Starting School: The expectations of parents of disabled children

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

The focus of this study is twofold. Firstly, it aims to find out more about parents' expectations as their disabled child starts school and secondly, to explore ways in which parents of disabled children can become involved in the research process.

Legislation sets out what parents have the right to expect in terms of their child's education and current government initiatives and policies are encouraging parents to play a more significant role in the development of services. Yet services for disabled children and their parents continue to adopt a needs based approach. Such an approach is contrary to the social model of disability that focuses on removing the barriers that prevent disabled people being included in society.

By adopting a social model of disability the study aims to conduct the research from the parents' perspective. To this end it attempts to develop a parent participatory research approach which is derived from an emancipatory research approach advocated by disabled researchers and their allies. It investigates methods whereby parents of disabled children can participate in developing the research methods used and be offered a voice to express what is of importance to them.

This research study is a longitudinal study that investigates the expectations of 19 parents of disabled children as their child moves into school. It helps to identify the sources, nature and outcome of their expectations and so the barriers that can help and/or hinder positive outcomes. The implications of the findings are discussed in terms of parent's knowledge and understanding of their child's disability, relationships developed between parents, professionals and practitioners, the effect of government policy and the disabled people's movement for social change.

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Abbreviations

IEP	Individual education plan
LEA	Local education authority
OFSTED	Office for Standards in Education
SEN	Special educational needs
SENCO	Special educational needs co-ordinator
PAG	Parents' advisory group
PPS	Parent Partnership Service
PSSS	Pre-school Support Service
QCA	Qualification and Curriculum Authority

Introduction

> *From that moment my life diverged from the way of the lists. It was as if I had been following some roughly mapped route and, suddenly the car swerved wildly and I began to plough through terrain I had never dared venture into. When a baby is diagnosed with cerebral palsy, it is unclear where in this foreign land she will fall. Low expectations of children with cerebral palsy – as with all children with disabilities – inevitably encourage such children to underachieve. My daughter might do all sorts of things – and she might not. There would be no certainties. When I tried to construct a Life List it dissolved into daily tasks. I could no longer imagine what lay ahead.* (Birkett 2000 p. 190)

At the time of the diagnosis of their child's disability, parents[1] can find their expectations of parenthood shattered. What they envisage will happen to themselves and their child in the future can be difficult to imagine until they start to develop some understanding of their new situation and rebuild their expectations.

As a parent of a young person with a learning disability and an early years practitioner supporting families of disabled children, I have experienced this process from a parent's perspective. I have become increasingly aware that, despite the development of services that are based on a philosophy of partnership and designed to respond to parents' needs, their experience of building new expectations during the child's early years is diverse. Some parents have existing experience of disability and education and/or receive information on which to develop new expectations whilst others remain uninformed and confused.

In my experience of talking to parents of disabled children, of particular concern is their child's transition into school because parents have to deal with different

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[1] 'Parents' in the context of this thesis will refer to the main carer of the child. This may be the natural parent, a close relative, such as a grandparent, a foster parent or an adoptive parent.

procedures when selecting and securing a place for their child who may need additional resources. These procedures can help inform parents and widen their experience so develop their understanding and expectations of their child, their role as a parent and what will happen with regards to their child's education. However parents' experiences of these and their experience of their child in school can vary and change over time. Some parents are satisfied with the child's placement and develop positive relationships with practitioners who establish good channels of communication between home and school, whilst others are dissatisfied with the provision available for their child and contact they have with school.

One of the aims of this study is to find out more about parents' expectations of their child's transition into school. Nineteen parents of pre-school disabled children participated in a series of three interviews. Information was gathered about parents' expectations prior to their child going to school, the sources of their expectations and their outcome after the child has been in school for three terms. The parents were invited to comment on the way in which their expectations developed over time and the causes identified. In addition to parents' individual expectations, information was gathered and activities used to identify the shared expectations of the group. During the analysis process, the information from different parents was compared and examined to indicate what helped and hindered parents in developing their expectations.

This study adopts the parents' perspective by exploring ways in which they could become involved in the research process. For example, the style of interviewing used allowed parents to talk about issues that were important to them so the content of the data reflected this. A different group of parents who had older disabled children were involved through a research advisory group. They offered advice and helped in the analysis of the data.

The research study therefore, firstly, provides information about the focus, development and outcome of the expectations of parents of disabled children at the time of their child starting school. This can aid professionals' and practitioners' understanding of the processes involved in parents' adjustment to the news of their child's disability. Secondly, it explores ways in which parents can have a greater involvement in research about issues that concern them and their child.

The initial chapter provides an account of the current issues that impact on the lives of parents of disabled children. Chapter 2 provides a rationale for the methodology used in the study and information about the research design. These are reported and discussed in Chapters 3 and 4. Parents' expectations, their basis and outcome are described in chapter 5 and discussed in chapter 6. Finally, the conclusions and implications of the study are outlined in chapter 7.

Chapter 1

Parents of Disabled Children: Current issues

1.1 Introduction

Following the diagnosis of a child's disability there are a number of issues that impact on parents' lives. Of particular relevance to this study are those associated with changing views about working with parents in education and issues concerning disability. In this chapter these will be examined and related to the aims of the study and the research questions that were addressed.

1.2 Changing views about working with parents

Society expects all parents to care for their child, support their learning and become involved in their education. The recognition of the value of good relationships between home and school dates back to the 1960s when research indicated links between parental attitudes towards education and pupil attainment (Douglas 1964, Plowden 1967).

Subsequent legislation (Education Acts 1980, 1986, Education Reform Act 1988) increased the power of parents to influence what happens in schools. Parents then had rights as 'consumers' of education for their children, which include, for example, the right to:

- express a preference for a school for their child,
- to receive information about the school and their child's progress,
- contribute to the management of the school through parental representation on the governing body,
- be consulted as part of an OFSTED inspection,
- be consulted about home-school agreements,
- appeal against decisions made concerning their child's education.

The Warnock Report (1978) and the 1981 Education Act, although concerned with pupils with special educational needs (SEN), introduced the notion of working in partnership with parents. The term *partnership with parents* has been widely researched and debated by many people working in education, for example Bastiani

(1987, 1988, 1989), McConkey (1985), Pugh (1989), Pugh et al. (1994), Wolfendale (1989, 1992, 1999) and Wolfendale and Bastiani (2000).

1.2.1 Models of working with parents

Dale (1996) offers an account of the historical development of partnership between parents of children with SEN and professionals, which can be equally applied to all parents. Originally professionals were perceived to be experts who educated children with little input from parents. With the advent of greater parental involvement in the 1970s and 1980s opportunities were given to parents to participate in school and curriculum focused activities to support the work of the school. This has ultimately resulted in attention being afforded to the parental role as a complementary educator outside of school, which supports the view that a child's educational achievement is a joint responsibility of home and school (Tett et al. 2000, Tett 2001).

However the imbalance of power in parent-professional relationships was recognised and the notion of partnership introduced, which for some meant that parents would adopt a more influential role in education and associated services. Dale (1996) argues that its meaning was vague and misleading and partnership was not a reality for many parents. Differences of opinion resulted in further analysis leading to the consumer and empowerment models of partnership. The consumer model (Cunningham and Davis 1985) was based on the premise that parents should have control over selecting appropriate schools and services for their child whilst the empowerment model (Appleon and Minchom 1991) endeavoured to promote parents' sense of control over their involvement whereby they could enter into relationships with professionals at the level they wished. Dale (1996) offers an alternative model called the 'negotiating' model of partnership, which she defines as:

> *a working relationship where the partners use negotiation and joint decision making and resolve differences of opinion and disagreement, in order to reach some kind of shared perspective or jointly agreed decision on issues of mutual concern* (p.14).

The basis of the negotiated model is a two-way dialogue involving each partner sharing his or her own perspective to aid the decision-making process. She envisages transactions to be cyclical whereby agreements and differences of opinion change over time but actions and responsibilities can be negotiated.

1.2.2 Government policy

The policy of the current government reflects the recent developments in working in partnership with parents. The principles are evident in two documents - Excellence in Schools (1997a) and Supporting Families: A consultation document (DoH 1998).

The first, Excellence in Schools (1997a) acknowledged the role parents play in helping their children learn and enlisted their help in raising standards in education through outlining practical ways in which schools can help establish partnerships with parents. Examples of family learning initiatives were provided which work from the premise that, by supporting parents' learning, not only do parents enhance their own skills but become more interested and confident in helping their children's learning. However, if such initiatives are to be successful, consultation and negotiation with families is necessary (Haggart 2000). Excellence in Schools (1997a) also reinforced the need to keep parents involved and proposed the introduction of a mandatory home-school contract. As a result of this paper, the School Standards and Framework Act (1998a) states that every school must now have a home-school agreement and parent declaration. The aim of this agreement is to clarify the responsibilities of the school and the rights and responsibilities of the parents so parents know what they can expect of schools and what is expected of them.

Secondly, Supporting Families: A consultation document (DoH 1998) reaffirmed the government's commitment to working with families and provided details of programmes aimed at supporting parents in their role of parenting. One example in the document is Sure Start, which aims to support families of young children through empowering their parents. It was envisaged that local programmes would respond to the wishes and needs of their communities and families, with parents themselves becoming involved in the planning, management and delivery of services.

Fundamental to many of the current government initiatives to help raise standards and promote social inclusion, is a change in the approach to involving parents in service delivery. The development of projects associated with family learning initiatives and Sure Start are based on the principle of consultation and negotiation whereby parents' input is valued and they have a role in developing, managing, delivering and receiving services. They are principles that comply with Dale's negotiation model of partnership (Dale 1996).

1.2.3 Summary

Legislation sets out what parents have the right to expect from their child's schools whilst current initiatives and policies are encouraging all parents to play a more significant role in the development of services. Although the experience of individual parents will be diverse, the government is developing policies that are moving towards a model of partnership that encapsulates empowerment, consultation and negotiation, such as that proposed by Dale (1996).

1.3 Changing views about disability

During recent years views about disability have changed as a result of a move for political change organised by disabled activists and their organisations (Johnstone 2001). This is now beginning to have an impact on the education of children with disabilities and their parents.

1.3.1 Defining disability

Disabled activists and their organisations define disability as:

> *The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from participation in the mainstream of social activities. Disability is therefore a particular form of social oppression. Impairment (is) the functional limitation within the individual caused by loss or damage to physical, intellectual psychological or emotional make-up.* (Rickell and Parry 1999 p.3)

But disability is a term that continues to have different meanings to different groups within society and an individual's understanding will have implications upon his or her attitude toward disabled people.

1.3.2 Models of disability

Oliver (1996) describes the above definition of disability as being based on a *social model*, which is concerned with how society disables people with impairments and imposes restrictions thus preventing them form being fully included within that society. He contrasts this model with the *individual theory* that locates the 'problem' of disability within the individual in that a functional limitation or psychological loss leads to disability. It is viewed as a personal tragedy because it suggests that 'disability is some terrible chance event, which occurs at random to unfortunate individuals' (p.32). This approach is referred to as the *individual, medical* or *deficit model of disability.*

Some disabled people believe that, in practice, the approach used in education, health and other services associated with disabled people continues to be located within the individual, medical or deficit model of disability. It shapes the structure of these services and the way they are organised to help individuals with their perceived problems (Marks 1999). The focus is upon assessing and defining what is abnormal or 'wrong' with the person and thereby defining an individual's 'needs'. In the process, disabled people argue they are regarded as helpless and dependant so able bodied people perceive they have the right to take care of and control the lives of those people *they* define as disabled (Vlachou 1997). Disabled people become objects of pity and charity (Morris 1991) and are disempowered by the systems, procedures and by people's attitudes towards them (Morris 1991, Rioux and Bach 1994, Oliver 1996).

In contrast, the social model of disability rejects the idea that disability is about individual characteristics. Instead it is concerned with the structural and personal barriers created by society which prevent people with impairments fully participating. By listening to the individual and collective experiences of disabled people and bringing about social change the imbalance of power between disabled and non-disabled people can be redressed. Over the last three decades disabled activists and their organisations have sought to redefine disability according to this model. They argue that fundamental to the social model of disability is a movement for social change whereby disabling barriers and attitudes are removed so disabled people can be fully included (Barnes et al 1999).

Barton (2001) argues that removing disabling barriers and changing attitudes calls for the empowerment of disabled people, through raising their self awareness, identity and skills. They can inform others about discrimination and disablement and challenge the status quo thus establishing different values in government policies and legislation. Essential to this struggle for social change, Barton says, is the belief that change is possible – an attitude that needs to be encouraged by those involved.

1.3.3 Personal experience of disability

Whilst other writers support social change, they argue that this approach denies disabled people's personal experience of disability (Morris 1992, Brett 2002). Morris (1992) writes:

> *… … to experience disability is to experience the frailty of the human body. If we deny this we will find that our personal experience of disability will remain an isolated one; we will experience our differences as something peculiar to us as individuals – we will commonly feel a sense of personal blame and responsibility* (p.164).

Brett (2002) expresses a parent's perspective when arguing that the social model of disability and its call for collective action is inadequate for disabled children, as it allows little room for parents and others involved to voice their children's and their own experiences of marginalisation. She and others (Brandon 1997, Carpenter 1997, Widdows 1997, Case 2000, Mason 2000, Read 2000) have provided accounts of parents' experiences of caring for a disabled person and their role in bringing about social change.

1.3.4 Disability and education

The deficit model of disability continues to be the dominant model within the education system. Although the Warnock Report (1979), from which subsequent legislation (DES 1981, DfE 1993, DfEE 1996, DfES 2001a) and guidance (DfE 1994, DfES 2001b) originates, attempted to move away from the labelling of categories of disabilities, they were simply replaced with an alternative category of

SEN. The definition of a child having SEN is based on the child's individual characteristics and their ability to access educational opportunities alongside their peers. Although the recently revised Code of Practice (DfES 2001b) perpetuates this approach there have been changes in educational provision for disabled pupils to promote inclusion.

1.3.5 Inclusion of disabled pupils

Rieser (2001) traces the development of people's thinking since the time of the Warnock Report from integration or placement of pupils with SEN in mainstream schools, to inclusion, which involves valuing all pupils irrespective of their impairment and removing institutional barriers that prevent this happening. The Index for Inclusion (Booth et al. 2002) is a tool that has been promoted by the government, to review current practice in schools from different perspectives with regard to including and valuing all pupils. The aim is to help move practice and thinking forward, so bring about change (Ainscow 1999). Rieser (2001) describes a 'shifting climate of opinion' (p. 145) in education towards disabled pupils. For example, the QCA and OFSTED now provide guidelines for the delivery of teaching and learning for all pupils and inspection for educational inclusion. The SEN and Disability Act 2001 (DfES 2001a) have also supported the current government's policies to encourage the inclusion of disabled pupils in mainstream schools. Rieser concludes that, although still not plain sailing, 'inclusion involving the wholesale re-structuring of education to meet the needs of all pupils in mainstream schools is at least a real possibility and a reality for thousands of disabled pupils.' (p. 148)

Dyson (2001) considers a historical perspective of the development of special needs education. From one perspective greater inclusion can be identified, as described above, but the alternative view is less optimistic as the vested interests of professionals would be damaged by increased inclusion therefore they are less likely to support such social and political change. He describes what he calls 'the dilemma of difference' (p24) because current approaches are contradictory. They are proposing that all learners are the same, in that they all have the same human characteristics and the right to participate in the process of education, resulting in a system with common schools delivering a common curriculum using common teaching approaches. Conversely, learners are perceived as different because they have different learning styles, interests and needs which should be responded to through different teaching approaches, including variations in the common curriculum and the development of individual teaching programmes. Such dilemmas, he argues, require closer examination to understand and resolve but it is these dilemmas that face the parents of disabled children.

1.3.6 Summary

Disabled activists have endeavoured to redefine disability in social terms through raising awareness of the ways in which they are disempowered by society. In education, although the identification of pupils with SEN continues to be based on an individual, deficit model, there are moves to fund schools directly to develop inclusive practices and so respond to the diversity of need amongst all pupils. However this development is problematic as there continue to be anomalies when putting the principles into practice.

1.4 Working with parents of disabled children

Although parents of disabled children are part of the main parent population they also have very different experiences as a result of caring for a child with additional needs, from which they will develop needs of their own (Carpenter 2000). Furthermore they will find themselves part of the group of people in society who are affected by disability so likely to encounter the marginalisation and discrimination that disabled people describe.

1.4.1 Parents' experience of their child's diagnosis

Dale (1996) describes a number of models to help professionals understand parents' reaction to receiving the news that their child has a disability. Cunningham and Davis (1985) draw on Kelly's (1955) *personal construct model* to describe parents' reaction to their child's diagnosis. Kelly proposes that people, in order to understand their world and predict what will happen, construct mental models of events. They are called personal constructs and are based on an individual's beliefs and experience. Cunningham and Davis (1985) argue that parents create personal constructs of having a child and so develop expectations of the event. However, when a parent hears their child has a disability, what they probably anticipated will not have happened. Murray (2000) argues most parents are non-disabled people who have experienced a segregated education system and will therefore have had little or no contact with disabled people. Consequently, on hearing the news about their child, parents can become confused and uncertain about future events. Dale (1996) explains how parents begin to rebuild a framework whereby they begin to adapt to their new-found situation through asking questions and clarifying what they can expect. Parents often need ongoing support with this process as they experience life with their child and encounter the discrimination that many parents have described (Murray and Penman 2000).

1.4.2 Expectations of parents

Society has high expectations of parents of disabled children. They are expected to meet their child's needs through attending numerous hospital appointments or therapy sessions, working on specific activities at home set by therapists or Portage workers, liaising with the many different professionals and practitioners involved and meeting their child's additional care needs. When the child enters school their parents have a very different experience to other parents as they have to respond to legislation and procedures that relate to pupils with SEN. As a result, services have been developed to support parents to fulfil their additional responsibilities through meeting their particular needs.

1.4.3 Parents' needs

The Warnock Report (1979) introduced the concept of need in education when it recommended the identification of pupils who required additional or different resources whom the report referred to as pupils with *Special Educational Needs*. Alongside their children, parents were also perceived as having particular needs for information, advice, support and practical help. Since the publication of this report, government policies (DfEE 1997a, 1997b, 1998b) and subsequent legislation have been based on these recommendations (DES 1981, DfE 1993, DfEE 1996, DfES 2001a). In addition the recently revised guidance on the implementation of assessment and monitoring procedures (DfES 2001b) focuses on the needs of children and of their parents to be involved at every stage of their child's identification and assessment. Parents need to understand these procedures and deal with the processes involved. The government has recognised this need by promoting the development of Parent Partnership Services (PPS) through the

Revised Code of Practice (DfES 2001b) introducing guidelines and minimum standards for such services. In 2001 it became the law for every LEA to 'arrange for the parent of any child in their area with SEN to be provided with advice and information about matters relating to those needs' (DfES 2001a p3). In addition to statutory services voluntary organisations, such as Mencap, Scope, Network 81 and IPSEA have developed services aimed at meeting the needs of families.

1.4.4 Partnership with parents of disabled children

As for all parents, the government recommended that services for parents of disabled children should be based on a philosophy of partnership. For example, the DfES and DoH (DfES 2002) are currently working together to develop practical guidance for professionals working with families of disabled children from birth to two years of age to work in partnership with parents. For parents of disabled children, the concept of partnership is thought to enable them to play an active role in identifying and planning for their child's and their own needs, so be able to access services and support. However, in practice, partnerships between parents of disabled children and professionals are complex, due to the unique characteristics of the people involved and families' individual circumstances, which are further influenced by issues associated with, for example, the power and authority bestowed on professionals and parents (Dale 1996). The elements Dale (1996) suggests are conducive to successful partnerships between parents of disabled children and professionals are:

> *Firstly, a willingness in attitude and a commitment to partnership work and power sharing in the staff, and secondly, a conceptual framework and methodology of practice that could encompass the 'diversity' and discrepancies between parents and between parents and professionals* (p.27)

However partnership with parents appears not be a common approach for many professionals. Parents involved in an evaluation of PPSs, aimed at empowering parents, raised issues concerning the quality of partnerships and the extent to which they were being achieved, especially given the imbalance of power between the LEA and parents (Wolfendale and Cook 1997). Another survey by Rathbone (2001) found that parents of pupils with SEN in mainstream schools did not feel involved in partnerships with schools, their contributions were not valued and they lacked the knowledge and understanding to monitor their child's progress effectively. Furthermore, a study of parents' experiences of their child's annual review identified built in organisational and attitudinal barriers preventing the principles of the Code of Practice being translated into reality (Jones and Swain 2001).

1.4.5 Summary

So despite the rhetoric of partnership, for many parents of disabled children, service delivery continues to focus on meeting their needs, which frequently remain unmet and are less likely to be met than those of their child (Beresford 1995). They experience stress arising from, for example, their child's needs, their own emotional needs and negative reactions by others to their child (Beresford 1995, Read 2000). Further anxiety can be caused when seeking and trying to understand information, accessing a large number of services and working with a variety of workers who are not co-ordinated (Beresford 1994, Mencap 1997, Sloper 1999, Mencap 2001). Johnstone (2001) argues that the perpetuation of needs based provision, that is determined by educational professionals, fails to alter many of the old prejudices of the models of medical care 'involving bureaucratic assessment and insensitive diagnostic procedures' (p. 30) and that services create the problems that they are designed to resolve. This is precisely what Read (2000) found, when talking to mothers of disabled children. She writes:

> *… … it was ironic that contact with the services that were ostensibly there to help them (the mothers) and their children had proved to be some of the most stressful and difficult experiences they had had* (p. 34).

According to Corbett (1996) using the term 'need' in relation to special education implies 'dependency, inadequacy and unworthiness' (p. 3) and a far cry from a model of partnership with parents proposed by the government in their initiatives for *all* parents.

1.5 Parents of disabled children and the movement for social change

Changes in the way disability is viewed may also add to the difficulties parents encounter. Many parents are unaware of the different models of disability and/or the implications of their child's disability. Some parents may even be regarded as the cause of their child's marginalisation because they are perceived as too protective and do not allow their child to make their own choices and so have control over their lives (Morris 1997, Murray 2000). In addition, from a parent's perspective, a move towards a more inclusive education system can be a dilemma. Parents may perceive that inclusion could be beneficial for their child but it could also result in their own identity and rights being eroded. Two examples are discussed in the following section.

1.5.1 Parents and inclusion

Although Johnstone (2001) argues that the inclusion agenda places a greater emphasis on the rights of the child accessing education, it confuses the separate issues of social inclusion and inclusion of pupils with disabilities. Whilst many are striving for social inclusion of disabled people in the wider sense, MacKay (2002) proposes there is a danger that the identity of disabled pupils will disappear in the process and the same may happen to their parents so their needs may be overlooked. In addition, although policies are promoting mainstream placements for all children, it is not the wish of all parents of disabled children whose main concern is meeting the individual needs of their child.

Furthermore, it is becoming increasingly difficult for pupils to have an assessment and get a statement of their SEN as the government has advised LEAs to review their funding arrangements for pupils with SEN and reduce the number of children with statements in their schools (Pinney 2002). It was intended that, by increasing the delegation of funding direct to schools, they would be able to respond quickly and flexibly to children's needs so the focus would transfer to preventative work rather than assessment of need. According to the 1996 Education Act, LEAs have a legal duty to identify pupils with SEN, assess their needs, issue a statement and arrange for the special educational provision that is set out in the statement. Simmons (1996) argues that the law is needs led and entitles children to have their needs identified and met but the current government's policy towards inclusion is an attempt to remove the link between need and provision, so weaken the child's rights to detailed and specific support. It can also weaken the rights of parents because, as Farrell (2001) suggests, the procedures introduced for statutory assessment make the whole process more accountable to parents and have been a major contribution to raising the status of parents and empowering them to become more active in their child's education. Florian (2002) distinguishes between the process of assessment and the statement as the product, which is a legally binding document that safeguards the rights of vulnerable children. Although the process of their child's assessment can be a difficult and stressful time for parents, if their child does not have a statement parents lose their right of appeal should their child's provision not be implemented. As a result, parents become reliant on the goodwill of the school and people involved.

1.5.2 Summary

The different experiences of parents of disabled children mean they will need to adjust to their new situation by developing new expectations of what will happen. They need support and guidance to access services on their child's behalf but frequently, in the process, more needs are created than are resolved. The development of an inclusive education system may be regarded by some as beneficial for pupils but it can be problematic for parents who can lose their identity and voice in the process. How will they then be supported through the very different experiences they encounter as a parent of a disabled child? One of the aims of this study is to give parents of disabled children an opportunity to voice their experiences as their child's needs are assessed when they move into full-time education either in a nursery or reception class.

1.6 Parents' aspirations

Marks (1999), in her examination of the notion of need, distinguishes between the terms *need* and *want*. It is perceived by professionals that the needs of disabled people can be assessed objectively whereas what they want 'is treated as if it is based on individual *subjective* desires, and is thus seen as a 'dispensable luxury' rather than an essential requirement' (p 95). Mason (2000) argues that if disabled people are to have control over their lives, they need help to achieve what they want to do. Therefore what people *want* becomes important. In the case of parents, if they are to act as their children's allies in helping them achieve control of their lives, what they want in terms of their child's education has to be listened to.

A survey of thirteen parents of pre-school children with SEN carried out as a pilot study for this research (Russell 1999) indicated that parents wanted and valued services that:

- helped their child's development and health
- offered regular contact
- provided information and advice
- communicated with other services involved
- listened to parents' views, involving them in decisions about the approach and treatment for their child.

The findings supported those of other studies of parents (Blatchford et al. 1982, Hughes et al. 1994) and parents of disabled children (Sandow et al. 1987, Bennett et al. 1998).

1.6.1 Opportunities to achieve parents' aspirations

Roaf and Bines (1989) suggest that a focus on *opportunities* available to disabled children to achieve their aspirations rather than identifying their needs offers a better approach to special education as it raises issues related to the system and to discrimination. This equally applies to their parents. Therefore if all parents want similar outcomes from schools and education, the difference for some parents, particularly those of disabled children, are the individual details of 'their wishes, feelings and perspectives on their children's development' (DfES 2001b, para 2.2) and the opportunities available to achieve them. It is to do with individual goals and how they can be achieved. In setting goals, however, the likelihood of achieving them will consciously or unconsciously be estimated and the parent will form expectations of what they think will happen. As such, developing expectations will help parents form a more realistic view of what they think will happen rather than simply considering their aspirations.

1.7 Parents' expectations

I propose that a greater understanding about origins and outcome of parents' expectations about their disabled child's education could provide information about the opportunities available to help them achieve their goals. This study will seek to explore the expectations of parents of disabled children concerning their child's education.

1.7.1 Previous research concerning expectations in education

Studies about expectations in education fall into three principle groups, which are

- Teachers' expectations of pupils. Examples include Blease (1983), Brophy (1983), Good (1987), Babad et al (1989), Goldenburg (1992), Doherty and Heir (1998) and Rogers (1998).
- Parents' expectations of schools. Examples are West et al. (1996), Crozier (1999) and Foot et al. (2000)
- Parents' expectations of teachers. Examples are Tomlinson (1991), Crozier (1999) and Tartar and Horenczyk (2000)

Amongst the studies I reviewed there is little evidence of research concerning the expectations of parents of disabled children. Au and Pumfrey (1993) compared teachers' expectations of children's attainment with those of parents of children with moderate learning disabilities, Bennett et al. (1998) considered parents' expectations of inclusion and Wolman et al. (2001) investigated the expectations of parents of children with chronic conditions. Further work has been carried out with parents of children with SEN by the Children's Society (Fisher 2002). An inquiry into what these parents expect from the information, help, support and other services available to them led to a charter being written setting out what all parents of special needs children have a right to expect from the professionals and services they encounter. The aim was to inform service providers but the report does not indicate how their aspirations could be achieved.

In none of the studies referred to above was the notion of expectations explored, yet their origins, the ability of a person to articulate them and their effect on behaviour and beliefs are very complex. A closer examination of these can help us to understand more about the relationships parents of disabled children have with professionals involved in education.

1.7.2 Defining expectations

> *The concept of 'expectancy' forms the basis for virtually all behaviour. Expectancies can be defined as beliefs about a future state of affairs. As such, expectancies represent the mechanism*

> *through which past experiences and knowledge are used to predict the future* (Olsen et al. 1996 p. 211).

Expectancies are therefore subjective predictions about the future. Olsen et al. (1996) also argue that expectancies are more realistic because people tend to want more than they can rationally expect.

Economists (Holden et al. 1985, Torr 1988) distinguish between two types of expectations. Convergent expectations are based on a firm underlying structure so there is a high degree of certainty that they will be realised whereas divergent expectations are associated with uncertainty due to the subjectivity of the knowledge from which they are derived. However the value in working through a process of setting and reviewing expectations is that an individual will learn because those that are not fulfilled will enable them to review and possibly modify their long term expectations in the light of their new experiences.

Expectations can be linked to a person's behaviour. Vroom (1964) defines an expectation as 'a momentary belief concerning the likelihood that a particular act will be followed by a particular outcome' (p.17). For example, in situations that are uncertain, the outcome a person expects and the degree to which they think that the outcomes will be probable will affect their behaviour. Tajfel and Fraser (1978) associate expectations with social interaction arguing that social encounters are affected by the interplay of implicit theories or expectations each of us have about others. They are based on the range of social behaviour expected of everybody, of particular social groups and of individuals based on the specific knowledge of that particular person and can affect people's behaviour during social interaction.

Expectations therefore originate from and affect a person's beliefs, knowledge and experience. They also affect a person's actions and behaviour during the social interaction they have with others. It is therefore useful to examine the origins and effects of parents' expectations using the ecological model proposed by Bronfenbrenner (1977) in his study of human development. It is a study of how a person develops through interaction with their social environment.

1.7.3 Examination of expectations through an ecological model

Bronfenbrenner (1977) describes an ecological environment as different structures or successive levels of relationships that have an affect upon an individual's development and understanding of their world. He describes the structures as

- The **microsystem** or the relationship an individual has with their immediate physical and social environment. In the case of a parent of a disabled child this refers to their role in the home and in relation to school and other settings attended, for example, hospital clinics.
- The **mesosystem** refers to the interrelationships between the most significant settings in which an individual is involved at a particular time. For a parent of a disabled child it would include relationships between the family, other parents, school and professionals.
- The **exosystem** includes other specific formal and informal social structures that impinge on and so influence events. Significant influences for a parent of a disabled child include the education system, voluntary organisations and the media.
- The **macrosystem** encompasses the prevailing ideology and the institutional culture that informs the other systems. It includes the economic, social, legal, educational and political systems that, for a parent of a disabled child, will determine the beliefs and values of the society in which they live and care for their child.

This model has been used in the past with reference to families of disabled children (see for example Hornby 1995). For the purposes of this thesis each of the levels can be used to examine the concept of expectations more closely with particular reference to parents of disabled children. A summary is provided in figure 1-1 (page 21).

Level of interaction	For a parent of a disabled child this concerns their experiences of ~	Expectations developed that are associated with ~
Microsystem	• Their child • Caring for a child who has additional support needs	• Their child's development • Their own role as a parent • The role of significant other people in their child's life
Mesosystem	• Services received to support their child's and their own needs	• The role of people delivering services • Interaction with people delivering services
Exosystem	• National and local systems and structures designed to meet the needs of children with SEN • The working practices of people involved in implementing these systems and delivering services and their attitudes towards disability, pupils with SEN and their parents	• How systems and services will meet their child's and their own needs
Macrosystem	• The social environment and cultural values	• The social values bestowed upon them and their child

Figure 1-1 – The relationship between Bronfenbrenner's ecological model of interaction and the experiences and expectations of parents of disabled children.

Detail of this analysis is provided in a paper prepared as part of my studies entitled 'A critical analysis of the concepts of needs and expectations and their implications for the relationship parents of disabled children have with professionals involved in education' (Russell 2001) and an article 'Expectations of parents of disabled children?' (Russell 2003). A summary is provided below.

1.7.3.1 The microsystem

According to the personal construct model (see section 1.4.1), when parents are told their child has a disability they will begin to develop new expectations. These expectations will be based on parents' experiences of their child and their own role in caring for a child with additional support needs. In addition, parents will have direct communication with others, including their child's doctor, teachers and therapists, who should provide factual information about the child's condition but will also convey social information and values, which will influence parents' new expectations. Goodnow and Collins (1990) argue that parents do not automatically change their expectations as a result of new information but may choose to ignore it or change their reference group. Parents of disabled children are no different and may benefit from opportunities and support to reflect on expectations that have not been realised. It can result in more complex expectations being formulated in the future, which enable parents' adjustment to their new role and help them to become more confident in their actions to support their child. This can be challenging for some parents who ignore relevant information or do not choose to consider alternative options. A number of people working with families in the period following diagnosis advocate counselling for some parents for this reason. Dale (1996) also encourages professionals working with parents of disabled children to focus on discussing their expectations as a means of enhancing an understanding of their new-found situation.

