APPENDICES

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SUMMARY DOCUMENT ONE: The factors which contribute to why parents register an appeal with the Special Educational Needs and Disability Tribunal (SENDisT)

Introduction

Since the Special Educational Needs Tribunal was established in 1994 as an independent panel to arbitrate in disputes between parents and LEAs more than 25,000 appeals have been registered. The average per year is now 3,400 (Hughes, 2005). In 2002, The Special Educational Needs Tribunal began hearing claims for disability discrimination and became known as the Special Educational Needs and Disability Tribunal (SENDisT). As part of a wider study which asked parents to talk about their experiences of SENDisT, parents spoke about why they had registered an appeal with SENDisT.

In summary, the study found that:

- Parents valued statements as a means of protecting their child's educational provision.
- Parents were divided over the policy of inclusion.
- Many parents were initially keen to try mainstream schooling but the placements often broke down.
- Parents expected to work in partnership with professionals, but found this difficult.
- Parents described how they felt that they and their children were often blamed for partnership breakdown.
- LEA officers were singled out for particular criticism by parents.
- Parents felt that Parent Partnership Services were of limited use in the Tribunal process.

- Parents doubted the impartiality of the mediation services. A large minority of parents were either unaware of the formal disagreement resolution mediation service available, or were refused mediation by the LEA.

Background

In this study, parents were asked to tell their stories of going to SENDisT. Their Tribunal stories were wide-ranging: parents spoke about the effect going to Tribunal had on their family, they talked about their experience of the hearing itself and about living in a family where one or more children has a label of 'special needs'. However, here the focus is on the reasons why parents registered an appeal with SENDisT. Seventeen mothers and seven fathers, who were contacted through three voluntary organisations and by word of mouth, told their Tribunal stories. Seven serving panel members and one former panel member were also interviewed about their experiences of SENDisT.

Policy Factors

The policy of statements and of inclusion were regularly cited by parents to explain why they went to SENDisT.

In general, the study found that:

- Service providers see **statements** as overly bureaucratic, costly and anti-inclusive (Pinney, 2003, OfSTED 2004, Audit Commission 2002). Parents and their organisations (IPSEA, 2005) see statements as the best way of protecting their child's educational entitlement and as a vital component in successful inclusion in all schools.

Parents differed in their attitudes to the policy of **inclusion** as their stories reveal below(See box 1, box, 2 box 3 and box 4).

Box 1: Barbara's story

We feel very strongly about inclusion in society. Why do children have education in the first place? They have education to prepare them for adult life. So that's where we come from.

Box 2: Tina's story

Our son is in mainstream but he may not stay in there. They have started taking him out of the classroom in the afternoons in the reception class, which is working quite well. But they can't do that in the juniors. They don't have a special needs room for one-to-one. There's nowhere for him to have speech therapy in the junior school.

Box 3: Fiona's story

At the junior school they kept him in to learn spellings and things which he was never ever going to learn. They said 'well that's our policy and that's what he has to do. 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.

Box 4: Mary's story

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. We had to get him into special school.

In general, the study found that:

- Since 1997, the policy of inclusion has been a key factor in parents' appeals to SENDisT. Parents are divided on the merits of the policy. Some parents are very committed to inclusive education for their children, whereas others fought for their children to attend special school.
- Despite the policy drive for inclusion, several parents tried and failed to get places for their children in mainstream schools.
- Parents repeatedly described having tried mainstream schooling but found that their children were excluded either by lack of resources or because of discriminatory attitudes.
- Some parents fought very hard for special schooling, in one case a parent was forced to return to SENDisT three times before she was able to secure a special school place for her son.
- A small minority appealed to SENDisT for disability discrimination claims. Some parents were unaware of their rights to do so.

Relationship Factors

The relationships between parents and professionals played a key part in parents' Tribunal stories. **Relationship breakdown** was cited by many parents as a reasons why they went to SENDisT. Leah's story (Box 5) describes the breakdown of her relationships with her son's school and the LEA.

Box 5: Leah's story

Max 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. His toe had gone septic. So I wrote a note to the head on the Friday explaining what had happened and asking if Max could sit down outside his office. I heard nothing that day and then on the Saturday a letter came excluding Max at lunchtime. The school is three miles from our home so Max spent lunchtimes in the park.

What we were trying to do was help the teachers to understand Max. 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. In fact, the head teacher told my husband 'To be quite honest it would be better if your wife got a job and let Max stand on his own two feet.'

In general, the study found that:

- Parents described how they had initially expected to work in partnership with professionals.
- Parents repeatedly described how they had tried to 'help' by sharing information about their children, but professionals refused to listen.

- Parents described the way in which they felt teachers and schools withheld information about their child from them.
- Parents who challenged felt they were blamed for their child's lack of progress or behaviour. This was particularly the case for mothers.
- Parents felt that their children were forced to fit the system rather than teachers and schools showing flexibility.
- Parents described the professionals' focus on their child's 'difficulties' rather than on systemic or attitudinal barriers.

Parents commented on their relationships with a variety of professionals including teachers, paediatricians, psychologists and a wide range of therapists. However, Leo's story (See Box 6) reveals that parents felt most strongly about their relationships with Local Education Authority Officers.

Box 6: Leo's story

The delaying tactics the LEA employed in dealing with our case was just extraordinary, extremely skilful on their part, you have to hand it to them, but totally immoral. They lead us a merry dance in circles.

The LEA played dirty tricks as we were going to Tribunal. The Educational Psychologist hadn't seen Christopher for three years, so they sent him to look at Chris 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.

