intimidating meetings	2
Information from psychologist	7		No information given	15
Information from parents	8		LEA sent leaflets	11
Information from teachers	14		Late information	3
Information from books	7		No mention of therapy	1
Information from Careers	1		Stress for family/child	25
Information from therapist	4		Siblings felt pushed out	4
Legal advice	5		Very fair process	1
Information from SCOPE [6]	1		**What would help?**	
Help from AFASIC [3]	8		More funding would help	8
Help from IPSEA [4]	2		Information would help	16
Help from therapist	5		Openness would help	7
Help from Careers	1		More speed would help	9
Help from parents	6		Partnership would help	6
Help from school	9		Liaison would help	4
Help from friends	2		**Things to change:**	
Strained relationship with LEA	13		Better information	5
Better relationship with LEA	3		Diagnosis of problems	3
Poor relationship with LEA	1		Teachers more involved	1
Very good LEA relationship	4		More funding	9
Average relationship with LEA	5		More approachable LEA	3
"LEA not listening"	3		Listen to parents	4
IPSEA helped with tribunal	1		Speech therapy	2

[1] National Educational Charity for Children with Speech and Language Impairments
[2] Advisory Centre for Education [3] Association For All Speech Impaired Children
[4] Independent Panel For Special Education Advice [5] Local Education Authority
[6] Organisation for people with cerebral palsy

Figure 5.6 Responses to open questions

5.2b Data display

Closed questions

The previous table shown in Figure 5.2 shows the numbers of responses for each question. What is apparent is that for each question, the majority of responses were either positive or negative, rather than neutral. Parents seemed to feel strongly one way or the other. The questions showed some overlap in terms of the themes being addressed. They were thus combined together to provide data about these themes. (See Figure 5.7).

	Theme	Negative	Neutral	Positive	Total
A	Help and support from the professionals (Questions 1/2/3/9)	71	14	36	121
B	Involvement/Partnership (Questions 4/12)	26	11	22	59
C	Information from the LEA (Questions 7/8/13)	58	14	16	88
D	Information and support from other parents (Questions 10/11)	19	11	30	60
E	LEA doing their best for the child (Questions 5/14)	35	10	16	61
F	Production of the statement (Questions 15/16)	34	6	18	58
G	Funding issues (Question 6)	11	4	16	31
H	Straight-forward process (Question 17)	21	3	6	30
	Total	275	73	160	

Figure 5.7 Themes from closed questions

The data was converted to percentages to facilitate comparison, (Figure 5.8), and displayed as a histogram, (Figure 5.9).

	Theme	Negative (%)	Neutral (%)	Positive (%)
A	Help and support from the professionals (Questions 1/2/3/9)	59	12	29
B	Involvement/Partnership (Questions 4/12)	44	19	37
C	Information from the LEA (Questions 7/8/13)	66	16	18
D	Information and support from other parents (Questions 10/11)	32	19	49
E	LEA doing their best for the child (Questions 5/14)	57	16	27
F	Production of the statement (Questions 15/16)	59	10	31
G	Funding issues (Question 6)	35	13	52
H	Straight-forward process (Question 17)	70	10	20

Figure 5.8 Themes from closed questions as percentages

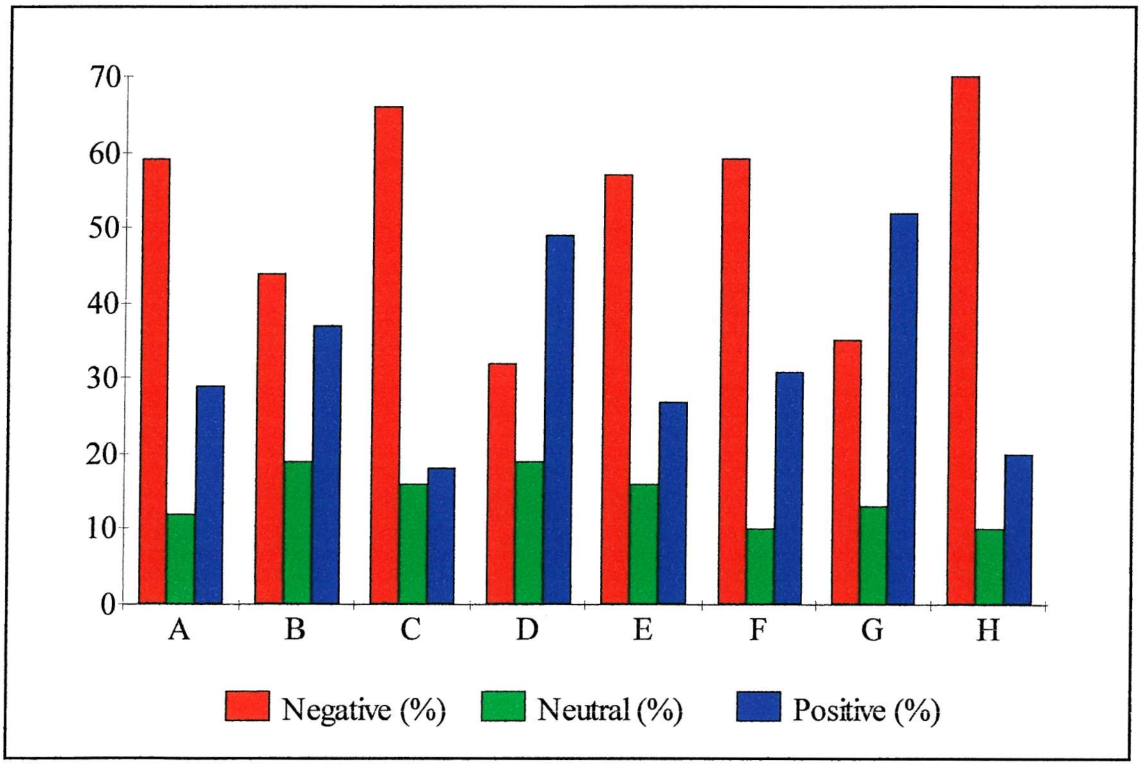

Figure 5.9 Graph of themes from closed questions

The graph gives a fairly clear picture of how parents felt about the various themes. All bar two of the themes have a much greater percentage of negative responses, and in all of them it is a very marked difference. The only two which do not follow this pattern are D and G. As already mentioned, questions six, ten and eleven did not follow the pattern of the others. Questions ten and eleven, (theme D), asked parents if they received help and support from other parents. A positive response thus indicated that they did not receive the information and support from the LEA. In a way, therefore, this question could be interpreted backwards with the negative and positive responses juxtaposed. Reading it this way showed 49 percent of parents being in the position of receiving help and support from other parents, (i.e. not from the LEA).

Theme G was a straight-forward question about funding. A positive response indicated that parents felt the problems were caused by lack of funding. 52 percent of parents felt that this was the case.

Theme A was concerned with how helpful the various professionals were. Almost twice as many people felt that the professionals were unhelpful as those who felt they were helpful. This would seem to be a significant difference.

The question of partnership was not so clear cut. About 44 percent of parents felt that there was no partnership, or that it was poor, compared with 37 percent who were satisfied with their relationship with the LEA.

The next theme was concerned with information from the LEA. It probed the question of whether information was readily forthcoming from the LEA and whether that information was easy to understand. The ratio of positive to negative responses was nearly four to one. Almost four times as many people were dissatisfied with the provision of information as those who were satisfied.

57 percent of the respondents felt that the LEA did not have the best interests of the child at heart. This compares with 27 percent who felt the opposite, less than half the amount.

The statement of special educational needs is often seen as the vital key to securing the appropriate provision for children. Many parent have to fight long and hard to get a statement. There were twice as many parents who felt disappointed with the statement and its impact as those who were happy with it.

In a way, the summary of these issues was the question of whether parents felt that the whole process was straight forward. Only twenty percent felt that it was. Seventy percent of parents who responded felt that the process was complicated. This represents three and half times as many people.

Open questions

The open questions gave parents the opportunity to answer in whichever way they saw fit. They were able to answer favourably or unfavourably in terms of the service provided by the LEA. The data was looked at in two ways. Firstly, it was analysed qualitatively, with the various responses used as a basis for discussion. Secondly, an attempt was made to analyse the data quantitatively. This proved very difficult because the responses were not specific answers to a particular question. Many parents included more than one of the responses shown in Figure 5.6 as the answer to one question. For this reason, simply adding up totals from the table would be meaningless. Converting the data to percentages therefore proved problematic. It was necessary to sift through the responses to each question very carefully. Where responses contained more than one category they were combined. If one respondent had given two different organisations as sources of information, it was important to bear in mind that this did not represent two responses. Regarding it as two responses would have corrupted the data, swaying it towards more negative responses. In truth, this example would simply indicate one parent with a negative experience even though they had information from two different sources.

The data was brought together into some broader themes akin to those used for the closed questions, (refer back to Figure 5.7). These attempted to reflect whether parents were responding positively or negatively. Neutrality was only an option sometimes, because the questions were not asking for a score, simply a factual answer, and this could usually be interpreted one way or the other with no middle ground. Thus, in the question about sources of information, where the response indicated the LEA, this was interpreted as a positive response for the purposes of this exercise. A response which indicated a private body or other parents for example, was interpreted as a negative response, since the information was not provided as it should have been. In order to calculate percentages, the total number of responses had to be counted and this varied for each theme. Not all of the open questions could be analysed in this way. For example, questions 26 and 27 were asking parents for their thoughts on how the system could be changed. Figures 5.10 and 5.11 show the results of this stage of the analysis. The percentage data was then displayed as a histogram, (Figure 5.12).