1.7.3.2 The mesosystem

Parents will automatically generate unconscious expectations of people involved in services designed to meet their own and their child's needs. The expectations will relate to what they expect of the person concerned in terms of information, support and interaction. Parents will often only become aware of these expectations if they are not realised because of lack of information and/or stereotypical views of the parent and teacher, which affects their behaviour towards each other. Interaction between parents and professionals that is based on honesty, openness and trust where information is shared can result in each party being explicit about what they expect of each other, which can change over time. Dale's (1996) negotiation model of partnership is based on this approach. By parents and professionals sharing information and ideas they can negotiate what they expect of each other. This can not only offer parents an opportunity to think through new situations and future events in order to reconsider expectations and plan accordingly but it also encourages them to adopt a more active role in relationships that develop between them and professionals involved with their child.

1.7.3.3 The exosystem

Social interactions between parents, teachers and schools cannot be viewed in isolation. Guidelines for meeting the needs of pupils with SEN, outlined above, are imposed nationally through legislation and locally by LEA directives and school management policies. Also influential are the working practices and attitudes of people involved towards disability, the pupils themselves and their parents. One of the guidelines of the Code of Practice (DfES 2001b) states parents should receive information about the procedures and support available within the LEA and school. Yet in my experience of working with parents, few have previous experience of this process and many have difficulty understanding and applying it to their situation without additional support. Furthermore, parents and practitioners alike appear to have problems keeping abreast of the frequent changes in policies both locally and nationally of which they need to be aware and they do not always agree with the principles on which they are based. This can lead to confusion for parents who are endeavouring to develop an understanding and knowledge of what they have the right to expect for their child and secure provision, sometimes in the face of conflicting attitudes and practices of the professionals and practitioners they come to meet.

1.7.3.4 The macrosystem

Tajfel (1978) describes the influence of cultural information and ideology as reciprocal in that the social environment and cultural values mould an individual but an individual can also create and change them. An outline of the campaign for social change undertaken by disabled activists and their organisations has been included in this chapter. For a parent of a disabled child, cultural beliefs concerning disability are critical in all aspects of their lives. They determine the social values bestowed upon them and their child and impact on any interaction concerning educational provision. They are interacting at all levels – the teacher, the school, the LEA, the government – with people who have greater power than themselves over their child's educational provision (Armstong 1995). For some parents, as their expectations for their child are not realised they become increasingly aware of such barriers and become more active in the move for social change to improve their child's experience. Others, however, continue to be unaware that such issues exist.

1.7.4 Summary

Expectations are beliefs about what may happen in the future. They originate from an individual's beliefs, personal experience and through the acquisition of information. They are influenced by social interaction with individuals as well as organisations, legislation and cultural values. As unrealistic expectations can set the scene for disappointment and poor relationships, it is important they are based on a firm structure to increase the probability of them being confirmed. A study of parents' expectations could help to identify barriers that prevent them developing realistic expectations.

1.8 Studying parents' expectations

Goodnow and Collins' (1990) review of research concerning parents' ideas includes studies, from a wide range of perspectives in the field of social science, about the nature, sources and consequences of ideas. They describe 'ideas' as:

> *… … marked with a touch of myth, are linked to action, have a possible 'executive' function, are suffused with affect, and are often accompanied by a sense of attachment and ownership on the part of the believer* (p. 12).

Ideas such as these form the basis of parents' expectations, which is a term Goodnow and Collins (1990) use to refer to ideas that are linked to actions. However their model for examining, both, the content of parents' ideas and, also, the quality can equally be applied to studying parents' expectations.

1.8.1 Content of expectations

Goodnow and Collins (1990) found that studies about the content of parents' ideas focused on goals for their child, expectations of becoming a parent, responsibilities of parenthood and methods by which their goals can be achieved. These ideas were based on parents' personal experience and interaction with their environment, which included the effect of cultural influences they encounter, such as social information and formal knowledge. Goodnow and Collins (1990) describe the sources of parents' ideas as being numerous, varied and sometimes contradictory so parents interpret what is of value and what they perceive to be legitimate. They found that, as parents interact with others through, for example, differences of opinion, shared experience, joint action, so their experiences change and new information is received. As a result parents' ideas change and develop over time.

I believe that by asking parents of disabled children about the content of their expectations could help them develop an understanding and clarify what they are expecting of their child, their role in parenting and ways in which they expect to achieve their goals. Exploring the sources of parents' expectations would provide information about their beliefs and experiences relating to education and disability and their existing knowledge base. Over time it would be possible to examine the relationship between parents' changing experiences, new information and developing expectations.

This information could help identify gaps in parents' knowledge, understanding and the support that is offered to them. It could also illuminate cultural and attitudinal barriers that prevent parents developing convergent expectations, which have a high degree of certainty of being realised, so avoid negative effects on parents' self esteem and confidence.

1.8.2 Quality of expectations

Goodnow and Collins (1990) refer to the quality of ideas as concerned with variations in 'the degree of accuracy, certainty, differentiation, openness to change, centrality for other ideas, consensus or congruence with the ideas of others' (p.15). The quality of parents' ideas is associated with their level of experience and knowledge and the opportunities parents have to reflect and compare them with the ideas of others. Ideas can be explicit or implicit but parents need to be aware of their ideas in order to consider them. Goodnow and Collins (1990) argue that it is only by parents articulating and discussing their ideas with others that a shared meaning and understanding can be achieved from which new ideas can develop. Where parents have more experience there is greater consensus with the ideas of other people but for parents with limited experience and fewer opportunities for comparison there is greater reliance on expert opinion. Ideas that are connected and structured to other ideas and beliefs the parent has are more difficult to change. Parents, however, use their ideas to test their personal theories, so confirm their current beliefs and develop firmer expectations of what will happen in the future. It is evident this is the experience of some parents of disabled children from the accounts written by parents themselves (see for example Hebden 1985, Philps 1991, Meyer 1995). Alternatively, expectations that are not realised are used to develop new ideas. Goodnow and Collin (1990) demonstrate how expectations arise out of actions and are precipitated from a person's actions and their outcomes can be a measure of the quality of a person's ideas.

I propose that helping parents to develop the quality of their expectations could enable them to act more confidently in their dealings with school practitioners and other professionals so achieve what they believe is right for their child.

1.9 Focus of the study

The focus of this study therefore is parents' expectations when they have a disabled child. Whilst this group of parents clearly have the need for support and information given their particular circumstances, which has been reflected in the development of services, their expectations are also of importance. Developing their expectations could help parents' understanding following their child's diagnosis, the development of relationships with professionals and practitioners involved with their child, their understanding of legislation and procedures that apply to pupils with SEN and raise their awareness of issues relating to disabled people. A study of this process could help to identify what helps and hinders parents' expectations being developed and realised over time. Research that focuses on expectations also reflects the changing attitude towards a rights based approach for working with parents and disabled people whereby people have greater involvement in determining and developing the type of support and services they need.

1.9.1 Studying parents' expectations at the time their disabled child starts school

A study of parents' expectations is appropriate during the time of their child's statutory assessment and transfer into full-time education. It is a clearly defined time when parents can be easily identified in that their children have started the statutory assessment process and therefore meet the criteria described in the Code of Practice (DfES 2001b). It is a time when children and parents are moving from one system to another so provides a valuable opportunity for parents to compare and comment. They will have formed some expectations based on their previous knowledge and experience. They will know what is valuable to them and therefore how they would like to become involved with the new setting – the school.

A second reason for choosing the period of transition into school as a basis for the study is outlined in the government's Green Paper, "Excellence for all children – Meeting Special Educational Needs" (DfEE 1997b). They state:

> *The best way to tackle educational disadvantage is to get in early. When educational failure becomes entrenched, pupils can move from demoralisation to disruptive behaviour and truancy. But early diagnosis and appropriate intervention improve the prospects of children with special educational needs, and reduce the need for extensive intervention later on* (p. 12 - 13)

For parents it is similar. It is important to establish, from the beginning of the parent's experience of their child's school, effective communication and positive partnership, characterised by value being given to the parent's role in their child's education and future. If this happens it will avoid the need for conciliation and appeals in the future to overcome disagreements and breakdowns in communication between home and school. It is important to get relationships right, at the beginning, as it is more difficult to rectify problems when there have been difficulties.

Bentley-Williams and Butterfield (1996), in their study of transition for disabled children from early intervention programmes to school, found that parents' perceptions and beliefs guided their actions and developed as a result of parents' previous experiences. This study, at the time of transition into school, will therefore draw on parents' experiences of pre-school services from which they will have developed their perceptions and beliefs and so their expectations. As they enter into a new situation, it provides an opportunity for parents to reflect on what some parents described as very dramatic changes in the way that they work with professionals who are involved with their child. The findings can raise professionals' and practitioners' awareness of the experiences encountered by parents so enable them to reflect on their practise when establishing relationships with parents of disabled children.

1.9.2 Summary

Research into the content and quality of parents' expectations could help the parents involved to develop an awareness of their expectations, monitor their development and assess to what extent they have been realised over time. Following the experiences of these parents during their child's statutory assessment and transfer into school could help to identify what has helped or prevented their expectations from being realised. It could help evaluate the quality of parents' expectations and the barriers that prevent parents of disabled children developing realistic expectations concerning their child's education. A focus on parents' expectations also reflects the current changing opinion towards working with parents and disabled people.

1.10 Parents' roles in the research process

This study is therefore based on a commitment to a social model of disability, which aims to change perceptions of disability, thereby creating opportunities for disabled people to fully participate in everyday life. The study is also based on the belief that parents have a role as an ally to their disabled child but they can only achieve this if they are given the opportunities to have an active role in working with professionals who are responsible for their child's education and care. There is a growing movement in the research community for the people who are being researched (for example disabled people and children) to participate more in the research process and to have a voice in deciding what is important to study, to express their experiences and to report them from their perspective. Only in this way can discriminatory practice be identified and changed (Oliver 1992, Rioux and Bach 1994). An additional aim of the study is to explore this model in relation to parents of disabled children.

The reasons for involving parents are based on the notion of working in partnership with parents and giving them a voice to express their views. There are an increasing number of parents' accounts of their experiences of caring for a disabled child (see for example Lloyd 1986, Kimpton 1990, Philps 1991, Fitton 1994 and Murray and Penman 2000) but there is a need to recognise their experience and expertise. As Carpenter (1997) highlights parents are carrying out action research all the time when caring for their child by finding out about what is available for them and what is of benefit. He proposes that the role of parents in research needs to be reconsidered. Similarly, Wolfendale (1999) argues that if parents are to become partners then how they become engaged in the research process needs to be reviewed. By exploring ways of extending the notion of partnership with parents to the research process in this study, it is intended to involve parents as research participants who are active in the process from gathering the data to its analysis and dissemination. Adopting such an approach will provide a model to illustrate how communication and negotiation with the parents involved in research can lead to establishing more effective working partnerships between professionals and parents, where parents can have greater control over events. How this will be achieved is discussed in the next chapter.

1.11 Conclusion

Changing views about the rights of parents and disabled people in education have had an impact on the parents of disabled children. The current focus of support and services offered to parents of disabled children is needs based. Whilst their different experiences of education for their child lead to them having very real needs, for example, for support and information, such an approach offers little opportunity for them to enter into partnerships with professionals and practitioners where they can share their wishes and expectations so negotiate outcomes. A study of the expectations of parents of disabled children at the time their child starts school could provide valuable information about the content and quality of what they are expecting. It could identify policies and practices that help or hinder them becoming a reality. Involvement of parents themselves in the research process could strengthen their voice when sharing their thoughts and experiences.

1.12 The aims of the study

The aims of this research are therefore as follows:

1. To give parents a voice to express their expectations of schools for their disabled child and to establish to what extent parents perceive that these expectations are realised in the child's first year in school;
2. To explore methodological issues and ways of involving parents as active participants in the research process;
3. Through aims 1 and 2, to contribute to methodological and professional knowledge so practitioners can better understand the viewpoint of parents and so work more effectively with them.

1.13 The research questions

The questions that this study will particularly address are:

1. What are the expectations of parents of a child with a statement of SEN prior to their child's entry to school?
2. What are the bases for parents' expectations?
3. Do their expectations change over time and if so in what way and why?
4. Do parents of disabled children have similar expectations to each other?
5. What do parents think about having the opportunity to express their expectations?
6. To what extent do parents feel that their expectations are realised after their child has been in school for a year?
7. How can a representative group of parents become actively involved in the research process? How can they participate in collating the data, analysing it to highlight what is of importance to them and disseminating the findings to other parents and appropriate services or professional organisations?

Chapter 2

Research Design and Methodology

2.1 Introduction

One of the aims of this study was to explore methodological approaches that involve parents as active participants in the research process. This chapter outlines the rationale for this approach and details of how it was implemented.

2.2 Methodological approach

This study sought to extend the notion of emancipatory research to the participation of parents of disabled children. It explored ways in which these parents could become involved in the research process so be offered a more powerful voice in raising issues that directly concern them and their disabled children.

2.2.1 A feminist research approach

Emancipatory research is based on a feminist research approach, the guiding principle of which is that of subjectivity. The approach explores what is happening through the eyes of those involved and gives value to the perceptions of those groups of people in society who are believed less powerful, for example women, children and disabled people. There are similarities with qualitative and interpretative approaches, where researchers seek to understand and learn about the social world from those that take part. So in making assumptions about what counts as knowledge and, therefore, what can be the focus of research, the experience of individuals, their feelings, beliefs and ways in which they make sense of their worlds are given importance.

A picture of social reality can be built up through the perspectives of all those who participate. The researcher is critical in establishing research relationships and interaction during the research process (Stanley and Wise 1983, Robson 1993, Olesen 1994, May 1997) and traditionally in the research community, they aim to be objective and in control of the research process. This includes deciding the focus of research to writing the research report, which is the researcher's interpretation of events. However the feminist researcher also takes account of his or her own values and believes experiences should be made central to the research process and explicit in the research report (Stanley and Wise 1983). Acknowledging the imbalance of power between the researcher and the researched and the exploitative potential of the research process are issues highlighted by Oakley (1981) and Finch (1984) in their studies of women and interviewing. Both these researchers emphasise the value of reciprocity. Morris (1992) adds that the personal experiences of individuals portrayed through research can become political in that they give a voice to less powerful groups in society and so help overcome oppression and barriers to greater equality rather than adding to them.

In this research I aimed to give a voice to parents of disabled children. While exploring their experiences, feelings and beliefs I believed that my views had an impact on the understanding and interpretation of what parents said. I could not become totally objective particularly given my personal experience of having a son with a learning disability and working with other parents of disabled children. Indeed, as Finch (1984) argues, shared experience can help elicit information from research subjects so therefore reciprocity in the research process would be of value.

2.2.2 An emancipatory research approach

Oliver (1992) argues that whilst the feminist values of reciprocity and empowerment are important, it is the traditional research paradigms that need to be challenged if researchers are going to bring about change for groups in society who experience oppression. He sees the positivist paradigm as explaining disability in terms of individualism so reinforces the view that problems occur as a result of an individual's impairment rather than structures and barriers within society. He believes that many researchers are perceived as powerful experts who aim to define the worlds of relatively passive research subjects. Within an interpretative paradigm Oliver (1992) argues the experiences and views of the researched group are given importance so as to understand the meaning of events from their perspective. He therefore proposed a new research approach paradigm of *emancipatory research*, which aims to change the social relations of research production and create links between social research and policy thus improving the lives of disabled people.

At the time of Oliver's proposal (1992) and since there have been many debates about the exact nature of emancipatory research. If emancipation is concerned with empowerment, as Oliver (1992, 1997) suggests, and empowerment is not something that can be bestowed upon a person or group but is something that people do for themselves or collectively, then it is the whole research process that needs addressing. Zarb (1992, 1997) argues emancipation is an ongoing process of growth and development and sees participatory research as a step along the way in that previously excluded groups in research are allowed to participate.

Barnes and Mercer (1997) define emancipatory research as:

> *… … a political commitment to confront disability by changing: the social relations of research production, including the role of funding bodies; the relationship between research and those being researched; the links between research and policy initiatives.* (p. 5)

It is part of a wider emanicipatory movement by disabled people.

Recently writers when considering researching disability issues have begun to identify a model with key principles that characterise the *disability research* paradigm. Priestley (1997) describes them as:

1. *the adoption of a social model of disability as the ontological and epistemological basis for research production;*
2. *the surrender of falsely-premised claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation;*
3. *the willingness to undertake research where it will be of some practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;*
4. *the devolution of control over research production to ensure full accountability to disabled people and their organisations;*
5. *the ability to give a voice to the personal whilst endeavouring to collectivise the commonality of disabling experiences and barriers; and*

6. *the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.* (Priestley 1997 p 91)

Barnes (1992) reiterates the value of establishing a workable dialogue between researchers and disabled people whereby the knowledge and skills of the researcher can be put at the disposal of disabled people. The researcher needs to be open-minded, encourage participation by and be accountable to those participating. He describes how, whilst it is not necessary for a researcher to be disabled themselves, their personal experience and interest motivate their research and aid the relationships established through the research process. Others give accounts of how their own disability allows them to have useful insights and closeness with the people and culture they are researching (Morris 1989, Shakespear 1996, Vernon 1997). Whether disabled or not what is paramount is the researcher's commitment to a social analysis of disablement and the disabled people's movement (Stone and Priestley 1996).

2.2.3 Proposal for a parent participatory research approach

Based on the emancipatory research approach, I propose that a participatory research approach is appropriate for parents of disabled children. This approach cannot necessarily meet Oliver's (1992) criteria for bringing about social change because the parents involved may not all hold to a social model of disability and so perceive a need for change. However it can give them a more influential role in the research process on behalf of their children. The voices of children should, wherever possible, be listened to directly, and not through their parents as proxies (Alderson 1995, Beresford 1997, Morris 1998), so children themselves need to be encouraged to participate in the research process (Ward 1997, Alderson 2000, Lewis and Lindsay 2000). However, in this instance, it is the experience of the parents that is the focus of the research. In this way they can act as allies for their children working towards overcoming the barriers they experience.

There are, in the literature, examples of parents giving individual accounts of their experiences (Lloyd 1986, Philps 1991, Brandon 1997, Read 2000) and being involved in the evaluation of services both individually (Cameron 1986, Clare and

Pistrang 1995) and through focus groups (Wolfendale and Cook 1997). However there are few examples reported of parents participating in the research process. Parents of seven-year-old children have been involved in action research with teachers to involve them more closely in their child's learning. It was informed by earlier research with parents who wanted to know more about the educational process (Collins and Holden 1996, Holden et al 1996). Mothers of children who had been sexually abused were included in a participatory action research project with social workers to help improve future practice (Bond et al 1998). A large research study has been carried out in Queensland, Australia using a participatory action research approach to identify programme quality indicators for an early special education service from the viewpoint of teachers and parents (Beamish and Bryer 1999).

The lack of evidence of the participation of parents of disabled children in research is the basis for Carpenter's proposal of the 'parent as a researcher' paradigm (1997 p175). He argues that action research is carried out regularly by parents of disabled children in assessing their needs, marshalling professional resources and reviewing outcomes. There is also, he says, a wealth of literature written by parents that is not valued by the academic community but which powerfully illustrates the experiences of families (see for example Hebden 1985, Lloyd 1986, Philps 1991, Meyer 1995 and Murray and Penman 2000). He proposes that the direct contribution of parents to the research process needs to be acknowledged without fear of recrimination from the research community.

Although parental involvement and the notion of partnership in education are a prime focus for many policies and initiatives, this is not replicated in educational research. Wolfendale (1999) suggests a partnership model for co-operative research with a code of ethical guidelines to include parents as partners but using a disability research approach could further empower and enable them to influence practice that directly affects themselves and their children.

2.2.4 Summary

Although parents of disabled children do not have impairments themselves, they can be subject to the disabling barriers and attitudes of the professional world and in the wider community. Using a combination of a feminist and a disability / emancipatory research approach I attempted to give parents a voice and enable them to have greater control over the research process in this study. I endeavoured to give value to parents' personal experiences and help them express what they thought were important issues. I provided parents with opportunities where they could have involvement in the choice and implementation of the research methods used. In this way, any barriers they encountered in their dealings with the LEA and schools on behalf of their disabled child could be made explicit. The research participants, with the expert knowledge of what were real experiences for them, and the student researcher, learning research techniques, worked together to produce the research.

I therefore investigated methods to enable myself, as a parent researcher, to help other parents of disabled children to participate throughout the research process and so work towards an emancipatory model of research. Adopting this approach raised two issues. Firstly, the complex role of a researcher who is researching a familiar setting or experience. Secondly, meeting the demands of the academic community, when embarking on doctorate research, particularly the need for research rigour and reliability, balanced against involving participants as in a disability research approach (Barnes 1996, Priestley 1997, Dyson 1998).

2.3 Role of the researcher

Although little has been written concerning parents' role in the research process, the dual role of parent and researcher can be likened to that of other researchers who have personal experience of their area of study. Examples include race (Nehaul 1996, Hylton 1999), gender (Oakley 1981, Finch 1984) and disability (Morris 1989, Vernon 1997). In addition many other part time research students have a dual role in that they study an issue related to their area of work, for example teaching (Rose et al 1999), social work (Diemert Moch and Gates 2000) and the education advisory service (Attfield 1999). In my particular case, rather than a dual role, I had a triple role in that I was a research student, a parent with a disabled child and I worked as a teacher, advising parents and practitioners in early years education. Within these roles there were areas of commonality that aided my research but also areas of difference where boundaries needed to be established in order to adhere to ethical guidelines (British Psychological Society 2000).

2.3.1 Parent researcher

When gathering data from participants, a researcher needs to be able to listen and help others explore their thinking about particular issues. Being close to the research area can help them to understand and interpret what is said, as they will have personal experience (Oakley 1981, Finch 1984, Morris 1991, Vernon 1997). Their closeness to the group can also help them to gain access and acceptance by people within it, as they are not considered outsiders (Coffey 1999, Hylton 1999). Clough and Barton (1995, 1998) discuss the notion of 'voice' in research and the importance of giving value to the knowledge and experience of the researched group in articulating the injustices they encounter in education. The dual role of the researcher and parent, for example, can give a more authentic 'voice' to the group they wish to research through a greater understanding and shared experience. Conversely, it can be argued that over-identification with a situation can obscure the researcher's perception of situations so familiar occurrences are considered the norm and overlooked in the process of critical analysis (Coffey 1999). Vernon (1997) states:

> *… … there is no neutral ground in researching the experience of oppression. One is either on the side of the oppressed or the oppressors and for me as an 'insider', there was no question as to which side I would rather be on.* (p. 173)

Particularly in emancipatory research, the researcher's role is partly one of an activist to highlight issues for the community they are researching (Hylton 1999) and it is also evident in disability studies (Morris 1989, Watson and Priestley 1999). It is, however, important that the researcher's experience, beliefs and values are made explicit in the research report (Stanley and Wise 1983).

One of the primary aims of this research was to highlight areas of difficulty experienced by parents of disabled children in education and my personal experience was one of the reasons for embarking on this course of study. My dual role as a parent / researcher aided the gathering and interpretation of the data as I was a member of the researched group with knowledge and understanding of the culture. To avoid familiar situations becoming overlooked, it was advantageous for other people to look at the data during the process of analysis to include their understanding and interpretation of events. This was part of the process of involving parents in the research process, which was one of the aims of the study.

2.3.2 Teacher researcher

In my role as a teacher I provided information and discussed issues with parents regarding their child's early learning and educational placement. In this way the service enabled parents to make informed decisions concerning their disabled child and take action to make them occur. In this sense the role of the researcher differs in that they are gathering information about what decisions have been made, what action has been taken and the reasons why. Their role is not to participate in that process. Diemert Moch and Gates (2000) write of the complexity of relationships when involved in practitioner research. In (2000) Diemert Moch's experience, as a nurse researching with women with breast cancer, it was difficult to draw boundaries between her relationships with them as patients and as research participants. On reflection she decided they were inseparable and both roles should be equally valued and recognised. Whilst I agree with her sentiment, in my case, some boundaries were already imposed for me. Professionally as a teacher I could not become involved in working with children and parents who were not part of my caseload. Parents who I worked with were discounted from the sample so my role as a researcher was more clearly defined. As a parent when I heard stories told by other parents it was more difficult to remain detached but I felt, like Diemert Moch, I could provide information about voluntary and statutory services and legislation, for example, without interfering with the findings of the research study. Indeed this added to the reciprocity between myself and the parents, which is a principle underlying disability research. I needed, however, to be consistent to resist becoming involved in the parent's decision making process because it might have interfered with the research findings and caused difficulties for the parent and child in their dealings with other professionals and the LEA. It also could have created difficulties in the relationships parents choose to build with the researcher where the parent could become dependent and so withdrawing contact at the end of the research project could become problematic (Booth 1998). Causing such difficulties does not comply with the ethical guidelines of social research (British Psychological

Society 2000). It is a fine dividing line between establishing reciprocity, where the researcher is a real person with experiences close to the participants, and exploiting the participants in order to achieve the aims of the study.

2.4 The sampling procedure

Parents were invited to take part in the research study by the local education authority where I worked as an early years (SEN) teacher. Approximately 60 children a year are referred for a statutory assessment of their SEN prior to them attending a nursery or reception class full-time. A letter was sent to all the families as soon as the authority had made a decision to conduct the child's statutory assessment. The letter provided information about the study and what was involved, together with a form to return if they wanted to take part (see Appendix 1). I contacted parents who responded, by telephone, to introduce myself and answer any questions. A meeting was arranged at a time and place to suit the individual parents. I planned to respond in this way to the first twenty families who contacted me.

A random sample from as wide a population as possible should be representative and avoid bias (Robson 1993). I have already discussed some practical ways in which sample bias was avoided in this particular study. Excluding any families I personally worked with, parents were invited to take part from all the families that had a child referred for a statutory assessment of their SEN at a given time within the authority. Therefore the first twenty families who agreed to take part in the study would provide a representative sample and so a variety of experience.

2.5 Parent participation in the research process

This study investigated different ways in which two groups of parents could participate in the research process. Firstly, through the use of a research advisory group which was made up of parents of disabled children and, secondly, through the parents who were being asked about their experiences of their disabled child starting school being involved in decisions about the research process.

2.5.1 The parents' advisory group

At the outset of the study I invited six parents of older children and young adults with disabilities to support me with the study by forming a research advisory group. It was called the Parents' Advisory Group (PAG) and had three functions. Firstly, for consultation so that the researcher could discuss issues with them such as the focus of the study, the participation of parents and the content of schedules for the interviews. Secondly, the group was asked to help with the analysis of the findings and thirdly to comment on the findings and outcome of the study. These aims were achieved in a number of ways.

The group met regularly with me during the course of the research either as a group, in pairs or individually as appropriate for the task. During the meetings the parents were kept informed about the progress of the study and issues involved were shared and discussed. Each parent was involved in the analysis of data concerning the experiences of the parents interviewed and invited to comment on the findings. These were compared with the findings from my analysis and then discussed with the group as a whole. As the study progressed members of the PAG adopted different roles in supporting the research. These are described in the next chapter.

2.5.2 Involvement of parents in the sample in the research process

In was intended that by giving the parents in the sample the opportunity to be involved in the research process, they too would have a voice in how the study proceeded. It was important to select a method of collecting the data that allowed the parents to express what was of importance to them. In addition, the methods adopted were flexible so parents themselves could be involved in decisions about how information was gathered and confirmed, the details of which are outlined in the sections that follow.

2.6 The research methods

In order to explore people's views and beliefs and understand their personal perceptions of events, it is necessary to find out directly from them. This could be done through the use of questionnaires or interviews. The use of semi-structured interviews allowed the participants involved in the research to have greater control over the content of what counts as important. This supported the principle of partnership in my approach.

Semi-structured interviews are commonly used in disability emancipatory research for this reason (Swain et al 1998, Stalker 1998, Watson and Priestley 1999). Alternatively researchers have used focus groups where participants have met to discuss issues together (Brigham 1998, Rolph 1998, Kitchen 2000) but the findings may not be representative because:

- It is often difficult for parents with young disabled children to make the practical arrangements to attend meetings outside the home
- Parents' reasons for attending the group may be different to the aims of the researcher
- The views expressed by a focus group are likely to be those of articulate parents who feel confident to share their views.

In this study I interviewed parents in a venue of their own choice where they could feel more relaxed and speak openly about their individual circumstances in a non-threatening way. This had worked well in some pilot interviews I had carried out with parents, whereby I felt the rapport established through interviewing at home was better than in a nursery setting. At home, parents seemed to be more in control of the situation and willing to share their experiences. In some cases their partner was also there to contribute and offer support.

Following the initial data collection, I sought ways of reflecting views back to the participants without the parents participating having to meet together. In this way a more representative view was gained by involving those who do not usually participate in group activities outside their home due to lack of confidence or other restrictions placed upon them. The views of parents who may otherwise be hard to reach were therefore included.

Information was gathered over a series of three interviews at particular times during the progress of the child's formal assessment procedure (DfES 2001b). Interview 1 was carried out with each parent during the early stages of the child's assessment. Interview 2 took place prior to the date when the child was due to start school. Each parent was contacted a year later and interview 3 arranged when the child had been in school for at least three terms.

The interviews were semi-structured. A number of themes were introduced for the parents to talk about so they could emphasis issues they thought were important. The content of the interviews is outlined in figure 2-1 and details of the key interview questions that were used are provided in appendix 2. Parents were informed in writing prior to the interview of the topics that would be discussed. Through this process parents could, over the period of their child's transition into school, develop and express their own ideas about their expectations and explore why they had such views.

Interview	**Information concerning -**
1	• The child • Parents' views about services and support they had received • Where the parents wanted their child to go to school and why • Parents' experience of disability • What parents were expecting when their child started school
2	• Parents' experience of the assessment process • Parents' individual list of expectations which was either confirmed or modified • Shared expectations of the group – activity to complete
3	• Parents' experience of their child's school including the support the child received and communication between home and school • Parents' experience of the child's annual review meeting • Parents' knowledge about their child's school, its policy for pupils with SEN and the Parent Partnership Service • The outcomes of the parents' individual list of expectations with parents' views about what helped or prevented them from happening • Shared expectations of the group – activity to complete

Figure 2-1 ~ Information gathered at each interview

The parents interviewed were invited to compare their expectations with those of the other parents in the sample group by completing an activity concerning the shared expectations of the group. Following interview 1 fourteen expectations that more than six parents identified were written on small cards. During interview 2 parents were asked to place the cards in three categories according to whether they considered them to be 'very important', 'fairly important' or 'not so important' when there was a defined number of spaces in each category (see appendix 3). A record was kept of each parent's responses and the comments they made. This activity was repeated during interview 3.

2.7 Complementary sources of information

It is sometimes difficult for people to accurately recall events when questioned so I decided to adopt an approach used by Rustemier (2000) when involving young people with learning difficulties and/or disabilities in research about inclusion in a college of further education. In her study participants used audio-diaries or photo-portraits to record their experiences. Parents in this study were offered written or audio diaries to record events as they happened and their thoughts at the time, which could provide a useful additional source of information and a basis of discussion during follow up interviews.

Robson (1993) describes the use of diaries as ranging from unstructured accounts of events that have happened to a set of responses to specific questions. Obviously as with any research tool the more unstructured it is, the greater power the respondent has of determining what is significant. If, in disability research, there is to be a transfer of power to the respondents then what they are asked to record should be as open as possible with only general guidelines being given so participants record what they think is of interest. In this study the decision to record in diaries at all remained with the parents, as it required a high level of commitment.

The use of diaries in research also raises ethical considerations. One of the ethical codes stated by the British Psychological Society (2000) is the right to anonymity, privacy and confidentiality. When diaries are used ownership needs to be established with individual parents and methods should be employed to ensure anonymity.

2.8 Analysing the data

The data gathered during the interviews with parents was processed, organised and analysed using the methods described in the following sections.

2.8.1 Initial processing

With the permission of the parents, audio-tapes were used to record all the interviews. This was less intrusive than note taking and provided an accurate account of what was said (Powney and Watts 1987). In accordance with Robson's (1993) guidelines, the tapes for interviews 1 and 2 were fully transcribed and reference coding was introduced consisting of the number of the interview plus the number of the utterance (Alexander and Willcocks 1995). For interview 3, the tapes were listened to several times and a report prepared providing a summary of what had been said at the interview using the topic headings in the interview schedule. A word-processed copy of parents' diaries was also completed. During this process all the children's names were replaced with pseudonyms[2] of the parents' choice to ensure anonymity. Where parents used the names of professionals and practitioners they were replaced by the person's role.

