

**ESRC Parents, Professionals and Disabled Babies:  
Identifying Enabling Care**

<http://www.shef.ac.uk/disabledbabies/>

**EXECUTIVE SUMMARY:  
DEVELOPED VERSION FOR DISSEMINATION**

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## **Aims of Project**

This research project was jointly carried out by researchers at the Universities of Sheffield and Newcastle, funded by the Economic and Social Research Council (ESRC grant RES-000-23-0129). We examined the care experiences of parents of babies and children needing specialist care and support in hospital and community settings. We wanted to make parents' voices heard in debates around care provision. We were particularly interested in looking at how parents and young children up to the age of 5 were treated by professionals in the care they received, and how this has helped or hindered their lives as families with disabled babies and young children. We aimed to identify:

- responsive care that enabled the disabled child to find a place in the parents' and family's lives with positive views about future development.
- beneficial care practices, primarily from the perspective of parents

- good practice on the part of professionals including neonatal and paediatric consultants, health visitors, GPs, community nurses, midwives, social workers, physiotherapists and speech therapists
- how professionals work with parents in ways which support them in caring for their child
- how 'impairment' and 'disability' are negotiated between parents and professionals and evaluate how these meanings impact on the provision of care, perceptions of the disabled baby and the resultant understandings of parenting and professional practice.

### Fieldwork

The fieldwork was broken down into distinct but related stages. This involved working with different groups of families of disabled babies and children in the following ways:

1. Retrospective narrative accounts of parents of young disabled children regarding their experiences of services, professionals and related interventions in the early years;
2. Narrative interviews of parents tracing the experiences of care received and provided over an 18 month period;
3. Observations of parent-professional interactions;
4. Observations of parents' support networks;
5. Focus group interviews with professionals.

The breakdown of fieldwork is reflected in the following tables:

	No of Families		Interviews		Observation		Professional Focus Group
	Retr o	Lon g	Retr o	Lon g	Retr o	Lon g	
<b>Newcastle</b>	8	4	28	12	13	12	3
<b>Sheffield</b>	15	12	18	35	2	28	3
<b>Total</b>	23	16	45	46	15	40	6
<b>Overall Total</b>	39		93		55		6

Where 'retro' indicates retrospective parents and 'long' refers to longitudinal parents

The ethnographic approach adopted for the study encouraged the researchers to immerse themselves in the lived worlds of the parents and their children as much as possible. This was established from the earliest point of contact with each family through initial meetings prior to consent, and re-negotiated throughout the duration of the research. This meant developing methods that 'fitted in' with families' interests and preferences, while ensuring any issues raised could be followed through, in depth, in subsequent fieldwork. Much of the nature and pace of the research was established through initial contact with each parent to discuss ethical concerns and practicalities associated with participation. The emergent relationship between researcher and those being researched was constantly reinforced and renegotiated as the fieldwork progressed. As such, they were able to develop a research context that allowed the parents to speak openly about their situation and perspective, without the risk of loss of support, in a context negotiated very much on the parents' own terms. This relationship was further enriched through the active participation of families in the analysis as it unfolded. This included open invitations for parents to see and keep copies of data being produced (such as interview transcripts and observation notes), and then reflect back on and review how they were being represented in the research.

## **Findings**

Through the commitment of the researchers and the involvement of the families, our study has uncovered a number of key findings which are of relevance to policy makers, professionals, parent groups and researchers. A number of these are presented in this document:

- (1) medical practices
- (2) gaps in service provision
- (3) parental priorities
- (4) professional practice
- (5) enabling care

These analyses complement those developed in other writing and outputs of the research team (see <http://www.shef.ac.uk/disabled-babies/> for more details).

## **(1) Medical Practices**

### Rethinking diagnosis

Issues around diagnosis came up over and over again during the fieldwork. Diagnosis, the identification of a condition or illness by recognising signs and symptoms, may seem like a straightforward scientific procedure. Once a child is presented to a medical specialist, tests should reveal the nature of the condition, and a diagnosis can then be made. However, medical knowledge is not static, nor is it uncontested and, even once a diagnosis has been made; questions often remain unanswered about the child's future development. We, therefore, engaged with families of children diagnosed with a broad range of conditions, but also some without a clear diagnosis, and several who were given diagnoses and prognoses that changed over the course of the fieldwork.

Diagnosis is often experienced as a process rather than a single, one off event. As such, it may occur over time, and often in stages. Some parents have described this as feeling like they were drip-fed information, while others spoke about being given extreme possibilities one day which are then retracted soon after and replaced by alternative and at times contradictory information. Furthermore, diagnosis is often inconclusive; hence uncertainty may remain over the long term. This inevitably has implications for the way parents view their own future and the future of the child, but also affects their immediate situation. For parents such as Gill and Sam, this was seen very much as a constantly shifting set of possibilities dependent on several interconnected sets of variables.

Gill: [The geneticist] is ninety-nine percent certain. He says she can still fit in others, but he said the face actually just tells him that it is that. So he's leaving it until she's two before he sees her again, because he said then, 'you would literally walk into the room and I would go, it's a hundred percent'... We went on the internet, had a look at, [pause] because he was so certain, I looked on the internet, had a look at what, what it was all about... So it's sort of like I know what I'm dealing with, I know what's expected... But [the geneticist] said it can vary from a child that never learns to read or speak, to they know of one who's actually gone to university.... it's like any other child really. I mean you don't know [laughs] when they're born

whether they're gunna have special needs, learning difficulties anyway.

As Gill's comments suggest, even though they had waited over a year for a diagnosis, when it did eventually come it was nevertheless shrouded in uncertainty. This uncertainty was located partly in medical knowledge and practices leading to an inconclusive diagnosis from the geneticist who could not give them a definitive label for Lauren's condition until she reached an age-related stage in life. But even once this was resolved, potential outcomes for both them and their child remained unclear until Lauren developed further. This in itself did not necessarily mean added pressure (though that was a very common reaction by other parents) and, as revealed in this example, could be seen as a reassuringly 'normal' feature associated with all children.

One of the main concerns for families trying to manage this uncertainty was the importance of consultants responding to their personal circumstances and needs. For some parents this meant being given honest information from health professionals, even when that might mean nothing could be firmly substantiated. For others, the experience of being given a succession of multiple and changing diagnoses left them worn down and frustrated. Parents' views change over time and in different situations and it is difficult for professionals to gauge parents' responses. Some parents resisted medical labels for their children, while others sought diagnosis and wished for a feeling of control of that process. Parents generally looked for honesty and openness from professionals as well as wanting them to consider wider implications of information, or lack of it, for families.

#### Changing context around the child and family

Diagnosis, then, does not occur in a vacuum and neither do any of the care, support and information available to the child and family (McLaughlin 2005). Taking context into account allows us to consider the individual and changing circumstances in which information may be received. For example, issues of concern around the child may have been raised over time, in some cases over a number of years, which is likely to add weight to circumstances around diagnosis when even a few hours or days may feel like an eternity for parents and carers, and, of course, for the child who is often very aware of increased tensions. A variety

of factors influence how parents are respond to a diagnosis. These include social and family dynamics, cultural influences as well as the assumptions and knowledge that parents and others hold about the child.

A range of social factors influence the ways in which people experience the diagnosis process and engage with medical practices. For example, a common factor for mothers in particular was to have those around them, both others in the family and medical actors, reject their concerns over their child's development, for some time before a diagnosis was provided:

Jane: The last time I went up, by this time we'd had the holiday and it kept stewing in my mind, I don't know what other people go through, but what I found any way was Jack [husband] just didn't want to see what I could see, so it was a constant battle where I was keeping being the only one, actually soundin' like being obsessed about it, and he just, he just didn't really, I don't know if he was just avoiding the subject.

The ways in which parents', particularly mothers' concerns were discounted so easily by others is influenced by social assumptions about over protective mothers who are 'neurotic' about their children (Landsman 1998). In contrast, as discussed below, parents can often have unique and undervalued knowledge of their children, which can add to the process of medical diagnosis if valued (McKeever & Miller 2004).