I should say at this point that I'd still brake if the LEA officer crossed the road in front of me, I just wouldn't do it quite so quickly...I might brake later! I can understand how some people wouldn't brake! 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 ...

In general, the study found that:

- Parents were particularly angry with LEA officers. Parents described feeling that they were "lied" to and "bullied" by LEA officers.
- Parents said LEAs were "playing dirty tricks". Several parents reported how the LEA used delaying tactics as a matter of course. Others described LEA officers falsifying evidence and lying in the hearing.

Box 7: Tim's story

As a Tribunal chair, I have to say 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 into account 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 ....

In general, the study found:

- The Tribunal has no effective power to reprimand an LEA which they believe has wasted public time and money, or treated parents badly.

Systemic Factors

Parents found that the systems which are in place to help resolve disputes between parents and the LEA were of limited use. Parents described the limitations of **Parent Partnership Services** and **Mediation Services** (See Box 8 & 9).

Box 8 Sue's Story

We had Parent Partnership which is a local group and we had a lady come round and talk to us. It was quite difficult, because they're part of the LEA, whether they're supposed to be independent or not, they are still funded by the LEA. She couldn't come to Tribunal with us. 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 voluntary organisation instead.

In general, the study found that:

- Parents doubted the ability of Parent Partnership Officers (PPOs) to act impartially. Parents felt that PPOs were limited in what they could offer.
- A minority of parents criticised the accuracy and quality of advice they received about their child's education from PPOs.
- Parents turned instead to voluntary organisations for support.
- Some professionals described how PPOs were thought to be 'too much on the side of the parent'.

Box 9: Sam's story

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?

In general, the study found that:

- The mediation service was not seen to be impartial.
- Many parents did not know that a mediation service existed.
- Some LEAs refused to take part in mediation. LEAs found mediation difficult as it was not possible to send one person to mediation with decision making power in authorities where decisions about statements are made jointly at panel meetings.
- Some parents felt that they were intimidated in the mediation sessions.

Several parents in the study appealed to Tribunal more than once. Derek's (a Tribunal panel member) story reveals why this is often the case.

Box 10: Derek's story

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. They 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 it's a long process because of the delays for each Tribunal and you need a very strong willed parent to keep on going back to Tribunal.

In general, the study found that:

- Many parents went to SENDisT more than once. One parent went to SENDisT for both her children.
- There are inherent factors within the system which cause parents to appeal repeatedly.
- The repeated appeals to SENDisT are also linked to the failure of LEAs to implement Tribunal orders.

Conclusion

The research findings suggest that:

- Parents value statements but fear the drive to reduce the number of statements.
- Parents are divided about the policy of inclusion with feelings running high.
- Partnership between parents and professionals remains difficult to achieve.
- LEAs are heavily criticised by parents.

- Parents did not put a high value on Parent Partnership Services.
- Parents had mixed experiences of mediation.
- Systemic factors require often require parents to appeal repeatedly to SENDisT. Many parents are unable to do so because of the stress and costs involved.

Acknowledgements

The support of the ESRC (The Economic and Social Research Council) is gratefully acknowledged.

References

Audit Commission Report (2002): *Statutory assessment and statements of SEN: in need of review?* Wetherby: Audit Commission Publications

Hughes, R (2005) 'The SENDisT – ten years on' in *Education, Public Law and the Individual* Vol. 9 pp 4-5

IPSEA (2005) (Independent Panel for Special Education Advice) *Submission to the Education and Skills Select Committee Inquiry into Special Education Needs* Suffolk: IPSEA

OfSTED (2004) *Special Educational Needs and Disability: Towards Inclusive Schools* London: HMSO Available online at http://www.ofsted.gov.uk/publications/index.cfm?fuseaction=pubs.summary&id=3737 Accessed on 10th October, 2005

Pinney (2003) *Reducing Reliance on Statements* HMSO: London

SUMMARY DOCUMENT TWO: Parents' experiences of attending the Special Educational Needs and Disability Tribunal (SENDisT)

Introduction

Since the Special Educational Needs Tribunal was established in 1994 as an independent panel to arbitrate in disputes between parents and LEAs more than 25,000 appeal have been registered (Hughes, 2005). In 2002, The Special Educational Needs Tribunal began hearing claims for disability discrimination and became known as the Special Educational Needs and Disability Tribunal (SENDisT). As part of a wider study which asked parents to talk about their experiences of SENDisT, parents spoke about the experience of attending a Tribunal hearing.

In summary, the study found that:

- The venues and room lay-out could be intimidating for parents.
- Parents found the hearings more formal than they had expected.
- Some parents felt that they had a 'fair' hearing, others did not.
- Parents felt the panel members had read the case statements thoroughly, but some parents felt the panel members had not understood all the issues involved.
- The majority of parents would prefer to be represented in hearings, but this is frequently not possible.
- Parents are worried that having a representative will disadvantage their case before the panel.

- Panel members aim to make the process fair regardless of the quality of representation.
- Some parents felt the process was very detached from their child.

Background

In this study, parents were asked to tell their stories of going to SENDisT. Their Tribunal stories were wide ranging: parents spoke about why they went to Tribunal, their relationships with professionals, how going to Tribunal had affected their family and they talked about the experience of living in a family where one or more children has a label of 'special needs'. However, here the focus is on what parents said about attending the Tribunal itself. Seventeen mothers and seven fathers, who were contacted through three voluntary organisations and by word of mouth, told their Tribunal stories. Seven serving panel members and one former panel member were also interviewed about their experiences of SENDisT.