Denscombe (1998) suggests a way of checking the accuracy of data is to ask the interviewee to confirm what was said during the interview by reading through the transcript. In this study, as soon as possible after the date of the interview, the transcript and any copies of diaries were returned by post to the parents concerned. They were asked to check them for accuracy and add any comments they wanted in a column provided on the right of the page. They were also invited to change and/or remove any information, which in retrospect, they did not want to be used. They were then requested to return the transcript to me in the stamped, addressed envelope provided. If parents had not responded within three weeks I contacted them by telephone to confirm that they agreed with the content of the transcript. This procedure was followed for interview 1 but, in response to parents' comments about the transcripts, for interview 2 and 3 they were offered a choice of the full transcript or a written summary of the interview. The same process was followed where parents chose a written summary.

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[2] The pseudonyms chosen will be used throughout this thesis when referring to the children.

2.8.2 Organising and analysing the data

Using suggestions offered by Miles and Huberman (1994), the transcripts or summaries that had been confirmed or amended by the parents were organised in two ways. Initially the transcripts and reports were coded according to categories of information required and the data transferred to analysis sheets to provide a summary for each family (see appendix 4). Over the course of the three interviews individual profiles of each family were prepared, which provided an overall picture of the parents' circumstances and experiences.

Subsequently, following interviews 2 and 3, the findings were organised in a tabular form to allow comparison across the group so emerging patterns could be identified. Key findings were noted and summarised.

Both the family profiles and the tabular analysis were used to compare and contrast the findings in relation to the research questions. Hypotheses were developed and tested against the data collected.

Following interview 2 and 3 the findings from the activity concerning shared expectations were analysed by transferring the parents' responses to a table then presenting the information on bar charts to establish the expectations parents most frequently placed in each category. Expectations with equal numbers of parents categorising them as 'very important' and 'not so important' were also identified and possible reasons explored. This process was repeated for interview 3 and the overall findings compared across families and over time. In this way the most important shared expectations of the group were identified.

2.8.3 The role of the PAG in analysis

A key role of the PAG was in the analysis of the data and subsequent development of theoretical thinking. Following interviews 1 and 2 each member of the group analysed six or seven transcripts using the analysis sheets provided. I analysed all the transcripts and my findings were compared with those of the parents and any necessary amendments were made. The overall findings plus the summaries of interview 3 were given to the PAG for comment and issues were brought to group meetings to discuss. In this way the PAG were involved directly in the analysis of data and influenced the theoretical analysis through contributing their ideas at group discussions.

2.9 Establishing trustworthiness of the data

Meeting the demands of the academic community to be rigorous and reliable throughout the research process is one of the challenges in disability research. The importance of reflexivity and the political nature of emancipatory research are not in keeping with the traditional view of research. Researchers adopting this approach should aim towards establishing the trustworthiness and ensure the credibility of their research within both the academic and the disabled community. Silverman (2001) states that social research is traditionally measured according to the extent to which it uses appropriate methods of study for the research topic and whether it is rigorous, critical and objective in its handling of data.

Objectivity in disability research is problematic as it rests on the assumption that the researcher has a commitment to the disability movement and the redefinition of disability according to the social model of disability. The researcher therefore cannot be objective but their standpoint should be made explicit so the researcher declares their personal interest and viewpoint to clarify understanding of how this may affect the research. In addition research participants could also be striving for social change but equally they could have different priorities depending on their personal view of disability. For example they could support segregation and the deficit view of disability. Their perspective would become evident through the data collection process. Reliability and validity throughout the research process is perhaps of greater importance in this instance to give value to the findings. These can be established through systematic and explicit records to show the progress of the research.

2.9.1 Reliability

Reliability concerns the consistency of data over place, time and between people (Robson 1993, Silverman 2001). This involves collecting accurate data from a representative number of sources that are free from bias. The methods used to gain a representative sample have been discussed above.

Through this study a picture of the parent's experience has been built up over time as they were interviewed on different occasions during the process of their child's transfer into school, which showed consistencies in what individual parents said. By taping the interviews and parents noting events as they happened, what they said and the views they expressed were recorded reasonably accurately. This information was further checked when the transcripts were returned to the parents for verification and comment. In these ways the reliability of the data collected for this research study was verified for accuracy and consistency.

2.9.2 Validity

Validity is described as establishing whether the techniques and research methods actually get at and answer the research questions (Robson 1993, Silverman 2001). In disability research the importance of personal experience is paramount and the opportunity for research participants to have control over what is deemed a reality and significant for them. Interviewing therefore is an appropriate way for the research participants to talk about their experiences. The less structured the talk, the more they have control over the subject matter.

However, in this case, to explore parents' expectations some degree of structure was necessary to focus their thoughts on the topic. In a model of interviewing suggested by Tomlinson (1989) the interviewer uses a process of hierarchical focusing to approach the subject of the research. The researcher first introduces the areas of interest but the respondent takes control over raising issues they deem to be important. This was the approach used in this study whereby the parents were told the areas of interest before the interview and were invited to talk about particular topics such as their child, their experience of pre-school services and their expectations. Additional prompts and open questions were used where required.

2.9.3 Triangulation of the data

During the analysis process the reliability and validity of the findings can be addressed by triangulation. A number of writers comment on the value of multi-method triangulation to corroborate findings (Bell 1993, Robson 1993, Denscombe 1998, Silverman 2001). This is described as using a variety of different methods to examine the same topic so different data can be compared and confirm the validity of the findings. In this study it was inappropriate to use multi-methods as it was the parents' thoughts and feelings I wanted to investigate, which can only be elicited directly from them. However the research was confirmed in other ways.

Burgess (1984) comments on the problems of being a lone researcher and indicates the value of the participants substantiating a researcher's account. This process of respondent validation was ongoing throughout the research study. The parents not only confirmed the content of the data through checking the transcripts but also confirmed their individual expectations over time and commented on the shared expectations of the group through completing the activity in interviews 2 and 3.

Another method of triangulation Burgess (1984) describes is the use of a number of investigators to confirm the findings. Although not possible in this study, a number of parents became involved in the analysis process. The PAG were not directly involved in the interviews with parents but were involved in the analysis of the transcripts and discussions that helped to identify key issues raised by the parents that were interviewed. In this way a number of parents of disabled children were in control of deciding important issues. This is a fundamental principle of disability research.

2.10 Ethical Issues

A number of ethical issues have been discussed but those that needed consideration in this research study are summarised here. I referred to the British Psychological Society's Code of Conduct (2000) for this purpose.

All the parents who participated in this study through the PAG or the interviews consented to take part. They were provided with written information about the aims of the study and what their involvement entailed. Also, their questions were answered so they were able to make an informed decision. As the study spanned a period of two years, the parents were asked at key points if they wished to continue. All parents were informed that they had the right to withdraw at any time and no pressure was put on any parent to continue against their wishes. I was in regular contact with all the parents who participated but each parent had a means of contacting me at any time if they needed.

It was my intention that the parents who chose to participate should find the experience a positive one. To this end I invited them to share with me any concerns they had about the research methods used so they could be adapted to suit their wishes and the needs of the study. I also consulted with the PAG, who were members of the same population as the participants, to ensure that the approach used with parents who were interviewed would not cause any offence.

I was aware that I might be perceived as an expert by the parents who were interviewed. As other professionals were involved with the families, I was cautious about offering advice because it might have caused them additional difficulties. However at the end of interview 3 I offered all the parents who were interviewed a parents' guide to SEN (DfES 2001c) and an information leaflet about the local PPS.

Finally, all the information the parents shared during the interviews was treated with the strictest confidence and measures were used to ensure anonymity. The PAG were also reminded throughout the study that the content of transcripts and discussions were not to be shared with people outside of the group.

2.11 Summary

This research study was based on a feminist research approach and attempted to develop a model for involving parents of disabled children in participatory research. Interviewing was the principal research instrument that was used with parents participating and their semi-structured style allowed the parents to raise issues they believed were important. Opportunities were provided whereby they could influence methods of data collection and confirmation. A research advisory group was also involved, consisting of parents of older disabled children, who participated in the analysis process. At all times during this study efforts were made to ensure that the data and analysis procedures met the demands of the academic community with regard to rigour, criticality and objectivity whilst endeavouring to be flexible so as to allow the participating parents to have a voice in the outcome.

Chapter 3

Procedures and Findings: Methodology

3.1 Introduction

The previous chapter outlined the rationale for the research approach that was used in this study and the details of how it was implemented. This chapter aims to present the findings concerning the methods that were used. It includes information about the parents who participated and their role in the research process plus details of the research methods and how they were developed during the study.

3.2 The parents involved

The two groups of parents involved in this study were the members of the PAG and the parents interviewed about their experiences of their disabled child starting school.

3.2.1 The PAG

The PAG consisted of six parents of young disabled people. Their sons and daughters were either attending school, at college of further education or employed, so the parents all had experience of dealing with the education system. However their experiences varied because some related to special education whilst others had experience of accessing mainstream schools. Three of the parents had been involved in their child's statutory assessment and two had involvement in the procedures through their work in Early Years Education. Another parent had experience of working with older pupils who had been excluded from school. Three of the parents also had close links with the local Mencap. We all knew each other well as we had worked together organising and operating a Parent to Parent telephone help line for parents of disabled children based on a model developed by Hornby (1988). One of the parents in the group volunteered to pilot the materials used with the PAG and chair the final meeting to discuss their experiences of being involved in the research study. This parent also proof-read and commented on the content of this thesis.

At the regular meetings throughout the study the parents were updated about the progress made and discussed issues arising. In addition I met with individual or pairs of parents for specific tasks related to the analysis of data. The meetings usually took place in the evening at one of the parents' homes unless a different time or venue was more convenient. The meetings were well attended with the exception of one parent who had a period of illness and another who withdrew from the group after a year due to family problems.

3.2.2 The parents interviewed

The second group of parents consisted of those who were interviewed. Of the sixty-five families initially contacted by the LEA, twenty-two parents contacted me to volunteer to take part in the study. One parent responded too late to be included in the sample and two families were not available for interview 1 as arranged. When they did not respond to my letter suggesting we arrange an alternative time it was assumed they no longer wished to participate. I met with the remaining nineteen families for interviews 1 and 2. Two parents (families 4, 7) were no longer able to take part by the time of interview 3 leaving seventeen families in the sample.

The sample included eleven boys and eight girls. The age of the children at the time of interview 1 ranged from 1 year 9 months to 4 years 7 months with the mean age being 3 years 6 months. The parents were asked to describe why their child was having an assessment of their SEN. Twelve parents gave the child's medical diagnosis as summarised in table 3-1.

Medical diagnosis	**Number of parents (n = 12/19)**[3]
Down syndrome	3
Cerebral palsy	2
Autistic spectrum disorder	2
Attention deficit disorder	1
Dyspraxia	1
Chromosome disorder	1
A named syndrome[4]	1
Undiagnosed condition	1

Table 3-1 ~ Medical diagnosis of the child given by parent (interview 1)

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[3] This describes the number of parents represented in this table out of the total number of parents in the sample available. It will be used where relevant in tables throughout this thesis.

[4] The syndrome is not specified in order to ensure anonymity.

Instead of, or in addition to, the child's medical diagnosis seventeen parents described the difficulties they thought that their child had (see table 3-2).

Child's needs	Number of parents (n = 17/19)
Language delay or disorder	12
Medical condition	8
Delayed social skills and / or behaviour difficulties	6
Physical difficulties	5
Developmental delay	3
Sensory impairment	3
Learning disability	2

Table 3-2 ~ Area of child's needs as described by the parent (interview 1)

Seven parents said that their child needed a statutory assessment so they would get extra help at school or nursery and one parent said it would identify their child's needs and enable him to have access to a special school.

All of the parents planned to send their child to school or nursery following their assessment. Sarah's mother (family 7) changed her mind during the course of the assessment so Sarah stayed in the early years setting she was attending and the family withdrew from the study for personal reasons. Kirsty's family (family 4) moved from the area so there was no follow up information after interview 2. The remaining children transferred to school as planned and the type of school the children attended is shown in table 3-3. Henceforth the term 'school' will refer to all or any of those listed unless otherwise specified.

Type of school children attended	Number of children (n= 17/17)
Mainstream – reception	5
Special school	5
Mainstream school with additional resources for children with specific needs	4
Mainstream – nursery	3

Table 3-3 ~ Type of school the children attended (interview 3)

3.3 The interviews

The findings relating to the interviews are considered in relation to the practical arrangements made, accessing information required and the parents' responses to a parent/teacher researcher.

3.3.1 Practical arrangements

When the families were invited to take part in the study it was not specified with whom the researcher would have contact. Sixteen of the nineteen families chose to arrange a meeting with the child's mother. In six cases the mother was the lone carer of the child. In the case of family 20 the child's grandmother was interviewed, as she was the child's main carer.

The parents were interviewed in their own homes. Two families (families 5, 20) requested evening appointments to allow for working parents to participate and one family (family 2) made arrangements for both parents to be present because the mother did not speak English fluently. I interviewed the father but the mother was able to convey information via him as she wished. An offer of an interpreter was made to the family but was declined.

The interviews varied in length according to how much the parents wanted to say. The average length was approximately three-quarters of an hour to an hour with a range of half an hour to one and a half hours.

3.3.2 Accessing information

The open structure of the interviews gave the parents an opportunity to talk about what they considered important. Common themes arose including parents' views about the assessment process and professional and/or practitioner attitudes towards their children and themselves. Issues important to parents were repeated over time at different interviews. Shabina's mother (family 14), for example, talked passionately and at length during all her interviews about negative attitudes towards people with disabilities and the systems in education that discriminate against disabled pupils. Other parents voiced their concerns about individual issues, including Paul's mother (family 15) who wanted to talk about her experience of policies that interfered with the continuity of support staff for pupils with SEN.

The schedule for the interviews provided some guidance for the topics to be covered enabling the relevant information to be gathered. Some parents simply gave the minimum information required whereas others elaborated and shared their thoughts. For example, when Kirsty's mother completed the activity about shared expectations of the group during interview 2, she conveyed her thoughts as she categorised the expectations. In contrast, Tom's mother (family 21) completed the activity without saying anything and needed to be encouraged to make some minimal comments about the categories she had chosen.

Where appropriate, when parents did not offer the information required, additional direct questions were used to elicit details but no pressure was put on them to talk about anything they did not want to share. For example, telling me about their child provided parents with a good opportunity to talk about something of which they had detailed knowledge. Whereas some parents provided extensive information about their child's medical diagnosis, reasons for their assessment, their development and progress, others simply provided a statement of the child's diagnosis or needs so were asked directly to elicit more information.

Dominic's mother became upset during interview 1 when talking about the concerns she had about choosing a school to meet Dominic's needs so the tape was turned off. She continued to talk about her feelings as she recovered and then asked to continue with the interview. When the tape was re-started, what she had said was summarised and she added:

> *I want what's best for Dominic. I want the right decision to be made for Dominic and I have never had to make any kind of decision as important as this one.* (1.67)

Other parents shared personal information such as their positive and negative feelings about professionals and practitioners involved with their child and their personal circumstances, including one parent who wanted to talk about her own mother who had died during the course of the study.

It was evident that some parents became more confident to talk to me as the interviews progressed. Rhiana's mother (family 1) was nervous during interview 1 but talked more freely by interview 3 when she thanked me for giving her the opportunity to be involved because, reading the interview transcripts and summaries, had helped her to reflect on what had happened.

The only difficulty some parents had with the interviews was completing the activity concerning shared expectations. Many found it difficult initially choosing only four 'very important' expectations to place on the chart as they thought all those listed were important but they all eventually identified those they considered to be most important to them.

3.3.3 Parents' responses to a parent/teacher researcher

I introduced myself as a parent with experience of having a disabled son and a support teacher for pre-school children with SEN at the beginning of interview 1. Many parents acknowledged my experience of having a disabled son by asking me directly about my situation. Their questions were answered briefly and they soon returned to talking about their child. Only Sarah's mother (family 7) asked me for advice about the assessment process and subsequently she showed me Sarah's draft statement for comment. I was able to simply provide factual information by confirming the different sections of the statement and information provided rather than discussing the content.

I met four of the parents, by chance, socially or at meetings for parents of disabled children. On each occasion we acknowledged one another and some of them enquired about my work.

3.3 Complementary sources of information

Although all the parents were offered a notebook or tape recorder to keep a diary of events as they happened and their feelings at the time, they all chose the notebook. Nine parents had recorded information in their diary and many referred to it during interview 2 but, by interview 3, only two parents (families 8, 18) made reference to their notes. Fay's mother (family 8) had written in her diary regularly throughout the study, which provided an account of events and her feelings at significant times that she referred to during the subsequent interviews. Andrew's mother (family 9) said that she had not had time to keep her diary and then lost her notebook but said that if she had recorded events as requested she would have become demoralised because there were so many negative things that had happened. Without the diary she could recall an overall picture that included some positive aspects on which she could focus. When parents did not have diaries to refer to they appeared to remember the key events that had happened to talk about in the interviews.

3.5 The analysis process

The analysis involved the initial processing, including the confirmation of data by the parents interviewed and subsequent organisation and examination by the PAG and myself.

3.5.1 The initial processing

All the parents agreed to the interviews being taped. Following interview 1 the tapes were transcribed with the names of people and places changed to ensure anonymity. The parents were invited to choose a pseudonym for their child and fourteen parents did so with only five asking me to choose for them. The transcripts were returned to the parents for confirmation. In response to comments made by two of the parents (families 8, 20), who did not like the transcripts, a summary of the interview was sent following interview 2, which they preferred. As other parents (families 3, 9, 10, 18, 21) also commented on difficulties they experienced with the transcripts, a summary was offered to all the parents for confirmation and comment following interview 3. Thirteen parents said that they preferred the summary of their conversation to the transcript.

The parents were asked to return the interview transcripts and/or summaries with any amendments or comments they wished to make. Some of the parents chose to wait for me to contact them by telephone to confirm the transcript or summary. Five parents chose this method following interview 1 and 2 and six following interview 3. After reading the transcript or summary some parents simply chose to confirm it whilst others made detailed alterations and/or attached personal notes commenting on the study or wishing me well. The content of parents' comments and alterations are summarised in table 3-4 (page 57).

Alterations and comments	**Number of parents**		
	Interview 1 (n = 8/19)	Interview 2 (n = 5/19)	Interview 3 (n = 6/17)
Clarification of information	6	2	6
Information removed	5	3	0
Details added about what had happened since	2	3	2
Further thoughts	2	0	2
Amended typing and/or grammatical errors	2	1	1

Table 3-4 ~ Alterations and comments parents made on the interview transcripts or summaries

3.5.2 Analysing the data

The PAG analysed six or seven transcripts each following interviews 1 and 2 and I analysed all the transcripts and summaries so the findings could be compared.

The PAG asked to be organised in pairs for the analysis process so they could get support from each other. The pairs were arranged so that a parent who was employed in education and familiar with the statutory assessment procedures, worked with a parent with less experience. The transcripts were allocated numerically ensuring that one parent, who knew a family involved in the interviews, did not receive their transcript. The parents asked to analyse the transcripts from the same families throughout the study so they could follow the families' experiences.

Each of the PAG parents was given verbal and written information about the purpose of the analysis and how to carry it out but two of the parents made additional contact with me to clarify details. Each parent therefore received the interview transcript and an analysis sheet (see appendix 4) on which to transfer the information that was to be extracted. This process worked well following interview 1 and 2. Whilst some of the parents' analyses were more detailed than those of others, there was general agreement and only minor additions or changes were made to the overall findings. The parents said that they had found it easier to extract factual information, such as, details about services received and school visits. It had been more difficult for them to make subjective judgements from the information they had available to them, for example, about the amount of experience that a parent had of people with disabilities. Any discrepancies were discussed and amendments agreed at the meetings following the analysis.

As there had been close agreement about the findings from interview 1 and 2, following interview 3, the analysis was based on a summary of the interview and the PAG was not involved. The information was added to the individual family profiles, which were returned to PAG for confirmation and comment. Descriptions of the experiences of each parent in the sample were prepared and circulated to each member of the PAG, which provided them with an overall perspective on which to base further discussions. Summarised versions of these are included in appendix 5.

During the meetings following the analysis of the transcripts and/or summaries, many members of the group said how they became interested in finding out how the family progressed with the child's transition into school and wanted to offer the parents concerned advice about how they should proceed. They made general comments about the data including the variability of professional support available to the families and the significance of positive attitudes towards parents and their children. They thought that parents' clear knowledge and understanding of the processes and events that they were experiencing and sources of support available to them were associated with them developing realistic expectations. Some parents in the PAG commented about the amount of time the analysis process had taken them but others said that it had been interesting and, because they had agreed to the level of commitment, time had not been an issue.

3.5.3 Presentation of the data for further analysis

Presenting the data through family profiles and in a tabular format provided a means whereby the findings could be compared within individual cases and across the sample. The family profiles illustrated the individuality of parents' experiences whereas a tabular display of data identified areas of commonality so hypotheses could be considered and conclusions noted.

The categories used in the tables were derived from what the parents said. For each table the relevant information on the analysis sheets was listed and categories identified. Each list was added to or revised as the process progressed and the final list rechecked before counting the number of parents included in each category. In this way the final categories reflected the information the parents gave rather than predetermined categories decided by the researcher.

3.6 Parental participation in the research process

The parents interviewed participated in the research process through influencing content of the data and the methods used to collate it and the PAG had a different but complementary role in the analysis of the data. Figure 3-1 (page 60) provides a summary of the ways each group of parents participated. All the parents were asked to comment on their involvement in the study.

3.6.1 The comments of the PAG about participating in the study

The final meeting of the PAG was arranged and chaired by one of the members of the group without me being present. They were provided with written information to remind them about the aims of the group and guidelines for their discussion (see appendix 6). This allowed them to feedback their comments through a written report so a summary could be included in this thesis.

The PAG thought that with their wide range of knowledge and experience about issues relating to the care of their sons and daughters they were able to contribute to the research study. They thought their support and contribution had been valued so felt comfortable sharing their views within the group. Although one parent had thought that her ideas might be out of date and originally doubted the contribution she would be able to make, she had been reassured by the group and eventually came to enjoy the challenge.

The parents were initially apprehensive about being involved in the analysis process saying that they had felt daunted by the 'academic work' and did not think they would understand what to do. However, they thought the materials provided for the analysis were well presented and I had been responsive to any difficulties they encountered. They thought it would have been useful to have an example of a

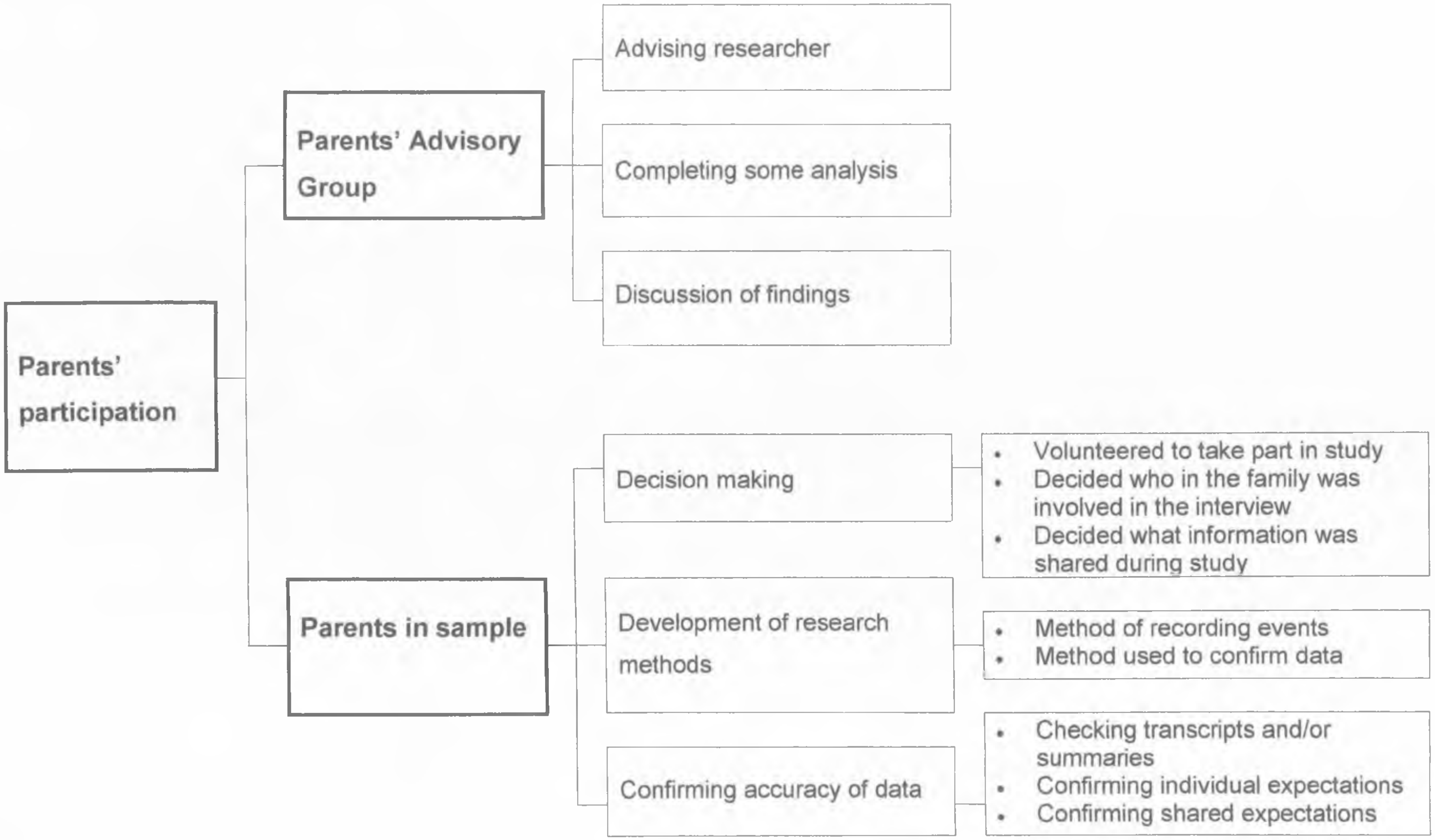

Figure 3-1 **Parent participation in the research study**

completed analysis sheet at the beginning but they did find that the task became easier with practice. They were pleased when, at the follow up meetings, they discovered that they had identified the same findings and issues as the rest of the group. The whole exercise, they felt, had helped me to be more objective and accountable during the analysis process.

The group said that they had enjoyed following the parents' stories and seeing them move on between interviews as their experiences broadened and ideas developed. When reading the transcripts they said that the parents' experiences had been portrayed well through this style of interviewing. They identified with the parents' experiences and one member of the group said it related to her work with pre-school children with SEN and their parents. From their perspective, they thought the study would broaden the knowledge amongst professionals and practitioners about what parents of children with SEN have to encounter.

The parents said that, through their involvement in the study, the group had begun to meet regularly again so they had the opportunity to socialise and support each other with information and advice, which one parent said had had a positive impact on her life. Another said it had helped her at work as it gave her the incentive to implement children's IEPs because she had come to realise how much parents valued them. They thought the study had helped the parents because the interviews had been similar to counselling sessions in that they were given the opportunity to talk about their experiences and feelings. They thought it would be interesting to re-visit the families in a few years time to find out how they progress.

3.6.2 The comments of the parents interviewed about participating in the study

When the parents interviewed were asked about their involvement their comments included that they had been happy to take part and there had been nothing difficult involved. Many indicated that they had valued having the opportunity to talk about what was happening and share their views, which helped some to think about wider issues and consider the future. Comments specific to the development of their expectations are reported in Chapter 5.

3.7 Summary

This study enabled a range of parents with a variety of experiences to participate in research about parents of disabled children. The two groups of parents had separate roles. The parents interviewed provided information about their experiences of their disabled child starting school and influenced the methods that were used whilst the PAG supported the researcher and became involved in the analysis process. Both groups provided positive feedback about their experience of participating.

Chapter 4

Discussion: Methodological issues

4.1 Introduction

One of the aims of this study was to extend the notion of a participatory research approach to parents of disabled children. In this chapter I will discuss to what extent it has been achieved through the course of this study.

4.2 How can a representative group of parents become actively involved in the research process?

This is one of the research questions of the study, which referred to parental involvement in collating and analysing data. In addressing this question it is necessary to consider the parents who were involved in the study and the extent to which they participated. It is also necessary to examine whether the study meets the demands of the research community in terms of rigour and reliability.

4.3 Representative group of parents

It was anticipated that the parents who participated in the interviews should be representative of parents of disabled children so the findings could be generalised to other groups with similar characteristics. To this end, during a period of seven months, all the parents who had a disabled child known to the LEA due to start school were invited to participate in the study. However, as Robson (1993) suggests, obtaining a truly representative sample is very difficult. He argues that non-response is an issue because those who choose not to participate are likely to differ from those who do.

Every effort was made to encourage a sufficient number of parents to take part by talking to groups of parents and professionals. The parents who volunteered were more likely to be vocal parents in the population who felt they had something to contribute. However, when the characteristics of those participating were examined, they appeared to be representative as the parents described their children as having a variety of diagnoses and needs and there were a mixture of boys and girls of different ages. Also the parents had selected both mainstream and special education for their child. Although two fathers and a grandmother did participate, the sample was biased in favour of mothers despite efforts being made to arrange interviews in the evening to encourage working parents to participate.

In retrospect the sample was not representative of the multi-cultural diversity in the area. Offers were made via other professionals to have interpreters available and materials translated but no parents volunteered who required them. Perhaps strategies should have been used when inviting the parents to volunteer to ensure they had equal access to the initial information.

The PAG were a convenience sample (Robson 1993) and were not selected because they would be representative of this population of parents but because they were a group of parents of disabled children with a range of different experiences. Through working together on previous projects they had demonstrated that they were committed and could work together as a group.

4.4 Parent Participatory Research Approach

By referring to Priestley's (1997) disability research model the extent to which this study conforms to the principles of emancipatory and participatory research can be examined. I will particularly consider whether this study gave parents a voice in the research process, gave them any control over the research production and adhered to a social model of disability.

4.4.1 Giving parents a voice

The research method selected for this study was semi-structured interviews in that the interviewer introduced the general area of interest so the interviewee could develop the content. Using this approach gave value to personal perspectives so gave the parents who were interviewed a voice to talk about what was relevant and important to them at this time (Powney and Watts 1987). However, answering the research questions required more than parents simply providing an account of events. For example, to identify the bases of parents' expectations it was necessary to explore their values and beliefs about issues such as disability and education. Using an approach based on Tomlinson's model of hierarchical interviewing (1989) enabled parents also to explore the impact of their personal experiences on their beliefs and attitudes. Wolfendale (1999) writes of the difficulties of parents verifying views retrospectively but in this longitudinal study they were asked about current events and offered ways of recording their feelings over time to relay during subsequent interviews. Even though not all the participants chose to use their diaries to record events, the parents participating provided detailed information about their experiences and thoughts as their disabled child started school.

A process of respondent validation (Burgess 1984) was ongoing throughout the study so parents were able to confirm, alter or add to the content of the information they gave. Furthermore, important issues they raised were verified by the PAG, which consisted of parents who had similar experiences to them, and the whole study was conducted by a parent with a disabled child. As a result the findings provided individual accounts of events plus the shared experiences of a group of parents of disabled children as told from their perspective. However all the parents participating did not share the same views so it was important through the analysis process and presentation of the findings to remain objective and give value to the range of voices that were evident.

4.4.2 Control over the research production

Priestley (1997) highlights the need for ‘the devolution of control over the research process’ and ‘the willingness to adopt a plurality of methods for data production and analysis in response to the changing needs of disabled people’ (p. 91). It was the aim of the study to achieve both for parents of disabled children, as there is little evidence of this happening previously in the literature despite the call for greater partnership with parents in the research process (Carpenter 1997, Wolfendale 1999).

4.4.2.1 Parent participation

As a parent researcher with similar experiences to the researched group I felt well placed to promote the participation of parents and also acknowledge and highlight issues that were of importance to them. Burgess (1984) argues that semi-structured interviews are flexible so conducive to developing rapport with interviewees, which is crucial to success in gaining the information required. This can happen more readily when the interviewer and interviewee share the same experiences. I could empathise with the parents interviewed and had the knowledge and experience to respond to questions they asked without influencing the data, which Oakley (1981) argues, helps to redress the imbalance of power within the interview context. Like Finch (1984), I felt that on many occasions, I was 'welcomed into the interviewee's home as a guest, not merely tolerated as an inquisitor' (p.73).