Medical practitioners are often influenced by assumptions they make about parents' capabilities and expertise. Parents who are perceived to be educated or medically trained are judged as able to cope whereas parents who are perceived to be from marginalised backgrounds are judged as less able to cope. These stereotypes are unhelpful for parents and professionals. Indeed at times, assumptions made about families serve as barriers to diagnosis, appropriate medical care and positive parent-practitioner relationships. A particularly stark example of this occurred over an Asian family whose baby was diagnosed as having water on the brain only after a family trip to Bangladesh. When concerns had been raised with both doctors and health visitors in the UK the family was told there was no problem and that, instead, big heads ran in their family. It was clear that the

family felt institutional racism in their case had got in the way of an appropriate and much needed diagnosis for their child.

### Alternative approaches to diagnosis

Both parents and professionals often used words such as, 'shock', 'grief', 'uncertainty', 'having to coming to terms with it', to describe their reaction to diagnosis. But there were also more positive words used by some of the parents to describe the impact diagnosis had on them such as 'relief', 'made sense', and 'helpful'. Indeed, diagnosis was not always experienced as receiving 'bad news' at all, and some parents marvelled at certain professional's apparent assumptions that this would be the case. For example, one parent described how a paediatric consultant, on telling the family their newborn baby had Downs syndrome, fled the scene immediately after as if he had been responsible for a major accident and did not want to face the consequences. The consultant's apparent discomfort around the condition was more shocking to deal with for the family than the information he was telling them. They were left having to come to terms with the diagnosis, but also with his behaviour and, perhaps just as importantly for the longer term, what that suggested about the nature of the condition.

When it occurs, diagnosis is experienced differently by each parent and carer involved with the child. It is clear that the time of diagnosis is a very sensitive period for families and that professionals have a key role to play. Often, as in the example below, when parents described the process of diagnosis in a positive light, it was when the professional had been as honest about what they did *not* know as what they could state for certain:

Jemma: So my mother said 'how much can Rosy see?' I said 'well I haven't been told'. So the next time I went and saw [the consultant] I asked about how much he thought she could see? And he said, 'well I do not like to tell parents what I think their children can see, because if I tell you she can see 30%, in seven years time we might turn round and do an eye-test and she can see 70%. I'm not going to give an opinion, I don't know. Until *she* can tell us, I can't tell you.' So I thought well that's fair enough, that's, that's fine, you know I would rather accept that than he'd said something else, that's fine by me. She can see a lot more than they think he can, definitely.

### Parental expertise and knowing parents

Parents have expert knowledge of their child, and there was some suggestion that this is increasingly acknowledged by professionals both from the parents' own accounts and also from the focus group research with professionals.

Maria: He [paediatrician] said himself that he's amazed how the communication is, what every single one of the professionals have said to me [is] - the communication is brilliant between me and Luke.

Educational psychologist: In my experience anyway a lot of parents that I've worked with had learnt an awful lot about their child's condition, but then they come up towards school as a whole new body of stuff to be learned. And some parents in my experience seem to cope by becoming absolutely expert on everything and having a far higher level of expertise than anybody that's trying to support them. (Focus Group)

Despite the diversity of the parents and children in this study, they shared common experiences. All the parents felt that they had faced and were continuing to face a steep learning curve. While some parents felt that they needed to develop 'expert' knowledge about their child, all parents felt that they had to learn about how the varied health, welfare, and education services operated and behaved. As one parent said, '[at first] it is like you don't know the rules of the game,' (Jane). Parents regarded other parents as key sources of information. Parents were constantly reviewing how they saw themselves and their children both now and in the future. Many parents were in the process of becoming experts in accessing appropriate support, and in learning what to expect from professionals in their different roles. Sometimes this led to parents re-considering their place and their children's place in society, prompting the parents to consider more fundamental questions about their own values and the wider values of society.

### Summary

- Diagnosis is contested and negotiated by parents and professionals

- A child's impairment, condition or healthcare needs are phenomena that change over time, subject to medical treatment, family input, professional and societal opinion.
- Professionals need to develop alternative approaches to diagnosis which are responsive to the needs of individual families rather than always approaching diagnosis as breaking bad news.
- Parents have sophisticated knowledge of their children, which they have built up from a wealth of different resources and experiences.
- The study shows the importance parents place on their relationships with other parents as sources of information and support.

## ***(2) Gaps in Service Provision***

Services, from across social and health care, play an important part in the experiences of families with a disabled child or children. Sometimes parents can feel overwhelmed by the number of people coming through the front door, at other times they feel left to fend for themselves. Parents spent a great deal of time discussing their experiences of receiving 'support'; what came across was a reality of service fragmentation, inadequacy and inequality. Currently a range of policy and legislative changes, in particular the *National Service Framework for Children, Young People and Maternity Services* (DfES 2003, 2004a, 2004b) *Removing the Barriers to Achievement: The Government's Strategy for SEN* (DfES, 2004c), the *Children Act* (HMSO 2004) and *Every Child Matters*, are being implemented with the aim of providing responsive and coordinated care, within a stated model of inclusion and recognition of difference. The problems raised by the parents reflect the level of service and cultural change required if the values laid down in the policy initiatives are to be embedded in everyday practice and to what others have identified as some of the limitations to the practices being put in place (see Williams 2004).

### Inadequacies in service support

Parents felt they had little say over what provision was offered by social services and education (a problem that often led them to become advocates for their children). This involved areas such as Statements of Special Educational Needs, the provision of support

within education, the identification of care plans and care assistance or respite care.

Within social services provision there seemed to be a lack of clarity about what was offered, what its purpose was, how much would be provided and why, at times, it would later be removed. Support that seemed to be working and making a difference to their lives could and did easily disappear:

Sarah: ... they provided the care worker, the same care-worker, and she was lovely, she really bonded with the children, the children bonded with her - Katy and Jenny thought the world of her, and then suddenly they just phum, stopped. Just, they told us, she's no longer a care-worker, she's now a crisis worker and you're not in crisis.

The withdrawal, without warning of this worker, was not only traumatic for the parents; it was highly upsetting for the children. In the last phone call with the withdrawn worker the child asked to speak to her and in the words of her mother said:

Sarah: 'why aren't you coming? I will be a good girl I promise I'll be really good'

Inflexibility of service provision often means in reality that parents are faced with a Hobson's choice - one offer, which although inappropriate to their needs, is the only option put forward. When one mother with a baby just diagnosed with a visual impairment went to social services for help, the response (in her words) was:

Maria: We don't have a social worker who deals with the visually impaired and the blind because there are not enough of them here. So we'll send along the one that deals with death.

Offers of support parents do not believe are appropriate, in a context of no negotiation, encourage distrust between provider and parent and can lead parents to decide to withdraw from service support:

Sameera (via an interpreter): I feel it is too much hassle when I ask for help, they don't listen, and nothing

happens...they offered to help by taking my son to school... however this just did not work for me... He didn't want to be seen to be different from the other children, and I was worried about potentially losing contact with the school. This contact is really important to know how my child is doing, and what is going on in school, and it is a good time to be with my son, a chance to bond with him and talk to him outside the home. So, because this was not suitable to our family, they would not give me the sort of support I wanted, and no alternative was offered. They did not take into account my needs.

The family above experienced another problem with service provision, which was shared by all the other families for whom English was not their first language. This is the issue of the availability of interpreters; although required in law, in practice interpreters were often not present in a range of service settings (with healthcare being cited most commonly):

Sameera: I can talk alright when it's about ordinary day-to-day matters, but I can't say important, sensitive things properly. This is my problem. Unless I have an interpreter I don't feel happy about them understanding my perspective. I believe I could not get the subtleties in information across to professionals so my meaning is lost and they don't appreciate my full point of view.