	Theme	Negative	Neutral	Positive	Total
A	Information from the professionals	52	0	10	62
B	Help/support from the professionals	26	0	4	30
C	Relationship with the LEA	20	5	5	30
D	Level of partnership	21	2	1	24
E	Kept informed by the LEA	15	9	5	29
F	Stress-free process	25	2	1	28
	Total	159	18	26	

Figure 5.10 Themes from open questions

	Theme	Negative (%)	Neutral (%)	Positive (%)
A	Information from the professionals	84	0	16
B	Help/support from the professionals	87	0	13
C	Relationship with the LEA	66	17	17
D	Level of partnership	88	8	4
E	Kept informed by the LEA	52	31	17
F	Stress-free process	89	7	4

Figure 5.11 Themes from open questions as percentages

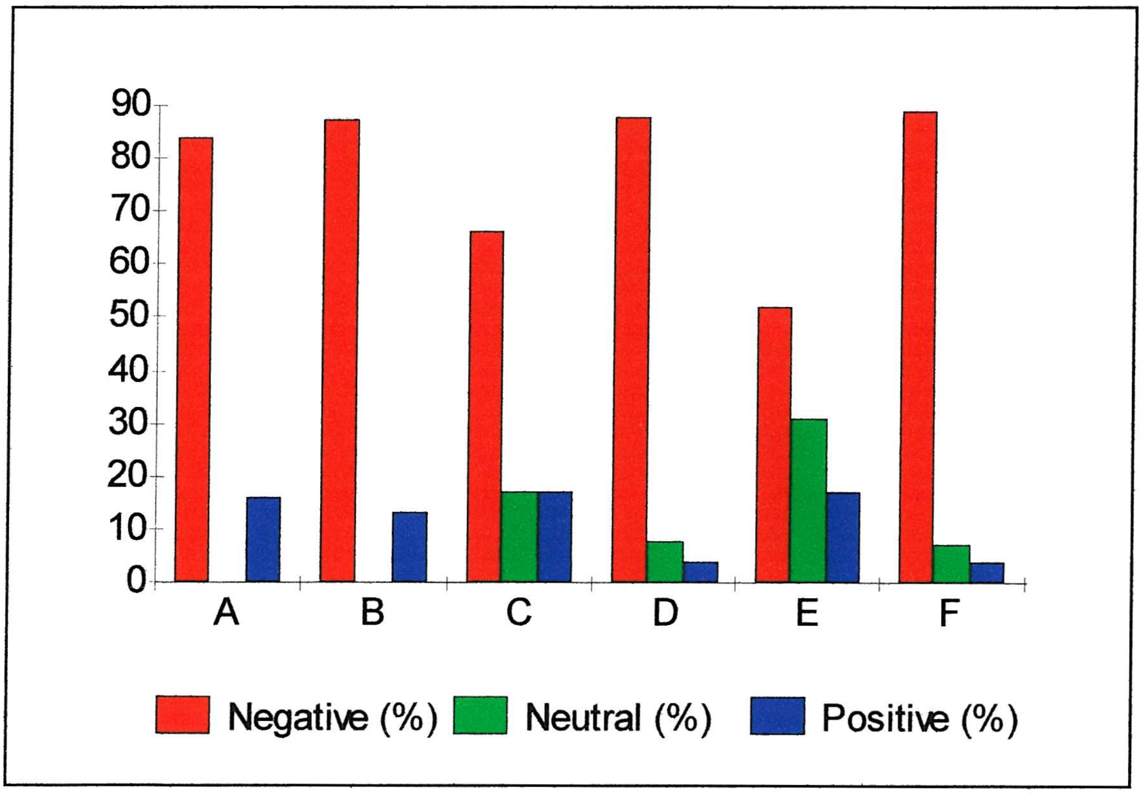

Figure 5.12 Graph of themes from open questions

Grouping the responses into these themes in this way shows a preponderance of negative responses. In all the areas there were many more negative responses. In the case of information from the professionals, there were five times as many respondents who did not receive appropriate information, as there were those who did. A similar ratio experienced a poor level of support from the professionals. In terms of the relationship experienced with the LEA, 66 percent of respondents felt that it was poor, compared with seventeen who felt that it was good. This is a ratio of about four to one. One parent had the following to say;

> *I find them very unhelpful as an organisation and believe they are more interested in evading the problem, rather than trying to find an acceptable solution.*

Although there were many negative responses, some parents could see the problems that the LEA experienced;

> *I do not put any blame on them [the LEA] at all as it appears to be all about funding from the government.*

Partnership was an idea which few parents felt manifested itself in practice. 88 percent of respondents claimed that there was a poor level of partnership, or no partnership at all, compared to four percent who considered there to be a good level of partnership, a ratio of twenty-two to one. One parent commented;

> *The LEA does not believe in partnerships. It is an anonymous presence concerned with meeting budgets and maintaining the status quo.*

Another parent felt that there was no partnership in evidence, but that the professionals are often constrained in what they can do;

> *It never felt like partnership; the meetings were very intimidating with four or five people there, who said they were working in our daughter's best interest but all they kept on about was an MLD school. The speech therapist gave a lot of advice but all off the record, and at the meeting agreed with the LEA.*

In terms of parents being kept informed by the LEA, the ratio of negative to positive responses was three to one. A selection of comments from parents;

> *We had to chase them on every occasion.*

> *We had to phone to find out information.*

> *I had to constantly chase for everything from where the statement was to transport provision.*

> *We were informed of decisions. No dialogue prior to decision-making. No attempt at arriving at the decision in the child's interest.*

Some parents had a positive story to tell;

> *The case worker informed me of when any meetings were taking place and rang me with any decisions immediately.*

The final category showed almost the same result as for the question of partnership. Four percent of respondents felt that the process was stress-free. The percentage who felt that the process was stressful was 89 percent. This again represents a ratio of twenty-two to one. The following comments from parents illustrate the effects that such a complicated process can have upon families;

> *Mother was under the doctor for a nervous breakdown from LEA bullying tactics i.e. if you don't agree with what we offer, you'll get nothing. Twins were out of school for three months with no help. The knock on effect with the elder two children affected the whole family and nearly split the marriage.*

> *A terrific strain, mostly on mother as father is away working. Long-term effect upon older sibling who in retrospect felt herself deprived of much attention.*

> *Devastating [effect] on my son; his whole life has been affected by the late diagnosis of what is a very serious learning difficulty. Very stressful and frustrating on the whole family.*

> *Very, very hard work. You feel like giving up, but you must carry on.*

> *Devastating! All my time and energy was spent trying to get the right help for Maurice, so my home and family were neglected, also my health and well-being. Maurice's progress was also delayed and he lacked confidence. Also, Maurice's sister has been badly affected by all that has happened, and for years has distanced herself from all family activities.*

> *Our son remained with an inappropriate peer group for three years. I ended up with acute anxiety attacks. It was a huge financial strain on the family.*

> *My child was delayed in getting the appropriate education for three years. For us it was close to a nervous breakdown.*

There were some positive comments from parents who had experienced a trouble-free time;

> *We have always been satisfied and pleased with our dealings with Shetland and Dorset LEAs.*

> *In my case the process was very easy. We had the backing of everybody involved in deciding which schools were best.*

In summary, parents were asked for suggestions as to how the process could be made easier. A few comments are shown here;

> *There shouldn't be a price tag on children with special needs.*

> *Speed up the process.*

> *I would like to see an Education Authority write a statement to meet a child's individual needs rather than write a statement to suit what the borough currently has on offer.*

> *Make the professionals who teach the children have a say in the LEA decision-making team. Allowing officials to make decisions based on reports alone is a recipe for disaster.*

> *When it was realised he needed help, it should have been available immediately and not totally governed by the cost involved. We feel <u>totally</u> let down by the system, and very bitter towards the LEA.*

Chapter 6: Interview data

6.1 Introduction

> *What is the relation between interviewees' accounts and the world they describe? Are such accounts potentially 'true' or 'false' or is neither concept always appropriate to them?*
> *How is the relation between interviewer and interviewee to be understood? Is it governed by standardised techniques of 'good interviewing practice'? Or is it, inevitably, based on taken-for-granted knowledge of interpersonal relations?* (Silverman 1993, p.90)

Silverman is asking about the notion of truth in the interview context. Is it possible to generate truths about the world as it is from interview data, or does one simply end up with one person's point of view? Baker (1982) suggests that;

> *When we talk about the world we live in, we engage in the activity of giving it a particular character.* (p.109)

She suggests that in the interview process, the interviewer and interviewee actively construct a version of the world. Thus, it is a dynamic which could generate different sets of data according to the interviewer/interviewer pairing. Silverman suggests ways in which these differences could be minimised which include random selection of the interview sample and the administration of standardised questions. He does offer an alternative theory based on interactionism which embraces the idea of these differences. It argues that the primary goal of interviewing is to generate data which gives an insight into the way people experience the world. This theory is concerned with people as experiencing subjects who construct their own social worlds.

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Scott and Usher (1996) argue that the only way we can come to understand a situation is at least second-hand and will depend on some kind of interpretation according to who the interviewer and interviewee are. Again, the dynamic is important in shaping what actually unfolds. They suggest;

> *...the only real purchase we can have on knowledge is through the perspectives and viewpoints of those actors that are central to the setting we wish to study...it has been suggested that such a research strategy can never fully provide us with the tools to unlock understanding of social reality.* (p.66)

The suggestion is that a researcher will never gain first-hand knowledge of an area of interest. In some ways, this has to be accepted before deciding upon interviews as an appropriate method of research. First-hand data can be collected by observation, action research or perhaps by analysis of historical records. Interviews by their very nature are concerned with a human perspective. Scott and Usher further suggest that analysis involves interpretation by the researcher. Interviews involve two layers of interpretation; one by the interviewee and one by the interviewer.

> *Thus researchers interpret through their own conceptual and perceptual lens the interpretations made by those being studied.* (p.67)

Interviews differ from questionnaires, not so much in the type of data they collect, but in the nature of the collection. Questionnaires are somewhat removed, whereas interviews are very personal. In some ways it is this personal aspect which makes them unique. It could be argued that in some cases, the difficulties inherent in the interview technique could be the very reasons for choosing that particular data collection tool in the first place. The present research is concerned with the experiences of people. Collecting the data face to face was a relevant approach.