The Venue

Parents described the effect of the venue on how they felt in the Tribunal hearing. Tina's story (Box 1) reveals how some parents felt about the Tribunal room lay out.

Box 1: Tina's story

When I walked into the Tribunal room, the biggest shock of all was how big the table was! And how formal that made everything seem. 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.

In general, the study found that

- The venue itself could be intimidating, especially if it was an unfamiliar for parents environment, for example a large hotel.
- The lay-out of the room could also be intimidating. Parents found themselves sitting in a long line opposite the panel. This made it difficult when the parents could not see witnesses who were talking.

Parents found the atmosphere in the hearing very formal as Ben's story (Box 2) reveals.

Box 2: Ben's Story

It wasn't a bit like the video you see . That's all friendly and everyone is putting you at your ease but it wasn't like that. There was this lady legal chairman and two men, and they really were very hostile.

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 there first names, don't do that.

The Tribunal is a court. They treat it as a court and you, the parent, are a criminal. I felt like I was in a court-case and I got ten years in jail!

In general, the study found that:

- Parents repeatedly described the hearing as more formal than they had expected, and more formal than the video (*A Right to be Heard)* they were sent to help them prepare for the hearing.
- Parents were very uncomfortable when they felt that the panel members and professionals engaged in banter or seemed to make light of the proceedings.

A fair hearing?

Parents were divided over whether or not they felt they had been given a fair hearing. This did not necessarily correspond with whether or not the parent had got what they wanted at Tribunal. Simon did not get an autism specific education for his son but felt that he had been heard, whereas Sally did get specialist dyslexia teaching for her son, but felt that she had not been allowed to say everything she wanted. Martha (See Box 3) and Brenda's (See Box 4) stories reveal parents' contrasting experiences in the hearing.

Box 3: Martha's Story

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. We thought that we would be given time to be heard before the end of the hearing. We were wrong.

Box 4: Barbara's Story

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.

In general the study found that:

- Parents had very different experiences from one another at hearings. Parents who attended more than one Tribunal suggested this was most influenced by the way the hearing was run by the Chair.

- None of the parents complained that they felt the members had not prepared before the Tribunal.
- A small minority of parents and panel members complained that some panel members did not understand the issues before them.
- Parents sometimes described how they felt they were being disciplined by panel members with 'glares' and being told to be quiet. One parent was threatened with ejection from the hearing for repeated interruptions.

Representation in the hearing

The study found that the majority of parents represented themselves at the hearing. A minority paid to be represented by a solicitor and a minority were represented for free by a member of a voluntary organisation. Parents' experiences of representation were mixed as Kirsty (Box 5) and Colin's (Box 6) stories show.

Box 5: Kirsty's Story

Now the advice line charity rep who represented us at the hearing, she had previous experience of educational psychology and she brought the points out and I wouldn't have had a clue about the dips and peaks and all this.

Box 6: Colin's Story

The solicitor was there at the Tribunal. He might as well 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 before the Tribunal began 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 hearing ....

In general the study found that:

- Most parents who represented themselves would have liked to have been represented at the hearing. They were not able to get representation because they could not afford it and because voluntary organisations are limited in the help with representation they can offer.
- Parents feared they might be given 'a harder time' by the panel members if they were represented by someone else. Parents wanted clarification from SENDisT on this.
- Parents and professionals found that the quality of representation available to parents from both solicitors and voluntary organisations varied greatly.
- Some parents were unfamiliar with the professional 'jargon' used within the hearing and this made parts of the hearing difficult to access.
- Panel members felt strongly that it was their job to make the hearing fair, no matter what the quality of the representation.
- Only one child in this study spoke in a hearing. Parents described taking photographs of their children into the hearing with them, but most felt that the hearing was very remote from their child.

The role of witnesses

The study found that parents and LEAs usually brought expert witnesses to the hearing. Parents felt that witnesses for the LEA who were also employees of the LEA could not be impartial. One panel member also raised questions about the impartiality of a witness employed by the parents. He suggested that:

> 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.

Stress and the hearing

Parents found the process of going to the hearing very stressful as Mia's story (Box 7) reveals.

Box : Mia's story

Somehow sitting there across the table from these three people one was good cop, one was bad cop and one was indifferent cop! And the bad cop was really going for us and being really negative. I felt the formality of it all was totally beyond me.

In general, the study found that

- Parents found the hearing very stressful and this sometimes made them feel they were unable to put their case.
- Parents' stress was increased by a number of factors including: the formality of the hearing, the parents' feeling they were unable to say what they wanted to say and the use of jargon making parts of the hearing inaccessible.

Conclusion

The research findings suggest that:

- The venue and the organisation of the room impacts significantly on parents.
- Parents find the proceedings very formal.

- Parents had mixed views about whether they felt they were given a fair hearing.
- Most parents would like to be represented at the hearing, but this is not possible for the majority.
- There are concerns about the quality of paid and voluntary representatives, although panel members strive to reduce the effects of this in the hearing.
- Children's voices are not represented directly in the hearing.
- The impartiality of witnesses is a concern for parents and panel members.
- The hearing itself is extremely stressful for parents.

Acknowledgements

The support of the ESRC (The Economic and Social Research Council) is gratefully acknowledged.