What has been identified as the postcode lottery of care has been echoed in this research (Boseley and Hall 2006; Bungay 2005). Parents found that a move down the street, into a different local authority, can either increase or decrease the form of support available:

Gill: We're looking to move next year and we already know that we're going have to stay in this area to get everything that Lauren's getting, because if we moved few miles that way or a few miles that way, I know that if I'm headed back over to the next area I wouldn't get half as much as what Lauren's getting which is a damn shame, that it changes from authority to authority, but that's the way it is.

Service fragmentation, commonly a result of the unclear boundaries within and between different service providers, is one of the biggest hurdles to effective care. For parents, particularly when they are first coming in to contact with different agencies, the different responsibilities, rules and procedures across different providers operated as a key barrier to support and made their participation in decisions about their children more difficult. In our focus groups with professionals there was recognition of this problem:

Parent Partnership Officer: ... when they are back home [after the baby is released from the hospital] they're in the community, they suddenly realize that by and large they are the people who co-ordinate in each area... you are going to have to talk to housing and you are gonna have to talk to other people who are administrative people who have systems, who are doing their system the way that they should and cannot understand why you would have a problem in understanding it's gonna take eighteen months to do it...

(Focus Group)

The gap between what is offered and what the parents feel their children need leads to parents subsidising provision from early on from the birth or diagnosis of their child. They buy books and videos to aid with learning makaton, they pay for adaptations to their home, they get loans out to get the appropriate pram or car, and they search out alternative provision, approaches and equipment via the internet, sometimes travelling far to access facilities and provision only available privately or via charities. When they do this, it is not always experimental treatment or expensive equipment they are discussing; many of the things they have found unavailable are everyday things that they feel will make a difference to their child:

Debbie: It is me who's had to check on the internet and check if there's anything, because there was only two suction machines that the health authority here would sanction to buy. But I still know there must be a small machine somewhere. And actually on Saturday night I checked the Great Ormond Street website... So at some point I'll be

writing a letter them and say, could you give me some advice on what other suction machines might be available, type of thing. So it is, it is me who has to do stuff rather than being told.

Parents often highlight what they see as the minimalist support they get to help them. One family had four hrs of respite a week, but were told this was under review; their assumption was that the review would lead to withdrawal of the support. Often parents felt that support for them would only appear when they reached breaking point, rarely was it provided as an every day resource which would ensure parents did not reach that point. For new parents dealing with the uncertainty and anxiety of a sick baby requiring treatment and support, there seems little proactively offered; instead the common theme is: "I mean for the first four months it was practically like you're isolated". (Gill and Sam)

The Children Act (2004) seeks to address many of these problems by providing a legislative, financial and organisational context that allows for the different services involved in provision for children in need to work across existing boundaries and monetary constraints. Crucial to this is the setting up of Children's Trusts to integrate the work of different groups and streamline accountability (Mallett 2006). Given this research was taking place as these new initiatives were being put in place we cannot say what a difference they will make. From the perspective of parents in this research there is clearly much for these new policies and legislative frameworks to address.

### Thinking differently about children

Disability writers have long argued for professionals to work with disabled people in a way that acknowledges the person and their context through a gaze not just informed by the impairment that person is deemed to have (Deeley 2000; Oliver 1990). As part of this work the disability movement has, for some time, drawn a distinction between impairment and disability. 'Impairment' refers to lacking some part of or all of a limb, or having a defective limb organism or mechanism of the body (including 'learning disabilities') whereas 'disability' refers to societal exclusion of individuals with impairments (UPIAS, 1976). When professionals, or others, speak of a condition as a personal tragedy and fail to see the social sources of disability they are said to be working

within a 'medical model' of disability. It appears that a medical model of disability continues to prevail in much of service provision, across the different areas of social services, health and education. One particular source of difficulty many of the parents experienced relates to assessment of their children, particularly in relation to disability living allowance and statementing in education. The assessment process frames the child in the negative, as lacking, in ways that refuse his or her humanity and the efforts of the parents to build a positive identity for their child and their relationship with them:

Maria: She said, 'he has quite, quite a lot of things you know wrong really hasn't he'? I said 'well what'? And then she started firing off, 'you know he's not toilet trained, and he has this, his sleep pattern's really bad, he has disturbed sleep pattern, he also his safety, his safety is a big issue because he has no fear, he also is very small for his age,' she said, 'his speech is behind,' and she was just rattling all these things off, and it's something like I never thought about really, you know and I thought well everything she says is right, which is something I said to her, it's something I didn't even think about. It's just Luke's Luke you know, it's to me they weren't negative things you know. I said it's just something that I deal with every day that I didn't think it was that negative really you know until she pointed them all out to me.

Viewing the issues the child faces in a framework which is **not** targeted towards finding the negative, requires time and space, getting to know children enough to have a broader picture of their needs and interests. Instead parents feel that across health and social care many times, their child is a condition first, a person second. A view that often was associated with GPs who appeared unwilling to look beyond the condition in order to see the child:

Angela: I mean the GPs are a major bugbear. They just look at Harry, see he's autistic, and they don't see past that.

When the condition and its associated negativity dominate it is easy to view disabled children as a drain on resources, as simply inconvenient:

Jane: ... When the head teacher down at his school wouldn't get somebody in to do one-to-one with Jack, she wasn't advertising the post until she knew she was going to get the money from the LEA. I actually phoned up the LEA and said, 'Well how can I make her employ somebody?' And they said, 'Well, we can't, we can't do anything.' And I said, 'But we're stuck in the middle, you know, you, you are saying this is what she should be doing,' I goes, 'and she just is going off and doing her own thing, we're the ones that's stuck in the middle with everything going wrong.' So it just seems as if it's getting worse and worse. I mean I hope things are going to settle down, now that's he's not like a drain on resources if you like.

In the healthcare and social services arena, professional knowledge and understanding of children seems to emerge from two sources. The first is via records:

Jane: You almost feel it's like a matter very much of the time they've got, like they've got so many children to look after. I mean they come in with their files and you can see his name on and his date of birth, and it's just like they've plucked out the file like ten minutes before they've come to the meeting, you know. They're not going to know him; they never are because they've got so many kids to look after.

The second is via asking parents to once more tell the story of their child's life, and focusing that narration on the medical and negative aspects of the child. While there is an inescapability of the need for records and repeated stories to communicate what is happening to the child, the danger is that what are often recorded and asked for from parents is a narrow representation of who the child is. When the records or repeated stories replace or are given priority over getting to know a broader vision of the child and their place in the world it is easier to make quick and formulaic judgements about what are their needs and what is their future potential.

Some professionals are able to create a positive relationship with the children they care for, through which they are able to move past forms and labels in order to capture the broader person they are working with. The difference this makes is clear to parents:

Jane: When he was at nursery at Waverly School the teacher and the nursery nurse there were brilliant but they both left within about a month of each other for one reason or another, and the two that they replaced them with just didn't have time for Jack at all, they just, I think they just thought he was a naughty boy. He, he couldn't do anything so what was the point in him being there... if we went to his school review meetings they virtually rattled off a list of things that he couldn't do and never said a thing about anything that he could... but in this school they just seem to have really small goals and they're all achievable, you know rather than sort of setting things like, he's got to be able to sit on the carpet for forty minutes there's no need for him to be able to do that but his reading skills and things like that are really, they're above average for his age which is great.

#### The loss of trust and its consequences

Parents often talk of particular service providers who they no longer trust and seek to avoid or replace. Loss of trust occurs for a number of reasons. First, parents talk of times where they have been misrepresented in meetings. One mother found out that after trying to speak to an agency service provider about the lack of respite care they were receiving that stories were going round about her being disruptive in the office (something she completely rejected):

Sarah: That evening someone phoned me and said, 'are you alright?' I said yeah, I said why do you ask? She says, 'oh because I've heard you went to our office today and you were raving and ranting at the manager's staff'. I said 'I beg your pardon'? She said 'oh yeah, the manager said that you were raving and ranting and you were shouting at everybody and you slammed the door and said bloody Sure Start.' I went, oh god. I said 'I'm going have to sort this out because I didn't'. And even if I had, I don't think she should have discussed it with anybody.