Interviews can generate a lot of data. The answer to an interview question can be long and rambling and require sensitive handling in terms of extracting the meaning from it. Seidman (1991) suggests that an open mind is necessary;

> *Most important is that reducing the data be done inductively rather than deductively. That is, the researcher cannot address the material with a set of hypotheses to test or with a theory developed in another context to which he or she wishes to match the data. The researcher must come to the transcripts with an open attitude, seeking what emerges as important and of interest from the text.* (p.89)

It seems important to let the data speak for itself and tell its own story. Seidman goes on to warn against bias infusing the analysis of the data, by allowing the pre-conceived ideas to influence the researcher. He overstates the case a little though by suggesting that interview research has no link to a hypothesis or theory. The interview has to have a focus and an aim; it has to be attempting to uncover some particular issue.

When analysing interview data, Hycner (1985) has put forward a fairly complex model involving some fifteen stages. These can be combined and summarised as follows:

- Transcription;
- Defining units of meaning;
- Relating these units to the research questions;
- Clustering units of meaning to determine themes;
- Conducting a second interview to check and modify themes.

This is a useful model and is not dissimilar to that explained by Westmeyer for questionnaire data analysis. Within the constraints of the present research it was not possible to conduct a second interview. That aside, the analysis of the present research data follows some of these themes.

Drever (1995) suggests a more succinct analysis model involving three stages. The first stage of *data preparation* involves tidying up the raw data and putting it into some kind of form which is easy to work with. He stresses the importance of spending time carrying out this process carefully. If the data has been well prepared, it will make it easier to become familiar with it and locate specific parts. The aim is to eliminate the superfluous material whilst retaining the key points in the data, as Drever points out;

> *Your main aim in data preparation should be to make the material manageable, while at the same time retaining as much of the original information as possible and avoiding any distortion. (p.60)*

The second stage is *analysis*. During this stage various methods are used to categorise and reorganise the data in an attempt to draw out patterns which have a bearing on the research. Drever is not particularly specific about exactly how the data should be categorised; that will depend upon the nature of the data and the research questions themselves. He does suggest that the categories should relate directly to the research questions, which will be easy if the interview questions have been carefully framed to reflect the research questions.

Summarising results involves the use of the developed patterns to draw conclusions. The data is related directly to the research questions to see what answers have arisen.

6.2 Analysing the research data

Data preparation and analysis are presented in this chapter. The third stage of summarising results forms the basis of chapter seven.

6.2a Data preparation

As Silverman (1993) observes;

> *The first thing to bear in mind is that, to become data, observations have to be recorded in some way.* (p.117)

In this research, interviews were recorded on tape. Two sets of parents asked that the interviews were not taped, so in these cases, field notes were kept. The tapes were played through and transcripts made. Because the interviews provided such a wealth of data, it was decided that condensing it in the form of mini case studies would be an appropriate first step. These gave a broad picture of the experiences of each of these parents. The case studies are presented here :

Case Study One: Mrs W (Isle of Wight)

Laura had a fit very early on in her life. A number of professionals became involved. Laura saw the doctor, the paediatrician, the health visitor and various specialists at the hospital. There were various tests carried out and a diagnosis of a prioencephaly cyst was given. Mrs W was not given any information about this diagnosis. She had to find out about it and what it meant herself. She said that it was, *"very frightening, I had nowhere to go."*

When Laura was about two and a half years old, Mrs W was advised to try to get a statement of Special Educational Needs; she was told that there was a lot of money about at this time for statements. The Educational Psychologist started the statementing process at the nursery where Laura was attending. Despite the statement, no support was offered to Laura. Information Technology was identified as a specific need for Laura, but this was ignored.

> *Statements seem meaningless. Only if parents fight for what's on the statement do they stand a chance of getting it.*

Laura went into a mainstream nursery followed by a mainstream primary school. Mrs W felt that both of these provisions were very good and they were well equipped. She particularly felt that the Headteacher of the primary school was very good which made all the difference. A support assistant was employed by the school, even though this was not funded by the Local Education Authority. This meant that Laura was able to manage. However, Mrs W was not impressed with what was happening generally, and didn't feel that what was being provided was sufficient. She herself felt very unsupported. As she put it:

> *Nobody took any responsibility - each one passed it on to the next. I had to fight to get any support for Laura. Now parents get a book of information, but no more than that. Parents need to be pro-active.*

When Laura transferred to middle school, things changed dramatically. Mrs W felt that the middle school was totally unprepared because they had had very little experience of children with statements. They also seemed to have very few resources. She also felt that the fact that parents are generally less involved in middle school life than they are in primary school life, made a difference.

Laura coped in Year five but had real problems in Year six. A speech and language therapist came to visit Mrs W and explained things to Mrs W which had never been explained before. This meant that Mrs W had to fight again for what she now felt Laura needed. A new statement was recommended and this named an MLD school. Mrs W opposed this, feeling that speech and language was a primary need and was not being addressed. The paediatrician explained to Mrs W that she could choose a school. This was news to her, never having been pointed out before. She visited St Catherine's and fought for a place there.

Once Laura was offered a place at St Catherine's, Mrs W felt that things settled down. She felt at last that the statement reflected Laura's needs, and that those needs were being met, but it had been a long hard struggle.

Mrs W felt that parents had to be willing to go through a lot of fights with the LEA but that many were frightened to lose any good will that might exist. They did not want to jeopardise their child's education.

Case Study Two: Mrs H (Isle of Wight)

The first concerns were expressed in 1989 when Maurice was two, and had yet to make any coherent speech. All other milestones were normal, but in terms of speech, he was merely "babbling". During the next six months, Maurice was seen by a paediatrician, an audiologist, specialists at the Nuffield Centre, a speech and language therapist and a home teacher. He was seen by the home teacher on a weekly basis, and six months later was referred to the Educational Psychologist. This led to Maurice starting at the nursery of the local school for moderate learning difficulties.

The statementing procedure started in June 1991, a year after first seeing the Educational Psychologist. Another paediatrician saw Maurice and described him as, *"a mystery, a puzzle."* He said;

> *I don't know what to do with him. Physically he's fine.*

A school for children with severe learning difficulties was recommended, but this was not followed through. Instead, Maurice started at a school for children with moderate learning difficulties, in January 1992. Mrs H accepted that this was a good school, but that it was not appropriate for Maurice.

> *I just felt that there was something more that could be done for Maurice, although I was constantly being told that everything possible was being done, and Maurice was rightly placed.*

Mrs H was then informed by a friend about ICAN and AFASIC, two organisations dealing with children with speech and language difficulties. She found out some information about the nature of these difficulties and about schools specifically set up to help these children. Through the GP, Mrs H requested a referral to a specialist at Guy's Hospital. She then visited two special schools for children with speech and language problems, and made a request that Maurice be placed at one of them, but to no avail. A draft statement was written in August 1992 which still recommended the MLD school. Mrs H was becoming very frustrated;

> *I had become increasingly unhappy at the school's unwillingness to incorporate any of Guy's recommendations.*

In January 1993, Mrs H paid for an independent psychologist to assess Maurice. She forwarded copies of the report to the school and the LEA and asked for Maurice to be reassessed. She visited St Catherine's School and requested a place for Maurice. Mrs H received another statement in July 1993 but again, the same school was named. Mrs H carries on the story;

> *This began a long round of meetings with the school, the LEA, the psychologist, a letter from my GP, an article in the local paper, letters to and from the LEA. I also sent them AFASIC and ICAN guidelines. I could not get through to them that Maurice needed small classes, more speech therapy, to be with children of a similar nature, plenty of visual aids and to be taught by people trained in speech and language.*
> *Unfortunately, the school took offence to all of this and asked me not to help any more which upset me greatly as it was my only contact with Maurice's world outside home. Maurice's behaviour was still bad at home which affected Karen [Maurice's sister].*
> *I was so upset over the loss of contact with Maurice at school, I cried for days and I just felt like giving up. My GP recommended weekly therapy sessions which lasted over three years.*

Mrs H felt that at this point, she didn't have the fight in her for an appeal. Her next strategy was to approach the Advocacy Consortium. This gave her a professional on her side who accompanied Mrs H to meetings. Mrs H felt that the big difference was that this person was treated as professional and therefore listened to.

In December 1993 there was another draft statement produced which was not accepted by Mrs H. *"More meetings but still no progress towards St Catherine's"* Maurice started attending the local primary school one day a week, increasing to two days a week with some ancillary support.

In December 1995 Mrs H asked the LEA to organise a reassessment of Maurice. This was duly completed and in summer 1996 a statement was agreed and signed with St Catherine's as the named school.

> *In that five years my relationship with my daughter was very strained, Bill, [her husband], nearly lost his job through lack of sleep and my health suffered severely. I do still feel affected by the lengthy ordeal.*

Case Study Three: Mrs G (Isle of Wight)

Jeff was recognised as having speech and language problems when he was four years old, but he didn't receive a statement until he was nine. He was assessed because he wasn't coping in school, but the recommendations from the report were initially ignored. A year later he started attending the tutorial unit three days a week where things were okay. However, when he transferred to high school, Mrs G described it as *"a disaster."* There was some SEN provision in the school, but not really enough for Jeff. Mrs G puts it down to a question of funding;

> *The council doesn't want to spend money on these children. If he'd been a noisy or destructive child, we'd have had much more done for him.*

Jeff suffered a lot of teasing and bullying at school. He attended from September until April, and then he was admitted to hospital suffering from stress. After that, he did not return to school. He was out of school for two years, during which time the Welfare Officer threatened Mrs G with court action. Mrs G did not give up, and eventually secured six hours a week home tuition. She explained;

> *I had to fight and fight. You need to harass them. You only get something done if you're persistent. Parents just don't count.*

Jeff was seen by an Educational Psychologist and a Health visitor. His case then went to the Review Board for the issuing of a statement. Mrs G explained;

> *It had to go to two boards. Nobody sitting on these boards has ever seen the child. Only the Educational Psychologist and he or she probably isn't on the board anyway.*

A new statement was produced, but it said nothing new. It still recommended a mainstream school.