When proposing the research study a flexible plan for data collection was outlined so parents participating could influence the development of the research methods and so have greater control over the research production. Action research has been utilised to involve parents in developing practice (examples include Collins and Holden 1996, Bond et. al. 1998) but in this study parents were consulted about the methods used to gather data about their experiences. Through listening and responding to their comments I was, for example, able to suggest alternative methods of confirming the data and completing the analysis.

Throughout this study I was supported by the PAG through their ongoing advice and involvement in the analysis process. Although it was recognised that considerable demands were made of them, efforts were made to simplify the tasks and support was ongoing. They made positive comments about their participation at the end of the study. The group was invaluable because their analysis of the data enabled triangulation with parents whom had similar experiences to those interviewed. In addition, I was accountable to members of the researched group, which is another principle of Priestley's (1997) model of disability research.

4.4.2.2 Parents as partners in the research process?

This study has endeavoured to involve parents as partners in the research process. Its effectiveness can be measured using Wolfendale's (1999) four key elements of partnership with parents, which she describes in her critique with reference to research.

Firstly Wolfendale (1999) considers the right/entitlement of parents to information, which was an ongoing process throughout this study. It was felt that all the parents participating required verbal and written information plus individual support as necessary so they could understand the purpose of the research and their role within it.

Equality of status, Wolfendale (1999) argues, ensures that parents are 'treated as vital and equal contributors to the research process' (p. 167). Certainly all the parents in this study were consulted about a variety of issues ranging from pseudonyms to be used and the content of the data to the research design and methods used for analysis and their contribution was valued and used. The comments of the PAG at the end of the study indicated that they thought the support and contribution they gave had been valued.

Reciprocal involvement is regarded as each person involved exchanging information, expertise and responsibility but in research Wolfendale (1999) sees the ultimate responsibility resting with the researcher otherwise the demands made on the parents would be too great. The rapport developed with the parents interviewed occurred as a result of me being willing to share information with them about my experiences as a parent of a disabled child. Information and expertise were shared with the PAG by updating them on recent developments in education for pupils with SEN, for example, and encouraging them to rise to the challenge of what they referred to as 'academic work' during the analysis process. Throughout the study I was aware of the additional demands I was making on the parents participating in the study but I felt that they entrusted me with the responsibility to convey their views to people who could make a difference to their lives.

The fourth element of partnership with parents Wolfendale (1999) writes about is concerned with empowerment whereby in research parents are regarded as participants and as such 'have an inbuilt right to express their views and constructively influence the process' (p. 167). In this she also included their influence on the focus of the research itself. In preparation for this course of study I not only considered my own views about what were relevant and useful areas to research but I also consulted with other parents of disabled children. In designing the study I felt it was imperative to use methods that gave parents a voice, hence the use of semi-structured interviews, respondent validation, consultation about research methods and the involvement of the PAG. In these ways the parents were empowered to express their views about the process of disabled children starting school and the course of the research process.

This study therefore demonstrates methods that can be further developed to enable greater partnership between parents and professionals in the research process.

4.4.3 Social model of disability

As Oliver (1992) argues emancipatory research requires adopting a social model of disability whereby structures and barriers preventing disabled people fully participating in society can be identified and removed. It is part of a movement for social change.

It has been argued in chapter 1 of this thesis that research focused on parents' expectations can help gain a better understanding of parents' aspirations for their child and opportunities to achieve them. This study of parents' expectations therefore focused on policies and practices that prevented them developing complex expectations that are likely to be realised and so adheres to a social model of disability.

Finding ways of involving parents of disabled children in the research process is also a step towards overcoming barriers and giving these parents a stronger voice in expressing their diverse views about policies and practices that affect their lives and those of their children. In these ways this study is supporting the movement for social change by aiming to influence the practice of those who work with parents of disabled children.

4.5 Establishing trustworthiness of the data

Achieving a balance between reflexivity and the political nature of participatory research and the demands for rigour and objectivity of the research community is a challenge. This was attempted in a variety of ways in this study, which are outlined below.

As Stanley and Wise (1983) argue, in feminist research the values and experiences of the researcher cannot be ignored and need to be made explicit in the research process. My status as a member of the researched group was made explicit at the beginning of this thesis as was my stance relating to the need for social change regarding the involvement of parents in their disabled child's education. The need to be rigorous was important if the findings are to be taken seriously. This was achieved by trying to remain objective and build a relationship with the parents that did not interfere with the outcome of the study. Also through the systematic and explicit records to show the progress of the research and the origin of the findings, which have been made evident in this thesis.

Establishing the reliability and validity of the findings are important in meeting the demands of the research community (Robson 1993, Silverman 1993). They were achieved in this study by having a representative sample of parents who provided information using a variety of methods. The accuracy of the data was confirmed through respondent validation by parents checking interview transcripts, reviewing information they gave and reiterating their views over time. It was not appropriate to check the reliability of the data with other parties as this study sought to gain the parents' perspective, which is likely to differ from others who were involved. Triangulation of the findings was therefore achieved through the PAG participating in the analysis process.

Ethically this study was conducted using the guidelines of the British Psychological Society (2000) but Wolfendale (1999) argues that these are insufficient in the case of researching parental involvement. She suggests the development of guidelines is necessary to confer rights and entitlements upon parent participants and promote the principles of partnership. She discusses a number of issues that relate directly to this study.

Firstly, the dilemma of informed consent, which she argues, requires the provision of clear information and a demonstration of parents' understanding of the purpose of the research and their role in it. All the parents in this study were given clear initial information about the purpose of the study and what was required of them. This information was reiterated and clarified at key times throughout the study and confidentiality assured. When parents had additional stresses in their lives they were encouraged to withdraw so the burden of the research did not add to the difficulties they were experiencing.

Secondly, Wolfendale (1999) promotes the need for transparency and honesty when researching with parents. She argues against categorisation of participants according to social class, for example, without their knowledge, as it is a demonstration of the power a researcher has over the participants. In this study parents were asked openly about information, including for example, the reasons why their child was having a statutory assessment and their experience of disability, and any categories were derived from the information they gave and not those designed by the researcher.

Finally Wolfendale (1999) writes about the responsibility of the interviewer and the 'ethics of intrusion' (p. 166). She argues that researchers should be sensitive to parents needs and well being and that undue pressure should not be placed on parents to provide information against their will. Certainly the approach adopted during this study encouraged parents to have control over the issues they wished to raise. They were given the opportunity to talk with prompts being used sensitively to gain more information if the parent was willing to do so. Some parents exercised their right to turn off the tape during an interview and to withdraw from the study when they wished.

4.6 Conclusion

One of the aims of this study was to explore ways in which parents of disabled children could become actively involved in research concerning their experiences. It has identified some practical ways in which parents can participate which adhere to the principles of a participatory research paradigm, the demands of the research community and the principles of partnership with parents.

Chapter 5

Findings: Parents' expectations

5.1 Introduction

This study aimed to give parents a voice to express their expectations as their disabled child starts school. The information the parents shared is described in this chapter including the origins, development and outcome of their expectations. The comparative findings are considered first, followed by an outline of three family profiles to illustrate the range of experiences of families in the sample.

As the basis of a person's expectations is their experience, knowledge and beliefs, the first part of the comparative findings will focus on the parents' experiences. Next the parents' knowledge and beliefs about education and disability will be described. Finally the nature of the parents' expectations and their outcomes will be examined including an analysis of the shared expectations of the group.

5.2 Sources of parents' expectations

People's expectations originate from their experience, knowledge and beliefs. During interviews 1 and 2 it was possible to identify the parents' experience, knowledge and beliefs about education and disability that formed the bases of their expectations. The main sources identified are listed in table 5-1.

Sources of expectations	**Number of parents (n = 19/19)**
Experience of visiting schools and meeting staff	15
Beliefs about education and / or disability	12
Advice and information from professionals involved in child's assessment	12
Previous experience of services or relationships with professionals with child or older child in family	8
Information from voluntary organisations	7
Professional involvement in education	3
Personal experience of disability	2
Advice and information from others – family, other parents of disabled children	2
Information from the internet	1

Table 5-1 ~ Sources of parents' expectations identified (interview 1 and 2)

5.2.1 Parents' experiences

The experiences of individual families varied according to their personal circumstances and their child's needs but there was some commonality of experience across the group. During interviews 1 and 2 parents talked about their experiences of:

- the services and support they had received for their child
- their child's formal assessment
- education and schools
- their contact with disabled people

During interview 3 parents talked about their experiences of:

- their child at school.

Each of these will now be considered in turn.

5.2.1.1 Services and support received for the child

The services families received are listed in table 5-2 (page 73).

All the parents made positive comments about the services and also described difficulties they encountered. The most frequent comments are summarised in table 5-3 (page 74). For example, Thomas's parents (family 5) received a variety of services from health and the voluntary sector. They said they helped because:

- different professionals worked together
- they received information, ideas to work on and were lent equipment
- they had some respite from caring for Thomas
- they had contact with other parents

They thought that the services had helped Thomas to make progress and he was happy. The difficulties they encountered were associated inconsistency of staff with people not having an overall view of what was happening and not listening to their contribution. They also commented on the lack of information and regular contact.

Ten families had experienced considerable difficulties. Robert's parents (family 12) made a formal complaint about the way services were delivered to Robert and the lack of information and support they received when referring him to the LEA for an assessment of his SEN. She also talked about the attitudes of professionals towards her following this complaint.

Services / support parents said they had received	No. of parents (n = 19/19)
Child attended early years provision[4]	19
Speech and language therapy	18
Consultant/s	11
Child development centre	10
Individual support in pre-school setting	10
Physiotherapy	9
Portage service	9
Health visitor	9
Support from a voluntary nursery for disabled children	6
Clinical psychologist	6
Pre-school support service	6
Educational psychologist	5
Responsible officer	5
Occupational therapy	4
Support from voluntary organisation	4
Respite / other childcare	3
Group for parent / child	3
Nursing support	2
Play therapy	2
Social worker	2
Deaf and hearing and visually impaired support service	1

Table 5-2 ~ Services / support parents said they had received for their child (interview 1)

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[4] Early years provision included early years centres, playgroups, education nurseries, private nurseries and crèches.

Parents comments	**No. of parents (n = 19/19)**
1. What parents said they found useful	
Help for the child to make progress	15
Ideas to work on with the child	15
Regular contact with the service	10
Information about their child's progress	9
Information about services available	8
Emotional support	8
Flexible service delivery	7
2. What parents said they found difficult	
Difficult relationship with professional	11
Accessing help when it was required	10
Disagreement with professional opinion	9
Service not meeting needs of their child	8
Lack of information given about the child	6
Issues related to assessment process	6

Table 5-3 ~ Parents' comments about what they found useful and difficult about services they received (interview 1)

All the parents talked about experiencing difficulties with some services whilst being satisfied with others. For example, Shabina's mother (family 14) found the negative attitudes of medical professionals towards Shabina and the number of tests and assessments she was subjected to upsetting. This contrasted with her experience of Shabina's nursery where the staff focused on positive aspects of her development and involved her in group activities with other children. The manager of the centre was very supportive and encouraged the family to find the provision they believed was right for Shabina. The family described how this support was ongoing after she had started at school.

5.2.1.2 The child's statutory assessment

The formal assessment of their child's SEN further added to parents' experience of the education system, the role of the LEA and their relationships with professionals involved in delivering services to families. Although there were mixed views about the value of the assessment, all nineteen parents talked about some difficulties they experienced through the process (see table 5-4).

Parents' comments	**Number of parents (n = 19/19)**
The assessment process had caused them worry and stress	10
The process had taken too long	9
Insufficient support through the process	7
Incidents when families experienced difficulties communicating with the professionals involved	6

Table 5-4 ~ Parents' comments concerning the difficulties they experienced with their child's assessment (interview 2)

Four of the families did not see the point of their child's assessment. Tom's mother (family 21), who found the experience very difficult, questioned the need to go through the process at all when it was obvious there was 'something wrong' with Tom. Her comments included:

- there was a lot of paperwork
- it took a long time to complete
- too many people were involved who sometimes did not know Tom
- she had to chase people for reports and information
- she had difficulty understanding the reports in the draft statement because of the 'difficult language' that had been used.

The only benefit she could see was getting help for Tom at school.

Sharon's mother (family 6) had found the assessment process difficult because of her lack of agreement with the professionals involved. She followed advice to look at a variety of schools before making a final decision, and decided that a particular special school she had visited would best meet Sharon's needs. She was also concerned about the LEA's future funding policy for pupils with SEN in mainstream schools. However some of the professionals involved did not want to accept her decision and tried to persuade her to change her mind. She describes how she felt, following one particularly difficult meeting:

> *I came out sort of feeling let down, upset and an outsider. I felt that my daughter's future has been taken out of my hands. It's*

> *as though I am not going to have a say in her education. It has all been mapped out for her without my consent.* (Parent's comments on transcript of interview 1.)

She did stand by her original choice and eventually the special school was named on Sharon's statement but she experienced a lot of stress and anxiety dealing with the disagreement.

Other parents were more positive about their child's assessment despite the difficulties that they had. Their comments are summarised in table 5-5.

Parents' comments	**Number of parents (n = 19/19)**
Received support from professionals	10
Secured funding / support for child at school	7
Identified child's needs	5
Written reports about the child	5

Table 5-5 ~ Parents' positive comments concerning their child's assessment (interview 2)

Although Lee's grandmother (family 20) had experienced difficulties initiating the assessment for Lee, she thought that:

- the process had been completed quickly and in time for Lee to start school on time.
- she had received clear information from the LEA officer
- the services concerned had worked well together and arranged a meeting when information was given to Lee's new school in preparation for him starting
- it had enabled Lee's needs to be clearly stated in writing, which had helped the family's understanding of him.

Meena's father (family 2) was also positive about her assessment saying that:

- it had confirmed their understanding of her needs
- they had received advice about appropriate schools
- it had enabled her to get a place at a special school.

Parents' active involvement in the assessment added to their experience and understanding of the process and eighteen of the nineteen parents followed during the assessment period participated actively in the ways described in table 5-6.

Parents' actions during assessment process	**Number of parents (n = 18/19)**
Attended meetings with professionals	15
Discussed options with professionals	12
Challenged professional opinion	11
Was assertive in their dealings with professionals	11
Took action to resolve problems	11
Asked for or found out information	10
Visited a variety of schools	9
Initiated contact with service or professional	8
Has or was planning to be involved in child's school	8
Acted according to very definite views about their child's provision	7
Contacted LEA about their child's assessment	6
Contacted people by telephone	6
Has done or expresses interest to be involved in working on child's IEPs	6

Table 5-6 ~ Ways in which parents were pro-active during the assessment process (interviews 1 and 2)

Kirsty's mother (family 4) said that she had valued the support she had received. This included the opportunity to talk through difficulties and discuss options with the staff at Kirsty's nursery, the teacher from the support services and the educational psychologist and support when visiting schools. Other parents did not experience the same level of support. Support for Aiden's mother (family 17) was not apparent and she continued to be unclear about how the assessment should proceed and what provision was available for Aiden. During the interviews she frequently said 'I don't know'.

5.2.1.3 Education and schools

In choosing a school for their child many parents said that they drew on their own experience of schools and education.

Eight parents (families 5, 7, 8, 10, 13, 14, 16, 20) talked about their experiences at school with older children in the family. Lee's grandmother (family 20) explained how she knew the staff at the school because her other children had attended and it made the task of establishing a relationship with school easier. Another, Shabina's mother, (family 14) said that she wanted the same opportunities for her disabled child as she had seen her other children enjoying. However, Thomas's father and Sarah's mother (family 5, 7) had experienced difficulties with older children at school and the parents said that they did not want the same difficulties to occur for their younger child so they took action to avoid it. Charlie, Joshua and James' mothers (families 10, 13, 16) referred to experiences they had with an older child at school who had a statement of SEN and Joshua's mother (family 13) was able to compare her experience of the assessment process in another LEA. Kirsty, Charlie and Robert's mothers and Lee's grandmother (families 4, 10, 12, 20) were professionally involved in education.

In some cases these experiences led the parents to have very clear views about where they wanted their child to be educated and the child subsequently attended their chosen type of school. However for other parents, during the course of the assessment, their ideas were modified due to the experience of visiting schools and talking to the staff.

Nine of the parents visited a variety of schools when thinking about their child's school placement. Sharon and Andrew's mothers (family 6, 9) visited a variety of special and mainstream schools before making a decision. Some families who were undecided were advised to look at particular schools. Dominic's mother (family 18) wanted him to go to the local school but when they visited they did not think he would receive the amount of support they thought he required. It was suggested that the family visit a school that had additional resources for children with language impairments. Although at first reluctant, when they visited the school, they liked it immediately and Dominic was allocated a place. Afterwards she said she saw the value of visiting schools saying:

> *I think any parent going through what we've been through – they really need to go and see the school to help make the decision. I don't think you can make the decision until you have gone to see the school … I was very unclear until I went to the resourced school and it feels right him going there.* (2.51)

Yvonne's mother (family 3) did visit a special school but was upset at what she saw and decided to keep Yvonne at the local mainstream school although she was unsure it would be able to meet her needs. Shabina's mother (family 14) applied for a place at the school her other children attended and was upset and angry when she was refused.

Of the ten families who only visited one school, seven went directly to their local mainstream school and the remaining three families visited only the school that had been recommended to them. All the parents had the experience of visiting a school or had contact with the school that was named on their child's statement.

5.2.1.4 Contact with disabled people

The parents were asked to talk about their experiences of people and children with disabilities before knowing about their child's disability.

Andrew and James' mothers (families 9, 16) talked about a member of their immediate family who was disabled and told of their life-long experience of disability. James' mother (family 16) said that she had not seen disabled people as any different until she became aware of the difficulties her family encountered. She then began to realise the need to stress negative aspects of their lives in order to prove their need for services and resources, which she continues to experience with her two disabled children. Andrew's mother (family 9) talked about her experience of being looked at and teased when out with her family. Kirsty and Charlie's mothers and Lee's grandmother (families 4, 10, 20) had been professionally involved in education with disabled people and Charlie's mother (family 10) had three adopted children with learning disabilities and provided long and short term care for disabled adults.

Four of these parents demonstrated, through talking about their experiences, an awareness of the issues relating to the lives of disabled people. Charlie's mother (family 10) acknowledged the negative attitudes towards and prejudice against disabled people in society and added that people often have difficulty communicating with disabled people, judging them on their appearance rather than who they are. She believes that getting to know disabled people makes you realise that they have a lot to give as well as take. Inclusion in education, she thinks, is helping to change attitudes but the needs of pupils with SEN also have to be met which she feels is not always possible in a mainstream setting. She sees equality of opportunity of experience, wherever possible, as important for all children.

A further five parents talked about a distant relative (families 2, 8, 13, 17, 18) and three about a person living in their community who was disabled (families 3, 12, 15) but their experience of disability was limited. Ten of the parents (families 1, 2, 3, 5, 6, 7, 13, 14, 17, 21) had limited experience of people of disability.

Four parents (families 5, 8, 12, 14) said that they had become more aware of the issues since caring for their own child. For example, Shabina's mother (family 14) admitted that prior to her being born, although she noticed disabled people, she had not given them much thought or consideration. Since Shabina's diagnosis she said that her values and goals had changed and now believed strongly that everybody has rights despite their disability and should have opportunities to be included in society and mainstream education. She also commented on her experience with professionals who adhere to a medical model of disability and use labelling of disabled people in a negative way in order to exclude them from the services and support they have a right to receive. Thomas's father (family 5) described situations where he had stared at disabled people, felt awkward in their company and thought about them as being very different. Since Thomas was born, he had more contact with disabled children and found it easier to communicate with disabled people or offer help in situations where previously he would have ignored them and gone away.

5.2.1.5 The child at school

At the time of interview 3 the parents were asked about their experience of their child's school placement including support for their child, their progress, communication between home and school and the review of their child's statement.

According to the parents all the children had additional support in school. Eight received individual support for all or part of the school day whilst nine were supported in small groups. Fay, Charlie and Shabina's mothers (families 8, 10, 14) talked about difficulties because their child had not received the level of support included on the statement due to recruitment problems of appropriately qualified staff. Paul's mother (family 15) had been informed that there might be a different support worker with Paul in the future which she was not happy about because she had been so pleased with the way the person had related to and helped him.

The number of support services involved with the child at school that parents talked about had reduced. Rhiana, Thomas and Sharon's parents (families 1, 5, 6), whose children attended special school, described how support from therapists came from within the school instead of being hospital based. Services outside school that were mentioned by two or more parents are listed in table 5-7.

Services and support received at school	Number of parents (n = 17/17)
Speech and language therapy	16
Educational psychologist	6
Physiotherapy	5
Consultant/s or medical officer	4
Occupational therapy	4
Parents' support group available	4
Pre-school support service	3
Child development centre	2
Clinical psychologist	2
Nursing support	2

Table 5-7 ~ Services / support parents said they had received since their child started school (interview 3)

The lack of support from therapists and external support services was one of the difficulties five of the parents talked about. Fay and Andrew's mothers (families 8, 9), who experienced difficulties with the child's school, described how the lack of support for the child's individual worker, both within the school and from external services, was a key problem. Andrew's mother (family 9) also talked about difficulties caused by her lack of contact with the speech and language therapist.

All the parents talked positively about some aspect of the school placement that was beneficial to the child and thought their child had made some progress at school. The comments made by five parents or more were:

- the benefit to the child of having an individual programme to work on
- the school's flexible approach with the child
- the school was meeting their child's individual needs.

Communication between the parents and the child's school was mainly with the class teacher or support worker. The methods of communication parents used are included in table 5-8.

Methods of communication with school	**Number of parents (n = 17/17)**
Parents visiting the school and talking to the staff	13
Home – school diary	9
Informal meetings as necessary at the beginning and end of the day	8
Review meetings / parents' evenings	8
Telephone conversations with staff	6
Regular meetings with support worker	3
School's communication with all parents	3
Information passed on via escort on school transport	3
Parent helps in school so gets information informally	2

Table 5-8 ~ Methods of communication with school that parents talked about (interview 3)

The parents said that they valued receiving information about their child in school and liked it when contact with school could be flexible and the staff were approachable. Eight parents (families 1, 2, 9, 12, 14, 15, 17, 18) talked about the difficulties they encountered visiting the school because of the distance, lack of transport or because of family or work commitments. Dominic's mother (family 18) said that, because her child used school transport, the only time she was able to visit the school was during the school day so the teacher was always busy and she was not able to speak to her.

The parents' experience of practitioners in schools varied. Many talked positively about them describing them as supportive and friendly, with experience, expertise and positive attitudes. Five of the parents (families 3, 8, 9, 10, 16) were not as positive. For example, Fay's mother (family 8) talked about the negative attitudes of the head teacher towards her and Fay and the lack of involvement of the nursery staff. This resulted in Fay's parents requesting an early review and a change of support worker to a qualified nursery nurse. The meeting consisted of a heated discussion between the school staff and therapists involved and Fay's mother said that their concerns were not listened to or resolved. The following term the head teacher left and was replaced by a person with a more positive attitude towards pupils with SEN who organised support for the practitioners involved and regular meetings between Fay's mother and the special needs assistant. She said that she thought it was unbelievable that one person could make such a difference.

Fourteen of the parents had attended an annual review meeting for their child where they were able to discuss their child's progress with people involved. Lee's grandmother (family 20) said that it would take place the following term and Meena's father and Tom's mother (families 2, 21) were not aware of any meeting taking place or being planned. Twelve of the parents received reports from the school and nine parents provided a written contribution prior to the meeting. The topics the parents said were discussed at the meetings are listed in table 5-9 (page 84). The parents' perceptions of the meetings were generally positive but Fay and Andrew's mothers (families 8, 9) said they found the experience difficult.

Topics discussed at annual review	Number of parents (n = 14/17)
Parents shared their views about their child in school	14
Child's progress	13
Written reports about the child	5
The support for the child in school	5
Changes to the statement	4
Child's future school placement	4
New IEPs	1

Table 5-9 ~ Topics discussed at child's annual review meeting (interview 3)

The parents' experience of their child's school was varied with most having positive comments to make but also describing difficulties that they encountered. Robert's mother (family 12) spoke highly of her child's school saying that he had settled well, made friends and was making good progress. Communication between home and school was excellent through the use of a daily diary system and the school offered parents' workshops so she visited each week to work with Robert in the classroom. Through the regular contact, parents' evenings and Robert's annual review meeting his mother said that she received detailed information about his progress and IEPs from the class teacher and the speech and language therapist. She thought the staff knew Robert well and she had come to trust them to make decisions concerning his education. He attended a school with resources for pupils with language impairments but his mother doubted if the place would be permanent and had dreaded going to the annual review meeting in case he was moved to a different school.

Six other parents (families 3, 8, 9, 10, 16, 17) experienced significant difficulties with their child's school. Yvonne and Charlie's mother's (families 3, 10) had made arrangements to move their children to a different school at the beginning of the next academic year because they did not think their needs were being met.

5.2.2 Parents' knowledge

Parents' knowledge and understanding were based on their experiences and the information and advice they received. Formal sources of information originated from people such as professionals involved in their child's assessment and informal sources from other parents, family, friends and the general public.

5.2.2.1 Formal information

People providing formal information will have received formal training, for example, therapists, education workers, officers of LEA. Another source is the official literature prepared by recognised organisations, such as voluntary organisations that support disabled people.

5.2.2.1.1 Formal information from professionals

Many of the parents indicated that they received formal information and advice from the professionals involved with their child (see table 5-10). The information was mainly obtained through parents attending meetings with professionals, discussing options with them or asking for information.

Ways in which parents received information and advice	**Number of parents (n = 18/19)**
Attended meetings about their child	15
Discussed options with professionals	12
Asked for or found out information	10
Contacted the LEA regarding their child's assessment	6
Contacted professionals involved by telephone for information	6

Table 5-10 ~ Ways in which parents said they received information and advice from professionals involved with their child (interview 2)

The information and advice parents said they received is included in table 5-11. Parents particularly talked about the ideas they were given to work on with their child.

Information and advice received	**Number of families (n = 19/19)**
Ideas to work on with their child	15
Information about their child's development	9
Advice about services	8
Advice about school for their child	5

Table 5-11 ~ Information and advice parents received (interview 2)

The information and advice given to parents had an impact on the decisions they made concerning their child's education. For example, Rhiana's mother (family 1) followed the advice of therapists to start the assessment process and sent Rhiana to a particular special school that they recommended but she was unsure at the time if it was what she wanted. Shabina's mother (family 14), who held very strong views about inclusion, listened to the advice of the head of Shabina's nursery and went to visit a school with resources for children with learning difficulties where she eventually sent her. However Sharon's mother (family 6) listened to the advice of professionals but ultimately decided against it and sent Sharon to the school she thought was best. Parents of disabled children are given too much choice in comparison to other parents of children starting school, was the view of Fay's mother (family 8), who said that she did not receive enough information and guidance and so had difficulties deciding where to send Fay to school.

Some of the formal information and advice received by parents was misleading. For example, Kirsty's mother (family 4) had been advised to look at mainstream schools for Kirsty but, when she visited prospective schools, she found the attitudes of the staff were very negative towards having a child with such complex needs especially as she was not toilet trained. Paul's mother (family 15) said that she had understood following a meeting with an officer from the LEA that the provision for Paul would be in place by a certain date and was very disappointed when it did not happen. She was confused further by the information a speech and language therapist gave her about educational support services. Paul's assessment was completed within the same time frame as the other families in the sample. Incorrect information about a course at a college of further education caused disappointment for Rhiana's mother (family 1) who had wanted to continue her own education whilst Rhiana was in school.

5.2.2.1.2 Formal information from the voluntary sector

Information and advice was also provided for parents by the voluntary sector. For the parents who were involved with a parents' group at a nursery for disabled children organised by the voluntary sector, (families 2, 5, 6, 7, 9, 10) the staff were involved in the child's assessment and supported the parents through the process by giving information and advice. Robert's mother (family 12) attended a group organised by a different organisation and Fay's mother (family 8) wrote to an organisation for advice and received a report commenting on her child's draft statement.

5.2.2.1.3 Formal information from written sources

Parents obtained information from written sources. Rhiana's mother (family 1) talked about the value of the information pack and video provided by the LEA. However Paul's mother (family 15) said that reading the literature that was sent to her was too time consuming when she had so many other commitments and Fay's mother (family 8) said that the letters she had been sent by the LEA were confusing. She also used the Internet as a source of information.

5.2.2.1.4 Formal information from schools

When their child was due to start school fourteen families talked about information they had been given by the school about what to expect. This included details, for example, about support for their child, classroom organisation, access to therapy and information about the child's individual programme. Six parents (families 1, 3, 7, 12, 18, 21) said that despite being given information, they still did not know or were confused about some aspects concerning their child's transfer to school. Rhiana's (family 1) said, a few weeks before Rhiana was due to start, that she did not know the day she was due to start, what she should send to school with her and what arrangements for school transport had been made. Tom's mother (family 21) was not able to tell me any arrangements that had been made to meet Tom's additional needs when starting school. The staff had contacted her to ask for information about Tom but did not appear to have provided her with any details about what would happen in school other than that he would receive the support written in the statement.

5.2.2.2 Informal information

Informal information and advice are gathered from other sources, such as other parents of disabled children, family, friends or the general public, all of whom may or may not be knowledgeable in matters concerning education and disability.

Some parents talked about informal information and advice they had received. Six families in the sample (families 2, 5, 6, 7, 9, 10) were involved with a parents' group which met regularly. Rhiana's mother talked about meeting with parents through a course organised by the PPS (family 1) and Robert's mother (family 12) attended a group run on a less regular basis. Four parents (families 3, 13, 14, 18) said that they would have liked to meet with other families but had not had the opportunity. However, only Yvonne and Sharon's mothers (families 3, 6) recalled discussions they had with other parents that influenced their thinking about their child's education. Sharon's mother (family 6) talked about her understanding of the new funding policy of the LEA that she heard about through the parents' group. She also talked about stories she had heard via families and friends about older children in mainstream schools with the same syndrome as Sharon and then based her decision about her choice of school on this information rather than advice from professionals working within the system. Yvonne's mother (family 3) talked about the lack of information she had received about schools available to Yvonne in the area and found out additional information from a neighbour, who has a disabled child, which she then acted upon.

5.2.2.3 Parents' knowledge and understanding

Advice implemented by the parents adds to their experience. Information and experience can enhance a person's knowledge and understanding of a situation. This includes their knowledge and understanding of:

- their own child's needs
- statutory assessment procedures
- the purpose of a child's assessment and statement
- services and support available to them.

For most of the parents their knowledge and understanding developed during the time of the study as a result of their experiences and the information they received.

5.2.2.3.1 Their child's needs

Sixteen of the parents said that the information they received during the process of assessment had helped their understanding of their child. For example, Robert's mother (family 12) said that the reports she received provided information about the professionals' views about the level of Robert's attainment. Lee's grandmother (family 20) also talked about how the assessment had not only confirmed her views about Lee's needs through her receiving the professionals' reports but that the additional information included helped her become clearer about why Lee was having difficulties. By contrast Aiden's mother (family 17) simply saw his assessment as a way of getting him a place in special school. She said that 'it was just a means to an end' (2.18) and was only worried about what the reports would say because she did not want him to go to a mainstream school.

5.2.2.3.2 Statutory assessment procedures

Kirsty, Andrew and Charlie's mothers (families 4, 9, 10), who themselves were professionally involved in services for disabled people prior to their child being referred for an assessment, were considered to be very knowledgeable about the procedures for statutory assessment. Robert's mother and Lee's grandmother (families 12, 20), also professionally involved in education, did not have such a detailed knowledge. Robert's mother (family 12), who was a teacher, had experienced great difficulty when initially referring her child for an assessment. She said that she thought it was partly due to her lack of knowledge and she had learnt a lot from the experience.

Thomas's father and Fay's mother (families 5, 8) demonstrated an awareness of the procedures and their rights, in Fay's mother's case it was because she had attended a course organised by the local PPS. Thomas's parents (family 5) were experiencing difficulties getting support in school for another of their children so had found out from the SENCO at the school about the procedures involved.

Most of the families had some knowledge and appeared to learn more about what was involved as the process progressed. Rhiana's mother (family 1), for example, developed an understanding as a result of experiencing her child's assessment and attending a course organised by the PPS at the school. By the time Rhiana's assessment was complete she felt able to advise a friend who lived in a different LEA about her rights.

By the time of interview 3, only seven parents of the seventeen parents interviewed (families 1, 3, 5, 8, 9, 10, 12) could be described as being knowledgeable about the procedures for the assessment and review of their child's needs. Meena's father and Tom's mother (families 2, 21) did not know that their child's statement should be reviewed annually.