References

SENDIST *Right to be Heard* Available to order online at
http://www.sendist.gov.uk/basic.cfm?aid=6970FC8A-6177-11D5-A1A600A0CC5E79D9&section=1
Accessed on 15th January, 2005

SUMMARY DOCUMENT THREE: The effect on families of going to the Special Educational Needs and Disability Tribunal (SENDisT)

Introduction

Since the Special Educational Needs Tribunal was established in 1994 as an independent panel to arbitrate in disputes between parents and LEAs more than 25,000 appeals have been registered. The average is about 3,400 per year (Hughes, 2005). In 2002, The Special Educational Needs Tribunal began hearing claims for disability discrimination and became known as the Special Educational Needs and Disability Tribunal (SENDisT). As part of a wider study which asked parents to talk about their experiences of SENDisT, parents spoke about the social, emotional and financial impact of Tribunal on the family.

In summary, parents said that:

- Parents were frustrated by the Local Education Authorities' failure to implement Tribunal orders. This was a major source of stress for parents. Appeals for help to the Department for Education and Science, and the local government ombudsman were described as 'useless'. Few parents had the financial or emotional resources to pursue their claim to Judicial Review. Several parents were forced to return repeatedly to SENDisT.

- All the parents in the study talked about the financial burden of going to SENDisT. All parents faced administrative costs, some paid for specialist reports and some paid legal costs.
- Parents spoke of the insignificance of the financial costs of going to Tribunal when compared to the emotional and health costs they suffered.
- Mothers were made particularly vulnerable in the Tribunal process as they often took the main responsibility for preparing for, and attending SENDisT.
- Parents described the process of going to Tribunal as very stressful for their relationships with one another, and some parents cited the Tribunal as a major factor in their decision to separate or to divorce.
- Parents described the effects of going to Tribunal on their other children. Siblings felt 'left out' when the family's focus was on the child with special needs.
- Parents felt that their children with special needs were largely unaware of the Tribunal process. However, parents were acutely aware of how preparing for the Tribunal prevented them from spending time with all their children.
- For a small minority of parents, the process of going to Tribunal was empowering, and led to positive changes in their lives. The experience of going to Tribunal gave one parent the confidence to do a university degree.
- Despite the stresses involved in going to SENDisT, the majority of parents felt that it had been worthwhile. They hoped for reform of the system to make it less stressful, not the abolition of SENDisT.

Background

In this study, parents were asked to tell their stories of going to SENDisT. Previous research (Simmons, 1996, NAS, 2003) suggests that the process of going to Tribunal is a very stressful frustrating one for parents, and parents in this study shared that view. Their Tribunal stories were wide ranging: parents spoke about why they went to Tribunal, their relationships with professionals, their experience of the hearing itself and they talked about the experience of living in a family where one or more children has a label of 'special needs'. However, here the focus is on what parents said about the effects of going to Tribunal on family life. Seventeen mothers and seven fathers, who were contacted through three voluntary organisations and by word of mouth, told their Tribunal stories. Seven serving panel members and one former panel member were also interviewed about their experiences of SENDisT.

The implementation of SENDisT orders

Ivor's story (see Box 1) demonstrates the difficulties parents had in getting the LEA to implement SENDisT's orders. His experience of repeated visits to SENDisT was comparable with those of other parents in the study.

Box 1: Ivor's story

I went to SENDisT because I wanted my son Michael to have extra support for his dyslexia. The Tribunal ordered that Michael was to have a lap-top, two hours extra support from a learning support assistant and five hours specialist teaching. The statement of special educational needs that we got from the Tribunal was everything we wanted. The Local Education Authority had five weeks to put the new support in place.

It took 10 months for Michael to receive a lap-top. It took four months for the extra learning support assistant time to be put in place. It took five months before the specialist teaching was in place and even then it was for three hours, not five.

I complained to the DfES who were basically useless. The local government ombudsman suspended her investigation when we decided to serve Judicial Review papers on the LEA. We served the papers on the basis that the LEA had not implemented the Tribunal's order. Shortly after the Judicial Review papers were served the LEA amended Michael's statement, following an Annual Review, and removed the specialist teaching from his statement. This, in effect, halted the Judicial Review as the revised statement was now being implemented. Our only option to get Michael his specialist teaching was to go back to SENDisT.

In general, the study found that:

- LEAs were slow to implement Tribunal orders and many were never implemented in full.

- Parents felt asking for help from the Local Government Ombudsman and the DfES was usually 'useless'.
- Judicial Review was beyond the financial and emotional means of most parents.
- Parents were left to 'police' orders alone. They found this very stressful.
- Tribunal members have no way of knowing if their orders have been implemented.

Financial costs

Violet's story (see Box 2) showed the extent of the financial costs of going to SENDisT.

Box 2: Violet's Story

And with the specialist reports, solicitors' fees, 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.

In general, the study found that:

- All parents were faced with the costs of telephone calls, photocopying, and postage.

- All but one parent paid for specialist reports about their child. The costs for these ranged from £70 - £900 individually but most parents paid for more than one report.
- Some parents paid to be represented by a solicitor, one parents was able to secure a flat fee of £1000, most paid substantially more.
- Parents repeatedly described the expenditure as money they did not have. The cost was funded by credit cards, re-mortgaging and using money from inheritance.
- The Joseph Rowntree Foundation (2001) found that 80% of families who have a disabled child in them live on an income of less than £300 a week. This suggests that even the basic administrative costs of going to SENDisT may put the system beyond the reach of many families.

The costs for family relationships

Michelle's story (see Box 3) reveals that parents felt that the financial costs of going to SENDisT were nothing compared to the emotional costs.

Box 3: Michelle's Story

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 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 though 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.

In general the study found that:

- Mothers bore the greatest responsibility for preparing for and attending the Tribunal.