> *Once the statement was produced, it didn't get any better. The statement listed a load of things without giving a diagnosis.*

Jeff was promised a computer for use at home, but this did not materialise. Jeff was now quite ill and would be sick at the mention of school. Mrs G was worried about what would happen to Jeff once he got to sixteen. Jeff went to behaviour unit on the Island. He attended for half a day and never returned. Mrs G was given no support and no advice. She was given the booklet, "Special Needs on the Isle of Wight" in 1996; she should have received it in 1989.

> *Nobody told me about St Catherine's. I found out about it by accident. The council don't keep you informed about anything. They don't reply to letters or anything.*

She felt that she got no support or advice from anybody except her immediate family. Mrs G has a mentally handicapped sister, so her mother was quite experienced at fighting with the local authority. Mrs G felt that the only reason she eventually secured a place for Jeff at St Catherine's was that she kept on at the authority and eventually wore them down.

Case Study Four: Mrs J (Isle of Wight)

From birth, Colin had problems sleeping. He had an operation for a hernia when he was nine months old. He didn't speak much. His hearing was tested and no problems were identified. Mrs J was not convinced, so she managed to get him tested again when he was three years old, and a significant hearing loss was diagnosed. He was given a hearing aid.

Mrs J reported that Colin had no sense of danger. He received a statement when he was four years old, labelling him as "backward". Colin's behaviour was getting worse. Mrs J couldn't get a second opinion so she paid to get a private assessment done. He then had an assessment done at the hospital and was referred to Southampton. He was diagnosed as having ADHD. Ritalin was prescribed, but nothing more was done. Mrs J felt that this was totally inadequate.

At Middle school, Colin received five hours a week of in-class support. He was experiencing a lot of bullying during this time. Mrs J felt that he was misunderstood. The other children were bullying him, but it was Colin who ended up getting in trouble. He often had to spend time standing outside the Headteacher's office. This was partly for his own safety, to keep him away from the other children.

The Education Department didn't want to know according to Mrs J. The Health visitors said there was nothing wrong. Mrs J went to a solicitor to try to get some help. Colin's behaviour was deteriorating so he went for an MRI scan. This did not reveal anything so Mrs J continued to push for further tests. After a lot of asking, Colin eventually had another test which indicated that the tip of the tenth chromosome was missing. Nothing was really known about this condition, and so nothing happened about it. The middle school felt that Colin had a speech and language impairment which was being masked by his hearing problems.

Mrs J was finding Colin very difficult to manage and was pushing for respite care, but none was forthcoming. Mrs J felt that she was not a priority case because she was not a single mother, and on the surface at least, she was managing. Mrs J attended an ADHD support group for a while, but was not particularly impressed. She again had to go to a solicitor for help. The solicitor approached the LEA and succeeded in gaining four community nurses to help Mrs J. This was the first help which she had received. As she puts it herself;

> *It's been a battle for twelve years, one fight after another. A lot of the issues are about who's paying for things. They stopped his speech therapy at one point because they couldn't afford it.*
> *They passed the buck at County Hall. The Education Officer's always at the dentist whenever I ring up!*

After much asking and arguing, another statement was produced. Colin was placed at St Catherine's and things improved. Mrs J felt that the previous statement had only really addressed the hearing loss and not touched on anything else.

> *There was really nothing done about all his other difficulties. I was managing most of it by myself.*

Ultimately, Mrs J feels that the Authority lied to her. For example, she says that the respite care was promised full-time, but was never delivered on that basis and only came at all because of extreme pressure being applied to them. She does, however, have a good word to say for the child psychologist at the hospital whom she feels helped her by writing letters supporting her case.

Case Study Five: Mr and Mrs G (Isle of Wight)

Problems with Allan's speech were first noticed at about age two. He saw a speech and language therapist and the paediatrician at the hospital, and gained a very quick placement at a pre-school. There was a Special Needs Assistant assigned for fifteen hours a week, but she was shared with others. He did not, however, receive any speech and language therapy. Mr and Mrs G therefore arranged private sessions of speech therapy and drama for Allan. They also arranged extra tuition, twice a week during school assembly time, which they again paid for.

Mr and Mrs G argued with the LEA and had an independent representative who helped them to put their case across. As a result of this, Allan received a statement when he was four. Mrs G felt that it was useful as a point of reference and because it actually had things written down in black and white. However, she was quick to point out that Allan still didn't receive the help he was entitled to. Mr G suggested that once the statement had been written, it was more or less forgotten;

> *The statement gets written, but then no-one follows it up. Monitoring means nothing.*

When it was time for Allan to move to Middle School, 25 hours of support was initially offered, but after only six weeks, this was reduced to ten. Allan coped, but was not getting what he needed. The school reports were initially good, and there was no indication that things were going badly wrong. In the February of his second year, Mr and Mrs G were suddenly told that they should be looking for a new school for Allan. They were told that Allan, *"has needed considerable help."* At this point they were advised to get a second opinion and to gather together some evidence. As a result, Allan had ten assessments done in a couple of months.

At the beginning of the third year of middle school, the parents were told that the school did not have any help available for Allan. They therefore refused to send

Allan back to school. When Allan did return, Mrs G arranged to go into school as a helper. A couple of hours after she arrived for her first day, the school managed to find some support for Allan. Mr G explained that the changes in what was happening for Allan came down to money in his opinion.

> *They never actually admitted it openly, but unofficially they said that the problems were to do with finance.*

The special needs panel met to discuss Allan's case. Despite the extra assessments which had been carried out, the panel said that there was not enough documentation. Mr G said that the meeting went one way, but the report said something different. As he put it; *"they were hiding behind words."* A school for children with Moderate Learning Difficulties was recommended. The Deputy Head there explained that the school had a waiting list of twenty pupils so that Allan would not have got in anyway.

Mr and Mrs G had another private assessment done which clearly showed that Allan had speech and language problems. When this was presented to the LEA, they came up with their own report which was very similar. Allan then gained a place at St Catherine's.

Mr and Mrs G felt that the only way that things happened for Allan was by paying for support and assessment themselves.

> *All the way through, we had to pay for extra help. There was very little provided for Allan except by us. To get anything done, you have to keep on and on.*

They felt a lot of anger for the way the LEA had managed things. Mr G summed things up by saying; *"I could have throttled the Education Officer."*

Case Study Six: Mrs L (Sussex)

Adrian's developmental milestones were normal up to the age of two, apart from the fact that he was very quiet. Adrian was assessed by the doctor who explained that his social development was poor, but that otherwise, he was fine. Nothing happened for the next three years. Adrian was still very quiet and although his speech was starting to develop, it was very hard to understand.

> *I didn't really know what to do and there was nobody to ask. There was no support or anything.*

At the age of five he attended a school for children with learning difficulties. There was not a lot of support available, although the teacher there was very helpful to Mrs L. This particular teacher suggested to Mrs L that she thought that Adrian had a language disorder. When Mrs L approached the Local Education Authority, she did not find them as helpful as the school had been.

> *I never got anything from the LEA without having to ask for it. I contacted them regularly and always ended up speaking to someone different. They seemed to pass me from one to the next. I just kept phoning them up almost every day.*

It was a long drawn out process which Mrs L found very tiring. She admitted that there were many times when she felt like giving up, but she just kept going. After a lot of effort, Adrian received a statement, but it had very little effect.

> *Things were not a lot different even with the statement. I began to feel like I'd been wasting my time.*

She received no reports or information from the LEA and always had to contact them herself. She found it hard, knowing where to go and felt that it would have been very useful to have had a designated person to speak to.

Adrian was then placed at a special school for children with speech and communication difficulties. Mrs L reported that from that point on, things became very positive. The school was well set up to help Adrian with his difficulties. He did well at this school and in Year 7 transferred to St Catherine's School. Since being placed there, Mrs L has had very little to do with the LEA.

> *They didn't even come to his annual reviews. It's as if they're no longer interested.*

Case Study Seven: Mrs G (Sussex)

Karla's speech was delayed. By the age of three she was not speaking as expected. The speech and language therapist said that it would pick up later. The doctors said the same thing. Things seemed to progress very slowly at first, and Mrs G felt that things were just dragging. However, once the Educational Psychologist became involved things moved quickly. Karla was given a statement, but Mrs G was of the opinion that it made very little difference to what was already happening.

> *The Educational Psychologist was very helpful. The statement was produced very quickly, but to be honest, things were already happening for Karla.*

Mrs G felt that the LEA were very helpful to her and that she didn't have to go searching around for support or advice. They suggested things to Mrs G and she just went along with them. *"It all happened fairly smoothly."* Support groups were mentioned to Mrs G, but she was not interested. She felt quite satisfied with the way things were progressing and didn't feel the need for help.

Karla attended three special schools, all of which were day schools. The Authority then suggested St Catherine's for Karla. Once Karla was in school, Mrs G had little contact from the LEA.

> *I just went along with what the LEA suggested. It all seemed to go very smoothly really.*

The main concern for Mrs G and her husband, was the nature of the reports. They felt that they were too long and that the language used was much too complex. They felt that they used unnecessary jargon. Mr G commented;

I found the reports too long and very difficult to understand. I'd let my wife read them. They used a lot of words which we didn't understand. The main concern is speech and language; they should concentrate on that and cut out the jargon. The meetings were the same. They were helpful, but hard to understand.

Case Study Eight: Mr and Mrs H (Sussex)

For the first nine months of her life, Helen gave no eye contact. The health visitor said that they shouldn't worry. At two years of age, her speech was delayed. Again, her parents were told not to worry, this time by the doctor. Mrs H reported constant visits to the health visitor, the doctor, the casualty department when Helen was around age two or three. Helen was referred to a speech and language therapist whom she visited for two years without ever speaking. At this point, her parents were advised to let Helen see a psychiatrist but they refused.