Second, trust declined when, often repeatedly, promises of help did not materialise. The family below had been assessed by an occupational health specialist who agreed their house was unsuitable:

Karen: We were awarded five hundred points by occupational health, which is the maximum points anybody could have. She said, 'you're the family with the top most points, so you should get a house within no time.' We waited, months went by, nothing. We kept phoning, I was phoning everyday, everyday, 'please, please, please, this is getting severe, it's getting dire, please help us, you do have houses we know'. One of the councillors from our area phoned me and she says, 'oh there was a house, four bedroomed bungalow with front and back garden, did you not get it?' No... The house went to some other person. The reason why was because although occupational health had allocated us five hundred points, nobody had put them on the computer, they were sitting in a file.

This failure to follow through on ensuring their housing needs were addressed created an irreparable breakdown in trust with the social worker who they blamed for not ensuring the housing information was forwarded correctly. Months later their view of social services was now:

Karen: don't go near social services. Go get yourself a chocolate fireguard; you'll have much more fun.... That's my advice, because they are helpful to a point, whereas the majority of us want that point. Not even want but need I would say, because want and need is different, I want to have a big, big, big, big, house and I want lots and lots and lots of things. What I need is just a little bit of help every now and again.

Once a negative experience has occurred expectations are low for what can be expected from others who subsequently work with a family:

Sameera (via an interpreter): I am disappointed with the social workers. They are not good at what they should be doing just good at messing things up. I've had some satisfaction with the latest one. She's doing quite well up to now, but we'll have to see for the future.

The danger is that in the end parents with such negative experiences of services withdraw rather than have to work with people they do not trust and feel have let them and their children down. In contrast a service provider able to listen to parents, respect their knowledge of their child, who is able to work round the inflexibility of the system can be a source of trust and positive care:

Kay: We, I wanted a wheelchair for Joe when he was about two and a half, and there's this stupid rule apparently, you're not allowed one until you're three, and she said, 'well we're not supposed to, explain to me why you need one.' So I showed her what Joe was like in our normal pushchair, hanging out the side. And she said, 'fine, I can understand that, I can't promise anything but I'll see what I can do.' Um, and went away and said, 'Well, you're not really meant to have it but I've got you one, and here it is,' and it was great, fabulous.

#### Secrecy around decision making

A distinctive element in the generation of mistrust lies in the secrecy parents experience around decisions about them and their children. Often important meetings around diagnosis, care plans and the process of issuing a statement of special educational needs, occur without representation or presence from families, sometimes even without parents being aware that such meetings were taking place:

Jane: on two occasions I phoned up and said, 'I believe you've just been discussing my son this morning, and can you tell us what's happening.' And the first thing both times they said was, 'How did you know the meeting was today?'

The professionals in the focus groups acknowledged the problems around lack of involvement and disclosure; while the policy shift is towards partnership with parents, in many areas this is still lacking and requires a broader culture shift in practice:

Play Worker:... I saw one parent who was absolutely furious, she was getting loads and loads of support but she also had a social worker that she automatically got when she had the baby, but she had never met this social worker

and it was the final straw, they were getting all these details about her child yet she didn't even know who this person was, which really upset her and in the end she rang up and goes, 'can I just ask who you are? Cos you know all about my child but I don't know you'.

Secrecy around decision making is followed up with a general level of secrecy about service provision itself. Word of mouth through other parents or professionals who also have disabled children in the family can make a big difference in knowing about equipment, entitlements, etc. Parents often talk about coming across such information by chance. Provision such as care support, disability living allowance and direct payments are a challenge to acquire and often something parents come across by accident, usually in conversation with a parent in a similar position. One parent put it succinctly: 'services are kept secret' (Kay, 3<sup>rd</sup> Interview). The role that parents in many cases play is that of the individual consumer having to seek out resources and support, once considered universal entitlements in the welfare state (Lister 2001). This shift in role and balance of responsibility towards individualisation brings with it increasing inequalities, as some fare better than others in the consumer market of care due to material resources and social and cultural capital (Lupton 1999).

### Summary

- Parents generally struggle more with coming to terms with gaps and fragmentation in service provision than with the 'disabilities' of their children;
- If 'every child matters' then professionals need to think more positively and openly about disabled children;
- When parents lose trust in the services they receive, it is difficult for other services to rebuild that trust;
- Parents still experience secrecy and lack of information around decisions made about their children.

### ***(3) Parental priorities***

Ethnographic work with parents has allowed us to identify a number of recurring priorities and experiences. In terms of parental identities and practices, a number of key issues emerge including the type and quality of support networks, the broadening of the

care role, how competency is (re)viewed by others and parenting as becoming. Participants have demanded that we ask broader questions about bringing up a child in a disabling society.

### The extended caring role

Our work with parents has highlighted Traustadottir's (1991) concept of the extended caring role of parents – especially mothers – of disabled children. On the one hand, caring can be extremely hard, tiring work that limits the mother in pursuing other roles and activities. One parent, Emma, for example, was unable to return to work because of caring responsibilities for her daughter with severe brain damage and epilepsy: a factor which has obviously had economic and social repercussions for her. On the other hand, caring can provide opportunities for more flexibility than the traditional mothering role, extending the caring role to embrace activities that are much more akin to a professional career:

When we rush from one part of the hospital to another, Emma gets out her phone with internet link and looks up clinical terms so she can stand her own with the professionals (ethnographic notes)

While there are clearly questions about the quality and form of knowledge available to parents on the internet the very fact that Emma uses this resource demonstrates her willingness to go beyond more tacit and informal forms of parental knowledge. She is preparing herself in readiness for a professional encounter:

Emma: I took Ashley into hospital. She'd been having loads of fits. It was just dreadful. They put her on these drugs which knocked her out. She didn't open her eyes for three days. They were just saying, 'right, we'll administer this drug again'. It stopped her fitting but wiped her out. I eventually snapped at the doctor. We spoke about the dosage. He looked again at the dosage, gave me permission to administer the drugs at home and we spoke about increasing dosage if the number of fits started to creep up. When this Dr was away on holidays I spoke to one of his colleagues who was concerned about me being responsible for the drugs. So I carefully took her through my thinking about increasing half a ml here and there, when needed. She told me off for doing

it. For increasing amounts. But when my Dr returned he said I'd done the right thing.

Emma clearly demonstrates her rights as an informed parent and knowledgeable recipient of the interventions of medical professionals. We are reminded that while many disabled families experience forms of exclusion, marginalisation and poverty, this does not automatically correlate with a lack of knowledge or confidence in seeking the best care possible for their children:

Tom: If you fell over, even though I have a First Aid badge, I wouldn't be any help to you. But if you were ventilated like my son is, I can help you. I can't do blood and broken limbs but I can do ventilation which terrifies a huge tranch of heath professionals, let alone social care professionals. Once, a paramedic has been in my house with my son who has ventilated and couldn't cope. With me doing it, he was in safer hands.

Another element of this extended caring role involves mothers seeking various forms professional and social change on behalf of their disabled children. This is crucial as it seems to expand further the notion of extended caring from pseudo-professional knowledge to advocate:

Tom: There are lots of members of my family who I have worked with, spending a lot of time listening to their worries and concerns. But, I'd much rather talk to a stranger because I'm hoping I'm contributing to some change.

Tom's clear vision of informing others outside of his immediate locality was a view shared by many parents in our research. Indeed, we were often welcomed by parental organisations who saw the need for more parent-focused research in this area. Promoting parental discourse is important, particularly when parenting experiences can inspire different and innovative ways of thinking about disability, impairment and childhood:

Linda: I would be happy to have another autistic child. They are lovely kids. They've really taught me something. They've taught me to look at people in different ways'.

