

**'Parents as Advocates: the experiences of parents who  
register an appeal with the Special Educational  
Needs and Disability Tribunal (SENDIST)'**

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## **Declaration**

**I declare that this thesis has been composed by me, Katherine Runswick-Cole, and that the research reported here has been conducted by me unless otherwise indicated.**

## **Abstract**

The focus of this study is on the experiences of parents of children with special educational needs who advocate for their children in the special needs system. The Special Educational Needs Tribunal was set up in 1994 and since then more than 25,000 appeals have been registered (Hughes, 2005). In 2002, the Tribunal began hearing claims for disability discrimination and became known as the Special Educational Needs and Disability Tribunal (SENDiST). The aim of this study is to foreground the parents' experiences of the system of SENDiST and to develop understanding of the experience of parenting a child with special educational needs and/or impairments.

SENDiST is more than ten years old, yet research into the workings of SENDiST has been very limited (Aldridge, 2003). A study which foregrounds parents' perspectives is, then, well overdue. As part of the narrative inquiry, parents were asked to tell their stories of going to SENDiST. Twenty four parents and eight professionals told their Tribunal stories.

This study has key implications for the workings of SENDiST but it also contributes to the current debates in special education, including the system of statements, the policy of inclusion, and the working of parent-professional relationships. The study has relevance for the stake holders in the system of special education including children, parents, teachers, panel members, psychologists, LEA officers and academics. At the same time, the study reflects the uncertainty that parents who engage with Tribunals will face in the future. In a policy climate which reflects the abilist assumptions of the wider society (DfES, 2005), it is difficult to remain optimistic about the outcomes for children and their parents. However, it seems certain that some parents, at least, will continue to resist, contest and challenge the limitations and interpretations put upon their families' lives.

## **PREFACE TO THE RESEARCH**

In recent years, it seems that mothers of disabled children have begun to straddle the divide between mothering and the academy in an attempt to understand their own lives and to promote tolerance and understanding of their experiences within a wider audience (Murray, 2000; Cole, 2004; Ryan, 2005). My research follows in that tradition.

I have two children and by the time our oldest child reached six, he had acquired a variety of labels including disorders and delays, and, not least, the label of having 'special educational needs.' I have been through the process of getting a statement for my child; I have advocated for him at meetings to discuss his Individual Education Plan and at the Annual Review of his statement; I have challenged and fought for his educational provision to be changed. This process is ongoing for our family.

The characters who appear in the research stories (teachers, teaching assistants, head teachers, LEA officers, occupational therapists, psychologists, speech therapists, physiotherapists, paediatricians, social workers, advice line workers, parent partnership officers, family members, friends) have played their part in my story too.

Unlike the parents in my research, I have not been to SENDisT, although I have twice been at the point of registering an appeal. Before I began the research, I had two friends who did go to SENDisT. Together, and with telephone advice from a voluntary organisation, we all worked to help prepare for their cases for Tribunal. It was those experiences which triggered this study.

I must acknowledge that I am on the parents' 'side', my research is partisan. However, I suggest that social research can never be objective and value neutral. Research is a 'political act' (Barton, 2005) which is always 'contaminated' (Goodley, 1996), no matter what the biography of the researcher. However, I hope that I have given a rich account of the parents' stories and that the narratives offer insights into the lived experience of parents of children with special educational needs and/or impairments and their children.



## **RESEARCH SUMMARY**

What follows is an over view of the thesis.

### **CHAPTER ONE: The historical, policy and legislative context**

Chapter One introduces the SENDisT. It also sets out the historical and policy background to the research, locating the present study in its policy context and drawing on the existing literature. The literature suggests that parents of children with special needs and/or impairments are required to work with professionals at a level and frequency of contact which is not required of parents of children not so labelled (Dale, 1996). Parents of children with special educational needs and/or impairments regularly act as advocates for their children, and parents find this a difficult role to manage (Read, 2000; Cole, 2004).

### **CHAPTER TWO: Theorectical approaches**

Chapter Two interrogates the theoretical concepts which underpin the analysis within the thesis. The study draws on the principles of philosophical pragmatism, using a number of theoretical approaches, or 'thinking tools' to develop authentic understandings of the parents' stories. Social model theories (Oliver, 1996) are central to the analysis within the thesis. Crucially, here, the oppression which disabled people face is seen to act not only on the child with special needs and/or impairments but on the whole family. The deconstruction of the term 'special education' draws heavily on social model thinking. The study also draws on the work of Foucault, Rorty and Bourdieu to explore parents' narratives and the constructions of 'special education'.

### **CHAPTER THREE: Methodological approaches and analytical framework**

Chapter Three focuses on the methodological approaches within the thesis. The research draws on a post-positivist epistemology, and is sensitive to a mode of research production which has as its primary aim the emancipation of disabled people and their families. The positionality of the researcher is also considered to be of key importance. Here the 'contamination' (Goodley, 1996) the researcher brings to the study, as a parent of a disabled child, is clearly acknowledged.



Narrative is the prime method of inquiry within the thesis; this is because narrative is seen as an accessible and transparent method (Oliver, 1996) which enables people to give authentic accounts of their own lives. The use of different forms of narrative (first person narrative, dramatic narrative and composite narrative) is designed to reveal the richness of the human stories. The aim is to find 'hidden stories' but at the same time to resist the tendency to look for extraordinary individuals. Over a period of six months in 2004-5, I interviewed 24 parents (7 fathers and 17 mothers) about their experience of SENDisT. The cases involved 25 children (1 parent had been to SENDisT for both her children).

#### **CHAPTER FOUR: The systemic, relational and policy landscape: the factors which lead parents to appeal to SENDisT**

Chapter Four explores the reasons why parents appeal to SENDisT. In short, parents can appeal to SENDisT either because they want to challenge the educational provision the LEA is offering their child or because they feel that their child has been discriminated against on grounds of disability in school. The parents' narratives reveal insights into why conflict between parents and the LEAs could not be settled outside the Tribunal hearing. This chapter outlines the systemic, relational and policy factors which lead parents to SENDisT. The chapter draws heavily on social model theories and the work of Rorty and Foucault to develop an understanding of the parents' perspectives.

#### **CHAPTER FIVE: The Tribunal Day**

Chapter Five examines the parents' experiences of the Tribunal hearing. The focus of this chapter is on one parent's story of the Tribunal day, but the chapter draws on other stories. The study found that the experience of preparing for and attending the Tribunal hearing was an extremely stressful one for parents. The thematic analysis within this chapter draws on Foucauldian concepts of power, surveillance and the panopticon. Parents found themselves subjected to the powerful gaze of a professional institution in which their behaviour was scrutinised and judged in an uncomfortable environment. Parents repeatedly described feeling constrained within the hearing, sometimes they were chastised with verbal remarks, but the body language and even the layout of the furniture in the hearing room all contributed to the formality of the hearing. The independence

of witnesses was also raised by both parents and professionals. The informal atmosphere which 'lies at the heart of SENDisT appeals' (Hughes, 2005, p3) was missing from parents' stories.

## **CHAPTER SIX: Families and the Tribunal**

In Chapter Six, the study draws on the shift in research perspectives away from the image of the tragic family where one or more member has a special need and/or impairment to an approach which focuses on the diversity of family experience (Read, 2000; Cole, 2004; Fisher and Goodley, 2006 in press).

However, the study highlights the stress and frustrations parents faced as a result of going to Tribunal. This was particularly the case when parents faced repeated appeals, Judicial Review and when the LEA failed to implement SENDisT's orders. The financial costs of going to SENDisT are high. Yet, the study found that parents felt the financial costs of going to SENDisT paled in comparison to the health and emotional costs they paid. Parents described the Tribunal process impacting negatively on their health and their relationships. For a small minority of parents, the process of going to SENDisT was empowering. Parents gained confidence in their abilities and transferred their new found skills to advocating for other parents or, in one case, pursuing an alternative career.

## **CHAPTER SEVEN: Families and Society**

The parents' stories also revealed something of their wider experiences of living in a family where one or more child has a special need and/or impairment. The analysis in this chapter draws on disability studies literature and the work of Bourdieu. The chapter challenges medicalised interpretations of the lives of disabled families. The 'push for diagnosis' by parents has been seen as part of attempts by parents to pathologise their children (Connor, 1997), yet this study found that parents engaged with diagnoses and labels with an awareness that in the fields of special education and medicine such labels carried with them important symbolic capital (Bourdieu, 1984). The parents' focus on the success of their non-disabled offspring can be seen, not as evidence of their trying to compensate for the loss sustained by the birth of a disabled child, but as parents'



recognition that, in an 'abilist' society, their non-disabled child offers important evidence of their parenting skill.

## **CHAPTER EIGHT: Conclusion**

The final chapter draws together the parents' experiences of going to SENDisT. The study found that the Tribunal stories are complex, and, at times, contradictory, but they are also compelling. They reveal the ways in which parents engage with theory, with stories, with policy, with professionals, with the Tribunal itself and with the wider social world.

The future for parents engaging with Tribunals is uncertain. Key policies, such as statements and inclusion, are under review (Education and Skills Select Committee, 2006). The outcome of the review will have an impact on the educational experiences of children with special needs and/or impairment. In a policy climate which reflects the assumptions of a disabling world (DfES, 2005), it is difficult to maintain optimism about the outcomes for children and their parents. Yet, the narratives reveal remarkable stories of parents' resistance and resilience.

# **CHAPTER ONE: THE HISTORICAL, POLICY AND LEGISLATIVE CONTEXT**

## **Introduction**

This chapter sets out the historical, policy and legislative context in which parents' stories are set. The chapter begins with a description of the Special Educational Needs and Disability Tribunal (SENDisT). I then discuss the research which has focused on SENDisT in the past, and I examine the key policy debates which impact upon the parents' experiences of SENDisT. These include:

- the policy of partnership with parents;
- the policy of inclusion;
- the system of statements of special educational needs.

The analysis offered here is a critical reading of the social policy drawing out the key policy themes and excavating the assumptions within the policy texts (For a fuller discussion of methods of analysis see Chapter Three). It is this legislative, research and policy context, alongside my own experience as a parent of a child who has been given the label of special educational needs, which have informed the research questions below.

## **Research questions**

The research questions focus on the parents' experiences and understandings of registering an appeal with SENDisT. The questions for the research are:

- What can we understand about the experiences which lead families to register for an appeal with SENDisT?
- What are the stories of families attending the Tribunal hearing?
- What can we understand from the families' stories about outcomes of pursuing a claim to Tribunal?
- What do the narratives reveal about families' experience of living in a disabling world?
- What implications do the research findings have for the implementation and revision of current policy, practice and legislation?



These research questions are set in context by a description of the history of the SENDisT and a review of the legislation, policy and research contexts outlined below.

## **The history of the Special Educational Needs and Disability Tribunal (SENDisT)**

Most parents find themselves, at some time or other, taking the role of advocate for their children within the education system. Sometimes, this is within the formal context of parents' consultations evenings, and meetings with a head teacher, and at other times advocacy takes place in less formal encounters such as ad hoc chats with the teacher at the school gates. Parents of children with special educational needs and/or impairments find they are required to act as advocates for their child with a frequency and at a level of complexity which other parents are not (Dale, 1996; Todd, 2006). Since 1994, parents of children with special educational needs and/or impairments have been able to appeal to a Tribunal to resolve disputes about their children's education and so their advocacy role has been formalised and extended.

In 1994, the Special Educational Needs Tribunal was introduced as an independent body to resolve disputes between parents and Local Education Authorities<sup>1</sup> (LEAs) about their children's educational provision. In 2002, it was re-named the Special Educational Needs and Disability Tribunal, in order to reflect its extended role of hearing claims for disability discrimination in schools. Since 1994, there have been more than 25,000 appeals by parents to SENDisT; the average per year is now 3,400 compared with 1,300 in the first year (Hughes, 2005). At the moment, about 80 claims a year are claims under the Disability Discrimination Act 1995 of which about half proceed to a full hearing (Hughes, 2005). There are several reasons why parents appeal to SENDisT, which are outlined below.

### *Reasons for appeals*

Parents appeal to SENDisT either to resolve disputes with the LEA about their child's special educational provision or if the parents feel that their child has been

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<sup>1</sup> Local Education Authorities have since become known as Local Authorities. Education and Social Services have been brought together under the new title of 'Children's Services'.

discriminated against (HMSO, 2001) in schools because of their disability. Appeals to SENDisT about educational provision fall broadly into three categories:

- parents can appeal to SENDisT if the LEA refuses to assess their child for a statement of special educational needs. The Tribunal can direct the LEA to do so;
- parents can appeal to SENDisT if an LEA assesses their child for a statement of special educational needs and then refuses to issue a statement or issues a note in lieu of a statement;
- parents can appeal to SENDisT if they disagree with the LEA about the contents of the statement. This could be a disagreement about the description of the child, the amount of specialist teaching time or support from a classroom assistant the child receives, or it could be about the amount of speech therapy or other therapies available to their child or, indeed, it could be about the school placement.

Appeals to SENDisT for disability discrimination are made on the basis that the child is treated less favourably on grounds of their disability. For instance, Lee Buniak was excluded from the school Christmas play and his class's school photo, he was also not allowed to make a Christmas card for his mother. The SENDisT ruled that the school had discriminated against Lee on grounds of his disability (Halpin, 2003). The reasons parents appeal differ, yet they all share the task of preparing for the SENDisT.

### *Preparation for an appeal*

The administrative task of preparing for SENDisT is time consuming and demanding for parents. Parents are required to prepare a case statement for the SENDisT which must include:

- the 'notice of appeal form' (see appendix 7);
- a copy of the LEA's letter telling the parent that they can appeal to SENDisT;
- the parents' reasons for making an appeal. The parents can fill in a box on the 'notice of a appeal' form or give reasons on a separate sheet of paper. They are encouraged to include as much detail as possible and they are given some advice on what their reasons might cover (SENDisT, 2002a);



- a photocopy of the child's final statement;
- a set of documents which were attached to the statement – the appendices or advises (e.g.: psychologist's reports, parental advice for the assessment, the child's end of year school report).

The parents' case statement is typically a lengthy document, sometimes running into hundreds of pages, including several professional reports in addition to the parents' arguments for the appeal.

The appeals are heard in front of an independent panel of three members which includes a legally qualified chair and two lay members. Parents and the LEA may represent themselves or they may use representatives. The LEA sometimes uses a legal representative and the parents, who are able to access representation, either use legal representatives or representatives from voluntary organisations (For a fuller discussion of representation see Chapter Five).

### *The role of Parents' Organisations*

For many parents who go to SENDisT, a number of voluntary organisations play a key role in their stories. Sometimes, impairment based charities support parents who appeal to SENDisT. Sometimes parents are supported by voluntary organisations which have special education advice and Tribunal support as the main focus of their work. Finally, some parents' organisations exist to support parents who want inclusion for their children.

- *Impairment based charity advocacy services*

Perhaps the best known example of an impairment based charity which offers advocacy support is the National Autistic Society's (NAS) Advocacy for Education Service. In 2003 – 4, cases concerning children with autism made up 18.6% of all Tribunal cases (SENDisT, 2005); it is not, then, surprising that part of the NAS's role includes an advocacy service. The NAS Advocacy for Education Service aims to enable parents who have children with a label of autistic spectrum disorder to get the most appropriate educational provision for their child. It does this by:

- providing accurate information, quality support and advice on special educational needs provision and entitlements through a telephone support line;
- offering specific telephone support and advice on preparing for Special Educational Needs Tribunals, and representation at Tribunal where appropriate;
- empowering and encouraging parents to be confident partners in their child's education, and enabling them to make informed choices and decisions;
- identifying special educational needs issues faced by parents to feed into our campaigning and public policy activities (NAS, 2005).

The service offers two main points of help to parents: the Education Advice Line and Tribunal Support Scheme. The NAS funds its advocacy service from its general income including donations, bequests, and corporate sponsorship.

- *Special Education Advice Voluntary Organisations*

There are a small number of voluntary organisations which exist to support parents of children with special educational needs with advice and with support for Tribunal. The Advisory Centre for Education (ACE) was founded in 1960 by Michael Young, Lord Young of Dartington, as a registered charity (ACE, 2005b). ACE aims to provide the information, support and legal advice that parents need to help their children at school. They provide information through telephone advice lines, publications and the Internet. They also provide training for education professionals and advice workers. ACE is funded by donations and legacies.

The Independent Panel for Special Education Advice (IPSEA) offers free and independent advice on Local Education Authorities' legal duties to assess and provide for children with special educational needs (IPSEA, 2006). IPSEA's aims are:

- to help ensure that children with special educational needs receive the special educational provision to which they are legally entitled;
- to help ensure that the views of parents/carers and children are taken fully into account when children's needs are assessed and decisions are made about special education provision and school placement (IPSEA, 2006).



In the past five years, IPSEA has grown from helping a few hundred parents/carers a year to a national organisation helping thousands of parents/carers a year. IPSEA has a high profile amongst other organisations in the disability field, such as SCOPE, the disability organisation whose focus is on people with cerebral palsy, the Downs Syndrome Association, AFASIC, which supports children and young people with speech, language and communication impairments, and the Council for Disabled Children. Approximately 33 per cent of the parents contacting IPSEA are referred by these larger organisations. IPSEA now receives funding from the National Lotteries Control Board, and The Association of Learning Providers as well as donations and bequests (IPSEA, 2006).

- *Inclusion focused organisations*

Some parents' organisations exist with the explicit aim of promoting inclusion in mainstream schools for *all* children regardless of their special educational needs and/or impairments. One such group, Parents for Inclusion, does not offer dedicated Tribunal support services, but they do run an advice line to offer support to parents who want mainstream education for their children. They aim to work closely with disabled adults, in order to bring their understanding and experience to parents, so that parents can become 'real allies' (Parents for Inclusion, 2006) to their disabled children.

The process of going to SENDisT occurs in a complex policy and legislative context and is the culmination of historical changes to the education of children with special educational needs and/or impairments in the post-war period. The legislative and historical contexts are outlined below.

## **SECTION ONE: The legislative and historical context**

The post-war era has seen marked changes in attitudes to children with special educational needs and/or impairments and there have been parallel changes in the special education legislation, policy and practice. To understand parents' experiences of the current system, it is important to have some understanding of the legislative changes which have led to the present system of statements of special educational needs and parental appeals to SENDisT.

## **1944 - 1978**

The 1944 Education Act (HMSO, 1944) established the principle that children's education should be based on their age, aptitude and ability. This resulted in the creation of eleven categories of 'handicap' which included 'the educationally subnormal', and 'delicate' as well as 'blind', 'deaf' and 'physically handicapped' pupils. Those children who were considered to be 'ineducable' were not included in the 1944 Act. It was left to parents and others to challenge attitudes towards children deemed to be 'ineducable' in post-war Britain.

The 1960s and 70s paved the way for a new approach to special needs. Attitudes to special education in general started to change (Evans and Varma, 1990). Special needs education was influenced by behavioural psychology which stressed the possibility of modifying children's behaviour and placed the responsibility for modification with the teacher. These behaviourist initiatives made the teaching of children with special educational needs seem more accessible to teachers in mainstream schools. Behaviourist ideas also helped to promote the possibility of inclusion of children with special educational needs. By 1970, the Education (Handicapped Children) Act brought children who had previously been seen as 'ineducable' and the responsibility of the health service, under the educational responsibility of the LEA. Changes in attitudes to 'handicapped' children led to pressure for a committee of enquiry into the education of 'handicapped' children (Evans and Varma, 1990).

### ***The Warnock Report (DES, 1978)***

In 1974, the Warnock Committee was established to look at the educational provision for 'handicapped' children in England, Scotland, and Wales. By 1974, the number of pupils attending special schools in England had risen to 128,410 representing 1.3% of the school population (DfES, 2006). The report was ground breaking in a number of ways.

- First, the report rejected the concept of eleven categories of 'handicap' and adopted instead a definition of special educational needs to take in all children who may have individual educational needs. Using this definition, it was suggested that 20% of children were likely to need special educational



provision of some kind at some time during their school careers. This figure has gone largely unchallenged since 1978 (Croll and Moses, 2004).

- Warnock also recommended that provision for special education should 'wherever possible' occur within mainstream settings. This was a key change, as under the 1944 Education Act, LEAs were expected to provide for 'handicapped' pupils in special schools and were only allowed to place children in mainstream schools if the 'circumstances permitted.' The 1981 Education Act (HMSO, 1981) was an exact reversal of the 1944 Act because the expectation, following the 1981 Act, was that special education provision should be in mainstream, not special schools.
- The Warnock Report marked a shift in attitudes to the role of parents in their children's education. A central section of the report was headed 'Parents as Partners' and partnership was a key theme in all the report's recommendations. The report insisted that:

The successful education of children with special educational needs is dependent upon the full involvement of their parents: indeed, unless the parents are seen as equal partners in the educational process the purpose of our report will be frustrated.  
(DES, 1978, p150)

The Education Act, 1981 (HMSO, 1981), was the Government's response to the Warnock Report.

### *The Education Act 1981*

Before the 1981 Act, parents were not consulted on a regular basis about their child's education and professionals were able to decide where a child with 'handicapping conditions' should be educated. Following the 1981 Act, parents were entitled to be involved in the assessment process. Parents were given new entitlements including:

- the right to ask for an assessment of their child if they believe that their child has special educational needs;
- the right to be present at any assessment of the child's educational needs;
- the right to give their own 'parental evidence' in the assessment process;
- the right to comment on any proposed statement of special educational needs;

- the right to appeal to the LEA, in the first instance, if they were unhappy with how the LEA were proposing to meet the child's special needs, and a right to appeal to the Secretary of State thereafter.

However, the next key development in special education policy was not to come until the Education Act, 1993 (HMSO, 1993) which brought about the creation of a key document for the practice of special education: *The Code of Practice for the Assessment and Identification of Special Educational Needs* (DfEE, 1994).

### *The Code of Practice for the Assessment and Identification of Special Educational Needs*

The Education Act 1993 (HMSO, 1993) required the Secretary of State to issue a *Code of Practice for Special Educational Needs* (DfEE, 1994). For the first time, practical guidance was given to LEAs and the governing bodies of all maintained schools about their responsibilities for all children with special educational needs. After consultation with schools, LEAs, the health services, social services and voluntary agencies, *The Code of Practice* was approved in Parliament. *The Code of Practice on the Identification and Assessment of Special Educational Needs* (DfEE, 1994) came into effect on September 1<sup>st</sup>, 1994. From that date, schools and LEAs and all those who are involved with children who have special educational needs, including the health service and social services, are obliged to adhere to *The Code*.

In 2001, a revision of the *Code of Practice* replaced the original code. The basic principles of the new *Code of Practice* remained the same:

- the needs of all pupils with Special Educational Needs are addressed; that the Code recognises a continuation of needs and provision;
- there should be the greatest possible access to a broad and balanced education, including the National Curriculum;
- the needs of most pupils will be met in mainstream schools without a Statement of Special Educational Needs and that children with special educational needs, with or without a Statement, should be educated in mainstream schools where appropriate and taking into account the wishes of their parents;
- the LEA, as well as the health authorities, intervene in the early years before the child becomes of compulsory school age;



- the assessment of need and provision is secured with the greatest possible degree of partnership between parents and their children, schools, LEAs and other agencies.

(Surrey County Council, 2006)

However, whilst the basic principles of the *Code* did not change, there are key differences between the old and the new *Code of Practice*. These changes are outlined below:

### *Changes to the Code of Practice in the light of Special Educational Needs and Disability Act (SENDA)*

The revision of the *Code* includes new rights and duties introduced by the Special Educational Needs and Disability Act (SENDA) (HMSO, 2001). Changes as a result of SENDA have been taken into account and these include:

- a stronger right for children with special educational needs to be educated at a mainstream school;
- new duties on LEAs to arrange for parents of children with special educational needs to be provided with services offering advice and information and a means of resolving disputes;
- a new duty on schools and relevant nursery education providers to tell parents when they are making special educational provision for their child;
- a new right for schools and relevant nursery education providers to request a statutory assessment of a child.

### *Changes for Early Years Settings*

Following the revision of *The Code of Practice*, the most important change for Early Years settings was that children with special needs were to be included in all types of Early Years provision including:

- formal educational settings;
- private establishments;
- approved networks of child minders.

Every Early Years setting is now required to have a nominated person (Special Educational Needs Coordinator) responsible for organising, planning, monitoring and coordinating the implementation of the *Code of Practice* within the setting. Practitioners in voluntary settings, including approved child minding networks should join the LEA's Early Years Partnership scheme to standardise provision, share best practice and resources.

### *Changes to the Stages of Assessment*

Another key change was the number of stages in the *Code of Practice*. The 1994 *Code of Practice* described five stages through which school children passed through if they are suspected of having a learning difficulty.

- **Stage 1:** if teachers feel that a certain child may have Special Educational Needs (SEN), they place the child on the school's SEN Register, and try to help the child as best they can within the classroom.
- **Stage 2:** if the individual teachers feel they are failing to provide the support and help needed by the child, they refer him/her to the SEN Co-ordinator (SENCO), who takes responsibility for the child's special educational needs. The SENCO draws up an Individual Education Plan (IEP) to monitor the level of difficulty experienced by the child and to see if the school's interventions are helping.
- **Stage 3:** if the SENCO feels that the child is not being helped enough, s/he will use specialist support from outside the school (educational psychologist, speech and language therapy). These outside agencies contribute to the IEP.
- **Stage 4:** if, following two reviews of the IEP, it is still felt that the child is not making appropriate progress, the school applies to the LEA for statutory assessment of the child, in order to obtain extra resources and help.
- **Stage 5:** if the child receives an SEN statement from the local education authority (LEA), then there are mandatory requirements, and extra funding, for the school to provide special help for the child (for example, annual review of needs and teaching assistants in the classroom).



Following the revision of the *Code of Practice*, LEAs and schools are now expected to adopt a graduated approach through three, not five, stages. See below:

- \* Stage 1 and 2 replaced by **Early Years/School Action –**  
child on special needs register in school but no outside agencies are involved with the child.
- \* Stage 3 replaced by **Early Years/School Action Plus -**  
child is on special needs register and outside agencies are involved (eg: speech therapy, occupational therapy)
- \* Stage 4 replaced by **Statutory Assessment –**  
child is assessed for a statement of special educational needs

The aim was to streamline the system and to make it less complicated for professionals and parents to follow.

*Changes to the ‘identification of needs’*

A further change was the way in which ‘needs’ were identified. In 1994, eight areas of need were identified, and this was reduced to four areas in 2002. This is set out in the table below:

**Identified Needs**

<b>1994 Code</b>	<b>2002 Code</b>
<b>8 areas of need</b>	<b>4 areas of need</b>
Learning Difficulties	Cognitive and Learning
Specific Learning Difficulties	
Speech and Language Difficulties	Communication and Interaction
Emotional and Behavioural Difficulties	Behavioural, Emotional and Social development
Sensory Impairments (Hearing)	Sensory and /or Physical
Sensory Impairments (Visual)	
Medical Conditions	

The changes in the identification of need were also intended to streamline and clarify the system. The emphasis on clarity also led to a change in the advice on how IEPs should be used.

### *The revision of Individual Education Plans*

An IEP builds on the curriculum that a child with special educational needs is following and is designed to set out the strategies being used to meet each child's identified needs. The new *Code of Practice* offers more detailed advice on how to devise and implement Individual Education Plans (IEPs) for children with special needs than the old *Code of Practice*. These are set out in the table below:

**Individual Education Plans**

1994 Code	2002 Code
Individual Education Plans	Individual Education Plans
Unlimited targets	3 or 4 targets set for and by pupils
Review at least 2 x a year	Review at least 2 x a year
No success or exit criteria	Success and exit criteria

The advice for professionals about individual education plans was intended to make the plans easier to write and more effective tools for learning.

In general, the aim of revising the *Code of Practice*, was to streamline the process and make the responsibilities of professionals clear. However, the difficulties presented here by the task of summarising the contents of and changes to the *Code of Practice* reveal the continuing complexity of the system. The *Code of Practice* also details the system of statements of special educational needs, which is outlined in the next section.

### **Statements of Special Educational Needs**

The 1993 Education Act re-confirms the 1981 Education Act policy of statements of special educational need, and this was reflected in the revised *Code of Practice*



(DfES, 2001a). If an LEA believes that a child has needs which call for special educational provision, it must consider whether to assess him or her. Parents must also give their consent. An assessment may result in a Statement of Special Educational Needs (Stage 4 of the *Code of Practice, 2002*).

A Statement of Special Educational Needs is set out in six parts:

- part 1 gives general information about the child;
- part 2 gives the description of the child's needs following the assessment;
- part 3 describes all the special help to be given for the child's needs;
- part 4 gives the type and name of the school the child should go to;
- part 5 describes any non-educational needs the child has;
- part 6 describes how the child will get help to meet any non-educational needs.

The document is a legal contract between the LEA and the parents, so any provision outlined must be delivered. The policy of statements of special educational needs is key to understanding the workings of SENDisT. (I return to the statement of special educational needs later in this chapter and again in Chapter Four, when considering why parents go to SENDisT).

### **The Right to Appeal to a Tribunal**

It was not until 1994, following the 1993 Education Act, that parents were given the right to appeal to an independent body if they were not satisfied with the way the LEA planned to meet their child's special educational need. Since 1994, if parents and the LEA are unable to agree educational provision for the child, parents have the right to appeal to the Special Educational Needs Tribunal.

The Special Educational Needs Tribunal considered parents' appeals against decisions made by LEAs about children's special educational needs in cases where the parents and the LEA were unable to reach agreement. The Tribunal's orders are binding, but there is no right of appeal against the Tribunal's decision. If the LEA or school fails to implement a SENDisT decision, then parents are able to take the LEA to a Judicial Review.

A Judicial Review is a form of court proceeding in which a judge reviews the lawfulness of a decision or action made by a public body, including SENDisT, the school or LEA. A Judicial Review is not really concerned with whether the conclusions of the Tribunal were 'right', as long as the right procedures have been followed, so it is not possible to use Judicial Review to challenge the Tribunal's decisions about provision or discrimination. However, a Judicial Review would be concerned with whether the Tribunal, LEA and/or school had followed the correct procedures.<sup>2</sup>

The panel which hears the appeals consists of a Chair and two members. The Lord Chancellor appoints the President of the Tribunal and the chairmen and women, and the Secretary of State for Education appoints the members. However, the Government cannot influence the Tribunal's decision, nor does the Tribunal have connections with any LEA. There are currently 204 Chairs and Members who hear appeals (SENDisT, 2005). The Chairs must be legally qualified, while the members must have experience and knowledge of either local government or special education (SENDisT, 2005). The legal Chairs tend to be solicitors with an interest in special education law, whereas the lay members are usually education professionals including teachers, psychologists and LEA offices.

In September 2002, the Special Educational Needs Tribunal began hearing claims for disability discrimination in schools in addition to claims about educational provision. The Tribunal has since been re-named the Special Educational Needs

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<sup>2</sup> This was the situation at the time the research took place, however, there are current plans to change the appeal process with a second level appellate tier to replace the current Judicial Review level appeals (Hughes, 2005). Another change to the Tribunal system, which came into force after the interviews for this study were completed, was the introduction of a new government agency in April, 2006. The Tribunals' Service was set up to provide common administrative support to the main central government tribunals. These include: Employment Tribunals, Asylum and Immigration Tribunals, Criminal Injuries Compensation Appeals Panel and others. The Tribunals Service is an executive agency of the Department for Constitutional Affairs (DCA) and its launch is considered to be the biggest change to the tribunals system in this country in almost half a century (Tribunals Service, 2006).



and Disability Tribunal to reflect its extended role. Disability discrimination hearings are a small part of the Tribunal's work: there were 169 Disability discrimination appeals heard by the Tribunal from 2002-4, whereas there were a total of 6,886 education appeals in the same period. It is expected that this aspect of the Tribunal's work will grow as parents become more aware of their right to appeal. Since the Tribunal started in 1994, there have been over 25,000 appeals registered with a year-on-year increase in appeals until 2003-4 when despite a 5 % decrease in the number of appeals the total still reached 3,354 (Hughes, 2005). Despite the large number of appeals over the last 10 years, and the implications for the individual children and families involved, LEAs and schools, the work of SENDisT remains largely under researched (Aldridge, 2003). However, some literature about the workings of SENDisT already exists and this is outlined below.

## **SECTION TWO: Key Issues for SENDisT**

This section explores the key issues and debates about SENDisT which have been the focus of research (Crabtree and Whittaker, 1995; Simmons, 1996; NAS, 200; Pace, 2003; Peach, 2003). However, in his annual report (2002-3), the outgoing Chair of SENDisT, Trevor Aldridge, regretted the limited amount of research into the work of the Tribunals. Crabtree and Whittaker (1995), Simmons (1996), Pace (2003), Peach (2003), and NAS (2003) offer some insights into the key issues for parents going to SENDisT. While SENDisT remains an under researched area, the aim of this study is to add to the existing research and, crucially, to do so in a way which foregrounds and explores parents' experiences within the system. The published research suggests that key issues for SENDisT are:

- the selection of Tribunal members;
- the independence of witnesses to the Tribunal;
- the bureaucracy of the system;
- the emotional and financial costs for families;
- the lack of monitoring of SENDisT's orders;
- the stress the process puts on the whole family .

Each of these areas are considered below.

### *The Selection of Tribunal Members*

In 1995, Crabtree and Whittaker sent questionnaires to the Special Educational Needs Tribunal panel members. Crabtree and Whittaker were interested in the background and experiences of the panel members and the political positions the panel members held, particularly with regard to the inclusion of children with special educational needs in mainstream schools. Crabtree and Whittaker found that members were predominantly male (60%), from the south of England (51%), and non-disabled (92.9%). Crucially, 64.3% of panel members had been employed within the 'Special Education' sector prior to becoming panel members (i.e.: directors of education, education officers, educational psychologists, teachers, and inspectors). This led Crabtree and Whittaker to conclude that:

Lay members may well be lulled into an acceptance of a conventional orthodoxy or a particular professional code of practice from which they themselves have emerged, working from within a particular paradigm which brought parents into conflict with the LEA in the first instance.

(Crabtree and Whittaker, 1995, p 8)

This was a key finding of Crabtree and Whittaker's research as it questions the 'independence' of panel members, whose expectations may be influenced heavily by their prior experience of the special education system.

Crabtree and Whittaker were also interested in the members' attitudes to inclusion. When presented with the statement that: 'It is possible for a child irrespective of nature or severity of impairment, to participate in a mainstream school given the appropriate support' 54.3% disagreed with the statement, while only 34.3% agreed and 11.4% made no comment. This suggests that parents committed to inclusive education are disadvantaged in their appeals to SENDisT.

Crabtree and Whittaker noted that few disabled people or parents of children with special educational needs and/or impairments were themselves panel members. Crabtree and Whittaker saw this as a reflection of the values of the Tribunal service. Following a series of interviews with the Chairs of Tribunals, Crabtree and Whittaker also questioned the consistency of approach among Chairs and the implications this might have for the orders made.



Crabtree and Whittaker argued that the background of panel members combined with the language of medical categorisation used in the Tribunal statistics suggests that the Tribunal is underpinned by a medical model of impairment (For a fuller discussion of models of disability see Chapter Two). Children with impairments were understood by panel members to be 'suffering' and 'handicapped' with the implication that 'suffering' results from an individual's impairment rather than inappropriate support or lack of resources from the LEA. Crabtree and Whittaker argued that the dominance of individual and medical models of disability amongst panel members has implications for the impartiality of SENDisT. While Crabtree and Whittaker's research was carried out only a year after the Special Educational Needs Tribunal was set up, there is evidence to suggest that the SENDisT is still underpinned by tragic and individual models of disability. In 2005 Rosemary, Lady Hughes, the President of SENDisT said that:

Our hearts are touched by the problems endured and the sacrifices made by parents for their children; many of the Tribunal members have personal knowledge of the difficulties surrounding life with a child with special needs from their own families or friends.  
(Hughes, 2005, p4)

Here again the focus seems to be on within-child and within-family deficits as the cause of 'problems' and 'sacrifices'.

While Crabtree and Whittaker were concerned about the independence of the panel members, Simmons (1996) also raised concerns about the independence of professionals who are called as witnesses.

### *The independence of witnesses*

The LEA and parents can call witnesses to the Tribunal hearing. Usually these witnesses are education or health professionals including psychologists, teachers, therapists and LEA officers. Simmons (1996) questioned the independence of witnesses who were employed by the LEA. She suggested that it was impossible for employees of the LEA to be impartial in the hearing because they would be aware of the possible consequences for their professional development within the LEA. Indeed, Simmons found evidence which suggested that LEAs manipulate their employees and that this damaged the impartiality of professional witnesses employed by the LEA.

The NAS (2003) found that, in order to present a robust case, many parents commissioned an independent assessment of their child by a professional such as an educational psychologist or speech and language therapist. This often incurred considerable costs for parents and it was difficult for parents to obtain reports within the time limits set for submitting their case statement. The pressure of finding an independent witness was part of the pressures associated with the bureaucratic procedure of preparing to appeal to SENDisT.

### *Bureaucracy*

Simmons's (1996) primary concern was the bureaucracy of the Tribunal system. Simmons suggested that the complexity of the system meant that it could only be used effectively by confident and articulate parents. The system, she argued, was, in effect, inaccessible to less articulate parents. This concern was echoed by the findings in the National Autistic Society (NAS) report *Autism and education: the ongoing battle: Experiences and outcomes of the Special Educational Needs and Disability Tribunal* published in 2003. The NAS report found that preparing the case statement for the Tribunal was very demanding of parents. It involves gathering together all the evidence and documentation needed to present a coherent argument before the Tribunal. For parents, this was often an overwhelming and intimidating task. Simmons (1996) found that even the most articulate parents found the system intimidating and very stressful. This was supported by PACE's (2003) finding that a number of parents gave up their appeal because they were exhausted. The strain of preparing for Tribunal was often linked to the financial costs of an appeal.

### *Emotional and financial costs*

Simmons (1996) found that only a small proportion of parents with the lowest incomes were eligible for legal aid to prepare a case statement, but there was no legal aid for parents to be represented at hearings. In 1994 the average cost of a solicitor was £1,000 (Simmons, 1996). In 2003, Pace found that of the families who went as far as the hearing 58% spent above £2,000 on legal advice, with £6,000 on legal fees being common. This figure did not include the amounts parents paid for expert witnesses and independent reports, which often amounted to several



thousand pounds. Only 4% of PACE's sample received any legal aid. Both Simmons' and the autism charities' research suggest that access to SENDisT may be denied to some families on grounds of cost.

The NAS also found that the emotional and financial costs incurred by parents were sometimes unnecessary. The NAS found evidence of LEAs settling the case, agreeing to everything parents had asked for, a few days before the hearing. The number of eleventh-hour settlements before the hearings may suggest that LEAs use the Tribunal process as a delaying tactic (NAS, 2003). If parents go to SENDisT, it means that the LEA can delay funding appropriate support until they receive the Tribunal's decision. There is also a chance that some parents will simply give up at some point during the complex four to six month process. These delays result in great emotional turmoil for families, and financial outlay for parents, LEAs and the Tribunal itself. In all the research published about Tribunals, parents' perception of the LEAs were very negative. At the Tribunal, Pace (2003) found that parents said the LEA made claims which were not true. Tissot (2005) reported that working with the LEA was identified as the most stressful aspect of the lives of 54% of parents of children with a label of autism.

The NAS (2003) also found that some parents were in the position of repeatedly appealing to Tribunal to have their child's educational needs met. Some parents appealed against a refusal to assess their child, then appealed against a refusal to statement, and appealed for the third time against the contents of a statement and the provision or placement identified to meet their child's needs. Finally, some parents had to return to SENDisT, yet again, because the LEA failed to implement the Tribunal's order.

### *Lack of Monitoring of Tribunal orders*

Despite the fact that the Tribunal's orders are legally binding and enforceable by law, many parents still found that, once they had their order, nothing happened (Simmons, 1996). The NAS (2003) reported that one third of parents found extreme difficulty in getting the LEA to implement the Tribunal's order. Indeed, the NAS found that only one sixth of Tribunal orders were implemented in full. There is no easy route for parents to seek redress if a decision is not implemented. Parents in

the NAS study contacted a wide range of bodies for support with implementation, including: the Local Government Ombudsman, the Department For Education and the Secretary of State. Of the 59 respondents seeking support for the implementation of a Tribunal order, only one found any of the 'watchdogs' to be helpful. The need to monitor the orders also contributed significantly to stress within the family.

### *Family stress*

The research (NAS, 2003; Peach, 2003; Pace, 2003) underlines the effect that going to Tribunal can have for the whole family. In addition to the distress caused to children who may be left unsupported at school, their parents can suffer from physical and mental ill health and unemployment as part of the Tribunal process.

Peach (2003) drew attention to the issue of representation at Tribunal as a cause of anxiety. Parents had mixed views about the quality of legal representation they had bought in from solicitors, but parents who went to SENDisT without a solicitor clearly felt disadvantaged. Hughes (2005) explains that one in five parents now engage a lawyer to present their case, and that this is twice as many as when the Tribunal started in 1994. The LEA is legally represented in around 10% of cases (Hughes, 2005). However, LEA officers who represent the LEA at Tribunal will normally have been to several hearings over a number of years.

Simmons (1996) also raised concerns about the support services available to parents funded by the LEA: the Parent Partnership Service (For a fuller discussion of Parent Partnership Services see Chapter 4). Simmons found that parents did not see Parent Partnership Officers as independent because they are employed by the LEAs against whose decisions parents are appealing. Few Parent Partnership Officers represent parents at Tribunal hearings and many simply refer parents directly to the voluntary sector when it becomes clear that an appeal is inevitable. However, the demand for representation from the voluntary sector outstrips supply (IPSEA, 2005a).



The research into the work of SENDisT raises a number of issues which are of concern for parents appealing to Tribunal. However, these research findings need to be contextualised within the policy framework which is outlined below.

### **SECTION THREE: The policy context**

This research is framed by the special education policy context in which SENDisT operates. Three key policy debates are crucial to understanding the parents' experiences of SENDisT: the policy of partnership with parents, the policy of inclusion and the system of statements of special educational needs. The discussion here introduces the key policy debates and they are revisited within the thesis, particularly in chapter four.

#### **i. Partnership with parents**

Since the Warnock Report (DES, 1978), the term 'partnership with parents' has become widespread in special education policy (DfES, 2001a; DfES, 2004), and it has also been the focus of much debate within research (Dale, 1996; Murray, 2000; Todd, 2003). However, the term 'partnership' is often so loosely defined within policy and research that it tells us little. 'Partnership' usually suggests some sort of co-operation and sharing of ideas and influence. Armstrong (1995, p18) states that partnership implies:

- mutual respect;
- complementary expertise;
- a willingness to learn from each other.

However, despite the frequent rhetoric about the importance of parenting, little practical recognition has been given to the weight and, indeed, usefulness of parents' expertise and experiences (Dale, 1996). Dale puts forward an analysis of parent-professional relationships which identifies different models of professionals working in partnership with parents in very different ways. Dale categorises the models as follows:

- The 'expert relationship'. This is similar to a doctor patient relationship where the professional takes the expert role and the parent is passive recipient of expert knowledge.

- The 'transplant relationship'. Here the professional takes on the role as instructor and consultant to the parent with the aim of 'training' the parents in professional skills.
- The 'partnership model' which seems to underpin much policy and practice within special education (DfES, 2001a). Here the concept of partnership remains vague. Partnership is heralded as 'important' and parents' views are 'key' (DfES, 2001a) but there are no minimum requirements of parent-professional partnership. In a sense, the rhetoric disempowers rather than enables parents in partnership with professionals.
- The 'parent as consumer model'. This model credits parents with knowledge but the professional is still considered to be the 'expert', 'instructor', or 'consultant'.
- Finally, Dale identifies his preferred model: the 'negotiating model'. In this model, it is accepted that parents and professionals have separate and valuable contributions to make, and that parents and professionals may hold multiple perspectives. A professional working in partnership, in this model, may adopt a variety of role positions and behaviours (such as the expert, instructor, consultant or facilitator or, perhaps, learner) but the positioning options are to be negotiated with the parent. In the 'negotiating model' the professional must avoid the assumption that parents have attitudes and beliefs in common or that an individual parent's views are fixed and unchanging. The reality of parents' interpretations is acknowledged and the professional must neither simply oppose or ignore them (Dale, 1996).

In policy and practice, there seems to be ambivalence towards Dale's 'negotiating model of partnership'. Indeed, Warnock said 'It [parent-professional relationships] is a question of collaboration, not partnership' (Warnock, 1985 cited in Blamires, 2001). The focus on partnership with parents has been a key Government response to the increasingly confrontational relationships many parents experience as they engage with the special education system. Yet the vagueness of the rhetoric and the lack of commitment to minimum standards means that a 'partnership model' (Dale, 1996) contributes to adversarial and conflict ridden relationships which often result in partnership breakdown.



The current policy rhetoric emphasises the enormous value of parenting and parental knowledge (DfES, 2001a; DfES, 2004). The aim has been to blur the boundaries between parents and professionals by exhorting teachers to treat the concerns of parents in the same way as if they had been raised by a professional (DfES, 2001a), yet, it remains the case that whoever makes decisions about the level of support available to a child in school is in control of the relationship, and this is usually the education professional, not the parent (Armstrong, 1995). Parents are often forced to draw on a sort of pseudo-power drawn from the information apportioned by professionals. Their informal, but intimate, knowledge of their child, can be deemed worthless within the parental-professional relationship (Dale, 1996) in a system which is underpinned by medicalised and specialist discourses of 'need' (For a fuller discussion of concepts of special educational needs see Chapter Two). Partnership takes place in a context where the unpaid and unlimited hours of parenting are in stark contrast with the professional's payment for limited hours of employment (Dale 1996), yet professional knowledge is privileged.

Armstrong (1995) has questioned whether the 'parents as partners' model should really be seen as a genuine attempt to work in partnership with parents. He suggests that the real intention is simply to incorporate parents into the bureaucratic procedure and so remove the 'genuine' power of parents. Partnership with parents, in this sense, is needed merely to enable the smooth operation of the 'bureaucratic' procedures (Armstrong 1995: 144 cited in Cole, 2004, p11). At times, it may be that partnership with parents is a method of passing the child's 'problems' back to the parents.

Professionals who work with children with special educational needs work in a context where the discovery of special needs and/or impairment is still seen as a 'personal tragedy' for the child and for the parents. The focus, then, is firmly on the psychological aspects of parents as they are pathologised in relation to their child's impairment (Cole, 2004). Yet parents themselves consistently claim that it is not caring for their child which causes the stress, but the processes which the families have to go through accessing provision (Murray and Penman 2001; Cole, 2004; Tissot, 2005). For many parents, working with professionals becomes the most difficult aspect of parenting.

Parents are, at times, attributed with negative characteristics and motivations by professionals. Parents who challenge are seen as adept at manipulating the system and stand accused of exploiting their child's diagnosis in order to win disproportionate resources (e.g.: special school places, individual specialist tuition). Parents are described as being part of 'advantaged groups' (e.g.: The Dyspraxia Foundation, NAS) which are said to voice their concerns at the expense of others (Gross, 1996; Riddell, 1994 cited in Martin, 2000). Indeed, Hunt (1994) cautions teachers against 'open meetings' with groups of parents as these become opportunities of vociferous pressure groups to dominate and distort a picture of parent views. Special education is thought to have become 'a middle class' battlefield.

Gross (1996) found that parents with middle class occupations were three times more likely to be unhappy with their child's provision than other parents. So middle class parents have been urged to stop disadvantaging others (Gross, 1996; Martin, 2000). Parents are characterised as being manipulative and selfish (Gross, 1996). However, the fact that the system makes demands upon even the most articulate of parents in negotiating and securing appropriate provision for their child, should, perhaps, be considered as an indictment of the system, rather than the parents themselves (Blamires et al., 1997).

Parents are expected to act with openness, honesty and trust in an environment where they perceive professionals to work in a closed, and dishonest manner (NAS, 2003; Tissot, 2005). Yet when parents blame the system, they are attributed with having an over demanding style and unreasonable expectations, or stand accused of using their child's special needs and/or impairments as a way of detouring their own conflicts or unhappy relationships (Minuchin, 1974, cited in Connor, 1997).

Parents often feel vulnerable in their relationships with professionals; they fear that a comment or act will offend a professional, not only jeopardising their child's access to support and resources but confirming their parental pathology in the eyes of the professional (Murray, 2000). Yet conflict is perhaps inevitable when the



parent wants what is 'right' for the child 'exclusively'; the professionals want what is right for him in a policy context where 'No child is entitled to "the best: no LEA should use their resources inefficiently".' (Simmons, 1996, p357). This means that parents and professionals could agree that a school is the 'best' placement for a child, but the LEA would still have the right to refuse the child a place at that school if it could be shown that a placement school at another school would meet the child's stated needs and was a more efficient use of resources.

The issues concerning parent-professional partnership outlined in this section are also reflected in the current policy, legislation and guidance for parent-professional partnership outlined below.

### *Policy, legislation and guidance for parental-professional partnerships*

The guidance in the DfES *Code of Practice* (2001a) asserts:

Partnership with parents plays a key role in promoting a culture of co-operation between parents, schools, LEAs and others.... All parents of children with special educational needs should be treated as partners.

(DfES, 2001a, p16)

The Audit Commission Report (2002a) states that involvement of parents in the education of children with special needs in the United Kingdom is considered not only a right, but also a necessary component of the delivery of effective and efficient provision (DfEE 1997, 1998, 2000 cited in Dockrell, Peacey and Lunt, 2002). Parental involvement covers the assessment process, decision-making, and educational intervention. Parents are also seen to provide an important source of information on the working of the systems designed to meet their child's needs (Dockrell, Peacey and Lunt, 2002).

However, *The Code of Practice* (2001a) also makes it clear that the key role envisaged for parents in this 'partnership' is that of an 'informant':

Parents hold key information.... They have unique strengths, knowledge and experience to contribute to the shared view of a child's needs and the best ways of supporting them.

(DfES, 2001a, p16)

There is no acknowledgement in *The Code of Practice* of the complex role parents are obliged to adopt in order to campaign for appropriate support and resources (IPSEA, 2002).

Despite the lengthy claims for partnership within current policy and guidance, parents, unlike professionals, need support in order to have 'positive attitudes' (DfES, 2001a). This stereotyping of parents as in some way deficient in comparison to professionals is also shown in the *Code's* (DfES, 2001a) advice that parents may need support in seeing their children as partners in education. There is no corresponding advice that professionals too may need support in seeing the child as a partner in education.

While the current policy of parent-professional partnership may not in itself make unreasonable demands on parents, research (IPSEA 2002; Tissot, 2005) suggests that it is the LEA's failure to adhere to the policy of partnership which places the greatest burden on parents. It is a burden which less articulate and/or less confident parents simply cannot manage. The consequence is that children with special educational needs whose parents are less articulate, receive less help (IPSEA, 2005a). This is supported by the Audit Commission's Report (2002b) which found that LEAs with socially deprived areas had lower levels of appeals to Special Educational Needs Tribunal (Evans, 1999, cited in Dockrell, Peacey and Lunt, 2002, p24). It is also a situation that is reflected in the DfES (2004) *Removing the Barriers to Achievement* which states that 'too much still depends on where you live, which school you attend, or on other factors such as their family circumstances.' (DfES, 2001a, p24).

The Audit Commission (2002a) also suggests that parents are an important source of information on the working of the systems designed to meet their child's needs (Dockrell, Peacey and Lunt, 2002), yet this is clearly not always the case in practice. Crucially, the new *Code* was revised taking into account 'the experiences of schools and LEAs in using the original code and developments in education since 1994 (DfES, 2001a, p27-28) and has been evaluated in terms of impact on 'schools and LEAs' (DfES, 2001a, p27-28). Parents were not consulted in the revision process. The current guidance for schools *Removing the Barriers to Achievement* (DfES, 2004)



was also written without consulting parents. Parents were the only group, it seems, not to be consulted in the generation of the strategy:

This strategy follows discussion with a wide range of practitioners and policy makers in local authorities, the health service and the voluntary sector, as well as children and young people.  
(DfES, 2004, p7)

Calls for partnership have been, at times, ignored by professionals and viewed with suspicion by parents. The aim of the partnership with parents policy was to reduce conflict and to make the system less adversarial, however, there is little evidence to suggest that this is what has taken place since 1978 (Simmons, 1996; Pace, 2003; Peach, 2003; NAS, 2003; Tissot, 2005).

## ii. Inclusion

In 1993, the general principle that children with special educational needs should – where this is what the parents wanted – normally be educated at mainstream schools was enshrined in law (DfES, 2001a). The UK supports the Salamanca Statement drawn up by United Nations Educational, Science and Cultural Organisation (UNESCO) in 1994 which called upon all Governments to ‘adopt as a matter of law or policy the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise’ (cited in DfES, 2001a, p1).