- Mothers, in particular, were criticised for their parenting and their views were questioned or cited as evidence of the mother's own 'anxiety'.
- Relationships between parents were put under great pressure as a result of the stress associated with the Tribunal. This stress was cited as a reason for separation and divorce.
- Parents described how the wider family, including siblings and grandparents were negatively affected by the Tribunal process.
- Parents tried to protect their child with special needs from the process, although some children were aware that the outcome would have a big impact on their future.
- Children do not usually attend SENDisT. Only one child in this study spoke at a hearing.

Empowerment and the Tribunal

Janet's story (see Box 4) reveals how the experience of going to SENDisT had a positive impact on her life.

Box 4: Janet's story

The Tribunal 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 do teaching degree.

In general the study found that:

- The process was empowering for only a very small minority of parents.

- Most parents found the process overwhelmingly stressful.
- Despite the stresses of going to SENDisT, the majority of parents valued its existence as a means of solving disputes. They advocated its reform, especially in terms of the implementation of orders, not its abolition.

Conclusion

The research findings suggest that:

- There is no effective monitoring of SENDisT's orders. Parents are left to 'police' the orders themselves.
- The financial costs of going to SENDisT may exclude families.
- Family members are put under extremely high levels of stress by the process of going to SENDisT. Mothers seem to experience the highest levels of stress.
- For a small minority of parents, the process of going to SENDisT is particularly positive and empowering.
- Parents value the existence of SENDisT as a means of resolving disputes with the LEA.

Acknowledgements
The support of the ESRC (The Economic and Social Research Council) is gratefully acknowledged.

References

Joseph Rowntree Foundation (2001) *The Impact of Childhood Disability on Family Life* http://www.jrf.org.uk/knowledge/findings/socialcare/631.asp
National Autistic Society (2003) *Autism and Education: the ongoing battle* http://www.nas.org.uk
Hughes, R (2005) 'The SENDisT – ten years on' in *Education, Public Law and the Individual* Vol. 9 pp. 4-5
Simmons, K (1996) 'Parents, Legislation and Inclusion' in H Daniels (Ed) *Special Education Reformed: Beyond Rhetoric*? Falmer: London

SUMMARY DOCUMENT FOUR: Living in a family where one or more children has a label of special educational needs.

Introduction

Since the Special Educational Needs Tribunal was established in 1994 as an independent panel to arbitrate in disputes between parents and LEAs more than 25,000 appeal have been registered. On average there are about 3,400 appeals registered each year (Hughes, 2005). In 2002, The Special Educational Needs Tribunal began hearing claims for disability discrimination and became known as the Special Educational Needs and Disability Tribunal (SENDisT). As part of a wider study which asked parents to talk about their experiences of SENDisT, parents spoke about living in a family where one or more child has a label of special needs.

In summary, the study found that:

- Parents spoke positively about their children.
- Parents of children with special needs often had extended caring responsibilities for their children.
- The issue of diagnosis was an important one for parents.
- Parents described mixed responses to their families from other people.
- Parents described battling for support and resources as a major source of stress. For many parents this was more stressful than the care needs of their children.
- Other parents of children with special needs and voluntary organisations were key sources of support for parents.

- Parents described the discrimination their children faced in general and by service providers.
- Parents were often anxious about the future for their children.

Background

In this study, parents were asked to tell their stories of going to SENDisT. Their Tribunal stories were wide ranging: parents spoke about why they went to Tribunal, their relationships with professionals, their experience of the hearing itself and the effect that going to Tribunal had on their family. However, here the focus is on what parents said about their experiences of living in a family where one or more children has a label of special needs. Seventeen mothers and seven fathers, who were contacted through three voluntary organisations and by word-of-mouth, told their Tribunal stories. Seven serving panel members and one former panel member were also interviewed.

Parents' attitudes to their children with special needs

Parents in the study talked positively about their children with special needs, as Robert's story (Box 1) shows.

Box 1: Robert's Story

He is an absolutely lovely child. He has an extraordinary sense of humour.

In general, the study found that

- Parents spoke positively and lovingly about their children.
- Several parents talked about the effects on the family of the extra demands of caring for a child with special needs.

Diagnosis

Several parents spoke about the experience of getting a diagnosis for their child. Parents had mixed feelings about diagnosis, as Leo's story shows.

Box 2: Leo's story

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.

In general, the study found that:

- Several parents who talked about their child's diagnosis expressed regret at having to label their children, but valued labels as a signpost to information and a gateway to resources.
- Some parents described the struggle they had in getting a diagnosis for their children, and the anxiety this caused them when they feared that 'no diagnosis' meant 'no support.'
- Some parents described the 'struggle' they had coming to terms with their child's diagnosis.
- Some parents described how they had 'tried everything' including cranial massage, diets and exercise programmes following diagnosis, and how stressful and expensive this had been.

The attitudes of others to the families

Parents often talked about how they felt they were seen by others when telling their Tribunal stories, as Sandra (Box 3) and Chris' story (Box 4) reveal.

Box 3: Sandra's Story

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.

In general the study found that:

- Some parents described how they were seen as 'extraordinary' by friends who felt they would not be able to cope in the same situation.
- Some parents felt that is was unhelpful to be seen as extraordinary and put a distance between their family and others.

Box 4 Chris's Story

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?'

- Parents described how being in public spaces with their children could be difficult. This was particularly true for parents of children with 'invisible' special needs. Parents faced hostile and discriminatory attitudes in the park or out shopping when their children's behaviour did not conform to what was expected.

- Some parents described how they became isolated as support from friends fell away.

Box 5: Tim's story

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.