> *West Sussex were very negative. They wouldn't assess Helen. Then we moved to East Sussex. They diagnosed a problem, but were not sure what the problem was.*

Mr and Mrs H were getting very desperate and decided that they would refuse to send Helen to school until they got more help or advice. They felt that nobody was helping them at all.

> *We really weren't told anything. The Authority didn't tell us anything, - not even what schools were possible. There was a support group of parents in Worthing who helped us quite a lot. But it was the Occupational Therapist who told us about statements. We'd never heard of them before.*

At some point, it was suggested that Helen go to Kings Cross Hospital for tests. Mr H was very upset by this; *"I nearly throttled the doctor."* Mr H described how he went to a meeting at which the Director of Education was speaking, and made a point of speaking to him about Helen. He explained that it was desperation that led to this decision; he felt he had no other way of getting his message across. He got quite angry and this was out of character for him. Shortly afterwards, Helen was offered a place at John Horniman School - a school for children with speech and language difficulties. Once Helen started at that school, Mr and Mrs H had very little contact with the LEA.

> *No professionals from the LEA ever came to annual reviews, - not even the last one.*

Mr and Mrs H felt that the school reports and the statement were hard to understand and that they were full of jargon. Mr H said that he had to read one report five times. They also felt that the reports, and indeed the annual reviews themselves were depressing, - focusing on the negatives.

Case Study Nine: Mrs V (Sussex)

Things seemed to be fairly normal until Jason was three. He'd started to develop some speech but it wasn't very coherent. Mrs V didn't worry at first, thinking he was just developing slowly. Everything else seemed to be developing as expected. The doctor did not seem to be concerned at that point. When Jason went to nursery, he had difficulty getting on with the other children. He was isolated. The teachers were concerned and asked for some assessments to be done. Nothing happened for a long time. By now, Jason was growing and his speech was noticeably delayed. His brother was nearly two years younger but was speaking more fluently and confidently.

> *For a long time, we just didn't know what was happening. Nobody seemed to be able to tell us what to do.*

Jason went to primary school and was given some individual help in class. It wasn't a lot, but it was the first time that anybody seemed to be actually doing anything. It took about a year before Jason saw an Educational Psychologist. At first he was offered extra help in class and then it was recommended that he attend an MLD school. He did go there for a year, but he made very little progress.

> *We asked for another assessment to be done and it was at this point that a speech and language problem was identified. It had taken about five years for someone to tell us clearly what was the matter.*

A statement was produced, but not until about six months after the assessment. Mrs V felt that everything just seemed to take a long time.

> *I just found the whole thing so frustrating. Nobody really seemed to know what to do; and all this time, Jason was struggling in school.*

After this, Jason attended a special unit at the primary school and things picked up from there. The unit was for children with speech and language difficulties. Jason made good progress there, and Mrs V felt happy for the first time in a long while.

> *When it was time for Jason to change schools, we began to worry again, thinking we were going to have to go through it all again. Fortunately, the LEA were very good and Jason was offered a place at St Catherine's without too much fuss.*

Case Study Ten: Mrs H (Sussex)

There were problems with Janet from birth. At first they were told she was blind, but later on the surgeon explained that it was some kind of brain problem that was causing the symptoms. At fifteen months she couldn't sit up. She was referred for an assessment to see if she had Fragile X Syndrome. Nobody seemed able to say what was the matter with Janet. She went from one assessment to another in a short space of time. She was seen by specialists at Harley Street, North Middlesex Hospital, the Maudesley Hospital and the Fragile X clinic. From all of these, there were no conclusive results.

These assessments did not happen automatically. When nothing seemed to be happening, Mr and Mrs H decided to pay for the first assessment themselves. They felt that the only reason that the other assessments were made at all was because they started the process off. They got very little done without a fight.

> *It was a fight all the way. We had to fight for the things, all the assessments, all the way along.*

Janet was displaying extreme behaviours at home which were very difficult to cope with. She slept very little which had an enormous effect on her parents. She was prescribed medication so that the family could get some sleep. They moved from the house they were living in, to a bungalow, because they believed that Janet would never walk.

> *There was no sleep for anyone in the family for about eight years.*

After one assessment at the Maudesley Hospital, it was decided that Janet had Autism so she was placed in a special nursery. She was given a statement which recommended a school for children with moderate learning difficulties. Mrs H said that she felt there were financial reasons why Janet was described as MLD rather than SLD, (severe learning difficulties). It would have been more expensive to send her to an SLD school. Mrs H went to the education officer and asked for a language assessment. This turned out to be another fight. In her own words;

> *I exploded. I got very angry with the education officer who didn't know her own job. She'd never heard of St Catherine's School, whereas I'd heard of all the special schools because of information from AFASIC.*

She did eventually have an assessment which suggested a language problem with autistic features. Mrs H was unhappy with this decision and argued with the authority. A report from the Maudesley Hospital suggested a language problem, so Mrs H was very keen to have the statement changed.

Janet then went to John Horniman School for a language assessment. Mrs H said that they were misled into believing that there was a place available at John Horniman when the authority knew that there was in fact no place there; *"It was just to keep us happy."* Mr and Mrs H paid to go to St Catherine's for a visit and were advised that they would have to go through the LEA. They therefore went to the authority and threatened to go to Tribunal. The authority then paid for an assessment and Janet was offered a place at St Catherine's.

> *The stress throughout was enormous. Nobody in the authority offered help or advice. I only got what I wanted because of my nursing background, and I only understood the reports because of it.*

Case Study Eleven: Mrs D (Dorset)

Problems first occurred with Tony when he went to school. He wouldn't settle at all. The teachers couldn't work out what was wrong. It was suggested that he have a brain scan. He received some help at school but it was not enough. Tony had some assessments done and it was agreed that he had a speech and language problem. Even so, Mrs D found that it was very hard to get the help for Tony that he needed.

> *Even when everyone agreed with what was needed, it still didn't happen. There just weren't enough places available.*

There was a language base attached to the school but there wasn't a spare place. Tony did eventually receive some help at the language base, but Mrs D felt that it would have helped him a lot had there been a place available earlier. Tony was very disruptive at the language base.

The professionals involved were telling Mrs D that she needed to get a statement for Tony, but she didn't know what this really meant. Nobody explained anything to her. Tony was assessed and eventually received a statement when he was in the second year of junior school. It was a drawn out process, and difficult for Mrs D, because she felt that she was in the dark about things. As she put it;

> *How could I ask for something which I didn't know existed? Tests happened, people agreed, but nothing happened, nothing moved. Even with the statement, it took time for things to happen. But without one he'd have got nowhere.*

The next step for Tony would have been a senior school language base, but one of the special needs teachers told Mrs D about St Catherine's School. She had not been given this information by the LEA, nor indeed information about any other provision.

Mrs D did hear of some parent support groups, but said she was too ill to go by then.

> *By the time groups were mentioned, I couldn't go. I was on anti-depressants and close to a breakdown. The stress on me and the family has been enormous. My other two children suffered as I had no time for them.*

Case Study Twelve: Mrs B (Dorset)

Robert was very slow to develop in most areas. He didn't walk until he was nearly two years old. He wasn't speaking, but Mrs B thought he was just a late developer. The doctor and the health visitor told her much the same thing and advised her not to worry. He did start to develop some speech, but it was difficult to understand.

Robert got on reasonably well at primary school. It was a good school and Robert got a lot of help.

> *The teachers were terrific and the Head kept us informed about everything. We knew that Robert had difficulties, but we thought he was just slow. We thought he'd catch up eventually. With the support he was getting, he managed okay in school.*

When Robert transferred to secondary school, there was not the level of support. Mrs B felt that Robert found the busy environment of the big school difficult to cope with. He had trouble making friends and he had trouble with the work. Without the support, he was very soon struggling. Mrs B had many meetings with the Head, but not much changed. The Head agreed that Robert was finding things difficult, but did not have the resources to offer any additional help. It was agreed that Robert should have an assessment, but this took a long time to happen.

> *Everything happened very slowly. I never felt that they were being difficult on purpose. Whenever we spoke to anyone they always seemed very helpful. But not much seemed to happen. We had to keep on asking until eventually someone did something. I think the whole system was unable to cope. Everyone was overworked.*

Robert had been at the school for nearly two years before he saw an Educational Psychologist. A speech and language problem was diagnosed but no school was suggested. Mrs B said that there wasn't anything locally and so she knew she'd have to start looking around. She knew of some other parents who had a child with special needs and they gave her useful advice. Some extra support in class was given to Robert, but it wasn't enough. Mrs B had to keep on at the authority and find out about schools herself. She visited four schools before deciding that St Catherine's would be the right place.

> *It was a long drawn out process. I had to do most of the work myself. If I hadn't bothered, Robert would still be where he was, struggling with the work.*

Case Study Thirteen: Mrs H (Dorset)

By the time Peter was four years old, he still had not developed any speech. Up to that point, there had been various professionals involved, and they'd all told Mrs H not to worry. The Health Visitor was involved, and did give Mrs H some helpful advice. The Health Visitor changed, and so did the opinion of what was wrong with Peter. He was referred to Poole General Hospital. He did gradually start to talk. When he went into the reception class the problems became more pronounced. He was there a year before he started receiving ancillary help.

Peter was seen by the Child Development Officer and it was suggested that he needed to go to a language unit. However, there was not a junior language unit locally. There then followed a series of meetings with a range of professionals.

> *I had a horrendous time with the LEA. I saw the Child Psychologist, people from the Education Authority, the Headteacher, the other teachers and the ancillary helpers. None of them seemed able to help. I got the impression that some of them just weren't interested.*

Peter received a statement when he was seven which stated that he needed speech and language therapy. It was carefully worded, saying that he needed this help, but not how much. Despite this, speech and language therapy didn't materialise at all. Mrs H involved a solicitor, who wrote to the LEA for her. On the strength of this, a place was found at a language unit. However, the day before Peter was due to start at the unit, Mrs H received a telephone call to say that there was no longer a place for Peter.