The legislation and guidance which underpins the Government’s policy for inclusion is referred to as ‘the inclusion framework’ and has been in place since 2002 – this includes the 1996 *Education Act* (HMSO, 1996), *SENDA* (HMSO, 2001), *The Code of Practice for Special Educational Needs*, (DfES, 2001a), and statutory guidance *Inclusive Schooling: Children with special educational needs* (DfES, 2001b). Within ‘the inclusion framework’ the principles of an inclusive education service are defined as follows:

- Inclusion is a process by which schools, local education authorities and others develop their cultures, policies and practices to include pupils.

- With the right training, strategies and support nearly all children with special educational needs can be successfully included in mainstream education.
- An inclusive education service offers excellence and choice and incorporates the views of parents and children.
- The interests of all pupils must be safeguarded.
- Schools, local education authorities and others should actively seek to remove barriers to learning and participation.
- All children should have access to an appropriate education that affords them the opportunity to achieve their personal potential.
- Mainstream education will not always be right for every child all of the time. Equally just because mainstream education may not be right at a particular stage it does not prevent the child from being included successfully at a later stage.

(DfES, 2001b, p2)

Crucially, the Department for Education and Science (DfES) recognises that 'Inclusion is far more than just about the location of a child's school placement' (DfES, 2004, p2). The child's inclusion in the social life of the school is also considered to be part of the inclusion agenda.

*Removing Barriers to Achievement* (DfES, 2004) is government guidance which aims to strengthen 'the inclusion framework' by insisting that:

All teachers should expect to teach children with special educational needs (SEN) and all schools should play their part in educating children from their local community, whatever their background or ability. We must reflect this in the way we train our teachers, in the way we fund our schools and in the ways we judge their achievements.

(DfES 2004, p5)

Her Majesty's Chief Inspector of Schools is responsible for monitoring the impact of the inclusion framework on schools and part of The Office for Standards in Education's (OfSTED) role is to monitor how inclusive schools are. The Audit Commission also has a role in monitoring how the local education authorities are supporting and facilitating inclusion and the quality of provision. The Secretary of



State for Education also has powers to intervene when schools act unreasonably or when local authorities fail to perform their duties.

IPSEA has also monitored the inclusion framework through its case work and in its response to the Audit Commission's Report (2002b) and its submission to the Education and Skills Select Committee Inquiry into Special Education Needs (Audit Commission, 2005).

### *The impact of 'the inclusion framework' on schools*

OfSTED (2004), The Audit Commission (2002b) and IPSEA (2002, 2005a) have found mixed responses to 'the inclusion framework' in their monitoring. OfSTED (2004) found that there was a growing awareness in schools of the benefits of inclusion, but that this had had little impact on the numbers of pupils in mainstream schools with special educational needs, nor on the range of entitlements the mainstream caters for. Indeed there has been an increase in the number of pupils in Pupil Referral Units and in independent special schools. The proportion of pupils in Pupil Referral Units rose by 25% between 2001-2003 (OfSTED, 2004). In 2004, 89,540 children had full-time special school places in special school and a further 2,200 children were attending special schools part-time (DfES, 2006). The number of children with full time places at special school represents in 2004 1.1% of the school population. The Audit Commission Report (2002b) also questions what is meant by the claim that provision for pupils with special educational needs in the mainstream is inclusive. Often children with special needs may be on the site of a mainstream school, but their opportunities for interaction with their peers are limited. OfSTED found that pupils at mainstream schools with units attached often had very limited opportunities for interaction with children in the mainstream. OfSTED (2004) found that most mainstream schools are now committed to meeting special needs, but pupils with social and behavioural difficulties are still considered to be 'difficult' to include.

At the moment, OfSTED claims that a minority of schools meet the needs of pupils with special educational needs well, but others are improving (OfSTED, 2004). OfSTED (2004) found that teachers make insufficient adaptations to the mainstream curriculum for pupils with special educational needs, and that teacher

expectations remain low and progress is slow. Dockrell, Peacey and Lunt (2002) found that the need to differentiate the curriculum in order to include pupils with special educational needs place demands on teachers which the evidence suggests teachers feel unable to meet.

OfSTED (2004) also drew attention to the role of teaching assistants who support children with special educational needs. The presence of teaching assistants in a classroom with a child may deny the pupil the opportunity to develop skills, understanding and independence. *On a Wing and a Prayer* (MENCAP, 2005a), MENCAP's paper on the role of teaching assistants, also suggests that the presence of a teaching assistant means that the class teacher delegates responsibility for the child with special needs to the teaching assistant, and that the teacher has little interaction with the child, or input into planning their differentiated work. Despite SENDA (HMSO, 2001), OfSTED (2004) also noted that over half of all schools visited had no disability access plans and then they only focused on accommodation.

For IPSEA, the key to successful inclusion lies in the statement of special educational needs. IPSEA found that it is only possible to pursue inclusion by:

Enhancing and guaranteeing adequate provision in mainstream schools through reinforcing, not weakening, the assessment and statementing procedure, and not by seeking to limit parents' access to professionals' opinions on their children's needs. There is a need to create a system in which parents will choose inclusion because there is a legal guarantee (via the Statement) that their child's needs will be met in the mainstream and because, with this guarantee, they can trust that this is where their child's needs will best be met. (IPSEA, 2005a, 8.7)

The policy of inclusion is key to understanding the special education system in which SENDisT operates. While the Audit Commission and OfSTED acknowledge that progress towards inclusive practice has been slow, the debates in the media also demonstrate that the policy is controversial among parents and professionals (See Chapter Four where these issues are discussed more fully). Just as the policy of inclusion is controversial among parents and professionals, the policy of statements of special educational needs have also been a source of conflict between parents and professionals.



### **iii. Statements of Special Educational Needs**

I outlined above how the system of statements of special educational needs was set up in the wake of the Warnock Report (DES, 1978). The current policy is set out in the *Code of Practice* (DfES, 2001a). However, since 2001, the Government has begun to signal that it wishes to move away from meeting individual needs through statements and the policy context has become unclear. While Government and LEAs (Audit Commission, 2002a; Derbyshire County Council, 2006) resist statements as time wasting and bureaucratic, parents and their organisations (ACE, 2005a; IPSEA, 2005) see statements as protecting children's entitlements to extra support.

In *Removing the Barriers to Achievement* (DfES 2004), the guidance states that:

We want parents to have confidence that their children's needs will be met effectively in school without feeling that the only way to achieve this is through a statement.  
(DfES, 2004, p12)

The Audit Commission (2002a) sets out the perceived difficulties of the statementing system:

- statutory assessment are costly and bureaucratic, and may do too little to address children's needs, parents may find it stressful and alienating;
- statements may provide little assurance to parents because of weak monitoring arrangements by LEAs and schools plus shortfalls of health and social services;
- statements lead to inequitable distribution of resources and may provide funding in a way which prevents early intervention and hinders inclusive practice.

(Audit Commission, 2002a)

The Audit Commission (2002a) also raises further concerns. The cost of statementing stood at £90 million a year in 2000. However, the Audit Commission suggests that the process of assessment reveals nothing new about a child as the advice will already have been requested before the period of statutory assessment. The Audit Commission also notes that a lack of a formal monitoring system means that statements may or may not result in provision for a child. Health provision, such as speech and language therapy, is often not delivered despite being set out

within statements. The Audit Commission also found that provision varies so much from area to area that parents become scared to move house because of the impact on their child's education.

The Audit Commission (2002a) suggested that the process of statementing might hinder the process of inclusion as:

The existence of separate structures and processes for children with SEN may have allowed their needs to be seen as somehow different – even peripheral – to the core concerns of our system of education.  
(Audit Commission, 2002a)

The attack on the system of statements is, then, two-pronged: first, there is the suggestion that statements are time-wasting, overly bureaucratic, expensive and difficult to implement. Second, is the claim that statementing is in some way incompatible with a policy for inclusion in education.

Organisations which support parents of children with special educational needs (ACE, 2005, IPSEA, 2005a) have resisted the attacks on statementing. First, they reject claims made about the bureaucracy of statements, IPSEA (2005a) points out that a system which allocates resources from the public purse must be accountable and that this necessarily involves a degree of bureaucracy. Secondly, none of the critics of statements have offered a suggestion for a less bureaucratic system. While LEAs and Government have criticised the system of statements, parents see a statement as a valuable protection for children with special educational needs. A clearly written statement, which quantifies the provision a child should receive, is enforceable and for that reason is generally honoured by an LEA (IPSEA, 2005a).

The apparent drive to reduce the number of statements has been linked to a rise in the number of appeals to SENDisT, particularly when the LEA has refused to assess a child for a statement. Appeals against an LEA's decision to refuse to assess a statement are the most common appeals – they make up 39.6% of all appeals (Hughes, 2004) and they are also the type of appeal most likely to be withdrawn or conceded before a hearing. Of 320 such appeals heard by a panel in 2004, 61% were upheld (Hughes, 2005).



IPSEA (2005a) also challenges the linking of inclusion with the attack on statements. In its Green Paper *Excellence for all children* (DfEE, 1997) the New Labour Government asserted that:

The process for assessing pupils and issuing statements is lengthy and expensive ... resources that could be used to give practical support to pupils are being diverted into procedures ... resources allocated to those with statements are diverted away from the majority of children with SEN but without statements ... statements can act as barriers to full inclusion of pupils with SEN.

However, while it seems possible that statements may label and stigmatise children and, therefore, act as barriers to inclusion, the entitlement to educational support that a statement brings can be crucial in ensuring a child's inclusion in mainstream school (IPSEA, 2005a).

*Removing the Barriers* (2004) contains cross-references to the Audit Commission Report (2002a) linking negative comments on the assessment and statementing processes e.g.: 'They [the Audit Commission] also found that statutory assessment was a 'costly and bureaucratic process' which could divert specialist staff from working in schools.' It was later revealed that *Removing Barriers to Achievement*, the Government's policy statement, was in fact written by the same person who wrote the Audit Commission report (IPSEA 2005a).

The Audit Commission (2002a) found that parents were often unhappy with the system and felt that the statement offered little assurance, but while the Audit Commission concludes that the system is in need of review, parents' groups (IPSEA, 2005a) have argued that the system is in need of enforcement, not review. The difficulties for children, IPSEA say, arise when LEAs disregard the law which is intended to provide for them.

Reactions to the system of statements is divided between LEAs and Government who criticise them for being costly, overly bureaucratic and incompatible with a policy for inclusion, and parents who see statements as protection for their children and supporting their children's inclusion in mainstream schools. The policy of statements, and the conflict associated with it, is, thus, key to understanding the SENDisT system, and associated debates and discourses.

## **Conclusion**

While a review of the policies underpinning SENDisT and the system of special educational needs provision is clearly important for this research, any discussion of the policy context should sound a note of caution. As Fulcher (1999) points out in a study of very different approaches to integration in the USA, Britain, Australia and Denmark, success is only due in small part to the nature of policy issued at central government level. In reality, policy is made and interpreted at all levels in any system: it may, then, be that the paramount factor in successful outcomes for children with special educational needs is a positive attitude among all the adults involved with the child (Hunt, 1994) (For a fuller discussion of the relational factors which lead parents to Tribunal see Chapter Four).

In the next chapter, the theoretical assumptions underpinning the policies for special education are considered.



## CHAPTER TWO: THEORETICAL APPROACHES

### Introduction

This chapter sets out the theoretical approaches which underpin the thesis. The study is driven by a pragmatic approach to theory. Theory is seen as a useful tool for developing understandings of parents' stories and the system of special education (Todd, 2006). The study draws on a number of theoretical concepts including social model theory, the deconstruction of special education, and the work of Foucault, Rorty and Bourdieu. The justification for a theoretically diverse approach is that the diversity of the theoretical approaches allows this study to engage with the complexity of the parents' lives.

### Pragmatism

Philosophical pragmatism dates from the 1870's. Its founders, John Dewey, William James and Charles Sanders Peirce, reacted against absolutist metaphysics and abstract concepts of truth and reality (Baggini, Bragg, Fricker and Grayling, 2005). Philosophical pragmatists reject the old philosophical search for real, final truths. For pragmatists, it is whatever promotes thinking, dialogue and rational inquiry which is to be encouraged (Pfeiffer, 2003). Pragmatism reaches out to all forms of thought while at the same time remaining self-conscious, self reflective and self critical.

For pragmatists, knowledge is only meaningful when coupled with action; nothing is true or false, it works or it doesn't. Pragmatism is deeply embedded in the reality of life and is above all concerned with the individual's direct experience of the world he or she inhabits (Brassier, 2003). For the pragmatist, practical application is all. Theory, then, is useful as a tool to understand and perhaps to challenge existing practice (Todd, 2006).

Pragmatism is described as a philosophical spur to social change (Baggini et al, 2005). Its primary epistemological concern is the practice of inquiry and how we discover the nature of the world. For a pragmatist, the inquiry must begin with something practical - there must be a problematic state that sparks an inquiry, and in the gaining of knowledge and the gathering of evidence the problematic state is calmed (Baggini et al, 2005). Knowledge is conceived of as the output of

competent inquiry. In special education, Danforth (1999) has suggested that pragmatism invites us to admit the fallibility of professional language and research knowledge and to construct equality for pupils with special educational needs and/or impairments.

This study was sparked by the problematic state of the parents' experiences of SENDisT. It is also primarily concerned with direct experience of the social world. A pragmatic approach allows the analysis of parents' stories to draw on a variety of theoretical concepts. The theoretical approaches were chosen because they are useful in helping to develop understandings of the parents' stories. They also offer the possibility for social change.

Pragmatism has been criticised by those who object to the claim that truth is what works. Critics insist that there are 'hard facts' independent of enquiry. Bertrand Russell (cited by Baggini et al, 2005) described how our experience of the world suggests that it is flat but that this is false. However, pragmatists respond that an individual cannot choose to believe the world is flat because such a belief cannot be sustained, it is not useful. The belief that the world is flat does not work.

Pragmatism has also been criticised for its 'supermarket trolley' approach to philosophy, where the consumer's own inclinations are the only criteria for choosing between competing philosophies (Brassier, 2003). However, again, the choice of concepts and philosophies cannot be on a whim, they must contribute to the production of knowledge. The pragmatist is interested in knowledge that helps every-day people solve problems and cope with dilemmas within the specific contexts of their lives (Danforth, 1999).

The pragmatic analysis, here, draws on a variety of theoretical concepts: social model theory and theories of special education, the work of French philosophers Michel Foucault (1973, 1977) and Pierre Bourdieu (1984) as well as the work of American pragmatist Richard Rorty (1980, 1989).



- Foucault's work encourages us to deconstruct the knowledge which underpins special education and to the discursive practices which sustain professional knowledge. Foucault also draws out attention to the power relationships within the SENDisT.
- Rorty's work offers us possibilities for understanding conflict within special education and the possibility for solidarity.
- Bourdieu's work is used here to focus on the lives of the family and how they experience the disabling world.

We begin, however, by considering the impact of social model theories within this study.

### **SECTION ONE: Social model theories**

Despite the existence of people with impairments across all times and cultures, it is only in the last three decades that disability theory has emerged within an academic community (Terzi, 2004). The development of models of disability and disability theory has been driven by close engagement between academic and political movements (Read, 2000). Models of disability have had the greatest influence within the discipline of Disability Studies and, significantly for this study, perspectives on education.

The 'big idea' (Hasler, 1963 cited in Chappell et al, 2001, p46) of British Disability Studies has been the social model of disability (Finkelstein, 1973, Oliver, 1990, 1996). Despite the criticisms (Shakespeare and Watson, 1997; Thomas, 1999; Terzi, 2004), the social model continues to have a positive and powerful impact on the lives of disabled people, and the Disability Studies context, in Britain in particular. Despite claims that social model theorists have 'over egged the pudding' to such an extent that it should be abandoned (Shakespeare and Watson, 1997), the social model can still be seen as relevant and compelling for political change and for enhancing understanding of disabled people and their families.

### *What is a model?*

While the term 'social model' is common in disability studies, the word 'model' is rarely unpacked. Within social science, models are 'heuristic devices' which are used to shape understanding and to develop arguments (Barnes, 2002):

A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints ... it is this multi-dimensional replica of reality that can trigger insights that we might not otherwise develop.  
(Finkelstein, 2002, p13 cited in Barnes, 2002, p10)

A model seeks to explain phenomena by reference to abstract systems or mechanisms. Models of disability are not, then, synonymous with theory as, although they may help to generate explanations in some way, they do not, by themselves, constitute an explanation (Llewellyn and Hogan, 2000).

### **Dominant theories of disability: medical and individual models of disability**

The social model of disability is a response to dominant models of disability which inform traditional approaches to impairments. Medical and individual models locate disability within individual pathology and see disability as a 'personal tragedy' (Oliver, 1996). In order to explore the social model, we need to begin with an excavation of the models which locate disability within individual pathology.

The medical model of disability constructs disability as the direct result of physical, sensory and/or neurological impairment due to damage or disease. A medical model framework emerges from models used in medicine in which practitioners think in terms of 'conditions', 'treatment', 'cure' and 'rehabilitation'. In this model, a disabled person who cannot be cured or rehabilitated may need to be segregated from society (Chappell et al, 2001) for their own good and for the general well being of the wider society. A medical model assumes that the disabled adult or child is deficient but, it is hoped, alterable, whereas society is fixed with limited capacity for, or willingness to, change. The courage and fortitude of the person who strives to overcome his or her disability are applauded as conquering disability is seen as a matter of personal effort and achievement (Llewellyn and Hogan, 2000).



Medical model approaches are not, however, limited to the world of medicine. Psychology and education also use diagnostic criteria, such as psychometric testing, which are allied to a clinical approach and use the same language of 'identification', 'deficit', 'rehabilitation' and 'cure' locating the 'problem' within the individual. Within education, medical model approaches underpin the concept of 'special educational needs' itself and segregated education. The medical model promotes an understanding of disability as primarily an individual condition. Medical and individual models offer a 'property' definition of disability – disability is something which belongs to the individual (Williams, 2001).

As Ong-Dean (2005) suggests, it is by classifying and identifying conditions that the medical model not only describes disability, it constructs it. A further consequence of a medical model approach to disability is that it reinforces professional authority, which, in turn, diminishes the perspectives of disabled people and their families and disempowers them. The influence of medical and individual models has also shaped research perspectives where the focus is on individual pathology, or the pathology of the family with a disabled child (Bruce and Schulz, 2002). Analyses shaped by medical and individual models of disability employ research methods which largely ignore the perspectives of disabled people and their families, as well as the wider political contexts including disabling attitudes, and physical barriers (Oliver, 1996).

### **The social model of disability**

The social model of disability challenges traditional conceptions of disability (Oliver, 1990, 1996; Morris, 1996; Thomas, 1999). The social model defines disability as the product of specific social and economic structures, and aims to address oppression of and discrimination against disabled people which are caused by institutional and cultural forms of exclusion (Thomas, 1999; Reeve, 2002). The social model has been conceptualised with reference to *The Fundamental Principles of Disability* (Union of the Physically Impaired Against Segregation, (UPIAS, 1976):

Impairment—lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.

Disability—the disadvantage or restriction of activity caused by a

contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities.

(UPIAS, 1976, quoted in Oliver, 1990, p. 11).

The separation of disability from impairment is key to understanding disability and disablement, as impairment, of itself, is not seen as being part of the problem, rather disablement is socially created (Oliver, 1996).

The social model's primary aim is to reject and deconstruct individual and medical models of disability. As the social model is situated in the direct experience and understandings of disabled people themselves, it aims to address the issues of marginalisation, and discrimination which disabled people face. The social model seeks to denounce and to remove disabling barriers which are the product of social and cultural institutions (Terzi, 2004). Although the social model does not constitute a social theory (Oliver, 1996), it does provide a definition of disability informed by historical materialism. Historical materialism attempts to place social relationships in a social setting *and* to provide an evolutionary perspective on history, with particular focus on the transition from feudal through to capitalist and socialist society (Oliver, 1990).

Oliver (1990, 1996) maintains that an ideology of normality originated within the rise of capitalism as the need for a work force defined people's abilities. People with impairments were identified as economically problematic because they were perceived to be ineffective workers and therefore became 'dis-abled' (Chappell et al, 2001). Oliver argues that the rise of the medical profession coincided with the rise of capitalism, which contributed to the medicalisation of disability as a personal tragedy or deficit in need of medical intervention. Challenging these individual and medical perspectives, the social model argues for full inclusion of disabled people in society with equal rights and responsibilities (Oliver, 1990, 1996). The social model shifts the 'problem' of disability away from the individual and into the collective responsibility of society as a whole (Tregaskis, 2002).

While the social model is not without its critics, it is important to recognise that it has had many positive outcomes for disabled people. Not least, it has enabled disabled people to make sense of their experience. For parents of children with



impairments, the social model explains the exclusion and discrimination their children face as part of the normalising and exclusionary attitudes embedded within institutions and society (Murray and Penman 1996, 2001). Social model discourses and understandings have begun to influence policy and practice in society (e.g.: DfES, 2004). The social model has, then, had profound practical and theoretical application over more than twenty years (Tregaskis, 2002).

### **Critiques of the social model**

Critiques of the social model have focused on the limits of a materialist account, the absence of cultural and feminist perspectives, and the exclusion of people with the label of learning difficulties. The distinction between impairment and disablement has also been seen as problematic for the social model and this has led to the development of a sociology of impairment. Each of these issues is considered below.

#### *Critique of the materialist account*

Oliver's (1990, 1996) materialist account has its limitations. First, it has been criticised for not making explicit how practical changes like removing physical barriers will lead to attitudinal change (Tregaskis, 2002). Other theorists have questioned the causal link between capitalism and disablism as they have suggested that all societies, whether capitalist or not, maintain some sort of inclusionary/exclusionary mechanism (Abberley, 1987 cited in Tregaskis, 2002). Materialist accounts (Oliver, 1990, 1996) have also been criticised for failing to account for contemporary developments in capitalist economic systems, and that by focusing on the economy, the cultural processes involved in the creation of disability have been marginalised. However, Oliver never claimed to offer a complete social theory, rather a model which he hoped would facilitate understanding and theory development (Oliver, 1990, 1996).

#### *Culture and disability*

Shakespeare (1994) criticises a materialist analysis for its focus on social structures, and maintains that it neglects questions of culture, representation and meaning. However, Oliver (1990, p18) acknowledges 'the cultural and situational relativity of both definitions and experiences of disability' and states that 'it is clear that the

individualised, tragic view of disability prevalent in modern industrial society is not universal by any means'. Indeed, Oliver wants to 'show that disability as a category can only be understood within a framework which suggests that it is culturally produced and socially structured' (1990, p18).

The cultural aspects of disability have been the focus of research for disability theorists (Thomas, 1982, pp. 12–16; Barnes, 1991, p. 51; Morris, 1991, p. 93; Hevey, 1992, pp. 107–108; Hafferty & Foster, 1994; Peters, 1996, p. 218; Mason & Rieser, 1999 cited in Tregaskis, 2002, p461). Researchers have shown how images have been used to construct disabled people as the 'other'. Morris (1991, p84) focuses on 'the messages, images and ideas about disabled people which are contained in all the different forms which reflect and promote Western culture.' For Morris, 'culture' reflects the interests of those social groups who hold power and resources within society. Morris is concerned with the ways in which the lives of disabled people are portrayed and the ways in which the misrepresentation or the absence of disabled people's experience in general culture contributes to the marginalisation of disabled people. 'Cultural' criticisms of social model theory also have their roots in feminist critiques.

### *Feminist critiques*

Feminists have been keen to point out that the social model was, originally, largely constructed by disabled male academics (Lloyd, 1992). However, this, in itself, is not a convincing critique of the social model. A more persuasive feminist critique of materialist accounts of disability is the absence of issues of age, race, sexuality and gender (Morris, 1996) from a social model understanding of disability. Feminists have invoked 'experience' (Thomas, 1999) and have challenged Oliver's position on the grounds that it rests on a problematic conceptual dualism: the private versus the public/political. Feminists have argued that it is impossible to separate the two. Crucially, feminists have argued that experiential accounts can act as windows on the social and that detailed accounts of one individual's life can tell us enormous amounts about disability and society in general (Crow, 1996; Thomas, 1999).



The social model has been criticised for wrongly assuming that disability is the sole or most significant identity for any individual (Shakespeare, 1996). Moreover, Morris (1991) suggests that the fact that the academic section of the disabled people's movement is dominated by men, has led to the privileging of economic factors and the world of work above disabled people's personal experience. Issues of sexuality, relationships, family and parenting are, at times, marginalised within the social model. The concept of disability and the family is an important one to which we return in Chapters Six and Seven.

Feminists have, in turn, been criticised by materialists for offering analyses which are too individualised and carry political risks. Oliver (1996) warns that there is a danger in emphasising the personal at the expense of the political while most of the world still constructs disability as an individual and personal tragedy:

To mention biology, to admit pain, to confront our impairments, has been to risk the oppressors' seizing on evidence that disability is "really" about physical limitations after all.  
(Oliver 1996 p 39)

However, the 'question of impairment' is an issue which a social model analysis must face.

### *The question of impairment*

The achievement of the disability movement has been to break the link between our bodies and our social situation, and to focus on the real cause of disability, i.e.: discrimination and prejudice.  
(Oliver, 1996, p39)

Despite Oliver's insistence that there is a distinction between impairment and disability, the prima facie link between impairment and disability has proved difficult to shake off. The social model has been criticised for failing to give an account of impairment or to explain how, in a society with barriers removed, impairment would be understood (Terzi, 2004).

The fear is that any discussion of impairment risks undoing the achievements of the disability movement. Any attempt to re-focus on the experience of impairment or on bodily limitations may damage the claim that the real cause of disability is discrimination and prejudice. However, despite the political dangers,

the debate continues within disability studies (Crow, 1996; Thomas, 1999; Reeve, 2002). Crow draws attention to the sense in which social modellers believe that 'Impairment is safer not mentioned at all' (Crow, 1996, p. 58). However, she insists that:

This silence prevents us from dealing effectively with the difficult aspects of impairment.  
(Crow, 1996, p58)

The social model has been described as an over socialised and reductive view of disablement which fails to give credit to individual experience and to the complexity of relationships between individuals and systems (Read, 2000). An unintended consequence of the distinction between disability and impairment has been that the social model has ceded control of the impaired body to the medical profession which has continued to pathologise and individualise impairment, so that an individual's impairment has become all encompassing (Tregaskis, 2002).

The response by social modellers to the issue of impairment has been an attempt by some researchers to bring impairment back into disability studies and to integrate an analysis of the impaired body at theory level – a sociology of impairment to complement the sociology of disability (Hughes & Paterson, 1997; Goodley, 2001; Tregaskis, 2002). A sociology of impairment suggests that disablement concerns all that involves systematic exclusion of impaired people from society, and disability is defined as all restrictions of activity caused by disabling arrangements. On the other hand, impairments have certain effects, which also have social origins but that is a completely separate matter from disability. Crucially, Thomas (1999) has stressed that impairment effects cannot be dealt with as 'pre-social 'biological' phenomena' (p 43). Rather it is the case that disability and impairment effects interact.

However, as early as 1987, Abberley (1987 reproduced in Barton and Oliver, 1997, p175 cited in Goodley, 2001, p 209) recognised the need to emphasise the social origins of impairment. So, rather than seeing a turn to impairment as de-politicising and re-medicalising the social model, writers argue that the focus on impairment within a social model framework re-socialises impairment (Goodley, 2001). By re-socialising impairment, disability theory challenges the idea of the



impaired body as naturalised and impairment is re-claimed (Tregaskis, 2002). A sociology of impairment also requires the deconstruction of the existing traditional and medicalised discourses of impairment; impairment is seen as more than a medical issue (Hughes & Paterson, 1997). The aim is that by tackling attitudes to and the discourses and language of impaired bodies, impairment will be re-framed more positively (Tregaskis, 2002). The impact of a sociology of impairment in this research is that the focus of the stories need not be seen as the consequence individual, biological phenomena, rather disability and impairment are seen to interact within the stories.

### Developing the social model

Critiques of the social model from feminist and cultural perspectives have led to theory development, not only in terms of a new sociology of impairment. Social Relational Theory and the Affirmation Model of disability both build on a social model perspective. The social model has also been criticised for leaving out people with learning difficulties and families too must be represented within the social model of disability.

### *Social Relational Theory*

While the sociology of impairment has brought the body back into disability studies, researchers have also criticised the exclusion of individual experiences of impairment and disablement from the social model (Morris, 1994; Thomas, 1999). Aspects of personal experience are increasingly seen as crucial in exposing attitudes to disabled people's lives (Tregaskis, 2002). Some researchers have suggested that the split between attitudinal and systemic barriers on the one hand and individual experiences of living with impairment and disablement on the other simply allow oppressive practices to continue (Morris, 1996; Thomas, 1999). Thomas (1999) has tried to bring personal experiences and relationships back into the debate. She suggests that disability is a social relational construct which oppresses disabled people:

Thus, in the same way that the concept of patriarchy refers to the relationship of male ascendancy over women, so the concept of disability refers to the relationship of ascendancy of the non-impaired over the impaired. Disability, like patriarchy, is a form of social oppression.  
(Thomas, 1999, p40)

Thomas argues that the emphasis on material disadvantage (e.g.: housing or employment) has meant that the aspects of disablism which restrict and shape personal identity and subjectivity have been ignored. Thomas calls these the 'psycho-emotional aspects of disability' (Thomas, 1999, p46):

To put it another way, the focus should include not only a concern for what 'we *do*' and 'how we *act*' (are prevented from doing and acting) as disabled people, but also a concern for 'who we *are*' (are prevented from being), and how we feel and think about ourselves. In everyday life, the impact of disablism along these two dimensions – shaping how we act and who we are – is interactive and compounding.  
(Thomas, 1999, p46)

Thomas suggests that the external barriers also construct restrictions *within* disabled people and place limits on their psychological well-being. Thomas stresses that the 'agents' or 'carriers' of disablism are sometimes close to the disabled person and they include 'husbands, wives, partners, parents, other family members, or they may be individual with whom we have direct contact such as health and social care professionals and workers.' (1999, p48). For children with special educational needs and/or impairments and their parents, this list might also include education professionals.

Thomas acknowledges that at times the disabled person him/herself may be the agent of disablism 'promulgating negative attitudes about people with impairments before acquiring their own impairments and disabilities' (Thomas, 1999, p48). Parents, too, must acknowledge that they act at times as the 'agents of disablism' in their children's lives and their own. At the same time, it is important to recognise that parents' experience of the disabling world impacts significantly on their own psycho-emotional well-being. (For a fuller discussion about families see Chapter Six and Seven).

While Social Relational theories of disability bring both the impaired body and the private lives of disabled people back into disability studies, there is, as Oliver (1996) cautions, a danger that this will be exploited by those who wish to locate disability firmly within individuals. However, the suppression of private lives of disabled people will only allow oppression to continue.



A social model of disability which includes both the structural and psycho-emotional dimensions of disablism has much to offer as it is able to acknowledge the personal experience of living with disability and impairment from a social, rather than individual or medical theoretical standpoint (Reeve, 2002).

### *The affirmation model*

While Oliver's (1990, 1996) conception of the social model rests on the distinction between impairment and disablement, Swain and French (2000) have challenged the assumption that the experience of being impaired is always and necessarily tragic. They suggest that while non-disabled people can generally understand that a wheelchair user cannot enter a building because of steps, they are much more challenged by the idea that a wheelchair user could be pleased and proud to be the person they are. Similarly, parents of non-disabled children are challenged by parents of children with impairments and/or special needs who are pleased and proud of their children. Nevertheless, disabled people (Oliver, 1992) and parents of disabled children (Murray & Penman, 1996) have demonstrated in their writing that living with impairment can give fresh perspectives on life which are interesting, positive and empowering (Swain and French, 2000). The affirmation model enables disabled people and parents of disabled children to assert their positive identities by actively rejecting dominant values of 'normality' (Swain and French, 2000). Swain and French do not set out to reject the social model, but to build upon it.

### *People with learning difficulties and the social model*

The social model has been criticised for failing to include people with particular types of impairments, for example, people with learning difficulties or mental health service users (Chappell, 1998, cited in Race, Boxall and Carson, 2005; Goodley, 2001). While it is the case that research and writing influenced by social model perspectives has largely overlooked people with learning difficulties, with a few notable exceptions (Chappell, et al, 2001; Goodley, 2001), the omission of people with learning difficulties may be more to do with a lack of application, than with any inherent failure of the social model. Oliver's seminal text *The Politics of Disablement* (1990) makes specific reference to the experiences of people with

learning difficulties, albeit brief (Race et al, 2005; Chapell et al, 2001).

While physical and sensory impairments are more likely to be constructed as fundamentally social, cultural, historical and discursive practices, learning difficulties are still constructed as part of an individual's 'naturalised' impairment (Goodley, 2001). People with learning difficulties continue to face discrimination in society and within the disability movement itself:

People with 'learning difficulties' face discrimination in the disability movement.

People without 'learning difficulties' use the medical model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as disabled people without 'learning difficulties'. We want concentration on our access needs in the mainstream disability movement.

(Simone Aspis of *London People First*, quoted in Campbell & Oliver, 1996, p. 97, cited in Goodley, 2001, p210.)

Yet, the socially constructed nature of learning difficulties is evident in many contexts. As Goodley (2001) points out, when the category of 'Borderline Retardation' was dropped from the *Manual of Terminology of the American Association on Mental Deficiency* (Ferguson et al, 1992 cited in Goodley 2001, p214) a whole group of people were cured overnight. The concept of the socially constructed nature of learning difficulties challenges the normative concepts of 'special educational needs'. (For a fuller discussion of the de-construction of special education see Section Two, below). The 'turn' to impairment and the social construction of learning difficulty, means that people with learning difficulties must be included within the social model.

### *Parents and models*

The responses of parents of children with impairments and/or special needs have been explained with reference to models of disability in research (Woolfson, 2004; Landsman, 2005; Fisher and Goodley, 2006 in press). Mothers' responses, in particular, have been analysed within social and/or medical model frameworks (Woolfson, 2004; Landsman, 2005).

Traditionally, the experiences of parents and children have been explained by



drawing on medicalised approaches to disability and within the context of intrafamily or intrapsychic functioning (Read, 2000). Families are often described as needing to go through a process of adjustment to the news that they have a child with an impairment; this is frequently characterised as a grieving process (Bruce and Schulz, 2001). However, there has been a recent shift in research perspectives towards a focus on the more positive aspects of parenting a disabled child. There is a growing body of research which explores the perspectives of parents and examines the underlying rationale and meaning they attribute to their actions (Beresford 1994a; Green 20023; Landsman 2005; McKeever and Miller 2004; Read 2000).

Researchers continue to try to locate parental responses in either medical or social models of disability. Woolfson's (2004) study of the behavioural difficulties of disabled children suggests that parents are likely to hold traditional and prevailing views of disability which locate the 'problem' within their child's pathology. The consequence for parents is that they have limited expectations of their disabled children as they locate difficulties within their child's impairment. Parents who view disability as a medical problem may believe that they cannot change much about the situation themselves, and rely on professional interventions (Woolfson, 2004). Woolfson suggests that parents who take a more social model approach, locating difficulties in society and barrier removal, are more likely to tackle difficulties themselves. Yet, they are also vulnerable to the expectations and attitudes of others towards their disabled children and themselves.

Landsman (2005) suggests that mothers' engagement with medical and social models of disability is more complex than Woolfson first suggests. While Woolfson appears to suggest that parents take either a medical or a social model line which they hold consistently across contexts, Landsman suggests that mothers' engagement with models is more intricate. Landsman found that mothers may locate disability within society and yet at the same time seek a solution which attempts to normalise their child. Models of disability have played an active role in shaping analyses of parental responses to living with a child with an impairment (Fisher and Goodley, 2006 in press). Within this study, parents'

engagement with models of disability forms a key part of the analysis of their stories and this is a point I will return to (See Chapters Four, and Six).

When focusing on the social model, it is crucial to note that by virtue of having a disabled child, parents, and mothers in particular, experience directly and by proxy many of the oppressive features of society which the social model has identified (Read, 2000; Traustadottir, 1999).

Despite the social model's development over more than twenty years, the dominant models of disability which permeate the media, the medical profession, psychology and education, draw on individual and medical accounts. Medical and individual models pathologise, marginalise and exclude disabled people and their families both from the wider community and from research agendas.

It is, then, important to reiterate that the social model, pioneered by Oliver (1990, 1996), has had a positive impact on the lives of disabled people. While the model has been critiqued from a number of perspectives and redeveloped to enhance its explanatory power and inclusive approach, the strengths of the social model as a means of challenging oppression and discrimination undoubtedly remain.

## **SECTION TWO: Deconstructing special education**

I have argued above that medical and individual discourses of disability have informed the construction of the concept of special educational needs. The special education policy context is built upon the seemingly uncontroversial assumption that 'rock solid' knowledge of special education exists (Thomas and Loxley, 2001). It is assumed within policy and practice that special educational needs can be identified by applying objective psychological or medical criteria and remedied with appropriate, professionalised interventions (DfES, 2001a; DfES, 2004). Yet, it is important to look behind the assumptions which support special education and to debate its grounding assumptions (Skrtic, 1991). Concepts of 'intelligence' and 'normality' have been taken to have a straight-forward and uncontested meaning within the special education system. The supposed existence of some sort of privileged knowledge of special educational needs has not only been seen to be self serving for special educators, but has had the effect of de-skilling 'non-specialist'



teachers and convincing them that they do not have the skill or the knowledge to teach all children. Skrtic (1991) suggests that functionalism<sup>1</sup> is consciously or unconsciously adhered to by professionals who continue to focus on deficient pupils and who have succumbed to the attraction of positivist science (Thomas and Loxley, 2001).

### *Special educational needs – whose needs?*

In 1978, The Warnock Report (DES, 1978, see also Chapter One) recommended that the term 'special educational needs' replace the eleven categories of disability defined in the 1944 Education Act (HMSO, 1944). It also talked of special education *provision* rather than *treatment* and asserted that 20% of the school population would at some time require special education provision. Crucially, the report was clear that 'special educational needs' were relative:

Whether a disability or significant difficulty constitutes an educational handicap for an individual child, and if so to what extent, will depend upon a variety of factors. Schools differ, often widely, in outlook, expertise, resources, accommodation, organisation and physical and social surrounding, all of which help to determine the degree to which the individual is educationally handicapped....

(Warnock, 1978:37 cited in Fulcher, 1999, p 154)

However, the 'relative' nature of special needs has been lost in subsequent policy and legislation and replaced by a deficit discourse.

This deficit discourse is reflected in the definition of 'special educational needs' which persists within current policy and legislation:

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

Children have a *learning difficulty* if they:

- have a significantly greater difficulty in learning than the majority of children of the same age; or
- have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority

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<sup>1</sup> Functionalism is seen as the dominant framework for social science in the Western world (Burrell and Morgan 1979, cited in Skrtic, 1991). Those who work within this paradigm apply positivistic methodologies in an attempt to predict and control social life.

- are under compulsory school age and fall within the definition at (a) or (b) above or would do so if special educational provision was not made for them.

(Section 312, HMSO, Education Act, 1996, bold my emphasis)

Yet, when we ask the question ‘Who has special educational needs?’ the answer is as much a reflection of our own beliefs as it is a reflection of a child’s needs (Solity, 1992). Special needs education is sustained by discourses of disability, difference and disorder (Solity, 1992). The term ‘need’ has come to reinforce these discourses of deficit and disadvantage and it upholds the perpetuation of exclusionary practices. The emphasis remains on individual deficits which are part of the child’s disposition – within-child factors (Thomas and Loxley, 2001). The consequence of the dominance of the language of the clinic is that individual remedies remain the focus of debate. The focus on the child’s deficits shifts the spotlight away from the teachers, schools and the education system. The response to the identification of a child’s need is seen to be appropriate and necessary decision making by concerned professionals (Thomas and Loxley, 2001).

Indeed, the familiarity of the concept of special educational needs, and the positive connotations of ‘help and remedy’ it is seen to convey, mean that it has the potential to mask the discriminatory attitudes and practices which the term promotes (Solity, 1992). The focus on the within-child factors inherent in the term ‘special educational needs’ leads professionals to concentrate on the child’s background, temperament and the parenting they receive, rather than look at the day-to-day operation of the school and the barriers to the child’s learning and inclusion (Solity, 1992).

Despite the dominance of the term ‘special educational need’ in day-to-day discourse and in policy and legislative contexts, the term can no longer be seen as helpful or positive. It reflects professional ownership, in which educational and medical knowledge determines who is special and what their needs are (Corbett, 1993 cited in Barton, 1996).

However, while ‘special educational needs’ is the language of policy and legislation and of SENDisT itself it would be impossible to avoid using it here. However, it is important to hold onto the idea of ‘special educational needs’ as a



*procedural category* (Fulcher, 1999, p22). As such, the term is used in contexts where the child may or may not have a need, but the presumption is made that he or she does.

### *Parents and special education*

The consequences of the focus on individual deficits means that, for teachers and education administrators alike, special need is synonymous with disorder in the classroom. The presence of children with special needs is seen to disturb the organisational calm within the school context as the boundaries of the academic curriculum and acceptable behaviour are stretched. In an attempt to hold on to what are believed to be organisational and pedagogical norms, teachers and educators appeal to psychological theories of individual pathologies of children in need of therapy to divert attention away from the need to adapt teaching and learning styles (Slee, 1996). Parents are, therefore, 'reduced to the state of beggars' (Slee, 1996, p117) as they appeal for redeeming interventions from a benevolent teacher or administrator.

Parents are caught between those who are forced to appeal for diagnostic labels to access services and special schools, and those who request the removal of diagnostic labels in order to access inclusion in mainstream schools. While at the same time, some parents hold on to labels which ensure their child's differences are recognised in an inclusive setting (Slee, 1996). Parents' stories engage with these debates particularly when they talk about the reasons for registering an appeal with SENDisT (Chapter 4). Parents of children with special needs, then, find themselves the subjects of a new 'parentology' (Wood, 1988) where the psycho-emotional aspects of parenting are the focus of assessment, and intervention. The private world of the family becomes public as part of the quest for 'help' and 'intervention' for the child with special educational needs.

In this section, the focus has been on the deconstruction of 'special educational needs' challenging the normative assumptions underpinning the discourses and practices of special education. The next section discusses the ways in which the

work of two theorists, Foucault and Rorty, might be helpful in developing understandings of parents stories and of special education.

### **SECTION THREE: Towards a theoretical understanding: the work of Foucault and Rorty**

The aim here is to discuss the ways in which the work of theorists, Foucault and Rorty, might be useful in developing 'thinking tools' (Todd, 2006) to create understandings of the parents' stories and the construction of special educational needs. Foucault's work has been used to develop accounts of social and educational practices (Skrtic, 1995; Allan, 1999). Foucault's texts including *Madness and Civilization* (1967) and *Discipline and Punish* (1977) have been seen as key to furthering understanding of the practices within schools and special education in particular (Skrtic, 1995; Allan, 1999). Foucault's work, then, may offer insights into the present study.

However, Foucault's theorising has often been criticised for being purely descriptive and nihilistic, having little to say about the possibilities for change (Allan, 1999). In contrast to Foucault, Rorty's pragmatist conception of knowledge is one which focuses on what humans do rather than what they find out through theorising (Guigon and Hiley, 2003). Rorty's key texts *Philosophy and the Mirror of Nature* (1980) and *Contingency, Irony and Solidarity* (1989) position Rorty as an 'anti-philosopher' and a pragmatist who exhorts us to focus on 'what works'. Indeed Rorty categorises Foucault, with Nietzsche and Derrida, in the world of private self-creation, and judging Foucault's work 'useless' when it comes to politics. Indeed Rorty states that:

You would never guess, from Foucault's account of the changes in European social institutions during the last three hundred years, that during that period suffering had decreased considerably, nor that people's chances of choosing their own styles of life increased considerably.

(Rorty, 1990, p 3, cited in Allan, 1999, p 228)

The aim here is to use Foucauldian concepts, as other researchers have done (Allan, 1999; Skrtic, 1995), to help develop an understanding of special education and of the parents' stories, but to develop the analysis by drawing on the Rortian



concepts which allow us to think about the possibility for action and for change. (I return to these concepts to develop understandings of why parents go to Tribunal in Chapter Four).

### **The Postmodern context**

Foucault and Rorty have both been described as 'postmodern' thinkers. The term 'Postmodernism' has been used to refer to the situation of contemporary civilisation in which modernity<sup>2</sup> is said to have exhausted itself (Rosenow, 1998). Postmodernism deconstructs and exposes the ideological and totalitarian character of modern political and social systems. It also uncovers the manipulative characteristics of social practice including education theory and practice.

Postmodernism 'celebrates' and 'valorises' difference and accepts plurality (Burbules and Rice, 1991, pp 385-396 cited in Rosenow, 1998, p254) so much so that postmodernism's endorsement of difference is synonymous with the rejection of the modernist meta-narratives which make general claims for the power of norms (Rosenow, 1998). The celebration of difference and rejection of norms have been seen as key concepts for disability research and critiques of special education (Skrtic, 1995; Oliver, 1996; Allan, 1999). Rorty admires Foucault's postmodern critique of Enlightenment rationalism, and describes himself as a 'postmodern bourgeois liberal'. However, Rorty sides with the Enlightenment social philosophers in believing that liberal democracy is the best political system we have had so far (Kwak, 2004).

Foucault and Rorty differ in their primary aims, and their concepts of power and truth, yet their concepts are, in some ways, complimentary and both can contribute to developing understandings of parents' stories and the discourses and practices of special education.

### *Primary aims: Foucault and Rorty*

Foucault has, as his primary aim, given a history of the ways in which 'human beings are made subjects' (Foucault, 1982, p208). For Foucault, human beings are

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<sup>2</sup>During the period of modernity, the general concept of knowledge was that there is a fixed set of criteria against which all knowledge claims can be judged.

made subject in two senses: first, they are made subject to others by 'control and dependence' (Foucault, 1982, p212), second, they are made subjects by what they understand themselves to be. These two aspects are part of a single dynamic process of subjectification (Roberts, 2005). In special education research, Foucault's concept of the subject has been useful for those who are interested in how pupils with special educational needs and/or impairment are controlled and made dependent as well as how they see themselves and how they resist (Allan, 1999).

Rorty has a quite different fundamental aim:

The fundamental premise of the book [*Contingency, Irony and Solidarity*] is that a belief can still regulate action, can still be thought worth dying for, among people who are quite aware that this belief is caused by nothing deeper than contingent historical circumstance.  
(Rorty, 1989, p189)

Rorty's fundamental liberal belief, albeit based on contingent historical circumstances, is to agree with Shklar (1984) that 'cruelty is the worst thing we do' (Rorty, 1989, p190) and that it is 'social institutions which have made us cruel' (Rorty, 1989, p41 cited in Barone, 1995). Rorty's concept of the cruelty of institutions is a useful one for understanding both the schooling and SENDisT system. As individual children are categorised and labelled by the institutional practices of the special education system, they lose their humanity, and become 'the special needs'.

Within the SENDisT system, children are categorised in relation to their impairment or special needs labels. The categorisation of the child as 'having a special need' serves to describe the child as 'other' (Rorty, 1989), and the categorisation of the child as 'other' locates the child with the 'infidel and the foreigner' (Rorty, 1989). The result is that children, and their parents, are marginalised, excluded and, at worst, de-humanised. Institutional practices of special education re-describe children in ways which deny them their common humanity with other children.

So, while Foucault and Rorty differ in their primary aims, both offer useful concepts for the analysis of the construction of special educational needs and of parents' stories. Foucault's concept of 'subjectification' highlights the ways in



which children with special educational needs and their parents are controlled and made dependent, whereas Rorty's concept of institutional cruelty suggests that the systemic re-description and categorisation of children and parents renders them 'other' and lacking humanity.

### *Power and solidarity*

Arguably, Foucault's greatest contribution to understanding social practices and systems is his conception of power. Traditionally, power has been understood as force which dominates or subordinates. This model of power is based on three assumptions:

- power is possessed;
- it flows from a centralised source and is hierarchical, flowing from top to bottom;
- it is primarily oppressive.

Foucault criticised this model for representing only one form of power (Mannias and Street, 2000). For Foucault:

- power is exercised and not possessed;
- power does not flow from a centralised source, rather it is multidirectional in operation both top down *and* bottom up, and circular;
- power is not primarily repressive but also productive, and circulates through net-like organisations.

Foucault says that

Where there is power, there is resistance, and yet or rather consequently, the resistance is never in a position of exteriority in relation to power.  
(1990, p 95)

Resistance is an issue for all individuals (Mannias and Street 2000). The exercise of power within special education can, then, be seen as distributed, and as being exercised and resisted by children, parents/ carers and professionals. Despite their professional knowledge claims, special educators do not have a monopoly on power.

Again, arguably, Rorty's greatest contribution to understanding social practices and systems is his conception of 'solidarity'. For Rorty, 'solidarity' conjures up positive images of the strength of togetherness and community, and it allows members of a group or community to feel a common identity and to mobilise together in action. Rorty uses the concept of solidarity as a means of understanding conflict:

The principal source of conflict between human communities is the belief that I have no reason to justify my beliefs to you, and none in finding out what alternative beliefs you may have, because you are, for example, an infidel, a foreigner, a woman, a child, a slave a pervert or an untouchable. In short, you are not "one of us", not one of the *real* human beings, the paradigm human beings, the ones whose persons and opinions are to be treated with respect.  
(Rorty, 2000, p15)

Rorty's appeal for solidarity between human communities has great resonance within disability research. When Rorty exhorts us all to show solidarity with other human communities, his exhortation might well include a appeal that disabled people and non-disabled people stop seeing each other as 'not one of us' and 'not one of the *real* human beings'. Rorty's call for 'solidarity' suggests that we should reject the traditional binary of disabled/ non-disabled and instead recognise one another's common humanity (Rorty, 1989, p. xvi). This is what Rorty means by 'solidarity'. The movement towards solidarity is achieved, not through theory development, but through ethnography, journalism, docu-dramas and the novel (Rorty, 1989). Moral progress is 'indeed in the direction of greater human solidarity' (Rorty, 1989, p190). Indeed, moral obligation to our fellow human beings derives from the fact that they are considered to be 'one of us'.

According to Rorty, solidarity should not be thought of as something pre-existing that can be realised once we give up our prejudices; rather, it is something that has to be created by imagination, the 'imaginative ability to see strange people as fellow sufferers' (1989, p. xvi). Of key importance is Rorty's claim that solidarity can be achieved in democratic societies by learning more about others (description), through which we become more sensitive to the pain suffered by unfamiliar people, and by learning more about ourselves (redescription), through which we reinvestigate ourselves. Although this description and redescription can be accomplished through a variety of media, for Rorty, the novel is accorded



particular significance (1989, p. xvi).

While Foucault and Rorty differ in their contributions to social understanding, they share a commitment to anti-foundationalism. During the modern period, the general concept of knowledge was foundational, this is the idea that there is a fixed set of criteria against which all knowledge claims can be judged. In contrast the postmodern concept of knowledge, shared by Rorty and Foucault, conceives of knowledge as anti-foundational, based on the idea that there are no independent criteria for judging knowledge claims (Skrtic, 1991). This commitment to anti-foundationalism gives opportunities for self description, and re-humanising marginalised groups and individuals by opening up the possibility for greater tolerance (Guigon and Hiley, 2003).

### *Power-knowledge and truth*

In Foucault's early work (1967, 1973), he was fascinated by the connection between power and truth and knowledge. Foucault's aim was to show that truth is the accomplice of power and that 'the more truth, the more power' (Wandel, 2001, p374). For Foucault, truth is, then, power in disguise, so that truth claims have power effects. Power and knowledge are so inextricably bound that rather than talk of them separately, Foucault introduced his concept of 'power-knowledge' (Foucault, 1998, pp 98-99, cited in Roberts, 2005).

There is an intimate relationship between the development of disciplinary power and the development of certain fields of knowledge, a notable example of this is the social sciences (Hindess, 1996). A discipline is always built on claims to knowledge about the character of the human subject, so change within a discipline often involves corresponding changes in the appropriate field of knowledge and in the construction of the human subject. In special education, professionals have made knowledge claims which have the power to diagnose conditions and label children with specialist discourses; despite the changes in professionals' knowledge claims over time and in different contexts, professionals' knowledge claims are widely considered to be authoritative and 'true' (Billington, 2000).

Rorty has also written about the nature of truth (1989). Rorty accepts that the world has a role to play in regulating our beliefs. We are involved in observation-reporting practices which involve causal triggering of reports influenced by external circumstances. But although the world plays a causal role in adapting our beliefs, it does not play an independent causal role (Danforth, 1999). This is because the situations that cause reports do not have to be described in particular ways. Nor do the events themselves determine the inferential or theoretical importance of the accounts. We cannot consciously control all the observations we make and so our beliefs are always vulnerable (Williams, 2003). Rorty's concept of truth challenges models of special education which rest on 'specialist knowledge' as it highlights the contingent nature of such knowledge. This compliments Foucault's view that truth is the accomplice of power.

However, as a pragmatist, Rorty is more concerned with 'what works' than theorising about truth.