Lisa is such an avid internet user. She is a major player and administrator in a virtual community for parents of premature babies. Within this environment, she is protected from the usually inadvertent insensitivities that can characterise her interactions with her parents. The tone is celebratory, all the 'premies' (premature babies) photographs are there to see and amongst all the informal advice that is given and received, there's plenty of scope for fun. Interaction between the parents is invariably supportive and parents can control just how much they engage with the community (ethnographic field notes)

These understandings of children and childhood are, of course, common to all families as parents and kids get to know one another, over time. This recognition of the shifting, negotiated and moving nature of parental knowledge contrasts markedly with the certainty of medicalised discourses associated with impairment and disability. The key priority for parents relates largely to their own knowledge base being taken seriously by professionals and being used by other parents.

### Becoming parents

Related to the above point, parents' understandings of their children evolve and change in a variety of ways. Some mothers saw their child's disability as not their greatest concern. Having enough food and a home were issues of more immediate concern (see also Traustadottir, 1991, p219). Others questioned the importance of the label and diagnosis:

Jen. When our boy was born, he was labelled with Down Syndrome. It wasn't a major disaster for us.

John: It just puts a different slant on things doesn't it?

Jen: I was on morphine at the time so wasn't taking much in anyway?

Jon: there were so many flowers that day, weren't there.  
(from an interview with the new parents of a baby boy).

The notion of parents' roles and perceptions as becoming is a key point of analysis in some of the writings of the project team (Fisher and Goodley, in press; Goodley, in press):

Rebecca: You see, I can't keep chasing the normal. I mean I've done so much to try and make my son normal but I can't keep that up ... I need to accept him in the ways that he is and just enjoy them and him. I must stop pressurising myself).

Rebecca's account is important because it stands in opposition to ideas about rehabilitation and cure that abound in many professional contexts. Her account demands us to think around ideas such as diversity, acceptance and difference:

Tom: I use a slide when I'm presenting saying "I'm going to give my son the label that will help you understand him more and understand who he is" and I put a slide up and it's called Tom Cross – Monkey Boy, because that's what we call him at home, you know, "you're a monkey", he is, he's five years old and he's so funny. He's non-verbal, has very limited physical movement ability below his shoulders – but he's just ... a tease.

For some parents becoming might be associated with uncertainty. Often, in the related literature, uncertain parents are presented as being in denial or lacking the awareness to 'properly' accept their children. In contrast, a number of parents have reminded us that uncertainty may promote openness to new ideas and locations. For the feminist philosopher Rosi Braidotti (1994, 2006) this is a crucial element of consciousness and subjectivity in the 21<sup>st</sup> Century, which she terms 'nomadic thought'. This refers to the kind of critical consciousness that resists settling into simplistic, often professional owned arenas of thought and behaviour. Nomads, instead, find themselves in different locations and lands (see also Bayliss, 2006; Roets, 2006; Goodley and Roets, forthcoming):

Rebecca: I have this booklet written by the mother of a special needs child. It's called Welcome to Holland. She talks about the wonderful dreams we attach to pregnancy, birth and having the child and likens it to going on a journey to Italy. It's what you've always dreamt of, you get on the plane and you're all excited. And then you get on this plane after a couple of hours later or whatever, you've now landed in Holland. And you were expecting this fantastic place, Italy, and you're just so disappointed. But if you look carefully and

don't let go of Italy you'll see the beauty that's in Holland, the beautiful tulips, the canals. It will have certain things Italy may never have. You'll meet people that you wouldn't meet if you were going to Italy. And you might not get Italian wine but, hey, they've got some really beer in Holland.

This notion of parenting as a journey into and within particular locations and communities raises questions about the quality of relationships.

### Networks of support and exclusion

Cheryl: My Danny is ... how do you put it? Wild. I used to go along to this nursery with him when he was little boy. It was held in my local library. There was a woman taking the register, a sort of committee and a list of rules as long as your arm. It was very cliquey. During coffee break, I was told by one of the other mothers that during coffee break 'we like the children to sit quietly at the table over there'. Then during sing-song time, all the kids were expected to sit cross-legged on the floor. Totally not Danny's place! You know that you and your child are not up to doing that sort of thing. But, if choose to give up at the first hurdle – thinking he just won't fit in – then you've given up. So we persevered. And when he was ... well, 'being Danny', I didn't get involved, I just let it fly over me and I'm thinking, 'no, I'm not letting that do us'. And so he went on. And they watched. And they watched.

Parents of disabled children often view their offspring as part of a whole rather than someone who has fragmented that whole (see Bogdan and Taylor, 1987; O'Conner, 1995). In contrast, many informants of this study experienced other people (including other parents) as difficult, exclusionary and, at times, confrontational:

Cheryl: I was in the supermarket and Danny was playing up. I told him that if he wasn't to walk nicely then he could sit in the pushchair. So in he goes and he's kicking and fidgeting and testing all the boundaries. Suddenly, this man came over to him and said 'now you just stop that' and points his finger into Danny's chest. I went berserk.

Many parents bemoaned those recurring times when their disabled children were not invited to the birthday parties of other children. Exclusion occurred even prior to formal education. Unsurprisingly, anticipating such responses, parents opted out of parental contexts that in a more enabling world might provide necessary networks of support:

On a later date, I observed a speech therapist with Jack and Lisa at home. The therapist was encouraging and supportive in her manner, suggesting on several occasions that Lisa and Jack should join a mother and toddler group. Lisa seemed relatively unenthusiastic about the idea and explained that she was worried that another child might pull at Jack's feeding tubes. After the speech therapist had left, Lisa confided in me that she would prefer to take Jack to Portage rather than have him attend a mainstream toddler group. She inferred that it would be painful for her if other parents commented on Jack's slightly delayed development compared with his contemporaries (ethnographic field notes)

That parents are prepared to pull their children out of exclusionary contexts raises huge issues associated with childcare, schooling and leisure activities. Too often parents experienced forms of alienation in mainstream contexts.

### Parental competency

We found many professional assumptions about the competency of parents. These assumptions are tied to long held beliefs and institutional knowledge, highlighted by a focus group in Sheffield:

Professionals ranged from information worker, community nurse, and specialist practitioner in Asperger's Syndrome. When asked about the ways in which parents made sense of their children and diagnosis, parents were pigeonholed into denial (the most prominent category), acceptance (which seemed to include acceptance of the professional role), professional parent (a problematic subject position where parents build up their knowledge of impairment labels often via the internet drawing upon, in the professionals' opinions, spurious information). Research notes from a professional focus group of health and social care professionals, 2005).

Early relationships with significant others – such as professionals – often lay foundations for a family’s engagement with services and support. Key to a good relationship is the professional assuming competence on the part of the parent. To reiterate a quotation from earlier:

Sofia: My consultant actually listens to me and he actually makes a note of everything I say. He takes in what I’m saying, positive or negative. Had he not been that responsive, I might have been quite negative towards him. As a parent you see you need to grab on to something that gives you a bit of hope. He was my pathway, my manual to this new world, this different planet

Listening to parents is a phrase we came across time and time again. However, how parents are listened to and by illuminates questions of tokenism or meaningful participation.

Tom: We had the deputy head teacher saying to us the other day, “I think your son might have problems with his eyesight”. The carer told us that he was bored with what he was doing so he was giving her the wrong answers with his non-verbal communication to a computer package but she didn’t see him laughing. She was interpreting the wrong answers so he can’t see the screen, the carer was watching him just laugh when she was getting a bit frustrated, whereas because the carer had been doing the same package with him for the past 20 minutes – and he was getting all the answers right.

Listening carefully to parents relies upon a view of the parent as willing and able. Professionals therefore must resist forms of knowledge and practice that formulate limited views of parents and their disabled children.