5.2.2.3.3 Purpose of the child's assessment and statement

Although most of the parents appeared to have some understanding of the purpose of their child's assessment and statement, others were confused. Meena's father and Aiden and Tom's mothers (families 2, 17, 21) had very little understanding other than they thought it would secure a place or support for their child at school. Five parents (families 4, 8, 9, 10, 14) demonstrated, through what they said, an awareness of the purpose of their child's assessment and statement. Kirsty's mother (family 4) talked about how the assessment had identified Kirsty's needs and helped the family to decide how and where they would best be met. She talked about the type of school, learning environment, curriculum and individual learning goals, support she was expecting Kirsty to receive and how it should be implemented. She also explained how she was expecting the statement, which would include this information, to be reviewed and amended over time.

5.2.2.3.4 Services and support available

During interview 3 the parents were asked directly about information concerning schools and services. Their responses are shown in table 5-12.

Knowledge of schools and services	Number of parents (n = 16/17)
Parent knew what a home-school agreement was	7
Parent knew who the SENCO at their child's school was	11
Parent had seen a school policy about pupils with SEN at their child's school	6
Parent knew about the local PPS	10

Table 5-12 ~ Parents' knowledge of schools and services (interview 3)

This information shows that parents' knowledge of school SEN policies and sources of support was limited. Eleven parents (families 1, 2, 3, 5, 9, 10, 12, 16, 17, 20, 21) had not seen a policy from their child's school regarding pupils with SEN and seven parents (families 2, 3, 13, 15, 16, 17, 20) did not know about the PPS. Rhiana, Fay and Robert's mothers (families 1, 8, 12) had contacted the PPS but their responses were mixed. Robert's mother (family 12) was disappointed when she telephoned them for advice but they had not been able to help. Rhiana and Fay's mothers (families 1, 8) had attended a training course they organised, which Fay's mother (family 8) said helped her to understand more about SEN procedures. She had valued their advice about asking to see the SEN policy at Fay's school and keeping in regular contact with the SENCO. In contrast Meena's father (family 2) had no information about the PPS or the school's policy regarding SEN and did not know who to contact at the school other than the class teacher.

5.2.3 Parents' beliefs

A number of the parents talked about the strong beliefs they had concerning disability and the education of pupils with SEN. Some indicated that they believed in specialist provision and wanted their child to be educated in a special school setting. Thomas's father and Sharon's mother (family 5 and 6) said they thought their child's needs could only be met in a special school with the resources and special curriculum available. Others felt strongly that inclusion in a mainstream school was important. Andrew's mother (family 9), who had a close family member who was disabled, said she believed that the inclusion of disabled pupils in mainstream schools was a way of influencing people's attitudes towards disability in the future. Shabina's mother (family 14) described how she felt strongly that Shabina, who had complex needs, should have access to the opportunities a mainstream school could offer. Most of the families did not appear to hold such strong views and were happy to be advised and guided by the people involved in the assessment when deciding where their child's needs would be best met.

5.3 Parents' individual expectations

Parents' individual expectations focused on a range of issues. Some were positive in that parents expected the outcomes to be what they wanted to happen: by contrast others were negative where they expected to be dissatisfied.

5.3.1 Focus of expectations

During interview 1 all the parents talked about what they were expecting when their child started school and a list of each parent's individual expectations was confirmed during interview 2. The findings described in this section are based on these. The number of different expectations parents talked about ranged from 9 to 28 with most parents talking about 13 to 16 things they were expecting.

The focus of the parent's expectations was categorised into four areas concerning:

1. type of school their child would attend and provision they would receive
2. their child's progress
3. parents' relationships with the school
4. other expectations that could not be included in any of the above

Each category included expectations associated with a range of issues. Expectations talked about by six parents or more concerned the topics listed in table 5-13.

Focus of expectations	**Number of parents (n = 19/19)**
1. School, services and support	
Type of school child would attend	18
Level of support for the child	14
Support for child from therapists	13
School's ability to meet the child's needs	12
Individual programme for the child	11
Inclusion of child in school	8
Flexibility of approach by the staff	8
Timing of the child starting school	7
Classroom organisation	7
Number of days child will attend school	6
School transport	6
Assessment and identification of child's SEN	6
2. Their child's progress	
Progress that will be achieved at school	14
Development of specific skills	13
Learning from other children	8
Child's response to school	7
Benefit to child of being in school	7
3. Relationships with school	
Parents' contact with staff	13
Receiving information from school about the child	11
Experience and / or expertise of the staff with pupils with SEN	9
Parents giving information to school	7
Parents' involvement in making decisions about their child	7
Working on child's programme at home	6
Attitudes of the school staff	6
Parents' involvement with school	6

Table 5.13 ~ Focus of parents' individual expectations (interviews 1 and 2)

There was less consistency within the group about ‘other expectations’ but those talked about most frequently included future provision, recruitment of staff, additional services outside of education and LEA policies and practice.

For some parents their expectations focused on their individual situation and child whilst other parents talked about expectations relating to broader issues. For example the expectations that Tom’s mother (family 21) talked about concerning:

- The type of school and level of support Tom would receive
- Support from therapists
- Tom’s inclusion in classroom activities
- The assessment and identification of Tom’s needs
- Development of specific skills
- Tom learning from other children
- Her own contact with school staff including exchange of information between home and school.

By contrast, Fay’s mother (family 8), in addition to the above, talked about expectations concerned:

- An individual programme for Fay
- Support from external support services
- Her own role in Fay’s education
- The content of Fay’s statement
- Timing of the annual review
- Fay’s progress and friendships at school
- Experience and expertise of staff
- Future school placement for Fay
- The range of appropriate schools available within the area
- Support for parents when choosing a school for their disabled child.

Fay’s mother had not just focused on her child and individual circumstances but had also considered issues related to the qualities and experience of the staff, the assessment, statement and review procedures, support for parents when selecting a school and LEA policies that affect the range of provision available in the area.

5.3.2 Positive and negative expectations

When the parents were asked about their expectations, they talked about positive and negative outcomes they were expecting to happen when their child started at school (see table 5-14 on page 95). For example Kirsty's mother (family 4) was expecting her to:

> *… … learn from other children in the kind of richness of the environment that being in a mainstream setting provides.* (1.45)

However she said that she was also expecting:

> *… … to find it difficult to find a school where her child would get the advantages of both the specialised setting and an integrated mainstream setting.* (1.75)

In the first instance Kirsty's mother was expecting a positive outcome but in the second she was expecting it to be negative in that she doubted if it would be possible.

The majority of the expectations parents talked about were positive. All of them had some positive expectations about the school, services and support and their child's progress. Eighteen of the nineteen parents talked positively about relationships they were expecting with school. Other positive expectations the parents had related to their individual circumstances.

When positive and negative expectations were examined for the group as a whole seven parents (families 1, 5, 10, 13, 15, 20 and 21) talked only about the positive outcomes that they were expecting and thought their child's transition into school would progress well. A further nine families had 75% or more of their expectations that were positive but envisaged difficulties mostly associated with the type of school, services and support they would receive for their child.

Family number	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**20**	**21**	Total	%
No. expectations parent talked about (n = 19)	13	10	15	16	19	13	13	28	21	13	12	9	21	12	15	12	16	16	10	**284**	
Positive expectations – no. concerning:																				**237**	
School / services / support	5	5	2	4	9	4	8	10	6	3	5	4	10	7	9	4	4	7	5	**111**	**39**
Child	4	1	1	5	2	2	2	6	3	5	2	1	3	2	3	2	3	4	2	**53**	**19**
Relationship with school	4	2	3	2	6	1	2	5	4	3	3	3	5	2		2	4	3	3	**57**	**20**
Other		1		1	2			2		2		1	2	1		1	1	2		**16**	**5.5**
% positive expectations	***100***	***90***	***40***	***75***	***100***	***54***	***92***	***82***	***62***	***100***	***83***	***100***	***95***	***100***	***80***	***75***	***75***	***100***	***100***		**83.5**
Negative expectations – no. concerning:																				**47**	
School / services / support			3	2		2		1	5				1			1				**15**	**5**
Child		1	4			1			1		2						2			**11**	**4**
Relationship with school			1												3	1				**5**	**2**
Other			1	2		3	1	4	2							1	2			**16**	**5.5**
% negative expectations	**-**	***10***	***60***	***25***	**-**	***46***	***8***	***18***	***38***	**-**	***17***	**-**	***5***	**-**	***20***	***25***	***25***	**-**	**-**		**16.5**

Table 5-14 ~ Positive and negative expectations (interviews 1 and 2)

The remaining three parents (families 3, 6 and 9), whose positive expectations were fewer than 75%, had negative expectations concerning mainstream placements for their children. For example, Yvonne's mother (family 3) had more negative expectations than positive. She did not expect to receive the support at the school from external support services and speech and language therapists that she thought Yvonne needed. She also had negative expectations about how Yvonne would cope with school and the progress that she would make. In addition she was expecting to have to support Yvonne over the lunchtime break due to lack of funding for staff. Sharon's mother (family 6) had been advised to send Sharon to mainstream school but did not expect that the school would be able to meet her needs. She thought that the new LEA policy concerning funding for pupils with SEN would result in her not getting the support she needed. As a result she expected that Sharon would not be happy, safe or succeed in that environment and she would have to fight to have a special school named on the her statement. The positive expectations she talked about concerned her views about the value of a special school placement for Sharon.

5.4 Developing expectations

Between interview 1, when parents were first asked about their expectations, and interview 2, when their lists of expectations were confirmed, all the parents except Meena's and Tom's parents (family 2, 21), had developed their ideas about what they were expecting when their child started school. All of them talked about at least one new expectation during interview 2. For example, Thomas's parents (family 5), who visited his school between interviews 1 and 2, developed clearer expectations from the information they were given about his starting date, the number of days he would attend and how the school would meet his needs. They also had new expectations, which they had not considered before, about the provision of school transport, a project offered by the school to support the motor development of children with complex needs and their involvement in school. They were also expecting Thomas to enjoy school and have some fun.

Developed expectations were therefore concerned with the same focus as the original expectation but had altered in some way due to parents' new experiences and/or information or advice. *New expectations* were those that had not been considered and/or articulated previously by the parent.

5.4.1 Reasons for developing expectations

The reasons for the development of parents' expectations and the emergence of new ones are shown in figure 5-1.

Information or advice **(n = 19)**	- following a school visit - acquired from school staff - acquired from professionals involved in pre- school support services - acquired from the LEA - following the completion of the child's assessment and receiving the draft statement - medical professionals
Experience **(n = 8)**	- Their child's progress - The school - The staff - Their child in school - Their involvement in the school
Making their expectations explicit **(n = 2)**	- Through talking to the researcher - Talking to school practitioners

Figure 5-1 ~ Reasons for parents' developing their expectations (interview 2)

5.4.2 Focus of new and developed expectations

The focus of parents' developed or new expectations were associated with a number of issues most of which related to provision for the child, with new expectations being developed concerning parents' relationships with school (see tables 5-15 and 5-16 on pages 98 and 99).

Focus of developed expectations	Number of parents (n = 17/19)
School / services / support (n = 17)	
Support for child	9
Date of starting school	4
School placement	4
Individual programme	4
Future provision	3
Classroom organisation	3
Number of days attending school	2
Speech and language therapy	2
Timing of assessment process	2
Attitude of staff	2
School curriculum	1
Expertise of staff	1
Equipment	1
School transport	1
Support from LEA	1
Inclusion in school activities	1
Their child (n = 5)	
Child's progress	5
Attitudes of others to their child	2
What would be of benefit to the child	5
Relationships with the school (n = 4)	
Home-school diary	1
Parents' groups	1
Meetings with staff	1
Communication with school	1
Involvement in setting programme	1
Other expectations (n = 3)	
Own expectations	1
Support when choosing placement	1
Child's reaction to school transport	1

Table 5-15 ~ Focus of parents' developed expectations (interview 2)

Focus of new expectations	**Number of parents (n = 19/19)**
School / services / support (n = 16)	
Support for child	5
School transport	4
Individual programme for the child	4
Speech and language therapy	4
Support from LEA services / child development centre	2
Assessment process, statement and review	2
Attitudes of staff	2
Role of staff in school	1
Transition process	1
Future placement for child	1
Child's school placement	1
School curriculum	1
Their child	
Child's progress	4
What would benefit the child	2
Child's attitude to school	2
Medical condition	1
Relationships with the school	
Meetings at school / access to staff	5
Parental involvement in school	4
Home-school diary	4
Communication with school	3
Attitudes of staff	2
Other expectations	
Availability of provision in the LEA	1
Future placement for child	1
Funding for pupils with SEN	1
Training for parent	1
Assessment process	1
Own expectations to be more positive in future	1

Table 5-16 ~ Focus of parents' new expectations (interview 2)

5.4.3 People and services instrumental in developing parents' expectations

The people and/or services that were identified during the analysis process that helped most to develop parents' expectations are listed in table 5-18.

People and services identified	**Number of parents (n = 17/19)**
Staff at the school the child is due to attend	16
External support services	7
Therapists / medical support services	7
Current early years placement staff	7
Family / other parents	3

Table 5-18 ~ People and services identified as having helped most to develop parents expectations (interviews 1 and 2)

Andrew's mother (family 9) visited a number of schools and talked to practitioners about provision available, discussed her options with key professionals involved with Andrew's assessment, including therapists from the child development centre and the LEA officer, and her family. She therefore added to her experience and knowledge so her expectations regarding support for Andrew and her relationship with school developed and became clearer. Meena (family 2) started school before interview 2 and her father talked about the new expectations he had developed concerning Meena's individual programme, support from a speech and language therapist and the use of communication aids. Furthermore, during interview 3, most of the parents talked about how some of their expectations had developed further and new ones were emerging as a result of their experience of their child in school and the information they received from the staff.

5.5 Shared expectations of the group

The fourteen expectations that were shared by the group were identified following interview 1 and are listed in figure 5-2 (page 101).

No.	Shared expectation
1.	Parent is expecting to work on their child's programme at home
2.	Parent is expecting to receive information about what their child is doing in school
3.	Parent is expecting their child to make progress at school
4.	Parent is expecting the assessment process to identify their child's needs and help decide which school will be best
5.	Parent is expecting to be included in making decisions about their child
6.	Parent is expecting their child to go to a school that they believe will best meet their needs
7.	Parent is expecting one to one support for their child
8.	Parent is expecting to be able to give information about their child to the school
9.	Parent is expecting their child to learn from other children
10.	Parent is expecting their child to be included in all aspects of the school
11.	Parent is expecting the staff involved with their child to be committed and have expertise or access to training
12.	Parent is expecting the school to be flexible in meeting their child's needs
13.	Parent is expecting their child to get support from therapists, eg. speech and language therapist,
14.	Parent is expecting their child will have an individual programme to work on at school

Figure 5-2 ~ Shared expectations of the group (interview 1)

5.5.1 Findings from interview 2

When the parents were asked to place these shared expectations in the categories of 'very important', fairly important' and 'not so important' there was some consistency across the group. When the results were analysed the shared expectations 3, 5, 11 and 13 appeared in the 'very important' category most frequently and the 'not so important' category least frequently indicating the parents perceived these as being the most important of their expectations. Conversely, shared expectations 1, 8 and 9 appeared most frequently in the 'not so important' category and least frequently in the 'very important' category indicating they were the least important on the list.

In the case of shared expectations 2, 4, 7 and 14, nearly equal number of parents placed them in the 'very important' and the 'not so important' categories. On closer analysis it was found, in some cases, that there were associations between the parents who chose each category (see figure 5-3 on page 103). They were as follows:

Expectation 2 ~ Parent is expecting to receive information about what their child is doing in school.

The differences in parents' responses were found to be associated with the relationships parents had established with the school and their previous experience of support during the assessment process. Where expectations of positive relationships with school staff and effective channels of communication had been established the parents deemed this expectation was not so important for them.

Expectation 4 ~ Parent is expecting the assessment process to identify their child's needs and help decide which school will be best.

The differences in parents' responses were found to be associated with access to provision and/or resources and parents' strong beliefs regarding the type of placement that they believed would best meet their child's needs.

Expectation 7 ~ Parent is expecting one to one support for their child.

The differences in parents' responses were found to be associated with the type of school the child was going to attend and a parent's knowledge about how their child would be supported in the classroom.

Expectation 14 ~ Parent is expecting their child will have an individual programme to work on at school

There were no associations found between parents' different responses.

Expectation 2 ~ Parent is expecting to receive information about what their child is doing in school

Response	*Factors identified*
Very important (families 1, 6, 9, 21)	Families who had not established a relationship with the staff at their child's school.
Not so important (families 2, 13, 16, 20)	Families had received a lot of support during the assessment process and contact with school staff was already established.

Expectation 4 ~ Parent is expecting the assessment process to identify their child's needs and help decide which school will be best

Response	*Factors identified*
Very important (families 1, 6, 8, 20, 21)	Parents who experienced some difficulties with their child's transfer to school.
Not so important (families 4, 5, 7, 9, 10, 14, 15)	Parents who, from what they said, held strong beliefs about where their child should go to school or who had a definite school or type of school in mind prior to the assessment starting.

Expectation 7 ~ Parent is expecting one to one support for their child

Response	*Factors identified*
Very important (families 3, 7, 8, 9, 13, 15, 20)	Parents had chosen a mainstream placement for their child and had received information about the support that their child would receive when they started school.
Not so important (families 1, 5, 6, 14, 17, 18)	Child was going to special school or a school with additional resources and the parents did not have detailed information about support for their child but demonstrated an understanding about how their child's class would be organised

Expectation 14 ~ Parent is expecting their child will have an individual programme to work on at school

Response	*Factors identified*
Very important (families 2, 5, 10, 18, 20)	No associations were found.
Not so important (families 7, 14, 16,21)	

Figure 5-3 ~ Associations found where equal number of parents thought expectations were 'very important' and 'not so important' (interview 2)

5.5.2 Findings from interview 3

When the activity was repeated during interview 3 there was also some consistency over time. Using the same method of analysis the parents were found to have chosen the most important shared expectations to be 3, 6, and 11 and the least important were 1, 8 and 9. The shared expectations with nearly equal numbers of parents placing them in the 'very important' and 'not so important' categories were shared expectations 4, 5, 7 and 14. Again there were some associations identified between the parents who chose each category (see figure 5-4 on page 105). They were as follows:

Expectation 4 ~ Parent is expecting the assessment process to identify their child's needs and help decide which school will be best

The differences in parents' responses were found to be associated with whether the parents chose the child's school regardless of the assessment or as a result of outcome of the assessment.

Expectation 5 ~ Parent is expecting to be included in making decisions about their child.

The differences in parents' responses were found to be associated with parents' perception of their role and the role of school practitioners in the child's education.

Expectation 7 ~ Parent is expecting one to one support for their child.

The differences in parents' responses were found to be associated with the type of school the child attended.

Expectation 14 ~ Parent is expecting their child will have an individual programme to work on at school

As for the findings from interview 2, there were no associations found between parents' different responses.

Expectation 4 ~ Parent is expecting the assessment process to identify their child's needs and help decide which school will be best

Response	***Factors identified***
Very important (families 1, 8, 12, 16, 18, 20)	These parents sought guidance about the choice of school for their child from the professionals involved in the assessment. With all the parents except family 20 there was a direct link between the guidance given and the parents' choice of school.
Not so important (families 3, 5, 9, 10, 14, 15, 21)	The parent chose the school placement for their child regardless of the assessment.

Expectation 5 - Parent is expecting to be included in making decisions about their child

Response	***Factors identified***
Very important (families 5, 13, 15, 17)	These parents said that they wanted to know what was happening in school with their child and wanted to be involved. In the case of the parents from families 15 and 17 they wanted to be involved but problems had arisen with the school.
Not so important (families 2, 6, 8, 12, 16)	The parents talked about trusting the staff with making decisions about the child's education because they had experience and expertise to do so. The parent of family 8 had not built up such trust but said that she thought it was the role of the school to develop the experience and expertise amongst their staff so they could make decisions about the child.

Expectation 7 ~ Parent is expecting one to one support for their child

Response	***Factors identified***
Very important (families 9, 10, 15, 16, 20, 21)	All the children attended a mainstream school except the child in family 16 who was at a school with additional resources but was not part of the specialist provision.
Not so important (families 1, 3, 14, 18)	All the children were either at a special school or school with additional resources except the child from family 3 and she was transferring to a special school the following term.

Expectation 14 ~ Parent is expecting their child will have an individual programme to work on at school

Response	***Factors identified***
Very important (families 1, 3, 5, 10)	No associations were found
Not so important (families 2, 13, 16, 20, 21)	

Figure 5-4 ~ Associations found where equal number of parents thought expectations were 'very important' and 'not so important' (interview 3)

5.5.3 Comparison of findings from interviews 2 and 3

When the findings were compared for interviews 2 and 3 there was consistency across the group and over time.

The shared expectations that parents deemed to be most important were:

Expectation 3 ~ Parent is expecting their child to make progress at school

Expectation 11 ~ Parent is expecting the staff involved with their child to be committed and have expertise or access to training.

The shared expectations that parents considered least important were:

Expectation 1 ~ Parent is expecting to work on their child's programme at home

Expectation 8 ~ Parent is expecting to be able to give information about their child to the school

Expectation 9 ~ Parent is expecting their child to learn from other children

There were nearly equal numbers of responses by parents as to whether shared expectations 4, 7 and 14 were most or least important during interviews 2 and 3. The reasons identified for this were:

Expectation 4 ~ Parent is expecting the assessment process to identify their child's needs and help them decide which school will be best.

The differences in parents' responses were found to be associated with parents' beliefs about the purpose of the assessment procedure.

Expectation 7 ~ Parent is expecting one to one support for their child.

The differences in parents' responses were found to be associated with the type of school the child attended.

Expectation 14 ~ Parent is expecting their child will have an individual programme to work on at school

There were no associations found that linked to the differences in the parents' responses.

5.6 Outcome of parents' expectations

Parents talked about the outcome of their expectations during interview 3 and discussed what factors had helped or hindered them being realised.

5.6.1 Outcome of individual expectations

The outcomes of parents' expectations are shown in table 5-18.

Outcome of expectations (n = 255)	**Total no.**	**%**
School / services / support	**112**	
Realised	81	72%
Developed	21	18%
Not realised	11	9%
Stayed the same	2	1%
About the child	**57**	
Realised	39	69%
Developed	10	18%
Not realised	1	2%
Stayed the same	6	11%
Relationships with school	**58**	
Realised	38	65%
Developed	12	21%
Not realised	7	12%
Stayed the same	1	2%
Other expectations	**28**	
Realised	12	43%
Developed	5	18%
Not realised	2	7%
Stayed the same	9	32%

Table 5-18 ~ Outcome of parents' expectations (interview 3)

66% of the 255 total expectations parents talked about had been realised at the time of review. When considered according to the focus of the expectations, 98%

of expectations about the children, 91% concerned with the type of school, services and support for the child and 88% about parents' relationships with school had been realised, developed or stayed the same.

On reflection, parents said that some of their expectations had developed over time. For example, Thomas's parents (family 5) had expected him to gradually build up the number of days he attended school to full time, but he attended full time from the second week. As a result their expectations had developed because of their experience of Thomas and the school.

Long-term expectations the parents talked about concerning, for example, the child's progress and educational provision in the area, could not have been realised within this time period. For example, Meena's father (family 2) expected her to eventually be able to communicate using communication aids and was still expecting it to happen. Fay's mother (family 8) said she did not expect to find provision for children with moderate learning difficulties available in a special school in the area.

The largest proportion of expectations that had not been realised by interview 3 concerned parents' relationships with practitioners. For example, Charlie's mother (family 10) had expected that there would be good communication between home and school so information could be shared but it did not happen. Expectations concerning the child's provision were in some instances not realised. Fay's mother (family 8) was expecting Fay to have a qualified support worker, because it was included on her statement, but instead a special needs assistant was employed who, her mother thought, did not have the skills to work with Fay effectively.

Through this review process, five parents (families 3, 9, 10, 15, 16) talked about becoming aware of their expectations because they had not happened. Examples include Yvonne's mother (family 3) who had assumed that Yvonne would attend school full time but the staff sent her home early each day because they said she was tired. Charlie's mother (family 10), who expected detailed records would be kept about Charlie's progress at nursery, discovered at the end of the year that there was only a general report written.

5.6.2 Outcome of positive and negative expectations

During the analysis process the outcome of positive and negative expectations were examined separately (see table 5-19 on pages 110 - 111).

Overall there were fewer negative expectations (n = 42) than positive (n = 213). Parents described 69% of positive and 55% of negative expectations as realised and 8% of positive and 5% of negative expectations as not realised by the time of interview 3. A negative outcome to a positive expectation resulted in some parents lowering their expectations. For example, when James' mother (family 16) did not have the regular contact with the staff involved with James she had expected, she thought they were not going to provide her with information without being asked. Shabina and Dominic's mothers (families 14, 18) were expecting difficulties that did not happen so there was a positive outcome to their negative expectation. For example, Dominic's mother (family 18) was expecting him to have difficulty using the school transport but when he started school the escort on the taxi had developed a good relationship with him, so the problems she had expected did not arise. The remainder of the positive and negative expectations had either stayed the same or developed because of new experiences and/or additional information or advice.

5.6.3 Outcome of positive and negative expectations according to focus

Further analysis according to the focus of expectations allowed comparison between the positive and negative expectations. For example, a higher proportion of negative (31%) than positive (17%) expectations concerning *the school, services and support for the child* were developed resulting in parents developing clearer and higher expectations about the support their child would receive. However 61% of negative expectations in this category were realised which confirmed their original fears. For example, Andrew's mother's (family 9) negative expectations concerning the recruitment of a support worker were not realised so her expectations of support for Andrew in the classroom increased. However her expectations concerning school transport were not realised and she experienced the difficulties she had expected getting both of her children to school each day.

Family number	1	2	3	5	6	8	9	10	12	13	14	15	16	17	18	20	21	Total	%
School / services / support																			
Positive expectations (total)	***5***	***5***	***2***	***9***	***4***	***10***	***6***	***3***	***5***	***4***	***10***	***7***	***9***	***4***	***4***	***7***	***5***	***99***	
Realised	2	4	1	6	4	6	5	2	5	2	7	5	7	3	4	7	3	**73**	**74**
Developed	2			3		1	1			2	2	2	1	1			2	**17**	**17**
not realised	1		1			2		1			1		1					**7**	**7**
stayed the same		1				1												**2**	**2**
Negative expectations (total)			***3***		***2***	***1***	***5***				***1***			***1***				***13***	
Realised			3		2		3											**8**	**61**
Developed						1	2							1				**4**	**31**
Not realised											1							**1**	**8**
Stayed the same																			
About the child																			
Positive expectations (total)	***4***	***2***	***1***	***2***	***2***	***6***	***3***	***5***	***2***	***1***	***3***	***2***	***3***	***2***	***3***	***4***	***2***	***47***	
Realised	3	1	1	2	1	4	2	3	1	1	2	2	3	1	2	3	2	**34**	**72**
Developed	1	1				1	1	2	1		1					1		**9**	**19**
Not realised																			
Stayed the same					1	1								1	1			**4**	**9**
Negative expectations (total)			***4***		***1***		***1***		***2***						***2***			***10***	
Realised			2				1		2									**5**	**50**
Developed			1															**1**	**10**
Not realised															1			**1**	**10**
Stayed the same			1		1										1			**3**	**30**

Table 5-19 ~ Outcome of parents' positive and negative expectations (interview 3)

Family number	**1**	**2**	**3**	**5**	**6**	**8**	**9**	**10**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**20**	**21**	**Total**	**%**
Relationships with school																			
Positive expectations (total)	***4***	***2***	***2***	***6***	***1***	***5***	***4***	***3***	***3***	***3***	***5***	***2***		***2***	***4***	***3***	***3***	***52***	
Realised	1	1	1	4	1	3	3		3	2	2	2		1	2	3	3	**32**	**62**
Developed	3	1	1	1				1			3			1	1			**12**	**23**
Not realised				1		1	1	2		1					1			**7**	**13**
Stayed the same						1												**1**	**2**
Negative expectations (total)			***2***										***3***	***1***				***6***	
Realised			2										3	1				**6**	**100**
Developed																			
Not realised																			
Stayed the same																			
Other expectations																			
Positive expectations (total)		***1***		***2***		***2***		***2***		***1***	***2***	***1***		***1***	***1***	***2***		***15***	
Realised		1		2		1		1			1			1	1			**8**	**54**
Developed										1	1					1		**3**	**20**
Not realised						1						1						**2**	**13**
Stayed the same								1								1		**2**	**13**
Negative expectations (total)			***1***		***3***	***4***	***2***							***1***	***2***			***13***	
Realised			1		1	1	1											**4**	**31**
Developed							1							1				**2**	**15**
Not realised																			
Stayed the same					2	3									2			**7**	**54**

Table 5-19 (continued) ~ Outcome of parents' positive and negative expectations (interview 3)

Concerning parents' expectations about their *relationships with schools*, there was no development of their negative expectations and all of them were realised. In addition 23% of positive expectations were developed. Some developed into higher expectations, for example, Rhiana's mother (family 1) found she received more support for herself from the school than she originally expected. Other developments resulted in parents lowering their expectations, for example Charlie's mother (family 10) had expected to have regular contact with the school through a home-school diary, which had not materialised, so she developed different ideas about what to expect.

Finally, expectations concerning *their child* were positive (n = 47) rather then negative (n = 10). During the period of the study, negative expectations were either realised (50%) or were long term so stayed the same (30%). For example, Yvonne's mother (family 3) thought Yvonne would find it difficult to cope in a mainstream school, which she said had been confirmed after her first year. All the parents talked about positive expectations they had about their child that had been realised. The majority of positive expectations were realised (72%) or developed (19%). Parents talked about the milestones they expected their children to achieve when moving into school, for example, to develop skills related to early development including movement and feeding and to be able to enjoy themselves and have some fun (family 5). Many of these were confirmed over time and some parents began to talk about their future expectations developing as they came to expect more of their children.

5.6.4 Reasons parents gave for outcomes of expectations

Reasons parents' gave for their positive expectations being realised are listed in table 5-20 (page 112). Factors that particularly helped were associated with school organisation, the experience and expertise of the staff and the attitudes of the staff. Fay's mother (family 8) described how her expectations about Fay's school placement had not been realised because of the lack of qualified staff, school organisation, the lack of external support and the negative attitude of the head teacher towards pupils with SEN and their parents. She recognised that the situation changed rapidly with the leadership of a new head teacher part way through the year.

Reasons given	**Number of parents (n = 17/17)**
Positive expectations	
Concerning the parents' experience of school	
School organisation	11
Experience or expertise of staff	10
Attitudes of staff	10
Support from therapists	6
Communication with staff	4
Resources available	4
Information given on school visit	1
Concerning the child	
Experience of child	10
Child's personality	1
Other factors	
Content and implementation of statement	7
Parent's own attitude / actions	6
Attitudes of other children	1
Experience of visiting other schools	1
Involvement of disability rights advisor	1

Table 5-20 ~ Reasons parents gave for positive expectations being realised (interview 3)

Also important for some parents was support from therapists, the content and implementation of the statement and parents' own attitudes and actions. They considered their own experience and knowledge of their child was important in developing expectations of their child that could be realised.

Where negative expectations were realised, parents offered fewer explanations. Their reasons are summarised in table 5-21 and focus on, for example, staff attitudes, lack of resources and LEA policies.

Reasons given	**Number of parents (n = 6/7)**
Concerning the parents' experience of school	
Lack of resources	2
Attitudes of staff	2
Attitudes of other parents	1
Other factors	
LEA policies and practice	2
Assessment procedures	1
Availability of provision in the area	1

Table 5-21 ~ Reasons parents gave for negative expectations being realised (interview 3)

Reasons parents gave for developing their expectations during their child's first year in school were associated with additional experience and information. Parents had new experience of the school organisation, working practices of practitioners and their child in school. They also were given additional information and advice (see table 5-22 on page 115). New experiences and information helped parents to develop clearer expectations. For example, Shabina's mother (family 14) had expected to know what Shabina was doing in school through having regular meetings every few months with the staff and to be involved in setting her learning goals because this was what she had experienced in the previous early years setting. As a result of new information she received from the head teacher and her experience of school organisation including the working practices of practitioners, she developed her expectations. She then expected that she needed to create opportunities to talk to practitioners so she could ask for information and the following year was planning ways in which she could have a greater involvement in determining Shabina's individual programme and working on tasks at home.