Liberals are people who think that cruelty is the worst thing we do.... Somewhere we all know that philosophically sophisticated debate about ... objective truth ... is pretty harmless stuff.  
(Rorty, 1989, p 189)

Rorty accepts Foucault's claim that truth is the accomplice of power but, for Rorty, the debates about truth are secondary. Rorty insists that solidarity and the reduction of cruelty in the world are more important than theorising about the nature of truth.

### *Discourse and final vocabularies*

The concept of discourse is key within Foucauldian analysis. For Foucault, discourses are evidence for underlying power relations. Foucault's *The Archaeology of Knowledge* (1969) was the most important text in Foucault's formulation of the concept of discourse (Wandel, 2001). For Foucault, bodies of knowledge cannot be seen as universal and objective but are historically and politically situated. It is such bodies of knowledge that Foucault calls discourses. (Roberts, 2005). Discourses are not the effects or the end products of power but power is absorbed within discourse, such that discursive practices maintain power relations and knowledge. Indeed, dominant discourses determine what constitute relevant,



important, and true knowledge (Chadwick, 1996). Discursive practices mean that there is a reciprocal, mutually sustaining relation between the flow of knowledge and the control of behaviour. In special education, professional discursive practices have been seen to be self serving as part of an attempt by professionals to sustain their role as 'expert' (Skrtic, 1995).

Rorty, too, is sceptical about knowledge claims. The pragmatist's understanding of language reflects a Foucauldian awareness of the dynamics of power (Danforth, 1999). Rorty rejects the claims to 'hard facts' of science saying 'the reputed hardness of facts [is] an artefact produced by our choice of language game' (Rorty, 1989, p73). He has described this language game in the context of what he calls a person's 'final vocabulary':

All human beings carry about a set of words which they employ to justify their actions, their beliefs and their lives. These are the words in which we formulate praise of our friends and contempt for our enemies, our long-term projects, our deepest self-doubts and our highest hopes. They are the words in which we tell, sometimes retrospectively, the story of our lives. I shall call these words a person's 'final vocabulary'.  
(Rorty, 1989, p73)

For Rorty, the key is to be an 'ironist', that is, to remain in constant doubt about our own 'final vocabulary' — the unquestioned set of statements that serve as the basic foundation of statements of truth (Danforth, 1999) — and to accept that 'final vocabularies' are necessarily contingent. This scepticism about final vocabularies seems to have parallels with discourse analysis, however, for Rorty, it is only by recognising the contingency of her final vocabulary that an ironist gradually extends her solidarity with other human beings (Rorty, 1989).

Final vocabularies are made up of terms such as 'true', 'good', 'right', and 'beautiful' (Rorty, 1989, p. 73.). Logical positivists rely on terms like 'objectivity', 'measurable', and 'empirical data', while the Freudians use terms such as 'libido', and 'Oedipal complex' (Danforth, 1999). For Rorty, change can only occur when people are ironic about their final vocabularies and open to using new vocabularies to speak about and understand the world (Rorty, 1989).

The importance of Rorty's concept of 'final vocabularies' for the parents' stories is that it suggests that we should question the 'final vocabularies' of special education. The 'final vocabularies' of professional practice serve to validate professional knowledge (See above). Within special education, a hierarchy of knowledge exists which means that the words of the professional are taken to be more truthful or more valuable than the words of pupils and parents. As Danforth (1999) suggests:

When the volume of a few voices engaged in one language game is turned up, we shouldn't be surprised by the number of voices that are no longer heard.  
(Danforth, 1994, p 746-747)

In special education, it is the voices of pupils and parents which are drowned out.

So while, Foucault's concept of discourse allows us to focus on the power claims made by truth claims, Rorty's concept of final vocabularies urges us to see the contingency of such claims and the value of the alternative vocabularies of parents and children.

### *Panopticism and utopia*

Within *Discipline and Punish* (1977) Foucault draws on the work of Jeremy Bentham in relation to what he described as 'panopticism' to critique society. The panopticon is used to illustrate the associated techniques of discipline: surveillance, regimentality and classification (Hindess, 1996). The panopticon has become symbolic for many people with learning difficulties, both in its literal, and architectural state (MacIntosh, 2002). Foucault (1991) describes the panopticon thus:

At the periphery, an annular building; at the centre, a tower; this tower is pierced with wide windows that open up onto the inner side of the ring; the peripheric building is divided into cells, each of which extends the whole width of the building; they have two windows, one on the inside corresponding to the windows of the tower; the other on the outside allows light to cross the cell from one side to the other. All that is needed then is to place a supervisor in the central tower and to shut up in each cell a madman, a patient, a condemned man, a worker or a schoolboy .... They are like so many cages, so many small theatres, in which each actor is alone, perfectly individualised and constantly visible .... In short it reverses the principle of the dungeon; or rather its three functions — to enclose,



to deprive of light — and to hide — it preserves only the first and eliminates the other two. Full lighting and the eye of a supervisor capture better than darkness, which is ultimately protected. Visibility is a trap.

(Foucault, 1991, p. 200)

In a panoptic society, every deficiency is logged and plans are drawn up to correct it. The process is monitored, and evaluated. The person is subject to social demands and professional expectations. The minutiae of lives are explored (McIntosh, 2002). Panoptic power is said to have enabled the emergence of the human sciences including psychology and psychiatry. Foucault's account of a panoptic society provides the means to develop an understanding of the subtle forms of power functioning within special education. The special education system can be said to employ a variety of panoptic strategies e.g.: various levels of observation of parents and children, assessments, planning implementation and evaluation of 'professional interventions'. While such interventions are seen as essential and benevolent elements of education, from a Foucauldian perspective, they can be re-conceptualised as interventions which maintain within children with special educational needs and/or impairment and their parents 'a state of conscious and permanent visibility' (Foucault, 1991, p201 cited in Roberts, 2005). In Chapter Five, the panopticon is used to illustrate the surveillance and control which operates within the Tribunal hearing itself.

Parents and children are aware that they are being continually monitored and that any 'indiscretion' will lead to a period of 'interventions'. While the emotional and educational well-being of the child with special needs and/or impairment is cited as the reason for the monitoring, this cycle of surveillance can be seen as part of the maintenance of power relationships. From a Foucauldian perspective, intervention can be understood to create and maintain the power relations that ensure that the parents and children regulate their own conduct in accordance with the educational norms. The process is 'disindividualised' and de-centred so that the parents and children can be monitored by any number of people including teachers, teaching assistants, psychologists, occupational therapists, speech and language therapists and social workers. Children and parents may not even know who is monitoring them and are, then, subjected to the 'faceless gaze' (Foucault, 1991, p214). Whereas researchers have considered the 'gaze' upon children with

special educational needs and/or impairment (Allan, 1999), here the focus is on the 'gaze' upon the children and their parents in the context of SENDisT.

In contrast to Foucault's use of panopticism to offer a political critique of the present state of affairs, Rorty does not offer a critique of society, but appeals to an ideal state of affairs: a liberal utopia. This is a place where cruelty is decreased and solidarity increased. In the field of special education, utopia would be a place where children with an impairment and or special educational needs would cease to be the 'other'. Professionals and parents would be in a state of constant doubt about their final vocabulary and human 'solidarity' would be maximised. Rorty urges us to read books about slavery, poverty and exploitation and prejudice to see the ways in which human beings are cruel to one another and to become less cruel (Guigon and Hiley, 2003, P26). Rorty's utopia is full of liberal ironists aware of the contingency of their final vocabularies seeking solidarity. Rorty's account of a liberal utopia offers us an ideal for education, where there is solidarity between parents, children and professionals.

Foucauldian concepts have much to offer an analysis of parents' stories. Foucault's description of 'power-knowledge' and his concept of discourse are key to understanding the power relationships within the parents' stories. Rorty's pragmatic approach also challenges the power of professional voices within special education (Danforth, 199). While Foucault offers a panoptic critique of the current state of affairs, Rorty urges that we move towards a liberal utopia, where there is solidarity between groups and individuals. Rorty's concept of solidarity helps us to move away from the simplistic bifurcation of 'disabled/non-disabled' and to move instead towards a more tolerant society.

In this section the analysis has focused on the discourses and practices of special education within the context of parents' stories. However, the parents' stories about going to Tribunal were also stories about families in a disabling world. The work of the French philosopher Bourdieu is used to develop understanding of the families' experiences in the wider social world.



#### **SECTION FOUR: Bourdieu: towards a theoretical understanding of the family**

Families with children who develop atypically have been studied extensively (McKeever and Keller, 2004). Parenting of children with special needs and/or impairment has been conceptualised as relentless and stressful. In turn, parents are characterised as over-protective, difficult, unrealistic or in denial about the extent or impact of their child's difficulties. Parents who have negative feelings or disappointment about their children's diagnoses are pathologised as well as those who 'idealise' their children McKeever and Miller cite Beresford (1994, 1995, 1996) and Read (1991, 2000) as being among those who have challenged pathologised maternal behaviours and insisted that they are understandable and predictable responses to wide-spread societal discourses that devalue atypically developing children. McKeever and Miller use Bourdieusian concepts to develop an understanding of how mothers, in particular, resist the discourses of the devalued 'bodily capital' of their children and the 'courtesy stigma' (Goffman, 1963) with which they are tainted. Bourdieu's concepts are, then, useful in developing understanding of the parents' narratives and of the family.

Bourdieu (1984) argues that people are born into particular social locations and acquire a set of dispositions or 'background understanding' (Taylor, 1999, p43 cited in Edwards & Imrie, 2003, p243 cited in McKeever and Miller, 2004, p1179)) that explain how individuals generally understand how they are expected to behave, think and even feel in everyday life. Bourdieu describes these learned dispositions as 'habitus'. Social disadvantages including class, gender and disability are incorporated into the 'habitus' and individuals adjust their behaviour and desires according to their understanding of their social positioning. 'Habitus' gives individuals a sense of their own place as well as a sense of the place of others.

According to Bourdieu, 'habitus' works in every day situations and shapes attitudes and behaviour which he calls 'practices'. He illustrates this point by using the analogy of 'fields' and 'games'. Fields are described as social or symbolic institutions such as the family, medicine, law and education which together constitute social life. Individuals hold different social positions within different fields which are determined by their power within a given field. The power

individuals hold is determined by the amount of 'capital' they possess (McKeever and Miller, 2004).

Bourdieu uses 'capital' to represent the resources available to individuals within various fields. Bourdieu identifies four types of capital

- economic e.g.: inherited or generated wealth;
- cultural e.g.: educational credentials, aesthetic preferences, bodily characteristics and comportment, speech dialect;
- social e.g.: networks group membership;
- symbolic e.g.: role, legitimacy, authority, prestige.

Each type can be represented materially or symbolically (McKeever and Miller, 2004).

Bourdieu suggests that the actions of individuals, and those of groups of individuals, including families, are the result of complex interrelationships between habitus, particular forms of capital and different fields (McKeever and Miller, 2004). Bourdieu suggests that an important condition for the family's accumulation of economic, cultural and symbolic capital is 'normality'. Bourdieu defines the 'normal' family as one which has the privilege of being 'comme il faut' ('as it should be') (Bourdieu, 1998, p69 cited in Silva, 2005, p88). The family which is able to conform to the 'norm' profits from its 'normality' as it is able to maximise its 'capital'. Bourdieu's concept of 'capital' is important in this study as it can be used to develop understanding of parents' and families' experiences of living in a disabling world (See Chapter Seven).

According to Bourdieu, families possess different amounts of symbolic and material resources, or social capital, which enable them to gain advantage for their members. The ability to accumulate social capital is connected to a family's ability to connect to local communities including neighbourhoods, schools, places of work and other institutions. Families differ in their capacity to connect with local communities as they differ in their capacity to draw on common norms and, therefore, levels of trust, commitment and attachment with members of the local community (Bourdieu, 1984).



Furstenberg (2005) notes that the arrival of children in the family introduces a new and crucial element into the family's ability to acquire social capital; children provide critical links to the community when connections are often made at visits to the park, at child care settings, and schooling. Indeed parents' skill at gathering and using social capital is linked to the child's success. Bourdieu was particularly interested in how social class and ethnicity operate to narrow or broaden contact with communities and the impact this has on a family's social capital. While Bourdieu focused on social class and ethnicity, McKeever & Miller (2004) suggest that Bourdieu's concepts can also be used to provide a theoretical framework within which parents' responses to the presence of a child with special needs and/or impairment can be explored

An obvious criticism of Bourdieu's concept of 'habitus' is that it is overly deterministic, allowing little opportunity for social change, however, McKeever and Miller (2004) argue that change is possible and that the ultimate aim is to change the rules of the game in the fields of public policy and practice and thus improve the 'habitus' of children with special needs and/or impairments and their families.

## CONCLUSION

This study is a pragmatic inquiry which is deeply embedded in the lived experiences of children with special needs and/or impairments and their parents. It is concerned with their direct experience of the worlds of special education, SENDisT and the family. The aim of the inquiry is to gain knowledge and promote understanding of the families' experiences.

The research is informed by a number of theoretical concepts, or tools, including social model theory, the deconstruction of special educational needs and the work of Foucault, Rorty and Bourdieu. Social model theory offers a powerful tool for exposing and challenging oppression and discrimination in the lives of children with special needs and/or impairments and their families. The deconstruction of special educational needs draws on social model theory to challenge the assumptions which underpin anti-inclusionary and discriminatory practices within education. The work of Rorty, Foucault and Bourdieu offer 'thinking tools'

(Bourdieu, 1984, cited in McKeever and Miller, 2004) to develop understandings of parents' experiences of the system of SENDisT and special education and of their family lives.



## **CHAPTER THREE: METHODOLOGICAL APPROACHES AND AN ANALYTICAL FRAMEWORK**

### **Introduction**

This study uses methodological approaches which draw on emancipatory, ethnographic and narrative research agendas. The aim is draw on parental perspectives, disability studies literature and theory with the hope that this will contribute to the debates about the policy and practice of special education. In the next section, we return to the research questions.

### **Research questions**

The research questions focus on the parents' experiences and understandings of registering an appeal with SENDisT. The questions for the research are:

- What can we understand about the experiences which lead families to register for an appeal with SENDisT?
- What are the parents' stories of attending the Tribunal hearing?
- What can we understand from the parents' stories about the outcomes for the families of pursuing a claim to Tribunal?
- What do the narratives reveal about families' experience of the disabling world?
- What implications do the research findings have for the implementation and revision of current legislation, policy and practice?

The methodological and analytical approaches to the research questions are outlined below.

### **SECTION ONE: Methodological approaches**

Lived experience is the territory of qualitative methods and analyses. Qualitative researchers stress the intimate relationship between the researcher and what is studied. Qualitative researchers emphasise the value-laden nature of inquiry, with the aim of answering questions which focus on how social experience is created and given meaning. In contrast, quantitative methods have emphasised the measurement and analysis of causal relationships between variables, within a value-free framework (Denzin & Lincoln, 2000a). This study draws on qualitative

methods and tools of analysis because the aim, here, is to address questions about the lived experience of parents' and professionals' experience of SENDisT.

Qualitative methods are sometimes marginalised in the social sciences (Silverman, 2001) and seen as no more than useful tools for the researcher to familiarise him/herself with the setting before the more serious work of sampling and counting begins. For some, statistical analysis is still seen as the foundation of research (Sellitz et al, 1964, Singleton et al., 1988, cited in Silverman, 2001, p33). However, I argue that despite positivist attacks on qualitative methods, and narrative inquiry, in particular, qualitative methods have much to offer; they allow us to focus on rich accounts of lived experience, in a way which quantitative methods cannot (For a fuller discussion of this see Section Three: Methodological Issues and Debates below).

Within qualitative research, the biographical, ontological and epistemological position of the researcher is key to the analysis. Qualitative researchers are challenged to be explicit and reflexive about their positionality and so I set out my positionality below.

#### *The positionality of the researcher*

Qualitative researchers accept that the position of the researcher influences the choice of research topic, the methods chosen and the analysis of the data. In qualitative research, it is considered impossible to 'remove' the researcher from the research. In recognising the 'hand' of the researcher, it is important to be clear about the positions the researcher holds. In the preface (above) I set out some of the aspects of my biography (in particular, my position as the parent of a disabled child) which may have influenced the research, but here I outline my ontological and epistemological position. There is a logical relationship between ontology, epistemology, and method (Scott, 2005). Just as my biography has influenced my choice of research topic, so my ontological and epistemological position has influenced the choice of research methods and approach to analysis.

Positivist and quantitative approaches to research are usually underpinned by ontological and epistemological realism. Realism usually refers to the ontological



position that reality exists independent of our ideas of it, and the epistemological position that this reality is to some significant extent knowable (Proctor, 1998). An example of a realist position is empiricism – the view that reality is knowable through direct experience. Empiricist realism asserts that our observations of the world ideally represent reality as it ‘really’ is. Truth is a matter of correspondence to reality. However, traditional empiricism become untenable over the last 40 or so years (Smith and Deemer, 2000). Hanson (1958, p7, cited in Smith and Deemer, 2000, p879) made the now seemingly obvious point that ‘the theory, hypothesis, framework, or background knowledge held by an investigator can strongly influence what is observed’. By the 1980s, the claim for ‘theory free knowledge’ had become untenable (Smith and Deemer, 2000).

One response to a rejection of empiricism is relativism. Relativism has been defined in three ways (Proctor, 1998):

- radical relativism – all knowledge claims are equally correct;
- nihilism – nothing is knowable;
- standard relativism – our criteria for judgement are inescapably context-bound.

Relativists reject a realist epistemology which holds that there is some unmediated, direct way of knowing the empirical world and that knowledge simply mirrors what is out there. However, some theorists go further than simply rejecting realism by maintaining that they have no interest in an ontology of the real (Schwandt, 2000). Potter (1996 cited in Schwandt, 2000, p197) states that social constructionism is not an ontological doctrine at all and has no position on what sort of things exist. He is concerned instead with how it is that language *appears to be* stable, factual, neutral, independent of the speaker and to mirror the world. The difficulty for relativist and social constructionist accounts is that they are open to the charge of extreme relativism – a situation where ‘anything goes’.

Between these two extremes, realism and relativism, sits critical realism. Critical realism attempts to straddle the ontological assertions of empiricism (the view that true ideas are objective phenomenon) and the epistemological stance of relativism (the view that ‘truth’ is subjective phenomenon). For the critical realist, ideas are social concepts with an ontological basis but are understood via a social

framework. Knowledge for critical realists is, then, neither wholly objective nor subjective (Proctor, 1998).

Critical realism can acknowledge that direct access to a 'reality' is impossible and that knowledge is always fallible and incomplete (Scott, 2005). However, acknowledging the fallible and incomplete nature of knowledge does not damage the prospect of finding better explanations of 'reality'.

Critical realists have been criticised for being over confident in the possibility of establishing 'the truth'. Proctor (1998) suggests that critical realism has, then, something to learn from pragmatism (See Chapter Two above for a fuller discussion of pragmatism). Pragmatism, too, rejects a correspondence theory of the truth. However, for pragmatists the focus is not so much on the truth as on justification i.e.: the conditions under which we ought to accept that  $x$  is true. In this way, a pragmatist can accept that a proposition is true, but without making any foundationalist or correspondence based claims about truth (Proctor, 1998). Pragmatism asks us to be reflexive about our epistemological claims.

By adopting a critical realist position, which draws on pragmatist concepts, the intention is not to discount Foucault's claim that 'Each society has its regimes of truth' (1980, p131). Critical realists and pragmatists accept that all knowledge is partial, but they maintain that despite this, it is still possible to have something to say about beliefs and the possibility for social change. Social change is a primary concern for social model theory and emancipatory research agendas which are outlined below.

### **The social model and an emancipatory research agenda**

The social model of disability (For a fuller discussion of the social model see Chapter Two) is closely associated with what has been described as an emancipatory research agenda (Barnes, 2002). Indeed, Stone and Priestley (1996, p706) suggest that emancipatory disability research requires 'the adoption of a social model of disability as the ontological and epistemological basis for research production'.



Just as the social model of disability can be understood as a reaction to traditional individual and medical conceptions of disability, emancipatory disability research can be seen as a reaction to traditional modes of research production which exclude the perspectives of disabled people and their families. Disabled people (Oliver, 1992) have rejected the idea that a small group of (non-disabled) experts could get together and set an agenda for disability research. In contrast, emancipatory disability research has as its primary aims the emancipation of disabled people and barrier removal (Barnes, 2002).

Emancipatory disability research assumes a post-positivist epistemology. Research cannot be seen as a set of technical, objective procedures carried out by experts, rather it is a messy process challenging the marginalisation of disabled people in their daily lives. The need for emancipatory research stems from a rejection of the pursuit of absolute knowledge through scientific method, searching instead for socially useful knowledge (Oliver, 1992).

Disabled people, and their organisations, have argued for research which is useful and relevant for them (Oliver, 1992) and are explicitly concerned with issues of social justice, equity and citizenship, which inevitably results in the need to address political issues. Emancipatory research cannot be disinterested or neutral as it is allied to the struggle for change (Danieli and Woodhams, 2005). Emancipatory research, then, must explore institutional discrimination, and exclusion, and the lack of political will at both local and central government level to engage with these issues.

### *The place of emancipatory research within this thesis*

This study is carried out with a sensitivity to the change in attitudes promoted by emancipatory disability research and the research method used here, narrative inquiry, is closely allied to emancipatory research practice (Goodley, 1996). Yet, the research draws from traditional modes of research production. I chose the research questions for my research, so, the 'expert' has set the agenda for this research. As an insider researcher, the issue becomes more complicated, but, as I cannot and do not claim to stand for a whole group of parents of children with

impairments and/or special needs, the thesis remains researcher led and is not, then, emancipatory.

The methodological approaches have been chosen because they sit comfortably within a social model framework; the research draws on narrative and ethnographic perspectives. Each of these perspectives is outlined below.

### i. Narrative inquiry

Narrative inquiry has been closely associated with an emancipatory research paradigm within disability research (Goodley, 1996; Cole, 2004). The word 'narrative' comes from the Greek 'narros' to know (Emihovich, 1995). Put simply, narrative research is used to answer the question 'what happened?' (Zeller, 1995). Narratives can take the form of life story, (auto)biography, vignettes and composite narratives. Narrative method is a 'way of knowing' (Amos Hatch & Wieniewski, 1995, p115) which moves researchers beyond traditional methods of inquiry and away from numbers, variables, tables, and questionnaires.

The narrative method is most often used by researchers who share a subjectivist understanding of the social world (Goodson and Sikes, 2001), and are interested in meaning making and multiple realities. However, narrative inquiry differs from other types of qualitative research production as the 'data' in narrative inquiry is in the form of a story. Stories 'uniquely describe human experience' (Polkinghorne, 1995, p6), and the stories are not only 'told' but 'created' in the telling (Clough 2004, cited in Goodley et al, 2004).

Stories can be emotive, irrational, funny, sad and, often, imaginative (Emihovich, 1995). Readers are invited to understand the personal aspects of the story and to respond at an emotional level. However, narrative knowledge is, at the same time, more than an expression of emotion, it is a 'legitimate form of reasoned knowing' (Polkinghorne, 1995, p9). Indeed, it is the response to the emotional and the personal which offers the route to understanding human action. Narratives vary in the way they are constructed. They differ in their use of tone, rhetorical devices and discursive structures, but they unashamedly cross the 'social science/arts' divide (Blumenfeld-Jones, 1995).



For many human beings, story telling is an important part of a sense of identity, indeed, humans have been described as 'homo narrans' (Gilman, Swain and Heyman, 1997, p680). Many people use stories and metaphors to make sense of their everyday experiences in life (Thomas, 2004). By telling and re-telling stories they make connections and frame events (Bruner, cited in Polkinghorne, 1995, p64). The strength of stories is that they can make any subject meaningful and interesting, and they offer a less simplistic, and more intricate and complex view of 'reality' than some traditional research methods.

Whereas social researchers have been criticised in the past for indulging in methods of research production which tend to alienate the 'researched' (see above Oliver 1990, 1996), stories which reverberate with human experience are accessible and transparent. This is a key advantage of narrative inquiry in this research. Stories can be shared among parents with similar experiences, or they can draw people into another world. For parents of children with special educational need and/or impairments, the telling of stories offers parents a chance to share experiences and feelings. For a wider audience, the stories offer a powerful insight into the 'hidden' world of the 'other' (Rorty, 1989). In this way, the 'findings' of narrative research have more worth than other forms of social research (Sparkes, 1995, cited in Amos Hatch and Wisniewski, 1995).

The function and types of narratives vary depending on the context in which they are used. Anthropological narratives have been used to define and express cultural categories and the sharing of individual experience (Preston, 1978, cited in Coffey & Atkinson, 1996, p62). Teachers' stories have been used as a way of reflecting teachers' cultural identity (Goodson & Sikes, 2001). Feminists, too, have engaged in narrative in order to contradict gender discourses, resist patriarchy and stories of the body (Bloom & Monro, 1997).

In addition, narrative has often been used by researchers working with an interest in disability and special education (Goodley, 1996; Booth & Booth, 1998; Armstrong, 2003; Cole, 2004). Researchers have sought to use narratives to enable people to give an authentic account of their own lives (Thompson, 1988,

p265, cited in Goodley, 1996) with the belief that the telling of the story may empower the tellers. Stories of resistance and resilience have been used to counter normative assumptions and to make both the familiar strange and the strange familiar (Goodley et al, 2004). Stories can offer a unique way of informing policy and current practice. The story tellers are introduced below.

*The story tellers*

The table below introduces the parents and professionals who told their stories. The parents who are described as 'key informants' were interviewed in their homes and the telephone interviewees were interviewed on the phone. I interviewed all but one of the professionals over the telephone. I went to Mark's office, at a Local Area Education Office in a city in the North of England, to interview him. The participants in the research were able, if they wanted to, to comment on their stories and to shape the direction of the research by sharing their thoughts, questions and documents, they were also given the opportunity to comment on chapter summaries (See appendix 1-5).

Parents – key informants	Details
Ben	A father and primary carer for Callum, aged 14. Ben is a former dustman who gave up his job to teach his son at home, when they were refused a mainstream school place at SENDisT.
Gina	A mother and primary carer for Toby, aged 11. Gina is a former social worker. She went to Tribunal to get a mainstream school place for her son. The LEA were suggesting that her sonr went to special school.
Diane	A mother and primary carer for George, aged 6. Diane was a former police officer. She went to Tribunal to get a more detailed description of her son's needs and more time from a teaching assistant for George in a



	mainstream school. She also wanted the delivery of a diet and toileting programme in school.
Donna	A mother and primary care giver for David, aged 6. Donna works part time running her own pre-school. She went to Tribunal to get a more detailed description of her child's needs and more teaching assistant time for David in mainstream school.
Pam	A mother and primary care giver for Tom, aged 13. Pat is currently employed as the escort for her son's taxi rides to special school. She went to Tribunal to secure a residential special school placement.
Sally	A mother to Peter, aged 10, and a teacher. She went to Tribunal to get specialist dyslexia teaching for Peter in mainstream school.

<b>Parents – telephone interviewees</b>	
Margaret	A mother to Stuart, aged 12, and a pig farmer. She went to Tribunal to get a special school placement for her son.
Tina	A mother to Andrew and Adam, aged 7, and 13. Tina was employed by the LEA as a teacher in a Pupil Referral Unit. Tina went to Tribunal for both sons – one for more teaching assistant time in mainstream school and the other for a special school place.
Sandra	A mother and primary care giver to Terry, aged 6. She went to Tribunal to get more teaching assistant time for her son in mainstream school.
Tracy	A mother and primary caregiver to Alison,

	aged 8. Tracy went to Tribunal to get speech therapy for her daughter.
Richard	A father, to Robert, aged 14, who runs his own business. He went to Tribunal to get residential special school for his son.
Ivor	A father, to Michael, aged 11, who was a banker who gave up work because of ill health. He went to Tribunal to get specialist teaching for his child. He also started the process of Judicial Review when the LEA failed to implement the Tribunal's decision about specialist teaching. The Judicial Review was suspended.
Paul	A father and primary caregiver to Lilly, aged 8, who went to Tribunal to get music therapy for his daughter.
Fiona	A mother and primary caregiver to her son, Christopher, aged 13. Fiona was a former solicitor who went to Tribunal to get a place at an independent school with a specialist dyslexia facility.
Leo	Leo, a father and businessman, who went to Tribunal and the High Court to claim for disability discrimination against his son, Max, aged 13.
Michelle	A mother and primary care giver to her daughter Leah, aged 15, who went to Tribunal to make a claim for disability discrimination against her daughter. Her daughter was excluded for refusing to attend a foreign language lesson.
Kirsty	A mother and primary care giver to her son, Brian, aged 7. Kirsty was a former police officer who went to Tribunal to ask for



	occupational therapy for her son.
Barbara	Barbara, a mother and primary care giver to Isobel, aged 6, who went to Tribunal to get a mainstream school for her daughter.
Colin	A father to Nick, aged 11, and a market researcher. Colin went to Tribunal to ask for a mainstream faith school with a special unit for children with learning difficulties.
Sue	A mother and primary care giver to Fred, aged 11, who went to Tribunal to get a different special school place from the one the LEA offered.
Simon	A father and primary care giver to Ian, aged 6. Simon went to Tribunal to ask for an autism specific provision rather than a school for children with 'Severe Learning Difficulties'.
Mary	A mother to Jack, aged 16, and writer. She has published books on Attention Deficit Hyper Activity Disorder (ADHD). Mary registered for Tribunal but the case was resolved before the date. She got the special sixth form provision she wanted.
Martha	A mother and primary care giver to Sean, aged 14. She went to Tribunal to get her preferred choice of special school.
Mia	A mother and primary care giver to Ryan, aged 9. She went to Tribunal to get special dyslexia provision for her son.

Professionals – telephone interviewees	Details
Thomas	A practising solicitor and Tribunal panel chairperson.
Tim	A panel member and LEA officer, who had previously taught children with special educational needs in mainstream and special schools.
Scarlett	A practising solicitor and Tribunal panel chairperson.
Mark	A former panel member and a practising LEA educational psychologist, who had also acted as a witness for his LEA.
Karen	A panel member and LEA officer, who had previously taught children with special educational needs in schools.
Julia	An LEA educational psychologist who had been a witness at a hearing.
Derek	A panel member and LEA officer, who had previously taught children with special educational needs in mainstream and special schools.
John	A panel member and LEA officer, who had previously taught children with special educational needs in mainstream and special schools.

The parents' and professionals' stories appear in the study in different narrative forms, which are outlined below.

### Narrative forms

Different narrative forms are often used within the research, including first person narratives (Goodley, 1996; Booth & Booth, 1998), life history (Cole, 2004), composite narratives (Papadopoulos et al., 2002) and vignettes (Read, 2000). Here,



the narratives in each chapter take a number of different forms; the reason for this is that the different narrative types are intended to add both clarity and interest to the stories and to answer the different research questions which each chapter addresses. The intention is that different forms of narrative will capture and hold the reader's attention, while at the same time re-telling stories which have fidelity, they reflect what the story means to the teller.

### *First person narratives*

In Chapter Four, two short stories, written in the first person, are used to answer the question: what can we understand about the experiences which lead families to register for an appeal with SENDisT? First person narratives are used here because they offer rich, complex accounts of two parents' stories which give insights into their reasons for going to SENDisT. While Ben's story tells of a struggle for mainstream schooling and Pam's story illustrates a parent's fight for special schooling for their child, the stories are not offered as 'typical' accounts representing groups of parents. One story cannot stand for a whole group of people, each story the parents told was unique. However, Ben and Pam's stories offer a window into the informants' worlds. The stories were chosen because they were highly illustrative of the policy, relational and systemic landscapes which contribute to parents' registering an appeal with SENDisT. However, Ben and Pam's stories were also chosen because I found them moving, remarkable and potent accounts.

The first person narratives were constructed from the interviews with Ben and with Pam. In the process of telling the stories, decisions were made by me about what would be included and what could be left out of the very long and complex stories Ben and Pam told. The decisions were driven by my aim to answer the research questions and to emplot the story so that the narratives flowed in chronological order and without repetition. There are huge and complex tensions in editing stories which changing the story in any way risks breaking fidelity with the teller of the story. It could be that aspects of the stories which were important to Ben and Pam were not included in the stories which appear here. However, Ben and Pam were able to comment on their stories and both

were happy with the stories as they stand here. An example of how a transcript was turned into a story appears below:

Parm's transcript began as follows:

K: Can I just start by asking you to tell me something about your family and why you went to Tribunal?

P: We went to tribunal to get the right help for our little boy – yeah? That's what its all about really isn't it. But urm, you only go to Tribunal if everything else fails. It's always the last resort isn't it? And erm everything failed for us, so we went to Tribunal.

This part of the transcript appears at the beginning of her story as :

We went to Tribunal to get the right help for our little boy. That's what it is all about. You only go to Tribunal if everything else fails. Everything failed for us.

Short accounts from other parents, in the form of vignettes, complement Ben's and Pam's stories and draw together common experiences and threads within parents' stories. The threads reveal the ways in which their lives have been shaped by the Tribunal process and the wider special education system (Booth and Booth, 1998).

### *Dramatic narratives*

In Chapter Five, the story is what I have called a dramatic narrative. The story is one parent's account of the day of Tribunal itself. This story responds to the question: what are the stories of families attending the Tribunal hearing? Martha wrote an account of the Tribunal hearing shortly after the event. Martha's reason for writing a story was not connected to this research, she simply wanted to write down what had happened to her as a way of making sense of the day. Martha did subsequently use this story to help other parents preparing for Tribunal. I chose to use Martha's story because she gives a rich, detailed insight into the experience of the hearing, but it is also complex. Martha's story is an edited version of the written story she sent me. Again, this raises some questions about how the decisions to edit the story were taken. Again, the aim was to use the story to answer the research question and to do so in a way which facilitated an emplotted story.



An extract from Martha's original story refers to the case files she carried:

We had two files with us but we didn't have room for them both on the table so one had to sit on the floor, and I wrote on my lap.

In the annotated story which appears within the thesis, Martha's story appears with an explanation in the margin:

<p>The files include the submission form the LEA and the parents' case statement. This includes professional reports. Children often see numerous therapists and each of these may be asked to contribute evidence to the case statements.</p>	<p>We had two files with us but we didn't have room for them both on the table so one had to sit on the floor. I had to take notes on my lap.</p>
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In order to try and make the story easier to follow, the dramatic narrative has a 'cast list' at the beginning of the story and annotations in the margins which, like stage directions, are intended to add clarity to the narrative without detracting from the emplotted story. The moment-by-moment account gives the sense of the drama unfolding. Again vignettes are used to complement the analysis and to reveal the way the stories have been shaped by parents' common experiences.

### *Composite narratives*

In Chapter Six, three composite narratives are used to answer the research question: what can we understand from the stories of families about outcomes of pursuing a claim to Tribunal? A composite narrative is also used in Chapter Seven to explore parents' experiences of the wider social world. Composite narratives are constructed from parts of more than one original story (Papadopoulos, Scanlon and Lees, 2002). So, for instance, in the story *Because he looks normal it makes it very hard*, the story focuses on the parents' experience of diagnosis, but the narrative is made up of several parents' voices. The composite narratives were written by combining and overlapping parents' stories. Composite narratives are used to select and combine data in order to focus attention on common elements in people's lives. In Chapter Six, they are used to explore recurring themes of the child's educational provision, the impact of going to Tribunal on family life and the empowerment of parents who go to SENDisT. In Chapter Seven, they are used to explore parents experiences of living in a family where one or more children has a label of special educational needs and/or impairment.

The 'narrative turn' in social sciences has been called a 'blind alley' and narrative researchers have been criticised for their preoccupation with personal experience (Atkinson and Silverman, cited in Bochner, 2001, p133). However, the turn to narrative has significantly widened how social science research is conducted.

Researchers who use composite narratives, in particular, face the question of whether or not the story or, indeed, the story teller is 'real'. However, composite narratives, like other forms of narrative, are not offered as accurate descriptions of empirical reality, but for their 'interpretative and heuristic value' (Papadopoulos et al, 2002). By combining perspectives in an emplotted story the aim is not to 'reproduce' reality, but to explore the parents' experiences. Vickers (2002, p8) describes narrative (first person narratives, self-narratives, and composite narratives) as 'risky'. Again, decisions were made about what was to be kept in and what was to be left out of the composite stories. Here, again the composites were intended to answer the research question and decisions about what was included and what was not were driven by the search for overlapping themes and the aim of developing emplotted narratives. So, for example, in the



story 'Because he looks normal it makes it very hard', three parents' accounts of diagnosis were part of the final story:

'We were posted abroad when E was diagnosed and because I can't feasibly be posted any more because of the kids education and medical requirements, it's kind of put the mockers on my career...'  
(Simon)

It was like, um, grieving, the diagnosis and everything (Diane).

I still haven't come to terms with it totally, really and you know it's just massive and you've got to cope with that emotionally that you have lost your child. That's how it feels that you've lost your child, you are never going to know your child, you are never going to have a conversation with him, I still feel that now (Diane).

No parent wants to be hear that their child is autistic. We tried everything brain gym and cranial massage (Leo).

These extracts appear in the composite below:

We were posted abroad when George was diagnosed with autism. After the diagnosis, we felt I couldn't be posted any more because of the kids' education and medical requirements, so it's kind of put the mockers on my career. When we got the diagnosis, I was grieving, it was like a bereavement. You've lost your child, that's how it feels, you've lost your child and you are never going to know your child, you are never going to have a conversation with your child and that's how you feel. No parent wants to hear that their child is autistic. We tried everything: brain gym and cranial massage.

Story telling in social sciences is described as 'writing on the edge – and without a safety net' (Vickers, 2002, p8), yet, the search for new ideas and for new perspectives is at the heart of social research, and different narrative forms are part of this process.

Composite narratives allow parents' fragmented, but overlapping, experiences to be emplotted. The process of emplotment is used to engage the reader and to strengthen the stories and to fortify the analysis. Again, Ivor's story has annotations in the margins in order to explain some of the legal and technical aspects of the story.

Chapter Seven considers how the research findings inform understandings of the families' experiences of the disabling world. Here the chapter begins with one composite narrative which gives an account of living with a child with an impairment and/or special need. Again, a composite narrative is used to draw together the parents' fragmented experience in an emplotted story in an attempt to engage the reader and to bind the stories together. The composite narrative is complemented by vignettes which are not composites, but individual parents' stories.

A concluding chapter considers the implications of the research findings for current policy, legislation and practice (Chapter Eight).

Narrative inquiry has often been linked with ethnography, and although this study does not claim to be an ethnography of SENDisT, it engages with the principles underpinning ethnographic approaches.

## ii. Ethnography

Ethnography has been understood as a means of learning from people, and as a process of looking for 'an extraordinary individual who stands for their culture' (Reed-Danahay, 2001). The ethnographic methods include observation, interviews, written documents, and, of course, stories.

This research has ethnographic tendencies in so far as the aim is to learn from parents, to look at their 'hidden cultures', and to make human experiences visible. Yet, it does not set out to find 'extraordinary individuals' to stand for a culture, or to hold them up as objects of curiosity, rather the aim of this research, influenced by the emancipatory research agenda, is to capture 'hidden voices' in order to further the interests of the researched (Vlachou, 1997).

The use of documentary evidence is also part of ethnographic research and the focus, here, on the policy documents and legislation of special education also suggests an ethnographic leaning. However, these 'official' documents were not the only written source of information. An unexpected source of 'data' came from



parents' volunteering to send me their 'paper work'. The volume of paper work generated by going to SENDisT is great. Many parents referred to this in their stories. One parent sent a summary of events, another sent a copy of a key psychologist's report, one parent emailed her story and one parent sent a huge file which included a detailed account of the experience of going to Tribunal written shortly after the hearing. The use of documentary evidence draws on ethnographic approaches to research. The scope and time scale of the empirical work is set out below.

## **SECTION TWO: The study**

The scope of the empirical work grew as the research progressed. My initial aim was to find parents who would be prepared to talk about their experiences of an often emotional and sensitive event in their lives. I originally planned to interview ten parents of children with special educational needs who had registered an appeal with SENDisT since 2001. There were no other criteria for choosing informants, although I was hoping that parents would reflect diverse experiences of the Tribunal – those who had 'won' or 'lost', those who wanted special school or mainstream, and those who had represented themselves and those who had been represented by representatives from voluntary organisations or legal professionals. However, as a result of asking for informants to contact me through the newsletters of three voluntary organisations, I was contacted by 33 parents, 24 of whom agreed to take part. The scale of the response suggested that parents were, indeed, willing to talk about their experiences. The empirical work was carried out in three phases between October 2004 and April 2005.

### *Interviewing*

We live in an 'interview society' (Denzin and Lincoln, 2000b) – it is taken for granted that interviews generate useful information about lived experience. However, the interview is too often seen as a search-and-discovery mission in which the challenge is to extract the information as directly as possible (Järvinen, 2000). Here, the interviews are best understood, not as funnels for transmitting knowledge from interviewee to interviewer, but as 'meaning-making occasions' (Holstein and Gubrium, p4 cited in Roulston, de Marrias, and Lewis, 2003). The interview is influenced by the personal characteristics of *both* the interviewer and

the interviewee – issues of gender, race, class (among others) intersect and influence the relationship. The interview process for this study is outlined below.

### *Phases*

*Phase One – parents face-to-face interviews* : I carried out six in-depth face-to-face interviews with Ben, Gina, Diane, Donna, Pam and Sally in their homes. These interviews lasted from an hour-and-a-half to two-and-a-half hours each. The selection criteria for the face-to-face interviews was based on where the informants lived. For practical reasons, I chose participants who lived in the north west region of England. I was able to carry out interviews with informants who lived in four different LEAs.

Each interview began with my asking the parents to tell me a little about their family and why they appealed to SENDisT. Parents spoke very fluently, often with few interjections from me aside from 'mmm', 'yes' and nods. When I did comment on what they were saying, it was usually asking for clarification of the chronology of events. Parents were to recall the detail of events including dates and times. A marked feature was that parents often indicated that they were quoting what professionals had said to them verbatim, by explicitly stating that they recalled the exact words used.

The fluency of the telling of the stories may suggest that they had re-told the stories several times before to friends and family. Despite their fluency, telling the stories was clearly difficult for parents and tears were shed. Two parents stopped to compose themselves during the interview, but none of the parents asked for the tape recorder to be turned off. Most parents seemed comfortable with the tape recorder, only one parent added significantly to her story once the tape recorder was turned off. Her additional comments are not recorded in the research. All the informants were given copies of the full transcripts of the interview. Two informants told me that when they read their transcripts back they cried.

*Phase Two – parents telephone interviews*: I carried out 19 telephone interviews with parents who lived all over England. The telephone interviews usually lasted about forty five minutes with the shortest interview lasting thirty minutes and the



longest four hours (over two nights!). The telephone interviews began with the same question as the face-to-face interviews: 'can you tell me a little bit about your family and why you registered an appeal with SENDisT?' Some telephone interviews followed the same pattern as the face-to-face interview when I only interrupted for clarification. However, I used an 'aide memoir' to prompt further questions. Two parents asked for copies of the questions before we spoke and one parent, before the interview, provided me with a written summary of their experience. Another two parents sent me paperwork about their case, and one shared a story that she had written and presented at a meeting of parents in her local area. Parents were given copies of the transcribed extracts of the tapes and asked to comment if they wished.

The parents spoke clearly and had very little trouble with re-call of what were sometimes fairly distant events. The transcripts are, perhaps, unusual as they were often made up of long passages spoken by the informants without hesitation. The stories were often told in sequence with a beginning, a middle and an end. The fluency of the story-telling gave me a sense that many of the parents had told their stories before. Indeed, some parents were using their Tribunal experiences to help other parents so they were used to re-telling their stories. The parents saw the Tribunal as a key event in their lives and so it seems very likely that they have told and re-told the story to their friends and families.

All informants were asked if they were willing for their interviews to be tape recorded and none refused. Several informants added notes of clarification to the typed extracts. Only one participant asked me to take out some of the content of the extracts. Most were happy to leave the transcripts/extracts as they stood. Several informants commented on it being uncomfortable to read what they had said as text with all the accompanying hesitations, repeated phrases and pauses.

The participants were identified by approaching three voluntary organisations and asking them to publicise my research and some participants heard about the research by word of mouth. Not all parents who appeal to SENDisT make contact with a voluntary organisation before the Tribunal, so there is a group of parents, who went through the process with no external support at all, who are not

represented within this research. It was impossible, however, for me to identify these parents independently. I chose not to use SENDisT to contact parents about my research for fear that parents may feel either obliged to take part or that they may think that the research was not independent of SENDisT itself.

*Phase Three – professionals:* The primary aim for this research is that the voices of parents are heard. Parents have been ignored (Murray, 2000) and been the subjects of 'deficit' discourses (Todd, 2003) in special education policy debates. However, in order to broaden and strengthen the research, I also conducted six telephone interviews with SENDisT panel members from all over England. I also spoke to one member face-to-face in the north west region. This enabled me to draw on the experiences of a variety of the stakeholders in the Tribunal process, as I was able to speak to lay members who had been LEA officers, teachers and educational psychologists as well as the legally qualified Chairs. Contact with panel members was granted through SENDisT itself which circulated details of my research. Informants responded by contacting me by email. Of the 204 panel members currently hearing appeals, 60 contacted me and said they would be willing to take part.

The task of interviewing professionals was very different from that of speaking to parents. All but one of the professionals had experience of more than one Tribunal. This meant that they did not retell 'a story' in the way the parents did. Their responses were shorter and more hesitant. Despite being assured of anonymity and confidentiality in the research and the fact that they were able to comment on their transcripts, some of the professionals were quite guarded in their responses. One of the professionals asked me to turn the tape off while he took time to think about what he wanted to say. He was the only informant to do so. However, the scale of the response from panel members seems to reflect their commitment to SENDisT and their sense of duty to the children and families that they meet.



### *Summary of Informants*

I interviewed 24 parents (17 women, 7 men) about their experience of SENDisT which involved 25 children (one parent had been to SENDisT for both her children). The parents' claims were wide ranging:

- Two parents went to SENDisT for claims of disability discrimination.
- One parent went to SENDisT because the LEA refused to assess her child for a statement.
- Ten parents wanted to secure special school placements, two of these parents wanted a special residential school.
- Three parents wanted extra support specified in the statement at the mainstream school their child was already attending.
- Three parents were trying to secure a mainstream school placement for their child.
- Three parents were trying to get therapies written into their statements (speech and language therapy, music therapy and occupational therapy).
- Two parents wanted specialist teaching for their children (dyslexia teaching) at mainstream school.
- One of the parents who registered an appeal to secure a special school place, settled before the hearing.

The informants' names and the names of their children have been changed to protect their identity.

I interviewed 7 professionals. I conducted telephone interviews with 6 professionals and visited one, Mark, at his office. This decision was, again, influenced by travel constraints.

- Two professionals were solicitors and chaired SENDisT panels.
- Three professionals were LEA officers who had worked in special education in schools before moving into administration.
- One professional was a former panel member and serving LEA educational psychologist who had also acted as a witness for his LEA at Tribunal.
- One professional was a serving LEA educational psychologist who had acted as a witness at Tribunal.

In this section, the focus has been on how the study was carried out and who the informants were. In the next section, the focus is on the issues and debates which surround the study.

### **SECTION THREE: Methodological issues/debates**

I have already suggested above that the qualitative methodological approaches used within this thesis are, for some, controversial. Qualitative approaches and narrative, in particular, are vulnerable to a variety of attacks from positivist and quantitative researchers. Issues of validity, generalisability and objectivity are among the debates which surround narrative inquiry. Below I examine these and other methodological debates and issues.

#### *Post-positivism*

As a qualitative method, narrative inquiry is vulnerable to a number of positivist attacks. Narrative research is usually based on very small sample sizes (Cole, 2002,) which may not be 'representative' of the population, nor can the 'results' be easily 'generalised' or 'tested for validity'. Objectivity is a further problem and although researchers have sometimes claimed to use narratives to report events in an 'objective' way, where the account is said to be 'purely descriptive' and emotion is banished from the text. However, even the claims to objectivity of the most 'descriptive' research are, in fact, no more than a thinly veiled attempt to obscure the role of the researcher. Yet, positivist attacks are based on the contested assumption that it is possible for social science to be free of historical and discursive assumptions. Indeed, in a post-positivist world, lack of 'objectivity' is not just a problem for narrative inquiry, but for social sciences and natural science alike. The purpose of narrative inquiry cannot be to relate the 'truth' in an 'objective way', rather the aim is to come to a shared understanding of what is known (Emihovich, 1995).

#### *Truth and Lies*

Sikes (2000) has written about the difficulty of discriminating between 'truth' and 'lies' in narrative research. This is certainly a problem for narrative researchers. Sikes cited instances where researchers found that they had been deliberately misled by informants. She highlights the case of Nigel Bruce. Nigel Bruce took



part in research examining the experience of male child-care workers in early years settings. He presented himself as a caring teacher, yet he was later convicted on charges of child abuse in the child-care setting in which he was employed. The lies he told seemed to serve as a sinister attempt to cover his tracks and it seems possible that the researcher was manipulated by her informant for his own ends. I did not sense that any of the parents I spoke to were 'lying' in the sense that there was a deliberate attempt to deceive (Sikes, 2000). Yet, it is impossible for me to know whether I was 'lied to' or not. Yet, it seems, in a sense, that the parents' stories validate one another as they share their common experiences of SENDisT.

Crucially, the issue of 'truth and lies' is not just one for narrative, or indeed qualitative research. Informants may be just as likely, or even more likely, to lie in questionnaires completed anonymously and in private than they are when they deal with another person directly. For a form of research production, where stories are understood to be a joint endeavour between the teller and the listener, the issue of 'truth' can only ever be muddied.

### *Politics, opinion and stories*

The stories revealed complex relationships involving authority and power and the expression of strongly held opinions, principles and sympathies. One parent, Leo, a father and telephone interviewee, openly admitted that he had become 'political' as a result of fighting the 'powers that be' for his son. He described himself as being a 'conspiracy theorist' now, to the point where he no longer believed that a man had walked on the moon. Another father and telephone interviewee, Richard, had set up a website to record the number of Tribunals in his LEA which he said was the second worst in the country. One of the professionals, Derek, also spoke passionately about 'cronyism' in SENDisT. Derek and some of the parents regarded the interview as a good opportunity 'to get things off their chest', and spoke openly of having 'an agenda'. Parents showed a keen awareness of political issues, particularly around what some parents describe as 'the dogma of inclusion', and the view that while the Government was encouraging 'specialist' schools, the only thing schools are no longer allowed to specialise in is 'special needs' (Fiona). Indeed, Margaret asked if I still wanted to interview her because she had been campaigning for her child to go to special school. I reassured her that I was

interested in parents' experiences of Tribunal regardless of whether they had asked for mainstream or special schooling.

### *Life to text: freezing stories*

A further criticism of narrative inquiry is that a text cannot 'authentically' tell a spoken story, because of the difficulties of moving from life to text. As Nesper and Barber (1995, p57) point out 'people do not speak on paper'. Many of the parents and professionals themselves commented on the difficulties of moving from speech to text when they said how uncomfortable they felt when they read the transcript back. Michelle, a mother and telephone interviewee, commented that it was strange to read her story in 'Geordie' and that she had resolved to stop saying 'you know'. Narrative researchers have to accept that events are not only 'told, but created' (Clough, cited in Goodley et al, 2004). The shift from word to text reconstructs the story as some elements are discarded and others given prominence within the narrative.

The limitations of 'freezing' (Nesper and Barber, 1995, p57) the story in text must also be acknowledged. I spoke to Gina, a key informant, a couple of months after I interviewed her and she told me that Toby had been excluded from his High School and she felt she was heading back to Tribunal or Court. As this encounter clearly demonstrates, the stories the parents have told are not static or complete. They are constantly developing as events move on and as the parents frame and re-frame their experiences. It is simply not possible to reflect this fully in a written story. Narrative researchers have to accept these limitations and acknowledge that the 'data' would be different if the story was told at a different time, or indeed to a different person. While at the same time arguing that the 'excluded lives' of marginalised individuals and groups can inform public debates.

### *Perceptions: angry, upset parents*

Some research suggests that parents of children with special educational needs and/or impairments are angry and upset and that they detour their anger about their child's difficulties by making unreasonable demands of professionals (Minuchin 1974 cited in Connor, 1997, for a fuller discussion of this see Chapter One and Chapter Four). Parents are, then, perceived as 'unreasonable' and 'over



demanding' (Azzopardi, 2000). The greatest danger presented by 'freezing' the story is that the researcher, while using narrative in the name of empowerment, unintentionally reinforces the power imbalances which lead to the marginalisation of groups and individuals. Goodson (1995, p93) explains that by 'sponsoring voices at the periphery, the centre may well be strengthening its hand' – in other words, care needs to be taken that the stories do not simply reinforce dominant discourses. Some informants themselves were aware of this danger. When Gina had finished telling her story, she asked me to be careful with what she had said. She realised that someone might read her story and say 'she could have avoided all this [the Tribunal and conflict with professionals] if she'd sent him to special school.' However, while narrative researchers have been particularly conscious of this danger in their writing (Goodson, 1995; Goodley, 1996) and have not sought to side-step this issue, the challenge that research merely reinforces stereotypes could equally be applied to the wording of a questionnaire, or the design of an experiment. The danger of reinforcing power imbalances is not a difficulty peculiar to narrative inquiry, but one that all research must guard against.