> *I felt like I was starting all over again. The LEA was doing anything it could to avoid its responsibilities.*

By secondary school age, there was still no language place available, so Mrs H decided to start looking for a residential placement. Nobody in the LEA offered any kind of help. Mrs H joined AFASIC, but they weren't a lot of help to her. She found out about St Catherine's herself and arranged a visit. She telephoned the LEA every single day in order to ensure that Peter got a place.

> *I had to push every inch of the way. Each day when I rang I spoke to a different person and at one point, they lost Peter's folder. I guess in the end it all comes down to money But the emotional problems were enormous, - I very nearly had a breakdown.*

Once Peter started at St Catherine's, Mrs H had nothing more to do with the LEA. They didn't send anyone to Peter's first two annual reviews.

Case Study Fourteen: Mrs W (Dorset)

Matthew suffered from fits when he was three years old. He had a three-year check and it was suggested that he had a speech delay. He received speech therapy at the clinic. Matthew attended the local nursery followed by a mainstream junior school. He then went to a school for children with Moderate Learning Difficulties, where he received speech therapy once a week.

Mrs W had concerns about the help that Matthew was getting. She didn't think that it was enough. Matthew's speech at home was not improving as she thought it should. Mrs W had never received any advice from the authority about statements, but a friend whose son had Special Educational Needs explained about them. Mrs W then telephoned the Education Department to ask for a statement. Up until this point, she had had no contact with the LEA - they had never contacted her. Mrs W explained;

> *When Matthew was in Year seven, we were told by his teacher that St Catherine's would be the best place for him. But we knew nothing about statements. If we'd known about them then, we'd have asked for a statement.*

Mrs W felt that the whole process took a long time, but wasn't particularly difficult. They just hadn't been given the information that they needed when they needed it; and they hadn't been given it by the people who should have given it to them.

Matthew was assessed and a statement was issued fairly quickly.

> *We visited St Catherine's and felt that it would be a good school for Matthew. He wasn't getting enough speech therapy where he was and at St Catherine's he gets it every day.*

The LEA agreed to a place at St Catherine's and Matthew started in Year ten. Mrs W felt that it was a good move, but that it should have happened sooner. She felt that they weren't given the information.

Case Study Fifteen: Mr A (Dorset)

At the age of about two or three years, it was recognised that Patrick had some kind of delay with his speech. The G.P. said that he was simply a little immature and that it really wasn't a cause for concern. He saw a speech and language therapist who said that there was clearly a problem, but she didn't know what it was.

Patrick attended a mainstream school until he was six. At this point, the Headteacher said that Patrick needed a statement because he had learning difficulties. The G.P. referred Patrick to the Nuffield Centre where he was diagnosed as having dyspraxia. A residential school was recommended, but the parents were unhappy with this idea.

Patrick transferred to secondary school and a new statement gave Patrick ten hours a week of support time. The annual reviews around this time gave Patrick's parents the impression that things were improving. Suddenly, and without any warning, Mr A was told that Patrick couldn't read, and that he needed a special school. Mr A was totally taken aback by this. He felt that; *"nobody was being honest with us."* Shortly after this revelation, Mr A decided to keep Patrick out of school because he was getting bullied.

Mr A read in the newspaper about another boy who seemed to be in a similar position to Patrick. He went to see the boy's parents, and from this meeting found out a lot of information that he hadn't been given by the LEA.

> *All the information that we got came from other parents.*

Patrick's parents arranged an independent Educational Psychologist's report. This again indicated that Patrick had dyspraxia, and would need speech and language therapy as well as occupational therapy. Patrick's parents visited four different residential schools which they heard about from the support group AFASIC. They settled on St Catherine's, but the LEA refused to agree. They recommended a school for children with moderate learning difficulties. Patrick's parents decided to go to the Special Educational Needs tribunal.

> *It was a fight all the way, but the Authority were just seeing how far we were prepared to go. Going to the tribunal is a very expensive business and would mean bankruptcy for most parents.*

Eventually the Authority gave in when it became clear that Patrick's parents were not going to. Up to this point though, they'd had to spend a lot of money on independent reports and solicitor's fees in order to make sure their case was strong enough. Not only was the financial cost high, the impact on the family was also severe.

> *My daughter stopped eating because all the attention was focussed on Patrick. She became very thin with her bones protruding. She then developed M.E.*

6.2b Analysis

It will be recalled that the research involved interviews with parents in three different Local Education Authorities. The data from these interviews was analysed in two ways. Firstly, for each of the three counties, the data from the five interviews was combined to give a picture of the experiences of parents in that county. A summary of the key points is shown in Figure 6.1.

Isle of Wight	Sussex	Dorset
▪ No support/advice from the LEA ▪ Lack of information about statements ▪ Decisions driven by funding ▪ Statement not always translated into action ▪ Large emotional costs ▪ The need for single-mindedness from parents	▪ Lack of information ▪ Misinformation ▪ Other parents offering support ▪ Statements ineffective ▪ Reviews very useful ▪ LEA attendance at reviews erratic ▪ Dense language used in reports ▪ Some children kept out of school ▪ High levels of stress for the families	▪ Lack of help from the LEA ▪ Perseverance required ▪ Emotional problems for the whole family ▪ Ineffectual statements ▪ Lack of funding ▪ Help from other parents ▪ Some children kept out of school

Figure 6.1: Key points relating to each county.

All three counties showed a similar picture, with the themes being the same in each. Parents in all three counties felt that they were not supported or helped by the LEA. In two of the counties, other parents were cited as sources of help. In all three counties, the statements of special educational needs were not felt to be useful. Parents felt that the statements were ineffectual and not translated into action. Parents in two counties claimed that they were not given appropriate information, and in one of those counties, parents went so far as to suggest that they were actually misinformed. Funding was cited as the problem in two counties. In all three, emotional problems and stress were quoted as consequences of the whole process.

The second stage of analysis involved drawing out a list of themes directly related to the interview questions, and scoring each interview accordingly. This information is shown in Figure 6.2.

	Theme	Negative responses	Neutral responses	Positive responses	Total
A	Relationship with the LEA	12	2	1	15
B	Level of partnership	12	2	1	15
C	Relevant information received from the LEA	10	1	4	15
D	Support from the professionals	12	0	3	15
E	Effectiveness of the statement	8	2	5	15
F	Emotional impact	13	2	0	15

Figure 6.2: Themes from the interviews

This information was converted into percentages, (Figure 6.3), and histograms were drawn, (Figure 6.4).

	Theme	Negative (%)	Neutral (%)	Positive (%)
A	Relationship with the LEA	80	13	7
B	Level of partnership	80	13	7
C	Relevant information received from the LEA	67	7	26
D	Support from the professionals	80	0	20
E	Effectiveness of the statement	54	13	33
F	Emotional impact	87	13	0

Figure 6.3: Themes from the interviews as percentages

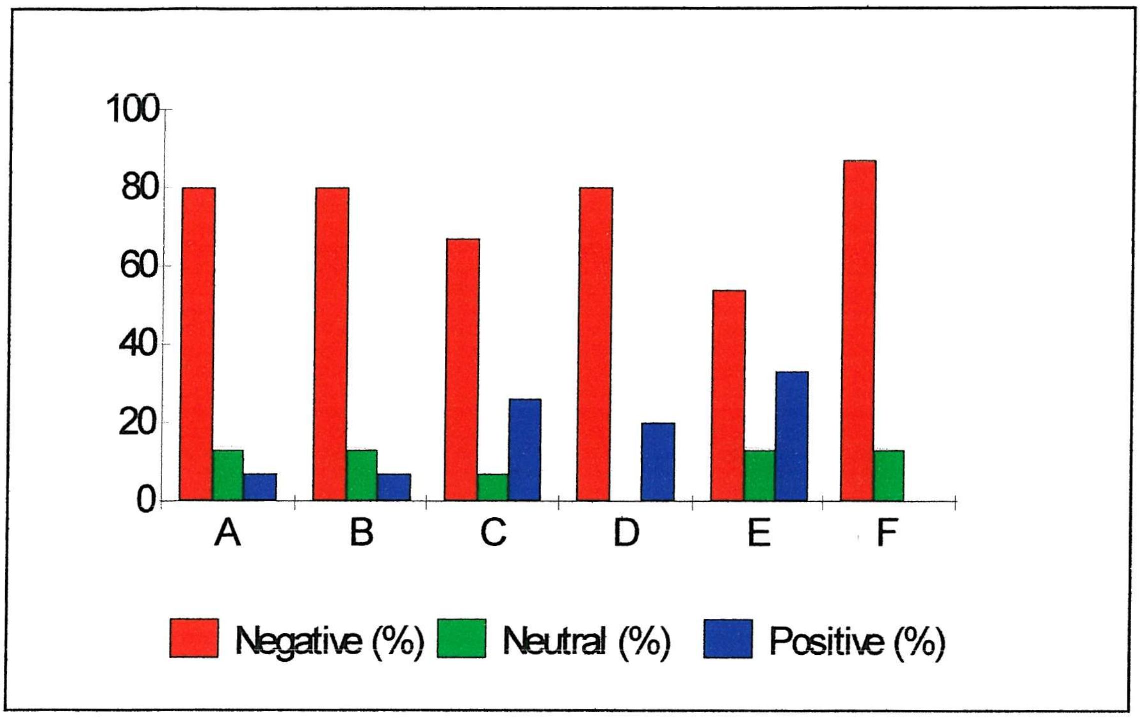

Figure 6.4: Graph of themes from interviews

For all of the six themes identified, there were many more negative responses than positive ones. Neutral responses in all cases counted for a small percentage. For both the relationship with the LEA, and the level of partnership, twelve times as many parents were dissatisfied as those who were satisfied. Over twice as many parents were unhappy with the information they received, if they did indeed receive any, as those who were satisfied.