- Panel members expressed an awareness of some of the difficulties involved in parenting a child with special needs.
- While parents described professionals focusing on the difficulties of the day-to-day care of a child with special needs as the cause of stress, parents cited battling for resources and support from schools, LEAs and social services as the biggest source of stress.

Sources of support

Parents talked about the sources of support available to them as Tina's story shows.

Box 6: Tina's Story

I love my friends. They're a good old support network and we know how each other feels .

- Parents repeatedly described other parents of children with special needs as a particularly important source of support.
- For many parents, charities which supported children with special needs were a key source of support.
- Faith groups were also important for a minority of parents.
- A small minority of parents in the study talked about the contact they had with social services. This was usually in the context of battling for support. Some parents were challenging social services for support at the same time as preparing for Tribunal.

Life chances

Parents described how they felt the life chances for their families were different from those of other families (See Gina's story Box 7).

Box 7: Gina's Story

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.

- Parents described how their children were discriminated against in the community and by service providers.
- Several parents talked about their concerns for their child's future and what would happen when they were no longer able to support them.

Conclusions

The research findings suggest that:

- Parents of children with special needs take on extended caring roles.
- Diagnosis is an important issue for parents, particularly because of the perceived link to the allocation of resources.
- Professionals have an awareness of some of the difficulties the families face, but they underestimate the outside pressures on the family.
- Peer support is extremely important for parents.
- Parents of children with special needs face discrimination and restricted life chances.

Acknowledgements

The support of the ESRC (The Economic and Social Research Council) is gratefully acknowledged.

References

Hughes, R (2005) 'The SENDisT – ten years on' in *Education, Public Law and the Individual* Vol. 9 pp 4-5

'PARENTS AS ADVOCATES': THE EXPERIENCES OF PARENTS WHO REGISTER AN APPEAL WITH THE SPECIAL EDUCATIONAL NEEDS AND DISABILITY TRIBUNAL (SENDisT)

Introduction

Since the Special Educational Needs Tribunal was established in 1994 as an independent panel to arbitrate in disputes between parents and LEAs more than 25,000 appeals have been registered (Hughes, 2005). In 2002, The Special Educational Needs Tribunal began hearing claims for disability discrimination and became known as the Special Educational Needs and Disability Tribunal (SENDisT). This document is a summary of four documents:

- ***The factors which contribute to why parents register an appeal with the Special Educational Needs and Disability Tribunal (SENDisT).***
- ***Parents' experiences of attending the Special Educational Needs and Disability Tribunal (SENDisT).***
- ***The effect on families of going to the Special Educational Needs and Disability Tribunal (SENDisT).***
- ***Living in a family where one or more children has a label of special educational needs.***

Background

Parents were asked to tell their stories of going to SENDisT as part of an ongoing Economic and Social Research Council funded PhD study carried out by Katherine Runswick-Cole, a student at the University of Sheffield. Their Tribunal stories were wide-ranging: parents spoke about why they went to Tribunal; they spoke about attending the Tribunal itself; how going to Tribunal had affected their family and they talked about the experience of living in a family where one or more children has a label of 'special needs'. Seventeen mothers and seven fathers living in England were contacted through three voluntary organisations and by word-of-mouth. Seven serving panel members and one former panel member were also interviewed about their experiences of SENDisT.

What parents said about why they registered an appeal with SENDisT

In summary, the study found that:

- Statements were at the heart of why parents went to SENDisT. Parents valued statements as a means of protecting their child's educational provision.
- A small minority of parents registered appeals because ofdiscrimination against their children on grounds of disability.
- Parents were divided over the policy of inclusion. Some parents went to SENDisT to secure mainstream provision for their child, whereas others went for a special school place.
- Several parents were initially keen to try mainstream schooling but the placements broke down, leading them to appeal for a special school place.
- Parents expected to work in partnership with professionals, but found this difficult. Parents described how they felt that they and/or their children were often blamed for partnership breakdown.
- LEAs were heavily criticised by parents for not implementing the system properly.

- Parents felt that Parent Partnership Services were of limited use in the Tribunal process.
- Parents doubted the impartiality of the mediation services. A large minority of parents were either unaware of the mediation service, or were refused mediation by the LEA.

What parents said about attending the hearing:

In summary, the study found that:

- The venues and room lay-out could be intimidating for parents.
- Parents found the hearings more formal than they had expected.
- Some parents felt that they had a 'fair' hearing, others did not. Parents felt this depended to a great extent on the Chair of the panel.
- Parents felt the panel members had read the case statements thoroughly, but some parents felt they had not understood all the issues involved.
- The majority of parents would prefer to be represented in hearings, but this is frequently not possible.
- Parents are worried that having a representative will disadvantage their case before the panel.
- Panel members aim to make the process fair regardless of the quality of representation.
- Some parents felt the process was very detached from their child.

What parents said about the effects of going to SENDisT on the family:

In summary the study found that:

- Parents were frustrated by the Local Education Authorities' failure to implement Tribunal orders. This was a major source of stress for parents. Appeals for help to the Department for Education and Skills, and the local government ombudsman were described as 'useless'. Few parents had the financial or emotional resources to pursue their claim to Judicial Review. Several parents were forced to return repeatedly to SENDisT.