### *Is it really research?*

If narrative inquiry assumes that there is no 'objectivity', no 'variables' and no 'generalisations' merely 'shared understandings', can it *really* be described as research? The answer to that question, of course, depends on how we define research. Clough and Nutbrown (2002, p4 cited in Goodley et al, 2004) state that:

All social research sets out with specific purposes from a particular position and aims to persuade readers of the significance of its claims; these claims are always broadly political.

I have already argued above that parents and professionals told their stories for a specific purpose, and from a particular, sometimes political, position. The narratives also address the research questions. The parents' narratives arose from their campaigning for their children, and may move both the teller of the stories and the readers towards further activism. Thus, this narrative inquiry meets Clough and Nutbrown's criteria for research.

### *Making a good story*

It is difficult to judge a text which crosses the arts/social science divide. Yet, researchers have suggested different possible ways to judge narratives. Madeline Grummet (1988, p26, cited in Blumenfeld-Jones, 1995) has focused on fidelity. She has suggested that 'fidelity rather than truth is the measure of these tales'. Truth, which she defines as what happened in the situation, is replaced with fidelity, or what the story means to the teller of the tale. Whereas truth treats events as objective, fidelity sees them as subjective (Blumenfeld-Jones, 1995). The difficulty lies in maintaining fidelity to the story teller *and* to the context in which the story takes place (Blumenfeld-Jones, 1995).

Emihovich (1995) argues that a narrative can be judged if it has a 'moral purpose', and challenges researchers to consider how they will make their research available to others as part of this moral purpose. With this in mind, I produced summaries of the research in accessible format for parents. These summary documents are included in the appendix {Appendix 1-5}. However, the most exacting test for a narrative research must be simply 'does it ring true?' (Connelly and Clannadin, 1990 cited in Emihovich, 1995, p44). The story works if people say 'yes, that's what it's like' (Clough, 2004, in Goodley, Lawthom, Clough and Moore 2004). Stories cannot be 'validated' by reference to their data or findings, rather they must strike a chord with people's lives (Clough, 2004, in Goodley, et al, 2004). I hope that my stories will be judged on whether or not they strike a chord with the lives of parents, professionals and others.

### *Ethics*

For narrative research to be ethical, Emihovich (1995) argues that research must have a moral purpose to effect change, as without a purpose, the collection of stories could be seen as simply satisfying the researcher's curiosity and as being voyeuristic. My hope is that the research will contribute to effecting change in policy, and practice in special education and as such has a moral purpose. However, the most important ethical consideration in this research is that no harm comes to the tellers of stories. Issues of confidentiality and anonymity are key here. This is particularly important for parents whose children are still in the education system, where a breach of confidentiality may affect their children's



education. Parents themselves expressed the fear of speaking out may put their child at risk. Anonymity and confidentiality are also important as the children themselves have not given consent for their stories to be told. The professionals and parents who took part may risk significant harm to their careers and/or emotional distress by being identifiable within the research. It is essential that names, dates and any geographical details which could identify people, are changed in the stories. However, there are more complex issues which may potentially cause harm.

Simply by re-telling a story, the teller may come to feel differently about events. For some story-tellers, reading transcripts or the written story was difficult. Re-telling and re-reading their story provoked strong emotional responses. Some researchers acknowledge the emotional aspects of telling the story, and have suggested that informants may gain something from the process of telling their story. The informants were aware that I was a parent of a disabled child and had had my own battles with the LEA over education. They were told that my work was for a PhD thesis and that I hope to publish in academic journals and in formats more accessible to a wider audience.

The informants were able to withdraw from the research at any point. Several parents made initial contact, but then withdrew, whereas another withdrew after agreeing a date for a face-to-face interview. Informants were given their transcripts and were able to comment upon them. All informants were able to continue contact with me after the interview if they wished, and some did for a number of weeks after the interview. This contact was picked up again when the parents were sent chapter summaries and, again, parents took the opportunity to fill me in on what had happened since the interviews.

Although researchers argue for reciprocity (Sikes, 2002), when the researcher shares some of his/her experiences with the participants, it quickly became clear that this was not always appropriate. All the parents I interviewed were aware that I had a disabled son. When I tried to share a parallel experience at the end of one of the first face-to-face interviews, the informant looked at her watch. Reciprocity was not what she was expecting or needed. After that experience, I

followed the principle that if a parent or professional asked me about my own experience, as they frequently did, I would talk about it. We had conversations about my experience of the education system, about Direct Payments and Disability Living Allowance. One parent talked about her child needing a laptop in school, so I gave her information about how to get one from a central government fund, and she contacted me later to say that her application had been successful. We talked about experiences of diagnosis. As part of their stories, two parents told me about the surgery their children had had. We talked a lot about the surgery because, at the time my son, was waiting for a similar operation. However, some parents did not ask about my family, or commented only very briefly, and I did not impose my experience on them.

It was clear from the outset that what I found out may have an emotional effect on me, and it was agreed with my supervisor that this was something that we would need to address in supervision meetings.

#### *When the researcher is an insider*

A further difficulty for this narrative inquiry is that my 'empathy' with other parents, and possible 'antipathy' to professionals, is as much a weakness as a strength, there is a danger that I will have seen only what I wanted to see and imposed my experience of the world of parent of a disabled child on to the 'voices' of others. However, this 'danger' exists for any researcher and by being clear about my biography, and methods of analysis, I have tried to expose my positionality and reflexivity.

#### *Privileging Accounts*

In all qualitative interview studies, the researcher seems to have a number of favourite interviews, that is, interviews that are quoted far more often than others. Although the criteria for selection are seldom made explicit.  
(Järvinen, 2000, p373)

I must also acknowledge that I too have 'privileged' the accounts of some parents above others in the research. Some parents' stories appear almost in full, whereas others appear only in part in vignettes which complement the longer narratives. Some parents' stories have contributed more to the analysis than others. This was



in part due to the number of interviews I did – it was simply not possible to give each story the same amount of space within the thesis. However, there were other reasons why I drew on some parents' stories more than others. Some accounts answered the research questions more directly than other stories. Some stories illustrated themes within the story better than other stories. However, some stories drew me in more, some parents 'connected' with me more, and some were simply more engaging story tellers. By acknowledging the privileging of some accounts, the study is open to the charge that the research is partisan and that I have promoted some parents' views above others. However, I have argued above that it is simply not possible to offer 'objective', 'value free' research. The researcher will always 'pollute' the research process; what is important is to be open and reflexive about the 'contamination'.

### *Unheard voices*

I have already acknowledged that there is a group of parents who went to who SENDisT are not represented here – those who did not contact a voluntary organisation. However, there is another group of children with special needs and/or impairments who are notable by their absence from this study – those children who are 'looked-after' by the Local Authority. All the children in this study were living in the care of the parents, none were in the care of the Local Authority. The points of contact for the research meant that it was very unlikely that the study would include 'looked-after' children. However, it is important to recognise that 'looked-after' children are particularly disadvantaged within the SENDisT system. Julia Thomas, a solicitor for the Children's Legal Centre, explained to the Education and Skills Select Committee (Education and Skills Select Committee, 2006) that:

We have a huge concern about looked-after children because at the moment the only people who can make an appeal to the tribunal on behalf of a looked after child are the social workers who are employed by the same authority that the appeal is being made against.

(Education and Skills Select Committee Report, 2006, p54)

This suggests an important area for further research.

## SECTION FOUR: Analytical approaches

The place of analysis within narrative inquiry is controversial. Blumenfeld-Jones (1995, p25) has offered a useful distinction between narrative analysis used by 'those who focus upon the stories of individuals as story with meaning' and analysis of narrative used by 'those who analyse narratives in order to generate themes for further analysis'. This inductive approach has clear links with Grounded Theory (Glaser and Strauss, 1967 cited in Polkinghorne, 1995). Conrad and Reissman (1990 cited in Charmaz, 2001) argue that it is unhelpful to offer an analysis of narrative. They claim that the generation of themes for further analysis does not increase understanding, rather it fractures the data. The result is that informants are portrayed less fully.

However, Goodson (1995) has challenged the assumption that empowering marginalised voices alone can bring about change. Instead, he argues that 'New stories do not by themselves analyse or address the structures of power' (Goodson, 1995, p95.) Analysis, then, can fortify stories, and it can be used to oppose unsympathetic readings which might exclude and oppress marginalised groups. (Goodley, 2000, cited in Goodley et al 2004). Analysis can also expose the telling of stories according to a 'prior script' imposed upon the teller by others for their own purposes (Zeller, 1995). Stories are, therefore, made stronger by being closely analysed and interrogated. It is only through analysis and interpretation that the strands which reveal the influence of a wider society can be drawn out (Booth and Booth, 1998). However, while arguing strongly for analysis here, at the same time the stories can and do speak for themselves.

### Background to qualitative analysis

There is no single method for analysing qualitative data (Bannister et al., 1999), however the aim is to use modes of analysis which to look 'deep' into social experiences (Silverman, 2001). The tool of analysis used within this study is thematic analysis.



## **Thematic analysis**

Thematic analysis focuses on identifying themes and patterns within the narratives. The researcher condenses the bulk of the data into analysable units by creating categories with and from the data. A criticism of thematic analysis is that the coding of the data which takes place in order to generate themes serves to break up the data, or reduces stories to some sort of general common denominator. However, the generation of themes is used here to expand and tease out the data in order to look at new levels of interpretation. Thematic analysis makes it possible to expand, transform and reconceptualise data, opening up analytical possibilities (Coffey & Atkinson, 1996).

The process of line by line reading of the stories and policy texts brought together components or fragments of experience which taken on their own may have little meaning, but together form a picture of collective experience (Aronson, 1994). For the analysis, I tried to identify categories which encapsulated important themes. New categories were added as I read and re-read the stories. Some categories generated new categories as they developed and the complexity of the stories grew. There was constant comparison between and within categories and themes. The aim is that organisation of the data into categories provides a new body of knowledge on the experiences of parents of children with special needs and/or impairments. This inductive approach has close links with grounded theory (Glaser and Strauss, 1967 cited in Charmaz, 2001). However, the influence of Disability Studies literature and the work of Rorty, Foucault and Bourdieu moves the analysis away from a strictly 'grounded' approach.

## **An overview of the approaches to analysis in each chapter**

The analysis draws on a range of methods and theoretical concepts which drive the analysis and with the aim of developing understanding of parents' stories.

In Chapter Four, the analysis draws on the social model of disability (For a fuller discussion of the social model see Chapter Two) to understand why parents registered appeals with SENDisT. The chapter examines parents' attitudes to the policy of statements and inclusion. Foucault's concept of 'knowledge and power'

and Rorty's concept of 'solidarity' between groups are seen as useful tools for developing an understanding of the relationships between parents and professionals and how these contribute to why parents go to SENDisT. The theory development is strengthened by the thematic analysis of the policies and systems of special education, including the Parent Partnership and Mediation Services (For a fuller discussion of the ideas of Rorty and Foucault see Chapter Two).

In Chapter Five, the focus is on the power relationships revealed within the Tribunal day story. Drawing on Foucault's concepts of truth, power-knowledge and surveillance and control, there is a critical, thematic analysis of the parents' Tribunal day. Foucault's work has often been used to support discourse analysis of stories and texts, and, although close attention is paid to the discursive practices within the hearing, the analysis here draws on Foucault's work but does not claim to be discourse analysis (For a fuller discussion of Foucault see Chapter Two).

In Chapter Six the parents' stories are analysed drawing upon research from the British and Scandinavian disability studies contexts which focuses on disability and the family (Read, 2000; Traustadottir, 1991, 1999; Joseph Rowntree Foundation, 2001; Carpenter, 2002). Analytical knots have been tied with the strands of parents' stories. Families' stories about Tribunal reveal knots which have been reflected in much of the research about the disabled family. A thematic analysis, influenced by the social model, was carried out, reading and re-reading the data for emergent themes. (For a fuller discussion of the Disability Studies Literature see Chapter Two).

In Chapter Seven, the analysis also draws on the disability studies literature (Beresford, 1994; Read, 2000; Green, 2003; Cole, 2004; Landsman, 2005; Fisher and Goodley, 2006 in press) and the work of Bourdieu to develop an understanding of the experiences of parents of children with special needs and/or impairments in the wider social world beyond education and the Tribunal. McKeever and Keller (2004) have encouraged researchers to use Bourdieusian concepts in order to develop understandings of the social worlds of families with children with special needs and/or impairments (For a fuller discussion of Bourdieu see Chapter Two).



Chapter Eight is the concluding chapter which considers what the implications of the research. As well as offering a summary of the research, Chapter Eight also includes key recommendations for SENDisT, policy makers, professionals and parents.

### **Dissemination**

Dissemination is a key issue for all researchers, but this is particularly the case for researchers drawing on emancipatory research perspectives. The parents and professionals who took part in the study were able to read and comment on their transcripts and stories. In addition, they were able to comment on the documents<sup>1</sup> which summarised the parents' and professionals' stories. These summaries are also available online at [www.shef.ac.uk/applieddisabilitystudies](http://www.shef.ac.uk/applieddisabilitystudies). The intention is to disseminate the research within the academic community and within parent and professional communities<sup>2</sup> so that the research is available to the widest possible interested audience.

### **Conclusion**

The study draws on a variety of methodological approaches underpinned by a post-positivist epistemology, which embraces an understanding of research production as a messy procedure. The research draws from emancipatory and ethnographic approaches, but is most influenced by narrative methodology. The issues and debates highlighted above suggest that such an approach is not without its limitations, but at the same time, narrative inquiry is a methodology which allows researchers to give accounts of previously 'hidden' lives.

Analysis which draws on concepts from different theoretical perspectives can also appear to be messy. However, this reflects the complexity of lived experiences and the need to be pragmatic in the search for theoretical concepts which help to develop understandings of intricate and fragmented lives.

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<sup>1</sup> See appendix 1-5

<sup>2</sup> See appendix 6

## **CHAPTER 4: THE SYSTEMIC, RELATIONAL AND POLICY LANDSCAPE: THE FACTORS WHICH LEAD PARENTS TO APPEAL TO SENDisT**

### **Introduction**

This chapter asks what we can understand about the experiences which lead parents to register an appeal with SENDisT. I aim to respond to the question by foregrounding two parents' stories. The stories present two different 'fights' with the LEA: Ben, a father, fought for his son to be included in mainstream school and lost, whereas Pam, a mother, went to Tribunal and secured a special school boarding placement for her son. I chose the narratives because they are stories which answer the research questions; these parents' stories focused particularly on the reasons which contributed to the parents' journeys to Tribunal. However, a key factor in influencing my choice of stories was that the stories stood out as compelling and powerful stories which were told in an engaging and dramatic way by the tellers.

The stories are contrasting in that they say something about the successes and failures of families' appeals to SENDisT. The parents, Ben and Pam, also described their children very differently: Pam talks about her child's IQ and impairment labels in her story, whereas Ben did not talk about impairment labels and diagnoses. Ben and Pam engaged in conflict with professionals but they differed in their types of engagement: Ben challenged professional knowledge and advice by using his knowledge of his child as a parent, whereas Pam countered professional judgements with different professional perspectives. She paid for assessments from different professionals and used these to challenge the LEA's assessments. However, here, Ben does not stand for all parents who fight for mainstream schooling, just as Pam cannot represent those parents who want a special school placement. It is not my intention that parents' accounts should be essentialised or treated as indicative of how things really are. Nor is it my intention that we should simply compare and contrast these stories in order to generalise from them. Rather the focus here is the drawing together the common experiences and threads which connect Ben and Pam's stories. Ben and Pam's stories are strengthened by other parents' accounts of the Tribunal which also reveal the complex ways in which parents' lives are shaped by wider social,



attitudinal and systemic factors (Booth and Booth, 1998). These accounts take the form of short vignettes (See Chapter Three for a fuller discussion of narrative forms) and they complement Ben and Pam's first person narratives by drawing out the common themes and threads in the stories.

The analysis draws on the voices of panel members with the intention that this strengthens the narratives. Their comments offer insights into the Tribunal process and their views about why parents appeal. As I described in Chapter Three, the informants were able to comment on their stories. Ben made several changes to his story, mainly correcting the chronology of events. In the end, he said of the story 'that's perfect. That's exactly how it was'. Pam was happy to receive a copy of her story but she chose not to make any comment about it.

The analysis of the stories suggest that the narratives depict a complex and unstable policy, relational and systemic landscape which lead parents to Tribunal. Both stories foregrounded here are tales of the breakdown of parent-professional relationships. Both Ben and Pam found themselves in conflict with professionals working with their families including teachers, psychologists and LEA officers. However, the structure of the system suggests that there are systemic elements inherent within the workings of SENDisT itself which lead parents to return to Tribunal. Ben went to Tribunal once, but Pam went three times. As a result, Pam's story includes more details about her experience of the Tribunal itself as this was a key reason why she made subsequent appeals.

The aim here is that data from the stories and the literature are intertwined to drive theory development and to offer an analysis of the reasons why parents go to Tribunal. I aim to paint the landscape in which parents' Tribunal stories are set.

As I argued in Chapter Three, *Methodological and Analytical Approaches*, the theoretical concepts used to drive the analysis can best be understood as 'thinking tools' (Bourdieu cited in McKeever and Keller, 2004). In Section One, I offer a critical analysis of the policy of statementing which draws on the social model of disability to understand parents' attitudes to inclusion; in Section Two, Foucault's concept of 'knowledge and power' and Rorty's concept of 'solidarity' are seen as

useful 'temporary constructs' (Bourdieu cited in McKeever and Keller, 2004) for helping to understand the reasons why parents go to Tribunal. In Section Three, I offer a critical analysis of the systems, mediation and conciliation within special education and of the system of SENDisT itself.

### **Ben and Callum's story – 'A fight for Mainstream'**

*Ben is Callum's father and primary care giver. He is married to Danielle, an office worker, and they have a daughter as well as their son Callum. Ben used to work 'on the bins' before giving up work to care for Callum full-time.*

Since he started in school, our son has been treated like a piece of meat. It sounds awful to say those words, but that is the way it has come across to us.

When Callum started school, he went to a mainstream nursery school just like everybody else. He was offered a place at Lower Beck Primary school, which was in our borough and was where all his friends were going. The head teacher had told us not to worry, that 'Callum would be one of us'. She was right, in a way, because the children were brilliant, to them Callum was just Callum. But it was different with the adults. In the classroom, the staff had built this little room in the corner, and he was segregated in there away from the rest of the children. We knew things weren't right when Callum's carer<sup>1</sup> started to tell us things like '*she* wasn't there to take him to the toilet'. Then they kept Callum back a year at the end of reception, although they knew we didn't want them to. We didn't know what to do, who to ask, but then we decided we'd better ask someone from the LEA's behaviour support team to go in to help the teachers, really. At the Individual Education Plan meeting which followed, the woman from behaviour support spoke up for Callum.

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<sup>1</sup> Ben described Callum's teaching assistant as his carer.



She stood up to the rest of them and said 'Callum's not being allowed to be involved with the other children. The teachers are pushing him away. He can do more than everybody thinks, you know'. But they wouldn't listen.

So it had got to the point where we felt we had to find another school. We couldn't leave him there, not when they were treating him like that. Anyway, we were lucky and got him into Main Road, another mainstream primary school. The head teacher seemed really nice. The teachers were superb. He settled in well. He had a lovely carer there, Michelle, in fact he got to know her so well that we exchanged presents at Christmas and Callum even went round to her house. But, again, things began to get more difficult. Callum was getting a bit big for Michelle to manage so they got in a male carer instead. Again, the school kept him down a year which we weren't happy about because he was two years behind his peers then. At review meetings, we tried to help and offer suggestions, but the teachers just took it as a criticism. If we said anything, they thought that we were complaining about what they were teaching and how they were teaching it. One of the teachers got upset and started blaming Callum and me for things going badly at school.

We had yet another meeting at school, this time with the LEA psychologist. He said that he felt that 'as a professional' he needed to be 'straight' about things. He told us that our son 'was never going to achieve anything in life.' He made that judgement after taking Callum into a ten by six foot room and testing him for forty minutes. He said Callum couldn't do this and he couldn't do that, and then he commented on Callum's lack of eye contact.

I'd been watching all this and taking everything in. So I said 'we've been in a meeting for an hour and a half, and you've spoken about my son, and you've spoken to other people, and you've spoken to

my wife and you didn't give one of us eye contact. So what does that say to you 'as a professional?'

At the final review meeting, when Callum had been at the school about four years, they turned round again and said 'we can't meet his needs'. I asked the male carer to talk about what Callum *could* do, about the work they'd been doing on the computer. All the carer would say was 'the teachers here are superb'. I felt like Callum had been bought and sold. After four years there, he had to leave the school. When Callum left, we got letters from some of the other children, and the lollipop lady. They missed him; he was part of their community.

So we had to find yet another school! We'd got into the situation where we needed support and we asked someone from a regional charity. We thought he was on our side. He advised us, he said the best thing was for Callum to go to a special school called King's. He took us round, there were no children in the school at the time, it was the holidays. He told us it was a lovely school. We weren't too sure, but we felt we ought to keep the man from the charity on side. Really, the whole family was under a lot of stress at the time, our marriage was under stress. We felt our hand was being forced over going to special school, so we said we'd go for a dual placement at King's and Main Road. We were told that Callum could go to King's, but the compromise was that he would still be able to do after school activities at his old school to give him contact with his old friends. That wasn't how it happened. You see Callum has clubbed feet, and at the time he was fourteen stone. The only after school activities they offered him were football and cooking, and they were both on the same night.

So Danielle, my wife, went down to see the head at Main Road about the after school activities. The head said that she didn't know what the LEA had promised and she didn't know anything about after



school activities, and, anyway, there was no way she was going to have Callum back at her school. We realised the LEA had lied to us and we discovered that the man from the charity was involved with it all too. There was a meeting at our house with us, the LEA man and the charity man, but after the meeting the LEA and the man from the charity went outside and had another meeting on the pavement, without us. They stood outside our house having a meeting about our son for an hour without us, while we watched from the window. The charity were too close to the LEA. So, you don't just have to blame the LEA for all of this. You blame the charity work and the 'disabled' part of it too<sup>2</sup>.

When Callum started at King's Special School, he was in a classroom with six children. All of them had autism. Of course, Callum started copying the other children's mannerisms. He was coming home and beating himself up in the face. He was rocking. You couldn't leave him by himself. He was soiling himself at school and at home, and he'd never done that before. It got to the point that when he was getting his uniform on one morning to go to King's and as the bus turned up he became hysterical, crying. When I spoke to the head teacher all he said was 'if you're having that much trouble in the morning, just push him out of the door and if he sits outside and soils himself or wets himself or takes his clothes off, just put him in the taxi and we'll sort him out when he gets to school.' We had an assessment by a clinical psychologist, who said that Callum was happy once he was there. But we knew the reality was that he was very unhappy. So we decided 'that's it, he's not going.'

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<sup>2</sup> 'The disabled part of it' was how Ben described the impairment based voluntary organisation which his family had been involved with. He said that he felt, in the beginning, that the voluntary organisation was there to support his family, but over time his feelings changed. He saw the charity's links with the LEA as part of the problem and suggested that the charity no longer put its members first. He felt that the LEA and the charity worked together against his wishes.

After lots of meetings with the LEA and visits to other schools, Callum got a place at Park, another primary mainstream school, they offered him a part time place. We were made up! Danielle would drop him to school and he came back in a taxi. It was only for two hours a day at first, so we tried to get him to stay for a bit longer. The school said Callum could stay for lunch, until twelve-thirty. But then it all happened again, just as it had done before. The school said they 'couldn't meet his needs' and we were advised that we would have to go to Tribunal to get a full-time place in mainstream education for our son.

We did go to Tribunal and in the end, the panel members ordered that Callum go to special school. So I finished up at work on the Friday night after twenty five years in my job and said I'd educate him at home.

### **Pam and Tom's Story – a fight for special**

*Pam is married with Tom and two other children. She is the primary care-giver while her husband is a taxi driver. Pam has two older children and she currently works as an escort in the taxi which takes her son to residential special school each week and brings him home at the weekend.*

We went to Tribunal to get the right help for our little boy. That's what it is all about. You only go to Tribunal if everything else fails. Everything failed for us.

When Tom went to pre-school he had a problem with his speech and they sent him to a pre-school assessment unit. As he was about to go into school a psychologist from the LEA came and assessed him. She gave our little boy an IQ of 56 and said that he was 'autistic spectrum'. His speech was in line with his IQ so we couldn't expect anything more. That is what they said.



We couldn't see what they could see. I mean at home he was doing things, communicating but at school he was mute. We knew he had speech problems, but I felt they were wrong about the autism. I questioned myself perhaps I was missing something. I went to the library and got a book on autism. I read it all and I learnt that a child with autism can't turn a toy or anything into something else. I knew that my son had turned a cardboard box into a cage for the dinosaurs. I knew he was putting tea towels round his head and pretending to be Darth Vader from Star Wars, so I knew it didn't add up. So now I had a problem, I didn't agree with his diagnosis, but for a parent fighting professionals it isn't easy.

We didn't have much spare money for independent reports from an educational psychologist or a speech therapist and we didn't know what to do. Then a friend mentioned dyslexia to me and I thought 'no!' but I looked at it. I went to the library again and I got books on dyslexia. I read one book and I could see our whole family in there and I realised that we had speech problems in our family going back to my grandfather. So we took Tom to see a dyslexia specialist and speech therapist. The LEA psychologist gave Tom an IQ of 56 in December, and the following April the dyslexia specialist gave him an IQ of 105. The results were completely different.

So we went back to the LEA and we felt we'd proved what we were saying. He didn't have a low IQ, he wasn't autistic and because of his speech problems he was actually an elective mute. They seemed to listen to us at first. The LEA gave him two hours of specialist dyslexia teaching a week, but the local speech department at the health trust wouldn't budge. They wouldn't acknowledge he was an elective mute, so our next battle was with the speech department. We made a formal complaint about the department, they were highly criticised by an independent review, but they still didn't give our son speech therapy, so we decided we'd have to go to Tribunal.

At the Tribunal in July, 2000, we got speech therapy. The Chair said that the fact that a child is an elective mute should not prevent them from obtaining speech therapy. He was very clear about that in his ruling. Yet, the Health Trust would still not give us speech therapy. The LEA were frustrated too, they were probably working with us at that point, but things still weren't working for Tom at school so we went to Tribunal again in May, 2001.

This time, I wanted a specialist speech and language school. I'd joined a charity that supports children with speech and language difficulties. I didn't really want to at first. I didn't know anything about 'special needs' and all that. I had never dealt with 'help lines' and 'support groups' before, but I'm glad I joined. There was an article in their newsletter. It was written by a mother about her son, she was similar to me, fighting for her son and she'd come across this school, Wooley School. Her son went there and was happy. In the end, her son ended up having a degree in computers and for the first time I felt 'my God, there's hope!' So I started to look at special schools, but I knew that Wooley was the one. We chose it and we, as a family, were focused on getting Tom there.

The second Tribunal didn't go well. The LEA and I were clearly enemies by now. They brought in Tom's head teacher as their key witness. He said that Tom would never be able to cope in boarding school without us because he relies on us so heavily. I felt the panel did everything they could to keep Tom at home. They gave him Occupational Therapy, more Speech Therapy and directed that Tom's learning support assistant should have more training. We were to be involved in all Tom's IEPs and the Chair said that special attention should be paid to Tom's annual review. The Tribunal was in May and the aim was that this should all be in place for September – it wasn't. There was no OT, the LEA decided the Learning Support Assistant didn't need extra training, that she could get it while she was working with other professionals, so she didn't need to go on



any courses. The LEA decided to have another multi-disciplinary assessment of Tom. I was worried sick. I went to Social Services crying my eyes out because I knew that they were abusing my child mentally by ignoring his elective mutism and trying to label him with autism. I got hold of a clinical psychologist from the learning disability team, we wanted him to be part of the multi-disciplinary assessment, but the LEA didn't let him know when it was happening. After the assessment, the LEA took the OT and dyslexia teaching away from Tom, so we decided we had to go back to Tribunal. In December 2003, four days before the Tribunal, the LEA caved in, but they didn't issue the statement<sup>3</sup> so we had to go to Tribunal anyway. Tom started at special school in January 2004.

I go in the taxi with him. I'm the official escort. So we leave on a Monday at about half past six, stop on the way for breakfast, and Tom is in school at about half ten. On a Friday, we leave at about 11 o'clock, but the traffic can be really bad and we get back sometimes as late as half eight, nine o'clock. We're a normal family, it's just that our son happens to go to residential school. He's away for four days and home for three and it's worth it for what he gets. I feel like he's just going to mainstream really because I ring him every morning and every night before he goes to bed. I'm used to it, I don't complain. I'll do it for the next five years if Tom needs it.

All through this, the letter writing, the fighting, when my other children didn't know what mood I'd be in when they came home;

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<sup>3</sup> When Pam says that the LEA didn't issue the statement, she means that they did not send her a copy of the final statement. Without it, Pam could not be sure that the LEA would keep to their word, so she went to Tribunal to make sure they put it in writing.

when my older son was typing letters for me on the computer at the same time he was doing his GCSEs; I told the family 'this is the best thing we can do for Tom, this is the ultimate present we can give him.' And they came through for me.

## **SECTION ONE: The policy landscape**

In this section, I map out the policy landscape in which the parents' stories are set. First, I return to the policy of 'statementing' (See Chapter One) children with special educational needs in relation to parental appeals to SENDisT; both Ben and Pam's stories are illustrative of parents' involvement with the statementing system. I then look at the policy of 'inclusion' which has also been described by both parents and professionals as a key reason why parents go to SENDisT. For Ben, it was his commitment to mainstream school for Callum which led to his appeal to SENDisT, whereas for Pam it was her certainty that her son, Tom, would not thrive in a mainstream school which led to her appeal.

### **1. Statements of special educational need**

Both Ben and Pam's stories are concerned with the contents of their children's statements. For Ben, the conflict was over whether the statement named a mainstream or a special school. For Pam, at the beginning, the conflict was over the type and amount of support in Tom's statement at mainstream school, then the conflict shifted to focus on which school should be named in his statement.

Since the Education Act 1981, children with 'complex' special needs have been given statements of special educational need. The vast majority of appeals to SENDisT are about the child's educational provision (See also Chapter One). At the most basic level, parents go to SENDisT because statements of special educational need exist, without them, there would be no Tribunal. While the system of statements is more than 20 years old, it remains controversial within special education.

The process of making statements of special educational needs was based on Warnock's (DES, 1978) progressive thinking about 'children with special educational needs'. She re-focused thinking on children's education rather than



on their 'handicaps' and was concerned with how provision for children could be organised and protected (See Chapter One).

The system of statements has come under scrutiny from researchers and policy makers in recent years (Williams and Maloney, 1998; Warnock, 2005a). The benefits of the system of statements include the increase in the number of children with statements in mainstream schools since 1990 (Williams and Maloney, 1998). There has also been an increased awareness among mainstream schools of their role in meeting special educational needs. Statements have also 'protected' individual children's provision as the statement carries resource specific funding for the individual child (IPSEA 2005a). However, the statementing process has also been criticised from a number of different perspectives. First, the emphasis on 'individual need' within statements continues to focus interventions on within-child rather than systemic barriers to learning, and this has been seen as a barrier to inclusion of children with special needs and/or impairments in mainstream schools. The statementing system, some claim, sits uncomfortably in a policy context which has tried to shift the emphasis onto removing the barriers to learning (DfES, 2004).

The system has also been criticised for being very long-winded, overly bureaucratic and expensive, which has led to delays in the delivery of support for children (Williams and Maloney, 1998; Warnock, 2005a). Increasingly, the statementing system has also been credited with having contributed to the adversarial nature of the parent-professional relationship. There is a sense in which statements have raised parents' expectations and parents fight for statements because they no longer have any confidence that, without a statement, their child's needs will be met (Warnock, 2005a). Critics also claim that the system can be manipulated by the most articulate parents to gain disproportionate resources for their children. Funding for children with empowered parents is, they claim, disproportionate to that received by other less well represented individuals or groups of children (Gross 1996; Williams and Maloney, 1998). However, parents' organisations (IPSEA, 2005a; ACE, 2005) challenge the view that bureaucracy is a problem for parents as parents' complaints are largely about the failures of the system rather than about the system itself (ACE, 2005). Parents

fear that 'bureaucracy' is frequently used by service providers as an excuse to reduce information, accountability and legal duties owed to parents (See Chapter One).

While Warnock intended that statements should be for children with only the most complex level of needs, the number of statements has continued to grow (Pinney, 2003). The introduction of the *Code of Practice* (DfEE, 1994) was an attempt to provide a model for consultation with parents which would reduce the demand for statements, but this has had little impact on the number of statements nationally (Pinney, 2003).

Following reports by the Audit Commission and OfSTED (Audit Commission, 2002a; OfSTED, 2002 cited in Pinney, 2003), there has been a focus on the drive by Local Education Authorities to reduce the number of children with statements. Both these reports suggest that this has been done by the LEAs delegating a greater share of the special education budget to schools, and by investing in developing skills and capacity to meet a wider range of pupil needs. This, they suggest, has obviated the need for many statements, as schools have become increasingly able to meet most pupils' special needs from within their own resources - leaving the LEA to make additional provision through a statement for a much smaller group of children, typically those with severe and complex needs (Pinney, 2003). However, between 1998-2003, twice as many authorities have increased the number of statements than decreased them (Pinney, 2003). Surprisingly, there are more appeals against the LEA's refusal to assess a child for a statement in authorities which already have high levels of new statements. Areas which issue fewer new statements, have lower levels of appeals against the LEA's refusal to assess a child. This is the opposite of what might be expected.

Pinney suggests that there are a number of key benefits to reducing the number of statements:

- a fairer distribution of SEN resources, better reflecting the pattern of needs;



- **more support for more children – including those at school action and school action plus<sup>4</sup>, as support is targeted at a wider group of children and schools are able to use their resources more creatively;**
- **greater stability and flexibility in school funding, with most SEN resources distributed through formula funding and a smaller share of the budget being tied to individual pupil needs. Pupil-specific funding was moderated to ensure a fair and consistent approach to providing additional resources to support the inclusion of pupils with more severe and complex needs;**
- **increased transparency about the available resources and the responsibility of the LEA and schools in meeting children’s needs;**
- **less paperwork and SEN-related bureaucracy – this was an important benefit for SENCOs, educational psychologists and other LEA teams. Linked to this was:**
- **increased involvement in schools by the educational psychology service and specialist staff; educational psychologists and specialist staff are able to spend less time on assessments and paper work and more time with children;**
- **a more positive role for SENCOs, spending more time on classroom observation, advising colleagues and working with children (and less on administration);**
- **improved relations with parents and schools – markedly less adversarial than in the areas visited in previous research projects. (Pinney, 2003, p40 bold her emphasis)**

However, Pinney also highlighted a number of areas which caused concern:

- **a high level of anxiety about reducing statements, where the authority had not made this an explicit strategic aim, nor engaged schools and parents in developing an alternative approach. Reducing statements was perceived to be a cost-cutting exercise, rather than achieving a fairer distribution of the available resource;**
- **continued variation in the capacity and commitment of local schools to meeting children’s SEN, across all areas. Parent Partnership Officers<sup>5</sup> felt that having a statement increased the scope for challenging poor practice and parents valued the additional assurance a statement brought;**

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<sup>4</sup> See Chapter 1 for a fuller discussion of the stages of the Code of Practice.

<sup>5</sup> Parent Partnership Officers (PPOs) are employees of the LEA, but the service is at ‘arm’s length’ from the LEA. PPOs work with parents of children with special educational needs and support them in meetings or in filling-in forms.

- concerns that some children, particularly those with less visible or demanding needs (for example moderate or specific learning difficulties) would receive less attention if they did not have a statement;
- shortfalls in the availability of health and social services, this was the only area where the views of LEA officers compared to those of parent and SENCOs differed on the whole – the former being much more positive than the latter;
- concerns about the loss of ‘passported benefits’ linked to statements – including access to some health services, priority in school admissions and so on.  
(Pinney, 2003, p41)

Statements have been seen by parents as a crucial element of protecting the support for children with special needs and/or impairment in schools (IPSEA, 1997, 2005a). Indeed IPSEA found that children with detailed statements were more likely to be included successfully in mainstream schools. Yet the bureaucratic and adversarial nature of the process has been cited as an inherent cause of conflict between parents and professionals (Williams and Maloney, 1998, Warnock, 2005a). However, as Allan argues, Warnock regards statements as her ‘biggest mistake’ (1997, p13, cited in Allan, 1999, p 87) not because the system does not serve the interests of parents or pupils or because it is too intrusive but because she regrets the way that parents have turned the system to their advantage. Parents’ and professionals’ views of statements are considered in the next section.

### *Professionals’ and parents’ views of the system of statements*

Some of the professionals in this study shared the view that the system of statements encourages conflict between parents and professionals. Thomas, a SENDisT Chair, said that the ‘protection’ that statements give children was the key reason parents went to SENDisT:

First of all, I think that parents still have in their mind, often reinforced by school, that the only thing which quote ‘protects’ unquote their vulnerable child is a statement, and if they are not then offered one that worries them.

He added that parents’ wish for statements was a cause of conflict between parents and LEAs:



The protection part is very important to them [parents] as opposed to the LEA who are, not surprisingly, trying to cut down on the number of statemented children.

Derek, a panel member, also identified the demand for statements as a cause of conflict, not least because of the resource implications for the LEA of issuing a statement.

I suspect there's a feeling that they are guarding budgets because on that panel [which decides on the content of statements] there are primary school heads, secondary school heads, LEA officers and they recognise that every statement means a potential hefty drain on the budget.

(Derek, a panel member)

There is also anecdotal evidence from parents' stories that LEAs wish to reduce the number of statements and perhaps get rid of them all together. Indeed, Robert a father and telephone interviewee said of my research:

Any way this [your research] may well be academic. I mean in the sense that they [LEAs] are trying to get rid of statements.

(Robert, a father and telephone interviewee)

It remains the case that while statements can be seen to be the cause of conflict, for parents the statement is often seen as the only way to safeguard their child's support. LEAs have responsibility for assessing a child's educational needs and for funding the delivery of support for those needs. Parents see this as a conflict of interests (ACE, 2005a).

Ben and Pam disagreed with the LEA about school placements and the type and amount of support their children received in school. For other parents the conflict centred not only on the content of the statement, but they made criticisms of LEAs who, they said, did not implement the statementing process properly:

They just drag everything out the LEA. They are just trying to avoid paying for support.

(Donna, a mother and key informant)

Although parents would undoubtedly value more support during the statementing process, their criticisms were focused on what they described as the deliberate failure on the part of the LEA to implement the existing system, rather than making criticisms of the system itself. Parents value a system which offers them a chance of appeal. Moves to remove the system of statements because they

are burdensome for the parents suggest a welfarist view that parents need protection more than they have a right to express their view about their child. Parents, who advocate for their children, fear that any reduction in their rights to participate could have detrimental effects for the child (ACE, 2005a).

## **2. Inclusion – a policy for conflict?**

Inclusion is a widely debated term, which is difficult to define clearly. Within current education policy, inclusion is defined as children with special educational needs and/or disability ‘usually’ attending mainstream schools, unless this is incompatible with parental wishes or the efficient education of other children (HMSO, 2001). Inclusion is more than just a geographical placement. Inclusion means that children with special needs and/or impairment will not only be present in mainstream schools but participating and accepted (See Chapter One). Despite the policy shifts towards inclusion since 1997 (HMSO, 2001; DfES, 2004), the debate about whether children with special educational needs and/or impairments should be educated in mainstream or special schools continues to rage in the media (Brennan, 2005; Marrin, 2005). Media stories reveal feelings running high on both sides of the debate.

Inclusion was a common knot within the parents’ stories. Parents held conflicting views about the policy and practice of inclusion: some parents were wholly committed to mainstream school whereas others believed special school was the only environment where their children’s educational needs could be met – Ben and Pam’s stories are illustrative of these different views. Like Ben, Gina went to SENDisT because she wanted a mainstream place for her child:

Toby was statemented at three; it was obvious that he should be. Right from the beginning we chose to have it written clearly on his statement that Toby should be educated in ‘a mainstream school’. I felt, I still do, that it would not be in anybody’s interest for Toby to be educated only with other children with special needs. Toby picks up behaviours, he copies other children, so I knew it wouldn’t do him any good. And segregated schooling doesn’t do the other kids any good and it doesn’t do society any good. It just won’t do anyone any good to deny Toby an integrated<sup>6</sup> life.

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<sup>6</sup> Gina used the terms inclusion and integration interchangeably.



However, Tina, a mother like Pam, went to SENDisT to gain a special school place for her son:

Alex's place at special school was the most defining thing – it was life or death. School was a chance to start again, to live again. It is significant beyond words. It changed his life.

Tina, a mother

The parents' stories revealed that the issue of inclusion was one where parents felt the stakes were high and the possible gains or losses were great.

Professionals, too, commented on the inclusion debate as a key reason why parents went to Tribunal. Both a SENDisT Chair and a member hi-lighted this issue as an increasingly common reason for appeal:

More recently the Government's press towards inclusion means that parents of children who are acutely vulnerable children, who find the transfer to secondary education virtually impossible to have organised properly. For them, there isn't a choice. And I don't believe many comprehensive schools have the ability, funding or the drive really to provide an education which is suitable for many vulnerable children.

(Thomas, a Tribunal Chair)

And increasingly I've found since inclusion's become on the agenda, the authorities have gone down the Government road on inclusion and there are a number of parents who are increasingly appealing for their child to go to special schools.

(John, a panel member & LEA officer)

Inclusion is an ongoing process, parents' stories and professionals' views offer some insights into how much progress towards inclusive practice has been made so far.

### *Inclusion in the UK*

A common perception within the media (Brennan, 2005; Marrin, 2005) is that since the Warnock Report (DES, 1978) there has been a rapid and unstoppable drive towards inclusion which has seen a reduction in the number of special school places and limited choice for parents of children with special educational needs and/or impairments. Brennan (2005) claims that the 'special education' provision has been all but destroyed. However, policy commitments to inclusion (DfES, 2001a; DfES, 2004) have been made within a wider educational context which

remains, at times, antithetical to the concept of inclusion. In fact, during 2002-2004 the percentage of 0-19 year olds placed in special schools and other segregated settings by LEAs fell from 0.84% in 2002 (103,721 pupils) to 0.82% in 2004 (101,612 pupils) (CSIE, 2005), while the number of children in Pupil Referral Units has risen by 25% between 2001-2003 (OfSTED 2004). If the process of inclusion can be measured by the decline of numbers of pupils in segregated provision, it seems that inclusive practice is limited.

Research suggests that there has been little progress towards inclusion for children with special educational needs and/or impairment in terms of attitudes towards inclusion among teachers. Croll and Moses (2004) found that very few of those at the 'chalk face' are committed to inclusion for *all* children. Croll and Moses' (2004) research found that 100% primary school head teachers thought that there is a continuing role for special schools, as did 98% of primary teachers. Only 8% of primary head teachers thought that fewer children should attend special schools and only 6% of primary teachers (Croll and Moses, 2004). Crabtree and Whittaker (1995) also found that that SENDisT panel members were equally committed to the continued role of special schools. The overwhelming majority of panel members (91.4%) felt that there was a continuing role for special schools. Although Crabtree and Whittaker's research was carried out before the accelerated policy drive for inclusion from 1997, the view that it is not possible to include *all* children in mainstream school was shared by some of the members in the present study:

What actually happened was that the parent was asking for a mainstream provision and the LEA was saying 'well this kid has got so many problems, so many difficulties that what she's asking for doesn't actually exist in our LEA or any neighbouring LEA ... it doesn't actually exist. And I was thinking 'well, I've never come across that level of provision in a mainstream'. It's just defying all rational approach to the use of scarce resources.  
(Derek, a panel member and LEA officer)

Despite the sluggish march towards an inclusive education system, which is still more evident in policy (DfES, 2004) than in practice, the modern myth is that the move to inclusion has been one of 'cult-like' proportions (Connor, 1997).



## ***Inclusion in the media***

**There is a political dogma of inclusion.  
(Leo, a father and telephone interviewee)**

**In the popular press, the hostility towards inclusive schooling is motivated by two factors. On the one hand, the segregation of pupils with special needs and/or impairment is seen as an act of beneficence because it is only in this type of 'special' setting that the children's individual 'problems' can be met. The aim is to 'save' children with special needs and/or impairment from the 'trauma' of a mainstream schooling. On the other hand, the hostility towards inclusion for pupils with special needs and/or impairment is also fuelled by less charitable motives as children with special educational needs and/or impairment are characterised as deviant and a threat to the education of their peers:**

**It [The Warnock Report, 1978] was a policy that created a classroom revolution - one which has caused chaos and misery for countless thousands of children and their teachers and made many schools all but ungovernable.  
(Phillips, 2005)**

**Despite the apparent opposition towards inclusion in the media, there has been a moderate shift in popular attitudes towards inclusion since Warnock (DES, 1978). Whereas pre-Warnock, many disabled children, whatever their impairment label, were excluded from mainstream education, now the popular mantra is that it is possible to include *some* disabled children in mainstream schools. So 'Physical needs are (with the right resources) more easily met than emotional and behavioural needs.' (Baker, 2005, p 2). The reason given for the distinction between children with physical impairments and others is that children with physical needs need not impact negatively on non-disabled children, whereas children with emotional and behavioural needs necessarily do (Baker, 2005). In the popular imagination, it seems that there is a group of children whose deficits make them so delinquent that no amount of systemic change or resource allocation will render them benign to the school population. In fact, the current 'dogma' is that those who fit current systems with minimum support will be suitable for inclusion – those with challenging behaviours will not (Cole, 2004). It is in this social context that parents' stories are set.**

### *Analyses of parents' attitudes to inclusion*

As part of the academic debate about the policy of inclusion, parents' motivation for mainstream and special schooling has been the subject of comment within the academic community. Connor (1997) offered an analysis of parental choice of special or mainstream schooling. His analysis is based on a bereavement model of parenting a disabled child. He suggests that parents' demands for a special school place stems from the parents' continuing sense of loss for the 'normal' child they hoped to have. This sense of loss, Connor argues, is translated into a focus on protecting the child by sending them to a special setting, rather than on focusing on the child's learning in a mainstream placement. Connor also argues that the wish for special school protects parents from constant reminders of 'loss suffered' when they compare their children to the non-disabled children in a mainstream setting. However, parents who choose mainstream schools do not escape Connor's parental pathology. Parents who choose mainstream do so, Connor argues, because they are in 'denial' about their child's level of difficulties. Conflict about mainstream schooling follows as the parents, who are in denial, make excessive demands for and of mainstream placements.

A bereavement model of parents is of limited use in understanding parents' stories. Here I suggest that parents' stories are not best understood in terms of 'loss' or 'denial'. In what follows, I offer an alternative analysis of parents' motivation for special or mainstream schooling. I reject Connor's (1997) 'bereavement model' analysis and suggest that a social model analysis can be used to develop an understanding of parents' stories.

### **3. Understanding parents' perspectives on inclusion – a social model analysis**

Clearly, inclusion is a common thread in parents' stories often cited by them as a reason for appealing to SENDisT. Here, I argue that parents' stories about inclusion broadly fall into three types:

- those parents who would accept nothing but mainstream schooling for their children;
- those parents who were committed to mainstream schooling for their children, but later changed their minds;



- those who never considered mainstream for their child and always wanted them to go to special school.

A social model analysis is useful here to try to understand parents' attitudes to inclusion. However, the analysis is not straightforward, as the parents' complex and pragmatic engagement with models of disability is revealed.

*'It won't do anybody any good to deny Toby an integrated life' Gina – parents who want inclusive schooling*

Using a social model approach, it seems that parents who chose inclusive schooling for their children, like Ben and Gina, engage with a model of disability which focuses on the need to remove the barriers to children's learning and acceptance within mainstream settings. These parents describe the organisational and pedagogical barriers to their children's inclusion. Their stories reveal attitudes to special education which focus on pedagogical barriers, not within-child factors.

*They [teachers] are responsible for altering the curriculum and the schemes of work to meet the child's needs.  
(Gina, a mother)*

In addition, for parents who want inclusion, mainstream education is seen as a key pathway to an inclusive experience of adult life:

*We feel very strongly about inclusion in society and when we look at, well, why do children have education in the first place? They have education to prepare them for, you know, adult life. So that's where we come from.  
(Barbara, a mother and telephone interviewee)*

Parents who chose mainstream placements for their disabled children tended not to talk in terms of their children's impairment labels, and here they differed from other parents. Crucially, parents who wanted mainstream schooling were sceptical about the objectivity and value of the knowledge of special education. Instead they seemed to place a high value on their own parental knowledge of the child and rejected professional expertise and knowledge (Skrtic, 1995). Remember, Ben:

*He made that judgement after taking Callum into a ten by six foot room and testing him for forty minutes.  
(Ben, a father and key informant)*

Parents who wanted mainstream did not seem to be 'in denial' about their children's level of difficulty (Connor, 1997), rather they accepted their child's difficulties but did not see them as insurmountable barriers:

We are in no doubt at all about where she's at, we know she won't be a great academic, but so what?  
(Barbara, a mother)

Parents who want mainstream education for their children with special needs and/or impairment seem, then, to tend towards a social model understanding of disability. This means that they focus on barriers to physical, attitudinal and systemic barriers to their child's participation, rather than focusing on their child's individual differences. In addition, parents who seem to have an understanding of disability underpinned by social model concepts reveal their scepticism about professional assessments and knowledge, and have more confidence in their parental knowledge of the child.

*'There's nowhere for him to have speech therapy in the junior school' – parents who try mainstream but move their children to special school*

Among the parents who went to Tribunal to secure special school places for their children, there was a group of parents who had initially wanted their child to be included in mainstream schools:

At this stage, we were frightfully keen, realising he was different and so, still trying to include him in the local community.  
(Richard, a father and telephone interviewee)

However, their decision to send their children to special school was not necessarily driven by a change of ideology, rather it was a response to their child's experience in mainstream school. Richard described his son's encounter with mainstream school: 'he was being sort of parked in a corridor, and he was actually being quite literally excluded because he was at the primary school.' Diane also had a wish for mainstream schooling for her son at the beginning but this changed as she felt that her son would get a better education in special school:

I want him to go to his local school and I want him to be part of his community. I have a dream that when he is a teenager, his friends will call round and take him to the pictures. But if I want the best education I might have to move out of the area to be near a special school.

(Diane, a mother and key informant)



Fiona, a mother and telephone interviewee, cited lack of flexibility as a barrier to her son's learning and a reason for her moving him to special school:

[At the junior school] they kept him in to learn spellings and things which he was never ever going to learn and they just wouldn't, they said 'well that's our policy and that's what he has to do, even if it won't benefit ... we admit he won't benefit from it but there's nothing we can do because that is what we do'. They just wouldn't change.

Tina, a mother and telephone interviewee, was motivated to move her son from mainstream school because of lack of resources:

But he may not stay in mainstream ... They have started taking him out of the classroom in the afternoons in the reception class, which he is doing and coping quite well. But they can't do that in the juniors. It is a separate school and they don't have a special needs room for one-to-one. If he's distressed occasionally he'll be taken out of the classroom to do one-to-one work, because we've got a special needs room which is excellent. There's nowhere for him to have speech therapy in the junior school.

(Tina, a mother and telephone interviewee)

Parents like Diane, Fiona, Tina and Richard found that despite the policy shifts towards inclusion since 1997, the barriers to their children's participation, including lack of resources, hostile school cultures, inflexible teaching styles and attitudes to difference in mainstream schools, have not been removed. Parents seemed to have to give up on their initial hopes for a mainstream education for their children because of the effective exclusion their children experienced within mainstream settings. This view was also echoed by a professional, Derek, a panel member and LEA officer, who said:

I find increasingly that the parents look at mainstream, try mainstream and then want out of mainstream.

The parents' stories are reflected in other research. MENCAP (2005) found that for many parents of children with 'moderate learning disabilities' local mainstream provision was their first choice, but parents reported that schools often lacked experience and commitment to pupils and that often pupils with moderate learning disabilities were taught almost entirely by teaching assistants. Parents'

decisions were driven by experience and the need to find environments where their children would not be excluded.

Crucially, these parents' stories differ from the dominant narratives in the news media and from Connor's analysis (1997). The parents did not argue in their narratives that their children could not be in mainstream schools because of their individual deficits or because of the 'damage' they may cause to the education of other children, nor did they suggest that their choice of schooling was motivated by a sense of loss. Rather they focused on the attitudinal barriers and lack of resources which excluded their children and constructed their vulnerability.