### Summary

- Parents are engaged in long-standing processes of negotiating, brokering and fighting for the rights of their children
- Parents occupy roles that are constantly evolving and ‘becoming’
- Parents often make use of their own parent support networks but these do not always present positive perspectives on living with disability

- One barrier to the inclusion of disabled children, experienced by their parents, is the (perceived) prejudice of others in society, including other parents
- Parents of disabled children are often expected to achieve levels of parental competency that are not always expected of parents of non-disabled children
- The treatment of disabled infants is a key part of the process of inclusion or exclusion of disabled children from mainstream life

#### ***(4) Limits and opportunities in professional practice***

Work in the health, social care and education sectors is often frustrating. Parents empathise with professionals. Many professionals were clearly working with the best intentions. Too often, though, long held beliefs seeped into ways of working, limiting professionals and parents. Simultaneously, both professionals and parents also found opportunities for working together towards enabling forms of care. In this section we draw upon the accounts of parents – and professionals – in order to interrogate positive and negative articulations of care of disabled children.

#### Deficit and capacity thinking

As mentioned earlier in this report, diagnoses from a deficit-thinking perspective, threatens to present hopeless prognoses. A group of professionals – aligned to a particular NHS Trust represented in our study – spoke to the research team of an informal / tacit policy being adopted in the local children’s hospital: that all Doctors should be accompanied by a nurse when diagnoses were being offered to parents. The reasoning behind this ‘policy’ was that many doctors could not be trusted in this process.

When Emma finally got the diagnosis from ‘Dr Dooms’, ‘he simply blurted it out’ and left the room. The nurse was left to pick up the pieces. As Emma put, ‘she was doing his job.’ ‘Dr Doom’ presented the bleakest prognosis – Cindy will never look at you, lift her head, nor cry. The experience of being told this, Emma explained, was devastating. As ‘Dr Doom’ used technical and medical terms, Emma gleaned little information from their transactions. Once he had left the room, the nurse would ‘translate’ what he had said into plain

English for Emma. This was something that repeated itself on several occasions. Emma explained that she came away from these interactions with the consultant 'feeling little.' At the local Children's Centre, Emma was referred to another consultant of whom she speaks warmly. Apparently, he avoids jargon and treats Emma as an equal (ethnographic field notes)

These stories mirror the findings of Lundebj and Tøssebro (2003) who report:

In our own research we have met parents saying things like: the heaviest part is not having a child with a disability, the heaviest part is how you have to *fight* the system (p2, our italics).

'The system' can also refer to systemic forms of either professional incompetence or disabling forms of professional practice linked to deficit thinking. In order to challenge deficit thinking, one hopeful route is offered by those who aim to work with the whole family associated with the disabled child. We are reminded here of Traustadottir's (1995) research on families with disabled children. She reports that the limitations the child brings to the family depend only partially on the actual severity of the disability. Parents tend to evaluate the disability in terms of the limitations it imposes on the family, and they describe the restrictions of the child's disability in terms of how much they see the child as restricting or limiting their family life. From the parents' point of view, the most important issue is for the family to be able to function as a unit. This of course raises issues about how the whole family is connected with professional contact and practice.

Soon after Cindy's birth, Emma had needed to find somewhere to live. She had been living with her parents but there wasn't room there for Cindy as well. Emma was offered a council house quickly, her position as a new mother of a baby with special care needs meant that she was a priority case. However, there was a major drawback as the house she was offered. It needed replastering on the inside and the high levels of dust that this would inevitably cause would be a serious problem for Cindy who has difficulties with breathing. Emma asked the Council if she could move into

the house with Cindy a week later than the official 'handover' date, explaining to me, "they told me at the hospital if she gets a chest infection she could die". Despite this, she was told "it's not our problem, you've got to move in this weekend or give your property up." Fortunately, Emma has an excellent social worker who managed to persuade the Council otherwise (story of Emma).

The matter of fact way in which the input of the social worker is mentioned fails to do justice to their efforts in working hard to support and keep the family together. Capacity thinking, then, shifts the focus away from the individual child and offers up opportunities for supporting the family as a whole.

At one point, Helen was feeling depressed. To provide her with support a nursery nurse came to provide her with company and to play with Roberto. The nursery nurse was of a similar age to Helen and was a great help in combating the feelings of social isolation. She was also able to teach Helen a few useful techniques to help her play with Roberto. Helen was not entirely clear whether the nursery nurse had been sent to help her in her depression and isolation or whether to assist her in developing appropriate skills to play constructively with her Roberto. Nevertheless, she confirmed that these visits had been useful in a number of ways: they had provided a certain respite, helped to overcome isolation and depression; and, had enabled her to develop good skills with Roberto (Story of Helen).

Opportunities for enabling care on the part of professionals are linked to the development of deep, supportive relationships. Indeed, many of the parents of our study were able to quickly identify those professionals who not only supported the family but also expressed belief in their capacities:

Sophia: We just parted last week. I cried my eyes out, honest to God, I was very emotional. Because not only has she been my physio, she's been my counsellor, my support. She's really advised me and helped me with a lot of things. There's so much she's helped me with. I'll be honest with

you, losing her is like losing a big part of my life. It's losing one of the main support mechanisms I've got. She's my confidante, she helped me with a lot of my immigration problems. She's supported my housing. She went with me to get my car.

The 'caring professional', for Holmes (2002), acts, relates and responds in human ways associated with caring, reciprocity, ordinariness, extraordinariness, intuition and empathy. Such a view of caring – assuming and promoting capacity – fundamentally questions the role and the construction of the 'professional'. As Nolwazi Mpumlwana, an African student of Speech and Hearing therapy in Durban, Republic of South Africa states:

I am human; I am one with you – and you are one with me. We all help. We all need to help. It is part of us ... and we should do this freely. I cannot set principles upon this helping ... If I set principles on the act of helping, then I would set principles upon my humanness. I would set up divisions in my mind that would separate me from others. If I did this, I would become truly alone ... This western thinking of yours is not concerned with being one with all others. It is concerned with *you*; with what you need, with your place and with your space ... Instead of giving yourself to another, you have created a monster and placed it in that dark division between you and all others ... It is called 'The profession' and it has already eaten you (Mpumlwana, 2000, pp535-536)

#### Paternalism and a sociology of acceptance

As Taylor et al (1995) have argued previously, professionals must learn to appreciate the expertise of the family and the significance of their fundamental bond. They must relinquish the role of expert and decision maker who judges what is best for each family in favour of forging a partnership with them and allowing families to accept and reject advice that is offered. In contrast, many parents spoke of the hierarchical relationship between themselves as parents/service users and professionals/ service providers:

Although confident and articulate, she described that her encounters with medical professionals left her feeling 'like a sixteen year old in a first job interview.' This sense of

powerlessness, quite alien to Sadie, was reinforced on a daily basis. Sadie expressed particular resentment towards the guarded language of risk assessment that characterises the reports of social workers. 'Sadie appears intelligent - she says that she went to university' or 'Thomas appears well looked after.' (Sadie's story)

Paternalism on the part of professionals not only undermines the foundations of a trusting relationship but, also, promotes blinkered assessments of parents.

Sharon told me that she felt 'policed' by the services. She had recently been visited by Sure Start workers. When they arrived, she explained, she appeared distressed because she had been peeling onions. The Sure Start people had left saying they would call at a more convenient time. In fact, they alerted the Social Services and shortly afterwards a social worker had visited the family. This had incensed Sharon as she had not requested support from Social Services (Story of Sharon).

Paternalism is, of course, never gender-blind. Service providers seem to have different views and expectations of mothers and fathers. The mother, who plays a central role in the caring work, is typically also the main contact person for the service providers. While service providers and professionals do not see themselves as having authority over fathers and are reluctant to put demands on fathers, they are less reluctant to pressure the mothers. They routinely demand a certain level of co-operation and performance from the mother, and most of them see it as their duty to influence what she does with her child with a disability. This raises concerns about the way family support services influence and control the lives of mothers who have children with disabilities (Traustadottir, 1999).