- All the parents in the study talked about the financial burden of going to SENDisT. All parents faced administrative costs of photocopying, postage and telephone calls; most paid for independent reports about their child and some paid legal costs.
- Parents spoke of the insignificance of the financial costs of going to Tribunal when compared to the emotional and health costs they suffered.
- Mothers were made particularly vulnerable in the Tribunal process as they often took the main responsibility for preparing for and attending SENDisT.
- Parents described the process of going to Tribunal as very stressful for their relationships with one another, and some parents cited the Tribunal as a major factor influencing their decision to separate or to divorce.
- Parents described the effects of going to Tribunal on their other children. Siblings felt 'left out' and that the family's focus was on the child with special needs.
- Parents felt that their children with special needs were largely unaware of the Tribunal process. However, parents were acutely aware of how preparing for the Tribunal prevented them from spending time with all their children.
- For a small minority of parents, the process of going to Tribunal was empowering, and led to positive changes in their lives. The

experience of going to Tribunal gave one parent the confidence to do a university degree.

- Despite the stresses involved in going to SENDisT, the majority of parents felt that it had been worthwhile. They hoped for reform of the system to make it less stressful, not its abolition.

Parents' comments about living in a family where one or more child has a label of special needs:

In summary, the study found that:

- Parents of children with special needs often had extended caring responsibilities for their children.
- The issue of diagnosis was an important one for parents.
- Parents described mixed responses to their families from other people.
- Parents described battling for support and resources as a major source of stress. For most parents, this was described as more stressful than caring for their children.
- Other parents of children with special needs and voluntary organisations were key sources of support for parents.
- Parents described the discrimination their children faced.
- Parents were often anxious about the future for their children.

Conclusions

The study found that:

- Policy, relationship and systemic factors all contributed to why parents appealed to SENDisT.
- Parents had mixed experiences at the hearings but all found the process stressful and a huge undertaking. Many would have liked more support, particularly with representation in the hearing.

- The process of going to SENDisT has a significant impact on the financial and emotional well-being of the whole family.
- Parents' experience a variety of pressures on their families, for many the greatest pressure comes from battling for resources and against discrimination.

Acknowledgements

The support of the ESRC (The Economic and Social Research Council) is gratefully acknowledged.

References

Hughes, R (2005) 'The SENDisT – ten years on' in *Education, Public Law and the Individual* Vol. 9 pp. 4-5

OTHER DISSEMINATION ACTIVITY

PUBLICATIONS

- Runswick-Cole, K. (2007, in press) 'The Tribunal was the most stressful thing: the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDisT)' *Disability and Society*
- Runswick-Cole, K. (submitted) 'Infidels and foreigners: parent-professional relationships and the Special Educational Needs and Disability Tribunal (SENDisT) *International Journal of Inclusive Education*
- Mallett, R., Runswick-Cole, K. and Collingbourne, T. (submitted) 'Presenting Protocols for Accessible Research Dissemination' *Disability and Society.*
- Runswick-Cole, K. and Ryan, S. (in preparation) 'Repositioning mothers; mothers, disabled children and disability studies' *Disability and Society*
- Runswick-Cole, K. (in preparation) 'Between a rock and a hard place: parents' attitudes to the inclusion of their disabled children in mainstream schools' *British Journal of Special Education*

CONFERENCES

27TH FEBRUARY, 2007 THE UNIVERSITY OF EXETER
- Runswick-Cole, K, (forthcoming) "The Tribunal was the most stressful thing: more stressful than my son's diagnosis or behaviour': the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDisT)' *Research Seminars at Exeter, 2006-7,* School of Education and Lifelong Learning, October – June, Exeter, UK

18TH – 20TH SEPTEMBER, 2006 THE UNIVERSITY OF LANCASTER
- Runswick-Cole, K. 'Infidels and Foreigners: parent-professional partnerships and the Special Educational Needs and Disability Tribunal (SENDisT)' DSA: *Disability Studies: Research and Learning,,* Lancaster, UK

6TH APRIL, 2006 THE UNIVERSITY OF SHEFFIELD
- Runswick-Cole, K. 'Parent-professional relationships and the Special Educational Needs and Disability Tribunal (SENDisT)' *Social Science Seminar Day,* 6th April, 2006, Sheffield, UK

12TH MAY, 2005 THE UNIVERSITY OF SHEFFIELD
- Runswick-Cole, K. 'Parents as Advocates: the experiences of parents who register an appeal with the Special Educational Needs and Disability Tribunal (SENDisT)', Inaugural Seminar of Applied Disability Studies Researchers, 12th May, Sheffield, UK

WIDER DISSEMINATION ACTIVITY

NOVEMBER, 2006: THE UNIVERSITY OF SHEFFIELD
- Seminar presentation for dentists: 'Disability & Dentistry: enabling care'

OCTOBER 2006: SHEFFIELD HALLAM UNIVERSITY
- Seminar presentation for undergraduate students: 'Disability & Family: some issues and uncertainties'

MAY, 2006: THE UNIVERSITY OF SHEFFIELD
- Seminar presentation for PQ Social Workers: 'Parent-Professional Partnership'

MARCH, 2006: THE UNIVERSITY OF SHEFFIELD
- Seminar presentation for BA/MA Social Work Students: 'Parent-Professional Partnership'

APPENDIX 7.

SENDIST

Special Educational Needs and Disability *Tribunal*

Notice of appeal form check list – What to send us

If you decide to appeal, please use this checklist to make sure that you have included all the information we need. You should use the tick boxes below to make sure that you provide the right information. It may take us longer to deal with your appeal if you do not send us all the information we need.

In all cases, we will need:

a copy of the **LEA's letter** telling you that you can appeal to us; and

your reasons for making the appeal. You can fill in the box at section 6 of this form or give your reasons on a separate sheet of paper. You should include as much detail as possible. Your reasons are important. There is some advice on page [11] on what your reasons might cover and more detailed help on page [8] if you are appealing against the contents of a statement.