A social model analysis (Oliver, 1996) situates parents' experiences within an educational system which continues to construct barriers to inclusion. In a society which focuses on within-child factors and characterises children with special needs and/or impairment as deviant and disruptive, parents can be easily deterred from pursuing a mainstream education for their child. Parents and children are aware that their children are not always welcome in mainstream schools. Toby (aged 7 at the time) told his mother Gina as she picked him up from school 'they don't want me here, mummy'. This hostility to including children with special needs and/or impairment is particularly the case in a system driven by market forces and the drive for ever improving standards (Cole, 2004). When parents find their children are being excluded or when, like Richard and Diane, they feel their children have been denied the support they need to be included successfully in mainstream school, parents look for an environment where their children will be welcomed and for some this means they choose special school. A social model approach suggests that parents are looking for environments where there are fewer barriers to their children's inclusion. For some children and parents, in the current context, special school becomes the only place where they feel their children can be included.

#### *'His very life was at stake' – parents who want special school*

Clearly, not all parents want a mainstream education for their child, even at the beginning of their child's education. Some parents' stories reveal that the parents only ever wanted their children to be educated in special schools. For some



parents, mainstream was never an option for their children. These parents' were less likely to focus on barriers to learning in their stories and more likely to use medicalised discourses and to focus on within-child factors:

If ADHD is unaddressed and untreated and particularly if a person is on the low IQ side ... the prognosis is horrific and it includes depression, suicide, being in trouble with the law, jail, you name it. The worst things that happen in our society happen to people with ADHD .... And, therefore, his very life was at stake, and when viewed in that light you can't do anything else if you've got the means to do it.

(Mary, a mother and telephone interviewee)

Parents who wanted special school also put a high premium on 'professional' and 'scientific' knowledge

It's [special provision] what was recommended by the scientific community.

(Paul, a father and telephone interviewee)

For some parents, special schools are seen as the best chance of their children living a 'normal life' – Pam felt that special school would give her son the chance of a 'normal' life and that he might be able to go to university afterwards. In contrast to parents who want mainstream schooling, it seems that parents who want special school education seem to tend towards medical understandings of disability which put a high value on professional knowledge, from which follows the choice of a school which offers specialist interventions and possibly cure.

There are dangers in offering an analysis based on a typology of parents which locates their responses within social or medical model perspectives. This can suggest that parents' responses are unitary and fixed and that parents sit comfortably within one type. However, *all* parents' perspectives are at times fragmented, inconsistent and more complex than a simple typology can suggest (Goodley & Fisher, 2006 in press, for a fuller discussion of this see also Chapter Seven). The choice of a special or mainstream school placement cannot be used as a simple litmus test to establish whether parents' hold medical or social model perspectives about their child. In fact, parents actively engage with different models of disability (Landsman, 2005) for different purposes, and, often, parents were driven not by ideology, but pragmatism.

#### **4. Problems within and between special schools**

While special schools have been promoted as a 'safe haven' (Warnock, 2005a) for pupils with special needs and/or disability, parents' stories reveal that choosing a special school placement does not mean that the parents will cease to be in conflict with professionals. Some parents went to Tribunal because they were unhappy with the 'package' the special school offered their child. Paul went to Tribunal because the special school his daughter attended would not give his daughter music therapy. Other parents went to Tribunal because they disagreed with the LEA about which special school their child should attend:

There are two autism specific schools in our county, which is why we moved here. The LEA came up with the idea that on top of his autism, Ian had severe learning difficulties, and, therefore, we might want to consider such a school. And that was a total bolt out of the blue which we still don't accept that to this day. Because there are all these Severe Learning Difficulties schools that are half empty, they're putting the lower functioning autistic kids into those and the school that Ian was supposed to go to has actually got 15 empty spaces ....

(Simon, a father and telephone interviewee)

Sue, a mother and telephone interviewee, also rejected the special school chosen by the LEA:

The school had a new head in who seemed to be, to have all the money the LEA had got thrown at him and take in basically what he wanted. And he was taking children with Severe Learning Difficulties, but also he was taking a lot of children with Emotional and Behavioural difficulties and putting them all in one class. And when we went and looked at it, it frightened me. It was full, you know, it had children rolling round my feet fighting and queuing up for their Ritalin at the staff room door. There were holes in the locked doors where obviously someone had thumped them in temper. Children spinning around, nobody seemed to know where they were going. I just didn't like it.

(Sue, a mother)

So, while disagreements about mainstream or special school led parents to Tribunal, conflict within and between special school placements was also a reason for parents to appeal to SENDisT.

The stories reveal that the policy of 'inclusion' is the cause of conflict within special education. However, parents' perspectives differ from the dominant stories in the



news media, as many parents focus on barriers to inclusion within individual schools and systems, rather than their children's 'difficulties'. A social model analysis seems to suggest that parents who lean towards individualised or medicalised models of disability are more likely to choose special schools, whereas those who focus more on barriers to learning rather than within-child factors, will choose mainstream schools, at least at the beginning of their child's education. However, the limitations of a simple typology should be acknowledged.

Parents' stories suggest that choosing special schooling is not the panacea to the 'problem' of inclusion that has been suggested (Warnock, 2005a) and that conflict is just as likely to arise within and between special school placements as it is in mainstream schools. Inclusion is an issue which continues to evoke high emotions among those on both sides of the argument. In 1996 Oliver argued that:

Individual impairments of whatever kind are not the cause of the problem, rather it is society's failure to provide adequate services and to meet the needs of disabled people.

Yet within education and society the dominant discourse is that of the 'personal tragedy' of disability (Oliver, 1996), and while society as a whole struggles to include disabled people, the process of inclusion in schools will be fragile.

The policy landscape reveals the seemingly inherent potential for conflict embedded within current policy. However, the tensions which lead parents to SENDisT are, perhaps, only due in small measure to the nature of policy issued at the level of central government (Fulcher, 1999). In reality, policy is made and interpreted by individuals at all levels in any system. The paramount factor in successful outcomes for children with special educational needs is, perhaps, a positive attitude among all the adults involved with the child working together (Hunt, 1994). This means that adults must be flexible, compassionate and accepting of children with differences in schools. In the next section, we consider what parents' stories reveal about the ways in which parents and professionals work together: the relational landscape.

## **SECTION TWO: The relational landscape**

The description of the policy landscape, in which parents' stories are set, suggests a context for conflict. However, it is often the individual relationships between parents and professionals which drive and sustain conflict, so here we consider what parents' stories also reveal about relationships in their stories: the relational landscape. All the parents' stories demonstrated to a lesser or greater extent the complexities of parent-professional relationships. It is not surprising that parent-professional partnership breakdown was seen, by parents and professionals, as a key factor in explaining why parents go to SENDisT. Both Ben and Pam's stories are highly illustrative of the breakdown of relationships between parents and a variety of professionals. In order to develop an understanding of the nature of these partnership failures, I draw on the work of two postmodernist philosophers: Rorty and Foucault (For a fuller discussion see Chapter Two). Foucault's concept of 'power and resistance' is used to develop an understanding of the complex power relationships which are played out between parents and professionals. Rorty's concept of 'solidarity' is used to tease out the reciprocal construction of 'otherness' by parents and professionals towards one another.

### **1. Power and resistance in parents' stories (Foucault, 1973, 1977)**

A key theme in the narratives was the exertion of and resistance to power between parents and professionals. The relationships between parents and professionals can, perhaps, best be understood as power relationships. In these relationships power is understood to be exercised and not possessed; it is multidirectional in its operation both top down *and* bottom up, as well as circular; power is not primarily repressive but also productive (Foucault, 1990). The stories suggest that parents and professionals struggle over the discourses which describe the children, they struggle to control the relationships between parents and professionals and, crucially, they struggle over the allocation of resources. These conflicts are underpinned by conflict over knowledge.

Parents are 'quite simply the best authority on their own lives, experiences and views' (Stalker, 1998:5 cited in Allan, 1999, p2), so it is crucial to examine the parents' perspectives in the context of the power-knowledge relationship in which they were acquired. Here the work of Foucault seems to provide a useful tool of



analysis (Foucault, 1973, 1977). Allan (1999) suggests that from a Foucauldian perspective, pupils' accounts of special education can be seen to create a space in the relationship between the pupil and the professional in which there is a two-way gaze 'with the figure of authority turning its gaze on the victim and the victim looking back' (MacCannell and MacCannell, 1993: 214 cited in Allan, 1999, p 2). Whereas Allan considers the effects of a professional gaze upon the pupil, in this study the focus is the professional gaze upon the parent. In this way, it is possible to analyse the ways in which parents feel constrained within their relationships with professionals as well as considering how parents resist the power exercised upon them. Issues of power imbalances within parent-professional relationships have often been noted in research (Wood, 1988; Dale, 1996; Armstrong, 2003; Cole, 2004), and parents' stories make specific references to the exertion of and resistance to power.

### *Power and Subjects*

Foucault (1973) is concerned with the ways in which individuals are constructed as social subjects, knowable through disciplines and discourses (Allan, 1999). Foucault argued that the effect of the mechanisms of power was to construct the individual as a subject in two senses:

- as subject to someone else, through control and restraint;
- as subjects tied to their own identity by their conscience and self-knowledge and subjectification.

(Allan, 1999)

A central theme for Foucault is the way in which the professional 'gaze' constructs the individual. In *Birth of the Clinic* (1973), Foucault illustrates how the medical gaze has opened 'a domain of clear visibility' for doctors by allowing them to construct an account of what is going on inside a patient and to connect signs and symptoms with particular diseases. Within special education, Allan (1999) uses the Foucauldian concept of 'gaze' to suggest that the surveillance by special educators of pupils with special educational needs constructs pupils as passive subjects, amongst other things. Within this study, I argue that just as the gaze of special educators constructs pupils as passive subjects, the professional gaze upon

parents also constructs the parents as passive subjects. The parents' stories show them resisting such subjectification with varying degrees of success.

Allan's study (1999) revealed how children with special educational needs are put under close supervision by teaching assistants, teachers, head teachers, parents and others, and that a network of power relations is, thus, established; this is what Foucault terms 'hierarchical observation' (Allan, 1999). Whereas all pupils are the objects of scrutiny at school, for pupils with special educational needs the scrutiny is pervasive. For example, children with special educational needs and/or impairments are routinely scrutinised in the playground and their social interactions are seen as suitable targets for interventions. For a child with special needs and/or impairments, all aspects of their interpersonal relations are considered suitable for the scrutiny of staff. In turn, this legitimises a search within the child for signs that he or she is happy or gaining confidence, to an extent that teachers would not scrutinise 'mainstream' children (Allan, 1999).

However, this form of intrusive gaze is also applied to the parents of children with special educational needs and/or impairments. Parents are observed interacting with their child and with professionals. The parents' interpersonal relationships, too, are considered worthy of scrutiny and every aspect of family life is seen as a legitimate area of inquiry. The constant round of meetings to plan Individual Education Plans and Annual Review meetings offer opportunities for professionals to scrutinise parents' responses to their children. The methods of communication between home and school with regular chats or a home-school diary give professionals the opportunity to scrutinise every area of the families' life.

Just for once we'd been out for the weekend, and David was tired on Monday morning. So I had a note in the home-school diary [written by his teaching assistant] 'David was tired today at school. Please can you make sure he goes to bed early tonight.'  
(Donna, a mother and key informant)

Parents are encouraged to be 'open' for the sake of their children so that every aspect of family becomes suitable for the professional gaze and for professional comment. Parents, like their children, are then subject to hierarchical observation, and, just as for their children, the network of scrutiny is extensive including



teachers, teaching assistants, therapists, paediatricians, taxi drivers and escorts, and others.

### *Surveillance and control*

The surveillance, which forms part of the process of hierarchical observation, implies control. Professionals scrutinise and judge parents with the aim of influencing their behaviour. In this study, parents described what were sometimes insidious forms of control employed by professionals which threatened to render the parents as passive subjects. LEA officers, in particular, were described as trying to manipulate and disempower parents.

Parents repeatedly described LEA officers as showing 'insensitivity', 'not caring', 'lying' and of 'playing dirty tricks' or 'tactics'. They also gave examples of LEAs not complying with legal requirements (IPSEA, 2005a):

They [the LEA] provided a monitoring statement, it's a statement with no funding, a plate with no food ... my charity think it's illegal.

(Mia, a mother and telephone interviewee)

The LEAs were also accused of failing to carry out the statutory assessment within the time limit and were accused of delaying the process unnecessarily:

There was no trouble getting the proposed statement, the proposed statement came through faster than the guidelines times, but it then took nine months and the threat of legal action to get the final statement.

(Fiona, a mother and telephone interviewee)

The LEA's failure to issue a final statement meant that under SENDisT's rules, Fiona was unable to appeal to Tribunal.

When statements did come they were often vague (IPSEA, 2005a; ACE, 2005), contrary to the guidance in the *Code of Practice* (DfES, 2001a):

The statement was very, very vague ... there was no mention of how many hours he'd get. They just said we will provide funding for a learning support assistant. So we got it in the end to ten hours [Learning Support Assistant time] ...

(Ivor, a father and telephone interviewee)

Some parents felt they were deliberately misled about the legal duties that the LEA have. Diane was told that she could not have a specific statement as her child has a placement in an integrated resource school and that integrated resource statements were different from 'mainstream' statements. Sally was told that the LEA couldn't statement her son because he did not fall into the bottom 2% of all children and that it was 'illegal' to statement a child for dysgraphia. The *Code of Practice* (DfES, 2001a) makes no distinction between resource school statements and others, nor is there any legal requirement for children to fall into the bottom 2% to be statemented.

Some parents felt that LEAs 'fixed' their evidence either by omitting evidence:

What was interesting was that the LEA did not put any of Peter's hand-written work in their case statement as evidence. The only piece of Peter's work was a typed spelling test. We thought the LEA didn't want the panel to see how bad Peter's work was.

(Sally, a mother and key informant)

Sally felt that the LEA were deliberately trying to control the information available to the panel in order to divert attention away from her child's difficulties. Leo, a father and telephone interviewee, shared the same concern. He described his child, Max, as having Asperger's Syndrome and felt that his strengths were with computers not people, so he was frustrated when the psychologist's assessment took place during an IT lesson:

There were dirty tricks played by the LEA as we were going to Tribunal. The Educational Psychologist hadn't seen Max for three years, so they sent him to look at Max in an IT lesson. This is a child who has social communication difficulties so they sent the Ed Psych to watch him working on his own at the computer. That is one of his strengths. All the LEA try to do is minimise the evidence.

(Leo, a father and telephone interviewee)

Both Sally and Leo felt that the LEA were deliberately controlling the available information for their own ends.

While parents sometimes described the ways in which they felt the LEA tried to control information, they also described the ways in which they felt the LEA was trying to control their behaviour. Sometimes what they described, they felt, had been treated as tantamount to bullying:



Then two days before the hearing date, I had a phone call from my psychologist saying the LEA had contacted him [the psychologist], and asked him if I would ring them to see if this could all be resolved before the hearing. I was hopeful that we could sort something out and I wouldn't have to go. So while I was at a friend's house, who was trying to help me to prepare for the Tribunal, I rang the LEA. I explained that I'd been asked to ring and that I understood they wanted to negotiate before the Tribunal. Her answer was 'No, sorry, no. We are not prepared to come to any agreement. I'm afraid we can't possibly provide the kind of provision that you are asking for in that type of school. I suggest you go and look elsewhere.' Those were exactly her words. I felt as if I'd been set up, it felt like they were trying to bully me.

(Diane, a mother and key informant)

Diane went on to describe how vulnerable this conversation made her feel. She began to feel that she might be being unreasonable in her demands for her son George's schooling. She also feared that George would end up with no school placement because she had challenged the LEA.

A key difficulty for parents was when they went through the process of preparing for Tribunal only to find that the LEA agreed the provision the parents wanted at the last minute:

Then on the day we had to put in our case statement, a lady from SENDisT phoned me and said that the LEA had conceded and the LEA would do a statutory assessment for Peter. I think they hadn't prepared their case statement, so they had no choice but to concede. Of course, we had spent a lot of time preparing our statement!

(Sally, a mother and key informant)

Gina was refused her offer to negotiate before Tribunal and then the LEA agreed to negotiate at the hotel, just before they went into the Tribunal, and so the order was given 'by agreement'.

Parents felt that delaying tactics were used as a matter of course:

The delaying tactics they [the LEA] employed in dealing with it was just extraordinary, extremely skilful on their part you have to hand it to them, but totally immoral from a kind of moral perspective what they were doing so they managed to fob the whole thing off and lead us a merry dance in circles.

(Mary, a mother and telephone interviewee)

Colin, a father and telephone interviewee, felt that many parents would be 'scared off' by the LEA's tactics, and that this was a deliberate strategy on the part of the LEA. Parents felt that 'dirty tricks' were employed to stop parents going to SENDisT, and that the LEA tried to exploit parents' lack of knowledge of the law and policy to the LEA's best advantage.

Panel members, too, were aware of deliberate delays on the part of the LEA:

Some LEAs definitely mess about, they will settle cases the day before the hearing. Now the charge on the public purse is prohibitive. I mean I think somebody once said to me it costs about £10,000 to get the Tribunal heard, by the time you've taken all the admin and all the rest of it. So they've now settled the day before and it is patently obvious they should have settled six months before. Now I think that that there is a capability to put the charges onto the LEA. It has never been done, but I think it ought to be, and there ought to be some mechanism where an independent person or group can come to a conclusion about this if need be ..... There's another thing, there's no monitoring of members by the management of the Tribunal.

(Derek, an LEA officer and member)

Yet, as Derek, suggests SENDisT are unable to hold the LEA to account over delays. Sometimes the panel members' frustration was clear - Thomas, a Tribunal Chair, felt that 'some LEAs are just diabolical about the way they treat parents.'

Parents' stories reveal the ways in which they are scrutinised, manipulated and disempowered by some professional practice. Parents struggle to resist in a system which offers them little hope of redress if the parents are judged to have been treated unfairly.

### *Power and resources*

Above all, parents' stories reflect an underlying conflict between parents and professionals about resource allocation. The conflict concerning resources takes place against a background of increased marketisation of schooling and special education provision (Cole, 2004). Parents have become the consumers of education services in the market place (Simmons, 1996). There is a sense in which the effective parent is also the effective consumer. So parents of children with special educational needs and/or impairment are regarded less favourably than



other parents because their demand for resources is greater. The inevitable result of scarce resources is that parents of children with special needs and/or impairments are driven into demeaning relationships with professionals as they plead for resources and services (Wood, 1988).

Parents described how resource implications affected every aspect of their child's education, including the children's placement at school. Barbara, a mother and telephone interviewee, felt this was the key factor which led to the LEA suggesting a special school place for her daughter:

She had a statement and basically the school was claiming that she needed more hours, they went to the LEA and they refused ... numbers at the special school were low at the time.  
(Barbara, a mother and telephone interviewee)

The pressure around resources was acknowledged by panel members too:

Too many LEAs start on the basis 'we know what's best, we're now going to have consultation and be seen to be modern and progressive about how we deal with these things and we are very happy to do all that, provided we don't have to move our position one iota because my job's on the line if I allow my SEN expenditure to increase.'  
(Thomas, a Tribunal Chair)

Another Chair commented on the issue of resources, citing budgetary constraints as a key difficulty for LEAs.:

I suspect there's a feeling that they are guarding budgets because on that panel there are primary school heads, secondary school heads LEA officers and they recognise that every statement means a potential hefty drain on the budget. I mean maybe I'm wrong, but I can't think of other reasons why you can have a dossier on your desk where one and sometimes two LEA psychologists have submitted reports saying this kid's got X, Y and Z he needs a statement, the school have been in and said 'well we can't reach this kid he needs a statement' and then this group meeting once a month somewhere says, 'no, no you've got it all wrong.' I mean what other conclusion can you come up with?  
(Derek, a Tribunal Chair)

However, conflict about resource allocation was not always about significant amounts of money:

We had letters from school saying that they couldn't even afford a lap-top for the head of department, there was no way that Leah was gonna get a lap-top ... we actually bought her a computer in but

they weren't going to insure it, so we thought alright you can at least take that responsibility for its security given that we've had to pay for it, but we need it on her statement....  
(Michelle, a mother and telephone interviewee)

The school's refusal to insure the lap-top seems to be part of the wider conflict between parents and school.

The system of statements of special educational need focuses on the individual needs of children with special needs and/or impairments. The educational provision a child receives is tied to the 'needs' the child is believed to have. When parents and professionals disagree about the child's 'needs' conflict about provision follows. As Foucault suggests, what constitutes knowledge about a child's needs is problematic. Knowledge is linked to the exercise of power and to the allocation of resources. The views of the professional are, then, often considered to have more weight than those of the parents. Crucially, the LEA has the power to make an assessment, *and* to allocate resources to meet the needs identified by their assessment. This link between assessment and resource allocation leads parents to feel that when LEAs set out the needs of a child in a statement, the description of the child is influenced by the amount of money available to meet those needs, and not by what is in the best interests of the child. Parents enter into conflict with the LEA over the assessment and allocation of resources and, ultimately, about the constructions of 'specialist' knowledge about their child.

### *Knowledge and resistance*

One of the most important themes in Foucault's work is his evolving description of what knowledge is (Foucault, 1977). For Foucault, knowledge, itself, is just another effect of discourse, although it is a pervasive and important effect (For a fuller discussion see Chapter Two). Knowledge becomes the unstable, complex set of relations which make it possible for a statement to qualify as knowledge. The history of special education knowledge has been told largely by policy makers and the professionals who have constructed the structure of special education (Armstrong, 2003) and within the structure, professional knowledge is seen to be objective, not an unstable complex set of relations (See Chapter Two). The special



education sector has assumed a knowledge of its own which has, at times, served the interests of the mainstream sector by removing 'troublesome' children. The interests of professional groups are furthered as their 'specialist' identities are legitimated by the system (Armstrong, 2003, p82). There continues to be an assumption within the system of special educational needs that there is 'specialist' knowledge which is privileged above parental knowledge (See also Chapter Two).

Within the special education system, the concepts of 'intelligence' and 'need' are taken to have a straight forward meanings, but as Foucault (1977) argues, there is no language which is not contaminated by power relationships. Special education remains dominated by cultural orthodoxy – what Bourdieu describes as *Doxa* (Thomas and Loxley, 2001) - which serves to oppress powerless groups (Skrtic, 1995).

The dominance of a discourse of special education of power and knowledge means that: 'many [parents] may find themselves in the difficult position of trying to insist that their child be treated as 'normal' and socially integrated whilst at the same time arguing for additional resourcing and, perhaps, placement in a special setting.' (Riddell, 1996, p101.) This leads to confusion and frustration for parents working with professionals.

The stories reveal that parents engage with professional knowledge in different ways. Some parents attempt to 'buy in' professional knowledge by appointing their own psychologists to support their claims about their child. They choose the 'professional gaze' which they hope will support their views; for parents some 'professional gazes' are more helpful than others. On the other hand, they resist professional constructions of their children which they find unacceptable by seeking alternative professional views. For these parents, professional knowledge itself is not problematic, they simply do not agree with one professional view and try to resist it with another.

I paid to see an educational psychologist myself, which proved exactly what I thought, that she had an extremely high IQ, she's in the top 2%.

(Michelle, a mother and telephone interviewee)

I've just had a private assessment done, and it's very opposite to their's [the LEAs]. They say he's only mild and my private says severe. So I'm very dubious, I'm not saying they are not being truthful but I think they bend the truth a bit.

(Tina, a mother and telephone interviewee)

One mother realised the potential benefits of acquiring and using professionalised discourses in her battle with the LEA:

With having a Cambridge educational background I was well set up to do that because I knew how to do research. And it had to get to the point, where I knew and I still do, know more about ADHD than the people in the LEA.

(Mary, a mother and telephone interviewee)

Mary was keen that professionals should be aware of her academic status. She seemed to feel that this had had an impact on her dealings with the LEA. Indeed, Mary may have been justified in thinking this was the case, as she was the only parent in this study who settled her differences with the LEA before the Tribunal hearing.

Another mother, Margaret, felt disempowered because she was unable to use professional discourses.

I felt he [LEA officer] had a personal vendetta against me, because I was I farmer and I know nothing.

(Margaret, a mother and telephone interviewee)

Mary and Margaret were both acutely aware of the power of professional judgements. Mary challenged professional judgements by asserting her academic status, whereas Margaret felt unable to do so. Yet, some parents refused professional judgements, by challenging the status of professional knowledge claims about their children. Some parents simply rejected professionalised discourses, asserting, instead, the status of their knowledge, as parents, about the child. In Ben's story, we see Ben refusing to use professionalised discourses and challenging professional judgements by turning them back on the psychologist.

The inherent tension for parent-professional relationships is that parents feel that they are able to focus on what is best for their child exclusively while professionals are obliged to focus on the best use of resources (Connor, 1997). Parents and



professionals have necessarily different aims which makes partnership difficult. However, when professionals and parents focus almost exclusively on the differences between them, partnership becomes impossible. In the next section, Rorty's concept of 'solidarity' is seen as a useful tool to explore the differences between parents and professionals.

## **2. 'Solidarity' (Rorty, 1989), parents and professionals**

Rorty (2000, p213) identifies the root of conflict between groups of people as their inclination to regard those who are different as the 'other'. This failure on the part of individuals or groups to recognise one another's common humanity (Rorty, 1989) is the key cause of discord which results in a lack of 'solidarity' with the 'other' and conflict between groups occurs. The parents' stories reveal how both parents and professionals describe and re-describe one another in ways that emphasise the differences between the two groups. At times, the distinction between 'us' and 'them' is not simply one of 'professional' or 'parent' - differences of class, gender, ethnicity and/or disability may equally contribute to the process of 'othering' which takes place in the parent-professional relationship. It is the failure to see each other as 'one of us' rather than as 'other' which contributes to the breakdown of parent-professional relationships and leads to conflict (Runswick-Cole, 2006).

### *Professionals and the 'Other'*

Ben's story is, perhaps above all, about his experience of being 'othered' by professionals; Ben reveals how he is seen as the 'other' at every level of the parent-professional relationship. Ben finds himself in conflict with teachers who he said 'thought that we were complaining about what they were teaching and how they were teaching it.' Then, Ben was in conflict with the LEA psychologist who told Ben that Callum would 'never achieve anything in life.' Ben also talks of a breakdown in the relationship with the LEA when he realised that 'the LEA had lied to us'. And finally, the relationship with the impairment based charity worker breaks down when the charity worker holds a meeting with the LEA, which excludes Ben, outside Ben's house. None of the professionals in Ben's story seems to feel the need to justify their beliefs to Ben or to find out what Ben's beliefs are

because he is the parent of the disabled child, and not, therefore, one of 'us'. Partnership breaks down and conflict ensues.

Partnership is a key theme within policy texts (DES, 1978; DfES, 2001a) and parents' stories (Murray and Penman, 1996, 2000). At its most simple, partnership implies two or more parties working together, however, Dale's (1996, see Chapter One) models of partnership suggest that the workings of partnership can be much more complex. Parents of children with special educational needs and/or impairment are much more likely than parents of children not so labelled to have prolonged and frequent contact with professionals, whether it is their child's teacher, psychologist, health care worker or LEA officer (Vincent and Tomlinson, 1997, cited in Martin, 2000). Whereas parents of non-disabled children may see their child's teacher at termly parents' consultation meetings, parents of children with special needs and/or impairment meet frequently with professionals at assessments, meetings to discuss individual education plans (IEP) and Annual Reviews. Although parents of children with special needs and/or impairment are often called upon to work with professionals with a closeness that parents of typically developing children are not, it is the school which usually determines the form and regularity of the contact (Solity, 1992). One of the mothers described the difficulty this caused:

This was another thing they [the school and the LEA] kept changing the dates of the meeting and we were really cross, because we had a date, my husband was in England at the time and then they couldn't make it.

(Mary, a mother and telephone interviewee)

The level of contact between parents and professionals has meant that this relationship has long been a focus of policy makers' attention. Since the term 'partnership with parents' was first declared as a key aim of the Warnock Report (DES, 1978, See Chapter One), it has generally been regarded as a 'good thing'. Partnership is seen as both desirable and beneficial to the child (Murray, 2000). However, both in policy (see Chapter One) and in practice, the notion of partnership remains unclear. Partnership with parents continues to be a term favoured by politicians, policy-makers and practitioners, but questions have been raised about the reality of partnership and it has been suggested that there is little evidence of real partnership between parents and professionals (Armstrong, 1995).



Indeed Warnock, herself, re-ignited the debate about partnership when she called instead for 'collaboration' (Warnock, 1985 cited in Blamires, 2001). This suggests that parents should be 'informants' but not necessarily 'partners' in any decision-making process (See Chapter One for a fuller discussion of models of partnership). Warnock is drawing a clear distinction between 'professional' and 'parent' or 'we' and the 'other' (Rorty, 1989). This distinction means that partnership with parents continues to be negotiated and contested within current policy, guidance and practice.

There are examples in the current policy of attempts to re-describe and re-frame the role of parents within special education, what Rorty might describe as attempts by professionals to show 'solidarity' with parents (Rorty, 1989). The current *Code of Practice for Special Educational Needs* (DfES, 2001a) emphasises that parents are considered to 'have a vital role to play in supporting their child's education' (DfES, 2001a, p7). The *Code* affirms that parents hold key information and have a critical role in their children's education (DfES, 2001a, p17) and that they have 'unique strengths, knowledge and experience' (DfES, 2001a, p17), which means that 'All parents of children with special educational needs should be treated as partners' (DfES, 2001a, p17). Indeed it states that parents' concerns should be treated in the same way as if a teacher had raised those concerns, in other words, the *Code* exhorts professionals to treat a parents as 'one of us', stating that 'Stereotypic views of parents are unhelpful and should be challenged' (DfES, 2001a, p17). Yet the parents' stories suggest that this understanding of partnership is not always reflected in everyday experience and that parents continue to be treated as 'the other' by professionals. Indeed Armstrong (1995) suggests that the bureaucratic re-description of parents as partners may really be part of an attempt to facilitate the smooth operation of the procedures, and thereby removes 'genuine' power from parents.

While a shared sense of purpose, or 'solidarity', is crucial to working in partnership (Pugh et al., 1987, cited in Cole, 2004), parents consistently described their feeling that professionals failed to share a sense of purpose with them.

I'm pretty confident that they [the LEA] don't want to help Ryan, they're just there to try and get out of it.  
(Mia, a mother and telephone interviewee)

Indeed, Bowers (1995, cited in Connor, 1997) offers an analysis which highlights examples of parents 'othering' professionals. He describes an education context in which parents regularly attribute negative characteristics to professionals, particularly to LEA officers, but attribute their own behaviour to situational factors such as lack of resources or stresses in the home. Although Bower's (1995, cited in Connor, 1997) claim that parents ascribe negative characteristics to professionals is evident in the stories, it is worth noting how this may have come about. In this study, several parents expressed a willingness and expectation that they would be able to work in partnership with professionals, at the beginning of their children's education. Ben's description of teachers at Main Road suggests a respect for teachers as he describes the head teacher as 'really nice' and the teachers as 'superb'. Leo, a father and telephone interviewee, felt at first that 'the LEA was there to help us', just as Tina, a mother and telephone interviewee, thought that the 'LEA case worker and I would be in partnership'. Parents' stories suggest that parents do not invariably see professionals as the 'other' and, indeed, they do not expect that this is how they will be seen by professionals.

However, the parents' stories suggest that feelings about teachers and other professionals are changed by the parents' experience of working with them over time. Indeed, Leo, who had felt at the beginning that the LEA were there to help, concluded his story by saying:

I should say I'd still break if the LEA officer crossed the road in front of me, I just wouldn't do it quite so quickly... I might break later! I can understand how some people wouldn't break! The evil that has been done to us, they 'know not what they do'. I have to believe that those people don't actually realise how hurtful and nasty they are ....

(Leo, a father and telephone interviewee)

Leo began with a positive attitude to LEA officers which became hostile. This experience differs from Bowers' analysis that parents ascribe LEA officers with negative attributes from the start of their relationship with them. Yet Leo's description of how partnerships broke down suggests that there was a failure on the part of professionals (and, perhaps, on Leo's part) to show 'solidarity' with 'the other'. The result is that conflict follows.



### *Solidarity and 'the other'*

In Chapter Two, I argued that Rorty's concept of solidarity is key for understanding conflict between groups. Rorty argues that solidarity can be achieved by learning more about others (description), so that we become more sensitive to the pain suffered by unfamiliar people. In turn, by learning more about ourselves (redescription), we reinvestigate ourselves. Remember, for Rorty:

The principal source of conflict between human communities is the belief that I have no reason to justify my beliefs to you, and none in finding out what alternative beliefs you may have...  
(Rorty, 2000, p. 15)

Rorty emphasises the need for people to *justify* their beliefs to one another in order to achieve 'Solidarity' (Rorty, 1989). The process of justification requires groups and individuals to share their beliefs with one another. Yet the narratives show that there is an absence of justification and that this absence leads to conflict. Ben feels unable to share information about Callum with his teachers and this frustration was shared by other parents:

I tried to explain to them [the teachers]... they don't really want you to give them any information. They think they know it all and if I saw his teacher now, I'd poke her eyes out because I just think how dare you be like that with me, when I'm trying to communicate with you about my son.  
(Kirsty, mother and telephone interviewee)

Similarly, Leo expressed his frustration at not being able to share his knowledge of his son with the school:

What we are trying to do [with teachers] is help them to understand Max, and they need to take time out to understand Max and they need to allow us to help them to do this. It is quite a challenge to actually go through that process.  
(Leo, a father and telephone interviewee)

However, just as partnership relationships break down when parents felt unable to give information to professionals, partnerships are strained when parents feel that professionals will not share information with them. Parents described some professionals' reluctance to share information. Sometimes, psychologists would not share information about the child's assessments and sometimes teachers

refused to share details of the child's day at school with the parents. Diane told of how she felt alienated by her son's school when she wanted to ask for information:

Other mums have been shouted down and cried and still been shouted at because they've asked about provision and they've been told that the teachers are sick of being asked. I don't want that to happen to me!

(Diane, a mother and key informant)

Gina also felt that the school would not share information with her:

At the beginning of Year 2, I began to suspect that Toby was not being educated in the classroom with his friends. At first there were a few hints from other parents. It was clear that Toby wasn't building up any friendships and his speech and language skills were not improving. At the end of Year 1, I'd been given a lot of Toby's work but at the end of Year 2 all I got was a few pieces of paper with not much on it. I asked for the missing work and I've never got it. Toby was also supposed to be getting full time one to one support from a teaching assistant. I found out later that he didn't get it. I don't know what happened to Toby during that time.

(Gina, a mother and key informant)

Parents were frustrated when they were unable to give professionals information about their children and they were upset when professionals would not give them information about their child. The difficulties parents experienced in passing and receiving information from school seem to be both the symptom of their conflict ridden relationships and the cause of further conflict.

Rorty's concept of solidarity, then, seems key to whether the partnerships work or breakdown. Some professionals were clearly committed to partnership working focusing on the importance of receiving and giving information:

It is about recognising that the parents first of all have valuable knowledge about that child .... Just listen to them ..... It is about working together and mutual understanding, but I want to go beyond that and expect them to inform us and to improve the way we do things.

(Karen, a panel member & LEA officer)

Karen clearly describes information sharing as a two-way process. However, another professional, Tim, also an LEA officer, describes sharing information as a one-way process:

[Parent partnership] means sharing with parents all the knowledge you have about the child, what the Authority is able to offer the



child, what we feel is the best provision, and being quite open with [parents]. Share with them all the information that you have available so that they know why you have made your decision.  
(Tim, a panel member and LEA officer)

Tim clearly sees partnership as the LEA explaining their beliefs to the parents, but he makes no mention of asking what beliefs parents hold. Here the professional wishes to control the parent–professional relationship, assuming the role of ‘decision maker’ and ‘expert’ (Dale, 1996), rather than integrating and consulting parents in a negotiated decision-making process. Parental needs and issues are limited by professional control (Oliver & Barnes, 1998 cited in Case, 2000), in a way which marginalises and ultimately disempowers the parent (Appleton & Minochom, 1991, cited in Case, 2000).

Wolfendale’s (1997) analysis of local education authorities’ special needs documentation for parents contributes to the view that there is a mixed level of commitment on the part of LEAs to listen to parents. In the documentation for parents Wolfendale examined, half of the 67 LEAs had documents which encouraged parents to contribute to the statutory assessment of their child, but a quarter of those offered only very weak encouragement to do so – this meant that the documents were unclear about the parents’ role in the assessment or that they were not made readily available to parents. Wolfendale’s study took place before the introduction of the current *Code of Practice* (DfES, 2001a), yet parents’ experiences and some professional’s attitudes to partnership suggest that some LEAs’ commitment to partnership remains equivocal. Other studies have shown that some LEAs have a weak commitment to sharing information. Beveridge (1997 cited in Jones and Swain, 2001) found that parents felt that they were not heard at Annual Review meetings, and Tissot (2005) reported that working with the LEA was identified as the most stressful aspect of the lives of 54% of parents of children with autism.

However, despite the recurring theme that parents feel that they are not given the opportunity to share their beliefs with professionals, some researchers have still offered an analysis which locates the problem in the parents’ ‘otherness’. As the parents’ ‘guilt’ or ‘anger’ or ‘distress’ over the child’s difficulties may be directed

towards the LEA or individual therein and a negative cycle of poor relationships will be established.' (Connor, 1997, p108). Connor's analysis reveals the assumption held by many professionals that parents are 'hostile'. However, as Azzopardi (2000) suggests, parents are categorised as well adjusted only if they are able to work in partnership with professionals, whereas they are categorised as difficult when they ask for additional information or quality assurance. Connor's interpretation seems to stem from what Todd (2003) has described as a 'deficit' discourse of parents where parents are described as needing professional help to parent their children with special needs and/or impairments. This suggests that the refusal to partner parents often stems from a professional adherence to a deficit model of parents who have children with special needs and/or impairments which focuses on the 'disadvantage' arising from the child's impairments and the parents' adjustment to living with a child with impairments, rather than focusing on institutions and systems or professional assumptions and attitudes.

#### *'Justifying' the difference – the infidel and the foreigner*

Discourses which describe the differences between parents and professionals sustain the parent-professional relationship as 'them' and 'other.' A professional discourse which describes and re-describes parental deficits sustains a position in which professionals have no need to justify their beliefs to parents. By focusing on the deficits of parents and children, parents and children are categorised with the 'infidel and the foreigner' (Rorty, 2000). A deficit model of parents and children with special needs and/or impairment is built on the assumption that it is the presence of a child with an impairment in a family which always and necessarily disables the family (See chapter Six). Within this deficit model, the needs of the family and child are seen to require interventions from professionals focused on curing or preventing the child's impairment. Stresses on families are seen as occurring as a direct and inevitable result of the child's impairment (Sloper, 1999). Bruce and Schulz (2001) describe parents of disabled children as suffering from 'non-finite' loss to describe a pervading sense of grief from which all parents of children with special needs and/or impairments suffer. Bruce and Schulz (2001) suggest that professionals are uniquely able to empathise with parents given their experience as 'counsellors, educators and researchers'. So a deficit model of parents and children is also one in which 'you, the parent and child, are the



problem' whereas 'I, the professional, own the answers'. Parents are pathologised to the extent that they are no longer referred to as parents but as 'grieving clients' (Bruce and Schulz, 2001). In contrast, personal accounts (e.g. Murray & Penman, 1996, 2000), which challenge and resist these pathologised conceptions of family life, are, at times, de-valued in the academic community and by professionals (Russell, 2003). Again, the distinction between 'them' and 'us' and the lack of 'solidarity' between groups becomes evident (Rorty, 1989).

Allied to a deficit model of the family is a form of 'parentology' (Wood, 1988) which sees the child's performance as the measure of parental competence. Thus the child's lack of 'progress' is blamed on unco-operative or challenging parents. Indeed, some research into teachers' views on the nature of children's difficulties implies that teachers are likely to suggest that difficulties are often caused by the child's home background. This attitude cannot be an encouraging basis for parent-teacher collaborations. (Solity, 1992). It is yet another example of a professional group marking the difference between itself and parents.

### *Parents as 'the infidel'*

Parents' stories show the frequency with which parents are almost routinely pathologised by professionals. One mother experienced an extreme form of 'mother-blaming' (Read, 2000):

My son went into school as Leah went into year six, and had major problems, behaviour problems, because I asked for help with that they started going for it big time, saying that I had said the same about both children, and Munchausen's came into the picture, it wasn't officially made but there were definitely suggestions. I found out by accident that they'd been involved in a meeting and hadn't told me.

(Michelle, a mother and telephone interviewee)

Other parents had similar experiences:

The head teacher told my husband 'To be quite honest it would be better if your wife got a job and let Christopher stand on his own two feet.'

(Fiona, a mother and telephone interviewee)

This pathologising of parents led to parents being accused of being over protective:

He [the LEA officer] even had the audacity to say 'in my view, you are giving him too much, you are over-providing for him now, you are molly-coddling him and you are stifling.'  
(Ivor, a father and telephone interviewee)

Often the literature has concentrated on the psychological aspects of parenting children with special needs and/or impairment (Bruce and Schulz, 2001). Parents have been blamed and pathologised in relation to their children's impairments, particularly in the case of children perceived as being on the autism spectrum or with labels of ADHD (Cole, 2004, p51). In a 'mother-blaming' culture (Read, 2000), Cole (2004) describes how negotiating with professionals has become the most difficult part of being a mother of a child with special needs and/or impairment, especially when parents fear that to comment or to act will run the risk of being written off as someone who either exaggerates their child's difficulties or is over protective. Parents also run the risk of being seen to underestimate their child's difficulties and failing to accept their child's 'condition' (see also Chapter Six).

Parents who advocate for their children find themselves negotiating with professionals who may hold a deficit view of their family. At the same time, many non-disabled parents, who are often the products of a segregated education, may have had little or no contact with disabled people before having a disabled child. This puts the parents in a vulnerable position with professional 'experts' (Murray, 2000). Parents find themselves having to work in partnership with professionals who see parents as pathologised, objectified and lacking in competence. The unquestioned, rock-solid set of terms or statements that serve as the basic foundation or grounding of statements of truth, the final vocabularies of special education, validate professional knowledge and de-value parental knowledge (For a fuller discussion, see Chapter Two). Parents are, then, caught between using the 'final vocabularies' of the professional, in an attempt to show 'solidarity' with the professional, while at the same time the focus by parents on their child's deficits is seen, by professionals, as evidence of their parental pathology.

### *Children as 'the foreigner'*

As early as 1978, Warnock (DES, 1978) implied that the educational needs of a child are relational and may vary according to factors occurring within the school



attended (See Chapter One). Yet, parents' stories reveal that a focus on within-child factors remains a dominant discourse within the education system.

Parents' stories support the view that schools still retain structures which render pupils difficult to teach. (Skrtic, 1991). While Oakeshott (1967 cited in Thomas and Loxley, 2001) exhorts us to use our common sense to make schools more humane, inclusive places, parents' stories are rich with examples of inhumanity and exclusion. Ben described the educational psychologist saying his child would never amount to anything after a twenty minute meeting. Parents reported how individual teachers and schools focused on the child's behaviour as the cause of the problem. Leo was told simply that his child had to 'behave'. Gina explained that Toby was given several short term exclusions and the school had failed to give a written reason for the exclusions. Gina challenged the school to give her a reason in writing and she received a letter saying that he had been excluded for 'touching a soap dispenser'. It seems that Toby, as 'other', was considered to be so different from his typically developing peers, that touching a soap dispenser was put forward as an adequate reason for an exclusion.

A focus on individual children's 'difficulties' is linked to a deficit view of the parent:

Toby was segregated, he was sat down at a table and asked to do work that was way beyond his abilities. I was told that 'this is the work that the children do in this class and you want him to be included and so it is your fault if he's distressed.'  
(Gina, a mother and key informant)

Lack of flexibility and the view that the child must be made to 'fit' the system led to dire consequences for some children:

He had been kept in at lunch time and made to stand outside the head's office every day for a week. On Wednesday of that week he complained to me that his toe was hurting, on Thursday I took him to the doctor and the doctor said that it had been caused by anxiety as Max had been rubbing his toe inside his shoe standing outside the head's office. It had gone septic. So I wrote a note to the head on the Friday explaining what had happened and asking that Max could sit down. They did nothing, I heard nothing that day and then on the Saturday a letter came excluding him at lunchtime. I was told that I would have to take him home at lunch time. The

school is three miles from our home so Max spent lunchtimes in the park.  
(Leo, a father and telephone interviewee)

Leo describes a child who is injured and anxious, yet his status as a child with special educational needs renders him 'other', and this, it seems, justifies his exclusion.

At times, it seems as if the focus on children's deficits, and their label of having special educational needs, means that children were not seen as 'real human beings' (Rorty, 2000) by professionals, causing children and parents great distress and ending partnerships.

A further consequence of the focus on children's deficits is that teachers lose confidence in their ability to teach (Thomas and Loxley, 2001) as they focus on the child's 'condition'. A fundamental attribution error (Ross et al, 1977 cited in Thomas and Loxley, 2001) persists in education – the easy attribution of events and behaviour to the disposition of the individual rather than to the failings of the institution. School systems are often mentioned as an afterthought in discussions which focus on the child's disposition. Interventions are based on individual treatment. The consequences for the child are that 'his or her failures explained in terms of personal deficiencies and his or her successes dismissed as due to external circumstances!' (Norwich, 1999, p 179). The focus is on the child's 'otherness' and 'need' and, yet, 'need' is, perhaps, in this context more usefully seen as the school's need for calm and order (See Chapter One). The deficit discourse steers the response of professionals toward an individually based action plan (Norwich, 1999).

However, Rorty's focus on description and re-description of groups and by groups offers the possibility for change. Parents and professionals who remain in a constant state of doubt about their 'final vocabularies' and who resist de-humanising practices which label and blame can hope to recognise one another's common humanity and show solidarity with one another.



In this section, Foucauldian concepts have been useful in developing understanding of the relational landscape between parents and professionals. Foucault's concepts are also helpful in deconstructing dominant discourses and emphasising the complexity of individual experiences and understanding, but it is not clear how deconstruction, alone, can be used in the struggle for political change (Riddell, 1996). Postmodern approaches have led Rorty to mourn the loss of hope for change and the loss of emphasis on justice (Rorty, 1990)

Rorty's concepts of solidarity and justification are also key to understanding the relationships between parents and professionals in this study. In addition, it is important to recognise Rorty's message that in fields like education, change is possible. However, for Rorty, change can only be effected by an unremitting focus on the particular – by concentrating on the mundane and on the detail. Rorty cautions that theorising alone can offer 'barren explanations' (Rorty, 1998) which distract academics from the proper focus of social science which is reform. For Rorty (1998) piecemeal reform and consensus is key. Piecemeal reform at the level of individual relationships between human beings who recognised one another's common humanity is, then, key to partnership.

In this chapter so far, I have considered the policy landscape (Section 1) and the relational landscape (Section 2) and how they have contributed to the reasons why parents register an appeal or a claim for disability discrimination at SENDisT. In the next section, I offer a critical analysis of the systems intended to reduce conflict between parents and professionals and consider how the limits upon the way the Tribunal works result in repeated parental appeals.

### **SECTION THREE: The systemic landscape**

#### **Introduction**

In the 1990s two forms of conciliation service were established to support the parent-professional partnership in special education – Parent Partnership Schemes and formal mediation services. These services form part of the systemic landscape in which parents' stories are set, and are examined in detail below. The foci of both services were to reduce the conflict between parents and professionals in the area of special need and, doubtless, the hope was that this would reduce the number of

parental appeals to SENDisT. Despite the creation of these services, the number of appeals per annum have risen from 1,300 in 1994 to an average of about 3,400 in 2005 (Hughes, 2005). Parents' stories reveal something of the impact of these services. For many parents, these formal conciliation services had limited success. In addition to the limited success of mediation, the SENDisT system is organised in a way which leads parents to appeal repeatedly and this is also outlined below.

### **1. Parent partnership schemes**

Following the publication of *The Code of Practice on the Identification and Assessment of Special Educational Needs* (1994), the Government offered temporary funding to Local Education Authorities, (LEAs) to help them set up Parent Partnership Schemes. Most schemes were established in 1994. The main focus of the work was to encourage the development of effective partnerships between parents of children with special educational needs and staff working in schools and LEAs. Services were designed to provide information and advice, and to support parents of children and young people with special educational needs and/or impairment, particularly during the statutory assessment process and the issuing of a statement. The brief was sufficiently wide that it encouraged diversity of practice and innovation in the ways that services to parents were subsequently developed at a local level.

The aims were:

- to promote parent partnership work;
- to encourage parent partnership services to learn from each other, to share information and reduce duplication of effort;
- to encourage the development of co-operative arrangements with the voluntary sector providing services to parents of children and young people with SEN;
- to promote the development of interesting and innovative practices in the area of SEN.

(National Parent Partnership Network, 2006)



Since the publication of the revised *Code of Practice* (DfES: 2001a), Parent Partnership Services have become statutory and every LEA in England now has a Parent Partnership Service. Services continue to work in a wide variety of ways to provide support to parents.

The policy commitment and the financial investment in Parent Partnership Schemes seem to suggest that the work of Parent Partnership officers would play key roles within parents' stories. However, what is striking about parents' narratives is the absence of comments about Parent Partnership Services. This may be because parents did not know about the existence of Parent Partnership Services. Wolfendale (1997) found evidence to suggest that Parent Partnership Services were not always well publicised or accessible to parents. Russell (2003) found, as part of her research with parents of disabled children, that only 10 out of 17 parents knew about the existence of Parent Partnership Schemes. Moreover, Russell found that only 2 parents reported that the scheme was useful. In this research, the parents who refer to Parent Partnership Schemes in their stories were often ambivalent about the value of the service:

We had Parent Partnership and we had a lady come round and talk to us ... it's difficult, because they're part of the LEA, whether they're supposed to be independent they are still funded by the LEA....  
(Sue, a mother and telephone interviewee)

The key difficulty for parents was that the service was not seen to be impartial. Parents were aware that Parent Partnership Schemes were meant to be at 'arms length' from the LEA but they were also aware that the Schemes were funded by the LEA. Professionals too were aware that Parent Partnership Schemes were not seen as independent:

The fact that our Parent Partnership people are accommodated in Local Education Authority buildings, you know, that the note-paper still says [Education Authority] on it, I think does give parents some concerns as to the complete impartiality of the Parent Partnership Officers. Despite what they say and the fact that they do help parents, if you like, to construct a case against the authority if I put it that way, then I think it can be a problem for them.  
(Tim, a panel member and LEA officer)

Parents also felt that the role of the Parent Partnership officer was too limited and none of the parents were accompanied to Tribunal or represented by Parent Partnership officers:

She couldn't come to Tribunal with us, she couldn't, there was so much she couldn't do, she couldn't tell us this she couldn't tell us that, because it was seen as not acting in our interests or not acting in the LEA's interest so we actually got in touch with a national support group.

(Sue, a mother and telephone interviewee)

One parent felt let down by the service because she was given poor advice:

I had no idea until then [when I spoke to a solicitor] that George's statement was weak. I felt let down, because I'd spoken to Parent Partnership when I first got it. It turned out that their advice was useless.... But, at the time, how could I have known any different?

(Diane, a mother and key informant)

It is difficult to generalise from a small scale qualitative study, especially as the work of the Parent Partnership Service was not a key focus of the research, however, this study suggests that a more visible and clearly impartial service might help to resolve parent-professional conflicts. Parent Partnership Schemes may be heralded as an attempt to engage with partnership with parents, but the parents' stories suggest that structural difficulties with the schemes mean that parents remain often unsupported in their partnership role (Armstrong, 1995). Far from shifting the balance of power from professional to parent, Parent Partnership Services can be seen to feed into the system of special education which disempowers parents.

## **2. Mediation services**

The Special Educational Needs and Disability Act (2001) put a legal duty on local education authorities to make independent arrangements available for the resolution of disagreements between parents and carers of children with special educational needs, and schools and/or LEAs. Mediation arrangements for resolving disagreements between parents of children with special educational needs and the LEA or their child's school were introduced in 2002. They are formally described as Special Educational Need Disagreement Resolution Arrangements, and use specially trained mediators. Mediation is more commonly used to resolve a disagreement between the parent of a child with a statement of



special educational needs and the LEA, but it is also appropriate for resolving disputes between parents and the school where the child is not statemented. The aim is to find practical solutions as quickly as possible without disrupting the child's education (Mediation UK, 2006).

LEAs have a duty to make the service known to potential users. This means LEAs should alert all schools of the existence and purpose of the service. SENCOs and LEA officers should then routinely inform any parent who has a disagreement with the school or the LEA over special educational need assessment or provision at any stage of the *Code of Practice*. The parent should be given written information about the mediation service.

Mediation is a voluntary activity and using the mediation service does not affect parents' right to make a complaint, an appeal or a claim of disability discrimination. When the service is approached by the 'first party', a parent, school or the LEA, the mediators have a role in trying to get the other parties to engage in the process, but they cannot compel any of the parties to take part (SEN Regional Partnership (South West) 2005).