In contrast to paternalism is an approach to professional practice in which parents are view as resources and partners in the care of the disabled child. This positive image of the family links in with the an emerging body of literature that raises new questions about how families view members with a disability (see O'Conner, 1995 for useful overview). This perspective, which Bogdan and Taylor (1987) term the *sociology of acceptance*, focuses on families and individuals who have developed caring, loving relationships with

people who are seen as different by others. The sociology of acceptance is directed to the understanding of how people with 'deviant attributes' become accepted in individual relationships, families, or communities. In families, reasons for acceptance are often as simple as family membership: the family relationship supersedes the difference (Bogan & Taylor, 1987, p.36), and the relationship, not the difference, becomes the binding force. The sociology of acceptance views the family – based on sentiment and relationships – as potentially allowing for a very persevering and enduring relationship (O'Conner, 1995; p68). And in the family we explore the ways in which members work together towards acceptance:

June: All the family have had to learn so much about Rebecca and Chris, everybody took their diagnosis in a different way, my mum took it in a bad way, and said, they've got it wrong, she's just a little bit behind because she were born early, and she'll catch up. That was my mum's way of dealing with it, so I've had to give her a lot of books to read up as well, and she's Chris's carer, she looks after Chris for me at weekends, she cares for our Chris at weekends because Chris is more demanding than Rebecca, so I need more help with Chris.

### The privatisation of care

This project was implemented in a period of increasing marketisation of care and education in the UK. Much that is written about privatisation and the market presents a view of the citizen as passively shaped by the forces of globalisation and late capitalism, where users are now consumers, professionals providers and knowledge a currency to be bought and sold. Interestingly, parents pointed to some of the ways in which they sought positions and outcomes through active engagement with the market:

Tom: I'd rather be seen as a customer than a user but that word is.... it has like connotations hasn't it, you are a user of a system? Whereas if you're a customer then you expect that service to come to you a little bit.

Tom's account is interesting because he reminds us that parents are not simply consumers but also play an increasing role in the employment of particularly staff in the lives of their children:

Tom: We've just put an advert in and we're really pleased with it, for a new F Grade link nurse and some carers. And we wrote the first half of the advert and they wrote the second half, and the first half it reads like, you know, "there are many labels to our son, fun, cheeky, naughty, lovely.... and ventilated..." and we try not to let the last label rule our life.

Just as one might plan a bespoke holiday with a travel agent, Tom talks of working closely and specifically on the details of care required for his son: in ways that augment his son's humanity whilst identifying particular forms of required support. Moreover, as professional services enter the market, so to do other forms of knowledge. The knowledge of parent groups and more traditional forms of professional knowledge vie with each other. They are bought by parents at particular times, for specific reasons, with potentially informative outcomes. It is of course important to recognise the inequities of the market; some parents can be more active consumers than others due to class, status and location. Simultaneously, there are also examples of parents using the market in reflexive, considered and ultimately empowering ways.

### Summary

- A number of established and senior medical professionals must embrace alternative models of impairment and disability that challenge 'deficit thinking' about disabled children
- Just one committed professional can make all the difference to the lives of children and their families;
- Parents often experience difficulties and problems but they are not the problem
- Parents and professionals are caught up in the processes of privatisation and marketisation of health, social care and education

### **(5) Enabling Care**

Enabling care involves many practices on the part of formal sources of support, alongside the informal family, friendship and community networks that families are part of. Enabling care is framed as values and practices that allow for positive visions of the child and the family to emerge, which ground the child not in their condition, but instead in their life world. It is aware of the social

constraints and inequalities, which are experienced by disabled people, and seeks to challenge such problems by both action and also the form of relationship people are willing to build up with the family and their child/children.

### The product of breaking the rules

As discussed in relation to the lack of support within service provision, parents often find the instrumentality of service procedures opaque and unresponsive to human need and compassion. There often seemed little logic to why some support was allowed and others were not. Policy guidelines replace a genuine needs assessment of the particular child. The rules and boundaries amongst organisations appeared a significant barrier to any form of encompassing connection with the family that could recognise the particularity of that family's needs. A key form of enabling care became for parents, occasions where professionals refused to be bound solely by the written rules of their job specification and instead acted within a form of ethical judgement that could see the justice and fairness in ignoring rules in particular situations. At times professionals found ways round such rules 'on the sly' to provide for the families they were working with; as was the case when the physiotherapist organised a buggy for Kay's son Joe, even though he was too young.

Making that extra effort for parents, recognising that their evaluation of their child's needs was a more appropriate one than that laid out in a distant rule book, enabled, in such instances, not just a particular support need to be met. It also allowed a relationship to develop between parents and professional that was ultimately sustained over time. In contrast to mistrust, trust and respect had been forged in the small action that signalled to parents - you will listen to me and follow through practically and responsively. Below Debbie explains why she has built up a sustained relationship with the community paediatrician who works with her young son:

Debbie: Because when she first came she actually came out to our house to see Frank. And she came out once or twice to talk about what support she could give us and what services we needed. And she was just fantastic, I mean she was playing with him and had him on her knee and everything. So from the starting point she wanted to know

what we needed as a family and what support we needed. And then, she even phoned once or twice to see if it was working out all right... I had an initial feeling that everything was going to be, I felt comfortable with it straightaway. And then the other part, I suppose it's built up through us needing different services and support, and her actually coming up with the goods, and being there really.

### Relationship and commitment to parents

Such actions of support and understanding are a corner stone to building a relationship with parents and children that brings a human dimension to the new world of service provision parents enter with their children. It is easy for providers to forget that the world they belong to, which to them seems, logical and obvious, is for many parents, a mystery of different norms, expectations, language and relationship. Often parents spoke of one particular person who consistently made a difference to them and their family (such as the community paediatrician working with Debbie above). What made a difference constituted a variety of things. It involves simply the power of listening and taking the time to explain fully to parents the world they have now entered:

Sofia: He actually listens to me and he actually makes a note of everything I say. He takes in what I'm saying, positive or negative. [...] Had he not been that responsive, I might have been quite negative towards him. As a parent you see you need to grab on to something that gives you a bit of hope. [...] He was my pathway, my manual to this new world, this different planet.

It can include a model of friendship; however it is not the same as friendship amongst parents' own personal connections. Instead what is asked for is a form of responsible friendship, where service providers are **responsive** enough to hear what they and their children say, while also **responsible** enough to do the jobs that are required of them, following through on promises and providing a service that makes a difference:

Jemma: And with the likes of the community nurse, I mean they will come to the house and they do take some of the burden for you, you know they do, they see it all the time, they understand a little bit of what it's like. I think the

friendship part of it as well because the nurse has become I would say more than just somebody that comes into the house, a professional, she's become more like a friend. And, yeah I think it is just trust.

Parents battle with trying to find time to just be a mum or dad to both the disabled child and any other children they have, amongst all the responsibilities they have as treatment provider, care giver, care coordinator and planner. While parents want to be involved in many aspects of their child's care this takes its toll and can drown out all other aspects of being a parent. Therefore, when they have a professional they can trust, one of their roles can become lifting some of the responsibility off parents' shoulders. For example attending meetings with them, or making first contact with or coordinating different services they may need or seeking information on their behalf:

Debbie: First, it would mean somebody who is interested in Frank as being Frank along with his, his other bits and pieces. Not just as a medical case. And to see Frank in the whole, the whole thing of his speech, and is he is a happy little boy? And everything else, his nursery and his education and how he is. And seeing us as a family as well, being interested in us as a family and wanting to know how are we and are we dealing with things, and do we need any additional support?

In a way what the Debbie is pointing to, and is the role her community paediatrician has adopted, is that of key worker, networking and advocating on their behalf. This role has been identified as a key aim in standard 8 (disabled children and young people and those with complex health needs) of the *NSF for Children, Young People and Maternity Services* (DfES 2003, 2004a, 2004b). Indeed the government has acknowledged that key workers (sometimes called care-coordinator or family support worker) are "one of the key issues for improving standards" (DfES & DoH, 2003:22, quoted in Mallett 2006). It seems clear that such a role is a core element of enabling care, ensuring both a level of coordination across services missing in current provision and also, crucially from the parents' point of view, enabling them time to spend being a family.