If you are appealing against the contents of your child's statement, we will need:

a photocopy of your child's **final statement** of special educational needs; and

a set of the documents which were attached to the statement – these are usually called the **appendices or advices.** If these documents did not come with the final statement, send the ones which came with the proposed (draft) statement if there was one.

If you are asking for the LEA to change the name of the school, we will need:

the **name and address** of the school you would like named in the statement, or a **description of the type of school** you would like if you cannot name a school (there are boxes at section 5 for you to provide these details); and

confirmation that you have **told the school** that you have asked the LEA to name it in the statement.

When preparing your appeal, it would help us greatly if:

You fill in this form clearly, in black ink and using CAPITAL LETTERS;

the papers you send are single-sided A4 copies and not stapled;

the papers are in black and white (we cannot make colour copies so we suggest that you make a copy of any booklets, such as a school prospectus, and send these in.);

you do not add your own page numbers; and

you could provide a contents list or summary of what you have sent.

If you do not have a representative or another person to help you fill in the form, contact our SEN helpline on 01325 392555 and we will help you fill in the form.

Notice of appeal form

- To make an appeal, please fill in this form and send it to the address at the end of the form.
- There is a time limit for making an appeal. We must **receive** it no later than the first working day **two months** after the LEA wrote to you with its decision. If that two-month period ends in August, your form is still in time if it arrives on the first working day in September.
- We may be able to accept a late appeal. If the form will not arrive in time, please write to explain why.
- We have to photocopy this form so please use **black ink** and **CAPITAL LETTERS.**

Section 1: Your child

Surname	Date of birth
First names	Boy Girl

Section 2: Your contact details

Parents can make a claim together.

Parent one	**Parent two**
Mr Mrs Miss Ms	Mr Mrs Miss Ms
Other *(please give details)*	Other *(please give details)*
Surname	Surname
First names	First names
Relationship to the child	Relationship to the child
Address and postcode	Address and postcode
Daytime phone number	Daytime phone number
Other telephone number	Other telephone number
Fax number	Fax number
E-mail address	E-mail address
Your signature	Your signature
Date	Date

Your representative (if you have one)

Surname

First names

Profession

Daytime telephone number

Other telephone number

Fax number

E-mail address

Address and postcode

Ethnic monitoring

It would help us if you would tick one of these boxes. You do not have to, but the information gives us useful statistics. We keep all information confidential. We are registered under the Data Protection Act.

Your child's ethnic origin:

Bangladeshi	Black other	Pakistani
Black African	Chinese	White
Black Caribbean	Indian	Other

Who should receive information about the appeal?

We can only send papers and documents to one of the people you name on this form.

If you do not say who you would prefer to receive the papers, we will send them to your representative, if you name one. Otherwise, we will send papers to the first parent named on this form.

First parent Second parent Representative

Section 3: If you live in Wales

Do you want the hearing to be in Welsh? Yes No

Section 4: Can we help when contacting you?

If we can help by translating our letters to you into another language or into Braille, or if you have any other special needs, we will do our best to meet your needs (this will be free of charge). This may mean that your appeal takes us longer to prepare. Please tell us what you need.

Section 5: Your appeal

Which LEA made the decision you are appealing against?

On what date did you receive the LEA's letter giving you that decision?

Does your child have a statement of special educational needs? Yes No

If 'Yes', what is the date the statement was issued.

What are you appealing against?

Statutory assessment

a I (or the school) asked the LEA to assess my child but it refused.

b My child already has a statement. I (or the school) asked the LEA to reassess my child but it refused.

Refusal to make a statement of special educational needs

c The LEA assessed my child but refused to make a statement.

Statement of SEN

d The LEA made a statement for my child, or refused to change it after a formal reassessment, and I disagree with:

1 what part 2 of the statement says about my child's special educational needs;

2 what part 3 of the statement says about the educational help my child should receive; or

3 the school named in part 4 of the statement (or, the LEA name no school).
You may tick more than one box in this section.

e. My child's statement was issued at least a year ago. The statement was a year old when I asked the LEA to change the school named, but it refused. (The school you asked for must be maintained (funded) by an LEA.)

f. The LEA decided to cancel (no longer maintain) my child's statement.

Important: If you ticked box d3 or e, you must give the name and address of the school you would prefer to be named in Part 4 of the statement.

School name

Address and postcode

Or if you ticked box d3 and cannot name a particular school, describe the type of school you would like your child to go to.

If you have ticked box d3 or e and are asking for the LEA to change the school named in the statement, have you told the school you want it named in the statement?

Yes No

Section 6: Your reasons

Please explain the reasons for your appeal and give us all the information you feel is important. You can use the space here and continue on a separate sheet if necessary.

The check list at the front of this form points you to the sections in this booklet that will help you to set out your reasons and tells you the information you need to give us. You can also send us any other information or reports that you feel are important.

Section 7: Claims about disability discrimination

We also deal with claims about discrimination in schools – see page [25].

If you would like us to send you a copy of our booklet 'Disability discrimination in schools: How to make a claim', please tick this box.

Would you like your SEN appeal to be heard at the same time as an existing disability discrimination claim? Yes No

If 'Yes', please give details of the disability claim.

Date the claim was sent

Claim number

Section 8: Sending us your appeal

Once you have filled in this form and signed it, please send it to us with the documents we need to:

SENDIST,
SEN Appeals,
Mowden Hall,
Staindrop Road,
Darlington DL3 9BG
Helpline: 01325 392555
Fax: 01325 391080
Email: tribunalqueries@sendist.gsi.gov.uk