Reasons given	**Number of parents (n = 16/16)**
Concerning the parents' experience of school	
School organisation	9
Experience or expertise of staff	5
Attitudes of staff	3
Contact with therapists	2
Contact with external support services	1
Concerning the child	
Experience of child in school	7
Child's progress	4
New information received about the child	2
Other factors	
New information from the school	3
Professional advice from school/LEA	2
Change in families' circumstances	1
Parents' views about their roles	1
Amendment to statement	1

Table 5-22 ~ Reasons parents gave for developing their expectations (interview 3)

The reasons parents gave for their expectations not being realised are listed in table 5-23 (page 116). Parents commented on the lack of experience and expertise of practitioners, people's attitudes and school organisation as hindering the realisation of their expectations. Andrew's mother (family 9) described the negative attitudes of the nursery staff towards including him in activities and their lack of willingness to take advice about adapting the curriculum to allow him access.

Most of the parents talked about new expectations that were emerging. They particularly focused on future provision, support for the child and aspects of the child's progress. For example Yvonne's mother (family 3), who had decided to move Yvonne from a mainstream to a special school, talked about the new school, the level of support she expected her to receive and how she would benefit from the move.

Reasons given	**Number of parents (n = 10/11)**
Concerning the parents' experience of school	
Lack of staff's experience or expertise	4
Attitude of staff	4
School organisation	3
Attitude of other parents	1
Lack of multi-agency working	1
Resistance to change	1
Lack of support for the support worker	1
Concerning the child	
Experience of child in school	1
Other factors	
LEA transport policy	2
Misunderstanding / given inaccurate information	2
Family / work commitments and school organisation	2
Recruitment of staff	1
Lack of provision available	1
Lack of information about assessment process	1

Table 5-23 ~ Reasons parents gave for their expectations not being realised (interview 3)

5.7 Parents' views concerning talking about their expectations

Sixteen of the parents said it had been useful talking about their expectations and reviewing them over time. The reasons given are listed in table 5-24.

James' mother (family 16) said that she used her expectations like a checklist to review what had happened. Yvonne's mother (family 3) said that talking about her expectations had helped her not to just deal with one day at a time but to think about what she was expecting for Yvonne in the future. Being involved in the study had helped Lee's grandmother (family 20) think about what she was expecting and so be clear when speaking to the staff at his school. By doing so, she said, problems were resolved before they occurred and so conflict was avoided.

Comments made	Number of parents (n = 16/17)
Talking about expectations	
Raised parents' awareness of what they were expecting	12
Useful having expectations written down	6
Awareness of expectations helped parent resolve problems	5
Helped parent think about issues related to child / SEN / education	4
Useful to talk about expectations to an independent person	1
Reviewing expectations	
Useful to review expectations after period of time	7
Realised how much been achieved	4
Helped understanding of what happened and why	4
Helped think about if expectations too high / low / realistic	3
Helped to develop future expectations	2
Helped to realise that their expectations develop over time as their experience increases	2

Table 5-24 ~ Parents' comments concerning talking about and reviewing their expectations when their child started school (interview 3)

5.8 Family profiles

These profiles provide detailed information about three of the families in the study. They include information about the child and the parent's knowledge and experience of disability and education. They also provide information about individual expectations each parent talked about prior to their child starting school and their outcome a year later. They were selected to illustrate the range of experiences of families in the sample. Rhiana's and Tom's mothers (families 1, 21) had very little knowledge and experience of disability and education for children with SEN until they experienced it with their own child. Rhiana's mother (family 1) received support from the services involved in Rhiana's assessment. As a result she developed her knowledge, understanding and also her confidence in communicating and working with the staff at her child's school and over time she was able to develop clearer expectations. Tom's mother (family 21), despite her personal experience of Tom's assessment, had not developed her understanding and continued to be confused about what she could expect when her son started school. She did not appear to have received a lot of support through the assessment process and Tom's transition into school. The effect of a parent's personal experience of disability through a close family member is illustrated by Andrew's family profile (family 9). His mother was knowledgeable of her rights and appears to have been very active in ensuring Andrew receives the provision he is entitled to. She talked about how she considered the different options available to her before making decisions. Unlike Rhiana and Tom's mothers (families 1, 21), Andrew's mother's expectations and actions reflect her awareness of the wider issues concerning the education of disabled children. Her expectations were not only focused on her child and personal circumstances but also considered the barriers she thought she might encounter as both her children moved into school.

5.8.1 Family 1

Rhiana was under two years of age when interview 1 took place with her mother and was the youngest child in the sample. Her mother said that she had Rhiana when she was in her teens and cared for her on her own, with support from her family. She described Rhiana as having cerebral palsy, epilepsy and being partially sighted as result of an illness she contracted in her first weeks of life. She said that Rhiana could not do anything for herself.

Professionals working with Rhiana had initiated her assessment and supported her mother through the process. She wanted Rhiana to attend a special school because the professionals involved had recommended a particular school. She thought Rhiana would get specialist help but was worried about her starting school so young and how she would feel handing over her care to other people.

Rhiana's mother did not know anybody who was disabled and appeared to have a stereotypical view of disabled people, describing them as 'lovely people', 'a lot more loving' and said that she felt sorry for them. People with disabilities, she said, should be treated the same as other people but she wanted her daughter to go to a special school with other disabled children. She recalled her own experience of school where she witnessed pupils being bullied because they were different and did not want it to happen to Rhiana. Since her daughter's diagnosis she said that she had become more aware and now sees Rhiana as an individual rather than focusing on her disability.

Prior to and during the assessment process Rhiana had received hospital-based services plus support from the visually impaired support service. She had attended regular therapy sessions at the child development centre where her mother said she had been given information, advice and support. During the course of the interviews she talked about the close relationship that she developed with one of the therapists whom she felt she could contact at any time. She was initially concerned about losing this support when Rhiana went to school.

Rhiana's mother said that the assessment process had been easier than she had expected without the stress and worry that she had anticipated. The reports she received confirmed her understanding of Rhiana's impairment and the statement was not as daunting as she had prepared herself for. The professionals involved had supported Rhiana's mother through the process and praised her contribution. Aspects of the assessment that she had found difficult were when people who did not know Rhiana or herself wrote reports; worries about the content of the reports before she received them and the length of time that the process took. By the end of Rhiana's assessment she was more knowledgeable about SEN procedures and was able to advise a friend about her rights.

During the course of Rhiana's assessment her mother visited the school that had been recommended. She liked the head teacher who agreed that Rhiana could attend for two days a week, rather than full time, and that her time at school could increase when her mother wanted. Rhiana's mother was invited to attend a course at the school organised by the PPS. During this period Rhiana began to go into the classroom with the other children and her mother got to know the staff and the school routines.

Since the time of Rhiana's diagnosis her mother had, through contact with services, school, other parents and information provided by the LEA, gradually increased her knowledge and experience of the assessment procedures for children with SEN and what she and Rhiana were entitled to in terms of services and support. As a result she had become more actively involved in Rhiana's education and care so by the time of interviews 2 and 3 she talked about ways in which she had become involved in school and decisions being made about Rhiana, challenging those with which she disagreed.

Rhiana's mother's expectations focused on Rhiana and her own involvement with school (see figure 5-5 on page 121). They appear to be based on her beliefs, knowledge and experience of disability and education and her understanding of Rhiana's needs which developed as a result of her experiences. Initially her expectations developed and became clearer because of advice from professionals involved in Rhiana's assessment, her contact with the school and her understanding of Rhiana's needs. Her expectations reflected her positive feelings about Rhiana starting school. However, just before Rhiana was due to start school, she was unsure about the practical arrangements, such as the starting date, what to send with her to school and the organisation of transport, which was a worry to her.

Rhiana's mother said that it had been useful being involved in the study. Through talking about and reviewing her expectations she realised how much had been achieved otherwise she would not have remembered. At first she thought that she had been expecting too much but she said that the school had been able to realise her expectations.

The school placement worked well for Rhiana. She described the school as being flexible in meeting Rhiana's and her own needs. Practitioners were friendly, supportive and encouraged her involvement in school. They provided detailed information about the activities Rhiana took part in through a home-school diary and by sending home a book each term with examples of Rhiana's work and photographs of her in school. Rhiana's mother felt that she had got to know the practitioners, could contact or visit the school whenever she wanted and was able to discuss any problems she had. Rhiana's first annual review meeting had been positive as her mother had been able to discuss her progress in school and future provision with the class teacher and head teacher. The only difficulties she encountered during Rhiana's first year in school were with school transport arrangements.

Expectations		Original	Developed	New	Outcome
What type of school, services and support the parent is expecting for their child					
Expectation 1	Rhiana to go to a special school	/			Realised
Expectation 2	To go 2 full days a week to begin with and gradually build up days to full time by Christmas		/		Developed
Expectation 3	School to be able to meet Rhiana's needs	/			Realised
Expectation 4	Rhiana to have school transport			/	Developed
Expectation 5	Rhiana's mother to be able to accompany her on school transport			/	Not realised
What parent is expecting for their child					
Expectation 6	Rhiana's progress to be slow but not as slow as originally thought		/		Developed
Expectation 7	The school to follow an individual programme to meet the Rhiana's needs rather than adhering to the national curriculum	/			Realised
Expectation 8	Rhiana to be part of a group but to have some time when she has individual one to one attention		/		Realised
Expectation 9	Rhiana to experience a different environment with different people at school	/			Realised
What parent is expecting of their relationship with school					
Expectation 10	Rhiana's mother to get support when Rhiana goes to school through the parent group and from the staff		/		Developed
Expectation 11	To exchange information through a home – school diary		/		Realised
Expectation 12	To attend a parents' group at school			/	Developed
Expectation 13	To attend FE course at school			/	Developed

Figure 5-5 ~ Family 1 - Expectations and their outcome

Rhiana's mother said that most of her expectations about Rhiana starting school were realised because of the attitudes of practitioners and the school organisation. Some expectations had developed because of her positive experience of Rhiana being in school, which was more flexible in meeting both their needs than she had expected. Although she was not involved with the parents' group, because of the days she had chosen for Rhiana to attend school, she felt supported by the staff. Some expectations were developed or not realised because she found that the information she had been given was incorrect. She had expected to be able to use school transport to visit school but could not because of LEA policy. Also she had been advised by a therapist to apply to a college course and expected to be able to get a place but when she contacted the college she found the information she had been given was incorrect and she was not eligible.

Rhiana's mother said that she had enjoyed being involved in the study but did not think that she had a lot to offer because Rhiana's move into school had gone so well. However, through the information she gave and her participation in the interviews, it is evident that as her knowledge and experience grew so did her confidence and increasing participation in Rhiana's education.

5.8.2 Family 9

Andrew and his twin sister were preparing to go into nursery. Although their mother is their main carer, their father has been involved in the process of transferring the children into school by, for example, participating in the discussions regarding the different options available and taking time away from work to attend Andrew's annual review meeting. Andrew's mother has extensive knowledge and experience of issues related to disability as she has a close family member who has a complex learning disability. She has also worked professionally in the health service. As a consequence she considers the wider issues related to Andrew's education, her role in promoting a more inclusive society as well as the effects Andrew's disability will have on his twin sister.

Andrew's family referred him to the LEA for a statutory assessment because they believed that he needed additional help at school due to his cerebral palsy and a medical condition that will affect his development. His mother wanted him to go to a mainstream nursery because she thought that, with additional resources for Andrew, they could meet both her children's needs and other children would provide him with good role models for language development. In addition she thought that Andrew being in school would add to the other children's experience of disability which may influence their attitudes in the future.

Andrew's mother described how her personal experience of having a close relative with a disability had influenced her attitudes. She believed strongly that disabled people should be included in the community and thought that it was happening more now than in her childhood when she had experienced abuse and embarrassment when out with her family. She also talked about the need for peer support for Andrew and the family from other disabled children and their parents that she thinks is lacking when a child attends mainstream education.

Prior to attending nursery Andrew received a variety of services through the hospital, LEA, voluntary organisations and Social Services. Andrew attended a specialist nursery for disabled children organised by the voluntary sector and a local playgroup. Andrew's mother valued these services because it helped her support Andrew's development, provided information and resources and emotional support. She was critical of the overall organisation of pre-school services, in particular the difficulty accessing appropriate services and help when they were needed and the lack of a key worker system for families. She also commented on the difficulty of meeting the needs of all family members when so much attention is focussed on one child.

The assessment process provided Andrew's mother with an opportunity to explore the options available to them in terms of future educational provision for both the children. She discussed her ideas with professionals involved and visited potential schools. She was pleased that everybody was in agreement with a mainstream placement and thought that the process had been more straightforward than she had expected. She commented on the importance of the parental contribution to the assessment and the value of receiving copies of reports as the process progressed. She encountered difficulties with processing the reports through the LEA and had to chase up a lost report, liase with services herself to move the assessment along and had difficulty communicating with the LEA officers who had assumed that she was knowledgeable about the process. She thought there was a lot of paperwork that was duplicated and the whole process was time consuming. She did however receive a lot of support throughout this period from professionals involved, other parents in a group she attended and from her own mother. She also got information and advice from voluntary organisations.

During the summer holidays Andrew's family had visited a special school as part of a summer play scheme but his mother believed strongly in inclusion and wanted both children at the same school so looked at two local schools. They considered the positive and negative aspects of each school in terms of locality, academic achievement, physical access, resources available and the knowledge, experience and attitudes of the staff. After discussing their findings with the therapists, LEA officer, other parents and her family she decided on the school that would meet both the children's needs. It was physically accessible but the attitudes of the staff were not positive towards inclusion. This school was named on the draft statement and Andrew's mother continued to make visits to meet with the staff and make the necessary arrangements for him to start. She had found making a decision about which school to send the children to very difficult and time consuming.

Andrew's mother was pro-active during the assessment process. She had:

- initiated the assessment
- liased with the LEA and services involved to ensure the assessment process continued to progress
- asked for provision to be included in the statement
- visited schools and arranged meetings between school staff and therapists
- helped resolve problems concerning Andrew's equipment
- been involved in setting Andrew's learning goals.

She said that she saw this as part of her parental role.

The expectations Andrew's mother talked about concerned a range of issues including support for Andrew, his transition into school, his participation and progress at school, her involvement and the attitudes of practitioners (see figure 5-6 on page 125 - 126).

Expectations		Original	Developed	New	Outcome
What type of school, services and support the parent is expecting for their child					
Expectation 1	Andrew to have a place at local MS school – nursery – mornings only		/		Realised
Expectation 2	Nursery nurse to support Andrew in nursery	/			Realised
Expectation 3	Nursery nurse not to be in post by start so there will be a temporary person initially		/		Developed
Expectation 4	Andrew to follow an individual programme but also be included in activities with the whole class	/			Realised
Expectation 5	To have additional equipment in school to meet Andrew's needs (No physical adaptations needed because of choice of school)		/		Developed
Expectation 6	Andrew to need support from therapists in school but not to be available so regularly as previously, particularly at the beginning so parent will have to help training the people involved	/			Realised
Expectation 7	Transfer to school not to be flexible so as to meet family and Andrew's needs due to expected difficulties with transport arrangements.		/		Realised
Expectation 8	Andrew's mother to stay with him while he settles	/			Realised
Expectation 9	For Portage to have no contact with school but for the PSSS to become involved		/		Realised
Expectation 10	Not to have transition period with services as Andrew transfers into school			/	Developed
Expectation 11	For school to help with toilet training			/	Realised

Figure 5-6 ~ Family 9 - Expectations and their outcome

Expectations		Original	Developed	New	Outcome
What parent is expecting for their child					
Expectation 12	Andrew will be a distraction to other children as he becomes more vocal		/		Developed
Expectation 13	Andrew to continue to make progress and be fairly intelligent with support and continuity		/		Realised
Expectation 14	Andrew to learn from his peers	/			Realised
Expectation 15	Andrew not to have access to activities designed for disabled children e.g. riding for the disabled and swimming	/			Realised
What parent is expecting of their relationship with school					
Expectation 16	To continue to be involved in working with Andrew	/			Realised
Expectation 17	School to keep Andrew's parents informed about what he does and his progress. To have this information written down and to have access to his records.	/			Realised
Expectation 18	Andrew's mother to share information about how he is at home with people working with him in school	/			Realised
Expectation 19	The staff in nursery who she will have contact with to have more positive attitudes than the head teacher			/	Not realised
Other expectations					
Expectation 20	For Andrew and his mother to experience a lack of peer groups	/			Realised
Expectation 21	For Andrew's mother to find it difficult to hand responsibility for meeting Andrew's needs to school. To be worried about whether the programme is being done.	/			Developed

Figure 5-6 (continued) ~ Family 9 - Expectations and their outcome

Andrew's mother's expectations had developed over time as she gathered more information from the school and professionals and as Andrew's development progressed. In many respects she was anticipating difficulties to arise during the transition into school. These included the support not to be in place by the time Andrew was due to start, to have to train practitioners in lifting and handling Andrew and transport not to be flexible to allow her to get both children to school. She also expected there to be no transition period between services and for therapy support not to be as frequent as previously.

Andrew's mother said talking about her expectations to a person not involved with the family had been useful because she was more aware of what she expected to happen. For a parent with no experience, she thought it would raise their awareness of what may happen and what problems may arise. It was valuable to have her expectations written down so she could review them. Through this process she realised that most things had happened as she had expected but some expectations had developed. She did not think it would be useful to talk about her expectations to the school staff because of the need for her to manage situations for the best outcome. For example, she described meetings where she could not be honest about her negative expectations of the people involved, as she did not think it would help to change the attitudes of practitioners and so make her son's school placement more successful. Instead she focused on the positive aspects of what was happening and encouraged them to seek further support from the LEA.

When Andrew started school he made progress with his language but his mother thought that he showed possible signs of anxiety. The support worker developed a good relationship with him and had positive attitudes towards including him in classroom activities. The school had made contact with the LEA so had accessed external support and links were being established with a special school to get advice and support. Facilities at the school were improving and funds had been raised for special equipment. However Andrew's mother encountered a lot of difficulties, namely the attitudes of the nursery staff towards Andrew being in the class, difficulties recruiting qualified staff and a lack of co-ordination to support Andrew's placement. There were also organisational barriers within the school causing difficulties with external support services and therapists. The organisation of school transport caused further problems for the family. Trying to resolve these issues had required a high level of time and commitment from Andrew's mother, which had caused her a lot of stress.

When considering the outcomes of her expectations, Andrew's mother thought that the content and implementation of Andrew's statement had been important in achieving the positive outcomes. She also thought that her attitude had been significant, as she wanted the placement to work and had been proactive in making it happen. External support services had contributed, especially the involvement of a person offering information about disability rights. By the end of Andrew's first year at school she thought that the negative attitudes of some of the staff were beginning to change. The negative outcomes of her expectations, she thought were due to the lack of availability and organisation of resources and the implementation of the LEA inclusion policy with its lack of flexibility to offer opportunities for disabled children and their families to meet together. Negative expectations she had developed were due to the lack of experience and expertise of the school staff and their negative attitudes, particularly in the nursery class. With the exception of Andrew's individual support worker and the SENCO, she regarded them as being resistant to inclusion and unwilling to adapt to change. They had not been open to working with other services and had not wanted to take part in the training provided. Although the head teacher had become more positive over time, he had made negative comments to Andrew's mother about the inclusion of disabled pupils in the school. She thought that he continued to be unhappy with the idea of inclusion and the involvement of parents and this was reflected in the school's organisation and management.

Andrew's mother had developed very clear expectations, based on her own experience and knowledge and the advice from professionals and family members. Some of her expectations were negative because she was aware of where difficulties might arise. Her expectations were largely realised or developed further due to her experience of Andrew being at school. Throughout this period Andrew's mother was very involved and aware of what was happening and endeavoured to work through the difficulties she encountered with very little support. At the end of the year she faced further problems transferring the children to the reception class at the same school because the LEA had unexpectedly allocated the children a different school. If the authority had not agreed to change the allocated school, the family would have had to appeal against the decision but there were different procedures that applied to each child because Andrew had a statement and his sister did not. Andrew's mother said that she had found the year extremely stressful.

5.8.3 Family 21

Tom's mother said that she had tried to do everything she could to help with her son's assessment but admitted that she had difficulty understanding the paperwork. She received little support and it was apparent that she was very confused by the whole process of transferring Tom into school.

At the time of interview 1 Tom was attending a local nursery and was due to start school the following September. His mother wanted him to go to a mainstream church school they had visited. She said it was close to their home and she liked the school, describing it as 'a beautiful little school ... and the teachers look brilliant.' (1.85) Tom was offered a place but when his mother told them about his assessment she received a letter to say they would not take him without funding for additional support.

His mother thought Tom was very clever because he could operate the video and television and knew colours, numbers and shapes but his speech she described as 'just a load of babble so we are trying to get him to talk properly.' (1.2) She also talked about problems he had with pencil skills and feeding. She understood Tom had a helper with him one day a week in nursery and the staff told her that he would need additional help in school so he was referred for a statutory assessment. She had no experience of other children with SEN or people with disabilities and thought Tom would overcome his difficulties.

The LEA officer visited the family at home to explain what would happen during the assessment process but Tom's mother said to him that she found it difficult to understand why the assessment had to go ahead. She said:

> *I know what he's like with other children … … Why can't he just take my word for it, why he needs help? Well he needs to see independent psychologists and independent this and independent that and I thought well why can't you just take my word for it. I'm not going to make it worse for my son by saying he needs stuff and he doesn't.* (1.52)

As the assessment progressed the only benefit she could see was that help was organised for Tom at school. She thought that the whole process took a considerable time to complete, involved a lot of paperwork and reports that were written by people who did not know Tom and she had problems understanding because of the difficult language used. Communication with the numerous people involved was difficult especially when she was trying to find out how the process was progressing.

A number of professionals were involved including a speech and language therapist, a paediatrician, clinical psychologist and health visitor. Tom also had some support in nursery but his mother did not talk about any person who particularly supported her and appeared to be confused about who people were and what their role was. She said she did go into nursery frequently to see how he was getting on 'I do that all the time at nursery. I'm usually first in and last out because I'm always gabbing.' (1.21) She said that she valued being involved, being given information and finding out how Tom was progressing. She also liked to be given ideas of things to do with him at home. She did not like the negative attitudes of some people and when she was not kept informed.

When I asked Tom's mother about Tom starting school, she was not clear about what to expect but she did expect him to benefit from being in school. When she was encouraged to talk about other issues she spoke of the support she was expecting him to have in school and her communication with the staff (see figure 5-7 on page 131). Her expectations appear to have been based on her beliefs about the school and information provided through Tom's assessment and by the nursery staff. Between the time of interview 1 and 2 her expectations developed very little and only in relation to lunchtime support and speech and language therapy.

Expectations		Original	Developed	New	Outcome
What type of school, services and support the parent is expecting for their child					
Expectation 1	Tom to have a place at local mainstream school from September	/			Realised
Expectation 2	The assessment to identify the Tom's needs	/			Realised
Expectation 3	1 to 1 support for part of the time he is in school with help over the lunchtime period		/		Developed
Expectation 4	Tom to have help with his speech and pencil skills	/			Realised
Expectation 5	Tom to have 20 minutes speech and language therapy per week		/		Developed
What parent is expecting for their child					
Expectation 6	To learn from other children	/			Realised
Expectation 7	To be included in the class and do the same activities as the other children	/			Realised
What parent is expecting of their relationship with school					
Expectation 8	Tom's mother to have regular daily contact with the school	/			Realised
Expectation 9	Tom's mother to get information from school	/			Realised
Expectation 10	To give information about Tom to school	/			Realised

Figure 5-7 ~ Family 21 - Expectations and their outcome

Before Tom started at the school the support worker visited him in nursery and met his mother and Tom visited the school with his mother. During these visits and subsequent telephone calls Tom's mother said that the support worker asked her numerous questions but, from what she talked about, they did not appear to provide her with any information and did not respond to her requests for help. Tom started school as planned but the amount of classroom support he received was immediately increased from part time to full time. His mother did not know how this was arranged but understood it was necessary in order to meet his needs. She liked the person who was supporting him and talked to her at the end of each day to find out what was happening in school. The support worker offered Tom's mother ideas to try with him at home and the materials to carry out the activities, which she said helped him. There was little contact with the class teacher because Tom's mother said she was always busy with other parents and she did not want to take up her time. By the time of interview 3 Tom had been in school for three terms but a review meeting had not taken place nor did his mother know of any being planned for the new term. She thought Tom was going to see a doctor and wondered if that could be the review.

During interview 3 Tom's mother's said that most of her expectations had been realised. The only developments were those associated with the change in the level of support Tom received and the amount of speech therapy he had. She said that she knew he had seen a speech therapist sometime but was not sure how often this had happened. She said that she thought that her expectations had been realised because of Tom's assessment and because she had pushed for the help for Tom in school.

Tom's mother said that it had been useful talking about her expectations but wondered how useful her contribution to the study had been because she said that nothing really had happened. Compared to the other parents, Tom's mother had been very unclear about what to expect as he started school and her expectations were general and focused only on Tom and his needs. Throughout the period of the study she continued to be confused and did not develop any clear understanding about what had happened in order to meet Tom's needs.

Chapter 6

Discussion: Parents' expectations

6.1 Introduction

The findings from this study of expectations provide a new insight into the experiences of parents of disabled children as well as adding to current research in the field. Both will be discussed in this chapter with reference to the research questions.

6.2 What are the expectations of parents of a child with a statement of SEN prior to their child's entry to school? Do parents of disabled children have similar expectations to each other?

Norwich's (1993) model of the needs of pupils in education can be used to discuss the content of the parents' expectations in the sample group. In his model he described pupils' needs as arising from the characteristics they share with others. He suggested that the *common needs* of pupils arise from the characteristics shared by all pupils, *exceptional needs* are those based on characteristics shared by some pupils and *individual needs* are associated with individual characteristics and circumstances that are different from all others.

6.2.1 Common expectations of all parents

Goodnow and Collins (1990) found the content of parents' ideas related to two key areas. Firstly, parents developed ideas about the direction of their child's development and secondly, the conditions of development, including for example, environmental factors and the roles, responsibilities and actions of parents. Research studies confirm that parents have common expectations concerning:

- educational settings, which informed their choice of school for their child (West et al 1996, Foot et al. 2000)
- the process of transition into school, including parents' and children's reactions to a child starting school (Blatchford et al. 1982, Fabian 1996)
- teachers' roles (Tomlinson 1991)
- parents' roles in their child's education (Pugh 1989, Crozier 1999).

The findings from this study suggest that the parents interviewed had expectations that are common to all parents, namely expectations concerning the school and practitioners, benefits to their child and communication between home and school.

6.2.2 Exceptional expectations

Exceptional expectations, are those that are shared by a particular group of parents but there is little evidence from research about the shared expectations of parents of disabled children. A study concerning the inclusion of disabled children in inclusive settings focused on parental wishes rather than their expectations (Bennett et al. 1998). Parents' aspirations related to their child, the setting, the attitudes and expertise of practitioners and opportunities for communication and parental involvement. The shared expectations of the parents in this study were found to be similar in content to parents' aspirations in Bennett's study (1998) plus additional expectations that focused on systems designed to meet the needs of pupils with SEN. Overall the shared expectations that the group deemed to be most important were concerned with their child's individual progress and the commitment and expertise of practitioners involved to work with pupils with SEN.

6.2.3 Individual expectations

Goodnow and Collins (1990) found parents' common expectations of the direction of their child's development related to cultural influences and their experience of child development, although there was variation between parents' individual views. Children with a disability may not follow the same pattern of development and/or progress at the same rate as other children. Consequently parents' expectations of their child will be influenced by and reflect their knowledge and understanding of the child's impairment and will be individual to them. Equally their expectations about the conditions necessary for their child's development will vary and be reflected in the type of provision the parent agrees to and their perceptions of the experiences they describe.

This is illustrated in the content of the parents' expectations of the three families (1, 9, 21) described in chapter 5. Each parent had expectations of their child's development that varied according to their knowledge and understanding of their child's impairment. Each held different beliefs about how and where their child's needs would best be met which were reflected in their choice of school. They had different perceptions of their own role and those of professionals and practitioners involved in their child's education. The expectations they described varied in detail and complexity with Andrew's mother (family 9) providing a comprehensive list of detailed expectations whilst Tom's mother (family 21) had a limited number of general expectations. Therefore, whilst the focus of these parents' expectations was exceptional to the group, the detail was individual to the child and family.

There were also individual differences identified concerning the range of expectations for the profile families, which were replicated within the group. Rhiana and Tom's mothers (families 1 and 21) simply focused their expectations on the direction of their child's development and the conditions necessary to support it, namely the school, support and role of parents and practitioners. Andrew's mother's (family 9) expectations focused on broader issues, such as the implications and outcome of sending Andrew to a mainstream setting. She considers particularly LEA policy regarding transition between pre-school and school, the attitudes of practitioners and children to disabled people and parents' lack of contact with other families who have a disabled child. She believes that people's attitudes can change through the inclusion of disabled children in mainstream schools. There were a few parents in the group that had such expectations, yet if parents are to become involved in disabled people's struggle for social change, as some writers suggest (Mason 2000, Barton 2001, Rieser 2001, Brett 2002), then this requires them to develop such expectations.

6.2.4 Positive and negative expectations

The majority of the parents' expectations in the study were positive (83.5%), indicating that the parents were expecting to be generally satisfied with their child's transition into school. Parents' negative expectations related to the school, services and support and their child's adjustment to school. Mixed feelings about events are a natural part of the parenting experience (Goodnow and Collins 1990) and represent a realistic view of what is likely to happen (Olsen et al. 1996).

It is debatable whether parents who had mostly positive expectations were anticipating their child's transition into school to progress without difficulty or whether the content of their expectations were an indication of what they aspired to rather than what they expected. Olsen et al. (1996) argue that people want more than they can rationally expect so details of parents' expectations can provide a more realistic picture. Expectations and aspirations can be confused and require reflection and clarification. For example, a working group of professionals and parents was set up to develop a charter stating what parents of children with SEN had the right to *expect* from the professionals and services (Fisher 2002). The resulting charter, however, appeared to be a statement of what parents' *aspired to* rather than what they *expected* given their experience of service delivery.

6.2.5 Summary

Existing research concerning parents of disabled children has focused on their need for support but the findings from this study indicate that parents of disabled children, like all parents, have expectations of their child starting school. Common to all parents is the focus of their expectations on the school, the child and roles of those involved plus the detail that reflects the individuality of the child and family. What is exceptional for this group is that in addition they have expectations concerning the different procedures imposed on them by legislation and guidance governing the education of pupils with SEN and the diversity of attitudes amongst professionals and practitioners towards themselves and their child. It is these differences that are imposed on parents of disabled children that segregates them from the main stream population of parents but, despite disabled activists' call for social change, few of these parents held expectations about their role in such a movement.

6.3 What are the bases for the parents' expectations?

Olsen et al. (1996) describe people's expectations as being derived from:

- direct experiences
- communication with others
- deduction whereby expectations are inferred logically from other beliefs.

Goodnow and Collins (1990) also noted that parents' ideas and expectations are derived from personal experience and social interaction but emphasise the variety of sources, including formal and everyday knowledge that frequently result in conflicting information being received.

The experiences and interactions a parent of a disabled child has are likely to vary from those of most parents (Carpenter 1997) so the sources of their expectations will be different. The principal sources of expectations of parents in the study, identified through what they said and the outcome of the activity concerning shared expectations, were found to be associated with:

- experience of visiting schools and talking to staff
- advice and information from professionals
- beliefs about education and disability
- experience of contact with services and professionals.

These will now be discussed, firstly, in relation to parents' knowledge gained through interaction with others and, secondly, their direct experiences.

6.3.1 Parents' knowledge

Like all parents, those in the study received information and advice from informal and formal sources, which helped them to develop their knowledge and understanding.

6.3.1.1 Informal knowledge

Grimshaw (1999) found that a group of fifty parents valued the informal support, help and advice they received from their own families rather than that provided by services. They also valued the contact they had with other parents through attending a parenting programme where they could share their experiences and learn from each other. In addition, Goodnow and Collins (1990) describe the way parents passively absorb cultural information through social interaction. When comparing their own experiences and exchanging information parents can develop their knowledge and understanding of their child and their role as a parent.

Carpenter (2000) provides accounts of the support parents of disabled children received from their families and the significance of contact with other parents of disabled children. For the parents interviewed it appeared that informal information and advice from their family and parents' groups was less significant than formal information from professionals. Only three parents talked about advice they received from their families or recalled discussions they had with other parents that influenced their decisions about their child's education. Yet half the parents attended parents' support groups or had friends with a disabled child and four more parents said they would have valued the opportunity to meet other parents of disabled children. What is not evident from the findings is the extent to which the parents interviewed passively absorbed informal information through attending groups that are designed to help them develop networks of support and share information (Beresford 1994). Certainly Goodnow and Collins (1990) found that how parents develop their ideas when they have no immediate reference group is an area that is relatively unexplored.