When questioned about support from the professionals, the ratio of negative to positive responses was four to one. There were no neutral responses; parents felt either one way or the other. The area in which the responses were the closest was in relation to statements. Of those parents interviewed, about half were dissatisfied; the other half were either satisfied or non-committal. Some 33 percent were positive about the provision of a statement. In some ways, the provision or not of a statement, and its subsequent effectiveness, is one of the more concrete areas. Either there was a statement or there wasn't, and it either had the desired effect or it didn't.

Perhaps the most striking result was in relation to the effects on the family of the process. 87 percent of parents claimed that there were serious emotional effects upon members of the family. This was sometimes the parents, sometimes the other child/children. In some cases it was claimed that the whole family suffered. None of the parents interviewed made any kind of positive response to this question.

Chapter 7: Findings

7.1 What kind of support do parents receive, and from whom?

Furneaux (1988) claims that parents need a number of things from the professionals in order to fulfil their role in their children's education adequately. Among these are; *the need for support and reassurance and the need for practical help* (p. 41). The questionnaire data indicates that very few parents received support from the Local Educational Authority professionals. In answer to the closed questions, 29 percent of the parents felt positive about the support from the LEA, compared with 59 percent who felt negative. When asked about support from other parents, half of the respondents agreed that this was their main source. When responding to the open questions, parents were able to be more forthright. 87 percent of parents gave a negative picture of the support received from the LEA.

Data from the interviews gave a similar picture. In all three counties surveyed, parents complained that there was little support available to them officially, and that they only received it from other parents. Four out of five parents were negative about the LEA with respect to support services.

The main sources of support cited by parents were:

- Association For All Speech Impaired Children (AFASIC)
- Independent Panel for Special Education Advice (IPSEA)
- Speech and Language Therapists
- Other parents
- Schools

The government has a duty to provide information to parents; it is not quite so clear about their duty to provide support. The new Code of Practice states categorically that all LEAs must make arrangements for parent partnership services. They do not have to set up these services, but they need to inform parents about the arrangements. These services have a role in supporting parents, so LEAs have some responsibility in this area. The research by Vaughan (1989) showed some 86 percent of LEAs failing to mention the concept of parent-professional partnerships. This figure is about the same as the result in the present research. It would seem from the information here that the LEAs in this survey are not providing as comprehensive a service as they ought.

7.2 Do parents receive relevant, and accessible, information from their LEA?

The questionnaire data showed a similar picture to the previous section regarding support. 66 percent of parents in the survey were unhappy about the level of information provided by the LEA, compared with eighteen percent who felt positive about the provision of information. Half of the parents received the information from other parents.

The data from the open questions revealed 84 percent of parents as not receiving information from the LEA. 52 percent of parents felt that they were not kept informed by the authority.

The main sources of information for parents were:

- National Educational Charity for Children with Speech and Language Impairments (I-CAN)
- Association For All Speech Impaired Children (AFASIC)
- Independent Panel for Special Educational Advice (IPSEA)
- Teachers
- Other parents
- Books

Almost half of the respondents quoted teachers as their main source of information, and about one third received their information from AFASIC. This compares with one tenth of respondents who did receive information from the LEA.

The data from the interviews showed 67 percent of the parents in the survey as dissatisfied with the level of information provided. Seven percent were in the middle, and 26 percent were positive about the provision of information by the LEA.

The new Special Educational Needs Code of Practice has this to say:

> *They [parents] should be supported so as to be able and empowered to have access to information, advice and support during assessment and any related decision-making processes about special educational provision.* (DfES 2001, p.16)

The government places great emphasis on providing parents with relevant information, but it is clear from this research that LEAs are not meeting their obligations. As with support, parents are having to actively seek the information they need. This is difficult for many parents as they do not know what it is they are looking for in the first place. One parent explained her experiences;

> *Once in the system, we became aware that if we did not go out and find out for ourselves, our child could well be placed inappropriately. The advice was mainly gained from the Headmaster, teachers and health professionals at Maudesley who encouraged us to fight our case and directed us appropriately.*

7.3 What kind of relationship do parents have with the LEA professionals involved?

> *LEAs need to ensure that they are accessible, welcoming and value the views and involvement of parents. (DfES 2001, p.18)*

The data from the questionnaires showed that nearly half of the respondents (40 percent) felt that the relationship with the LEA was strained. At the other extreme, thirteen percent felt that they enjoyed a very good relationship. Parents whose relationship was good did not elaborate on this, whereas parents who were dissatisfied often went on to explain in more detail how they felt;

> *They were not really listening to what we were saying - hoping that we would back down and believe what they were saying was in our daughter's best interests. I think they were quite shocked when they realised that we had found out what was available and were prepared to go the tribunal to get it.*
>
> *!!! Had to write to the Director of Education and did lose my own dignity in order to get our case heard as our child was going to be put in an SLD school with an IQ of 80. We found this disgraceful as so many children it would seem are being inappropriately placed.*

The data from the interviews showed that 80 percent of parents felt that the relationship which they had with the LEA was negative. For a government which places such store on effective relationships with parents, these figures do not show it in practice.

7.4 How valuable is the statement of Special Educational Needs to parents?

The statement of Special Educational Needs is potentially a very important document. It details precisely what provision is required for a child's education, and as a legal document should act as a guarantee of that provision. Paige-Smith (1996) explored the issue of statements and concluded that in reality the statement was not always translated into practice.

The data from the questionnaires in the current research showed 59 percent of the parents as feeling that the statement was not a valuable document compared with 31 percent who valued it. The interviews showed a similar picture with 54 percent of parents feeling that the statement was ineffective and 33 percent feeling that it was useful. One parent said;

> *The statement seems meaningless. Only if parents fight for what's on the statement is it any use.*

Another parent explained how she fought for five years to get a statement written. Her son attended a variety of schools which she felt were not meeting his needs. Once the statement was signed, everything went smoothly, but it had taken a massive struggle to get there. The effect of this was a stain on her marriage and family relationships. Another parent had this to say;

> *Once the statement was produced, it didn't get any better. The statement said nothing new.*

For the majority of parents in this survey, the statement was not the immediate solution to their problems.

7.5 What are parents perceptions of the professionals involved?

This question is a little more difficult to answer, dealing as it does with a more general view of things. In some ways, it is a summary of the findings from the other questions. For most parents, the perception seems to be a rather negative one. There were some parents who felt very happy with the way things happened for their children. The following examples from the open questions illustrate this;

> *They were very helpful and were supportive towards myself.*

> *We had a totally different experience with Derbyshire, who were excellent/supportive throughout the process of finding a placement/reviews etc. Felt "consulted" throughout and that child's needs were paramount.*

> *I realise that our experiences are not the norm, but we have always been satisfied and pleased with our dealings with Shetland and Dorset LEAs.*

One thing which is apparent is that there is a great discrepancy between different authorities; and that within an authority there are variations in the provision. It is interesting that even in the quote above which is very positive, the parents are somehow aware that their positive experiences are unusual. Another parent who had a good experience with the LEA explained how things had happened and finished by adding: *"We had no difficulty with the LEA.....very unusual I believe."* However, in this survey, there were certainly more parents whose experiences were negative than those for whom it was positive.

> *I find them very unhelpful as an organisation and believe they are more interested in evading the problem, rather than trying to find an acceptable solution.*

> *The Educational Psychologist and Speech Therapist wrote their reports with financial constraints in mind.*

> *The process was further drawn out by the LEA trying to manufacture (inappropriate) provision.*

> *It was necessary to use the "iron fist in a velvet glove" approach and remind them of their statutory obligations.*

This last comment is a telling one. How many parents would be well versed enough to know the statutory obligations, and how many would be confident enough to explain them to the authority? Many parents would be much too intimidated. There is certainly a need for parents to become more confident in dealing with professionals, but also a need for professionals to be more approachable. One parent explained how she gained satisfaction from the LEA because she grew in confidence;

> *They have largely done what I asked for because I knew what to ask for and how to ask for it (eventually).*

Another parent explained how she had to be very determined in order to get the answer she was looking for;

> *If I came across an unsympathetic person, I went above her head to find the sympathy I needed.*

7.6 Do parents feel that they are partners in the process of assessment of their children's needs?

Partnership has been an important theme for the government. The new Code of Practice makes many references to it.

> *LEAs should work in partnership with local parent and voluntary organisations, as well as the parent partnership service, to produce materials and ensure that parents receive comprehensive, neutral, factual and appropriate advice.* (DfES 2001, p.18)

The data from the closed questions in the questionnaires showed that 44 percent of respondents felt that there was no real partnership in evidence. This compares with 37 percent who felt that there was a positive feeling of partnership. This is not a great difference and indeed is the narrowest margin between positive and negative responses for all the questions. The open questions gave a different picture with 88 percent feeling negatively about the concept and only four percent feeling positive about it.

> *We had to seek a special solicitor to help us. There was no "relationship" with the LEA.*
>
> *They did not involve us in the decision process other than the usual asking for comments.*
>
> *I have had to do all the work of finding schools for Jason. They've done nothing at all.*
>
> *Never spoke to the same person twice.*

Most of the other comments were, *"poor"*, *"nil"* or *"non-existent"*. The difference between the open and closed questions is quite striking. In the closed questions, the data comes from two distinct questions, one about partnership, and one about involvement. In analysing the questionnaires, there were more favourable responses to the question of involvement, so perhaps the difference comes down to terminology.

The data from the interviews showed the same pattern as for the open questions; 80 percent of interviewees were negative in their descriptions of partnership, compared with seven percent who were positive. The themes were of struggle and of lack of communication or discussion.