There are different models for providing mediation, but typically the experience follows the process outlined below:

- parents/or school/or LEA makes contact with the regional mediation service;
- the mediator takes the referral, explains the process and establishes whether all parties are willing to consider the mediation. If all parties agree, a mediator is appointed;
- the mediator will explore the situation with all the individuals involved;
- the mediator will invite the parties to a joint meeting at a neutral place. Parents may bring a friend or a Parent Partnership Officer to the meeting;
- the LEA must send someone with authority to make a decision to the meeting.

(Mediation UK, 2006)

Mediation is confidential and the aim is that everyone should be able to put their view. If agreement is reached, it is put in writing and signed by all parties.

Some research suggests that mediation can help to resolve disputes before the parents reach SENDisT. In London, the mediation service reported an 81% success rate for the period 2002-3 (ADRnow, 2005). However, parents reported mixed experiences of mediation.

A few parents had very positive experiences of mediation and valued it highly:

So it [mediation] was a very good way of getting everything off your chest.

(Kirsty, a mother and telephone interviewee)

The mediator herself was very good ... professional and very good.

(Tina, a mother and telephone interviewee)

Other parents saw no value to the mediation process:

We were offered mediation, but there didn't seem to be anything to mediate about. It was a straight case of this school or that school and there wasn't anything in between.

(Fiona, a mother and telephone interviewee)

While some parents, like Diane, a mother and key informant, were simply not aware of the existence of a mediation service, other parents' requests for mediation were refused by the LEA:

Almost at the same time as I appealed [to SENDisT], I asked for mediation to take place, and I got a sort of what I call a stalling letter back saying that they need to you know have the educational psychologist available and other parties, and it will take a while to set the meeting up. So it took from May until July to set up this meeting and at this meeting, we were, we sort of laid down, you know, our position and it was agreed to have a follow up meeting, um, all parties agreed to a follow up meeting. Anyway, subsequently the LEA refused to carry on being involved in the mediation process.

(Simon, a father and telephone interviewee)

Some parents were offered mediation but it came too late in the process to be useful:

The mediation was offered before their case statement went in, so after we'd objected and we'd put our appeal in ...

(Colin, a father and telephone interviewee)



Colin was upset that he was offered mediation after he had put in the work to prepare his case.

Another difficulty was that one parent felt that mediation, like Parent Partnership Schemes, was not impartial:

The mediation service get paid £10,000 a year [by the LEA] so although they are meant to be middle men, how can they possibly be?

(Sue, a mother and telephone interviewee)

One parent felt that the LEA were exploiting the mediation process in order to find out information which might help their case:

We also smelt a rat when they [the LEA] suddenly said they wanted more time cos I don't think they bothered, and I also have the suspicion that they wanted to see what came out of the mediation. Not in the sense that we'd get anything agreed, in the sense of seeing what we might say that would help their case statement.

(Colin, a father)

For some parents, mediation was described as a very unpleasant experience:

Like I say, there was no mediation, they were there to bully me.

(Mia, a mother and telephone interviewee)

The parents' experience of the mediation suggest that mediation may be an attempt to engage with partnership with parents, but does so in a way which again disempowers parents (Armstrong, 1995).

Professionals, too, were aware of the limitations of the mediation service. Thomas, a panel chairperson, agreed with parents that some LEAs were simply not prepared to take part in mediation:

I could also say I think some LEAs are just diabolical about the way they treat parents. I mean if you just took the pressure that the law has put on LEAs to have mediation, I've sat on cases where the correspondence between parents and the LEA, and the LEA says 'we don't believe in mediation, we prefer our own officers to resolve these things'. Well, that's just disgraceful. The problem is the Tribunal people have absolutely no remedy about that.

(Thomas, a panel chairperson)

An LEA officer and panel member explained the organisational difficulties that some LEAs had with mediation:

The difficulty that we have is that a lot of the decisions that we make are decisions that are made by a panel rather than individual officers and the mediation people find it difficult that we are not able to send anybody to a mediation meeting that is able to overrule a decision that's been made by a panel.... They like to get it sorted at the meeting rather than the parents going away feeling 'well I'm no further forward, all that's happened is that the authority is saying they'll reconsider.' And I think that's the difficulty we have with mediation. In some authorities, I understand it isn't a difficulty because individual officers have the power to make specific decisions, whereas here in [our authority] we tend to rely on particular groups to decide ....

(Tim, a panel member and LEA officer)

Parents' and professionals' views of mediation services seem to suggest that mediation services, like Parent Partnership Schemes, have limited impact, thus far, on resolving disputes between LEAs and parents. While LEAs refuse to engage with the process and parents see mediation as not being impartial, mediation will continue to be a structural factor contributing to parents' appeals to SENDisT.

### 3. Repeated appeals

Several parents, like Pam, went to SENDisT more than once. There was often a pattern of repeated appeals. For example, Ivor, a father, went to SENDisT because the LEA would not assess his son; the Tribunal ordered a statutory assessment, but the statement was vague and Ivor returned to SENDisT to appeal the contents. Derek, an LEA officer and SENDisT member noted this as a reason for repeated Tribunals:

So if a parent has to go to Tribunal on a refusal to assess and wins and the child is then assessed, they then may need to come back to the Tribunal if the local authority either refuse a statement or only have a note in lieu. Then if the local authority get ordered to produce a statement, the parents might need to come back for a third time about the content, so I mean that means two things in my point of view A) it's a long process because of the delays for each Tribunal and B) you need a very strong willed parent to keep on going back to Tribunal.

(Derek, a panel member and LEA officer)

John, a SENDisT panel member and LEA officer explained that the panel were unable to truncate the process:



We ought to be able to move them on to the next stage we ought to actually say, we think you ought to issue a statement on this, but of course you can't do that and its very difficult.

John was aware that this caused the parents to appeal repeatedly.

Sometimes the LEA seemed unaware of SENDisT's powers. Ivor, a father and telephone interviewee, reported the exchange in his Tribunal when the panel member reminded the LEA of the force of the Tribunal's orders:

They asked how many dyslexia teachers there were in [the City] employed by the LEA and they said 'well, teachers we have ... don't actually teach, they just help learning support, they just direct the learning support' and the Tribunal found this amazing. And they [the LEA] said 'we couldn't supply a dyslexia teacher if you asked us to.' And one lady panel member said 'if we direct you to provide Michael with five hours of specialist teaching time, you will go out to the private sector and you will find a teacher!'  
(Ivor, a father and telephone interviewee)

Ivor's story reveals that LEAs are sometimes unaware of the force of a SENDisT order.

Tracy, a mother and telephone interviewee, expressed concern that the Annual Review was an opportunity for the LEA to subvert the outcome of a Tribunal:

We know that they [the LEA] are trying to chip away at it at the statement, and we know we are in for a fight again. We know its coming and my husband and I are absolutely dreading it....

Tracy was acutely aware that the provision she secured for her child at Tribunal could be taken away by the LEA at the next annual review of her child's statement.

Parents spoke of the stress that repeated Tribunals cause them (For a fuller discussion of this see Chapter Six) and, of course, this delayed the implementation of extra support for the child in school.

Parent Partnership and mediation services seem to have a limited impact on the parents' experiences of going to SENDisT. Parent Partnership services are described by parents as lacking impartiality and of having too narrow a role. Mediation services, too, are not seen to be impartial by parents and this means that

they can have little real impact in reducing the amount of conflict between parents and professionals.

The way SENDisT itself is structured mean that some parents appeal repeatedly to SENDisT. The Tribunal's inability to truncate the process for parents is a source of stress for panel members and parents.

## **Conclusions**

Finally, the effects of the policy, relational and systemic landscapes in which the stories are set combine to make an inhospitable and, at times, hostile terrain. Parents struggle to navigate an unfamiliar and complicated landscape. Their stories demonstrate the challenges they face on their journey.

Parents engage with a very complex policy landscape. The system of statements of special educational needs seems to be an area which contributes to conflict between parents and professionals, however, parents continue to value the 'protection' the statements bring. The policy of inclusion also seems to be a policy for conflict, however, parents' perspectives on inclusion challenge both popular perceptions in the media and some analyses within the academic community.

The relational landscape is particularly rocky. The narratives reveal the intricate power relationships at work within parent-professional relationships as well as the struggle by parents and professionals to be able to show solidarity with one another. It is not surprising, then, that for some parents the journey to SENDisT becomes too difficult and that they abandon their attempts (NAS, 2003).

The systemic landscape seems to offer parents inadequate support and, at times, contributes to parents making repeated appeals. Some parents make the journey to SENDisT more than once. For these parents, the terrain is more familiar but no less difficult to traverse and this contributes to considerable stress for parents and families (For a fuller discussion of family stress see Chapter Six). The experience of attending the Tribunal itself is also stressful and it is to the Tribunal day itself to which I turn in the next Chapter.



## **CHAPTER FIVE: THE TRIBUNAL DAY**

### **Introduction**

The previous chapter focused on the reasons for an appeal, this chapter focuses on the informants' experience of the Tribunal day itself: what are the parents' stories of attending the Tribunal hearing? Again, the analysis begins with a story. This time it is Martha's story which is given prominence, although other parents' narratives are again used throughout the analysis. Martha's story was chosen because it gives a rich account of the Tribunal day written shortly after the event. Martha's story cannot represent the variety of parental experiences of the Tribunal day, but it is strengthened by the references to other parents' experiences. The experience of the Tribunal itself is very stressful for parents, who are required to present their case in a formal meeting. For parents, the stakes are high and the outcomes of the Tribunal, they believe, are crucial for their children's education and development. The moment by moment account of the Tribunal day presented here is intended to give a detailed insight into the parents' experiences.

The approach to analysis in this chapter is a thematic analysis which draws on Foucauldian ideas to develop an understanding of the Tribunal day story. Foucault's work has been used to inform discourse analysis of texts (Burman and Parker, 1993), however this is not the method used here. Foucault's ideas inform the analysis and the reading of the stories. Foucault's primary aim was to explore the ways in which humans 'are made subjects' (Foucault, 1982, p208. For a fuller discussion of Foucault's work see Chapter Two; for a discussion of thematic analysis see Chapter Three). We have already seen that Foucault's concept of the subject has been used in special education research to explore the ways in which children are controlled and made dependent (Allan, 1999). Here, these concepts are used to develop an understanding of the parents' Tribunal day experiences.

Foucault was convinced that truth is no more than power in disguise; indeed, for Foucault, power and knowledge are so inextricably bound that he introduced the concept of 'power-knowledge' (Foucault, 1998, pp 98-99, cited in Roberts, 2005). Issues of what constitutes knowledge and truth are a dominant theme within the Tribunal hearing and Foucault's insights into the relationship between power and knowledge offer useful analytical tools for understanding Martha's story.

Foucault argues that it is discursive practices which maintain power relations and construct 'truths', and so the analysis here pays careful attention to the effects of the discursive practices within the hearing, paying particular attention to the use and effects of professional discourses (Billington, 2000).

The story teller is Martha, a mother and primary care-giver to Sean. Sean is the youngest of her four children, aged 14. The Tribunal day Martha describes is the culmination of what she calls 'eight years of failure' within the education system. Martha's story was long and complex and I have focused on only one aspect of her story; the Tribunal day itself. The reason for this was that in the vast amount of paper work Martha sent me after I interviewed her on the telephone, Martha had included detailed notes of the Tribunal written shortly after it finished. Martha did not keep a record because she was an informant in a research process, but she used her account as a way of making sense of what had happened to her. Martha has since used her record of events to help other parents preparing their cases for SENDisT.

The story is presented as a dramatic narrative (For a fuller discussion of narrative forms see Chapter Three). The cast list details the characters who were involved in the Tribunal day and the annotations in the margin are intended to add clarity to a complex and, at times, legalistic story, without detracting from the story line.

### **Martha and Sean's story - I wanted to speak up for Sean and I never got the chance**

*At the time of the Tribunal, Martha's son Sean had been out of school for over a year. Sean has a diagnosis of Down's Syndrome and autism. Martha and her husband had taken Sean out of school, West School – a non-residential special school, because they felt he was very unhappy there. They were concerned about how Sean's behaviour was managed and about the effect of the behaviour of other pupils on Sean. They felt that Sean was distressed at school and that he had learnt challenging behaviours from other pupils. The family was also under considerable pressure from caring for Sean at home with only a few hours respite support a week. They described how their social life had become very limited and that they were unable to take Sean to friends' houses. They also described the difficulties of taking*



*Sean to the park or to the shops. The parents felt that the best education for Sean was a residential special school, and they had found South School, which they liked and they felt Sean would be happy there. The LEA argued that Sean's needs could be met at West School and that the parents should give this placement another chance. The LEA did not support the parents' view that Sean needed residential school.*

*Present at the Tribunal were:*

*Martha and her husband, Mr and Mrs Ellingham.*

*Sarah Clark, the Ellinghams' representative from a voluntary organisation, which exists to support parents of children with special educational needs. Sarah Clark has several years experience of representing parents at Tribunal.*

*Mrs Brown, the Ellinghams' private psychologist. She has assessed Sean and produced a report for the Tribunal. The parents called her to be a witness.*

*Mr Marks, Head of South School. Mr Marks is head of the school the Ellinghams would like Sean to go to. He too has met Sean and believes that his school would be a suitable placement for Sean. He was called as a witness by the parents.*

*A friend of the family. Parents are allowed to bring a supporter with them, however, they may not contribute to the hearing. They can give support only by being present.*

*Mr Holmes, the LEA officer. Mr Holmes represented the LEA during the hearing.*

*Mr Sutton, Head of West School. Mr and Mrs Ellingham withdrew Sean from West School more than a year ago, worried about Sean's learning and behaviour there. Mr Sutton believes West School can meet Sean's needs.*

*Mrs Heath, the LEA psychologist. The LEA called Mrs Heath as a witness.*

*Three panel members – there was a legally qualified Chair and two lay members.*

*As Martha explains below, she didn't catch their names and did not know what experience they had of special education.*

### **Waiting for the Tribunal**

We arrived at the address for the Tribunal at about 9.20 am; it was due to start at 9.30 am. We went up in the lift to the sixth floor and into a reception area. There was a receptionist at the desk who made us wait for a minute then asked our names.

She shuffled through some papers and seemed unable to find us, she asked us to wait and left. We stood waiting at the desk, eventually she returned to answer a phone call. When she'd finished the call, she told us that the person dealing with us had been held up and would be late. She gestured erratically and said we could wait a little way away from the desk.

After a few minutes, the receptionist led us to a small room and shut the door. One of our witnesses, Mrs Brown, a psychologist popped her head round the door, looking for the right room and then our representative from a voluntary organisation, Sarah Clark, arrived. Sarah Clark was going to put our case forward for us in front of the panel. She was looking a bit flustered and apologised for being late.

Sarah Clark is an experienced representative from a voluntary organisation specialising in Tribunal support. She is not a lawyer, but has extensive experience of Tribunal cases.

We'd just started talking about our son, when the fire alarm went off. We walked down six flights of stairs and waited outside the building. The alarm stopped and people started to go back inside, so we went back in. The receptionist came in and said there was a problem – the room we had been allocated was not big enough for all of us so they were looking for another one. It was now 10.30 am.

This is an hour after the start time.

After a while, the receptionist came back and told us they had found a room in the building across the road, so we went back downstairs, across the road and up in the lift. There was an awkward atmosphere in the lift. We were standing there with our representative, Sarah Clark, and our

There is no guidance available about where parents should



witnesses as well as the witnesses and representative for the LEA. This time the lift took us to a room on the seventh floor. We were asked if we would all sit together as only one room was available. Sarah Clark said it would not be appropriate – we still had things to discuss before the hearing, but we were not offered a different room.

wait, but Sarah Clark's response suggests it is unusual for the LEA and parents to sit together before the hearing.

### The Tribunal begins

At about 11.05 we were told that the panel members were ready to start. We were shown into yet another room. As we went in, the panel members were already seated, facing the door. Our representative, Sarah Clark, sat in the middle, opposite the Tribunal Chair, we sat on her left with our psychologist and the head of the South School. To Sally's right sat the LEA officer, the head of West school and at the far end, Sandra Heath, the LEA psychologist. The seats on our side of the table were jammed solid. There was no room to move. Our supporter, a friend of ours, sat behind us, out of sight, in a chair by the door.

Parents may take a supporter who must remain silent during the hearing.

We were still trying to sort out our paper-work when the Chair of the Panel began. He introduced himself and the other two panel members, but, as we were still trying to find a space for our papers, we missed the names of the panel. Because of the way we were sitting in a row, we couldn't actually see Mr Holmes, the LEA officer, or Mr Sutton the head of West School. After the Chair had introduced the panel we introduced ourselves. We also put a photograph of Sean on the table to which

Voluntary organisations often encourage parents to take

photographs of their children with them to the hearing.

The files include the submission form the LEA and the parents' case statement.

This includes professional reports.

Children often see numerous therapists and each of these may be asked to contribute evidence to the case statements.

the Chair responded 'oh that's Sean, we'll come back to him'.

We had two files with us but we didn't have room for them both on the table so one had to sit on the floor. I had to take notes on my lap. My husband kept asking me to write down points for us to come back to, as they had suggested on the Tribunal video. We felt we needed to return to virtually every point, but the pace of the hearing was too fast for me to jot everything down. At one point, Sarah Clark, our representative, was whispering points to me while the LEA team were speaking. We were asked to keep quiet by one of the panel members. I felt the formality of it all was totally beyond me.

The Chair was quite abrupt and said that as it was gone 11 o'clock he wanted to get on with things and that we should be done by 2 o'clock. He said that he had read the 'somewhat large amount of paper-work' and that he had identified a number of issues which he had listed in front of him. He said he would like us to work through the points – he didn't read out what his list contained.

### Setting the scene

The next thing we remember is the Chair looking at Sarah Clark, our representative, and saying 'Been at home for a year! That's a bit unusual isn't it?'. Sarah replied that it was not unusual and that many children with special needs were out of school for longer than Sean.

The Chair asked Mr Holmes, the LEA's

The video is produced by SENDisT - 'A Right to be Heard'(2002b) - and is sent to parents in advance of the hearing



West School is a non-residential special school.

representative, about West School. Mr Holmes said that the LEA and school had always maintained that Sean's needs could be met there. He was keen to come to some resolution especially because Sean had been out of school for a year. He said that in his opinion a residential placement was not appropriate because Sean was well supported both in and out of school. Mr Holmes said that West School had indeed changed and improved since Sean had been away from it.

A panel member asked about the children with Emotional and Behavioural Difficulties at West School. How were they managed in school and what impact did this have on Sean? Mr Holmes, the LEA officer, did not answer the question himself, he passed it on to Mr Sutton, West School's head teacher, but Mr Sutton did not answer the question directly either. He simply re-iterated what Mr Holmes had said about the changes at West School and that they were able to meet Sean's needs.

Again the panel members asked about the behaviour of children with Educational and Behavioural Difficulties (EBD) at the school and again Mr Sutton avoided the question. This was a key point for us. We wanted to show that poor management of the children with EBD was having a negative effect on Sean.

For the third time, a panel member asked about children with EBD in the school - what sort of children attended the West school? Mr Sutton said

some had mild learning difficulties and some more severe learning difficulties. 'Any others?' the Chair asked. 'No, no others,' said Mr Sutton.

We interrupted at this point and said that, of course, there were children with EBD at the school. At first, Mr Sutton denied it, but we and the panel members pointed to the OfSTED report about the school. The OfSTED Report actually comments on the behaviour of children with EBD. Mr Sutton said that some of the children had emotional problems at the school, but many had left and there were now fewer. The Chair asked Mr Sutton exactly how many children with EBD were in the school. Mr Sutton seemingly could not answer then replied 'ten, no eight,' and the Chair said 'eight?' Mr Sutton stuttered 'um, ah, oh, no perhaps ... six.' 'You must know how many you have now?' the Chair said.

Mr Sutton then said that the school had a policy not to admit children with behavioural problems, and that 'for the three or four children with problems we have Behaviour Management Plans'. Our representative interrupted 'But a moment ago you had six children!' Mr Sutton replied firmly 'no, about three EBD children.'

We were very worried about Sean's behaviour in West school so Sarah asked how it had been managed there. She asked Mr Sutton, the head of West School, if the school had a Behaviour Management Plan for Sean. Mr Sutton replied that not all children needed a plan and that 'no' there



was no plan for Sean. I asked why there was no plan for Sean when his IEP clearly stated that one of his goals was to interact with peers without aggression, and why there was no plan given that the LEA had put in Sean's statement that staff need to be aware of Sean's potential to harm property and peers. The Chair stopped me and said we could come back to that later. Mr Sutton carried on and said that he felt West School needed longer to work with Sean. My husband whispered something to me and I was given another stern look by a panel member.

Mr Sutton referred the panel to what he described as the school's excellent OfSTED report. My husband and I tried to draw the panel's attention to the part of the OfSTED report saying that when behaviour is not well managed it affects other pupils but the panel moved on again.

#### **A bad school?**

One of the panel members said that West School could not be a bad school because of the good OfSTED report it had received. I tried to say that we did not think it was a bad school, we knew some children and parents who were happy there. What we were trying to say was that it was not the school for Sean. It has a lot of challenging children there and Sean is very easily upset by the behaviour of other children, it confuses and frightens him. Sean needs to be in an environment where any outbursts of behaviour are well-controlled as he copies them so easily. The Chair seemed to hear me and said 'I see, so he needs an

environment where there is greater control'.

We tried to explain to the panel how difficult it is for us as a family. Sean has picked up bad language, which he then has no control over whether he uses it or not. We explained that we couldn't go out with friends with young children and how difficult it was for us when we go out in public. There was no response from the panel.

One of the panel members asked about our other children and what they did. We told them that the oldest two were at university and that our other son was studying for A levels. Again, there was no response from the panel.

The Chair then turned to the panel member on his left who spoke for the first time. I don't know who she was, I didn't catch her name. She asked about Sean's health and I explained that his hearing was deteriorating and that his teaching assistant needed to sit opposite Sean, so that he could lip read. Sean has a particular difficulty with background noise and needs a distraction-free environment. Sean was also waiting for an operation on his back which would mean three to twelve weeks at home after the operation.

At this point the Chair asked if we had lost confidence in the school and I said 'yes, but in actual fact it is the LEA we have lost confidence in because for the last eight years they have not supplied Sean with his educational needs'. Nothing further was said on this point.



## Truth and Lies

The Chair returned to Mr Sutton again. Mr Sutton said that he'd encouraged us to return Sean to West School that the school was concerned about Sean's education and that he had offered to meet with us at school. He said Sean was happy and confident at school and there had been no reports of bad behaviour, and that Sean was given one to one support from a teaching assistant. We were shocked because we knew so much of what was being said was untrue.

I tried to say that it was not true. There were reports of Sean's bad behaviour. I held up a record of events reported to me by the class teacher, subject teachers, the deputy head and other children. The panel ignored me. I tried to say that West School did not want Sean back at school, that they had not offered a meeting, but before I could finish the Chair turned back to Mr Holmes, the LEA officer.

I think it was at this point that the Chair asked about Social Services and how much respite care we got. I said that we got 28 nights per year but used to get 42. We didn't know why they changed it, we weren't consulted.

The Chair turned to Mrs Heath, the LEA psychologist. Mrs Heath said that she had seen Sean at home and felt that it was important to get Sean back into school as quickly as possible. She supported Sean returning to West School with the

appropriate support from other agencies. We felt that Mrs Heath had previously supported Sean's placement at South School and suspected that she had changed her mind under pressure from the LEA. So Sarah asked why she had changed her mind when she had already supported a residential placement for Sean in her report. Mrs Heath insisted that she had never supported Sean's placement at South School and she was sure that a 24 hour curriculum could be achieved for Sean at home. Sarah insisted that Mrs Heath had changed her mind, but the Chair stopped her. 'Mrs Heath has already said that she has not changed her mind and that Mr and Mrs Ellingham have drawn support from her recommendations without fully understanding its implications'.

The Chair asked us more about the respite we got at home. We explained that we got three hours a week, not six as the Social Service report said, from a sitting service and that this would cease when Sean returned to school. We had no promise of support after school as the LEA had suggested. The Chair asked if Sean had received any therapies while he'd been out of school. I told him that I'd been too preoccupied with the Tribunal to get him speech therapy although I had meant to. Then he asked 'aren't there any clinics for you to take him to?' I didn't really know what he meant. He just muttered 'there are no clinics? Disgusting!'

It was one o'clock, the Chair suggested a fifteen minute break and that we would return and conclude the Tribunal by two o'clock.



### **The Break**

We had lunch in the staff room with the administrative staff present. Our representative, Sarah, asked if she could buy some lunch and a drink. We were told there was nothing available. Sarah had a banana and Mrs Brown gave her a biscuit, while Mr Marks shared out a tube of fruit pastilles. We went back into the Tribunal at about 1.20 p.m.

### **The Tribunal continues**

The Chair turned his attention to the head of South School, Mr Marks, and apologised for not including him in the discussion before now. The panel said that, as they had seen the prospectus, they had little to ask him; they only asked what happened in the assessment term and how many children were refused at the end of it. Mr Marks said it was very rare for that to be the case.

The Chair asked how we felt Sean would cope with being away from home. I said that if the environment was calm and right he would be happy. He was used to staying away from us for respite and he had also spent nights away with relatives happily. I think the chair then turned to Mrs Brown, our psychologist witness. She talked about the opportunities that South School offered Sean, that really this was his last chance to be in an environment where his behaviour could be managed and where Sean could develop and grow to take his place in society.

The Chair asked what it meant that Sean had Autistic Spectrum Disorder. Mrs Brown explained that it was very difficult to tell in children like Sean who have Down's Syndrome, how much is a symptom of Down's Syndrome and how much is purely autism. But whatever the label, children need appropriate provision.

I think the next thing to happen was that the chair asked Mrs Heath, the LEA psychologist, whether she agreed with Mrs Brown, our psychologist, that South School was the last chance for Sean. She said she did not agree and that a placement at West School would work if the school, Social Services and parents worked together. Mr Sutton said that it could only work if the parents were prepared to talk to all those concerned.

#### **The hearing hurtles towards its end**

With the hearing hurtling towards its end, we felt that we still had not had time to answer what the LEA had said. We felt that every time we had tried to interject we had been ignored, but we thought that we would be given time to be heard before the end of the hearing.

At this point, Mrs Heath, the LEA psychologist asked 'Do you mind if I say something else?' 'No, go ahead,' said the Chair. Mrs Heath said that the South School was a 'Rolls-Royce' school and the LEA could not consider it fair to send some children to Rolls-Royce schools. Mr Marks commented 'I'll remember that when I write our next prospectus!'



We sat in stunned silence. Sarah had asked before we started that we let her lead events, so we gave her our trust and chose not to intervene.

There was then a discussion between the LEA and the Chair. The Chair said that he felt that West School could meet Sean's needs, that it had changed and that we hadn't given it a long enough chance when Sean was there before. But he quipped to Mr Sutton that the parents 'were not likely to send him back to your school'. He asked if there were alternative day school placements and the LEA replied that there were. At this point, our representative Sarah intervened and insisted that although those placements had been discussed, they were not on this agenda and it would require a further hearing if the Chair wanted to explore the possibility. The Chair seemed taken aback by this but gave no further comment.

The Chair continued to discuss the detail of the provision at West school. He asked why Sean's previous statement had contained 20 hours one-to-one but the present statement had no specific hours of support. Mr Holmes said it was not the LEAs policy to name the number of one to one hours of support on a statement when it all came out of funding for the school. The Chair simply said 'oh, its your policy' and nodded.

This is contrary to the *Code of Practice (2001a)* which states that statements must specify provision.

It seemed useless to try and say anything. Mr Sutton was talking about Sean's behaviour improving at West school and that they had

worked hard with us to achieve this. We shook our heads – one of the panel members noticed – but we did not say anything.

Mr Sutton insisted that ‘the family were very well able to meet Sean’s needs’. We continued shaking our heads. No one asked for our views. I passed a piece of paper to our representative on which I’d scribbled ‘parents cannot meet Sean’s needs’ but she concentrated on what Mr Sutton was saying. When she summed up she did not include this vital statement.

At 2.15 p.m. after Mr Holmes and Sarah had summed up the meeting ended abruptly. I said a polite ‘thank you’ to the panel members, one of them caught my eye, but there was no glimmer of an expression. I felt awful. Sarah apologised. She felt she had not done her best and said that she had been tired and hungry since the break and could not function properly.

I don’t think any of us were put at our ease. There was an atmosphere of ‘let’s get this over with’ and ‘we would like to be somewhere else’ from the panel.

I wanted to speak up for Sean and I never got the chance.

Tribunal decisions arrive by post, usually about two weeks after the hearing. Martha was not successful in getting the school place she wanted for Sean.

### **The Tribunal Day – Foucauldian concepts as analytical tools**

Martha’s Tribunal story is more than a simple description of an event. The discourses at work in the narrative are revealing about the nature of relationships



between the characters in the story. Crucially, Martha's story can be used to expose the power relationships within the hearing.

By a process of critical reading and an unravelling of terms, influenced by Foucault's concept of power-knowledge and the panopticon. I argue that three key themes emerge from Martha's story:

- surveillance and control;
- truth and knowledge;
- resistance and representation.

Each of these are considered below.

### **SECTION ONE: Surveillance and control**

An emergent theme in Martha's story is that of surveillance and control. In *Discipline and Punish* (1977), Foucault expands on the concepts of surveillance and control by drawing on the work of Jeremy Bentham in relation to what he described as 'panopticism' to critique society. As we saw in Chapter Two, the panopticon is a society or an institution in which individuals are subject to social demands and professional expectation. Just like the residents of the panopticon, Martha's story reveals that within the Tribunal hearing parents are observed, corrected and constrained.

Foucault describes how within the panopticon surveillance can be 'disindividualised' (Foucault, 1991, p202) so that individuals are not always aware of who is monitoring them, and they are subjected to a 'faceless gaze' (Foucault, 1991, p214). The disindividualisation of the monitoring process at the hearing is evident before the hearing begins. Martha described how she was made to wait at the enquiry desk for some time while a member of staff disappeared and returned only to answer the phone. What followed, including the search for an alternative room, the fire alarm and the late start were all disquieting for Martha and yet her only attempt to express her discomfort, when her representative asked if they could wait in a different room from the LEA representatives, was rebuffed, thereby reinforcing Martha's position of powerlessness. Martha's experiences also support Foucault's description of power as not simply hierarchical; power does not only flow from a centralised source, rather it is multidirectional in operation both top

down *and* bottom up, and circular (Foucault, 1990). In Martha's story, there are examples of hierarchical power as the panel members control the proceedings of the hearing, however, Martha too tries to exercise and resist power within the hearing and while waiting before the hearing with varying degrees of success. She is also subject to the 'disindividualised' gaze of the receptionist while she is waiting for the hearing to begin.

As in the panopticon, we see how parents begin to regulate their own behaviour in the hearing. In the panopticon, corrective interventions take the form of linguistic, and sometimes physical actions, which constrain behaviours and disempower dissenters. In the Tribunal hearing, the interventions included glances, comments and the physical arrangement of the room itself.

The arrangement of the furniture in the hearing room, with a large table in the middle, the panel on one side and the parents, LEA representatives and witnesses on the other, seemed to be set up in a way which allowed the panel members to monitor parents' behaviour, but prevented the parents' from seeing all the other people in the room. Martha was intimidated by the room lay-out and she was unable to see her supporter:

The chairs on our side of the table were jammed solid. There was no room to move. Our supporter, who was not allowed to take part in the proceedings, sat behind us, out of sight, in a chair by the door.

Similarly, another mother, Tina, also felt intimidated by the layout of the room:

The biggest shock of all when I walked into the Tribunal room, was the size of the table! And how formal that made everything seem.  
(Tina, a mother and telephone interviewee )

Martha's detailed account of the Tribunal also reveals the corrective interventions used by the panel members as part of the hearing. The Chair of Martha's Tribunal said that he had read the 'somewhat large amount of paperwork' provided by the parents for the case. The implication of this statement could have made the parents feel that their preparation had been in some way unsatisfactory. It was not clear whether the remark was intended to suggest that the paperwork was inadequate or over zealous. His reaction to the fact that Sean had been out of school for a year reveals him scrutinising and judging the parents: 'Been at home



for a year! That's a bit unusual isn't it?'. His remark about this being an unusual situation again focused on possible parental deficits. The Chair also made direct references to what he perceived to be the parents' deficit in understanding when he commented:

Mrs Heath has already said that she has not changed her mind and that Mr and Mrs Ellingham have drawn support from her recommendations without fully understanding its implications.  
(Martha, quoting the Chair of the panel)

This focus on parental deficits was picked up on by the LEA officer who said that:

Mr Sutton said that it [the placement] could only work if the parents were prepared to talk to all those concerned.

The implication was, then, that the placement had broken down because of the parents' unwillingness to co-operate with the professionals. Such discursive practices work to position the professional as rational and objective and the parents as irrational and obstructive.

Some panel members used more overt methods within hearings to keep control within the hearing. Martha described being asked to be quiet. Mia, a mother and telephone interviewee, also described being 'told off a few times' and eventually she explained that:

I was warned 'Mrs Crouch we'll have to ask you to go outside the room' ... I wasn't being aggressive, I just found it hard to keep quiet!

(Mia, a mother and telephone interviewee)

Richard, a father and telephone interviewee, echoed these feelings of being disciplined, when he described the atmosphere in the hearing as being a bit like being up in front of the head master.

Some parents seemed to be able to understand and to resist the processes of monitoring and intervention within the Tribunal better than others. Diane began to regulate her behaviour when she quickly realised how important it was not to interrupt a panel member when the LEA officer was pilloried for doing so. Leo tried to use his understanding of his place within the hearing to his advantage:

If you understand, play the part, play the rules, it does help. I called her 'Madam Chair', 'sir', 'madam', 'yes sir, no sir'. It definitely helps in making them think you are working with them.

If you try and be Mr British on Holiday ... or try and use their first names ... don't do that.

(Leo, a father and telephone interviewee)

What Leo describes suggests that the formality of the hearing leads Leo to practice self-governance.

Several parents commented on the lack of informality within hearings, especially in comparison with the video that SENDisT<sup>1</sup> sends to parents before the hearing:

It wasn't a bit like the video you see ... it's all friendly and putting you at your ease and it wasn't [like that]. I mean there was this lady legal chairman and two men, and they really were very hostile.

(Fiona, a mother and telephone interviewee)

A sense of being monitored and corrected was a recurrent discourse within the parents' stories. Again the panopticon has resonance for the Tribunal hearing as the parents describe their experience of monitoring, correction and control.

Sometimes it was overt when parents were directly told to be quiet, sometimes it was less overt when parents experienced indirect constraints, as Martha and Fiona did, sitting opposite the panel over a large table.

Colin, a father and telephone interviewee, summed up how he felt about his hearing:

You actually felt you were in a court and you felt challenged and there was a lot more things which I would have said which you, I mean, (a) they wouldn't allow me to say certain things and (b) you actually felt put off. It wasn't what, I thought was going to be a sort of discussion to come to something. It wasn't informal, I would say it was very structured and they were, I don't think they were at all accommodating or trying to make us feel at home despite what they say. They had their rules. She said 'I've got the rules this is how its gonna be this is what we are going to discuss before we had even started'.

(Colin, a father and telephone interviewee)

Colin's language was echoed by other parents:

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<sup>1</sup> The parent is referring to the Tribunal video which is sent to parents to help them prepare for the hearing - *A Right to be Heard; What to expect at the Special Educational Needs and Disability Tribunal* (SENDisT, 2002b). The video show parents a 'mock' Tribunal from the point of arriving at the venue where the Tribunal takes place to the end of the hearing. The roles are taken by actors.



The Tribunal is a court. They treat it as a court and you [the parent] are a criminal.

(Leo, a father and telephone interviewee)

Kirsty and Diane were both former police officers married to serving police officers. Both also described the hearing as feeling like being in a court, but it was Ben, a father and key informant, who gave the most vivid description of the court-like atmosphere of the Tribunal hearing:

The Tribunal was supposed to be informal, but it was never! The Chair was really pompous. I felt like I was in a Court Case and I got ten years in jail!

(Ben, a father and key informant)

Some parents were upset by what they described as courtroom banter between witnesses and solicitors. Diane, a mother and key informant who was a former police officer, explained that:

For everyone but me, it had all been a bit of a game. The banter between my psychologist and the panel reminded me of barristers in court playing off each other. And after it had finished the LEA psychologist came up to my psychologist and said 'oh, by the way you spelt a word wrong' and they laughed together. And I was standing there and I thought 'this is my life, and my child and you are having a laugh about a word spelt wrong!'

Martha commented on the banter within the hearing:

The Chair said that he felt that West School could meet Sean's needs, that it had changed and that we hadn't given it a long enough chance when Sean was there before. But he quipped to Mr Sutton that we 'were not likely to send him back to your school'.

(Martha, a mother and telephone interviewee)

While one panel member, Mark, was careful to point out that the aim in setting up SENDisT was that it should not be an adversarial system, and that it was intended to be a meeting to achieve agreement between the parties, he did acknowledge that this was not the experience for all parents:

I think the biggest problem with the system was, right from the beginning it was supposed to be an informal method of getting two parties together to arrive at a consensus which was shared by all and an understanding of what the needs of the child were and how these needs would best be met. The first one I went to which was in the first week of the tribunal a barrister was employed by the other side [the parents], a barrister, now once you're into barristers, solicitors, we live in an adversarial system of justice, it's not inquisitorial. The Tribunal is in fact an inquisitorial system, but it has got tagged onto

it an adversarial component in the sense that both parties try to vie with each other.

(Mark, former panel member and LEA educational psychologist)

At times parents felt they were not heard in the Tribunal. Martha was frustrated by feeling that no one had listened to her:

With the hearing hurtling towards its end, we felt that we still had not had time to answer what the LEA had said. We felt that every time we had tried to interject we had been ignored, but we thought that we would be given time to be heard before the end of the hearing.

(Martha, a mother and telephone interviewee)

This feeling was shared by Sally, a mother and telephone interviewee:

I would have liked to be able to say more, and I would have liked our witness to say more, but we didn't get the chance. I suppose it was all in our case statement, but it was a bit frustrating.

(Sally, a mother and telephone interviewee)

Despite the formality of the meeting, this was not the experience of all parents. In contrast to Martha's experience, Barbara, a mother and telephone interviewee, said that:

They [the panel] were very sensitive, listened very carefully, and were totally different to the professionals who were working with my daughter at the time. And that is significant in itself.

(Barbara, a mother and telephone interviewee)

One of the panel members also stressed that the intention was that everyone should have their say:

It aims to be fair, everybody is heard.

(Scarlett, a panel chairperson)

Yet, sometimes professionals shared the parents' feeling that it was difficult to make themselves heard or to put across key points to the panel:

The actual process I felt didn't enable people, well it certainly didn't enable me to enter into issues like why hadn't the school done what it had been recommended, why weren't they supporting this little girl

(Julia, an Educational Psychologist and witness for the LEA)

The parents' satisfaction with the way the panel conducted the hearing was not necessarily connected to whether or not they were happy with the panel's conclusions. Simon, a father and telephone interviewee, felt that the panel had



listened and that he and his witness were able to put their points across, but the panel did not give him the autism specialist school he wanted. Whereas Sally, a key informant, got teaching assistant support for her son and dyslexia teaching, but she still felt that she wasn't able to put her points across in the hearing.

The formal meeting affects parents' behaviour; they feel constrained, and at times frustrated and unsure of how to play their part. However, at times, parents made attempts to challenge the constraints put upon them. Martha objected to being asked to sit in the same room as the representatives of the LEA before the Tribunal, but her request for a change of room was rejected. Martha also tried to take some control at the start of the hearing by putting a picture of her son on the desk. However, her act of resistance was rebuffed as the Chair responded by saying 'oh that's Sean, we'll come back to him'.

Maria, a mother and telephone interviewee, used passive resistance to good effect within the hearing when she said:

I started off by saying 'I must apologise, I'm not used to speaking in public, I'm just a pig farmer.

Her more passive approach was met with a conciliatory 'you mustn't worry about that' from the Tribunal Chair, and Maria was able to shift the balance of power in her favour.

Fiona, a mother and telephone interviewee, described how she felt that it was not possible to resist:

We had gone in with such high hopes and you could just tell after about the first two minutes, this was all a waste of time.  
(Fiona, a mother and telephone interviewee)

The emphasis on a sense of surveillance and control is indicative of the formality of the meeting. It is perhaps impossible to avoid this in a formal meeting, however, at times, the language of the hearing, including professional discourses, professional banter and the language of the law courts, acts to disempower parents within the hearing.

In the next section we turn away from issues of surveillance and control to the allied issues of truth and knowledge within the Tribunal hearing.

## **SECTION TWO: Truth and knowledge**

Much of the conflict within Tribunal hearings centred on disagreement about what constituted 'truth' about the child. Parents and professionals asserted and resisted truth claims within the hearing. Pam challenged her son Tom's diagnosis and his IQ score. Simon challenged his son's diagnosis of autism *and* severe learning difficulties. Martha challenged whether or not it was true that Sean's needs could be met at a non-residential school. Within the field of special education, parental knowledge is, contrasted with professional knowledge; parental knowledge is intimate yet subjective whereas professional knowledge is considered to be authoritative and true (Billington, 2000).

Within the hearing, the use of medical, psychological and educational technical language, at times, excluded parents from the process. Diane described her feelings about the language used within the hearing:

It was very daunting, I was a bit overcome by it all and some of the words they used, it wasn't that I didn't understand them but it was their 'talk', not mine.

(Diane, a mother and key informant)

For other parents, rather than being intimidated by professional discourse, they simply rejected professional views. Instead they asserted their own knowledge about the child and applied 'common sense'. Sandra's description of her interaction with a speech therapist within the Tribunal hearing illustrates this point:

I said to this woman [the speech and language therapist] 'well, have you ever met Terry?' (knowing full well that she hadn't). And she said 'no,' so I said 'I don't know how you can even talk about him like this, you have never met him!' By this stage, he had been talking for eight months ... she said we would like to teach him a better form of communication like PECS [Picture Exchange Communication System] or Makaton [a simple sign language], and I said 'but he talks! With all due respect who in his school knows Makaton? This is mainstream school. His peers do not know Makaton, the shop keeper over the road from us does not know Makaton if he had speech, which he has, then that's what we should be building upon' .... The speech therapist that was there came to see us at home the



next day to discuss it further and agreed and changed the speech therapy.

(Sandra, a mother and telephone interviewee)

Other parents resisted and contested the professional knowledge given by LEA employees by bringing their own witnesses, including speech and language therapists, psychologists and doctors. These parents chose the 'professional gazes' and assemblage of truth which they found enabling and empowering. Pam challenged the LEA assessment of her son's IQ by bringing in her own psychologist and Simon employed his own psychologist to challenge his son's label of autism and severe learning difficulties. At times, the professionals involved in a case, those employed by the parents and those employed by the LEA, agreed in their judgements about the child - Diane said that the only disagreement between her psychologist and the LEA psychologist was over the spelling of a word. However, when professionals disagreed, it was left to the panel to decide which professional judgements were 'true' and which were not. Simon, a father and telephone interviewee explained:

They [the panel] didn't respect it [the private psychologist's report] in the hearing, you know, it was just another piece of paper, you know, the lady that wrote it is an expert in autism, she's written books on the subject, she is a chartered educational psychologist. It was an excellently written report and you know, totally factual, and they didn't give it any, you know, any credence. So it was a waste of all the time, compiling our case, a waste of money and no sort of credit was given to the validity of the report or our case, really.

(Simon, a father and telephone interviewee)

Mark, a former panel member and LEA psychologist, acknowledged that there was a question about the independence of expert witnesses who were either in the pay of the LEA or the parents. He proposed an alternative system:

The answer would be to make the educational psychologist a friend of the court, so they are not paid by the parent and they are not paid by the local authority, they are paid by the court or the Tribunal.

(Mark, a former panel member)

Despite the conflict over the 'truth' about a child, the dominant discursive practices of need, deficit and diagnosis largely went unchallenged within the hearing (See Chapter Two for a fuller discussion of the deconstruction of special education). Parents and professionals seemed to accept that psychological

assessments of the children were simply 'true'. Yet Pat's story illustrated the contentious nature of psychological knowledge, remember she explained that:

The LEA psychologist gave Tom an IQ of 56 in December, and the following April the dyslexia specialist gave him an IQ of 105. The results were completely different.  
(Pat, a mother and key informant)

For Foucault (1990,) power-knowledge is closely associated with resistance.

Remember:

Where there is power, there is resistance, and yet or rather consequently, the resistance is never in a position of exteriority in relation to power.  
(1990, p 95)

The parents' attempts to resist are the focus of the next section.

### **SECTION THREE: Resistance and representation**

For Foucault, power is always accompanied by resistance. The issue of how to resist the exertion of power within the hearing is a key concern for parents. The majority of parents have no choice but to represent themselves in the hearing. However, some parents are able to choose to be represented by a member of a voluntary organisation, and others pay for representation by a solicitor. If parents choose to be represented, they usually relinquish their power to represent themselves within the hearing and the job of resisting fell to their representatives, either solicitors or members of voluntary organisations.

Parents talked about representation in their stories and focused on three main issues:

- whether to have a representative or whether to represent themselves;
- the availability of representation;
- the quality of representation.

These are considered below.

#### *To have a representative or not?*

Colin, a father and telephone interviewee, expressed a common concern - that he would be treated less favourably if he had a representative than if he represented himself:



The Chair questioned the LEA very hard as well, she put them under a lot of pressure and she wasn't difficult with us, but she was a little bit difficult with the solicitor, I think. Funnily enough ... I actually asked SENDisT when I rang them up and said we're having a solicitor 'is it an advantage or do they think 'oh these people have got a professional we're going to make it harder for them?' And they said 'no, it wouldn't make any difference.' But I feel it did make a difference.

(Colin, a father and telephone interviewee)

Richard, a father and telephone interviewee, chose not to be represented but felt that there were disadvantages with his decision too:

We looked at that [being represented] ... we were actually advised against it on the grounds that actually the Tribunal was likely to be more sympathetic if we weren't represented ...but there was some sort of crucial point which I failed to make which probably a professional barrister would have known about immediately ...

(Richard, a father and telephone interviewee)

Mia, a mother and telephone interviewee, also followed advice to represent herself and felt that this had not disadvantaged her:

'The general view and they [impairment based charity] told me this ...that when people are represented how do I put this, parents can't get away with quite so much some times. So the general idea is we're finding now that when parents are represented the panel can be just as hard on them as they are the LEA.

(Mia, a mother and telephone interviewee)

However, an LEA officer, Tim, described how a parent who did not have an experienced representative might be disadvantaged compared to an experienced LEA officer:

So from that point of view the more experienced you are in doing them, then you know it snowballs, you know the easier you find it. So you're doing quite a lot over a period, certainly it helps you. When I started doing them ten years ago I did all the cases that [our Education Authority] had so I was, I probably averaged one a month, or something like that. So, you know, as time went on I found it easier. Also you had a better idea then of what the Tribunal expected of you. So you know, the questions weren't being thrown at you where you didn't have the information available. You knew in advance, you had a good idea what kind of thing the Tribunal was likely to ask so you were able to prepare ...

(Tim, LEA officer)

One former panel member, Mark and educational psychologist, spoke candidly about his views about the advantages and disadvantages of representation, echoing the parents' concerns:

I don't think you'll ever find this written down anywhere but if a parent comes in unrepresented the tribunal members will represent the parent, they will ask the hard questions of the local authority. They will try to tease out from the information that the parents give what the parents need etc. Now I won't say they are on the side of the parent but they try to redress the imbalance of the power in the putting forward of the case. And also they are quite willing to argue, I won't say on behalf [of the parents], they are willing to be a little bit more forensic in terms of the opposing side so that the sort of questions that they think should be asked if that person had a good representative will be asked. If you've got two solicitors or barristers on either side the Tribunal is not going to interfere with that, they are going to let them go at each other and sometimes it can be counter productive, you know.

However, other panel members felt that it was their job to make sure that whether the parents were represented or not was not an issue. Lady Rosemary Hughes, the President of SENDisT also expressed her concerns about the presence of lawyers at a hearing:

A legalistic approach destroys the informal atmosphere that lies at the heart of SENDisT appeals and I encourage chairs to take a robust line in not allowing advocates to take over the running of the hearing.  
(Hughes, 2005, p4)

In July, 2006, the Education and Skills Select Committee Report, *Special Educational Needs: Third Report of Session 2005-6* (Education and Skills Select Committee, 2006) was published and this quotes the Department for Constitutional Affairs Research Unit (DCA, 2006) findings that legal representation for parents does not improve the success rates of appeals. Although represented parents were more likely to be successful - represented cases had a higher success rate by 7 percentage points than non-represented cases (82% to 75%) - the differences were not found to be statistically significant. However, despite these findings, the parents' stories reveal that the issue of representation remains a significant concern for parents.



### *The availability of representation*

The second issue for parents was that of the availability of representation. Many parents wanted to be represented, but this was not always available to those who were unable to pay for it:

The second time [I went to Tribunal] I asked [the advice line charity] if they could represent me ... and the man said 'I am very sorry but you can do this [represent yourself]' ... I thought I'm cracking up here! I felt awful but I went on my own.  
(Tina, a mother and telephone interviewee)

All the parents interviewed in this study had had some telephone advice from voluntary organisations before the Tribunal, but few parents were able to have a representative from voluntary organisations at the Tribunal itself. Parents understood that funding was limited but felt that this was unfair. Diane, a mother and key informant, summed up her feelings about representation:

The system needs to be restructured. It should be like the criminal legal system where you are allowed to speak to a duty solicitor. You should get representation, that would have really helped...  
(Diane, a mother and key informant)

Parents talked about the quality of the support they had received from telephone advice and representation at Tribunal. For many parents the presence of a representative at the Tribunal had, they felt, had a key significance for the positive outcome of the Tribunal:

Now the [advice line charity] rep who represented us there, she had previous experience of educational psychology and she brought that point out and I wouldn't have had a clue about the dips and peaks and all this. But it [the Tribunal] was embarrassing for the LEA to be honest....  
(Kirsty, a mother and telephone interviewee)

However, other parents described the presence of the representative as being of little help:

The solicitor was there [at the Tribunal]. He might as well as have not been but he was there ... the solicitor told us he'd won 16 of the last 17 cases but he came out to see us ... and he said 'bad news, this is the Chair that I lost my only case against.' And there was no question, he was totally fazed by it. They didn't get on. She didn't like him and you could feel that throughout the thing ...  
(Colin, a father and telephone interviewee)

### *The quality of representation*

The third concern for parents was the quality of representation. A few parents described their dissatisfaction with the representation they received both from voluntary organisations and from solicitors. Martha's story described how she felt her representative was unable to do her best for Sean.

Colin, a father and telephone interviewee, appointed his own solicitor but was dissatisfied with the representation he received and took control back from the solicitor in the hearing at times. He said that 'in the end, we sort of overrode him [the solicitor] on a couple of things'. Martha and her husband had also given control of events to their representative but even as things were not going well, they did not take control back back:

We sat in stunned silence. Sarah had asked before we started that we let her lead events, so we gave her our trust and chose not to intervene.

(Martha, a mother and telephone interviewee)

Professionals also talked about their views of the representation that parents' received. John, an LEA officer and member, spoke about representatives from voluntary organisations as being very mixed in their ability:

The advice and the help that parents get from these voluntary organisations is so mixed. There are some very, very good representatives, there are some who, you know, you feel very sorry for the parents. They're relying on these people, and these people don't really help them. There are even some, I don't really know if they're around any more, there are even some mavericks around who purport to help parents but really are fighting their own problems and things .... When [voluntary organisations] reps are good, they are very, very good, it's like the old rhyme, isn't it, but when they are bad, it can be awful at times.

(John, member and LEA officer)

The panel members' criticism was not limited to volunteers, Mark and Thomas also criticised solicitors who knew little about education law, or seemed to drag the hearings out unnecessarily.

The issue of representation is key to how parents resist in the hearing, yet parents' experience of representation were not unitary. Indeed, representation was not something that was available to all parents. Certainly, the inequity of the system



of representation and the lack of availability to those unable to pay contributed to the parents' anxiety.

## **Conclusion**

Parents' feel that they are the subjects of surveillance and control within the Tribunal hearing. At times, this results in them regulating their own behaviour and becoming disempowered. The formality of the hearing is overwhelming for some parents, and they feel unprepared by the advice given in the video sent to help them prepare. The most articulate parents who have well rehearsed arguments struggle to put them across in the hearing itself. It seems that the need for order is super-ordinate. The issue of representation is a key concern for parents who fear that their case will be treated less favourably if they use a representative, while at the same time they fear the burden of taking the responsibility of representing themselves.

The Tribunal hearing is clearly a highly charged and stressful environment for parents. In the next Chapter, the stories move away from the Tribunal day itself to reveal the longer term effects of going to Tribunal on the family.

## CHAPTER SIX: FAMILIES AND TRIBUNALS

### Introduction

This chapter considers the impact of going to Tribunal on the whole family: what can we understand from the parents' stories about the outcomes for the families of pursuing a claim to Tribunal? Clearly, the Tribunal has outcomes which affect the educational provision for the child (teaching time, learning support assistant time, therapies, school placement) but it also has implications for the financial, social and emotional well-being of each of its members.