6.3.1.2 Formal knowledge

Formal sources of information and advice can become more important when parents have no reliable informal source of support so there is an increased likelihood of them developing an inaccurate understanding of their situation (Goodnow and Collins 1990). The need of parents of disabled children to have formal information about their child's impairment, how to help their development, accessing services and the formal procedures concerning the statutory assessment of their child's SEN is well documented (Beresford et al. 1996). Much of this information was new to the parents concerned and they needed support to develop their understanding as they went through the process of transferring their child into school. They needed up to date, accurate information about systems that are currently changing rapidly as a result of government policy.

The findings indicate that only three parents had formal information through their own professional involvement in health and education. Other parents gained formal knowledge principally through communication with professionals involved in education and health services as a result of meetings and discussions that were a part of the child's statutory assessment. They provided information about the procedures involved, the child's needs and provision available at school. Few parents talked about written information such as those provided by the LEA, voluntary sector in the form of information booklets or websites, for example.

6.3.1.3 Knowledge about the child's needs

The parents in this group said they valued information and advice they received about their child's development, which helped them develop a clearer understanding of their child's impairment and additional needs. For some of the parents, information received about their child was confirmed through the meetings and written reports as a part of their statutory assessment. Robert's mother said:

> *The most useful thing was having the reports at the end. To have a summary of what people felt and I found out what level he was at with his speech and so on.* (2.6)

Lee's grandmother (family 20) said that the information she received about Lee through the meetings she had as a result of his assessment gave her a clearer understanding about why he was having difficulties.

6.3.1.4. Knowledge about statutory assessment procedures

Parents should 'have access to information, advice and support during assessment and any related decision about special educational provision' (DfES 2001b 2:2). All the parents in the study received some information and guidance about statutory assessment procedures. However, by the end of the study, the majority of the parents had demonstrated only a limited knowledge and understanding about the purpose and procedures of the assessment and review of their child's needs. Reasons identified included difficulties with initial and ongoing communication with the LEA and parents being confused by conflicting and inaccurate information.

All the parents needed ongoing information to support them to develop their understanding of procedures they became involved in but professionals and practitioners supporting them frequently assumed that parents had that understanding. For Aiden's mother and Lee's grandmother (families 17, 20) it was their involvement in the research study that prompted them to find out more.

6.3.1.5 Knowledge about services and support available

As a result of their child's assessment and visits to prospective schools parents become aware of the provision that they thought would be available for their child. However, for parents of disabled children of school age, information has been highlighted as an unmet need (Beresford et al. 1996) and, in this study, not all of the parents knew about the networks of formal support and information available to them. The PPS, for example, has been developed as a key source of ongoing information and support for parents of pupils with SEN (Wolfendale 2002). Ten of the parents knew about the service but, surprisingly, only three parents (families 1, 8, 12) had direct contact with them. Two of them, as a result of the PPS training became very knowledgeable about procedures for assessing and monitoring the needs of pupils with SEN.

6.3.2 Parents' experiences

Expectations that are based on direct experience are stronger and more confidently held (Olsen et al. 1996). All the parents talked about their experiences of their contact with professionals and practitioners and were asked directly about their experiences with disabled people.

6.3.2.1 Experiences of interaction with professionals and practitioners

The additional support needs of a disabled child results in parents' involvement in more community services than other parents, particularly in the child's early years (Pugh et al 1994, Beresford et al. 1996). The findings from this study indicate that the children received a number of services provided by health, education and the voluntary sector that non-disabled children would not receive so their parents had a greater experience of working with a variety of people. For example, Andrew's mother (family 9) explained that he attended two early years settings, received support from three different therapists at the child development centre, had contact with a voluntary organisation plus met with professionals involved in Andrew's statutory assessment.

As a result the parents interviewed had developed different and additional roles to those recognised traditionally (Pugh et al. 1989, Crozier 1999). For example, they described how they worked with therapists and Portage workers and chased up reports that were required from professionals for their child's assessment. Like other parents of disabled children, they were not only expected to support the work of professionals (Brett 2002) but also had to adopt a role of a co-ordinator as they are the only people who have the whole picture of the child (Beresford et al. 1996).

Parents' perceptions of the attitudes of professionals and practitioners towards disability and working with parents seemed to be a key indicator of whether their experience of working together was to be positive. Shabina's mother (family 4), for example, talked at length about the negative attitudes of the health professionals compared to the positive ones of practitioners involved with the early years setting Shabina attended. As a result she looked for a school placement where she expected practitioners would have positive attitudes towards working with her and Shabina.

As is the case for all parents, those interviewed had to deal with contradictory information and experiences (Goodnow and Collins 1990). For example, Kirsty's mother's (family 4) found little evidence of the LEA's positive attitude towards inclusion when visiting mainstream schools, which had been recommended for Kirsty. Instead she encountered the negative attitudes of practitioners who did not welcome inclusion, which was confusing to her.

Similarly, it was evident from the parents' experiences that there were a variety of different approaches to working with parents. The Code of Practice (DfES 2001b) states one of the critical success factors of meeting the needs of pupils with SEN is that 'special education professionals and parents work in partnership' (1:6). It recognises that parents are 'informed experts on their children' (Wolfendale 2000 p.7) so a two-way dialogue is necessary for an effective relationship to develop between them, whereby parents are involved in decisions that are made.

The parents interviewed had diverse experiences of partnership. Some talked about opportunities they had to discuss their ideas with professionals concerned and negotiate outcomes but the PAG thought that other parents were guided to make choices so they had little real involvement in the decision-making process. Parents who resisted professional recommendations said they experienced stress and anxiety until the issues were resolved. As Sharon's mother (family 6) noted on her transcript following interview 1:

> *After the meeting at the Early Years Centre I came out sort of feeling let down, upset and an outsider. I felt that my daughter's future has been taken out of my hands. It's as though I'm not*

> *going to have a say in her education. It's all been mapped out for her without my consent.*

Experiences such as this were common amongst this group of parents and were perhaps indicative of the *constant vulnerability* that Carpenter (2003 p.6) describes as symptomatic when parents of disabled children live in fear of *further unanticipated bad news* (p.6) about their child.

Parents' experiences of interacting with professionals and practitioners will have helped them to develop expectations of their own role in their child's education and the role of others involved (Olsen et al. 1996).

6.3.2.2 Experience of their child's assessment

The parents' experiences of transferring their disabled child into school, as Shabina's mother (family 14) explained, were very different to their experiences with other children. Many parents commented about the stress caused by the statutory assessment procedures, citing difficulties with the amount of paperwork, the time it had taken, problems with communication and lack of support as the causes. Even parents who had been through the process before with an older child experienced difficulties and some questioned the need for the process at all.

However, the procedures, although stressful, did enable parents to develop their understanding of their child additional needs and what would happen when they started school. This happened through meetings and communication with professionals and practitioners including the reports they received. As Farrell (2001) suggests parents have to be involved in their child's statutory assessment and agree to the statement so professionals are more accountable for their actions and parental involvement is not left to chance.

6.3.2.3 Experience of education and schools

Contact with schools was an important and influential source of parents' expectations but few had personal experience of the relatively recent changes in education relating to pupils with SEN resulting in an increased number of pupils with impairments attending mainstream schools (Rieser 2001). Andrew and Dominic's mothers (family 9, 18) stressed the importance of visiting different schools. They thought by comparing schools they could make an informed decision about which school would welcome their child and meet their needs. However it can be distressing for some parents because of the mixed reactions of the school staff towards having their child at the school and/or their own reactions. When the school Shabina's mother (family 14) had visited would not offer her child a place, she said:

> *I was really, really gutted. I was so upset. It was like I had focused for two – three years nearly on what I wanted. I put every input into my child. I focused. I did every single thing. Maybe I didn't do enough. It's like going for a grade 'A' in an A-level and I walked away with a 'D'.* (1.43)

It was because of reactions like this that parents valued the support offered to some of them when visiting schools.

Further contact with the chosen school added to parents' understanding of what they could expect. Lee's grandmother (family 20) said that she had valued this process. She said:

> *… … school's been great because we had a meeting at nursery …… the class teacher and the special needs co-ordinator – they both came so he got sort of a proper hand over.* (2.26)

Other parents however did not have such a positive experience and the amount of communication between the parents and school was limited leaving them unsure about what to expect when their child started.

6.3.2.4 Experience of disability

Some of the parents had a wider experience of disability than caring for their own child. Parents who had a close family member who was disabled or worked with disabled children talked about their personal experience of the stigma associated with disability. Most of the group had little or no contact with disabled people before having their disabled child, which Murray (2000) suggests is the case for many parents with similar experiences.

Through caring for their disabled child parents said they had become more aware of the prejudices affecting disabled people. They talked about issues such as the individuality of disabled people, the manner in which society excludes them from provision and the need to fight for the rights of their children and disabled people. Thomas's father (family 5) talked about this growing awareness of disability by saying:

> *If you don't know people that have disabilities, you don't think about it, do you? You don't think about it one way or another. You just sort of empty your mind. ... ... I think for me it (having his son) made me realise that they were people ... ... I used to tend of ignore them or not talk to them but you kind of realise, when you know Thomas, that they are people as well and that although they have got disabilities they are like human beings.* (1.206/217/219)

Parents' lack of experience and awareness arises from society's dominant perception of disability, which Barnes et al. (1999) argue, is based on the individual model of disability so the general population have little experience or awareness of how disability impacts on people's lives. Most parents had little or no opportunities to interact with disabled people and their families. They focused on their individual experiences of disability and were unaware of any movement for a collective movement for social change. Barton argues (2001) this awareness is essential if the struggle for social change is to achieve the inclusion of disabled people in our society.

6.3.3 Parents' beliefs

The range of beliefs held by the parents was illustrated by their comments about educational provision for pupils with SEN and issues relating to disability and demonstrated by the decisions they made. Some parents said how they believed disabled people were perceived as different in society, the focus of negative attitudes and there is a need to fight for their rights particularly in education.

Research conducted by Foot et al. (2000) illustrated how parents' beliefs and expectations of pre-school settings influenced their choice of provision for their child. In the same way, the beliefs of the parents of disabled children in this study influenced their expectations of the different types of provision available to their child and so their choice of school. Whilst some firmly believed in the need for separate specialist schools for their children, others wanted their child to be part of mainstream provision. Thomas's father (family 5) held very strong beliefs about special education saying:

> *It is more specifically geared to what he needs. It is like, it is no good him going to mainstream and having an assistant helping him to write if he can't crawl or feed himself. It is like going back a stage, isn't it?* (1.123)

During a later interview he added:

> *I am not bothered about social inclusion but I am bothered about parental inclusion.* (2.117)

In contrast Shabina's mother (family 14) argued:

> *My feelings are 'Why can't she?' It shouldn't be me asking the schools for a place. The schools should be saying 'Let me accommodate your child.' That's the way I feel about it. ... ... Why do you have to fight for a place for your child? Your child has a right like any other child.* (1.6)

Such beliefs reflect the wider debate that continues about the marginalisation of disabled people in our society (Morris 1991, Barnes et al. 1999, Mason 2000, Barton 2001, Johnstone 2001)

6.3.4 Summary

Parents of disabled children need to develop an understanding of their child's impairment and the different procedures and provision designed to meet their child's needs. The parents in this group described during their child's transition into school how this happened through their encounters with professionals and practitioners. The role of the statutory PPS is to inform and support parents yet many in this study were unaware of its existence, supporting the findings of an evaluation which concluded that 'not enough parents were being reached by PPSs' (Wolfendale and Cook 1997 4.2.3). Like the parents in a survey conducted by Rathbone (2001), they lacked the knowledge and understanding they required to monitor what was happening. Rather than experiencing partnership with professionals, whereby information is shared and outcomes negotiated (Dale 1996), some professionals exerted their power and authority so influenced parents' decisions. Furthermore, parents had limited experience of contact with disabled people but many had an increasing awareness of the conflicting attitudes towards disabled people that, disabled activists argue, are present both in the education system and society (Morris 1991, Rioux and Bach 1994, Oliver 1996). Dyson (2001) considers dilemmas in education for pupils with SEN but this is a dilemma for their parents as their lack of knowledge and experience causes difficulties for them to act as partners in their child's education. It is further exacerbated when others involved hold diverse views.

Where expectations are based on accurate information and experiences that connect and confirm a person's beliefs, they are likely to be held with greater certainty. Also of importance is a high level of agreement with other people (Olsen et al. 1996, Goodnow and Collins 1990). Parents can then be more confident about their outcome. These parents often drew on incomplete information and contradictory experiences, which they had to make sense of when developing their expectations. As a result some parents developed general expectations that lacked detail.

6.4 Do parents' expectations develop over time and, if so, in what way?

It was evident from the review of parents' expectations during interviews 2 and 3 that they were not static but developed over time with new expectations emerging. The reasons identified were due to the sources changing and the parents' awareness of them being heightened through their involvement in the study.

Goodnow and Collins (1990) argue parents' ideas will re-align as a result of discrepancies between new and existing information and experience. They illustrate how parents' ideas change considerably at times when their child is developing rapidly but stabilise when there is little change in their progress. Parents, on hearing the news of their child's disability, will experience a time of rapid change and will begin to rebuild their personal constructs as they gain knowledge and experience of their child's additional needs so develop new expectations of the future. This process can be difficult, because people, at times of change, will seek information that confirms their existing ideas and beliefs (Olsen et al. 1996) and may be resistant to advice given by others (Goodnow and Collins 1990).

From listening to the parents interviewed, it was evident that they had been through a time of rapid change. They gathered new information through the time of their child's transition into school and gained more experience of their child's development so their knowledge and understanding increased. As a result of visits to school and contact with professionals during the child's assessment parents developed more complex expectations concerning their child and the school organisation to meet their individual needs. Also new expectations emerged that parents had not previously considered so they became clearer about what to expect. This process was ongoing throughout their child's first year at school.

Tom's mother (family 21) did not develop her expectations over the period of the study. She did not appear to receive additional information or support to clarify her understanding of Tom's impairment or the support to meet his additional needs. However it could have been, as Olsen et al. (1996), suggest that she only considered information that confirmed her belief that Tom would be able to overcome his difficulties.

It is necessary for a person to be aware of their ideas in order to develop them and interaction can help a person test the accuracy of their ideas and the extent to which they comply with those of others (Goodnow and Collins 1990). The statutory assessment process and school visits enabled parents to gather additional information over time from practitioners in schools and pre-school settings and professionals from health and education. However the parents appeared to have little opportunity to share their expectations, yet discussing them with all concerned can help parents become aware of and clarify their understanding of what might happen. It can also support the development of partnerships between parents, professionals and practitioners (Dale 1996).

6.5 To what extent do parents feel that their expectations are realised after their child has been in school a year?

The outcomes of a person's ideas and expectations can be an indicator of their quality (Goodnow and Collins 1990) and a person's behaviour and self-esteem (Olsen et al. 1996).

When a person's expectation is realised it can confirm their original belief, so associated expectations are stronger in the future as a person's confidence in predicting events increases. If it is not realised the person engages in thought processes to reflect on what has happened and why so as to adjust future expectations accordingly (Olsen et al. 1996). Future expectations can become higher if the outcome is more than expected but can be lowered as a result of confusion following outcomes where expectations are not realised.

Expectations have positive and negative outcomes depending on the nature of the expectation and whether or not it is realised (see figure 6-1). Olsen et al. (1996) argue people are motivated towards pleasant outcomes and take action to avoid unpleasant ones so reflecting on the outcomes of the parents' expectations can help understand parents' behaviour and what can help parents to have more positive outcomes.

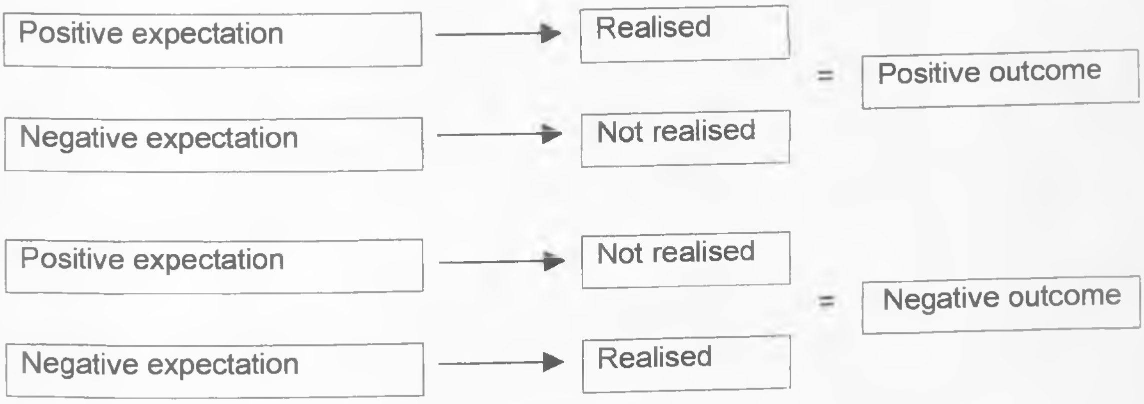

Figure 6-1 Positive and negative outcomes of expectations

6.5.1 Quality of parents' expectations

Expectations can be factual or convergent, where there is absolute certainty about their outcome, and subjective or divergent, which are less certain as they are derived from a person's perceptions and understanding (Holden et al 1988, Torr 1988). However, the quality of expectations that are based on personal experience or have had previous positive outcomes and those where there is a high level of agreement with others are more confidently held.

Pancer et al. (2000) found that mothers who had considered the implications of becoming a parent on different dimensions and from a variety of perspectives had more complex expectations of the impact of parenthood. In turn this led to improved adjustment after the birth of their child compared to mothers who demonstrated simpler thinking. The quality of expectations is therefore associated with the accuracy and variety of sources as well as the opportunities a person has to compare them with other people's ideas so develop their complexity. Certainly some of the parents, like Andrew's mother's (family 9), had gathered information from a variety of sources and discussions they had with people involved. Consequently the quality of their expectations was more complex in that they were detailed and they were expecting positive and negative outcomes given her understanding of the situation. In contrast Tom's mother's (family 21), for example, who had little knowledge and experience on which to base her ideas, had fewer and more general expectations that focused only on the positive aspects of Tom's transition into school.

When examining the outcome of the parents' expectations in the study, those concerning their child and the provision at school were more positive than those about parents' relationship with practitioners. Expectations about their child and provision were held with greater certainty as they were based on their personal experience and the information provided as part of the child's assessment, which ultimately should be written on the child's statement. Expectations concerning the parents' relationships with school were based on their previous experience of working with services and information and advice from professionals and practitioners prior to their child starting. When the parents interviewed were preparing for their child to start school, it was not evident that details of their involvement were discussed and clarified. Although general information about the availability of a home school diary and an open door policy at the school was given to some parents, there was no accurate basis for the parents' expectations concerning their relationships with school. As a result there was less certainty about their outcome and a larger proportion were either developed or had negative outcomes.

6.5.2 Effect of outcomes of parents' expectations

The positive outcome of an expectation can induce a positive effect by confirming the person's original belief so making future associated expectations be held with greater certainty or help change negative beliefs about an event (Olsen et al. 1996). As a result, parents can become more confident about their future expectations which gradually become higher over time. Rhiana's mother (family 1), for example, described how she had initially thought the expectations she had of Rhiana going to school had been too high but they had mostly been realised or increased over time. When parents gain confidence in this way, they are more likely to become involved in their child's education (Pugh et al. 1989, Lindstrand et al. 2002). Certainly Rhiana's mother became increasingly involved in Rhiana's school after she had started.

Alternatively a negative outcome to parents' expectations can have the opposite effect. It can confirm a parent's negative expectation as in James' mother's case (family 16) when her negative expectations about her relationship with practitioners were realised, as they did not involve her. It can raise their awareness of what they assumed would happen, such as when Yvonne's mother became aware Yvonne was not attending school full time because she was sent home early each afternoon. It can draw attention to discrepancies between parents' ideas and experiences. Charlie's mother (family 10), for example, became aware of her expectations of the expertise of practitioners when they did not correspond with her experience. In such circumstances, Olsen et al. (1996) argue counterfactual thinking is triggered whereby a person will examine the related information more carefully and adjust their ideas accordingly. However people are reluctant to change their thinking immediately so may create new subcategories of their ideas which are held less confidently until they are tested and confirmed.

Continued negative outcomes lead people to feel helpless because they lower their expectations which eventually affects their self-esteem as they come to believe they have no influence over events (Olsen at. al. 1996). There was little evidence of this amongst this group of parents who were typically very active in their dealings with professionals and schools. Many were involved in meetings and discussions where, at times, they challenged professional opinion and took action to change events they were not happy with, including Fay and Robert's mothers (families 8, 12) who used formal channels to resolve problems they encountered. However it was also apparent that such events caused stress and anxiety for the parents concerned.

6.5.3 Achieving positive outcomes

Considering parents' views about what helped or hindered the positive and negative outcomes of their expectations can provide an insight into what barriers need to be overcome in order to achieve more positive outcomes, which are likely to increase parents' confidence and participation.

Parents' expectations were more detailed and held with greater confidence when they had a clear understanding of what would happen when their child started school. Most of the information that the parents received focused on support for the child and the statement provided a written account of the child's needs and the resources required to meet them. However there was no information provided about how the statement was to be implemented and monitored and no agreement about how parents were to be involved. If parents are to develop expectations they can hold with greater certainty this information needs to be clarified.

It was evident that parents' expectations continued to develop after their child started school, which was largely a result of their experience of their child in a school setting and their own experiences with the school and practitioners. Where the child settled well and parents were happy with the communication between home and school, the developments resulted in their expectations having more positive outcomes. Thomas and Dominic's parents (families 5, 18) found that their negative expectations had positive outcomes following their experience of the school organisation and their children in school. Rhiana's mother (family 1) had an opportunity to spend time in school with her and meet the staff before she started.

Her expectations developed during this the period as they became more detailed and so had positive outcomes. Providing parents with opportunities to experience the school environment, meet staff and ask questions can help them to develop their expectations so remove some of the anxiety caused by parents' lack of experience about education for disabled children.

The parents interviewed identified people's attitudes as an important reason for positive outcomes being achieved. They included the attitudes and expertise of practitioners and the attitudes of the school managers towards organising events to support the child's needs. The parents also talked about their own attitudes when they said they were determined to ensure their child received the provision they were entitled to. Yvonne's mother (family 3) also cited the attitudes of other parents towards children with SEN at a mainstream school which had contributed to her deciding to transfer Yvonne to a different school the following year. As Robert's mother (family 12) described, positive attitudes of practitioners can influence practice and enhance relationships between parents and school where trust develops between them.

6.5.4 Summary

Parents of disabled children are undergoing a period of rapid change during their child's early years as they are exposed to new and different experiences and information, which they need to make sense of to develop their expectations. Where this results in the development of complex expectations based on clear information that is confirmed by experience, there is more likelihood of positive outcomes that can enhance a parent's confidence and participation. Conversely negative outcomes of expectations can result in confusion, conflict and distrust causing anxiety and stress, which is reported to be an issue for some parents caring for a disabled child (Beresford 1995, Sloper 1999, Read 2000). Consequently they can interfere with partnerships developing between parents and professionals or practitioners.

6.6 What do parents think about having the opportunity to express their expectations?

People need to be aware of their ideas in order to develop them (Goodnow and Collins 1990). Most expectations are generated unconsciously and only become explicit when they are not realised or when they are articulated (Olsen et al. 1996). The parents interviewed said they found it useful to talk about their expectations during the course of the study. It particularly raised their awareness with some parents using the opportunity to reflect on what was happening and develop their ideas further.

Expectations can also fulfil a planning function because people are motivated towards pleasant outcomes and take action to avoid unpleasant ones (Olsen et al. 1996). This is the basis for Dale's (1996) negotiated model of partnership. She advocates discourse with parents where expectations are shared, which aids the understanding of all parties so they can negotiate roles and outcomes. The parents had ways of communicating with school and exchanged information about their child's progress. Some of the children had annual review meetings, which the parents attended. Most of the parents said that they had responded to the school's invitation to contribute in writing prior to the meeting. Although, as Hughes and Carpenter (1991) argue, this is a move towards schools engaging in active partnerships with parents, there was little evidence that parents discussed and reviewed their expectations, which would have raised the awareness of all involved to parents' concerns. Instead many parents interviewed took action to overcome the difficulties they anticipated so achieved positive outcomes. Lee's grandmother (family 20) explained how she discussed her list of expectations with Lee's school and felt that by doing so avoided difficulties arising in the future. In this way the difficulties experienced by parents like James' mother (family 16) could have been avoided because professionals and practitioners would have understood her perspective and been able to share and discuss information so negotiate ways of involving her in James' education.

What is necessary for this to happen, as Dale (1996) argues, is for practitioners to be willing and committed to working in partnership with parents and to recognise 'the diversity and discrepancies between parents and professionals' (p.27). It was evident that this was not the experience of many parents interviewed.

6.7 Conclusion

Referring again to Bronfenbrenner's (1977) ecological model reinforces the view that the expectations of the parents interviewed had an impact on their development and understanding of having a disabled child. It also shows how focusing on expectations can aid a clearer understanding of their experiences.

At a micro level, parents' expectations refer to their child and their own role as a parent. It is evident that the parents interviewed, as Cunningham and Davis (1985) suggest, did reconstruct their mental models of events as a result of their experience of having a disabled child and the knowledge they received. As a result many parents developed new and more complex expectations about their child and their own role in their education. The outcome of these will influence future ideas and beliefs. However, as Goodnow and Collins (1990) suggest, this is not straightforward and these parents experienced periods of uncertainty. What was important was the availability of accurate information that complied with parents' experiences and the child's statutory assessment appeared to be a means whereby parents received information about their child's additional needs and provision available to them.

The mesosystem refers to parents' expectations of the role of others involved with their child and interaction between them. A parent's expectations can influence their behaviour because their previous experiences will lead them to hold certain expectations of events and people involved. Evident amongst the parents interviewed was their lack of previous experience with disabled people and their greater reliance on formal professional support and information, which will have influenced their expectations. Parents', professionals' and practitioners' expectations of a child, provision and relationships can vary and, if not made explicit so differences can be resolved, cause distrust to develop resulting in conflict between them. The parents interviewed had little opportunity to discuss the content and outcome of their expectations so problems could be avoided.

The exosystem is concerned with the implementation of legislation regarding pupils with SEN and the working practices of those involved. Many of the parents interviewed had difficulty developing detailed expectations of these due to the lack of knowledge and their varied experiences of the attitudes of professionals and practitioners who were involved. The PAG thought that professionals did little to ensure parents had an understanding of the procedures they became involved in and there was little evidence of support being provided by the PPS. As a consequence many parents appeared to be guided to comply with professional opinion and LEA policy.

At a macro level the parents interviewed were affected by the dominant cultural values in society. Current ideology is going through a period of change as a result of the influences of disabled activists and their organisations but the individual, deficit model of disability continues to dominate the views and practices of many involved in education, which impacts on the lives of parents of disabled children. Many of the parents interviewed described their experience of the social values bestowed upon them and their child and their feelings about the diverse attitudes of professionals and practitioners but few expected to be involved in any movement to change opinion.

As these findings demonstrate, focusing on expectations of parents of disabled children can provide a useful insight for people involved in education. As Cunningham and Davis (1985) suggest it can support parents' understanding of their child's needs and provision available and as Dale (1996) argues it can enable partnerships to develop by encouraging the sharing of information and negotiation of roles. It can also highlight barriers preventing parents becoming fully included in their disabled child's education.

Chapter 7

Conclusion

7.1 Introduction

This concluding chapter aims to relate this study to current issues for parents of disabled children. It considers the possible implications for the fields of research and education in terms of developing policy and practice and provides ideas for further research.

7.2 The aims of the study

The aims of this study were threefold. Firstly, to give parents a voice to express both their expectations as their disabled child starts school and the extent to which they are realised. Secondly, to explore ways of involving parents as active participants in the research process. Finally, through the first two aims, to contribute to methodological and professional knowledge so inform researchers, professionals and practitioners of parents' viewpoints so they can work more effectively together.

7.3 Current themes and issues

The study was conducted against a background of current themes and issues relating to the lives of parents of disabled children, namely government policy and the movement for social change promoted by disabled activists.

Initiatives of the current government are promoting a model of partnership with all parents that encapsulates empowerment, consultation and negotiation, such as that proposed by Dale (1996). Yet despite this, services for disabled children and their parents continue to be developed from the notion of need which, with its implication of dependency, creates a barrier to partnership. Furthermore services frequently do not meet parents' needs and can create more problems than they resolve.

The government's policy for the inclusion of disabled pupils in mainstream education is part of a wider movement for social change led by disabled activists. The aim is to remove structural and personal barriers created by society, which prevent disabled pupils fully participating in education and schools. Parents of disabled children experience discriminatory practices and marginalisation but are often unaware of broader issues relating to disability.

7.4 Relationship to previous research

This study has extended previous research on two levels. In the field of research methodology it has explored and demonstrated new ways of involving parents in the research process. In education it has added to the body of knowledge and presented a new perspective on the involvement of parents of disabled children.

7.4.1 Parent participatory research approach

Previous research relating to parents' participation in the research process has focused on parents providing information as individuals or groups and through action research. This study proposed a new approach of *parent participatory research* based on the key principles Priestley (1997) describes as characterising a disability research paradigm. It has demonstrated a variety of methods that can be employed to enable parents of disabled children to have a voice in research that affects their lives and those of their children. Through investigating ways in which parents can have greater control over the research process, it has extended the notion of working in partnership with parents (Carpenter 1997, Wolfendale 1999) to the field of research.

7.4.2 Expectations of parents of disabled children

From the time parents receive the news of their child's disability they will begin to develop, consciously and unconsciously, new expectations about the future (Cunningham and Davies 1985). As Olsen et al. (1996) describe, parents' expectations originate from their beliefs, experience and through the acquisition of information. All of these will be influenced by social interaction with individuals, organisations, legislation and cultural values and their outcomes will have an effect on parents' wellbeing. Although Dale (1996) has argued that sharing expectations can facilitate the development of partnership when working with parents, the expectations of parents of disabled children have been afforded little attention in service delivery or educational research, which to date have focused on parents' needs.

In this study I proposed that, whilst parents of disabled children need support and information, their expectations are also of importance. The findings indicate that, over time, the parents who participated developed expectations concerning:

- their child's impairment;
- their relationships with professionals and practitioners involved with their child;
- legislation, procedures and provision for pupils with SEN;
- society's reaction to disabled people.

Reviewing the outcome of their expectations illustrated:

- the development of more complex expectations over time in the light of new information and experience;
- the effect of parents' expectations on decisions they made about their child's education;
- the effect of parents' expectations on the relationships established with professionals and practitioners involved.

The consideration of both positive and negative outcomes highlighted what can help and hinder parents developing the sort of complex expectations that are more likely to have positive outcomes. Three key themes emerged.

Firstly, most of the parents relied mainly on formal sources of information and advice. Despite this they did not have a clear understanding of the procedures designed to assess and monitor the needs of pupils with SEN, had limited information and opportunity to experience the organisation of provision for disabled pupils and knew little about support available to them through the PPS. Although stressful, the child's statutory assessment and resulting statement provided the parents with opportunities to discuss their child's progress and clarify provision being made for them in school so they knew what to expect. However these systems provided no information on which to base their expectations about how their child's provision would be organised and communication between home and school established. Where schools provided this information, parents developed more detailed expectations but for many they remained unclear about what to expect until their child actually started at school.

Secondly, apart from parents' experience with their own child, many had a limited awareness of disability issues and little contact with disabled people. They had not experienced for themselves recent developments in education to include disabled children in mainstream schools. They expected practitioners working with their child to have experience, expertise and positive attitudes towards children with SEN but, from what they said, it was not always the case. Instead it was evident from the encounters the parents described that they experienced the diverse attitudes of people involved in education towards disabled children and working with parents. In many instances parents' experiences of marginalisation did not confirm their understanding of policies about inclusion and parental involvement resulting in confusion. Consequently it was difficult for them to develop clear expectations about how their child's needs would be met and their role in their education.

Thirdly, the parents who participated talked freely during the interviews about what they were expecting as their child started school and said that the exercise had been useful for them because they became more aware of their expectations and were able to reflect on what happened. However, services designed to support parents continue to focus on their needs and not their expectations.

7.5 Implications for practice and policy

These will be considered firstly in terms of research methodology and secondly with reference to parents' expectations.

7.5.1 Implications for research methodology

This study drew on the notion of emancipatory research originally proposed by Oliver (1992) and developed by researchers interested in giving a voice to disabled people (Zarb 1997, Barnes and Mercer 1997, Priestley 1997). Exploring ways of involving parents in the research process demonstrated that parents can be given a voice but these methods need to be replicated and developed further so partnership with parents within the field of research can become established.