Part of the process that enables parents to build a more positive future for themselves and their children is to begin to distance themselves from the medical aspects of care of their children, becoming more choosy about which interventions, appointments, supports, even diagnosis are from their point of view necessary for their child:

David: And then it was one day we just said, you know, we've got to stop this, we've got other kids as well and it was having an effect on them because we weren't sleeping and eating and things like that. They were noticing a difference in our moods and the way, you know, things were for us. And, it just had to be one day, we just said, you know, right from this day forward, as long as X's happy, and she's doing fine, then nothing else matters. And you just get on with it. If they come with information now it's great, you know, we've get'n a bit more information, but if they don't you just, well, we're no worse off.

In some ways, one of the clearest forms of evidence that service provision has got to a point where enabling care is present is where they are least noticeable. When, at least for a time, there are no battles to be won, where there is a steady routine and clear expectations and predictability about what services are being provided. Where there is someone coordinating on behalf of the family, service provision drifts into the background to allow families a space within which treatment, support and intervention, however needed, do not dominate. This space is a vital component to enabling alternative positive visions of what the future might be for such families and it is clear parents cherish getting to the point where this occurs. Getting to this point can depend on the needs and condition of the child, in particular the level and variety of intervention required. However, we would argue that as important, if not more so, is the approach of service provision and the willingness to provide a flexible approach to the family, which acknowledges the broader social and cultural world they live within and seek to be participants in.

### Understanding children

This aspect of enabling care is a far broader issue than service provision. It touches on the responsibilities of both immediate friends and community and broader society to respect the different

lives of families and in particular, to treat disabled children with respect and recognition. Too often, instead what parents find is that their children, either due to their physical difference or because of the different kind of behaviour they exhibit, are thought of as freaks or naughty or something to be stared at. As Corinne and Luis said so clearly (through an interpreter): 'Carla is not a tourist attraction' (3<sup>rd</sup> Interview).

What such negative attitudes towards the children are testimony to is the significant discrimination and pathology aimed at disabled people; both children and their families are offered two subject positions by society: the tragedy to feel pity for, or the uncomfortable/disruptive presence that people – family, friends and community - withdraw from. Parents also have to face societal judgements about them. Such judgements about good and bad parents are particularly aimed at mothers who are more often visible in the public realm with their children:

Lisa: I'd walk along with the pram and I've got this little bundle screaming like mad, she was always bright red, manic screaming, she's going 'huh,' ca', like couldn't breathe properly. And other people would kind of tut and shake their heads, and, 'eeh that poor bairn,'... I mean, people offering us, people offering us a lot of, disguised as advice, or like thinking badly of us, thinking I'm not doing something that needs doing... me mother-in-law's had seven kids and she was really kind of, 'oh well you should be doing this with her and you should be doing that, and the other.' And I was like, hang on a minute, I had Josh and I did fine by him, d'you know what I mean?

Families live, not just with prejudice aimed at disability. As the quote above indicates stereotypical views about gender and mothering affect parents too. Young single mothers, as is the case above, are particularly vulnerable to the public reading of them as poor mothers and somehow the cause of their child's troubles. Some families are acutely aware of how discrimination of various forms overlap and at times contribute to their marginalisation and the withdrawal of enabling care from those around them:

Nick: well, my dad is also a racist. So when I first got involved with Sarah, he didn't like that, and, I would say my sister's also that way too. So, they've never really bonded with Sarah. You know, with Katy as well, it comes in to that. So that's one thing,

and then, that's another reason why they have stepped back. They don't like Sarah, and with Katy also they, they took another further step backwards.

These multiple and overlapping forms of societal prejudice are the cultural barriers to the values of *Every Child Matters*, and point to the need of government to tackle both the failure of services to support children, while also seeking to change societal attitudes that also do little to provide enabling care and inclusion for children.

### Enabling visions of disability

What the above indicates is that enabling care is closely tied to how disability itself is viewed by both social services and broader society. Parents themselves often went through a process of re-orientation in their own thinking about disability once it entered their lives:

Richard: I mean when I was little you didn't see disabled people, and if you did they were the butt of jokes weren't they? ...we went to a chemist the other week and there was a man there who has Downs... and he wanted a cuddle off Joe and Joe was just totally, it was the fear on his face cos this bloke was sort of coming towards him with this big bulky coat on. And his dad was saying, "it's alright," he says, "the man just wants a cuddle."... and I think because this bloke was so slow, he could track him so well by the time he got to there Joe was like, [holds arms out] "cuddle me!" and he was like jumping up and down for this bloke to cuddle him because he'd taken so long to get from standing to him. And the woman was like, "eeh is he alright?" I says well he's visually impaired I says, he's moving so slow it's great for him I says he's gagging for this cuddle... I just thought you know fifteen - twenty years ago that wouldn't have happened. And I think if it had been me with my dad, no way would that have happened.

Rethinking disability and embedding their child's impairment into family life and visions of the future is no easy process, particularly in a context where families experience marginalisation and hardship on a daily basis. In keeping with other research that has been undertaken with parents of disabled children (Landsman

1998, 2003; Larson 1998), the parents seek a balance, managing both a feeling of pain for the difficulties their child will face in life and a love for who they are, which is not contingent on overcoming disability or becoming normal:

Maria: You know I've many a time think you know I would give, give both arms for Luke to grow up without this disability but there again when I'm thinking on the other hand, Luke without the disability wouldn't be Luke you know. Luke is Luke because of how he is. And he has his own little character because of the way he is you know, but you still would like him to grow up without the disability.

Enabling care is not just a requirement for social services; there is a broader need for social care and enabling visions of different family forms and life in broader social and community relations. Families are placed in a position where they feel they always have to explain their children in ways others don't, particularly where it is a learning difficulty. One coping mechanism for families is to no longer feel the need to explain:

Angela: I'm just so used to it now (laughs) sometimes I don't bother explaining I just think oh well if they think we're a weird family they think we're a weird family, who gives a monkey its their problem not mine, and I'm sure many people probably do.

Parents seek out friendships and connections that are expansive towards their family. Previous relationships may disappear due to the discrimination of family and friends, but in response parents seek out new spaces and connections that offer warmth and respect to them and their child. Some of this comes through support groups, some through more informal friendships that emerge and are sustained over time. Below Jane talks about a local trip to the cinema, organised by a support group, where for a brief period of time she and her child were protected from the prejudice of others and the space became theirs:

... it was lovely 'cos it was just, they'd booked out two halls and there was one with subtitles, and there was another one, and they had obviously like disabled sitting areas... I don't know if you know him, Mark who runs it, he just came in and

he says, 'the last time we had something like this all you could hear all the way through the film was the parents going shh, shh. Don't do this, don't do that, if any of you get told to like be quiet, or shh, or anything like that,' he goes, 'you've got to tell me straight away and I'm gonna pull your parents out.' (laughs)... Jack ended up, he sat beside us, then he was slouching, he went to the toilet four times in an hour... and I just thought, oh, just let him do it. But I couldn't have done that normally, because I would've had somebody behind us goin', 'Look what that kid's doing. She's just letting him do that.'

Not having to accommodate to the discomfort of mainstream society is an important aspect of Swain and French's (2000) affirmative model of disability. Holding up the possibility that a disabled child can have (and perhaps more importantly has a right to) enjoy themselves in the public realm is an important aspect of enabling care. What needs to happen in addition to the example above is for this to occur without the need of segregated access to the cinema.

### Summary

- Care does not have to simply reflect assumptions and aims that underpin current policies and practices, enabling care often emerges in spite of or in reaction to current priorities;
- Enabling care embraces nurture, support, friendship, partisanship and responsible forms of expertise;
- Children must be understood in terms of their political, social, cultural and historical context;
- Enabling care develops particular visions of the 'disabled child' – some which are more positive than others

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