In section one, the focus is the effect of Tribunal on the child's educational provision. Ivor's story about his son Michael, *I don't want you to think we're terrible people*, illustrates how, for parents, often the Tribunal is not the end of the process, and the limited impact that a Tribunal decision can have on what is happening day to day for a child. In section two, the story *Four and a half years of sheer hell* is also a composite narrative which is used to explore the recurrent theme of family stress and well-being in an emplotted story. The section focuses on the impact of going to Tribunal for all the family members. In section three, the story, *I've got a brain in my head I'd forgot I had*, is another composite narrative which explores the idea the positive consequences of going to Tribunal, empowering individuals and strengthening relationships.

### *Disabled families*

And what I've found is that when you have a disabled child the whole family becomes disabled.  
(Ben, a father and key informant)

The analysis here engages with the literature which examines disability and family. However, to describe a family as 'disabled' is controversial. Many parents would doubtless reject Ben's description of the family as they talk instead of their children's 'problems', 'special needs' and 'disabilities'. The term 'disabled families' is controversial within the context of British disability studies. Dowling and Dolan (2001, p22) reject the term:

We prefer the term 'families with children with disabilities' or 'families with disabled children' because 'disabled families' is not a common anti-oppressive term.



Yet, Kiernan (1999) embraces the concept:

If society creates disability and disadvantage then it is the families of people with disability, ... who also suffer from the 'oppression' of disabled people  
(Kiernan, 1999, p46 cited in Case, 2001)

The term 'disabled families' is used here because it firmly locates the families' experiences in a social model framework and reinforces the concept of disability as a form of social oppression, which acts upon the whole family, not just the child. Parents and siblings of disabled children have clearly described their experiences of discrimination and intolerance (Murray and Penman, 1996). However, it is important to be clear that by saying a family is a 'disabled family' it does not mean that the child with impairments has disabled the family, it is society which threatens to disable the family.

### *Research and the disabled family*

Habitually literature about disabled families has focused on the 'deviant' characteristics of the family member with impairments (Greenfeld, 1996, Powell & Gallagher, 1993, Samuelson, 1986 cited in Taylor, Bogdan and Lutifiyya, 1995). Personal and psychological variables have often been the focus of research to the exclusion of other issues. The experiences of parents, and children have been explained within the context of intrafamily or intrapsychic functioning (Read, 2000). Darling (1979, cited in Read, 2000) suggests that parents are often caught in a 'no win situation': parents are characterised either as unable to cope, or those who appear to be coping well are considered to be deluding themselves about the extent of their child's difficulties or practising 'well-disguised rejection'. Families are often described as needing to go through a process of adjustment to the news that they have a child with an impairment; this is frequently characterised as a grieving process (Bruce and Schulz, 2001). Those parents who construct positive, non-grief stricken images of their family life are often seen as delusional and denying reality (Taylor, Bogdan and Lutifiyya, 1995). Goffman (1963 cited in Taylor, Bogdan and Lutifiyya, 1995, p30) suggests that within research and among some professionals the family of the child with an impairment is forced to share 'some of the discredit of the stigmatized person to whom they are related'. The

family is pathologised in relation to the child's impairment (Cole, 2004); they suffer a 'courtesy stigma' (Goffman, 1963, p30 cited in Taylor, Bogdan and Lutifiyya, 1995).

However, within recent research there has been a shift in approach to families (Baldwin and Glendenning, 1981 cited in Read, 2000). There is now a greater resistance to research perspectives which are underpinned with parental models of grief and denial. Much research looks instead at the diversity of family experiences including, rewards, stresses, happiness, love and disappointment (Fisher and Goodley, 2006 in press). Parents' perspectives are seen as crucial within this type of research (Read, 2000).

By exposing their lives to professionals and to researchers, families are made vulnerable. Their actions are held up to scrutiny with the consequence that they can be judged to be well adjusted or dysfunctional families or good or bad parents. For the disabled family the private world of family life, enjoyed by other families, becomes public. Parents and children are the subjects of scrutiny and surveillance (Allan, 1999). Professionals have rightly been encouraged to see families as experts in their own lives and to learn from what each family has to teach, but disabled families, like others, have a right to privacy. All too often, families feel they must give up their privacy in order to access services and support or, indeed, to contribute to a research agenda. Parents allow a wider audience into their private lives in the hope that they will not be judged, but that their stories will promote understanding.

In this chapter, the effects of going to SENDisT on the families are the focus. While the voices of parents of disabled children (Beresford, 1994) and mothers, in particular (Traustadottir, 1999; Read, 2000; Cole, 2004), have been the focus of research, here the spotlight falls on the effect of the experience of the *whole* family: mothers, fathers, the child with special needs and/or impairments, siblings and grandparents. In Section One, the outcomes of going to SENDisT for the child's educational provision are outlined; in Section Two, the outcomes for the family members are explored, and, finally, the issue of parental empowerment is considered in Section Three.



## SECTION ONE: Educational provision

*Ivor is a father who gave up work during the process he described. He had a career as a successful banker, but that faltered because of ill health. He felt that the stress of going to Tribunal had played a part in this. The annotations in the margins of the story are intended to make his complex and legalistic story clear. Ivor's story was chosen because it is a poignant example of how the delivery of the Tribunal order is often not the end, but the beginning of the story.*

**I don't want you to think we're terrible people but...**

LEAs are supposed to implement an order from SENDisT within 5 weeks.

The statement of special educational needs we got from the Tribunal was everything we wanted. You'd think that was the end of it, but it was really only the beginning. You see, in October of last year, Michael got a lap-top, so it took ten months after the Tribunal order for the lap-top to come through. The increase in the hours of Learning Support Assistant teaching time should have been very straight forward, it was basically only a matter of asking the person that was doing the job already to increase her hours, but that took four months. I think there was a delay because, going on in the background, there was a disagreement about who was going to train the Learning Support Assistant. The LEA said the school should do it, the school said 'we don't know nothing about dyslexia, why are you asking us to?' The school said they weren't prepared to increase the hours until the issue of training had been resolved.

Again, the delay is unacceptable, the Tribunal's order is not carried out within the time limits.

The dyslexia teacher took over five months to get in place and then it was for initially two hours a week, and then after two weeks it increased to three hours and it

has been three hours ever since, despite the statement saying it should be five hours. But the teacher in question is in her seventies, is hard of hearing, and she is by far the cheapest. We know that because we had to help them get the teacher, we had to personally come up with people.

The LEA wrote to us this July to say we are not going to employ anybody for more than three hours, because his dyslexia teacher has said it would be stressful for Michael to have two different people coming in. So we said 'you can't do that by the Tribunal's rules', and promptly got in touch with an educational solicitor. I don't want you to think we are terrible people, or anything, but the same time we also lodged a complaint with the local government ombudsman and complained to the DfES.

The DfES were basically useless. They said their powers were very limited, they basically weren't interested in us. The Ombudsman was still looking into the case six or seven months down the line.

On November 22<sup>nd</sup>, we served judicial review papers on the council and that was on the basis of they hadn't complied with the Tribunal's order with respect to the specialist teaching, they'd acted unreasonably throughout the whole process, they hadn't allowed the additional liaison time that was required for the dyslexia teacher to talk to the class teacher, and also we were not convinced that the training the Learning Support Assistant was getting was an ongoing and intensive training course. Also in the end, we were asking for costs. While the judicial review was ongoing the

The LEA is refusing to implement the SENDisT order.

The local government ombudsman can investigate malpractice on the part of the LEA.

The LEA has responsibility for implementing SENDisT's orders.

Parents can complain to the DfES if the LEA does not implement a Tribunal order.

Judicial review allows people with a sufficient interest in a decision or action by a public body



to ask a judge to review the lawfulness of a decision, action or failure to act in relation to the exercise of a public function.

Judicial review may be used where there is no right of appeal or where all avenues of appeal have been exhausted.

Ombudsman had to stop looking at our case, you can't do both at the same time.

The Annual Review of Michael's statement was held in the October before we served the papers for a judicial review. At the Annual Review, there was a lady from the LEA pupil support team who had taken it upon herself to do some tests on Michael on the morning of the meeting. She suggested that Michael was in fact making substantial progress in his reading and written work. We were gob smacked! His teachers disagreed with the woman from the LEA pupil support team, and they said they felt that they were not seeing that level of improvement day-to-day. So in that meeting it was accepted that all of his needs were still the same. No change was suggested to his statement and there was no recommendation to change his provision. So that was that, and we went away happy.

Shortly after the judicial review papers we received in November, we got a letter saying that the LEA intended to amend Michael's statement as a result of the Annual Review where substantial progress was considered to have been made. Of course, the only thing they changed in his whole statement was his dyslexia teaching. They wanted to take that out because that was the whole basis of our judicial review. So our solicitor said 'this is an extraordinary development'. He wrote to the Council, he said 'you are bullying Mr and Mrs Smith you are being discourteous to Michael. And all of these things are just totally inappropriate behaviour from you and we cannot understand what you are trying to achieve. He began to threaten them with negligence, breach of duty of care and said this is just not on.

Parents would expect a discussion of proposed changes to their child's statement at every Annual Review meeting.

Once the dyslexia teaching was taken out of Michael's statement, the Judicial Review could not go ahead. A Judicial Review can only go ahead if the contents of the statement are not delivered. If the statement is changed to take out the dyslexia teaching the LEA can no longer be accused of failing to deliver the contents of the statement.

At this point, the LEA said they would come to a meeting and to discuss the rationale for the intended changes to Michael's statement. While we were waiting for the meeting to be arranged, we had another letter to say the statement had been finalised. They finalised the statement before we'd had the meeting. The solicitor asked what the purpose of the meeting was as the LEA were finalising the statement. I think they were desperate to get the dyslexia teaching off the statement, that there would be no question of this judicial review going ahead.

It worked, and we couldn't go ahead. Instead, the only road we'd got was to go back to SENDisT! Then out of the blue the Council's senior solicitor said 'we do feel there is some merit in having a meeting we do feel you should come and meet, although the statement has been finalised we are prepared to change it.'

The meeting was horrendous. An LEA officer even had the audacity to say 'in my view, you are giving him too much, you are over providing for him now, you are molly coddling him and you are stifling'. He was quite prepared to ignore all this expert opinion.

Our solicitor said we are very close to a position where we will start an action against the Council for a breach of duty of care for Michael, a negligence case, because they had failed to meet his special educational needs. He said we will be looking for damages of at least £60,000. Shortly after he said this, he said we needed a break and went out with the LEA officer. When they came back into the room, the atmosphere had changed

Without cause to go to Judicial Review, Ivor must go back to SENDisT to try and get the dyslexia teaching back on the statement.



completely and they said 'we've got a proposal' and the proposal was to reinstate five hours of teaching back in the statement. So we'd gone full circle! They'd put us through all this turmoil, cost and they were basically just putting back in place what we'd requested, what the Tribunal had ordered. So we're waiting for that revised statement.

It's quite tempting to get personal and to get involved in a fight, but I always stand back and think that Michael and his education is at the crux of all this. This has never been about a personal vendetta between us and the LEA, this is all about our son getting the best education possible. We were really lucky that we had the right sort of legal cover on our home insurance to be able to take them on.

I just wish that there was a sort of follow up from the Tribunal. If they're not doing what they should be doing something with teeth should get at them and impose some financial penalties Some penalties or some sanctions, name and shame them, punish them, that sort of thing. That's what's desperately needed.

Ivor faces the possibility of going back to SENDisT, if he does not agree with the revised statement.

Ivor went to the DfES, the local government ombudsman and to judicial review, but still felt that the LEA was not held to account over its failure to honour the Tribunal's decision.

### **The outcomes of going to Tribunal for a child's education**

Ivor's story shows that even with a statement that was 'everything' the parent wanted for his child, this did not mean that that was the provision which his son subsequently received. Ivor found that after months of battling with the LEA, the only way to get the dyslexia teaching the Tribunal had ordered originally, was to go back to Tribunal. Ivor found himself back where he started. The barriers to his son's inclusion remained.

Ivor was not the only parent to be successful at Tribunal and then had difficulty in getting the LEA or the school to implement the decision. Tracy, a mother and telephone interviewee, got a Tribunal order for her child which required that her daughter had an hour's speech therapy a week. The LEA would not fund it so in the end she got the DfES involved and 'miraculously it was all in place in September.'

Tracy remained worried that the entitlement for her child would be eroded:

We know that they [the LEA] are trying to chip away at the statement, and we know we are in for a fight again. We know it's coming and my husband and I are absolutely dreading it... I wonder if we'd have known what we were getting ourselves into would we have bothered? I like to think, I hope we would have done, but the tears and the upset. It never goes away!  
(Tracy, a mother and telephone interviewee)

Diane, a mother and key informant, expressed her concern that she didn't know what her child was actually getting at school and whether or not the Tribunal order was being implemented.

So I went through all this trauma of going to Tribunal and I'm left with one question 'how do I know what he is getting?' And I find it so difficult to go into school and ask because it feels like you are questioning them. I am so dependent on them, I value what they do so much and I don't want to be someone that they talk about in the staff room!  
(Diane, a mother and key informant)

Diane felt that she was the only person monitoring the delivery of the Tribunal order (the Tribunal ordered that George receive half an hour with a special needs teacher every day, and that he should have a toileting programme and an eating programme delivered in school) and this put her in a difficult position with her relationship with her son's school.

Professionals recognised the difficulty of monitoring the Tribunal order. Tim, an LEA officer, said that the LEAs relied on schools to deliver:

If it is a provision that is going to be made in a mainstream school ... we have to a large extent to rely on the school to deliver that, I know it is the authority's ultimate responsibility but certainly in [this county] we delegate the resources to the school, we have to rely on them to deliver... [the statement] is monitored through the review process and educational psychologists visiting the school



but other than that we do tend to rely on head teachers because they have the funding to do whatever the statement says.  
(Tim, an LEA officer and panel member)

The local authority must review a child's statement at least once a year, checking the child's progress and making sure that the statement continues to meet their needs (DfES, 2001a). The child's school invites parents to the review meeting and asks parents to send in their views on their child's progress over the past year. The review meeting looks at written reports and at the child's statement, and will see if changes are needed. After the meeting, the school must send the parents a copy of its report. The head teacher sends a report to the local authority recommending any agreed changes to the statement.

The level of monitoring by the LEA shows that parents may well find themselves in the position of having to monitor the Tribunal's orders. Thomas, a SENDisT Chair, acknowledged that there was no way that a panel would know whether or not their order had been implemented.

Parents who were unhappy with the Tribunal's decision also found themselves at a dead end:

They did suggest that we could appeal against the Tribunal ... but that was going to cost us quite a lot of money. They did put us in contact with a solicitor who would have helped but we just didn't have that sort of money ... if we'd failed again we'd have ended up not just with our own expenses but the LEAs as well. And you just can't do it ....

(Michelle, mother and telephone interviewee)

Parents' stories are supported by other research findings. Simmons (1996) noted that once parents had their judgements nothing happened. The NAS (2003) reported that parents had extreme difficulty in getting the LEA to implement Tribunal orders. The NAS (2003) also found that, like Ivor, parents had limited success in appealing to the local government ombudsman or the Department For Education and Science (DfES). IPSEA (2005a) also highlight the difficulties parents have in enforcing Tribunal orders.

Parents' experience of Tribunal are complex and time-consuming, yet despite their best efforts, parents can still be thwarted by the LEA or a school in getting what the Tribunal has ordered. Some parents were frustrated in their appeals to the local government ombudsman and the DfES for help, others were unable to go to Judicial Review because of the costs involved. Not surprisingly some parents were simply worn down by the process, or the financial constraints made it impossible for them to carry on. The lack of monitoring and the difficulty of appealing against a SENDisT decision is seen by parents as a major weakness of the system.

## **SECTION TWO: Family life**

*The following story is a composite narrative informed by a number of parents' perspectives on the effect that going to Tribunal had on their family in terms of financial cost, emotional and health cost and on family members and relationships.*

### **Four-and-a-half years of sheer hell**

We've had four-and-a-half years of sheer hell. It has been just one thing after another. My husband also suffers from Asperger's Syndrome and the planning and preparing for the Tribunal, along with the pressure of our daughter's exclusion from school was too much. My husband got into trouble with the police, and was asked to leave our home for 24 hours to calm down. I was dealing with the exclusion and things and he just could not handle it.

Our daughter has behavioural difficulties and a specific learning difficulty and it's not any good for her to be in the centre of all this: a mother that is so up to her neck in paperwork that she is not able to give her any time, and a dad that can't cope with stress and reacts badly, so it impacted on everything really. I really felt I was failing my daughter. Sometimes she would cry for hours in the night really upset, other times she just wanted to play, bouncing on the bed. I was drained, I didn't know what day of the week it was and



so the prospect of preparing for Tribunal was unbearable. And the Government expects parents like me to have a job!

So when I went to the Tribunal I was on tablets for depression. I thought I just can't do this any more. I just wanted an ordinary family life, where we are not spending every waking moment thinking about this and fighting about that. We just want to enjoy things, but the sleepless nights, the hours of agony obviously coincided with our other child growing up. Our son, who is now nineteen, felt he was being rejected, he couldn't understand why we were giving so much time over to our daughter. My mum and dad have cried their eyes out too, watching us go through all of this. We are very lucky to be together at the end of this because the road to Tribunal is definitely a family destruction course.

So, in one sense, it's not about the financial costs, but it is the costs to yourselves, and just the whole situation in terms of the relationships, and the hours of time that you put in to prepare for the case. I would say, the way I am is if I am going to do something I do it properly. So I did hours of preparation. You end up trying to do it when your child isn't at home with you, because you can't go and stand at the photocopier in the post office when your child is screaming blue murder and running for the door. And with the specialist reports, the cost of faxing documents backwards and forwards, paying for therapists to attend the Tribunal and the extra specialist tuition we paid for our daughter over the years. It has cost us thousands of pounds. Money we didn't have. We used some money my husband inherited from his father, but we've still got the credit card debt and we're still paying the interest.

### *Financial costs*

The financial impact of having a disabled child in the family has been the focus on much research and has been identified as a key concern for government:

The Government's goal to halve child poverty by 2010 and eradicate it by 2020 will require specific targeting of families with disabled children.

(Cabinet Office, 2005)

Research suggests that 29% of disabled children live in poverty (Department of Social Care, 2005). The Government acknowledges that having a disabled child in the family can mean that parents find it harder to maintain full time employment, their housing may be inadequate for their child's needs and spending on basic needs is increased (Cabinet Office 2005). The Joseph Rowntree Foundation (2001) found that parents of disabled children spent twice as much as parents of non-disabled children on items and services for their child. 80% of families with a disabled child in them have an income of £300 or less a week and spending on the disabled child accounted for one fifth of the total family income. Inadequate income is naturally a source of anxiety for parents (Dowling and Dolan, 2001) and a barrier to the families' inclusion in society.

Parents incur the costs of going to SENDisT in a context where disabled families are already likely to be amongst the most financially disadvantaged. The costs of going to Tribunal vary for each family. Some parents employ a solicitor to represent them, and although Gina had a solicitor for a flat rate of £1000, most had more open-ended costs to meet. Some parents did not incur solicitors' fees as they represented themselves, a few were fortunate enough to be represented for free by voluntary organisations, but all parents were faced with some level of financial costs. Parents paid for independent reports from speech and language therapists, occupational therapists, physiotherapists and educational psychologists to support their case at SENDisT. The costs varied considerably

It [the psychologists report] was quite reasonable, so I've been told, it was £270 ... I rang up one and he was charging nearly £700.

(Mia, mother and telephone interviewee)

Parents also faced hidden costs including photocopying and faxing reports and in one case paying for accommodation for themselves and witnesses before the Tribunal hearing.



For the first Tribunal, I spent between £700-800 on travel, hotel bills for myself, our GP, the Educational Psychologist and an independent representative. The Tribunal was at 10 o'clock in the morning in London, so we had to be there the night before.  
(Leo, father and telephone interviewee)

For Donna the only way to meet the costs was by putting them on a credit card putting the family into long term debt: she was paying £400 a month in interest. Some parents, like Leo, were able to opt for private education with enormous financial consequences for the family:

From a financial point of view, including school fees and everything, it has cost us in the region of £50-60,000. We never planned for any of our children to have a private education. We used the money I inherited from the death of my father to pay.  
(Leo, father and telephone interviewee)

One parent, Barbara, described how she was surprised to read newspaper reports of other parents paying large costs. Barbara was able to represent herself and used a psychologist's report provided by the National Health Service as evidence, but her case was the exception.

In a wider context, where disabled children are more likely to live in poverty, it seems likely that SENDisT will be inaccessible to some parents on grounds of cost. For a family on an income of less than £300 a week, even the administrative costs of going to Tribunal like photocopying, stamps, and phone calls will make the system inaccessible.

### *The emotional and health costs*

Parents struggled with the cost of Tribunal but it seems that the financial costs of going to Tribunal were considered to be small in comparison to the emotional costs parents experienced:

So, in one sense, it's not about the financial costs, but it is the costs to yourselves, and just the whole situation in terms of the relationships, and the hours of time that you put in to prepare for the case. I would say, the way I am is if I am going to do something I do it properly. So I did hours of preparation.  
Tina, mother and telephone interviewee

Just as the financial costs of Tribunal are in addition to the extra costs associated with caring for a disabled child, there is evidence that the emotional and health

costs of going to Tribunal take place within families who already experience considerable stress in their day-to-day lives. Contact-a-Family (2003), an organisation for the parents of disabled children, found that 78% of parents experienced stress or depression which they linked to having a disabled child; 51% of parents had financial worries which they linked to caring for a disabled child, and 72% of parents suffered from tiredness and lack of sleep because of their caring commitment.

The consequences of the additional stress parents faced when going to Tribunal had an impact on parents' emotional well being and health. Some parents ended up on medication, and some found the experience so difficult that they found it difficult even to retell it. Sally's health also suffered and she ended up taking sleeping pills. Diane thought she'd probably had 'a breakdown without knowing it'. Leo described the impact on his wife's health, and that she had 'nearly ended up on Prozac'.

However, when considering the stresses on parents of disabled children, it is important to consider what parents mean when they are asked whether they link stress with having a disabled child. The Government suggests that parental stress is caused by the extra caring responsibilities involved in looking after a child with an impairment:

Families with disabled children often face particularly high stress and family breakdown owing to the increased pressures of looking after a disabled child. If a child has difficulty sleeping or behaving in a way that does not allow them to join in with mainstream activities, parents can often face significant anxiety and social isolation.

(Cabinet Office, 2005, 5.3)

Parents did talk about the stresses of caring for a child with an impairment. Diane described the sleepless nights and the limitations put upon her because of her son's behaviour. Martha too talked of being worn down by caring for her son. However, Read (2000, p2) suggests that 'some of the most debilitating features in the lives of disabled people and adults are not necessary consequences of living with impairments.' Rather it is the socially and politically constructed stresses which are the most devastating and debilitating experiences for parents. As Tina, a mother and telephone interviewee, explained:



The Tribunal was *the* most stressful thing. More stressful than Andrew's behaviour or diagnosis.  
(Tina, a mother and telephone interviewee)

### *The effect for family members and relationships*

So far this research has talked only about parents, there has been no distinction made between mothers and fathers. Studies which have focused on parents as the smallest unit of analysis at the expense of analysing the differences *between* family members have been criticised (Traustadottir, 1999). Researchers (Traustadottir 1991; Read 2000; Cole, 2004) have shown that it is mothers who take the overwhelming responsibility for caring for their disabled children, yet when the research is written up mothers become 'parents'. 'Gender blind' research (Eichler, 1988 cited in Traustadottir, 1991, p212) which ignores the differences between fathers and mothers, diminishes mothers' contributions to caring for their children. So here the impact on mothers, fathers, children, siblings, the extended family and the relationships between them are considered in turn.

### *Mothers and the Tribunal*

Mothers tend to have overwhelming responsibility for the caring role (Cole, 2004; Read, 2000). Almost all mothers undertake the work of caring for their children but for mothers of disabled children this role is often expanded. The consequence for these mothers is that they are often limited in pursuing other roles separate from that of caring for their child. Because mothers shoulder the majority of the caring role and have the most knowledge about their child, they take on the job of advocating for their child in meetings with health and education professionals (Traustadottir, 1991). Mothers keep track of outside organisations and take responsibility within the family for working with them. The role becomes established as belonging to the mother, and the role is self-sustaining. In families where the mother has no paid work, the father is under increased pressure to maximise the family income and cannot take time off work to attend meetings.

Sometimes mothers take on what Traustadottir (1991) has described as an 'extended caring role' – the mother extends their care beyond their own child and starts to advocate for disabled children in general and to challenge the way they are treated. The majority of parents in activist groups are, in fact, women

(Traustadottir, 1991). These campaigning activities are not always understood as traditionally female roles, yet advocacy, and sometimes academic research, is closely allied with the role of the mother of a disabled child (Murray, 2000; Cole, 2004; Ryan, 2005).

A further consequence of the mother taking on the caring role is that it is the mother who is most vulnerable to criticism of her parenting. Mothers, more than fathers, are held to account by professionals for not mothering in the prescribed way (Read, 2000). While it has been frequently suggested that a child with impairments produces a dysfunctional family, mothers have also been blamed for producing a dysfunctional child. Until the 1960s, it was not unusual for 'refrigerator mothers' to be blamed for the behaviour of their autistic children (Badinter, 1981 cited in Read, 2000).

The mothers' Tribunal stories reflect these research themes. Mothers talked about their organisational role collating reports and circulating information:

I went to the educational psychologist, I went to the speech therapist and I basically went round everyone and said 'right this is the situation'... and I hurried them all up so I had all the reports ready, went to the review ....

(Michelle, a mother and telephone interviewee)

Mothers talked about their limited opportunities for taking up roles outside the home:

I work freelance ... and I only work part-time and the reason for that is because of the life-consuming task of making sure that Jack's needs are met.

(Mary, a mother and telephone interviewee)

Mary faced the additional difficulty of her husband working away from home, and being unable to attend meetings. She described how this was not taken into account by professionals:

My husband was abroad at the time. This was another thing they kept changing the dates of the meeting and we were really cross, because we had a date, my husband was in England at the time and then they couldn't make it ....

(Mary, a mother and telephone interviewee)

Several of the mothers in this study were members of the voluntary organisations which acted as the point of contact for the research, some mothers expressed a



wish to become advice line volunteers following their experience of Tribunal. Martha was already supporting other parents in preparing for Tribunal as was Mary. Sandra also took on an extended caring role:

I've become a governor at the school and I'm the SEN governor and this year we had two more children with autism and a Downs syndrome child start at the school, and I've helped all three of them with their statements ... they've all got their full hours. Their original statements were appalling and they've [the LEA] not even queried the changes they've asked for.

(Sandra, a mother and telephone interviewee)

The mothers also suffered 'mother-blaming' as part of the process of going to Tribunal. Kirsty was made to feel that she had exaggerated her son's difficulties:

On the day he arrived [at the Speech and Language unit] the teacher said when she met him she said 'oh' she said 'I thought he would be much worse than this!' And I thought 'what are you saying like? He doesn't warrant a place here?' They make you feel as if you are taking up the place of a child who's more needy all the time. That's what they make you feel like the education people.

(Kirsty, a mother and telephone interviewee)

Michelle also described how she was blamed and her competence as a mother was called into question:

My daughter had bladder problems ... and at the end of year 5 I had comments made to me that I had sent her to school in a soiled uniform.

(Michelle, a mother and telephone interviewee)

Mothers were most often blamed for being 'over-anxious' and their anxiety was linked to their child having a 'low IQ':

It was very obvious that they were thinking that I was just an over anxious mother and she had a very low IQ ....

(Michelle, a mother and telephone interviewee)

For one mother, her experience of 'mother blaming' was aggravated by the fact that she was an employee of her son's LEA, and her professional competence was also called into question:

I'm actually employed by the LEA and at the time I went to Tribunal for Andrew I was a SENCO in a Pupil Referral Unit. So on an almost daily basis I was having to phone the SEN team about a pupil in the school I was working with, and then I was having to deal with exactly the same people as Andrew's mother. And it did actually become a bit personal, it had a personal edge to it. My own head called me to her office and said I should be very, very careful

what I said because it could get very nasty for me. And I said 'I am a mother. I fight for the children I teach and I fight for my son.' ... I got a reputation which wasn't fair.  
(Tina, a mother and telephone interviewee)

The mothers' stories about going to Tribunal illustrate the extent of their caring roles and the construction of their vulnerability. The mothers' roles are tangibly different from the majority of fathers and it is fathers' experiences to which we now turn.

### *Fathers and the Tribunal*

We get lots of tearful parents ... mum will obviously be the one doing most of the speaking but she will often be very tearful, and dad mysteriously says very little.  
(Thomas, Tribunal Chair)

Thomas's description of the difference between mothers and fathers within the Tribunal hearing highlights the different roles and approaches mothers and fathers take to caring for their child. Research has shown that from the earliest days of their child's life, fathers can have difficulty in asserting their involvement (Carpenter, 2002). There seem to be several reasons for this difficulty. The father's nurturing role often goes unrecognised by professionals. Carpenter (2002) described one father's outrage at a diagnosis being given to his partner without him being present. Fathers have been described by researchers in the field as 'hard to reach' (McConkey, 1994 cited in Carpenter, 2002) and as 'the invisible parent' (Ballard, 1994 cited in Carpenter, 2002). Yet fathers' reactions can go unnoticed in a service system which focuses almost exclusively on the needs of the mother and the child. Fathers come under pressure to return to work or to work longer hours in order to support the family and to keep a sense of 'normality' in family life. Work also becomes a refuge for fathers who are struggling, without support, to manage both their emotions and the day-to-day aspects of care. While fathers feel that they must be the emotional support for their partners, they often feel that this relationship is not reciprocated (Carpenter, 2002).

A recurring theme within the mothers' stories was the difficulty fathers had with accepting that their child had special needs or an impairment. This was often a source of tension between the couples:



[Preparing the case statement] was horrendous. I had a lot of stress at the time anyway. I was fighting to get our son diagnosed with autism and it wasn't just against the medical profession. My husband found it extremely difficult to come to terms with it. (Sandra, a mother and telephone interviewee)

Sandra describes how the experience of Tribunal made her husband 'accept' things and 'believe' in her, which she felt he had not been able to do before. However, it is not surprising that fathers have difficulty in accepting information about their child's impairment or special needs. Fathers who are working and unable to attend meetings receive information filtered by their partners, which they sometimes suspect focuses on the negatives more than the positives (Carpenter, 2002).

The exclusion of fathers from the world of the disabled family is the result of dominant attitudes to the role of the father and the financial need for one parent to work. This might suggest that fathers would be largely absent from this study, and yet fathers are represented here, and several seem to have taken a leading role. However, Read (2000) suggests that fathers often become involved in caring for their child for a particular reason. Researchers (Read, 2000; Cole, 2004) have found that if mothers have a fight on their hands, the fathers are called in. One mother in Read's study described how her husband was 'shipped for the biggies' (Read, 2000, p22). A Tribunal hearing is clearly seen by most parents as a 'biggy' and so fathers are shipped in. Sometimes they take the leading role like Leo, Richard and Ben, but more often, as Thomas said, fathers are present but maintain a 'mysterious' silence. The 'mystery' is explained by the fact that fathers who have handed the caring and organisational role to the mother, do not have the information and knowledge required for them to make confident contributions to the Tribunal. When the stakes are high, and fathers are not confident with the information, they feel it would be better to stay silent.

It is all the more difficult for fathers to contribute in a context where the expectation is that the parents must speak with one voice. Professionals are allowed to disagree about the child, but parents are not. A 'gender blind' approach to parents by professionals has the consequence that at best different

parental perspectives are ignored, and, at worst, different perspectives are seen as problematic and as part of the parents' pathology.

Parents' stories show that the pressure of the Tribunal process has an impact on the relationship between mothers and fathers, and this is considered below.

### *Relationships between mothers and fathers*

The relationship between mothers and fathers of disabled children has also been a subject for research. Research has shown that mothers of disabled children are more likely to follow the traditional pattern of the bread winner husband and the full time mother (Traustadottir, 1991). Contact-a-Family (2003) conducted a survey into the effects of having a disabled child on the parents' relationships. The survey showed that 23% of parents thought that it had brought them closer together, however, 31% felt that it had caused them some problems and 13% felt it had caused major problems, and 9% felt that it had led to separation. The impact of Tribunal on relationships takes place in a context where the relationship between parents may already be strained.

For some parents, the Tribunal was blamed for having an adverse effect on the relationship between the couple:

My husband got made redundant at the same time as the Tribunal, so it can't be all down to the Tribunal, but before the Tribunal we did actually break up for a week, I think that was a combination of him having difficulties and me having a stress. We just decided enough is enough, have a break ....

(Mia, a mother and telephone interviewee)

Michelle describes the pressure of going to Tribunal put on her relationship with her disabled husband and Diane also felt that the burden of preparing for Tribunal affected her relationships with her partner. However, in the end, Mia saw the Tribunal as having a positive effect on her relationship with her partner:

I feel a lot stronger for it, I have to admit, I feel I can conquer anything now. There is always a silver lining, you know, our marriage got stronger...

(Mia, a mother and telephone interviewee)



The relationship between fathers and mothers is clearly impacted upon by going to Tribunal, but other relationships are also affected by the family's experience of Tribunal and this includes relationships with siblings and the extended family.

### *Siblings, grand parents and the Tribunal*

Parents' stories highlight their concerns about the impact of going to Tribunal on their other children and on the extended family. Several families were concerned about the impact of going to Tribunal on their other children:

I think my daughter found it quite hard because a lot of talk was going on about Terry all the time ... they do get jealous. It's not that I give Terry more attention ... it's the fact that my time might be taken up talking about him or writing things or doing letters. I do think she gets quite upset sometimes about it.

(Sandra, mother and telephone interviewee)

Diane explained that the tension had affected her parents too as they watched her struggle with the Tribunal process. Parents were very aware of the impact of the Tribunal on the whole family, not just themselves and the disabled child.

The research is divided about the impact of living with a child with an impairment and/or special need upon siblings. Burke (2004) found that 'able bodied' siblings experienced exclusion from mainstream activities and were not given enough attention by their parents. However, Connors and Stalker (2000) found that siblings generally gave positive accounts of their brothers and sisters and did not feel their activities were curtailed or that they were denied their parents' attention. Yet, for some, the presence of a child with an impairment or special need in the family had resulted in bullying and taunting at school.

Much of the research on grandparents of children with an impairment or special need has been carried out in the United States (Carpenter, 2002). Grandparents experience what has been described as a 'double whammy' (Contact-a-Family, 2003) because they are concerned about their children and their children's children. Beresford (1994) found that parents report that grandparents often found it difficult to accept a child's impairment and disablement. This sometimes led to parents hiding or playing down the child's difficulties in front of the grandparents. Again, sometimes, this caused tensions in the relationships

between the parents, and their parents. So, the Tribunal takes place in a context where the relationships between children, parents and grandparents may already be strained.

### **The impact of Tribunal on the child with special needs and/or impairments**

Clearly, the outcome of the Tribunal's decision has a major effect on the life of the child who has special needs or is disabled. A further impact of the Tribunal comes from the knock-on effect of having a parent who is preparing for Tribunal as well as providing care for the child. Parents were acutely aware of being torn in two directions – the need to care for and play with their child, and the need to prepare for Tribunal. Parents who did not work and had all their children in full time education felt able to manage the preparation without this having a major impact on their children:

It didn't have a big impact on Fred because he didn't know it was going on!

(Sue, a mother and telephone interviewee)

Other parents felt that the stress they were under did have a negative impact on their children.

Sometimes, children were directly aware of the consequences of the Tribunal's decision. Fiona, a mother and telephone interviewee, was able to reassure her son Christopher that whatever the Tribunal decided, they would carry on paying for her son to attend a private school with a specialist dyslexia unit. However, Colin's son was left unsure of his future:

It was a lot of stress, I spent hours on the PC. Nick, he wasn't affected by very much at all. Except the one thing was, yeah, which school he was going to ... when the Tribunal doesn't take place until the middle of June and all the other boys get their places in March he kept asking 'what's happening, where am I going?' From his school all the boys either go to X or Y ... and they kept asking him 'where are you going?' and he sort of felt disadvantaged because he didn't know what was happening.

(Colin, a father and telephone interviewee)

For Simon, who went to Tribunal to try and get an autism specific special school place for his son his biggest regret was the time he wasted:

With the value of hindsight, I think it [preparing for Tribunal] was a waste of time that I could have spent working with my son, or spending time with my family. Anything!



(Simon, a father and telephone interviewee)

Lady Rosemary Hughes, the President of the Tribunal has made a commitment to the 'centrality of the child in the work of SENDisT' (Hughes, 2005, p5), yet it is not clear how this commitment operates in practice. Christopher, Fiona's son, was the only child to speak at a Tribunal in this study. Christopher spoke about what he wanted for his education and described the process as 'alright', but his mother felt that the panel treated him unsympathetically and tried to trip him up. In general, children do not attend the Tribunal process and, in this way, their views are not prioritised. The children are the 'absent guests' (Todd, 2006) at the hearing. Parents are sometimes encouraged by voluntary organisations to take a photograph of their child, but parents said that the process can feel very detached from the child it is intended to help. Indeed, it may be that the arguments and preferences stated by parents and professionals at the hearing do not reflect those preferred by the children themselves (Murray and Penman, 1996).

The absence of the child's voice within the Tribunal process is worthy of some attention. Parents can and do provide insights into their child's situation, but the child's understanding and experience of the world is different from that of their parents (Case, 2000). While current policy for special educational needs aims to privilege the voice of the child (DfES, 2001a), this is not often the way the Tribunal hearing operates.

### **SECTION THREE: The Tribunal experience empowering parents**

*This story is a composite narrative which explores the theme of the empowerment of parents who go to Tribunal. The story illustrates that for some parents the experience of going to Tribunal has positive outcomes for their sense of self and their life chances.*

**I've got a brain in my head I'd forgot I had**

The LEA wanted to place our son in a special school, and that is what we wanted too. The school they suggested for us had a new head and the school seemed to have all the money the LEA had got thrown at it. The head could take in basically what he wanted and he was taking children with Severe Learning Difficulties, but also he was taking a lot of children with Emotional and Behavioural

difficulties and putting them all in one class. And when we went and looked at the school, it frightened me. There were children rolling round my feet fighting and queuing up for their Ritalin at the staff room door. There were holes in locked doors where obviously someone had thumped them in temper. Children were spinning around, nobody seemed to know where they were going. I just didn't like it.

We just kept saying 'no, no it's not the school for our son'. I just couldn't have left him there. I knew I'd take him there the first day and take him home again. I could not have left him there.

I had support from an advice line charity, but I don't think I ever thought about anything else but representing myself to be honest. I mean, you know, it's only in the last year that I've read the newspapers and these people have said 'oh, it cost us £30,000 to go ... they don't listen to you if you don't have a solicitor' and I didn't find that at all. I didn't even pay for the psychologist's report, I just used the one from our local hospital psychologist. I thought we put quite a good case together actually. I was quite pleased with it.

The Tribunal was very fair and very thorough really.

The head of the other school, the one we wanted came over to us at the end, and she said 'you did do very well. She said 'you know it's not personal' and she said 'if we do take your son, I promise you, the Tribunal means nothing and we will do our best'. I was glad about that. I have still got worries about my son's school, I don't think any school is perfect. But I would hate to think they wouldn't keep him there, I just don't know where we would go from there. It is a worry.

I think that's what made our Tribunal easier than it is for some parents, the school we wanted were willing to have him but they



were full. I think if they'd said 'no we can't take him because of this because of that', that's when it starts to get personal.

And sometimes I think 'where would I be now if I hadn't had him?' I'd have a boring job along with everybody else, taking your kids for granted. All this does stop you taking them for granted. You do enjoy them, so sometimes I think, 'no I'd rather, in a way, with all the hassle, I'd rather be me.' I'd rather really enjoy the good times, and not take my kids for granted like other parents do.

And actually it was quite good my husband going to Tribunal with me, because it made him face things he didn't like. And he made him accept things a bit more, and it made him have a bit more belief in me. Leading up to the Tribunal I didn't do anything, all I did was focus on the Tribunal and things got left on the side-lines. It caused quite a few arguments and actually in the break at the Tribunal my husband broke down. He said 'I can't believe what you are coming out with. I didn't appreciate all the work that you've done.' So that was quite good in a way, it made him think a bit more, and it made me more confident. I learnt an awful lot, and the whole process made me realise I can learn. That's why I'm doing the degree that I'm doing now. I've realised I've got a brain in my head that I forgot I'd had. I might even go on to a teaching degree.

### *Tribunals and the empowerment of parents*

So far, the focus of parents' stories has often been on the negative effects that preparing for and attending Tribunal has had on the family as a whole. Yet the story suggests that some parents, at least, find the process empowering. Kelly (2005) found that parents of disabled children often commented on the benefits of having a disabled child including increasing their parental advocacy skills.

The story illustrates how the confidence the mother acquired by going to Tribunal led her into a degree course and to thoughts of a career in teaching. Mia also described the experience as empowering:

Now I've been through this, I really feel I could go through anything. I'm not afraid of any body whatever their status, I'm not afraid to speak up to anybody. It's hardened me. I'd take all of Ryan's conditions away like that but I wouldn't take this experience away, really. I think it has helped me.

(Mia, a mother and telephone interviewee)

This was a view shared by Barbara

I would say it [going to Tribunal] has made us stronger. We are very, very aware of our daughter's needs. We are very aware of the systems, and how they should work and how they don't.

(Barbara, a mother and telephone interviewee)

While parents find the process of going to Tribunal extremely demanding and stressful, for some, at least, the process has positive outcomes for their sense of self and for their future life chances. Parents were critical of a number of aspects of the process of going to Tribunal including the time and skill needed to prepare their case statement, the lack of access to representation and lack of monitoring of the orders. However, the parents advocated reform of the system and not its abandonment. SENDisT enables parents to voice their views and, in that sense, the institution is empowering for parents.

## Conclusions

This chapter has shown that the Tribunal's decision is often not the end of the process for the parents but the beginning. The process of challenging the Tribunal's order and of monitoring whether it is being carried out is a very stressful one for parents. The implications for the family in terms of emotional costs and financial costs mean that challenging a decision and forcing the LEA to deliver an order is beyond the means of even the most affluent and resourceful of parents. The financial costs of going to Tribunal in the first place can be high, and even in cases where parents do not pay for professional representation or private reports, the hidden expense of stamps, and phone calls place the Tribunal beyond the means of families living in poverty.

The Tribunal process clearly affects the *whole* family, while mothers carry the main responsibility for the advocacy role, fathers often step into the role of advocate at times of conflict, and this is particularly the case when parents go to Tribunal. The different parental perspectives about their child and the process of going to



Tribunal is a source of tension between couples who may already be experiencing additional stress on their relationships. Parents feel that their other children and grandparents are also affected by the family involvement in the Tribunal process.

Despite the many negative aspects of pursuing a claim to Tribunal, some parents find the process empowering, particularly in developing their advocacy skills. This sometimes has positive outcomes for the parents as they become more confident and pursue different life experiences including career changes and advocating for others. The experience of going to Tribunal has immense implications and costs for each member of the family. Professionals and parents must be mindful of this in their relationships in the run-up to Tribunal.

In this chapter, the focus has been on what the stories reveal about the effects of going to Tribunal on the family, this leads into the question of how the families experience the wider social world living in a family where one or more child has special needs and/or impairments.

## CHAPTER SEVEN: FAMILIES AND SOCIETY

### Introduction

In this chapter, the research focuses on the families' experiences in the wider social world. Whereas Chapter Six explored what the narratives revealed about the impact upon the family of the Tribunal, here the focus is on what the parents' stories reveal about the living in a family where one or more child has a label of special educational needs and/or impairments. It is important to recognise that parents' Tribunal stories do not take place in isolation, parents talked about their experience of Tribunal and their day-to-day lives. This chapter puts the Tribunal stories in context as well as offering an analysis of the family experiences which were part of the parents' stories.

The chapter begins with a composite narrative: *Because he looks normal, it makes it very hard ....* The parents' accounts of the experience of living with a child with a special need and/or impairment were many and fragmented, so by using a composite narrative it is possible to use emplotment to bring together the stories in a way which engages the reader and binds the stories together. The aims to offer an authentic account of the parents' common experiences. The story is complemented with parents' vignettes – short stories which illustrate how parents feel about particular aspects of having a child with special educational needs and/or impairments. Vignettes are used to strengthen and broaden the emplotted composite narrative.

The chapter uses a thematic analysis which draws on the disability studies literature (Beresford, 1994; Read, 2000; Green, 2003; Cole, 2004; Landsman, 2005; Fisher and Goodley, 2006 in press) and the work of French philosopher Pierre Bourdieu (For a fuller discussion of Bourdieu see Chapter Four) to examine attitudes to children with special educational needs and/or impairments. The themes which emerged from the analysis were:

- the attitudes of parents and others to children with special needs and/or impairments;
- the parents' sense of isolation in society and possible sources of support;
- the life chances of children with special educational needs and/or impairment.

Each of these themes is addressed in the sections below.



## **SECTION ONE: attitudes to children with special educational needs and/or impairments**

*This story is a composite narrative which explores parents' attitudes to their children with special educational needs and/or impairments. By combining' perspectives in an emplotted story the aim is to explore the parents' experiences, not to reproduce one parent's 'reality'.*

**Because he looks normal, it makes it very hard ....**

We were posted abroad when George was diagnosed with autism. After the diagnosis, we felt I couldn't be posted any more because of the kids' education and medical requirements, so it's kind of put the mockers on my career. When we got the diagnosis, I was grieving, it was like a bereavement. You've lost your child, that's how it feels, you've lost your child and you are never going to know your child, you are never going to have a conversation with your child and that's how you feel. No parent wants to hear that their child is autistic. We tried everything: brain gym and cranial massage.

But just for once, I'd like somebody to say something positive about my child, you have to be so negative if you're going to get anything. As a parent it is so debilitating. Everybody has an opinion when your child has a problem and you really feel it's you against the world! I sometimes wish that my son looked like he was disabled because he's exceptionally tall, so he looks an awful lot older than his nine years. He is a beautiful boy with a big smile on his face but he acts like a four-year-old, well six-year-old probably now, and it is very hard. It puts a lot of stress on you and your family. I don't wish my son looked any different but it might have made it easier if he had. Because he looks normal, it makes it very hard. I mean the first thing that has been said to me by many unknowing parents is 'Is he dangerous?'

On the day of the Tribunal, you would not believe the arrangements I had to make for child care for George. I always

pick George up from school, but the Tribunal was set for 2 o'clock, just before school finishes. So my husband had to take the day off work, go and pick George up early – he couldn't go at the normal time, because George would be expecting *me* then, and if I hadn't been there George would have gone mad! So of course, my husband couldn't come to the Tribunal, so my dad had to come with me and he had to come and stay the night before. The Tribunal must know that two o'clock is close to school finishing time, but they don't think about that. At the end of the day, when you have a child with special needs it is not as if you can ask the neighbour to look after them, it's just not possible! George is never asked for anybody to come home for their tea and he never gets asked to go anywhere.

I worry for the future. If we were to have a car accident tomorrow, then George would need someone. My brother wouldn't know the first place to start, nor my sister who is a leading head teacher. They would not know where to start. He would need an advocate.

Here the analysis focuses on what the narratives, such as the one above, reveal about social attitudes to families with children with an impairment or special need. The aim is to explore the attitudes the parents themselves expressed about their children, as well as the attitudes of others in their families, friends and strangers and to discover what impact this has on family life.

### *Parents' attitudes to their children*

The Occupational Therapist wouldn't diagnose Dyspraxia, they said we can't diagnose Dyspraxia with him having learning difficulties. I felt he didn't have learning difficulties. I was desperate to get the diagnosis not just to get him into the right school but because I knew he had it! They think he might have dyscalculia along with everything else, and I'm like, I don't want to go there along with everything else, I'm just a wreck. I tried to do the OT programme at home, but I wasn't sure he was doing the exercises the way they were meant to be done, and I was quite worried that I could be damaging him because I thought 'I haven't



got the professional expertise, so I need help'. In the end, I had to acknowledge that as well as having Dyspraxia he actually does have bordering on moderate learning difficulties because he's just not being able to problem solve or whatever. So I think I found that, I think I found that quite difficult to come to terms with ....  
(Kirsty, a mother and telephone interviewee)

As we saw in the previous chapter (Chapter Six), the attitudes of parents to their children with impairments and/or special needs has been the focus of much academic research and comment (Read, 2000; Ferguson, 2001; Bruce and Schulz 2002; Cole, 2004). Recent studies reflect a shift in research perspectives from those which look at the intrafamily and intrapsychic aspects of the disabled family to one which values the positive aspects of parenting a child with a special need and/or impairment, and acknowledges the parents' status as experts in their own lives (Read, 2000; Cole, 2004). However, it remains the case that parental responses are scrutinised and judged by professionals and by the academic community: do the parents accept or deny their child's impairment and do they celebrate or pathologise their child's differences? The temptation has been to offer a typology of parents which tries to locate their responses to their children in either a medical or a social model of disability (Fisher and Goodley, 2006 in press, see Chapter Four).

Parents' attitudes towards diagnosis have been used as a litmus test for which model of disability they embrace (Fisher and Goodley, 2006 in press). Parents who 'push' for a diagnosis are seen to be constructing a pathological and medical model of their child, yet the parents' narratives are self-contradictory and reveal a greater level of complexity. Parents engage with medical and social models of disability at different times and in different contexts; their responses cannot always be simply sub-divided into medical or social model responses. Diagnosis was often an important event in parents' stories. This was particularly the case for parents of children with 'invisible' impairments, including labels of autistic spectrum disorder, attention deficit hyperactivity disorder and Dyspraxia. These parents had often had confirmation of a diagnosis in the recent past and, for some, it had not occurred until their child had been in school for some time.

While policy and research documents often talk as if there is a moment of diagnosis (Read, 2000), for parents of children with invisible impairments, there was usually no one point of diagnosis. Instead, diagnosis is a long and drawn out process, often initiated by the parents themselves. Sandra explained how she pushed for a diagnosis:

My paediatrician was very 'well, he's got autistic tendencies' and I felt that's not enough. He's either autistic or he's not autistic'. And she was like 'we'll leave it another six months and then we'll have another look'. But I was 'well, he's going to be in school by then.'

(Sandra, a mother and telephone interviewee)

Sandra's attitude to the value and importance of diagnosis seems to position her response within a medical model of disability. Sandra appears to be accepting the binary of disabled and non-disabled, as she demands to know 'autistic or not?'

Yet, while the stories sometimes show parents engaging with and at times embracing medical models of disability, at other times, they engage with and embrace the social model of disability. In fact, the parents sometimes seemed to move easily between the two opposing models. Diane expressed her 'grief' about the diagnosis, asking at the same time why no-one ever said anything positive about her child. Parents' views about their children were inconsistent, fragmented and complex (See also Chapter Four).

In fact, parents seem to behave pragmatically and at times politically. Sandra pushed for a diagnosis, but she did so because she believed that a diagnosis of autism would open the gateway to services and support. In seeking access to services and barrier removal for her son, she was also engaging in what could be described as a social model approach to her child's impairment. Michelle also engaged with a medical model of disability as a pragmatic means of achieving barrier removal and support for her son:

None of us like labels, but without a label you can't get anywhere, you've got to have a label to make you fit the system.  
(Michelle, a mother and telephone interviewee)

Michelle understood that labels are problematic and unwelcome, but realised that in certain contexts a label would help her child.



Yet, the parents' push for diagnosis is still construed as evidence of the parents' pathology. Julia, an educational psychologist and telephone interviewee, described how she felt parents individualised and pathologised their child's difficulties at school and, in contrast, over invested in their non-disabled child:

The parents had a certain take on this little girl and it was obviously important that she was perceived as the way that they saw her, which was that she was not functioning as a normal child. And there was the whole family sort of dynamic. The older girl was described as being perfect ... it fed into their view of things that this little girl did have something wrong with her.

(Julia, educational psychologist and telephone interviewee)

The perception here seems to be that in this case a diagnosis serves the interest of the parents, not the child. However, in a context of 'mother-blaming' (Read, 2000) where medical and rehabilitative discourses dominate policy and practice, it is not surprising that, at times, parents embrace medical models which offer labels for their children. A label offers two valuable assets to the parents: first, the parents have a means of protecting themselves from the charge of being inadequate parents and, second, a label is seen to offer a gateway to information, resources and support. The search for a diagnosis, rather than being seen as evidence of parents embracing a medical model of disability, can also be seen as a political act of pragmatism by parents who advocate for barrier removal. In this way, the push for a label may be consistent with a social model approach. Parents actively, then, engage with different models of disability (Landsman, 2005) to meet different purposes (See Chapter Four).