However the views of parents and their children are not necessarily the same. Whilst parents may be perceived to act as their children's allies, it is important to acknowledge the views of children themselves. The notion of a parent participatory research model could therefore be extended to explore ways in which disabled children could be given a voice and participate in research studies concerning issues that are of importance to them.

7.5.2 Implications for policy and practice in education

If parents' lack of information, experience of disability and opportunity to express their expectations were key barriers to them developing expectations they could be confident would result in positive outcomes, there are a number of implications for policy and practice. These will be discussed using Bronfenbrenner's (1977) ecological model of interaction with reference to individual parents, relationships developed with professionals, current government policy and social ideology.

7.5.2.1 Implications for individual parents

At the micro-level parents, following the news of their child's disability, develop new expectations of their child and their role as a parent (Cunningham and Davies 1985). Formal and informal sources of information are important in developing parents' ideas (Goodnow and Collins 1990) and more complex expectations develop when information and experience are derived from a variety of sources (Olsen et al. 1996). Through discussing their expectations with different professionals, practitioners and other parents who have similar experiences, parents can become more confident about future events. Parents of disabled children will need encouragement and opportunities to articulate and share their expectations but doing so can raise their awareness of what they expect to happen and highlight areas where difficulties may be encountered. In this way they can develop more complex expectations for the future that are likely to have positive outcomes.

7.5.2.2 Implications for relationships with professionals and practitioners

The meso-level refers to the relationships parents develop with professionals and practitioners. Their approach to date has been based on the notion of need despite the government's policy to foster partnerships with parents in education. An alternative focus based on parents', professionals' and practitioners' expectations could have a number of benefits to all concerned.

Firstly, when parents are encouraged to express their expectations it will highlight areas where they need additional information or clarification to develop their understanding of their child's impairment, support needs and how they will be met. Professionals involved can then respond to parents' individual needs.

Secondly, Dale's negotiating model of partnership (1996) advocates that parents are encouraged to share their expectations about relevant issues so that decisions can be negotiated. Such an approach helps to redress the balance of power between parents and professionals, as parents' contribution can be valued so they can adopt a more active role in the relationships that develop.

The clarification of information and negotiating outcomes can help parents develop more complex expectations based on clear information that are more likely to have positive outcomes. This can avoid the confusion, conflict and distrust that can cause stress and anxiety for all concerned.

However, if such an approach is to be successfully adopted professionals and practitioners require training not only to meet the needs of pupils with SEN but also to work effectively with parents. They will need to understand the relevance of expectations for parents of disabled children and how their development over time can support parents' understanding of the implications of their child's disability. Professionals and practitioners need to develop skills to listen to parents and negotiate outcomes, whereby parents are able to play an active part at the level they choose in the relationships they develop with people involved in their child's education. It also appears from this study that many professionals and practitioners need to explore more fully the meaning of working in partnership with parents of disabled children and develop more positive attitudes as government policy suggests.

7.5.2.3 Implications for current government policy

In Bronfenbrenner's model (1977) the exosystem refers to national and local systems and structures that are designed to meet the needs of children with SEN. These include procedures that have been developed in accordance with the Code of Practice (DfES 2001b) to assess the needs of pupils with SEN and monitor their progress. It is a fundamental principle of the Code of Practice (DfES 2001b) that parents should be involved at every stage of this process so they are invited to provide written information and attend annual review meetings.

For many of the parents in this study the assessment process was a method by which they developed their understanding of their child's needs and how they would be met so they could develop clearer expectations. Meetings during the child's assessment provided opportunities when parents could discuss their child and details about the provision they could expect their child to receive were set out in the child's statement. Parents could also be encouraged to express and discuss their expectations at this time, which could be recorded and subsequently reviewed. However many parents in the study had limited knowledge of such procedures and knew little about sources of support available to them, suggesting there is a continued need for ongoing information and support such as that which should be provided by PPSs (DfES 2001b).

Parents' expectations concerning their relationships with school were not clear and had fewer positive outcomes, suggesting there is also a need to clarify and agree a means of communicating between home and school so parents know what to expect and what is expected of them. Such agreements might avoid conflict arising from a lack of communication between home and school.

The Audit Commission is recommending an increase in the delegation of SEN funding direct to schools and a shift of emphasis from assessment of pupils' needs to early intervention (Pinney 2002). It is anticipated this will result in fewer families being subjected to statutory assessment procedures in the future. In these cases the involvement of parents should not be left to the goodwill of the school and people involved. Parents need information on which to base their expectations of their child, how their additional needs are to be met and their own role in their child's education. They also need opportunities to discuss what they are expecting with people involved so they can develop more detailed expectations of the future. Government guidance on the delivery of services for disabled children from birth to two years of age and their families advocates the use of family held individual service plans containing information about the child's needs and services parents can expect to receive (DfES 2002). Similarly home-school agreements should clarify the schools' and parents' responsibilities so parents know what to expect and what is expected of them. In the case of a disabled child, who does not yet have a statement of SEN, a personalised agreement or plan could be drawn up providing information about the child's educational needs, how they will be met and how channels of communication are to be established between home and school. Such a plan could be negotiated with the child's parent and reviewed regularly with a copy being given to the parents so they know what they can expect from the school and what is expected of them.

7.5.2.4 Implications for social change

At the macro-level parents' expectations are influenced by societal attitudes towards disability. Many of the parents in this study had a growing awareness of the barriers preventing disabled people from being fully included in society and their experience of negative attitudes of people towards disabled people and their carers reinforced this. Through the actions of disabled activists' organisations there is an increasing public awareness of discrimination on the grounds of disability with some of these barriers beginning to be removed and this needs to continue. However, as part of this movement, it is vital that people who work directly with disabled children and their parents are aware of these issues. Disability equality training should become an essential part of induction training for people working in education in order to help develop more positive attitudes concerning disability. It should also be made available to parents.

7.6 Ideas for further research

This study provides information about the expectations of a small group of parents, over a short period of time, in one LEA. It also explores the development of research methodology but focuses on one study with a specific group of parents. In these respects the study is limited but further research could confirm and extend the findings outlined in this thesis.

In terms of research methodology there is a need to explore further methods of involving parents in research both in an advisory role and as participants in the research process. As Carpenter (1997) argues and this study demonstrates, parents have the skills to do so but if this approach is to be developed it is essential that ethical guidelines are developed that confer rights and entitlements upon parent participants and promote the principles of partnership, as Wolfendale suggests (1999). Methods of extending this model to research with children could also be investigated.

In relation to parents' expectations, there are a number of research studies that could supplement this work. Firstly, replicating this study in a different LEA or with a group of parents of children with SEN who did not have a statement would enable the findings to be compared with a different group of parents in similar, but slightly different, situations. Secondly, it would be interesting to compare the expectations of parents with those of professionals and/or practitioners to see how and to what extent they differ. Thirdly, the PAG in this study suggested extending this study over time to investigate how parents' expectations developed as their child's education progressed. Finally, it would be useful to consider the barriers to parents developing complex expectations and explore in greater detail ways in which they may be overcome.

7.7 Benefits to the parents?

In a study that aims to give a voice to parents it is only fitting that the final words should be those of the parents who participated. Whilst they supported me in my goal to gain a further qualification, helped to develop practice within the field of research and added to knowledge that will benefit parents, professionals and practitioners in education, many also said that the study had been beneficial to them personally. For the PAG they had enjoyed taking part because they had gained new knowledge and skills and they felt that the study would be of help to other parents as it would raise people's awareness of what parents of disabled children have to face. When the parents who shared their experiences were asked about the benefits of discussing their expectations with me, many said that it had raised their awareness of what they were expecting and helped them reflect and acknowledge what had been achieved for their child over the time of the study. Lee's grandmother (family 20) however, used the opportunity to discuss what she was expecting with the staff at Lee's school. The outcomes of her expectations were all positive and, she explained, were more than she had originally expected. She said about sharing her expectations:

> *I would have told them (the school staff) what I wanted but a few of the things I probably would not have said straight out. It would be as it arose and then I would have had to go into school and say. But doing it this way, with you, I had it all in there before I actually went and could sort of give them a complete package of what my expectations were and so they knew.* (3.13)

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Appendix 1

Initial letter sent to parents inviting them to participate in the study

Dear Parent / carer

I have a son who has a learning disability and believe that it is important for all parents and carers of children with special educational needs to have opportunities to say what they want for their child and families. In my experience communication between parents and schools can sometimes be difficult to establish, especially when the child has special educational needs. I am interested in finding out more about this in order to make it easier for parents when their child moves into school. I am therefore writing to invite you to take part in a study I am doing at the University of Leeds.

The aims of the study

- To find out what parents expect when their child with special educational needs moves into school and why
- To see if these expectations are met
- To share this information with people who parents think can help improve the situation for other parents, carers and children.

Who will it help?

I hope this study will benefit families in the future by improving communications between home and school when a child has special educational needs.

I hope that parents who decide to take part will find it interesting to share their experiences and to hear about those of other parents and carers in similar situations.

What is involved?

If you decide you would like to take part ~

- I will ask to meet with you on three separate occasions over the next 1½ - 2 years. I can come to your home or we can meet elsewhere at a time that is convenient for you.

- I would like to talk to you about your child. In particular I will ask you about what happens as he / she moves into school and what you feel about it. We can discuss things that you think were good and any difficulties you have.

- I will keep any information you share with me in strictest confidence. I will always check with you before sharing anything you have told me with anyone else and I will not reveal your name in any report I make.

- If you agree to take part in this study but later change your mind you can stop at any time or for any reason.

What to do next

If you would like to become involved or just want to find out more please return the form over the page in the envelope provided and I will contact you.

Thank you for your time Fran Russell

Starting School ~ the expectations of parents of children with SEN

Please complete this form by ticking one of the boxes and return it to me in the envelope provided

☐ I am interested in taking part in the study ~ Please contact me to discuss it further

☐ I would like to have some more information before I decide ~ Please telephone me so I can ask some more questions

☐ I do not want to take part ~ Please do not contact me

Name

Address

Contact telephone number

Please say if there any time of day that is best to ring you?

{Stamped and addressed envelope provided for reply.)

Appendix 2

Interviews ~ key questions

Interview 1	
Child / school	Tell me about (CHILD) and why s/he has been referred for an assessment of their SEN. Tell me about what help and support you have received. What about school - Where do you want or think (child) will go to school and why?
Expectations	Tell me about what you are expecting when (child) goes to school?
Additional information	Tell me about your experience of people and children with disabilities before (child) was born? Tell me about your feelings now about disability?
	Is there anything else you want to say?
Interview 2	
Child / school	Tell me about what has happened since we last met. You can use the diary you kept to remind you if you want.
Expectations	From the conversation we had last time we met I have listed the things that you said that you were expecting when (child) went into school. Can we go through them and you can say if you still agree with them or if they have changed at all?
Shared expectations	I have a list of expectations that parents have talked to me about the most. You may recognise some of them. What I would like to know is which of these you feel are the most important to you and which are not so important? We can use this to help. (Activity explained) There are not wrong and right answers. I just want to know what you think.
	Is there anything else you want to say?
Interview 3	
Child / school	First of all I want to find out about what has happened since we last met. Tell me about ~ • How (child) is getting on at school • How you find out about what is happening in school • Any review meetings you have been involved in at school I want to know about the things that you think have gone well and what has been difficult.
Expectations	When I came to talk to you before, we listed the things that you were expecting when (child) went to school. Can we go through them and you can tell me if you think they have been realised? Also can you tell me about anything that has helped or prevented them from happening.?You might have found that some of them changed.
Shared expectations	Last time we did an activity about the shared expectations of the group. I would like to do this activity again with you now to see if your ideas have changed at all since your child started school
Additional information	Have you had any contact with the Parent Partnership Service? Have you seen the SEN policy at your child's school? Have you seen or contributed to a home-school agreement at the school? Do you know who is responsible for pupils with SEN at the school? Did you find it useful to talk about and review your expectations with me? Tell me about what you thought about being involved in the study. Was there anything that you found useful or difficult?
	Is there anything else you want to say?

Appendix 3

Materials used with parents to determine the importance of the shared expectations of the group

The parents were given cards shown below on which were written the shared expectations. They were asked to place them onto the chart below to indicate whether they considered the expectation to be ‘very important’, ‘fairly important’ or ‘not so important’. Only one card could be placed in each marked box.

Cards listing shared expectations

You are expecting to work on your child's programme at home

You are expecting to receive information about what the child is doing in school

You are expecting your child to make progress at school

You are expecting the assessment process to identify your child's needs and help you decide which school will be best

You are expecting to be included in making decisions about your child

You are expecting your child to go to a school that you believe will best meet their needs

You are expecting one to one support for your child

You are expecting to be able to give information about your child to the school

You are expecting your child to learn from other children

You are expecting you child to be included in all aspects of the school

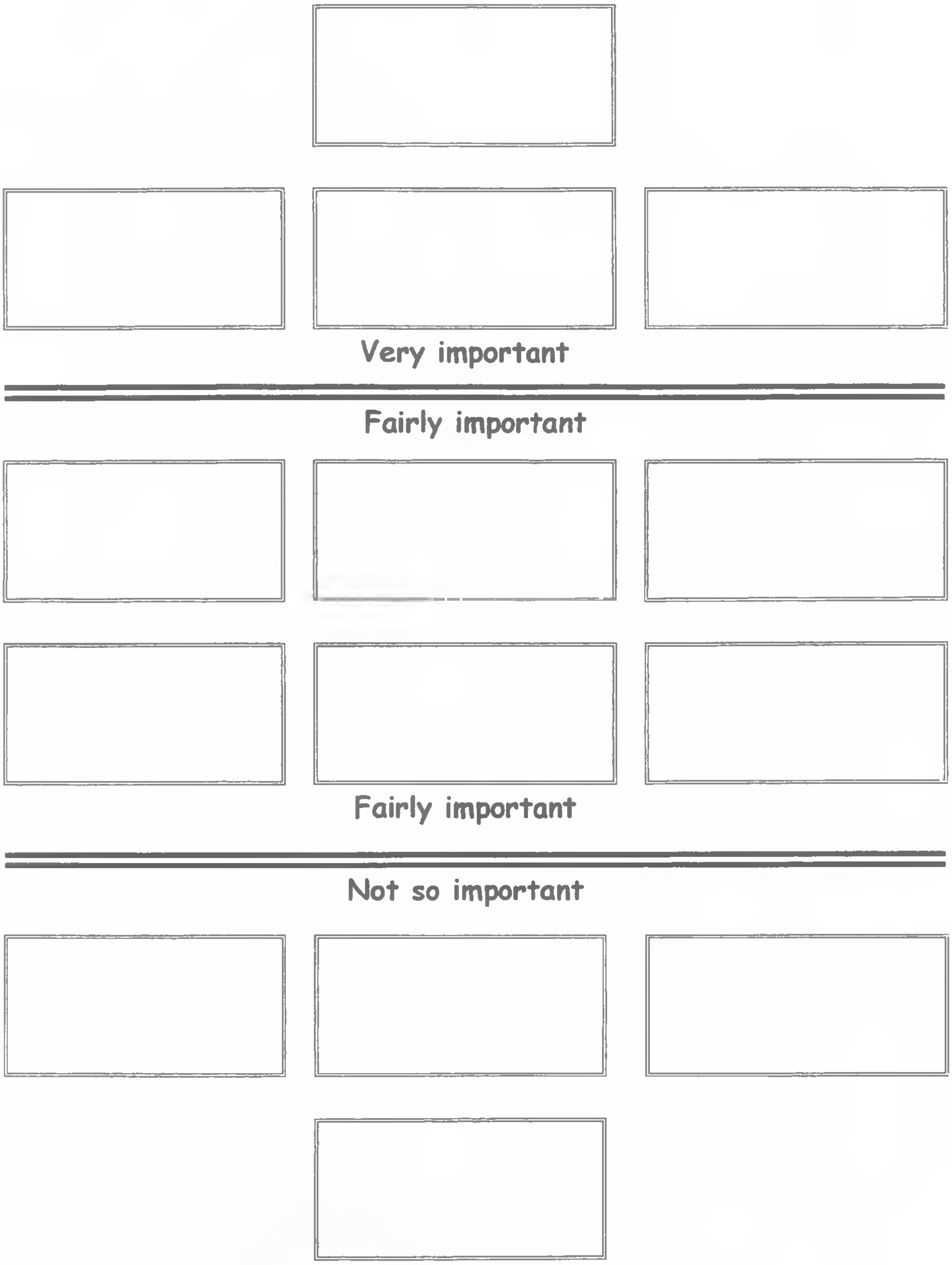
You are expecting the staff involved with your child to be committed and have expertise or access to training

You are expecting the school to be flexible in meeting your child's needs

You are expecting your child to get support from therapists, eg. speech and language therapist,

You are expecting your child will have an individual programme to work on at school

Chart on which parents placed the cards during the activity



Appendix 4

Analysis sheet used for interview 1

Analysis of interview 1

Family Number			Transcript reference
1. THE CHILD			
What reasons did the parent/carer give for the child having an assessment of their SEN?			
2. SERVICES / SUPPORT RECEIVED			
What support / services had the parent and child received?			
Did the parent / carer say that they found anything particularly helpful about these services / support?			
Did the parent / carer say that they found anything particularly difficult about these services / support?			

3. SCHOOL PLACEMENT

What type of school does the parent / carer want for their child?	Special school ~		
	Mainstream school ~		
	Other – please specify ~		
Did the parent / carer give reasons for choosing this type of school?			

4. PARENT / CARER'S EXPECTATIONS

What did the parent / carer say they were expecting when their child went to school? From what they said, can you say why you think they had these expectations?[1]	Expectation		
	Why do you think this?		
	Expectation		
	Why do you think this?		
	Expectation		
	Why do you think this?		
		(If there are more expectations – continue over page)	
Did the parent / carer say anything else about *expectations*?			

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[1] Why you think the parent had their expectations ~ Parents' expectations could relate to some of the following:

- what they want or think they are entitled to
- services they have received
- their knowledge about the systems in education and what they think is possible or available
- their experience and beliefs about disability

5. TERMINOLOGY

What comments did the parent / carer make about the following terms?	Disability		
	Special educational needs		
Which term did they prefer and why?	Disability		
	Special educational needs		
Did they mention any other term they preferred to use?			

6. EXPERIENCE OF / FEELINGS ABOUT PEOPLE WITH DISABILITIES

		✓	reasons	
How would you describe their previous experience of people with disabilities / special educational needs? (✓ appropriate box) What are your reasons?	Extensive			
	Average			
	Limited			
Did the parent / carer make any comment about their feelings towards people with disabilities or special needs prior to having their child?				
Did they say how their feelings had changed since having their child?				

7. THE ASSESSMENT

From the information you have been given, at what stage in the assessment process is the child at?	1. The process has only just begun		
	2. Information is being gathered and reports are being written		
	3. The draft statement is being written		
From the information you have been given, have the parents looked at or are planning to visit any schools? If yes – please give details	Looked at schools ~		
	Planning to visit schools ~		

8. WHAT YOU FOUND INTERESTING

Is there anything else you found particularly interesting in the transcript you think we should take notice of? – Anything that surprised you, shocked you, concerned you, pleased you, for example?		
Have you any other comments about this transcript?		

Thank you for your help

Appendix 5

Overview of families in the study

Family 1

A detailed account of Rhiana's family's experiences is provided in Chapter 5.

Family 2

Meena has complex needs and now attends a special school. Previously she had attended a specialist nursery for disabled children run by a voluntary organisation and her mother attended their parents' support group. English is not the first language used by the family but her father declined my offer of an interpreter and her mother made some contributions via him.

The parents expected the school to meet Meena's needs, which were realised. Their expectations of her development were changed because the parents received a diagnosis for Meena from the paediatrician, the implications of which were explained to the family.

Communication with the school was limited. Meena's father said that it was difficult to attend the parents' group, for example, because of his work commitments and his wife's need for support. The school sent a diary home with information and the family telephoned the school when necessary, which they seemed happy with. I was confused about the review meeting because Meena's parents had copies of the reports written by the school but had not attended a meeting other than a parents' evening.

Family 3

Yvonne has complex needs and attended a mainstream playgroup, before moving to the reception class at the local school.

Yvonne's mother had negative expectations of her move into school. From the discussions she had during Yvonne's assessment and transfer she thought that the high level of external support that she had received at playgroup would not be available at school so would delay Yvonne's progress. She doubted if the attitudes and expertise of practitioners in the school were conducive to the inclusion of pupils with SEN because, for example, she had been asked to come into school during the lunch time break to provide support for Yvonne. She decided on the mainstream placement because she had visited a special school but had found it emotionally very difficult and did not believe that it was the right place for Yvonne.

After a year in school Yvonne's mother's negative expectations were realised so, she decided to move Yvonne to another special school she heard about from a neighbour who had a disabled child. She was generally knowledgeable about the statutory assessment and review procedures so initiated a review, contacted the LEA and Yvonne moved to the new school at the beginning of the following year. Yvonne's mother said the study had helped her to think about what she was expecting of the future and not to struggle on with a situation that she was not happy with.

Family 4

Kirsty had complex needs and attended an early years setting that had additional resources for disabled children. Her mother received support from the practitioners who worked there and she thought this inclusive setting met Kirsty's needs.

Kirsty's mother's expectations were concerned with the difficulties she was experiencing finding a mainstream school with practitioners who had the expertise and attitudes to meet the needs of disabled pupils and their families. Through visiting a variety of schools and discussing her experiences with a number of professionals she had thought about the issues carefully resulting in clear and considered expectations. The family had to move from the area part way through the study for family reasons so the outcome of her expectations could not be followed up.

Family 5

Thomas has complex needs and now attends special school. Previously he had attended a specialist nursery for disabled children run by a voluntary organisation and his mother attended their parents' support group. I interviewed both Thomas's parents, who have very strong views about special education and parental involvement.

Following a visit to prospective special schools, they developed clear and considered expectations about the support Thomas would receive and their involvement in his education. Through the support of pre-school services they also understood what to expect of Thomas's development. They were knowledgeable about SEN procedures because they had another child with SEN.

Thomas's parents were pleased with his school placement and their expectations were realised or developed as a result of them changing their views or finding situations were better than they had originally expected.

Family 6

Sharon has a syndrome that affects her language and social development plus a medical condition and now attends a special school. Previously she had attended a specialist nursery for disabled children run by a voluntary organisation and her mother attended their parents' support group. She also attended a local mainstream early years setting.

Sharon's mother had high expectations that the special school would meet all Sharon's needs but the professionals involved with her assessment had recommended a mainstream placement. She looked at a variety of schools and talked to practitioners, professionals and other parents, all of which influenced her decision but she had difficulty getting her wishes acknowledged. As a result of the difficulties she experience Sharon's mother's was expecting to continue to have to fight to keep Sharon at the school of her choice and says she becomes anxious when meetings were due.

Sharon's mother's expectations of the school were realised after the first year in school and the outcome of the annual review was that the school was meeting Sharon's needs so her mother said she stood by her decision to go against the professional advice she had been given.

Family 7
Sarah has a syndrome and had attended a specialist nursery for disabled children run by a voluntary organisation and her mother attended their parents' support group. She also attended a local mainstream early years setting but her mother wanted her to move to a nursery attached to a primary school so Sarah was referred to the LEA for a statutory assessment.

Sarah's mother expected that a mainstream school environment would help Sarah to learn from other children and further develop her skills. She also expected good communication between herself and practitioners. Her expectations of the early years setting Sarah attended developed through her experience and additional information provided by the staff and professionals so during the time of Sarah's assessment she decided to let her continue there for another year. The family withdrew from the study for personal reasons.

Family 8
Fay has a syndrome that affects her language and social development plus a medical condition. She attended a local playgroup before moving to a mainstream nursery.

Fay's mother's was unsure if Fay's needs would be met in a mainstream environment and thought parents should receive more advice and guidance when choosing a school for their disabled child. Her expectations of Fay's school focused on the support from external services, which she expected would help practitioners, especially the support worker, to develop skills to help Fay learn. She expected the school to take a leading role in setting learning goals and planning ways to included Fay in classroom activities. She expected that the assessment and statement would be a means by which this could occur.

Her experience of Fay in school was very different, she believed, because of the negative attitudes of the head teacher, who was also the SENCO, towards inclusion and working with parents. The support worker received little help and difficulties also arose when support services wanted to visit Fay in school and implement a programme. Fay's mother was familiar with SEN assessment and review procedures because she had trained as an Independent Parent Supporter with the local PPS so requested a review meeting to try to resolve matters. It was a very difficult meeting for Fay's parents because a heated discussion developed between the professionals involved with no positive outcome. After the review meeting an acting head teacher came into post who had a different attitude and organised and supported the support worker, provided materials to use and set up regular weekly meetings to involve Fay's mother in setting weekly targets. As a result Fay made progress.

Eventually some of Fay's mother's expectations were realised although she remained unsure of what to expect in terms of support and provision in the future. Despite her limited experience of disability, she was developing an awareness of wider issues related to disability and the education of disabled pupils.

Family 9

A detailed account of Andrew's family's experiences is provided in Chapter 5.

Family 10

Charlie has a syndrome, a sensory impairment and a medical condition. Previously he had attended a specialist nursery for disabled children run by a voluntary organisation and a playgroup but moved to a mainstream nursery that his brother and sister had attended.

Charlie's mother worked professionally in education and was very knowledgeable about SEN procedures and provision. She has other disabled children and an extensive experience of working with and caring for disabled people. She was also a parent governor at a local school. She was very confident when expressing her views and shared her beliefs with me about the inclusion of pupils in mainstream education. She had clear expectations of Charlie's development, the support he would receive and communication between home and school. She also expected that other children and teachers to learn from the experience of having a disabled child in the school.

Not all her expectations were realised because of the difficulties associated with the recruitment and organisation of a support worker and poor communication between home and school. The feedback from school through the year about Charlie's progress had been positive so his mother was surprised when his end of year report had not reflected this so she challenged the content with the school but nothing was done.

Family 11

This family was not available for interview 1.

Family 12

Robert has a social and communication disorder. He moved from a private nursery to the reception class of a mainstream school with additional resources for pupils experiencing language and communication difficulties.

Robert's mother worked professionally in education but had limited experience of disability and did not have a clear understanding of SEN procedures. She said that her experience with Robert had raised her awareness of pupils with SEN. She talked about the difficulties she encountered trying to meet Robert's needs during the pre-school period, initiating his assessment and transferring him to school resulting in her making a formal complaint. The whole experience caused her stress, which resulted in her having to reduce her hours at work.

Robert's mother's expectations were detailed and were based on a visit she made to the school before he started when she was able to ask questions. She expected that the school organisation and the experience and expertise of the staff would enable Robert's needs to be met and her to be informed of his progress. After a year in school she was impressed with the quality of the education Robert had received and the detailed information she had been given about his progress so her expectations had been realised.

Family 13

Joshua has language difficulties and attended a mainstream school with additional resources for pupils with language and communication needs, which is their local school. His mother has an older child with SEN who was assessed in a different LEA.

The school identified Joshua's difficulties and his mother was kept informed throughout his assessment and transfer to school. She did not appear to know that the school had resources to meet children's additional needs until Joshua was in the reception class but expected they would be able to meet his needs.

Joshua's mother's expectations were based on her experience with her older child, what people had told her and her beliefs about the education system. They were largely realised or developed as her experience and understanding changed and as a result of practitioner's attitudes towards communication with parents.

Family 14

Shabina has complex needs and attended a mainstream school with additional resources for pupils with complex learning needs. She spends part of her time in the class with other pupils with SEN and part in the mainstream classroom.

Shabina's mother expressed her views strongly throughout the study about the rights of disabled people to be included in all aspects of society. Prior to school, Shabina had attended an inclusive mainstream early years provision that was flexible in their approach so included children with complex needs in all nursery activities. She had also valued the support she received from the manager and other professionals involved who agreed with her request for a mainstream placement for Shabina. However, the family approached the school their other children attended but Shabina was not offered a place. Eventually Shabina's mother agreed to send her to a school with additional resources for pupils with learning difficulties and, after a year, she said she was particularly impressed with the experience and expertise of the practitioners.

As a result of her previous experience her expectations focused on flexible, inclusive practices and parental involvement. However during Shabina's first term her mother was told by the school that the placement was not working because the school did not receive sufficient funding to support Shabina to access the mainstream provision. Shabina's mother found it stressful but, after taking advice from the manager of the early years setting, told the school she wanted Shabina to stay and the LEA agreed to fund the additional support. Afterwards she said that her expectations were realised or developed because of the school's positive attitude towards inclusion and the experience and expertise of practitioners.

Family 15

Paul has language difficulties and attended a local mainstream school where he moved from nursery into reception during the time of the study.

Paul's mother was involved in the initial identification of his needs. She expected him to get additional help in school to help him make progress. She also expected to be involved in his education and communicate with school regularly. She was initially frustrated at the amount of time the assessment process took but when the support was eventually in place she was pleased with the person appointed and the progress Paul had made.

During the period of Paul's transfer into school his mother developed her expectations as a result of the advice and information she received from the professionals involved. She thought they had been realised because of the attitude, experience and expertise of practitioners and the organisation in the school for pupils with SEN.

Family 16

James has language, social and emotional needs and attends a local mainstream school that receives additional resources for pupils with sensory impairment. James does not have a sensory impairment but the school is his local school. James had an individual support worker who worked with him on a structured programme under the guidance of a clinical psychologist.

James's mother has personal experience of disability as two of her close relatives were disabled. Both her children have a statement of SEN and she was knowledgeable about SEN procedures. She expected James to get the support he needed at school and believed strongly that she should know what was happening in school so she could help the children at home.

James's mother used the list of the expectations we made as a 'checklist' to ensure what she was expecting actually happened. However, when they were reviewed she thought that, although those concerning James's support had been realised, her negative expectations about her relationship with school continued. She did not feel that the staff at the school wanted her input and were reluctant to share information with her.

Family 17

Aiden has a social and communication disorder. He attended a local playgroup before starting at a special school.

Aiden's mother had visited a variety of schools and was very concerned about Aiden's safety in a mainstream school so decided to send him to a special school. She expected that special education would give him the support he needed to make progress but was aware of the LEA policy for inclusion and thought it may be recommended in the future that he attends a mainstream placement.

Her expectations were realised or developed as a result of his assessment, the school organisation and the experience of practitioners.

Family 18

Dominic has dyspraxia and attends a mainstream school with additional resources for pupils with language and communication needs. He previously attended a local playgroup where his mother was a regular voluntary helper.

Dominic's parents wanted him to go to the local mainstream school but they were not sure he would get the support he needed. When they visited the school with additional resources, they liked it immediately and requested it for Dominic. Following this visit his mother developed clearer expectations of the support available but continued to be anxious and unsure about how Dominic would react to school although she did expect he would make progress. She expected to be involved in his education but was uncertain about how to help him so had enrolled on a college course that she thought might help her to understand his development better.

When her expectations were reviewed she thought that they had been realised and her concerns about Dominic adapting to school had been unnecessary. She was very proud of his end of the year school report, which she showed me.

Family 19

This family was not available for interview 1.

Family 20

Lee has social, emotional and language difficulties. He attended a mainstream early years setting before starting at a local mainstream school. Lee's main carer is his grandmother who was involved in the interviews. She worked professionally in education and has worked with people with disabilities.

Lee's grandmother had been very involved in Lee's assessment and transfer to school and had developed good relationships with practitioners at the early years setting and the school. Through her contact with the school and contact with professionals involved in Lee's assessment she had developed clear expectations of the support she expected him to receive in school and how it would be implemented. She also used our discussion to clarify certain aspects and shared her final list with the school.

All her expectations were realised but those relating to Lee's progress were better than she had expected and she proudly gave me his end of year report to read. She had commented that Lee's school placement had exceeded her original expectations.

Family 21

A detailed account of Tom's family's experiences is provided in Chapter 5.

Appendix 6

Aims of PAG and guidelines for discussion at the end of the study

Aims of the PAG

1. To develop a parent participatory research approach.
2. To consult with a group of parents who have disabled children, so have similar experiences to the parents in the sample, about issues related to the study.
3. To validate the findings by involving the group in the analysis process.
4. To discuss the findings of the study with a group of parents who have similar experiences to those who were interviewed.

Discussion questions

1. In what way do you think you were able to share your views about the study and to what extent do you think the contribution made by the parents in the group was acknowledged and used in the development of the study?
2. What do you think were the positive aspects of being involved in the study?
3. What were the difficulties that you encountered concerning your involvement? What do you think were the reasons for these and how could they have been avoided?
4. Do you have any other comments you would like to add?