> *It was a long drawn out process. I had to do most of the work myself. If I hadn't bothered, Robert would still be where he was.*

> *It was a fight all the way. We had to fight for the things, all the assessments, all the way along.*

> *I didn't really know what to do and there was nobody to ask. There was no support or anything.*

> *It's been a battle for twelve years, one fight after another.*

The idea of partnership, which the literature indicates to be vital, and which the government certainly seems to be championing does not seem to be in evidence in the LEAs involved in this research.

7.7 What are the factors leading parents to consider taking an LEA to an SEN tribunal?

Very few of the parents in this research had cause to turn to the tribunal. Many parents had, however, considered it, and thought that they would have used its services if they had not eventually gained a successful outcome.

> *It would have been our next step if Maurice hadn't been accepted at St Catherine's when he was.*

For these parents it was about the struggle that they were having with the LEA and whether or not they felt it would be resolved. The question of cost was one which deterred many.

> *Going to the tribunal is a very expensive business and would mean bankruptcy for most parents.*

> *My family helped us to fund the legal process.*

Those parents who did become involved in tribunal proceedings had mixed stories to tell. For some it was further turmoil;

> *The Special Educational Needs tribunal was harrowing due to the lengthy legal process. The tribunal came down on our side and described perfectly a specialist speech and language school.*

> *Very stressful, money/funding was more of an issue than appropriate provision.*

For other parents the tribunal process was more favourable;

> *It was very fair. We, as parents, were allowed to speak first and give an account of our child's needs and how they should be met, and to comment throughout the tribunal.*

> *Very helpful and very friendly on the telephone before the hearing.*

7.8 What is the emotional impact upon the parents and/or the family of the process of assessment of their children's needs?

The literature revealed much research detailing the stresses upon parents of children with special needs. The data from the current research confirms this picture and shows very clearly that the emotional cost of the assessment process is very high. The open questions revealed a 22 to one ratio of negative to positive responses. 89 percent of respondents felt that the assessment process was stressful. Only four percent felt that it was stress-free. Chapter five gives many examples of parents' feelings towards this issue; here are some further examples;

> *Traumatic and devastating effect on the whole family until the tribunal decision and even afterwards when the LEA have tried to get their own back because they lost so badly.*
>
> *Stressful. Everything we did to secure an appropriate placement was a battle.*
>
> *My child was delayed in getting the appropriate education for three years! For us it was close to a "nervous breakdown".*

What is striking with these and the other comments is their passion. Words such as "*devastating*" and "*highly traumatic*" are unequivocal in how they portray things. Phrases such as; *"nervous breakdown", "my home and family were neglected", "very stressful on my son",* make it very clear. The great majority of parents in this research suffered a variety of ill effects because of the system.

The interview data was much the same as for the questionnaires. All three counties revealed the same picture of high levels of stress for families. Overall, 87 percent of interviewees felt that it was a stressful experience, and none felt it to be positive. This is the most stark picture in the whole survey. The comments which parents made in the interviews were very similar to those quoted from the questionnaires, and again, most paint a very extreme picture;

> *I was on anti-depressants and close to a breakdown. The stress on me and the family has been enormous. My other two children suffered as I had no time for them.*

7.9 Conclusions

There is certainly evidence of good practice revealed by this research. Those parents who were impressed by the service they received were very impressed.

Clearly, in some cases, the Local Education Authority has been able to meet the needs of the children in question. However, this is not consistent, and indeed, seems to be the exception rather than the rule. By far the majority of parents in this study were not content with the level of service they received, nor with the provision made for their children. Most parents felt that partnership was not a feature of their relationship with the LEA and that for the most part they were in opposition with the authority. The processes for helping their children did not happen naturally, and generally only when the parents were prepared to fight did they happen at all.

The impact of all of these issues is that for families which have children with speech and language difficulties there are enormous stresses and strains. Some of these are a natural result of the fact that their children have special needs; but they are compounded and exacerbated by a system which seems resource-driven and impervious to the human suffering. The evidence suggests that parents of children with speech and language difficulties have to take on a number of additional roles and go to great lengths to demand the things which, by law, should be provided automatically.

7.10 The way forward

The themes that come out of this research suggest a number of areas for change. Parents were asked to contribute suggestions for change. Broadly, these can be summarised in the following four points:

- Better information. Parents are entitled to accessible and relevant information. This should be provided as a matter of course.
- A speedier process. The length of time for assessment and provision to be made is very stressful for parents and the children involved. While it is going on, children are very often out of school, or in an inappropriate school.
- More empathetic professionals. The stresses on parents are great and professionals who understand this and can work to help reduce them would be extremely important.

- More funding. For most parents, their perception was that this was the ultimate barrier. In some ways, this governs all the other points. If the funding isn't there, it doesn't matter what else happens, the appropriate provision isn't going to materialise. Two comments from parents sum this up;

  > *Eradicate the financial aspects away from the needs of the child. These two things should not be juggled together.*

  > *There shouldn't be a price tag on children with special needs.*

Appendix

i) Interview Questions

These questions were asked in each interview session. Some parents were more forthcoming than others, so elaboration was asked for in some instances with extra questions or comments.

- How was your child's problem first diagnosed?

This gives some background to the situation and gets the parents thinking back to the early days when the problems were coming out.

- Which professionals were involved?

The research is concerned with parents' perspectives of the whole assessment process, and one aspect is the nature of the relationship between the parents and the professionals involved.

- Could you describe the relationship you had with the LEA?

This question explores not only the practical details of transactions between the parents and the LEA, but also the parents' feelings associated with them. Inevitably, when talking about the things that the authority did, (or didn't do), parents will describe those things in terms of how they were affected by them.

- What is your understanding of the term, "partnership", (and would you say it applied to your relationship with the LEA)?

The term "partnership" is one which has become more and more popular recently. It is one which is often described as being essential, but one which, according to much of the literature, is not well understood. As parents are the other key players in this partnership, it seems important to find out what their understanding of the term is. It is then vital to ask whether they feel that this applies to their own situation.

- What kind of information did you receive about the help your child could be offered?

Exploring the literature indicates that relevant information which ought to be forthcoming does not always reach parents. In some instances, parents only receive information once they have actively sought it.

- Where did you receive the information from?

Relevant information ought to come direct from the LEA in the first instance. In recent years a number of parent groups have come into being in recognition of the fact that useful information is not always forthcoming.

- What kind of support was available to you? (From where?)

Because of the difficulties which are involved in this whole process, many parents find themselves under a lot of stress. Again, the parent groups have been instrumental in offering support as well as advice to parents. Of course, this is not the only source of support open to parents, and this question explores what avenues are available.

- When was a statement of special educational needs issued?

The statement of special educational needs is an important document in many ways. As a legal document, it should be the means of ensuring that children with special needs receive the clearly defined help which they need. In many cases this is exactly what happens, but the literature indicates that this is by no means always the case. There are cases where the authority assesses the child's needs, issues a statement and the process runs relatively smoothly. There seem to be other cases where parents have to be very pro-active in seeking a statement. Coupled with the issue of parents receiving relevant information, this can prove difficult for many parents.

- What was the effect of the statement?

Because it is a legal document, what is written on the statement should materialise in practice. I am interested in looking at whether this is in fact always the case. Do LEAs adhere to everything on the statement? Are there differences between the different authorities? The other important point about this is that the statement becomes a seriously sought-after document and often takes a long time to be produced. Parents hopes are often riding on this and so if it does not have the desired effect, what does this mean to the parents?

- How did the whole process affect you personally?

The emotional impact of the whole process is one which interests me greatly. Because it is such an emotive issue it can affect people greatly. The fact that it is often far from straight-forward, and can take a great deal of time and energy, means that the process can have very serious repercussions for the parents.

- Where there any effects on the rest of your family?

The emotional impact on the parents can be great. It can be drawn out over a long time and which could have implications for the rest of the family. I'm interested in exploring how great the impact might be.

ii) Questionnaire

SPECIAL EDUCATIONAL NEEDS
Research questionnaire

Thank you for agreeing to take part in this research project by completing this questionnaire. Please give as much information as you feel able, and use the back of the sheet if you need more space. All responses will be treated in strict confidence.

Person completing questionnaire: Mother / Father / Carer

Local Education Authority: ___________________________

Please answer each question by circling a rating from 1 to 5
(1 = not at all; 5 = completely)

1. How helpful were the LEA?
   1 2 3 4 5

2. How helpful was the Educational Psychologist?
   1 2 3 4 5

3. How helpful was the Health Service?
   1 2 3 4 5

4. How involved did you feel?
   1 2 3 4 5

5. Did you feel that the LEA did everything they could for your child?
   1 2 3 4 5

6. Do you feel the LEA were constricted in what they could do because of finances?
   1 2 3 4 5

7. Did you receive information from the LEA without having to seek it?
   1 2 3 4 5

8. Was the information you received clear and easy to understand?
   1 2 3 4 5

9. Did you feel supported by the LEA?
   1 2 3 4 5

10. Was your main source of information other parents?
   1 2 3 4 5

11. Was your main source of support other parents?
   1 2 3 4 5

12. Did you feel like a partner in the process?
   1 2 3 4 5

13. Were you kept fully informed throughout the process?
   1 2 3 4 5

14. Do you feel that the interests of your child were at the heart of the matter as far as the LEA were concerned?
   1 2 3 4 5

15. Was a statement produced fairly quickly?
   1 2 3 4 5

16. Did the statement have an immediate impact?
   1 2 3 4 5

17. Did you feel that the process overall straight-forward?
   1 2 3 4 5

Please answer the following questions in as much detail as you feel able:

18. What were your main sources of information?

19. What were your main sources of help/support?

20. How did you find out information about appropriate courses of action?

21. What sort of relationship have you had with the LEA?

22. Can you describe any involvement you had with the Special Educational Needs tribunal?

23. Can you describe the level of partnership which you experienced with the LEA?

24. What mechanisms did the LEA employ to keep you fully informed?

25. Can you sum up the effect the whole process has had on your child and on your whole family?

26. How could the process be made easier for parents?

27. What single thing would you change about the system if you could?

Many thanks for your help and co-operation.

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