McKeever and Miller (2004) further explore the parents' complex and at times contradictory responses to their children by drawing on the Bourdieusian concept of 'capital'. In an 'abilist' society parents are acutely aware of the devalued 'bodily capital' of their children, and the stigma with which the parents are also 'tainted' by virtue of their parenting relationships (See also Chapter Six). The parents share the stigmatisation of their offspring. Yet, the acquisition of a label for their child gives the parents 'capital' in both the fields of medicine and education, and indeed in some social fields. The accumulation of such capital gives parents the power to access both services and resources and parents are able to defend themselves from stigma by using a label to assert their parental competence.

Several parents in this study focused on the successes of their non-disabled children when telling the story of their child with special needs and/or impairment. While Julia, an educational psychologist, suggests that this is evidence of parents pathologising their children and some sort of dysfunctional family dynamic, it may suggest that the parents' have a (subconscious) awareness that their typically developing child offers evidence of their parenting skill. In an 'abilist' society where a child's bodily and behavioural norms are crucial to achieving symbolic capital for the family, it is not surprising that parents draw attention to the success of their typically developing offspring.

*The attitudes of others: the extraordinary family*

My friends who have got normal children say 'how do you do it, how do you do it?' They've looked after Terry and they say 'how can you do it when you've got all that' and I make time, you find time.

(Sandra, a mother and telephone interviewee)

Parents' stories also reflect their exposure to the attitudes of others to their child and their family. Sandra's friends valorise her role as a mother, characterising her mothering as extraordinary and something they could never do. Sandra's friends no doubt intended that their comments should be seen as positive and encouraging, yet by distancing their own family experience from Sandra's there is, perhaps, a suspicion that the friend wishes to escape the 'courtesy stigma' (Goffman, 1963) which affects the people closest to the child with special needs and/or impairment. The consequence of attributing extraordinary characteristics to a parent or a family is that the family ceases to be 'ordinary'. Without the 'ordinary' status enjoyed by other families, the disabled family is no longer regarded as having the same rights and aspirations as other families. 'Ordinary' families conform to societal norms and are, thus, more able to accrue symbolic and material capital than 'extraordinary' families.

Parents of children with learning difficulties, particularly those with hidden impairments, often talked about the affect of the attitudes of others on their family. Public places were among the most difficult for families (Read, 2000). Ryan (2005)



found that mothers who go out with their 'learning disabled' children in public places experience a lack of awareness, understanding and very little support from other people. Fiona explained how she felt about her son behaving differently in public, and encounters with strangers being more difficult because he 'looked normal'. Parents encounter public perceptions, supported by the media (Phillips, 2005), of the danger to public order and to society posed by children with impairments, particularly those with emotional and behavioural difficulties. Parents' experiences in public places suggest that their children's and their own failure to conform to social norms, excludes them from the community links which other families access. Their opportunities to build up community links are restricted and the ability to accumulate social capital is diminished. Parents also experience a good deal of emotional turmoil when they cope with the reactions of others to their children, and this is especially so in the early years of the child's life and/or in the period immediately following a diagnosis (Green, 2003).

Not only did parents come up against hostile or critical attitudes from strangers, but their long standing friendships were also tested. Parents find that friends and family members do not understand the complexity of their daily lives and that this leads to conflict (Green, 2003). Martha had stopped going out to friends' houses because of her son's behaviour. Ben explained how having a disabled child had negatively affected his wife's friendships:

When Callum was born, Danielle had loads of friends, but noone phones her now. It was like she was walking round with the Black Plague! She's had to go out on the road again and make new friends.  
(Ben, a father and key informant)

While support from friends was fading, Ben also explained how support from the extended family had fallen away:

We've had very little support. We've got big families on both sides, but for them our Callum doesn't exist, they're not interested. They used to ask how he is on the phone but then they'd talk over you and you realise they're not interested. Now, when you talk to them on the phone and they say, very quickly, 'how's Callum?' I know it's for no reason so I bite my tongue and say 'everything's OK'.  
(Ben, a father and key informant)

As social and extended family links break down, the family becomes more and more isolated within the community. Parental distress caused by relationship breakdown also serves to limit opportunities for social contact in other fields.

The categorisation of the family as 'extraordinary' also influenced professionals' attitudes:

I think all of us who sit are on occasions really struck by how difficult it must be to be a parent of a child who has special educational needs of the severity which is likely to be before us and particularly in those areas which involve behavioural problems whether they are emotional and behavioural whether they are autism, Asperger, hyperactivity or whatever it is, how physically draining that must be and mentally draining. I think unless you've had that experience yourself you could never fully understand. I think because we have a number of expert members who have been in that field for a long time, and because we see and hear from parents what it's like. I think we are very moved by that.

(Thomas, Tribunal Chair and telephone interviewee)

Thomas expressed his sympathy for disabled families. This sympathy is shared by Lady Rosemary Hughes, the President of SENDisT:

We care deeply about these children with special educational needs and disability; they are 'our' children and deserve the best of our endeavours in the future as in the past.

(Hughes, 2005, p5)

However, even though Thomas had described the behaviour of some LEAs as 'diabolical', he and Lady Hughes still locate the difficulties firmly within the family with the consequence that the disabled family is stripped of the positive image enjoyed by other families. The family's experience is seen as a matter of regret which denies the disabled family their emotional and social worth; this transforms the sympathy of others into pity and the disabled family becomes tragic.

The categorisation of the family as 'extraordinary', while on the surface seeming to valorise the family, is, perhaps, a manifestation of the 'courtesy stigma' Goffman (1963) described. Coleman (2001, p221) describes stigma as a 'special and insidious kind of social categorisation .... People are treated categorically rather than individually and in the process are devalued'. There is a sense that some families irrationally feel that if they distinguish their family from the



'extraordinary' family, they reduce the risk of acquiring the stigma themselves (Coleman, 2001). The categorisation and stigmatisation of families of children with impairments and/or special needs constructs the families as 'others' (Rorty, 1989); they are grouped as the objects of experience rather than as fellow subjects of experience (Wendell, 1997).

When parents face hostility or discrimination in public places this reflects the family's lack of social capital within the 'field' of the park, school or the supermarket. The children are unable to play by the 'rules of the game' in public spaces, and so the family is excluded from the networks and group membership which other families enjoy. The categorisation of families with children with special needs and/or impairment results in a devaluation of their social capital as their relative power in a given field is diminished.

### *The positive aspects of family life*

Recently research into family life has shifted its focus to consider the positive as well as the negative aspects of being a member of a family of a child with an impairment and/or special educational need (Read, 2000, see also Chapter Six) and this was also expressed in parents' stories. Parents spoke with great affection about their children

He is an absolutely lovely child. He has an extraordinary sense of humour.

Richard, a father and telephone interviewee, describing his son  
(Robert, a father and telephone interviewee)

The composite narrative describes the child as a 'beautiful boy with a big smile on his face'. Tracy described the positive change in her as a person:

You start to reassess your priorities, don't you?  
(Tracy, a mother and telephone interviewee)

Barbara, a mother and telephone interviewee, echoed this sense of changing priorities when she acknowledged that 'our daughter won't be a great academic, but so what?'

Parents' attitudes to their children and to life were changed, and they described the changes positively. Other parents have told stories which celebrate their

family lives (Murray and Penman, 1996), yet these positive experiences, with a few exceptions (Read, 2000, Cole, 2004), remain under-represented within research output and public consciousness.

## **SECTION TWO: Isolation and support**

I used to be dead fit. I was always out, talking and I knew everybody whereas now I do suffer terrible stress, I've got psoriasis back again. I don't drive and I have to push Callum for an hour to get to the park; he weighs sixteen stone. It's not just that you're isolated, it's that you end up thinking and talking and being Callum. If I'm in another room, I can hear everything he does in the house. The slightest movement and I know what he's going to do. I haven't slept in the same bed as Danielle for seven years. I sleep on the office chair or on the couch, because Callum can go to bed at half nine and be up at twelve and that's it. So I just don't sleep. I can tell when he's going to be ill, I know his mannerisms. I know him so well, that when people come to see us, I have to push myself into a corner to stop myself answering for him. I'll start being him! I feel like I'm doing everything for Callum and getting nothing back. I'm just wearing myself out. I've been to the doctor's and everything, but he just said 'look in the Yellow Pages and have a break.' I said 'what do we do with Callum? Leave him the house?' And, anyway, there's only one of us working now, bringing money into the house. I have to support Danielle. She goes out at eight in the morning and comes back at six at night.

(Ben, a father and key informant)

Isolation and stress was a common theme in parents' stories. As friends and family drift away, the parents of children with special needs and/or impairments become increasingly isolated. Their isolation is compounded by the fact that they cannot access mainstream activities either because of attitudinal barriers to their inclusion, or because of their restricted family budgets (Joseph Rowntree Foundation, 2001). The consequences of isolation are social exclusion and stress.

Within a social model framework, it is tempting to focus solely on the attitudinal and physical barriers to social inclusion which parents undoubtedly face. However, parents also spoke about the day-to-day stresses of caring for a child with an impairment and how their lives were influenced by impairment effects, not just social and physical barriers. In a society which is dominated by individualised and tragic models of disability, raising the spectre of impairment effects carries political risks. It is possible that a discussion of impairment effects



could encourage unsympathetic readings of the parents' stories which locate the tragedy, not in the attitudinal, systemic and physical barriers to inclusion, but within the individual child's or family's pathology. However, by shying away from a discussion of impairment effects there is a greater danger and that is that the parents' narratives presented here would not give an authentic account of their lived experience.

Shakespeare and Watson (2002) suggest that impairment is 'completely bracketed' (p11) within the social model, and insist that denial of difference is a big problem for disability studies. Shakespeare and Watson argue that impairment is 'salient' (p11) to many disabled people at the individual, psychological, social and structural level. They argue that impairments affect appearance and functioning. However, while impairments have certain effects, they also have social origins. Crucially, Thomas (1999) has stressed that impairment effects cannot be dealt with as 'pre-social 'biological' phenomena' (p43) (For a fuller discussion of impairment see Chapter Two).

Parents spoke about their children's appearance (looking different, being stared at) and their child's functioning (behaving differently). However, it is important to stress that impairment effects were not cited as the primary source of isolation or stress by parents. The times of greatest stress for parents were when they felt unable to access appropriate support. Child care arrangements were a particular difficulty for parents of disabled children as they are excluded from the reciprocal baby-sitting arrangements enjoyed by other parents (Read, 2000). When your child 'has never asked to have anybody home for tea, and is never asked anywhere' (Kirsty, a mother and telephone interviewee), it is difficult to build up supportive social relationships with other parents. Families are often unable to access formal child care from nurseries or child-minders in part because of their reduced income, but also because service providers say that they are unable to 'cope' (Joseph Rowntree Foundation, 2001) with the children. The families' reduced cultural and economic capital limit their social opportunities (McKeever & Miller, 2004).

Parents described themselves as constantly battling for support and resources and this was the primary cause of stress. Remember, the experience of the Tribunal does not take place in isolation. Parents may find themselves challenging the Health Authority or Social Services Department at the same time as they are challenging the LEA. Parents found the battle for resources both degrading and debilitating.

Kirsty felt that her son still needed Occupational Therapy after it had been withdrawn, but hadn't pursued this with the Health Authority, because she was having a 'rest from the fight'. Richard and Martha had been in conflict with the LEA, the Health Authority and Social Services since their children were born. Parents are ground down as they seek support in the education system at the same time as challenging other service providers. Even parents who are successful at Tribunal feel that 'it never stops' because they fear their child's educational entitlement will be eroded over time and a battle with another service provider is running concurrently or is just round the corner. For some parents, this has a huge impact on their emotional well-being and their self-esteem as they become embattled and embittered. They find themselves attributed with negative characteristics which trap them in their role as 'awkward' parent. Crucially, the multi-faceted nature of the parents' struggles is a key cause of stress and isolation for the family.

The parents' struggles with education and health professionals reflect their lack of capital and their powerlessness within the fields of health and education. These conflict ridden relationships are at odds with the expectation that the professional is the superordinate and the parent the subordinate in parent professional relationships. Challenging these cultural norms is a source of great stress for parents. Parents become aware of their lack of capital and power and fear retributive or discriminatory behaviour on the part of professionals. Some parents are forced to withdraw from conflict or to 'play the game' because they are dependent on the 'treatment' offered by the professional. Parents begin to 'know their place', moderate their behaviour and they learn to internalise the oppression (Thomas, 1999).



### *Sources of support: new friends*

While support from family members and long standing friends sometimes fell away, parents turned to other sources of support. Ben described how Danielle had lost friends when their son was born (above), but he also described how she had made new friends who were also parents of children with an impairment or special need. Diane also spoke of the support she had received and given to 'other mums.' Goffman (1963) describes these other parents as the 'wise'. Their experience of stigma moves them from the category of the 'other' to the category of 'the wise'. For Sue, contact with other parents who had children with impairments or special needs was very important:

I love my friends. They're a good old support network and we know how each other feels.

(Sue, a mother and telephone interviewee)

By sharing experiences, parents can break the feeling of isolation and offer support to one another. Sometimes, it was voluntary organisations which played the key support role in parents' day to day lives, as well in helping parents to prepare for Tribunal:

[Impairment based charity] is sort of our first support group both locally and nationally.

(Sandra, a mother and telephone interviewee)

For Richard's family their local church was a very supportive community which included his son, Robert, in a youth choir and holiday club.

Parents said little about formal support from Social Services, except to say, like Richard and Martha, that they had difficulty in getting the support they felt they needed. The Joseph Rowntree Foundation (2001) found that only 4% of disabled children are supported by social services, so it is not, perhaps, surprising that parents did not mention this as a source of support. Beresford's study (1994) suggests that parents are reluctant to access social services because they hear so much about other parents' poor experiences. There is also a reluctance among parents of disabled child to ask for help and a feeling that the 'right' kind of help is not readily available. Beresford reports that parents found unwanted or unexpected change in social services provision disruptive and disturbing, and that the repercussions of such changes were a period of confrontation between parents and social services.

With the exception of Richard's family, who were supported by their local church, the parents drew most support from within their own community: other parents of children with an impairment or special need - the 'wise' (Goffman, 1963). Peer support is clearly an invaluable resource in parents' lives. However, it may be that the consequences of an almost exclusive dependency on support from the 'wise' is that the process of social exclusion becomes self-sustaining. This suggests that parents may limit their own and their children's exposure to the wider social world for fear of being stigmatised by others.

In an effort to avoid being stigmatised, parents seek out fields in which they are able to maximise their social capital. With other parents of children with special needs and/or impairment, bodily and behavioural norms do not carry capital or power, and the absence of norms does not devalue the children. Among parents of children with special needs and/or impairments, successful parenting is not judged by how productive or independent the children are. Mothers who do not work and families who have limited incomes are not, within this field, deemed to have less symbolic capital. Here their role as parent has legitimacy, authority and prestige.

### **SECTION THREE: Life Chances**

I also asked for him to be assessed for a radiophonic hearing aid during his time there. That just didn't happen, it wasn't until three years later that the head of the hearing impaired service said in a very large review meeting that 'we don't provide hearing aids for children of his age with Downs Syndrome'. A gasp went round the room and I asked for the policy and practice document that supported that decision.

(Gina, a mother and key informant)

Some parents took their claims for disability discrimination to SENDisT, but parents who went to SENDisT over their child's educational provision also talked about the discrimination they and their child had faced in school. Parents' narratives were punctuated with stories of discrimination and restricted opportunities. Some families were the victims of very public and overt discrimination. Gina's son Toby was discriminated against because of his label of Downs Syndrome and his story illustrates the systemic discrimination people with



learning difficulties have faced within the National Health Service (MENCAP, 2004). Leo described how his son was discriminated against within the education system as he 'was never taken on trips' in the LEA mainstream school or in the private school.

Richard also described how his son, a wheel chair user, was excluded from joining in with activities in the local community:

The scout hut is not designed for it, Robert can't participate in their activities and so on.

(Richard, a father and telephone interviewee)

The effect of Robert's social exclusion within the local community was one of the reasons that his parents wanted him to go to a special boarding school. They were concerned that Robert had no peer group at home and wanted him to have children of his own age to interact with. They felt that Robert got a peer group when he went to board, and, so, for Robert his segregated placement offered an inclusive experience (See also Chapter Four).

Parents were also worried that the life chances of their children with an impairment or special need would be less than other children's. For Mary:

If ADHD is unaddressed and untreated and particularly if a person is on the low IQ side ... the prognosis is horrific and it includes depression, suicide, being in trouble with the law, jail, you name it. The worst things that happen in our society happen to people with ADHD ....

Mary, a mother and telephone interviewee

The future of their child after the parents' death was also a concern raised by parents. Leo doubted that his child's guardians would have the knowledge or the advocacy skills needed to do the best for his son. Not surprisingly, the parents' experiences of discrimination and their fear that their children would have limited life chances further contributed to parental stress.

All parents worry about the future for their children, but for parents of children with an impairment or special needs, these worries are magnified by concerns about their children's access to support and services in a profoundly ablist society. Parents worry about a future in which they are no longer around to protect their child from a world of 'stigmatising others' (Green, 2003, p1367).

## **Conclusions**

Parents' stories reveal complex and contradictory engagements with models of disability. For some, diagnosis was a key aspect of their Tribunal stories. This has often been seen as part of parental pathology, but parents are aware of their subordinate position in relation to health professionals and the quest for diagnosis is often part of their efforts to play the medical 'game'.

The parents' stories also show that they have been categorised as 'extraordinary' families by their friends, relations and by professionals. Yet, the unintended consequences of these outpourings of sympathy are to locate difficulties firmly within the pathology of the family and the child, and to deny disabled families the positive image which other families enjoy. This renders the family powerless within a wide variety of social fields.

Parents suffer segregation as a result of their 'extraordinariness' which results in stress and isolation. However, the perception remains that it is the burden of care, and not the social exclusion and discrimination families face, which is the locus of parental stress.

While some forms of support fall away from families or remain inaccessible on grounds of cost or discriminatory attitudes, other sources of support emerge. Parents value support from voluntary organisations, faith groups and above all other parents. Using Bourdieu's concept of social capital, parents can be seen to be seeking social fields where it is possible to maximise symbolic capital and communities of peers provide such opportunities. Crucially, parents' stories challenge negative stereotypes of the disabled family and reveal the positive aspects of their family lives.



## **CHAPTER EIGHT: Conclusions**

### **Introduction**

This chapter answers the research question - what implications do the research findings have for the implementation and revision of current legislation, policy and practice? It includes key recommendations for the revision and implementation of policy in the light of the parents' stories. The policy context in which the study was carried out is in a constant state of flux, as the Government rolls out yet more policies for education, and so the impact of recent initiatives (DfES, 2005) for schools is considered here also. In July, 2006, the Education and Skills Select Committee published its eagerly awaited report into Special Education: *Special Educational Needs: Third Report of Session 2005-6*. Several of its conclusions and recommendations resonate with the experiences parents describe in their narratives and some of these are also included here.

It seems almost impossible to switch on the radio or open a newspaper without discovering an issue which is relevant to this research and which moves the debates on. However, there must come an end point for gathering information for a thesis and this, for me, is July, 2006.

In this final chapter, the strands of the parents' narratives are brought together under several themes: their engagement with theory, stories, policy, professionals, Tribunals and society. At the end of each section, there is a 'key recommendations' box, which sets out suggestions for the development of theory, policy and practice.

#### **1. Parents engaging with theory**

Parents' narratives reveal them engaging with a number of theoretical concepts in their every day lives. First, parents engage with models of disability in a variety of ways. In Chapter Four, the parents' engagement with social and individual models of disability was evident in their stories about their choice of school placement. The study showed that many parents are looking for school environments where the barriers to their children's inclusion are minimised. However, some parents feel that for their children this is not achievable in mainstream schools. In contrast, another group of parents seem to embrace

individualised models of disability and search for rehabilitative and specialist environments which offer the possibility of 'normality' and 'cure'.

In the end, many parents' choices about school placements were driven not by ideology, but by pragmatism. When mainstream placements broke down, parents looked for environments where their children would be included, usually special school, although some parents (Ben and Simon) chose to educate their children at home. There has been a tendency to account for parents' attitudes to diagnosis by positioning their responses within medical or social model theory (Fisher and Goodley, 2006 in press). However, parents actively engage with different models of disability to meet different purposes (Landsman, 2005). In an abilist society, parents are aware of the capital (Bourdieu, 1984) an impairment label can bring both in terms of accessing resources for their child and as a means of re-claiming their parental competence. As a result, parents accept labels, irrespective of the models of disability they embrace (Chapter Seven).

Within this study, the work of Foucault, Rorty, Bourdieu and Social Model Theory have been used as 'tools' to develop understandings of parents' stories. Here, I argue that these theoretical 'tools' can teach us about parents' stories. From Foucault, we learn about power and resistance. The parents' experiences in working with professionals (Chapter Four) and in the Tribunal (Chapter Five) reveal how parents engage in power relationships. Foucault has given a history of the ways in which human beings are made subjects and in the parents' stories Foucault's ideas show us how parents are controlled and made dependent as the subjects of the professional gaze. Foucault teaches us that power is exercised not possessed and that it multi-directional and circulates through net-like organisations. Parents' interactions with professionals both in the period before the Tribunal and in the hearing itself reveal the ways in which power circulates in the parent-professional relationship (Chapter Four, Chapter Five). Foucault's concept of 'power-knowledge' (Foucault, 1998, pp 98-99, cited in Roberts, 2005) is also useful for developing understandings of parents' stories as the parents' resist diagnoses and labels for their children (Chapter Four) in contexts which are underpinned by discursive practices which sustain both the power relationships and professional knowledge claims. In addition, Foucault draws on 'panopticism'



(Chapter Two) to critique society, and, here, the panopticon can reveal how and why parents come to regulate their behaviour within the Tribunal, and within the special education system itself, as they become aware of the disindividualised gaze of a multitude of professionals. Rorty's work, too, offers insights into parent-professional relationships.

Rorty's work has been used as a tool within this study to explore the nature of partnership and solidarity within parent-professional relationships. Rorty's appeal for solidarity between human communities is key to understanding the breakdown of parent-professional relationships. The stories reveal professionals and parents 'othering' one another as the differences between them are aggravated by a failure to 'justify' their beliefs to one another (Chapter Four). Rorty's understanding of 'final vocabularies' reflects a Foucauldian awareness of the dynamics of power (Chapter Two) as he urges us value voices at the periphery (Chapter Two). However, Rorty is optimistic about the possibility for change. Rorty sees possibilities for human beings to share solidarity and to become less cruel and this teaches us to be optimistic about the possibilities for parent-professional partnership.

Bourdieu's ideas about 'habitus', 'games' and 'fields' allow us to develop our understanding of the disabled family. The 'normal' family has the privilege of being 'comme il faut' (Bourdieu, 1998, p69 cited in Silva, 2005, p88). The experiences of families who cannot conform to the 'norm' reflect their lack of social, cultural and economic capital in a variety of fields. As Furstenberg (2005) suggests the arrival of a child in a family introduces a new and critical element into the family's ability to acquire capital. Here Bourdieu's concept of social capital reveals families struggling to accrue capital in an abilist society as families turn instead to fields where diversity has value and legitimacy (Chapter Six). Bourdieu teaches us about isolation and exclusion in the lives of disabled families.

Finally, I have argued strongly here for the social model and that, despite the criticisms levelled against it within the disability studies context, it is still a powerful tool for disabled children and their families. The social model situates the parents' stories in a context where the barriers to the inclusion of disabled

children and disabled families are made visible. However, despite the revisions of the model following Thomas (1999), Swain and French (2000), and Chappell, et al, (2001) and Goodley (2001), the social model has yet to account fully for the experiences of the disabled family. By insisting that impairment is a pre-requisite for disablement, the social model cannot account for the stories of parents of disabled children who experience directly and by proxy the impact of living in a disabling world (Chapter Seven). The development of the social model to include the lives of disabled families is an area for future development.

The use of theoretical 'tools' within this study is diverse and complex and reflects the diversity and complexity of parents' lives. However, each 'thinking tool' allows us to reflect upon and to develop an understanding of the parents' stories, and it is to parents' engagement of stories which we turn below.

## **2. Parents engaging with stories**

Like many people, parents engage with stories and metaphors to make sense of their day-to-day lives (Thomas, 2004). They tell and re-tell stories to friends and families about their experiences of the social world; this is particularly the case when parents have experienced significant events like going to Tribunal. It seems likely that the stories were, in some sense, rehearsed, as the fluency with which parents spoke suggests that they had told the stories many times before to family and to friends. In a complicated policy context and dry legal framework, the stories make the parents' experiences of SENDisT meaningful and interesting. In disseminating the research (See appendix 1-6), the stories are being shared between parents and with professionals, with the hope of drawing them into the marginalised world of the other. The parents' stories are linked to a new social movement and collective action. By re-telling the stories in an effort to air their experiences, parents hope to escape the trajectory of the past (Van Wynsberghe, 2001).

## **3. Parents engaging with policy**

Since the 1944 Education Act, parents of children with special needs and/or impairments have actively engaged with the education policies which have shaped their experiences. The post-war era has been one of significant change for special



education policy. Children with special needs and/or impairments are no longer classified as 'ineducable' or as 'educationally handicapped' within policy. Instead, the seemingly more benign and inclusive term 'special educational needs' has become common currency as a result of the Warnock Report (DES, 1978). Also following the Warnock Report, there was a new emphasis on the role of parents within their child's education and shift in attitudes which meant that for the first time provision for children with special educational needs should 'wherever possible' occur within mainstream provision. The key policies underpinning parents' experiences appear to be partnership, inclusion and statements.

### *Partnership with parents*

In Chapter One, we saw that the 1980s and 1990s saw the introduction of a wave of new policy initiatives for special education. In 1981, the Education Act heralded the introduction of the system of statements of special educational needs. In 1994, the Secretary of State for Education was required, for the first time, to produce a *Code of Practice on the Identification and Assessment of Special Educational Needs* (DfEE, 1994). These changes were important as they brought parents into the assessment process for the first time. The introduction of the Special Educational Needs Tribunal in 1994, which became the Special Educational Needs and Disability Tribunal in 2002, gave parents, again for the first time, an independent forum in which to settle their disputes with the LEA.

The policy rhetoric of the 1990s saw a renewed emphasis on the parents' role as 'partners' in their child's education. However, the ill-defined and contested nature of parent-professional partnership means that parents engage with the policy of 'partnership' in a context where they remain, at times, unaccepted and unsupported by professionals (Chapter One, Chapter Four).

The narratives reveal that parents' attempts to engage in partnership with professionals are frustrated and that for many 'partnership' has become a policy for conflict (Chapter Four). The rise of the policy of 'partnership with parents' occurred simultaneously with the rise of the policy of 'inclusion', which was also revealed as a policy for conflict within parents' stories.

## **Inclusion**

In 1993, the general principle that children with special educational needs should be educated in mainstream schools, where this is what the parents wanted, became enshrined in law (DfES, 2001a) and in 1994 the UK signed up to the Salamanca Statement drawn up by UNESCO calling on all governments to adopt the principles of inclusive education (DfES, 2001a). Since 1997, the Government has developed an 'inclusion framework' (DfES, 2001b, p2) which has framed the policy context in which parents' narratives are set.

In Chapter Four, parents' engagement with the policy of inclusion is revealed as a key part of their narratives and the reasons why they go to SENDisT. Parents hold passionate and conflicting views about the merits of the policy of inclusion. Their narratives describe some parents pushing for inclusion for their children and others pushing for segregated placements. Indeed, the stories illustrate the parents' complex and, at times, contradictory engagement with the policy of inclusion.

However, the parents' stories contest dominant media images and discourses of inclusion. Within the media, the inclusion of children with special needs and/or impairments is still characterised negatively (Brennan, 2005; Marrin, 2005, Phillips, 2005). Children's impairments and/or special needs are cited as the barriers to the children's inclusion in the mainstream (Baker, 2005). Yet the parents' stories suggest that, above all, it is the attitudinal and systemic barriers which render their children difficult to include (Chapter Four).

Within the academic community, parental attitudes to inclusion have been the objects of scrutiny and analysis (Connor, 1997). Their actions have been explained by pathologised models of parenting where the parents are said either to be 'grief-stricken' or in 'denial' about the child's 'needs' (Chapter Four, Connor, 1997). Within this study, the parents' stories counter discourses of grief and denial. Instead the parents' actions are characterised as political and pragmatic responses to the policy for inclusion.



### *Statements of Special Educational Needs*

The 1980s also saw the introduction of the system of statements of special educational needs which has remained controversial within the special education system (Chapter One, Chapter Four). Despite the best efforts on the part of LEAs, the number of children with statements has continued to rise (Pinney, 2003). Statements of special educational need are a source of on-going tension between LEAs and parents. Service providers continue to assert that statements are bureaucratic; they contribute to conflict between parents and professionals; they are an inefficient use of resources and they are anti-inclusionary (Audit Commission, 2002a). On the other hand, parents and their organisations insist that statements offer valuable protection for children with special educational needs and that clearly written statements, which quantify provision, enable children's inclusion in mainstream schools (IPSEA, 2005a).

Parents' stories reveal that their engagement with the policy and practice of statements of special educational needs is both time consuming and complicated, but parents are frustrated not necessarily by the system itself, but by what is perceived as the deliberate failure on the part of some LEAs to implement the system properly (Chapter Four).

Parents' stories reveal their complex engagement with the policies of special education (See Chapter Four), yet policy is made and interpreted by individuals at various levels within the system and the parents' engagement with professionals is key to understanding the parents' Tribunal stories.

#### *Key recommendations for policy*

- The policy of 'parents as partners' should be clearly re-articulated in policy and in practice
- Moves to reduce the number of statements must account for parents' fears that the reduction in the number of statements is budget driven and will result in an erosion of entitlements for children with special needs and/or impairments.
- The implementation of the policy of inclusion is in need of review. Parents' stories suggest that rather than having 'gone too far', the policy has yet to be implemented effectively in many mainstream schools. Any policy review must

take into account parents' views: parents value choice and fear that they will be co-erced into accepting what they believe are unacceptable school placements for their child.

- There must be a debate about the quality and the meaning of inclusive education, rather than a focus on the simple either/or choice – special or mainstream. Parents' engagement with the policy of inclusion show that it is a complex issue which is in need of review.

#### **4. Parents engaging with professionals**

Parents' engagement with individual professionals is a key part of their stories. While policy is made at central and local government level, it is re-negotiated and enacted at the level of individual relationships. In parents' stories, their individual relationships with professionals are the key to understanding conflict. The parent-professional relationships are examples of both power relationships (Foucault, 1973, Chapter Two, Chapter Four), and the failure of parents and professionals to show solidarity with one another (Rorty, 1989, Chapter Two, Chapter Four).

##### *Power and relationships*

Parents engage with professionals in a context where they are subject to a disindividualised professional gaze (Foucault, 1973, Chapter Four, Chapter Five). Parents are scrutinised as they interact with their children and with professionals in a variety of contexts: at the school gates, in Annual Reviews, at meetings with therapists and within the Tribunal hearing itself (Chapter Five).

Surveillance is allied to control, and as such, parents' narratives describe the ways in which they are subjected to control by professionals. Sometimes parents described control that was overt when they said that professionals 'lied to', 'bullied' and 'tricked' them (Chapter Four). At other times, the control was less overt when parents were denied information by professionals, or were unable to share information with professionals (Chapter Four), or when parents described being constrained by the formality of the Tribunal hearing. The Tribunal stories clearly challenge the assertion that the Tribunal hearing is 'informal' (Hughes, 2005; See also Chapter Five).



Conflict between parents and professionals was also driven by resource allocation. Parent-professional relationships were underpinned by the inevitable tension between parents who are driven by the aim of securing the resources which are right for their child alone and professionals who are driven by the need to allocate resources to a child in a context (Simmons, 1996; Chapter Four). In an increasingly market driven system (Cole, 2004), parents of children with special educational needs and/or impairment are disempowered in their relationships with professionals as they plead for scarce resources (Chapter Four). Parents of children with special educational needs and/or impairments are characterised as ineffective consumers, and, in turn, over demanding parents.

Closely allied to conflict over resource allocation is conflict between parents and professionals over what constitutes knowledge about the child. Medicalised and individualised discourses of impairment and special need dominate policy and professional attitudes (Chapter Two, Chapter Four, Chapter Five). The task for professionals is to incorporate new and challenging concepts of 'need' and 'disability' within policy and practice.

Parents differed in the ways they engaged with professional knowledge. Some parents accepted the status of professional knowledge about their children, and resisted this type of knowledge of their child by buying in other professional views. Other parents refused to accept or to engage in professionalised discourses about their children (Chapter Four, Chapter Five). Contested knowledge claims about the child also contributed to parent-professional conflict.

Finally, it is important to recognise that there are good examples of parent-professional partnerships and enabling forms of professional knowledge. However, the parents' Tribunal stories are set in a context of conflict and partnership breakdown which meant that the focus was, inevitably, on more negative and disabling aspects of parent-professional relationships, rather than on more positive and enabling experiences.

### *Solidarity and relationships*

Crucial to understanding parents' engagement with professionals is the failure on the part of parents and professionals to regard each other as 'real human beings' (Rorty, 2000, p15). The parents' stories are rich with descriptions of how they felt that they were 'othered' in their relationships with professionals (Chapter Four). While there were examples also of parents 'othering' professionals, often parents began by being optimistic about the possibility of working in partnership with professionals and were disappointed by what occurred in practice (Chapter Four). The failure on the part of professionals to 'justify' (Rorty, 2000) their beliefs to parents, either by sharing information with them or by listening to parents' beliefs, was a key source of conflict between the parents and professionals.

Despite the vast amount of published literature urging professionals to work with parents as partners (DES, 1978; Dale, 1996; Wolfendale, 1997; DfES 2001a) relationships were damaged by the persistent adherence by professionals to deficit models of children and parents (Chapter Four). In spite of calls for partnership, parents and children continue to be blamed and pathologised (Chapter Four, Chapter Five). The systems in place to reduce conflict between parents and professionals (Parent Partnership Services, Mediation Services) seem to have had little impact on the relational landscape.

Parents' engagement with professionals takes place in a fraught landscape in which the policy and practice of partnership remains contested and ill defined. Relationships continue to be driven by market forces, resource allocation, contested knowledge claims and deficit discourses, which fuel conflict.

'Solidarity' requires us all to have the 'imaginative ability to see strange people as fellow sufferers' (1989, pxvi). Solidarity can be achieved by learning more about others (description), by becoming more sensitive to the pain suffered by unfamiliar people, and by learning more about ourselves (redescription) – solidarity is key for parent-professional partnership.



### ***Key recommendations for solidarity***

- Professionals should be encouraged to re-examine and question the assumptions they hold about parents in the light of what parents have to say about their lives.
- Parents' stories reveal that genuine partnership is still absent from a large number of parent-professional relationships, and that professionals and parents receive inadequate support to enable these relationships.
- Parent Partnership Services and Mediation Services should be reviewed with a view to them being able to demonstrate their independence from LEAs.
- The tensions between the policy drive for inclusion and the increased devolution of funding and marketisation of the school system need to be explored.
- The aim for parent-professional relationships must be to promote and enact solidarity between parents and professionals.

### **5. Parents engaging with Tribunals**

Parents' accounts of the Tribunal day itself illustrate another facet of the parent-professional relationship. The analysis of the Tribunal day story, in Chapter Five, was used to interrogate the power relationships within the hearing. Again the discourse of surveillance and control was evident in the parents relationships with professionals (Chapter Five). Here the image of the Tribunal as panopticon illustrates the relationship between the parents and panel members. The discursive practices within the Tribunal hearing served to reinforce deficit discourses of parents and to 'other' the parents in relation to professionals.

The nature of the surveillance and correction within the hearing was such that parents struggled to resist within the hearing. Passive resistance, which involved parents 'playing the game' or being self-deprecating about their abilities, seemed to be more effective than more active or confrontational attempts to resist (Chapter Five).

Again, the discursive practices within the hearing reinforced the 'objectivity' of professional knowledge discourses. The use of specialist discourses can disempower parents in a number of ways. Some parents were unable to access the specialist language used in the hearing and were, therefore, excluded from the process. Some parents bought in their own 'specialist knowledge' by employing independent therapists to act as witnesses. Other parents were able to adopt specialist language and challenge professionals themselves. However, despite the conflict over claims to knowledge about children in the hearing, the status of that knowledge remained uncontested within the hearing itself. Within the hearing, the need for order seems to be super-ordinate to all other needs, including the need for the parents to be heard. With representation or without, parents struggle to put their views across in a well-controlled environment and under the scrutiny of the professional gaze.

Parents' engagement with the Tribunal process does not end at the hearing. Parents wait for two weeks to discover the outcome of the hearing, and, then, even if they are successful, they wait again to see how the order is implemented by the LEA. Parents themselves monitor the implementation of the order and the process sometimes requires that they return to Tribunal, or complain to the DfES, or local ombudsman, or, at worst, they face the prospect of a High Court action (Chapter Six).

The Tribunal process impacts upon the whole family. The financial cost of the process is significant and may exclude financially disadvantaged families, yet, parents stressed that financial concerns were nothing compared to the emotional and health costs they faced. Parents' engagement with the Tribunal process reveal that contrary to the media and policy rhetoric, parents experience high levels of stress as a result of the disabling barriers and attitudes they experience, rather than as a direct result of their individual children's impairments (Chapter Six).

Family relationships are strained by the Tribunal process as couples are put under stress, and parents have less time for their children. Mothers, in particular, are made insecure as part of the Tribunal process as their competence is scrutinised and questioned (Chapter, Four, Chapter Five). The Tribunal takes place in a policy



context where the voice of the child is said to be privileged (DfES, 2001a), yet at the Tribunal the child is the 'absent guest' (Todd, 2006). Voices of parents and professionals dominate.

### ***Key Recommendations for SENDisT***

- The choice of venues and the layout of the hearing room should be re-evaluated by SENDisT in the light of parents' stories.
- Parents would value a system where parents who want access to representation have it, regardless of their ability to pay.
- Parents would value better information about the hearing before they arrive at the Tribunal and the Tribunal video *A Right to be Heard* could be revised in the light of parents' comments. The recommendations here could be used to redraft guidance and resources, including the video.
- SENDisT should consider the role of 'independent' witnesses in hearings in the light of comments from parents and professionals.
- The role of monitoring and enforcing SENDisT's orders should be removed from parents and given to an independent body (for example, this role could be given to OfSTED).
- SENDisT should pursue the implementation of a second appellate tier<sup>1</sup> so that parents need no longer pursue claims to the High Court.
- The financial costs of going to SENDisT should be reviewed and more financial support should be made available, particularly to the least advantaged families.
- Professionals need to review their interactions with parents, and mothers in particular, in the Tribunal process.
- The needs of working parents should be taken into account by professionals working with families.
- Professionals, and LEAs in particular, need to be mindful of the level of stress attending SENDisT puts the families under, including siblings and extended family. The costs involved in appeals cancelled at short notice are not just financial.
- SENDisT should consider how the views of the child can be represented within the hearing. With a view to including the voices of all children, the Tribunal should explore the use of video, pictures, objects, artwork as a means of

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<sup>1</sup> The details of a second level appellate tier are not clear. However, the intention is that a level of appeal should exist between the SENDisT and a Judicial Review.

enabling the child to participate actively in the process, recognising that for many children attending the hearing itself may not be appropriate.

## **6. Families engaging with society**

The parents' narratives reveal not only their experiences of the special education system and the Tribunal process but also something of their experiences of the wider social world. The parents' stories are set in a context where the disabilism and disadvantage suffered by disabled children is understood to affect the family as a whole (Chapter Six).

Financial disadvantage was a key part of parents' lives (Chapter Six). However, the narratives reveal that lack of economic capital is only one of the disadvantages faced by families. In a profoundly abilist society, parents are acutely aware of the devalued bodily capital of their disabled children (McKeever and Keller, 2004). Parents share the stigmatisation of their children (Goffman, 1963) and this reduces their capital in a variety of social fields (Chapter Seven).

The narratives suggest that parents try to maximise their social capital in a number of ways. In the fields of education and medicine, they embrace impairment labels which allow them to defend their position as competent parents and offer a gateway to services and support; they focus on the successes of their non-disabled offspring as a means of giving evidence of their parenting skill. In public spaces, the general lack of awareness, understanding and support available (Ryan, 2005) denies parents the opportunity to build up community links and parents turn, instead, to a community of the 'wise' (Goffman, 1963). Parents prioritise their contact with other parents of children with special needs and/or impairments as these parents offer a social field in which it is possible to accrue social capital, and where the role of parent is both prestigious and legitimate.

Disabled families continue to be categorised as 'extraordinary' (Chapter Seven) and 'other' (Rorty, 1989). The (unintended) consequence of the valorisation of the disabled family is that an image of the disabled family as tragic is reinforced. The loss of the status of ordinary family brings with it the loss of the positive image



and rights associated with 'ordinary' families. Parents worry about a future in which they will not be around to protect their children from a world of 'stigmatising others' (Green, 2003, p1367).

In contrast to the stigmatised and deficit images of the families' experiences, parents talked about the positive aspects of their family lives. Parents described how their attitudes to their children and to life had changed, and they characterised the changes positively. Other parents have told stories which celebrate their family lives (Murray and Penman, 1996), yet these positive experiences, with a few exceptions (Read, 2000; Cole, 2004), remain underrepresented within research output and images in the media. Those parents who took on 'extended caring roles' (Traustadottir, 1991) also described the confidence they had gained and for some this was empowering in terms of career opportunities and choices (Chapter Six).

***Key Recommendations emerging from families' engagement with society***

- 'Grief stricken' models of parents of children with special needs and/or impairments are of limited use in understanding families' experiences.
- Parent-to-parent contact is key and should be well supported by service providers and voluntary organisations.
- There is a need to challenge disability studies literature which blames parents for not choosing mainstream schooling for their children (Parents for Inclusion, 2006).
- There is a need to consider a more sophisticated view of parents within the development of social theories of disabled families.

## **7. Parents' empowerment**

The study reveals how for some parents the process of going to Tribunal was empowering as they acquired skills and knowledge in the process of preparing for and representing themselves at the hearing. Parents in this study have used these new found skills to support other parents. In this section, the focus is on what this study can offer to parents in their struggles within the education system.

The parents' stories reveal the extent to which parenting a child with a special need and/or impairment makes the whole family, not just the child, visible and vulnerable to the judgements of others – teachers, health professionals, family members and members of the public (Chapter Seven). The power of professional language is also revealed in the stories as parents describe the difficulty they had in resisting professional judgements and diagnosis. However, the study also reveals that it is possible to oppose these judgements and to challenge the assumptions which underpin them. Parents do this by having confidence in their own knowledge, judgements and their parental competence.

In partnership working, the study suggests that partnership with parents depends on parents and professionals exchanging views and information. Parents can sometimes be in awe of professionals, but the study suggests that it is legitimate for parents to have confidence in expressing their views and the expectation that professionals will share information with them in return.

In the wider social world, the stories reveal the families' exclusion and isolation. Yet, the study also emphasises the importance of the key support that parents gain from parents of other children with special needs and/or impairments as sources of support. Parents offer one another invaluable sources of information and support. They give one another confidence as they value each other's children and their parenting roles.

Finally, parents in the study succeed in challenging negative interpretations of their parenting and their families by focusing on the barriers to their child's inclusion, challenging professionals to look at attitudinal and systemic factors.



### ***Key Recommendations for parents – fighting your corner***

- Parents views are important and it is OK for parents to challenge professionals' use of language and judgements about their children.
- You, as parents, have valuable information about your children which has equal value to professional judgements.
- In working with professionals, you have the right to put forward your views and to ask professionals to share information with you on equal terms.
- Other parents of children with special educational needs, your extended family and voluntary organisations can be key sources of support for you and your family. It is OK to ask for help. Ask other parents for ideas about where to get support.
- Some parents, in this study, found their advocacy role for other parents both rewarding and empowering. They found a use for the skills which they developed in the Tribunal process.
- Disabled families are neither 'extraordinary', nor 'dysfunctional'. Disabled families have the right to enjoy life just as other families do.

### **8. Future challenges**

This study took place in a dynamic policy context where educational reform remains high on the Government's agenda. The future for special education seems uncertain and there is a degree of confusion over how the policy for special education will be implemented in the future.

#### ***Partnership with parents***

The policy of parent-professional partnership, which is reflected in parents' narratives, will continue to be contested and re-defined within special education. The nature of parent-professional partnerships has been scrutinised by the Education and Skills Select Committee Report on Special Education (Education and Skills Select Committee, 2006). They acknowledge the high level of conflict between parents and professionals. The Report concludes that problems arise because parents feel ignored or that their views and preferences are not being given proper consideration under the current system. The Committee found evidence of 'very poor communication between local authorities, schools, and

parents' (Education Skills Select Committee, 2006, p35). Indeed, the Education and Skills Select Committee acknowledged that:

All too often parents had little choice in taking an adversarial approach during the appeals process in order to obtain what is in the interests of their children.

(Education and Skills Select Committee, 2006, p. 55)

The Education and Skills Select Committee goes on to urge the Government to re-think their approach to involving parents in special education. It suggests that the Government should set out clear expectations for parents in terms of minimum standards of provision and access to a broad and flexible range of appropriate provision. Indeed the Government should 'try to ensure that local councils and schools do their utmost to co-operate in this process' (Education and Skills Select Committee, 2006, p85). This is clearly a challenge for Government, parents and professionals in the future.

#### *Statements of special educational needs*

In a context of increased marketisation and devolution of funding to schools (DfES, 2005), there are questions about the future of statements of special educational needs for children with special needs and/or impairments.

The Government seems to have re-confirmed its commitment to statements in *Higher Standards: Better Schools for All* (DfES, 2005) to statements of special educational needs:

In addition statements ensure where appropriate, access to the school and to other services which can best meet the needs of the pupil.

(DfES 2005, p54)

However, in practice, many local authorities are coupling delegation of funding with a policy of no more statements except for special school placements, leaving schools to decide whether to buy in expertise (ACE, 2005). This reduction in the number of statements contradicts the Government's principle that reductions in statements are only to be made when children's needs are securely met by schools (ACE, 2005). Since 2004, the number of statements issued by LEAs has finally begun to fall (ACE, 2005). The result has been that appeals to SENDisT against the LEAs for refusal to assess have risen from 30% of appeals in 1998 to 40% of appeals in 2002-3 (SENDisT, 2003). The evidence also suggests that despite the Secretary of



State's advice (IPSEA, 2005b) to LEAs demanding that they comply with the law on specificity within statements, there is continued non-compliance on specification by LEAs. As many parents remain unaware of the duty of LEAs to specify and the majority of parents do not appeal, LEAs are described by parents and their organisations as being 'allowed to get away with it' (IPSEA, 2005a). There is an in-built conflict of interest in that it is the duty of the local authority both to assess the needs of the child and to arrange provision to meet those needs, within limited resources. The Education and Skills Select Committee suggest that the link must be broken between assessment and funding of provision (Education and Skills Select Committee, 2006, p32). The future of statements of special educational needs seems unclear. This lack of clarity has also been condemned by the Education and Skills Select Committee Report (Education and Skills Select Committee, 2006). The Select Committee has also called for clarity from the Government about the policy of inclusion.

### *Inclusion*

The inclusion framework also seems to sit uncomfortably with the Government's plans for devolving budget and decision-making powers to schools. The Audit Commission (2006) found that schools are continuing to resist admitting pupils who are hard to place even when the LEA has directed them to do so, and the new guidance for admissions which will follow the implementation of the recommendations in *Higher Standards, Better Schools for All* (2005) does not include special provision for children with special needs but without statements. Indeed, there is scant reference to children with special needs within the document (Education and Skills Select Committee, 2006). The admission of pupils with statements of special educational needs is a particular problem for the growing number of academy schools. Unlike most other publicly-funded schools, academies are not 'maintained schools' and are not, therefore, legally required to admit pupils where LEAs name them in statements (ACE, 2005). The proposals to increase the number of academies may have significant consequences for pupils with special needs and/or impairments. A further cause for concern is that academies' exclusion rates of pupils with special educational needs and/or impairments are already twice that of other secondary schools (ACE, 2005).

The Government's emphasis on a 'zero tolerance' behaviour policy (DfES, 2005) also has possible consequences for the inclusion of children with special educational needs and/or impairments in mainstream schools. It is already the case that two thirds of exclusions are of pupils with special educational needs (ACE, 2005). Appeals against exclusions are currently held before a non-specialist panel. ACE (2005) believes that this disadvantages pupils with special educational needs and argues that such appeals should be heard before SENDIST. The Education and Skills Select Committee found that it is widely recognised that there is a strong correlation between exclusions and children with SEN — particularly those with social, emotional and behavioural difficulties and autistic behaviour. The Committee found it unacceptable that such a well known problem 'continues to occur' (Education and Skills Select Committee, 2006, p32).

Following *Higher Standards, Better Schools for All* (DfES, 2005) it would seem that LEAs will cease to operate as service providers. LEAs currently provide specialist support services, but, when the white paper is implemented, LEAs will no longer be able to provide services but only commission them. It is unclear where, once these services have been broken up, such services will come from in the absence of LEAs as providers (BATOD, 2006). Indeed, the policy of increased delegated funding to schools also sits awkwardly with the Government's acknowledgement that the majority of LEAs have yet to develop adequate arrangements for monitoring outcomes for pupils with special educational needs (DfES, 2004).

In *Higher Standards, Better Schools for All* the Government says that:

We seek to designate 50 new SEN specialism specialist schools within the next two years.  
(DfES 2005, p55)

While this commitment to new special schools will be welcomed by some parents, it is not clear what impact this will have for parents who want mainstream placements and are already struggling to secure the placements and to make them work effectively (See Chapter Four). The Education and Skills Select Committee (2006) has urged the Government to 'work harder to define exactly what it means by inclusion.' (p26). It notes that some disability organisations, such as the National Autistic Society and MENCAP, who until recently were strong



supporters of a strict line on inclusion, are now taking a more pragmatic approach. MENCAP now says that it 'supports the concept of inclusive education, which means that every child should have access to education appropriate to their needs and potential.' (2006, cited in Education and Skills select Committee, 2006, p26). This shift in approach is reflected in the parents' narratives and may help to inform future debates about inclusion.

The Government has heralded its commitment to extended school hours allowing parents who work to have 'wrap around' child care, yet it is unclear if and how children with special educational needs and/or impairments will access care and who will pay for support for the children in extended hours. Children with special needs and/or impairments have been side-lined in the policy. While the Government's strategy for taking children out of poverty is to encourage parents back into work, it seems that parents of disabled children will continue to struggle to access child care, and, therefore, employment.

Finally, the evidence given to the Education and Skills Select Committee (Education and Skills Select Committee, 2006) suggests that 'looked-after' children are unlikely to be the subjects of appeals to Tribunal. Again this presents a challenge for the SENDisT system in the future.

### ***Key Recommendations for future challenges***

- Children with special educational needs and/or impairments should be at the heart of *all* decisions about policy and practice within education.
- 'Special needs' must be seen as a 'mainstream' issue; this is where the majority of children with special educational needs are and will continue to be educated.
- The link between assessment and funding of provision must be broken.
- There must be a debate about the tension which exists between operating a market-driven, results-orientated education system and the development of a policy of inclusion.
- There must be a wide-ranging debate about how to define 'inclusion'.
- The rights of 'looked-after' children must be upheld within the Tribunal system.

## **8. Conclusion**

Parents' stories about their experience of going to SENDisT are, at times, complex, and contradictory, but they are also compelling. The stories offer a unique and authentic insights into the worlds of parents and children with special educational needs and/or impairments. The narratives reveal the extraordinary stories of ordinary families who are trying to make sense of their challenging experiences.

Simple typologies of parenting cannot account for their complex engagement with theory. Parents appear to be pragmatists, seeking an education that will work for their child.

Parents' stories take place in a complicated and contested policy context. The policies of statements of special educational need and inclusion seem to be inextricably linked with conflict between parents and professionals. Despite the repeated demands in policy and by the academic community (Dale, 1996; DfES, 2001a) for professionals to work in partnership with parents, parent-professional relationships are dogged by deficit images of parents, children and families. There is clearly work to be done in enabling these partnerships.



The Tribunal system is, above all, a stressful one for parents, yet it is valued by parents as an independent body which settles disputes between parents and the LEAs. Parents do not advocate for its abandonment, rather they hope for its reform. In particular, parents would value more support with preparation of the case statement, representation in the hearing and in ensuring that what the Tribunal orders is delivered.

Tribunal stories take place in an abilist society, where the dominant image of the tragedy of the disabled family persists in policy, among professionals, within the hearing and within the wider social world. With a renewed emphasis on parental competence, academic achievement and a 'zero tolerance' attitude to behaviour, and in a climate of devolved funding and increased marketisation and competition in schools (DfES, 2005), it is difficult to be optimistic about the future for children with special educational needs and/or impairments.

Yet, the parents tell remarkable stories of their resilience and resistance. Despite the pressures upon their families, the parents describe the ordinary and the positive aspects of family life, including changes in perspectives and drawing strength from 'wise' communities. In this study, parents challenge traditional images of the disabled family and their insights offer the possibility for change, not only within the special education system, but for the wider society. There is no doubt that parents will continue to resist, contest and challenge the limitations and interpretations put upon their families' lives for the sake of their own children and for other families.

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